

Article Title: 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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30 Online Resource 2. Insights into patient experiences with LA-OCSCC and its treatment

<u>Key Perspectives</u>	<u>Supporting Verbatims</u>
Theme 1: Physical and functional impairments from tri-modality treatment and its impact on quality of life	<i>"...having terrible sleep... around my throat and stuff, I've got this constant feeling of being strangled... It's not like it used to be... I've got a PICC tube^a that I've got to feed... A part of my hearing has been affected, in my left ear. I noticed my eyesight has noticeably deteriorated... chemo and radiation, it just kept on giving ..."</i> – Australia, Patient <i>"...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 really hard. Eating anything small is impossible."</i> – Australia, Patient <i>"100% rely on (their) PICC^a for (their) nutrition... that's been for 6 months... developed trismus so can't open (their) mouth."</i> – Australia, Caregiver <i>"...tinnitus for 24 hours and long-term. This is a consequence of radiotherapy"</i> – Hong Kong, Patient <i>"Very painful. I even needed help when I went to the toilet."</i> – Hong Kong, Patient <i>"The biggest impact is that I cannot chew well... cannot bit and swallow well, I try not to eat much, and if then I don't have much energy"</i> – South Korea, Patient <i>"(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."</i> – Taiwan, Caregiver <i>"(Their) speech has been unclear because half of (their) tongue was removed and replaced with flesh from (their) neck, making it difficult for (them) to chew and swallow... now (they) (have) difficulty eating, chewing, and swallowing. After a long time without eating, (their) stomach has also been affected, as it has shrunk."</i> – Vietnam, Caregiver
Theme 2: Psychosocial impact from OCSCC and tri-modality treatment	<i>"...doesn't want to go to work... is terrified that (patient) might meet someone... don't want to talk in a lisp..... It's devastated (patient's) sex life, it's devastated (patient's) speech... lost a lot of weight, (they) prematurely aged."</i> – Australia, Caregiver

“...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.” – Australia, Caregiver

“...there was a bit of denial... everything I read pointed to heavy smokers, heavy drinkers, over age of 50, male... I don’t fit the profile... if I had known tongue cancer was a thing, I probably would have... pushed for a referral to a specialist at... that first dentist appointment.” – Australia, Patient

“I don’t want to go out. Because I can’t eat now. I can only use my feeding tube to eat. 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.” – Hong Kong, Patient

“...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? How can I know! Even my doctor can’t answer me these!” –Hong Kong Patient

“my (family member) suffered from a very serious psychological problem, (they) refused to communicate with people... Since the day my (family member) got sick and had to undergo treatment, (they) refused all visits and showed signs of depression. (They) did not like to talk to (their spouse) and children at all and preferred to be alone in the room.” – South Korea, Caregiver

“These patients complain of pain a lot, and their psychological aspect is very sensitive, so outpatient ward nurses and inpatient ward nurses find it difficult to treat them. 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.” – South Korea, Nurse

“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” – Taiwan, Patient

“(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.” – Taiwan, Caregiver

“...as soon as people find out my (family member) had oral cancer, straight away they assumed (they) chewed betel nuts.” – Taiwan, Caregiver

	<i>"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. It also changes the aesthetic structure, so they also have an inferiority complex." – Vietnam, Radiation Oncologist</i>
Theme 3: Fear of cancer recurrence and progression impact coping behaviors	<i>"(Patient) has been a bit thrown away by the ones who had terrible outcomes, the young ones who've had recurrences and things" – Australia, Caregiver</i> <i>"... there's always that concern that after they finish 'oh now I'm getting evaluated I'm scared what's that going to be' the anxiety around that 'is it going to be clear or not'? Then they get their regular interview until 5 years post so it's a long time to still be dealing with that cancer diagnosis even though you've technically finished the curative intent treatment..." – Australia, ENT Surgeon</i> <i>"Even if I saw someone who succeeded in the surgery, they would talk about recurrence. I would feel upset if I think about recurrence." – Hong Kong, Patient</i> <i>"This cancer was ferocious and aggressive. Even till now, we are not certain whether recurrence would happen... I hope (patient) won't have recurrence. I always feel worried." – Hong Kong, Caregiver</i> <i>"The fact that it's Stage 4 of oral cavity cancer gives a lot of psychological burden to me. Since the metastases on the lymph node were detected, so I always have anxiety that it can relapse or metastasize at any time." – South Korea, Patient</i> <i>"I still have to wait for the results like waiting for the lottery results. On the day of the regular check-up, my mood is very unpredictable because the disease can come back at any time" – Vietnam, Caregiver</i>
Theme 4: Negative coping strategies exacerbated by inadequate support systems	<i>"None of us have been offered to see a psychologist. We've all just been put on anti-depressant or anti-anxiety... all these different countries. There's no follow-up care for that side of it, which I think is the biggest side of this, how it mentally affected..." – Australia, Patient</i> <i>"There is a lack of psychologic... routine psychologic support for cancer patients in general and in particular, head and neck" – Australia, ENT Surgeon</i>

“...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.” – Hong Kong, Patient

*“I don’t currently assess such things and refer patients for psychological counselling.”
– South Korea, Medical Oncologist*

“We don’t connect them to psychological counselling. There isn’t a psychologist in the cancer hospital...” – South Korea, Psychologist

“Each time the patient is admitted, we take (the patient’s) “mood thermometer”, which is a simple 1-10 brief symptom rating scale... patient is assessed each time (patient) is hospitalized” – Taiwan, Psychologist

“We haven’t had any contact with such (support) groups” – Taiwan, Caregiver

“Our treatment team is quite complete. We have... psychological counselling” – Taiwan, Speech Therapist

“If there is a support group for psychological help for patients, I would join that group.” – Vietnam, Patient

“...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” – Vietnam, Radiation Oncologist

31 **Abbreviations:** Peripherally Inserted Central Catheter (PICC) ^a

32 ^a **Note:** A PICC (Peripherally Inserted Central Catheter) line is used for intravenous access, typically for
33 medications or fluids but not for feeding. Feeding typically required a Nasogastric tube (NG) or Percutaneous
34 Endoscopic Gastrostomy tube (PEG) tube.