

Various types of grief and emotional impacts during pregnancy with a diagnosis of hydatidiform mole

Lutos diversos e impactos emocionais na gestação com diagnóstico de mola hidatiforme

Diversos duelos e impactos emocionales del embarazo con diagnóstico de mola hidatiforme

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Abstract:

Objective: to understand and reflect on grief and hydatidiform mole based on publications in the area. **Methods:** narrative review based on the Virtual Health Library database in October 2023, using the descriptors: *doença trofoblástica gestacional* (gestational trophoblastic disease), *aspectos psicológicos* (psychological aspects), *mola hidatiforme* (hydatidiform mole), *luto materno* (maternal grief), *psicanálise* (psychoanalysis), *perda precoce da gravidez* (early pregnancy loss), and *aspectos emocionais* (emotional aspects). Articles, theses, and dissertations fully available in Portuguese or English, published in the last five years were considered. The analysis of the studies was done through critical reading, considering objectives, methods, and results relevant to the topic, with the creation of a core of meanings. **Results:** the *corpus* of this article included nine studies that reflected on how the diagnosis of Hydatidiform Mole impacts pregnant women. Three core of meanings were constructed: *Perinatal grief versus grief due to hydatidiform mole*; *Psychological factors and emotional reactions to hydatidiform mole*; *Mechanisms for coping with grief and support for pregnant women with hydatidiform mole*. **Conclusion:** the most frequent symptoms associated with grief experienced in pregnancy loss due to hydatidiform mole were anxiety and depression. Reference Centers are indicated to provide appropriate treatment. Among health professionals, Psychology is the category that has the greatest potential to contribute with the most qualified support and prevent the impacts of these losses.

Keywords: Gestational trophoblastic disease; Hydatiform mole; Psychology; Stress, Psychological; Bereavement.

Resumo:

Objetivo: conhecer e refletir sobre luto e gestação molar a partir de publicações na área. **Método:** revisão narrativa a partir da base de dados da Biblioteca Virtual em Saúde em outubro de 2023, utilizando os descritores: *doença trofoblástica gestacional*, *aspectos psicológicos*, *mola hidatiforme*, *luto materno*, *psicanálise*, *perda precoce da gravidez* e *aspectos emocionais*. Considerou-se artigos, teses e dissertações disponíveis em português ou inglês, na íntegra, publicados nos últimos cinco anos. A análise dos estudos foi feita por meio de leitura crítica, considerando objetivos, métodos e resultados relevantes ao tema, com a criação de núcleo de sentidos. **Resultados:** o *corpus* deste artigo incluiu nove estudos que refletiram como o diagnóstico de Mola Hidatiforme impacta as gestantes. Construiu-se três núcleos de sentidos: *Luto perinatal versus luto pela gestação molar*; *Fatores psicológicos e reações emocionais à mola hidatiforme*; *Mecanismos de enfrentamento ao luto e suporte às gestantes com mola hidatiforme*. **Conclusão:** os sintomas mais frequentes associados ao luto vivenciados na perda gestacional da mola hidatiforme, foram os estados ansiosos e depressivos. Os Centros de Referência são apontados para se fornecer o tratamento adequado a esta enfermidade. Dentre os profissionais da saúde, a Psicologia é a categoria que tem o maior potencial de contribuir com o suporte mais qualificado e prevenir os impactos destas perdas.

Palavras-Chave: Doença trofoblástica gestacional; Mola hidatiforme; Psicologia; Estresse psicológico; Luto.

Resumen:

Objetivo: conocer y reflexionar sobre el duelo y el embarazo molar a partir de las publicaciones en el área. **Método:** revisión narrativa a partir de la base de datos de la Biblioteca Virtual en Salud en octubre de 2023, utilizando los descriptores: *doença trofoblástica gestacional* (enfermedad trofoblástica gestacional), *aspectos psicológicos*, *mola hidatiforme*, *luto materno* (duelo materno), *psicanálise* (psicoanálisis), *perda precoce da gravidez* (pérdida precoz del embarazo) y *aspectos emocionais* (aspectos emocionales). Se consideraron artículos, tesis y disertaciones disponibles en portugués o inglés, completos, publicados en los últimos cinco años. Los estudios se analizaron mediante lectura crítica, teniendo en cuenta los objetivos, métodos y resultados relevantes para el tema, con la creación de un núcleo de significados. **Resultados:** el *corpus* de este artículo incluyó nueve estudios que reflexionaban sobre cómo afecta el diagnóstico de la mola hidatiforme a las mujeres embarazadas. Se construyeron tres núcleos de significado: *Duelo perinatal frente a duelo por embarazo molar*; *Factores psicológicos y reacciones emocionales ante la mola hidatiforme*; *Mecanismos de afrontamiento del duelo y apoyo a las embarazadas con mola hidatiforme*. **Conclusión:** Los síntomas más frecuentes asociados al duelo experimentado durante la pérdida gestacional de la mola hidatiforme fueron la ansiedad y la depresión. Se han identificado Centros de Referencia para proporcionar un tratamiento adecuado a esta enfermedad. Entre los profesionales sanitarios, la psicología es la categoría con mayor potencial para proporcionar el apoyo más cualificado y prevenir el impacto de estas pérdidas.

Palabras-Clave: Enfermedad trofoblástica gestacional; Mola hidatiforme, Psicología; Estrés Psicológico, Aflicción.

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Gestational trophoblastic disease (GTD), is a spectrum of cell proliferations arising from the placenta. Its most common and benign form is hydatidiform mole (HM), also known as molar pregnancy¹. GTD is characterized by a gestational anomaly that occurs from aberrant fertilization². Data indicate that 80% of pregnancies with GTD are hydatidiform mole³.

Since this is an uncommon condition, the responsibility for treating the disease lies with the Reference Centers (RC). These locations are recognized by the Brazilian Association of Gestational Trophoblastic Disease and the Brazilian Ministry of Health for appropriate intervention in cases of GDT⁴.

The incidence and etiological factors of hydatidiform mole are difficult to determine. Issues in gathering reliable data can be attributed to several causes, such as inconsistencies in case definitions, inability to adequately characterize the population at risk, lack of centralized databases, lack of control groups with which to compare risk factors, and rarity of the disease⁵.

In this sense, epidemiological studies report wide regional variations in the incidence of hydatidiform mole. HM has a frequency of 1 case for every 1000 pregnancies in North America and Europe⁶. In Brazil, the incidence is approximately 2 to 3 times higher. A molar pregnancy normally begins with the same aspects as a normal pregnancy, including a positive test for the hormone human chorionic gonadotropin, known as hCG⁶.

After a positive result for HM, immediate uterine evacuation is recommended, thus preventing the development of more serious cases of the disease, such as Gestational Trophoblastic Neoplasia (GTN)⁷. Post-molar monitoring is essential and contraceptive measures are essential to avoid a new pregnancy, where placental hCG would not allow the differentiation of hCG of tumoral origin⁸.

Regarding studies correlating GTD and emotional impacts, it is worth highlighting the scarcity of research, especially in the field of psychology. Medicine has focused on discussing the physiology behind this disease, but there are few studies that cover its psychological impacts. Another aspect, however, no less important, is the fact that society knows little about this condition⁹ and there is a lack of data that measures the social impacts resulting from the disease and its treatment.

Hydatidiform mole is often confused with incomplete or missed miscarriage. It is an uncommon gestational pathology that subjects women to two simultaneous loss conditions: the loss of the pregnancy and the loss of ideal health. In this sense, in a condition such as HM with

all its emotional component, some mourning is imposed on the lives of those who receive such a diagnosis¹⁰.

The subject in the grieving process experiences something like an exclusive dedication to the memories of what was lost, losing interest in other aspects of life¹¹. Loss of any kind generates the feeling of mourning, being particularly notable in the context of molar pregnancy¹².

Regarding the processes of pregnancy loss, there are many difficulties in coping with grief, and therefore it is important to offer listening to families who are going through this moment¹³. The role of the Psychology professional in providing care to pregnant women is extremely important for promoting the health of these women¹⁴.

The care received from those working in health after a pregnancy loss can have lasting effects and influences on parents experiencing grief¹⁵. From this perspective, health services can be considered an extremely essential part of social resources and a great support in managing these cases.

Understanding the different impacts, demands and grieving processes of pregnant women who suffer from a disease such as HM is important so that professionals can be trained to act in the management of cases, and to think of ways to support and cope not only for women, but for families and society as a whole. With this in mind, this study aims to understand and reflect on grief and hydatidiform mole based on publications in the area.

METHODS

This study is a narrative review, a method adopted in academic research because it offers a comprehensive view of the current state of knowledge in a given field. It allows for the critical synthesis of a variety of topics, facilitating the analysis of concepts and theories in a contextualized and descriptive manner¹⁶.

This study followed a six-step process for its completion: definition of the central question that guides the investigation; research in existing publications; data collection from the selected studies; critical analysis of the data; discussion of the findings and presentation of the review.

The research universe encompasses published studies on the emotional impacts of a molar pregnancy and what sheds light on ways of managing cases. The main aim was to understand the grieving processes experienced by pregnant women who face a diagnosis of hydatidiform mole.

The search was carried out in October 2023, and the survey was carried out through the Virtual Health Library (VHL) with searches in the databases of the Latin American and Caribbean Health Sciences Literature (LILACS) and the International Literature in Health Sciences (MEDLINE). The guiding question was: “How can psychologists and psychoanalysts act in the emotional support of pregnant women with hydatidiform mole, assisting them in a possible grieving process?”

The following descriptors were used for the search: “*doença trofoblástica gestacional*” (“gestational trophoblastic disease) AND “*aspectos psicológicos*” (psychological aspects); “*mola hidatiforme*” (hydatidiform mole) AND “*luto materno*” (maternal grief); “*doença trofoblástica gestacional*” (“gestational trophoblastic disease) AND “*luto materno*” (maternal grief); “*doença trofoblástica gestacional*” (“gestational trophoblastic disease) OR “*mola hidatiforme*” (hydatidiform mole) AND “*psicanálise*” (psychoanalysis); “*perda precoce da gravidez*” (early pregnancy loss) AND “*luto materno*” (maternal grief) AND “*aspectos emocionais*” (emotional aspects).

The inclusion criteria were: articles, theses and dissertations available in Portuguese or English, fully available, published in the last five years. And as exclusion criteria: duplicate research and research that did not correspond to the object of the study.

This research was approved by the Ethics and Research Council (CEP) of the Maternidade Escola da UFRJ, under number 6,137,126.

RESULTS

From an initial search of 116 articles, 9 were considered for reading in full, as shown in Table 1, which demonstrates the process of searching, selecting and screening the articles.

Table 1. Search, selection and screening of studies. Rio de Janeiro/RJ, Brazil, 2023.

Search Terms	a+b	a+d	c+d	a “or” c + e	f+d+g	Total	Excluded
Results	28	0	2	0	86	116	-
Published between 2018 and 2023	8	0	0	0	14	22	94*
In Portuguese or English	8	0	0	0	14	22	-
Selected after reading title	5	0	0	0	6	11	11***
Available in full	4	0	0	0	6	10	1****
Selected after reading abstract	4	0	0	0	6	10	1***
Selected after reading full text	4	0	0	0	5	9	-

Key: a. gestational trophoblastic disease; b. psychological aspects; c. hydatidiform mole; d. maternal grief; e. psychoanalysis; f. early pregnancy loss; g. emotional aspects. *Outside specified publication period **Different Language ***Studies that did not correspond to the study objective and duplicates **** Paid Studies

The studies selected to integrate the *corpus* of this research are presented in Chart 1 below, according to their authors, year of publication, objective(s) and main results.

Chart 1. Characteristics of selected studies on various types of grief and emotional impacts on pregnancy with a diagnosis of hydatidiform mole. Rio de Janeiro, RJ, Brazil, 2023.

Author/Year	Objective(s)	Results
Tenório, Katz, Amorim 2023 ¹⁷	Analyze symptoms of anxiety and depression in women with GTD and women who have had a miscarriage	Lack of partner support and low education are risk factors for anxiety and depression, symptoms were high in both groups
França <i>et al.</i> 2022 ¹⁸	To assess emotional and clinical aspects in women with GTD monitored at a referral center by a multidisciplinary team	Depression and anxiety were more frequent in women over 40 years old, with less education, who developed GTN, who required chemotherapy with multiple agents or hysterectomy
Blok <i>et al.</i> 2021 ¹⁹	Assess the short-term psychological consequences of GTD	Anxious feelings were more frequent than depressive ones, 88% of patients had moderate to severe adjustment problems. Patients with previous pregnancy loss had lower distress scores than those without loss.
Di Mattei <i>et al.</i> 2021 ²⁰	To investigate mental representations of illness, coping and psychological distress in women with GTD	Avoidant coping can lead women to develop emotional representations of illness typified by negative affects, which consequently increase levels of distress
Bohn 2023 ²¹	Discuss how certain terms used by healthcare professionals can increase patient guilt and shock	The topic should be discussed carefully with patients and families. Changing the language to describe intrauterine death and premature birth clearly and accurately helps to mitigate disenfranchised grief, guilt and shock, and makes it more obvious why certain stages occur.
Vescovi <i>et al.</i> 2022 ²²	To investigate the process of constructing meanings of pregnancy loss in 11 couples	There was a lack of meaning in the death, strengthening the bond between the couple and relatives. Spirituality was the main coping strategy. The process of constructing meaning was similar to that of other losses.
Smith <i>et al.</i> 2020 ²³	To explore the healthcare experiences of parents whose babies died before, during and after birth to identify what could be improved	Parents who were told they were “losing a baby” rather than “miscarrying” were more prepared for the realities of labor, the birth experience, and deciding whether to see and hold their baby. Using appropriate terminology is vital to validating loss and preparing for the labor and birth experiences.
Watson <i>et al.</i> 2019 ²⁴	Report personal experiences of perinatal grief and the support of health professionals	Most families felt they did not receive enough information, support and professional care. More than half experienced stigma from healthcare professionals and many believed they were not well prepared to care for them.
Wool e Catlin 2018 ²⁵	Provide an overview of perinatal bereavement services in the health system and their areas of improvement	Integrating the care system increases quality, safety and patient satisfaction. Regardless of where the contact occurs in the health system, bereavement support should be provided for respectful care at all levels.

DISCUSSION

From the articles collected, three core meanings were constructed: *Perinatal grief versus grief due to hydatidiform mole*; *Psychological factors and emotional reactions to hydatidiform mole*; and *Mechanisms for coping with grief and support for pregnant women with hydatidiform mole*.

Perinatal grief versus grief due to hydatidiform mole

Regarding pregnancy loss in general, a study showed that spontaneous abortion (miscarriage) is the most common obstetric complication during pregnancy, and that approximately 15% of identified pregnancies result in miscarriage¹⁷. Thus, GTD would be an obstetric complication that culminates in early pregnancy loss. The morphology and clinical issues related to pregnancy loss are well documented, however, the emotional impacts only began to be exposed in a considerable way in the 1980s and 1990s, with the rise of research on grief¹⁷.

The experience of losing a child or giving birth to a premature baby are traumatic experiences in themselves. However, intrauterine death incurs additional psychological damage. Patients who lose their babies while still pregnant often suffer from disenfranchised grief. This loss is not or cannot be openly acknowledged, socially supported or publicly mourned²¹.

When it comes to GTD, a double mourning is required: mourning for the loss of pregnancy and for the loss of health. This context requires an adaptation that includes not only the loss of the pregnancy, but also the possibility of surgery, chemotherapy treatment, among other health considerations¹⁷.

Another study indicates that parents grieving a pregnancy loss are underrepresented in grief studies²². PG imposes unique characteristics that need to be investigated through research aimed at this audience. Despite its great psychosocial impact, there is a reluctance to discuss this issue²². In the HM, it is worth adding that little was found about the social implications of this illness.

Common sense understands mourning due to intrauterine death as something less stressful and quickly resolved when compared to other types of mourning²². In the mourning processes in HM, recognizing the place of the disease and considering a path of mourning becomes difficult to some extent, starting with the fact that often the pregnant woman herself is unaware of her condition, as is the family.

Pregnancy loss contributes to a feeling of helplessness in regards of the dream and can be a circumstance surrounded by profound silence, often experienced in solitude¹⁷. Thus, few studies point to the importance of talking about the losses represented in a diagnosis of HM. Definitely, the specific grief of HM is not covered in the publications.

Psychological factors and emotional reactions to hydatidiform mole

Women diagnosed with GTD experience a sudden change in their lives, going from feelings of joy, normally associated with pregnancy, to feelings of anguish and worry brought on by a potentially fatal diagnosis²⁰.

Some studies also state that the difficulty that many pregnant women have in understanding the diagnosis, in addition to the uncertain prognosis, contributes to social and psychological impacts that follow the treatment of the disease^{17,18}. The psychosocial impacts must be observed so that multidisciplinary teams can improve the approach and directions of the treatment adopted^{17,18}.

For the assessment, standardized questionnaires such as quality of life, assessment of depressive symptoms, satisfaction with life and WHO quality of life scales were applied¹⁸. However, even with results indicating quite expressive emotional symptoms, it is proposed that, for a more detailed assessment of the psychological impact of the disease, qualitative tests should be used, focused on issues such as anger, grief and death, the possibility of getting pregnant again and the impact of not being able to have another child in the short term.

In a study involving thirty-eight women diagnosed with GTD, of whom 18 had hydatidiform mole, they were asked to complete a revised illness perception questionnaire, a guidance on coping with the problems experienced, a state-trait anxiety inventory (Y form) and the Beck's depression inventory (short form). In addition, demographic and clinical information was collected through self-report²⁰. Avoidant coping, which is a process that involves the way in which the subject manages, cognitively and behaviorally, internal or external demands that arise from a stressful situation, was significantly linked to symptoms of anxiety and depression, as well as with other emotional reactions to the disease. Avoidant coping contributed to the presence of negative affects, which in turn increased the level of distress²⁰.

Another prospective multicenter observational cohort study sought to assess the psychological impact of gestational trophoblastic disease in the Netherlands, with sixty patients with GTD, included between 2017 and 2020, applying the following instruments: Hospital Anxiety and Depression Scale, Distress Thermometer, Impact of Event Scale, and Reproductive Concern Scale¹⁹.

The results of this research showed that anxiety symptoms (27%) were less present than depressive feelings (47%); 88% presented moderate to severe adjustment problems; childless patients presented greater concern about reproduction; pregnant women with previous losses had higher scores in distress than those who had never lost a baby; and women with children still in infancy and alive had lower distress rates¹⁹.

All studies indicated that the most common emotional impacts on women experiencing molar pregnancy are depression and anxiety. Lack of support from a partner was found to be a risk factor for anxiety and depression, while low levels of education contributed to a 3.43-fold increase in the risk of symptoms of depression after pregnancy loss¹⁷.

The social role of women, historically linked to their reproductive capacity, when placed in a position that completely deviates from expectations, can give rise to feelings of failure, guilt and shame. The emotional impact of the loss of fertility is often reported as a devastating experience¹⁷.

The diagnosis of GTD has a substantial effect on the well-being of patients soon after diagnosis. Careful follow-up for a long time after the disease is still needed. The psychosocial aspects involved need greater attention and implementation of intervention measures to address persistent mental disorders during this period of mourning, avoiding emotional sequelae, future reproductive problems and additional health care costs. Almost all the studies here indicate that research needs to be advanced regarding the emotional impacts of a diagnosis of gestational trophoblastic disease.

Mechanisms for coping with grief and support for pregnant women with hydatidiform mole

Healthcare professionals can make a positive difference in how a loss is experienced and in the overall well-being of those involved in the process. Many families report that they felt they were not adequately informed, supported and cared for by healthcare professionals when they were going through a grieving process²⁴.

Ongoing support, especially from the psychology team, can help to recognize the impact of loss, minimize uncertainty and isolation, and reduce the stigma experienced by grieving families. Providing consistent, high-quality bereavement care helps to create a culture of compassion and improve the experience of the patient and family²⁵.

Another study indicated that health services, based on active listening, need to use the parents' preferred terminology regarding the loss²³. Parents who were given terminology such as "baby loss" instead of "miscarriage" were more prepared regarding the reality of grief.

Most research has indicated that GTD Reference Centers are the places that will provide adequate multidisciplinary care to pregnant women with all types of Gestational Trophoblastic Disease. The RCs are able to direct care towards the physical and emotional recovery of pregnant women, in addition to preserving fertility and improving quality of life¹⁸.

Doctors, who are usually the patient's first contact with the process of understanding what the disease is, need to be aware of the emotional consequences, with a view to assessing the psychological course over time and recommending personalized psychological support for patients who maintain high levels of suffering¹⁹.

From a clinical point of view, it is important to promote adaptive coping strategies that adjust to the patient's demands; as well as to provide accurate data on the mental condition, for a better psychological adjustment to the feelings that may arise from such an emotionally difficult condition²⁰.

CONCLUSION

The most frequent symptoms associated with grief experienced in pregnancy loss due to Hydatidiform Mole were anxiety and depression. Reference Centers are the places that should provide the appropriate treatment for this disease. Among health professionals, Psychology is the category that has the greatest potential to contribute with the most qualified support and prevent the impacts of these losses.

Gestational trophoblastic disease is a disease that encompasses a wide range of conditions resulting from the abnormal development of placental tissue. Although the diagnosis usually offers a high chance of cure, dealing with the emotional impact that this condition can cause is usually complex for women.

Although hydatidiform mole is not very representative from an epidemiological perspective, for women to experience a grieving process, it is necessary, as it involves a place of loss and confrontation with life and death. Thus, some mourning needs to be worked through. The mourning of the expectation of pregnancy, the mourning of the absence of a baby, the mourning of facing a disease that can evolve into more severe conditions and the changes regarding sexuality and fertility. There is a lack of publications that address the mourning present in an issue such as HM.

Some pregnant women are completely unaware of the disease, as it is not widely publicized. In this sense, HM can be a disease that affects women socially. Although this information was not found in the studies, clinical practice reveals that there are numerous

social impacts at work and often various forms of abuse due to the fact that women need to be absent at least once a week for treatment.

It was also found that few studies with psychological interpretations have been published regarding the emotional impacts of hydatidiform mole, which constitutes one of the main limitations of this study. There is a shortage of materials that offer strategies for dealing with this peculiar and painful issue.

It is worth noting that no study representing Psychoanalysis was found in the research, which reflects another limitation. Despite this scarcity of productions that address this topic, indications of psychotherapy and therapeutic groups emerge as support and treatment measures for pregnant women with HM.

In addition to the scope of obstetric medicine, a multidisciplinary approach can be of great value in the treatment of moles. Psychology can contribute with listening and educational work, emotional support after intrauterine aspiration, support for pregnant women and support for family members.

The fact that GTD is not a very common condition does not exempt the need for care measures for women who are going through it. It is necessary to investigate more deeply the psychological impacts of gestational trophoblastic disease and its nuances, in addition to understanding the grieving process of pregnant women with HM, which suggests some specificities.

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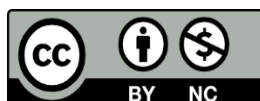
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