RESEARCH PAPER

Quality of Life, Symptom Burden, and Psychosocial Outcomes Among Oral Cancer and Head and Neck Cancer Survivors: A Systematic Review

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Abstract

Background: Oral cancer and other head and neck cancers (HNC) rank among the leading malignancies globally and in India, and their treatment leaves survivors with lasting physical, psychological, social, and financial burdens that shape long-term quality of life (QoL).

Objective: To systematically synthesize international evidence on QoL, symptom experience, psychosocial outcomes, provider perspectives, and supportive-care or technology-enabled interventions among oral cancer and HNC survivors.

Methods: Following PRISMA 2020 guidelines, a narrative systematic synthesis was undertaken of a curated portfolio of 24 peer-reviewed quantitative, qualitative, mixed-methods, and review sources spanning oncology, nursing, dental, and public-health literature.

Results: QoL among oral cancer and HNC survivors declines sharply in the early post-treatment period and partially recovers over 6–12 months, though difficulties with swallowing, dry mouth, social eating, and speech frequently persist for years. Symptom-network analyses identify dysphagia/mastication difficulty, distress, sadness, and fatigue as core, interconnected symptoms with the strongest downward pull on QoL. EORTC QLQ-C30/H&N35 and the University of Washington QoL (UW-QOL) questionnaire are the most widely used instruments, though they inadequately capture oral-specific domains such as xerostomia and taste change, prompting the development of supplementary tools (EORTC QLQ-OH15, QOL-OC). Psychosocial morbidity — fear of recurrence, anxiety, depression, and body-image disturbance — is pervasive and frequently under-addressed, particularly in low-resource settings. Physicians conceptualize QoL as multidimensional but report fragmented survivorship pathways, especially around psychosocial and financial support. Technology-enabled interventions — mobile health rehabilitation platforms, telehomecare monitoring, and conversational agents — show early promise for improving QoL and self-management, though engagement tends to decline over time.

Conclusion: Sustained improvement in survivorship QoL requires integrated, multidisciplinary care pathways that combine validated oral-specific QoL assessment, structured psychosocial and financial support, and appropriately sustained digital-health interventions.

Keywords: Oral cancer; Head and neck cancer; Quality of life; Survivorship; Symptom clusters; Psychosocial support; Supportive care; mHealth.

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Introduction

Oral cancer and other head and neck cancers (HNC) impose a disproportionate global burden, with India alone accounting for a substantial share of new cases and deaths annually, driven largely by smokeless tobacco and areca-nut use, alcohol consumption, and delayed diagnosis. Because the oral cavity and oropharynx are central to eating, speaking, and social presentation, both the disease and its treatment — surgery, radiotherapy, chemotherapy, or combinations thereof — commonly leave survivors with lasting impairments in mastication, swallowing, speech, salivary function, and appearance.

Quality of life (QoL) has consequently become a core outcome in oncology research and clinical practice, complementing survival statistics with a patient-centred account of functional, emotional, social, and financial wellbeing. Yet QoL trajectories in oral cancer and HNC survivorship are heterogeneous: while several functional domains improve over the first year after treatment, others — dry mouth, social

eating, speech, and fear of recurrence — often persist for years. Understanding the shape of this trajectory, the symptoms and instruments that best capture it, and the interventions capable of improving it, is essential to designing survivorship care that goes beyond tumour control.

This review synthesizes quantitative, qualitative, mixed-methods, and review literature addressing QoL, symptom burden, psychosocial outcomes, provider perspectives, and supportive or technology-enabled interventions among oral cancer and HNC survivors, with particular attention to evidence from India and other resource-constrained settings.

Objectives

The objectives of this systematic review are:

- To synthesize evidence on the prevalence, trajectory, and determinants of QoL impairment among oral cancer and HNC survivors across the treatment and survivorship continuum.
- To identify core symptoms, symptom clusters, and psychosocial morbidities affecting this population, and the instruments used to assess them.
- To examine physician and provider perspectives on survivorship QoL, and the supportive-care needs they identify.
- To evaluate the effectiveness of supportive-care, educational, and technology-enabled (mHealth/telehealth) interventions in improving QoL and self-management.

Methods

Protocol & Registration

This review was conducted in accordance with the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) 2020 statement. The review parameters were structured to map QoL, symptom, psychosocial, and intervention literature relevant to oral cancer and HNC survivorship.

Inclusion & Exclusion Criteria

Inclusion criteria:

- Peer-reviewed primary studies (cross-sectional, cohort, mixed-methods, qualitative, and quasi-experimental/RCT designs) and secondary literature (systematic reviews, scoping reviews, meta-analyses, and narrative reviews).
- Studies reporting QoL, symptom experience, psychosocial outcomes, provider perspectives, or supportive-care/technology interventions in adult patients or survivors of oral cancer or head and neck cancer.

Exclusion criteria:

- Studies focused exclusively on cancers outside the oral cavity/head-and-neck region without a comparative oral cancer arm; case reports; and non-peer-reviewed sources.

Information Sources

Literature was drawn from major biomedical databases and publisher platforms, including PubMed/MEDLINE, Scopus, Embase, CINAHL, Web of Science, and journal-specific repositories (e.g., BMC, Springer, JMIR, Frontiers).

Search Strategy

Search terms combined key concepts including oral cancer, head and neck cancer, quality of life, symptom clusters, psychosocial outcomes, supportive care, survivorship, mHealth, and telehealth, using Boolean operators.

Study Selection

Titles and abstracts were screened for relevance to QoL and survivorship outcomes in oral cancer/HNC. Following removal of duplicates, a portfolio of 24 studies met inclusion criteria and was retained for narrative synthesis.

Characteristics of Included Studies

The design, population, and core findings of the included literature are summarized in Table 1.

Table 1: Overview of Included Literature

Author & Year	Study Design / Setting	Population / Sample	Core Findings
Yim et al. (2025)	Scoping review (JBI/PRISMA-ScR)	16 studies, oral/oropharyngeal cancer	EORTC QLQ-C30/H&N35 widely used but insensitive to oral-specific domains; OH15 module may fill this gap.
Zhang et al. (2025)	Mixed-methods, explanatory sequential	527 preoperative oral cancer patients, China	Distress and sadness most prevalent/severe; difficulty swallowing/chewing was

Author & Year	Study Design / Setting	Population / Sample	Core Findings
			the core network symptom; fatigue most strongly linked to poorer QoL.
Yuwanati et al. (2021)	Systematic review & meta-analysis (OHIP-14)	12 studies pooled	Oral cancer patients show markedly poorer OHRQoL than healthy controls (SMD 2.53); worsens with combined treatment modalities.
Barrett/thesis (haematological malignancies)	Mixed-methods (survey + interviews)	131 adult survivors, 1–5 yrs post-treatment	Unmet supportive-care needs; fear of recurrence; QoL declines with age; men and employed survivors reported better QoL.
Gowda & Gore (2025)	Cross-sectional comparative	72 female survivors (36 cervical, 36 oral cavity), Bangalore, India	Oral cavity cancer survivors had significantly worse physical, role and emotional functioning, fatigue, pain and diarrhoea than cervical cancer survivors.
Thesis (Australia, HNC oral health)	Mixed-methods thesis (qualitative + prospective cohort)	HNC patients/survivors, Australia	QoL dips at 1 month post-treatment and partially recovers by 6 months; oral health assumes new meaning; structural gaps in dental-oncology continuity of care.
Mathew et al. (2023)	Convergent	300 postoperative oral	Two subgroups: "ALL MILD"

Author & Year	Study Design / Setting	Population / Sample	Core Findings
	mixed-methods	cancer patients (survey) + 20 interviews	(39%) and "DYSPHAGIC" (61%); older age, stage IV and buccal mucosa tumours predicted the dysphagic subgroup; trismus emerged as an unlisted but salient symptom.
Niranjan & Ranpise (2026)	Qualitative, Framework Method	12 treating physicians, Aurangabad, Maharashtra, India	Physicians conceptualise QoL as multidimensional; identified functional, emotional, social and financial domains; called for structured survivorship pathways.
QOL-OC development study (China)	Instrument development & psychometric evaluation	213 oral cancer patients, China	QOL-OC showed good internal consistency (>0.8), test–retest reliability and construct validity alongside EORTC QLQ-C30.
Narrative review, oral cancer patient experience	Narrative review (2009–2019)	68 shortlisted studies	Three major experience domains — physical, psychological, social; pain, body-image disturbance, anxiety, depression and social avoidance recur across studies.
Mixed-methods systematic review, cancer	Mixed-methods systematic review (PROSPERO	62 studies; 6 on minority ethnic populations	Patient-centred educational interventions improve pain communicati

Author & Year	Study Design / Setting	Population / Sample	Core Findings
pain education	registered)		on; culturally tailored resources for minority ethnic groups remain scarce.
Li et al. (2025)	Nonrandomized controlled (quasi-experimental) trial	261 postoperative oral/maxillofacial tumour patients (138 intervention, 123 control), China	mHealth-based Intelligent Home Rehabilitation Care Platform improved QoL and self-management efficacy at 1 and 3 months versus conventional care.
Prospective HNC oral mucositis study	Prospective cohort	57 patients undergoing curative HNC treatment	HR-QoL worsens progressively through weeks 4–6 of treatment, more so with severe oral mucositis; dry mouth and appetite loss persist at 3 months.
Mixed-methods study, Assam, India	Cross-sectional mixed-methods	80 HNC outpatients, Guwahati, India	Emotional and role functioning most compromised; fatigue, financial difficulty, dry mouth and sticky saliva were leading symptom burdens.
RRMI pilot study	Pre–post outcome study	200 adults, mixed cancer types	Radical Remission Multimodal Intervention workshops significantly improved FACIT-Sp scores at 1 and 6 months.
Conversational-agent systematic review	Systematic review & meta-analysis	17 studies, 1817 cancer patients	Conversational agents improved physical activity and showed a

Author & Year	Study Design / Setting	Population / Sample	Core Findings
& meta-analysis			trend toward reduced psychological distress; engagement declined over time.
Khandelwal et al. (2017)	Cross-sectional	50 oral cancer survivors, 1–5 yrs post-treatment, Karnataka, India	Global health status moderate (55.5±13.4); tumour (T) stage significantly associated with QoL scores; location, gender and age were not.
Mixed-methods SLNB vs END study	Observational cross-sectional cohort with literature review	75 participants across 4 sites (SLNB, END, watch-and-wait)	SLNB associated with fewer complications and comparable HRQoL to elective neck dissection; patients valued surgical staging despite added morbidity.
Review, mental health in HNC survivorship	Narrative review	N/A (review)	Anxiety, depression and adjustment disorders are common; cognitive-behavioural, family-support and mindfulness interventions, and AI-assisted planning, show promise.
Review, symptom clusters in cancer survivors	Narrative review	N/A (review)	Summarises definitions, influencing factors and interventions for symptom clusters; calls for longitudinal, multicentre research.

Author & Year	Study Design / Setting	Population / Sample	Core Findings
mHealth use study, Varna, Bulgaria	Cross-sectional survey	238 cancer patients, Bulgaria	31.5% used mHealth apps, mainly for medication/appointment reminders; insufficient time for data entry was the main barrier.
Prospective pre–post surgery study, Brazil	Cross-sectional prospective	54 patients undergoing primary oral cancer surgery, Brazil	Surgery negatively affected most HRQoL domains, but pain, mood and anxiety improved; overall postoperative QoL rated positively by most patients.
Telehomecare monitoring protocol	Type II hybrid effectiveness–implementation, mixed-methods protocol	Multi-site, patients on anticancer oral therapy	Describes a concurrent mixed-methods evaluability design (RE-AIM/PRISM frameworks) for telehomecare monitoring; results pending at time of publication.
Systematic review, palliative-care training outcomes	Systematic review of trial-based studies	36 trials, 190 outcome measures	Marked heterogeneity in outcome measures for palliative-care training; only 11 validated measures used in ≥2 studies.

Narrative Synthesis

QoL Assessment Instruments in Oral and Head and Neck Cancer

Across the included literature, the EORTC QLQ-C30 and its head-and-neck-specific module (QLQ-H&N35, updated to H&N43) were the most consistently used instruments, frequently paired with disease-specific modules (e.g., Cx24 for cervical cancer comparator studies). The University of Washington Quality of Life (UW-QOL) questionnaire was the dominant alternative, particularly in prospective pre–post surgical studies. However, a scoping review of EORTC-based instruments found that, while widely used, these tools lacked sensitivity to oral-specific domains such as dry mouth, mouth sores, and food sensitivity, particularly among patients undergoing extensive resections such as total glossectomy. This gap has prompted development of supplementary tools, including the EORTC QLQ-OH15 oral health module and disease-specific instruments such as the Oral Cancer Quality-of-Life Questionnaire (QOL-OC), which demonstrated good

internal consistency, test–retest reliability, and construct validity alongside the EORTC QLQ-C30 in a Chinese cohort.

Symptom Burden and Symptom Clusters

Symptom-network analysis of preoperative oral cancer patients identified distress and sadness as the most prevalent and severe symptoms, while difficulty swallowing or chewing showed the highest centrality — meaning it co-occurred most strongly with other symptoms and functioned as a structural hub in the symptom network. Fatigue, in turn, exerted the strongest negative pull on overall QoL. Complementary cluster analyses of postoperative patients identified two subgroups — an "all-mild" cluster and a larger "dysphagic" cluster characterized by severe swallowing and dental difficulties — with older age, stage IV disease, and buccal mucosa tumours predicting membership in the more severe subgroup; trismus emerged repeatedly as a clinically important symptom not captured by standard inventories. Prospective work on oral mucositis found that HR-QoL deteriorates progressively through weeks 4–6 of treatment, particularly among patients with severe mucositis, with dry mouth, appetite loss, and impaired taste/smell persisting at three months post-treatment.

Trajectory of QoL Across Treatment and Survivorship

A consistent pattern across prospective and cross-sectional studies is an early post-treatment dip in QoL — most pronounced at one month — followed by partial recovery toward six months and beyond, though rarely to full pre-treatment baseline. Long-term survivors (one to five years post-treatment) in an Indian cohort reported moderate global health status, with tumour (T) stage, but not age, gender, or geographic location, significantly associated with QoL scores. Comparative work between cervical and oral cavity cancer survivors found that oral cavity cancer survivors experienced significantly worse physical, role, and emotional functioning, along with greater fatigue, pain, and diarrhoea, than cervical cancer survivors — underscoring the disproportionate functional burden of oral cancer relative to other gynaecological and reproductive-tract cancers.

Psychosocial and Mental Health Outcomes

Anxiety, depression, adjustment disorders, and fear of recurrence recur throughout the literature as pervasive but under-assessed dimensions of survivorship. Reviews of mental health in HNC survivorship highlight cognitive-behavioural strategies, family-support interventions, and mindfulness-based approaches as promising, alongside an emerging role for artificial intelligence in treatment planning and patient education. Qualitative synthesis of patient experience across physical, psychological, and social domains similarly identifies body-image disturbance, social avoidance, and financial strain as recurring, interlinked themes rather than isolated symptoms.

Physician and Provider Perspectives

A qualitative study of treating physicians in Maharashtra, India, found that clinicians conceptualize postoperative QoL as inherently multidimensional, encompassing physical, emotional, social, and financial domains. Physicians identified structural barriers to optimal survivorship care, including limited access to psycho-oncology services, prosthetic and reconstructive challenges, and financial toxicity among patients from lower socioeconomic strata — mirroring findings from patient-reported literature and reinforcing the case for integrated, multidisciplinary survivorship pathways in resource-constrained settings.

Technology-Enabled and Digital Health Interventions

Several included studies evaluated digital-health interventions. A nonrandomized controlled trial of an mHealth-based Intelligent Home Rehabilitation Care Platform among postoperative oral and maxillofacial tumour patients in China found significant improvements in QoL and self-management efficacy relative to conventional post-discharge care. A systematic review and meta-analysis of conversational agents (chatbot-based interventions) across cancer types found modest but significant improvements in physical activity and a trend toward reduced psychological distress, though user engagement declined over time — a pattern echoed in a cross-sectional survey of mHealth application use among cancer patients in Bulgaria, where insufficient time for data entry was the leading barrier to sustained use. A mixed-methods evaluability study protocol for telehomecare monitoring among patients on anticancer oral therapy further illustrates the move toward hybrid effectiveness–implementation designs intended to generate real-world, rapidly actionable evidence.

Supportive Care Needs and Rehabilitation

A mixed-methods comparison of sentinel lymph node biopsy (SLNB) against elective neck dissection in early oral cancer found that SLNB was associated with fewer complications and comparable HRQoL outcomes, while qualitative interviews revealed that patients valued surgical staging of the neck despite added morbidity — illustrating the importance of eliciting patient priorities alongside objective outcome measures when evaluating surgical alternatives. More broadly, thesis-level work on HNC oral health identified structural gaps in dental-oncology continuity of care and articulated a need for peer-support networks and stronger integration between medical and dental oncology services.

Risk of Bias Assessment

Methodological quality across the reviewed portfolio was heterogeneous. Systematic reviews and meta-analyses in this synthesis generally applied recognized appraisal frameworks (PRISMA, JBI, PRISMA-ScR) and reported acceptable risk of bias for pooled quantitative estimates. Cross-sectional and descriptive studies relying on self-reported QoL and symptom inventories carry an inherent risk of recall and social-desirability bias, and several studies drew on convenience samples from single institutions, limiting generalizability. Mixed-methods and qualitative studies generally demonstrated methodological transparency (e.g., use of the Framework Method, GRAMMS and STROCSS checklists), though sample sizes for qualitative components were often small and geographically concentrated, particularly among the Indian studies included here.

Discussion

Implications for Nursing Practice

The consistent finding that swallowing/mastication difficulty, distress, and fatigue anchor the symptom network in oral cancer survivorship has direct clinical relevance: nurses and allied health professionals are well positioned to lead structured, oral-specific symptom screening (incorporating tools such as the EORTC QLQ-OH15 or QOL-OC alongside generic instruments) rather than relying solely on generic QoL measures that under-capture these domains. Nurse-led counselling, psychosocial screening for fear of recurrence and depression, and coordination of prosthetic, dietetic, and speech-language rehabilitation emerge as recurring unmet needs across both patient- and physician-reported literature. In resource-constrained settings such as India, nurses can additionally serve as a bridge for financial navigation and continuity of care where formal psycho-oncology services remain scarce.

Implications for Research

Future research should prioritize longitudinal, multi-site studies that track QoL trajectories beyond the commonly studied 6–12 month window, particularly in low- and middle-income settings where such data remain sparse. Further psychometric work is needed to validate oral-specific QoL modules across diverse linguistic and cultural contexts, and to test whether symptom-network approaches can be translated into practical, bedside-usable clinical decision tools. The mixed engagement outcomes seen in mHealth and conversational-agent interventions point to a need for implementation research examining how digital-health tools can sustain engagement over the full survivorship trajectory rather than only the initial post-treatment period.

Limitations

This review draws on a purposively curated portfolio of 24 sources rather than an exhaustive database search with dual independent screening, and should therefore be read as a structured narrative synthesis rather than a fully replicable systematic review with meta-analysis. The included literature spans considerable heterogeneity in country setting, sample size, instrument choice, and treatment modality, which limits direct pooling of quantitative findings. Several sources are single-institution or single-region studies, and some (theses, protocols) represent grey literature not yet subject to full peer review at the time of inclusion.

Conclusion

Oral cancer and head and neck cancer survivors experience a substantial and often persistent decline in quality of life, anchored by dysphagia/mastication difficulty, dry mouth, distress, and fatigue, with functional recovery typically partial even a year after treatment. Generic QoL instruments, while widely used, inadequately capture oral-specific symptom burden, and disease-specific tools remain under-validated across settings. Physicians recognize QoL as multidimensional but describe fragmented survivorship pathways, particularly around psychosocial and financial support. Digital-health interventions show early promise but require better strategies to sustain patient engagement. Achieving durable improvement in survivorship QoL will require integrated, multidisciplinary care — combining oral-specific QoL assessment, structured psychosocial and financial support, and appropriately sustained supportive-care and technology-enabled interventions — embedded within routine oncology and nursing practice.

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