


# A Study on Challenges to Health Care Delivery Faced by Cancer Patients in India During the COVID-19 Pandemic

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Manasij Mitra<sup>1</sup> and Maitraye Basu<sup>1</sup> 

## Abstract

**Introduction:** Access to health care and care delivery during the COVID-19 pandemic may be challenging for cancer patients. Several guidelines have been developed, which recommend treatment adjustments depending on the site of cancer, grade, and stage. However, few studies in India and across the globe have looked into the real challenges faced by cancer patients and assessed the effectiveness of the adopted interventions. This study was undertaken with the objective to study the challenges faced by cancer patients in India during the COVID-19 pandemic. **Materials and Methods:** This was a cross-sectional study undertaken between May 1, 2020 and May 15, 2020. A link to a prestructured questionnaire was sent through email to 100 randomly selected cancer patients in different stages of treatment and follow-up. Data were decoded and entered in Microsoft Excel 2010 and analyzed using descriptive statistics. **Results:** Slot availability for teleconsultation, network issues, deferral of radiotherapy dates and long waiting hours beyond appointment time, transportation problems from residence to hospital, restriction of visitors/attendants, deferral of surgery, deferral of tumor boards, delay and deferral of advice of the nutritionist, problems faced in extension of visa, unavailability of peer group support services and psychological counseling sessions, difficulty in maintaining precautionary measures, availability of chemotherapy medications and availability of chemotherapy slots in day care were cited as problems faced by cancer patients. Majority (91.7%) of the study respondents mentioned an increase in their anxiety levels. **Conclusion:** As highlighted in the study, cancer patients faced challenges in cancer care delivery during the COVID-19 pandemic. This study suggests the need for larger studies on cancer patient care during a pandemic.

## Keywords

COVID-19, cancer patients, “choosing wisely”, health care delivery, expert committees, support services

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## Introduction

Since the end of December 2019, after the initial coronavirus commonly known as COVID-19 outbreak in Wuhan in the Chinese province of Hubei, the disease rapidly spread across the globe striking 215 countries. On March 11, 2020, the World Health Organization declared it a pandemic.<sup>1</sup> The COVID-19 pandemic disrupted health care services, including cancer services, forcing transformations in health care delivery across the globe.<sup>2,3</sup>

The risks for cancer patients during the COVID-19 pandemic are multiple. Access to health care and care delivery during the COVID-19 pandemic may be challenging for cancer patients. Moreover, due to the inherent disease condition and the immunocompromised state often caused by anticancer treatments, cancer patients are at increased risk

of COVID-19 infection.<sup>4-7</sup> Though the magnitude of this risk is unknown, yet evidence suggests an increased risk of mortality with COVID-19 in cancer patients.<sup>5,8</sup> This risk is perhaps manifold in cancer patients older than 60 years and those with pulmonary compromise and associated comorbidities like cardiovascular diseases and diabetes are at greatest risk.<sup>8,9</sup>

As many of the patients with COVID-19 infections are presenting with pneumonia and severe respiratory distress

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<sup>1</sup>MGM Medical College and LSK Hospital, Kishanganj, Bihar, India

### Corresponding Author:

Maitraye Basu, Department of Biochemistry, MGM Medical College and LSK Hospital, Purab Palli, Kishanganj, Bihar 855107, India.  
Email: maitraye.basu@gmail.com



requiring ventilator support, the intensive care units are already stretched with such patients and may fail to provide the optimum level of care for cancer patients requiring critical care admissions.<sup>10</sup> Moreover, there may be a shortage of the health care workers delivering care to cancer patients like the oncologists, nursing professionals, pharmacists, radiation physicists, and radiotherapy staffs due to the COVID-19 infections or their need to remain in quarantine postexposure to COVID-19 positive cases.<sup>11</sup>

In an attempt to optimize health care and limit the risk for cancer patients and health care professionals amid the limited knowledge available about this new infection, oncologists are compelled to make difficult triage decisions and confront ethical dilemmas in an attempt to balance the risks and benefits for the patients and the society at large.<sup>12,13</sup>

Though review articles have collated and opined on the different treatment guidelines and management options to continue treatment of the cancer patients unhindered at the same time minimizing their COVID-19 infection risks, few studies in India and across the globe have looked into the real challenges faced by the cancer patients and assessed the effectiveness of the adopted interventions.

This study was undertaken with the objective to study the challenges faced by cancer patients in India during the COVID-19 pandemic.

## Materials and Methods

This was a cross-sectional study undertaken between May 1, 2020 and May 15, 2020. The study was initiated following approval from the Institutional Ethics Committee of MGM Medical College and LSK Hospital (MGM-PRI-87(A)/20). A link to a prestructured questionnaire requiring not more than 5 minutes to answer was sent through email to 100 randomly selected cancer patients in different stages of treatment and follow-up from the database of a 600-bed multispecialty hospital having facilities for medical, surgical, and radiation oncology department. The prequestion section dealt with the informed consent of the patients. The first part of the questionnaire consisted of the demographic details and disease-related questions like age, sex, nationality, site of cancer, stage in diagnosis, and treatment and the second part dealt with the challenges faced by the patients during this pandemic. The questionnaire had a section on self-grading anxiety by the respondents and documenting the reason for their anxiety.

Data were decoded and entered in Microsoft Excel 2010 and analyzed using descriptive statistics.

## Results

The response rate from the online survey was 36% with 36 out of 100 cancer patients responding to the survey. Among the study participants, 16 (44.4%) were female patients

**Table 1.** Cancer Types and Stages in the Diagnosis and Treatment Among the Study Respondents.

Cancer type	Percentage (n)
Head and neck cancer	25.0 (9)
Breast cancer	16.6 (6)
Colon cancer	13.8 (5)
Uterine cancer	11.2 (4)
Gastrointestinal cancer	8.3 (3)
Hematological malignancy	8.3 (3)
Lung cancer	5.6 (2)
Thyroid cancer	5.6 (2)
Prostate cancer	5.6 (2)
Total	100 (36)

**Table 2.** Stages in the Diagnosis and Treatment Among the Study Respondents.

Stages in the diagnosis and treatment	Percentage (n)
Diagnosed and under active treatment	50.0 (18)
Recently diagnosed and about to start treatment	27.8 (10)
Treatment complete and on follow-up	22.2 (8)
Total	100 (36)

while 20 (55.6%) were male patients. The mean age of the study population was 56 years ( $\pm 4.26$ ). Of the 36 respondents, 6 (16.7%) were foreign nationals from Bangladesh while 30 (83.3%) were Indian nationals.

Patients with head and neck cancers accounted for 9 (25%) of the respondents, patients with breast cancer accounted for 6 (16.6%) of the respondents, patients with colon cancer accounted for 5 (13.8%) of the respondents and patients with uterine cancer accounted for 4 (11.2%) of the respondents, patients with hematological malignancy and gastrointestinal tract cancer each accounted for 3 (8.3%) of the respondents and patients with thyroid, lung, and prostate cancer each accounted for 2 (5.6%) of the respondents. This is depicted in Table 1.

As depicted in Table 2, 10 (27.8%) of the respondents were recently diagnosed with cancer and about to start treatment, 18 (50%) of the respondents were diagnosed case of cancer under active treatment while, 8 (22.2%) of the respondents had their treatment complete and were on follow-up.

The various health care delivery issues as highlighted by the cancer patients responding to the survey are depicted in Table 3. Slot availability for teleconsultation was cited as an issue by 15 (41.7%) of the respondents, network issues was cited by 12 (33.3%) of the respondents, deferral of radiotherapy dates and long waiting hours beyond appointment time was a problem cited by 8 (22.2%) of the respondents, transportation problems from residence to hospital was faced by 28 (77.8%) of the respondents, restriction of visitors/attendants

**Table 3.** Health Care Delivery Issues as Highlighted by the Cancer Patients Responding to the Survey.

Health care delivery issues <sup>a</sup>	Percentage (n)
Unavailability of peer group support services and psychological counseling sessions	94.4 (34)
Delay and deferral of advice of the nutritionist	88.9 (32)
Transportation problems from residence to hospital	77.8 (28)
Restriction of visitors/attendants	72.2 (26)
Availability of chemotherapy slots in day care	55.6 (20)
Slot availability for teleconsultation	41.7 (15)
Network issues	33.3 (12)
Difficulty in maintaining precautionary measures	33.3 (12)
Deferral of radiotherapy dates and long waiting hours beyond appointment time	33.3 (12)
Availability of chemotherapy medications	22.2 (8)
Deferral of tumor boards	19.5 (7)
Deferral of surgery	13.8 (5)
Extension of visa	11.2 (4)

<sup>a</sup>There were multiple responses.

was cited as an issue by 26 (72.2%) of the respondents, deferral of surgery was a matter of concern for 5 (13.8%) respondents, deferral of tumor boards was cited as an issue by 7 (19.5%) of the respondents, delay and deferral of advice of the nutritionist was cited as an issue by 32 (88.9%) of the respondents, problems faced in extension of visa was cited as an issue by 4 (11.2%) of the respondents, unavailability of peer group support services and psychological counseling sessions was problematic for 34 (94.4%) of the respondents, difficulty in maintaining precautionary measures was cited as an issue by 12 (33.3%) of the respondents, availability of chemotherapy medications was cited as an issue by 8 (22.2%) respondents and availability of chemotherapy slots in day care was problematic for 20 (55.6%) of the respondents. Needless to mention there were multiple responses to this question, which means that patients faced multiple problems concerning health care delivery. The average delay in surgery was 3.22 days ( $\pm 0.26$ ), which was mainly due to the availability of COVID-19 results from throat or nasal swabs without which many hospitals that do not have dedicated operation theatres for COVID-19 positive cases are not allowing surgeries specially in patients coming from stamped containment zones. Surgeries are being allowed only if the results are negative. There was 1 patient, a follow-up case of laryngeal cancer after total laryngectomy, who had surgical delay due to delay in supply of the voice box.

All the 36 (100%) respondents mentioned that they faced more problems in the early phases of the lock down in end March and the first week of April till the health care system got organized. All the respondents pointed out to dearth of guidance from health care personnel of the health care facilities on what needs to be done to get access to care.

Among the study respondents, 33 (91.7%) mentioned an increase in their anxiety levels, 3(8.3%) mentioned their anxiety levels remained unaltered while none reported a

**Table 4.** Reasons for Increased Anxiety in Cancer Patients Responding to the Survey.

Reasons for increased anxiety in cancer patients <sup>a</sup>	Percentage (n)
Fear of COVID-19 as there is increased chance of infection	91.7 (33)
Fear of the inherent disease getting aggravated for delay in treatment	86.1 (31)
Treatment not optimum	55.6 (20)
Fear of death	27.8 (10)
Fear of losing jobs and financial crisis for family members	22.2 (8)

<sup>a</sup>There were multiple responses.

reduction in their anxiety levels. Among the 3 patients who reported unaltered anxiety levels, 2 were thyroid cancer patients and 1 was a laryngeal cancer patient declared cancer free for the past 1 year and on regular follow-up now.

The reasons for increased anxiety as highlighted by the study respondents are depicted in Table 4. Fear of infection with COVID-19 was the reason for increased anxiety in 33 (91.7%) of the respondents, fear of the inherent disease getting aggravated for treatment delay was the reason for 31 (86.1%) of the respondents, 20 (55.6%) of the respondents mentioned treatment not being optimum as the reason for their increased anxiety, 10 (27.8%) reported increased anxiety due to fear of death and 8 (22.2%) respondents mentioned fear of losing jobs and financial crisis for the family members as the cause of their increased anxiety.

## Discussion

Anticipating the care concerns for the cancer patients and keeping in mind the risks and benefits of cancer treatment

vis-a-vis the chances of COVID-19 infection from the hospital settings, guidelines have been framed by expert committees. Standard clinical protocols have been laid down by expert bodies like the American Society of Clinical Oncology, European Society for Medical Oncology, National Comprehensive Cancer Network, Italian Association of Medical Oncology all of which suggest a tiered approach to prioritizing and categorizing patients. Recommendations for treatment prioritization include immediately life threatening or clinically unstable conditions, or cases where the intervention is expected to result in substantial overall survival gain or improvement of quality of life.<sup>12,13</sup>

Studies recommended avoidance of complex surgeries likely to require multiple transfusions and prolonged intensive care unit stays.<sup>14,15</sup> However, where chances of metastasis over time is high and the patients may require ICU stay postsurgery, the risks and benefits of surgery vis-a-vis COVID-19 infection should be weighed.<sup>16</sup>

Studies also suggested deferral of myelosuppressive systemic therapy especially in patients with marginal benefit with conversion to oral agents whenever possible keeping in consonance with the standard international recommendations.<sup>16</sup> There are recommendations for administration of growth factor support in the current scenario and the need for re-evaluation before using immunomodulatory agents like steroids, cytotoxic agents, tacrolimus, JAK (Janus kinase) inhibitors, and biologics like anti-TNF (anti-tumor necrosis factor) antibodies as these increase the risk of severe COVID-19 symptoms.<sup>15</sup>

Similarly, in patients in whom radiotherapy is the treatment advised, priority should be given to patients with rapidly proliferating tumors and those whose planned radiotherapy has already begun. Hypofractionation with an aim to shorten the treatment duration is recommended wherever possible specially in breast, prostate and lung cancers. Palliative radiotherapy in a single fraction or weekly regimens are also recommended to reduce the number of contacts with hospital settings.<sup>14,15</sup>

The guidelines recommend treatment adjustments depending on the site of cancer, grade, and stage. On the whole, the recommendations speak of “choosing wisely,” limiting hospitalization to absolutely necessary cases and balancing the risk/benefit ratio of treatment benefit versus risk of infection.<sup>11-13</sup> Counseling of the cancer patients on the treatment plan is also important.<sup>17</sup>

Reducing footfalls in the outpatient clinics by rescheduling visits, restricting entry of friends and relatives accompanying cancer patients and conducting consultations through telemedicine facilities, ensuring supply of oral chemotherapy medications at the doorstep of the patients and biological sample collection from the patient’s residence, conducting the multidisciplinary tumor board meetings through an online interactive platform have been suggested by experts and implemented by hospitals to ensure unabated optimum treatment with risk minimisation.<sup>12-15</sup>

Creating a core COVID-19 action group, implementing employee oriented initiatives like staff rotations to avoid mass quarantines and hospital bus services maintaining social distancing to facilitate staffs from reporting for duty on time during lockdown are other administrative strategies adopted to ensure ongoing health care services. Involvement of the hospital leadership and the human resource department is important to ensure success of these initiatives.<sup>14,18,19</sup>

Despite standard treatment guidelines being in place and every effort made to ease access to health care and reduce chances of contacting infection with COVID-19 at the same time optimize treatment for cancer patients, cancer patients faced multifaceted problems in health care delivery as depicted in this study. Starting from delay in getting teleconsultation and day care chemotherapy slots to deferral of tumor boards and surgeries to availability of chemotherapy medications, maintaining precautionary measures, transportation problems in reaching the hospital and issues concerning visa extensions have been highlighted.

The guidelines framed by expert committees stress on the core treatment modalities. But the importance of keeping the supportive care ongoing in the form of nutritional support which is an integral part of cancer care and is particularly of importance for patients with head and neck cancers and gastrointestinal tract cancers,<sup>20,21</sup> psychological and peer group support<sup>22</sup> have not found importance. The strategies adopted by the organizations providing cancer care also did not spell out clearly their standpoint to keep these services running. Needless to mention, these services are important to make the cancer care holistic.<sup>23-25</sup> Moreover, these services can be provided effectively through teleconsultation.

Many study respondents mentioned that their anxiety levels were increased as they felt that the treatment was not optimum or their disease will be aggravated due to delay in treatment. Thus, the need for counseling of the patients on the inherent disease and the treatment plan is highlighted.

## Conclusion

Cancer patients faced several problems during this COVID-19 pandemic situation such as transportation to hospital, unavailability of peer group support services and counseling services, delayed and deferred services by the nutritionists, difficulty in getting a slot (date) for chemotherapy. Moreover, a major portion of those patients also suffered a higher anxiety such as getting infected with COVID-19 and the inherent disease condition getting aggravated.

This study suggests the need for larger studies on care of cancer patients during a pandemic.

## Limitations

The small sample size of the study population hailing from a specific geographical area and under treatment in a specified hospital may limit the generalizability of the study findings.

Anxiety levels in the cancer patients was assessed through their own perception and not by any standard psychometric assessment technique.

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### ORCID iD

Maitraye Basu  <https://orcid.org/0000-0002-2547-2392>

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