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Qualitative assessment of the concerns on treatment and patient health among patients with gestational trophoblastic neoplasia and their caregivers during the COVID-19 pandemic

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Abstract:

BACKGROUND: The COVID-19 pandemic has immobilized and impaired the operation of hospitals, clinics, and other health-care facilities leaving a plethora of patients and persons-at-risk in a more precarious position. Cancer patients were vulnerable to infections and complications due to the nature of the malignancy. Their caregivers were likewise predisposed to infection while taking care of them. This paper focused on determining the concerns of both gestational trophoblastic neoplasia (GTN) patients and their caregivers and identified possible factors of improvement in the delivery of essential cancer care.

OBJECTIVE: The objective of the study was to describe the different concerns of GTN patients and their caregivers during chemotherapy and other adjunctive treatments during the COVID-19 pandemic in a Tertiary Government Hospital.

MATERIALS AND METHODS: A qualitative type of research was employed in this research, for which an in-depth interview was used. A total of 12 respondents, 6 patients and 6 caregivers, were interviewed using a semi-structured pretested questionnaire.

RESULTS: Findings showed that infection with COVID-19, financial and logistical constraints exacerbated by the pandemic were the main concerns of both patients and caregivers. Other concerns recorded include change in their attending physician, survivability of the patient, and the availability of caregivers.

CONCLUSIONS: Despite the recorded apprehensions from the patients and caregivers, there was a general satisfaction in the delivery of health care at the Division of Trophoblastic Diseases due to the clarity in the follow-up and treatment schedules which have been optimized through the revised guidelines and protocols set by the division to adapt to the COVID-19 pandemic.

Keywords:

COVID-19, gestational trophoblastic neoplasia patients, health-care delivery

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Introduction

Gestational trophoblastic neoplasia (GTN) is a group of uncommon malignant gynecologic tumors arising from the

trophoblasts. It is considered one of the most curable malignancies.^[1] Histologically, it has four subtypes which include invasive mole, choriocarcinoma, placental site trophoblastic tumor, and epithelioid trophoblastic tumor. Early diagnosis, effective chemotherapy regimens, and sensitive serum assays for *beta*

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human chorionic gonadotropin has led to the excellent prognosis of GTN patients.

Chemotherapy is the cornerstone and mainstay of treatment for GTN. While chemotherapeutic drugs target malignant trophoblastic cells, they also affect normal rapidly dividing tissues, leading to different medical toxicities that affect the physical well-being of the person. These toxicities may delay the administration of treatment and eventually cause resistance. During treatment patients are not affected only physically, but the mental and emotional well-being is also affected, thus altering the overall quality of life. In a study done on the quality of life of GTN patient survivors, it was found that the younger the patient, the better the quality of life. A direct correlation was found between educational level and the physical capability of the patient, whereas the stage of GTN and the general health of the patient were indirectly related.^[2]

The COVID-19 pandemic brought about by the novel SARS-CoV-2 exacerbated the concerns, struggles, and fears of cancer patients. Compared to the general population, cancer patients are immunocompromised, whether from the disease itself or due to chemotherapy, making them more prone to infection. The presence in the hospital for the diagnosis, treatment, and follow-ups leads to a greater chance of exposure and acquiring the infection.^[3-5] Infection with COVID-19 would lead to treatment delays and possibly serious complications, which may result in poor prognosis. In a study done by Wang and Zhang in 2020, cancer patients had limited access to health-care facilities, and in some high-risk epidemic areas such as in Wuhan, China, they were not able to immediately access the necessary medical services.^[6]

There are different studies regarding gynecologic cancer during the pandemic; however, at present, there are no studies that address the perspective of GTN patients and their primary caregivers on the patient's health and treatment during this time. This study aimed to provide a better understanding of their experiences which may help in improving their quality of life during treatment. Hopefully, this will lead to a holistic approach in the management of GTN patients the pandemic.

General objectives

The objective of the study was to describe the different concerns of GTN patients and their caregivers while receiving chemotherapy and other adjunctive treatments during the COVID-19 pandemic in a Tertiary Government Hospital.

Specific objectives

1. To identify the sociodemographic profile of GTN patients and their caregivers which includes age, obstetric score, occupation, marital status, educational

attainment, religion, distance of the place of stay during treatment, the relationship between the patient and the caregiver, combined household income, and the number of household members that may affect their concerns during the course of treatment

2. To determine the clinical profile of GTN patients undergoing chemotherapy such as the International Federation of Gynecology and Obstetrics (FIGO) anatomic stage, World Health Organization (WHO) prognostic score, chemotherapeutic agents received, and length of hospital stay and treatment which may affect their acceptance to treatment
3. To describe the physical, psychological, emotional, and social factors affecting the experience of patients with GTN and their primary caregivers
4. To determine the financial, emotional, and psychological factors affecting the continuity of care among patients with GTN during the pandemic
5. To describe the current experience of patients with GTN and their caregivers when receiving care during the pandemic.

Materials and Methods

After approval of the Research Ethics Board, a qualitative methodology utilizing in-depth interviews following Consolidated Criteria for Reporting Qualitative Research Guidelines (Tong *et al.* 2007) was used to gather the participants' perceptions and experiences on their management during the pandemic.^[7]

All GTN patients aged 18 years and above who were diagnosed and being treated under the management of the Division of Trophoblastic Diseases from July 1, 2021 to December 31, 2021, along with their caregivers were recruited. Patients who did not have a caregiver and were lost to follow-up were not included in the study.

A semi-structured, open-ended interview guide questions were used to elicit participants' responses to the following domains of interest: (1) experience and satisfaction with health care received during the COVID-19 pandemic through virtual and remote platforms and (2) the perceived risks associated with COVID-19 during their treatment. Guide questionnaires were written in English which were translated to Filipino. Testing for its validity was done among patients and caregivers in a similar group but was not included in the research. All interviews were conducted by a trained research assistant. The participants' responses were recorded, transcribed, and translated into English for consistency and record keeping.

Results

Nine patients diagnosed with GTN and managed at the Division of Trophoblastic Diseases from July 1, 2021,

to December 31, 2021 were recruited. There were two patients and one caregiver who did not consent to participate in the study, hence a total of six patients were interviewed along with their six caregivers.

Tables 1 and 2 show the summary of the patients and caregivers profile, respectively. The mean age of the

Table 1: Summary of the patient's sociodemographic and clinical profile

Characteristic	n (%)
Age	6 (37.7 mean)
Obstetrics score	
G1P0 (0010)	2 (33.3)
G2P1 (1010)	1 (16.7)
G4P3 (3003)	1 (16.7)
G5P5 (5005)	1 (16.7)
G6P5 (5014)	1 (16.7)
Marital status	
Married	4 (66.7)
Single	2 (33.3)
Educational attainment	
High school graduate	3 (50)
Vocational graduate	2 (33.3)
College graduate	1 (16.7)
Occupation	
Blue collar job	3 (50)
White collar job	1 (16.7)
Unemployed	2 (33.3)
Religion	
Roman catholic	4 (66.7)
Iglesia Ni Cristo	1 (16.7)
Christian	1 (16.7)
Distance of residence to PGH (km)	
<5	0
>5	6 (100)
FIGO anatomic stage	
Stage I	2 (33.3)
Stage II	0
Stage III	3 (50)
Stage IV	1 (16.7)
WHO prognostic score	
3	1 (16.7)
4	1 (16.7)
9	1 (16.7)
13	1 (16.7)
15	1 (16.7)
20	1 (16.7)
Chemotherapy	
Multiple agent	6 (100)
Length of treatment (months)	
1	2 (33.3)
3	1 (16.7)
5	1 (16.7)
6	1 (16.7)
7	1 (16.7)

WHO: World Health Organization, FIGO: International Federation of Gynecology and Obstetrics, PGH: Philippine general hospital

patients was 37 years old which was almost the same as their respective caregivers which was 36.5 years of age. Two of the patients were primigravida and the other four patients were multigravida with at least three living children. Most of the patients (4 out of 6) were married, high school graduates (3 out of 6), blue-collared workers (3 out of 6), and were Roman Catholic (4 out of 6). All of the patients were also residing more than 5 km from the hospital.

Three of the caregivers were males and the other three were females. The majority of the caregivers were at least high school graduates (4 out of 6), blue-collared workers (4 out of 6), and were Roman Catholic (5 out of 6). All caregivers were observed to be of close consanguinity who belonged to the patient's immediate family member. Further, the estimated monthly family income among the respondents was notably divided almost equally between low (<10,000 Php), and mid-to-upper (30,001–50,000 Php), showing a variation in the financial capacity of the family to support the

Table 2: Summary of the caregiver's profile

Characteristic	n (%)
Age	6 (36.6 mean)
Gender	
Male	3 (50)
Female	3 (50)
Marital status	
Single	1 (83.3)
Married	5 (16.7)
Educational status	
High school graduate	4 (66.7)
Vocational graduate	1 (16.7)
College graduate	1
Occupation	
Blue collar job	4 (66.7)
Unemployed	2 (33.3)
Religion	
Roman Catholic	5 (83.3)
Iglesia Ni Cristo	1 (16.7)
Relation to the patient	
Spouse	2 (33.3)
Parent	1 (16.7)
Sibling	1 (16.7)
Partner	1 (16.7)
Child	1 (16.7)
Estimated monthly family income (Php)	
<10,000	3 (50)
10,001–30,000	0
30,001–50,000	2 (33.3)
>50,000	1 (16.7)
Number of household members	
3	1 (16.7)
5	2 (33.3)
6	2 (33.3)
7	1 (16.7)

patient's treatment, other medical needs related to GTN, and at least three or more household members to share with. The patient population was diverse in terms of FIGO anatomic stage and WHO prognostic score categorization, but most had metastatic, high-risk disease, and they were all treated with various agent chemotherapy for at least 3 to 7 months.

Patients' perspectives

Generally, the participants expressed satisfaction in terms of the quality of services and treatment that the hospital provided. However, some of the recorded concerns of the patients included the following:

Prognosis of the disease and COVID-19 infection

Contracting COVID-19 and treatment delays were shown to be of great concern among the patients aside from the progression of their disease. Among the patients' replies include: "Fear because it is pandemic, Fear of going to consultation due to pandemic and may contract COVID" or "Fear of death and not being able to seek treatment because of the current pandemic situation."

Barriers to accessing treatment and follow-up consultation

Financial constraints

Given that most of the patients were resource constrained, the financial burden was still a major barrier to accessing treatment. The expenses incurred for transportation, food, and the treatment itself; allocation of money to cover cancer treatment and follow-up consultation expenses were the concerns raised by most of the patients. One of the patients also mentioned the difficulty to ask assistance during the pandemic due to the loss of jobs and businesses.

Logistics

Transportation and mobility were major barriers to accessing cancer treatment and follow-up consultation, considering that all patients resided more than 5 km away from the hospital. During the height of the pandemic, the availability of modes of transportation posed a huge challenge in transporting an immunocompromised cancer patient from one place to another. The extensive COVID-19 restrictions and lockdowns also significantly contributed to the problem. Not being able to continue and complete the treatment were the common concerns of patients.

Availability of caregiver

An important concern is the availability of the caregiver. Two patients expressed apprehension since their caregivers already had plans to depart from the responsibility in pursuit of job opportunities. One patient expressed distress since she viewed the time rendered by her husband as her caregiver, equivalent to income lost for the family.

Service delivery

General satisfaction

Despite concerns about COVID-19 and the progression of their disease, general satisfaction was documented from the patients, particularly on how the follow-up consultations were done in the cancer institute. The ease in follow-up due to the specified and exact time given to the patients with lesser waiting time added to the comfort. This satisfaction in cancer care shed hope for the possibility of eventual remission and improvement of their health condition.

Preference to the type of consultation

Some patients indicated a preference for telemedicine which lessened physical and financial burden by staying at home. Others, however, still desired face-to-face consultations since their needs and queries can be addressed immediately by their attending physicians.

Caregivers' concerns

The patients' caregivers reported almost similar concerns with their patients and among the caregivers' perspectives were the following:

Prognosis of the disease and COVID-19 infection of their patient

Like the concerns and worries of the patients, the caregivers' main apprehensions revolved around the probability of getting infected with COVID-19, including its implication in treatment delays, and the overall well-being of the patient, they are caring for. The repeated COVID swab tests gave an anxiety for a possible delay in treatment if the result turned out positive. Another health concern of the caregiver was poor nutrition of their patients from eating unhealthy foods, thus not gaining enough weight, which in turn resulted in a more reduced immune status. The long-term effect of chemotherapy to the patient was also a common worry among the caregivers.

Barriers to accessing treatment and follow-up consultations

Financial constraints

Having to accompany the patient during treatment, consultations, and admissions was viewed as a lost opportunity to earn since it meant giving up a day of work to accompany a loved one to the institute. Notably, the same sentiments were recorded as that of the patient, citing inadequate financial capability to sustain treatment. There was fear of not being able to continue the treatment due to financial burdens.

Logistics

With the caregivers traveling together with the patient, they concur with the responses recorded by the patients, which cited the difficulty in traveling given the lack of adequate transportation and the frequent travel which

placed them at risk to contract COVID. In addition, their concerns included the tolerance of the patient to move from one place to another.

Availability of caregiver

Many caregivers faced the dilemma of choosing between going to work/school and attending to the patient's needs during treatment or consultation. *"During the treatment, our main problem is the availability of the person who will accompany the patient during her admission,"* as stated by one of the caregivers.

Service delivery

General satisfaction

Despite the concerns and barriers relating to the treatment and health of the patients, caregivers' outlook and perspective on the services rendered by the Division of Trophoblastic Diseases were generally positive – they were content even with the COVID-19 guidelines and policies of the division. Some of the responses when asked if they had any concerns included: *"Consultations were more efficient this time since we don't need to go to outpatient department and wait for a long time before being seen;"* *"No other concern since we are given schedules for our treatment at the Cancer Institute;"* and *"None because we are confident that my mom is getting better with the treatment being given."*

Discussion

In general, the main concern of both patients and caregivers was contracting infection with COVID-19, citing that acquiring the disease will negatively affect the health of the patient and may interfere with the treatment they were receiving. This echoes the study conducted by Lou *et al.* in 2020 which revealed that cancer patients receiving treatment reported greater concern about infection from the SARS-CoV-2 coronavirus. In terms of cancer care, COVID-19 had an overall negative effect among patients with metastatic cancers compared to nonmetastatic disease.^[8] In a similar study conducted by Jeppesen *et al.* among 4571 cancer patients, 9% refrained from consulting in the hospital due to fear of COVID-19 infection. A high percentage of patients preferred appointments through videoconferencing (48%), telephone (58%), or mail correspondence (65%) as alternatives to face-to-face consultation. The general fear of being infected with COVID-19 among patients may be attributed to their heightened susceptibility to infection due to the immunosuppressed condition brought about by the malignancy itself as well as anticancer treatment or surgery.^[9]

Other recorded sources of concern for both patients and caregivers included financial constraints and logistical strains, which have been in existence even before

COVID-19 but were exacerbated by the pandemic. The participants were noted to belong to lower- to middle-income backgrounds; therefore, their main concern was the availability of financial resources to continue cancer care. Given that most of the patients were resource constrained, the financial burden was still a major barrier to accessing treatment. The expenses incurred for transportation, food, and the treatment itself, allocating enough money to cover cancer treatment, and follow-up consultation expenses were proven to be more difficult to sustain during the pandemic due to the loss of jobs and businesses. Obtaining financial assistance during this time was limited because COVID-19 cases were a priority and cancer care was put on hold. In a systematic review conducted by Iragorri *et al.*, which focused on the out-of-pocket cost burden of cancer care in low- to middle-income countries including the Philippines, cancer patients and caregivers spent, on average, 42% of their annual income on out-of-pocket expenses related to cancer care, compared to 16% spent on average by patients and caregivers in high-income countries (HICs).^[10] HICs have efficient health-care system where expenses for hospitalization does not come from a patient's out-of-pocket expenses.

The pandemic has also brought about limited public transportation, and one had to find a private or for-rent utility vehicle just to go to the hospital to continue chemotherapy. Consequently, considering that all study participants resided more than 5 km from the hospital, logistics or transportation was one of the imposing difficulties in receiving cancer care. Several participants expressed their apprehensions about being infected with COVID-19 while traveling to have their consultations or treatment during the pandemic. Some mentioned the seemingly unbearable stress caused by traveling on the patient's well-being. In the study by Abila *et al.*, the restrictions of public and private transportation as well as the observance of other guidelines and protocols against COVID-19, significantly hampered the delivery of cancer care in Uganda. This caused delays in treatment and cancer diagnosis, which negatively affected the prognosis of the patients.^[11] A similar study revealed that the majority of the cancer patients who experienced treatment delays had reasons related to logistic difficulties, which encompassed travel restrictions, lockdown policies, and the closure of chemotherapy centers. These logistics-related reasons were significantly associated with an increased incidence of treatment delays (odds ratio 35.36, 95% confidence interval 11.74–106.47), ($P < 0.0001$).^[12]

Prepandemic, patients and caregivers had little to no problem securing hospital admission since a ward was specifically allocated for them. During the start of the pandemic in the country, the hospital was designated as a COVID referral center, and the beds allotted for

GTN patients were re-allocated to those afflicted with the viral infection.

Despite the recorded concerns and apprehensions of both GTN patients and caregivers about their health and treatment during the pandemic, there was overall general satisfaction with the delivery of cancer care. This satisfaction was brought about by the observed efficiency and convenience of the hospital's revised protocols, which integrated telemedicine with the face-to-face scheduling of consultation and treatment. This blended system relieved some of the concerns and fears of the participants and afforded them some comfort in accessing cancer care.

Conclusions

The risk of contracting COVID-19 remained to be the main concern for both GTN patients and their caregivers, apart from the previously existing barriers to accessing cancer care which included economic constraints and logistic difficulties. Given the patients' increased susceptibility to infection, it is imperative to provide a safe and conducive avenue for consultation and treatment to promote and maintain their well-being. General satisfaction was observed among the patients and caregivers with the limited re-opening of the division for face-to-face consultation and treatment with modified guidelines and protocols, together with the integration of alternative strategies such as telemedicine and conversion of the mode of treatment that provide both patients and caregivers an easier and more convenient approach in accessing cancer care.

Limitation

This study is limited to GTN patients of UP PGH who may be residing near the institution, limiting the generalization of the results to all GTN patients. The baseline information is not yet established, given the novelty of the subject. However, the data presented in this paper may be considered a reference for future research focused on a similar objective and nature.

Recommendation

Some recommendations to improve the research include the recruitment of other patients and caregivers from other cancer centers and incorporation of a quantitative tool to describe the frequency and severity of determined sources of concern affecting the GTN patients and their caregivers.

Authorship contributions

Jessabeth B. Mercado - Conceptualization, Methodology, Validation, Formal analysis, Investigation, Data

Curation, Writing -original draft, writing – review and editing, supervision, project administration.

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Maria Stephanie S. Cagayan - Conceptualization, Methodology, Validation, Formal analysis, Investigation, Data Curation, Writing -original draft, writing – review and editing, supervision, project administration.

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Conflicts of interest

There are no conflicts of interest.

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