Shreya Das Adhikari<sup>1</sup>, Anuja Pandit<sup>2</sup>, Bhawesh Pangaria<sup>3</sup>, Sushma Bhatnagar<sup>3</sup> <sup>1</sup>Kasturba Medical College, Manipal, India <sup>2</sup>National Cancer Institute, All India Institute of Medical Sciences, Haryana, India <sup>3</sup>Dr. BRA IRCH, All India Institute of Medical Sciences, New Delhi, India

# Quality of life of palliative care cancer patients during COVID-19 lockdown phase

### Abstract

**Background:** Coronavirus pandemic in 2019 led India to implement a complete lockdown except for essential services. Cancer patients faced hindrances in seeking medical help. This caused stress and worry, leading to reduced quality of life (QoL). This study evaluated QoL and pain management in palliative care cancer patients during the lockdown.

**Patients and methods:** This was a cross-sectional observational study at a tertiary cancer hospital, over one month period with convenience sampling. Participants included all who were unable to visit the palliative outpatient department during the lockdown during the COVID-19 pandemic. They were contacted telephonically and a valid QoL questionnaire was filled out. Disease, demographic details and pain were assessed.

**Results:** A total of 51 were interviewed, 45% (n = 23) patients reported difficult access to medication during the lockdown; 18 (35.3%) required morphine to alleviate pain and 6 (33.33%) faced difficulty in acquiring morphine tablets. QoL scores did not differ based on access to morphine (p = 0.648). Mean QoL scores were 12.7  $\pm$  3.76 and 15.0  $\pm$  3.60 amongst patients who did not have access to other medications and those who did have access, respectively (p = 0.03). Overall QoL FACT G7 mean score was 14  $\pm$  3.8. The variables NRS (pain intensity) and QoL scores were found to be negatively correlated (Pearson's Correlation Coefficient: r (49) = -0.69, p < 0.00001).

**Conclusions:** Evaluation of QoL of palliative care cancer patients during global crises plays an important role in the assessment of patients' overall condition as well as to maintain a continuum of care.

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Key words: COVID-19, palliative care, quality of life, cancer, oncology

Address for correspondence: Anuja Pandit Department of Onco-Anaesthesia & Palliative Medicine, National Cancer Institute, All India Institute of Medical Sciences, Jajjar, Haryana, India e-mail: anujapandit@yahoo.co.in



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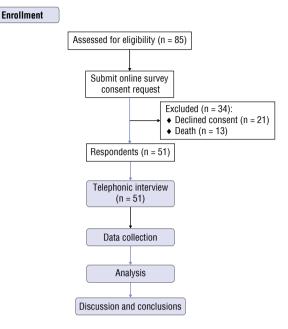
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# Introduction

The novel coronavirus, SARS-CoV-2, first surfaced in Wuhan, China in November 2019. This eventually spread worldwide and was declared an International Public Health Emergency by World Health Organisation on 30<sup>th</sup> January 2020, and control of the spread was implemented by social distancing [1]. The pandemic has induced fear, and a timely understanding of mental health status is urgently needed for society [2]. In many countries including India, a complete 'lockdown' except for essential services resulted in hindrances in travelling to hospitals and seeking or continuing medical treatment for cancer patients. Stress during an infectious disease outbreak can induce fear and worry about own health and the health of loved ones. This can cause changes in sleep or eating patterns, difficulty in concentration, deterioration of chronic health problems and worsening of mental health conditions. The fear and anxiety about the progression of cancer can be overwhelming. Patients with cancer in particular can be affected by delays in routine medical care in addition to experiencing heightened anxiety and stress associated with the threat of the viral disease itself. All this leads to poor quality of life (QoL), which has been defined by the World Health Organisation as an individual's perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns. Palliative care patients are especially vulnerable to further exacerbation of psychological symptoms because of their pre-existing anxiety, high symptom burden, treatment concerns, fear of cancer progression or recurrence, and higher susceptibility to infections. Hence, it is important to assess QoL and to prevent, treat and reduce the discomfort of cancer patients receiving palliative care. The study aims to evaluate the QoL and pain in cancer patients registered with the palliative medicine department during the lockdown during the COVID-19 pandemic.

# **Patients and methods**

This was a cross-sectional observational study conducted at National Cancer Institute (NCI). The participants were adult palliative care cancer patients who were unable to make their scheduled visit to the palliative outpatient department during the lockdown in India during the COVID-19 pandemic, imposed on March 25<sup>th</sup>, 2020. Institutional ethical clearance informed consent was obtained via Google form via WhatsApp messaging service between 13<sup>th</sup> June to 30<sup>th</sup> June 2020 (CTRI/2020/06/025797). Those who



**Figure 1.** Flow Diagram of the study population. Among the 85 adult patients who were contacted, 51 patients consented to participate in the study; 21 did not respond to the interview and 13 reported deaths of patients during the lockdown

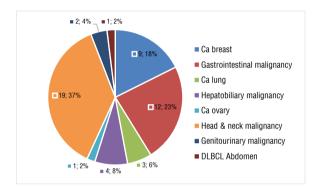
responded were interviewed telephonically and guestions were asked regarding their disease, pain and medications and QoL during the lockdown (Fig. 1). Patients were interviewed by one of the researchers using structured questionnaires in both English and Hindi (Supplementary Appendix 1: Questionnaire). Tools used were the Functional Assessment of Chronic Illness Therapy system of Quality of Life questionnaire - FACT G7 and the Numerical Rating scale (NRS) for pain intensity assessment. FACT G7 is a rapid index of 7 questions (a subset of the 27 items of FACT-G, which encompasses physical well-being, social/family well-being, emotional well-being, and functional well-being domains) [3]. Higher scores for the scales indicate better QoL. It usually does not require assistance and is most responsive to the limitations of clinical and research settings. The FACT-G7 has shown good internal consistency for comparisons in the National Comprehensive Cancer Network (NCCN) cancer sample and the general USA population sample with Cronbach's alphas of 0.74 and 0.80, respectively [4]. The forms were filled out entirely by the researcher. Patients who do not understand Hindi or English were excluded from the study.

### Statistics

All data obtained were tabulated into a Microsoft Excel sheet. The data was tabulated and statistically analysed using SPSS v21. Student t-test was applied to

Table 1. Demographic characteristics of patients
who were interviewed

Age in years	Number of patients (total = 51)
18–30	2 (3.9%)
30–50	15 (29.4%)
50–65	19 (37.3%)
> 65	15 (29.4%)
Sex (male : female)	30 : 21
Distance of hospital from home	Number of patients (total = 51)
< 5 km	1
5–10 km	2
> 10 km	19
Another state	29



**Figure 2**. Distribution of cancer diagnosis among the patients interviewed; Ca — carcinoma; DLBCL — diffuse large B–cell lymphoma

compare QoL between comparable groups. Pearson's Correlation Coefficient was used to find a correlation between NRS for pain intensity and QoL. For all purposes, the p-value was considered significant if it was less than or equal to 0.05.

# Results

# Patients

Eighty five adult patients were contacted, and 51 patients consented to participate in the study; 21 did not respond to the interview and 13 reported deaths of patients during the lockdown. Amongst the patients interviewed, 15 were more than 65 years (29.4%), 19 were 50–65 years (37.3%) and 15 were 30–50 years of age (29.4%). The male-to-female patient ratio was 30:21 (Table 1). The majority who were unable to visit belonged to a different state (56.9%, n = 29) or resided more than 10 km from the hospital (37.3%, n = 19).

Most of the patients had either advanced disease (43.1%, n = 22) or were not aware of their disease status (39.2%, n = 20). The distribution of diagnosis of cancer is demonstrated in Figure 2. Amongst all who responded 52.9% (n = 27) were under active treatment for cancer whereas 37.3% (n = 19) were under supportive care only. The QoL scores (supportive care only:  $12.79 \pm 3.33$ ; active treatment:  $14.68 \pm 3.9$ ) were not statistically significant (p = 0.091). There were 4 (7.8%) patients who were still under evaluation and were yet to start definitive treatment. They were under palliative clinic follow-up for pain management. Most of the participants feared their cancer shall progress during the lockdown phase (76.5%, n = 39), 19.6% (n = 10) feared getting infected by COVID-19 and 3.9% (n = 2) feared infection of their family members. Most had their treatment delayed (51%, n = 26) due to the travel restrictions while 5.9% (n = 3) had opted to stay at home instead of continuing their treatment; however, 27.5% (n = 14) were continuing cancer treatment despite lockdown (Table 2).

### Pain

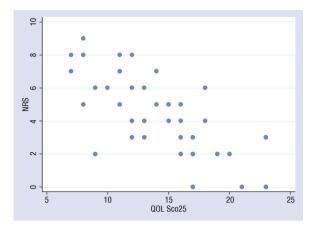
Sites of maximal pain were noted in the head and neck region in 19 patients (38%), the chest in 14 patients (28%), in the back in 5 patients (10%) and 11 patients complained of pain in the abdomen (22%). The mean NRS for pain was 4.5  $\pm$  2.1. The variables NRS (pain intensity) and QoL scores were found to be negatively correlated (Pearson's Correlation Coefficient: r (49) = -0.69, p < 0.00001). Figure 3 illustrates the distribution of NRS scores and QoL scores.

### Quality of life and access to healthcare

Twenty three patients (45.1%) faced inconvenience to gain access to their regular medications during the lockdown. Eighteen patients (35.3%) required morphine to alleviate their pain and six patients (33.33%) faced difficulty in acquiring morphine tablets. To understand the effect of lockdown, in the present study the mean FACT G7 score was compared between those living outside the state and were, therefore, not able to visit the hospital and those living within the state. A total of 57% (n = 29) of the respondents were from outside the state of Delhi while the rest were residents of Delhi. This difference was not significant (p = 0.275), possibly as the patient outside the state were actively followed up by teleconsultations. Another possible effect of the lockdown was difficult access to medication. A total of 45% (n = 23) of the patients reported that they had difficult access to medication. Those people who reported difficulty in access to medication reported poor quality of life.

Stage of disease	Number of patients (total = 51)
Stage 1	0
Stage 2	2
Stage 3	4
Stage 4	3
Cancer has spread	22
Not aware	20
Disease status	Number of patients (total = 51)
Under evaluation	4
Under active therapy	27
Under palliative care	19
Cancer survivor	1
Patient has complaints of pain?	Number of patients (total = 51)
Yes	39
No	12
Need morphine for pain relief?	Number of patients (total = 51)
Yes	18
No	33
Have difficulty accessing morphine?	Number of patients (total = 18)
Yes	6
No	12
Have difficulty in getting access to other medicines?	Number of patients (total = 51)
Yes	23
No	28
My fear is	Number of patients (total = 51)
Getting infected by COVID-19	10
Cancer will progress	39
Family will get infected	2
None	0
Treatment	Number of patients (total = 51)
Undergoing treatment despite lockdown	14
Therapy delayed due to lockdown	26
Opted to stay at home	3
Completed treatment and is on follow up	5
Recently diagnosed and treat- ment not started	2
Other	1

# Table 2. Disease and symptom characteristics of the patients interviewed



**Figure 3.** Scatter diagram showing the distribution of NRS scores vs QoL scores; QOL — quality of life; NRS — numerical rating scale for pain intensity assessment

The QoL scores did not differ based on access to morphine (p = 0.648). However, the mean QoL scores were 12.7  $\pm$  3.76 and 15.0  $\pm$  3.60 amongst patients who did not have access to other medications and who did have access, respectively (p = 0.03). Overall QoL assessed by the FACT G7 questionnaire showed a mean calculated score of 14  $\pm$  3.8.

# End-of-life care

Out of the 13 deaths reported by caregivers, 9 were taking morphine for pain in the last 3 days of life. One of these patients had refractory pain despite dose modification via telemedicine consultation. 2 patients had complaints of refractory vomiting despite prescribed medications and 2 had complaints of shortness of breath during the last 3 days. One of these 2 patients had adequate relief of dyspnoea with low-dose morphine. Ten patients had advanced malignancies with ongoing palliative management and 6 were already counselled regarding best support and end-of-life care. Of the 13 patients, 10 passed away comfortably at home with the family at bedside and 3 were rushed to the emergency department of a nearby hospital for symptom relief and expired in the hospital.

# Discussion

Cancer patients suffer due to delays in routine medical care, progressive disease and symptom burden, in addition to experiencing heightened distress associated with the threat of COVID-19 itself. Immune suppression due to psychological stress is known to adversely affect cancer survival and incidence [5, 6]. Social distancing efforts and travel restrictions aimed at controlling the spread of COVID-19 can cause delays in diagnosis and initiation of cancer treatment, disrupt ongoing treatment and supportive care, and hinder optimal patient-physician interactions via regular face-to-face appointments. All these unfamiliar situations can worsen suffering in patients with cancer and their caregivers.

In a study in the USA conducted with 4912 cancer patients mean QoL by FACT G7 was found to be 19.1 ± 5.5 [7]. The mean FACT G7 score was  $14 \pm 3.8$ . in the present study. Though the data of QoL of these patients before the outbreak has not been obtained for comparison, there is a remarkable difference between the two groups of cancer patients with the mixed diagnosis. In the present study, the mean QoL scores of the patients between 18–30 years of age was 13  $\pm$  7.01, 30–50 years was  $13.27 \pm 3.1, 50-65$  years of age was  $14.42 \pm 3.1$  and more than 65 years of age was 14.2  $\pm$  5.05; all of which lie in the middle of the spectrum but lower than the USA cancer patients [7]. In a study by Asthana et al. [8] European Organization for Research and Treatment of Cancer (EORTC) QLQ-C15-PAL was used to assess QoL in cancer patients under palliative care. Female patients had more needs than males including statistically significant sleep quality (p < 0.05) [8]. This was, however, not reflected in the present study where there was no statistical difference in QoL between male and female patients.

There was significant impairment of health-related QoL using SF-36 scoring at 6 months in 110 survivors with confirmed SARS who were evaluated at the Prince of Wales Hospital SARS in 2003 [9]. This shows the importance of recording QoL scores in cancer patients routinely so that any deterioration from the baseline can be quickly assessed and managed. As we are only beginning to grasp the ramifications of the COVID-19 outbreak, there is an urgent need to address the enormous psychological and physical burden it is inflicting.

During the COVID-19 pandemic, in a published survey of 1,210 individuals in China, 58.3% reported a psychological impact of the outbreak: 28.8% reported anxiety, 16.5% reported depressive symptoms, and 8.1% reported stress [10]. All these symptoms were rated as moderate to severe, and they can be a significant detriment to QoL, negatively impacting physical activity [11] and disrupting sleep [12]. In the present study as well the cancer patients have low mean scores of  $14 \pm 3.8$  reflecting a poor QoL during this pandemic. However, the absence of reference data from the pre-pandemic study is acknowledged.

In India, annually almost one million patients are newly diagnosed with cancer and approximately 80% of the patients present at a late stage of their disease [13]. The public health care system in India has limited resources and cannot provide palliative care to all patients in need of symptom relief [14, 15].

Factors which positively influence the extent of the QoL include good doctor-patient communication, economic status, education, socioeconomic support and spirituality. The negative factors are social isolation, lack of employment, poverty, rejection and stigmatization and experience of symptoms, such as uncontrolled pain. Studies have shown that regular visits to palliative care centres have improved the QoL and mood of advanced-stage cancer patients [13, 16]. It has been estimated that only 3% of cancer patients in India receive adequate pain management [17, 18]. Palliative care in India is at an early stage of development and is often hampered by limited access to morphine and other effective medication, as well as a lack of education in pain management [19, 20]. During the COVID-19 crisis, the healthcare system has augmented its services via telemedicine. However, the Indian teleconsultation guidelines prohibit the prescription of opioids and psychotropic drugs [21]. In the present study survey, the mean pain NRS score was 4.5 ± 2.1 and 18 out of 51 (35.29%) patients required morphine for their pain relief and amongst them, only 6 (33.33%) had difficulty accessing it. There was a statistically significant negative correlation between pain scores and QoL. The low NRS scores and low rate of failure to procure morphine even during the lockdown phase may be attributed to the telemedicine practice at the authors' institute, along with successful collaboration with various palliative care physicians/centres/non-profit organisations. This collaborative effort maintains a strict vigil on opioid access and procurement to provide adequate pain relief to the remotely placed patients who had difficulty accessing conveyance to the outpatient department. Those able to maintain their scheduled appointments were prescribed medications for at least one month [22]. However, there were some lacunae in the care of patients; 23 out of the total of 51 had faced difficulties in procurement of other medications and analgesics due to the local shutdown of chemist shops or reduced drug stocking. The evaluation of the quality of service provided is an important aspect of palliative care and scoring of QoL of patients proves to be an important procedure in the identification of a patient's overall condition and re-evaluation of the palliative care facilities [23].

Limitations include the uncertainty of using QoL measurement tools originally constructed in high-income countries, with different populations. The used scales FACT G7 can, on the other hand, be viewed as global in its choices of subjects and are validated in large populations worldwide. The sample size for the study was also small. Even though validated Hindi forms were used by the interviewer for questioning, with the background of illiteracy and unfamiliarity with the terms of the questionnaire used, patients may find it difficult to understand during the interview.

# Conclusions

The evaluation of QoL of patients in palliative care plays an important role in the assessment of a patient's overall condition as well as in the evaluation of the quality of palliative care provided, especially during global crises to maintain a continuum of care. Decentralisation of palliative care services to primary care physicians and community health workers, education of caregivers, empowerment and collaboration with NGOs, better access to opioids, strengthening of telemedicine practices, using video consultations to reduce the barrier of face-to-face consultations, inclusion of opioids into telemedicine prescription services, more aggressive approach to the management of the vulnerable population suffering from chronic and debilitating diseases is recommended.

### Declaration of conflict of interest

The authors declare that there is no conflict of interest.

### Funding

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### Appendix. Questionnaire

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### Quality of life of palliative care cancer patients during COVID-19 lockdown phase

1. Consent to participate: I have reviewed the information provided in the participation information sheet provided above and have made the required clarification if required from the investigator. I understand that my participation in this survey is voluntary, and I can decline my participation without giving any reason. By clicking on the "I Agree" button, I give consent to be part of the study. Mark only one oval

Yes
No
Demographic profile
2. Age. Mark only one oval
18–30
30–50
50–65
> 65
3. Gender. Mark only one oval
Other:
Female
Male
Prefer not to say
4. Residence. Mark only one oval
Less than 5 km
5–10 km
> 10 km
Other state
Disease Profile
5. Diagnosis
6. Stage of disease. Mark only one oval
Stage 1
Stage 2
Stage 3
Stage 4
I do not know
My cancer has spread
7. Mode of treatment ongoing. Mark only one oval
Curative
Palliative
Under evaluation
Cancer survivor
8. Receiving chemotherapy. Mark only one oval
Yes
No
9. Receiving radiotherapy. Mark only one oval
Yes
No

10. Planned for surgery. Mark only	one oval							
Yes								
No								
11. Best supportive care. Mark only	one oval							
Yes								
No								
12. Complaint of pain? Mark only o	one oval							
Yes								
No								
13. From 0 to 10 what is your maximum level of pain during the day, 0 being no pain and 10 being the maximum possible pain imaginable? Mark only one oval								
1 2 3	4	5	6	7	8	9	10	
14. Site of pain. Check all that apply	у							
Head and Chest Upper	Lower	Upper	Lower	Upper	Lower	Hands	Feet	
neck back	back	abdomen	abdomen	limb	limb			
15. Characteristics of pain. Mark on	nly one oval							
Somatic								
Visceral								
Neuropathic								
Mixed								
16. Are you taking any pain medica	ition? Mark	only one ov	al					
Yes								
No								
17. Which medication are you taking? Check all that apply								
NSAIDS (Flexon/Ibuprofen/Diclofenac/Aceclofenac)								
PCM								
Anticonvulsant (Gabapentin/Pregabalin/Carbamazepine)								
Tricyclic Antidepressant								
SNRI (Duloxetine)								
Tramadol/Ultracet								
Fentanyl Patch Morphine								
Flupertine								
Muscle Relaxant (Tizanidine/Baclo	ofon)							
18. My Fear Is. Check all that apply								
Getting infected by COVID-19								
My cancer will progress								
My family will get infected								
Other								
19. Treatment for cancer. Mark only	/ one oval							
I am undergoing therapy despite		wn						
My therapy is delayed or postpor			n					
I have opted to stay at home instead of seeking cancer treatment								
I have completed treatment for cancer and now I am on follow up								
I was recently diagnosed and yet to start treatment								
Other								
20. FACT–G7 (Version 4)								