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Grief after fetal death: a voiceless mourning

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Abstract

The Ministry of Health advises that death certificates should not be issued in cases of fetal death for a pregnancy of less than 20 weeks or fetus weighing less than 500 g or shorter than 25 cm in height; however, the legislation allows the issuance of the certificate in cases where the family wishes to bury the fetus. Given this context, abortion cases in which the certificate is issued are few. This article presents an integrative review that answers the question: would the death ceremonies, particularly the burial (made possible by the issuance of the death certificate), in case of fetal death under 20 weeks of gestational age help in the parents' mourning process? The literature consulted presented favorable information for the issuance of the death certificate and enabled a medical, legal and anthropological discussion of the theme.

Keywords: Miscarriage. Grief. Fetal death.

Resumo

Pesar no óbito fetal: luto sem voz

O Ministério da Saúde orienta que a declaração de óbito não seja emitida em casos de óbito fetal com gestação inferior a 20 semanas ou feto com peso inferior a 500 g ou estatura menor que 25 cm, acrescentando que a legislação permite a emissão da declaração em casos em que a família deseje fazer o sepultamento do feto. Nesse contexto, são poucos os casos de aborto em que a declaração é feita. Este artigo realizou revisão integrativa que responde à pergunta: os rituais de fechamento, particularmente o sepultamento (possibilitado pela emissão da declaração de óbito) em caso de morte fetal inferior a 20 semanas de idade gestacional, ajudariam no processo de luto dos pais? A literatura consultada trouxe informações favoráveis à emissão da declaração de óbito e possibilitou discussão médica, jurídica e antropológica do tema.

Palavras-chave: Aborto espontâneo. Pesar. Morte fetal.

Resumen

Pesar por la muerte fetal: duelo sin voz

El Ministerio de Salud brasileño recomienda que no se debe emitir el certificado de defunción en los casos de muerte fetal de menos de 20 semanas de gestación, feto con peso inferior a 500 g o estatura inferior a 25 cm, pero agrega que se puede permitirlo cuando la familia opta por el entierro del feto. En este contexto, el certificado se emite en pocos casos de aborto. Este artículo realizó una revisión integradora a partir de la pregunta: ¿Ayudarían en el proceso de duelo de los padres los rituales de inhumación, sobre todo el entierro (habilitado mediante la emisión de un certificado de defunción) en caso de muerte fetal con menos de 20 semanas de edad gestacional? La literatura consultada aportó con informaciones favorables a la emisión del certificado de defunción y permitió fomentar la discusión médica, jurídica y antropológica del tema.

Palabras clave: Aborto espontáneo. Pesar. Muerte fetal.

Research

The authors declare no conflict of interest.

Is there a place where death LIVES? Ah, it lives in farewells, in rituals of closure, when finality is legitimized. But life remains in the place of forever, in the place where memories are kept, in a space of affects [1].

The arrangements to dispose of a fetal body in the event of demise vary worldwide. However, according to Laurenti and Jorge [2], several countries, Brazil included, have based their disposal procedures on the 10th Revision of the International Classification of Diseases (ICD-10) of the World Health Organization (WHO). In Brazil, issuance of a death certificate (DC) and consequent burial (or cremation) are mandatory in cases of fetal death at or over 20 weeks of gestation and/or fetus weighing over 500 g and/or measuring over 25 cm long.

If the fetal death does not fit these parameters, the Brazilian Ministry of Health (MS) and the Federal Council of Medicine (CFM) advise against the issuance of the death certificate. However, in practice, according to Brazilian legislation, there is no impediment to burial and issuance of the certificate depends on the parents' wish [3]. If they do not express any desire in this regard, the body will be sent to incineration.

Medicine is currently undergoing a very positive period of appreciation of doctor-patient communication skills. However, mothers who experience fetal loss commonly report little appreciation of their pain and do not feel supported by society in general, including healthcare providers and even family members [4].

Adequate guidance and listening to these women by healthcare providers can identify those for whom closure rituals and/or the possibility of keeping watch over their child's body and burying it are an important way of grieving, with positive therapeutic consequences [5,6]. And if maternal grief is undervalued, paternal grief is simply ignored by academia and medicine [7].

Iaconelli observes that (...) *the ritual with the corpse; its cleaning, clothing, watching over, cremation, all of that is absolutely anachronistic when considered objectively. Nonetheless, we do not dispense with this prolongation of the existence of the other as a way of grieving their loss. In perinatal bereavement* [in which the author includes bereavement related to fetal demise and stillbirth] *the desire of the parents to perform ritualistic procedures that are part of other kinds of loss due to death is not always heeded and, when carried out, invariably create some embarrassment. These differences in treatment reveal an impossibility of attributing to the death of a baby (pre- or post-term) the status of the death of a child* [8].

In view of the above, the following question arose: might closure rituals, especially burial (enabled by the issuance of a DC) in case of fetal demise under 20 weeks of gestation, help in the parents' grieving process? The objective of this work is to investigate this effect based on the literature.

Concepts and legislation

Brief theoretical background

It is important to point out some conceptual differences. Abortion is the expulsion or extraction of an embryo or fetus weighing less than 500 g (approximately 20 to 22 weeks of gestation), regardless of the presence or absence of vital signs. Fetal death is the death of the product of conception that occurs before its complete expulsion or extraction from the maternal body, regardless of the time of gestation. Death is confirmed when, following separation, the fetus does not breathe or show any other signs of life, such as heartbeat, umbilical cord pulsation or voluntary muscle movements [9].

As of ICD-10, WHO considered the gestational age of 22 weeks (weight equivalent to 500 g) as the lower limit of the perinatal period. According to Laurenti and Jorge [2], this new ruling greatly influenced CFM's decision-making that culminated in CFM Resolution 1,601/2000, which was amended by CFM Resolution 1,779/2005, according to which, *in the event of fetal death, the mother's attending physicians are obliged to issue a Death Certificate when the pregnancy lasts for 20 weeks or more or the fetus weighs 500 grams or more and/or measures 25 cm long or more* [10].

In addition, the Ministry of Health advises that the DC should be issued *when the child is born alive and dies soon after birth, regardless of the gestational age, the newborn's weight and how*

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long the child lived [3]. On the other hand, the DC should not be issued in the case of fetal death with gestational age under 20 weeks, or the fetus weighing under 500 grams or measuring under 25 centimeters long [3]. Lastly, the MH adds: *according to the current legislation, in practice, issuance of a DC is optional in cases where the family wants provide a burial for the fetus* [3].

The Brazilian National Health Surveillance Agency (Anvisa), through Resolution of the Collegiate Directorate (RDC) 222/2018, regulates healthcare waste. The following are classified as group A, subgroup A3: *human anatomical parts (limbs); product of fecundation with no vital signs, weighing less than 500 grams or measuring less than 25 centimeters long or with gestational age under 20 weeks, which has no scientific or legal value and has not been requested by the patient or their family members* [11].

Also according to Anvisa, *subgroup A3 healthcare waste must be disposed of by burial, cremation, incineration or other method licensed by the competent environmental agency*. (...) *When sent to incineration, the waste must be packed in red bags and identified with the label "ANATOMICAL PARTS"* [11].

According to article 14 of the aforementioned resolution, *bags used for Group A healthcare waste should be replaced when they reach the limit of 2/3 of their capacity or every 48 hours* (...), *regardless of volume, aiming at environmental comfort and the safety of users and professionals*. (...) *Bags containing easily putrefying Group A healthcare waste should be replaced every 24 hours at most, regardless of volume* [11].

Method

The study consists of an integrative review, following these steps: identification of the theme and formulation of the research question; definition of inclusion and exclusion criteria of articles; definition of the information to be extracted from the selected studies; evaluation and categorization of studies included in the integrative review; analysis and interpretation of results; and presentation of the review/synthesis of knowledge [12].

The databases used for the search were Virtual Health Library (VHL) and PubMed, using Health Science Descriptors (DeCS), with the search strategy "miscarriage and grief." The initial inclusion criteria for the publications were: research with humans, full text available for free in Portuguese or English, published in the last five years.

Based on those requirements, 37 articles were selected, of which 17 were excluded for being duplicates and 13 for not meeting the guiding question (three after reading the abstract and ten after reading the full article). Thus, the final sample was composed of seven articles capable of answering the research question.

Results and discussion

Charts 1 and 2 feature the analyses of the final sample.

Chart 1. Presentation of articles by authors, year of publication, setting and journal

	Authors; year	Setting	Journal
1	Cesare and collaborators; 2020 [13]	United States	*Paediatric and Perinatal Epidemiology*
2	Smith and collaborators; 2020 [14]	United Kingdom	*British Journal of Obstetrics and Gynaecology*
3	Obst and collaborators; 2020 [15]	Australia, Canada, United States, Europe, Middle East and United Kingdom	*BMC Pregnancy and Childbirth*
4	Miller, Temple-Smith, Bilardi; 2019 [16]	Australia	*PLoS One*
5	Bellhouse and collaborators; 2018 [17]	Australia	*BMC Women's Health*
6	Cassidy; 2018 [18]	Spain	*BMC Pregnancy and Childbirth*
7	Meaney and collaborators; 2017 [19]	Ireland	*BMJ Open*

Chart 2. Presentation of articles by objectives, type of study and results

	Objectives	Type of study	Relevant results to the research question
1	To characterize how users discuss the topic of "miscarriage" and "preterm births" on Twitter, analyze trends and drivers, and describe the perceived emotional state of women who have experienced a miscarriage.	Descriptive-exploratory study with a qualitative approach. A total of 291,443 posts in English were obtained (from 138,658 users) between January 2017 and December 2018.	The main topics of discussion were identified and combined, resulting in eight groups. Two tweets were selected as sample from each group. In the "Politics" group there is a tweet with the following: "It's awful that they classify this as a late miscarriage and therefore there is no birth/death certificate. This law needs to be changed!"
2	To explore the healthcare experiences of parents whose baby died before, during or shortly after birth, in order to identify practical ways to improve healthcare provision.	Qualitative study through analysis of narrative interviews with 38 parents: 10 couples and 18 mothers.	Parents report the difference between receiving an informal paper stating the death of their child and an official document declaring their death. For parents, while the informality of the hospital hurts and insults them, as it shows that there is no document capable of formalizing the situation, the official document confirms that they were parents and validates the birth of their babies, besides being important in the creation of memories that help in grieving.
3	To identify how men experience grief following pregnancy loss and neonatal loss and the factors and/or predictors that contribute to men's grief.	A systematic review of a final sample of 46 articles published between 1998 and October 2018.	Male parents reveal that rituals, symbolic objects and the sharing of memories help establish connections with their lost child.
4	To explore men's overall experience of miscarriage and the support received or neglected by both healthcare providers and social media.	A qualitative study through semi-structured interviews with 10 Australian men.	Male parents claim the death certificate confirms that the loss really happened and that, despite playing a small role, it helps in creating a memorial for the lost child as well as coping with grief.
5	To analyze the experience of women after miscarriage with a view to making the surrounding community aware of their need for emotional support.	A qualitative study through interviews with 15 women.	Some women reported missing some sort of memorial for their babies and feeling as if they didn't really exist for anyone else.
6	To evaluate the quality of care provided to women in the event of a diagnosis of intrauterine death or "life-limiting fetal anomalies" and a comparative assessment with other countries.	A cross-sectional descriptive study using an online self-completion questionnaire administered to 796 women who had experienced intrauterine fetal death between 16 weeks and birth, due either to late miscarriage/stillbirth or termination of pregnancy for medical reasons.	In 35.8% of the cases, the families had no choice or were denied any possibility of private burial or cremation, with a strong correlation with the gestational age of the fetus (in 70.1% of the cases, less than 26 weeks), in disagreement with Spanish legislation, which grants parents the power to decide on the fate of the fetus' body, regardless of gestational age.
7	To explore the experiences of miscarriage, focusing on the accounts of men and women.	A qualitative study—phenomenological framework—focusing on the report of 16 participants (10 women and 6 men).	Recognizing the loss of the child through rituals was important to mark the occasion or remember the child. For parents, one such ritual was a funeral or similar ceremony.

Chart 2 shows that the objectives of all selected articles were not directly or exclusively related to the guiding question of this integrative review, which was answered through the information contained in the results, which were invariably broader in the papers. Only one study (14% of the sample) was carried out exclusively with men, two (28%) were undertaken with women only and the rest involved both genders, in couples or separately. Using the method described, no Brazilian study was found that answered the research question.

All the articles in the sample provided information favorable to the issuance of a death certificate for the fetus, even below 20 weeks of gestation, although it was not possible to identify the percentage of family members who would recognize themselves as having benefited from such issuance.

Fetal loss is one of the most frustrating episodes in a woman's life. It is hard to cope with, besides being a professional failure for the obstetrician [20]. Thus, this healthcare provider may have difficulty to communicate the bad news and, as a result, the patient may feel helpless due to the lack of medical information.

Issuing a DC and offering a burial for the fetus are often avoided for fear of negatively affecting the statistics of the healthcare facility (hospital or maternity) or of the actual physician with intrauterine fetal demise (IUFD) data. There is a difference in notifications: miscarriages do not enter statistics, whereas IUFD does. Issuing the DC to allow burial requires a notification of fetal demise.

Although, as previously mentioned, current legislation provides that, *in practice*, *the issuance of the DC is optional for cases in which the family wants to carry out the burial of the product of conception* [3], this results in data being recorded for the healthcare provider.

According to data from the Information Systems Department of the Unified Health System (DataSUS), in 2019 there were 2,803 fetal deaths under 500 g in weight and 2,055 fetal deaths under 22 weeks of gestation [21]. This shows that the DC is issued in very few cases of miscarriage and that the burial of the fetus is hardly ever offered to the family as a possibility.

These data are from the Mortality Information System (SIM), managed by the Department of Health Situation Analysis of the Health Surveillance Department, together with the state and municipal health departments. These departments collect the DC from notaries and enter their information in SIM. Such data can then be sorted by location (such as hospitals and maternity hospitals) and entered in health service statistics. Many physicians may avoid offering fetus burial for fear that the data resulting from the issuance of the DC will have a negative impact on the service.

Discussion grounded in law and anthropology

Based on the results shown in Chart 2, it can be said that death and the relationship with people who pass away are part of human life. This is not linked to any specific religion or spirituality, but rather to human experience itself. It is not, however, a relevant fact only in the private sphere. Although the experience is in the personal sphere, there is an evident social transcendence, since the family is the nucleus of society.

Based on this premise, one may consider that the articles analyzed in this review meet this human dimension of a personal relationship with death. First, it is evident that this relationship cannot be privatized, that is, it cannot be viewed merely from the individual perspective of the people involved, but must have a social outlook and, to that end, political recognition. Thus, facts that have a public impact are usually imbued with solemnity and expressed with appropriate formality so that their social, political and legal importance is acknowledged.

Such relevance is indubitable in the case of fetal demise, for both the objective data, which contribute, for example, to analyzing birth rates and statistics on syndromes, and the subjective data, such as assessment of effective respect for dignity and human rights. Absence of public and legal recognition—manifested in the DC—denies the existence of a personal relationship, and even the fact that a person may suffer from the loss of a child during pregnancy. It is not a mere formality, but a social acknowledgement of something that exists and needs to be experienced.

Such acknowledgement enables parents, close people and society itself to take their farewell of loved ones through different ritualistic and symbolic forms of farewell, of mourning. Thus, it is possible to establish a much healthier relationship from the human point of view—considered in the integrity of the material and spiritual dimension—which makes it possible, once the grief of loss is overcome, to establish memories of the period of human relationships of the moments they experienced together. In addition, spirituality itself—regardless of the way it is lived—is reinforced in the actual experience of human relationships, whether during the life or after the demise of these loved ones.

That is why it is essential to strengthen a support network to help with the experience of loss. Thus, one expects a disposition towards giving a new meaning to the grieving process, attributing dignity to suffering and helping overcome it. To this end, there is no legal obstacle that prevents the creation of memory through the formalization of death, since, based on the principle of legality as established in Article 5, II, of the Federal Constitution, *no one will be obliged to do or refrain from doing anything other than by virtue of law* [22].

There is a natural right to bury and keep watch over the dead, as well as the ethical and legal recognition of the human nature of the fetus. Indeed, the Pact of San José (or the American Convention on Human Rights, introduced in Brazilian legislation by Decree 678/1992) [23] provides, in Article 4(1), the right to respect for life, which is protected by law and, in general, from conception.

Hence is the human nature of the fetus recognized, as well as the right to have its life and dignity respected. Likewise, the need to support the family is acknowledged, especially as its awareness of the legal system and medical deontology is insufficient.

Lastly, it is necessary to understand that the social recognition offered by the DC, which enables rites and symbols of a funeral farewell, does not grant the state the right to determine how this should be experienced. It will always be a deeply personal reality, marked by the parents' beliefs and decisions, which cannot be disregarded in the decisions of which rituals and symbolic forms should be used in this farewell. This emphasizes the relevance of the solemn acts to celebrate the existence of the child, making it possible to remember them in the intimacy of each family, which, being the nucleus of society, extends this celebration to society as a whole.

Final considerations

Some parents who have experienced fetal death, even before 20 weeks of gestation, recognize in the issuance of the DC important effects on their grieving process, including before society. Supporting and identifying these parents are made possible by the communication skills of the physician. It is very important to discuss whether potential professional concerns about healthcare service statistics stemming from the issuance of fetal death certificates negatively influence the legitimate need to support these parents in coping with grief.

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