


## ORIGINAL ARTICLE

# Financial toxicity and mental well-being of the oral cancer survivors residing in a developing country in the era of COVID 19 pandemic – A cross-sectional study

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## Abstract

**Objectives:** The primary outcome measures evaluated the financial toxicity and mental well-being of the oral cancer survivors.

**Methods:** A cross-sectional study of oral cancer survivors who were disease-free for more than 6 months after treatment and visited the hospital for a routine follow-up is included in the study. Mental well-being and financial toxicity were evaluated using the Depression, Anxiety, and Stress Scale - 21 (DASS 21) and Comprehensive Score for financial Toxicity (COST- Functional Assessment of Chronic Illness Therapy) questionnaires. A literature review was done to compare the results with financial toxicity and mental health in cancer patients from the pre-pandemic era.

**Results:** A total of 79 oral cancer survivors were included in the study, predominantly males (M: F = 10:1). The age ranged from 26 to 75 years (The median age is 49). The full-time employment dropped from 83.5% in the pre-treatment period to 21.5% post-treatment. Depression was observed in 58.2% and anxiety in 72.2%. Unemployed survivors were observed to have more depression (OR = 1.3, 95% confidence interval (CI) = 0.3–5.4,  $p = 0.6$ ), anxiety (OR = 3.5, 95% CI = 0.3–21.2,  $p = 0.1$ ) and stress (OR = 1.6, 95% CI = 0.3–6.6,  $p = 0.5$ ) than rest of the cohort. On univariate analysis, unemployed survivors ( $M = 11.8 \pm 3.8$ ,  $p = 0.01$ ) had significantly poorer financial toxicity scores. Survivors with depression ( $M = 16.4 \pm 7.1$ ,  $p = 0.06$ ) and stress ( $M = 14.4 \pm 6.8$ ,  $p = 0.002$ ) had poor financial toxicity scores. On multifactorial analysis of variance, current employment ( $p = 0.04$ ) and treatment modality ( $p = 0.05$ ) were significant factors impacting the financial toxicity.

**Conclusion:** There is a trend towards increased incidence of depression, anxiety, and stress among oral cancer survivors compared to the literature from the pre-COVID era. There is significant financial toxicity among either unemployed or part-time workers. This calls for urgent public/government intervention to prevent the long-term impact of financial toxicity on survival and quality of life.

**KEYWORDS**

anxiety, cancer, cancer survivors, COVID 19 pandemic, depression, financial toxicity, mental health, mental well-being, oncology, oral cancer, stress

## 1 | INTRODUCTION

The World Health Organization declared the novel coronavirus outbreak a public health emergency of international concern on 30 Jan 2020, and named the disease COVID-19 on 11 Feb 2020.<sup>1</sup> By the second week of September 2020, India had reported the highest number of COVID cases during the first wave. By May 2021, nearly two million confirmed cases had been reported.<sup>2</sup> The burden was unprecedented, and the health care system was not ready to handle it adequately. Cancer Care, in particular, was adversely affected. *Ranganathan et al.* observed a 54% reduction in the registration of new cancer patients, and there was a 46% reduction in follow-up visits of cancer survivors during the first wave of the pandemic in India.<sup>3</sup> The current pandemic has had a great deal of impact on society. In the wake of social distancing, lockdowns, virtual meetings, and consultations, a radically altered standard of living emerged and influenced multiple disciplines.

Most Head and Neck cancer (HNC) patients undergo multimodality treatment that can impact speech, swallowing, breathing, and bodily image.<sup>4</sup> Head and Neck cancer survivors are a particular group of people who require continued care in physical and psychosocial domains.<sup>5</sup> Psychological well-being is an essential aspect of survivorship care since a substantial percentage of HNC survivors (15%–50%) experience some depression at any given time.<sup>6</sup> As per Neilson et al., 30% of patients experienced anxiety before and 17% after the treatment.<sup>7</sup>

Patients with cancer usually suffer from economic consequences due to high out-of-pocket (OOP) expenses and loss of income affected by the change in work.<sup>8</sup> In a developing country like India, where medical insurance is not popular, most people seek health care at public sector institutions with high OOP expenditure. An Indian study by *Chauhan et al.* reported that 93% of patients with HNC seeking treatment at their institute had a per capita income of < ₹ 10,000/year.<sup>9</sup> Poor financial status impedes quality health care and quality of life; further adding to the woes is the recent pandemic among cancer survivors. To the best of our knowledge, there is a lacuna in the scientific literature comparing the mental health and financial well-being of oral cancer survivors in relation to the COVID pandemic. The article aims at studying the mental well-being and financial toxicity using the Depression, Anxiety, and Stress Scale - 21 Items (DASS 21) and Comprehensive Score for financial Toxicity (COST) -Functional Assessment of Chronic Illness Therapy (FACIT) questionnaires in the COVID 19 pandemic era.

## 2 | METHODS

### 2.1 | Design and settings

The present cross-sectional study was conducted in a tertiary care hospital in a sub-Himalayan city in North India. The study included all the post-treatment disease-free oral cancer survivors (for more than six months) that visited the hospital for routine follow-up from May 2020 to October 2021.

### 2.2 | Measures

Primary outcome measures were mental health and financial toxicity. Patients diagnosed or treated for second primary or recurrent disease and non-consenting patients were excluded from the study. After recording the demographic and clinical details, participants were asked to answer the DASS 21 and COST -FACIT questionnaires following all the COVID precautions. Informed consent was obtained from all the study participants. The current research has been approved by the institutional ethics committee and registered with the Clinical Trials Registry - India (CTRI/2020/07/026848).

### 2.3 | Literature search strategy for comparison of mental health and financial toxicity

We conducted a literature search in PubMed for articles published between 1 January 2000, and 1 October 2021. First, the following key terms were used: Oral cancer, HNC, cancer, mental health, Depression, anxiety and stress, and financial toxicity with COST FACIT scores. Then, some of these terms were used in combination for the search. Finally, a result was manually checked for relevant pre-pandemic era data studies. Both prospective and retrospective cohort studies that evaluated Depression, anxiety, stress and financial toxicity were considered to compare our study results.

### 2.4 | Analysis

Statistical analysis was done using Statistical Package for Social Sciences 26 software. Numerical uniform and non-uniform data are presented as mean  $\pm$  standard deviation and median  $\pm$  interquartile range. Categorical data is entered as percentages. For parametric

data, one-way Analysis of variance (ANOVA) is used for the single-factor analysis of variance and multi ANOVA for the multi-factor variance of analysis. For analysis of DASS 21 results, final depression, anxiety and stress are represented as binary data (Yes/No), and Logistic regression is used to describe the relationship between depression, anxiety, stress and other independent variables. A Pearson product-moment correlation was run to determine the relationship between DASS 21 scores and COST FACIT scores.

### 3 | RESULTS

Table 1 shows the demographic and clinical details of the survivors. Seventy-nine patients were included in the study, predominantly males (10:1). The age ranged from 26 to 75 years (The median age is 49). It was noted that the majority (60.7%) of tumours were located in the buccalveolar complex. Most patients (74%) presented with advanced-stage disease. Therefore, it is understandable (81%) that the majority required multimodality treatment. It is an interesting observation that post-treatment employment (21.5%) decreased drastically compared to pre-treatment employment (83.5%).

Table 2 illustrates the depression, anxiety, and stress levels among the survivors in detail. It was observed that more than half of the study cohort had depression (58.2%) and anxiety (72.2%). Supplementary Table 1 illustrates the log regression analysis of depression, anxiety and stress with various demographic and clinical factors. Unemployed survivors were observed to have more depression (OR = 1.3, 95% CI = 0.3–5.4,  $p = 0.6$ ), anxiety (OR = 3.5, 95% confidence interval (CI) = 0.3–21.2,  $p = 0.1$ ) and stress (OR = 1.6, 95% CI = 0.3–6.6,  $p = 0.5$ ) than rest of the cohort. Patients with more than 1-year follow-up showed higher odds for depression (OR = 2.0, 95% CI = 0.5–7.2,  $p = 0.2$ ) and anxiety. (OR = 1.2, 95% CI = 0.3–4.7,  $p = 0.7$ ).

Table 3 illustrates detailed univariate and multifactorial ANOVA of COST FACIT scores and various demographic and clinical factors. The mean financial toxicity score among the study population was ( $M = 17.9 \pm 8.4$ ); Unemployed survivors had significantly poorer financial toxicity scores compared to the whole cohort ( $M = 11.8 \pm 3.8$  vs.  $M = 16.4 \pm 7.0$ ,  $p = 0.01$ ); Survivors with depression ( $M = 16.4 \pm 7.0$ ,  $p = 0.06$ ) and stress ( $M = 14.4 \pm 6.8$ ,  $p = 0.002$ ) had poor financial toxicity scores. Current employment ( $p = 0.04$ ) and treatment modality ( $p = 0.05$ ) were the only significant factors in the multivariate analysis.

Pearson product-moment correlation was used to determine the relationship between COST FACIT scores and DASS 21 scores as illustrated in Supplementary Table 2. There was significant negative correlation between depression ( $r = -0.2$ ,  $p = 0.04$ ), anxiety ( $r = -0.29$ ,  $p = 0.008$ ), stress scores ( $r = -0.34$ ,  $p = 0.001$ ) and COST FACIT scores, indicating that greater the financial toxicity, severe is depression, anxiety and stress.

Table 4 illustrates the mental well-being and financial toxicity of studies from the pre-pandemic era. Depression rates ranged from 17% to 65%, Anxiety rates ranged from 20% to 35%.<sup>14–16</sup> Our study shows depression among 58.2% and anxiety in 72.2%. Mean financial

toxicity scores (COST FACIT) among cancer patients varied from ( $M = 20.18$ – $21.9$ ).<sup>25–27</sup> Our study cohort has Mean COST scores of ( $M = 17.9 \pm 8.4$ ).

### 4 | DISCUSSION

The present generation has not witnessed such a large scale catastrophe as this COVID 19 Pandemic. COVID 19 has affected almost every facet of life, including physical health and social and family life. In particular, cancer patients are a vulnerable group who require special attention during and after the treatment. There is a significant compromise in the care of cancer patients during the pandemic. *Teveoğlu et al.* observed a significant delay in diagnosis and treatment initiation; they also observed that most patients were presented in an advanced stage than the historical data.<sup>10</sup> *Chen et al.* reported that almost 50% of the patients had treatment interruptions during the pandemic.<sup>11</sup> There was a delay in follow up for 58% of patients and cancer-related complications in almost 68% of patients during the pandemic, as observed by *Claudine et al.*<sup>12</sup> Mental well-being is an essential domain among cancer survivors, and the recent pandemic has impacted the mental well-being of cancer survivors. Incidence rates of worse mental health are higher among cancer patients than in the general population.<sup>5</sup> It is essential to address the psychosocial impact of the pandemic on cancer survivors. A cross-sectional study was conducted to evaluate the toll of the current pandemic on mental health and financial toxicity in oral cancer survivors.

Notably, more than half of our study cohort suffered from depression and anxiety. There are very few studies that reported the mental well-being of oral cancer survivors during the pandemic. *Eva Pigozzi et al.* reported a 9% increase in vulnerability in HNC patients compared to the pre-pandemic period.<sup>13</sup> A study by *Oliveira et al.* on HNC patients showed that almost one fourth had depression and anxiety, which was a marginal rise compared to the historical data.<sup>14</sup> However, our study results show increased depression, anxiety and stress compared to the above studies. The literature search was done to compare the results with the pre-pandemic era. *Lulu Yuan et al.* reported that the prevalence of anxiety symptoms and depressive symptoms were 36.96% (85/230) and 65.21% (150/230), respectively.<sup>15</sup> *William F Pirl et al.* studied the published literature of almost 40 years on depression in cancer patients and said that rates of major depressive disorder associated with cancer are 10%–25%.<sup>16</sup>

Amongst various factors associated with depression, anxiety, and stress, it was discovered that employment status significantly affected mental health. Patients who underwent extensive resection leading to bodily disfigurement, multimodality treatment, and changes in job profile have more chances of developing depression, anxiety, and stress. In concordance with the current study, *Michelle Cororve Fingeret et al.* reported that 75% of the patients during their treatment had embarrassment about one or more types of bodily change.<sup>17</sup> *Christine Callahan et al.* also reported that patients with facial disfigurement due to HNC experience severe psychological trauma and low self-esteem.<sup>18</sup>

TABLE 1 Clinical and demographic details of the study population

Clinical and demographic details		Frequency (n = 79)	Percentage
Gender	Male	72	91.1%
	Female	7	8.9%
Education status	Illiterate	37	46.8%
	Literates	42	53.2%
Marital status	Single	3	3.8%
	Married	76	96.2%
Prior employment	Full time	66	83.5%
	Part-time	4	5.1%
	Homemaker	5	6.3%
	Retired	4	5.1%
Current employment	Full time	17	21.5%
	Part-time	32	40.5%
	Unemployed	15	19%
	Homemaker	6	7.6%
	Retired	9	11.4%
Subsite	Bucco alveolar complex	48	60.7
	Floor of mouth and tongue	28	35.4
	Others	3	3.7%
Final stage	Stage I	7	8.9%
	Stage II	14	17.7%
	Stage III	14	17.7%
	Stage IV	44	55.7%
Primary surgery	Segmental mandibulectomy	39	49.4%
	Marginal mandibulectomy	8	10.1%
	Partial glossectomy	10	12.7%
	Hemi glossectomy	12	15.2%
	Near-total glossectomy	3	3.8%
	Wide local excision	4	5.1%
	Total maxillectomy	3	3.8%
Reconstruction	Primary closure	19	24.1%
	Local flap	7	8.9%
	Regional flap	50	63.3%
	Free flap	1	1.3%
	Obturator	2	2.5%
Radiotherapy	Yes	64	81%
	No	15	19%
Complete treatment	Surgery only	15	19%
	Surgery + Radiotherapy	47	59.5%
	Surgery + Chemo-Radiotherapy	11	13.9%
	NACT + surgery + Chemo-Radiotherapy	6	7.6%

Abbreviation: NAST, Neo-Adjuvant chemotherapy.

TABLE 2 Depression, anxiety and stress of study population

DASS 21		N <sup>a</sup>	Percentage
Depression	Yes	46	58.2%
	No	33	41.8%
Depression	Mild	11	13.9%
	Moderate	23	29.1%
	Severe	9	11.4%
	Ext severe	3	3.8%
Anxiety	Yes	57	72.2%
	No	22	27.8%
Anxiety	Mild	6	7.6%
	Moderate	24	30.4%
	Severe	14	17.7%
	Ext severe	13	16.5%
Stress	Yes	33	41.8%
	No	46	58.2%
Stress	Mild	14	17.7%
	Moderate	15	19%
	Severe	04	5.1%

<sup>a</sup>N = 79 total study participants.

In our study cohort, survivors with more than 1 year of follow up had higher depression rates, indicating the effects of cancer treatment on mental health in the long term survivors. A systemic review by Mary *et al.* based on the literature available between the years 1986 and 2008 reported that prevalence rates of depression were high at the time of diagnosis, and a small number of survivors had persistent depression even up to 6 years post-treatment.<sup>19</sup> Contrary results were published by Kumar *et al.* that there is a significant increase in depression and stress levels among the cancer patients in the long term than at the time of diagnosis.<sup>20</sup> A longitudinal study by Yi-Shan Wu *et al.* observed prevalence rates of depression as 8.5% at pre-treatment, 24.5% at 3 months, and 14% at 6 months.<sup>21</sup> Adaption to newer circumstances of living, fear of recurrence, and accessibility to health care in pandemic times may justify persistent depression, anxiety, and stress.

Financial toxicity is the less explored concept in oral cancer survivors in India. With the recent inflation and rising costs of cancer care, the magnitude of the resulting economic burden is less studied in the low and middle-income group countries. The financial burden on the person is related to many factors like income, socio-economic status, and disease burden. Treatment-related costs can be substantial, covering chemoradiation, surgery, rehabilitation, and follow-up.<sup>22</sup>

Our study cohort's mean financial toxicity score was  $17.9 \pm 8.4$ , with worse and best scores being 3 and 39, respectively. Chen *et al.* studied the financial distress among low-income cancer patients during COVID 19 pandemic and reported that changes in employment status were associated with an increase in distress.<sup>23</sup> Bridgette

Thom *et al.* reported high financial toxicity among young cancer survivors with mean COST scores of  $14 \pm 9.3$ .<sup>24</sup> Compared to the pre-pandemic data by K.A. D'Rammo *et al.* on financial toxicity among patients attending radiation oncology clinics, the mean score of their study cohort was  $21.86 \pm 9.26$ .<sup>25</sup> Kazunori Honda *et al.* reported that the mean COST score in Japanese cancer patients was  $20.18 \pm 8.17$ .<sup>26</sup> Chinese study by Jing *et al.* reported a mean score of  $21.2 \pm 8.1$ .<sup>27</sup> Financial toxicity may differ based on the population's economic, cultural, and sociodemographic conditions. However, the financial toxicity scores were worse in studies published in the COVID era compared to the data published pre-COVID period. Current study scores indicate more significant financial toxicity in the cohort than those published from other Asian countries (Table 4).

In the current study cohort, 47% of the full-time workers switched to part-time employment, and 22.7% of part-time and full-time workers pre-treatment became jobless during the pandemic. A study by Pamela N Schultz *et al.* regarding the work-related issues in 4364 cancer survivors showed that only 35% worked at the survey time, and 8.5% were considered unfit for work.<sup>28</sup> Age and gender do not appear to affect financial toxicity in our study; however, K Robin Yabroff *et al.* reported that more financial hardship was associated with the younger patient population.<sup>29</sup> Yu-Ning Wong *et al.* said that the female population had more financial hardship than the male population.<sup>30</sup> Lower education levels and lower earnings at diagnosis ( $p < 0.001$ ) had more financial toxicity, as reported by Leila J Mady *et al.*<sup>31</sup> Survivors in our study, who underwent multimodality treatment, had more financial distress than the rest of the cohort. In concordance with a study by Smit *et al.*, chemotherapy is associated with an increased cost burden; however, surgery was not an independent risk factor. Inferring that the multimodality treatment likely to drain them financially.<sup>32</sup> A systemic review by Smith *et al.* stated that 49% of cancer patients had a high psychological and financial burden among the uninsured patients.<sup>33</sup>

Financial toxicity may lead to emotional distress. In our study cohort there is a significant correlation between financial toxicity and depression, anxiety and stress. Similarly, Meeker *et al.* reported a strong association between financial and emotional distress, suggesting that emotional distress accounts for almost 24% of the impact of financial distress on overall distress among cancer patients.<sup>34</sup> A study by Rogers *et al.* among HNC patients with almost 47% constituting oral cancer discovered that patients with low income have worse scores in the social and emotional domain ( $p < 0.001$ ).<sup>35</sup> Kale *et al.* study on cancer survivors reported that the cohort with financial burden had 1.95 times higher odds of having a depressed mood than those without. Odds were even higher with more significant financial problems.<sup>36</sup> Most studies report that financial toxicity/distress and mental well-being are interrelated.

#### 4.1 | Clinical implications

The COVID-19 pandemic has impacted cancer care globally and more severely the developing countries. From the perspective of a

**TABLE 3** Univariate and multifactorial analysis of Comprehensive Score for financial Toxicity (COST) Functional Assessment of Chronic Illness Therapy (FACIT) scores and various clinical and demographic factors

Univariate analysis of COST FACIT scores				
COST FACIT		N <sup>a</sup>	Mean/SD <sup>b</sup>	P <sup>c</sup>
Gender	Male	72	17.9 ± 8.7	0.87
	Female	7	18.4 ± 4.1	
Age (Years)	</ = 50 Years	44	16.9 ± 7.7	0.24
	>50 years	35	19.2 ± 9.1	
Education status	Illiterate	37	15.9 ± 6.5	0.05
	Educated	42	19.6 ± 9.5	
Marital status	Single	3	23.6 ± 15.5	0.23
	Married	76	17.7 ± 8.1	
Past employment	Full time	66	17.5 ± 8.2	0.77
	Part-time	4	20.7 ± 10.9	
	Homemaker	5	18.6 ± 2.8	
	Retired	4	21.0 ± 14.7	
Current employment	Full time	17	21.5 ± 10.2	0.01
	Part-time	32	18.1 ± 7.0	
	Unemployed	15	11.8 ± 3.8	
	Homemaker	6	17.5 ± 3.7	
	Retired	9	20.8 ± 12	
Follow up duration	6–12 months	29	15.6 ± 7.0	0.008
	>1 year <2 years	36	17.5 ± 8.1	
	>2 years	14	23.9 ± 9.4	
Subsite	BAC	48	17.14 ± 7.9	0.135
	Tongue and Floor of mouth	28	20 ± 9.2	
	Others	3	11.3 ± 3.2	
Stage	Stage I	7	23.57 ± 6.8	0.219
	Stage II	14	19.4 ± 7.7	
	Stage III	14	16.6 ± 6.09	
	Stage IV	44	17.0 ± 9.2	
Surgery	Segmental	39	17.3 ± 8.9	0.19
	Marginal	8	13.2 ± 6.3	
	Partial glossectomy	10	22.8 ± 7.9	
	Hemi glossectomy	12	20.16 ± 9.05	
	Near-total glossectomy	3	12 ± 2.64	
	Wide local excision	4	19 ± 8.4	
	Total maxillectomy	3	18.6 ± 0.5	
Reconstruction	Regional flap	50	16.7 ± 8.3	0.1
	Primary/local flap	29	20.0 ± 8.2	
Complete treatment	Surgery only	15	23.5 ± 7.8	0.04
	Surgery + Adjuvant therapy	64	16.6 ± 8.06	

TABLE 3 (Continued)

Univariate analysis of COST FACIT scores				
COST FACIT		N <sup>a</sup>	Mean/SD <sup>b</sup>	P <sup>c</sup>
Depression	No	33	20 ± 9.6	0.05
	Yes	46	16.4 ± 7.1	
Anxiety	No	22	20.0 ± 9.4	0.13
	Yes	57	17.0 ± 7.9	
Stress	No	46	20.4 ± 8.6	0.002
	Yes	33	14.4 ± 6.8	
Multifactorial analysis of COST FACIT scores				
COST FACIT		N <sup>a</sup>	Mean/SD <sup>b</sup>	P <sup>c</sup>
Education status	Illiterate	37	15.9 ± 6.5	0.34
	Educated	42	19.6 ± 9.5	
Current employment	Full time	17	21.5 ± 10.2	0.04
	Part-time	32	18.1 ± 7.0	
	Unemployed	15	11.8 ± 3.8	
	Homemaker	6	17.5 ± 3.7	
	Retired	9	20.8 ± 12	
Follow up duration	6–12 months	29	15.6 ± 7.0	0.6
	>1 year <2 years	36	17.5 ± 8.1	
	>2 years	14	23.9 ± 9.4	
Complete treatment	Surgery only	15	23.5 ± 7.8	0.05
	Surgery + Adjuvant therapy	64	16.6 ± 8.06	

Abbreviation: BAC, Bucco-Alveolar Complex.

<sup>a</sup>N = 79 total study participants.

<sup>b</sup>Mean financial toxicity scores; SD is standard deviation.

<sup>c</sup>p value is significant if <0.05.

TABLE 4 Summary of the articles that have studied depression, anxiety, stress levels and financial toxicity in cancer survivors, in pre and post COVID era.

Study	Cancer site	Depression/Anxiety/Stress		Mean financial toxicity scores	
		Pre COVID era	Current pandemic time	Pre COVID era	Current pandemic time
Rodrigues et al <sup>14</sup>	HNC	17%/20%	22%/22%	-	-
Lulu Yuan et al <sup>15</sup>	Oral cancer	65%/37%	-	-	-
Pril et al <sup>16</sup>	General cancer <sup>a</sup>	10%–25%/-	-	-	-
Current study	Oral cancer	-	-	-	17.9 ± 8.4
Thom et al <sup>24</sup>	General cancer <sup>a</sup>	-	-	-	14 ± 9.3
Kevin A D'Rummo et al <sup>25</sup>	General cancer <sup>a</sup>	-	-	21.9 ± 9.26	-
Honda et al <sup>26</sup>	General cancer <sup>a</sup>	-	-	20.18 ± 8.17	-
Jing et al <sup>27</sup>	Breast cancer	-	-	21.2 ± 8.1	-
Current study	Oral cancer	-	58%/72%/42%	-	-

<sup>a</sup>General cancer - patients with cancer of various sites.

developing country where patients still struggle to get standard medical care, the consequences of the pandemic on cancer care are still not well understood. Early studies from India reported an almost 46% reduction in cancer patients' follow-ups.<sup>3</sup> In the current scenario, the current health care status is struggling to balance COVID care and routine cancer-related services. Increased incidence of financial toxicity and poor mental health can take a tremendous toll on future cancer care among the survivors in general. The high incidence rates of depression, anxiety, and stress levels among oral cancer survivors can significantly affect various domains of cancer survivorship. Increased probability of relapse of substance abuse, reduced functional abilities, sleep-related/nutrition-related issues leading to weight loss and malnutrition. *Chen et al.* reported that insomnia, pain, anorexia, and fatigue occurred significantly more often in depressed cancer patients.<sup>37</sup> *Lazure et al.* reported that depressed patients with HNC had higher mortality and cancer recurrence. However, a well-structured longitudinal study might answer the impact of mental well-being on cancer recurrence.<sup>38</sup>

Financial toxicity causes significant stress in patients undergoing oral cancer treatment. Significant financial toxicity may affect the survivor's in many aspects of living. Mainly affecting the social and environmental domains of life may influence the survivor's employability and ability to maintain employment. This becomes a vicious cycle. A study from north India by *Ghatak et al.* quoted that the monthly expenses for cancer treatment were 7.2 times the monthly per capita income of the Indian population.<sup>39</sup> In low and middle-income nations, men continue to be the primary breadwinners in the family, and the (M: F = 10:1) ratio in our study reflects the survivor's financial toxicity, which indirectly reflects the burden on the entire family. Another important finding of the study is that full time employment has come down to 21% from 83% during the pandemic; part-time occupations in India are not well rewarded, and somehow this indirectly reflects the family's financial situation, which impacts their standard of living and social well-being. In oral cancer survivors, this financial toxicity affects the rehabilitation services that most of them need on a long-term basis. Nevertheless, the effect of financial distress on monetary terms and cancer-related rehabilitation needs to be studied further.

There is an urgent need to identify mental and financial distress at an early phase. This is required to tailor rehabilitative efforts to address the underlying problem. As per *Fawzy et al.*, education, behavioural training, individual psychotherapy, and group interventions are the four psychosocial interventions commonly used among cancer patients to address psychological issues.<sup>33</sup> Cochrane review by *Cherith Semple et al.* on psychosocial intervention for patients with HNC found significant heterogeneity in intervention methods used in the literature and duration of intervention and outcome measures. Indicating that no particular method can be used as a standard of care.<sup>40</sup> Given the socio-cultural differences among the Indian population, it is difficult to standardize the interventions. However, it is wise to choose a timely, appropriate intervention that fits the local population to address the mental well-being of the survivors.

Initiating schemes that include comprehensive cancer care providing physical, social, professional and financial assistance to eligible survivors might improve their mental well-being and relieve the financial burden on cancer survivors. Evaluations of implemented schemes should be continual with repeated re-evaluation and identification of problems in implementation with subsequent efforts to improve cancer care.

## 4.2 | Study limitations

This study was conducted in a government funded institute of national importance situated in the northern part of India, which caters for patients from all parts of the country. Patients of all socio-economic groups, cast and creed are included in the group making it a real-world cohort. To the best of our knowledge, this is one of the few studies that have addressed the mental well-being and financial toxicity among oral cancer survivors from developing countries, particularly India. At the same time, this study gives some new insights into the employment status, mental well-being and financial distress of oral cancer survivors; however, there are considerable limitations.

Quantitative analysis in this study is based on the cross-sectional observations, so significant findings do not indicate causation. A cross-sectional design is one of the major limitations of the study. A longitudinal study will give better insights into the reliable and long-term outcomes of oral cancer survivors' financial toxicity and mental well-being. However, considering the situation of an ongoing pandemic, multiple encounters with the survivors are not feasible, as there is a high risk of COVID exposure during hospital visits. However a comparison of study results with the data of studies published in the pre-pandemic era was done.

We concede that another major limitation of the study is the sample size. Large sample size would give more accurate results and less margin of error. Though our cancer clinic handles a considerable load of oral cancer patients nevertheless poor follow-up is also a known fact in most of the public-funded cancer centres of our country due to various socio-cultural, geographic and financial factors. Adding to the woes is the pandemic; there is a significant reduction in the registrations of patients at the oncology clinics. Another important consideration is that, may be poor follow up is related to increased financial toxicity and poor mental health of the survivors, necessitating future studies with more extensive, representative samples and longitudinal data to generalize the results.

## 5 | CONCLUSION

There is a trend toward increased incidence of depression, anxiety, and stress among oral cancer survivors compared to the literature from the pre-COVID era. There is significant financial toxicity among either unemployed or part-time workers. This calls for an urgent public/government intervention to prevent the long-term impact of financial toxicity on survival and quality of life.



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## CONFLICT OF INTEREST

The author declares that there is no conflict of interest that could be perceived as prejudicing the impartiality of the research reported.

## DATA AVAILABILITY STATEMENT

The data that support the findings of this study are available on request from the corresponding author. The data are not publicly available due to privacy or ethical restrictions.

## ETHICS STATEMENT

All procedures performed in the study involving human subjects were in accordance with the ethical standards of the institutional and/or national institutional guidelines. The current research has been approved by the institutional ethics committee (AIIMS/IEC/20/405).

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#### SUPPORTING INFORMATION

Additional supporting information can be found online in the Supporting Information section at the end of this article.

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