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A systematic review of social impacts of treatment and rehabilitation of head and neck cancer patients

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ABSTRACT

The objective was to examine the social impacts of treatment and rehabilitation on patients with head and neck cancer (HNC). Following a comprehensive search of OVID (Embase, Medline, Pubmed, PsycINFO) and Web of Science, the Mixed Methods Appraisal Tool (MMAT) was used to assess the methodological quality of all included studies. The findings were reported using Preferred Reporting Items of Systematic review and Meta-Analyses (PRISMA) checklist. From 14,661 papers identified, 46 were eligible for inclusion of which 25 were quantitative, 14 qualitative and 7 mixed methods. Most papers focussed on the theme of eating and swallowing impacts (n = 16), with the next most frequent group using general quality-of-life measures (n = 11). Methodological inadequacy concerned small sample sizes and relatively short follow-up times. Qualitative studies revealed a wide range of social impacts which affect patients relating to the cancer, therapeutic education, and the negative impact of treatment side effects over time. The literature suggests that HNC patients experience a range of social impacts linked to identity, relationships, activities undertaken, and cultural issues. This review concludes that more in-depth larger scale prospective research as well as qualitative research is urgently needed to ascertain how to optimize care for HNC patients.

1. Introduction

Head and neck cancer (HNC) makes up more than 4.9 % of all malignant neoplasms globally and is associated with increasing mortality worldwide over the last decade [2]. These cancers and their treatment effects impose a great physical, psychological and social burden on patients and their carers; however, relatively little is known about the social impacts of the disease or treatment compared to the physical or biomedical ones [3–5].

In the context of this review the term 'social impacts' refers to the ways in which HNC and treatment for HNC affect people's day to day lives and can include anything from the way people see themselves, to relationships, to the ability to complete activities of daily living such as eating or washing. The focus of this review is on understanding the effect of HNC and its treatment on the wide-ranging everyday activities of those who experience it. HNC comprises around 30 different sites in the head and neck and a multifaceted range of types and aetiologies of cancer [6]. These heterogeneous cancers have been linked to a range of largely modifiable behavioural risk factors (including tobacco, smokeless tobacco, betel quid, alcohol, human papillomavirus, occupations, hormonal factors in women, diet), however there is also the suggestion of socioeconomic deprivation as a known risk factor which is likely to be linked to the other main behavioural risk factors [7].

Due to the anatomy and physiology of the head and neck, these cancers can be hypothesised to have a greater core impact on a person's function and aesthetics, and therefore quality of life (QoL), than would be the case for many other types and sites of cancer. Disfigurement of the face can be particularly distressing for a person and their close family and friends as the face is strongly linked to a person's sense of self, relationships, and ability to communicate [4]. The ability to eat is also central as adequate nutrition is clearly vital for survival and eating may also be pleasurable and social [8]. Due to the intensive treatments required for many types of HNC the social implications of an HNC diagnosis may continue for some time after treatment is completed, and depending on their specific circumstances, potentially for the remainder of their lives.

Systematic reviews have been undertaken to look at specific questions in relation to HNC such as quality of life (QoL) assessment [9], the relationship with the Human Papillomavirus (HPV) [10], and psychological experiences and nutrition [11,12]. However, this systematic

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review on social impacts examining the recent literature from 2010 to 2020 has a broader scope than prior searches. It aims to examine the social impacts of treatment and rehabilitation including those as mentioned above alongside further variables of interest including eating, sleep, experience of carers, employment, and the effect on interpersonal or intimate relationships. This review is, therefore, important in understanding more about the wider social impacts of diagnosis and treatment on the lives of people with HNC worldwide and how these impacts could be mitigated in the future as well as for identifying further research areas.

2. Materials and methods

2.1. Protocol and registration

The protocol for the study is registered under the International Prospective Register of Systematic Reviews (ID ref: CRD42021269780).

2.2. Search strategy and search terms

The search strategy was informed by library support at King's College London. A systematic literature search was conducted in OVID (Embase, Medline, Pubmed and PsycINFO) and Web of Science to identify studies published between 2010 and 2020. The Preferred Reporting Items of Systematic review and Meta-Analyses (PRISMA) guidelines were followed [1]. The search strategy included keywords and MeSH headings. For the final searches, search terms within each group were combined with 'OR' and the different groups were combined using 'AND' (Table 1). E.g. Additional limits including English language and human subjects. Furthermore, this strategy was implemented across all databases discussed to ensure all relevant studies were captured. Manual forwards-backwards searching of key review paper bibliographies ensured full coverage.

2.3. Eligibility criteria

2.3.1. Inclusion criteria

1. Qualitative, quantitative and mixed design studies; including, but not limited to, descriptive, correlational, causal comparative/quasi-experimental studies as well as case studies, ethnographic studies and narrative synthesis
2. Published between 2010 and 2020 to capture most recent evidence
3. Examining experiences and/or beliefs/views of people with head and neck cancer or their carers
4. Considering the social impacts of head and neck cancer and/or head and neck cancer treatment
5. Involving people who have, or have had, head and neck cancer

Table 1
Search terms and strategy outlined using PICO framework.

		OR
AND	Population (People who have currently, or previously been diagnosed with HNC)	Head and neck cancer, head and neck neoplasm, head and neck maligna*, oral cancer, oral neoplasm, people, patient, person, survivor, individual*
	INTERESTS (treatment, rehabilitation)	Treatment, therapy, therapeutics, rehabilitation, rehabilitat*, reconstruction, reconstruct*
	OUTCOME (social impact)	Experience*, expectation*, understand*, outcome, satisfaction, comprehension, perception, knowledge, access*
	Limits: 2010–2020, English	

2.3.2. Exclusion criteria

1. Secondary research including systematic reviews, narrative reviews, or meta-analysis studies
2. Not available in full text
3. Not available in English
4. Grey literature

2.4. Screening and study selection

Screening was conducted in three stages: removal of duplicates, screening of title and abstracts and then full-text screening. The process was piloted among reviewers to maintain consistency against the set eligibility criteria. Titles and abstracts of all studies captured by the literature after removal of duplicates were scanned by the author. Full texts obtained for the studies that met the inclusion criteria were then screened in duplication (by SS and RB) with disagreements resolved by consensus within the research team.

2.5. Data extraction

Data extraction was carried out independently by the author using a customised data extraction table developed a priori and pilot tested, clarified, and refined in consultation with the wider research team prior to data extraction.

2.6. Methodological quality assessment

Assessment of study quality was conducted independently by the author. The studies found in the search were a mix of quantitative and qualitative designs and study quality was assessed via the MMAT (Mixed Methods Appraisal tool) [13]. This tool has been tested to be capable of assessing reliability, quality and risk of bias across qualitative, quantitative and mixed method studies with moderate to perfect agreement found between reviewers [14]. Each study category within the MMAT tool contains five criteria for evaluation. A percentage is given for each study according to how many of these criteria are achieved.

2.7. Ethical considerations

This is a review paper; the ethical consideration was to ensure that the research was reviewed rigorously. The MMAT was used to ensure that the review was consistent.

3. Results

3.1. Search outcome

The electronic search resulted in 14,661 results. Duplicates were removed to retain 11,321 articles for title and abstract screening. An additional 13 papers were identified from forwards-backwards screening of key review papers. A total of 103 articles were shortlisted for full-text evaluation, of which 46 met the defined inclusion and exclusion criteria and were retained for evaluation. A PRISMA flow chart details the process of identification, database source, inclusion and exclusion of the publications (Fig. 1. PRISMA Flow Chart).

3.2. Study characteristics

Forty-six papers were included in the data extraction and synthesis shown in Table 3 [15–60]. Table 2a presents participant gender and mean age within studies of comparable data. Table 2b shows the worldwide distribution of research with Europe producing 22 of the papers and Asia the next largest provider. Table 2c shows the distribution of follow up duration studied (where data was clearly available). Table 2d shows the number of studies in each category of study design

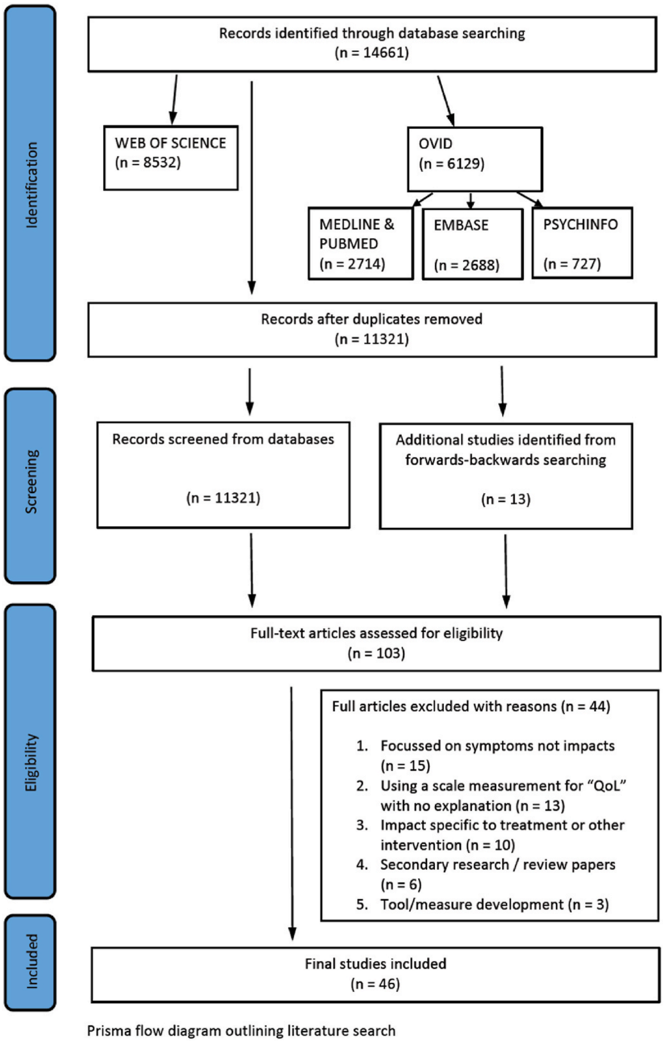

Fig. 1. Prisma flow diagram outlining literature search

Table 2a
Participant sociodemographic characteristics.

Sociodemographic Characteristics	
Mean age of participants in years (Number of papers where available n = 18)	Percentage of male participants (Number of papers where available n = 27)
58.3	69.3 %

Table 2b
The geographical location where studied completed.

Geographical location of study	Number of studies
Europe	22
USA/Canada	7
Asia	10
Australia	5
Other	2

with quantitative methodology employed in 25 of the papers, qualitative methodology in 14 of the papers and mixed methods in 7. Prospective methods accounted for 6 of the total. Table 2e shows the distribution of key outcome variables of interest as categorised by the author into broad themes of function or activity.

Table 2c
Maximum length of follow-up post definitive treatment (where specified).

Time in months	Number of papers
≤ 3	6
≤ 6	9
≤ 12	7
>12	2
≥ 24	6
≥ 36	1
≥ 48	11

Table 2d
Methodology employed.

Method Type	Number
Quantitative only	25
Qualitative only	14
Mixed method	7

Table 2e
Variable of interest (grouped into broad domains of social impact).

Main specified study variable	Number of studies
Eating, swallowing, nutrition	16
Loneliness, caring relationships, socialising	6
Intimacy or sexuality	3
Distress: anxiety, depression	3
Oral care or dental status	2
Financial or work	2
Speech	1
Body image	1
Socioeconomic Status	1
Other or general QOL measures:	11

3.3. Participants

The participants ages ranged from 19 to 99 with 60 % of papers giving a mean age of ≥ 50, whilst only one paper specifically looked at younger age groups below the age of 40 years [60]. Whilst age was usually recorded it was displayed using a variety of different measures such as ranges, means or medians. The gender distribution was predominately male (69 %). Patients were the participants in 40 of the papers, whilst 6 papers involved carers and relatives, with 1 including healthcare professionals. Only 11 papers included more than 100 participants in their final samples. Some studies used phone or postal communications with patients and one developed innovative technology using interactive screen methods [48].

Exclusion criteria frequently implemented included young age (usually under 18 or under 21), cognitive or language barriers, addiction or psychiatric morbidity and other major co-morbidities, relapse of cancer or very poor HNC prognosis.

3.4. HNC characteristics and treatments

Most studies included a wide range of tumour sites or stages of severity although most excluded participants receiving only palliative care thus disregarding many who may only live for some weeks or months post diagnosis. However, two studies did focus on the tongue as the primary site of cancer [55,60] and some specified the type as squamous cell carcinoma [22,26,37,46,53,59]. Types and combinations of treatments for patients varied widely in time course and type (including surgery, radiotherapy, intensity-modulated radiation therapy (IMRT) and/or chemotherapy although any adjunctive therapies such as physiotherapy were often left unspecified).

Table 3
Extracted data from 46 papers found from the systematic review of social impacts of treatment and rehabilitation of head and neck cancer patients.

Author, Year & Location Published	Participant numbers	Aim & Location of study	Design	Variable of Interest	Main Findings	Conclusion
FINDLAY, M., RANKIN, N. M., BAUER, J., COLLETT, G., SHAW, T. & WHITE, K. 2020. Australia	11	To understand the perspectives of patients and their caregivers about nutritional care and how their unmet supportive care needs can be better addressed in designing a new model of care. The results will contribute to documenting the barriers and enablers to implementing best practice nutrition care for patients with HNC.	Mixed Methods	Nutritional care experience	4 main themes found from analysis: 1. Being ill-prepared for the impact of treatment, even when advised 2. Navigating complex systems to meet significant care needs 3. Depleted by overwhelming and prolonged suffering 4. Information lost in translation The results identify the barriers and enablers to delivering best-practice nutrition care and ultimately support translation of research evidence into patient-centred MOC in clinical practice. People with HNC and caregivers experience high levels of shock with regards to severity of symptoms despite warnings and require complex support and education to prepare them for care required. Staff education with regards to language used to convey accurate and consistent nutritional advice is very important. At first patients did not understand why allied health professionals were required but as their treatment progressed this became clear.	Although this study set out to establish the patient and caregiver experience of nutrition care for patients with HNC, responses revealed a greater learning in that it may not be possible to extricate this aspect of care from a person's overall experience. It is important to consider that nutrition care may in fact be inextricably linked to the overall package of care and therefore cannot be readily separated and analysed as a separate phenomenon, highlighting the unique and complex care needs of people with HNC and those caring for them. Coordinating early and ongoing access to specialist supportive care staff before and during acute care through to recovery is best delivered via an integrated service model that supports patients' physical, psychological, social, and emotional wellbeing.
DAHILL, A., AL-NAKISHBANDI, H., CUNNINGHAM, K. B., HUMPHRIS, G. M., LOWE, D. & ROGERS, S. N. 2020. United Kingdom	140	To assess the issue of loneliness and associations of loneliness	Quantitative	Loneliness	6 % had 'serious' issues feeling lonely. Patients who were younger, in more deprived circumstances, with advanced disease and had been treated with chemotherapy or radiotherapy reported greater levels of loneliness. Loneliness was associated with a worse overall quality of life, and worse physical and social-emotional function.	Lonely patients need to be identified as early as possible so that support and interventions can be implemented, and outcomes improved.
MCDOWELL, L., SO, N., KESHAVARZI, S., XU, W., ROCK, K., CHAN, B., WALDRON, J., BERNSTEIN, L. J., HUI HUANG, S., GIULIANI, M., HOPE, A., O'SULLIVAN, B., BRATMAN, S. V., CHO, J., KIM, J., JANG, R., BAYLEY, A. & RINGASH, J. 2020. Canada	85	To report the long-term rate of sexual satisfaction in NPC survivors using several tools together with neurobehavioural assessment tools. To open the dialogue on this unmet need. To stimulate future research.	Quantitative	Sexual satisfaction	Sexual satisfaction was associated with multiple patient-reported measures on univariate analysis, including quality of life, fatigue, a priori selected HNC symptoms (pain, taste), emotional distress, frontal lobe function, body image and relationship strength. On multivariate analysis, only relationship strength and emotional distress remained significant. Sociodemographic factors (age, sex, marital status) and other selected orofacial toxicities were not	47 % reported being in the higher satisfaction range which was compatible with normal population data. Several factors including toxicity, psychological and social factors were associated with sexual satisfaction responses. Prospective evaluation of unmet need is required, exploring factors in addition to pain and taste.

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Table 3 (*continued*)

Author, Year & Location Published	Participant numbers	Aim & Location of study	Design	Variable of Interest	Main Findings	Conclusion
					significant variables within the analysis.	
ABED, H., BURKE, M., FENLON, M. R., SCAMBLER, S. & SCOTT, S. E. 2020. United Kingdom	80	To assess the use, satisfaction, and impact of denture use following radiotherapy for HNC. To determine patients' satisfaction with information about replacing their missing teeth postradiotherapy. To assess interest in replacing missing teeth for those who had not done so.	Quantitative	Missing teeth. Interest in denture support. Satisfaction with information on missing tooth support.	Participants had an average of 12 missing teeth (SD = 8.05). 75 % had not replaced their missing teeth. Of these, 58 % were very or extremely interested in doing so. For HNC survivors who wore dentures, there was variable satisfaction and a number of side-effects of wearing dentures. Satisfaction with information about replacing missing teeth was low. There was no statistical difference in QoL or oral functioning between participants who wore dentures and participants who did not wear dentures. However, those with dentures reported fewer problems with carrying out daily routines as measured by the oral functioning tool.	QoL and oral functioning were similar regardless of denture use, highlighting reduced oral function in both those with and without dentures. In those who had not replaced their missing teeth, there was substantial interest in doing so and thus may be an unmet need. The dental team could offer HNC survivors more support after radiotherapy and following denture provision to improve information about denture use and increase satisfaction with dentures.
YIN, X., SHAN, C., WANG, J. & ZHANG, H. 2020. China	294	To elucidate factors which may affect the QOL of HPV-related OPSCC patients after treatment.	Quantitative	QoL various	Treatment decreased the QOL of HPV-related OPSCC patients. Factors including marital status, consumption of tobacco and alcohol, tumour sites, clinical stages, therapeutic strategies, and neck dissection were associated with level of QOL of HPV-related OPSCC after treatment.	Several factors influence the QOL of HPV-associated OPSCC patients after treatment and can be used to improve QOL after treatment.
BOLT, S., BAYLOR, C., BURNS, M. & EADIE, T. 2020. United States of America	5	This study explores the lived experience of cognitive changes in survivors of non-nasopharyngeal head and neck cancer and how these changes affect communication in their daily lives.	Qualitative	Experiences and attitudes/perceptions, phenomenological focus.	Two major themes emerged: (1) I would have told you about being forgetful, but I forgot; and (2) It's such a journey that much of it is uncharted. Participants described problems with memory, focus/attention, and task initiation along with slowed processing and language difficulties. These difficulties affected communication at work, socially, and at home. Participants expressed feeling unprepared for the possibility of cognitive changes, not knowing why they were happening or what to do about them.	Results of this study have implications for counselling and other treatments of individuals with head and neck cancer, as well as advocating for these patients to receive appropriate information and intervention. A useful preliminary study as very small numbers.
ROICK, J., DANKER, H., DIETZ, A., PAPSDORF, K. & SINGER, S. 2020. Germany	83	Study assessed predictors of temporal changes in quality of life over a 6-month period among patients treated for head and neck cancer.	Quantitative	QoL various	Quality of life decreased during treatment and slowly recovered thereafter. From T1 to T4 there were adverse changes that patients consider to be relevant in physical and role functioning, fatigue, dyspnoea, insomnia, loss of appetite, financial difficulties, problems with senses and teeth, limited mouth opening, mouth dryness, social eating, coughing, and sticky saliva.	Quality of life decreases during treatment, half a year after hospital stay there are still restrictions in some areas. A special focus should be given on head and neck cancer patient's quality of life in the aftercare.

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Table 3 (*continued*)

Author, Year & Location Published	Participant numbers	Aim & Location of study	Design	Variable of Interest	Main Findings	Conclusion
					Temporal changes in global quality of life between T1 and T2 were predicted by tumour stage (B = −5.6, p = 0.04) and well-being (B = 0.8, p = 0.04); radiotherapy was a predictor of temporal changes in physical functioning (B = −12.5, p = 0.03).	
WANG, T. F., LI, Y. J., CHEN, L. C., CHOU, C. & YANG, S. C. 2020. Taiwan	126	To assess the postoperative health-related quality of life (QOL) and care needs of oral cancer patients comprehensively and to evaluate the correlation between health-related QOL and care needs.	Quantitative	QoL, health related care needs	Female patients and patients receiving 3 or more chemotherapy treatments were variables significantly associated with increased Short-Form Cancer Needs Questionnaire scores (higher level of care needs) (β = 0.177 and 28.49, both P < 0.05) and receiving 3 or more chemotherapy treatments was significantly associated with increased Head and Neck Cancer Quality of Life Scale scores (higher level of symptoms and problems) (β = 27.77, P = 0.007). Results of stepwise multiple linear regression analysis indicated that 4 oral cancer–related symptoms and problems, "trouble with social contacts," "swallowing problems," "teeth problems," and "feeling ill," were significantly associated with higher care needs in oral cancer patients (all P ≤ 0.05).	A significant correlation exists between health related QOL and care needs. Implications for Practice: Using a valid health related QOL scale may help nurses determine their perceived physical and psychological care needs.
SANDMAEL, J. A., SAND, K., BYE, A., SOLHEIM, T. S., OLDERVOLL, L. & HELVIK, A. S. 2019. Norway	10	The purpose of this study was to describe how patients with HNC experience the nutritional situation and perceive nutritional support from diagnosis to the post-treatment phase.	Qualitative	Nutritional experiences adverse effects, diet, food, and nutrition, head and neck cancer	Undergoing surgery was experienced as a poor nutritional starting point for the upcoming radiotherapy. During radiotherapy, increasing side effects made the participants customise their meals to improve food intake. About halfway through radiotherapy, virtually no food intake was experienced, and hospital admissions and initiations of tube-feeding occurred in this period. Oral nutritional supplements were recommended for all, but eventually became unbearable to ingest. When radiotherapy was finally completed, the participants felt discouraged about the persistent side effects preventing them from resume eating. The participants missed tailored information about development of side effects and involvement of a dietitian when reflecting on the treatment-period.	The comprehensive nutritional problems experienced by patients with HNC require early nutritional assessments and improved individually tailored nutritional support.
KRISTENSEN, M. B., MIKKELSEN, T. B.,	40	Purpose twofold: (1) To explore head and neck	Qualitative	Nutrition/food intake	Through the qualitative content analysis, four	Eating problems affect the everyday life of HNC

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Table 3 (*continued*)

Author, Year & Location Published	Participant numbers	Aim & Location of study	Design	Variable of Interest	Main Findings	Conclusion
BECK, A. M., ZWISLER, A. D., WESSEL, I. & DIEPERINK, K. B. 2019. Denmark		cancer (HNC) survivors' experiences of everyday life with eating problems after cancer treatment (2) To explore their experiences of participating in a multidisciplinary residential rehabilitation program with a primary focus on physical, psychological, and social aspects of eating problems after treatment.			themes related to HNC survivors' experiences of everyday life with eating problems were derived from the interview transcripts. The headlines of the four themes were "To eat is to practice," "The last third of the pie is missing," "I'll just come by for the coffee," and "On your own." Through the qualitative content analysis, four themes related to HNC survivors' experiences of the multidisciplinary residential rehabilitation program with a primary focus on the physical, psychological, and social aspects of eating problems were derived from the interview transcripts. The headlines of the four themes were "All in the same boat", "Increased courage to eat," "A getaway from everyday life," and "focus on the specific problem but still on the whole person."	survivors in various ways. For many HNC survivors, eating becomes an obligation or a training situation, and the eating problems challenge their relationships with their relatives and may lead to social withdrawal. Unmet needs for support to cope with the eating problems are frequent, and HNC survivors often feel left by themselves after completion of treatment.
CHEN, S. C., HUANG, B. S., HUNG, T. M., LIN, C. Y. & CHANG, Y. L. 2019. Taiwan	174	To compare the levels of social support, physical function, and social-emotional function between oral cavity cancer survivors who did or did not resume work 6 months or longer after treatment completion.	Quantitative	Return to work	We examined 174 survivors of oral cavity cancer, 55.2 % of whom returned to work after treatment. Relative to survivors who returned to work, those who did not return to work reported needing greater tangible social support, having fewer positive social interactions, having poorer physical function, and having poorer social-emotional function. Multivariable analysis indicated that younger age (OR = 0.864, $P < 0.05$), higher family income (OR = 10.835, $P < 0.05$), sufficient tangible social support (OR = 0.943, $P < 0.05$), positive social interaction (OR = 1.025, $P < 0.05$), and better physical function (OR = 1.062, $P < 0.05$) were significantly associated with the return to work.	Survivors of oral cavity cancer who did not return to work had worse physical and social-emotional function and required more tangible social support and positive social interactions. Providing occupational rehabilitation and counselling for oral cavity cancer survivors may help them return to work.
PEZDIREC, M., STROJAN, P. & BOLTEZAR, I. H. 2019. Slovenia	109	To evaluate the prevalence of dysphagia in a group of patients treated for HNC in Slovenia, and to identify factors contributing to the development of dysphagia.	Quantitative	Dysphagia	Problems with swallowing were identified in 41.3 % of the patients. Dysphagia affected their social life (in 75.6 %), especially eating in public (in 80 %). Dysphagia was found the most often in the patients with oral cavity and/or oropharyngeal cancer (in 57.6 %) and in those treated less than 2 years ago ($p = 0.014$). In univariate analysis, a significant relationship was observed between dysphagia prevalence and some of the consequences of anti-cancer treatment (impaired mouth opening,	In order to improve swallowing abilities and, consequently, quality of life of the patients with HNC a systematic rehabilitation of swallowing should be organized. A special emphasis should be given to gastroesophageal reflux treatment before, during and after therapy for HNC.

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Table 3 (*continued*)

Author, Year & Location Published	Participant numbers	Aim & Location of study	Design	Variable of Interest	Main Findings	Conclusion
					sticky saliva, loss of smell, impaired taste, oral and throat pain, persistent cough, and hoarseness), radiotherapy ($p = 0.003$), and symptoms of gastroesophageal reflux ($p = 0.027$). After multiple regression modelling only persistent cough remained.	
VERMA, N., TAN, X., KNOWLES, M., BERNARD, S. & CHERA, B. 2019. United States of America	58	To examine and characterize survivorship issues among patients treated with radiation for head and neck cancer with regard to dental health, shoulder-neck dysfunction, and overall quality of life (QOL).	Quantitative	Dental health, shoulder pain, dysphagia, overall QOL	35 % reported having more problems with their general dental health as compared to before treatment and 38 % reported having pain at night in the neck/shoulder after treatment. With regard to pre-treatment counselling, 79 % of patients reported being counselled about their dental health prior to treatment, while 31 % reported being counselled about possible shoulder-neck dysfunction. Patients younger than 65, patients receiving higher doses of radiation, and patients undergoing definitive surgery + postoperative radiation reported more functional and symptomatic issues.	Patients treated with radiation for head and neck cancer face a number of survivorship issues, including problems with dental health and shoulder-neck dysfunction, and are not necessarily thoroughly counselled about these issues prior to treatment. Patients younger than 65, patients receiving higher doses of radiation, and patients undergoing definitive surgery + postoperative radiation may experience more survivorship issues.
BOSSI, P., DI PEDE, P., GUGLIELMO, M., GRANATA, R., ALFIERI, S., IACOVELLI, N. A., ORLANDI, E., GUZZO, M., BIANCHI, R., FERELLA, L., INFANTE, G., MICELI, R., LICITRA, L. & RIPAMONTI, C. I. 2019. Italy	129	To assess the prevalence of fatigue and its interference with daily life activities and examine the association between fatigue and gender, age, primary tumour site, Human Papillomavirus (HPV) status, previous oncologic therapy, and time since end of treatment.	Quantitative	Fatigue	Oncologic treatment was completed 12–96 months earlier (median = 34 months). Fatigue was reported as absent in 15 % of the patients, mild in 67 %, moderate in 11 %, and severe in 7 %. No association between BFI average score and the analysed variables was identified. Moderate and severe fatigue was reported in 18 % of HNC survivors.	Further research is needed to assess causes of fatigue and improve the management.
CHANG, Y. L., HUANG, B. S., HUNG, T. M., LIN, C. Y. & CHEN, S. C. 2019. Taiwan	168	To identify factors associated with self-reported overall body image, perceived attractiveness, and dissatisfaction with body appearance in those treated for OCC.	Quantitative	Body image, mental health indices	Negative overall body image was associated with greater degree of depression, greater fear of social interactions, poorer social-emotional function, receipt of surgery, female gender, and greater avoidance of social interaction; these factors explained 49.0 % of the variance in this outcome measure. Poor perceived attractiveness was associated with greater depression, greater fear of social interaction, and receipt of surgery; these factors explained 25.4 % of the variance in this outcome measure. Dissatisfaction with body appearance was associated with poor social-emotional function, greater fear of social interaction, receipt of reconstruction, advanced cancer stage, and	Depression and fear of social interaction strongly influenced overall body image, perceived attractiveness, and dissatisfaction with body appearance.

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Table 3 (*continued*)

Author, Year & Location Published	Participant numbers	Aim & Location of study	Design	Variable of Interest	Main Findings	Conclusion
					female gender; these factors explained 52.2 % of the variance in this outcome measure.	
BOZEC, A., SCHULTZ, P., GAL, J., CHAMOREY, E., CHATEAU, Y., DASSONVILLE, O., POISSONNET, G., DEMARD, F., PEYRADE, F., SAADA, E., BENEZERY, K., LEYSALLE, A., SANTINI, L., MESSAOUDI, L. & FAKHRY, N. 2019. France	200	To assess the evolution of quality of life (QoL) in patients with head and neck squamous cell carcinoma (HNSCC) undergoing oncologic surgery and to determine the predictive factors of post-therapeutic QoL.	Quantitative	Post therapeutic QOL-role and social functioning	There was no significant deterioration of global QoL and no significant increase in general symptoms between the pre- and post-therapeutic periods, but a significant deterioration in role and social functioning, and an increase of most head and neck symptoms. Tumour stage, tumour site and treatment modalities (type of surgery, adjuvant therapy) were the main predictors of QoL scores. We found a negative correlation between satisfaction with the information received and global QoL score or several functioning scales.	HNSCC surgical treatment affects patients QoL mainly by increasing head and neck symptoms, which results in social and role functioning deterioration. These results are of great interest to improve multi-disciplinary care of HNSCC patients.
BICKFORD, J., COVENEY, J., BAKER, J. & HERSH, D. 2019. Australia	28	To explore the experience of living with and/or supporting individuals with a laryngectomy at least 1 year after surgery.	Qualitative	Personhood/identity roles	The phenomena of “validating the altered self after total laryngectomy'' highlighted how individuals, post laryngectomy, navigate and negotiate interactions due to the disruption of their self-expression, related competencies, and roles. Several reframing patterns representing validation of the self-emerged from the narratives. They were as follows: destabilized, resigned, resolute, and transformed. The data describe the influence of the processes of developing competence and building resilience, combined with contextual factors, for example, timing and turning points; being supported; and personal factors on these reframing patterns.	The findings further our understanding of the long-term subjective experience of identity change after laryngectomy and call attention to the persisting need for psychosocial support. Implications for Practice: This research provides important evidence for evaluating and strengthening the continuum of services (specialist to community) and supporting social participation, regardless of communication method, and for competency training for all involved to optimize person-centred practices.
AOKI, T., OTA, Y., SUZUKI, T., DENDA, Y., AOYAMA, K. I., AKIBA, T., NAITO, M. & ARAI, T. 2018. Japan	83	To investigate how the QoL for patients with oral cancer changed perioperatively.	Quantitative	QOL	The FACT-H&N, PWB, FWB, and HN, were lowest at treatment completion due to declines; then, it showed significant improvement over time.	The treatment-associated declines in subscale area may be compensated for by gains in other subscale areas. Psychological support is better introduced prior to cancer treatment. As it is often difficult to recover from declines in HN functioning subscale, strategies that promote compensation in other areas must be explored. Clinicians should become thoroughly familiar with how patients' QOL changes over time and provide holistic treatments that honour patients' autonomy.
BADR, H., HERBERT, K., BONNEN, M. D., ASPER,	60	Examined associations between patients' and	Qualitative	Dyadic coping	Baseline multilevel Actor-Partner Interdependence	The SHARE intervention improved positive and

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Author, Year & Location Published	Participant numbers	Aim & Location of study	Design	Variable of Interest	Main Findings	Conclusion
J. A. & WAGNER, T. 2018. United States of America		spouses' dyadic coping (and satisfaction with dyadic coping; SATDC) and their own/each other's psychological and marital adjustment. Examined the effects of SHARE relative to usual medical care (UMC) on patients' and spouses' dyadic coping. Examined whether changes in dyadic coping were associated with changes in patients' and spouses' psychological and marital adjustment.			Models revealed significant actor effects of PFSC (effect size $r = -0.32$) and PFDC ($r = -0.29$) on depression. For marital adjustment, significant actor effects were found for PFSC, PFDC, EFDC, and SATDC ($p < 0.05$, $r = 0.23$ to 0.38). Actor ($r = -0.35$) and partner effects ($r = -0.27$) for NEGDC were also significant. Moderate to large effect sizes were found in favour of SHARE on PFSC (Cohen's $d = 1.14$), PFDC ($d = 0.64$), NEGDC ($d = -0.68$), and SATDC ($d = 1.03$). Improvements in PFDC were associated with reductions in depression and anxiety ($p < 0.05$); and improvements in SATDC were associated with improvements in anxiety and marital adjustment ($p < 0.05$).	decreased negative dyadic coping for patients and spouses. Increases in positive dyadic coping were also associated with improvements in psychological and marital adjustment. Although findings are preliminary, more research on ways to integrate dyadic coping into oncology supportive care interventions appears warranted.
TRIBIUS, S., MEYER, M. S., PFLUG, C., HANKEN, H., BUSCH, C. J., KRÜLL, A., PETERSEN, C. & BERGELT, C. 2018. Germany	161	Examined QoL differences between patients with different socioeconomic status (SES) after intensity-modulated radiation therapy (IMRT).	Quantitative	QoL	Patients with high SES report worse QoL at the end of IMRT in the domains global health status (−15.2; $p = 0.005$), role function (−23.8; $p = 0.002$), and social function (−19.4; $p = 0.023$) compared to patients with middle and low SES. QoL improved during the first 12 and 24 months. However, 2 years after IMRT, middle and low SES patients report lower QoL in the domain's global health status, physical function, and role function, and report a higher general (fatigue, pain, dyspnoea) and head and neck cancer-specific symptom burden (pain, swallowing, senses, speech, social eating, opening mouth, and felt ill) than patients with high SES.	Conclusion After IMRT for LAHNC, patients with high SES report worse QoL compared to patients with middle or low SES. There is a marked improvement within the first 24 months in many domains. However, the magnitude of improvement in patients with middle or low SES is significantly smaller compared to patients with high SES.
MU, J. W., ZHANG, M. J., LUAN, B. Q., WU, J. & SUN, P. 2018. China	59	Explored the quality of life (QoL) in Chinese patients with laryngeal cancer (LC) after radiotherapy.	Quantitative	QOL	Three months after the radiotherapy, all items of QLQ-C30 and QLQ-H&N35 scales changed significantly ($P < 0.05$), except the social functioning ($P = 0.09$), role activities ($P = 0.81$), and global ($P = 0.12$) in QLQ-C30 scale and social contacts ($P = 1.00$), teeth problems ($P = 0.21$), trismus ($P = 1.00$), and feeling ill ($P = 0.07$) in QLQ-H&N35 scale, compared with these items before the radiotherapy. The results of this study showed that most items of QoL changed significantly after 3 months of radiotherapy in Chinese patients with LC.	The results of this study showed that radiotherapy may significantly impact the QoL in Chinese patients with LC 3 months after radiotherapy.
NEMETH, D., ZALECZNA, L., HUREMOVIC, A.,	35	The primary objective of this study was to investigate the	Quantitative	Chewing, saliva	Nearly three-quarters of OSCC patients perceived	The results of this study may help guide treatment

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ENGELMANN, J., POESCHL, P. W., STRASZ, M., HOLAWE, S., KORNEK, G., LASKUS, A., SACHER, C., EROVIC, B. M. & PERISANIDIS, C. 2017. Austria		quality of life (QOL) of patients with oral squamous cell carcinoma (OSCC) undergoing curative neoadjuvant chemoradiotherapy followed by radical tumour resection and simultaneous oral cavity reconstruction, using two validated questionnaires. A secondary objective was to assess clinical variables predicting post-treatment dysfunction in chewing, saliva, and swallowing.			good to excellent levels of overall QOL after preoperative chemoradiotherapy. Chewing difficulties, decreased salivary function, and swallowing dysfunction were the most frequent complaints of OSCC patients. Items related to food intake were significantly worse in OSCC patients older than 60 years and those with T4 tumours, as well as those without alcohol intake. Chewing, saliva, and swallowing are the most significant issues in patients with OSCC undergoing preoperative chemoradiotherapy.	decisions for OSCC patients based on more accurate expectations of adverse effects of cancer treatment.
WORRELL, E., WORRELL, L. & BISASE, B. 2017. United Kingdom	10	To investigate the impact of the resection and reconstruction, the patients' perceived needs, and their use of supportive care services	Mixed Methods	QoL	Their experiences were in line with current treatment of head and neck cancer. Whether they would survive the cancer was an initial fear (up to a year postoperatively), and some subjects reported problems more than five years after treatment, particularly with swallowing, quality of saliva, and intelligible speech. This small group of survivors of head and neck cancer maintained a good quality of life physically, socially, and emotionally. Limitations were put down to their age rather than their diagnosis of cancer or their rehabilitation.	Analysis of their perceived needs showed that supportive care services were readily available and were valued by the patients, and that all their needs were met.
RINKEL, R. N., VERDONCK-DE LEEUW, I. M., DOORNAERT, P., BUTER, J., DE BREE, R., LANGENDIJK, J. A., AARONSON, N. K. & LEEMANS, C. R. 2016. The Netherlands	60	To assess swallowing and speech outcome after chemoradiation therapy for head and neck cancer.	Quantitative	Swallowing/speech	Swallowing and speech problems were present in 79 and 55 %, respectively. Normal food intake was noticed in 45, 35 % had a soft diet and 20 % tube feeding. Patients with soft diet and tube feeding reported more swallowing problems compared to patients with normal oral intake. Tumour subsite was significantly associated with swallowing outcome (less problems in larynx/hypopharynx compared to oral/oropharynx). Radiation technique was significantly associated with psychosocial speech problems (less problems in patients treated with IMRT).	Swallowing and (to a lesser extent) speech problems in daily life are frequently present after chemoradiation therapy for head and neck cancer. Future prospective studies will give more insight into the course of speech and swallowing problems after chemoradiation and into efficacy of new radiation techniques and swallowing and speech rehabilitation programs.
ISAKSSON, J., WILMS, T., LAURELL, G., FRANSSON, P. & EHRSSON, Y. T. 2016. Sweden	66	To investigate employment status at diagnosis, sick leave, and returning to work patterns in correlation to quality of life, anxiety, and depression in patients treated for HNC. To explore patients'	Mixed Methods	Return to work	53 % of the patients had returned to work at 24 months after treatment, and 17 % were deceased. Several quality-of-life parameters were significantly worse for patients not working at 24 months after treatment.	Returning to work is an important part of life because it structures everyday life and strengthens the individual's identity. The quality-of-life results showed significant

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		experiences of the process of returning to work.			Nine categories were found to describe the return-to-work process starting with symptoms causing sick leave, thoughts about the sick leave, and ending with the return to work and/or retirement.	differences between workers and non-workers at the 24- month follow-up. The patients need to be both physically and mentally prepared for the process of returning to work. It is important to take an individual rehabilitation approach to guide and support the patients in returning to work and regaining an important aspect of their everyday life. In such an approach, it is vital to understand the patients' overall life context and the patients' own perspective on the process and meaning associated with work.
WU, Y. S., LIN, P. Y., CHIEN, C. Y., FANG, F. M., CHIU, N. M., HUNG, C. F., LEE, Y. & CHONG, M. Y. 2016. Taiwan	106	To assess psychiatric morbidities of patients with head and neck cancer (HNC) in a prospective study at pre-treatment, and 3 and 6 months after treatment, and to compare their health-related quality of life (HRQL) between those with and without depressive disorders (depression).	Quantitative	Anxiety and depression	High rates of anxiety were found at pre-treatment, but steadily declined over time (from 27.3 % to 6.4 %, and later 3.3 %). A skew pattern of depression was observed, with prevalence rates from 8.5 % at pre-treatment to 24.5 % and 14 % at 3 and 6 months, respectively, after treatment. We found that loss of sense ($P = 0.001$), loss of speech (P,0.001), low libido ($P = 0.001$), dry mouth (P,0.001), and weight loss ($P = 0.001$) were related to depression over time. The depressed patients had a higher consumption of painkillers ($P = 0.001$) and nutrition supplements (P,0.001). The results showed that depression was predicted by sticky saliva (P,0.001) and trouble with social contact (P,0.001) at 3 months, and trouble with social eating (P,0.001) at 6 months.	Patients with HNC experienced different changes in anxiety and depression in the first 6 months of treatment. Dysfunction in salivation, problems with eating, and problems with social contacts were major risk factors for depression.
GANZER, H., ROTHPLETZ-PUGLIA, P., BYHAM-GREY, L., MURPHY, B. A. & TOUGER-DECKER, R. 2015. United States of America	10	To study the eating experience and related QOL meanings/perceptions in long term survivors of head and neck cancer (HNC) $\geq$3 years post concurrent chemoradiation.	Mixed methods	QoL eating	Four categories (psychological, social impact, functional status, and the current eating experience) containing 15 subthemes and 1 overarching theme (adaptation) emerged. Current health status, QOL, and QOL related to eating were viewed favourably despite the impact of treatment late effects on participants' daily lives. Adaptation and maladaptation in regard to food choice and downplaying of symptoms were recognized. Interviews as well as the VHNSS 2.0 scores indicated that xerostomia, mucosal sensitivity, swallowing	Psychological, functional, and social losses associated with eating were identified. Participants modify or avoid foods that are challenging yet report enjoyment with eating. Challenges with eating were downplayed. Due to the potential negative nutritional and social implications of avoiding specific food/ food groups, standard of care in long-term survivors of HNC should include assessment of the eating experience and functional challenges. Nutrition professionals can help patients optimize

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					difficulty, length of time required to eat, and dysgeusia remained problematic.	dietary intake and the eating experience.
WELLS, M., CUNNINGHAM, M., LANG, H., SWARTZMAN, S., PHILP, J., TAYLOR, L. & THOMSON, J. 2015. Scotland	280	To identify the distress, unmet needs and concerns of head and neck cancer (HNC) survivors in the first 5 years after treatment.	Quantitative	Distress	One-third of the survivors had moderate or severe levels of distress, and 74 % had at least one unmet need. The most common concerns and unmet needs included oral and eating problems, fear of recurrence and fatigue. Multivariate analysis revealed that being younger, out of work (not retired), ever having had a feeding tube fitted, having a greater number of comorbidities, and living alone were associated with higher levels of distress, concerns, and unmet needs.	The diversity of concerns and unmet needs identified in this study highlights the importance of holistic needs assessment as part of follow-up care for HNC survivors with tailoring of support for particular concerns. Specific information resources and self-management strategies are required to help HNC survivors with the practical and functional consequences of HNC treatment.
ROGERS, S. N., HAZELDINE, P., O'BRIEN, K., LOWE, D. & ROE, B. 2015. United Kingdom	177	To collate the various prompts available in a routine follow-up clinic using an intimacy screening question and Patient's Concerns Inventory (PCI), and to identify how often these problems were raised by patients and what possible actions took place as a consequence.	Mixed Methods	Intimacy and sexuality	PCI identified that 9 of the 24 reporting the worst problems wanted the topic discussed in clinic, and clinic letters suggested that 5 of these discussed the issue in clinic with 4 being referred on, 3 to a clinical psychologist and 1 to a clinical nurse specialist. Intimacy problems are underreported in clinic reviews. It is a difficult subject to discuss.	Intimacy will remain a potential unmet need unless attempts are made to advance the opportunities for patient screening, information leaflets, staff training on how to talk about such sensitive issues and referral for counselling.
SCHALLER, A., LIEDBERG, G. M. & LARSSON, B. 2014. Sweden	21	To describe how the relatives of patients with HNC experienced the patient's situation, especially with respect to pain, and how the relatives themselves experienced the situation.	Qualitative	Relatives' experiences	The relatives experienced that the patients suffered from physical, psychological, and social pain. A dark picture consisting of lack of participation and knowledge, psychological distress, and lack of support were reported. Thus, a main category: relatives struggle with loved one's pains related to head and neck cancer treatment and with their own demanding situation e was based on the following four categories: inability to relieve and comprehend the physical suffering of the patients; overwhelming emotions were experienced that affect the patients and the relatives themselves; in need of support from the health care service; and altered daily activities and family roles due to illness and treatment.	In patients physical, psychological, and social pain were prominent and in relatives, psychological distress, lack of knowledge and support were experienced. Thus, to reduce pain and anxiety in patients and relatives, the health care professionals should provide relevant knowledge about pain management. The health care professionals should also provide educational interventions that address the psychological and social factors that impact pain for HNC patients and their relatives. Well thought supporting care and easily accessible information about practical concerns should be offered to HNC patients and their relatives.
RINKEL, R. N., VERDONCK-DE LEEUW, I. M., VAN DEN BRAKEL, N., DE BREE, R., EERENSTEIN, S. E., AARONSON, N. & LEEMANS, C. R. 2014. The Netherlands	198	To validate questionnaires on voice, speech, and swallowing among laryngeal cancer patients, to assess the need for and use of rehabilitation services, and to determine the association between voice, speech, and swallowing	Qualitative	Voice speech and swallowing, QOL, distress, perceived need for rehab.	Cut off scores of 15, 6, and 14 were defined for the VHI, SHI, and SWAL-QOL (sensitivity >90 %; specificity >80 %). Based on these scores, 56 % of the patients reported voice, 63 % speech, and 54 % swallowing problems.	Psychometric characteristics of the VHI, SHI, and SWAL-QOL in laryngeal cancer patients are good. The prevalence of voice, speech, and swallowing problems is high, and clearly related to quality

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		problems, and quality of life and distress.			VHI, SHI, and SWAL-QOL scores were associated significantly with quality of life (EORTC QLQ-C30 global quality of life scale) (r = 0.43 (VHI and SHI) and r = 0.46 (SWAL-QOL)) and distress (r = 0.50 (VHI and SHI) and r = 0.58 (SWAL-QOL)). In retrospect, 32 % of the patients indicated the need for rehabilitation at time of treatment, and 81 % of these patients availed themselves of such services. Post-treatment, 8 % of the patients expressed a need for rehabilitation, and 20 % of these patients actually made use of such services.	of life and distress. Although higher during than after treatment, the perceived need for and use of rehabilitation services is limited.
NUND, R. L., WARD, E. C., SCARINCI, N. A., CARTMILL, B., KUIPERS, P. & PORCEDDU, S. V. 2014. Australia	24	To describe the experiences of people living with dysphagia in the months and years following non-surgical treatment for HNC.	Qualitative	Dysphagia related experiences, lifestyle impacts	The themes identified included: 1) physical changes related to swallowing; 2) emotions evoked by living with dysphagia; 3) altered perceptions and changes in appreciation of food; and 4) personal and lifestyle impacts. The data revealed the breadth and significance of the impact of dysphagia on the lives of people treated curatively for HNC.	Assessment and management in the post-treatment period must be sufficiently holistic to address both the changing physical states and the psychosocial needs of people with dysphagia following HNC. Rehabilitation services which focus only on impairment-based management, will fail to fully meet the support needs of this clinical population.
NUND, R. L., WARD, E. C., SCARINCI, N. A., CARTMILL, B., KUIPERS, P. & PORCEDDU, S. V. 2014. Australia	24	To explore the lived experience of people with dysphagia following non-surgical treatment for HNC and examine their perceptions of service needs.	Qualitative	Adjustment to dysphagia, life after treatment, accessing support	Within this integrative theme were five additional themes including: (1) entering the unknown: life after treatment for HNC; (2) making practical adjustments to live with dysphagia; (3) making emotional adjustments to live with dysphagia; (4) accessing support outside the hospital services; (5) perceptions of dysphagia-related services.	The interviews revealed the need for both greater access to services and a desire for services which address the multitude of issues faced by people with dysphagia following HNC in the post-treatment period. Speech and language therapists managing this caseload need to ensure post-treatment services are available and address not only the physical but also the emotional and psychosocial changes impacting people with dysphagia in order to assist them to adjust to and live successfully with dysphagia. Further research should be conducted to support the development of innovative services and to highlight dysphagia-related survivorship issues to governing bodies/ policy makers.
CHEN, A. M., DALY, M. E., FARWELL, D. G., VAZQUEZ, E., COURQUIN, J., LAU, D. H. & PURDY, J. A. 2014. United States of America	50	To analyse quality of life among long-term survivors of head and neck cancer treated with IMRT.	Quantitative	QoL	Five years after completion of IMRT, 42 patients (84 %) reported that their health-related quality of life was “much better” or “somewhat better” than at the time of cancer diagnosis. With respect to recent	Our findings add to the body of literature that supports the acceptance of IMRT as standard treatment for head and neck cancer. The fact that most 5-year survivors were satisfied

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					health-related quality of life during the preceding 7 days at the time of completing the UW-QOL questionnaire, 40 patients (80 %) treated with IMRT reported "outstanding" or "very good" levels of functioning. Five years after completion of treatment, 41 (82 %) rated their overall quality of life as "outstanding" or "very good." The lowest domain score on the UW-QOL questionnaire at 5 years pertained to salivary dysfunction. However, 42 patients (84 %) reported saliva "of normal consistency" or "less saliva than normal but enough" compared with 8 (16 %) reporting "too little saliva." No patient reported having "no saliva."	with their quality of lives points to the ability of IMRT to preserve long-term functioning.
PARKER, V., BELLAMY, D., ROSSITER, R., GRAHAM, V., BRITTON, B., BENNETT, L. & GILES, M. 2014. Australia	12	Explored the experiences of cancer patients who underwent surgery for head and neck cancer.	Qualitative	QoL	Critical aspects of patients' experiences are described through the following themes: only having half the story, shocks, and aftershocks, living with the aftermath, and being supported. Participants identified difficulties arising from receiving insufficient, confusing, and often untimely information. The persistent and traumatic nature of what patients endure challenges their physical, mental, and emotional coping capacity and, in some cases, their motivation to live.	There is a need to address gaps in support and education of patients and carers. Of particular concern is the problem related to information provision and comprehension. Critical examination of current practices, together with efforts toward coordinated care tailored to individual needs, is required, along with outreach services for patients in rural areas. Implications for Practice: The development and evaluation of targeted resources in a variety of forms such as DVD, Internet, and pamphlets are needed. Robust assessment strategies are required to inform supportive interventions matched to stages and significant events in patients' journeys.
PATTERSON, J. M., RAPLEY, T., CARDING, P. N., WILSON, J. A. & MCCOLL, E. 2013. United Kingdom	208	Preliminary study reports on carer QOL over time and investigates the relationship with dysphagia.	Mixed Methods	QoL, swallowing QoL	Seventy per cent of carers returned a questionnaire at least once. There was no change in CQOL-C scores between pre-treatment and 3 months, but a significant improvement was found between 3- and 12-months post-treatment ($p = 0.012$). Patient-reported outcomes accounted for 52 % of variance in carer QOL measurements ($R2 = 0.52$, $p < 0.001$). Four themes emerged from the qualitative data food provision, monitoring, motivation, and changes to lifestyle.	Findings suggest a relationship between carer and patient QOL. Elsewhere, these two characteristics have been associated such that the greater the patients' physical care needs, the poorer the carers and patients' QOL. Living with someone with dysphagia not only involves managing the physical swallowing difficulties but is also likely to impact on social activities such as participation in shared meals, leading to permanent lifestyle changes.

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BAHARVAND, M., SHOALEHSAADI, N., BARAKIAN, R. & MOGHADDAM, E. J. 2013. Iran	22	To evaluate taste condition after head and neck radiotherapy and its impact on quality of life.	Quantitative	Taste problems -dysgeusia QoL	Significant changes were observed in concentrations and intensities of different perceived tastes before and after radiotherapy. All patients had dysgeusia after radiotherapy and 72.2 % had total taste loss. Impairment was observed mainly in salt and bitter tastes followed by sour and sweet. Subjective dysgeusia reported by 3/4 of the patients, which was correlated with objective taste disorder in terms of different tastes intensity. Age, sex, radiotherapy fractions, dosage and patients' level of education had no significant effects on taste alteration. Quality of life was significantly deteriorated after the occurrence of dysgeusia in both total and partial taste losers. None of the aforementioned factors had significant effects on quality of life.	Head and neck radiotherapy causes impairment in taste perception, and life quality is influenced by dysgeusia.
HUNG, H. C., TSAI, M. C., CHEN, S. C., LIAO, C. T., CHEN, Y. R. & LIU, J. F. 2013. Taiwan	142	To examine changes in social support and predictors in caregivers of oral cavity cancer patients over the 3 months after patients' first discharge.	Quantitative	Social support needs	Caregivers had mild-to-moderate levels of needs and were satisfied with available social support during the first 3 months after discharge. The peak for both overall and individual needs of social support was before discharge. Caregivers overall and individual satisfaction with social support peaked at 3 months after discharge. Spouse caregivers had greater overall needs for social support. Caregivers with longer caregiving time were associated with dissatisfaction during the first 3 months after discharge.	Caregivers of oral cavity cancer patients had unmet needs of social support, especially wife caregivers.
ZHANG, X., FANG, Q. G., LI, Z. N., LI, W. L., LIU, F. Y. & SUN, C. F. 2013. China	63	Investigated the quality of life in patients younger than 40 years with tongue squamous cell carcinoma.	Quantitative	QoL	Young patients (under 40 yrs) reported better function, notably regarding activity, recreation, shoulder, taste, and saliva compared with the old patients with anterior tongue squamous cell carcinoma. The patients younger than 40 years tend to have a good quality of life. Most of them were not significantly affected by pain.	Quality of life should be used as part of our treatment of anterior tongue squamous cell carcinoma.
WANG, J., LUO, H., LIU, F., FU, K. & ZHANG, M. 2013. China	62	To evaluate postoperative quality of life in patients who have had resections of tongue cancer and reconstruction by flaps and to collect information about their sociocultural situation.	Quantitative	QoL, psychological distress social disability	Short Form 36, the best-scoring domain was bodily pain, whereas the lowest scores were for social functioning and vitality. In the 14-item Oral Health Impact Profile, the lowest-scoring domain was	The postoperative quality of life in our patients was significantly influenced by tongue resection. This should be considered for surgical planning. The sociocultural data showed a rather low

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					psychological disability, followed by psychological discomfort and social disability.	education level and life standard level for the majority of the patients.
OTTOSSON, S., LAURELL, G. & OLSSON, C. 2013. Sweden	13	To describe the experience of food, eating and meals following radiotherapy in patients with head and neck cancer.	Qualitative	Food/eating experience	The experience of food, eating and meals up to nine months after radiotherapy was captured in six categories: ‘A long journey – taking small steps to an uncertain future’, ‘A new way of eating’, ‘Eating without satisfaction’, ‘Challenging meals outside the family’, ‘Support and information – the key to a successful journey’ ‘The creation and acceptance of a new normal’.	This study provides new information on the long-term aspects of food, eating and meals in patients with HNC. HNC signifies a long journey with problems affecting physical, psychological, and social aspects of food. Information and support and the use of strategies are important for patients with head and neck cancer to adapt to new possibilities for living after cancer treatment. Relevance to clinical practice: All members of the multi-professional team need to be aware of the struggles with food and eating experienced by patients with head and neck cancer during the convalescent period. It is therefore important that the follow-up focuses on all aspects of food, eating and meals as a part of a holistic approach.
O`BRIEN, K., ROE, B., LOW, C., DEYN, L. & ROGERS, S. N. 2012. United Kingdom	16	This paper reports the experiences of former patients who have undergone a range of head and neck cancer treatments and their perceptions of the changes in intimacy experienced, as an individual and through their relationships with partners, family, and friends.	Qualitative	Personal identity themes.	Analysis of the data produced three broad themes. These were ‘personal identity’, ‘re-establishing social networks’ and ‘intimate relationships’ and explored the person as an individual and their perceived changes to self-esteem and image. The perception of their altered position in society, the impact this has on their willingness to re-engage with society and the degree to which treatment can alter an individual’s ability to resume former intimate relationships with family and partners.	Patients’ definitions of intimacy are multifaceted and related directly to the type of relationship that existed prior to treatment. The concerns and challenges faced by patients need to be addressed and support opportunities considered as part of the rehabilitation process. Relevance to clinical practice: The paper gives insight for nurses and other healthcare professionals who are expected to provide effective emotional and therapeutic support for patients who have undergone treatment for head and neck cancer. Understanding of patient concerns and recognition of adaptive and coping strategies are essential for this practice.
PSOTER, W. J., AGUILAR, M. L., LEVY, A., BAEK, L. S. & MORSE, D. E. 2012. Puerto Rico	46	To ascertain the most important HNC HRQOL issues, so that research and practice can be directed toward enhancing patient QOL.	Quantitative	QoL	Correlation findings included statistically significant negative correlations between the three QLQ-C30 outcome variables and the QLQ-H&N35 variables pain, swallowing, social eating, social contact, and sexuality. Multivariable linear regression identified	Problems with pain, social eating, social interactions, and loss of sexuality are critical indicators of degraded HRQOL in HNC patients living in Puerto Rico. These findings add to the overall knowledge base regarding QOL among HNC patients. The promise of improved

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Table 3 (*continued*)

Author, Year & Location Published	Participant numbers	Aim & Location of study	Design	Variable of Interest	Main Findings	Conclusion
					statistically significant inverse indicators of the outcomes: (1) “lessening of sexuality” with “overall health” ($p = 0.02$), (2) “problem with social eating” ($p = 0.023$), “taking pain killers” ($p = 0.025$), and “problem with social contact” ($p = 0.035$) with “overall QOL,” and (3) “problems with social eating” ($p < 0.009$) and “taking pain killers” ($p = 0.016$) with the “global health/QOL” domain.	QOL for the HNC patient is attainable through additional research in conjunction with advances in clinical treatments and patient management protocols.
MOLASSIOTIS, A. & ROGERS, M. 2012. United Kingdom	16	To explore and understand the experience of receiving treatment for head and neck cancer with particular focus on symptom experiences over a one-year period from diagnosis.	Qualitative	Nutritional concerns, QOL range themes	Key themes derived include nutritional concerns, tiredness, and experiences related to the radiotherapy mask and regaining normality. These data highlight issues of importance in the first year of living with head and neck cancer: impact of nutritional changes on the lives of patients, including weight loss, dysphagia, xerostomia, and taste changes; debilitation from ongoing fatigue; unpreparedness for and distress from the radiotherapy mask; and attempts to maintain a normal life amidst the interference of symptoms.	Multitude of symptoms impact the patients’ life, particularly nutritional symptoms and fatigue, and interfere with the patients’ survivorship and quality of life. The changing nature of symptoms over the first year from diagnosis in head and neck cancer patients and the identified issues in the attempt to normalize their lives need to be incorporated more fully into the supportive care of head and neck cancer patients in order to improve their experience and enhance their survivorship.
MORTENSEN, G. L. & PAASKE, P. B. 2012. Denmark	7	Examined the long-term health-related quality of life (QoL) in patients with TC.	Qualitative	QoL, hearing, psychosocial QoL	Treatment sequelae peaked within the first three months and included severe pain in the radiated area, nausea, and fatigue. Within this period, patients were unable to eat solid food and often had difficulty speaking. Half of the participants lost some of their hearing due to radiation. Even two years after treatment, most participants had persisting sequelae, mainly xerostomia, porous teeth and reduced mobility of the tongue and jaw. Fatigue and difficulties eating and communicating, in particular, had a very negative effect on the participants’ psychosocial QoL.	This study allowed for a deeper understanding of the negative effects of HNC on patients’ QoL. These QoL effects ought to be included in future considerations of HPV vaccination of boys as well as girls.
MCQUESTION, M., FITCH, M. & HOWELL, D. 2011. Canada	17	This paper highlights participants’ perspectives about their experiences and the disruptions caused by treatment, with a specific focus on the losses associated with the changed meaning of food.	Qualitative	Meaning of food	There are physical, emotional, and social losses associated with a changed meaning of food for Head and Neck cancer patients.	Acknowledging the significance of eating problems and the changed meaning of food is required in order to provide patients with the appropriate support, strategies, and interventions to manage with the changes and losses.

3.5. Main outcome variables of interest

The main outcome variables of interest were distributed strongly towards the function and experience of diet, eating and swallowing problems with 16 papers focussing on this theme [18,27,28,31,33,34,37–39,41,43,44,46,47,49,50]. Social eating was specifically addressed by Psoter, Aguilar [45].

The second most frequent theme (n = 11) assessed 'quality of life' on a very broad range of factors which covered health, sensory or psychological frames and included in this grouping is the issue of fatigue [21].

The next theme categorised as loneliness, caring relationships and socialising were the focus in 6 papers [17,19,22,26,29,51]. Intimacy and sexuality were the focus of 3 papers [32,40,48], and a further 3 focussed on psychological distress [55,56,58].

Two papers focussed on the theme of oral/dental care [15,53], and 2 on finances and working [25,30]. Speech as a specific outcome was addressed in only 1 study [20], as was body image [23] and socio-economic status [52].

The qualitative papers used a range of approaches which highlighted concerns around cognitive or information overloads [20], coping methods [30], therapeutic education [42], and many aspects of social roles and identities, such as those of being a mother, carer or employee.

3.6. Quality assessment

Using the MMAT tool guidance, an overall quality score was given for each study. The different types within the MMAT utilised were mixed-methods, qualitative, quantitative non-randomised and quantitative descriptive. No studies scored lower than 3* and no studies were excluded due to quality score. The mean overall quality appraisal score is given for each methodology employed. Thus, studies of quantitative design (n = 25) achieved a score of 87 %, qualitative studies (n = 14) a score of 83 % and mixed methods designs (n = 7) achieved 100 %.

3.7. Discussion

The body of evidence reviewed suggested that HNC has multiple social impacts that are detrimental across time, and which implicate many areas of their everyday life including the social systems within which these patients live, relate to others and unless retired, often work.

Regarding the social impact variables most studied, it is of interest that the theme of eating, nutrition and swallowing is clearly prioritised. The next most frequent theme studied was Quality of Life 'QoL'. It is also notable that the topic of communication which arguably includes a wide range of areas such as speech, sexuality, relationships and socialising (which may also include aspects of mealtimes) is comparatively less frequently studied, representing about a fifth of the total studies reviewed. Thus, the question of bias as to the type of outcome variables chosen for study in the current literature is raised.

It is relevant to emphasise that eating is a complex interactive social function which itself carries a core communicative function. As one paper from Asia points out, cultures vary in their valuation of diet compared to communication and this sort of cultural preference may be important to consider in decisions over directions for future research of outcome variables [60]. It follows therefore that any categorisation of outcome variables into specific eating versus communication domains needs careful thought. Some studies focussing on issues of eating in public recognized this functional overlap in highlighting the need for more 'holistic' frameworks of care relevant to mealtime interventions [24,28,45].

Furthermore, the review shows up the possible methodological limitations raised by the experiences of shame and stigma. This is likely to be relevant for patients, their carers, and healthcare professionals themselves. Intimate and culturally sensitive aspects of social function or identity remain difficult to discuss clinically, as indeed they are to talk about in everyday life. This problem is highlighted in the finding that females were less likely to consent to participate in studies assessing sexual satisfaction [32].

The social impacts of experiencing HNC are clearly complex and include a range of possible effects over undulating time courses relating to diagnosis, treatment, and any adaptation to the cancer and rehabilitation goals. There are research challenges because of the many confounding dependent and independent factors likely to be implicated. Other methodological challenges include the problem of adequate sample sizes alongside suitable timeframes for data collection. This review shows that very few studies are currently prospective or large enough across centres treating similar types of HNC to allow for the recruitment and retention of representative samples. This is further complicated by the problem that HNC involves a wide range of sites in the head and neck, aetiological types, and prognoses as well as a panoply of treatment side effects affecting patients differently.

Other key findings are that the role of ethnicity was not adequately addressed in most papers. In addition, palliative care patients are mostly excluded from the studies, which leaves many patients' journeys overlooked. As regards gender, the papers were biased towards males, albeit this uneven proportion does reflect the overall demographics of HNC. The interrelated issue of gender and body image is highlighted in considering aspects of facial change and emphasises the need for studies to include pre-treatment baseline measurements to understand any ongoing or adaptive impacts across time and age [23]. Gender is also important to look at when examining the needs of carers as the study by Patterson, Rapley [43], reports that the overwhelming majority of informal carers were female.

Socioeconomic factors are often omitted from papers on HNC which is particularly important when the risk of being diagnosed with HNC is greater for those who fall at the lower end of the social gradient. Such factors may be very important to any synthesis of data if they weight studies towards the socially stable, and therefore those who are in general prognostically advantaged. It has been found that those who are least socially stable, are fragile or unavailable due to work or family pressures may be underrepresented in studies [17].

It is also known that loss of social roles such as caregiving or work may also greatly impact identity [5]. The social role of work and the issue of finance were only specifically addressed in two studies [24,30] arguably evidencing this sort of omission in studies concerning HNC patients and their contexts of everyday living. Nevertheless, the social security cultures of different countries or subgroups in a population were considered as significant to discuss when interpreting results in one paper which highlights the need for more sophisticated study of socio-economic variables [52].

The issue of cognitive overload and difficulty of processing information and emotional pain at a time of great stress such as diagnosis or when consenting to treatment was found to be a consistent problem in the qualitative research papers reviewed. Information on treatment side effects and availability of hospital accommodation have also been cited as core concerns for patients and relatives [61]. Patients want to choose how best to receive information about their treatment pathways or cancer itself across different medias of communication. Likewise, the same may be said of relatives and informal carers. One paper proposes empowerment through therapeutic education, at appropriate times when the patient can process information optimally [42].

A final suggestion is that future research should focus on the intersection of dentistry, surgery, oncology, radiology, psychiatry, psychology, philosophy and sociology. This kind of multi-disciplinary collaboration in developing future research protocols will enable research teams to explore, and better understand, the full implications of a diagnosis like HNC. Identity and belief systems must also be considered in future work, especially because many health systems globally are now turning towards more sustainable solutions to care with less paternalism stemming from traditional biomedical models within medicine [62]. The review suggests that what matters to patients in everyday life involves a complex mix of social needs and health needs. Currently there are many social needs which affect both the quality and quantity of HNC patients' lives. This systematic review highlights the strong value to be gained in further larger scale in-depth research in this important area.

3.8. Conclusion

This review demonstrates that those with HNC experience many and varying social impacts underpinned by personal and cultural issues across widespread timescales after diagnosis. Communication problems and sensitive issues such as stigma may be hidden and make impacts harder to define and study.

This review highlights several research inadequacies which make conclusions limited, thus giving impetus to further work. A wide range of confounding variables and the heterogenous nature of the cancers themselves make for social impact research difficulty. Larger scale prospective studies with more power are therefore urgently called for. In addition, more sophisticated, larger qualitative studies are needed to unpick the social impacts of HNC and treatment from the sociocultural and psychosocial frameworks that they exist within.

Not only is the prevalence of HNC increasing globally, but with any advance in treatment and rehabilitation there is the potential that more people will have to live with any social impacts of HNC for longer post-treatment. With improved research comes the possibility of optimisation of person-centred rehabilitation for the benefit of head and neck cancer patients and those who care for them.

Declarations

I can confirm there are no competing interests and that this research did not receive any funding.

This study does not involve any human or animal subjects and as it was a systematic review no ethical approval or patient consent was required.

I can confirm that all authors have viewed and agreed to the submission.

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Declaration of competing interest

The authors declare that they have no known competing financial interests or personal relationships that could have appeared to influence the work reported in this paper.

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