

# Psychological Aspects Influencing Perception of Illness in a Rare Pregnancy-Related Tumor

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## Background

Gestational Trophoblastic Disease (GTD) is an extremely rare condition; our clinic in the San Raffaele Hospital, in Italy, is a reference center at the national level for the diagnosis and the treatment of this disease. GTD encompasses a group of pregnancy-related tumors that can be both benign and malignant and lead to an abnormal development of the placenta after conception. The benign form is called hydatidiform mole or molar pregnancy; the malignant forms (Gestational Trophoblastic Neoplasia: GTN) include: malignant invasive mole, choriocarcinoma, placental site trophoblastic tumor and epithelioid trophoblastic tumor. All forms of GTD can be treated and many cases (80%) are cured completely [1].

An interesting aspect of GTD is that it can be detected via a biological tumor marker (human chorionic gonadotropin:  $\beta$ -hCG). Weekly  $\beta$ -hCG level monitoring is indicated until undetectable (<5 mIU/ml) for 3 weeks, then monthly for at least 6 months. If the patient undertook a chemotherapy treatment, the  $\beta$ -hCG level monitoring is longer, up to 1 year [2]. During this period, women are advised not to become pregnant and to practice contraception; the  $\beta$ -hCG production in pregnancy can indeed hamper detection of post-molar progression to GTN [3].

Even though a complete recovery is usually expected, women diagnosed with GTD have to go through losing a pregnancy, acquiring a potentially life-threatening diagnosis, and being subjected to surgery and/or chemotherapy treatment [4]. Consequently, GTD diagnosis, treatment and follow-up represent a sudden and prolonged factor of stress, which obligates the patient and her partner to find a new psychological accommodation [5].

In the past our lab group has done much research on GTD and its psychological outcomes, including examining patients' anxiety and depression [6]. We found that women suffering from GTN had higher depression scores compared to women suffering from molar pregnancy. Patients with GTN undergo chemotherapy, whereas those with molar pregnancies do not. This result is consistent with previous cancer research whereby this difference may be due to more tiredness, more limitations in daily activities and the treatment of side effects, which could lead to more pain and distress in this group of women [7]. These women could therefore perceive their disease as more serious and perhaps feel a greater threat to their life.

## The Study

In light of these considerations, using Leventhal's Common-Sense Model [8,9] as a theoretical framework, we tried to investigate patients' perceptions with respect to their condition [10]. In total 31 women

took part in the study. Although that may seem like a small sample size, GTD is very rare and we believe the study is pertinent. Patients were asked to complete the Illness Perception Questionnaire-Revised (IPQ-R) [11] to measure: illness Identity, illness Opinions and the factors personally considered as possible causes of GTD. The age range of our sample was from 16 to 56 years (mean age=35.97; SD=9.745). The mean time elapsed from the moment of diagnosis to questionnaire completion was 4.65 months (range=1-25; SD=4.652).

	HM		GTN		
	N	%	N	%	$\chi^2$
<b>Marital status</b>					.22 (.90)
<b>Married</b>	19	82.6	6	75	
<b>Cohabiting</b>	2	8.7	1	12.5	
<b>Single</b>	2	8.7	1	12.5	
<b>Profession</b>					1.7 (.63)
<b>Employed</b>	17	73.9	6	75	
<b>Freelancer</b>	3	13	0	0	
<b>Unemployed</b>	1	4.3	1	12.5	
<b>Student</b>	2	8.7	1	12.5	
<b>Presence of children</b>					.09 (.77)
<b>Yes</b>	10	43.5	3	37.5	
<b>No</b>	13	41.9	5	62.5	

**Table 1:** Patient- and illness-related characteristics separated by type of diagnosis (adapted from Di Mattei et al., 2016) HM=hydatidiform mole group (N=23); GTN=gestational trophoblastic neoplasia group (N=8); p-values in brackets.

Our results showed that there was a significant difference between patients with the benign forms of the disease compared to the malignant forms, whereby women affected with GTN reported a significantly higher score on the Identity subscale. This result seems to indicate a real difference between the two diagnoses with regards to the clinical presentation and women's perception of illness. Molar pregnancies, usually diagnosed during the 1<sup>st</sup> trimester of pregnancy, present as pregnancy failure and are often asymptomatic. In GTN, bleeding due to uterine perforation or metastatic lesions may result in abdominal pain, hemoptysis or melena. Moreover, patients may have

central nervous system metastases, which may cause headaches, seizures, or hemiplegia. Further, patients may present with pulmonary symptoms, for example dyspnea cough and chest pain, caused by extensive lung metastases [12]. Although these specific symptoms are not directly measured by the IPQ-R questionnaire, we hypothesized that the more severe clinical presentation of GTN, together with the more invasive treatment (chemotherapy or hysterectomy), may affect patients' illness Identity representations, which are more serious in GTN when compared to hydatidiform mole.

We also found high mean scores on the Emotional representations and Treatment control subscales of the IPQ-R. High scores indicate a response to illness characterized chiefly by negative emotions, reflecting intense emotional reactions that a disease, such as cancer, can invoke. Fear and anxiety, together with symptoms of abandonment and anger, invoked from the sense of vulnerability and loss of control of one's life, represent the most frequent psychological reactions when a person discovers a potentially lethal disease and its consequent treatment. With respect to Treatment control the high scores demonstrated confidence and a certain degree of control over the treatment.

Furthermore, a significant correlation emerged between "time since diagnosis" and the Treatment control subscale. This result is in contrast with previous research and our study can be interpreted in light of the fact that a specific service and psychological support are offered to the patients by the healthcare staff at this hospital in Italy. The presence of a multidisciplinary team (gynaecologists, nurses, and psychologists), which supports patients from diagnosis to the end of follow-up could promote a more supportive climate that welcomes insecurities, misunderstandings, and emotions tied to GTD. The constant contact with medical and psychological staff could contribute to a more realistic illness perception as well as a willingness to have confidence in treatment and future fertility, and also acquisition and reinforcement of self-efficacy. This could, in time, help develop a higher confidence in treatment effectiveness and a perceived control over treatment.

## Implications

This study was the first to investigate illness perception in Gestational Trophoblastic Disease, and despite its limitations concerning sample size it provides a detailed description of the mental representations that patients with GTD have of their illness. These representations have certainly been influenced by the information patients receive from significant authoritative figures (such as doctors or nurses), but they may also depend on cultural beliefs that surround the illness (that may be incorrect) and on the experience that an individual goes through regarding this illness [8]. The presence of more symptoms, for example, could influence one's illness perception (as was found in our study) and could determine a belief of increased severity and pervasiveness.

Furthermore, the relevance of such a construct is also tied to the fact that mental representations of illness are associated to coping mechanisms (adaptive or maladaptive) that a patient implements to try to manage the sudden onset of this disease [13], to recover functionality [14], and to adhere to the treatment regimen prescribed by the oncologists [15].

With this in mind, it is important that the entire treatment team understands how a woman with GTD perceives her condition, in order to: confront any possible misconceptions, reconceptualise expectations and fears, and favour an adaptation to the condition, which for the

majority of patients is only transient. This could require clinicians to adopt a different approach with these patients and to the medical examination; the acquisition of certain skills and communication abilities that are useful for exploring illness perceptions in patients and their implications are important.

A particularly important aspect for patients affected with GTD is represented by the perception of their fertility. Patients with GTD and GTN can expect to achieve complete remission while retaining their fertility [1]. A systematic review demonstrated that there is no proof of a decreased fertility after chemotherapy [16]. The pregnancies conceived after chemotherapy treatment for GTN should be followed with clinical surveillance (because of higher rates of certain pregnancy complications), but studies present reassuring evidence about the future fertility of these patients. Despite this, the delay in future pregnancies due to  $\beta$ hCG levels follow-up could negatively affect patients' perceptions about their possibility of conceiving again [17].

Wenzel and colleagues [18] observed that 40% of women treated successfully for GTD felt that they had no control on their reproductive future. Moreover, 17% felt angry that their ability to have children had been compromised. Another study [17] found that these patients scored highly on the fear of infertility and fear of conceiving again, and they were troubled by the advice to refrain from pregnancy during the follow-up period.

In one of our studies, we found that younger women presented higher Global Stress scores regarding infertility-related stress [6], especially tied to Need for Parenthood and Relationship Concern subscales. This result reflects other studies that showed that younger women with cancer tend to report significantly more concerns about infertility, premature menopause, and menopausal symptoms [19], which may increase the levels of distress and negatively affect adaptation to cancer [20].

From the literature, it is evident that first it is important to provide patients and their partners (if present) with clear and precise information regarding fertility and on the possibility of bringing to term another pregnancy after the treatments and follow-ups have been terminated. Special attention should be paid to younger women and women with malignant forms of the disease. Moreover, exploring their beliefs and opinions with regard to these topics can help correct false beliefs that can bring with them distress and anguish. The presence of a psychologist within the treating team could favour the emotional elaborations of possible fears and worries connected to fertility, and favour a present and future adaptation of the patient to the disease.

In future research it will be interesting to compare the patients' illness perceptions alongside their partners' to see if there are any discrepancies, which may compromise their relationship in any way. It would also be intriguing to examine if and how illness perception changes over time. A particularly critical moment is when the  $\beta$ -hCG values start to plateau or rise again (rather than decrease), which means that the patient will most probably have to undergo chemotherapeutic treatment. This phase, which is experienced by many patients as causing much anxiety, does not mean a worsening of the prognosis per se, but could bring about changes in the mental representations of illness, especially in terms of disease severity, disease length, or more severe consequences.

The Gestational Trophoblastic clinic at the San Raffaele Hospital opened in 1992 and has demonstrated its efficacy and capacity in supporting GTD patients, offering additional emotional care and

meeting the specific needs that many GTD patients necessitate. It should be considered the norm for patients worldwide.

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