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"In the hospital there is no protocol for action": Experiences and interventions in perinatal loss in Spain

Running Title: Professionals and perinatal loss

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"In the hospital there are no care guidelines": Experiences and practices in perinatal loss in Spain

Abstract

Background and objectives: Health care professionals play an important role in supporting and attending to families that experience a perinatal loss. Previous research has identified the existence of obstacles that professionals may encounter during their practices. The main objective of the current research was to identify and examine the subjective experiences and practices of experienced professionals attending to perinatal loss in the hospital context in Spain.

Design: Qualitative descriptive design.

Setting: Three different hospitals in Spain.

Participants: 16 professionals were interviewed, including doctors, nurses, midwives, nursing assistants, a psychologist and a funeral home manager.

Methods: Individual semi-structured interviews focusing on three areas were carried out: practices with the baby-fetus, practices with parents and interaction with the team. A thematic analysis was performed using the three main focuses of the semi-structured interview (deductive approach) and the codes that emerged from the data (inductive approach).

Results: Regarding guideline-based care for the baby/fetus, participants made a distinction between the initial process of care for the baby and the decision-making process with parents. Where support for families was concerned, participants identified considerable variability in the practices used and lack of organizational and care guidelines, psychological support, and follow-up. Finally, interactions with other team

members were perceived as a source of support, although participants identified a significant lack of coordination.

Conclusion: Participants reported variability of practices in care for the baby and parents, lack of continuity-of-care guidelines, and the importance of support from a coordinated health care team.

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Introduction

In Western society, the birth of a child is generally an event expected and received with optimism and joy for parents. Medical advances have significantly reduced perinatal mortality in developed countries. A recent epidemiological study in Europe (1) showed remarkable heterogeneity between countries regarding stillbirth (with values ranging between 1.5‰ in the Czech Republic to 4.3‰ in France) and neonatal deaths (with values ranging between 1.1‰ in Slovenia to 4‰ in Malta). Perinatal loss includes infant deaths at less than 28 days of age and fetal deaths with a period of gestation of 20 weeks or more (2). The loss of a baby or fetus can occur for a variety of reasons (e.g., poor maternal health and nutrition, inappropriate management of complications during pregnancy or delivery) and assumes many forms related to the length of gestation or life after birth and other factors outside of medical or nursing control. These forms include stillbirth, intrauterine death, termination of pregnancy (due to fetal anomalies incompatible with life or risk to the life of the pregnant woman), or death during the first days of life (2,3). Such losses have been included among types of disenfranchised grief (4) since, in such cases, the loss is usually not socially acknowledged and parents are expected to quickly return to "normal" functioning, as if nothing (or something minor) had happened to them.

The psychological and emotional impact and process that occurs after this type of loss has been termed perinatal grief (5,6). In the USA and Europe, perinatal loss has been found to have a substantial emotional impact on parents (6, 7-9). Moderate associations between grief intensity and high levels of depression (10), anxiety (11), post-traumatic stress disorder (PTSD) (12) and decreased quality of intimate relationships (13) were found among mothers who experienced perinatal loss. These symptoms can seemingly last for many months after the loss. For example, bereaved

mothers had four times higher levels of depression and seven times higher levels of PTSD symptomatology, in comparison with a control group, when assessed nine months after the loss (14). The case of fathers is less studied, although they share some grief reactions with mothers such as feelings of shock, anger, emptiness, helplessness or loneliness after the death of an unborn child (15). Various studies indicate the central role of neonatal health care professionals in providing emotional support and helping parents deal with their reactions after a perinatal loss (16,17).

During the last three decades, specific professional practices have been recommended around perinatal loss (18). They usually counteract the taboo and silence around a baby's death and recognize parents' suffering and loss. They directly involve parents by inviting them to see and hold their baby, and by preparing a memory box with hair strands, foot and/or hand prints and pictures of the baby (15, 19, 20). However, the importance of promoting flexible care guidelines based on joint decision-making has been highlighted, so that practices are appropriate and attuned to the parents' experiences and needs (21, 22).

Regarding perinatal loss, there are significant limitations in the Spanish health care system. First, there is no global and generalized care protocol for families after the death of a baby in neonatal or intensive care units (23). Second, it is not known if the practices recommended by international (24, 25) and national (26, 27, 28) associations are implemented by health care professionals. Finally, there is little data regarding the actual care practices, results and experiences of health care professional in Spanish hospitals. A recent cross-sectional study which assessed mothers that have gone through a perinatal loss indicated that in Spain, many of the standard practices that are common in other high-income countries are not integrated in the care provided (23).

In addition, several studies reported obstacles and difficulties encountered by professionals in providing adequate care to parents experiencing perinatal losses in the Spanish context (29, 30, 31). First, a cross-cultural study that compared nurses working in perinatal loss in Spain and the United States found that the former showed significant deficits in communication skills, a lack of knowledge and coping strategies, and poorer regulation of their own emotions compared with American nurses (30). Second, professionals have shown reactions of avoidance when coping with the various emotions that they experience as well as feelings of failure, guilt, and a lack of competence (29, 31). This may negatively influence the support that they provide to parents in the grief process. Finally, regarding organizational obstacles, a recent systematic review indicated the importance of interacting with other health care professionals and of having at one's disposal specific hospital policies on perinatal loss (32) – something which, significantly, is lacking in the Spanish health care system. In sum, previous studies indicate clear and well-established recommendations on supporting parents experiencing a perinatal loss (21, 22, 33), but these may not be systematically applied depending on the health care system.

Taking these aspects into consideration, this study adopted a qualitative descriptive design to examine (a) the specific practices and (b) the subjective emotional experiences of experienced professionals who typically attend to perinatal loss in the hospital context in Spain.

Method

Design

A qualitative exploratory descriptive design was carried out. The practices used to deal with perinatal loss in hospital as well as health care professionals' emotional

experiences were analyzed. Participants involved in the different moments of the perinatal loss process were selected. A thematic analysis of semi-structured interviews was performed (34).

Participants

Intentional or discriminant sampling based on maximum variation of participants and situations was performed to obtain an adequate representation of the diversity of health care professionals involved in perinatal care (35,36). The aim was to obtain a wide representation of the different types of practices and emotional experiences of professionals who participate at different points in the process of perinatal loss. Participants were recruited from three public hospitals in the province of Granada (Spain) according to two main criteria: relevance (professionals with extended experience in attending to perinatal loss) and diversity (different degrees/majors). Inclusion criteria for participation were: (i) being a professional in a discipline (health care or other) regularly involved in intervening in cases of perinatal loss and (ii) having at least 5 years of professional experience in attending to perinatal losses. MFA established contact with the head of neonatal units in the hospitals. Basic information about the objectives of the research was given to health care professionals so they could decide whether to participate in the study. The professionals who were willing to participate were contacted by telephone and fully informed about the study and data collection process. Nineteen professionals were contacted, of whom 16 agreed to participate (see Table 1): 4 nurses, 2 neonatologists, 1 psychologist, 4 midwives, 4 nursing assistants, and 1 funeral-home staff member. The three participants who declined to participate in the study were two gynecologists and one social worker, due to personal reasons (n=2) and lack of time (n=1).

Participants were mainly women (87.50%), and had a mean age of 52 years(*SD* = 13.21, Min = 33; Max = 64) and an average of 28.06 years of experience (*SD* = 9.56, Min = 9; Max = 42). The main perinatal loss situations (including stillbirth, intrauterine death, termination of pregnancy, death during labor and neonatal death) faced in Spanish hospitals were represented in the sample, making it possible to compare them.

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Data collection

A semi-structured interview was used, divided into three main areas: practices with the baby/fetus, practices with parents and interaction with other health care team members. Participants were asked three main open-ended questions: "What practices do you perform with the baby/fetus at the time of death?"; "How do you act with parents in the moments after the death of the baby/fetus?" and "What types of interdisciplinary practices are used when a perinatal death occurs?". Additionally, further questions were asked to explore the reasons and the subjective experiences associated with each practice (see Supplementary Material).

The interviews were conducted in the workplace of each participant by one researcher (MFA) from February to September 2016. The interviewer had no previous relationship with any of the participants, who received no remuneration for their participation. The study was approved by the Committee of Health Care and Research Ethics of the province of Granada. At the beginning of the interview, each participant was provided with an information sheet on the study, and written informed consent was obtained. Participants were told that they would remain anonymous and that they could leave the study at any time without explanation. The mean duration of the interviews

was 51 minutes, with a range of 35-88 minutes. The interviews were recorded in audio format and transcribed by the researcher who performed them.

Data analysis

A thematic analysis was used following the suggestions of Braun and Clarke (34). First, recorded interviews were transcribed, adding body language, annotations or interviewer notes that could provide useful information regarding the participant. Second, each interview was read independently to obtain an overall impression. Third, an initial line-by-line coding was produced using an inductive approximation. This coding was performed by two members of the research team (MFA and MPGC). In this phase, a series of initial codes was obtained; these codes were progressively refined and integrated into larger codes (inductive approach). Body language was not analyzed separately from participants' discourse. Fourth, codes with similar meanings were merged into the three basic themes (deductively extracted from the three main focuses of the semi-structured interview).

Rigor

The creation and modification of the codes had to be agreed on by two of the researchers (MFA and MPGC). In cases of doubt or disagreement, the researchers discussed them to ensure that each new code was as close as possible to the participants' experience. This strategy was used to maintain the rigor and trustworthiness of the findings (37). In addition, the steps followed during the analysis were systematically reported, and the codes and themes were generated through triangulation between the researchers. Similarly, a clear distinction was made between *verbatim* quotations of the participants and the interpretations of the researchers. The quotations selected to illustrate the results were translated into English and back-translated into Spanish to

ensure accuracy. Throughout the analysis process, Atlas.ti software version 7.2 was used.

Results

The three themes were derived from the main focuses of the interview and the main codes that formed the subthemes are included in Table 2.

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Theme 1: Guideline-based care for the baby/fetus

1. Initial process of care and decision-making regarding the baby/fetus

The great majority of care practices described by participants were associated with the technical aspects of care during the first moments after the death of the baby and the subsequent decision-making process. The care of the baby/fetus performed by the participants was characterized by being planned and based on defined protocols. A significant variability in practices was identified depending on (i) the profession of each participant, because each intervened at a specific moment during or after the pregnancy and responded to different needs of the parents or requests from other professionals and (ii) the type of perinatal loss (e.g., stillbirth or neonatal death).

In the case of stillbirths, midwives and nursing assistants stated that they first weighed, covered, and prepared the fetus after attending to the mother during labor. Subsequently, they were responsible for sending the fetus to the pathological anatomy department and for performing cultures and diagnostic tests. In most cases, they were responsible for reporting the death to the parents. If the weight of the fetus was greater than 400 or 500 grams, an entry was made in the birth book. After discussion with the

parents, an autopsy was proposed, after which the baby/fetus was taken to the hospital morgue (see Table 3).

---------- Insert Table 3 here ----------

The funeral-home staff member indicated that he was responsible for processing the burial license and scheduling a burial with the help of the father. This stage of the process involved cremation and later burial in a common grave provided by the hospital or an individual burial at the family's expense (see Table 3).

Physicians intervened when there were complications (e.g., a need for caesarean section; use of forceps) during labor or in cases of termination of pregnancy (TP) (e.g., fetotomy or fetalysis), both at the technical level and to deliver the bad news to parents. Nursing staff members intervened in cases of TP and in neonatal deaths, providing attention and care to newborns in the Intensive Care Unit (ICU) and removing life-support devices. The interviewed psychologist (I9) was not including in the process but intervened on request, particularly in cases of neonatal death.

2. Symbolic and affective care for the baby/fetus

Participants indicated how they related to the deceased baby affectively and in terms of the respect they showed during the entire process. All of them noted the importance of humanizing the care of the baby/fetus through different practices that they performed: putting themselves in the place of the parents, treating the deceased baby/fetus affectionately, and treating him/her as a person. In the case of neonatal deaths, participants indicated that they clothed the fetus so that the parents could see it and say farewell. This practice did not always occur following stillbirths, because in those cases, an autopsy was usually performed and the baby was considered by participants to be in an unsightly state (see Table 3).

Regarding symbolic or spiritual practices, several participants spoke about the influences of their own beliefs on their practices with the baby. They reported the need to perform some type of farewell act or ritual even if this wish was not explicitly expressed by the parents. The most common ritual was baptism, and some participants also spoke about sharing moments and spaces of silence with the baby. For them, it was a way to recognize and symbolize that the baby had been alive, had been a human being. Being dependent on the participant's spiritual beliefs, these practices were not set out in any protocol.

3. Difficult emotions associated with the baby/fetus

Confronted with the death of a baby, participants identified emotions such as sadness, pain, dissatisfaction or a need to share such moments with another team member. Unexpected losses, such as when an emotional bond had been established with the child (i.e., neonatal deaths) or when the death occurred during birth, appeared to be particularly unpleasant for participants. In addition, feelings of peacefulness and acceptance were reported, particularly in cases of limitation of therapeutic effort (LTE), where professionals withhold and/or withdraw treatment from the baby.

4. Lack of emotional skills to cope with perinatal loss

Participants identified the use of avoidant coping responses in situations related to perinatal loss that caused them stress and anxiety (see Table 3). They reported feelings of sadness and isolation after the death of the baby, which appeared especially when they identified a lack of support from the health care team.

Theme 2: Variability in the emotional support offered to families

Practices regarding families were less defined than those regarding the baby/fetus; they focused on the provision of emotional support and varied according to

the profession (see Table 4). The interviewed nurses, assistants, and midwives showed intimate and affectionate attitudes toward grieving parents when using empathy-based interventions (including active listening, physical contact, or emotional expression). Midwives also noted the use of specific bereavement techniques with parents, such as writing a letter to the baby to say farewell. The doctors emphasized providing the family with adequate information and helping with decision-making about possible treatments (in cases of TP), or about the medical problems of their child (in cases of neonatal death). The psychologist stressed the power of putting the recent traumatic experience of the parents into words. Finally, the funeral-home staff member fostered a protective attitude toward the mother, indicating that one of his objectives was to avoid over-involving the mother in the process (see Table 4), which may indicate some difficulties with the shared decision-making process.

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1. Lack of organizational and administrative resources in the hospital

Nurses, assistants and midwives reported a lack of space and facilities in hospitals to accompany parents emotionally. Having private areas or rooms in which parents could express their emotions without feeling watched or inhibited by others was a need identified by all interviewed professionals. In addition, other participants emphasized administrative problems related to the baby, such as the recognition of the baby by the parents, the lack of a place in which to discuss burial or cremation issues with the family, and the lack of training at the relevant hospital department required to process the necessary documents concerning the death (see Table 5).

2. Lack of guidelines on care for parents after a perinatal loss

Almost every participant indicated that there were no specific guidelines on providing emotional support to the parents (see Table 5). Only one of the midwives (I8) had guidelines on dealing with parents' emotions; she had designed these herself based on the literature and her own experiences. Thus, participants were obliged to fill the gaps in emotional support to be provided to parents with their own experience accumulated over the years, their common sense, and/or performance guidelines provided by organizations outside the hospital. This approach resulted in substantial disparities among the actions performed by the different members of a team. Finally, in the specific case of neonatal deaths, participants identified a lack of clarity in the LTE criteria, which prolonged the baby's suffering:

"I miss some rules that say that when therapeutic limitation is appropriate it should be introduced as soon as possible, and above all that every possible means should be used to prevent these children from suffering." (I7 - Nurse)

3. Lack of psychological support and follow-up of parents

Participants agreed on the need to provide a psychological intervention with the parents after their loss. However access to the psychologists was not easy in any of the three units, and they were not integrated in the team (the same also being true of other professionals such as social workers). Once the parents had left hospital after the perinatal loss, follow-ups were typically not conducted to assess their reactions to their loss or their grieving process (see Table 5).

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4. *Lack of continuing learning and training*

Participants expressed a substantial need for specific training in dealing with perinatal bereavement, particularly in the following areas: (i) how to deliver bad news,

(ii) knowledge of guidelines on appropriate care for parents, and (iii) skills in regulating their own emotions.

Theme 3: Care and interactions within the health care team

1. The team as a source of support

For a large number of participants, the team was an important source of help and support, particularly when a professional encountered problems with a family or when a situation was emotionally complex.

"We are like a family; we spend many hours together. It's almost like your second family, and when you see that someone is unwell and is having a bad time, you take them aside, and someone else comes along, as long as there are staff members, and we try to help each other." (I16 - Nursing Assistant)

2. Conflict with members of the team

Along with the perception of the team as a source of support, participants identified substantial differences in how each member of the team interacted with the baby/fetus and the families. On numerous occasions, participants acted independently of other team members, giving rise to feelings of isolation and causing emotional discomfort in the rest of the team members.

"I recognize that I create many enemies among professionals, many problems, because as with everything else you have to stick to the rules. For example, if the grandparents cannot see from the windows and I decide that they can enter the unit, other co-workers scold me." (I7 - Nurse)

"[I miss] the little interactions among the health staff, that take place among all of us. We are very isolated. The doctor provides information on the one hand, then the

nurse tries to comfort if he or she wants to and can, on the other. When information is being given, I often wish that we were all together … to give support" (I6 - Neonatologist)

Certain practices not based on any protocol, such as allowing parents to hold their baby in their arms even though he or she was in the incubator or intubated, generated conflicts with other team members. Participants also indicated that, in many cases, there was inadequate communication between the team members, which had a negative effect on their daily practice: they were more attentive to not generating more conflict than to providing compassionate and appropriate care to the baby/fetus or families.

"We don't all have the same information. We have always said that when parents have been informed about the state of their baby, about a limitation, about anything, the nurse should be there, because the nurse needs to know what the parents know […] You have to avoid saying too much. This restricts you a lot, because you say 'What should I say? I don't know if they have told you the whole truth", so you don't know. Then it is very difficult to act with these parents." (I 10 – Midwife)

Discussion

The objective of this investigation was to examine the practices and the subjective emotional experiences of different professionals in cases of perinatal loss in the Spanish health care context. The results of the descriptive thematic analysis revealed the existence of well-established practices for taking care of the baby, but also variability and various obstacles in the provision of emotional support to parents. The results also indicated that working as an integrated team that would share a common approach regarding perinatal care was perceived as essential.

One of the most surprising results was that, although health care professionals performed practices included in well-known perinatal bereavement care guidelines (5, 6), they did not attend to key aspects of care such as shared decision-making (23,38). This lack of communication with parents was reflected in the exclusion of mothers from decisions regarding the preparation of the burial, autopsy and funeral arrangements – an exclusion which was perceived as protectiveness. In addition, health care professionals indicated that, after autopsy, the baby was not in an appropriate state to be presented to parents and they did not discuss this with them. When parents are not involved in the decision-making process (i.e., if parents are not offered the opportunity to hold the baby, or keep some objects as mementos), professionals may experience feelings of distress and guilt (23, 39). Finally, participants performed individual rituals with the baby (with or without parents' acceptance) which seemed to be useful in alleviating and regulating their own anxiety. Such rituals were not directed toward providing better care to parents. Previous research has indicated that the use of rituals in the perinatal context is related to specific coping responses such as regaining a sense of control and mastery over one's emotions and as a way of honoring the child (40).

Another important aspect outlined in the present research was the remarkable variability in the bereavement care provided to parents. Although several professionals performed practices with an affective and supporting attitude, they had difficulty in providing consistent and continuous emotional care to the bereaved parents, especially during the first days after the loss. Participants identified a lack of specific guidelines or modes of action, in line with previous Spanish studies (29, 30, 31, 41). This variability has been found in other countries where perinatal care is not totally integrated in hospitals. For example, a recent study in Turkey (42) identified that depending on the region, professionals implemented recommended practices differently such as allowing

parents to see and hold the deceased baby (93% of hospitals), allowing them to take photos and mementos (36%), providing a remembrance pack (6%), or assisting parents in the burial and funeral (67%).

International guidelines on appropriate professional practices have been found to be associated with lower levels of anxiety and depression in the parents after a perinatal loss. Professional attitudes turn out to be an important factor in grief resolution (43, 44). Parents particularly value professionals' presence, which is defined as a form of physical and affective supportive care, the individualization and continuation of care during bereavement, and health care providers' non-judgmental and empathic attitudes (45-48). Importantly, in the present study, other professionals such as psychologists or social workers with the skills to provide such care were in fact not integrated in the care team. This underlines the difficulty of integrating different professionals in the Spanish health context (49).

The reactions of professionals may be explained by a lack of training in attending perinatal loss, given that bereavement support care is a new phenomenon in the health care system in Spain (23). The complex emotions professionals experience when supporting parents after a perinatal loss (i.e. sadness, anxiety and emotional pain) may trigger protective avoidant coping responses (50). Such coping strategies could then have a negative impact on the practices and interactions they have with parents, resulting in practices or attitudes that are not supported by research evidence (e.g. the use of rituals to regulate the professional's own emotional reactions). This seems to be a common response in the Spanish perinatal context (29-31), and in other European countries such as Italy, where only around 28% of professionals created mementos of the baby and less than 3% fulfilled the recommendations for adequate care for the baby and the family after a perinatal loss (38).

In addition, participants did not indicate the existence of any support groups, specific meetings, or coordinated guidance within the team that could support them in providing care (32, 51). This can be explained by the lack of visibility of and failure to assign importance to perinatal grief, which forces professionals to resort to external and personal resources, such as individual psychological support or external training. Similarly, a recent qualitative study of Australian professionals found that they tend to learn about providing emotional care to parents not through learning, but through their own experiences (50).

Finally, the health care team has been considered by previous research to be a source of support in which professionals are able to manage and express their emotions, and also adjust and receive supervision of their own practices (51). In the present research, the healthcare team was perceived by some participants as an important source of support in emotionally intense situations, but as a source of stress and anxiety by others. These seemingly contradictory results could be explained by the structure of the teams. In those cases where the team was integrated, shared time and performed common actions and practices, participants found that their colleagues were an important source of support. In cases where the team was not perceived as a source of support, obstacles regarding lack of coordination, feelings of loneliness and emotional problems in interactions with other professionals emerged.

Clinical implications

The results of our investigation have important clinical implications. Regarding families, each hospital should consider creating common care guidelines on dealing with perinatal loss. Previous research suggested that having specific spaces available in which to provide support to bereaved parents and adopting joint decision-making can be

of great help (21,22). The follow-up of parents experiencing perinatal grief must be considered as a process in which each professional performs specific and complementary practices. Finally, the creation of support groups for professionals in which they can describe and share their emotions and experiences may foster their bonds and common work.

Limitations

This investigation has a number of limitations. First, perinatal loss was addressed in its different modalities without a criterion of homogeneity or heterogeneity being established. Many of the participating professionals indicated that their practices were reduced to one or two types of perinatal loss. Future studies should therefore examine the differences and similarities in the relevant discourses, taking this variable as a criterion. Second, the potential generalizability of our results needs to be addressed with caution because of the variability of the health care system in Spain (each region has its own competences and programs). Nevertheless, our research, conducted in one of the most populated regions of the country (with more than eight million inhabitants), potentially outlines a known general problem of the Spanish perinatal care system (23). Thirdly, the sample of the present study included only professionals with previous experience in attending to perinatal losses. Future studies should also consider the experiences and practices of professionals encountering perinatal loss for the first time. Finally, regarding the sample size of the present research, some professionals may be under-represented (i.e. gynecologists/obstetricians, psychologists or social workers). However, the difficulty for these professionals of participating in the study reflects the current situation of the Spanish healthcare system, in which psychological and social professionals are not assigned to specific hospital units and are not involved in end-of-life care. Finally, most of the participants in the present research were women, and

future studies to address difference between subjective experiences and obstacles in men and women are needed.

In conclusion, this study has revealed the main practices and experiences of Spanish professionals in perinatal loss, identifying the variability of practices, the lack of continuity-of-care guidelines, and the important role of the support of a coordinated health care team.

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1 Table 1. Sociodemographic data of participants

Participants	Age	Sex	Profession	Type of perinatal loss	Years of experience
I01	56	W	Nurse	Neonatal death	36
I02	61	W	Midwife	Stillbirth	39
				Intrauterine death	
				Termination of pregnancy	
				Death during labour	
I03	57	W	Nurse	Neonatal death	25
I04	57	W	Nurse	Neonatal death	36
I05	33	W	Neonatologist	Neonatal death	9
I06	41	M	Neonatologist	Neonatal death	16
I07	50	W	Nurse	Neonatal death	28
I08	49	W	Midwife	Stillbirth	29
				Intrauterine death	
				Termination of pregnancy Death during labour	
I09	59	W	Psichologist	Neonatal death	39
				Death during labour	
I10	64	W	Midwife	Stillbirth	42
				Intrauterine death	
				Termination of pregnancy Death during labour	
I11	44	M	Funeral home manager	Stillbirth	15
				Intrauterine death	
				Termination of pregnancy Death during labour	
				Neonatal death	
I12	56	W	Assistant	Intrauterine death	35

				Death during labour	
I13	59	W	Assistant	Intrauterine death	37
				Death during labour	
I14	58	W	Assistant	Neonatal death	35
I15	56	W	Midwife	Stillbirth	31
I16	49	W	Assistant	Neonatal death	29

Note. W= Woman, M= Man.

Table 2. Themes and sub-themes identified through the thematic analysis

Main themes	Sub-themes
Theme 1: Guideline-based care for the baby/fetus	1. Initial process of care and decision-making regarding the baby/fetus
	2. Symbolic and affective care for the baby/fetus
	3. Difficult emotions associated with the baby/fetus
	4. Lack of emotional skills to cope with perinatal loss
Theme 2: Variability in the emotional support offered to families	1. Lack of organizational and administrative resources in the hospital
	2. Lack of guidelines on care for parents after a perinatal loss
	3. Lack of psychological support and follow-up of parents
	4. Lack of continuing learning and training
Theme 3: Care and interaction within the health care team	1. The team as a source of support
	2. Conflict with members of the team

1 Table 3. Sub-themes and quotations regarding Theme 1: Guideline-based care for the
2 baby/fetus

Sub-themes	Quotations
Initial process of care for the baby	*"The treatment of the baby consists of weighing it, taking samples for culture, and paperwork; then, we label it with stickers, wrap it in a green cloth, and take it to the morgue, where the autopsy is performed, and that's what the midwives do."* (I8 - Midwife) *"As for the certificate, if you live for a second, you are considered human. And you are considered as a fetus if the death occurs during childbirth or you are born dead. With one second of life, a baby receives the treatment of normal death and a death certificate. If it is a fetus, official certification takes place in the civil registry."* (I11 - Funeral Manager)
Symbolic and affective care for the baby	*"You treat the baby with all the affection in the world, giving whatever it needs, the affection and love of those parents that it does not have."* (I7-Nurse). *"We have an identification protocol: weight, wristband for mother, wristband for baby, the family are notified and invited to see it. If they want to perform some kind of mourning ritual, you accompany them. There are co-workers who do not accompany them; in these cases, I do accompany them as far as I can."* (I12 - Nursing Assistant) *"We usually take some water and sprinkle it on the child [to baptize it]. All these are our things because the protocol as such is to remove the breathing tubes, do the cultures, and that's it, and everything else comes from you."* (I14 - Nursing Assistant)
Difficult emotions associated with	*"Those births [death during labor] are so silent, so sad, so ... the truth is that I do not ... I think the time comes when you get used to everything,*

unexpected perinatal loss	*but you do not feel good, you are sad, in a situation a little like this ... emotionally difficult."* (I12 - Nursing Assistant) *"The nursing staff, the assistants, everyone is going to look for closeness, but nobody is with the parents; then, you are a little lonely. They leave you alone with the parents suddenly, with the whole family, and now how do you manage ... one against five?"* (I5 - Neonatologist)
Lack of emotional skills to cope with perinatal loss	*"At first, what I was doing was hiding. Fleeing, from the anxiety, and fear and ignorance. Then, I would leave to avoid everything I could, and when it was my turn, I had no choice but to stay with the woman. I had no skills or weapons to overcome my own anxiety. I gave the woman a technically correct treatment: put in her IV, give her oxytocin, with her husband or her companion, and then, leave. Because I was unable to look the woman in the face, incapable, incapable."* (I8 - Midwife)

Table 4. Main codes and quotations associated with Theme 2 Variability in emotional practices with families according to participant's profession.

Codes	Professionals	Quotations
Empathy	Nurse Nursing Assistant Midwives	*"There are people who are very good professionals, but maybe the kind of comfort [they provide] is different, e.g., saying 'well, it's OK, you are young, you can have more', 'nature is very wise, and when it leaves us [the baby], it is for a reason; do not worry', and you maybe will sit with the woman, you try to comfort her, and you even cry with her."* (I8 - Midwife) *"If they have given me permission, I embrace them, which not everyone does ... and I do not say anything; I have nothing to say, simply that I am with you."* (I4 - Nurse) *"I believe that also experience and all that gives you a bit of 'tranquility' [with regard to accompanying bereaved parents]; you do not have to do much, just accompany, listen and say 'I am here' because I think we should do no more. To say that 'we are there for whatever you need, whatever you want' and with the greatest affection."* (I12 – Nursing Assistant)
Specific grief techniques	Midwives	*"The only thing I tell them after listening to them is 'write'. 'Write', 'write it down'. [...] 'Write down the feelings, stir up all those things, stir up your sadness, your anger, what you feel, allow it, allow yourself many things, do not hold back the tears. Cry, whatever your body asks, go and do it, kick, whatever you want, allow it, allow it, you have the right.'"* (I2 - Midwife)

		"Ask them if they want to take some memento because many times you find that afterward they regret not having taken anything. I know there are hospitals that make a box of memories that is taken and handed over, and that's good because it helps with mourning." (I4 - Nurse)
Giving information and helping in the decision-making process	Neonatologists	*"I try to explain in the simplest way what the problem was."* (I5 - Neonatologist)
		"Normally, you have to be very serene and very cold to give security to the family. You come in confidently and say, 'I'm here, do not worry because we're going to organize it like this, you have to give me this, and don't worry about that'; the family thanks you." (I11- Funeral-home staff member)
Symbolizing the experience	Psychologist	*"Simply the fact of beginning to speak about what is happening to you already has a function, already fulfills a function. We won't say it's therapeutic, but for now it enables them to put words to something that at first is an amalgam of distressing sensations, emotions and impressions."* (I9 -Psychologist)
Protective attitude	Funeral-home staff member	*"Normally, we do not want the baby's body to be viewed unless the family insists a lot. [...] So, we advise that it is never the mother who sees it because they present it to you with a blanket, bundled with the staples from the autopsy, quite purple and unpleasant."* (I11 - Funeral Home Manager)

1 Table 5. Quotations regarding the main sub-themes in Theme 2

Sub-themes	Quotations
Lack of organizational and administrative resources in the hospital	*"The family has nowhere to cry about the baby or to be with the mother; that's what is missing. There is no room where you can invite the family to sit, and cry, or to offer them some chamomile or a linden tea, or sit with them."* (I12 - Nursing Assistant) *"Burials are expensive, and not everyone can afford them. They [the parents] are offered the garden, the Garden of Ashes, which is a common grave. It is another difficulty over which family members stumble and which troubles me. It is not cleaned up or regularized; it is a no man's land*." (I2 - Midwife)
Lack of guidelines on care for parents after a perinatal loss	*"We can have 20,000 guidelines on what to do in each patient's clinical situation, but there are none about this [support]; there is no protocol. And it's like you more or less manage it yourself. There are more timid people who take a more reserved approach, others who do it in another way. I do it based on my experience and the personal work I have done, which I think is the best."* (I6 - Neonatologist) *"What I have seen in the hospital is advice or procedures from other organizations, like Umamanita*[1]*, for example. What should be said, what should not be said, what is most appropriate, what is not and so on. But as such, in the hospital, there is no protocol for action, and the truth is that there should be."* (I15 - Midwife)

[1] *Umamanita* is an important association which supports parents after a perinatal loss in Spain. It has developed one of the first guides on attending to perinatal and neonatal death (available at http://www.umamanita.es/guia-de-atencion-a-la-muerte-perinatal-y-neonatal).

Lack of psychological support and follow-up of parents	*"In practice, no matter how well you have done, you always ask yourself, 'Were they satisfied? Will they have gone in peace? Were they OK when they left?' I may have been able to do my best, but you always have doubts; when it's over, the baby leaves, the parents leave, you're left with a void and saying ... poor things. And you do not know if it really has helped them or not. That is always in doubt."* (I16 - Nursing Assistant) *"I hope someday the health system recognizes the need for more multidisciplinary teams [attending to perinatal bereavements]. Because there are some now, but I think there are still professionals from other disciplines missing, such as psychologists or psychiatrists, and hopefully someday, we will be able to use an approach that will also take care of professionals."* (I15 - Midwife)
Lack of contining learning and training	*"The inadequate training offered about this, because I think normal grief is very different from the death of a baby, that is to say, it is a new life as I say, and it is loaded with very great expectations. In any case it is always bad, it is a death, a death, but for these parents, it happens very suddenly; it is unnatural; it is not normal. Then, there is no training. We should have it, and it is not considered."* (I7 - Nurse)

Supplementary material. Script of the open-ended interview

Main area	Open-ended questions
Baby/Fetus	What practices do you perform with the baby/fetus at the time of death?
	How do you perform such practices?
	How do you feel during these practices?
	Why or what are the reasons for doing these practices?
Family	How do you act with parents in the moments after the death of the baby/fetus?
	How do you perform such practices?
	How do you feel during these practices?
	Why or what are the reasons for doing these practices?
Health care team	What modes of interdisciplinary practices are used when a perinatal death occurs?
	How is the health care team organized?
	How do you feel during the team practices?