



Listening to the voice of patients with head and neck cancer: A systematic review and meta-synthesis

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Abstract

The aim was to conduct a systematic review and a meta-synthesis of primary qualitative studies exploring experiences of head and neck cancer patients (HNC) undergoing radio and/or chemotherapy, in order to provide a better understanding of this phenomenon and supply new directions for care and clinical practice. Six databases were systematically searched, and 13 studies were included. The meta-synthesis methodology was adopted to conceptualise the way in which patients lived their cancer journey and the impact of treatments on their daily life. Four themes embracing various aspects of HNC patients' experiences were identified: (a) self-body image and perceived quality of life; (b) experiences and treatment of symptoms; (c) cancer journey; and (d) the relationship with health professionals. The finding demonstrates the importance of acknowledging that treatment sequelae and patients' daily issues do not appear, develop and affect people's lives in isolation and should be considered and analysed as a whole within the social and cultural context of patients' lives. Further research is needed to explore the treatment experience of HNC patients throughout their cancer journey with a more holistic approach that involves health professionals, caregivers and other family members and peers in the community.

KEYWORDS

head and neck cancer, meta-synthesis, qualitative study, quality of life, radiotherapy, systematic review

1 | INTRODUCTION

Head and neck cancer (HNC) is a spectrum of upper aero-digestive tract tumours, with causes known widely (Baddour, Magliocca, & Chen, 2016). Tobacco and alcohol abuse, and human papillomavirus (HPV) infection are the major risk factors for oral cavity cancer; moreover, smoking and alcohol together produce synergistic effects (Canova et al., 2010; Pelucchi, Gallus, Garavello, Bosetti, & La Vecchia, 2008). New treatments for HNC are being developed continually to preserve organ function and increase survivorship (Mehanna, Paleri, West, & Nutting, 2011). Although treatments such as radiotherapy, chemotherapy or their combination do contribute to local disease control and patient survival, they also may be

responsible for multiple side effects and toxicity that affects HNC patients' quality of life (QoL; Haisfield-Wolfe, McGuire, & Krumm, 2012; Rathod et al., 2013). Treatments may lead to acute side effects that may become permanent or manifest as delayed effects (Ganzer, Rothpletz-Puglia, Byham-Gray, Murphy, & Touger-Decker, 2015; van den Berg et al., 2014). Treatment sequelae may compromise patients' ability to speak or eat, thereby leading to a variety of functional limitations and special nutritional needs. Patients also may have to modify their daily and social lives, and experience feelings of shame (McQuestion, Fitch, & Howell, 2011; Moore, Ford, & Farah, 2014; Nund et al., 2014a; Semple, Dunwoody, Kernohan, McCaughan, & Sullivan, 2008; Ward & van As-Brooks, 2014). Relationships with others can cause insecurity and discomfort, as

well as embarrassment, and patients perceive themselves as different from other people (Björklund, Sarvimaki, & Berg, 2010). In many cases, HNC compromises independence and autonomy, and patients are often forced to depend on caregivers, even to cope with simple daily activities (Björklund et al., 2010; Nund et al., 2014a; Semple et al., 2008). Studies have explored the issues of the system used to assess malnutrition in HNC patients (Dechaphunkul et al., 2013), assessment and management of treatment side effects and their toxicities (George, Yom, & Wang, 2014; Pimentel, Filho, Araujo, Gomes, & Costa, 2014) and patients' QoL (Bilal, Doss, Cella, & Rogers, 2015; Rathod et al., 2013; Singer et al., 2015).

However, these largely are quantitative studies (Dechaphunkul et al., 2013; Ganzer, Rothpletz-Puglia, et al., 2015), and few qualitative studies have investigated patients' treatment experiences. Qualitative research facilitates a richer, more dynamic investigation of a topic, as well as the patients' individual characteristics (Polit & Beck, 2013). It also helps explore patients' experiences of illness, as well as their perceptions and interpretations of several life dimensions (Mason, 2012). Thus, this meta-synthesis was designed to identify qualitative studies that have explored the life of HNC patients undergoing radio and/or chemotherapy. Further, it analysed which life dimensions have been explored most to achieve a deep understanding of HNC patients' experiences and provide useful implications for clinical practice and research.

2 | METHODS

2.1 | Search strategy

We conducted this review according to the PRISMA statement (Liberati et al., 2009; Moher, Liberati, Tetzlaff, Altman, & PRISMA group, 2009) and Paterson's, Thorne, Canam, and Jillings (2001) meta-study research process. Google Scholar and five electronic databases were searched: MEDLINE (PubMed); The Cumulative Index to Nursing and Allied Health Literature (CINAHL); Scopus; American Psychological Association (PsycINFO); and Cochrane Central Register of Controlled Trials (CCTR). Specific MESH terms, free words and keywords, including *patient experience*, *qualitative research*, *head and neck cancer*, *radiotherapy* and *chemotherapy*, were included and combined using Boolean operators to guarantee

all possible combinations (Sandelowski & Barroso, 2006). Manual search and snowballing strategies (Ridley, 2012), including reviewing reference lists and appraising related articles, also were adopted to identify additional studies. Inclusion and exclusion criteria were applied to all records identified (Table 1).

2.2 | Study selection and data extraction procedures

Two authors conducted the literature search and selected the studies independently. All studies that met the inclusion criteria were retrieved, and the full text was analysed; in cases of disagreement, a third researcher was enlisted. One researcher extracted the findings from the final sample of studies selected using a data extraction table created for this review (Evans, 2002; Paterson et al., 2001). Our methodological approach focused on findings rather than "on researchers' claims about how they were produced" (Sandelowski & Barroso, 2006), which allowed us to include findings that did not necessarily embody the stated method and evaluate their meaning to reveal the voices of HNC patients.

Four authors examined the data independently and recorded all details of the studies on forms (Evans, 2002; Paterson et al., 2001). Further, they defined meaning and content inductive coding, created a potential descriptive themes database (Thomas & Harden, 2008) and then analysed each to identify key findings and potential themes (Evans, 2002). The main findings list identified common themes that were gathered and categorised into similar areas. Subthemes extracted were analysed repeatedly to provide a different interpretation of each theme's content and to detect possible inconsistencies and incongruities. Finally, we synthesised the findings by describing the themes and subthemes, together with examples from the original studies (Evans, 2002).

2.3 | Quality appraisal

Two researchers appraised the quality of the papers independently, explored their possible contribution to the synthesis, evaluated methodological quality and identified any major shortcomings (Atkins et al., 2008; Thomas & Harden, 2008), using the Critical Appraisal Skills Programme (CASP, 2014). Previous meta-synthesis have adopted this tool (Kim, White, & Patterson, 2016; Song & Kong,

TABLE 1 Articles inclusion and exclusion criteria

Inclusion criteria	Exclusion criteria
<ul style="list-style-type: none"> • Primary research studies that explored perceptions, life perspective, experiences, beliefs of HNC patients undergoing RDT/CHT. • Studies with abstracts available and published in both English and Italian language. • Studies that adopted qualitative methodologies. • Studies that included HNC adult patients undergoing RDT/CHT. • Studies published between January 2006 and June 2016. 	<ul style="list-style-type: none"> • Qualitative findings deriving from mixed-method studies that cannot be separated from quantitative findings. • Mixed sample qualitative studies in which findings regarding HNC patients cannot be separated from the ones related to other population. • Grey literature, alternative-style qualitative research where findings cannot be extracted, not primary research or quantitative studies and reviews.

Note. CHT: chemotherapy, HNC: head and neck cancer, RDT: radiotherapy.

2015; Zheng, Lee, & Bloomer, 2016) to assess qualitative studies' quality in different contexts quickly and systematically (Angus et al., 2015; Davies, Maio, Rait, & Iliffe, 2014). The CASP consists of 10 appraisal domains with specific questions designed to detect the logical and coherent flow of the research process, ethical issues and theoretical and practical contributions of the research. We rated the studies selected as high, moderate or low quality (Clark et al., 2012; Kim et al., 2016; Table 2).

3 | RESULTS

3.1 | Selection and characteristics of studies

Databases and manual searches yielded 94 records initially. Twenty-one full-text articles were assessed, and 13 met the selection criteria (Figure 1). Two were conducted in the same setting with the same participants and therefore were analysed as one (Nund et al., 2014a, 2014b). With respect to design, two were mixed-method studies (Cartmill, Cornwell, & Ward, 2012; Ganzer, Rothpletz-Puglia, et al., 2015) and the remainder was qualitative. Seven of 13 studies used a phenomenological approach to study the lived experiences of HNC patients, which helped define meaningful themes to reinterpret in this meta-synthesis compared to mixed-method studies, which provided little qualitative understanding. Eleven collected data from interviews that assessed HNC patients' perspectives and reported rich data and quotations. Table 2 summarises the studies' characteristics, and Table 3 presents the population's characteristics.

3.2 | Quality criteria

Most studies were of moderate quality (Table 2). Of these, three were of low to moderate quality (Cartmill et al., 2012; Ganzer, Rothpletz-Puglia, et al., 2015; McQuestion et al., 2011), and one was high quality (Nund et al., 2014a). In general, the studies followed a phenomenological approach and were evaluated as moderate, moderate to high and high quality. The authors used appropriate methods to assess and analyse data, even if the methodology some adopted in data analysis was not described adequately (Table 2). Some studies lacked detailed descriptions of the analysis methodology used, or failed to justify the study design (Cartmill et al., 2012; Ganzer, Rothpletz-Puglia, et al., 2015; McQuestion et al., 2011; Ottosson, Laurell, & Olsson, 2013), but we selected them for their conceptual richness. All 13 studies selected described the research goals and study design, and one reported the research questions (Moore et al., 2014). Four recruited participants via convenience sampling (Cartmill et al., 2012; Haisfield-Wolfe et al., 2012; Ottosson et al., 2013; Tong, Lee, Yuen, & Lo, 2011), while the other eight recruited patients through purposive sampling (Charalambous, 2014; Chou, Liaw, & Tang, 2007; Ganzer, Rothpletz-Puglia, et al., 2015; Larsson, Hedelin, & Athlin, 2007; McQuestion et al., 2011; Nund et al., 2014a, 2014b; Patterson, McColl, Wilson, Carding, & Rapley, 2015).

All of the researchers defined the samples' characteristics and participants' inclusion/exclusion criteria. The sample size ranged

from 8 to 60 HNC patients with a total sample of 235: 163 were men and 48 women, with an age range of 24–86 years. Two studies reported the rigour of the research (Chou et al., 2007; Larsson et al., 2007), seven described the studies' limitations (Charalambous, 2014; Chou et al., 2007; Ganzer, Rothpletz-Puglia, et al., 2015; Haisfield-Wolfe et al., 2012; Moore et al., 2014; Nund et al., 2014a; Patterson et al., 2015), five suggested implications for clinical practice (Chou et al., 2007; Haisfield-Wolfe et al., 2012; Larsson et al., 2007; McQuestion et al., 2011; Patterson et al., 2015), and six made suggestions for future research (Ganzer, Rothpletz-Puglia, et al., 2015; Haisfield-Wolfe et al., 2012; Larsson et al., 2007; McQuestion et al., 2011; Moore et al., 2014; Nund et al., 2014a, 2014b).

3.3 | Themes and subthemes

The meta-synthesis identified four themes and related subthemes that included various aspects of the experiences of HNC patients' undergoing radio and/or chemotherapy (Table 4).

3.3.1 | Self-imagine and perceived quality of life

One of the main themes detected in the analysis was the treatments' effects on patients' self-image and QoL.

Fear and interruption of daily life

Head and neck cancer compromised patients' QoL and social activity greatly and resulted primarily in feelings of stress, anxiety and uncertainty about the future (Larsson et al., 2007; Moore et al., 2014). Treatments are responsible for changes in several aspects of daily life: For example, the duration of radiotherapy requires strict planning of daily life for 5–7 consecutive weeks, with even more frequent visits to the hospital (Larsson et al., 2007). In many cases, patients are no longer able to perform simple daily activities and must depend on others (Moore et al., 2014). Further, during radiotherapy, the mask that blocks both the head and shoulders, and the movement of the machine itself, was a traumatic experience for some patients (Larsson et al., 2007; Moore et al., 2014). Physical changes attributable to the treatments had negative effects on nutrition and social relationships and created a sense of inadequacy, inability to cope with daily life and a strong sense of uncertainty about the future (Charalambous, 2014; Ganzer, Rothpletz-Puglia, et al., 2015; Haisfield-Wolfe et al., 2012; McQuestion et al., 2011; Ottosson et al., 2013). The patients experienced an altered body image because of the treatments and the weight loss indicative of the disease (Larsson et al., 2007; McQuestion et al., 2011; Nund et al., 2014a), which contributed to social isolation (McQuestion et al., 2011).

Eating issues and social isolation

With respect to relationships with others, especially eating with others, in most of the studies (McQuestion et al., 2011; Moore et al., 2014; Nund et al., 2014a; Ottosson et al., 2013; Patterson et al., 2015), the respondents emphasised the difficulty of eating in public and even with acquaintances and friends (Haisfield-Wolfe et al.,

TABLE 2 Characteristics of the included studies

First author, Country	Aim	Study design	Data collection strategy	Data analysis method	Strengths (+) and weaknesses (-)	Quality Appraisal (CASP)
Ganzer, Rothpletz-Puglia, et al. (2015) USA	To explore and obtain a comprehensive understanding of the eating experience in long-term HNC survivors	Mixed-method approach with explorative qualitative research	Phone individual semi-structured interviews	Content analysis and thematic analysis	+expertise researchers were involved in the analysis process +pilot interviews were conducted -researchers did not justify the research design -the description of data analysis method was not sufficiently understandable	Low to moderate
Patterson et al. (2015) UK	To explore changes over time of HNC patients undergoing (CHT)RDT and their dysphagia experience	Ethnographic observation and interviews	Observation and semi-structured interviews	Thematic analysis	+2 recruitment sites and multi-method study +good description of sample selection +findings from interviews were reported with quotes -the description of ethical issues was not sufficiently understandable -reporting findings discussion too brief	Moderate to high
Charalambous (2014) Cyprus	To explore the in-depth experiences of HNC patients living with RDT induced xerostomia	Hermeneutic phenomenological study	Narratives	Thematic analysis and hermeneutic phenomenological structural analysis	+good explanation of data interpretation process +clear analysis and comprehensive discussion -the description of sample characteristics was insufficient -influence and role of researcher not reported	Moderate to high
Moore et al. (2014) Australia	To explore the treatment experience of HNC patients To describe support needs that had an influence on their QoL during and after the treatment	Explorative, descriptive qualitative study	Semi-structured interviews	Content analysis	+rigour of the study was reported and discussed +data collection, analysis and findings explained -small sample size which limited findings -the description of sample characteristics was insufficient	Moderate to high
Nund et al. (2014a) Australia	To explore the lived experience of the impact of dysphagia on HNC	Qualitative descriptive study with a phenomenological approach	Individual in-depth semi-structured interviews	Thematic analysis	+researchers justified the study design and sample collection +themes supported by quotes +detailed description of methodology, data analysis +researchers took into account their role during data collection and analysis -patients recruited from only one site	High
Nund et al. (2014b) Australia	To explore the lived experience of HNC patients with dysphagia not undergoing surgical treatments To examine patients perception of service needed	Qualitative descriptive study with a phenomenological approach	Individual in-depth semi-structured interviews	Thematic analysis	+themes supported by quotes +good description of methodology, data analysis -researchers did not take into account their role during data collection and analysis -patients recruited from only one site	Moderate to high

(Continues)

TABLE 2 (Continued)

First author, Country	Aim	Study design	Data collection strategy	Data analysis method	Strengths (+) and weaknesses (-)	Quality Appraisal (CASP)
Ottosson et al. (2013) Sweden	To describe the HNC patients' experience of food, eating and meals up to 9 months after RDT	Qualitative study	In-depth semi-structured interviews	Content analysis	+Interviews were conducted following a pretested topic guide +trustworthiness was discussed ±low proportion of women in the sample -study design was not specified and clearly declared -interview guide was not appended	Moderate to high
Cartmill et al. (2012) Australia	To examine the functional swallowing, nutritional status and general and swallowing-related patient-rated function at 2 years after treatment with AFRT To explore patients perspective of side effects and barriers to oral intake at 2 years after AFRT.	Mixed-method design	Semi-structured interviews	Patients' description was reported as frequencies and analysed using the ICF core set for HNC	+good description of the sample +detailed discussion ±limited description of data analysis -brief and unclear description of study design and methodology -limitation of the study and new researches were not reported	Low to moderate
Haisfield-Wolfe et al. (2012) USA	To describe coping in laryngeal and oropharyngeal cancer patients during definitive RDT or CHTRDT	Descriptive qualitative study	Open-ended questions	Content analysis	+two recruitment sites +repeated interviews during treatment ±low proportion of women in the sample -interviews were recorded manually	Moderate
McQuestion et al. (2011) Canada	To report the changed meaning of food in HNC patients undergoing primary RDT	Qualitative study	Interviews	Qualitative descriptive analysis	+themes supported by quotes +detailed description of implication for practice and research -brief description of study design, methodology and data analysis -ethical issues were not reported	Low to moderate
Tong et al. (2011) China	To explore the perception and experiences of swallowing difficulties in NPC patients undergoing RDT	Phenomenological approach	Semi-structured interviews	Colaizzi's phenomenological methodology	+large sample +the interview questions were reported +themes supported by quotes -the study design was not described and clearly declared -limitations of the study were not reported	Moderate

(Continues)

TABLE 2 (Continued)

First author, Country	Aim	Study design	Data collection strategy	Data analysis method	Strengths (+) and weaknesses (-)	Quality Appraisal (CASP)
Chou et al. (2007) Taiwan	To explore life attitude of NPC patients and treatment-related issues	Phenomenological approach	In-depth interviews	Colaizzi's phenomenological methodology	+rigour, trustworthiness of the study were reported +strengths, limitations and recommendations were reported ±the sample size was quite small -too brief description of the sample characteristics -too brief discussion	Moderate
Larsson et al. (2007) Sweden	To understand HNC patients lived experience of daily life during treatment	Phenomenological approach	Interviews	Colaizzi's phenomenological methodology	+good description of study design chosen appropriateness +detailed data analysis description +rigour of the study was reported -small sample -brief description of ethical considerations	Moderate to high

Note. AFRT: altered fractionation radiotherapy, CHTRDT: chemotherapy and radiotherapy, HNC: head and neck cancer, ICF: World Health Organization International Classification of Functioning, Disability and Health, NPC: nasopharyngeal carcinoma, QoL: quality of life, RDT: radiotherapy, UK: United Kingdom, USA: United States of America.

2012). Patients suffered constant embarrassment because of their need to change food textures and types (Nund et al., 2014a). In two studies (Ottoosson et al., 2013; Patterson et al., 2015), informants indicated that the symptoms of the disease and the treatments affected their social relationships, in that they had to clean their mouths constantly, and coughed whenever they ingested food, which caused a sense of inadequacy and insecurity, and led them to decline invitations (Ottoosson et al., 2013). They perceived experiences with food as stressful, and eating took twice as long, as much to chew the food ingested as to swallow it (Ottoosson et al., 2013). Further, the symptoms of treatments and the related physical dysfunctions were so burdensome for some that even eating with their families became a source of shame (Patterson et al., 2015). Thus, they preferred to eat alone (Moore et al., 2014). Symptoms such as dysphagia made it difficult to eat favourite foods and caused dissatisfaction with meals (Nund et al., 2014a, 2014b). At the same time, difficulty swallowing produced anger, frustration, anxiety, depression, shame and a sense of defeat. Eating became a mandatory action in which they engaged only to gain, or at least not lose weight, and continue with treatments (Cartmill et al., 2012; McQuestion et al., 2011; Tong et al., 2011). At the same time, their diet became limited severely (Ganzer, Rothpletz-Puglia, et al., 2015; Ottoosson et al., 2013; Tong et al., 2011).

Changes in relationships with family and friends

Although social relationships are a significant problem for many HNC patients, many authors have emphasised the essential role of family (Cartmill et al., 2012; Haisfield-Wolfe et al., 2012; Larsson et al., 2007; McQuestion et al., 2011; Nund et al., 2014b; Ottoosson et al., 2013). The emotional support families provide to patients is an important element that assists them and is the starting point in handling the "long journey" from disease to cure (Ottoosson et al., 2013). Family members were a very important resource for some patients, as they encouraged them and helped them prepare food (Cartmill et al., 2012; McQuestion et al., 2011; Nund et al., 2014b). However, in some cases, family support failed to eliminate the patients' sense of loneliness and did not guarantee them the help necessary to address food problems and side effects of treatments (Larsson et al., 2007; Nund et al., 2014b). In contrast, for some patients, help from friends or peers was significant, especially at the end of treatment (Haisfield-Wolfe et al., 2012; Moore et al., 2014). Finally, symptoms patients experienced also had a significant effect on family members (Cartmill et al., 2012; Nund et al., 2014a). One study (Nund et al., 2014a) reported that, as the partners needed to adapt their eating habits to those of the patient, they were restricted from eating preferred foods, while in another (Cartmill et al., 2012), caring for their beloved for a long time became a source of stress to family members.

3.3.2 | Experiences and treatment of symptoms

Description of symptoms

For many patients, having HNC is a long and arduous journey (Ottoosson et al., 2013). Dysphagia, dysgeusia, dry mouth, fatigue and

loss of weight, appetite and energy are examples of symptoms that occur during and after treatment and compromise QoL (Cartmill et al., 2012; Ganzer, Rothpletz-Puglia, et al., 2015; Moore et al., 2014). Some symptoms, such as dysphagia, are present even before they begin radiotherapy, but often are perceived little or undervalued (Patterson et al., 2015; Tong et al., 2011). During and after treatments, however, their presence is prominent; swallowing becomes increasingly difficult and intensely painful. The absence of saliva also impairs swallowing (Nund et al., 2014a, 2014b ; Patterson et al., 2015), and the loss of oral and pharyngeal sensitivity, coughing and changes in smell and taste compromise eating further (Nund et al., 2014b). For some, all of these symptoms are associated with a fear of choking and the constant perception of food stuck in the throat (Nund et al., 2014a; Tong et al., 2011). Xerostomia contributes to difficulties in food intake and the onset of mouth ulcers, infections, bad breath and pain; it also has significant adverse effects on sleep and energy (Charalambous, 2014; Moore et al., 2014). In many cases, symptoms patients experience are associated with fear because they will require invasive devices and supplemental feeding with artificial food (Moore et al., 2014; Ottosson et al., 2013; Tong et al., 2011). In addition, many patients suffer from depression manifested by agitation, sleep disturbances, difficulty concentrating and loss of interest, energy and pleasure in eating (Moore et al., 2014). These increase and continue during treatment and decrease thereafter, but depression is linked to the fact that, for many patients, symptoms persist even after treatments conclude (Haisfield-Wolfe et al., 2012; McQuestion et al., 2011), although with less intensity (Ottosson et al., 2013; Patterson et al., 2015). For some patients, this continues to restrict the foods they can eat (Ganzer, Rothpletz-Puglia, et al., 2015; McQuestion et al., 2011; Ottosson et

al., 2013) and the time required to eat (McQuestion et al., 2011; Nund et al., 2014b; Ottosson et al., 2013).

Symptom management strategies

Faced with the difficulties associated with eating, most patients experiment independently with what they can eat (Cartmill et al., 2012; McQuestion et al., 2011; Nund et al., 2014b; Tong et al., 2011). They change the textures of foods, add seasonings to facilitate swallowing and taste perception and eat small, frequent meals (Cartmill et al., 2012; Nund et al., 2014b; Patterson et al., 2015; Tong et al., 2011). To address xerostomia, patients tend to consume more liquids and use sauces and chewing gum to stimulate saliva production (Cartmill et al., 2012; Nund et al., 2014b; Ottosson et al., 2013; Patterson et al., 2015). They also avoid foods that are too dry, spicy and acidic (Cartmill et al., 2012; Ganzer, Rothpletz-Puglia, et al., 2015; Ottosson et al., 2013). Another strategy reported was confronting their problems, thinking that it is necessary to try to adapt and accept the situation (Ganzer, Rothpletz-Puglia, et al., 2015; Larsson et al., 2007; Moore et al., 2014), as their difficulties would disappear in time and they would return to normal (Nund et al., 2014b).

3.3.3 | Cancer journey

Strategies to deal with cancer

Patients adopted several strategies to deal with cancer and to facilitate coping and peer support from people who had the same experiences after treatment, as well as to increase their satisfaction undergoing the process, and their reconsideration and reorganization of their lives (Larsson et al., 2007; Moore et al., 2014). Pessimism, negative thoughts and feelings of rejection inhibit adaptation

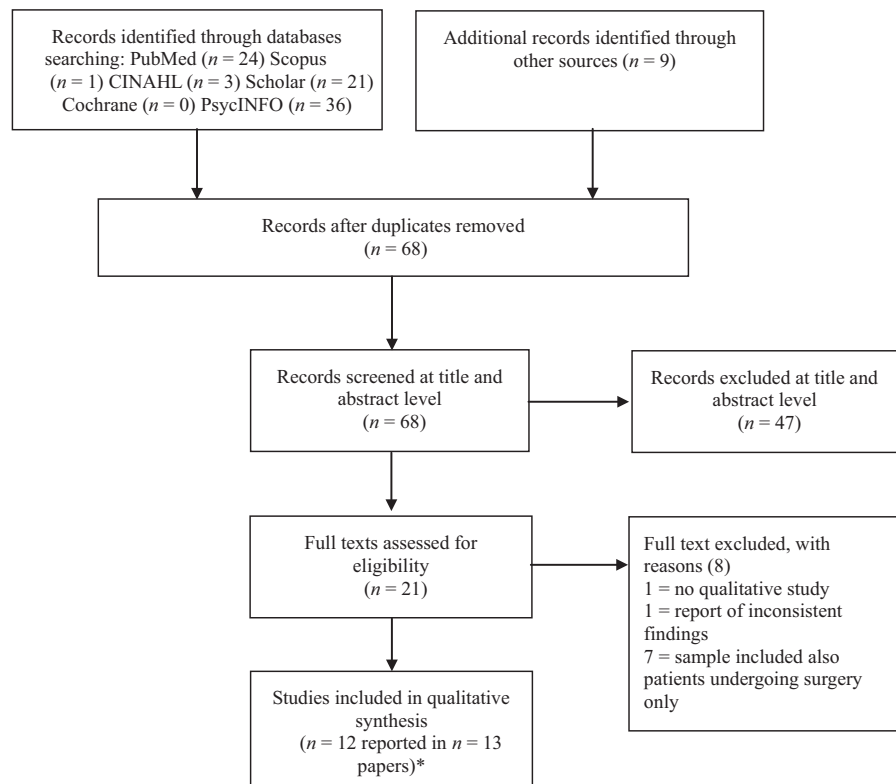


FIGURE 1 PRISMA flow diagram. *Nund et al. (2014a) and Nund et al. (2014b) were pooled because they reported different data and analysis from the same study

TABLE 3 Characteristics of studied sample

Author	Study population	Tumour location	Treatment
Ganzer, Rothpletz-Puglia, et al., 2015	11 patients (F = 4, M = 7): range age: 40–67, mean age: 55.70	Tongue, tonsil, larynx, larynx and base of tongue	CHT, CCR, CCR+surgery, CHT+CCT+surgery
Patterson et al., 2015	12 patients (ethnographic observations): (F = 2, M = 10) range age: 45–77, mean age: 62.1; 9 patients (interviews; F = 1, M = 8) range age: 50–72, mean age: 63.1	ND	CCR, RDT
Charalambous, 2014	15 patients (F = 7, M = 8): range age: 39–66	ND	RDT
Moore et al., 2014	8 patients (F = 1, M = 7): range age: 51–60, mean age: 60 years	Base of tongue, parotid gland, submandibular gland, oropharyngeal, tongue	CCT, surgery+RDT, surgery+RDT+CHT
Nund et al., 2014a	24 patients (F = 4, M = 20): range age: 43–71, mean: 57.4 years, SD: 8	Tonsil, base of tongue, hypopharynx, nasopharynx	RDT, RDT and systemic therapy
Nund et al., 2014a	24 patients (F = 4, M = 20): range age: 43–71, mean: 57.4 years, SD: 8	Tonsil, base of tongue, hypopharynx, nasopharynx	RDT, RDT and systemic therapy
Ottosson et al., 2013	13 patients (F = 2, M = 11): range age: 47–70, mean age: 60	Oral cavity, pharynx, larynx	RDT, RDT+surgery
Cartmill et al., 2012	12 patients (F = 2, M = 10): range age: 53–82, mean age=66 years, SD 20.3	Tonsil, pharyngeal wall, supraglottic	RDT
Haisfield-Wolfe et al., 2012	21 patients (F = 3, M = 18): mean age: 59.2, SD 9.2	Oropharyngeal, laryngeal	RDT, CCT
McQuestion et al., 2011	17 patients (F = 2, M = 15): range age: 30–70,	ND	RDT
Tong et al., 2011	60 patients (F = 18, M = 42): range age: 34–71	ND	RDT
Chou et al., 2007	24 patients (F-to-M ratio 3:7): range age: 24–64, mean age: 42.5 years	Nasopharyngeal	CT, CCT
Larsson et al., 2007	9 patients (F = 2, M = 7): range age: 52–86, mean: 70 years	Oral cancer, pharyngeal	RDT, RDT+surgery

Note. CHT: chemotherapy, CCR: concurrent chemoradiation therapy, F: female, M: male, ND: not declared, RDT: radiotherapy, SD: standard deviation

(Larsson et al., 2007), while talking to peers offers support that encourages patients during treatments (Larsson et al., 2007; Pateman, Ford, Batstone, & Farah, 2015). Performing housework, gardening or visiting friends are some examples of strategies patients used (Larsson et al., 2007). Patients also considered returning to work, as well as using complementary treatments, such as meditation or cognitive training (Moore et al., 2014). Finding support on the Internet, going for a walk or to a mall for a few hours, browsing through magazines and newspapers, looking after pets or taking a short vacation also was considered good coping therapy (Haisfield-Wolfe et al., 2012). The support they received from family and friends was fundamental in facing the illness together, as well as thinking and acting positively (Haisfield-Wolfe et al., 2012).

The future

Some patients had a common opinion about HNC and its treatments and considered it a long journey filled with unanticipated insecurities and fears (Ottosson et al., 2013). After the acute phase of the disease, some improvements are still possible that allowed patients to hope that they would return to normal (Ottosson et al., 2013). For some, feelings of insecurity and pessimism about the future, fear of recurrent disease or that the side effects of the treatments

would become permanent, persisted (Larsson et al., 2007; Ottosson et al., 2013). Their greatest fear was the chronic nature of treatment and symptoms, in addition to their ambivalence in thinking, “*Is this how it will end?*” and hoping and trusting that they could resume the lives they led before their illness (Nund et al., 2014b; Ottosson et al., 2013). Thinking about the future also prompted them to address issues such as death, which many patients perceived as an inevitable and natural process (Chou et al., 2007). They experienced suffering, however, as a test, especially those who were religious (Chou et al., 2007). They saw it both as a penalty and compensation, and an opportunity to reflect on their own experience (Chou et al., 2007). Those who finished long treatments felt that they were lucky to overcome the disease and that what they experienced during treatment was the price they had to pay to do so (Ganzer, Rothpletz-Puglia, et al., 2015; Ottosson et al., 2013).

3.3.4 | Relationships with health professionals

Health professionals' support

Despite the management of symptoms related to nutritional issues, and healthcare professionals' involvement throughout the diagnostic-therapeutic process, many patients felt abandoned

TABLE 4 Overview of themes and subthemes

Themes	Subthemes	Key aspects	Studies
Self-body image and perceived quality of life	Fear and interruption of daily life	Food is linked to patients personal meaning; the body changes and it is not functioning; there is a sense of loss and emotional suffering linked with the food changes; patients live the interruption of daily life and lifestyle changes experiences	Cartmill et al. (2012); Charalambous (2014); Ganzer, Rothpletz-Puglia, et al. (2015); Haisfield-Wolfe et al. (2012); Larsson et al. (2007); McQuestion et al. (2011); Moore et al. (2014); Patterson et al. (2015); Nund et al. (2014a); Nund et al. (2014b); Tong et al. (2011)
	Eating issues and social isolation	It is difficult to eat out of the family environment; social interactions are affected by eating issues and cause embarrassment	Haisfield-Wolfe et al. (2012); Moore et al. (2014); McQuestion et al. (2011); Nund et al. (2014a); Nund et al. (2014b); Ottosson et al. (2013); Patterson et al. (2015); Tong et al. (2011)
	Changes in relationships with family and friends	Social networks and family supports change; family and friends relationships are affected by changes in eating and food choices, family and friend role changes during illness and treatment; patients' social life and activities change; social isolation	Cartmill et al. (2012); Ganzer, Rothpletz-Puglia, et al. (2015); Haisfield-Wolfe et al. (2012); Larsson et al. (2007); McQuestion et al. (2011); Nund et al. (2014a); Nund et al. (2014b);
Experiences and treatment of symptoms	Description of symptoms	Symptoms experience heightens awareness of what patients cannot eat; symptoms cause feelings such as fear, anxiety or worrying; symptoms experience changes during treatment; patients become aware of eating issues too late; treatments' side effects are persistent for the whole time; living with symptoms evokes bad emotions	Cartmill et al. (2012); Charalambous (2014); Ganzer, Rothpletz-Puglia, et al. (2015); Haisfield-Wolfe et al. (2012); McQuestion et al. (2011); Moore et al. (2014); Nund et al. (2014a); Nund et al. (2014b); Ottosson et al. (2013); Patterson et al. (2015); Tong et al. (2011)
	Symptoms management strategies	Patients choose food with a specific texture and flavour, they struggle to find new food and to enjoy eating; the primary aim is "to get food down"; patients learn what they can and what they cannot eat; patients self-manage eating problems; the familiarity with treatment increases the coping; trial and error	Cartmill et al. (2012); Ganzer, Rothpletz-Puglia, et al. (2015); Moore et al. (2014); Nund et al. (2014a); Nund et al. (2014b); Ottosson et al. (2013); Patterson et al. (2015); Tong et al. (2011)
Cancer journey	Strategies to deal with cancer	Patients find ways to cope with treatments' side effects; patients use liquids to facilitate swallowing; patients change their abilities to cope with stress and treatments' side effect during treatment; patients accept symptoms and treatments' side effects as something inevitable	Ganzer, Rothpletz-Puglia, et al. (2015); Haisfield-Wolfe et al. (2012); Larsson et al. (2007); Moore et al. (2014); Nund et al. (2014b); Ottosson et al. (2013)
	The future	Patients believe that they can survive and they try to develop a new way to love themselves and others; patients are often not aware of what happens during and after treatments; patients try to see their experience in a positive light; new way to see life; acceptance of the new way life is going to be	Chou et al. (2007); Ganzer, Rothpletz-Puglia, et al. (2015); Nund et al. (2014b); Ottosson et al. (2013)
The relationship with health professionals	Health professional support	It is important to receive information during treatments; supports and information represent the key strategies to a successful ill journey; it is important to build confidence with health professionals; when treatments are over patients feel completely left to their own devices; it is important to receive education from health professionals regarding treatments and their side effects; patients live a sense of incomprehension	Chou et al. (2007); Larsson et al. (2007); Charalambous (2014); Moore et al. (2014); Nund et al. (2014b); Ottosson et al. (2013)

by the healthcare system, especially after the end of treatments (Charalambous, 2014; Larsson et al., 2007; Moore et al., 2014; Nund et al., 2014b). In Moore et al. (2014), respondents highlighted their feelings of isolation and disorientation once discharged from the referring healthcare facility. They believed they were unprepared

and lacked sufficient information to cope independently with the long-term side effects of treatments. This sense of abandonment was a lesser problem during treatments, when patients placed full confidence in their healthcare professionals (Chou et al., 2007; Larsson et al., 2007); further, they saw the hospital itself as a safe

place (Larsson et al., 2007). However, Charalambous (2014) contradicted this in part and reported that patients felt healthcare professionals ignored them because they evaluated and monitored the side effects patients experienced during treatments poorly. This situation frustrated patients greatly and made them feel misunderstood. They also reported that inadequate communications among healthcare professionals caused confusion about treatments (Larsson et al., 2007; Moore et al., 2014), while various professionals' skills also seemed confusing (Nund et al., 2014b). Finally, having daily meetings with healthcare professionals did not always help patients ask questions, organise the amount of information received and overcome feelings such as anxiety or despair (Larsson et al., 2007; Nund et al., 2014b). However, the presence of experienced staff throughout treatment helped patients cope with the pathology, treatments and related problems (Larsson et al., 2007; Moore et al., 2014).

Information and treatment

The studies analysed highlighted the need to place more emphasis on the information patients receive before, during and after treatments. It was noted that an inadequate and superficial knowledge of the management of treatments' side effects can cause concern, anxiety, confusion and difficulty understanding (Larsson et al., 2007; Moore et al., 2014). For example, Ottosson et al. (2013) reported that patients stated that they would like to remain informed throughout treatments, while others did not like being informed about the duration of symptoms and the time required to return to a situation similar to normal (Ottosson et al., 2013). Therefore, to facilitate the care process, this population requires constant and personalised education about cancer and the management of side effects, in addition to emotional support and practical advice (Larsson et al., 2007; Nund et al., 2014b).

4 | DISCUSSION

Head and neck cancer patients experienced changes in their body image, depression, isolation, eating problems, and, in many cases, the consequences of their illness and treatments persisted (Blanco & González-Botas, 2011). Accordingly, this meta-synthesis explored simultaneously the different aspects of the lived experience of HNC patients undergoing radio and/or chemotherapy.

4.1 | The price to pay

As Henry et al. (2014) reported previously, as well as in the studies herein, patients indicated that, as the treatments progress, they undergo significant physical deformities that compromise their QoL. This provokes feelings of inadequacy with respect to others, embarrassment and low self-esteem in particular (Henry et al., 2014). As Semple et al. (2008) reported, in some cases, patients experience these conditions as *"the price to pay"* for surviving (Charalambous, 2014), and accept them, at least in part. This led us to reflect that studies have reported frequently what patients experience because

of physical deformities, but little is known about the coping mechanisms they adopt. In accordance with Moore et al. (2014), this knowledge gap remains even after treatments, although the first 6–12 months post-treatment is a critical time for these patients to take charge of their lives (Moore et al., 2014). In view of these findings, it is essential to conduct further studies that explore those dimensions and investigate more thoroughly the meanings and significance that both patients and caregivers attribute to these transformations (Henry et al., 2014).

4.2 | The experience of treatments

A very significant factor for patients explored widely is the change in their dietary habits, as well as the onset of symptoms, and functional problems related to treatment. Even in our review, as Bressan et al. (2017) indicated, many studies reported experiences related to nutritional symptoms, difficulty eating and strategies adopted. Researchers have reported considerable information about the difficulties patients experienced because of the change in food consistency or the increased time they needed to eat (McQuestion et al., 2011; Nund et al., 2014b; Ottosson et al., 2013). These findings confirmed that, although these issues have been explored, little is known about their effects on patients and their real adaptation to nutritional problems. We know that patients often use trial and error to determine what they can eat (Cartmill et al., 2012; McQuestion et al., 2011; Nund et al., 2014b; Tong et al., 2011), but very little is known about why they often prefer to act without asking for support from healthcare professionals.

4.3 | The experience of illness

Consistent with other studies (Chen, 2012; Henry et al., 2014; McLaughlin & Mahon, 2014), a further significant issue is HNC patients' compromised social life, which can lead to self-isolation, as well as affect the families' attitudes about care management (Nund et al., 2014a, 2014b).

In several studies, family members' presence was crucial for patients (Cartmill et al., 2012; Haisfield-Wolfe et al., 2012; Larsson et al., 2007; McQuestion et al., 2011; Nund et al., 2014b; Ottosson et al., 2013). However, these results appear to conflict in part with those of Björklund et al. (2010), who observed that constant dependence on a caregiver, together with the changed roles within the family, is associated with feeling a sense of captivity, lack of autonomy and passivity. In some cases, patients preferred to seek support from peers and friends rather than from their families (Haisfield-Wolfe et al., 2012; Henry et al., 2014; Moore et al., 2014; Pateman et al., 2015; Semple et al., 2008).

4.4 | Interpersonal relationships

In addition to family relationships, many studies also have found that relationships between patients and healthcare professionals are problematic. Many respondents reported a strong sense of

abandonment, especially after the end of treatment (Charalambous, 2014; Larsson et al., 2007; Moore et al., 2014). In contrast, a constant relationship with patients guaranteed through control and specialist visits helped decrease their feelings of loneliness and abandonment during treatments (Larsson et al., 2007). In our view, this confirms that health professionals need to develop a personalised and lasting relationship with patients, both to earn their trust and to allow them to play an active role in managing their disease (Björklund et al., 2010; Henry et al., 2014). Considering that resources are limited in many healthcare systems, we believe it is essential to develop a multidisciplinary, structured approach in treating HNC patients to ensure a comprehensive understanding of their needs. Because health professionals differ in their roles, in the frequency of care after treatment, and employ different care provision standards (Chan et al., 2017), improving communication and coordination between professionals, especially primary care physicians and oncologists (Klabunde et al., 2013), will help ensure optimal follow-up care.

5 | LIMITATIONS AND RECOMMENDATIONS

This review increased our knowledge of the phenomenon studied. However, the findings must be interpreted carefully, because of the study's limitations, especially with respect to the heterogeneity of samples and study characteristics. These include variation in the phase of the treatment reported in the studies, few of which followed patients for an extended period (Cartmill et al., 2012; Patterson et al., 2015) or enrolled long-term survivors (Ganzer, Rothpletz-Puglia, et al., 2015; Moore et al., 2014). Another limitation is the possibility that some studies were not included in the review, as we focused only on primary studies. In our opinion, more research is needed on HNC patients' experiences and needs during the entire course of treatments. The studies included in this meta-synthesis were conducted primarily in Anglo-Saxon cultures, and researchers have paid little attention to cultural, regional and ethnic diversity in patients' responses to cancer treatments. Therefore, we recommend that studies explore the possible differences in care in various cultures. We also would suggest that research resumes on themes that emerged from published works that lacked methodological information. In particular, it is necessary to include in-depth, comprehensive interviews that address patients' perspectives of side effects and perceived barriers to oral intake (Cartmill et al., 2012) with a methodology that allows researchers to capture rich descriptions and situate HNC patients' meaning-giving process with respect to food and eating experiences within a coherent epistemological framework (Ganzer, Rothpletz-Puglia, et al., 2015; McQuestion et al., 2011); the phenomenological approach in qualitative research seems a promising way to do so. Finally, future research should address various dimensions of patients' lives, such as their relationships with caregivers and their point of view, why patients often are reluctant to ask for help during treatments and healthcare providers' role.

The key outcome of our study was the recognition that treatment sequelae and patients' daily issues do not affect people's lives in isolation and should be considered holistically within their social and cultural context. Further research also is needed to explore novel approaches to address patients' feelings of abandonment, and their treatment experience throughout the cancer journey with a similar approach that involves health professionals, caregivers and family members and peers in the community.

6 | CONCLUSION

The literature analysed demonstrated that, at present, little information is available about the way in which patients see their future and about those who reported feelings such as fear, insecurity and pessimism (Chen, 2012; Ottosson et al., 2013; Roing, Hirsch, & Holmstrom, 2007). Further, few qualitative studies exist that have analysed directly the strategies patients adopt to cope with the disease throughout treatment (Haisfield-Wolfe et al., 2012; Larsson et al., 2007; Moore et al., 2014). Our findings are consistent with those of studies that explored the psychological variables associated with HNC patients (Dunne et al., 2017; Morris, Moghaddam, Tickle, & Biswas, 2017) or nutritional issues in different stages of HNC (Bressan et al., 2016; Ganzer, Touger-Decker, Byham-Gray, Murphy, & Epstein, 2015). Despite this, according to Lang, France, Williams, Humphris, and Wells (2013), topics such as connections between coping/self-management and prospective HNC, or potential stage-specific associations between coping and psychological distress, remain unexplored (Morris et al., 2017). This knowledge gap suggests the need to conduct further studies to enhance our knowledge of the care healthcare professionals provide to HNC patients and its effects on their and their families' QoL.

CONFLICT OF INTEREST

The authors declare no conflict of interest.

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