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Exploring lived experiences in oral cavity cancer: an Asia–Pacific perspective on psychosocial challenges and opportunities for enhanced patient-centric care

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Abstract

Purpose Locoregionally advanced oral cavity squamous cell carcinoma (LA-OCSCC) has marked physical, psychological, and functional burden. Patients remain at high risk of relapse, often experiencing psychosocial distress. This study examined lived experiences of LA-OCSCC patients in the Asia-Pacific region to identify opportunities to reduce anxiety and improve coping strategies.

Methods 115 participants were interviewed across Australia, Hong Kong, South Korea, Taiwan, and Vietnam, including LA-OCSCC patients who underwent surgery and adjuvant chemoradiotherapy, their caregivers, and multidisciplinary care teams (clinical radiation and medical oncologists, supportive care specialists, nurse/case managers, psychologists, dietitians, speech therapists, and dentists). The Psycho-Onco Emotional Anxiety (POEM) framework informed research materials and analysis.

Results Physical and functional impairments from tri-modality treatment led to profound psychosocial distress, negative psychosexual well-being, and social withdrawal, diminishing quality of life. Patients also faced stigma associated with OCSCC and social constraints, including gender norms discouraging men from showing vulnerability or seeking support. Fear of recurrence driven by awareness of the aggressive and recurrent nature of OCSCC further exacerbates anxiety. Limited access to psychosocial care, coupled with a lack of recognition among patients and caregivers of its benefits, further restricted the implementation of patient-centered care.

Conclusion Defining the psychological and emotional burden of LA-OCSCC is a crucial step toward enabling HCPs to recognize distress early and apply targeted screening strategies that strengthen patient support, engagement, and adherence to care.

Implications for Cancer Survivors Timely and integrated psychosocial and rehabilitative care is crucial to restoring function and reducing anxiety, addressing the long-term effects of treatment and ultimately improving cancer survivorship.

Keywords Oral cavity cancer · Cancer survivorship · Psychosocial impact · Patient-centered care · Quality of life · Asia-Pacific

Introduction

Oral cavity cancer (OCC) is a significant global health concern, with its prevalence increasing in recent years. Within the broader context of head and neck cancer (HNC), GLOBOCAN reported OCC as the sixteenth most common malignancy worldwide, accounting for approximately 390,000 incident cases and 189,000 mortalities reported annually in 2024 [1, 2]. Asia accounts for a significant portion, with 66% of new cases and 75% of deaths [1, 3]. Around 95% of HNC cases exhibit morphological traits of oral cavity squamous cell carcinomas (OCSCC), with the majority (60%) presenting at a locoregionally advanced (LA) stage III/IV, carrying a poor prognosis of the disease [4, 5].

Characterized by a dual burden for patients undergoing treatment and adapting to post-treatment changes, the nature of LA-OCSCC treatment is complex and associated with long-term toxicities, late-occurring symptoms, and a heightened susceptibility to relapse and comorbid illnesses

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[6, 7]. The mainstay of treatment involves surgical resection, reconstruction, radiotherapy, and concurrent systemic therapy, presenting unique challenges to patients [8, 9]. Specifically, as treatment involves alterations to critical structures for speaking, eating, and breathing, patients who survive the disease often encounter physical impairments and psychological morbidities [10–12]. Severity of these long-term toxicities can range from scarring and disfigurement, osteoradionecrosis, swallowing and speech issues, loss of teeth, and other additional concerns such as swelling, drooling, hair loss, and weight loss [13, 14]. These impairments are often serious and persistent, which impact physical and mental health and the quality of life (QoL) of both patients and their caregivers [7, 15].

Psychological distress is particularly high in LA-OCSCC patients, with levels of depression, anxiety, and post-traumatic stress disorder (PTSD) among the highest reported of any cancer population [16]. Research indicates up to 50% of patients have experienced major depressive disorders at some point during treatment [11]. This psychological burden is compounded by significant financial strain on both patients and caregivers [7, 16]. High out-of-pocket expenses, unemployment, and limited access to healthcare benefits and insurance further exacerbate the challenges, negatively impacting their QoL [7, 11, 16].

Despite the higher incidence of comorbid anxiety in LA-OCSCC patients, there are notably few studies specifically addressing the psychosocial aspects, especially in the Asia-Pacific region. Our study aims to bridge this gap by investigating the effects of diagnosis and treatment on the emotional, social, psychological, and physical QoL of LA-OCSCC patients across Australia, Hong Kong, South Korea, Taiwan, and Vietnam. Findings from a multi-stakeholder perspective will help identify opportunities to establish a robust support system to enhance patient-centric care, improve coping mechanisms, and alleviate anxiety and distress among LA-OCSCC patients in the Asia-Pacific region.

Methods

Study design and ethics

This qualitative study interrogated the experiences of LA-OCSCC patients, caregivers, multi-disciplinary team (MDT), and supportive care healthcare professionals (HCPs) in Australia, Hong Kong, South Korea, Taiwan, and Vietnam. The study protocol and materials underwent review by local institutional review boards (IRB) or ethics committees and received approval in Australia (Bellberry Human Research Ethics Committee (2022-07−751)), Hong Kong (Oncology Study Group Research Ethics Committee (2022/24)), South Korea (Public Institutional Review Board Designated by the Ministry of Health and Welfare (2022-1483-002)), Taiwan (National Taiwan University Hospital IRB (202210028RSA)), and Vietnam (Ho Chi Minh City Oncology Hospital IRB (3393/BVUB-CDT)). All participants provided informed consent with assured confidentiality. Only anonymized information was collected and analyzed. Participants had the right to refuse or withdraw from the study at any time.

Study population and recruitment

Purposive sampling was used to recruit the participants. Participants were recruited through head and neck cancer (HNC) healthcare professionals, local patient support groups, HNC-related organizations, and databases maintained by local research partners. Patients were eligible if they had stage III–IVB LA-OCSCC as defined by the AJCC 8th edition [17], were diagnosed within 6 months to 3 years prior to recruitment, and had undergone curative-intent surgery followed by post-operative chemoradiotherapy (CRT). At the time of interview, patients needed to be 12–18 months post-treatment (up to 24 months in Hong Kong and Vietnam). Patients were excluded if they had been treated with palliative intent, had a history of another malignancy within the past 3 years (excluding non-melanoma skin cancer or in situ cervical cancer), or were currently enrolled in a clinical trial or receiving investigational therapies.

Unpaid informal caregivers who were the primary caregivers of patients with stage III–IVB LA-OCSCC following post-operative concurrent CRT were recruited. Caregivers were permitted to join interviews to support patients experiencing speech difficulties.

Multidisciplinary team (MDT) HCPs included surgeons and clinical, radiation, and medical oncologists. Supportive-care HCPs included case managers, care coordinators, psychologists, speech therapists, dietitians, and dentists. Eligible HCPs were required to be board-certified in their specialty and have at least 5 years of professional experience. They were also required to meet minimum patient-care thresholds (MDT HCPs: ≥ 10 LA-HNSCC patients in the past 6 months; supportive-care HCPs: ≥ 5 LA-HNSCC patients in the past 6 months, or 12 months for psychologists). HCPs were recruited through purposive sampling from professional databases, expert panels, and referrals.

Data collection

Virtual qualitative interviews (40–60 min) were conducted using Zoom and Microsoft Teams platforms from November 2022 to January 2024. Interviews were conducted by trained moderators in local languages and relied on a semi-structured guide. Prior to the interviews, the patients completed an attitudinal self-completion sheet (SCS). All data collection material was initially developed in English by the OLS study team and reviewed notably by the ninth and the tenth authors and translated by professional translators. Proofreading and review for cultural adequation were performed by either subject matter experts or a professional translation agency. All interviews were recorded and transcribed. To ensure participant confidentiality, recordings and transcripts were stored on servers accessible only to the authorized study team. All identifying information was removed during transcription, with participants assigned a unique label. De-identified transcripts were used throughout the analysis, and verbatim quotes were edited to remove any context that could risk identification. All procedures complied with institutional ethics requirements and regional data protection standards.

Theoretical framework

The Psycho-Onco Emotional (POEM) Anxiety Framework [18, 19] and the COM-B model (Capability, Opportunity, Motivation–Behavior) [20] were used to guide the development of the discussion guides, ensuring that questions captured the full range of psychological, functional, and contextual factors influencing patient and caregiver experiences. COM-B informed the structure and breadth of inquiry—particularly around behavioral drivers, treatment engagement, and support needs—while POEM guided the exploration of emotional processes and anxiety-related mechanisms. For the analytic phase, the POEM framework was applied to map the psychological and emotional factors contributing to disease burden and to examine how these factors interact throughout survivorship. COM-B was therefore used to inform comprehensive question design, whereas POEM provided a lens for coding and thematic interpretation, and a mapping of the triggers and interactions inducing the psychological burden of OCSCC. This dual-framework strategy ensured broad, behaviorally informed data collection via COM-B while enabling an in-depth, psychologically grounded analysis through the POEM framework.

Data analysis

Thematic analysis [17], a method for identifying and analyzing patterns of meaning in qualitative data, was performed to group codes into themes to uncover participants' experiences using NVivo Lumivero (version 12) to facilitate the data categorization from the uploaded transcripts. Using a combined inductive (organically emerging from the dataset) and deductive (related to the study objectives and the discussion guide) approach, two researchers coded the first transcripts to establish a preliminary coding system and reconciled any discrepancies into a final codebook. Each study subgroup, i.e., patients, caregivers, and HCPs, were analyzed separately. Expected concepts emerged, including participants' experiences on the physical, emotional, and psychosocial QoL of patients and caregivers. The coding process, including the development of codes and categories, was collaborative and reflective. The research team met throughout the study to develop and review the codebook iteratively and to discuss identified themes relevant to study objectives. The codebook was continuously refined until the research team agreed that all important themes from the interviews were captured. Thematic saturation was examined for participants overall. By the last interview, no new key themes were identified.

The research team engaged in ongoing reflexive practice throughout the study. Researchers had professional backgrounds in qualitative health research and oncology, which provided familiarity with the clinical context but also required continual reflection to minimize assumptions related to clinical pathways or patient experiences. Local research partners contributed contextual insights to mitigate cultural bias and ensure that country-specific norms were accurately represented.

Results

Study population characteristics

Table 1 illustrated the demographic profile of patients and caregivers. The median age of patients was 51 years, and 57% were males. All caregivers interviewed were family members of OCSCC patients, and most were employed (82%). Caregivers provided emotional support (100%), daily activities (100%), and treatment and care decisions (89%) for the patients. The majority of patients (68%) and caregivers (60%) did not report any comorbidities. HCP demographics are detailed in Online Resource 1.

Key themes

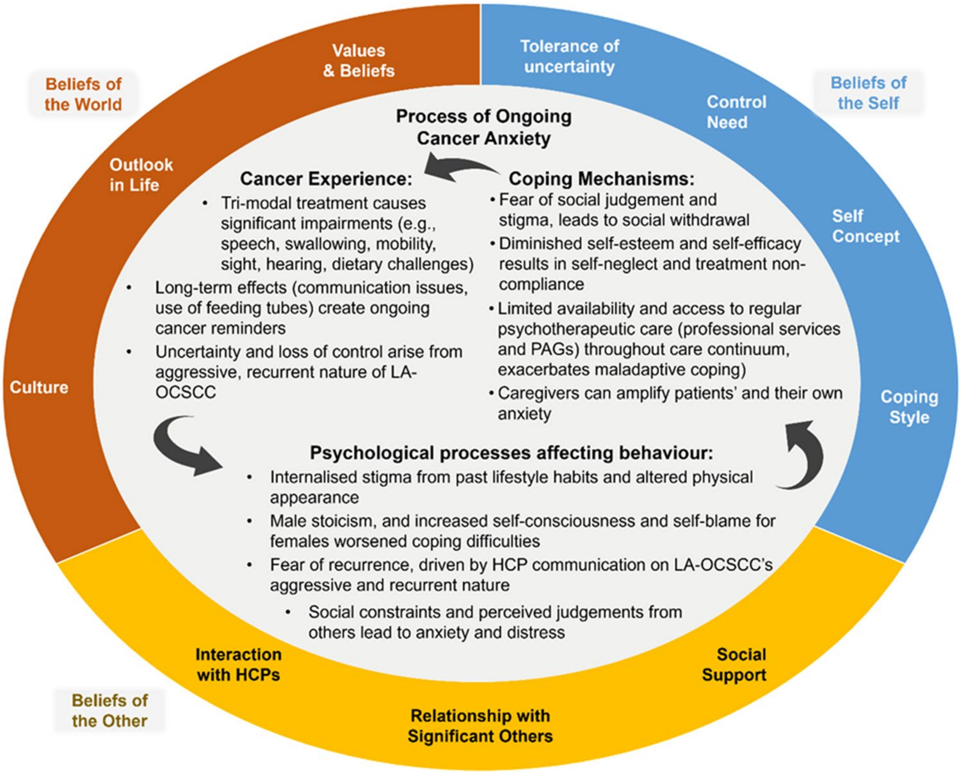
Insights from the POEM framework provided a deep understanding of patients' experiences with cancer, mechanisms related to how they react and cope, and resulting emotional anxiety experienced with LA-OCSCC (Fig. 1 and Online Resource 2).

Theme 1: Physical and functional impairments from tri-modality treatment and its impact on quality of life

Most patients reported experiencing several adverse consequences throughout their tri-modal treatment for

Table 1 Demographic profile of patients and caregivers

		Patients (*N* = 28)		Caregivers (*N* = 27)	
		N	%	N	%
Age (years)	*Median (Q1–Q3)*	51 (41–60)		52 (40–64)	
Sex	*Male*	16	57%	12	44%
	Female	12	43%	15	56%
Primary caregiver	*I have a primary caregiver (e.g., family)*	22	79%	n/a	
	No caregivers	6	21%	n/a	
Duration since diagnosis	*6 months to 1 year*	4	14%	n/a	
	1 year to 3 years	24	86%	n/a	
Duration of care	*6 months to 1 year*	n/a		9	33%
	1 year to 3 years	n/a		18	67%
Type of caregiving	*Emotional care and help*	n/a		27	100%
	Medications, treatment, and care decisions	n/a		24	89%
	Daily activities	n/a		27	100%
Type of comorbidities	*General anxiety disorder*	2	7%	3	11%
	Depression	1	4%	2	7%
	Chronic conditions	6	21%	8	30%
	Other cancer	0	0%	2	7%
	Immunology disorders	1	4%	0	0%
	Other mental disorders	2	7%	0	0%
	Compulsive disorder, post-traumatic stress disorder, etc.	1	4%	0	0%
	None of the above	19	68%	16	60%



Cancer Experience:

- Tri-modal treatment causes significant impairments (e.g., speech, swallowing, mobility, sight, hearing, dietary challenges)
- Long-term effects (communication issues, use of feeding tubes) create ongoing cancer reminders
- Uncertainty and loss of control arise from aggressive, recurrent nature of LA-OCSCC

Coping Mechanisms:

- Fear of social judgement and stigma, leads to social withdrawal
- Diminished self-esteem and self-efficacy results in self-neglect and treatment non-compliance
- Limited availability and access to regular psychotherapeutic care (professional services and PAGs) throughout care continuum, exacerbates maladaptive coping)
- Caregivers can amplify patients' and their own anxiety

Psychological processes affecting behaviour:

- Internalised stigma from past lifestyle habits and altered physical appearance
- Male stoicism, and increased self-consciousness and self-blame for females worsened coping difficulties
- Fear of recurrence, driven by HCP communication on LA-OCSCC's aggressive and recurrent nature
  - Social constraints and perceived judgements from others lead to anxiety and distress

Fig. 1 Mapping of the psychological burden triggers and their interactions of the LA-OCSC cancer based on the POEM framework

LA-OCSCC (surgery, followed by chemoradiation) course, often simultaneously (Fig. 2). While some symptoms were intermittent or fluctuated over time, others persisted well into survivorship, contributing to a substantial and ongoing burden. These physical, functional, and psychosocial impairments had profound implications for emotional and psychological distress. The immediate consequences of surgery and chemoradiotherapy frequently resulted in debilitating physical and functional changes that disrupted daily life (Table 2). Following surgery, many patients described pronounced swelling that hindered eating and led to reliance on liquid nutritional supplements.

> I've got this constant feeling of being strangled… It's not like it used to be... I've got a PICC tube that I've got to feed.

Early postoperative phases were also marked by speech difficulties, muscle and weight loss, and in some cases temporary mobility limitations. In the weeks following chemoradiotherapy, patients commonly reported severe mouth pain and dryness, which further restricted their diet and intensified nutritional challenges. Collectively, these treatment-related consequences significantly impaired core daily functions including speaking, swallowing,

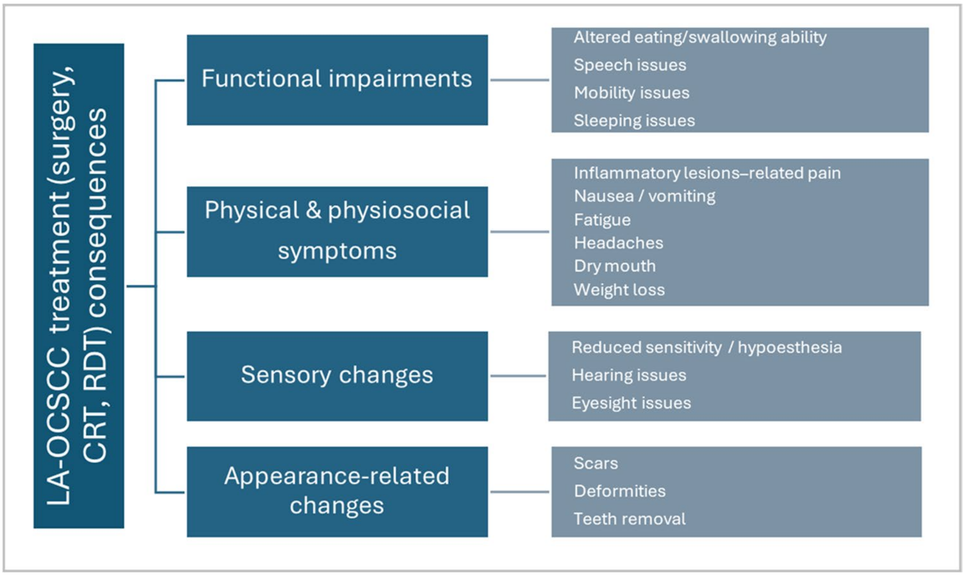


Fig. 2 List of LA-OCSCC treatment (surgery, CRT, RDT) adverse consequences reported by patients and grouped by category

Table 2 Physical and functional impairments from tri-modality treatment and its impact on quality of life sub-themes and illustrative quotes

Theme 1: Sub-themes	Supporting quotes
Immediate treatment consequences	
Impact on speech	Patient: "For example, I am unable to speak clearly low, I can't talk legibly and that is very annoying and frustrating; sometimes this makes me not wanting to go out and face other people"
Swallowing issues	Patient: "The pain was there but I just… I would swallow water or liquid. I would swallow food. It was like having a real, raspy, rough throat but I got through all of that, which was good"
Hearing & eyesight issues	Patient: "Yes, tinnitus for 24 hours and long-term. This is a consequence of radiotherapy."
Sleeping issues	Caregiver: "[They] couldn't eat. [They] couldn't sleep for the whole night."
Persistent symptoms	
Pain	Physician: "I went to the local dental clinic, the dentist saw my condition, and prescribed medications for sensitive teeth and medication to kill bacteria. But I continually had the pain even a year passed…"
Fatigue	Supportive HCP:" Particularly with cancer in the head, neck, and oral cavity, patients will often be accompanied by pain and fatigue because the cancer is in the mouth area."
Mobility	Patient: "It was very difficult to walk by myself"
Long-term treatment effect	
Dietary changes	Patient: "I don't want to go out. Because I can't eat now. I can only use my feeding tube to eat."
Speech impairment	Caregiver: [They] cannot articulate well, and [they] say that it's hard because [they] use so much energy when [they] speak

hearing, eyesight, and sleeping, leading to marked reductions in quality of life (Fig. 2). Swallowing difficulties were particularly pronounced, with many patients requiring feeding tubes or prolonged reliance on non-solid foods, necessitating long-term dietary modifications for both patients and caregivers.

> It was swollen for over 6–7 months which made eating basically impossible. Learning to talk again, the flap is still causing me issues, I'm having a further surgery… the actual reconstruction, it's impossible for me to move food around my mouth. It's hard. Eating anything small is impossible.

Persistent symptoms like pain and fatigue continued to hinder daily activities and reduced QoL. Patients experienced post-surgical pain and swelling, affecting not only their speech and mobility, but also disrupted their sleep. Mobility limitations, due to muscle weakness from resection, made even simple tasks like walking challenging. At times, the overwhelming pain and immobility severely impacted patients' independence to perform their routine activities and self-care (Table 2).

> Very painful. I even needed help when I went to the toilet.

The long-term effects of tri-modal treatment often persisted after the completion of the treatment regime. Patients reported experiencing discomfort from treatment persisting six months on average after completion of treatment. While some patients managed to regain partial functionality, others continued to experience eating and speaking difficulties, necessitating long-term dietary changes and lifestyle adjustments. Patients and caregivers reported adapting to softer and liquid diets as patients struggled with consuming solid foods, with the use of feeding tubes persisting after treatment.

> 100% rely on (his) PICC for (his) nutrition… that's been for 6 months… developed trismus so can't open (his) mouth.
>
> (patient) still can't speak clearly, so (they) can get upset when trying to speak…… After the (oral) blockade was removed and unused (patient) was no longer able to ingest solid food and only ingest slowly on liquid food.

This dietary change placed considered strain on patients and caregivers, in terms of adjusting to new routines and lifestyles. Furthermore, surgery and radiation aftereffects contributed to persistent speech impairments for most patients, particularly articulation issues (Table 2). These ongoing communication difficulties strained personal relationships for some patients, creating barriers to engaging with others. Many patients had to undergo further interventions, including speech therapy or additional procedures, to address these issues, with many not achieving full recovery.

Theme 2: Psychosocial impact from OCSCC and tri-modality treatment

The psychosocial impact of these physical and functional impairments had also been significant. Visible changes resulting from treatment, such as facial asymmetry, disfigurement, speech difficulties, and the use of feeding tubes, had contributed to feelings of shame and social withdrawal. The majority of patients had internalized these changes, leading to negative self-perception, diminished self-esteem, lower self-efficacy, and increased anxiety (Table 3).

> [Patient] doesn't want to go to work… He is terrified that (he) might meet someone… don't want to talk in a lisp…… It's devastated (his) sex life, it's devastated (his) speech… lost a lot of weight, (he) prematurely aged.

This internalized stigma was particularly heightened in Asian cultures, where some patients tried to hide their altered appearance even from their HCPs. While not explicitly mentioned by patients, there were also reports from caregivers on impacts on their psychosexual well-being, including the effect on intimate relationships and interacting with peers (Table 3).

External stigma associated with oral cavity cancer was also pervasive, often resulting in individuals feeling judged and discriminated against (Table 3). Many patients reported they frequently faced judgement from others, even their healthcare professionals, around their lifestyle choices that were commonly believed to have caused their cancer, such as betel nut chewing, alcohol consumption, smoking, or the association of their cancer with lower socio-economic status—a factor which impacted how they were perceived by others to be capable of managing their illness.

> I read pointed to heavy smokers, heavy drinkers, over age of 50, male... I don't fit the profile…
> …I've got anger towards the dentist, the delay and the assumptions that it is the over 60, 70, smoking, drinking population.…It is an old adage, when you hear hooves are you thinking horses or zebras. Sometimes you've actually got to look out of it. It's not always horses.

This stigma manifested in various forms, often leading to social exclusion (Table 3) or negative treatment with peers bluntly attributing OCSCC to patients' personal habits,

Table 3 Psychosocial impact from OCSCC and tri-modality treatment sub-themes and supporting quotes

Theme 2: Sub-themes	Supporting quotes
Negative self-perception and diminished self-esteem due to changes in appearance	Patient: "Some people would ask me very strange questions like, my face is asymmetrical now, will I receive another surgery in the future? How will I manage that? Physician: "[Cancer in the head, neck, and oral cavity], also changes the aesthetic structure, so patients also have an inferiority complex." Caregiver: "[They] resist showing [their] mouth to anyone, even to doctors. It's [their] inferiority that made [them] think [their] tooth is in no good shape."
Impact on intimate and social relationships	Supportive HCP: "Since the inside of their mouth is inconvenient, they cannot eat properly, and they think that they are smelly, so they become more temperamental. Their relationship with their caregivers doesn't look that good."
Feeling of judgment and social exclusion	Supportive HCP "No one is sympathetic "you brought this on yourself, who told you to chew betelnuts", etc. many think this way" Physician: "A part of patients will be isolated from society, because of their unclear speaking and appearances, so, they can only partake in works that do not involve too much talking." Patient: "When other people see me use a syringe to put milk into my feeding tube, I feel like they are watching a "monkey show" or "circus show.""
Social withdrawal	Patient: "In the past, when I went to a church, I met other people after the service. But my appearance looks a little unnatural, so I come home after the service"
Gender specific psychosocial impact	Supportive HCP: "Patients typically harbor an escape mentally, especially male patients… Oral cavity cancer patients are predominately males. Escapism is a common mentality. They don't know how to handle or know the right way, to cope with what's happening or the stress, be it emotionally or physically."

commenting that patients "brought this on yourself". Facial alterations or speech impediments further contributed to social withdrawal (Table 3), especially among the patients who mentioned feeling embarrassed and frustrated by their new appearances.

> I can't talk legibly and that is very annoying and frustrating; sometimes this makes me not wanting to go out and face other people

Challenges posed by both internal and external stigma were more pronounced in males, specifically older patients who typically adhered to traditional male gender norms of stoicism and self-reliance (Table 3). Several caregivers and HCPs reported male patients' tendency to hide their emotions, lacking outlets to express their emotions, making it more difficult to cope. A Taiwan nurse highlighted the unique burden of OCSCC for male patients:

> The suicide rate of head and neck cancer patients is twice as high as other cancers… Oral cavity cancer patients are predominately males. Escapism is a common mentality. They don't know how to handle or know the right way, to cope with what's happening or the stress, be it emotionally or physically.

For many HCPs, this inability to express emotional vulnerability and seek the necessary psychosocial support to cope with the physical, functional, and emotional impact of OCSCC and its treatment affects the patients' ability to effectively manage their illness.

Females also experienced stigma, albeit in a different manner, based on the same stereotypes of the OCSCC profile. Female patients were reported to struggle with self-blame, questioning why they had OCSCC despite not fitting with the typical demographic profile of the illness—being male, older, or having unhealthy lifestyle habits. Some physicians reported that the impact of physical changes and speech impairments had been particularly distressing for them, leading to a loss of confidence and a tendency to avoid social activities. Several female patients' caregivers described them becoming more self-conscious and withdrawing socially, which they associated with a negative impact on their mental well-being and their day-to-day ability to cope with their condition.

Theme 3: Fear of cancer recurrence and progression impact coping behaviors

The vast majority of the OCSCC patients experienced significant psychological distress, largely driven by persistent, heightened anxiety on potential disease recurrence or progression (Table 4). This anxiety often manifested as emotional distress, with patients expressing fears about their future and health status.

> Even if I see someone who succeeded in the surgery, talking about recurrence. I will feel upset if I think about recurrence.

Table 4 Fear of cancer recurrence and progression impact coping behaviors sub-themes and supporting quotes

Theme 3: Sub-themes	Supporting quotes
Fear of recurrence induced anxiety	Patient: "Even if I saw someone who succeeded in the surgery, they would talk about recurrence. I feel upset if I think about recurrence." Patient: "The biggest fear and anxiety were metastasis and relapse."
Information seeking induced anxiety	Patient: "I searched for various data, and I saw the information with the statistical figure showing the likelihood of relapse and metastasis, so I inevitably felt anxiety…"
Maladaptive coping behaviors	Physician: "They feel scared of it and do not want to receive radiotherapy anymore or the patient may take a break for one week or even a month due to not wanting to go for radiotherapy or when it stops hurting… Sometimes the patient has just received 5 rays and feels too much pain, so they give up."
Caregiver behaviors adding to the psychological burden	Caregiver: "On the day of the regular check-up, my mood is very unpredictable because the disease can come back at any time."
Constant disease reminders adding to the psychological burden	Physician: "There are cases of lesions caused by concurrent chemoradiotherapy, patients have long-lasting mouth ulcers, for example, may be due to the effects of chemoradiotherapy, not recurrence."

These fears were grounded in a preoccupation with the possibility of relapse or progression, influenced by HCPs providing information of the highly aggressive, fast-growing, and recurrent nature of OCSCC, further intensifying their anxiety on relapses. Patients also learnt about relapse and progression of OCSCC when searching for information online, further exacerbating their fears (Table 4). A South Korea patient shared, "I searched for various data… saw the information with the statistical figure showing the likelihood of relapse and metastasis, so I inevitably felt anxiety. The biggest fear and anxiety were metastasis and relapse."

Patients' and caregivers' anxiety was compounded by maladaptive coping behaviors. Some became overly focused on managing their health, while others withdrew from treatment due to fear of side effects (Table 4). A Vietnam specialist noted, "They feel scared… do not want to receive radiotherapy anymore or may take a break for one week… even a month". This avoidant behavior disrupted the treatment plan and undermined HCPs' ability to deliver effective cancer management. Several physicians reported that the fear of recurrence (FCR) was particularly pronounced in the first two years post-treatment, necessitating reassurance from HCPs to alleviate anxiety.

Some caregivers described experiencing their own anxieties, particularly around the time of the patient's follow-up tests, and at times these worries were perceived by patients, potentially amplifying the patients' own sense of fear (Table 4). Such dynamics appeared to occasionally complicate patients' coping efforts, potentially affecting their engagement with recovery and treatment. Additionally, reminders of cancer—persistent pain, side effects, speech and appearance changes—served as constant reminders of the disease, adversely impacting self-image and self-esteem (Table 4). These reminders led to reduced confidence and hence, avoidance of social interactions, compounding the psychosocial burden. This ongoing self-consciousness coupled with the emotional load of OCSCC made it more difficult for patients to interact with others and maintain their psychosocial well-being.

Theme 4: Negative coping strategies exacerbated by inadequate support systems

Many patients reported having limited access to specialized psychotherapeutic care, often leaving them to manage the mental impact of oral cavity cancer without essential professional support (Table 5).

> None of us have been offered to see a psychologist. We've all just been put on anti-depressant or anti-anxiety…[…] There's no follow-up care for that side of [things]

> Some physicians made the same observation.

> There is a lack of psychologic... routine psychologic support for cancer patients in general and in particular, head and neck

The shortage of professional psychotherapeutic support, especially pronounced in Vietnam, followed by Hong Kong and South Korea, leaves patients without the guidance needed to develop healthier coping mechanisms. Additionally, mental health assessment was not a core part of care, apart from certain regions in Australia and Taiwan (Table 5). For example, the regular use of a distress thermometer for screening was mentioned by a Taiwan psychologist.

> Each time the patient is admitted, we take his "mood thermometer", which is a simple 1–10 brief symptom rating scale… patient is assessed each time (patient) is hospitalized.

Even in these regions, mental health assessments were not regularly used throughout the care continuum. This is

Table 5 Negative coping strategies exacerbated by inadequate support systems sub-themes and supporting quotes

Theme 4: Sub-themes	Supporting quotes
Limited access to psychological care	Supportive HCP: "We don't have an in-patient psychologist. We do have one attached to the cancer center, but obviously they are not going to cover everything. So, we give patients the options for referral." Physician: "In Vietnam, there is still a lack of psychotherapy… after surgery, the facial structure will change, so the patient may have inferiority complex, so it is necessary to have a psychotherapist to provide additional mental support for the patient
Mental care not a core part of the cancer treatment plan	Patient: "I had to google everything. I think none of that was offered. Or even support for my [family member], like psychological support." Caregiver: "I did not hear the doctor say anything about physical therapy or psychological support."
Low awareness and access to PAG	Patient: "If there is a support group for psychological help for patients, I would join that group. When someone is sick, their thoughts are always dark, but if there are experts or a group of experts who can make my thoughts more positive and provide advice about my disease, that would be great." Patient: "We haven't had any contact with such (support) groups."

also further compounded by a lack of recognition among patients and caregivers of the importance of managing their mental well-being and the value of psychotherapeutic care.

Limited awareness and presence of patient advocacy groups (PAGs) further exacerbates patients' sense of isolation. Many were unfamiliar with the concept of OCSCC support groups or lacked access to specific OCSCC networks that could offer valuable resources and a platform for shared experiences.

In South Korea, patients noted they had "never heard of support groups," underscoring a disconnect from helpful resources. Likewise, many patients from different countries also wished for a dedicated organization specifically on oral cancer, highlighting the lack of cancer-specific support in the region (Table 5).

> Very limited information about oral cancer in Hong Kong. There is no specific cancer organization for oral cancer patients in Hong Kong… I wish there could be an organization specific for oral cancer patients.

Patients frequently reported limited access to formal mental health support and patient advocacy groups (PAGs), which appeared to leave them with few structured resources for managing the emotional and psychological challenges of OCSCC. In these circumstances, some patients described relying on coping strategies that may have been less effective. Several accounts suggested that this relative lack of support contributed to feelings of isolation and heightened stress, which patients themselves perceived as influencing their ability to cope and potentially increasing the overall psychosocial burden during treatment and recovery.

The interactions between these emotional challenges and coping responses are illustrated in Fig. 1, which maps the key psychological burden triggers using the POEM framework. The diagram reflects how patients' accounts often pointed to overlapping influences, such as fear of recurrence, appearance-related concerns, communication difficulties, and limited support, which appeared to reinforce one another over time. As shown in the figure, these interconnected factors created a dynamic in which distress could accumulate, particularly when effective coping resources or support systems were lacking. This mapping provides an overview of how patients described the psychological landscape surrounding their illness and highlights the complex interplay of triggers shaping their emotional experience.

Discussion

This study offers a comprehensive understanding of the multifaceted challenges and significant impact faced by LA-OCSCC patients and their caregivers. The themes underscore critical areas where targeted interventions are essential to improve the QoL and alleviate the psychosocial burdens experienced by this unique but overlooked patient cohort.

These findings align with this study's objective of characterizing the lived psychosocial experience of LA-OCSCC patients and caregivers across the Asia-Pacific region. By mapping the psychological burden and identifying key drivers of distress, the study highlights critical opportunities for a more patient-centric care model, consistent with the article's focus on psychosocial challenges and pathways for enhanced patient-centered care.

Our findings uncovered the immense, lasting impact of physical disfigurement and functional loss from OCSCC treatment. Changes especially from pain, facial disfigurement, speech and eating difficulties severely disrupted daily activities [7, 18, 19]. Given the long-term toxicities of trimodality treatment, early interventions like facial reconstruction surgery, facial prosthetics, speech therapy, and physical rehabilitation to restore function and improve the appearance of the affected areas are crucial. These interventions should be integrated from early treatment stages throughout survivorship to reduce psychosocial impact and help patients return to a normal lifestyle, enhancing their long-term well-being.

Typically, OCSCC has predominantly been diagnosed in older males with high-risk lifestyle factors such as smoking and excessive alcohol consumption [20, 21]. However, recent research indicates increasing incidence among younger women without these traditional risk factors [22, 23]. In our study, younger female patients exhibited heightened anxiety, likely due to their atypical profile compared to the traditional patient population. The physical and functional impairments associated with OCSCC may exacerbate psychological distress, leading to diminished self-worth and fear of social rejection driven by both external and internal stigma and chronic anxiety about recurrence and progression [24–27]. Our observations are consistent with the broader head and neck cancer literature, which similarly reports that disfigurement, functional impairment, and social withdrawal contribute to long-term anxiety and reduced health-related quality of life (HRQoL) [10, 13]. Studies have shown that unmet psychosocial needs are particularly prevalent in HNC compared with other cancers [13], underscoring the importance of system-level strategies to detect and address these needs early. While surgery and CRT remain the cornerstone of care, the evolving treatment landscape, including the integration of immunotherapy, offers promise for improving survival outcomes, which may in turn help alleviate anxiety about disease progression and enhance patient well-being [28, 29]. This underscores the pressing need for an integrated multidisciplinary approach that not only optimizes oncologic outcomes but also incorporates comprehensive psychosocial support systems to address the unique challenges faced by an evolving patient population.

The research also highlighted disparities in availability and accessibility of psychotherapeutic services, leaving many patients and caregivers without essential support and where chronic cancer anxiety remains largely unaddressed. Caregivers, already strained by care demands, frequently experience increased anxiety, depression, and sleep disturbances [30–33]. This dual burden, affecting patients and caregivers, highlights an urgent need for comprehensive, person-centered care that includes psychological support as a core component from diagnosis to survivorship. Incorporating regular psychological assessments and interventions [34], along with the consistent use of sensitive and specific patient-reported outcome measures and patient-reported experience measures throughout the care continuum, is essential, allowing for a more precise understanding of patient experiences to tailor interventions to individual needs and enhance their overall well-being.

In this context, routine HRQoL assessments represent a practical and evidence-based approach to strengthen patient-centered care. Regular use of validated HRQoL tools can support early identification of psychosocial distress, guide timely referrals to supportive services, and improve communication between patients and providers. Integrating HRQoL monitoring into routine practice may therefore facilitate more personalized care plans and better long-term outcomes, particularly for patients experiencing persistent functional loss and anxiety.

Given regional disparities in mental health access, there is a compelling case for policies and guidelines that incorporate mental health screening and programs to patients and their families as a core part of OCSCC management throughout the care pathway. Embedding HRQoL assessments and psychological screening tools into routine practice can also help standardize supportive care across diverse health systems in the region, reducing disparities in access to psychosocial services. For instance, Taiwan's government disease accreditation system requires hospitals treating HNC patients to meet specified criteria, including provisioning of psycho-oncological support, fostering more holistic patient-centered care [35]. Additionally, task sharing with community providers such as community care workers and peer support networks could also alleviate caregiver burden and provide patients and caregivers much-needed psychosocial support [36, 37], particularly when HCP resources are constrained.

There is an observed lack of PAG presence within the Asia-Pacific region and having a dedicated PAG for OCSCC is critical to address the unmet needs of this underserved population. Despite OCSCC not being the most common of cancers, its impact on patients' QoL is tremendous, imposing a high burden on patients and their caregivers. This underscores the need for more dedicated groups focused on OCSCC, establishing umbrella organizations like the Global Network for Rare Disease in the APAC region to provide a dedicated platform for properly supporting such efforts.

Limitations

This study explored the perspectives of patients, caregivers, and HCPs, with a focus on LA-OCSCC patients who underwent tri-modality treatment. While we identified differences in healthcare infrastructure, referral pathways, and socio-cultural influences on treatment experiences and coping behaviors, other related factors like caregiver characteristics may also influence how patients receive care. Although caregivers were included in the study, participants were not specifically recruited nor data was analyzed based on socio-demographic profiles or characteristics that may influence both caregiving and patient coping behaviors (e.g., socio-economic status, age, comorbidities, caregiving experiences).

This qualitative study employed in-depth narratives and purposive sampling to gather rich insights. To enhance credibility, findings were triangulated across multiple participant types using established behavioral science and psych-oncology frameworks (POEM framework, COM-B model) alongside existing literature. Notwithstanding this, findings may be less generalizable to other HNC types and their caregivers with different treatment pathways, distinct support needs, and coping strategies. Future studies should explore how specific socio-demographic and contextual factors influence coping strategies to inform the development of more tailored, targeted patient-centered psychosocial interventions.

Conclusion

This study examined the lived experiences of LA-OCSCC patients and caregivers in the Asia-Pacific region to identify opportunities to reduce anxiety and strengthen coping strategies. The findings highlight the profound and interrelated physical, functional, and psychosocial burdens patients face throughout the care continuum, showing how psychological distress both shapes and is shaped by patients' ability to engage in patient-centered care. Addressing these unmet needs requires tailored interventions delivered at key stages of treatment and survivorship, with integrated caregiver support to improve adaptive coping and quality of life. Routine incorporation of Patient-Reported Outcome Measures and HRQoL assessments can facilitate earlier identification of distress, enhance communication, and guide more personalized, responsive care.

The study also reveals pronounced disparities in supportive care access across the region, underscoring the need for policies that embed psychological care into standard guidelines and optimize staff resources through task-sharing models. By strengthening psychosocial services, integrating routine PROMs, and promoting equitable access, healthcare systems can advance truly holistic, patient-centered care for LA-OCSCC patients and their caregivers in the Asia-Pacific region.

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Author contribution E.D.H., P.S., H.R.K., K.T.N., T.E.N., H.L.T., Y.C.L., P.J.L.: conceptualization, validation, resources, writing—review and editing; C.S.: conceptualization, funding acquisition, supervision, validation, writing—review and editing; R.G.: conceptualization, methodology, resources, supervision, writing—review and editing; Y.J.Y.: conceptualization, data curation, formal analysis, methodology, project administration, resources, visualization, writing—original draft, writing—review and editing.

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Data availability All data generated in this study can be found in this article and the online resources files.

Declarations

Ethics approval This study was performed in line with the principles of the Declaration of Helsinki. Approval was granted by the relevant Ethics Committee and IRB in each participating country/territory: Bellberry Human Research Ethics Committee, Australia (2022-07-751); Oncology Study Group Research Ethics Committee, Hong Kong (2022/24); Public Institutional Review Board designated by the Ministry of Health and Welfare, South Korea (2022-1483-002); National Taiwan University Hospital IRB, Taiwan (202210028RSA); and Ho Chi Minh City Oncology Hospital IRB, Vietnam (3393/BVUB-CDT).

Consent to participate Written consent was obtained from all individual participants included in this study.

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