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REVIEW ARTICLE

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Support needs and quality of life in oral cancer: a systematic review

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Abstract: *Purpose:* This review aims to systematically review the literature describing quality of life (QoL) outcomes and support needs in patients with oral cancer along the cancer trajectory. This is needed to form an evidence base for the design of interventions that enhance outcomes for this group. *Methods:* Six electronic databases were searched. The results were screened for eligibility, and articles were included if they described patient-reported QoL outcomes that were translatable to support needs in patients with oral cancer. Data were extracted and synthesized according to the support needs identified and their relative impact on QoL. Methodological quality was assessed using the Effective Public Health Practice Project (EPHPP) Quality Assessment Tool. *Results:* Thirty-one articles met the inclusion criteria. Support needs related to coping with the burden of radiotherapy in both psychosocial and physical aspects, swallowing dysfunction, dry mouth and oral functional deficits. Issues of depression, anxiety and malnutrition were identified as having a significant impact on QoL. *Conclusions:* Oral cancer support needs are highly subjective and varied in severity across the cancer continuum. Support needs that may warrant further investigation include management of changes to oral health and functioning, swallowing and nutritional compromise and psychological effects of cancer and treatment.

Key words: mouth neoplasms; needs; oral cancer; quality of life; support; systematic review

Introduction

Oral and oropharyngeal cancer is the sixth most common cancer worldwide, with the annual incidence of oral cancer estimated to be 275 000 (1), with developing nations sharing a disproportionate burden of disease (2). Oral cancer is associated with significant mortality, with global 5-year survival rates estimated to be 50% (1). Treatment for oral cancer is particularly disabling and disfiguring and disrupts the core aspects of daily life (3). The mouth is central to an individual's ability to eat, speak and interact with others, and as such, the treatment of oral cancer is associated with a significant physical and psychological burden.

Oral cancer describes malignancies of the oral cavity, including structures such as the gingiva, buccal mucosa, hard palate, floor of mouth, salivary glands and anterior two-thirds of the tongue (4). Cancers of the oropharynx and oral cavity share several risk factors, and the term 'head and neck cancer' (excluding nasopharyngeal carcinoma) is commonly used to define cancers of the oral cavity and oropharynx (5). This review focuses on oral cancer but makes reference to the findings of studies

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incorporating mixed head and neck cancer samples that are inclusive of patients with oral cancer. Quality of life (QoL) is greatly affected by oral cancer diagnosis and treatment. QoL is a measure of an individual's subjective well-being, in the context of the culture and value system where they live (6). Health-related quality of life (HRQoL) is a subset of QoL that encompasses four domains: physical functioning, psychological functioning, social interaction and disease- and treatment-related symptoms (7). HRQoL is an important indicator in patients undergoing treatment for head and neck cancer, as it is a measure of disease experience and is a predictor of disease survival (7).

The assessment of QoL as a treatment outcome has become an important aspect of oral cancer research and has allowed the evaluation of the impacts of treatment from the patient's perspective (8). Validated questionnaires form the mainstay of QoL assessment and have provided an indication of patient-related factors associated with worse QoL after treatment (9). There is little evidence however as to how the QoL deficits reported by patients may be improved, especially after treatment, by offering practical and appropriate support for patients.

In this sense, support needs assessment may be used to complement QoL evaluations in patients with oral cancer. In contrast to QoL assessment, support needs assessment aims to directly investigate and identify issues and their perceived importance to patients. In practical terms, 'needs' can be defined as the requirement of some action or resource that is necessary, desirable or useful to attain optimal well-being (10). Needs relating to cancer and its treatment are broad and may include physical, psychosocial and practical needs (11).

There are several long-term side effects associated with the treatment of oral cancer. Surgical removal of the cancer may result in physical disruption to the anatomy and neuromuscular control structures of the oropharynx. Post-treatment radiotherapy may further compound the functional deficits caused by surgery (12). Patients who have received radiotherapy to the oral cavity report ongoing issues with dysphagia and xerostomia several years after treatment (13, 14).

The diagnosis and treatment of oral cancer has a significant burden on the psychological well-being of patients. Suicide rates are higher among patients with head and neck cancer than the general population and the general cancer population, and patients with oral cancer report significantly worse QoL across physical and psychosocial domains when compared to people with other cancers (15, 16). Additionally, patients with oral cancer perceive higher support needs than patients with other cancers, particularly related to physical and daily living needs, patient care and support needs, and health system and information needs (17).

Patients with oral cancer require professional support in coping with the consequences of treatment, including adjusting to changes in swallowing, nutritional intervention and psychological support (18–20). The symptom-specific scales of commonly used QoL questionnaires measure several of these treatment outcomes (17, 21). Although not a direct measure of support need, the issues identified on symptom-specific QoL scales associated with poor QoL may provide evidence as to the type of support needs perceived by patients with oral cancer across the cancer trajectory (22).

There have been a number of reviews published previously evaluating QoL outcomes in oral cancer; however, there are few that discuss support needs or a supportive care approach (3, 23). This article aimed to systematically review the literature describing QoL outcomes in patients with oral cancer, along the cancer trajectory, to (i) provide an evidence base for the support needs perceived by this patient group and (ii) describe their impact on QoL.

Methods

Literature search

The search aimed to answer the following question: 'what support needs are identified by patients with oral cancer during cancer diagnosis, treatment and post-treatment and how do they affect quality of life'? Electronic databases Cochrane, Embase, PubMed, CINAHL, Scopus, Web of Science and PsycINFO were searched using a combination of keyword, Medical Subject Heading (MeSH) or equivalent database thesaurus subject headings. See Table 1 for a description of the search strategy used for PubMed. This search strategy was adjusted for each of the databases used.

One author (KM) screened the abstracts of the complete data set, while another author (PF) independently screened a subset, and the selections were then compared. The full-text versions of the potentially relevant articles were then obtained and assessed for eligibility by one author (KM).

Eligibility criteria

Articles were included if they described patient-reported QoL outcomes that were translatable to support needs in patients with oral cancer, were in English and were original studies. Studies reporting QoL findings from heterogeneous head and neck cancer samples were also included if they were inclusive of patients with oral cancer.

Articles that described findings only in participants with cancers outside the oral cavity, were not translatable to support

Table 1. **Description of search strategies (PubMed)**

1. Exp Nutritional support/ OR Exp Social support/ OR Exp Financial support/
2. Support need* or social support
3. #1 OR #2
4. Exp mouth neoplasms/ OR 'oral cancer'
5. (Mouth or oral) AND (cancer* OR malignan* OR carcinoma* OR tumor* OR tumour* OR neoplasm*)
6. #4 OR #5
7. Exp Quality of life/
8. 'Health-related quality of life' OR 'quality of life' OR 'lived experience' OR QoL OR HRQOL
9. #7 OR #8
10. #3 AND #6 AND #9

needs and were published in languages other than English were excluded. Studies reporting findings from heterogeneous head and neck cancer samples in which patients with oral cancer were unable to be identified were also excluded, as were qualitative and case report studies.

Quality assessment

The Effective Public Health Practice Project (EPHPP) Quality Assessment Tool for Quantitative Studies was used to assess the methodological quality of the included studies (24). This tool classifies the strength of a study as strong, moderate or weak based on assessment of several components of the methodology and results (24).

Data synthesis

Fundamental differences in study design, study population, outcome measures and methodology presented a challenge in synthesizing the key findings of the included studies. Support needs were interpreted by the authors and were formed based on the outcomes reported from symptom-specific QoL questionnaires used in the included studies. For data synthesis, 'support needs' were defined as a QoL issue that had the potential to be improved by the provision of an action or resource (10). Support needs were extracted from the studies by one author and were then discussed with a second author to ensure clinical relevance.

For each study, the relative impact on QoL for the reported support need along with its prevalence was categorized and reported in table form (see Table 2). The relative impact of each support need on QoL and their prevalence was described as low, moderate or high. The cut-off for each category was determined by the authors and is described in Table 3. To ensure reliability and trustworthiness of data extraction, categories of support needs directly related to the quality of life symptoms or domains reported by the included studies.

Results

The initial database search yielded 1124 potentially eligible articles. Thirty-one articles met the inclusion criteria. A description of the selection process is described in Fig. 1.

A range of methodological approaches and a variety of outcome measures were used to measure QoL and support needs in the studies included in this review. A majority of the included studies were of cross-sectional design ($n = 21$), followed by smaller proportion of longitudinal or prospective designs ($n = 7$). Two studies were of case–control design, and one study used a retrospective chart review methodology. Qualitative studies were excluded from the analysis. A summary of study characteristics and the support needs identified is provided in Table 2.

The use of cross-sectional design by several of the studies contributed to a high number of 'weak' appraisals when examined for methodological quality (see Table 2). Studies that used longitudinal or prospective methods were generally awarded a stronger EPHPP rating. Most studies that used a non-validated outcome measure also included previously validated measures in their study designs to strengthen and validate the results of the self-designed measures (25–28). One of the included studies used a non-validated self-designed outcome measure and therefore was awarded a weak rating (29).

A range of physical, psychosocial and practical support needs were identified in the included studies and varied according to treatment modality and time points relative to treatment.

Physical support needs

Physical support needs extracted from the studies were the symptoms and physiological functioning difficulties expressed by patients that could be improved by access to tailored professional support, for example to allied health disciplines for issues related to oral health and rehabilitation, nutrition, dysphagia, difficulties in speech, or shoulder morbidity.

Oral health-related support needs

Several of the included studies described a high prevalence of oral health and functional support needs, particularly related to the side effects of radiotherapy and chemoradiotherapy (8, 13, 30–35). Issues relating to pain, mucositis, xerostomia and eating difficulties were identified in several of the included studies describing QoL issues in the acute treatment period of radiotherapy (32) and chemoradiotherapy (35, 36). Both treatment modalities were associated with significant oral morbidity in the respective cohorts.

Patients with oral cancer formed the majority of patients who reported concern or embarrassment with speech or eating (53% or $n = 46/86$) in a mixed head and neck cancer population following treatment (26). Epstein *et al.* (32) described significant issues with speech ($n = 15/20$) and oral pain ($n = 15/20$) among patients at the end of treatment. Six months post-treatment, patients reported continued issues with chronic pain ($n = 15/20$), xerostomia ($n = 19/20$), taste ($n = 18/20$) and speech ($n = 13/20$) (32). A lack of clinical or statistical improvement for the symptoms of xerostomia and taste dysfunction 12 months following treatment with chemoradiotherapy for advanced-stage disease was reported in 58% ($n = 27/46$) of patients, despite a gradual improvement in other functional and physical scales (35). A clinically significant deterioration in sticky saliva between 1 and 5 years post-treatment was reported in patients who had received radiotherapy as their primary treatment or as an adjunct to surgery (8).

Cross-sectional studies described long-term support needs related to symptoms of xerostomia, chewing, trismus and sticky saliva 1–2 years post-treatment and significant issues with xerostomia 7–11 years post-treatment (13, 39).

Duke *et al.* (31) reported that a lack of teeth or no teeth secondary to cancer was associated with worse QoL compared with non-edentulous patients. A lack of denture use was also associated with worse QoL. The same study reported an association

Table 2. **Summary of reviewed studies**

References (country)	Study type	Study population	Data collection method	Time frame of QoL assessment	Support need/ needs identified	Relative impact on QoL*	Prevalence among patients[†]	EPHPP global rating
Abendstein *et al.* (8) (Norway)	P *n* = 167	HNC	EORTC QLQ-C30; EORTC QLQ-H&N35	Diagnosis, 1 year and 5 years after treatment	Sticky saliva	High	n/a	Moderate
					Sexuality	Moderate		
Al Nawas (60) (Germany)	C-C *n* = 42	OC	EORTC QLQ-C30; EORTC H&N35 and objective measures of salivary flow	After treatment. Mean time from irradiation 46 months	Xerostomia	High	Low	Weak
Bekiroglu *et al.* (39) (UK)	CS *n* = 641	OC	UW-QoL	1–2 years after treatment	Adjuvant RT group			
					Xerostomia	High	High	Strong
					Swallowing	High	High	
					Chewing	High	High	
					Speech	High	High	
Bjordal (13) (Norway)	L *n* = 213	HNC	EORTC QLQ-C30 and EORTC H&N35; GHQ-20; measures of general satisfaction with life and strength and fitness	7–11 years after RT	Xerostomia	High	Low	Weak
Duke *et al.* (31) (USA)	CS *n* = 86	HNC	UW-QOL; PSS-HN; FACT; dental evaluation	5 years post-treatment	Tooth loss	Moderate	Moderate	Weak
					Compromised dentition (DMF >14)	High	High	
					Denture use	Moderate	High	
Epstein *et al.* (25) (Canada)	CS *n* = 65	HNC	EORTC QLQ-C30 plus addendum sheet to assess oral symptoms and function[‡]	6–12 months after completion of treatment	Xerostomia	High	High	Weak
					Dysphagia	High	High	
					Taste	High	High	
					Tooth decay	High	Moderate	
Epstein *et al.* (32) (Canada)	P *n* = 20	HNC	EORTC QLQ-C30 Oral symptoms and function scale	Pretreatment, 1 month and 6 months post-treatment	Chronic pain	High	High	Weak
					Xerostomia	High	High	
					Taste	High	High	
					Speech difficulties	High	High	
					Eating difficulties	High	High	
Fang *et al.* (33) (Taiwan)	L *n* = 77	HNC	EORTC QLQ-C30 & H&N 35	Pre-RT and 2 years post-RT	Teeth	High	Moderate	Strong
					Xerostomia	High	Moderate	
					Sticky saliva	High	Moderate	
					Social eating	High	Moderate	
Fingeret *et al.* (26) (USA)	CS *n* = 280	HNC	BIS; FACT-HN; survey designed for study[‡]	Pretreatment and post-treatment	Body image concerns	High	High	Moderate
					Dissatisfaction with information received	High	Low	

(Continued)

Table 2. **(Continued)**

References (country)	Study type	Study population	Data collection method	Time frame of QoL assessment	Support need/ needs identified	Relative impact on QoL*	Prevalence among patients[†]	EPHPP global rating
Fingeret *et al.* (57) (USA)	CS *n* = 280	HNC	BIS; FACT-G; survey designed for study[‡]	>1 month–5 years post-diagnosis	Speech/eating concerns Body image concerns	High High	Low High	Moderate
Handschel *et al.* (29) (Germany)	CS *n* = 1652	OC	Impairment scale[‡]; depression and anxiety scales	>6 months after treatment	Psychological support	High	Low	Weak
Hassanein *et al.* (43) (UK)	CS *n* = 68	OC	HADS; UW-QoLv1; EORTC QLQ- C30; MAC-Q;	Mean 23 months after treatment	Anxiety Depression	High High	Low Low	Weak
Hassanein *et al.* (34) (UK)	CS *n* = 68	OC	UW-QoL; HADS; MAC-Q; SSQ-6	6 months to 6 years after treatment	Depression/anxiety Coping	High Moderate	n/a n/a	Weak
Jenewein *et al.* (47) (Switzerland)	CS *n* = 31	OC	WHOQOL-BREF; EORTC QLQ-C30 &H&N35; DAS	Post-treatment Mean 3.7 years since diagnosis	Marital satisfaction Anxiety	Low Low	High Low	Weak
List *et al.* (35) (USA)	P *n* = 46	HNC	KPS; PSS; McMaster University Head and Neck Radiotherapy Questionnaire; FACT-H&N	3 months intervals during treatment; 6 months after treatment	Xerostomia Difficulty tasting	High High	Moderate Low	Strong
List *et al.* (48) (USA)	CS *n* = 79	HNC	WOC-CA; FACT; PSS-HN; KPS; CAGE	Pretreatment	Emotion-focused coping	High	Low	Weak
Low *et al.* (27) (UK)	CS *n* = 350	HNC	EORTC QLQ-H&N35 sexuality scale; UW-QoL and self-designed intimacy questions[‡]	Post-treatment	Sexuality and intimacy dysfunction	Moderate	Low	Moderate
Millsopp *et al.* (46) (UK)	R *n* = 278	HNC	UW-QoL	Pretreatment or 6 or 12 months after treatment	Appearance	n/a	Low	Weak
Pandey *et al.* (44) (India)	CS *n* = 123	HNC	DIC2; FACT-HN	During treatment	Psychological distress	High	n/a	Weak
Potash *et al.* (49) (USA)	CS *n* = 283	HNC	HNCI; BDI; MAST	1 year post-treatment	Alcohol use Alcohol abuse	Moderate Low	Low Low	Moderate

(Continued)

Table 2. **(Continued)**

References (country)	Study type	Study population	Data collection method	Time frame of QoL assessment	Support need/ needs identified	Relative impact on QoL*	Prevalence among patients[†]	EPHPP global rating
Rogers *et al.* (37) (UK)	CS *n* = 123	HNC	UW-QOL v4; list of PCI issues	<6 weeks after completion of treatment	Depression	High	Moderate	Weak
					Anxiety	High	Moderate	
					Fear of recurrence	High	Low	
					Dental health/teeth	High	Low	
					Mouth opening	High	Low	
					Swallowing	High	Low	
Rogers (7) (UK)	C-C *n* = 68	HNC	UW-QoLv4; PCI; FOR questionnaire	Post-treatment	Fear of recurrence	High	Moderate	Strong
Rogers *et al.* (23) (UK)	CS *n* = 243	HNC	UW-QoL v4 and self-designed PEG questionnaire[‡]	Post-treatment	Chewing dysfunction	High	High	Weak
					Dysphagia	High	Moderate	
					Long-term PEG use	High	Low	
Rogers *et al.* (41) (USA)	CS *n* = 65	HNC	BMI; CES-D; FACT-H&N	>6 months post-treatment	Weight loss	High	Low	Weak
					Depression	High	Low	
					Nutritional support (gastrostomy)	High	Low	
Rogers *et al.* (51) (UK)	CS *n* = 447	HNC	SDI; EORTC QLQ-C30; UWQOL; self-designed questions about financial burden[‡]	Post-treatment	Financial burden	High	Low	Weak
Van Cann *et al.* (38) (Netherlands)	CS *n* = 105	HNC	EORTC QLQ-C30 and EORTC QLQ-H&N35	2–7 years after treatment	Post-op RT			
					Swallowing	High	n/a	Weak
					Social eating	High	n/a	
					Xerostomia	High	n/a	
					Trismus	High	n/a	
					Nutritional supplements	High	n/a	
van den Berg *et al.* (40) (Netherlands)	P *n* = 47	HNC	EORTC QLQC-30 and EORTCH&N35	Pretreatment, end of treatment and 6 months after treatment	Weight loss	High	Low	Strong
					Malnutrition	High	High following RT	
Van Wilgen *et al.* (42) (Netherlands)	CS *n* = 154	HNC	CES-D; RAND-36	>1 year post-treatment	Shoulder and neck pain/morbidity	High	n/a	Moderate
					Depression	High	Low	
Vartanian *et al.* (50) (Brazil)	CS *n* = 301	HNC	UW-QoL	>2 years after treatment	Decreased income	Moderate	Low	Weak

(Continued)

Table 2. **(Continued)**

References (country)	Study type	Study population	Data collection method	Time frame of QoL assessment	Support need/ needs identified	Relative impact on QoL*	Prevalence among patients†	EPHPP global rating
Verdock-de Leeuw *et al.* (52) (Netherlands)	CS *n* = 85	HNC	EORTC QLQ-C30 & H&N35; HADS; Study-specific questionnaire re-employment	2 years post-treatment	Difficulty returning to work Social eating Social contact Trismus Sticky saliva	Moderate High High High High	Low n/a n/a n/a n/a	Moderate
Verdock-de Leeuw *et al.* (45) (Netherlands)	P *n* = 55	HNC	EORTC QLQ-C30 & H&N35; HADS	Pretreatment and follow-up (median time since diagnosis = 4.2 months)	Emotional distress	High	Low	Moderate

BDI, Beck Depression Inventory; BIS, Body Image Scale; CAGE, Alcohol Screening Tool; C-C, Case–control; CES-D, Centre for Epidemiologic Studies Depression Scale; CRT, Chemoradiation Therapy; CS, Cross-sectional; DAS, Dyadic Adjustment Scale; DIC-2, Distress Inventory for Cancer, version 2; EORTC QLQ-C30 and EORTC QLQ-H&N35, European Organisation for Research and Treatment of Cancer Quality of Life – Core 30 and Head & Neck 35; EPHPP, Effective Public Health Practice Project; FACT, Functional Assessment of Cancer Therapy; FACT-H&N, Head and Neck; FOR, Fear of Recurrence; GHQ-20, General Health Questionnaire; HADS, Hospital Anxiety and Depression Scale; HNC, Mixed Head and Neck cancer sample; KPS, Karnofsky Performance Status; L, Longitudinal; MAC-Q, Mental Adjustment to Cancer Questionnaire; MAST, Michigan Alcohol Screening Test; MSPSS, Multidimensional Scale of Perceived Social Support; n/a, Prevalence figures not available. OC, Oral Cancer; OSCC, Oral Squamous Cell Carcinoma; P, Prospective; PCI, Patient Concerns Inventory; PEG, Percutaneous Endoscopic Gastrostomy; PSS, Head and Neck Performance Status Scale; R, Retrospective; RAND-36, Dutch Version of Short Form-36; R-C, Retrospective Correlational; SDI, Social Difficulties Inventory; SSQ-6, Short Form Social Support Questionnaire; UW-QoL v4, University of Washington Quality of Life Scale version 4; WHOQoL-BREF, World Health Organisation Quality of Life abbreviated version; WOC-CA, Ways of Coping – Cancer Version.

*Low = no clinically relevant change in QoL. Moderate/high = clinically relevant change, subjective classification based on authors conclusions.

†Percentage of participants who reported support need. Low = <45%; Moderate = 65%–40%; High = >65%.

‡Non-validated outcome measure.

Table 3. **Description of support need classification**

Relative impact on quality of life (QoL)	
High	Strongly significant clinically relevant change reported by authors*
Moderate	Clinically relevant change reported by authors*
Low	No clinically relevant change reported by authors
Prevalence	
High	Support need perceived by more than 65% of population
Moderate	Support need perceived by 45%–65% of population
Low	Support need perceived by less than 45% of population

*Classification based on authors' conclusions about significance of impact on QoL.

between a compromised dentition (measured as number of decayed/missing or filled teeth) and worse QoL and weight loss 5 years after treatment. Rogers (37) found that dental health/teeth, chewing and eating and pain in the head and neck were among the most frequent concerns identified by patients with head and neck cancer (inclusive of patients with oral cancer, *n* = 89/123) for discussion during a follow-up appointment at an outpatient clinic.

Dysphagia

Dysphagia following radiotherapy was a significant issue identified in the included studies (32, 38, 39). All participants of a small cohort study (*n* = 20) experienced dysphagia at the end of treatment; however, the small sample size limited the generalizability of results (32). The impact of dysphagia over time was reported to be most severe immediately following treatment, with gradual improvement up to 12 months after treatment (35). Rogers (37) reported 'swallowing' ranked among the most frequently selected concerns (ranked sixth of a total 45 concerns) that patients wished to discuss with a consultant at an outpatient clinic.

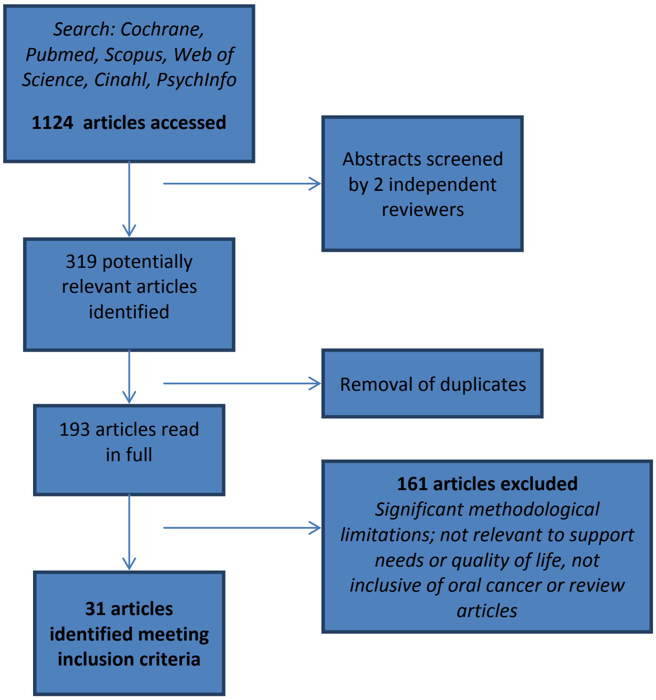

Fig. 1. Literature search methodology summary.

Nutrition and weight loss

Van den Berg (40) identified that 32% (*n* = 15/47) of participants were malnourished (defined as ≥10% weight loss) following treatment with surgery, radiotherapy or chemotherapy. Malnutrition was recorded in 13 of 15 patients who had radiotherapy included in their treatment regimen (40). A small number of patients who received nutritional support from a dietitian (6.3% or *n* = 3/47) did not report malnutrition during treatment (40). Rogers and colleagues (41) reported that lower body mass index (BMI) was significantly associated with depression and poor physical well-being in a cohort of 65 patients at least 6 months post–treatment; however, a majority of the sample (*n* = 50/65) had advanced-stage disease (stage III or IV).

Long-term nutritional support via percutaneous endoscopic gastrostomy (PEG) feeding was associated with limited chewing, swallowing, taste and worse overall QoL in 8% (*n* = 20/243) of respondents to a mail-based survey (28). Respondents also described difficulties with the PEG and interfering with family life, intimate relationships, social activities and hobbies (28).

Neck and shoulder morbidity

One study described the impact of shoulder morbidity on QoL following surgical treatment with neck dissection (42). Shoulder morbidity was associated with poorer physical and social functioning 1 year post-treatment and was also associated with depression (42).

Psychosocial support needs

The psychosocial support needs extracted from the studies referred to wider social or emotional issues that affected quality of life and had the potential to be improved by appropriate professional support, for example counselling.

Depression, anxiety and emotional distress

The prevalence of depression reported by the studies that used the Hospital Anxiety and Depression Scale (HADS) varied between 18% and 25% following treatment (43–45). There was great variability among the studies in the prevalence and outcome measures used to report anxiety and depression. However, depression was identified as a significant issue in several studies and was associated with lower physical well-being (41), functional impairment and issues regarding pain, disfigurement and worse overall QoL (43).

A majority of studies used cross-sectional methodology to describe depression and anxiety, which limited the conclusions able to be drawn about the impact of anxiety and depression over time. Verdonck-de Leeuw *et al.* (45) reported that 18% (*n* = 10/55) of participants had high levels of distress at the time of diagnoses compared with 25% (*n* = 14/55) at follow-up (median 4.2 months since diagnosis); however, only 21% (*n* = 3/14) of patients with distress were referred for psychosocial care at follow-up. The authors suggested that a belief among health practitioners that emotional distress was an expected consequence of cancer diagnosis and treatment may have influenced referral patterns (45). Handschel *et al.* (29) reported worse QoL in patients who wished to have a psychological interview but did not receive one (17% or *n* = 280/1652). The results of this study were limited by the use of a non-validated 'impairment scale' to assess QoL.

Appearance and body image

Appearance dissatisfaction and body image concern were more frequent in participants who also reported speech and eating concerns in a mixed head and neck sample (26). This group also reported a greater level of interest in psychosocial intervention to address appearance-related difficulties than those without speech and eating concerns. Thirty-four per cent of the entire sample (*n* = 96/280) indicated a need for psychosocial intervention at the time of the survey or previously (26).

A retrospective chart review found that 41% (*n* = 114/278) of participants reported appearance-related concerns on the University of Washington Quality of Life Scale (UW-QoL); however, only seven participants had these appearance concerns noted in their charts. The influence of appearance-related concerns on QoL was not discussed in the study (46).

Sexuality, intimacy and relationships

Low *et al.* (27) found that one-third (*n* = 116/350) of respondents to a postal survey reported substantial issues with sexuality and intimacy after cancer treatment. However, a further third of respondents (*n* = 116/350) refused to answer the intimacy or sexuality questions. Abendstein (8) reported that patients aged more than 65 had more problems with sexuality 5 years post-treatment than younger patients.

The stability of marital relationships after cancer treatment and its effect on QoL was examined by one study (47). In this sample, overall QoL was associated with high levels of marital satisfaction. However, the study sample was not representative of the wider oral cancer population as only patients and their spouses in a stable relationship were included (47).

Coping

A wide range of coping strategies were used by patients; behavioural escape–avoidance and cognitive escape–avoidance comprised 20% and 14% of the total coping strategies, respectively (48). Hassenein (34) described an association between poor coping style and functional impairment after treatment, although the study lacked statistical significance. List (48) reported the preference for the emotion-focused coping strategies of behavioural escape–avoidance and cognitive escape–avoidance was associated with worse QoL before treatment.

Alcohol use

Alcohol abuse 12 months after head and neck cancer treatment was associated with depressive symptoms in a cross-sectional study (49). Twenty-two per cent of participants (*n* = 63/283) were classified as problem drinkers and reported worse overall QoL and more depressive symptoms than others reporting alcohol use 1 year after diagnosis (49).

Practical support needs

Financial support

Cancer treatment resulted in a restricted ability to work and significant decrease in household income for 41.9% (*n* = 126/301) of Brazilian patients (50). One-third (*n* = 138/447) of patients responding to a postal questionnaire reported cancer had affected their working status. Poorer social and emotional functioning was associated with increased financial burden and greater loss in income due to their condition in the previous week (51).

Verdonck-de Leew *et al.* (52) reported a high rate of return to work within 6 months of treatment among their study population (71% or *n* = 60/85). However, for those participants who did not return to work (*n* = 9/85) or changed jobs (*n* = 16/85), employment difficulties were associated with significantly worse QoL relating to loss of appetite, social contacts, social eating, a high level of anxiety and oral dysfunction.

Discussion

Oral cancer diagnosis and treatment is associated with considerable functional and psychosocial deficits for those with the disease. Multiple QoL domains are affected, as patients must cope with the physical and psychological changes as a result of their illness and its wider social implications. Treatment often results in permanent changes to communication, appearance, eating and oral function that have marked effects on individual's self-confidence and relationships with loved ones (53, 54).

Access to individualized support from a multidisciplinary professional team that reflects the perceived support needs of patients with oral cancer may enhance QoL outcomes in this group. The members of the multidisciplinary team should reflect the broad support needs expressed by the patients with oral cancer. The range of support needs described in this review indicate that in addition to specialists and oncology nurses, speech pathologists, dentists and oral health therapists, psychologists, physiotherapists, dietitians and social workers may play an important role in the supportive care of patients with oral cancer (55).

Several of the included studies described findings from small sample sizes and a lack of statistical power limited the conclusions able to be drawn from some studies (25, 31). The heterogeneity of outcome measures and study populations limited the comparability of findings, a limitation reported by other reviews reporting on QoL in patients with oral cancer (56).

The results of prospective and longitudinal studies were impacted by loss of follow-up from participants due to death or withdrawal due to the physical or psychological burden of cancer treatment (13, 31). Participants with an advanced stage of disease (stage III or IV) were more commonly lost to follow up and also received more extensive treatment (8, 13). This suggests that patients with poor prognosis or advanced tumour staging may have higher support needs and that the QoL issues reported in the literature may be under-represented.

Among the included studies, support needs varied throughout the cancer journey and according to treatment modality. Oral and functional deficits were significantly associated with radiotherapy and chemoradiotherapy, whereas surgical treatment was associated with appearance-related concerns (25, 57). The highest prevalence of symptoms from the side effects of radiotherapy and chemotherapy were reported at the completion of treatment (32, 35). The post-treatment period has been described by patients with oral cancer as the most difficult in coping with xerostomia, dysgeusia, poor dentition and a mouth that does not function normally (53). The need for emotional and physical support may be greatest at this time point (53).

Despite improvements in treatment toxicity and overall QoL in the first 12 months following oral cancer treatment, continued concerns with chronic xerostomia, sticky saliva and taste issues were reported in a number of studies evaluating long-term QoL (8, 13, 39). Long-term oral functional impairment and dental morbidity, especially among patients who have received radiotherapy, indicate a need for long-term supportive care in managing permanent changes to oral health and function (31).

Dysphagia was a commonly described issue in the post-treatment period for patients with oral cancer and is regarded as the most common nutrition-related problem arising from treatment of head and neck cancer (21). A common sequela of dysphagia is nutritional compromise that has an impact on overall well-being and QoL. Adverse effects of treatment that cause disruption to physiological functions of taste, smell, swallowing and salivary function may contribute to long-term nutritional deficits and changes in social interaction and willingness to socialize (12, 21, 54). Malnutrition and changes in social functioning have significant psychological implications and have been linked to depression and emotional distress (21).

Depression and anxiety were reported to have a significant influence on QoL in the included studies (34, 43). The relationship between depression, QoL and functional deficits remains poorly defined in the included studies (56). In the included studies, cross-sectional methodology limited the conclusions able to be drawn about the relationships between poor function and depressive symptoms (34, 43, 44). Depression has significant implications for the patient with oral cancer as depressed patients are less likely to complete the prescribed treatment plan, more likely to have longer hospital stays and less ability for self-care after treatment, influencing mortality and morbidity (20).

Evidence for the classification of alcohol misuse and sexuality and intimacy concerns as high impact support needs were less well supported than other physical and psychological support needs described in this review. While there is evidence that continued tobacco use post-treatment, in addition to being a risk factor for developing a second primary malignancy, is associated with depression and poor QoL (58), the influence of continued alcohol consumption on QoL is less clear (56). Nevertheless, smoking and alcohol cessation are important support needs among this group of patients. Problems with sexuality and intimacy were largely unreported in the included studies, despite the inclusion of a sexuality question on the European Organisation for the Treatment of Cancer Quality of Life Questionnaire (EORTC QLQ-30) (59). It is suggested that a lack of experience of clinicians is a barrier to approaching this sensitive topic with patients (27). Sexuality and intimacy should be considered as an issue affecting QoL in future research in the light of the relationship of intimacy issues with depression, mood and body image (20).

Limitations of review

There are a number of limitations that are important to consider in the light of the findings of this review. First, the findings include results from studies with heterogeneous head and neck cancer samples, which may affect the validity of the support needs identified as it assumes that the broader head and neck cancer population and the oral cancer population share the same support needs and QoL issues. Head and neck cancer is a broad term referring to cancers of the oral cavity, oropharynx, hypopharynx and larynx. Ambiguity exists in the literature relating to the definition of head and neck cancer and oral cancer, with the term ‘head and neck cancer’ often being used to refer to cancers of the oral cavity and oropharynx. While a sincere attempt was made to describe the support needs and QoL outcomes related to only patients with oral cancer, some studies did not provide enough description of the findings to allow this. Therefore, the results included support needs identified from heterogeneous head and neck cancer populations that met the inclusion criteria and included patients with oral cancer in the study sample. An effort was made to control this by only including studies with head and neck cancer populations that included patients with oral cancer.

Additionally, the results comprised a large number of studies that described changes to QoL and function associated with radiotherapy and chemotherapy. Surgery is also associated with adverse effects, and its importance in terms of support needs may be under-represented in the results.

The support needs described in this review are largely derived from the findings of QoL questionnaires and as such are not a conclusive list of the support needs of patients with oral cancer, rather a suggestion of areas that may be relevant to patients. This method of analysis also may underreport the true clinical impact of anxiety and depression as these issues typically have a low prevalence, but marked impact on QoL. There may be other relevant support needs beyond the scope of this review, for example the role of familial and professional support networks in coping with oral cancer diagnosis and treatment (53, 54). Future research is required to investigate the short- and long-term support needs of patients with oral cancer. Exploring ways in which the multidisciplinary team can better meet support needs in the local setting should also be the focus of future research, especially related to oral health-related support needs.

Conclusion

The support needs expressed by patients with oral cancer are varied and highly subjective, reflecting the complex nature of the disease and its treatment. This review has provided evidence for areas of support need relating to oral health and functional impairment, swallowing issues, nutritional issues and psychological issues that affect overall QoL. Future research is required to explore the types of support needs most relevant to patients with oral cancer across the cancer continuum.

Clinical relevance

This review provides an overview of the physical and wider psychosocial issues that are experienced by patients with oral cancer across the cancer trajectory. Oral health practitioners play an important role in the long-term maintenance and care of people who have been treated for oral cancer. The findings of this review are of interest to all oral health practitioners and may contribute to greater understanding of the influence of oral health-related and general health-related support needs on quality of life.

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