

Experiences with perinatal loss from the health professionals' perspective¹

Sonia María Pastor Montero²

José Manuel Romero Sánchez³

César Hueso Montoro⁴

Manuel Lillo Crespo⁵

Ana Gema Vacas Jaén⁶

María Belén Rodríguez Tirado⁶

The purpose of this paper is to know the experience of health professionals in situations of perinatal death and grief and to describe their action strategies in the management of perinatal loss. A qualitative study with a phenomenological approach was carried out through interviews conducted with 19 professionals. Three thematic categories were identified: Healthcare practice, feelings aroused by perinatal loss and meaning and beliefs about perinatal loss and grief. The results revealed that the lack of knowledge and skills to deal with perinatal loss are identified as the main reason behind unsuitable attitudes that are usually adopted in these situations. This generates anxiety, helplessness and frustration that compromise professional competency. The conclusion reached is that the promotion of training programs to acquire knowledge, skills and abilities in management of perinatal bereavement and the development of a clinical practice guideline for perinatal loss are necessary.

Descriptors: Fetal Death; Grief; Professional Competence; Attitude to Death.

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² RN, Doctoral Student in Nursing, Universidad de Alicante, Spain. Hospital de Montilla, Agencia Pública Empresarial Sanitaria Alto Guadalquivir, Córdoba, Spain. E-mail: smpastor@ephag.es.

³ RN, M.Sc. in Nursing, Universidad de Cádiz, Spain. E-mail: jose.romerosanchez@mail.uca.es.

⁴ RN, BA in Social and Cultural Anthropology, Ph.D. in Nursing, Professor, Escuela Universitaria de Enfermería, Universidad de Granada, Spain. E-mail: cesarhueso@ugr.es.

⁵ RN, BA in Social and Cultural Anthropology, Ph.D. in Biological Anthropology and Health, Associate Professor, Escuela Universitaria de Enfermería, Universidad de Alicante, Valencia, Spain. E-mail: manuellillo@ua.es.

⁶ RN, Hospital de Montilla, Córdoba, Spain. E-mail: Ana Gema - agvacas@ephag.es, Maria Belén - mbrodriguez@ephag.es.

Corresponding Author:

Sonia María Pastor Montero

A 309, Ctra. Montoro-Puente Genil, km. 63,350

Montilla

14550, Córdoba, España

E-mail: smpastor@ephag.es

A experiência da perda perinatal a partir da perspectiva dos profissionais de saúde

O objetivo deste artigo foi conhecer a experiência dos profissionais de saúde em casos de morte perinatal e o pesar decorrente e, ainda, descrever as estratégias de ação frente à perda perinatal. Trata-se de estudo qualitativo com abordagem fenomenológica, por meio de entrevista com 19 profissionais. Três categorias temáticas foram identificadas: a prática de cuidados de saúde, os sentimentos despertados pela perda perinatal e o significado e crenças sobre perda e pesar perinatal. Os resultados mostram que a falta de conhecimento e recursos para lidar com a perda perinatal torna inadequada as atitudes nessas situações, gerando sensação de desamparo, ansiedade e frustração que compromete a competência profissional. Conclui-se que é fundamental promover programas de treinamento para adquirir conhecimentos, aptidões e habilidades em pesar perinatal e desenvolver uma diretriz de prática clínica para o cuidado da perda perinatal.

Descritores: Morte Fetal; Pesar; Competência Profissional; Atitude Frente a Morte.

La vivencia de la pérdida perinatal desde la perspectiva de los profesionales de la salud

El objetivo de este artículo es conocer la experiencia vivida por los profesionales de la salud en situaciones de muerte y duelo perinatal y describir las estrategias de actuación ante la pérdida perinatal. Se trata de un estudio cualitativo con un enfoque fenomenológico realizado a 19 profesionales a través de entrevistas. Se identificaron 3 categorías temáticas: la práctica asistencial, los sentimientos que despierta la pérdida perinatal y significado y creencias sobre la pérdida y el duelo perinatal. Los resultados ponen de manifiesto que la falta de conocimientos y de recursos para enfrentar la pérdida perinatal hace que se adopten actitudes poco adecuadas en estas situaciones, generando una sensación de ansiedad, impotencia y frustración que compromete la competencia profesional. Se concluye que es fundamental promover programas de formación para adquirir conocimientos y destrezas sobre el duelo perinatal y elaborar una guía de práctica clínica para la atención a la pérdida perinatal.

Descriptorios: Muerte Fetal; Pena; Competencia Profesional; Actitud Frente a la Muerte.

Introduction

The image of motherhood is culturally advertised as a synonym of success⁽¹⁾. The birth of a child is considered a happy event for families but, unfortunately, some pregnancies end in loss.

Great scientific advances and healthcare quality for pregnant women and infants have managed to decrease perinatal mortality rates⁽²⁾. This rate corresponds to 4.47 per thousand liveborns in Spain⁽³⁾. One of the phenomena that explains the causes why losing a wanted child affects the parents so strongly nowadays is the drop in the number of children per pair, due to the social, economic and cultural changes that have occurred in the Spanish

society at the end of the twentieth century⁽¹⁾. As a result of this modification in the reproductive pattern, Spain figures among the countries with the lowest fecundity rates, i.e. 1.4 children per woman⁽³⁾.

The perinatal loss concept includes losses occurred at any time during the pregnancy and until the infant's first month of life and the cession of a child for adoption⁽⁴⁾.

Perinatal loss is an indescribable experience for the parents, difficult to assimilate, as babies represent the start of life and not the end. After suffering a loss, a series of tasks starts, which is called the elaboration process of grief. Grief is the normal and healthy response to a loss⁽⁵⁾.

The parents experience the same reactions observed in other situations of grief, such as feelings of an interior void, guilt, irritability, overwhelming sorrow, fear of a new pregnancy, rage, skepticism and apathy^(4,6). About 20% of the mothers suffer some psychological disorder like depression or anxiety within one year after the loss, and can develop psychiatric disorders that can affect further pregnancies and the relation with the next infant⁽⁶⁾.

At professional level, death is a taboo theme and provokes negative feelings, including: frustration, disappointment, defeat and sadness⁽⁷⁾. In Spain, few hospital centers exist that have proposed action guidelines towards perinatal loss, which is why interventions, care and education for care delivery in these situations remains a pending task⁽⁸⁾.

Addressing perinatal loss is a delicate task. Professionals do not react to this experience with indifference. They neither know how to behave, nor to accompany and deliver care to a woman and her partner after suffering a loss. Therefore, knowledge is needed on how perinatal losses are interpreted and approached and on the perceptions related to this phenomenon.

Within the conceptual framework of holism, qualitative research focuses on the phenomena that happen to people, emphasizing the processes and meanings of human experience or related phenomena; therefore, to understand human experiences, a theoretical framework is needed with a systematic and subjective approach, which permits describing and signifying the experiences of life⁽⁹⁾.

The aim of this study was to get to know the experience of health professionals from the Maternal-Infant Unit of a tertiary-care public hospital in Spain in situations of death and perinatal grief, their feelings, emotions, concerns; all in all, their human reactions, and to describe the action strategies towards perinatal loss, as well as the difficulties faced in their approach.

Methods

A qualitative and descriptive study was accomplished with a phenomenological focus⁽¹⁰⁾. Within the constructivist paradigm, phenomenology will be used as the research strategy, as it most closely approximates the research proposal. Phenomenology is both a philosophy and a research method. More concretely, Husserl's phenomenology permits understanding an experience and intends to unveil its essence.

The study was accomplished at the Maternal-Infant Unit of the *Hospital de Montilla* in Córdoba, Spain, which

provides health coverage for 63,354 inhabitants. It is a provincial center affiliated with the hospital network of the *Agencia Pública Empresarial Sanitaria Hospital Alto Guadalquivir* and part of the Public Health System in the autonomous community of Andalusia. The Maternal-Infant Unit offers 22 beds, distributed among gynecology, obstetrics and pediatrics patients; the Neonatal Unit offers three incubators and two warming beds, while the Surgical Ward includes five operating rooms, two delivery rooms and one dilation room.

Approval for the research project was obtained from the Research Committee at Hospital de Montilla and from the Institutional Review Board. Ethical aspects were addressed, explaining the research goal and informing about how information would be collected before requesting the participants' informed consent, which all professionals signed. Anonymity, data confidentiality and voluntary participation were respected at all times.

The inclusion criteria were: health professionals from the Maternal-Infant Area who had witnessed some case of perinatal loss at the studied hospital, were not working on a temporary contract and voluntarily agreed to participate. The participant group was intentionally selected, the number of participants was determined according to the data saturation principle⁽⁹⁾, according to the representativeness of the concepts that emerged during data analysis.

In-depth interviews with a semistructured script were used for data collection. The script was elaborated mentioning various theme areas, introducing each of them with a theory-based open question, with a view to complementing the study goals⁽⁹⁾. The script comprised the following guiding questions:

Could you describe your experience regarding some perinatal loss situation in your professional practice? How do you feel when you have to face these situations? What does perinatal loss mean to you? How do your beliefs about perinatal loss affect the parents' death and grief experiences? How do you believe the parents live this experience?

All interviews were recorded after the participants' approval and literally transcribed. They lasted between 60 and 90 minutes and were held at the place of work between April 2007 and September 2008. The participants selected the exact data and place, establishing calm environments without interruptions and which would guarantee privacy. During the interview, field notes were made that referred not only to the general impression, but also to observations during the interview, specifically non-verbal communication aspects like gestures, facial

expression, postures, tones of voice and silence towards certain themes⁽⁹⁾; these nuances were reflected through square brackets in the informants' discourse. All of these observations were written down in a research diary, together with analysis, methodological and personal notes by the authors of these diaries.

The interviewees validated the interview contents. After the transcription, they were returned to the informants for revision and content verification.

The analysis followed the proposal of Taylor & Bogdan⁽⁹⁾. After successive reading of the transcribed interviews and field notes, the units of meaning were identified and grouped in common themes. Finally, the categories and sub-categories were elaborated, in the attempt to capture the meaning of discourse and considering the context they were collected in. The identification of units of meaning and their grouping into themes took into account the previously elaborated script of established dimensions, despite leaving open the possibility of including other dimensions besides those previously considered. For this analysis, NVivo 9 software was used.

Scientific rigor is guaranteed through research reliability, validity and reproducibility⁽⁹⁾, which the researchers intended to achieve in this case through: detailed description of the method used, transcription of all interviews, theoretical saturation and data and researcher triangulation. For data triangulation purposes, data collection at different times during the study was established, in different sections of the Maternal-Infant Unit, such as the Delivery Room, Neonatal Unit and Hospitalization Floor, by different interviewers and comparing different informants' reports. Researcher triangulation was based on teamwork and consisted in having three research team members serve as interviewers, while the entire team analyzed the data in line with the method proposed above.

Results and discussion

Nineteen health professionals participated in the study, 16 women and three men, between 26 and 48 years of age. The professionals belong to four different categories, with nine nurses, three midwives, five nursing auxiliaries and two obstetricians. Professional experience ranged between 5 and 20 years.

No neonatologist could be interviewed during the research because no neonatal death occurred within the first 28 days of life at the studied hospital. This is due to the fact that no Neonatal Intensive Care Unit (NICU)

was present at this provincial hospital center, so that all infants who needed this care were transferred to the referral hospital, where they died later. This aspect represents a study limitation.

Three essential and interlinked themes were identified: healthcare practice, feelings aroused by perinatal loss and meaning and beliefs about perinatal loss and grief. Also, various sub-themes were detected, including education on perinatal grief, knowledge on perinatal losses and grief, emotional strategies, guidelines, sensitization, assertiveness, humanization and evidence-based practice. Care practice was the main theme.

The results and discussion are presenting mentioning the theme category, explaining the most relevant findings and illustrating these findings with literal excerpts from the interviews, identifying the professional type through a code given to the interview, so as to guarantee anonymity and confidentiality of the collected data and, finally, in contrast with the respective scientific literature.

Healthcare practice

One fact verified in all interviews is that the care episode is experienced distinctly according to the professional category. The common trend for professionals in this study is to focus on physical care, avoiding the emotional aspect in the attempt to decrease their anguish. Therefore, they put in practice different mechanisms, attitudes and behaviors in the experience of these situations. As a result, on many occasions, their actions are not the most correct, reacting distantly, almost coldly and denying the severity of the loss, mainly in early pregnancies. The interviewed professionals' lack of strategies, skills and resources to face these situations and respond to the parents' demands is evidenced. They are not aware that an inadequate professional attitude can influence the correct evolution of the parents' grief and feel hardly prepared to establish an empathetic relation.

I do not usually enter the woman's room unless I have to measure the vital signs, install a catheter or medication, then I get in [lowers her voice further], but I do not ask her anything, I'm ashamed of not knowing what to say, [silence] I am not prepared to address the emotional aspects (EP10, nurse)

I don't go to the room often because I think I might bother her, but [lowers her eyes] that's the excuse I put up for myself (EP8, nursing aid).

Most of the times you forget about the psychological aspect and focus on the physical aspects, but that's because you

lack skills when you have to face the situation and do not know how to act or what to say, we are not empathetic enough with the woman and her partner (EP03, midwife).

This is much about the individual ability of the doctor-patient relation, I can be more or less humane but I don't master the theme. That's like when I'm facing a terminal patient and what are you going to do? You think about what focus to adopt, how to talk, but a bad obstetric result is not common of course and there are some emotional aspects I don't master (EP12, midwife).

You try to treat these patients a bit differently, special; but I have never considered that the fact that I treat her one way or another will modify her grief process (EP05, obstetrician).

The moment when bad news is given makes the professional responsible for this information feel anxious, the obstetrician, who sometimes compromises his competency and human worth by not knowing to what extent the way the news was communicated will help or hamper the grief process and will influence future doctor-patient relations.

The professional informant is always the doctor and, depending on his personality, he does this more or less delicately (EP17, nurse).

When you put on the monitor and do not hear the fetal heartbeat your face changes and the women notice that. I calm them down by saying that sometimes one cannot notice the heartbeat because of the position of the child's heart and that I'll let the doctor know in order to do an echo, but I don't inform them about my suspicions, that's for the doctor (EP07, midwife).

They notice the sorrow in your gestures and you tell them that there's no fetal heartbeat, that the fetus is dead. Then they no longer listen anymore because they start to cry and the first thing is always asking why and then they look for someone to blame (EP12, obstetrician).

You receive the first impact, because you're the one who has to give the bad news, you don't get accustomed to that and, hence, the way of giving the news depends on each professional's individuality (EP05, obstetrician).

The work⁽¹¹⁾ highlights these characteristics by affirming that, although the professionals make efforts to offer comprehensive and holistic care to the women and their partners, as a result of emotional or knowledge issues, common practical conducts sometime oppose humanistic modes based on the help relation.

The problems and difficulties that can affect care quality are related with lack of knowledge on the particularities of parents who were victims of a loss. In this sense, they express that education would facilitate their knowledge on the best possible evidence to accompany the parents in this process.

During your degree course they do not teach you the necessary strategies to provide support in these situations and experience is not enough in these cases, we need education (EP15, nurse).

Guidelines would be good, that would enhance a consensus and teamwork (EP03, midwife).

Workshops and courses with information and training about what to do and not to do (EP13, nursing auxiliary).

I don't believe that education is necessary, because we know intuitively how to manage these situations (EP05, obstetrician).

Thus, education appears as a challenge to be developed with regard to perinatal care and a cross-sectional issue in many other facets of professional work, like patient safety for example⁽¹²⁾.

Concerning delivery care in case of a dead fetus, the strategy followed is the humanization of the entire birth process, decreasing unnecessary interventions and respecting the woman and her partner's decisions with regard to intimacy, accompaniment and birth plan. The interviewed midwives find it difficult in their common practice to witness a fetal death, mainly in full-term pregnancies.

You need to humanize the delivery and make it easier as much as possible for the woman to feel comfortable, supported and informed by the midwife and gynecologist and be as little interventionist as possible (EP12, obstetrician).

We have to welcome their needs and offer them all possibilities, like analgesia, delivery position, accompaniment, etc. and let the woman decide (EP18, midwife).

The delivery of a dead fetus in advanced pregnancies is very hard, it is not a pleasant situation (EP05, obstetrician).

The crying is what I miss most [sad look], I am so accustomed to hearing the baby cry as soon as he's born, it's difficult, it overwhelms me (EP07, midwife).

A study⁽¹³⁾ reveals that, when the woman and her partner receive the option to decide on issues like birth induction, pain control or delivery position, this contributes to the normal development of grief and that, therefore, no correct decision can be made with regard to these issues, except for oversedation, which should be avoided.

Through the research, a central element in their actions is revealed, which is respect for the parents' decision about seeing and touching their child.

The parents have to decide, they say that it's better to show the child but if she doesn't want to I respect it (EP03, midwife).

They should say goodbye and the way to say goodbye is by seeing and touching the child (EP04, nurse).

The mother hardly sees the child, the father more, although I respect his decision to see the child I always wait to see how the child is born (EP07, midwife).

I always offer them to see the child, sometimes the parents do not want to and the grandmothers or uncles see him and, by the way, I prefer that someone sees him to avoid suspicions about whether the child was really dead or not (EP12, obstetrician).

Different reactions arose concerning whether to give the parents' keepsakes of the infant, appointing that they do not know to what extent these options can help the parents to endure the grief better.

I don't know how to offer these things, but if it occurs to the woman then yes (EP12, obstetrician).

This theme is more for the midwife, anyway, I don't know how this can benefit the parents, I wouldn't, but I respect other decisions (EP05, obstetrician).

I believe that photographs are not adequate, but I would do what the parents asked, the small packet of memories does not sound bad, but of course the parents have to decide on these issues (EP18, midwife).

It seems a bit macabre and unpleasant to take photographs, dress them and hold a wake with the entire family [indicates these issues trouble her]; I wouldn't want my entire family to see my macerated baby and even less take photographs, I wouldn't feel well (EP07, midwife).

There's a lot of prejudice on all this, but due to a great lack of knowledge on the theme (EF9, nurse).

Recommendations from scientific literature evidence that seeing and holding the infant and keepsakes like pictures, footprints and handprints or a lock of hair enhance the overcoming of grief⁽¹³⁾.

Feelings aroused by the perinatal loss

The participants not only mentioned feeling overwhelmed by the sorrow, frustration or impotence the parents feel who go through a perinatal loss situation, but their gestures and expressions also revealed this. These situations exert a strong emotional impact, as they do not only have to face their own feelings, but also those of the parents. Frequently, the emotional response is to avoid the situation in order to control professional stress.

It means facing death [becomes very thoughtful and lowers her voice] and it's difficult (EP01, nurse).

I attempt not to look her in the eyes [silence], never, I feel a lot, when the child is born, looking the mother in the eyes makes me feel so much (EF19, nursing auxiliary).

Our feelings do not get out, but the pain they go through affects me [touches her chest with her hand] (EP07, midwife).

Many parents complain about the solitude they experience in these situations, the fact is that the professionals react by moving away (EF05, obstetrician).

A significant relation also exists among the attitudes, reactions and feelings that involve the loss process and the weeks of pregnancy.

An abortion is not the same as a large fetus (EP06, auxiliary).

When the pregnancy is already advanced, the fact itself is already shocking (EP09, nurse).

If it's a spontaneous abortion of a few weeks I usually console the woman by saying [changes to a sweeter tone of voice] "do not worry, it's for the best, it could have a malformation", but in case of larger fetuses, on the other hand [indicates agitation, anguish] I know neither what to do nor to say (EP03, midwife).

Spontaneous abortions are so routine that sometimes we do not grant them due importance and do not show this (EP12, obstetrician).

The consulted bibliography reveals that perinatal loss exerts a strong emotional impact not only on the parents and their environment, but also on the care professionals⁽⁴⁾. Health professionals find it difficult to address adverse perinatal outcomes, which demands great emotional competency⁽¹⁴⁾.

The interviewed professionals manifest feelings of sorrow, anxiety, insecurity, resentment, guilt, rage, feeling of failure and impotence, which are mainly related with not knowing how to face and manage these situations.

I feel totally powerless for not know what to say in this situation (EP02, nurse).

I feel so much sorrow, I feel very sad (EP13, nursing auxiliary).

It is a mixture of everything, anxiety, rage, oppression, impotence and, hence, it takes you a week to think over the case, thinking about whether you did well (EP07, midwife).

This finding coincides with the findings of another study⁽¹⁵⁾, which in turn indicates that perinatal loss situations oblige professionals to use defense mechanisms like taking distance from desolated parents to protect their own emotional vulnerability, feeling incapable of accompanying and delivering care to the woman and her partner in this kind of losses.

Failure and guilt are feelings the obstetricians in this study face and which are strongly related with the duration of pregnancy and with the doctor-patient relation. The feeling of guilt increases with the number of pregnancy weeks so that, the more full-term the loss happens, the more the guilt experience increases.

Bad perinatal results are a bad experience [lowers her eyes], it is a feeling of rage, of frustration more than anything, you feel very powerless about what has happened and you ask if you could have done something to change this situation and you think over the case, asking yourself what might have happened. Besides, the closer to birth the loss happens, the more guilty you can feel and other factors also exert influence, like the degree of involvement during the pregnancy, because it's not the same when you see a patient for the first time while you're on duty and when you've controlled her during pregnancy, in the latter case you get emotionally involved and feel more frustrated and guilty and, for a couple of days, you feel restless [signs with her hands on her abdomen]. Until you digest this awful experience your morals are down, you feel a bit discouraged, but the worst is the impotence that you've done everything correctly and it has happened (EP12, obstetrician).

Very little is known about how perinatal losses affect obstetricians. In a study involving American obstetricians, it was observed that, in one year, these professionals could delivery care to 12 women having a spontaneous abortion and one or two cases of death before birth or infant death. That research highlighted the emotional repercussion of these losses on the obstetricians, particularly the feeling of guilt, mainly when the cause of death has not been justified⁽¹⁶⁾.

Meaning and beliefs about perinatal loss and grief

The participants perceive spontaneous abortion and delivery of a dead fetus as an actual loss for the parents. The meaning of the perinatal loss is related with the gestational age, which is why an early loss is not considered as the death of a baby, but the loss of illusions and expectations. As this situation is more common, they do not give it due importance. Late losses, in turn, are considered a very painful experience for the parents.

The impact is much greater the closer to birth it happens (EP05, obstetrician).

Early pregnancies do not receive that much importance [moves the shoulders and makes a gesture indicating this nuance], but it is very demanding to assimilate how a child about to be born can die (EP03, midwife).

It is an important loss, but it depends on the month of pregnancy one has reached, (EP14, nursing auxiliary).

It's a frustration of some expectations, a feeling of void and very difficult for the couple (EP04, nurse).

Literature shows that the parents gradually elaborate a number of expectations, promises, fantasies, dreams and illusions about the infant's arrival and that

technological advances permit an early bond between the parents and their child⁽¹¹⁾.

The interviewees' discourse showed that perinatal grief is a process the parents go through to overcome the loss. It is a natural and necessary process and each mother and father experience distinctly according to the gestational age, difficulties to conceive and the parents' own personality and family. The duration and manifestations of grief are in line with the weeks of pregnancy.

It is experienced distinctly according to the weeks of pregnancy (EP08, nursing auxiliary).

It is the response of the parents and family surrounding this child who dies, how they react to this (EP10, nurse).

It depends on many variables, it's not the same if it's your first pregnancy or you've already got other children or you've had other abortions and think you can't have any more children (EP18, midwife).

The duration depends on the weeks of pregnancy, some spontaneous abortions are inconsolable but, as the pregnancy advances and the perinatal loss happens closer to birth, the grief is much greater and deeper (EP12, obstetrician).

The psychosocial impact of perinatal loss has been widely studied in the last 25 years. These parents experience the same reactions of affliction as observed in other grief situations, which can even be more intense due to the lack of social visibility of perinatal grief⁽⁴⁾. Spontaneous abortion and fetal death are devastating experiences for the parents and some women go through great difficulty to recover after the loss⁽⁶⁾.

Final considerations

This research allowed us to understand the phenomenon of perinatal losses, based on the experience of the professionals involved in care delivery, revealing facets of its approach.

It should be highlighted that, when a perinatal loss occurs, all professionals at the Maternal-Infant Unit are involved in the process, which indicates the multidisciplinary nature of this kind of phenomena.

In this sense, accompanying and delivering care to parents who have suffered a perinatal loss is not something that should be improvised. Therefore, specific training is needed on perinatal grief, communication skills and help relation techniques. Education is the key that will allow health professionals to manage perinatal loss in a constructive way.

This study should be a source of reflection and encouragement towards the elaboration of a care guide

to deal with perinatal loss, reducing professionals' anxiety and offering more sensitive and empathetic care to the parents.

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