

Dual challenges of oral cancer and COVID-19: a qualitative exploration of barriers, experiences, and coping strategies among patients in Pakistan

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ABSTRACT

Objectives: To explore the physical, psychological, and social experiences of oral cancer patients six months after diagnosis and completion of treatment during the COVID-19 pandemic in Khyber Pakhtunkhwa, Pakistan.

Methods: This qualitative follow-up study was conducted in January 2021 during the second wave of COVID-19. Seventeen patients with oral squamous cell carcinoma (OSCC), originally recruited at diagnosis in July 2020 from the Department of Maxillofacial Surgery, Khyber College of Dentistry, Peshawar, Pakistan, were re-interviewed using face-to-face semi-structured interviews. Maximum-variation purposive sampling ensured diversity in age, gender, and cancer stage. Interviews were conducted in Pashto, audio-recorded with consent, transcribed ad verbatim into English, and analyzed thematically using Braun and Clarke's framework with ATLAS.ti 8.0 software. Methodological rigor was maintained through peer debriefing, member checking, and confirmability audits.

Results: Five themes emerged: (1) psychological vulnerability due to treatment delays, facial disfigurement, and COVID-19-related restrictions; (2) physical impairments including speech difficulties, dry mouth, and restricted jaw movement; (3) reliance on faith as a source of emotional strength; (4) social support systems, particularly family support and the Sehat Sahulat Program, which facilitated access to care; and (5) financial decline aggravated by treatment costs, unemployment, and long-term indebtedness.

Conclusion: Six months after diagnosis, oral cancer patients in Khyber Pakhtunkhwa experienced persistent physical symptoms, emotional distress, and financial strain, compounded by the COVID-19 pandemic. Reliance on faith and social support were central coping strategies. These findings highlight the need for integrated, patient-centered cancer care addressing psychosocial and financial dimensions, particularly during public health crises in resource-limited settings.

Keywords: COVID-19 (MeSH); Lived experiences (Non-MeSH); Mouth Neoplasms (MeSH); Coping Skills (MeSH); Health Care (MeSH); Social Support (MeSH); Pakistan (MeSH).

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INTRODUCTION

Evidence indicates that the COVID-19 pandemic disrupted the delivery of diagnostic and curative services for most chronic diseases.¹ In addition to delays and postponements of elective surgeries and non-urgent medical care services, patients also avoided seeking medical care due to fear of COVID-19.² Hence, in addition to the direct disease burden,

the pandemic posed a significant risk of indirect morbidity and mortality from other diseases because of health services disruption.³

Oral cancer is a significant public health issue with increasing cases and poor prognosis over the past few decades.^{4,5} Oral cancer management depends on appropriate timing and sequence of care. This involves interdependent multiple specialties and treatment

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modalities, and the disrupted health service delivery due to COVID-19 affected the processes.⁶ Delayed diagnosis and treatment were reported in many countries, particularly those which are resource-limited.⁷⁻⁹

Apart from physical suffering, oral cancer patients may experience significant psychological and social distress related to the disease and therapies.¹⁰ Thus, coping with oral cancer can be difficult and challenging for patients and their families even at the best of times. Studies have suggested that the prognosis, quality of life, and lived experiences of oral cancer patients may have been significantly impacted by the COVID-19 pandemic-related diagnostic and treatment delays.

Limited literature is available on the personal experiences of oral cancer patients undergoing treatment during the COVID-19 pandemic, particularly in low- and middle-income countries of the Asia-Pacific region. To address this gap, we conducted a qualitative study in Pakistan to explore the physical, psychological, and social experiences of newly diagnosed oral cancer patients during different phases of the pandemic. Patient experiences were captured at three points: diagnosis (coinciding with the first wave), six months after diagnosis (second wave), and one year

after diagnosis (third wave) of the COVID-19 pandemic in Pakistan. Our initial interviews with newly diagnosed patients revealed that delays in medical care and inadequate support systems adversely affected patients' quality of life.¹³ In the present paper, we present findings from the second round of interviews, conducted six months after diagnosis, during Pakistan's second wave of the COVID-19 pandemic. The study specifically aimed to explore the physical, psychological, and social experiences of oral cancer patients six months after diagnosis and completion of treatment in Khyber Pakhtunkhwa, Pakistan.

METHODS

Study design and study participants: This study was part of a longitudinal qualitative project. Participants were recruited in July 2020 following a confirmed diagnosis of oral cancer at the Department of Maxillofacial Surgery, Khyber College of Dentistry, Peshawar, Pakistan. Eligible patients were 18 years of age or older and had not yet undergone any treatment for oral cancer. Using purposive sampling with maximum variation, we selected 20 patients across different cancer stages, age groups, gender, and education levels. Of these, 17 consented to participate. The first in-depth interviews were conducted in July 2020 at the time of diagnosis and have been reported elsewhere.¹³ All 17 participants were successfully followed up in January 2021, six months after diagnosis. By this time, they had completed their respective cancer treatments and were declared physically fit by the attending physician to take part in the second round of interviews.

Data collection: A semi-structured interview guide was used to explore how participants made sense of their oral cancer diagnosis six months after onset and to document changes in their physical, psychological, and social experiences since the first interview. All interviews were conducted in Pashto, the local language of the study area, by the first author, a dental public health specialist with extensive experience in qualitative research. Written informed consent was obtained from all participants, and interviews were audio-recorded with their permission.

Each session lasted approximately 30 minutes and was scheduled at a convenient time and location for the participant. To maintain confidentiality, participants were assigned unique study numbers, and only the interviewer and participant were present during each interview. A well-established interviewing approach was employed to foster rapport and trust, thereby enhancing the credibility of the findings.¹⁴

Data analysis: The interviews in Pashto were transcribed ad verbatim into English by the first author (fluent in both languages). The ATLAS.ti 8.0 software was used to organize the interview transcripts and analysis. The research team finalised the themes through collective agreement and validation. The procedures employed in this study were designed to address credibility, dependability, transferability, and confirmability, in accordance with the standards of methodological rigor.¹⁴ The study employed procedures such as prolonged engagement, peer debriefing, member checking, systematic audit trial, and confirmability audit, all of which are generally established methods of methodological rigor.¹⁴ Prolonged engagement was achieved by the first author addressing participants' questions before obtaining informed consent, which helped build trust and ensured a deeper understanding of their experiences. This approach created a comfortable environment for participants to openly share their stories. Peer debriefing sessions were held with the research team throughout the analysis process. These sessions allowed the researcher to discuss emerging themes, receive constructive feedback, and ensure that the analysis remained objective, with an effort to minimise personal bias. Member checking was implemented by inviting participants to review the findings and verify the interpretation of their responses, ask for clarification, and offer additional insights, ensuring their experiences were accurately represented and their voices faithfully reflected in the study, with no participants requesting any changes. Additionally, a confirmability audit was conducted by an external researcher who reviewed the data, the analysis process, and the conclusions to ensure that the findings were grounded in the

data and not influenced by researcher bias. This independent review helped confirm the objectivity and validity of the study's conclusions. The study employed consolidated criteria for reporting qualitative research (COREQ) to guide complete reporting, to ensure that the qualitative methodologies are acceptable for the inquiry.¹⁶

Phenomenology is a well-known approach for focusing on individual lived experiences, phenomena, and common behaviors among groups,¹⁷ was chosen as the foundation methodology for this study. The Braun and Clarke thematic analysis framework served as a guide for the data analysis.¹⁸ Thematic analysis is a method of choice, appropriate to phenomenology, having the ability to identify people's subjective opinions, perceptions, and experiences, and when there are no preconceived notions or assumptions about what may emerge from the data.

Ethical considerations: The study was conducted in accordance with the Declaration of Helsinki and received ethical approval from the Human Research Ethics Committee, Universiti Sains Malaysia (USM/JEPeM/20010013), and the Department of Maxillofacial Surgery, Khyber College of Dentistry, Peshawar, Pakistan (OMFS/020/15).

RESULTS

Sample characteristics: All interviews were conducted at the Khyber College of Dentistry. Each of the 17 participants was assigned a unique study number for confidentiality. Data saturation was reached when no new information emerged, after which interviews were concluded.¹⁵

Table 1 presents the participants' baseline characteristics. Most were married males (76.5%) with a mean age of 50.9 years (SD ± 15.52) and primary-level education (70.6%). All had been diagnosed with oral squamous cell carcinoma (OSCC), with the majority at stage II (47.1%), followed by stage III (35.3%) and stage IV (17.6%) [Table was previously published in: Khattak MI, et al., (2022).¹³ The submitting authors own copyright to the work.].

From the data analysis, five main themes were identified: (1) psychological vulnerability, (2) physical impairment

Table 1: Participants' demographic characteristics

Unique Identification code	Age (years)	Gender	Marital status	Level of Education	Religion	Type of cancer	Stage of cancer
1	60	Male	Married	Secondary	Islam	OSCC	3
2	50	Female	Married	Primary	Islam	OSCC	2
3	70	Female	Married	Primary	Islam	OSCC	3
4	65	Male	Married	Primary	Islam	OSCC	2
5	60	Male	Married	Secondary	Islam	OSCC	2
6	45	Male	Married	Secondary	Islam	OSCC	4
7	30	Male	Married	Secondary	Islam	OSCC	2
8	70	Male	Married	Primary	Islam	OSCC	3
9	45	Female	Married	Primary	Islam	OSCC	2
10	58	Male	Married	Secondary	Islam	OSCC	4
11	48	Male	Married	Secondary	Islam	OSCC	3
12	50	Male	Married	Primary	Islam	OSCC	3
13	40	Male	Married	Primary	Islam	OSCC	3
14	80	Male	Married	Primary	Islam	OSCC	4
15	25	Male	Married	Primary	Islam	OSCC	2
16	30	Male	Married	Primary	Islam	OSCC	2
17	40	Female	Married	Primary	Islam	OSCC	2

OSCC: Oral squamous cell carcinoma

and limitations, (3) reliance on God for protection, (4) availability of social support systems, and (5) financial decline.

Theme 1: Psychological vulnerability: The psychological vulnerability was evident in two contexts: concerns about the pandemic's impact on their treatment and recovery and anxieties about changes to their facial appearance. All participants were worried about treatment delays and the worsening of their condition.

"...Being diagnosed during the difficult time of COVID-19 was not easy because of the coronavirus situation, I was unable to get proper attention at that time for my disease and its treatment..." (Id11).

"...I have been hard hit by the COVID-19 pandemic and the travel restrictions in the country...I believe had my treatment started earlier I would be entirely well by now..." (Id10).

Some participants shared how the

COVID-19 pandemic added to their financial burden and emotional strain, on top of the costs of oral cancer treatment. This was especially difficult for those who had to travel long distances for treatment, and travel restrictions made the journey more challenging.

"...Speaking of today I got a test done for ten thousand rupees. When I was coming out of my house, I had eighteen thousand rupees and now I am left with two thousand rupees. I have left that for travel expenses to go back to my village. I can't bear the additional costs related to corona.... I keep coming and going to see doctors. It is emotionally draining to bear the expenses of two diseases." (ID7).

Although most participants were grateful for the care they received, they had negative feelings about their recovery time due to treatment delays. Some participants were also worried about how the pandemic would affect their future health care needs.

"...My treatment is complete but still, I

would need to get follow-up appointments which are not easy because they are also handling other patients...." (ID2).

The participants felt psychologically vulnerable due to changes in their physical appearance after treatment. Facial deformities resulting from the therapy caused them to hide their face, leading to emotional distress and sadness.

"...Even though I went through the surgery in the aftermath I had scarring on my face which is still very much there. When I looked at those scars, I got very upset...(ID2).

Participants described themselves as "incomplete" and "half-faced" due to their facial deformity. This emotional impact led some of them to discuss reconstructive surgeries with their doctor.

"...My consultant said that if I am so worried about my aesthetic look after some time, I can go through another surgery for correction..." (Id8).

Theme 2: Physical impairment and limitations: The first overarching theme concerned physical impairment and functional limitations was found in three contexts: speech, dry mouth, and limitation in the opening of the jaws. Although the participants' overall health had improved after treatment, issues related to their speech had begun.

"...But now I can speak a little. Previously, I was completely unable to walk. Now, I can walk around like I go out for a walk in the fields or somewhere else. Upon completion of the treatment, I am physically able to walk around on my legs..." (Id1).

Dissatisfied with their speech, and concerned that may not be well understood, most participants refrained from speaking, which left them feeling isolated and worsened their daily difficulties.

"...My lips and mouth are impaired I can't open my mouth properly. I am in such a desperate situation here that I can't even speak properly here. I stay quiet all day at home I don't talk to anyone because of my speech problems..." (ID12).

The participants suffered greatly from persistent dry mouth, causing significant physical discomfort. The problem also

affected their ability to speak.

"... My mouth feels really dry...it is such a horrific thing..." (Id9).

"... After completing the treatment, I have dryness in my mouth especially when I talk, it does feel a bit strange..." (Id4).

After oral cancer treatment, participants reported restricted mouth opening and jaw complications, and some participants expressed hope for the condition to resolve on its own.

"...Yes, currently I am unable to open my jaw properly, it clunks and gets stuck, but I have complete hope that with time this will go away..." (Id8).

Reassurance and solutions offered by the healthcare professionals are important. Participants expressed how the guidance and management from their doctor helped them in following certain treatment options.

"...So, as advised by the doctor I try to exercise and try to open my mouth. Previously my jaw was completely closed. The doctors gave me explanations and said it is normal and happens, it doesn't cause any harm..." (Id3).

Theme 3: Reliance on God for protection: The participants' reliance on God had served as a crucial coping factor amidst the challenges of the treatment and the pandemic. By seeking solace in prayers and embracing transcendent beliefs, most participants felt a sense of support throughout their treatment journey, and they experienced enhanced emotional resilience thereafter.

"...I have not lost hope, you can ask my consultant about how much strength I have had to bear with all of this. I have seen my face in a raw condition, and I have never despaired, I cope through the power of God..." (Id5).

"...The Lord has taken the responsibility of wealth and health. We depend on God for these basic provisions. If I live, God will give me wealth again and again. I have been thankful, and I pray at night..." (Id14).

Some participants' reliance on God resulted in them changing their initial apprehension due to delay of receiving treatment to gratitude.

"...I am thankful to God that I am alive, God gave me time for self-reflection. I

find deeper meanings through faith such as despite corona's situation my treatment was done at a fast rate, that's through God's mercy. Also, I am very happy with the doctor that he treated me even during times of corona and did my surgery..." (Id15).

Theme 4: Availability of social support systems: The value of social support networks during and after oral cancer treatment during the COVID-19 pandemic was viewed in two different contexts: regular social interactions with family and friends and the government's social welfare assistance provided through the Sehat Sahulat Program.

The participants unanimously agreed that social support from friends and family has positively affected their emotional well-being. During the COVID-19 pandemic, strict restrictions were implemented globally, including limitations on social gatherings, travel, and in-person visits to minimize the spread of the virus. In many countries, lockdowns and quarantine measures were enforced, and people were advised to practice social distancing. However, despite these restrictions, participants reported that their friends and family continued to visit them, offering emotional support without fear of COVID-19 transmission, which positively impacted their well-being.

"... Well, what should I say everyone has come to inquire about my health. If they wouldn't come now, when would they come? There has been no discrepancy in my social relations, corona has not undermined that..." (Id5).

Many participants were recipients of the Sehat Sahulat social welfare program. The participants claimed that without this program, they would not have been able to undergo successful treatment.

"...There are so many things in the hospital like radiotherapy, chemotherapy, tests, and all these various matters are very difficult to bear without the Sehat card. I have been saved from so many expenses thanks to this card..." (Id13).

Theme 5: Financial decline: All study participants experienced worsening financial difficulties due to oral cancer treatment during the COVID-19 pandemic, leading to a significant financial downturn. Although completion of treatment provided temporary relief, those experiencing

financial decline remained anxious about future healthcare expenses. Some participants were particularly worried about their ability to afford long-term health expenditures, such as follow-ups and doctor appointments after oral cancer treatment.

"...I feel like this disease is intolerable during such a crisis. I don't have the financial stability to fight this disease. A person who has money will spend endlessly on follow-up appointments till it is resolved still there will be room for improvement, but I don't have that..." (Id7).

Several participants expressed that the COVID-19 pandemic significantly impacted economic activity, leading to job losses and limited employment opportunities. The resulting economic instability and uncertainty caused many to delay or abandon their plans to re-enter the workforce, as the pandemic exacerbated financial hardships and reduced job prospects.

"...In the future, I might look for a job but because of the coronavirus pandemic, the opportunities for employment seem to be bleak..." (Id16).

Most participants indicated that they resorted to obtaining financial loans or borrowing to alleviate the short-term burdens associated with oral cancer treatment during the pandemic, perpetuating a cycle of indebtedness.

"...But currently, my financial state of affairs is deficient because whoever wanted to help me has given me loans during my treatment period, I have exhausted all my resources..." (Id17).

Most of the participants attributed their financial decline and instability to their inability to return to work because the job entails responsibilities that they would be incapable of assuming following their oral cancer treatment.

"As far as work is concerned, I cannot work because working or having a job is a matter of responsibility which I am unable to do so now." (Id4).

Hence, most of the participants wished to regain normality before returning to work, hoping to recover fully from their treatment and regain physical and emotional strength. They expressed a desire for stability and confidence in their health, as well as the ability to perform their job responsibilities effectively, without the ongoing

limitations caused by their recovery process.

“...I do believe that once I start feeling better, I would be able to return to work. I would start going to work and have a normal life. I am sitting waiting for the day that I will be able to return to work...” (Id6).

DISCUSSION

This longitudinal qualitative study offers important insights into the lived experiences of oral cancer patients in Pakistan during the COVID-19 pandemic. Six months after diagnosis and completion of treatment, participants continued to face significant physical, psychological, and social challenges shaped by both their illness and the wider public health crisis. These findings extend our earlier work at the time of diagnosis, which had already emphasized the adverse effects of delayed care, treatment-related side effects, and limited social support.¹³ By situating these patient narratives within the broader context of Pakistan, where oral cancer management is hindered by sociocultural barriers, absence of a national cancer registry, weak healthcare infrastructure, and limited awareness of the disease,^{21,22} our study highlights systemic challenges that exacerbate patient suffering. It also adds to the scarce literature from low- and middle-income South Asian countries, where the combined burden of cancer and pandemic-related disruptions remains poorly understood.

The participants voiced concerns about post-treatment limitations such as speech difficulties, mouth dryness, and restricted jaw movement. These functional limitations can affect patients' psychological and social experiences.^{10,23} Our study found that no specific intervention strategies for oral cancer patients were provided to improve their quality of life. Except for reassurance, health care providers did not provide patients with the necessary information to address their functional issues, for example, speech rehab exercises using a jaw mobilizing device to improve mouth opening,²⁴ and use of mouthwash or artificial saliva to relieve the symptoms of xerostomia.²⁵ The pandemic exacerbated these challenges by limiting access to in-person consultations and delaying the initiation of rehabilitation services, further impeding the recovery process.

The findings of this study revealed that during the COVID-19 pandemic, oral cancer patients experienced psychological vulnerabilities related to treatment delays and facial disfigurement. The emotional burden experienced by the participants in managing oral cancer during the pandemic was intensified, and concerns about delayed treatment and recovery were raised in the interviews. Uncertainty about future appointments and hospital visits also caused further psychological stress. Our findings are consistent with previous research conducted in Israel, which also identified worries about cancer treatment postponement during the pandemic.²⁶

Our study revealed that trust in God played a central role in participants' spiritual and emotional well-being. Prior research consistently demonstrates a strong association between cancer-related distress and spirituality,¹³ yet limited evidence exists on this relationship during the COVID-19 pandemic.²⁷ A recent study among African-American women with breast cancer reported reliance on spirituality as a coping mechanism during COVID-19 pandemic, and our findings similarly highlight the importance of spiritual and religious coping in mitigating treatment- and pandemic-related distress among oral cancer patients in Pakistan. Nonetheless, further research is needed to determine whether reliance on God alone provides sufficient long-term emotional protection.

The COVID-19 pandemic also caused substantial social distress, with cancer patients facing isolation and weakened support networks, particularly in low- and middle-income settings.^{12,28} Our participants highlighted the critical role of family and friends during treatment, reinforcing existing evidence of the protective value of social support for cancer patients during COVID-19,²⁹ especially in Pakistan's joint family system with its complex social networks.

Diverse financial hardships concerning oral cancer patients undergoing treatment may be intensified in low- and middle-income nations like Pakistan, where health care financing relies on out-of-pocket expenses.³⁰ Oral cancer patients are more likely to come from lower socioeconomic backgrounds, have less education, and have poorer

general health, making them more susceptible to financial toxicity during treatment.³¹ Our findings are in agreement with previous studies that showed individuals with oral cancer experienced financial vulnerability and difficulties before treatment as well as following treatment.³² We also revealed that these financial hardships were not isolated but intertwined with the emerging challenges of the COVID-19 pandemic.

The Sehat Sahulat Program is a social welfare initiative introduced by the Government of Pakistan to address social and economic disparities faced by vulnerable groups.³³ It aimed to enhance health care service delivery and alleviate financial burdens associated with critical treatments like cancer. Recipients of the program will receive a Sehat Insaf Card that entitles them to free health care services. Owing to the benefits of this program, the participants experienced resilience during oral cancer treatment amidst the pandemic. However, concerns about other economic challenges, including debt, unemployment, and apprehensions about future medical expenses, remain. Future research should explore potential financial resources to alleviate burdens during the pandemic or other unforeseen circumstances.

To the best of our knowledge, this is the first qualitative study that longitudinally examined the changes in the lived experiences of oral cancer patients from the time of diagnosis to the completion of treatment in a low-to-middle-income country during the COVID-19 pandemic. This paper reports the experiences of oral cancer patients 6 months after diagnosis and had completed treatment during the pandemic. Employment of the maximum variation sampling approach enabled the recruitment of participants from diverse backgrounds (oral cancer stage, age, gender, and education level). Although there was a limitation from late presentation such that none of the patients were diagnosed at stage I, this sampling technique facilitates the examination of shared experiences among participants regardless of their specific treatment impacts and prognosis.³⁴

CONCLUSION

Six months after diagnosis, patients continued to face persistent physical

symptoms and psychological vulnerability, such as speech impairments, xerostomia, and restricted jaw mobility. Concerns about facial disfigurement and the compounded impact of COVID-19 on their recovery further complicated their experience. The pandemic delayed treatments and restricted access to healthcare, increasing their emotional distress. Coping mechanisms, including religious faith and a positive mindset, helped participants manage. Despite government welfare support, pre-existing financial challenges intensified, with COVID-19 exacerbating economic strain. Health care providers in Pakistan should focus on evidence-based education and support to alleviate psychological stress. Future research should explore strategies to improve access to rehabilitation services and address the long-term effects of financial burdens on recovery, particularly in pandemic contexts.

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AUTHORS' CONTRIBUTION

The Following authors have made substantial contributions to the manuscript as under:

MIK: Conception and study design, analysis and interpretation of data, drafting the manuscript, critical review, approval of the final version to be published

SIK: Study design, analysis and interpretation of data, drafting the manuscript, critical review, approval of the final version to be published

SSB: Study design, drafting the manuscript, approval of the final version to be published

MK & HS: Acquisition, analysis and interpretation of data, drafting the manuscript, approval of the final version to be published

GD: Analysis and interpretation of data, drafting the manuscript, approval of the final version to be published

ZK & NS: Conception and study design, critical review, approval of the final version to be published

Authors agree to be accountable for all aspects of the work in ensuring that questions related to the accuracy or integrity of any part of the work are appropriately investigated and resolved.

CONFLICT OF INTEREST

Authors declared no conflict of interest, whether financial or otherwise, that could influence the integrity, objectivity, or validity of their research work.

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DATA SHARING STATEMENT

The data that support the findings of this study are available from the corresponding author upon reasonable request

DISCLAIMER

This study was part of a longitudinal qualitative research project conducted during a PhD programme. Academics, researchers, and the supervisory team from multiple institutions across different countries, including Universiti Sains Malaysia (Malaysia), Khyber Medical University (Pakistan), and the University of Leeds (United Kingdom), collaborated closely throughout the research process.



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