

Challenges and perceptions of cancer patients attending a tertiary care center during COVID 19 Pandemic Era: Patient's Perspective



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Submission: 13-08-2020

Revision: 27-09-2020

Publication: 01-11-2020

ABSTRACT

Background: Patients with cancer are more susceptible to acquire SARS-Cov-2 infection due to their immunocompromised state related to the disease and anticancer treatment. There is a lack of literature assessing the patient's perspective of the present crisis and its impact on their treatment. **Aims and Objective:** The present study aimed to address the challenges and sufferings faced by patients with cancer during their treatment in the current COVID-19 pandemic era. **Materials and Methods:** A single-institute, cross-sectional questionnaire-based observational study was conducted in a tertiary care teaching hospital. Patients attending the Oncology outpatient department were enrolled in the study. **Results:** One hundred patients (64 males, 36 females) with a mean age of 47.17 years (range-24-71) participated in the study. The majority of patients (89%) were aware of the COVID 19 symptoms and did not confuse them with cancer symptoms. Most of them were aware of preventive measures like frequent hand washing, sanitizer usage, and face masks to reduce the risk of infection. Almost half of them encountered difficulties in commuting to the Hospital. Most (83%) of them were worried about treatment delay and disease progression due to the COVID-19 pandemic. Almost half of the patients (54%) were fearful of acquiring the infection from the radiotherapy machine and immobilizing devices. Two-third of the patients (64%) were afraid to carry the virus back to their homes. Awareness regarding our Hospital's teleconsultation facility was limited among patients. **Conclusion:** The present study underscores the success of ongoing COVID-19 awareness programs run by the government. However, there is an urgent need to address the various challenges encountered by patients with cancer. The strengthening of telemedicine facilities may reduce the in-person visits made by the patients.

Key words: COVID 19; Radiotherapy; Cancer; Patient Perspective; Anxiety; Teleconsultation

INTRODUCTION

Coronaviruses (CoV) are a large family of viruses that cause illness ranging from the common cold to more severe diseases. A novel coronavirus (nCoV) was identified on Jan 7, 2020, and was temporarily named "2019-nCoV".¹ It was subsequently called the "COVID-19 virus". World health organization (WHO) announced the corona virus

disease (COVID-19) outbreak as a pandemic on Mar 11, 2020. Cancer patients are more susceptible to coronavirus infection because of their immunocompromised state.^{2,3} This risk increases even more if the cancer patient is elderly (>60yrs of age), or has associated comorbidities like diabetes, heart or chronic lung disease.² It is essential to recognize that, in addition to malignancy and its treatment-related cytotoxicity, COVID-19 infection itself

Access this article online

Website:

<http://nepjol.info/index.php/AJMS>

DOI: 10.3126/ajms.v11i6.30621

E-ISSN: 2091-0576

P-ISSN: 2467-9100

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leads to decreased lymphocyte count, which may further weaken the immune system. This decline in lymphocyte count poses a higher risk of mortality among patients with cancer compared to those with non-cancer-related diseases.³ Globally, oncology departments are making policies to reduce the exposure and transmission of the virus by (a) prioritizing patients, replacing outpatient visit with telephonic consultations, (b) limiting the number of attendants accompanying the patient, (c) reducing the radiotherapy time and visits by following hypo fractionated regimens, (d) using less cytotoxic therapies or converting intravenous chemotherapy to oral, (e) and delaying surgeries wherever possible.^{4,5} Standard hospital policies are also being reviewed to make alternate arrangements like initial screening of the patients for severe acute respiratory syndrome coronavirus-2 (SARS-Cov-2) infection in dedicated clinics before they visit the specialty clinics. However, it results in inconvenience to the patients due to long queues to ensure physical distancing, prolonged waiting time, difficult access to the specialists, and delay in the initiation of the treatment. All this culminates into anxiety and apprehension among patients with cancer.^{5,6}

Several articles have been published to highlight the impact of COVID-19 pandemic on the mental and physical well-being of healthcare workers.⁷⁻⁹ However, the implications of the COVID-19 pandemic have not been assessed from the prism of the patient's perspective. There is a need to focus on patients who are hit with the double whammy of cancer and COVID-19 pandemic related logistic problems.

The present study aimed to address the challenges and sufferings faced by patients with cancer during their treatment in the current COVID-19 pandemic. We believed the study would provide a clear understanding of the concerns of the patients to shape the health care policies during the current or future pandemics to offer the best possible patient care.

MATERIAL AND METHOD

Study design

A single-institute, cross-sectional observational study

Study duration

one month (From May 2020- June 2020)

Study setting

Oncology OPD at a tertiary-care teaching hospital in North India.

Sample size

Considering 50% awareness of the population about COVID-19 pandemic, the sample size was calculated to

be 97 with a 95% confidence level and 10% precision of estimate using the following formula.¹⁰

$$N = \frac{Z^2(p)(1-p)}{d^2}$$

Participants

Patients with cancer attending the Oncology OPD were requested to participate in the study. Those who were willing to participate were included in the study. Patients who did not give consent, or aged less than 18 years of age, had an ECOG performance score of 3 or more, or were unable to understand Hindi/English language were excluded from the study.

Questionnaire

Health care workers administered a pre-designed and pre-tested questionnaire (supplementary Material) to the study participants. The questionnaire consisted of 25 questions that were grouped under three major headings- Attitude and non-hospital related issues, logistics/hospital related issues and knowledge and awareness about COVID-19. The data were entered into an excel sheet. Finally, the data were analysed to look for the significant issues faced by the patient during his/her daily visits for cancer treatment.

Statistical analysis

Descriptive statistics such as mean, standard deviation, percentages, crosstabulations were used to present study results using an excel sheet. Chi-square test was used to estimate the significance of the correlation between categorical variables, *p value* < 0.05 was considered as statistically significant. All statistical tests were run using Statistical package for the Social Sciences (SPSS) software version 23.

RESULTS

The study included 100 patients who consented to participate in the survey. The baseline demographic features are enlisted in (Table 1). The mean age of the patients was 47.17 years ± 11.1 S.D. (Range 24-71yrs). There was more representation by men compared to women (64% vs. 36%). Almost half of the participants belonged to the lower-middle socioeconomic class (45%). The breast was the most common site of cancer (40%)-almost all the patients (97%) presented in the advanced stage of their disease.

Table 2 shows response of the patients to the survey questions. The majority of the patients (89%) were aware of the COVID 19 symptoms and did not confuse them with cancer symptoms. They were willing to take preventive measures like proper hand washing, using sanitizers and face

Table 1: Demographic features of the patients

Characteristics	No. (%)
Mean age with standard deviation, years Range	47.17 years ±11.1 S.D 24-71 Years
Sex	Male 54 (54%) Female 36 (36%)
Residence	Within state 58(58%) Outside State 42(42%)
Socioeconomic Status	Lower Middle 45(45%) Upper lower 39(39%) Lower 16(16%)
Site	Breast 40(40%) Head and Neck 13(13%) G.I. Malignancy 12(12%) Gynaecological 9(9%) Thoracic 9(9%) Hepatobiliary 5(5%) Genitourinary 4(4%) Lymphoma & leukemia 4(4%) Brain tumor 2(2%) Multiple Myeloma 2(2%)
Disease Status	Advanced 97(97%) Early 3(3%)
Intent of Treatment	Curative 67(67%) Palliative 33(33%)
Type of treatment	Radiotherapy 58(58%) Chemotherapy 42(42%)

masks attributing to the running health awareness programs on television and other social media platforms. A large number of patients (44%) were scared of visiting the hospital for their treatment during the current pandemic – 35% of them were females, and 9% were males *p-value-0.008*).

Moreover, they (54%) encountered difficulties in commuting to the hospital due to various reasons, among which transport issues and non-availability of a vehicle (39%) were the primary cause attributing to the lockdown situation. There was a significant correlation between female and transport-related problems (*p-value-0.005*).

Most (83%) of them were worried about treatment delay and disease progression due to the COVID-19 pandemic. Sixty-two percent of the patients were not aware of the changes in hospital policies because of which 50 % of them found it difficult to negotiate through a new system – long queues due to physical distancing was bothersome for around 56%. Most of them (75%) were afraid that delaying surgery or other required interventions would affect their disease outcome. Seventy-one percent of patients agreed

Table 2: Response to the survey

S no.	Questions	Yes	No	Maybe	Don't know
Part a-attitude and non hospital related issues					
Q1	Did you Confuse your disease symptoms with COVID Symptoms?	8%	89%	3%	0%
Q2	Were you Scared to visit Hospital during this COVID Pandemic?	44%	49%	7%	0%
Q3	Were you afraid that if you don't visit the Hospital then your disease will progress?	83%	15%	2%	0%
Q4	Did you face problems during your transit to Hospital?	54%	46%	0%	0%
Q5	Were Your attendants apprehensive regarding accompanying you to the Hospital?	18%	81%	1%	0%
Q6	Are you worried that children or elderly at your home will catch infection due to your close contact with them?	64%	31%	2%	3%
Q7	Do you fear that you won't be able to survive this COVID pandemic?	40%	58%	2%	0%
Q8	Is buying masks or sanitizer posing a financial burden on you?	45%	55%	0%	0%
Q9	Would you prefer telephonic consultation with your Doctor in case of non-emergency during this period?	83%	17%	0%	0%
Part b-hospital related/logistic issues					
Q10	Were you aware of the changed hospital policies of the Hospital?	36%	62%	1%	1%
Q11	Did you find it difficult to understand the changed consultation policies of the Hospital?	50%	48%	0%	2%
Q12	Did you face difficulty in meeting the concerned treating Doctor?	38%	62%	0%	0%
Q13	Did your Doctor give enough time for your consultation?	71%	29%	0%	0%
Q14	Did waiting time or long queue in the Hospital due to a new arrangement because of COVID 19, bother you?	56%	44%	0%	0%
Q15	Were you able to maintain social distance from other patients/Staff?	76%	20%	1%	3%
Q16	Did you face problems in getting prescribed medicines?	27%	71%	1%	1%
Q17	Did you have a problem in communication with the Doctor due to wearing of masks?	12%	83%	1%	4%
Q18	Were you tested for COVID or not?	38%	62%	0%	0%
Q19	Were you apprehensive about the procedure for COVID Testing?	34%	62%	4%	0%
Q20	Were you scared of COVID testing results or being detected positive?	44%	48%	6%	2%
Q21	Has delaying surgery or any required intervention procedure made you more anxious about your disease outcome?	75%	22%	1%	2%
Q22	Are you worried that if you touch objects or lie down on a radiotherapy treatment machine then you will catch COVID infection?	52%	30%	7%	11%
Part c-knowledge and awareness					
Q23	Are you aware of proper handwashing and sanitizing techniques to prevent infection?	68%	32%	-	-
Q24	Are you well aware of Coronavirus -its symptoms, mode of spread, prevention, and management?	68%	32%	-	-
Q25	Are you aware that telephonic consultation is available in the Hospital during the COVID situation?	43%	57%	-	-

that doctors gave them enough time for a consultation at this time of pandemic crisis. Almost half of the patients (54%) were fearful of acquiring the infection from the radiotherapy machine and immobilizing devices. Two-third of the patients (64%) were afraid to carry the virus back to their home and family members.

Although the majority of the patients were from lower socioeconomic class, they were aware of modes of prevention and spread of COVID 19 infection (68% & 62% respectively). A large number of patients (83%) responded that they would prefer telephonic consultation for non-emergency situations.

DISCUSSION

Across the continents and countries, health care systems and hospitals are faced with the enormous challenges posed by the COVID 19 pandemic. They have addressed it by adapting quickly to the pandemic by changing the health care policies and adopting several measures like ensuring physical distancing, using face masks, promoting frequent hand washing, reducing the number of visits by the patients, and augmenting telemedicine facilities.² The patients with cancer become more prone to acquire COVID-19 infection in the presence of associated comorbidities or if they are elderly. The patients with cancer find themselves in between the devil and the deep blue sea – they have to visit the hospitals for the continuation of cancer treatment while being at a high risk of acquiring COVID-19 disease.

Though several articles have addressed the challenges faced by healthcare workers during the COVID-19 pandemic, the patient's perspective has not been duly considered.⁷⁻⁹ A recently published study has focused on the problems faced by the patients with cancer receiving systemic chemotherapy during the current pandemic.¹¹ In the present study, we attempted to explore the attitude, the mindset, the plight, and the perspective of the patients with cancer who are either undergoing chemotherapy or radiotherapy during the current pandemic.

In our study, the mean age of the patients in our study was 47.17 years, out of which only 18% of the patients were elderly (60 years and above).¹² There were fewer elderly patients in our study cohort because these patients were more vulnerable and prone to acquiring the infection and, perhaps, were reluctant to visit the hospital for treatment. The majority of the patients in our study were males – this may be a sampling bias, or it may be attributed to gender bias. Moreover, many female patients reported that they were scared to visit the hospital during this pandemic era

and had difficulties during their transit to the hospital compared to males.

All our patients belonged to lower-middle and lower socioeconomic classes. To highlight, our institute is a public hospital that provides highly subsidized treatment to the underprivileged and needy patients. The majority of patients in our study presented in the advanced stage of their disease, which is unfortunately true for most rural and semi-urban regions of India.¹³ The majority of the patients hailed from within the state (58%). In comparison, 42% from outside state, probably because it was comparatively more comfortable to travel within the state. In contrast, interstate travel required government permissions and other transit issues like non-availability of public transport due to countrywide lockdown.⁶

The most common site of cancer in our study was breast (40%) followed by head and neck and gastrointestinal cancer - which is in concordance to the 2018 Global Cancer Incidence, Mortality and Prevalence (GLOBOCAN) report.¹⁴

The majority of patients were well aware of the signs and symptoms of COVID 19 viral infection and did not confuse them with their disease symptoms. There was a high level of awareness about the importance of proper handwashing, using masks and sanitizers. Even patients with financial constraints didn't perceive it as an additional financial burden on them. Although surprising, it could be reflective of the high anxiety in society and widespread dissemination of knowledge about preventive measures for coronavirus infection due to sustained government campaigns. Most of them were not apprehensive about being tested for COVID-19. This fact again reiterates that the social media and the healthcare campaigns have played a productive role in recent times in spreading awareness about symptoms and preventive measures of COVID 19.¹⁵ The concern of many patients of taking back the infection from the hospital back to their home was significant and has not been documented earlier. It needs to be adequately addressed while counselling patients regarding various aspects of COVID 19 infection.

As the hospitals are changing the health policies frequently to match the emerging information about the COVID-19 infection, it becomes difficult for the patients to navigate the currently ever-changing clinic and in-patient systems. The use of social media, pasting multiple signages, installation of in-hospital public address systems, and information desks may provide proper information to the patients and minimize their inconvenience to patients due to changing policies.⁵ Though the patients encountered many difficulties in the

hospital, they acknowledged that physicians gave them adequate time in the clinics. It is essential to consolidate the mutual trust between the physicians and patients in the current pandemic.

In our study, many patients who were undergoing radiotherapy had an apprehension that they may acquire COVID infection while using non-disposable accessories like headrests, breast board, knee rest, etc.¹⁶ The patients need to be counselled frequently and repeatedly that all these items are disinfected regularly according to the hospital infection control committee recommendations.

Radiation treatment requires recurrent hospital visits increasing the risk of catching coronavirus infection; hence treatment protocols should be modified based on available evidence. Many guidelines have been published recently by various academic societies to reduce the hospital visits of the patients without compromising the oncological outcomes.¹⁷⁻²⁰

Eighty-three percent of the patients preferred telephonic consultations for non-emergency situations, and females were significantly more in number than males asking for telephonic consultations, probably a reflection of more females facing transport issues. Many OPD visits for routine follow up can be easily handled telephonically. The need for telemedicine facilities has never been perhaps appreciated before the current pandemic to reduce the risk of transmission of infection. Telemedicine consultations, if appropriately implemented, would reduce the patient load in the clinics.²¹ It will not only curtail the spread of infection but also lower cost and burden on the healthcare system. Several alternative strategies that are being used in the current pandemic may also prove to be beneficial even after its cessation.

The present study underscores the success of ongoing COVID-19 awareness programs run by the government. However, there is an urgent need to address the various challenges encountered by patients with cancer. The strengthening of telemedicine facilities may reduce the in-person visits made by the patients.

ACKNOWLEDGEMENTS

We thank all our patients for cooperating with us to take up this survey. We would also like to thank our junior residents Dr Biswajyoti Das and Dr Sanjay for helping in administering the questionnaires to the patients.

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<https://doi.org/10.1089/tmj.2020.0068>

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Source of support: None, **Conflict of Interest:** None.