

Qiaomiao Zeng, MD, RN
 Donglan Ling, MD, RN
 Wenfeng Chen, MD, RN
 Yao Liao, MD, RN
 Ran An, MD, RN
 Lianxiang He, PhD, RN

Family Caregivers' Experiences of Caring for Patients With Head and Neck Cancer

A Systematic Review and Metasynthesis of Qualitative Studies

KEY WORDS

Head and neck cancer
 Caregiver
 Caring experience
 Systematic review
 Meta-synthesis

Background: Family caregivers of head and neck cancer (HNC) patients undertook heavy care tasks and role responsibilities. They were facing multiple challenges during the patients' cancer trajectory. **Objective:** The aim of this study was to synthesize existing qualitative evidence regarding family caregivers' experiences of caring for HNC patients. **Methods:** A meta-aggregation approach was used. Articles were collected from MEDLINE, EMBASE, CINAHL, Web of Science, PsycINFO, and Cochrane Library. Supplementary resources were collected by scrutinizing reference lists and performing citation tracking. **Results:** A total of 20 studies were included and synthesized. Three meta-themes covering "accepting the diagnosis and treatment on patients: a distressing process," "facing changes of life and adapting to new roles," and "appreciating the external supports" were identified with 10 subthemes. There was high confidence in the evidence for "facing changes of life and adapting to new roles" and moderate confidence in the evidence for the other 2 meta-themes. **Conclusions:** Taking care of HNC patients is a distressing process. Caregivers took on role responsibilities and developed strategies to make adjustments to life changes, so as to provide better care for patients. External supports regarding caregiving and self-care were desired. **Implications for Practice:** Psychological distress was common among caregivers and calls for routine clinical screening. Providing caregivers with practical strategies to deal with daily

Author Affiliations: Department of Nursing Education and Research, National Clinical Research Center for Geriatric Disorders (Xiangya Hospital of Central South University) (Drs Zeng, Chen, and He), Changsha, Hunan; Department of Nursing, The Second Affiliated Hospital of Guangzhou Medical University, Guangzhou (Dr Ling); Nursing Administration Department, Jingzhou Central Hospital, and Medical Institute of Tangze University, Hubei (Dr Liao); Institute of Nursing, Central South University, Hunan (Dr An), China.

The study was supported by funding from the Natural Science Fund of Hunan Province-Science and Technology Project (no. 2019JJ80089).

The authors have no conflicts of interest to disclose.

Correspondence: Wenfeng Chen, MD, RN, Department of Nursing Education and Research, National Clinical Research Center for Geriatric Disorders (Xiangya Hospital of Central South University) Xiangya Road No. 87, Kaifu District, 410008 Changsha, Hunan, China (136318979@qq.com).

This is an open-access article distributed under the terms of the Creative Commons Attribution-Non Commercial-No Derivatives License 4.0 (CCBY-NC-ND), where it is permissible to download and share the work provided it is properly cited. The work cannot be changed in any way or used commercially without permission from the journal.

Accepted for publication December 23, 2021.

DOI: 10.1097/NCC.0000000000001096

caregiving tasks was crucial. Healthcare workers can play a critical role in providing tailored support in different caregiving stages. The findings informed the interventions and future research to improve HNC caregivers' experiences.

Head and neck cancer (HNC) is a group of cancers arising in the lip, oral cavity, pharynx, larynx, and paranasal sinuses. In 2020, approximately 65 630 new cases of cancer of the oral cavity, pharynx, and larynx occurred, accounting for approximately 3.6% of new cancer cases in the United States.¹ In China, the total incidence of oral cavity and pharyngolaryngeal cancer was estimated at 48.1 per 100 000 with a mortality rate of 22.1 in 2015.² Treatment for HNC is complex and intermittent. Patients often undergo an intensive combination of surgery, radiotherapy, and chemotherapy, with a series of symptoms and persisting adverse treatment effects. These are associated with facial disfigurement; chronic functional impairments related to eating, swallowing, and speaking³; long-term psychosocial problems associated with anxiety, depression, and fear of recurrence,⁴⁻⁸ which can seriously undermine HNC patients' quality of life (QOL). The family caregiver, someone who consistently provides HNC patients with practical and emotional supports, unavoidably experiences challenges.^{9,10}

Family caregivers play a critical role throughout the HNC patients' illness trajectory. Along with the patients, they could be seen as a "dyad."^{11,12} Particularly, when patients return home from hospital, more substantial supports are required from caregivers.¹³ The HNC caring tasks are time-consuming, difficult, and disruptive.^{14,15} Caregivers frequently take on tasks that require nursing or technical skills such as tracheostomy care, enteral nutrition, tube feeding, and pain management, which can increase the challenges of caregiving.¹⁶ In addition, helping patients cope with their psychological problems is distressing; the process may trigger negative feelings in caregivers.¹⁷ These role responsibilities lead to a disruption in caregivers' life routine, such as less time and energy for work and other duties, impacting their social activities and relationships with partners.¹³


A proficient caregiver may positively affect the patient's clinical outcomes. However, the difficult tasks always put the caregivers at the greatest risk of distress.¹⁶ Sainath¹⁸ and Limonero et al¹⁹ detected high levels of distress in over 50% of the sample of cancer caregivers. Anxiety and depression were commonly

reported as high as 27.4% and 9.8%, respectively.²⁰ According to Lee and colleagues,²¹ 13% of HNC caregivers suffered from adjustment disorder. These negative emotions are correlated with poor resilience of carers, which in turn negatively affects their QOL.^{5,22} Previous dyadic studies in HNC have shown that the distress levels of patient and caregiver often covary. An increase in one dyad member's distress may exacerbate the distress of the other dyad member.^{23,24} Further, the distress of caregivers could leave impacts on the quality of care and support that they are able to provide for patients.¹⁶

High levels of unmet support needs were commonly reported among caregivers.²⁵ Understanding the experience of caregivers in caring for patients with HNC is a prerequisite for healthcare professionals to design training programs or interventions to better prepare caregivers to manage care activities. Although several qualitative studies from different views have been published in relation to caregivers' experience in caring for HNC patients, there has been no synthesis of the findings from these studies. As a result, the generalizability of conclusions remains unclear. The aim of this systematic review was to synthesize and analyze the existing qualitative and mixed-methods evidence, which examined the family caregivers' experiences in caring for a member living with HNC, and so as to get a deeper understanding of the phenomenon. These findings have the potential to expand findings from earlier research and may be useful for nursing science and improvement of clinical practice.

■ Methods

Meta-synthesis is a systematic approach to collect and analyze isolated qualitative studies and synthesize those findings.^{26,27} It preserves the meaning of the individual studies but produces a new and integrated interpretation toward these findings and helps to promote the development of clinical practice, research, or theory.²⁸ The goal of this study is to provide holistic insights

 **Table 1** • MEDLINE, EMBASE, and COCHRANE Search Protocol

Search No.	
#1	["Head and Neck Neoplasms" [Mesh] OR "head and neck cancer" (ti/ab) OR HNC (ti/ab)]
#2	["head and neck" (ti/ab) OR "oral cavity" (ti/ab) OR nasopharynx (ti/ab) OR oropharynx (ti/ab) OR hypopharynx (ti/ab) OR larynx (ti/ab) NOT esophag (ti/ab)]
#3	[Neoplasms [Mesh] OR cancer (ti/ab) OR tumor (ti/ab) OR tumor (ti/ab) OR malignancy (ti/ab) OR carcinoma (ti/ab)]
#4	#1 OR (#2 AND # 3)
#5	[carer (ti/ab) OR caregiver (ti/ab) OR famil* (ti/ab)]
#6	[experience OR perception OR attitude OR emotion]
#7	[qualitative (ti/ab) OR themes (ti/ab)]
#8	#4 AND #5 AND #6 AND #7
#9	#8 NOT [PT Editorial OR PT Letter OR PT Commentary]
#10	#10 Filters: English, January 1, 2000, to June 30, 2021

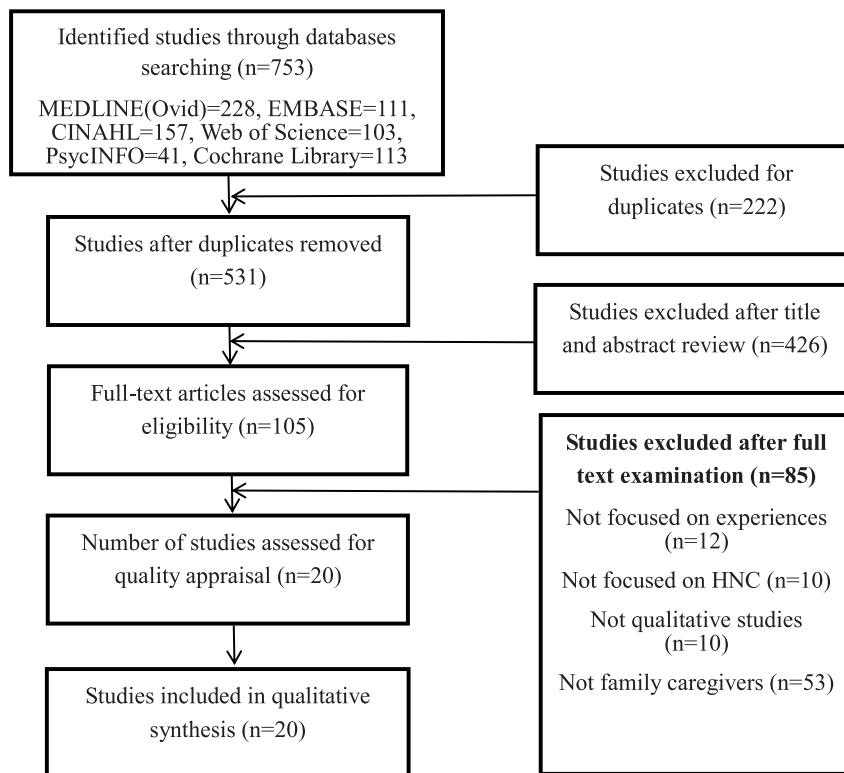


Figure ■ The flowchart for the search and selection process.

into HNC caregivers' experience of caring for patients to inform nursing practice and provide effective supports for them. The work of Sandelowski²⁹ was used to guide this meta-synthesis,

with 4 steps applied: (1) systematically searching for relevant literature, (2) study appraisal, (3) study classification, and (4) findings synthesis. In this review, we focused on 3 questions related

Table 2 • CASP Appraisal of Included Qualitative Studies

Studies	Q1	Q2	Q3	Q4	Q5	Q6	Q7	Q8	Q9	Q10
Badr et al (2016) ²⁵	√	√	√	√	√	-	√	√	√	√
Balfe et al (2016) ²²	√	√	√	√	√	-	√	√	√	√
Balfe et al (2016) ³⁴	√	√	√	√	√	-	√	-	√	√
Balfe et al (2017) ¹⁴	√	√	√	√	√	-	√	√	√	√
Balfe et al (2017) ¹⁵	√	√	√	√	√	-	√	-	√	√
Dri et al (2020) ¹¹	√	√	√	√	√	-	√	√	√	√
Fronczek (2015) ¹⁷	√	√	√	√	√	-	√	√	√	√
Goswami et al (2019) ³⁵	√	√	√	√	√	-	√	-	√	√
Halkett et al (2020) ¹³	√	√	√	√	√	-	√	√	√	√
Kitrungrote et al (2008) ³⁶	√	√	√	-	√	-	√	√	√	√
Liang et al (2019) ³⁷	√	√	√	√	√	-	√	√	√	√
Mayre-Chilton et al (2011) ³⁸	√	√	√	√	√	-	√	-	√	√
Nund et al (2014) ³⁹	√	√	√	√	√	-	√	√	√	√
Nund et al (2015) ⁴⁰	√	√	√	√	√	-	√	√	√	√
Patterson et al (2013) ⁹	√	√	√	√	√	-	√	-	√	√
Penner et al (2012) ⁴¹	√	√	√	√	√	-	√	√	√	√
Richardson et al (2015) ⁴²	√	√	√	√	×	-	√	-	√	√
Röing et al (2008) ⁴³	√	√	√	√	√	-	√	-	√	√
Schaller et al (2014) ⁴⁴	√	√	√	√	√	-	√	-	√	√
Waliyanti and Primastuti (2021) ⁴⁵	√	√	√	√	-	-	√	-	√	√

Abbreviation: CASP, Critical Appraisal Skills Programme.

Symbols indicate: √, Yes; -, cannot tell; × no.


Q1: Was there a clear statement of the aims of the research? Q2: Is a qualitative methodology appropriate? Q3: Was the research design appropriate to address the aims of the research? Q4: Was the recruitment strategy appropriate to the aims of the research? Q5: Were the data collected in a way that addressed the research issue? Q6: Was the relationship between researcher and participants adequately addressed? Q7: Have ethical issues been taken into account? Q8: Was the data analysis sufficiently rigorous? Q9: Is there a clear statement of findings? Q10: How valuable is the research?

 **Table 3 • Characteristics of 20 Included Studies**

Study Details	Setting	Sample Size and Characteristics	Study Design and Data Analysis
Badr et al (2016) ²⁵ USA	Icahn School of Medicine	N = 6; F/M = 5/1; age: 38–63 y, mean 50.8 ± 9.3 Family relationship: spouse = 6	Qualitative; grounded theory analysis
Balfe et al (2016) ²² Ireland	Specialist centers	N = 31 (selected from a previous quantitative survey); F/M = 24/7; age: mean 60.1 Family relationship: spouses = 28, others = 3	Qualitative cross-sectional study; thematic content analysis
Balfe et al (2016) ³⁴ Ireland	Specialist centers	N = 31 (selected from a previous quantitative survey); F/M = 24/7; age: mean 60.1 Family relationship: spouses = 28, other = 3	Qualitative research; thematic analysis
Balfe et al (2017) ¹⁴ Ireland	Specialist centers	N = 31 (selected from a previous quantitative survey); F/M = 24/7; age: mean 60.1 Family relationship: spouses = 28, other = 3	Qualitative study; thematic analysis
Balfe et al (2017) ¹⁵ Ireland	Specialist centers	N = 31 (selected from a previous quantitative survey); F/M = 24/7; age: mean 60.1 y Family relationship: spouses = 28, other = 3	Qualitative study; thematic analysis
Dri et al (2020) ¹¹ Italy	Friuli Venezia Giulia Laryngectomized Patient Associations	N = 12, F/M = 11/1; age: 47–76 y, mean = 63.8 Family relationship: spouse = 9, adult children = 3	Descriptive phenomenological study; Colaizzi's descriptive analysis framework
Fronczek (2015) ¹⁷ USA	Two hospital systems in New York	N = 9, F/M = 8/1 Age: 43–76 y, mean = 59.00 ± 11.56 y Family relationship: spouses = 8, adult children = 1	Phenomenology; van Manen's human science approach

Data Collection	Sampling Method	Phenomenon of Interest	Themes and Subthemes
Semistructured interviews	Purposive sampling	To understand patient and spouse unmet needs and relationship challenges during curative RT for HNC	(1) Unmet information needs; (2) unmet emotional and psychological needs; (3) partner impact and daily activities; (4) relationship needs
In-depth interviews	Purposive sampling	To identify and describe the triggers of emotional distress among long-term caregivers of people with head and neck cancer	(1) Understandings and fears of illness; (2) lifestyle restrictions and competing demands; (3) facial disfigurement; (4) financial problems; (5) negative life events; (6) witnessing suffering
Semistructured interviews	Purposive sampling	To explore the overall financial impact of HNC on caregivers; to describe the factors that mitigate this impact	(1) Primary treatment phase: enormous cost of commuting, overnight accommodation, plane tickets, jobs quit, reduced work; stressful (2) postprimary treatment phase: long-term consequences, jobs quit, macroeconomic external circumstances; compromised, distressing. (3) Mitigations: flexible work arrangements, supports from caregivers' communities (fundraising, private health insurance, medical card, social welfare payments)
Semistructured interviews	Purposive sampling	To explore adult HNC caregivers' experiences of accessing social support during the acute and extended survivorship periods of HNC	(1) Difficulties obtaining support (2) Inability to provide support (3) Impression management (4) Nonhuman coping mechanisms (5) Support from healthcare services
In-depth semistructured interviews via telephone	Purposive sampling	To explore factors that influence carers of patients with HNC experiences of commuting with their relative/friend for treatment	(1) Shocking and unexpected about the diagnosis (2) Accelerate time, tough time (3) Restricted schedule (4) Importance of commuting (5) Difficulties of commuting (6) Splitting (7) Emotional and intellectual disengagement (8) Support from families, friends, and hospitals
In-depth interviews	Purposive sampling	The lived experience and meaning of being a family caregiver to a HNC patient dealing with laryngectomy	(1) Experiencing disease and the pathway of care (receiving the diagnosis, dealing with the referral to surgical procedure, experiencing the illness of their loved one, uncertainty on the future); (2) Handling changes to everyday life (facing changes in daily life, the responsibility in providing care, strongly impacting aspects of disease: physical deformity and loss of voice); (3) Support received by others (external relationships: support and abandonment, The need for information)
Semistructured, conversational interviews	Purposive sampling	The lived experience of primary family caregivers of patients with HNCs following completion of treatment for new or recurrent disease	(1) Absorption of a large amount of information; (2) importance of support from others; (3) adaptation to new routines and responsibilities; (4) a desire to be vigilant and protect a loved one from harm; (5) feelings of fear, sympathy, and guilt

(continues)

 **Table 3 • Characteristics of 20 Included Studies, Continued**

Study Details	Setting	Sample Size and Characteristics	Study Design and Data Analysis
Goswami, Gupta and Raut (2019) ³⁵ India	Houses of participants	N = 24, F/M = 14/10 Age: 22–57 y, average = 37 y Relationships: spouses = 12, adult children = 10, siblings or cousins = 2	Qualitative study
Halkett et al (2020) ¹³ Australia	Two tertiary cancer centers	N = 20, F/M = 19/1 Age: 18–79 y, mean = 56.0 ± 13.5 y Family relationship: spouse = 16, adult children = 2, siblings = 1, parents = 1	Descriptive phenomenology; thematic analysis
Kitrungrote et al (2008) ³⁶ Thailand	University Hospital in Songkhla, RT unit	N = 15, F/M = 12/3; age: 37–64 y Family relationship: spouse = 15	Hermeneutic phenomenological Approach; analysis method used by Cohen, Kahn, and Steeves (2000)
Liang et al (2019) ³⁷ Taiwan	Oral outpatient oncology department of a teaching hospital in northern Taiwan	N = 22, F/M = 19/3; age: 25–71 y, mean = 51.9 y; family relationship: spouse = 19, parent = 2, other = 1	Interpretive descriptive method with an inductive analytical approach; qualitative content analysis
Mayre-Chilton et al (2011) ³⁸ UK	University College London Hospital	N = 3; F/M = 2/1 Age: 40–70 y Family relationship: spouse/partner = 2, adult children = 1	Qualitative study; thematic analysis

Data Collection	Sampling Method	Phenomenon of Interest	Themes and Subthemes
In-depth interviews	Purposive sampling	To understand the psychosocial impact of caregivers of oral cancer patients	(1) Impacts on physical health and lifestyle; (2) emotional impact; (3) impact on family and social relationship; (4) impact on financial and work status; (5) a need of improving hospital services; (6) spiritual concern; (7) acceptance of the disease
Semistructured interviews	Convenience sampling	The lived experiences of carers of patients diagnosed with HNC	(1) Silent suffering; (2) gamut of emotions; (3) causal attribution; (4) changing priorities (being available, taking an active role); (5) gaining support; (6) coping
Interviews	Not mentioned	To describe the experiences of caregivers of spouses with HNC undergoing RT	(1) Being committed for life to spouses, (2) enhancing the spouses' comfort, (3) being a cosufferer, (4) readjusting oneself, (5) appreciating supports; (6) being gratified with self-development and marital life growth.
Semistructured, open-ended interview	Purposive sampling	To identify the tasks performed by family members who care for oral cancer patients and the challenges and difficulties related to them	(1) Managing patients' nutritional issues (preparing nutritious food, and suitable diet, increasing the patient's willingness to eat, managing feeding tubes); (2) Researching and making decisions about patient care (making decisions, exploring the most suitable care, managing adverse effects); (3) Managing sudden and unpredictable patient conditions (managing sudden change of patient's condition, coping, handling uncertainty, cancer recurrence and patient death; (4) Managing patient's and one's own emotional distress; (5) Adjusting own attitudes toward patient care (negative emotions, patient's suffering, caring and end of life); (6) Seeking resource (consultation on the provision of patient care, financial support, substitute caregivers, respite)
Focus group interview	Purposive sampling	To ascertain a better understanding of the views and experiences of gastrostomy tube feeding at home for both HNC patients and their caregivers to identify improvements to services	(1) Developing positive coping strategies; (2) preventing nutritional decline; (3) Tube dependency; dentures; (4) finance; (5) active care; (6) psychological support

(continues)

 **Table 3 • Characteristics of 20 Included Studies, Continued**

Study Details	Setting	Sample Size and Characteristics	Study Design and Data Analysis
Nund et al (2014) ³⁹ Australia	Radiation oncology department at a tertiary hospital	N = 12, F/M = 10/2 Age: 45–67 y, mean = 53.9 ± 6.2 y Family relationship: spouse/partner = 12	Descriptive phenomenological study; thematic analysis following the phases outlined by Braun and Clarke
Nund et al (2015) ⁴⁰ Australia	A tertiary hospital in Brisbane	N = 9, F/M = 8/1 Age: 45–60 y, mean = 52.4 ± 5.05 y Relationship: spouse = 9	Descriptive phenomenological study; thematic analysis by Braun and Clarke
Patterson et al (2013) ⁹ UK	Patient-carer dyads home	N = 8, F/M = 7/1 Age: 46–70 y Relationship: spouse/partner = 8	Mixed method; thematic analysis
Penner et al (2012) ⁴¹ Canada	Home	N = 6, F/M = 4/2 Age: 49–64 y Relationship: spouse = 4, sibling = 2	Descriptive phenomenological study; Spiegelberg's 3-step approach
Richardson et al (2015) ⁴² New Zealand	Auckland City Hospital	N = 73, F/M = 61/12 Age: mean = 50 y Relationship: spouse/partner = 41, adult children = 22, sibling = 5	Qualitative study; thematic analysis outlined by Braun and Clarke
Röing et al (2008) ⁴³ Sweden	Clinic of oral and maxillofacial surgery and hospital dentistry in a university hospital	N = 7, F/M = 3/4 Age: 35–78 y, mean = 58 y Relationship: spouse = 7	Phenomenology

Data Collection	Sampling Method	Phenomenon of Interest	Themes and Subthemes
In-depth, semistructured, individual interview	Purposive, maximum variation sampling	To report on the experiences of carers of people with dysphagia (nongastrostomy dependent) following nonsurgical treatment for HNC and to identify the support needs of this group	(1) Dysphagia disrupts daily life: meal preparation; family; social life and eating out; emotional responses (2) Make adjustments to adapt: emotional adjustment; take on more roles; practical strategies (3) Out of expectations about dysphagia; (4) Experiences of dysphagia-related services and supports: information needs to be practical, personalized and straightaway; support given throughout trajectory of care; roles were not clear; importance of support for carers, family, friends
In-depth, semistructured interviews	Purposive, maximum variation sampling	To explore the lived experience of communication changes following chemoradiation therapy treatment for HNC from the perspective of survivors and carers	(1) Not sufficient support for carers to manage patients' communicating challenges in daily life; (2) communication changes leave impacts on family and social lives; emotion responses toward patients' communication difficulties; (3) adaption of the communication changes
Field notes of observations; dyad or individual interviews	Purposive sampling	To explore their perspective of living with someone with dysphagia	(1) Food provision; (2) health surveillance; (3) motivation; (4) changes to lifestyle
Face-to-face interviews	Purposive sampling	To explicate the lived experience of caring for a dysphagic relative with advanced HNC receiving tube feeding	(1) Negotiating changing roles; (2) negotiating an altered lifestyle; (3) negotiating ways of coping; (4) negotiating the meaning of the feeding tube
Open-ended Questionnaire	Convenience sampling	To explore the psychological support needs of patients with HNC and their caregivers	(1) Social support (from family and friends): being there; empathy; maintaining normality; practical support; (2) Social support (from healthcare professionals): information; honesty; positivity; empathy; (2) Psychological support: information; emotional expression; coping strategies; (2) Stress management: improved communication, honest approach, empathy, practical support
Interviews	Purposive sampling	To describe oral cancer and its initial treatment as experienced by the patients' spouses	(1) From spouse to supportive carer-lived relation; (2) negligence of self-experiences of lived body; (3) a restricted life-lived space; (4) altered sense of lived time

(continues)

Table 3 • Characteristics of 20 Included Studies, Continued

Study Details	Setting	Sample Size and Characteristics	Study Design and Data Analysis
Schaller et al. (2014) ⁴⁴ Sweden	Specialized pain care department at the University Hospital, Linköping	N = 21; F/M = 18/3; age: 20–39 y, n = 6; 40–59 y, n = 6; 60–89 y, n = 9 Relationship: spouse/partner = 15, adult children = 6	Qualitative interview study; content analysis
Waliyanti and Primastuti (2021) ⁴⁵ Indonesia	Regency, Yogyakarta	N = 6 Age, sex, and relationships were not mentioned	Qualitative method with phenomenological approach; thematic data analysis

Abbreviations: F, female; HNC, head and neck cancer; M, male; RT, radiotherapy.

to the study purpose: (1) What are family caregivers' experiences of caring for HNC patients? (2) What are the impacts on family caregivers when caring for HNC patients? And (3) what support needs do they want in caring activities?

Data Sources and Search Strategy

Journal articles were comprehensively searched by 2 researchers from the databases of MEDLINE (Ovid), EMBASE, CINAHL, Web of Science, PsycINFO, and Cochrane Library. The search was limited to articles published from January 1, 2000, to June 30, 2021. Search terms were developed, and subject headings were used where possible, and these were adjusted for different databases. Three groups of terms were combined: (1) *head and neck cancer, head and neck neoplasms, HNC*; (2) *carer, caregiver, famil**; and (3) *experience, perception, attitude, emotion*. The search protocols in MEDLINE, EMBASE, and COCHRANE databases were presented in Table 1.

Inclusion and Exclusion Criteria

Articles were eligible for inclusion in this review if they were (1) original research; (2) qualitative or mixed-method studies with a separate, clear qualitative section; (3) focused on family caregivers who are caring for HNC patients; (4) written in English; (5) pub-

lished from January 1, 2000, to June 30, 2021. The primary qualitative studies adopt a focus including, but not limited to, methodologies such as phenomenology, ethnography, grounded theory, action research, and feminist research. The qualitative components regarding caregivers in the mixed-methods study were included and analyzed. Reports published prior to 2000 were excluded in order to capture the most current experiences and insights and to avoid dated findings.³⁰ Abstracts only or studies not available in full text, and literature published repeatedly with incomplete data, or not peer reviewed were also excluded.

Study Selection

The initial search of the above strategy yielded a total of 753 articles, which were then imported into EndNote X7 software.³¹ After screening duplicates through EndNote, 222 duplicates were found. Retained articles were then assessed for relevance based on the title and abstract review using the inclusion criteria, with 426 citations being excluded. The full texts of the remaining 105 citations were retrieved by 2 independent reviewers for potentially relevant citations. After careful examination of the full texts, 85 articles were excluded. The remaining 20 studies were appraised for quality by 2 independent reviewers. Discrepancies on inclusion between the 2 reviewers were settled by discussion in the research group. The search results and process are illustrated in the Figure.

Data Collection	Sampling Method	Phenomenon of Interest	Themes and Subthemes
Interviews	Purposive sampling	How the relatives perceived the experiences of the HNC patient's situation, especially with respect to pain, and how the relatives themselves experienced the situation	Inability to relieve and comprehend patients' physical suffering (extensive physical pain/fear of medication/tolerated much pain/struggles to relieve the pain/inadequate knowledge about pain and pain relief); (2) overwhelming emotions (negative emotions with feeling of fear, anger, and unfairness/psychological symptoms/uncertainty of diagnosis/affecting psychological mood/worries/loneliness and powerlessness); (3) support needs from the healthcare service (lack of holistic approach/challenges about information/lack of information); (4) altered daily activities and family roles (lack of social activities/embarrassment/emotional and practical support/become closer)
In-depth interviews	Purposive sampling	To explore family experiences in providing support in the care of nasopharyngeal cancer patients in Yogyakarta	(1) Family perceptions in caring for patients, family knowledge about the disease, and family information sources could impact caregiving; (2) Family support regarding emotional, informational, instrumental, spiritual aspects, and appreciation are needed; (3) Transportation, administrative, and financial obstacles faced by families

Quality Appraisal

Twenty included studies were assessed for quality by 2 independent reviewers, and the discrepant views were discussed at consensus using the Critical Appraisal Skills Programme (CASP) qualitative research checklist.³² This critical appraisal tool is widely used for evaluating the quality of qualitative studies.³³ It consists of 10 questions that are designed to help appraise the research studies quickly and systematically requiring the researcher to select “yes,” “no,” or “can’t tell” for each question.³² In this review, 2 researchers from the research team assessed the quality of each study independently. After conferral of findings and scores, a decision was made about each study’s inclusion, and disagreements were settled in group discussion. The evaluative questions are outlined along with their results in Table 2.

Data Extraction

Qualitative data extraction involves identifying and transferring study findings using an approach agreed on by the reviewers.⁴⁶ This process was performed by Q.Z. and D.L. independently, by listing the descriptive data extracted from the included studies, including the study details (authors, publish date, and country), setting, sample size and characteristics (gender and age), study design and data analysis, data collection, sampling method, phenome-

non of interest, and themes and subthemes (Table 3). The reported discrepancies were addressed and resolved via group discussions.

Data Synthesis

The data were analyzed and synthesized using a thematic analysis approach.⁴⁷ The initial codes were extracted from the study findings; they were grouped into categories and then synthesized into meta-themes. Thomas and Harden⁴⁸ describe that this approach involves a generation of “interpretative constructs” across the original studies; the interpretation goes beyond the original context. The developed inductive themes could reflect a deeper insight into the topic.

The 2 authors repeatedly read each article to capture meanings and then listed identified topics and article concepts independently. The compilation and maintenance of comprehensive notes and research memos in regard to findings classification, content analysis, and synthesis decisions were documented in the EndNote X7 software. The process of comparing the relationships of concepts and meaning discussion were performed in a group meeting. These concepts were then continually and systematically compared in order to determine whether the data were consistent and provided the different aspects of the theme. The final construction of themes was determined by a reached consensus of authors. This data synthesis process preserves the

Table 4 • CERQual Qualitative Evidence Profile

Meta-theme	Methodological				Overall Rating	Explanation
	Contributing Studies	Limitations	Relevance	Coherence		
Accept the diagnosis and treatment on patients is distressing	Patterson et al (2013), ⁹ Dri et al (2020), ¹¹ Halkett et al (2020), ¹³ Balfe et al (2017), ¹⁴ Balfe et al (2017), ¹⁵ Fronczek (2015), ¹⁷ Balfe et al (2016), ²² Badr et al (2016), ²⁵ Balfe et al (2016), ³⁴ Goswami, Gupta and Raut (2019), ³⁵ Kirungrote et al (2008), ³⁶ Liang et al (2019), ³⁷ Mayre-Chilton et al (2011), ³⁸ Nund et al (2014), ³⁹ Nund et al (2015), ⁴⁰ Schaller et al (2014) ⁴⁴	Minor concerns about methodological limitations	Moderate concerns about relevance (9 countries represented in the studies; 81.77% participants were female; recruited from hospital, clinical center, house of participants or patient association)	Minor concerns about coherence (theme consistent across 16 studies and across experience of caring HNC patients generally)	Moderate concerns about adequacy (the primary studies used mostly thematic or content analysis and provided mostly descriptive findings)	This finding was graded as moderate confidence because of minor concerns regarding methodological limitations, and more relevance affected by predominantly female caregivers in hospital or clinical center. The meta-theme was consistent across 16 studies with some concerns that adequacy in that not all studies provided rich data.
Facing changes of life and adapting to new roles for caring	Patterson et al (2013), ⁹ Dri et al (2020), ¹¹ Halkett et al (2020), ¹³ Balfe et al (2017), ¹⁵ Fronczek (2015), ¹⁷ Balfe et al (2016), ²² Badr et al (2016), ²⁵ Balfe et al (2016), ³⁴ Goswami, Gupta and Raut (2019), ³⁵ Kirungrote et al (2008), ³⁶ Liang et al (2019), ³⁷ Mayre-Chilton et al (2011), ³⁸ Nund et al (2014), ³⁹ Nund et al (2015), ⁴⁰ Penner et al (2012), ⁴¹ Röing et al (2008), ⁴³ Schaller et al (2014), ⁴⁴ Waliyanti and Primastuti (2021) ⁴⁵	Minor concerns about methodological limitations	Minor concerns about relevance (11 countries represented in the studies; 80% participants were female; recruited from hospital, clinical center, patient association or home)	Minor concerns about coherence (Theme consistent across 18 studies and across experience of caring HNC patients generally)	Minor concerns about adequacy (Most of the studies used mostly thematic or content analysis and provided rich data)	This finding was graded as high confidence because of minor concerns regarding methodological limitations, and the finding was relevant to eleven cultures. The meta-theme was consistent across 18 studies with the themes were mostly richly described in the primary studies

(continues)

Table 4 • CERQual Qualitative Evidence Profile, Continued

Meta-theme	Contributing Studies	Methodological Limitations	Relevance	Coherence	Adequacy of Data	Overall Rating	Explanation
Support needs to manage the struggles during the caregiving	Patterson et al (2013), ⁹ Dri et al (2020), ¹¹ Balfé et al (2017), ¹⁴ Balfé et al (2017), ¹⁵ Fronczek (2015), ¹⁷ Badr et al (2016), ²⁵ Balfé et al (2016), ³⁴ Goswami, Gupta and Raut (2019), ³⁵ Liang et al (2019), ³⁷ Mayre-Chilton et al (2011), ³⁸ Nund et al (2014), ³⁹ Nund et al (2015), ⁴⁰ Richardson et al (2015), ⁴² Schaller et al (2014), ⁴⁴ Waliyanti and Primastuti (2021) ⁴⁵	Minor concerns about methodological limitations	Moderate concerns about relevance (10 countries represented in the studies; 81.31% participants were female; recruited from hospital, clinical center, or patient association)	Minor concerns about coherence (theme consistent across 15 studies and across experience of caring HNC patients generally)	Moderate concerns about adequacy (themes richly described through thematic or content analysis and some studies provided rich data)	Moderate	This finding was graded as moderate confidence with minor methodological limitations. The findings were relevant to females and across 10 countries. The finding was coherent across caring experience. Fewer studies contributed to this finding compared with other 2 themes

original contexts, while further generating themes and concepts for new understanding.

Confidence in the Findings

The Confidence in the Evidence from Reviews of Qualitative Research (CERQual) developed by the Grading of Recommendations Assessment Development and Evaluation Working Group was used to transparently assess the confidence placed in individual review findings from syntheses of qualitative evidence.⁴⁹ The assessment based on 4 components: methodological limitations (problems in the design or conduct of included studies), relevance (degree of the context supporting the findings, including perspective or population, phenomenon of interest, and setting), coherence (the extent to which the review finding is well grounded in data from the included studies and the convincing explanation of these data provided), and adequacy of data (determination of the degree of richness and quantity of data supporting review findings). Four levels of the assessment results were applied: high, moderate, low, or very low. The definition of each level was described below the table of CERQual Qualitative Evidence Profile (Table 4). The results from the CASP evaluation were used for the assessment of methodological limitations of the studies.⁵⁰

Results

Study Characteristics

Of the 20 studies included in this review, 19 were qualitative studies, and 1 was a mixed-methods study (Table 3). These studies were conducted in Ireland (n = 4), Australia (n = 3), the United Kingdom (n = 2), United States (n = 2), Sweden (n = 2), Italy (n = 1), New Zealand (n = 1), China/Taiwan (n = 1), Thailand (n = 1), Canada (n = 1), India (n = 1), and Indonesia (n = 1). The 4 studies from Ireland were published from the same research group.

Two hundred eighty-four caregivers took part in the 20 included studies (range, 3–73), with the age range from 20 to 78 years, and approximately 80.93% were female (n = 225). Four studies^{14,15,22,34} included the same 31 participants selected from a previous quantitative survey that investigated HNC patients' needs.⁵¹ Except that 1 study did not mention the family relationships,⁴⁵ the relationship of caregivers with patients in other studies were spouse or partner (n = 209 [73.59%]), adult children (n = 45 [15.84%]), sibling (n = 10 [3.52%]), and parent (n = 5 [1.76%]). Six studies included only spouse/partner caregivers.^{9,25,36,39,40,43} The included studies used appropriate methods for assessing and analyzing the data. Seventeen studies recruited participants using purposive sampling; 2 studies recruited a convenience sample,^{13,42} and 1 study did not mention the sampling method but had a detailed explanation of inclusion criteria.³⁶ No studies provided information on data saturation.

Four studies explored the overall experience of caring HNC patients^{11,13,17,36}; 3 explored how carers experienced patients' condition^{40,43,44}; 4 studies explored caring experiences of patients with dysphagia,^{9,38,39,41} and 1 focused only on patients with no tube feeding³⁹; 4 explored support needs or difficulties^{14,25,37,42}; 1 explored the commuting experience¹⁵; 1 explored carers' triggers

of emotional distress²²; 1 explored the financial impacts³⁴; 1 explored the psychosocial impacts³⁵; and 1 explored the experiences in providing support.⁴⁵ Other details of the included studies are listed in Table 3.

Results of Individual Studies

Four studies reported caregivers' overall experience of caring for HNC patients focused on the posttreatment period.^{11,13,17,36} Changes in normal daily life were identified, accompanied with feelings of frustration, feeling "tied down," fear, sympathy, and guilt. Caregivers make adjustments to the role transition by modifying their living arrangements. They take on new responsibilities, maintain hope to restore patients' self-care ability and social function, stay vigilant in the caring process, and are committed to care. Caregivers appreciate the received supports but are still faced with unmet needs. Tremendous information and education from healthcare providers were warranted. Another 3 studies explored carers' experience of patient's disease, overall condition, communication changes, or treatment^{40,43,44} and identified distress because of their inability to comprehend and relieve the function changes and suffering of patients. Caregivers were inclined to focus on patients more than themselves; a negligence of care for themselves was commonly reported.

The 4 studies that examine caring experience of dysphagia HNC patients with or without gastrostomy tube identified that dysphagia is disruptive and resulted in difficulties in meal preparation and a loss of mealtime, social activities, and intimacy.^{37-39,41} Providing diet is time-consuming and energy-consuming; caregivers need to consider the nutrition requirements, texture, and patients' preferences. Even though the feeding tube can create burdens for patients (such as liquid diet preparation, clogging), it is considered to be an indispensable part in preventing patients' nutritional decline. Frustration, guilt, and worry were common feelings among caregivers. Some carers tried to use positive reinforcement to motivate their families to eat and help them cheer up. The severity of swallowing difficulties was beyond carers' expectation; thus, they expected that services could provide long-term support, with more practical, personalized, and straightaway information.

Another 3 studies focus on caregivers' support needs.^{14,25,42} Social supports, especially those from healthcare services, were considered to be critical. However, caregivers reported difficulties in obtaining these supports, and some provided ineffective supports. Moreover, some caregivers put on impressions and tried to maintain the appearance that everything was normal, pretending to be optimistic and denied supports in order to protect patients and families from anxiety and distress. Some nonhuman coping strategies were adopted when social support was lacking. Information, long-term support, and psychological support specific for caregivers were desired. Relationship needs were also reported to cope with the changed relationship in patient-caregiver dyads.

The study examining the impacts of commuting found the influences on carers' experience involved practical aspects (time-consuming, costs, restricted schedule) and psychological aspects (emotion split, exhaustion).¹⁵ Carers' emotional distress and its triggers were explored in Balfe and colleagues'²² study. The understandings and fears of illness, facing the patients' suffering, financial

burden, and negative life events created emotional distress. The study, which explored the financial impacts, identified a prevalent psychological stress on carers.³⁴ Flexible work arrangements, fundraising, and social welfare systems were mentioned to mitigate these impacts. Goswami et al³⁵ explored the psychosocial impacts of oral cancer on caregivers' physical health, lifestyle, emotion, relationship, finance, and work; Waliyanti and Primastuti⁴⁵ identified the significance of providing support in regard to emotional, informational, instrumental, and spiritual aspects and appreciation.

Synthesis of Results

Fifty-eight codes were identified from the 20 included studies. The codes were then aggregated into 10 categories on the basis of similarity in meanings. From the 10 categories, 3 synthesized meta-themes were developed: accepting the diagnosis and treatment on patients: a distressing process, facing changes of life and adapting to new roles, and appreciating the external supports. See Table 5 for the process of meta-theme development.

The results of confidence in the evidence in relation to each theme rated by the CERQual approach are listed as follows: the meta-theme of "facing changes of life and adapting to new roles for caring" was rated as having a high confidence in the evidence; the other 2 meta-themes were rated as having a moderate confidence in the evidence. See Table 4 for the process of rating the evidence in each meta-theme.

Accepting the Diagnosis and Treatment on Patients: A Distressing Process

This meta-theme describes that accepting the diagnosis and treatment on patients is a distressing experience. The meta-theme comprised 3 categories: "diagnosis of an unknown disease," "living with uncertainty," and "emotional well-being." Learning that patients received the diagnosis of HNC was a huge life hit for caregivers. Shock was a common feeling among caregivers, because they were not expecting a diagnosis of cancer. An onslaught of information about disease and treatment given all at once is too much change for the dyad to absorb right away. Some caregivers who are caring for dysphagia patients reported a disconnect between expectations and the reality of swallowing difficulties, because of their inadequate knowledge about the adverse effects of treatments. As a "novice," caregivers often felt unconfident in caregiving ability, and are therefore eager to receive more information about disease and treatment trajectory to be well acquainted with caregiving.


Thinking about the patient living with cancer and a relentless threat of recurrence and death was always on caregivers' minds, and living in this uncertainty triggered fear and anxiety. It is worth mentioning that seeing the patients in a deteriorating status tends to aggravate these feelings. Caregivers may become more uncertain about disease progression and the availability of treatment.

The diagnosis of HNC in the patient, along with the treatment, had a substantial impact on caregivers' emotional well-being. The unexpected diagnosis, sufferings on patients, and heavy caring activities all caused distress in caregivers. Faced with traumatic "bad news," they may complain that life is unfair. Anxieties and worries were frequently reported and can be exacerbated if the

**Table 5 • Meta-Themes Development**

Themes	Category	Meta-Theme
Shocking ^{9,15,17,39,44}	Diagnosis of an unknown disease	Accept the diagnosis and treatment on patients is distressing
Absorption of tremendous information ^{39,43}	Living with uncertainty	
Fear of recurrence or death ^{11,13,17,22,35,37,44}	Emotional well-beings	
Uncertainty on the future ^{11,35-37,44}		
Unfairness ^{43,44}	Changed life routine	Facing changes of life and adapting to new roles
Loneliness and powerlessness ^{25,35,37,44}		
Anxieties and worries ^{9,11,13,17,22,35-37,39,44}		
Sympathy ^{17,39}		
Guilt ^{17,25,44}		
Exhausted ^{15,36,37}		
Loss ²²		
Emotion suppression ^{13,14,25}		
Distress ^{11,13,22,25,34-38,44}		
Frustrated ^{11,25}		
Distraught ¹¹	Take on Role responsibilities	
Altered sense of lived time ^{15,35,43}		
Changed family and social lives ^{9,11,13,17,22,25,35,36,39-41,43,44}		
Changed roles ^{11,13,17,25,41,43,44}		
Changed eating and mealtimes ^{9,17,39,40}		
Changed physical status ^{11,15,17,22,35,37,44}		
Restricted and competing schedule ^{15,22,35,41,43}		
Work or study negotiation ^{22,34,35,41}		
Self neglect ^{9,25,35,43}		
Financial problems ^{15,22,34,35,45}		
Changed relationships ^{25,35,40}	Develop coping strategies	
Frequent commuting ^{15,45}		
Being committed ^{13,37}		
Give intimate and compassionate love ³⁶		
Enhancing the spouses' comfort ^{36,43}		
Manage patients' physical symptoms ^{36,37,43,45}		
Emotional supporter ^{9,25,36,37,39,40,43-45}		
Managing patients' nutritional issues ^{9,13,37-39,41}		
Researching and making decisions about patient care ^{25,37}		
Managing sudden and unpredictable patient conditions ³⁷		
Health surveillance ^{9,17,22,25,39,44}	Perceived positive meanings of caregiving	
Information supporter ⁴⁵		
Spiritual supporter ⁴⁵		
Focus on other tasks ¹³		
Gastrostomy tube ³⁸		
Food and eating ³⁹		
Trial and error ⁴⁰		
Nonhuman strategies ¹⁴		
Being highly organized ¹³		
Religious beliefs ^{35,36}		
Emotional adjustment ^{15,35-37,39,40}		
Attributions of the cause of cancer ^{13,37}		
Sense of accomplishment ²⁵		
Introspective thoughts ²⁵		
Focus on patients' positive outcome ²⁵		
Become closer ^{25,35,44}		
Self-development and marital life growth ³⁶		

(continues)

 **Table 5 • Meta-Themes Development, Continued**

Themes	Category	Meta-Theme
Relationship needs ^{11,25,37,38}	Families and friends	Support needs to manage the struggles
Talking and sharing with other carers ^{14,37,39}		
Substitute caregivers for a respite ^{35,37}		
Information needs ^{25,35,39,40,42,44,45}	Healthcare services	
Psychological support ^{25,37,42,44}		
Financial support ^{34,37}	Communities or social system	
Difficulties in managing health insurance ⁴⁵		

patient's physical and psychological condition deteriorates. Caring for the patient is considered the primary task by caregivers, and the neglect of themselves results in diminished health and a feeling of loss. Caregivers sympathize with patients' suffering, while experiencing frustration when they deal with it. If they fail to help patients, a sense of loneliness, powerlessness, and guilt is generated. The overwhelming caregiving tasks are distressing, but caregivers suppress negative emotions in front of people and pretend to be optimistic, so as to protect patients and keep family atmosphere normal. In addition, the unwanted attention from others, worse financial consequences, or other irrelevant negative events also contribute to caregivers' distress.

Facing Changes of Life and Adapting to New Roles

This meta-theme encompassed 4 categories: "changed life routine," "take on roles and responsibilities," "develop coping strategies," and "perceived positive meanings of caregiving." Caregivers' daily life routine was disrupted. This was often associated with the large amount of time spent on special meal preparation, tube feeding, and commuting for medical appointments. The changes in eating and mealtimes were discovered and resulted in a changed meaning of eating for caregivers. The restricted caring schedule affected or curtailed their usual activities in paid work, socializing, family dinner, and eating out. And this also caused physical exhaustion, including a disruption of caregivers' sleeping quality and weight management. The increased cancer-related cost and reduced income caused families financial strain and increased the burdens of caregivers. The communication difficulties of patients changed the relationship of the caregiver-patient dyads. These patients have less interest in talking with others, weakening the socializing interactions.

Caregivers took on multiple roles and responsibilities across the cancer trajectory to provide patients with supports. For example, they took the role of health monitor for patients' physical and psychological health, in order to enhance their comfort. They were housekeepers who undertook the household tasks, dealt with transportation, and managed finances. They acted as chef and nutritionist experts and tried their best to provide enough nutrition for patients, especially for those with dysphagia or a feeding tube. In addition, they tried to motivate their partners to take in food to prevent nutrition decline, encourage healthy lifestyle behavioral changes, and maintain positive attitudes. Caregivers were committed to accompany patients and sometimes acted as a speaker of patients. They were actively involved in the treatment process and making suitable decisions through either active participation

in decision making or supporting patients' preferences. Moreover, they needed to manage sudden situations that happened with patients sometimes. The emotional, information, and spiritual supports were commonly provided by caregivers.

Caregivers looked for coping strategies with patient management as well as self-health maintenance. To manage dysphagia, caregivers relied on the feeding tube, gave patients the right to make decisions on food, slowly introduced food, and prepared appropriate meals after trial and error. Moreover, caregivers ate food alone to avoid hurting patients when the food is not suitable for them. To deal with patients' negative emotions, they adjusted attitudes to be positive toward patient care, as a way to inspire patients. To stay optimistic and preserve hope, caregivers responded by being highly organized or focused on other tasks to cope with helplessness. To deflect stress, some caregivers developed emotional and intellectual disengagement. Nonhuman coping mechanisms may also be adopted as a compensation of social support, which can include pets, medications, technology devices, music, religious beliefs, or spiritual forces.

Caregivers also mentioned the positive meanings of caregiving. They achieved a sense of accomplishment because of the significant roles they played in patients' recovery. Caregivers were more introspective, and some reported receiving gratification from self-development and marital life growth. The caring process brought them closer together in their relationships.

Appreciating the External Supports

This meta-theme encompassed 3 categories: "families and friends," "healthcare services," and "communities or social system."

Families and friends usually provide the most practical supports including childcare, shopping, driving, and so forth. These supports help caregivers to manage the domestic tasks and keep running the home. Having access to other HNC carers where it was possible, to talk and express feelings, could also be helpful. Relationship needs were expressed, especially for the spouses of caregiver-patient dyads. The decreased communication and physical intimacy changed social and leisure routines and increased conflicts, all increasing the distress of caregivers. Some felt they needed to shield others. They suppressed their distress or needs when interacting with public or social networks or family members, particularly the children, in order to protect others from distress. However, this way of pretending to be optimistic may prevent supports from coming in.

Although family and friends usually provided an appreciated network of safety and support, not all caregivers faced the same

situation. Some families and friends provided inept supports; it has been mentioned that the artificial positive reframing of emotions may suppress caregivers' feelings. Cancer may sometimes overwhelm them, which prevent them from being able to help caregivers or patients.

Caregivers spoke highly of the healthcare services that were involved in the care. The physical, psychological, and informational supports offered were considered as significant and particularly supportive. However, limited time was available for caregivers to interact with professionals, and these restrained them from getting more contacts or receiving ongoing support throughout patients' HNC trajectory. In particular, some areas of support are not specific for HNC caregivers, which makes them depressed. There were numerous challenges when the primary setting for care shifted from hospital to home; the guidance for practical coping skills for caregiving was particularly requested in this period. Caregivers desired to receive clear information about the severity of physical symptoms, timelines of disease, and treatment in a practical, understandable, and personalized way. Psychological support was not sufficient because of a lack of access. However, early support provided by psychologists could be beneficial. Caregivers prefer individual and face-to-face home counseling, because this way could help them express negative feelings directly and thoroughly. Caregivers expressed dissatisfaction with supports provided by different people or groups, as they could not identify the responsible one to ask for help. All these supports need to be in a holistic approach.

Communities and social welfare systems provided caregivers support to mitigate the financial problems. Cancer charities, fundraising, and private health insurance were helpful to offset heavy medical costs. Flexible work arrangements for caregiver's employment enable them to keep working and get income. Social welfare payments, medical cards, and health insurance were the primary supports provided by government to decrease their financial strain. However, some caregivers lack sufficient knowledge in gaining access to or are unaware of these supports. Some caregivers were even ashamed to ask for financial assistance.

■ Discussion

The results from this qualitative review show multiple components in caregivers' experiences of caring for patients with HNC. The 3 meta-themes reflect a distressing experience of caregiving. Caregivers were facing life changes and took on roles and responsibilities, while getting access to external support was essential to manage the struggles. These findings might serve as a foundation for providing appropriate support for caregivers, to improve their health status and well-being. In the following sections, some major issues within each main category will be discussed to highlight the clinical implications.

The findings suggest that accepting patients' disease and treatment was perceived to be a distressing process for caregivers. It was necessary for healthcare professionals to be aware of the emotional burden that was experienced by caregivers. Distress is a multifaceted, unpleasant, emotional experience of a psychological (ie, cognitive, behavioral, emotional), social, spiritual,

and/or physical nature. It could be defined as the emotional burdens, stressors, and frustrations that stem from supporting someone with cancer or a severe and complex condition,⁵² and it is viewed as the "sixth vital sign" as well as a critical component of QOL.⁵³ The most predominant feelings of caregivers in these studies were fear, uncertainty, anxiety, sympathy, frustration, depression, and loss. These feelings restricted caregivers' lives substantially and left potential impacts on the quality of care and support for patients and, as such, call for professional attention.¹⁶ However, people were inclined to care more about HNC patients, and caregivers were usually overlooked. Castellanos et al¹⁶ discovered that 40% of the caregivers of HNC patients reported moderate to high levels of distress. They experienced the same level of distress as HNC patients,⁵⁴ or even more severe.^{22,55} Parallel with the conclusion of the review of dyadic interventions for cancer survivors and caregivers by Badr et al,⁵⁶ this meta-synthesis study further underscores the need to prioritize the identification of the distress of caregivers so as to enable the initiation of alleviating actions. Given the growing acknowledgment that patients' and caregivers' emotional reactions to cancer are interrelated, there has been a growing emphasis on dyadic interventions that should be offered to patients and caregivers as a unit.⁵⁴ However, the causes of distress may differ between patients and caregivers, so it is necessary to appropriately match resources to address causal factors for compromised well-being.⁵⁴

To identify the value of caregivers makes the dyad become more emotionally attached to each other. When the patients are sucked into depression, they are more willing to receive caregivers' company and to be listened to. Moreover, patients may pay attention to caregivers' emotional needs and support each other. Avoidant communication with higher distress in both patients and carers has been found. A lack of communication on key issues between dyads, combined with the silent suffering of the caregiver, may result in strain relationship and permanent changes of emotion connection.¹³ To some extent, the emotional interdependence of a dyad may contribute to the development of an intimate relationship, resulting in less distress for both parties. To achieve this, supportive communication regarding full disclosure of emotions between dyads could be adopted.¹³

Dri and colleagues¹¹ found that the aged caregivers seem to be more positive toward illness compared with younger caregivers. This was consistent with the result of some investigative studies that the HNC caregiver's younger age is a risk factor of distress.^{16,57} This could be explained by the fact that younger caregivers facing more competing demands could result in additional physical and psychological efforts (eg, childcare, career, study). However, these findings do not adequately address differences in the experiences and needs of family caregivers in different age levels. Further studies focused on exploring the experience of different age generations of HNC caregivers may reveal profound caregiving dynamics.

Except for the consideration of individual-level needs of the dyad, the relationship needs could not be ignored when formulating care protocols.⁵⁶ Most of caregivers included in this systematic review are spouses or partners. Different from the child or parent caregivers, the spouse caregivers further reported that the changes that happened on their relationships with patients

were prominent. Some of them were confronted with problematic sexual life.^{25,35} Several studies that interviewed child caregivers claimed that this group was commonly impacted by emotions.^{13,35} Interestingly, the adult child takes a large proportion of caregivers in the study of Goswami et al³⁵ in India. In order to take care of his/her father, the child caregiver could cancel important activities, such as shift schooling, and quit better education. This may be associated with the patriarchy in some developing countries.⁵⁸ Father is at the prime role of a family, and taking care of a male HNC patient is put on the first place.

Caregivers developed coping strategies to better adjust their physical and psychological status when they take on the new roles and responsibilities. Providing caregivers with practical skills is crucial to help them deal with the actual tasks they are performing.^{16,59} A lack of training regarding HNC caregiving task may result in unprepared feeling, which was associated with a higher level of distress among caregivers.¹³ The improvement of caregiving skills should help both caregivers and patients through the augmentation of caregiver knowledge, confidence, and self-efficacy.⁶⁰ Caregiver training provided in an early stage of disease trajectory is essential, which includes the gastric/gastrostomy tube nursing, diet plan, and other nutrition-promoting skills. This training could accelerate the caregiver's adaptation process. In addition, there is a need to provide adequate information on disease/treatment and prognosis to the caregiver, which helps them to accept the changes happening to patients. An early initiation of intervention is not enough, and the supports that cover the entire phase of cancer treatment and recovery were warranted. In particular, if caregivers could not get direct help from professionals when patients transferred from hospital to home; this insufficient care training may result in a bad preparation for role transition.¹⁰ Among all the roles and responsibilities, meal preparation and tube feeding were nominated as the most time-consuming and labor-intensive tasks. The investigation of Nightingale et al⁶¹ first found that the HNC caregivers had a strong interest in diet and exercise programs, indicating that mastering diet is an essential skill for these caregivers. Dietary guidance and nutrition management implemented by dietitians at the early stage of radiotherapy would be of great help,⁶² as dietitians could provide caregivers with the suggestions of suitable kitchenware and tableware for making liquids, the oral nutritional supplements, or cooking tips for standard nutritious meal preparation. These things may give assistance to caregivers in preparing food in a better and faster way, which in turn increases their confidence and a sense of control in caregiving and alleviates their feelings of suffering.⁶³ The current authors also found that the caregivers developed mental coping strategies. Some even found the positive meanings in caring, which helped caregivers find and keep up their spirits.²⁵ Healthcare professionals may function as a catalyst for this adaptive process by facilitating caregivers in realizing the positive things and establishing confidence for the caregiving role.

Caregivers highly appreciate the supports from families, friends, other carers, healthcare services, communities, and social welfare. These supports greatly influenced their caregiving experience, making a huge difference in their life. Among all those support needs, the support of psychological care and information was highly demanded.^{10,42,60,64} In addition, the financial support needs are also profound, while caregivers often kept their financial-related

problems a secret. Even worse, some caregivers were unfamiliar with the social warfare system.³⁴ These resulted in obstacles for caregivers getting access to support, indicating that the healthcare professionals should incorporate financial counseling or information into the support program. Furthermore, the adjustment patterns changed as the dyad moved through diagnosis, treatment, and follow-up, due to the variabilities in symptoms and worries⁶⁵; the patterns of unmet needs in caregivers also varied by time. At the early stage of disease, the information needs are prominent, while during treatment and after patients return home, more practical supports are needed, such as taking care of the children and sharing housework to reduce physical exhaustion. As caregiving time went on, these needs were gradually decreasing because of the fact that caregivers had developed coping skills and had become accustomed to the HNC and treatment. Financial stress was also found to be dynamic.³⁴ This suggests that individualized and targeted support programs need to be tailored appropriately, to sufficiently meet the needs of caregivers according to the stages of caregiving. Moreover, research on exploring caregivers' experiences in different stages of HNC should be conducted to further understand the distinction.

■ Limitations

The authors found a lack of qualitative studies with a longitudinal design to enable better descriptions of fluctuations on needs and experiences in various phases of caregiving. Only 1 study explicitly described the financial impacts in different phases of treatment, although not in a longitudinal design. Because of this underrepresentation, it remains uncertain what kind of characteristic of needs and experiences that caregivers have in different phases of caregiving. This issue calls for further research.

Although the search strategy was thorough, there may have been studies missed. The authors included only those articles published in peer-reviewed journals and did not include gray literature, theses, or dissertations. The representativeness of these findings may be influenced by the relatively small numbers included in these studies. In addition, the included studies were all reported in English, and therefore, more materials may be available in other languages, and the results may not be relevant to non-English-speaking cultures. The CASP appraisal tool is a categorical evaluation of methodological quality and may not be the best tool for evaluating methodological limitations.

The thematic analysis conducted on these included studies was an interpretative process. Although the results were validated by the coauthors, there is a potential for other interpretations. However, the similarities between our findings and findings from reviews of caregivers' experiences in single conditions support our interpretations.

■ Research Implications

There is a need for the design and evaluation of interventions that provide support to help HNC caregivers to cope with difficulties

in physical, psychological, social, and financial aspects. Such interventions need to promote independence and a sense of control over their lives. However, caregivers often failed to attend programs because of limited personal time. Meanwhile, considering that the intervention implementation is greatly influenced by space and time, a form of dyad-focused online intervention based on technology could be feasible for HNC caregivers. One previous dyadic, web-based intervention developed in a qualitative study using interactive health communication technologies has shown a promising effect in facilitating the HNC survivors and caregivers during the usability testing period.⁶⁶ Sterba and colleagues²⁴ tested the acceptability and feasibility of a technology-based care planning tool (SNAP) and found it was productive to assess and address HNC dyads' dynamic needs. In a wellness program interest survey, caregivers reported their preference to receive programs delivered by mail including tangible and mobile materials. These online technologies are a great help in a convenient place and time and enable programs to be more easily accessible, which are desirable methods to provide supports for caregivers.⁶¹ However, few cancer caregiver-focused interventions capitalizing on technology have been developed and applied,⁶⁷ which requires further research.

■ Clinical Implications

The 3 main categories of “accepting the diagnosis and treatment on patients: a distressing process,” “facing life changes and adapting to new roles,” and “appreciating the external supports” cover important items that could be incorporated in an assessment tool suitable for both the active and passive state of caring for HNC patients and allow caregivers to make explicit their own evaluation of their experience. The evidence generated in this review demonstrated a need for healthcare professionals to focus on the experience of distress among HNC caregivers. The screening and management of distress for caregivers at all stages of caregiving should be routine clinical practice. A comprehensive HNC caregiver distress assessment involves questions in relation to the physical, emotional, social, financial, and spiritual domains. The National Comprehensive Cancer Network's Distress Thermometer and Problem List could be an option.⁵²

Caregivers showed interest in a variety of programs and at various time points, because they faced changing challenges across the cancer trajectory.⁶¹ There is some evidence that a collaborative care approach delivered by a group of physician, psychologist, nurse, therapist, and social worker is clinically effective. The interdisciplinary groups could provide supports that meet the needs of caregivers at all stages, and nurses could play a primary role in the team. Nurses should reach out to caregivers because they do not seem to be very willing to approach healthcare professionals, because of the underrecognition of minor issues impairing their well-being. In addition, some caregivers may pretend to be optimistic and deny the supports. Nurses need to consider how best to offer support without violating their feelings.

■ Conclusion

The results of this meta-synthesis are the first to collate qualitative and mixed-methods studies focusing on the caregivers' experiences of caring for HNC patients. The study found that the caring process is distressing, caregivers make adjustments to life changes and take on roles and responsibilities, and external supports are essential for them to manage struggles in caregiving. Nursing care for caregivers should match their experiences and support needs. Our review concludes that there is moderate to high confidence in the evidence for these 3 meta-themes identified. The results have direct implications for research and clinical care provision. These identifications enable healthcare professionals to provide effective tailored intervention to promote caregivers' adaptation tailored for all stages of caregiving.

References

1. Pfister D, Spencer S, Adelstein D, et al. Head and neck cancers, version 2. 2020, NCCN clinical practice guidelines in oncology. *J Natl Compr Cancer Netw.* 2020;18:873–898.
2. Chen W, Zheng R, Baade PD, et al. Cancer statistics in China, 2015. *CA Cancer J Clin.* 2016;66(2):115–132.
3. Bressan V, Bagnasco A, Aleo G, et al. The life experience of nutrition impact symptoms during treatment for head and neck cancer patients: a systematic review and meta-synthesis. *Support Care Cancer.* 2017;25(5):1699–1712.
4. Hodges LJ, Humphris GM. Fear of recurrence and psychological distress in head and neck cancer patients and their carers. *Psychooncology.* 2009;18(8):841–848.
5. Tsay SL, Wang JY, Lee YH, et al. Fear of recurrence: a mediator of the relationship between physical symptoms and quality of life in head and neck cancer patients. *Eur J Cancer Care.* 2020;29(4):e13243.
6. Neilson K, Pollard A, Boonzaier A, et al. A longitudinal study of distress (depression and anxiety) up to 18 months after radiotherapy for head and neck cancer. *Psychooncology.* 2013;22(8):1843–1848.
7. Lang H, France E, Williams B, Humphris G, Wells M. The psychological experience of living with head and neck cancer: a systematic review and meta-synthesis. *Psychooncology.* 2013;22(12):2648–2663.
8. Garcia-Torres F, Jabłoński MJ, Solís AG, et al. Caregiver burden domains and their relationship with anxiety and depression in the first six months of cancer diagnosis. *Int J Environ Res Public Health.* 2020;17:4101.
9. Patterson JM, Rapley T, Carding PN, Wilson JA, McColl E. Head and neck cancer and dysphagia; caring for carers. *Psychooncology.* 2013;22(8):1815–1820.
10. Chen SC, Lai YH, Liao CT, et al. Unmet supportive care needs and characteristics of family caregivers of patients with oral cancer after surgery. *Psychooncology.* 2014;23(5):569–577.
11. Dri E, Bressan V, Cadorin L, et al. Providing care to a family member affected by head and neck cancer: a phenomenological study. *Support Care Cancer.* 2020;28(5):2105–2112.
12. Langenberg SMCH, Van Herpen CML, Van Opstal CCM, et al. Caregivers' burden and fatigue during and after patients' treatment with concomitant chemoradiotherapy for locally advanced head and neck cancer: a prospective, observational pilot study. *Support Care Cancer.* 2019;27(11):4145–4154.
13. Halkett G, Golding R, Langbecker D, et al. From the carer's mouth: a phenomenological exploration of carer experiences with head and neck cancer patients. *Psychooncology.* 2020;29(10):1695–1703.
14. Balfé M, Keohane K, O'Brien K, Sharp L. Social networks, social support and social negativity: a qualitative study of head and neck cancer caregivers' experiences. *Eur J Cancer Care.* 2017;26(6):e12619.

15. Balfé M, Keohane K, O'Brien K, et al. In a bad place: carers of patients with head and neck cancer experiences of travelling for cancer treatment. *Eur J Oncol Nurs*. 2017;30:29–34.
16. Castellanos EH, Dietrich MS, Bond SM, et al. Impact of patient symptoms and caregiving tasks on psychological distress in caregivers for head and neck cancer (HNC). *Psychooncology*. 2019;28(3):511–517.
17. Fronczek AE. A phenomenologic study of family caregivers of patients with head and neck cancers. *Oncol Nurs Forum*. 2015;42(6):593–600.
18. Sainath S. Prevalence of emotional distress in caregiver's of cancer patients. *Int J Med Res Health Sci*. 2014;3(3):675–683.
19. Limonero JT, Maté-Méndez J, Mateo D, et al. Caregiver emotional distress: external open-behaviour signs. *BMJ Support Palliat Care*. 2019; Published Online First.
20. Simpson GK, Dall'Armi L, Roydhouse JK, et al. Does resilience mediate carer distress after head and neck cancer? *Cancer Nurs*. 2015;38(6):30–36.
21. Lee CY, Lee Y, Wang LJ, et al. Depression, anxiety, quality of life, and predictors of depressive disorders in caregivers of patients with head and neck cancer: a six-month follow-up study. *J Psychosom Res*. 2017;100:29–34.
22. Balfé M, Maguire R, Hanly P, et al. Distress in long-term head and neck cancer carers: a qualitative study of carers' perspectives. *J Clin Nurs*. 2016;25:2317–2327.
23. Litzelman K, Green PA, Yabroff KR. Cancer and quality of life in spousal dyads: spillover in couples with and without cancer-related health problems. *Support Care Cancer*. 2016;24(2):763–771.
24. Sterba KR, Armeson K, Zapka J, et al. Evaluation of a survivorship needs assessment planning tool for head and neck cancer survivor-caregiver dyads. *J Cancer Surviv*. 2019;13(1):117–129.
25. Badr H, Herbert K, Reckson B, et al. Unmet needs and relationship challenges of head and neck cancer patients and their spouses. *J Psychosoc Oncol*. 2016;34(4):336–346.
26. Sandelowski M, Barroso J, Voils CI. Using qualitative metasummary to synthesize qualitative and quantitative descriptive findings. *Res Nurs Health*. 2007;30(1):99–111.
27. Finfgeld-Connert D. Generalizability and transferability of meta-synthesis research findings. *J Adv Nurs*. 2010;66(2):246–254.
28. Finfgeld DL. Metasynthesis: the state of the art—so far. *Qual Health Res*. 2003;13(7): 893–904.
29. Sandelowski MBJ. *Handbook for Synthesizing Qualitative Research*. New York, NY: Springer Publishing Company; 2006.
30. Barroso J, Sandelowski M, Voils CI. Research results have expiration dates: ensuring timely systematic reviews. *J Eval Clin Pract*. 2006;12(4):454–462.
31. *Endnote X7, EDU (English) (PC) in Office*. Philadelphia, PA: Thomson Reuters. Datenbanken heise online.
32. Critical Appraisal Skills Programme (CASP), 2018. CASP Checklists. https://casp-uk.b-cdn.net/wp-content/uploads/2018/03/CASP-Systematic-Review-Checklist-2018_fillable-form.pdf. Accessed April 7, 2021.
33. Crowe M, Gillon D, Jordan J, McCall C. Older peoples' strategies for coping with chronic non-malignant pain: a qualitative meta-synthesis. *Int J Nurs Stud*. 2017;68:40–50.
34. Balfé M, Butow P, O'Sullivan E, et al. The financial impact of head and neck cancer caregiving: a qualitative study. *Psychooncology*. 2016;25(12): 1441–1447.
35. Goswami S, Gupta S, Raut A. Understanding the psychosocial impact of oral cancer on the family caregivers and their coping up mechanism: a qualitative study in rural Wardha, Central India. *Indian J Palliat Care*. 2019;25(3):421–427.
36. Kitrungrate L, Wonghongkul T, Chanprasit C, et al. Experiences of caregivers of spouses with head and neck cancer undergoing radiation therapy. *Thai J Nurs Res*. 2010;12(3):207–218.
37. Liang SY, Chang TT, Wu WW, et al. Caring for patients with oral cancer in Taiwan: the challenges faced by family caregivers. *Eur J Cancer Care*. 2019; 28(1):e12891.
38. Mayre-Chilton KM, Talwar BP, Goff LM. Different experiences and perspectives between head and neck cancer patients and their care-givers on their daily impact of a gastrostomy tube. *J Hum Nutr Diet*. 2011;24(5):449–459.
39. Nund RL, Ward EC, Scarinci NA, et al. Carers' experiences of dysphagia in people treated for head and neck cancer: a qualitative study. *Dysphagia*. 2014;29(4):450–458.
40. Nund RL, Rumbach AF, Debatista BC, et al. Communication changes following non-glottic head and neck cancer management: the perspectives of survivors and carers. *Int J Speech Lang Pathol*. 2015;17(3):263–272.
41. Penner JL, McClement S, Lobchuk M, et al. Family members' experiences caring for patients with advanced head and neck cancer receiving tube feeding: a descriptive phenomenological study. *J Pain Symptom Manage*. 2012;44(4):563–571.
42. Richardson AE, Morton R, Broadbent E. Psychological support needs of patients with head and neck cancer and their caregivers: a qualitative study. *Psychol Health*. 2015;30(11):1288–1305.
43. Röing M, Hirsch JM, Holmström I. Living in a state of suspension—a phenomenological approach to the spouse's experience of oral cancer. *Scand J Caring Sci*. 2008;22(1):40–47.
44. Schaller A, Liedberg GM, Larsson B. How relatives of patients with head and neck cancer experience pain, disease progression and treatment: a qualitative interview study. *Eur J Oncol Nurs*. 2014;18(4):405–410.
45. Waliyanti E, Primastuti HI. Family support: a caregiver experience in caring for nasopharynx cancer patients in Yogyakarta. *Open Access Maced J Med Sci*. 2021;9(T4):245–252.
46. Munn Z, Tufanaru C, Aromataris E. JBI's systematic reviews: data extraction and synthesis. *Am J Nurs*. 2014;114(7):49–54.
47. Crowe M, Inder M, Porter R. Conducting qualitative research in mental health: thematic and content analyses. *Aust N Z J Psychiatry*. 2015;49(7):616–623.
48. Thomas J, Harden A. Methods for the thematic synthesis of qualitative research in systematic reviews. *BMC Med Res Methodol*. 2008;8(1):45.
49. Lewin S, Bohren M, Rashidian A, et al. Applying GRADE-CERQual to qualitative evidence synthesis findings—paper 2: how to make an overall CERQual assessment of confidence and create a summary of qualitative findings table. *Implement Sci*. 2018;13(1):10.
50. Munn Z, Porritt K, Lockwood C, et al. Establishing confidence in the output of qualitative research synthesis: the ConQual approach. *BMC Med Res Methodol*. 2014;14(1):108.
51. Pearce A, Timmons A, O'Sullivan E, et al. Long-term workforce participation patterns following head and neck cancer. *J Cancer Surviv*. 2015;9(1):30–39.
52. Riba M, Donovan K, Andersen B, et al. Distress management, version 3. 2019, NCCN clinical practice guidelines in oncology. *J Natl Compr Canc Netw*. 2019;17:1229–1249.
53. Bultz BD, Carlson LE. Emotional distress: the sixth vital sign in cancer care. *J Clin Oncol*. 2005;23(26):6440–6441.
54. Sterba KR, Zapka J, Armeson KE, et al. Physical and emotional well-being and support in newly diagnosed head and neck cancer patient-caregiver dyads. *J Psychosoc Oncol*. 2017;35(6):646–665.
55. Badr H, Gupta V, Sikora A, et al. Psychological distress in patients and caregivers over the course of radiotherapy for head and neck cancer. *Oral Oncol*. 2014;50(10):1005–1011.
56. Badr H, Bakhshai J, Chhabria K. Dyadic interventions for cancer survivors and caregivers: state of the science and new directions. *Semin Oncol Nurs*. 2019;35(4):337–341.
57. Paek MS, Nightingale CL, Toozé JA, et al. Contextual and stress process factors associated with head and neck cancer caregivers' physical and psychological well-being. *Eur J Cancer Care*. 2018;27(2):e12833.
58. Patel T, Romani L, Oberoi P, et al. Gender role encapsulation as resistance to patriarchy: women politicians' work and gender equality in India. *Organization*. 2021;00(0):1–19.
59. Treanor C. Psychosocial support interventions for cancer caregivers: reducing caregiver burden. *Curr Opin Support Palliat Care*. 2020;14(3):247–262.

60. Van Houtven CH, Voils CI, Weinberger M. An organizing framework for informal caregiver interventions: detailing caregiving activities and caregiver and care recipient outcomes to optimize evaluation efforts. *BMC Geriatr*. 2011;11(1):77.
61. Nightingale CL, Sterba KR, Tooze JA, et al. Vulnerable characteristics and interest in wellness programs among head and neck cancer caregivers. *Support Care Cancer*. 2016;24(8):3437–3445.
62. Paccagnella A, Morello M, Da Mosto MC, et al. Early nutritional intervention improves treatment tolerance and outcomes in head and neck cancer patients undergoing concurrent chemoradiotherapy. *Support Care Cancer*. 2010;18(7):837–845.
63. Hiatt JS, Brown TE, Banks M, et al. Patient and carer experience of nutrition care throughout treatment for head and neck cancer: a systematic qualitative review and thematic synthesis. *Support Care Cancer*. 2020;28(12):5633–5647.
64. Dall'armi L, Simpson GK, Forstner D, et al. The information needs of patients with head and neck cancer and their caregivers: a short report of instrument development and testing. *Appl Nurs Res*. 2013;26(1):40–44.
65. Murphy BA, Deng J. Advances in supportive care for late effects of head and neck cancer. *J Clin Oncol*. 2015;33(29):3314–3321.
66. Badr H, Lipnick D, Diefenbach MA, et al. Development and usability testing of a web-based self-management intervention for oral cancer survivors and their family caregivers. *Eur J Cancer Care*. 2016;25(5):806–821.
67. Slev VN, Mistiaen P, Pasman HRW, et al. Effects of eHealth for patients and informal caregivers confronted with cancer: a meta-review. *Int J Med Inform*. 2016;87:54–67.