


ORIGINAL ARTICLE

The unmet needs of patients with advanced incurable head and neck cancer and their carers: A systematic review and meta-ethnography of qualitative data

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Abstract

Introduction: Patients with advanced-stage head and neck cancers (HNC) endure a significant symptom burden and suffer greatly towards the end of their lives. Qualitative evidence can provide insight into how existing services meet their needs. We aimed to synthesise qualitative data from patients with advanced HNC and their carers to inform improvements to services and care.

Methods: A systematic search was conducted in MEDLINE and EMBASE for studies containing qualitative data from patients with advanced HNC and their carers. An interpretive account was generated using the meta-ethnography methodology.

Results: We identified 8 studies including 38 patients and 25 carers. Twenty-six themes were synthesised into five concepts: psychological impact and adjustment, physical limitations and deliverance of symptomatic care, communication and information needs from healthcare professionals, social support and dependence, and needs of the primary caregiver. We identified that patients had complex psychological needs, centred on uncertainty and fear of suffering. Patients desired full information and found poor communication highly distressing. There was a dearth of literature on the subjective impact of physical limitations. Patients became reliant on social networks, and those with lower quality relationships coped poorly. However, caregivers struggled to meet patients' complex needs, resulting in distress and isolation.

Conclusions: Patients with advanced HNCs have complex needs that are not met in current systems. Further qualitative work focusing on the physical and psychological impact of advanced HNC would be of value.

KEYWORDS

advanced cancer, head and neck carcinoma, meta-synthesis, qualitative research

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1 | INTRODUCTION

Head and neck cancers (HNC) have a poor prognosis, with approximately a 20% mortality within a year of diagnosis (Medow et al., 2002). Up to 50% of patients present with advanced stage III or IV disease (Cooper et al., 2009), with approximately 20% being treated with palliative intent (Begbie et al., 2019). Furthermore, despite treatment, many patients develop recurrent disease (Coatesworth et al., 2002), following which their median life expectancy is less than 1 year (Price & Cohen, 2012).

Patients with advanced HNC struggle with a unique symptom burden due to both the cancer and the treatments they receive. Local tumour involvement of the aerodigestive tract can affect swallowing, nutrition, hydration, speaking, communication and breathing (Lokker et al., 2013). There are often residual side effects from treatment, such as dry mouth, altered facial appearance, pain and fatigue (Alt-Epping et al., 2016). Up to 40% of patients with advanced HNC become tracheostomy-dependent (Tennant et al., 2014), impairing communication and their ability to engage family, friends and health services (Alt-Epping et al., 2016). Beyond the physical symptom burden, HNC patients are prone to anxiety and depression which are associated with lower quality of life (QOL) (Barber et al., 2016; Dunne et al., 2017). The range and severity of such symptoms make the provision of adequate supportive care in HNC incredibly challenging, particularly for patients with advanced disease who are the most in need of this care.

For patients with incurable disease, the focus of care is on maintaining QOL and controlling symptoms. Little data are available on the care delivered at the end of life in advanced HNC patients, but most patients undergo invasive interventions such as radiotherapy, surgery, gastrostomy insertion or tracheostomy (Heinonen et al., 2018; Schwam et al., 2015). Furthermore, hospitalisations and in-hospital deaths are frequent and, conversely, engagement with palliative care services is low (Heinonen et al., 2018; Schwam et al., 2015). Mode of death is often unpredictable with predisposition to catastrophic terminal haemorrhage or asphyxiation, which are both sudden and distressing for the patient and their family (Fullarton et al., 2016).

Due to their symptom burden, patients with advanced incurable HNC often come to rely upon their family and friends quite considerably (Maguire et al., 2017). These informal caregivers have to adjust to a new role that takes up much of their time, whilst being both physically and psychologically burdensome (Maguire et al., 2017).

It seems likely that improvements to care would be warranted for those with advanced HNC. However, understanding what changes could, or should, be made relies on having a thorough understanding of the failings of the current systems. Qualitative studies allow in-depth exploration of patients' (and carers) experiences. Collation of the existing qualitative evidence could identify gaps in knowledge, demonstrate the strengths of the current system, highlight aspects of care which could be improved and inform future directions for the development of complex interventions to support advanced HNC patients at the end of their life. The aims of this study were to

systematically identify and synthesise the existing qualitative evidence from patients with advanced incurable HNC and their carers to better understand their unmet supportive care needs.

2 | METHODS

This review was registered on PROSPERO, ID: CRD42019127863.

2.1 | Search strategy

A systematic search of MEDLINE and EMBASE databases was performed identifying papers published prior to 1 November 2020. No limits were placed on date or language. Thesaurus terms and key words relating to qualitative research in patients with advanced HNC were searched (Table 1). Forward and backward citation searching were performed for each eligible paper to identify any further relevant studies.

2.2 | Paper selection

All abstracts were screened independently by two reviewers (ASN & LC) to determine eligibility for inclusion in the final synthesis. The full text of papers identified as being potentially eligible was assessed independently by two authors (ASN & LC) to determine relevance eligibility. Disagreements were settled by discussion between these authors and, if required, consultation with other authors.

2.3 | Inclusion/exclusion criteria

Inclusion criteria:

- Full-length research articles published in a peer-reviewed journal
- Original data exploring the beliefs, experiences, perceptions or feelings of patients with advanced incurable HNC or their caregivers
- Qualitative methodology
- Studies with mixed methodologies where the qualitative data for HNC patients (or caregivers) were reported separately from quantitative data

Exclusion criteria:

- Studies including mixed cancers in which the qualitative data from HNC patients (or caregivers) were not reported separately.
- Studies including HNC cohorts where the patients with advanced incurable disease could not be separated.
- Studies in which data were collected only from healthcare professionals involved in caring for HNC patients.
- Abstracts
- Non-English manuscripts

TABLE 1 Medline Search strategy of MeSH terms and free text terms

1	(Head and neck neoplasms) OR exp Laryngeal neoplasms/ OR Pharyngeal neoplasms/ OR Otorhinolaryngologic neoplasms/ OR exp Laryngectomy/ OR HNSCC OR SCCHN
2	Exp Neoplasms/ OR cancer OR cancers OR cancerous OR carcinoma* OR Neoplas* OR tumor* OR tumour* OR malignan*
3	Oral OR oropharynx* OR hypopharynx* OR Larynx* OR nasopharynx* OR pharynx* OR throat OR mouth OR (head adj3 neck)
4	#1 OR (#2 AND #3)
5	exp Palliative Care/ OR exp Terminal Care/ OR Terminally ill OR (supportive care) OR Palliat* OR Terminal* OR endstage OR hospice OR (end adj3 life) OR (care adj3 dying) OR ((advanced or late or last or end or final) adj3 (stage* or phase*))
6	exp Qualitative research/ OR exp interviews as topic/ OR focus groups/ OR narration/ OR "surveys and questionnaires"/ OR self report/ or exp attitude/ or exp tape recording/ OR (group discussion) OR (patient preference) OR (thematic* adj3 analysis*) OR interview
7	#4 AND #5 AND #6

2.4 | Synthesis

We employed the synthesis methodology of meta-ethnography as described by Noblit and Hare (Noblitt & Hare, 1988). The aim of this approach is to produce an "interpretive rather than aggregative" account of the studies to allow a more in-depth understanding of the patient experience (Noblitt & Hare, 1988). Meta-ethnography involves three levels of construct: i) first-order constructs (direct quotations from study participants describing their experience); ii) second-order constructs (interpretation of participants' experiences by original study authors'); iii) third-order constructs (the summation of first- and second-order constructs by the meta-synthesis team).

Two authors (ASN and LC) familiarised themselves with the included papers through multiple reads and independently extracted second-order constructs with the supporting first-order constructs for each. Once collated, these data were compared to the original studies to ensure accurate and complete representation of their content. The validated second-order constructs were synthesised into third-order constructs by implementing the lines of argument approach (Noblitt & Hare, 1988). This technique involves identifying new interpretations which encompass the second-order constructs across studies. ASN led the synthesis of third-order constructs which were then reviewed and checked by a second author (LC).

2.5 | Quality appraisal

Included papers were appraised independently by two authors (ASN and LC) using the Critical Appraisal Skills Programme checklist (CASP) (Critical Appraisal Skills Programme, 2018). This tool was selected due to widespread use in previous qualitative meta-syntheses. The CASP checklist involves ten questions of which the first two are screening questions. We scored the final eight questions as weak, moderate or strong and assigned a score of one to three, respectively. This generated an overall score in the range 8–24, with 24 representing a paper that scored as strong in all eight

domains. We did not exclude papers from the synthesis based on their adjudged quality. The CASP scores have been provided to aid the interpretation of the included papers.

3 | RESULTS

3.1 | Study characteristics

Database searches generated 3478 unique records, with 51 full texts being assessed resulting in eight papers which met the criteria for inclusion in the final synthesis (Foxwell & Scott, 2010, 2011; Lewis et al., 2014; Mayland et al., 2020; O'Sullivan & Higginson, 2016; Penner et al., 2012; Richardson et al., 2002; Roscoe et al., 2012) (Figure 1). Two of these papers were analyses of data from the same study and have been considered together (Foxwell & Scott, 2010, 2011). All papers were published between 2002 and 2020, with none identified prior to 2002 despite the search strategy allowing for these. Overall, included in these studies were 38 patients and 25 caregivers (Table 2). None of the studies were longitudinal, and the time point in relation to disease progression at which data were collected varied across studies. Study demographics are demonstrated in Table 2.

3.2 | Quality appraisal

The range of CASP scores for the included studies was 12–21, with a mean overall score of 17.3 out of a possible 24 (Table 2).

3.3 | Synthesis

Table 3 shows the twenty-six second-order constructs identified from the included studies and illustrative first-order constructs (quotes) (Table 3). These were synthesised into five third-order

TABLE 2 Study demographics of papers included within the final metasynthesis with assigned quality score following independent review by two authors using the critical appraisal skills checklist (CASP)

First Author	Year	Title
Foxwell	2010	Exploring the concerns and needs of patients with terminal head and neck cancer and their caregivers
	2011	Coping together and apart: exploring how patients and their caregivers manage terminal head and neck cancer
Lewis	2014	Social capital in a lower socio-economic palliative care population: a qualitative investigation of individual, community and civic networks and relations
Mayland	2020	A qualitative study exploring patient, family carer and healthcare professionals' direct experiences and barriers to providing and integrating palliative care for advanced head and neck cancer
O'Sullivan	2016	I'll continue as long as I can, and die when I can't help it': a qualitative exploration of the views of end-of-life care by those affected by head and neck cancer (HNC)
Penner	2012	Family members' experiences caring for patients with advanced head and neck cancer receiving tube feeding: a descriptive phenomenological study
Richardson	2002	Learning from patients with cancer and their spouses: a focus group study
Roscoe	2013	Beyond good intentions and patient perceptions: competing definitions of effective communication in head and neck cancer care at the end of life.

constructs (Table 4) through the process of meta-ethnography, including.

1. Psychological impact and adjustment
2. Physical limitations and deliverance of symptomatic care
3. Communication and information needs from healthcare professionals
4. Social support and dependence
5. Needs of the primary caregiver

3.4 | Psychological impact and adjustment

This construct relates to the psychological morbidity associated with a diagnosis of advanced HNC, and the coping mechanisms employed to help patients to adjust. Five second-order constructs from three papers contributed to the synthesis of this concept (Table 4).

The uncertainty associated with cancer was addressed by both patients and caregivers. This unpredictability often resulted in feelings of helplessness about their ability to influence the trajectory of cancer care, and powerlessness in influencing the eventual outcome.

"I can go to a fork, I can go to the left or to the right, but it's not going to make any difference 'cos it's still going to join up the road up a bit" (Male patient, 64 years) (Foxwell & Scott, 2010).

"That is living with cancer, because it... it, you don't know what's quite going to happen" (Female carer, wife, 69 years) (Foxwell & Scott, 2010).

Often the uncertainty related to the fear of suffering or the misery a protracted death. However, the uncertainty surrounding death was not always regarded as a negative, as some thought a prior knowledge of future suffering would only evoke further distress. Furthermore, the fact that the uncertainty existed allowed room for hope, specifically the hope that death would be quick and painless when the time came.

"With cancer you don't want to know dates beforehand, you just want to let it [death] happen." (Male patient, 53 years) (Foxwell & Scott, 2010).

"I hope to wake up one day and say 'oh my God I don't feel very well' bang and it's over [...] It's a shock for everybody around, but it, it's job and done" (Male patient, 64 years) (Foxwell & Scott, 2010).

There was difficulty in coming to terms with the diagnosis of an incurable cancer, and patients displayed varying coping strategies. Some were in denial, believing that accepting the diagnosis of an incurable cancer was akin to giving up.

"I can't, I won't accept, I've got to accept, but I don't want to accept it, because if you do, I think you give in... And it's just not my character" (Male patient, 64 years) (Foxwell & Scott, 2011).

Others chose to ignore their situation in the hope that a solution would come about on its own.

Interviewer: "When you do have any particular problems, how do you generally deal with them?"

Journal	Setting	Sample	Method: Data Collection	Method: Data Analysis	CASP Score (0–24)
Social Science & Dentistry Journal of Psychosocial Oncology	UK	7 patients & 6 caregivers	Individual Semi-structured interviews	Framework analysis	18
BMC Palliative Care	Australia	1 patient	Semi-structured Interviews	Framework analysis	17
Journal of Palliative Care	UK	9 patients, 4 caregivers	Semi-structured interviews	Thematic analysis (modified Colaizzi's framework)	20
BMJ Supportive & Palliative Care	Ireland	7 patients, 3 caregivers	Semi-structured interviews	Thematic content analysis	19
Journal of Pain and Symptom Management	Canada	6 primary caregivers	Interviews—unspecified	Speigelberg's three-step process	20
The journal of Laryngology and Otolaryngology	UK	6 carers of deceased patients	Focus Groups	Unspecified	15
Health Communication	USA	14 patients	Interviews—unspecified	Open coding	12

Patient: "Well, I just deal with them, I don't do. They most often go away anyway on their own. Which I think that's the way Social Services work, if they sit down and [...] drink enough tea and eat enough biscuits, the problem usually goes away on its own." (Male patient, 65 years) (Foxwell & Scott, 2011).

"The best advice I ever, ever had in all the years (was) [...] 'don't be so conceited—we've all got problems of our own, nobody's taking notice of you.'" (Female patient, 78 years) (Foxwell & Scott, 2011).

The concept of facing mortality evoked mixed emotions. Two common issues that emerged were as follows: a desire to exert control over their death and concerns about their loved ones. Almost universally, patients wished for a home death, finding comfort from their own surroundings.

"home is the best place because it's your own bed and you know where everything is" (Patient, age and gender uncertain) (O'Sullivan & Higginson, 2016).

"I want to stay in my own home for as long as possible... in the home environment you still have personal things around you, you're still able to move around your personal space whereas in a hospice or acute ward it's more regimented" (Patient, age and gender uncertain) (O'Sullivan & Higginson, 2016).

However, some were less focussed on the place of death and more on the avoidance of suffering.

"For me myself, its not only the actual comfort I want, it's the mental issue of feeling that I'm here [hospice] because I'm going to die" (Patient, age and gender uncertain) (O'Sullivan & Higginson, 2016).

"I'd be happy anywhere, anywhere at all as long as I could get a treatment – that's all I'd want" (Patient, age and gender uncertain) (O'Sullivan & Higginson, 2016).

Others found comfort in being able to plan their funeral, or in having time to spend with their family.

"I'm trying to make notes to arrange my own funeral. Oh I don't want that, and I won't have that..." (Female patient, 78 years) (Foxwell & Scott, 2010).

Some patients expressed their desire for direct psychological support which they felt had not been appropriately addressed in the current healthcare system.

"Just having somebody to explain or ask you what your fears are" (Female Patient, 60–69 years) (Mayland et al., 2020).

"I wish when I was diagnosed I could have been put in the direction of a head and neck support team, with people that have been through this." (Male patient, 60–69 years) (Mayland et al., 2020).

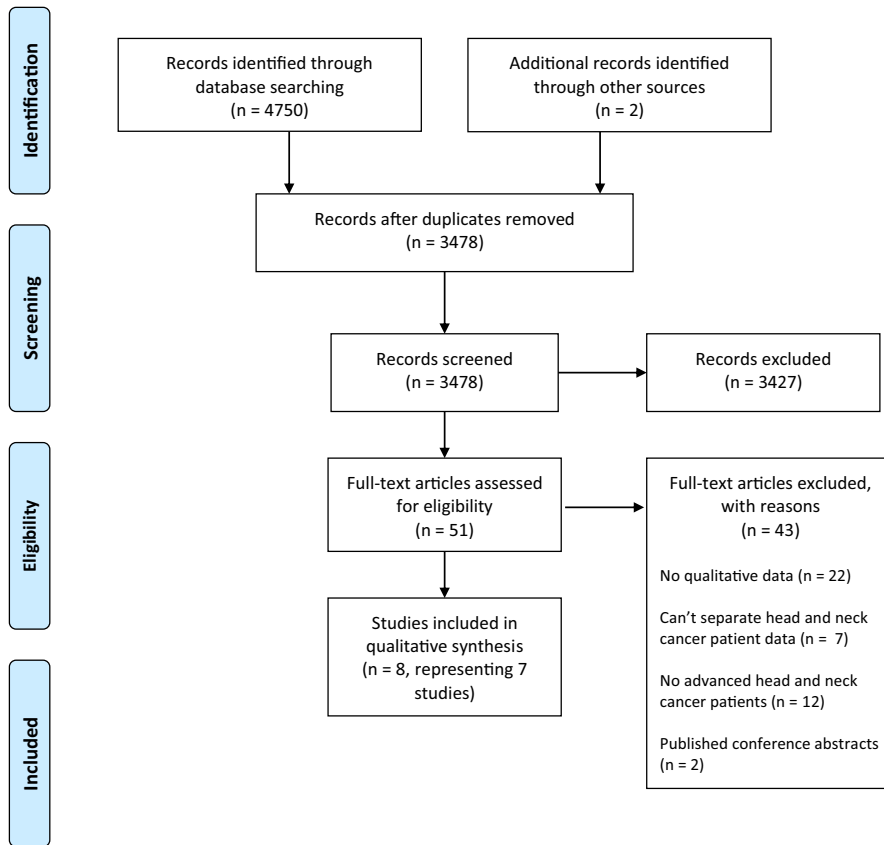


FIGURE 1 PRISMA flow diagram representing the stages of the search strategy and paper review process

3.5 | Physical limitations and deliverance of symptomatic care

This construct relates to the patient experience of the symptomatic burden associated with an advanced HNC and/or its treatment. This construct also encompasses the patient experience of interventions intended to relieve their symptoms, and the benefits or limitations of these services. Six second-order constructs from four papers contributed to the synthesis of this concept (Table 4).

Only one paper briefly addressed the physical symptoms or limitations of this group, discussing the restrictions suffered due to pain, fatigue or loss of independence of feeding or mobilisation (Foxwell & Scott, 2010).

"I seem to be getting a bit more pain now, and uh, I don't have much energy" (Male Patient, 65 years) (Foxwell & Scott, 2010).

"If I'm left on my own I can't do nothing" (Male patient, 53 years) (Foxwell & Scott, 2010).

"He keeps having to ask anybody to do anything. He thinks... 'why should I have to ask? Why can't I do it myself?'" (Male caregiver, friend, 57 years) (Foxwell & Scott, 2010).

Views on palliative care were addressed in the same paper by the same patient-carer dyad, with evident misconceptions about the role of this service.

"we've told friends that (name) seen a palliative care consultant and you can see them going... as if palliative care is in the last 6 weeks of your life." (Female caregiver, wife, age uncertain)

"the District Nurse who we saw first, I think was quite an experienced district nurse, clearly though the way that most people think about palliative care, is that they're the people that come in in the last 6 weeks of life" (Male patient, 60–69 years).

3.6 | Communication and information needs from healthcare professionals

This construct relates to the experiences of patients and their caregivers regarding their communication with healthcare professionals. It encompasses what information they desired to acquire from these encounters, and how their care plan was formulated. Six second-order constructs from five studies were synthesised to generate this concept (Table 4).

TABLE 3 Second order constructs extracted from each paper with an example first order construct (direct quotation from patient or carer)

Study	Second-order Constructs	Example of a Supporting 1st Order Construct
Foxwell (2010, 2011)	Physical symptoms and limitations	"If I'm left on my own I can't do nothing."
	Impact on caregiver	"it's breaking his heart, I know."
	Confronting death	"I'm trying to make notes to arrange my own funeral. Oh, I don't want that, and I won't have that..."
	Loss of control	"I can go to a fork, I can go to the left or to the right, but its not going to make any difference 'cos it's still going to join up the road up a bit."
	Support from healthcare professionals	"But you get the feeling that you can't ask Dr., well they haven't got the time."
	Individual coping strategies	"I can't, I won't accept, I've got to accept, but I don't want to accept it, because if you do, I think you give in... And it's just not in my character."
	(lack of) Social support and communication	"If you've got either a daughter or a best friend, it's to talk to them. I think that is good, I don't think I could have coped without my daughter."
	Co-dependence of caregiver and patient	"we'll talk – I'll tell him and he'll tell me, Well, we're sort of one person really."
Lewis (2014)	Quality of social relationships	[on describing the relationship with her spouse] "it's not excellent...fair".
	Level of community support	"... I hardly know anyone either... they generally get on well, mainly because they just don't communicate with one another."
	Social isolation	"We used to go down the club. I don't go on my own as I feel very self-conscious."
Mayland (2020)	Lack of preparedness when transitioning from curative to incurable	"until yesterday or the day before, I had no idea they were going to say you know, well this is it and you only have a few weeks, I had no idea that was going to happen at all."
	Uncertainty about meeting psychological needs	"... I don't feel that she (my partner) has had enough support, and I do worry about that... I think that's where you would need the HCPs to be even more supportive to these people, and so they get the additional support they need."
	Misconceptions about palliative care	"... we've told friends that (name) seen a palliative care consultant and you can see them going... as if palliative care is in the last 6 weeks of your life."
O'Sullivan (2016)	Information on prognosis	"If you're given straight answers you are able to set the goalposts and you know where you're aiming for."
	Shared decision making	"you can't make that decision without consulting your partner. It's my decision but I think you have to pay consideration to those who are around or behind you."
	Focus of care	"I'd continue as long as I could and die when I can't help it."
	Preferred place of care and death	"There's nowhere like home... your home environment is terribly important... hospitals are clinical and impersonal and all you're looking at is illness."
	Barriers to home care	"I suspect 9 times out of 10, dying at home isn't an option because the impact on the immediate family is too great... myself and my wife, that's the family... so, its all going to fall on her shoulders and that is colossally unfair."
Penner (2012)	Caregivers—adjustment to new role	"Three months before you're going merrily along in life and then all of a sudden you've got all these things coming at you that are new and just a little intimidating."
	Caregivers—restricted daily life	"we're two older people who have always had the freedom just to pick up and go wherever we wanted, when we wanted. And we really don't have that now."

(Continues)

TABLE 3 (Continued)

Study	Second-order Constructs	Example of a Supporting 1st Order Construct
Richardson (2002)	Communication of bad news	"There's so many words now... and half the people don't understand what they're talking about. I think it should be told that it's cancer."
	Provision of palliative care	Strong opinions expressed from focus group of bereaved carers about provision of palliative care and post-bereavement support. No first order constructs provided.
Roscoe (2013)	Communicating with healthcare professionals	"My Doctor was not warm, inviting or [maybe] in a hurry. I didn't feel comfortable taking [the doctor's] time."
	Information on prognosis	"... some questions you're afraid to ask and some you want to know and had to ask, but my doctor did not volunteer information."
	Misinterpretation of information	"My doctor told me that my cancer can't be cured, but that doesn't mean I'm dying."

The majority of patients and carers desired accurate and honest information from their clinicians (O'Sullivan & Higginson, 2016; Richardson et al., 2002; Roscoe et al., 2012).

"They should say these are your options, this is what we can do... as much information as they can give you. They should be prepared to sit there and talk with you. Knowledge is power and to share that knowledge is to share power. It's my body – I want to know all about it and have a voice" (Patient, age and gender uncertain) (Richardson et al., 2002).

Accurate and complete information regarding their prognosis and healthcare needs allowed patients to be better prepared for their cancer journey (Table 5.1).

Most patients, and carers, extended the wish for full disclosure to include information regarding a poor prognosis (Table 5.2).

One caregiver highlighted her frustration that specific prognostic information could not be delivered.

"He did ask "how long do I have left" and he did say "well I can't give you years, I could give you months, I could give you 12, I could give you 3. I don't know." So, you're always coming out of those places thinking, oh I wish, but I don't think they even know themselves to be frank. Then you think, well you see this everyday so come on, you must know something." (Female carer, Wife, age uncertain) (Mayland et al., 2020).

However, a minority of patients and carers did not wish to be informed about an unfavourable prognosis. Potential for conflict was identified when the wishes of the patient and the carer did not align (Table 5.3).

A common theme was that some sensitive information was only provided when it was asked for. Whilst some were happy with this, others wished for more information to be volunteered; they were

reluctant to ask daunting questions and perceived that this might be wasting the clinicians' time (Table 5.4).

The method of communicating sensitive information regarding prognosis was found to be poor, with specific reference to the setting and lack of follow-up (Table 5.5).

In one study, two caregivers were highly distressed by the lack of clear communication they had experienced (Foxwell & Scott, 2010). However, there was some incongruity between these caregivers and the respective patients. One of the patients in question had also found communication unclear, but did not express the same negative emotions, whilst the other patient did not express any concerns about the information she had received (Table 5.6).

3.7 | Social support and dependence

This construct relates to the dependence of HNC patients on their family, friends or caregivers and the implications of their terminal prognosis on these relationships. Furthermore, it encompasses socially isolated patients and considers the implications of isolation during the end-of-life phase. Six second-order constructs from three studies contributed to the synthesis of this concept (Table 4).

Concepts of co-dependence emerged from patients and carers who had long and sustained relationships, mainly marriages. Co-dependence allowed them to tackle problems as a team, whilst the prioritisation of the needs of the other provided purpose and the ability to cope.

"We'll talk – I'll tell him, and he'll tell me. Well, we're sort of one person really" (Female carer, wife, 69 years) (Foxwell & Scott, 2011).

"She's be lost without me, I'd be lost without her, we do so much for each other, with each other... We're tied together with an invisible string" (Male carer, husband, 73 years) (Foxwell & Scott, 2011).

TABLE 4 Third order constructs with demonstration of the second order constructs included in their synthesis and the papers which contributed to each

Concepts (Third order constructs)	Translated Second-order Constructs	Studies included in theme
Psychological Impact and Adjustment	Individual coping strategies	Foxwell (2010, 2011)
	Confronting Death	Mayland (2020)
	Loss of control	O'Sullivan (2016)
	Preferred place of care and death	
	Uncertainty about meeting psychological needs	
Physical limitations and deliverance of symptomatic care	Physical Symptoms and Limitations	Foxwell (2010, 2011)
	Focus of Care	Mayland (2020)
	Preferred place of care and death	O'Sullivan (2016)
	Barriers to home care	Richardson (2002)
	Provision of Palliative care	
	Misconceptions about palliative care	
Communication and Information Needs from Healthcare Professionals	Support from healthcare professionals	Foxwell (2010, 2011)
	Information of prognosis	Mayland (2020)
	Shared decision making	O'Sullivan (2016)
	Communication of bad news	Richardson (2002)
	Communicating with healthcare professionals	Roscoe (2013)
Social Support and Dependence	Lack of preparedness when transitioning from curative to incurable	
	Social support and communication	Foxwell (2010, 2011)
	Co-dependence of caregiver and patient	O'Sullivan (2016)
	Quality of social relationships	Lewis (2014)
	Level of community support	
	Social isolation	
Needs of the Primary Caregivers	Shared decision making	
	Impact on caregiver	Foxwell (2010, 2011)
	Co-dependence of caregiver and patient	Penner (2012)
	Caregivers—adjustment to new role	
	Caregivers—restricted daily life	

"You can talk about something [...] it just means... you're not sitting there blankly looking at each other, thinking oh goodness, you know" (Female carer, wife, 48 years) (Foxwell & Scott, 2011).

Patient: "She's managing enough, I think she's alright, for all the time she can help me."

Interviewer: "You think her helping you?"

Patient: "Helps her." (Male patient, married, 73 years) (Foxwell & Scott, 2011).

"It is a relief to know that if you need something there are people there who will come and help you" (Female carer, wife, 48 years) (Foxwell & Scott, 2011).

However, the benefit of such social support seemed dependent on the strength and personalities within the relationship. One patient, although she had a partner, was pessimistic about the quality of their relationship: "its not excellent" and had little in the way of further social support (Lewis et al., 2014). Others expressed their desires for communication and discussion regarding end-of-life issues, but had been unable to do so with their family:

"I want to talk to her [his wife] and she's not there (Male patient, married, 53 years) (Foxwell & Scott, 2010).

"I cannot believe that there is an afterlife. I just think I'll just go to sleep. But I need to talk about it. My daughter gets 'Mum, how can you be a Christian' she won't discuss it, she just thinks I'm an awful person as far as that's concerned. And my son just says 'well you're happy to believe in that, that's alright. He doesn't discuss it either.'" (Female Patient, married with children, 78 years) (Foxwell & Scott, 2010).

The experiences of two socially isolated patients with HNC were captured (Foxwell & Scott, 2011; Lewis et al., 2014). One study, which focussed on the experiences of palliative care in patients from poorer socio-economic classes, included one female patient with HNC. She perceived that her cancer had resulted in facial disfigurement, resulting in self-consciousness which prevented social interaction.

"We used to go down the club. I don't go on my own as I feel very self-conscious". (Female patient, age uncertain) (Lewis et al., 2014).

A socially isolated male patient with no caregiver found some comfort merely from the presence of others (Foxwell & Scott, 2011):

Interviewer: "What is it [...] that's good about going to the pub?"

Patient: "I don't know, I guess it's just the people around me [...] it's all strangers, I don't talk to anyone." (Male patient, isolated, 65 years) (Foxwell & Scott, 2011).

3.8 | Needs of the primary caregiver

This construct relates to the experiences of the primary caregiver of a patient with advanced HNC as they adapted to their role. It encompasses struggles which they faced and experiences of engaging with any services which may have supported them. Four second-order constructs from two studies contributed to the synthesis of this concept (Table 4).

Adjustment to the role of "caregiver" came as a shock to many, and although they desired to provide care for their loved one, many expressed concerns about their ability to transition to the role and balance it with their other commitments. The complex needs and rigid schedules evoked frustrations and had a drastic impact on the life of the caregiver. The inability to fully empathise with the unique symptom burden was discussed by some caregivers and contributed to their frustrations (Table 6.1).

Caregivers struggled to provide for the physical needs of the patients. A variety of reasons for this emerged, including lack of medical knowledge, unpredictable and complex needs of the patient, and physical limitations of the caregiver. The struggles of the caregivers could be detrimental to patient care, especially regarding the ability to provide end-of-life care at home (Table 6.2).

However, some caregivers found that with experience they were able to adequately provide care, such as feeding, and found the role rewarding.

"Practice makes perfect, I guess... we got to know how to set it up and we knew to watch the drip and the speed of the drip and we could adjust it and... gosh, we just got so good ... We were quite proud of ourselves once we got on to this. You know, we thought we were the only ones who knew how to do it." (Caregiver, age, gender and relationship uncertain) (Penner et al., 2012).

The role of caregiver had psychological and social implications, including feelings of guilt, social isolation and a perceived lack of support—including at the time of bereavement (Richardson et al., 2002). The burden on their caregiver was often evident to the patient (Table 6.3).

4 | DISCUSSION

This is the first meta-synthesis pertaining to the needs of patients with advanced incurable HNC and their carers. It demonstrates the information and social needs of the patients as well as the needs of

those caring for patients with advanced HNC. However, whilst some of the physical and psychological needs have been revealed, what is perhaps more evident is the lack of qualitative evidence exploring these concepts.

The studies included within this review have explored some of the psychological needs of patients with advanced HNC, including uncertainty, difficulties coping with the diagnosis and end-of-life issues. However, due to limited data, it is not entirely clear how these differ from those of HNC patients with earlier stage disease (Lang et al., 2013), and research to unpick this would be of value. Experiences demonstrated how patients have adopted negative coping strategies such as denial, which may inhibit their engagement with palliative care services and prevent advanced care planning. Furthermore, the desire for better psychological support was expressed. These findings highlight the need to develop services to provide psychological support for these patients, which may translate to better engagement with supportive care. This will improve the care delivered to patients with advanced incurable HNC patients and simultaneously reduce the burden and morbidity experienced by carers.

Our review demonstrated that communication of information is highly varied in terms of both clinical practice and patient and carer desires. When patients and/or caregivers perceived information from clinicians to lack clarity, particularly concerning prognosis, it led to pre-occupation and considerable distress. This underlines the importance of exploring what information individual patients desire and addressing this as best as possible. However, it is often difficult to explore these needs properly in a time-pressured clinic environment. These findings demonstrate the need for a more sophisticated service that would allow patients to be empowered with information, whilst simultaneously reducing the psychological burden of the uncertainty they face. The information needs of palliative patients should not be ignored; and serviced could be tailored to meet these needs through including a formal follow-up appointment with palliative care services, or informally through regular contact with specialist nurses. This review highlights the requirement for regular follow-up with these patients in order to meet these needs.

Head and neck surgeons have been shown to adopt a variety of techniques in communicating prognostic information, with positive and negative framing the two most common (Dronkers et al., 2018). However, the data here highlight the variability in patient desires and the need for communication approaches to be tailored to individuals. Previous research in advanced cancer patients has emphasised the importance of communicating hope, for example, that pain would be controlled (Hagerty et al., 2005). This would fit with our findings that some patients were worried about having a difficult death and that this was a bigger concern for them than where they would be at the time of death. Health care professionals should be aware of this important need to explore what the patient and carer wish to know, whilst being aware that the majority will desire open and honest information, but tailoring the delivery of this information to meet the individual needs of the patient and their carer.

TABLE 5 First order constructs (direct quotations) relating to the communication and healthcare needs from health care professionals for patients with advanced incurable head and neck cancer

Text Reference	Supporting First-order constructs (Direct quotation)
5.1	<p>"There's no point beating about the bush because I'll have to take it whatever it is" (Patient, age and gender uncertain) (O'Sullivan & Higginson, 2016).</p> <p>"Yes, I would want to know for sure because it's me and my life... how I deal with the next 6 months is down to me" (Patient, age and gender uncertain) (O'Sullivan & Higginson, 2016).</p> <p>"If you're given straight answers you are able to set the goalposts and you know where you're aiming for" (Patient, age and gender uncertain) (O'Sullivan & Higginson, 2016).</p>
5.2	<p>"There is no point hiding from the facts, that doesn't help" (Patient, age and gender uncertain) (O'Sullivan & Higginson, 2016).</p> <p>"Definitely ought to! I have a big thing about being told... if it's incurable, tell me!" (Female Carer, age and relationship uncertain) (O'Sullivan & Higginson, 2016).</p>
5.3	<p>"I don't go out of my way to find out anything because I am happy as I am" (Patient, age and gender uncertain) (O'Sullivan & Higginson, 2016).</p> <p>"I wouldn't like to be told exactly. I live very much in the present... you don't really look ahead" (Patient, age and gender uncertain) (O'Sullivan & Higginson, 2016).</p> <p>"I would prefer to know so I could prepare. My husband does not want to know. I found that very stressful..." (Female carer, wife, age uncertain) (O'Sullivan & Higginson, 2016).</p>
5.4	<p>"Communication was good if [I] asked the question, but some questions you're afraid to ask and some you want to know and had to ask, but my doctor did not volunteer information." (Patient, age and gender uncertain) (Roscoe et al., 2012).</p> <p>"When you push you got them to give you details" (Patient, age and gender uncertain) (Roscoe et al., 2012).</p> <p>"If you ask them [clinicians] a question you get a straight answer. I want a straight answer. I hate fluffing" (Male patient, 64 years) (Foxwell & Scott, 2011).</p> <p>"... he likes to know the ins and outs... and they [clinicians] will answer any question... and I admire them for it ... even though they hurt..." (Female carer, wife, 61 years) (Foxwell & Scott, 2010).</p> <p>"But you get the feeling you can't ask Dr., well they haven't got the time" (Female carer, wife, 61 years) (Foxwell & Scott, 2011).</p>

(Continues)

TABLE 5 (Continued)

Text Reference	Supporting First-order constructs (Direct quotation)
5.5	<p>"until yesterday or the day before, I had no idea they were going to say you know, well this is it and you only have a few weeks, I had no idea that was going to happen at all." (Male patient, 80–89 years) (Mayland et al., 2020).</p> <p>"In that consultation when I found out I was terminal, I felt that there should have been an additional appointment, or something so that my family could be there and we could discuss it all as a team." (Male patient, 70–79 years) (Mayland et al., 2020).</p> <p>"you know, if Dr (doctor's name) said "go away and absorb the information, I'll set up for you to come back in a weeks' time... I'll arrange for you to see a palliative consultant," that would have been to my mind... a really good way of managing a very difficult situation." (Male patient, 60–69 years) (Mayland et al., 2020).</p>
5.6	<p>"had the impression they didn't want to do a lot anymore...and plus the very fact that they got me a Macmillan nurse, it's not a good sign is it?" (Male patient, 65 years) (Foxwell & Scott, 2010).</p> <p>"They're covering things up [...] You can't plan things properly unless you have the truth. The not knowing is hard" (Male carer, friend, 54 years) (Foxwell & Scott, 2010).</p> <p>"When the nurse from the hospice came, I said 'I don't know why they've sent a nurse from the hospice. You usually go to a hospice when you die, but as far as we know, you're not dying Mum" (Male carer, son, 65 years) (Foxwell & Scott, 2010).</p> <p>"Once or twice I have got upset over the phone and I've said, 'What's happening? Why doesn't anyone tell us anything?" (Male carer, son, 65 years) (Foxwell & Scott, 2010).</p>

This review found that most patients wanted to be fully informed, highlighting a need for clinicians to become pro-active in exploring these sensitive topics with patients. Selection effects may impact the contentedness of these patients with the information received, as it is possible the patients who consented to these studies are more forthcoming, have stronger positive or negative feelings towards their experiences and more likely to communicate their concerns with their healthcare professionals. However, less forthcoming patients are likely to suffer from similar concerns but may be less likely to broach the subjects during consultation and furthermore is likely not captured by qualitative studies. This review emphasised that patients and their carers depend on exceptional communication from healthcare professionals, and the value in taking the time to explore their communication needs and adapting to these cannot be understated. Communication in the palliative setting is complex and difficult, and clinicians should be aware of these complexities and strive to improve their practice wherever possible. Teaching and training to improve communication skills,

TABLE 6 First order constructs (direct quotations) relating to the needs of the primary carer for patients with advanced incurable head and neck cancer

Text Reference	Supporting First-order constructs (Direct quotation)
6.1	<p>My role is to make sure that the food, you know, he was getting his nutrition, but then when it started getting more difficult for him to eat. then all of a sudden it went through a bit of frustration phase because, I can't envision how his throat must feel and to me it was just like swallow it. and he's going I can't swallow. So, all of a sudden you're in this frustration mode where my job is to try and get nutrition into him and he's not going along with it because it's hurting too much." (caregiver, age, gender and relationship uncertain) (Penner et al., 2012)</p> <p>"You couldn't plan in the morning what you were going to have in the evening, because he didn't know what he thought he might be able to eat...so there were a few stressful times there...you know, for God's sake! Give me a clue..." (Female caregiver, wife, 61 years) (Foxwell & Scott, 2010)</p> <p>"...you just sort of had things scheduled at specific times throughout the day. And, uh, my outside activities were sort of... between the feedings... I was sort of mostly retired but I was doing a little bit of contract work so I'd always get her feeding done, go out and do my little activity, but I would always be back in time to start the next feeding" (caregiver, age, gender and relationship uncertain) (Penner et al., 2012)</p> <p>"Well, I'm at work and I'm trying to figure out, well, how to do this. So last week we kind of had to juggle things a little bit... and I'm running back and forth from work and we had different friends that were stopping by... I'm just running back and forth during the day." (caregiver, age, gender and relationship uncertain) (Penner et al., 2012)</p>
6.2	<p>"...there's all these different things, you know. Three months before you're going merrily along in life and then all of a sudden you've got all these things coming at you that are new and just a little intimidating. It's been very comforting knowing that he's been getting his nutrition through this feeding tube, but it was just scary when we had to start using it because we didn't know how to use it." (Caregiver, age, gender and relationship uncertain) (Penner et al., 2012)</p> <p>"If he said "at home", that's not a problem. However, I'm not stupid, he's twice the size of me, I can't lift him and I'm not great with poo, so...I'd have to have a discussion about what stage do we.... Not admit defeat but say...we can't cope anymore" (Female caregiver, wife, age uncertain) (O'Sullivan & Higginson, 2016)</p> <p>Patient: "He's 82... and we take the car to [local town]and then get the train... he's not getting any younger and to have to run about like that..."</p> <p>Interviewer: "so is that a worry?"</p> <p>Patient: "watch him all the time. Well he's had four bypasses, he's had three stents, two that failed..." (Patient discussing her husband, 82 years)</p> <p>"I wouldn't have the authority to increase the pain relief" (Caregiver, age, gender and relationship uncertain) (O'Sullivan & Higginson, 2016)</p> <p>"...its split second decisions that save the day; the impact on family and amount of responsibility is colossal... impact on them personally is unfair, because... they want to do their best for you...but at the end of the day...it probably isn't enough, because there isn't the medical knowledge and expertise" (Patient discussing caregiver, age, gender and relationship uncertain) (O'Sullivan & Higginson, 2016)</p>
6.3	<p>"...every night I come home and we give him his tube feed and then I have to find something or myself for dinner. So, it's like you're cooking for one and you're eating alone... And it's not that (he's) not there - he's sitting there - but somehow, it's different... And, you know, we're obviously not going out for dinner because he can't eat out for dinner... we're not going out to any of the social things that we would normally go to... our whole life is here." (Caregiver, age, gender and relationship uncertain) (Penner et al., 2012)</p> <p>"you feel guilty for eating... I would have to go other places to try to eat because I didn't want to put him through, you know, the nausea... I hated eating." (Caregiver, age, gender and relationship uncertain) (Penner et al., 2012)</p> <p>"Oh, our combined social activities have come to a complete halt... there were other social activities that I just... uh, didn't go to because I just didn't feel like it." (Caregiver, age, gender and relationship uncertain) (Penner et al., 2012)</p> <p>"... the thought of going to social functions without her sort of made me feel guilty... like she was being left out. So, rather than going out by myself, and having to explain to everybody, you know, why I was there by myself... uh, I just didn't go." (Caregiver, age, gender and relationship uncertain) (Penner et al., 2012)</p> <p>"Everything's got to be... in order... which is fine, you know, but quite wearing" (Female caregiver, wife, 78 years) (Foxwell & Scott, 2010)</p> <p>"Oh aye, its breaking his heart, I know" (Female patient, discussing caregiver son) (Foxwell & Scott., 2010)</p>

especially in the palliative setting, should be considered by all who deal with palliative patients. Patient-centred pathways of care should allow easy informal access for patients to members of the team to help with ongoing communication out with the formal clinic setting.

The support imparted by close social relationships was imperative for patients with advanced HNC. These social needs are similar to those previously identified in other advanced cancers(Wang et al., 2018), and there is evidence that isolated patients with advanced

cancers have worse outcomes (Moore et al., 2018). The studies which assessed social support in advanced HNC patients did so by exploring the relationship between the patient and their closest caregiver. However, this method inherently excludes those without a recognised caregiver and therefore fails to capture the experiences of isolated patients. This may be a particular concern in HNC where patients often have challenging social backgrounds and be prone to isolation and loneliness (Dahill et al., 2020). There probably exists a cohort of patients who are socially isolated or with relationships where they are unable to communicate their needs who subsequently have unmet social needs, and whose views and experiences are underrepresented in the current qualitative literature; this makes it difficult to understand how services can be tailored to improve their care. Often these needs can be met by the coordination of patient groups, both physical and online, to facilitate communication between patients and carers. The relationships that are forged in this setting may continue for carers after patient's death.

This review highlights that informal caregivers for advanced incurable HNC patients also have multiple needs as they adjust to delivering the complex care required. Previous research found that most carers suffered psychological distress, loss of social life and often physically struggled to deliver care (Wang et al., 2018)—and those findings are echoed here. Furthermore, a qualitative study of long-term carers for HNC patients demonstrated intense feelings of loss, both in terms of their own needs and from witnessing the distress and suffering of their loved one (Balfe et al., 2016). There seems to be limited published evidence on interventions to adequately support carers for advanced HNC patients, but frameworks for supporting caregivers of a general advanced cancer population are available (Berry et al., 2017). Our findings suggest that caregivers would benefit from increased support as they transition to the role and incorporating a support system for caregivers into the care pathway for HNC patients would enable increased confidence and effectiveness in the delivery of care and likely improve the emotional wellbeing of the patient-caregiver dyad. Carers may require less support as time goes on, but as there is a lack of longitudinal data, this should not simply be assumed to be the case.

This review found that there is a lack of qualitative evidence addressing the symptomatic burden of patients with advanced HNC. In one study, there was brief discussion of pain and fatigue which limited patients and are known to be distressing symptoms in advanced HNC (Gandhi et al., 2014). Previous quantitative work has documented that advanced HNC patients commonly suffer from dysphagia, oral secretions and pain (Gandhi et al., 2014), but the experiences of living with some of these distressing symptoms have not been captured. Similarly, the benefit and/or burden from palliative therapeutic interventions has not been explored, nor the experiences of patients or carers from engaging with such services. A questionnaire study from the Netherlands including relatives of deceased HNC patients found that 50% believed interventions to be too intrusive (Ledeboer et al., 2008), but there is little insight into which aspects were found to be less acceptable. The palliative care service for patients with advanced HNC is intended to relieve their

suffering, but there is an absence of published literature exploring the symptomatic burden of these patients nor the benefits or limitations of interventions. Future exploration of physical symptom experiences, burden and limitations among advanced HNC patients is necessary before supportive care interventions can be tailored to reduce suffering and improve end-of-life outcomes. Furthermore, exploration of which aspects of health services these patients engage with, and the barriers to effective engagement, would enable a better understanding of the needs and provision of end-of-life care in this cohort. Furthermore, a better understanding of the symptomatic burden of palliative patients will allow a more informed discussion of palliative versus radical treatment.

4.1 | Limitations

This review is limited by the small number of heterogeneous studies including a small sample of patients and carers. The included studies had varying designs and aims and explored different topics which limit comparison between them. Furthermore, they are limited to Western countries and so fails to capture the views and experiences of patients out with this scope. Moreover, the establishment of palliative care practices within these countries, and at the specific institutions, is different and likely results in variations between studies in patient and carer experiences.

Due to the small overall cohort, it is likely that the views of a minority are over-represented. For example, one caregiver had a number of negative experiences which were strongly expressed. However, with only handful views expressed on the matter, it is difficult to decipher whether this is a true unmet need or an uncommon individual experience. Similar limitations could be argued for all points raised by a minimal number of patients, and it is an important consideration when interpreting the findings of this review. Needs of specific cohorts, such as patients with a tracheostomy or laryngectomy, are not represented at all (Bickford et al., 2018).

5 | CONCLUSIONS

Five overarching constructs emerged from meta-synthesis of the existing qualitative data relating to patients with advanced HNC and their caregivers. These include the following: psychological impact and adjustment, physical limitations and deliverance of symptomatic care, communication and information needs from healthcare professionals, social support and dependence and needs of the primary caregiver. The review identifies shortcomings within the current care system in meeting the needs of patients and caregivers across all five concepts. Developing patient-centred services which deliver care to patients in the palliative setting should meet these needs. Effective care involves excellent communication between the head neck team, palliative team and the patient with their caregiver; social support for patients and their carers; and support and training regarding symptomatic management delivered by carers in the community.

CONFLICTS OF INTEREST

No author has any conflicts of interest to declare.

AUTHOR CONTRIBUTIONS

We confirm that all authors have made substantial contributions to all of the following: (1) the conception and design of the study, or acquisition of data, or analysis and interpretation of data, and (2) drafting the article or revising it critically for important intellectual content. All authors have approved the final version which has been submitted.

DATA AVAILABILITY STATEMENT

Data relating to synthesis and quality assessment are available from authors upon request.

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