The palliative care needs and experiences of people with advanced head and neck cancer: A scoping review

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Abstract

Background: The palliative care needs of people with advanced head and neck cancer pose unique complexities due to the impact the illness has on eating, speaking, appearance and breathing. Examining these needs would help provide guidance about developing relevant models of care and identify gaps in research knowledge.

Aim: To identify and map out the palliative care needs and experiences for people with advanced head and neck cancer.

Design: A scoping literature review following the methods described by the Joanna Briggs Institute.

Data sources: An electronic search of the literature was undertaken in MEDLINE (Ovid), EMBASE and CINAHL covering the years January 1996 to January 2019.

Results: People with advanced head and neck cancer often had palliative care needs but there was variability in the timing and access to relevant services. A high prevalence of interventions, for example hospital admissions were needed even during the last month of life. This was not necessarily negated with early engagement of palliative care. Dissonance between patients and family carers about information needs and decision-making was an additional complexity. Studies tended to be descriptive in nature, and often involved a single centre.

Conclusion: This scoping review demonstrates the complexity of care for people with advanced head and neck cancer and the issues related to the current healthcare systems. Focus on appropriate referral criteria, increased integration and coordination of care and robust evaluation of specific care components seems key. Linkage between research and service design delivery across teams, disciplines and care settings seems pertinent.

Keywords

Head and neck cancer, palliative care, palliative medicine, end-of-life, healthcare services, review

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Introduction

On a global scale, head and neck cancer is the sixth most common cancer, representing a wide-ranging group of cancers arising from the epithelial lining of the upper aerodigestive track, and affecting the oral cavity including the lips; pharynx; larynx; paranasal sinuses and nasal cavity; salivary glands and middle ear. Within certain parts of the world, for example the United Kingdom (UK), the incidence of head and neck cancer is expected to rise by 50% over the next 20 years. This trend is attributed to more cases caused by Human Papilloma Virus (HPV). Although there is variability depending on the underlying histology, the overall 5-year survival rate has remained at 40% to 65%, due to factors such as advanced stage disease presentation and co-morbidities. Additionally, one in every five people with head and neck cancer will die within 12 months following diagnosis. Worldwide, poverty and socio-economic deprivation impact on survival, raising concerns about inequalities or disparities in access to healthcare services, including palliative care provision.

Compared with other cancers, the palliative care needs of people with advanced head and neck cancer pose unique complexities due to the impact the illness has on eating, speaking and breathing. Head and neck cancer can be very visible, often causing facial disfigurement and distorted or unintelligible speech. Patients have distinct care challenges and can require feeding tubes and tracheostomies to support their vital functions. Symptoms can cause significant psychological distress and social isolation and there is a higher risk of suicide compared with the general cancer population. Earlier in the disease trajectory, family carers to those with head and neck cancer also report distress and unmet needs.

Given the overall prognosis and potential for rapid demise for a significant proportion of head and neck cancer patients, it is important to consider support at the time of diagnosis for those with advanced disease. Understanding the palliative care needs and experiences of this vulnerable population is important to help devise relevant models of care and identify future research gaps. Although there have been two systematic reviews on unmet needs for advanced cancer patients, none have specifically focused on people with advanced head and neck cancer. Head and neck cancer brings unique challenges due to the anatomical location of the illness, and the fact patients are likely to experience significant symptoms (physical and psychological) and healthcare burden regardless of what treatment course is chosen. A scoping review is beneficial to examine broad areas and is particularly useful to report on the types of evidence which may inform practice or identify key gaps in the evidence. The aim of this scoping review was to examine and map the palliative care needs and experiences for people with advanced head and neck cancer. As the research objective was wide-ranging, and the identified study designs were expected to be heterogeneous, a scoping review approach...
was deemed more appropriate compared with systematic review methodology.

**Methods**

**Literature review question**

The specific question to be addressed was:

> What types of palliative care needs and challenges have been reported by people with advanced head and neck cancer, their family carers, and the healthcare professionals looking after them, in terms of their experiences and usage of healthcare services?

**Design**

The Joanna Briggs Institute Scoping Review framework was used to guide conduct of the review. This framework represents well-established, detailed guidance, has previously been used to assess the quality of scoping reviews, and helped, in part, frame the development of the PRISMA extension on the reporting of scoping reviews.

**Search strategy**

An electronic search of the literature was undertaken in MEDLINE (Ovid), EMBASE and CINAHL covering the years January 1996 to January 2019. It was undertaken using keywords and subject heading terms for ‘Palliative care’ and ‘head and neck neoplasms’ (Textbox 1) using specified inclusion and exclusion criteria (Textbox 2). The searches were initially run on 12th April 2017 and further updated on 8th February 2019. The full MEDLINE search is available in Supplemental Table 1 and the other searches are available on request of the corresponding author. Titles and abstracts were initially screened (CRM, QMH or MC) to identify potentially eligible papers and any areas of uncertainty were resolved by another reviewer (PD). The full manuscripts of potentially eligible papers were further independently screened against eligibility criteria by two reviewers (either CRM and PP, CRM and PC, HCD and PD), with a third reviewer (PD or CRM dependent on the team) resolving any conflicts of opinion, to determine a definitive list of included studies (Figure 1). No additional hand searching was conducted but references of the included papers were also screened for any other relevant papers that might have been missed by the search.

**Data extraction**

Data was extracted using a specially designed proforma by one member of the research team (CRM, PP, PC or PD) and 75% were checked by a second reviewer (CRM or PD). Data was mapped out in a descriptive manner according to the following: setting, country, population characteristics, study design, intervention (where appropriate) and findings. The World Health Organisation’s definition of palliative care includes the ‘early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual’. Therefore, prior to the search, the team had agreed key themes within the protocol based on the expert knowledge within the team, and anticipating the likely complexities relating to communication and need for interventions to support vital functions of relevance to people with head and neck cancer. These themes were: symptom control; psychological well-being; communication and/or decision-making;
place of care and death and medical interventions at the end-of-life.

Data analysis

Following the data extraction, the studies were categorised to one or more of these themes based on their findings, and the themes revised accordingly, following review and discussion by members of the team (CRM and PD). Following this, the data was tabulated and synthesised within each of the final themes. The final themes agreed were:

- overall palliative care need and access to palliative care services
- physical symptoms
- psychosocial and spiritual well-being
- medical interventions in the last 12 months of life
- communication and decision making
- place of death.

Due to the wide range of different study methodologies, and in keeping with the accepted remit of scoping review guidance, specific quality appraisal was not conducted. Instead, key study limitations, where documented within the manuscripts, were extracted to inform the synthesis of data within themes.

Results

Range of studies

From 1278 initial records, 185 papers were screened for eligibility, of which 46 were included in the full review. An overview of the characteristics of these 46 included studies is provided in Supplemental Table 1.

Studies were most commonly conducted in Europe (n = 23), with 12 being conducted in Asia, nine in North America, one in Saudi Arabia, and one in Australia. Quantitative methods were used for the majority of the studies (n = 41) with four using qualitative methods and one study utilising mixed methods. All the quantitative studies were descriptive or observational in nature (cross-sectional survey, case-control, or cohort studies). Ten studies were nation-wide studies, and four were based within a specific region. The remaining 32 studies were conducted within single institutions. Thirty-six studies focused purely on patients, and two on family carers alone. A further four focused on both patients and family carers, and two on patients and healthcare professionals.

For each key area, studies are presented in Tables 1 to 6; studies which have findings about more than one key area are reported separately within the different tables.

Overall palliative care need and access to palliative care services

There were 11 studies reporting on these areas (Table 1). Studies suggest that 18% to 21% of all people with head and neck cancer received palliative management following diagnosis, with a higher rate seen for those residing in more deprived areas. There was some evidence that access may be lower than need, however, with one study estimating 28.3% of hospital in-patients had relevant needs.

Head and neck cancer patients were more likely to receive palliative care or prompt a referral to palliative care services than other cancer patients due to the high degree of symptom burden. Timing of referral to palliative care teams varied, with two studies suggesting that head and neck cancer patients were referred early, and one study observing late referral, that is, in the last 30 days of life. Higher rates of access to palliative care services were observed among those with HNC who were older, white and female.

Patients’ physical symptoms

Nineteen studies included a focus on this area (Table 2). Patients reported a diverse range of symptoms with the most recent study reporting patients had an average of 10 somatic symptoms. Pain was commonly reported (prevalence ranging from 40% to 95%) and one study described it being worse for those with more advanced disease. Pain could be complex in nature, requiring multiple medications including the frequent use of opioids.

Fatigue or lack of energy (prevalence ranging from 77% to 81%) and weight loss were also frequently reported. Other symptoms were wide-ranging including difficulty eating or swallowing, dry mouth, incontinence, bleeding, dyspnoea, funnelling lesions, change in appetite, cough, communication difficulties, constipation, retained mucus and insomnia. One study described the intensity of nursing care needed to support patients, in part due to symptom control. Patients’ concerns about adequate symptom control were perceived as a barrier to whether or not they would be able to die at home.

From the family carers’ viewpoint, pain, inability to eat and tumour fungation were reported to be the most distressing symptoms. Bereaved relatives perceived there was scope to improve on symptom management, a view shared by General Practitioners. In one study, only 45% of General Practitioners perceived their patients had been satisfied with the level of symptom control.

Patients’ psychosocial and spiritual well-being

Sixteen studies included a focus on this area (Table 3). The reported prevalence of psychological distress
| Study | Aim | Main findings | Reported limitations |
|-------|-----|---------------|---------------------|
| Mayland et al. | Table 1. Overall palliative care needs and access to palliative care services for advanced head and neck cancer patients. | - Study Aim: Main findings: Reported limitations |
| Rylands et al. | 246/523 (47%) resided in the ‘most deprived’ IMD quartile; 37/67 (55%) of those receiving palliative treatments lived in ‘most deprived’ IMD quartile. | - PCN prevalence highest in HNC patients (135/477, 28.3%) compared with other cancer groups (as defined by WHO definition and assessed by treating physician). |
| Shah et al. | Small numbers: limited to 8 patients | - Mean survival 5.5 months: short duration. |
| Timon and Reilly | 60/286 patients (21%) deemed appropriate for palliative care following initial diagnosis. | - Most patients were enrolled in hospice care within 30 days of death (63.4% for oral cancer; 57.8% for pharyngeal cancer). |
| Mulvey et al. | 59/286 (21%) deemed appropriate for palliative care following initial diagnosis. | - Time to one surgeon hospitalised metastatic, incurable HNC patients (10.01 for PCP referral). |
| Enomoto et al. | Compare monthly Medicare costs for all services used during last 3 months of life for HNC patients. | - Multivariate analysis showed older age, being married, and specific cancer types (e.g., gynaecological, lung, HNC) significantly associated with PC referral (although OR 1.01 for HNC, 95% CI 0.53–1.96). |
| Hui et al. | Early referrals (ERs) = those who were receiving or had completed treatment with curative intent or had an expected survival time of more than 2 years. | - Logistic regression analysis showed having HNC was an independent predictor for early referral to palliative care service (OR 9.5, CI 3.0–27.08, p < 0.001) or radiation (OR 0.60, CI 0.37–0.97, p = 0.03). |
| Kwon et al. | Evaluate the relationship between palliative care encounters and inpatient outcomes, including mortality, length of stay, and costs. | - Determined incidence of palliative care consultation (PCC) among hospitalised metastatic, incurable HNC patients. |
| Tang et al. | Access to palliative care services by cancer patients referred early in the disease course to outpatient palliative care services. | - Analysis of long-term outcomes not possible. |
| Ulgen et al. | Examine relationship between palliative care encounters and inpatient morbidity, mortality, length of hospitalisation and costs. | - Certain costs (i.e., physician costs) not included in database. |

**Notes:**
- CI: confidence intervals.
- ED: emergency department.
- HNC: head and neck cancer.
- IMD: index of multiple deprivation.
- OR: odds ratio.
- PCC: palliative care consultation.
- PEG: percutaneous endoscopic gastrostomy.
- QoL: quality of life.
- WHO: World Health Organisation.
**Table 2. Physical symptoms in advanced head and neck cancer patients.**

| Study                          | Aim                                                                 | Main findings                                                                                              | Reported limitations                                                                 |
|-------------------------------|----------------------------------------------------------------------|-----------------------------------------------------------------------------------------------------------|---------------------------------------------------------------------------------------|
| Alt-Epping et al.22           | Assess symptoms and psychosocial needs of patients with incurable HNC | Mean QoL 87.7/148 for 22 patients – using Functional Assessment of Chronic Illness Therapy Head and Neck Module (FACT-H&N), 0 = worst, 148 = best QoL. | Small numbers, Questionnaires not fully understood by participants                     |
| Bisht et al.24                | Examine effect of palliative drug therapy on QoL in advanced HNC patients | Pain most frequent symptom (in 38/40, 95% patients); frequent polypharmacytherapy (mean 8.7 drugs)   | Small numbers, Short duration of follow-up, QoL measure not specific for HNC           |
| Forbes32                      | Outline nature, incidence and management of problems and the role of the hospice in the patients care | Patients had a median of 6 symptoms (range 2–12)                                                          | Not specifically reported                                                              |
| Gupta et al.34                | Measure QoL in upper aerodigestive tract cancer (UADT) cancer patients in comparison with hospital controls | Mean composite QoL score for cases was poorer at 62.85/100 compared with 89.14/100 for controls; patients with oropharynx and hypopharynx cancer had worst mean scores across all domains | Not specifically reported                                                              |
| Heimonen et al.36             | Describe current status of palliative care of HNC patients in one specific university hospital region | From 60 HNC patients, 45% had a PEG and 28% had a tracheostomy                                           | Small numbers, Retrospective nature                                                    |
| Lal et al.42                  | Evaluate range of symptoms, other needs and evaluation of treatment strategies, especially for pain management | Pain most common symptom (134/153, 87%), then fungating lesion (47/153, 31%) and difficult/painful swallowing (61/153, 40%) | Symptoms not systematically reported, Retrospective nature                              |
| Ledeboer et al.43             | Evaluate experience of GPs in the care of palliative HNC patients, experiences of communication and consultation of attending specialists | Only 45% GPs perceived their patients were satisfied with their symptom control | Retrospective nature, Views of GPs (rather than patients)                               |
| Lidstone et al.45             | Assess prevalence and severity of symptoms and concerns – identify patient groups who might benefit from routine SPC involvement in outpatient clinics | HNC patients reported highest prevalence of mouth and taste problems (38/60, 63%), and swallowing problems (30/60, 50%) | Not specifically reported                                                              |
| Lin et al.46                  | Describe symptom patterns of terminal HNC patients in palliative care unit | Most common symptom was weight loss (97.9%), then pain (96.8%), cough (95.7%), dysphagia (90.4%), feeding difficulties (89.4%) and communication difficulties (78.7%) | Not specifically reported                                                              |
| Lokker et al.8                | Determine prevalence and impact of symptoms on daily functioning in HNC patients during palliative phase | HNC patients reported an average of 14 symptoms (range 0–26) of which 10 were somatic symptoms | Didn’t use validated questionnaires, 44% non-response rate, Limited numbers             |

(Continued)
Table 2. (Continued)

| Study | Aim | Main findings | Reported limitations |
|-------|-----|---------------|----------------------|
| Mercadante48 | Establish degree of opioid sensitivity and possible factors involved in advanced stage HNC patients being followed up at home | Patients had mixed pain syndromes (23 somatic, 19 visceral, 19 neuropathic) 12/37 patients had good and 25/27 partial responsiveness to opioid 14/37 had steroids, 14/37 had anti-inflammatory drugs; amitriptyline and carbamazepine administered > 2 weeks in 8 and 11 patients respectively 13/47 patients had subcutaneous morphine | Not specifically reported |
| O’Sullivan and Higginson52 | Explore Irish HNC patient and care-givers views on EoL care | Concerns about symptom control perceived as a potential barrier to dying at home | Some patients were in remission so views may alter as disease progresses |
| Price et al.54 | Understand cause and location of death and symptoms experienced at the end of life | 89/93 (94.7%) patients had at least one symptom in the 6 months prior to death Most common symptom was pain, then dysphagia, anorexia/weight loss, fatigue/weakness and dyspnoea (mean of 4.7 symptoms per patient) | Retrospective nature Small number |
| Roscoe et al.56 | Understand ways in which end-stage HNC patients and their oncologists talk about end-of-life issues | Patients overall QoL rated 7.20 (SD 2.81) on 0–10 scale (10 = excellent) Most prevalent symptoms were pain, constipation, inability to use their mouth, dry mouth, mucus, weakness, fatigue, shortness of breath, anxiety, insomnia and speech problems | Small numbers Single assessment rather than longitudinal |
| Shuman et al.59 | Determine perceived quality of care for HNC patients at the end of their lives | Mean score for ‘management of symptoms’ = 31/100 (lowest mean score from all 9 assessed domains) as perceived by 58 bereaved family members | Poor response rate Retrospective nature Different environment for using validated tool |
| Shinozaki et al.61 | Examine relationship between QoL and functional status in terminally ill HNC patients | No significant change in QoL between baseline and week 3 (using the European Organization for Research and Treatment of Cancer Quality of Life Questionnaire (EORTC QLQ)-Core 15-Palliative Care (C15-PAL)) 32 (44%) had a ‘tracheostoma’; 53 (74%) had enteral feeding Median duration of hospital stay shorter for PEG-fed patients (21 days) compared with NGT-fed patients (64 days) Fungating tumours requiring dressing changes in 22 (31%) patients; 5 (7%) patients had severe bleeding – 2 were fatal (2.8%) | Small numbers Limited to in-patients only |
| Physical symptoms specifically in last 1–2 weeks of life | | | |
| Ethunandan et al.31 | Evaluate quality of dying experience by examining symptoms in the last week of life | 27/32 (84%) had pain in week preceding death; 25/27 received opioids (18 given parentally) 20/32 had difficulty swallowing – 6 had a PEG and 1 had NGT (none inserted in last week life). 11 had urinary incontinence and 3 had faecal incontinence Bleeding was an issue in 5 patients | Retrospective nature |
| Fullarton et al.33 | Record characteristics, mode of death and potential indicators of the quality of care at the end of life for HNC patients | In last week of life, 33/76 (43%) patients had pain; 20/76 (26%) had dyspnoea Prevalence of pain was higher in hospice (12/13, 92%) and was main reason for admission | Retrospective nature Missing data Heterogeneous group Limited number of hospice patients |
| Sesterhenn et al.58 | Describe end-stage disease in advanced HNC patients – circumstances of final period of life and describe period in hospice setting | Intensive nursing support needed in hospice – 11/16 patients had tracheostomy; 13/16 received CAN (10 = PEG, 3 = NGT) 7/16 were incontinent rising to 12/16 in the two weeks prior to death | Not specifically reported |

CAN: clinically-assisted nutrition; EoL: end of life; GPs: general practitioners; HNC: head and neck cancer; NGT: nasogastric tube; NOK: next-of-kin; PEG: percutaneous endoscopic gastrostomy; QoL: quality of life; SD: standard deviation; SPC: specialist palliative care.
Table 3. Psychosocial and spiritual well-being in advanced head and neck cancer patients.

| Study | Aim | Main findings | Reported limitations |
|-------|-----|---------------|---------------------|
| Alt-Epping et al. | Assess symptoms and psychosocial needs of patients with incurable HNC | Patients (n = 22) reported distress levels of ≥ 7/10 (using National Comprehensive Cancer Network distress thermometer) | Small numbers (n = 22); Questionnaires not fully understood by participants. |
| Gupta et al. | Measure QoL in upper aerodigestive tract cancer (UADT) cancer patients in comparison with hospital controls | Most affected QoL domain was anxiety (cases mean score 21.6 versus controls 7.1, p < 0.001). | Not specifically reported. |
| Henry et al. | Underestimated experience of disfigurement in HNC and explore what patients considered to be its influences | Main theme of disruption of self-image. | Selection bias—those who were comfortable talking about topic, who were selected by healthcare professionals, only those in urban hospital setting. |
| Lal et al. | Evaluate range of symptoms, other needs and evaluation of treatment strategies, especially for pain management | 33/253 (13%) patients perceived (by oncologist assessment) to have some level of depression | Retrospective nature. |
| Ledeboer et al. | Evaluate experience of GPs in the care of palliative HNC patients, experiences of communication and consultation of attending specialists | 25/41 (61%) GPs perceived their patients had sufficient psychosocial care with 5% perceiving it as insufficient | Retrospective nature. |
| Ledeboer et al. | Increase knowledge of how treatment and support are experienced by relatives of palliative HNC patients during the palliative stage and after death | From 45 relatives, 67% reported the patients were ‘sometimes’ or ‘often’ depressed; 59% had received psychosocial support during palliative stage. | Relatives feedback may not reflect actual patients’ perspective; time between death and questionnaire completion was a year. |
| Lidstone et al. | Assess prevalence and severity of symptoms and concerns—identify patient groups who might benefit from routine SPC involvement in outpatient clinics | Of 60 HNC patients, 31 (52%) had concerns about the future; 35 (58%) felt tense/worried/fearful; 34 (57%) felt low in mood/depressed. | Did not explore all head and neck specific issues. |
| Lokker et al. | Determine prevalence and impact of symptoms on daily functioning in HNC patients during palliative phase | HNC patients had an average of 4 psycho-social symptoms. | Did not use validated questionnaires. |
| Offner et al. | Evaluate interventions/impact of newly established ‘Expert Center’ on palliative HNC patients as perceived by bereaved relatives | After establishing an ‘Expert Center’ for HNC care, bereaved relatives perceived improved psychosocial support (68% vs. 51% satisfied with Head and Neck Department). | 44% non-responder rate. |
| O’Sullivan and Higgins | Explore Irish HNC patient and care-givers views on EoL care | Participants very willing to discuss most aspects of EoL care (preferences for place of care and death, prognostications with no signs of psychological distress). | Limited numbers. |
| Patil et al. | Identify the incidence of distress in HNC patients who are starting palliative chemotherapy and the factors associated with it | From 200 HNC patients, 50% reported levels of depression, fear, nervousness, sadness, worries. | Single centre study; post-hoc analysis. |
| Roscoe et al. | Understand ways in which end-stage HNC patients and their oncologists talk about end-of-life issues | Patients average depression scores were low (2.29, SD = 2.61) as were ratings of sadness (2.64, SD = 2.62) (measured on 10-point scale where 0 = never/not at all and 10 = very depressed or sad all the time). | Small numbers (n = 14); patients only asked on one occasion. |
| Schuman et al. | Determine perceived quality of care for HNC patients at the end of their lives | Perceptions by 58 bereaved relatives (from 286 deceased) deemed mean score for ‘emotional and spiritual support’ = 70/100. | Poor response rate. |
| Psychosocial and spiritual well-being, specifically in last 1–2 weeks of life | Psycho-social and spiritual well-being specifically in last 1–2 weeks of life | In the last week of life, 14/32 (44%) patients exhibited restlessness and confusion. | Retrospective nature. |
| Ethunandan et al. | Evaluate quality of dying experience by examining symptoms in the last week of life | Psychosocial and spiritual well-being specifically in last 1–2 weeks of life | | |
| Fularton et al. | Record characteristics, mode of death and potential indicators of the quality of care at the end of life for HNC patients | In the last week of life, 15/76 (20%) patients were agitated. | Retrospective analysis. |
| Sesterhen et al. | Describe end-stage disease in advanced HNC patients—circumstances of final period of life and describe period in hospice setting | Wide range of different mental statuses described by healthcare team about the 16 patients—including ‘depression’, suicidal episodes, confusion and agitation. | Limited number of hospice patients. |

EoL: end-of-life; GPs: general practitioners; HNC: head and neck cancer; QoL: quality of life; SD: standard deviation; SPC: specialist palliative care.
| Study                        | Aim                                                                 | Main findings                                                                                                                                                                                                 | Reported limitations                                      |
|-----------------------------|----------------------------------------------------------------------|-------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|-----------------------------------------------------------|
| Alsirafy et al.21            | Determine prevalence of hypercalcaemia in advanced HNC patients in a palliative care setting | Hypercalcaemic patients more likely to be referred to palliative care, while they were inpatients ($p = 0.004$) compared with non-hypercalcaemic patients. During the last 3 months of follow-up, hypercalcaemic patients more likely to be hospitalised for $>14$ days ($p = 0.01$) and visit emergency room more than once ($p = 0.04$). | Not specifically reported                                 |
| Chang et al.25               | Investigated relationships between demographics, primary physician’s specialty, hospital characteristic and ‘aggressiveness’ of their EoL care for oral cancer patients | Six indicators of ‘aggressiveness’ of EoL care in the last month of life: use of chemotherapy; $>1$ hospital visit; $>1$ day hospitalisation; an ICU admission; death in acute care hospital. 96% of 5386 deceased patients had at least one indicator – mainly ER visits and ICU admission. High utilisation of chemotherapy, ER and ICU in more than 50% of patients during the last month of life. | Potential misclassification errors                       |
| Chen et al.26                | Determine prevalence of CPR in Taiwanese cancer patients in the last month of life and association with patient and physical characteristics | 12% of 17,040 HNC patients had CPR in last month of life; higher compared with rest of cancers (10.5%). | Retrospective nature                                      |
| Ethunandan et al.31          | Evaluate quality of dying experience by examining symptoms in the last week of life | 13/20 HNC patients who died in hospital had a DNR order in place; none underwent CPR or had an ICU admission. 17/32 (53%) needed emergency admissions in last month of life – most commonly due to bleeding; then pain, respiratory problems, swallowing problems, not coping and fractured leg. | Retrospective nature                                      |
| Fullarton et al.33           | Record characteristics, mode of death and potential indicators of the quality of care at the end of life for HNC patients | Main reasons for last admission to surgical ward prior to death were: for operation, airway management, or cancer diagnosis; 13/63 died suddenly within hospital ward. | Retrospective nature                                      |
| Heinen et al.35              | Describe current status of palliative care of HNC patients in one specific university hospital region | Median survival 11 months; during this time, 37/60 patients (66%) attended emergency department $>1x$ (range 0–6); 21 (35%) were hospitalised (most common reason was infection). 12/34 (35%) who were referred to the specialised palliative home care died at home versus 3/36 (12%) of those who weren’t supported. | Small numbers                                              |
| Henson et al.57              | Identify socio-demographic and clinical factors associated with end-of-life emergency department (ED) visits | Multiple ED visits in last month of life associated with diagnosis of lung or HNC (AOR 1.67, 95% CI 1.4–2.0). | Symptoms not systematically reported                        |
| Ledeboer et al.64            | Increase knowledge of how treatment and support are experienced by relatives of palliative HNC patients during the palliative stage and after death | 10/20 responses from relatives perceived the medical treatment as ‘too intrusive’ for the patient. | Issues relating to routinely collected data for example, quality of data coding |
| Mercandet et al.40           | Assess patient characteristics who were hospitalised in last days of life after being assisted by a home palliative care team | 138/550 (25.1%) admitted to hospital, of which 20 had HNC. Logistic regression analysis showed patients with HNC (OR 2.62, 95% CI 1.24–5.54, $p = 0.01$) and lung cancer more likely to die in hospital (but very small numbers). | Retrospective design Feedback from relatives subjective |
| Offerman et al.51            | Evaluate interventions/impact of newly established ‘Expert Center’ on palliative HNC patients as perceived by bereaved relatives | Relatives perceived a reduction in satisfaction with medical treatment (77% vs 81%) and poorer perceptions about whether HNC department did ‘everything to make life for the patient as comfortable as possible’ (64% vs 75%). | Some patients were in remission so views may alter as disease progresses |
| O’Sullivan and Higginson52   | Explore Irish HNC patient and care-givers views on EoL care | 13% relatives perceived the patient had treatment against their wishes. | Not specifically reported                                   |
| Randen et al.55              | Describe how palliative chemotherapy is prescribed at the end-of-life to patients | Patients found it challenging to discuss preferred focus of care and ACP. All tended to favour maximum medical interventions associating palliative care with ‘giving up’ or ‘losing the fight.’ Whereas family carers perceived quality of life should have more priority compared with quantity of life. | Not specifically reported                                   |
| Schuman et al.58             | Determine perceived quality of care for HNC patients at the end of their lives | Average of 82 days (median 46 days) between last administration of chemotherapy and death (for all cancer groups). Palliative anti-cancer treatments (radiotherapy ± chemotherapy) improved perceptions about managing symptoms and care at the time of death ($p = 0.011$, $p = 0.017$). | Poor response rate                                          |
| Ullgren et al.64             | Describe HNC patients referred to palliative care and how care transition from acute oncological to palliative care impacted on Health Related Quality of Life (HRQoL) and information Explore HNC patients’ HRQoL and perceived information | Palliative care group reported more frequent ER attendance compared with group without palliative care (18/43, 43% vs 22/114, 19%). | Different environment for using validated tool Small proportion referred to PC |

ACP: advance care planning; AOR: adjusted odds ratio; CI: confidence intervals; CPR: cardio-pulmonary resuscitation; DNR: do not resuscitate; Ed.: end-of-life; ER: emergency room; HNC: head and neck cancer; ICU: intensive care unit; OR: odds ratio; QoL: quality of life; SPC: specialist palliative care.
Table 5. Communication and decision-making issues in advanced head and neck cancer patients.

| Study | Aim | Main findings | Reported limitations |
|-------|-----|---------------|---------------------|
| Alt-Epping et al. 21 | Assess symptoms and psychosocial needs of patients with incurable HNC (at time of diagnosing incurability) | 5/22 HNC patients depended on tracheostomy | Small numbers |
| Forbes 31 | Outline nature, incidence and management of problems and the role of the hospice in the patients care | Had practical implications for conducting study – communication by telephone (e.g. for making appointments) not possible and needed face-to-face communication | Questionnaires not fully understood by participants |
| Lidstone et al. 42 | Assesses prevalence and severity of symptoms and concerns – identify patient groups who might benefit from routine SPC involvement in outpatient clinics | From 38 HNC patients, 20 (53%) reported communication as an issue | Not specifically reported |
| Lin et al. 43 | Describe symptom patterns of terminal HNC patients in palliative care unit | Patients could only communicate by writing | Not specifically reported |
| Sesterhenn et al. 44 | Describe end-stage disease in advanced HNC patients – circumstances of final period of life and describe period in hospice setting | Communication difficult for most patients (due to tracheostomy, respiratory secretions or tumour obstruction); only 4/16 able to talk regularly and most had tracheostomy | Not specifically reported |
| Chiu et al. 45 | Identify most frequently encountered ethical dilemmas in the palliative care unit | HNC patients had more ethical dilemmas – 1.75/patient compared with other cancer sites (except gastric cancer) | Not specifically reported |
| Dronkers et al. 46 | Investigate whether prognostic information on life expectancy is included during communication and diagnosis and treatment plans between physicians and HNC patients in all phases of illness | For 460 patients, the H0N patients reported the highest prevalence of problems with communication (50%) compared with other cancer groups | Statistical significance of association of communication difficulties with presence of a tracheostomy (p < 0.001) |
| Lidstone et al. 47 | Evaluate experience of GPs in the care of palliative HNC patients, experiences of communication and consultation of attending specialists | From 460 patients, 20 (53%) reported communication as an issue | Bias due to patient participants being more engaged in this topic and physicians being aware their discussions are recorded |
| Leedeber et al. 48 | Increase knowledge of how treatment and support are experienced by relatives of palliative HNC patients during the palliative stage and after death | Patients had more ethical dilemmas – 1.75/patient compared with other cancer sites (except gastric cancer) | Relatives feedback may not reflect actual patients’ perspective; time between death and questionnaire completion was a year; didn’t explore all head and neck specific issues |
| Offeman et al. 49 | Evaluate interventions/impact of newly established “Expert Center” on palliative HNC patients as perceived by bereaved relatives | After establishing an ‘Expert Centre’ for HNC care, bereaved relatives perceived improved satisfaction about level of communication with surgeon (78% vs 59% perceived it as ‘good/very good’) | Can’t be certain improvements purely relate to Expert Centre feedback from relatives subjective |
| O’ Sullivan and Higginson 50 | Explore Irish HNC patient and carers views on EoL care | Patients’ mean score on general communication subscale from ‘Quality Of Communication’ (QOC) questionnaire was 8.47 (SD = 1.80) (10-point scale) | Some patients were in remission so views may alter as disease progresses |
| Roscoe et al. 51 | Understand ways in which end-stage HNC patients and their oncologists talk about end-of-life issues | Patients’ mean score on general communication subscale from ‘Quality Of Communication’ (QOC) questionnaire was 8.47 (SD = 1.80) (10-point scale) | Small numbers (n = 14); patients only asked on one occasion |
| Schuman et al. 52 | Determine perceived quality of care for HNC patients at the end of their lives | Patients’ mean score on ‘Information and Communication’ was 61.700 (SD = 32.05) | Poor response rate |
| Gillen et al. 53 | Describe HNC patients referred to palliative care and how care transition from acute oncological to palliative care impacted on Health Related Quality of Life (HRQLs) and information | Patients’ mean score on ‘Information and Communication’ was 61.700 (SD = 32.05) | Retrospective nature |
| Xueeb et al. 54 | Explore local decision-making, from an ethical point of view, about HNC | Ten participants asked whether it was ethical to withhold treatment for low prognosis HNC patients, 6/10 agreed to withhold treatment and 7 considered this decision unethical (but emphasised informed consent should always take priority) | Different environment for using validated tool |

DNR: do not resuscitate; EoL: end of life; GPs: general practitioners; HNC: head and neck cancer; SD: standard deviation; SPC: specialist palliative care.
| Study             | Aim                                                                 | Main findings                                                                                                                                                                                                 | Reported limitations                                                                 |
|-------------------|----------------------------------------------------------------------|-------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|----------------------------------------------------------------------------------------|
| Chen et al.        | Determine impact of patient demographics, disease characteristics,    | More than half of 2881 participants expressed preference to die at home ($n = 1,114$, 54.7%)
                              | prognosis awareness and support network variables on preference for home death                                                                                                                               | Convenience sample limiting generalisability
                                                                 |                                                                                       |                                                                                         | Didn’t specifically look at hospice deaths (just home vs not home)                      |
| Fullarton et al.   | Record characteristics, mode of death and potential indicators of the  | From the 76 HNC patients, those dying in the hospice were younger compared with those who died in the hospital (mean age 63.7 (SD 11.0) years vs 70.6 (SD 11.9) years) | Retrospective nature
                                                                 | quality of care at the end of life for HNC patients                                      |                                                                                         | Missing data                                                                            |
| Kuo et al.         | Assess end-of-life care for patients with HNCs in Taiwan              | From 98,221 HNC patients, those who were male, lived in more urbanised areas, had a higher family income, received hospice care in last month of life, had been prescribed opioids in last 3 months of disease were more likely to die at home or in hospice wards
                                                                 | Those who received chemotherapy, surgery or radiotherapy in last month of life tended to die during acute in-hospital admission (and total medical costs were higher) | Heterogeneous group
                                                                 |                                                                                         | Limited number of hospice patients                                                      | Retrospective data analysis                                                                 |
| Lock and Higginson | Describe the older population who die of cancer and the factors which  | From 315,462 cancer deaths, hospice death was most common among those dying of HNC (19%)                                                                                                                   | Unable to explore reasoning for decision-making                                          |
| Shah et al.        | Estimate frequency of referral of HNC patients to ‘terminal care’     | Place of death identified for 51 HNC patients (from 74) – hospice ($n = 22$, 43%), home or nursing home ($n = 13$, 25%), hospital ($n = 16$, 31%)                                                                  | Small numbers
                                                                 | Ascertain where and when the patient died                                                |                                                                                         | Short duration                                                                          |
                                                                 |                                                                                         |                                                                                         | No details about specifics of palliative care/hospice care received                     |

AOR: adjusted odd ratio; HNC: head and neck cancer.
In the two larger studies (with more than 100 patients), more than 50% expressed psychological symptoms such as ‘worrying’, ‘fears’, ‘sadness’, or ‘depressed mood’. Being a burden on family carers was one specific concern raised. Within a further study, over a third (35%) of people with head and neck cancer were perceived to have some level of depression by their oncologist. Psychological symptoms manifesting as agitation or confusion were also reported during the final weeks prior to death.

Perceptions from family carers varied. In one study, the ‘emotional and spiritual’ support was rated more highly (and hence needs better met) compared with management of physical symptoms. In another, however, almost 70% bereaved relatives perceived improved psychosocial support was needed during the palliative phase of illness, which led to the development of an ‘Expert Centre’ to help address these unmet needs.

No study specifically focused on spiritual well-being. One qualitative study explored the ‘lived experience’ of having disfigurement and described the subsequent existential impact. A further study reported only 10/45 (23%) bereaved relatives perceived spiritual well-being.

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**Figure 1.** Flow diagram for the scoping review process.
support for head and neck cancer patients had been provided.43

**Medical interventions in the last 12 months of life**

Fourteen studies had a focus on medical interventions (Table 4). Generally, having head and neck cancer was associated with a high prevalence of ‘intensive’ interventions, especially in the last month of life. These interventions included emergency department attendance, cardio-pulmonary resuscitation, hospital admissions, intensive care admissions and ongoing chemotherapy.25,26,31,35,37,55,64 Factors associated with hospital admission included the presence of hypercalcaemia,21 respiratory or airway management issues,31,33 infection35 and problems relating to bleeding, pain and swallowing difficulties.34 Hospital admission could still occur frequently even when palliative care teams were involved.64 Two retrospective studies, conducted after death, reported that having head and neck cancer was associated with a greater risk of dying in hospital,25,49 although one study had very small numbers.49

Differing views were reported about the appropriateness of interventions. Patients could favour maximum medical interventions52 and bereaved relatives perceived the palliative anti-cancer treatments improved symptom management.58 On the other hand, however, bereaved relatives reported that treatments had been ‘too intrusive’ or not in keeping with the patients’ wishes.44,51

**Communication and decision-making**

Fifteen papers including a focus on communication and decision-making for head and neck cancer patients (Table 5). Five papers focused more on the prevalence of the practical difficulties and issues relating to poor speech.12,32,45,46,59 Issues relating to communication were more common compared with other cancers,45 especially if the patient had a tracheostomy.22,46,59

Ten of the papers focused on communicating information and decision-making.28,29,43,44,51,52,56,58,64,65 An interview study of medical professionals in Malta, explored ethical factors influencing decision-making about treatment. The majority who were interviewed (7/10) perceived the need to provide full treatment for people with head and neck cancer, even if the prognosis was poor. Most agreed, however, that the patient formed an important part in the decision-making process.45 In a study assessing the communication of prognosis between healthcare professionals and patients, different ways were recognised. These included the use of numerical probability estimates, qualitative language or a combination of both.29 Although perceptions by patients and/or family members about the quality of communication could be good,44,51,57,58 there were reports of patients misunderstanding or misinterpreting information.56 One study described poorer levels of understanding about their illness when patients were known to palliative care teams.64 Within another qualitative study, dissonance between patient and family members’ information preferences was described. Patients varied between wishing for ‘full disclosure’ and a more ‘passive approach’ whereas family carers favoured being fully informed.52 Further communication and decision-making challenges included the information transfer between different healthcare teams43 and the ethical complexities that can arise relating to hydration and nutrition.28

**Place of death**

Five studies focused on place of death, of which two were population-based40,47 and three were smaller cohort studies (two having less than 100 patients) (Table 6).27,33,60 From the population-based studies, a Taiwanese study reported over 70% head and neck cancer patients died in the acute hospital.40 By contrast, the other study, conducted within the UK, suggested that head and neck cancer was associated with an increased likelihood of dying in a hospice compared with other cancers.47

**Discussion**

**Summary of main findings**

Compared with other cancers, this scoping review confirms head and neck cancer patients often have complex palliative care needs, especially if there is a high degree of symptom burden. Variability in the timing and access to palliative care services, however, is recognised. Dissonance seen between patients and family carers, specifically about information needs and decision-making, are additional recognised complexities. A high prevalence of interventions such as emergency department attendance and hospital admissions occur for patients with advanced head and neck cancer even during the last weeks of life. Sole engagement with palliative care services does not necessarily negate this.

Research in this area has tended to be via single centre, quantitative studies. Few qualitative studies have been conducted with advanced head and neck cancer patients and none have focused purely on the spiritual well-being of head and neck cancer patients. There were no interventional studies identified.

**What this study adds and implications for practice and research**

The key questions facing palliative care services surround the identification of who is in greatest need of referral, how these individuals should be identified, and what
model of care should be provided. \textsuperscript{66} These questions are particularly pertinent for head and neck cancer patients who undoubtedly have palliative care needs, but for whom the method of identification and the optimum model of care provision is less clear. Our review shows variability in access to palliative care services with some patients receiving referrals late and certain groups, such as older, white, female patients, more likely to be referred.

In view of the ‘scarcity of palliative care resources,’\textsuperscript{66} there are a number of potential ways to help identify which head and neck cancer patients would most benefit from palliative care input. Specific ‘triggers’ are recognised to help prompt palliative care consults in the emergency department, in-patient wards\textsuperscript{67} and from oncology services.\textsuperscript{68} These are generic tools aimed to screen a large population, however, rather than having been specifically validated within the head and neck cancer remit. More individualised ways to help illustrate patients concerns include the use of Holistic Needs Assessment (HNA) tools,\textsuperscript{69} and Patient Reported Outcome Measures, of which a vast array have been used within head and neck cancer.\textsuperscript{70} The Patient Concerns Inventory (PCI) is an item-prompt list specifically used to guide head and neck cancer clinical consultations including wider multi-professional engagement. Although extensively used globally, its focus of use has been with curative head and neck cancer patients, but it has potential to be adapted.\textsuperscript{71} Further research into which ‘screening’ tool or method would be most appropriate for initiating palliative care referral for head and neck cancer patients seems pertinent. Furthermore, clarity about how best to incorporate specific staging indicators for those recognised to be ‘high risk’\textsuperscript{72} in additional to individual patient needs would seem beneficial.

As well as establishing equitable referral methods, defining an appropriate model of integrated care is needed. This poses a further challenge for advanced head and neck cancer patients. Our review indicated there was a high level of interventions needed and a reliance on hospital-based care even during the last weeks of life. This finding may relate to issues arising from the use of feeding tubes and tracheostomies to help sustain vital function, and the fact that hospital admissions were commonly testing specific components of models of care would be beneficial. A broader approach to assessing holistic care, including the spiritual component, would also be important.

\textit{Strengths and limitations}

This scoping review followed an established systematic method and examined a breadth of different experiences.
and needs for a particularly complex subgroup of cancer patients. Our search included studies from a diverse range of countries and cultures and hence has wide-ranging relevance.

There were, however, limitations to this review. We did not conduct hand searching of key journals and grey literature was not included. Our definition of ‘advanced cancer’ was qualitatively defined rather than using specific disease staging criteria and we did not conduct additional searches using ‘place of death’ as a key search term. Additionally, we only included English language publications. In view of all these factors, some sources of data may have been overlooked. We did not focus on family carer needs per se but accept that this is an important area and would represent a focus for future study. Finally, we did not include a quality appraisal of all included studies, as within the remit of scoping reviews, risk of bias/quality appraisal is not generally recommended.17

Conclusion

This scoping review has demonstrated the complexity of care for people with advanced head and neck cancer and that there are issues related to the current healthcare systems. Specific focus is needed about the optimum way those in greatest need should be identified and referred to palliative care services. Additionally, further clarity and assessment about the particular model of integrated care is required, which can address the diverse symptom needs, the communication needed to further inform decision-making, and the frequent use of interventions and issues that can arise ‘out-of-hours’ relating to these. Linkage between research and service design delivery across teams, disciplines and care settings seems key for future success.

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Authors contributions

C.R.M. and P.D. conceived and designed the study with specific contributions from S.R.N. and S.M. Q.M.H., M.C. and C.M. completed all the searches and conducted the initial screening. Full manuscript reviews were conducted by C.R.M., P.P., P.C., H.C.D. and P.D. C.R.M. and P.D. analysed and interpreted the data. C.R.M. drafted the manuscript and all authors have approved the submitted version.

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Ethics

As this study represents a scoping literature review, not formal ethics approval was required.

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Data management and sharing

Further information about the search strategies are available from the corresponding author on reasonable request.

Supplemental material

Supplemental material for this article is available online.

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