

## Perception of cancer patients and their attendants during pandemic of COVID-19: an experience from tertiary care center, Pakistan

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### ABSTRACT

**Introduction:** Cancer patients have concerns about treatment during COVID 19 pandemic virus as well as its impact on their health. This survey was conducted to ascertain perception of cancer patients and their attendants during this pandemic.

**Method & Result:** This cross sectional study was conducted at Oncology OPD of SIUT, from May 2020 to July 2020 on cancer patients along with their attendants. Among 306 patients, 68.9 % received chemotherapy. In response of each question, 1st one belonged to patients and 2nd was related to attendants. Only positive answers are reported here. For increasing gap of chemotherapy during the pandemic COVID 19, 58.3% vs 38.4% agreed with doctor recommendation. For start of single agent chemotherapy instead of combination regimen, 41% vs 19% agreed. For hospitalization 41.5%, vs 47.7% depicted inclination towards admission whereas for mental health questions, 63.7% vs 51.3% were neither afraid nor had psychological issues 79.7% vs 25.8% respectively. About COVID -19 testing, 66% vs 22.5% wanted to be tested. If results turned out positive, 82.2% vs 24.7% would go in isolation.

**Conclusion:** This study provides evidence of perception of cancer patients with their attendants from resource restrained country. Our study confirms that for disease like cancer, fear of the illness is always more paramount than any infection.

**Keywords:** SIUT-Sindh Institute of Urology and Transplantation. OPD-out patient department/clinic. COVID 19-Corona virus infection

## INTRODUCTION:

In developing countries, like Pakistan, it is difficult to handle COVID -19 pandemic, as people are not following standard operating procedures (SOPs). Certain factors are responsible for control of spread of this infection in developing countries (1). It can be attributed to limited number of available COVID -19 testing facilities, people live in combined family system in small spaced houses with elderly members, densely populated cities leading to travel in crowded public buses and myths/rumors/false perceptions about COVID 19 (2). Pakistan has already frail healthcare system with 0.7 bed /1000 people, COVID19 is creating a burden on the healthcare system (3). The lockdown as observed in developed countries, if practiced in Pakistan, could led to increased mortality due to poverty (4).

Cancer patients have increased anxiety level with some concerns related to this viral infection. These concerns are: severity of this infection in them, their cancer treatment has negative impact on their immunity, is continuation of cancer treatment possible in these circumstances? (5), In Dr Guven et al study, cancer patients were afraid of acquiring infection and interruption in cancer care during this time(6) .Whereas, Ghosh et al observed participants wanted continuation of their treatment (7). Patients who were on active treatment had concerns of effects of COVID-19 (8). To protect vulnerable populations, telemedicine is a valuable tool. This approach has been practiced widely and accepted with positive experiences by patients and physician. This process needs to be accelerated (9).

Another important and undertreated issue is mental health of cancer patients. In Gao et al study, the incidence of depression in oncology patients was 48 % (10) .Mental health of cancer patient is more important during this time because these patients have been advised for social isolation for long time and they have disease related issues as well(11).Several myths and rumors about this viral infection are being circulated, regarding the treatment and prevention (12). One misbelief is that this virus affects only elderly. (12). Other myths are: this

virus is just like normal flu, it is not contagious, this virus is a fallacy and it does not have any existence. It has been experienced in previous pandemics such as SARS, 2003 negative attitudes leads to difficult control of spread of infection (12).The same myths are prevalent regarding Polio virus, which has led to uncontrollable situation of Polio Virus in Pakistan (13).

It is imperative for the caregivers that they observe strict SOP's for COVID-19. Attendants who put their household members (susceptible people at home) on risk if they won't follow SOPs. Awareness, seriousness and responsibilities of attendants is more important as cancer patients are already following the SOP's. We aimed to know the perceptions of cancer patients and their care giver for COVID-19.This study will play an important role in defining the perspective of cancer patients along with their attendants during this pandemic.

## Methodology:

This cross sectional study was approved by the institution board review and Ethics Committee, with a reference letter number: SIUT-ERC-2020/PA-212.

We conducted this survey in Oncology OPD of SIUT (Sindh institute of urology and transplantation), Karachi from April 2020 till the end of July 2020. In this study, during the pandemic of COVID 19, views and concerns of oncology patients and caregiver has been recorded. Our questionnaire comprises a brief introduction of this study, aims, procedure of data collection, voluntary nature of participation and maintaining confidentiality. Proforma was divided into 2 parts. First part included demographics i.e. age, gender, marital status, stage, type of cancer and type of cancer treatment Other part consisted of views , concerns , mental health and COVID 19 testing.. Few important issues that we observed during this period have been raised. There were total 10 questions. We compared both patient and attendant views and concerns. Proforma and consent form were translated in English and Urdu languages. We divided age of patients into 4 groups. Groups 1: 20-40 , Group 2: 40-60 ,Group 3: ≥60 respectively.

As this was the first study of its kind, we did a pilot study

on 25 patients and observed participant behavior. We put few questions in front of participants, options had been given to them. After pilot study, options frequently selected by patients have been included in this study. Interviewer, who filled proforma carried out all precautions for COVID-19. Oncology patients and available attendants coming to Oncology OPD and receiving cancer treatment were eligible for this study.

Total number of cancer patients who visited Oncology OPD in these 4 months was 306 in number along with their attendants. Assuming the proportion of perception is unknown in 50 % of cancer patients & their attendants with margin of error 5% and 95% confidence level. N of 100 patients was calculated as appropriate for this study, though we interviewed more patients in order to give statistically significant values to the findings.

Data was entered in SPSS version 21 and a database was established. Numerical variables were measured as mean and standard deviations, while categorical variables were expressed as frequencies and percentages. Chi-square tests were used to find differences in views/concerns of both participants a p-value of less than 0.05 will be considered significant in all tests.

## Results:

Characteristics of patients have been described in table # 1.

### VIEWS AND CONCERN OF PATIENTS AND ATTENDANTS.

In table# 2, both patient and attendant thought process was assessed and compared. We have analyzed patient perception in more details. These are as follows.

#### Patient perception

Patients have been asked pertinent questions related to awareness regarding COVID pandemic. The questionnaire was filled during initial time of first wave where guidelines were in the initial phases regarding cancer treatment during this pandemic. Among 306 patients, 136 (44.45%) had awareness about which population is most vulnerable. At least 52(17%) had idea that malignancy is associated with fatal consequences. Another cluster of patients, n-107(37%) are those who thought

that age and comorbidities are conditions that lead to fatal outcome). Similarly we asked whether they knew that chemotherapy can lead to worse outcomes: n- 87 (28.4%) replied yes (group 1) whereas 219 (71.6%) (Group 2) did not know.

We compared knowledge of above these two groups with their perception. We have put 2 questions related to their cancer treatment i.e. chemotherapy and given options also. Comparison has been mentioned in table 3.

#### Attitude of cancer patients

We tried to observe their attitudes with certain questions and our observations during interview. About continuation of cough etiquette and hand hygiene, they have been asked that will they continue after lock down or forever, 48% replied positively and 17% wanted to continue this habit. Prior knowledge of risk factors lead to better adoption rates of these habits vs no knowledge (55 % vs 47%), p=0.094, 95% C.I=-0.168, 0.088). In order to screen fear and depression during this pandemic, patients were asked set of questions such as changes in sleep pattern, appetite and daily routine life activities. We interrogated and found that n-59 (19%) were afraid. Earlier stage was correlated with more fear than advanced stages (34% vs 19%). p <0.001, 95% C.I= -0.337, 0.0171). Younger age group (20-39 year, 22%) vs other group (≥ 40 years, 17%) were found to be more afraid, p<0.001, 95% C.I=-0.166498, 0.066498). Almost equal number of genders in patients had no fear. Among knowledgeable population, only 23.5% patients had fear of this virus. Group of patients who were scared of getting chemotherapy during this pandemic were only 14%. Similarly, depression assessment was found to be low n-23 (7.5%). About COVID-19 testing, n-202(66%) wanted to get it done .People who were cognizance of vulnerability and positive reply of test were 60%. Familiarity about malignancy with worse outcome secondary to this infection wanted to be tested (73%). Age group 3 (≥60 years) wanted to get test more than other age groups (72 % vs 65%), p<0.001, 95% C.I= -0.04241, 0.20241). No difference in gender and stage wise testing. Almost 4/5 (82.2%) showed positive attitude for isolation after positive test. Awareness about malignancy, lead to acceptance of isolation easy for these

people, 69% agreed in this regard. About isolation, no difference in gender, stage and age group. During interview while patients were waiting for their appointment, their attitude was observed. We found that only 51% were wearing mask properly and 19% maintained social distancing. Only 50% had proper face mask even aware about risk factors and chemotherapy related immunosuppression. Awareness about risk factors increased social distancing practice to just 22%.

#### Attendant perception and attitude

We have evaluated attendant perception in detail that had impact on patient's health and treatment. About lethal nature of this virus, only 148(48.4%) knew about it. Knowledge about combined risk factors, including cancer was only 30%. One quarter attendant 77 (25.2%) had an idea that patients who receive chemotherapy are prone for serious complication secondary to this infection. About continuation of cough/sneeze adequate and hand hygiene, 114(37.2%) replied positively and nobody wanted to make it habit. About chemotherapy gap, 81(38.4%) agreed with doctor recommendations. People who were aware about decreased immunity after chemotherapy, only 17% agreed with doctor advice for gap in chemotherapy. Switching to single agent, 19% of same group had accepted this option on doctor recommendation. We tried to observe attendant attitudes similar to be observed in patients. We found that only 43% & 3.9% were wearing mask properly & physical distancing respectively. Even group of people who had good understanding about all risk factors and chemotherapy, only 50% & 39% were seen covering their faces properly. Awareness about risk factors and chemotherapy increased physical distancing practiced to just 8% from 3.9%

About COVID-19 testing, n-69(22.5%) wanted to get it done. There is no effect of awareness on attitudes of attendants. Positive reply of aware attendants for their COVID 19 test was only 26%. After testing positive, n-69(24.7%) would go in isolation. Awareness about susceptible population, this percentage is still low (16%) wanted to go for isolation.

#### Statistical analysis

We found statically significant p values ( $p < 0.001$ ) in all

perceptions of patients vs attendants except both participants are not afraid of consequences of this infection ( $p = 0.837$ ). Patients agreed with doctor recommendations, were more in comparison to their attendants in almost all questions. There is difference in attitude of patients vs attendants about COVID-19 test and isolation ( $p < 0.001$ ). During interview more patients were wearing face mask and maintaining distance. This difference is statistically significant for mask and physical distancing, 56.2% (patients) vs 43% (attendants) ( $p = 0.001$ ) and 19.3%(patients) vs 11.1%(attendants) ( $p = 0.005$ ) respectively.

#### Discussion:

Oncologists are working with the perspective of treating their patient with minimum exposure to COVID-19 virus during hospital appointment/stay/procedures without decreasing efficacy of treatment. One approach is delivering care through telemedicine. Before this pandemic, only 0-10% oncology patients used it and with passage of time this number has increased to 80% (14). Patients, who are on oral anticancer treatment, can be managed through this approach. But we need answer for patients who don't have this treatment option i.e. they have to come to hospital for parenteral anticancer agent. One program started in US, "Cancer Care at Home," provides certain cancer drugs in specific patient populations at home. This program saved patient's significant time. But this is not treatment option for developing countries (14). Another approach is modification in treatment plans. Dong et al (USA) searched their database to observe treatment modification during this time period. They found that 56.4% in 282 patients underwent treatment modifications. These changes have been made with curative intent ie adjuvant /neoadjuvant (41.4%) and palliative (62.9%) treatments. The most commonly observed strategy was to delay or omit scheduled treatment (49%) (15). This is the reason; for doing this survey at SIUT to enquire about patient perception during this unusual circumstances..

Majority of our patients either come from periphery or outside city. Due to lock down, intercity transport ser-

vices were suspended and patients faced difficulty in accessing the hospital for treatment. Patients could come to hospital after paying fare twice its value with risk of COVID 19 during travel also. Hospitals remain main source of nosocomial infections, people who come from villages can harbor this infection and transmit it to population of their village. For patient ease, we asked their views about increased duration of gaps between chemotherapy, but only 3.8% (Patients) vs 17.5% (Attendants) agreed for it because of logistic issues, while 31.7% (Patients) vs 36.9% (Attendants) had concern about disease progression with this approach. Similarly, some patients were given option of single agent effective chemotherapy in comparison to combination chemotherapy, 27% (Patients) vs 5.9% (Attendants) accepted it for logistic issues while 41% (Patients) vs 19% (Attendants) agreed with doctor recommendation in current scenario. For treatment, attendants were motivated more than patients and logistic issues were of secondary to them. This attitude shows respondents want continuation of their treatment without gaps irrespective of risk of exposure to deadly virus. This clearly shows that the fear of cancer is more overpowering than virus.

Patient's motivation for their cancer treatment is also depicted by this question. We asked if your doctor recommends you admission in hospital for any procedure or inpatient chemotherapy for few days, would you agree. Considerable proportion of patient depicted willingness without any hesitation 41% (patient) vs (10.4%) (Attendant). Whereas patient care providers showed reluctance to admit their patient (74.2%) (attendant) vs (43.5%) because of risk of acquiring infection in hospital.

The worldwide statistics has posed real questions in terms of mental health issues pertaining to COVID era. In Zheng et al study, 40.7% oncology patients reported symptoms of depression (16). In our study, about screening questions for depression, 7.5% (patient) vs 53.6% (attendants) accepted there is element of depression during this pandemic. Reasons behind fewer patients being depressed could be attributed to curative stage of cancer in  $\frac{3}{4}$  of patients and cancer is more devastating in comparison to COVID-19. Attendants were depressed

because of renewed restrictions that they are facing during lockdown situation. Similarly, we surprised to find that just only 19% respondents were afraid of consequences of this infection. There was controversy in their statement of fear. When they were asked about admission in hospital on doctor advice, half of patients vs just 2% agreed and 43% vs 74% gave reason of acquiring infection during hospital admission. Comparison of two questions i.e. if participants are not afraid of infection why they don't want to be admitted and gave reason that chance of acquiring infection. There might be hidden fear that they started to share with time. Participants shared the fear that experimental drugs will be used for research and development associated activities on their patients. They also said, if there is need of admission in COVID 19 ward, their attendants will be admitted with them to avoid these experiments. We did not add this option in our study, but attendant shared their thinking. As health care professionals, we not only have to provide treatment to our patients but also have to address this negative mindset that prevails among masses. This is another example of disbelief on health system that we have already observed for Polio vaccine (17).

Social stigma has been described in other infectious etiologies, like Tuberculosis. This is one of the causes of rapid spread of infections in community. Another disadvantage of this fear is increase morbidity and mortality in vulnerable groups after acquiring infection (16). Same scenario is observed with COVID 19 infection. People don't want to get tested. On our inquiry about COVID 19 testing, 66% patients vs 22.5% attendants had positive attitude. Patients wanted to get testing early, so gets treatment of COVID early and their cancer treatment should not be affected by this infection. But attendants think differently in this aspect, they consider there are fewer chances of complications. Reasons for avoid testing have been discussed in studies i.e. denial of existence of this infection, minimal symptoms, fear of the test procedure /consequences of results, disbelief in public health systems and government, financial instability. It is very important for caregiver to be tested and observe strict precautions because they can transmit infections to their patients.

Behavior and seriousness for this disease was observed by question asked from attendants. Not only about COVID 19 testing but attendants were not serious with respect to positive results. After positive results, attendants were not sure that they would go in quarantine. Only one quarter attendants vs <sup>></sup> three fourth patients were determined to go to quarantine. With those positive results, attendants do need more precautions to not transfer their infection to their patient. So they need quarantine more than the patient himself. Reasons attendants discussed with us for not going to quarantine were: that they are not immune compromised, will not face fatal consequences, earning responsibilities, have to take care of their other family members also etc. .

Strengths of this study are: 1st study in oncology patients from Pakistan to address concerns/views with comparison of attendant's views and concerns. Another important point in this study is mental health of patient and attendants. Motivation of patient and attendants with respect to treatment was assessed. Their myths have been discussed also.

Weakness of this study are: Number of patients belonged to stage IV are fewer. All patients belonged to either lower middle class or lower socio economic group. As it is the limitation of the study that lower socioeconomic class strata has been included in this study, they may have disbelieve in government / healthcare system and quickly act on hearsay evidence. We didn't use any proper scale to assess depression or anxiety. All patients included in this study had attendants with them; they might have good social/moral support. If we included patients who visited alone their mental health may be different. We didn't consider education and any family member is in health care profession, all these are linked to mental health.

**CONCLUSION:** This study provides some evidence of perception of cancer patients with their attendants during this pandemic from resource limited country. For diseases like cancer, fear of this illness is always more dreadful than any infection. Our study confirms that attitude. It is very important to treat patients in these special circumstances according to available resources with

proper satisfaction of these patients and their attendants.

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Declaration of Competing Interest

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