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Assessment of knowledge, attitude, practices and distress level of cancer patients in COVID-19 pandemic: A cross-sectional study

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ABSTRACT

The diagnosis and treatment of cancer can be an extremely stressful experience for the patient. COVID-19 pandemic has further created an environment of stress and anxiety amongst cancer patients. A cross-sectional study was conducted from March 2020 to May 2020 using google forms to assess the knowledge, distress level, practices, and attitude toward the COVID-19 pandemic in cancer patients. It was observed that the females and elderly patients (> 55 years) were more knowledgeable about the COVID-19 pandemic. Also, females were more prone to emotional stress compared to males. While the younger age group (18–35 years) had a more hard time in dealing with family-related issues compared to other age groups. Therefore, the younger age group (18–35 years) and female gender being more prone to distress, warrant more attention from health care staff and caretakers. Moreover, the study highlights the need for mental and general health screening and intervention to balance the oncological care and COVID-19 situation.

Introduction

The diagnosis of cancer is a life-altering experience for anyone and the introduction of the coronavirus disease 2019 (COVID-19) pandemic has further created an environment of stress and anxiety [1,2]. Since the first report of COVID-19 in Wuhan in December 2019, the spread of severe acute respiratory syndrome coronavirus 2 (SARS-CoV-2) has rapidly gone worldwide and has been declared a global pandemic by the World Health organisation (WHO) [3]. Moreover, a pandemic has startled and created unprecedented pressure on government and health services throughout the world including India. India is one of the developing countries with a 1.38 billion population residing in densely populated areas which emerges to be a constant risk for outbreaks and rapid spread of infection[4].

Cancer patients are predominately immunocompromised, weakened by the burden of the disease and its treatment and other co-morbidities and thus exposing them to the severe form of COVID-19 infection. Among 44,000 confirmed cases of COVID-19 in China, 0.9% of patients who had no underlying medical conditions died in the initial few months of the outbreak, but that number rose to 6% for people with cancer, reported by the Centres for Disease Control and Prevention [5]. A cohort study on the clinical impact of COVID-19 on patients with cancer showed higher 30-day-all-cause mortality among cancer patients [6]. Therefore, more attention should be paid to patients with cancer to prevent them from COVID-19 infection and provide them adequate support for cancer treatment. In addition, due to physical distancing measures, quarantine and lockdown in India, their social support is likely to be limited. It is important to recognize the increased level of distress that cancer patients and their families might face during this time, over and above the distress already experienced concerning their diagnosis and treatment.

The war against COVID-19 pamdemic is continuing and presently vaccination drive has been started all over the world but still, precautions and awareness are crucial steps to prevent COVID-19 infection. Recently a paper by ross et al. suggested for a booster vaccine dose after 2 doses of COVID vaccine to maintaine the neutralizing antibodies titre against COVID virus [7], which has been endorsed by the Indian government and booster vaccine dose is now given. Since human behavior is influenced by people's knowledge and perceptions, their behaviors and actions during the COVID-19 pandemic are crucial to controlling the spread of the novel virus. Assessing the knowledge related to COVID-19 pandemic among cancer patients would be helpful to provide better

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insight to address their query about the disease and the development of preventive strategies and health promotion programs. Many clinical oncology associations of repute have also issued recommendations for managing malignancy during COVID-19 pandemic [8,10,9].

Therefore the purpose of this study was to screen and assess knowledge, distress levels, attitude, and practices towards the COVID-19 pandemic amongst cancer patients in the western part of Rajasthan, India. The survey also gives a general picture of COVID-19 prevention practices among cancer patients registered in our institute and this can better prepare the health care system to address future health crises involving infectious diseases.

Material and methods

A web survey was conducted from the week immediately after lockdown 1.0 was declared on 25th March 2020 in India amongst the registered cancer patients irrespective of their disease status with the radiation oncology department in a tertiary care center.

This study included patients that were registered in the hospitals' electronic database with malignancy proven clinically and histologically, age above 18 years, and should understand the content of the form. Google Forms were used as a platform to create online questionnaires (in English / Hindi) that were automatically hosted via a unique URL link. This link was sent to registered mobile numbers of cancer fighters via what's app messenger. The form consisted of a brief introduction on the background, objective, voluntary nature of participation, declarations of anonymity, and confidentiality followed by a questionnaire. According to guidelines for clinical and community management of COVID-19 by the Indian Council of Medical Research, the questioner was prepared by authors and was divided into 5 major headings: Screening (total questions = 3), Knowledge Check (total questions = 12), Distress Assessment using National Comprehensive Cancer Network distress thermometer focusing on practical (Sub questions = 6), family (sub-questions = 4), emotional (sub-questions = 6), spiritual and physical problems (sub-questions = 22), steps practiced to prevent spread (total questions = 5) and Attitude (total questions = 3) of the patient towards COVID-19 pandemic [11]. The total knowledge score ranged from 0 to 12, with a higher score denoting a better knowledge of COVID-19. The distress thermometer helps to assess how much stress they were experiencing in the past few weeks including today by selecting the number from 0 to 10 on the thermometer, where 10 is extreme distress and 0 is no distress. While Score < 4 on the distress thermometer was considered mild distress. Knowledge and distress quest significantly differed across genders and agegroups (18–35, 36–55, and > 55 years).

Statistical analysis

Data were entered in an Excel sheet to prepare the master sheet and transported to statistical software for calculations. Descriptive statistics including numbers and percentages, distribution were calculated for each variable. Frequencies of correct knowledge answers and various attitudes and practices were described. Knowledge scores and attitudes and practices of different persons according to demographic characteristics were compared with independent samples *t*-test or one-way analysis of variance (ANOVA) test as appropriate. Statistical analysis was performed using the SPSS (Statistical Package for the Social Sciences) v22 software (IBM Inc., Chicago, IL, USA). The statistical significance level was set at $p < 0.05$.

Results

Between March 2020 and May 2020, a cross-sectional survey using google forms was conducted and responses were obtained from 86 cancer patients who were already registered and were under treatment in our institute. The mean age of the participants was 53.68 years (SD: ± 10.763) (range 23–85). The survey showed female predominance, 60.5% were females and 39.5% were males. All were screened for COVID-19 infection (Table 1) and then assessed for their knowledge, distress levels, attitude, and practices towards the COVID-19 pandemic.

Knowledge check

The correct answer rates of the 12 questions on the COVID-19 knowledge questionnaire were 25% −100% (Table 2). The mean COVID-19 knowledge score was 9.58 (SD: 2.07, range: 3–12), suggesting an overall ~80% (9.58/12 × 100) correct rate on this knowledge test. Knowledge scores significantly differed across genders and age groups. It was observed that the mean knowledge score (mKS) ± SD for females and males was 9.98 (± 1.73) and 8.87 (± 2.38), respectively, which was statistically significant ($p = 0.03$) (Fig. 1). Also, elderly patients (> 55 years of age) were more informative with mKS ± SD of 10 (± 2.12) compared to age groups 18–35 (mKS: 8.5) and 36–55 (mKS: 9.17), respectively. Although, results were not statistically significant amongst age groups ($p = 0.11$) (Fig.2). Additionally, patients were also questioned for use of any ayurvedic or homeopathic treatment or diet modification to boost their immunity. Only 9.3% of participants were consuming ayurvedic (5.9%) or homeopathic (1.2%) and 29.1% of patients had modified their diet by increasing daily consumption of stuff like turmeric, ginger, tulsi, lemon, and boiled water to boost their immunity. Cancer treatment was modified due to lockdown, as the patient had difficulty in reaching our hospital. Many of the patients were from remote places and also did not have their vehicles. All patients were telephonically informed regarding the treatment modifications. 87.2% of patients were satisfied with treatment modifications done during the outbreak of the pandemic.

COVID-19 and distress

COVID −19 pandemic, directly or indirectly has affected patient's physical, emotional and mental well-being. In the present study, a distress thermometer on a scale of 0–10 was used to assess participant's stress levels. A score < 4 on the distress thermometer was considered mild distress. 60.47% of patients presented with mild or no distress while 39.53% suffered from moderate to severe distress, ≥ 4 (Fig. 3). There were various reasons and problems that contributed to the escalation of the distress score.

Practical problems: Since many of the patients were from low socioeconomic status, so the most common practical problem was finance, faced by 38.4% of patients followed by transportation problems faced by 37.2% patients due to lockdown and non-availability of government transportation as shown in the sun-burst diagram (Fig. 4). Patients had to arrange for their transportation which added to a financial burden. Housing and accommodation were also a big problem faced by 37.2% of patients, as many patients were from remote village areas and needed to stay near the hospital for daily radiotherapy, and finding accommodations was difficult in lockdown duration. Practical problems differed across gender and age groups. Male gender and 18–35 years age group had more practical problems compared to females and other age groups,

Table 1
COVID-19 Screening Questions.

Sr. No.	Screening Questionnaires	Responses	
		Yes	No
1.1	Have you traveled to international or COVID-19 murky areas in the last 45 days	2 (2.3%)	84 (97.7%)
1.2	Did you or a member of the household have any contact with COVID-19 patients	–	86 (100%)
1.3	Did you have any problems with fever, dry cough, fatigue for the last 14 days	2 (1.2%)	84 (98.8%)

Table 2
Practices and attitude of Cancer patients toward COVID-19 pandemic.

Sr. No	Knowledge check Questionnaires	Responses		
		Yes	No	Don't know
2.1	The main symptoms of COVID-19 are fever, fatigue, dry cough, muscle aches, abdominal pain, or shortness of breath.	36 (41.9%)	47(56.5%)	3(3.5%)
2.2	Currently there is no effective cure for COVID-19	43 (50%)	26(30.2%)	17 (19.8%)
2.3	Early symptoms and supportive treatment can help most patients recover from the infection.	73 (84.9%)	5(5.8%)	8(9.3%)
2.4	Diabetes, hypertension, kidney diseases, any chronic disease or higher risk of the elderly	72 (83.7%)	5(5.9%)	9 (10.5%)
2.5	COVID-19 virus is transmitted by respiratory drops of infected individuals.	66(76.7%)	4(4.6%)	16 (18.6%)
2.6	Residents can wear common masks to prevent infection by the COVID-19 virus	74(86%)	5(5.9%)	7(8.1%)
2.7	One should avoid visiting crowded places during COVID-19	86(100%)	–	–
2.8	To prevent the infection by COVID-19, individuals should avoid going to crowded places such as train stations and avoid taking public transportations.	85(98.8%)		1(1.2%)
2.9	Isolation and treatment of people who are infected with the COVID-19 virus are effective ways to reduce the spread of the virus.	74(86%)	5(5.9%)	7(8.1%)
2.10	People who have contact with someone infected with the COVID-19 virus should be immediately isolated in a proper place. In general, the observation period is 14 days.	80(93%)	1(1.2%)	5(5.8%)
2.11	During Covid 19 Pandemic one should maintain a distance of 1 meter	85(98.8%)		1(1.2%)
2.12	Do you know COVID-19 test centres in Rajasthan or Jodhpur	40(58.1%)	36(41.9%)	
	Are you suffering from any of the above diseases (Diabetes, HTN, Old age, Kidney Disease)	35 (40.7%)	51(59.3%)	
	Are you taking any Ayurvedic or homeopathic remedies to prevent COVID-19 (Ayurvedic-5.9%, Homeopathic-1.2%, No-53.5%, Other - 39.4%)	8(9.3%)	78(90.7%)	
	Are you taking any special nutrition or fruit in your diet to prevent COVID-19 (Boiled Water, Coconut Water, Fruits, Tulsi, Milk, Lemon, Ginger, Protein base food, Turmeric, Vegetables, Vitamin C)	25(29.1%)	61(70.9%)	
	Are you satisfied with modified cancer treatment protocol/treatment protocol during covid 19 pandemic	Yes – 59 (68.6%) May be Yes - 16 (18.6%)	No - 7 (8.1%) Maybe No - 4(4.7%)	

respectively, although results were not statistically significant ($p = 0.46$ and $p = 0.59$) (Fig 1,2).

Family Problem: The present study observed that 38.4% of patients were involved in family health issues as routine outpatient services were suspended in many hospitals. Only 15.1% of patients faced a problem dealing with their children and 9.3% had difficulty in dealing with a partner (Fig. 4). It was observed that females faced slightly more family problems compared to males (0.75 vs 0.65), although results were not statistically significant ($p = 0.65$) (Fig 1). The current study also shows that family-related issues were dominant in younger age groups, 18–35 years with a mean score of 2.25 ± 1.09 and least in > 55 years, the elderly group with a mean score of 0.48 ± 0.81, which was statistically significant ($p = 0.002$) (Fig. 2).

Emotional Problem: Emotional problems were other issues that increased stress levels amongst patients. It was observed that 51.1% of patients worried about their disease and current situation, and 37.5% suffered from sadness while 20.9% of patients feared the present scenario and limitations faced by them in their daily routine due to COVID-19. 26.7% of patients suffered from anhedonia (Fig. 4). It was observed that females had more emotional issues with a mean score of 2.4 (± 2.13) compared to males with a mean score of 1.32 (± 1.71), which was statistically significant $p = 0.01$ (Fig. 1). Also, emotional problems were more seen in the 18–35 age group compared to mid and elderly groups, although results were no statistically significant($p = 0.72$) (Fig. 2).

Physical problem: In the present study, it was observed that fatigue and pain were the most common physical problems dealt by patients. 47.7% and 38.4% of patients complained of fatigue and pain respectively (Fig. 4). Physical problems were differed across gender and age groups. It was observed that females had slightly more health issues compared to males, although the results were not significant ($p = 0.91$) (Fig 1). The younger age group, 18–35 years had more physical problems with a mean score of 6.25 ± 1.79 compared to other age groups ($p = 0.16$) (Fig. 2).

Practices and attitude towards COVID-19

To find the patient's approach towards the COVID-19 pandemic, participants were questioned about precautionary steps taken by them to fight COVID-19 infection. It was observed that 91.9% of patients regularly used face masks, 84% followed proper handwashing protocols and 98.8% avoided going to crowded places (Table 3.1). But only 7% of patients could avoid frequent touching of the face. Practices differed across gender and age groups. Females were slightly better in following precautionary steps compared to males, although the difference was not significant ($p = 0.24$) (Fig. 1). It was observed that the middle age group, 35–55 years (mean score 4.86) were more efficiently following precautionary measures compared to 18–35 years (mean score 4) and > 55 years (mean score 4.84) age groups, This difference was found to be statistically significant $p = 0.01$ (Fig. 2). Despite perturbation all around, 97.7% of patients showed a positive attitude towards the present situation and believed that COVID-19 can be successfully controlled and 98.8% of patients had shown full faith in the Indian government and health services (Table 3.2). While 97.7% of patients believed that together we can fight and win the battle against COVID-19 .

Discussion

Global health care systems and governments are restlessly dealing with the COVID-19 pandemic. Management of cancer patients is another issue running parallel to the COVID-19 pandemic. The present situation has increased apprehension amongst cancer patients resulting in increased stress levels and mental imbalance. Therefore, it is important to have a basic knowledge of COVID-19 infection and precautionary measures. In the current study, it was observed that females and elderly patients had adequate knowledge and updates about COVID-19 infection. The overall correct response rate on our knowledge test was ~80%.

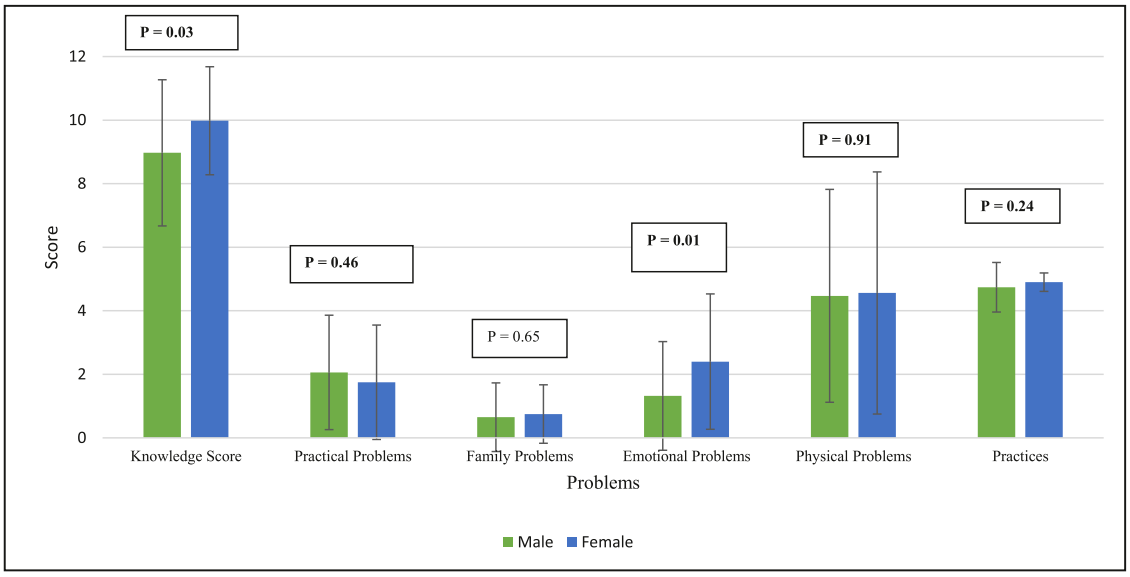

Fig. 1. Male versus female bar plot for knowledge score, different problems and practices towards COVID-19 pandemic.

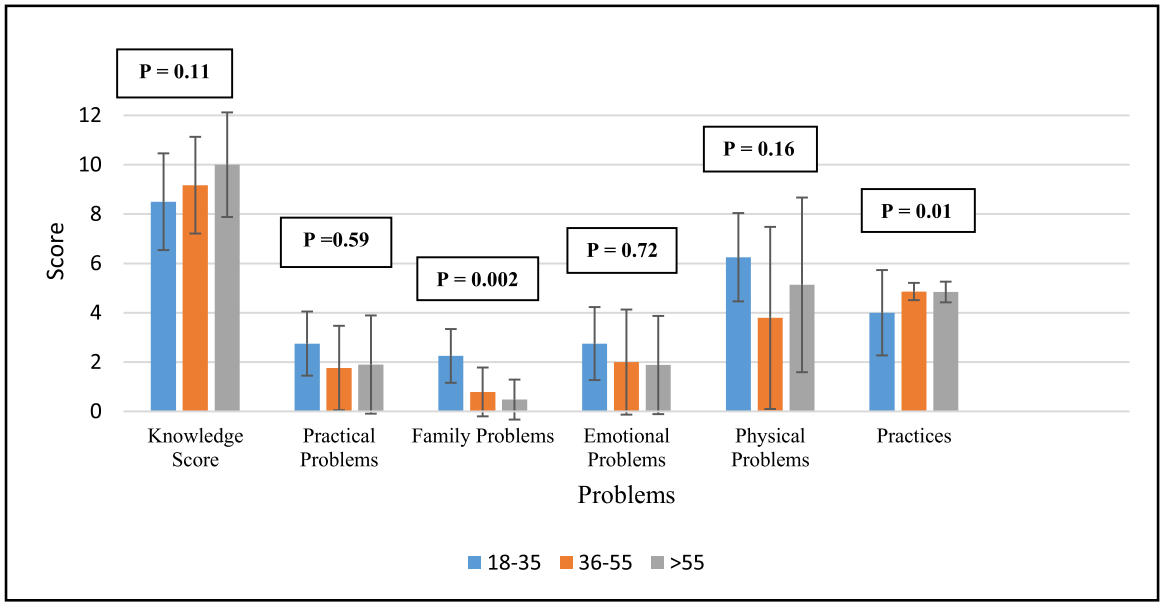

Fig. 2. Age group bar plot for knowledge score, different problems and practices towards COVID-19 pandemic.

It was observed that 91.9% of patients regularly used face masks, 84% followed proper handwashing protocols and 98.8% avoided going to crowded places. Females and middle age group participants were more sincere in practicing preventive measures like using a face mask, frequent hand washing, avoid crowded places, and frequent touching of the face. In a study done by Guru et al., the overall correct response rate of the knowledge regarding COVID-19 infection in cancer patients was 79.4% [12]. Most of the participants (89.7%) had a positive attitude towards accepting isolation if they had the COVID-19 infection. Only 4.5% reported that they had visited crowded places. More than 98% of the patients were found to be compliant with the recommended preventive behaviours.

The cancer population is at high risk of developing clinical levels of emotional disorder due to the distressing nature of the diagnosis, treatment, and side effects [13–15]. In addition the COVID-19 outbreak has created double edge situation for them. Social distancing measures and quarantine, limited the opportunities for family support and advocacy, affecting an important sense of connection and source of strength and well-being for cancer patients. During the COVID-19 crisis, two studies conducted by Wang and colleagues in the Chinese general population showed that 16.5% had depressive symptoms, 28.8% had anxiety symptoms, and 8.1% had stress symptoms, which was consistent over time [16,17]. It was observed in this study that 51.1% of patients worried about their disease and current situation and 37.5% suffered from sadness while 20.9% of patients feared the present scenario. 26.7% of patients suffered from anhedonia. Overall in this study 39.53% of patient suffered from moderate to severe distress. The female patients were more prone to emotional problems compared to males, and the younger age group (15–35) had difficulty in dealing with family issues and shortcomings.

During the COVID-19 pandemic, it is recommended high-risk groups be identified for psychological morbidities and screening be improved to provide quick, cost-effective psychological interventions via online platforms to manage symptoms. Moreover, it is recommended by the

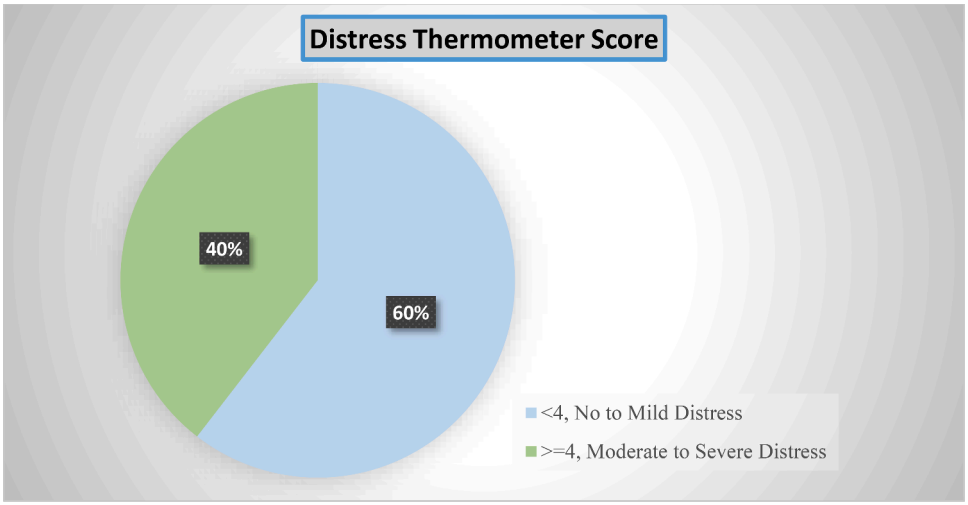

Fig. 3. Distress thermometer pie chart showing participant's stress level.

Table 3

3. 1 Practices	Yes	No
Have you gone to a crowded place?	1 (1.2%)	85 (98.8%)
Do you use face masks	79 (91.9%)	7(8.1%)
Do you touch your face very often	6(7%)	80(93%)
Are you following proper handwashing protocol?	84 (97.7%)	2(2.3%)
Are your family members taking the necessary precautions	84 (97.7%)	2(2.3%)
3.2 Attitude:		
Can COVID-19 be successfully controlled?	84 (97.7%)	2(2.3%)
Are you confident that India can win the battle against COVID-19 virus?	85 (98.8%)	1(1.2%)
Are you with us, to fight COVID-19?	84 (97.7%)	2(2.3%)

American Society of Clinical Oncology that all patients diagnosed with cancer should be screened for symptoms of depression and anxiety [18]. Therefore, supports must be in place in each cancer program and hospital to assess the level of distress and intervene appropriately to the best of the available resources. One way is to create a confidential online system to share COVID-19 experiences and cancer-related problems. Patients should be able to consult online and health care workers should provide support through telecommunication for daily consultation.

Many of the patients faced problems for getting the cancer treatment during COVID times at multiple levels. For example, finance, transportation and accommodation during lockdown were few such issue. Patients with their own vehicles were able to come to hospital during lockdown as travel pass were given from the hospital authority. However some patients who were financially not sound were not able to come to hospital for treatment as public transportation was stopped during lockdown. This was one of the problems which could be addressed by coordinating hospital authorities with local administration, by utilizing ambulances or government buses to ferry patients for treatment. Accommodation problem can be solved by coordinating with local authorities, which may help in provide safe accommodation to these patients. Many hospitals also faced challenges in maintaining the same level of care as before the pandemic, and therefore, they reduced or adjusted their services to different degrees using various approaches [19]. As expected, our hospital reduced their outpatient visits and switched to virtual clinics and teleconsultation. Also, the patient had difficulty in reaching our hospital due to lockdown as many were from remote places and did not have their vehicles. Cancer treatment was modified in few patients to the short course or oral chemotherapy and hypofractionated radiotherapy to limit hospital visits and stay, due to lockdown, as the patient had difficulty in reaching our hospital. Patients were telephonically informed regarding the changes in their treatment plan and were followed at timely intervals. 87.2% of the patients were satisfied with their treatment protocol modification. Despite the imbalance in physical, emotional, and mental well-being, the majority of the patients in the current study have a positive vision and belief that together we can win the battle against COVID-19 infection.

As the pandemic evolves, we are gaining new knowledge and adjusting some older approaches. Teleconsultation and digital health in oncology can be an excellent tool for real-time video consultations for primary care triage and interventions, such as counseling, medication prescribing, management, and post-discharge coordination supported by remote monitoring capabilities. It can be also a useful tool for wellness interventions and in areas such as health education, physical activity, diet monitoring, medication adherence, and cognitive fitness. Thus, we not only avoid harm in any future pandemic but also use the momentum gained from the current one to improve overall health care delivery for our patients and enhance the quality of care.

The current study has several limitations. First, the cause and effect cannot be established due to the nature of the cross-sectional design. Future longitudinal studies are needed for an in-depth understanding of the consequences of health problems in cancer patients. Participation in this study was voluntary and may have been skewed because responding patients are willing to share information while non-responding patients may not be willing or able to do so for various reasons. This is a web based survey, therefore only patients with access to the internet (and a high enough level of reading comprehension) would be able to complete this, resulting in selection bias. The study may not have adequate representation from all regions, but the sample size helped us to perform an analysis that enabled us to draw plausible conclusions about the challenges encountered in our region with limited resources.

Conclusion

COVID-19, although has created an environment of stress and anxiety for cancer patients. Knowledge and awareness can turn out to be the main strength to fight the battle against the COVID-19 pandemic. The study reveals that the majority of the cancer patients in our study have general information regarding COVID-19 and maintain a positive attitude and practice for protecting themselves against it. This study highlights that younger age group (18–35 years) and female patients appear to be more prone to distress and warrant more attention from health care staff and caretakers. There are chances that during epidemics other

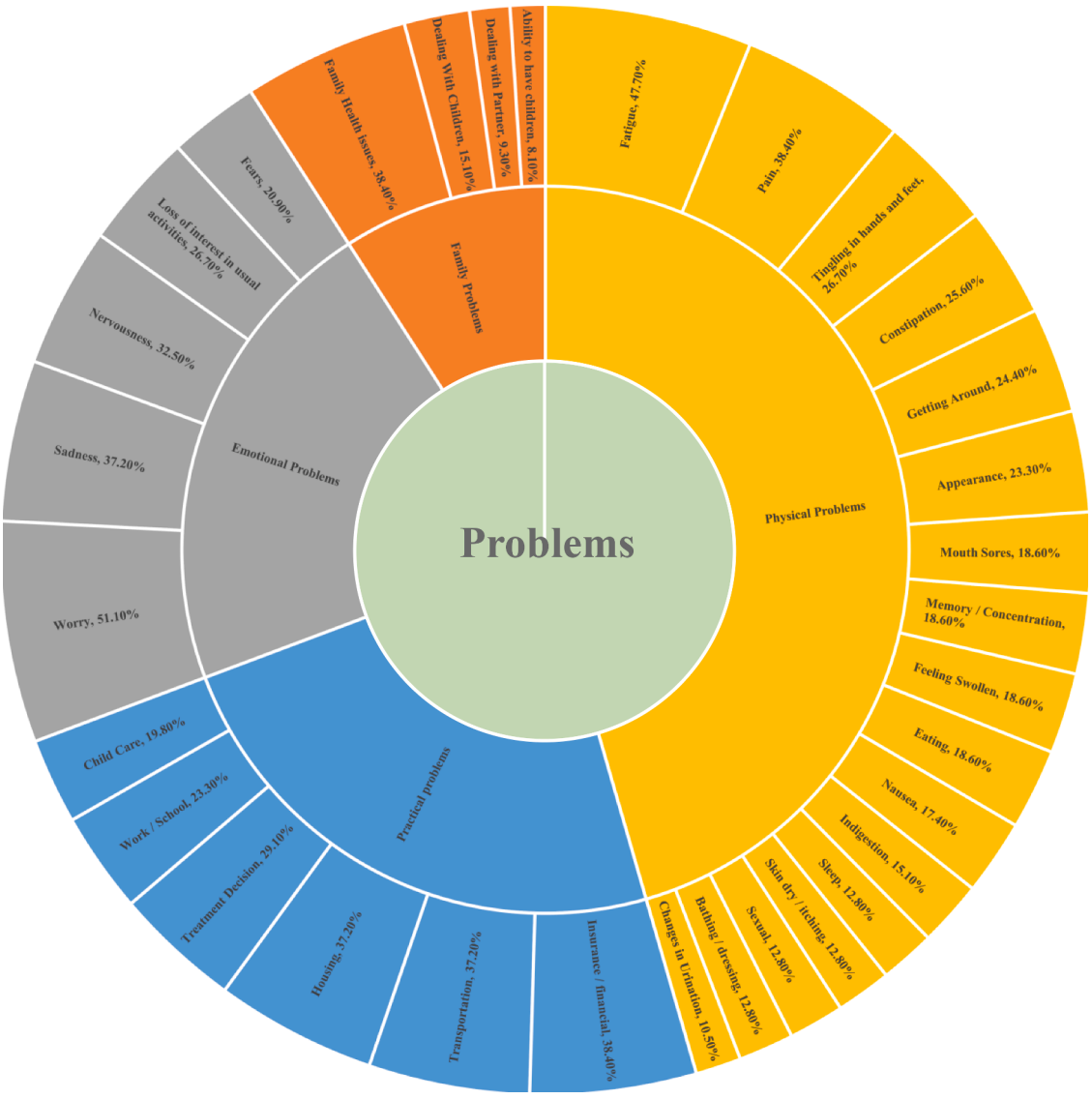

Fig. 4. Sunburst diagram showing problems faced by the participant`s. The problems are divided into four broad groups,represented by intermediate circle. The outer circle represents the topics of concern for each group and intensity of expression for each topic.

disease like cancer may get neglected due to various reasons, leading to progression of disease and death. We need to identify such issues that may lead to delay or disruption of treatment. Future longitudinal research should continue to monitor the longer-term effects of COVID-19 on psychological and general health in cancer patients.

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CRediT authorship contribution statement

Sweta Soni: Conception and design of this study, acquisition of data, analysis and interpretation of data, drafting and approval of the manuscript. **Ramakant Tiwari**: Conception and design of this study, acquisition of data, analysis and interpretation of data, drafting and approval of the manuscript. **Puneet Pareek**: Conception and design of this study, acquisition of data, analysis and interpretation of data, drafting and approval of the manuscript. **Sumanta Manna**: Analysis and interpretation of data, revising the manuscript critically for important intellectual content, approval the manuscript. **Ritika Sharma**: Analysis and interpretation of data, revising the manuscript critically for important intellectual content, approval the manuscript. **Rakesh Kumar Vyas**: Analysis and interpretation of data, revising the manuscript critically for important intellectual content, approval the manuscript. **Bharti Devnani**: Analysis and interpretation of data, revising the manuscript critically for important intellectual content, approval the manuscript.

Declaration of Competing Interest

The authors declare no potential conflict of interest with respect to the research, authorship, and/or publication of this article.

Supplementary materials

Supplementary material associated with this article can be found, in the online version, at doi:10.1016/j.ctarc.2022.100610.

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