JOURNAL CLUB

Needs of Informal Caregivers of Patients With Head and Neck Cancer: A Systematic Review

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PROBLEM IDENTIFICATION: Informal caregivers for patients with head and neck cancer perform complex caregiving tasks on a daily basis, but caregivers' needs are rarely acknowledged or addressed in current healthcare practice.

LITERATURE SEARCH: A thorough review of CINAHL®, MEDLINE®/PubMed®, and PsycINFO® was conducted by the authors.

DATA EVALUATION: 266 manuscripts were identified, with no time limit. The search was conducted in November 2019. In total, 19 articles were included in the review.

SYNTHESIS: Throughout the disease trajectory, caregivers' psychological and emotional support needs are consistently high, whereas information needs diminish over time.

IMPLICATIONS FOR PRACTICE: Informal caregivers are imperative in supplementing the continuing care demands of people living with head and neck cancer; however, they are at risk for experiencing caregiving burden. Skill training and psychological support interventions are needed for educating and supporting caregivers.

KEYWORDS head and neck cancer; informal caregivers; informational; psychological; social

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Head and neck cancer comprises 4% of all cancers in the United States, with an estimated 48,200 men and 17,430 women diagnosed in 2020 (American Cancer Society, 2020). Head and neck cancer is an umbrella term that includes malignancies in the oral cavity, pharynx, larynx, paranasal sinuses and nasal cavity, and salivary glands (National Cancer Institute [NCI], 2017). Head and neck cancer often requires multiple-modality therapies, including radiation therapy and chemotherapy, which makes patients at risk for treatment toxicities (Siddiqui & Movsas, 2017). Patients not only experience a varied degree of head and neck cancer site-specific symptoms, such as dysphagia, dysphonia, xerostomia, mucositis, dysgeusia, trismus, and neck stiffness, but also other general side effects, including chronic fatigue and loss of appetite (Epstein et al., 2012; Ganzer et al., 2013; Isaksson et al., 2016; Lang et al., 2013), which creates many complex self-care needs and psychological stress for people living with head and neck cancer.

Informal caregivers are critical for the successful transition from the hospital to the home, and they play a key role in helping patients adjust to these new realities. The Family Caregiver Alliance (2014) defines family (or informal) caregivers as "any relative, partner, friend, or neighbor who has a significant personal relationship with, and provides a broad range of assistance for, an older person or an adult with a chronic or disabling condition" (p. 1). Donnelly et al. (2008) found that 83% of patients with head and neck cancer identified living with informal caregivers at home. In some cases, patients receive extensive treatment while in the hospital and will need to return home with a tracheostomy or percutaneous endoscopic gastrostomy (PEG) tube. Their caregivers are expected to quickly learn and provide professional nursing care on an ongoing basis. Feeling supported by family caregivers is imperative to patients' psychological well-being.

The care that patients with head and neck cancer receive at home primarily falls to a large extent on their family or informal caregivers (Lang et al., 2013). Informal caregivers may experience additional caregiving burden because many complex care tasks can not only inflict pain and discomfort, but also carry high risk of causing harm to the patient. Caregivers often express the need to become more vigilant while taking care of their loved one because they do not want to cause the patient any additional harm or pain (Fronczek, 2014). A patient's social support system, including friends and family members, plays a vital role in assisting the patient with managing the illness (Lang et al., 2013). Patients with head and neck cancer feel as if they are being held captive (Björklund et al., 2010) by head and neck cancer and are more vulnerable to depression and suicide than the general population (Chen et al., 2013; Misono et al., 2008). In addition, psychological caregiving burden is also high because, in many cases, caregivers of patients with head and neck cancer experience more psychological stress than patients, and the prevalence of clinically classified anxiety disorder is 40% in caregivers of patients with head and neck cancer (Longacre et al., 2012).

Because of the aggressiveness of the malignancy, the trajectory of providing care to a patient with head and neck cancer is more dynamic and intensive in terms of cancer-related caregiving activities compared to non-cancer–related caregiving. The average length of caregiving for people with cancer is 1.9 years compared to 4.1 years for those with other non-cancer diseases (Hunt et al., 2015). Caregivers for patients with cancer also experience higher caregiver burden than non-cancer–related caregivers (Hunt et al., 2015). In addition, compared to caregivers of patients with other cancer types (colorectal, breast, prostate, melanoma, lung, and hematologic), a longitudinal study by Kim et al. (2010) found that caregivers of patients with head and neck cancer reported the highest level of unmet needs at both 6 months and 12 months postdiagnosis. Unique difficulties are present in head and neck cancer, such as facial disfigurement, dysphagia, sticky saliva, and permanent loss of taste and smell (Donnelly et al., 2008). In addition, caregivers of patients with head and neck cancer are expected to support patients with treatment side effects, medications, and nutrition, as well as perform complex technical skills, such as tracheostomy and PEG tube care (Mazanec et al., 2019). A report from the National Alliance for Caregiving (Hunt et al., 2015) noted that 72% of cancer caregivers performed complex medical tasks for their loved one, but only 57% reported that they received the related information and skill training to complete the complex tasks.

This systematic review aimed to synthesize the literature on the needs of informal caregivers of patients with head and neck cancer from diagnosis, through treatment, and to post-treatment survivorship. By analyzing the current state of science on the needs of caregivers of patients with head and neck cancer, the authors addressed the following questions:

- What theoretical constructs have been measured in studies examining caregivers of patients with head and neck cancer?
- What are the needs of family caregivers of patients with head and neck cancer during cancer survivorship?
- What interventions have been effective in supporting caregivers of patients with head and neck cancer?

Methods

Scope of the Systematic Review

The authors sought to identify quantitative descriptive studies, which will provide evidence and directions for future studies and answer the first two aims of this review. Mixed-methods studies were also considered when identifying interventions to support caregivers of patients with head and neck cancer, and will be used to address the third aim of this study.

A search of CINAHL®, MEDLINE®/PubMed®, and PsycINFO® was performed. The authors did not find any systematic review evidence in the literature on the topic of unmet needs for caregivers of patients with head and neck cancer. Therefore, with no time limit set, the search was conducted in November 2019 and was focused on peer-reviewed manuscripts in English-language publications only. The following keywords were used in CINAHL, MEDLINE, and PsycINFO: *head and neck cancer or oral cancer or oropharyngeal cancer* AND *caregivers or family members or relatives or informal caregivers* AND *need*. The corresponding medical subject heading (MeSH) terms were used in PubMed: *head and neck neoplasm* AND *caregivers* AND *need*. The first set of keywords (*head and neck cancer* or *oral cancer* or *oropharyngeal cancer*) focus on the patient population. The second set of keywords (*caregivers* or *family members* or *relatives* or *informal caregivers*) refer to the caregiver population, excluding other possible populations, such as patients with head and neck cancer or healthcare providers. Caregivers of interest in this review were informal caregivers, such as family

members, friends, or relatives who are recognized as the primary caregiver by the patient.

PRISMA Assessment

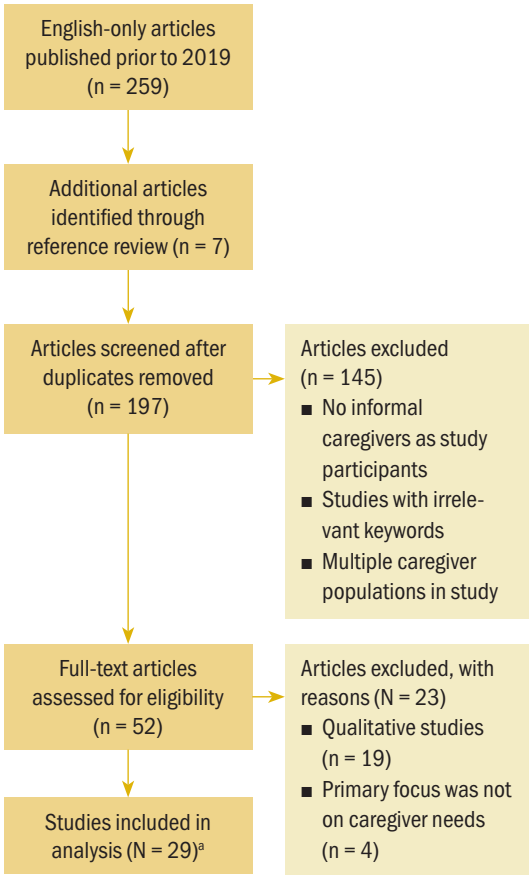
The Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) guideline is a validated tool to critically appraise and clearly summarize the current state of science in an area of specific interest (Moher et al., 2009). Studies meeting the PRISMA standards and contributing to the state of the science regarding the needs of caregivers of patients with head and neck cancer will be included in this review. Using the previously detailed search strategy, the authors identified 259 manuscripts: 114 manuscripts from CINAHL, 91 from MEDLINE, 33 from PsycINFO, and 21 from PubMed (see Figure 1). Seven additional manuscripts were identified after searching reference lists. Then, articles from each database were analyzed separately based on the inclusion criteria. In addition to the search criteria and keywords, one additional inclusion criterion was that the study must have a primary focus on caregivers of patients with head and neck cancer. After removing duplicates, the authors screened 197 manuscripts. After examining the title and abstract, the author removed 145 articles based on the following exclusion criteria: (a) no informal head and neck cancer caregivers as study participants; (b) irrelevant keywords, such as *oral chemotherapy agents* instead of *oral cancer*; and (c) study participants included caregivers of other cancer populations. Fifty-two full-text manuscripts were retrieved and analyzed. The authors excluded 19 qualitative studies, and an additional 4 were excluded because caregivers of patients with head and neck cancer were not the primary focus of the study.

A total of 29 articles were included in the final review. Six of the articles were published from 2004 to 2010. The other 23 were published after 2010. Included were 19 quantitative descriptive studies, 5 mixed-methods studies, 3 quasiexperimental studies, and 2 randomized controlled trials. The PRISMA checklist was used to perform a quality assessment on all of the studies (Moher et al., 2009). Three categories were used to analyze the studies: (a) studies that quantitatively described the needs of caregivers (n = 19), (b) studies that focused on constructing measurements to describe the survivorship needs for patients with head and neck cancer and their caregivers (n = 3), and (c) studies that tested interventions on caregiving support (n = 7). Within the first category, 19 studies applied quantitative descriptive approaches, which used different evaluative instruments to assess caregivers' situations in terms of informational, psychosocial, and social support needs (see Table 1). Caregivers' needs were classified based on their survivorship stages, including before treatment (chemotherapy, radiation therapy, or surgery), during treatment, and during post-treatment survivorship. Data collection time points were included to identify survivorship stages of patients with head and neck cancer. The other categories included seven intervention development and testing studies.

Findings

In this review, the authors identified three major needs for caregivers: informational, psychological,

FIGURE 1. PRISMA Flowchart



[a] Consists of 19 quantitative descriptive studies, 5 mixed-methods studies, 3 quasiexperimental studies, and 2 randomized controlled trials
PRISMA—Preferred Reporting Items for Systematic Reviews and Meta-Analyses

and social. The number of caregiver participants across all studies ranged from 21 to 301. Of note, five studies recruited patient–caregiver dyads. The majority of caregivers were female (range = 63%–96%) and in a spousal relationship with the care recipients (range = 52%–90%). Sociodemographic factors, such as older age ($r = 0.34$, $p < 0.01$) and lower annual income ($r = -0.33$, $p < 0.01$), were related to longer caregiving hours per week (Ross et al., 2010); however, age and gender were not significant in predicting caregiver burden (Hanly et al., 2016).

Quantitative Approaches to Assessing Caregivers' Needs

The systematic review identified 19 quantitative descriptive studies, consisting of 6 longitudinal and 13 cross-sectional designs. The 19 studies individually analyzed the needs of caregivers of patients with head and neck cancer at different time points along the survivorship trajectory, from diagnosis, through treatment, and into post-treatment. All quantitative studies chose to use surveys or questionnaires.

Main Constructs of Instruments in Quantitative Studies

Three main constructs emerged from analyzing the instruments selected in the 19 studies: (a) caregiving needs, burden, and support systems; (b) caregivers' psychological well-being; and (c) overall quality of life of patients or care recipients in the patient-caregiver dyad.

Twelve instruments were used to assess the following three groups of caregiver needs: informational, psychological, and social. The Partners and Caregivers Supportive Care Needs Survey (Girgis et al., 2011) was the most popular scale, used in three studies. This scale explicitly measures six domains of caregiving needs: information, emotional, daily living, financial, healthcare service, and interpersonal needs (Chen et al., 2014). Other instruments, such as the Head and Neck Information Needs Questionnaire (Dall'Armi et al., 2013) and the Cancer Caregiver Information Needs Checklist (Longacre et al., 2015), primarily focus on a single perspective of caregiving needs. To further analyze where the caregiving burdens were, two studies asked for self-reported time of caregiving, and another three studies used the Caregiver Burden (Pearlin et al., 1990), the Caregiver Strain Index (Robinson, 1983), and Carer Quality of Life survey (Brouwer et al., 2006). In addition, the Caregiver Reaction Assessment (Given et al., 1992) was used to assess caregiving burdens related to change in self-esteem, disrupted schedule, financial problems, and health problems. Of note, the Head and Neck Cancer Caregiving Tasks Inventory was developed and validated to provide a comprehensive assessment tool, with a total of 58 tasks in 11 domains of caregiving needs (Bond et al., 2016). In addition, five validated instruments—the Multidimensional Scale of Perceived Social Support (Zimet et al., 1988), the Social Support Needs Scale (Cohen & Hoberman, 1983), the OSLO-3 Social Support Scale (Dalgard et al., 2006), the Perceived Social Support Scale (Krause & Borawski-Clark, 1995), and the Inventory of Socially Supportive Behavior (Cohen & Wills, 1985)—were used to analyze caregivers' perceived support.

Five instruments assessed caregivers' status, mainly focusing on their psychological wellness, such as anxiety, depression, distress, and loneliness. Those instruments included the Caregiver Quality of Life–Cancer (Brouwer et al., 2006), the Hospital Anxiety and Depression Scale (Zigmond & Snaith, 1983), the Centre for Epidemiological Studies Depression Scale (Andresen et al., 1994), and the Loneliness Scale (Hughes et al., 2004). Researchers also used the Pittsburgh Sleep Quality Index (Girgis et al., 2011) as an indicator for psychological well-being. According to Badr et al. (2014), poor sleep quality is one of the top five most distressing factors for patients and their caregivers.

Another key construct that researchers attempted to measure was the patient's overall quality of life. Five studies assessed the quality of life of patients who were in a dyad relationship with their caregivers. Patient quality of life is likely to be influenced by the care they could receive; therefore, it is important to monitor patient quality of life while studying caregiver needs. Two studies used the University of Washington Head and Neck Disease Specific Questionnaire Quality of Life, version 4.0 (UW-QoL) (Ho, 2014). The majority of instruments in the review were validated and widely accepted, although, of note, five articles used author-developed instruments that aimed to assess similar constructs mentioned here (Chen et al., 2009; Ledeboer et al., 2008; Longacre et al., 2015; Precious et al., 2012; Rodriguez & Blischak, 2010).

Information Needs Diminish After Treatment Period

Two longitudinal and four cross-sectional studies, with sample sizes ranging from 49 to 208 participants, evaluated caregivers' needs for information and show that during early survivorship (the diagnosis and treatment periods), information needs are

TABLE 1. Summaries of Quantitative Descriptive Findings

Study	Design and Sample	Measurements and Outcomes
Before and after treatment		
Patterson et al., 2013 (United Kingdom)	Longitudinal (pretreatment, 3 months, and 12 months); with 208 patients receiving chemotherapy or radiation therapy (137 patient–caregiver dyads); using paired t test, correlation, and multiple regression analysis	■ Demographics: 66% of patients identified at least 1 caregiver. ■ UW-QOL: Patients had low pretreatment care needs ($\bar{X}$ = 80 [SD = 15.1] out of 100). ■ MDADI: UW-QOL and MDADI explained 52% (R^2 = 0.52, F = 20.66, p < 0.001) variance in CQOL-C at 12-months. ■ CQOL-C □ Pretreatment ($\bar{X}$ = 88.6 [SD = 140]), 3 months ($\bar{X}$ = 88.9), and 12 months ($\bar{X}$ = 95.3) □ Improved from 3 to 12 months (95% CI [2.9, 16.1]; p = 0.006) □ Only significantly (adjusted p = 0.03) improved in care burden domain; disruption domain did not change □ Caregivers of patients with gastrostomy at 3 and 12 months had poorer ($\bar{X}$ differences = 24.2 and 23.6, respectively; p < 0.001) quality of life than caregivers of those without gastrostomy. □ A moderate to strong correlation was noted between CQOL-C and patient-reported outcomes (UW-QOL and MDADI) at all time points.
Longacre et al., 2015 (United States)	Longitudinal (at diagnosis, treatment start, and treatment end); with 59 caregivers of patients receiving radiation therapy treatment; using chi-square analysis	■ Demographics: 81% female, 61% employed, 76% spouse ■ Patient clinical characteristics: month since diagnosis ($\bar{X}$ = 16.49 [SD = 12.31]); 71% also had chemotherapy; 39% also had surgery. ■ Cancer Caregiver Information Needs Checklist, abbreviated form □ Information need on medical communication at diagnosis ($\bar{X}$ = 3.39 [SD = 0.195]), treatment start ($\bar{X}$ = 3.07 [SD = 0.204]), and treatment end ($\bar{X}$ = 2.49 [SD = 0.229]) (low = 0–2; high = 3–5) □ No demographic variable correlates with information need (p < 0.05). □ Information need on medical communication at diagnosis (75%), treatment start (66%), and treatment end (51%) □ The employed caregiver had higher need of information on updates about the patient's condition at diagnosis (p = 0.016) and treatment start (p = 0.003) compared with the unemployed. □ The non-spouse caregiver needed more information on care decisions compared with the spouse (p = 0.048). ■ Author-developed pain-reducing information need question: 66% at diagnosis, 75% treatment start, and 44% at treatment end ■ Author-developed resource preferences: formal healthcare professional (77%); informal resources of Internet, family or friend, nonprofit organizations (23%)
Lee et al., 2017 (China)	Longitudinal (at diagnosis, 3 months, and 6 months) design; with 132 caregivers of newly diagnosed (pretreatment) patients; using chi-square, t test, linear mixed model, and logistic regression analysis	■ Demographics: 77% female, 60% employed, 69% spouse ■ DSM-IV □ Depression rate decreased from 14.7% to 12.9% in 6 months. □ Older age, hypnotics use, depressive disorder at baseline, and lower mental component score on the SF-36® are significant predictors for depression. ■ HADS □ Depression score decreased over 6 months ($\bar{X}$ = 3.8, 2.9, and 2.2, respectively; p < 0.05). □ Anxiety score decreased over 6 months ($\bar{X}$ = 5.6, 3.1, and 2.2, respectively; p < 0.05). ■ SF-36 □ Physical component: no difference noted over 6 months (p = 0.36) □ Mental component: increase over 6 months ($\bar{X}$ = 9.3, 10.3, and 11.1, respectively; p < 0.05) ■ Family APGAR Index: No significant difference over 6 months (p = 0.25)

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TABLE 1. Summaries of Quantitative Descriptive Findings *(Continued)*

Study	Design and Sample	Measurements and Outcomes
Before and after treatment *(continued)*		
Terro & Creen, 2017 (United Kingdom)	Longitudinal (at diagnosis, 1 month, and 3 months postoperatively); with 21 caregivers and 36 patients who had surgical resection and reconstruction; using t test and Wilcoxon signed rank test analysis	■ Demographics: 76% female, 25% employed, 55% retired ■ UW-QOL □ Physical function, including appearance, swallowing, chewing, speech, taste, and saliva ($\bar{X}$ = 82.4, 67.9, and 74.6, respectively) □ Social-emotional function, including pain, activity, recreation, shoulder, mood, and anxiety ($\bar{X}$ = 77.8, 62.8, and 70, respectively) ■ HADS □ Caregivers are more likely to have anxiety and depression (score greater than 7) than patients at preoperative (52% versus 39%) and at 3 months postoperative (60% versus 19%). ■ Davidson Trauma Scale □ 57% of caregivers rated extreme distress before surgery and 30% at 3 months after. □ 71% of caregivers reported twice or greater distress at preoperative and 90% at 3 months postoperatively.
During treatment		
Rodriguez & Blischak, 2008 (United States)	Cross-sectional; with 11 nonspeaking head and neck cancer surgical inpatients, 8 caregivers, and 8 RNs	■ Demographics: 54% of patients had temporary speech impairment; 55% had permanent speech loss. ■ Author-developed survey □ Caregivers worried about how the patients were feeling (88%), their pain (63%), breathing problems (63%), need to be suctioned (63%), being afraid (50%), and problems understanding instructions (50%). □ All caregivers reported patients' desire to communicate but their inability to do so during hospital stay. □ Caregivers were concerned about patients' ability to cope with the anxiety-producing challenge of being speechless.
Chen et al., 2009 (China)	Cross-sectional; with 122 patient–caregiver dyads, hospitalized, post–tumor excision surgery (10–14 days); using correlation, t test, and regression analysis	■ Demographics: 93% female, 73% spouse, 77% Buddhist, 75% had no previous caregiving experience; caregiving time per day =10.79 (SD = 7.44) hours ■ Karnofsky Performance Status: 87% of caregivers above 60 (range = 50–70) ■ Cancer Needs Questionnaire (short form): $\bar{X}$ = 35.5 (SD = 17.23) □ High in health system/information needs ($\bar{X}$ = 40.4 [SD = 23.3]), psychological needs ($\bar{X}$ = 36.97 [SD = 18.06]), and patient care/support needs ($\bar{X}$ = 32.51 [SD =19.36]) ■ Author-developed head and neck cancer needs questionnaire: $\bar{X}$ = 26.62 (SD = 14.07) ■ Caregiver Reaction Assessment: moderate caregiver burden = 2.91 (SD = 0.24) □ Self-esteem burden ($\bar{X}$ = 2.29 [SD = 0.21]), disrupted schedule burden ($\bar{X}$ = 3.08 [SD = 0.46]), financial problem burden ($\bar{X}$ = 2.75 [SD = 0.55]), health problem ($\bar{X}$ = 2.29 [SD = 0.46]) ■ Inventory of Socially Supportive Behavior □ Perceived support from family, friends, and healthcare providers in medical situations, including emotions, information, evaluation, and practical support □ Caregiving burden is predicted by caregivers' social support (β = –0.225), patients' health system/information needs (β = –0.006), patients' daily living needs (β = 0.005), and patients' psychological needs (β = 0.004), (adjusted R^2 = 0.411, $p < 0.001$).

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TABLE 1. Summaries of Quantitative Descriptive Findings *(Continued)*

Study	Design and Sample	Measurements and Outcomes
During treatment *(continued)*		
Badr et al., 2014 (United States)	Longitudinal (weekly during 6-week radiation therapy treatment); with 49 patient–caregiver dyads during intensity modulated radiation therapy; using unconditional base model, linear mixed models, and exploratory analysis	■ Demographics: 90% female caregivers, 68% spouse ■ MDASI □ Head and neck subscale: $\bar{X}$ = 4.37 (SD = 2.22) (out of 10) □ Core symptoms subscale: $\bar{X}$ = 5.11 (SD = 2.75) ■ Caregiver burden: Correlated with patient MDASI head and neck subscale (β = 0.83, $p < 0.05$). ■ National Comprehensive Cancer Network Distress Thermometer □ Before treatment: patient (3.02 [SD = 0.75]) versus caregiver (2.41 [SD = 0.6]) □ During treatment: patient (5.8 [SD = 2.4]) versus caregiver (6.46 [SD = 2.43]) □ Patients' top 5 distress: sleep, pain, mouth sores, eating, and fatigue □ Caregivers' top 5: worry, fatigue, sleep, dealing with the patient, and work □ High correlations between patient distress, patient MDASI, and caregiver distress (β = 0.37–0.64) ■ Statistical models □ Significant changes in distress over time for patients and caregivers □ Patient distress increases as a function of symptom severity ($t = 3.99$, $p = 0.001$). □ Caregiver distress increases as patient head and neck symptom burden increases ($t = 3.32$, $p = 0.005$). □ When one dyad member's distress increases, the other member's distress decreases (β = –0.99, $p = 0.01$). □ Only MDASI head and neck subscale (β = 2.6, $p < 0.001$) and caregiver's distress level (β = –1.65, $p < 0.001$) predict distress for patients and caregivers.
Chen et al., 2014 (China)	Cross-sectional; with 102 patient–caregiver dyads with newly diagnosed head and neck cancer receiving oral surgery; using correlation and logistic regression analysis	■ Demographics: average time since surgery = 17.5 days, 70% female, 57% spouse, 38% unemployed ■ PC-SCN: $\bar{X}$ = 31.38 (SD = 4.31), range = 0–100 □ High needs in information (40.69 [SD = 8.06]) and daily living (34.25 [SD = 9.82]) □ High unmet needs: psychosocial, information, healthcare service □ Cancer stage and caregiver's family support correlate with unmet needs ■ Caregiver Social Support Scale □ From family: $\bar{X}$ = 2.12 (SD = 0.53), range = 0.94–3 □ From healthcare professionals: $\bar{X}$ = 2 (SD = 0.54), range = 1.19–3 ■ Symptom Distress Scale modified for head and neck cancer: $\bar{X}$ = 1.7 (SD = 0.3), range = 1.2–2.4 ■ PSQI: $\bar{X}$ = 9.7 (SD = 4.83), range = 0–18 □ Main issues: use of sleep medicine (1.65 [SD = 1.35]), daytime dysfunction (1.57 [SD = 1.06]), sleep duration (1.58 [SD = 1.1]), sleep latency (1.53 [SD = 0.99]) ■ HADS depression subscale (patient): $\bar{X}$ = 7.18 (SD = 3.61), range = 1–14
Han et al., 2014 (China)	Cross-sectional; with 301 caregivers of hospitalized patients with stage II–IV esophageal cancer; using independent t test and correlation analysis	■ Demographics: 63% female, 42% employed, 52% spouse ■ CESD-10: indicative of clinical depression ($\bar{X}$ = 11.22 [SD = 0.62]; range = 0–30) ■ MSPSS: moderate level ($\bar{X}$ = 65.66 [SD = 10.3], range = 12–84) of support from family, significant others, and friends ■ Brief COPE Inventory: Top 4 identified copings are maladaptive coping ($\bar{X}$ = 24.09 [SD = 4.34]), problem-focused coping ($\bar{X}$ = 16.34 [SD = 4.29]), emotion-focused coping ($\bar{X}$ = 13.25 [SD = 2.24]), and adaptive coping ($\bar{X}$ = 9.53 [SD = 2.15]).

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TABLE 1. Summaries of Quantitative Descriptive Findings *(Continued)*

Study	Design and Sample	Measurements and Outcomes
During treatment *(continued)*		
Simpson et al., 2015 (Australia)	Cross-sectional; with 51 caregivers of outpatients undergoing treatment; using Pearson correlation, t test, Mann–Whitney U test, and logistic regression analysis	■ Demographics: 86% female, 75% spouse ■ RS: $\bar{X}$ = 152 (SD = 17.2), range = 87–175 □ No difference in RS between spousal and nonspousal caregivers (152.4 [SD = 17.5] versus 151.9 [SD = 16.7]) □ No correlation between RS and patient cancer stage □ RS correlates with anxiety ($r = -0.383$, $p < 0.01$) and depression ($r = -0.468$, $p < 0.01$). □ Each increase in RS decreases the chance of anxiety (OR = 0.95, p = 0.018) and depression (OR = 0.91, p = 0.028). ■ HADS: depression score ($\bar{X}$ = 2.8 [SD = 3.3]); anxiety score ($\bar{X}$ = 6.2 [SD = 4.8]) ■ HaNiQ: no difference between low- and high-resilience groups
During and after treatment		
Hung et al., 2013 (China)	Longitudinal (before discharge/T0, 1 week/T1, 1 month/T2, and 3 months/T3); with 142 caregivers (all patients received surgery and 53% also received chemotherapy or radiation therapy); using repeated-measures analyses of variance and generalized estimating equation	■ Demographics: 78% female, 59% spouse, 51% unemployed, 80% performed daily care ■ Social Support Needs Scale–Modified □ Instrumental: peak at T0 ($\bar{X}$ = 2.16, 2.04, 1.35, 1.42) □ Informational: peak at T0 (2.38, 2.36, 2.08, 1.86) □ Emotional: peak at T1 (2.44, 2.54, 2.33, 2.01) ■ Social Support Satisfaction Scale–Modified □ Instrumental: 7.8, 7.72, 8.21, 8.86 □ Informational: 4.43, 4.29, 4.65, 4.85 □ Emotional: 7.15, 6.49, 7.04, 7.4 □ Spousal caregivers had higher need of social support in the first 3 months. □ Frequent caregiving correlates with low satisfaction with social support.
Nightingale et al., 2016 (United States)	Cross-sectional; with 33 caregivers of patients with major surgery; the majority completed the survey after surgery (less than 6 months = 30%; 6 months or greater = 55%; before or on the day of surgery = 15%); using Fisher's exact test and t-test analysis	■ Demographics: 82% female; 73% spouse/partner, 39% employed □ 73% provide daily care. □ 28% less than 1 hour of daily care, 47% (1–4 hours), 50% (greater than 5 hours) ■ CanCORS: 67% had moderate physical activity 3 days a week; 79% never drink and 12% drink less than monthly. ■ Fruit and vegetable screener: comparable to average intake of U.S. adult ■ Tobacco use supplement: 18% current smoker, 42% former smoker ■ Hours of sleep: 42% had less than 7 hours per night, 58% had 7 hours or more per night ■ CESD-10: 45% had high level of depressive symptom ($\bar{X}$ = 9.7 [SD = 7.7]). ■ PROMIS–Anxiety: 33% had above-average anxiety ($\bar{X}$ = 54.1 [SD = 10.2]). ■ Zarit Burden Inventory: $\bar{X}$ = 5.4 (SD = 3.9) (out of 16) ■ Interest in wellness program: □ Prefer programs in diet/exercise (72%), cancer education (67%), stress reduction (64%), finances, caregiving, and well-being (64%) □ Prefer to participate during patients' medical treatment (64%), after diagnosis (52%), or fully recovered (52%) □ Prefer delivery via mail (50%), Internet (36%), at the clinic (35%), at home (29%), or by phone (13%) □ Interested participants reported higher depressive symptoms (p = 0.03), anxiety (p = 0.04), and care burden (p = 0.04). □ Being female, providing daily care, and smoking history were not associated with interest in wellness program.

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TABLE 1. Summaries of Quantitative Descriptive Findings *(Continued)*

Study	Design and Sample	Measurements and Outcomes
Post-treatment survivorship		
Donnelly et al., 2008 (Ireland)	Cross-sectional; with 94 caregivers of patients with esophageal adenocarcinoma who finished treatment; using regression and logistic regression analysis	■ Demographics: 83% had identified caregivers, 83% female, 80% spouse, days since diagnosis = 108 ■ Caregiver Strain Index: marked strain (score greater than 6) = 55% ■ GHQ □ Poor general health (score greater than 5) = 71% □ Types of strain between high (greater than 5) and low GHQ: caring role (97% versus 62%), financial strain (80% versus 20%), time demands (80% versus 36%), feeling overwhelmed (77% versus 39%), disturbed sleep (77% versus 31%) and feeling confined (73% versus 12%), physical strain (18% versus 3%), and inconvenience (44% versus 13%)
Ross et al., 2010 (United States)	Cross-sectional; with 89 caregivers of patients with nonmetastatic upper aerodigestive track cancer 6–24 months after diagnosis; using t test and correlation analysis	■ Demographics: 73% female, 90% married or partnered, 55% employed □ Average caring time per week = 16 hours (SD = 15) □ Spouses reported worse financial well-being than others ($r = -0.26$, $p < 0.05$). ■ CQOL–C: Higher ($\bar{X} = 96.2$ [SD = 21.7], t[348[= 3.36, $p < 0.001$) compared to caregivers of patients undergoing treatment □ Greater hours of caregiving correlated with less perceived disruption ($r = -0.45$, $p < 0.0001$), greater positive adaption to caregiving ($r = 0.24$, $p < 0.05$), and worse mental well-being ($r = -0.31$, $p < 0.01$). ■ Mental Health Inventory: 38% had moderate to high distress □ Higher psychological distress than the public (t[5175] = 2.46, $p < 0.05$) □ Lower psychological well-being than the public (t[5175] = 2.28, $p < 0.05$) ■ Family Inventory of Needs: measure of practical and informational needs □ Only 39% reported all needs were met. □ Information needs regarding services (10%–12%) and symptoms (12%–14%) was the most unmet needs compared with the practical. □ Gender, level of met needs, and time since diagnosis were not associated with caregivers' quality of life or mental health.
Precious et al., 2012 (United Kingdom)	Cross-sectional; with 386 disease-free participants; using Fisher's exact test, chi-square test, and Mann–Whitney U test analysis	■ Demographics: 46% had at least one caregiver, spouse 64% ■ UW-QOL □ Physical function: $\bar{X} = 74$ ($\bar{X} = 95$ for patients without cancer) □ Social-emotional function: $\bar{X} = 77$ ($\bar{X} = 83$ for patients without cancer) ■ Author-developed questions on care □ Patients' understanding of caregiver main roles: emotional support (75%), taking patients to appointments (62%), and grocery shopping (59%) □ 66% of patients felt caregiver had little burden, 34% considerable burden □ 68% of patients felt it was not too hard for caregivers, 32% felt it was very hard
Balfe et al., 2016 (Ireland)	Cross-sectional; with 197 caregivers of head and neck survivors in extended and permanent survival period (more than 2 years postdiagnosis); using Mann–Whitney U test, Kruskal–Wallis test, and negative binomial regression	■ Demographics: 76% female, 26% employed ■ PC-SCN □ Low unmet need (median = 3.7, range = 0–100) □ Higher need in emotional and health services than information and work/social ■ Cancer-Related Financial Stress and Strain: significant correlation with high unmet need ■ OSLO 3 Perceived Support Scale: measure of practical social support; no significant correlation with other variables ■ Loneliness Scale: significant correlation with high unmet need

Continued on the next page

TABLE 1. Summaries of Quantitative Descriptive Findings *(Continued)*

Study	Design and Sample	Measurements and Outcomes
Post-treatment survivorship *(continued)*		
Hanly et al., 2016 (Ireland)	Cross-sectional; with 180 caregivers of post-treatment head and neck cancer survivors; using multiple regression and bivariate correlation analysis	■ Demographics: 76% female, 68% unemployed, 67% spouse ■ Scale of financial stress: $\bar{X}$ = 4.7 (SD = 1.2) ■ Time spent caring per week: $\bar{X}$ = 9.5 hours ■ PC-SCN □ Psychological emotional need: $\bar{X}$ = 14.44 □ Information need: $\bar{X}$ = 11.93 □ Work and social need: $\bar{X}$ = 9.57 ■ CarerQoL □ Level of burden (range = 0–100): $\bar{X}$ = 23.2 (SD = 16.6) □ Level of happiness (range = 0–10): $\bar{X}$ = 7.5 (SD = 2.1) □ Unmet health service need (β = 0.28, p = 0.04) predicts carer burden. □ Unmet psychosocial needs (β = –0.38, p = 0.028), healthcare service needs (β = –0.3, p = 0.049), information needs (β = 0.29, p = 0.028), comorbidity (β = –0.18, p = 0.03), and gender (β = –0.16, p = 0.045) predict carer happiness.
Hospice care		
Ledeboer et al., 2008 (Netherlands)	Cross-sectional; with 45 surviving caregivers of palliative patients; using correlation and cross-tab analysis	■ Demographics: surviving spouse 53%, surviving offspring 29% ■ Author-developed survey on needs □ 69% of caregivers felt patients needed better psychosocial support. □ 81% of caregivers were satisfied with the treatment provided by head and neck department. □ More than half of caregivers found the quality, quantity, and understandability of information were good. □ 78% of caregivers reported no support during bereavement.
McMillan et al., 2015 (United States)	Cross-sectional; with 26 caregivers of newly admitted (24–48 hours) hospice home care patients; caregivers provided at least 4 hours of home care daily	■ Demographics: 96% female, 58% wife or significant other ■ CESD-10: $\bar{X}$ = 3.5; 54% (score greater than 4) indicative of clinical depression. ■ Perceived social support: measure of (tangible) practical, emotional, and information support; generally satisfied with their support, especially with emotional support ($\bar{X}$ = 10.2 out of 12) ■ SF-36: subscales of physical functioning and health perception; good to fair health status ($\bar{X}$ = 3.4 [SD = 1.2])

APGAR—Adaptation, Partnership, Growth, Affection, Resolve; CanCORS—Cancer Care Outcomes Research and Surveillance; CarerQoL—Care-Related Quality of Life; CESD-10—Center for Epidemiological Studies Depression Scale; CQOL-C—Caregiver Quality of Life Index–Cancer; DSM-IV—Diagnostic and Statistical Manual of Mental Disorders; GHQ—General Health Questionnaire; HADS—Hospital Anxiety and Depression Scale; HaNIQ—Head and Neck Information Needs Questionnaire; MDADI—MD Anderson Dysphasia Inventory; MDASI—MD Anderson Symptom Inventory; MSPSS—Multidimensional Scale of Perceived Social Support; OR—odds ratio; PC-SCN—Partners and Caregivers Supportive Care Need; PROMIS—Patient-Reported Outcomes Measurement Information System; PSQI—Pittsburgh Sleep Quality Index; RS—Resilience Scale; UW-QOL—University of Washington Quality of Life Questionnaire

the highest out of the three groups of needs (psychological, informational, and social) (Hanly et al., 2016). Information needs then begin to diminish as the caregivers move from treatment ($\bar{X}$ = 41 out of 100 on the Partners and Caregivers Supportive Care Needs survey) to post-treatment survivorship ($\bar{X}$ = 12 out of 100) (Balfe et al., 2016; Chen et al., 2009, 2014; Hanly et al., 2016; Hung et al., 2013; Longacre et al., 2015). Because caregivers communicating with healthcare providers about their loved ones' condition was the main reason for information needs during treatment, a decrease in information needs after patients finished treatment was expected (Chen et al., 2009). A study in China by Hung et al. (2013) also found that caregivers' satisfaction concerning their informational needs increased from treatment

completion to three months postdischarge. Long-term caregivers also stated that quality, quantity, and understandability of the postdischarge information they received was satisfactory (Offerman et al., 2014). Although statistics have shown that treatment-related information needs decline after patients transition into the post-treatment period, caregivers' needs for non-treatment–related information remained unknown, which might still position caregivers at high need for information support. Certain caregiving populations might require more information to perform care postdischarge than others. For example, Longacre et al. (2015) found that information needs of nonspousal caregivers are significantly higher than spousal caregivers, indicating that information support was still inadequate in both quality and quantity.

Psychological Needs Remain High Throughout the Caregiving Trajectory

There was a consistent lack of psychosocial support for caregivers, and caregivers' psychosocial needs remain high from treatment to post-treatment survivorship (Hanly et al., 2016; Ledeboer et al., 2008; Precious et al., 2012). It could be that caregivers are often too busy to neglect their own feelings and fail to access resources for psychological needs (Balfe et al., 2016). On the Partners and Caregivers Supportive Care Needs Survey, although information needs scores were higher than psychological and social needs scores during treatment, psychological needs scores were higher than informational and social needs scores during post-treatment (Chen et al., 2014; Hanly et al., 2016; Hung et al., 2013).

Most of the findings did not indicate an improvement in caregivers' psychological wellness throughout the patients' survivorship period. From diagnosis to six months, caregivers' psychological health declined significantly as they experienced cancer alongside their loved ones (Lee et al., 2017). Of note, during radiation therapy treatment, the caregiver's distress, anxiety, and depression levels were constantly higher than the care recipient's (patient). They experienced more worries, fatigue, sleep problems, and disruptions to their work schedule associated with caregiving (Badr et al., 2014; Terro & Crean, 2017). In addition, Ross et al. (2010) found that caregivers' psychological health status was not significantly associated with patients' time since diagnosis, revealing that there was little psychological and emotional support to effectively help these caregivers in cancer coping. However, two longitudinal studies in China (Hung et al., 2013; Lee et al., 2017) found that caregivers' psychological needs decreased from diagnosis to six months. The differences in the patterns of caregivers' psychological needs reveal that caregivers' needs may be subject to changes in their social-cultural environments.

High physical burden associated with caregiving tasks could also be one of the reasons why caregivers experience more psychological burden. Donnelly et al. (2008) found that 71% of caregivers of patients with head and neck cancer, at the end of the patient's treatment, had poor health status (score of 5 or greater on the General Health Questionnaire); a larger percentage of poor health status caregivers experienced physical strain (18% versus 3%), feelings of being confined (73% versus 12%), financial strain (80% versus 20%), and time demand (80% versus 36%) than caregivers with a score of less than 5 (Donnelly et al., 2008), indicating that the caregiving task might pose a negative impact on caregivers' quality of life. Patterson et al. (2013) found that there was a moderate to strong correlation (Pearson's r = 0.51–0.7) between caregivers' quality of life and patients' outcome from diagnosis to post-treatment. In addition, Patterson et al. (2013) showed that the level of life disruption on caregivers remained the same from diagnosis to 12 months after treatment.

Caregivers also tend to experience higher levels of stress when patients have higher symptom burden. Patients who are in treatment or close to treatment completion tend to experience symptoms caused by treatment sides effects or toxicities (Badr et al., 2014; Chen et al., 2014). The reduction in caregivers' psychological status could be explained by a decrease in the intensity of head and neck cancer treatment; for example, the concurrent use of chemotherapy and radiation therapy treatments is associated with a high symptom burden. Patients receiving concurrent treatment often require a PEG tube for nutritional support. Caregivers reported that dysphagia and gastrostomy care had more psychological impact on them than other daily caregiving tasks (Patterson et al., 2013). In addition, higher symptom burden indicates a lower physical function level. Level of physical function is much lower in patients with head and neck cancer than in other populations. Patients with head and neck cancer showed a mean physical function level decline from 82 at diagnosis to 74 at post-treatment on the UW-QoL, version 4.0, compared to the average physical function level for non-cancer patients at 95 (Precious et al., 2012; Terro & Crean, 2017), indicating a negative impact of symptom burden on patients' overall physical function. Of note, although

FIGURE 2. Proposed Interventions From the Literature

Care Diaries

Sharp et al., 2004 (Sweden)

- A loose-leaf A-5 size notebook containing information about care, treatment, and appointment, as well as space to journal
- Additional color-coded information session: pain management, nutrition, oral care, skin care, nausea, questions, general notes, and prescribed medications
- 2 phases
  - Radiation therapy nurse advises patients and family caregivers on the use of the care diaries.
  - Patients, caregivers, and healthcare providers use the same care diaries to share personal notes and information with each other during the radiation treatment period.

One-Day Multiple Family Group Workshop

Steinglass et al., 2011 (United States)

- Psychoeducational workshop with 3–6 families per group and 2 facilitators with expertise in psycho-oncology and family systems therapy
- Goals include educating families, normalizing the experiences, confronting and challenging the isolation, and exploring ways to find new balance between illness and non-illness issues and priorities in their lives.
- 4 phases
  - Introductory: Families share their cancer stories.
  - Illness impact: Use group-within-group technique to find shared experience and introduce metaphors to describe it.
  - Family development: Discuss family life before and after cancer.
  - Family-illness integration: Use family collage technique to describe and clarify coping strategies.

Tracheostomy Care Anxiety Relief Through Education and Support (T-CARES) Program

Loerzel et al., 2014 (United States)

- A comprehensive, 1-hour course on tracheostomy care for family caregivers. Each course had 1 RN instructor and 6 family caregivers.
- Teaching techniques include author-developed 18-minute home environment video demonstration, group discussion, return demonstration, hands-on practice on a low-cost anatomical trainer, and a competency assessment.

Computer-Assisted Oral Cancer Rehabilitation and Support (CARES) Website

Badr, Lipnick, et al., 2016 (United States)

- A validated interactive health communication website specifically designed based on the needs of patients with head and neck cancer and their caregivers to provide information, skill-building, and support services and connection with peers and healthcare providers
- Information support included what to expect, managing nutrition and swallowing issues, pain management, self-care, HPV, and living a healthy lifestyle after cancer.
- Other supports include emotional reactions, communication, and social connection or social support.

Intervention DVD

Parker et al., 2016 (Australia)

- Intervention is designed to support information needs at 5 stages from head and neck clinic, preadmission clinic, surgery, postsurgery inpatient, and discharge home.
- Topics include disease process, treatment choices, information about preoperative and postoperative care, pain management, tracheostomy care, where to seek support, contact person, and information at each stage.
- Videos were filmed with real patients and healthcare providers.
- Experimental study was stopped early from poor accrual.

Survivorship Needs Assessment Planning (SNAP) Tool

Sterba et al., 2019 (United States)

- SNAP is a data management system with an administrator interface that assess needs in symptom and functional abilities, health behaviors, and social challenges.
- 2 phases
  - Patients and their caregivers answer the surveys proposed by the SNAP tool during a clinic visit after completing treatment.
  - SNAP generates a treatment summary and a set of algorithm-driven educational materials and referrals, which are also approved by a nurse practitioner.

Build Family Caregiver Skills

Mazanec et al., 2019 (United States)

- Support family caregivers through vicarious experience via simulation, skill competency, and emotional support using education booklets from National Cancer Institute.
- Family caregivers have 4 one-on-one sessions with a nurse interventionist during the first, second, fourth, and sixth weeks of radiation treatment.
- 4 phases
  - Help the caregivers to understand the patient's experience.
  - Describe the typical caregiver experience.
  - Discuss how the illness can affect the caregiver–patient relationship.
  - Discuss common issues and concerns that may arise after cancer treatment.

evidence has shown that physical deformities and stigmatization of head and neck cancer with human papillomavirus (Lewis et al., 2015) often lead to issues related to intimacy or sexuality for their caregivers (Badr et al., 2014), these issues were not discussed in the reviewed studies.

Finance-related psychological issues were more prevalent in the head and neck cancer population secondary to the association between head and neck cancer and low socioeconomic status (Al-Dakkak, 2010) than in the matched control group (Hanly et al., 2016). About one in every three caregivers (29%) reported at least some financial burden, and caregivers for patients with head and neck cancer reported moderate to high financial stress ($\bar{X}$ financial stress = 4.7 out of 7 and $\bar{X}$ financial problem burden = 2.75 out of 5 on a subscale of the Caregiver Reaction Assessment) (Chen et al., 2009; Hanly et al., 2016). Not only was higher income level (more than $50,000 annually) associated with fewer hours engaged in caregiving tasks ($r = -0.33$, $p < 0.01$) (Ross et al., 2010), caregivers' financial burden was also explained by perceived social support ($\beta = -0.298$), patients' psychological well-being ($\beta = -0.031$), and three other disease-related factors, including patient's oral cancer disease-related needs, patient support needs, and patients' interpersonal communication needs (Chen et al., 2009).

Social Needs Peak in Post-Treatment Survivorship

In the literature, caregivers' social needs are not often assessed separately, but described as a root cause of caregiving burden. In a study by Chen et al. (2009), the more social support caregivers received, the less caregiving burden they experienced. Social needs likely persist throughout the trajectory as caregiver burden remains high. After patients begin their treatment, caregivers reported moderate caregiving burden (Chen et al., 2009), which was strongly associated with the severity of patient symptoms (Badr et al., 2014). Even after the treatment period, caregivers found that daily life disruptions associated with caregiving tasks remained high (Patterson et al., 2013). On average, caregivers continued to spend 10 hours per week performing patient care (Chen et al., 2009; Hanly et al., 2016). In addition, during the post-treatment survivorship period, caregivers' social needs appear to peak, particularly for patients receiving surgical treatment. Surgical treatment in the head and neck area causes more disruption to daily functioning and an individual's self-image than radiation therapy or chemotherapy (Katz et al., 2003). Some patients reported difficulty returning to work and often experience unemployment after finishing treatment (Lang et al., 2013). A longitudinal study by Terro and Crean (2017) found that patients reported significantly lower quality of social and emotional life at three months after resection or reconstruction surgery. Therefore, patients and caregivers are expected to assume more tasks to fulfill the social needs associated with head and neck cancer.

The inconvenience caused by treatment-related dysphasia or loss of taste makes it more difficult for patients and caregivers to attend social activities outside of the home setting (Patterson et al., 2013). Both caregivers and patients found that the new routines at home tended to be challenging to adjust to; therefore, they began to avoid activities, such as going out for dinner or traveling long distances (Patterson et al., 2013). Overall, it was frustrating for them to not be able to enjoy the leisure activities that they used to.

Solutions for Caregivers' Needs

Seven experimental interventions to address caregivers' needs were identified in the review (see Figure 2). Two of the seven interventions focus only on information need (Nightingale et al., 2016; Parker et al., 2016), and the rest focus on multiple caregiving needs, including informational and psychological support and skill training (Badr, Lipnick, et al., 2016; Loerzel et al., 2014; Mazanec et al., 2019; Sharp et al., 2004; Steinglass et al., 2011). All seven interventions encompassed informational support. The intervention DVD (Parker et al., 2016) and the Survivorship Needs Assessment Planning (SNAP) tool (Nightingale et al., 2016) focused on improving patient education with technology, such as videos and computer algorithms to provide instructions on care management. The intervention DVD provides videos to help head and neck surgical patients and their caregivers to better understand the treatment process, care management, and how to access existing resources (Parker et al., 2016). Similarly, the SNAP tool is an evidence-based algorithm that can assess patients' unmet needs and generate educational materials and referrals based on the assessment (Nightingale et al., 2016). The other five interventions incorporated additional psychological support components by creating opportunities to communicate with healthcare providers or peers. For example, the one-day Multiple Family Group (MFG) workshop (Steinglass et al., 2011) and the Tracheostomy Care Anxiety Relief Through Education and Support (T-CARES) program (Loerzel et al., 2014) both used a face-to-face group education technique

to improve communication among caregiver peers while delivering the information component. The MFG workshop has a total of 300 minutes of intervention time, during which patients with head and neck cancer and their caregivers are invited to discuss and work on their coping strategies (Steinglass et al., 2011). The T-CARES program is a one-hour education and interactive session, during which caregivers come together to learn and practice tracheostomy care and share their personal lessons and experiences (Loerzel et al., 2014). Participating caregivers in each study identified that having the opportunity to communicate with someone who is undergoing the same experience was beneficial and encouraging.

In addition, care diaries (Sharp et al., 2004) and the Computer-Assisted Oral Cancer Rehabilitation and Support (CARES) website implemented designated communication pathways by establishing a sharing platform with a notebook and a website (Badr, Lipnick, et al., 2016). The care diaries intervention is a customized notebook with appointment information, care management, and additional space designed for patients, family caregivers, and healthcare providers to log their notes on a community chat board (Sharp et al., 2004). The CARES website is a head and neck cancer–specific website with an interaction portal to improve connection and support among peers and their providers (Badr, Lipnick, et al., 2016). Another comprehensive intervention, Building Family Caregiver Skills, implemented simulations into four nurse-delivered, one-on-one support sessions to caregivers of patients with head and neck cancer (Mazanec et al., 2019). This intervention is more extensive compared with other interventions and required multiple meetings with the caregivers to provide informational and psychological support, but also involved the design of simulations to provide technical skill trainings (Mazanec et al., 2019). Overall, most interventions tended to emphasize caregivers' information needs, but were less responsive to psychological and social needs.

Discussion

The types of needs of informal caregivers of patients with head and neck cancer vary as the patients progress through the disease trajectory. Based on the need fulfillment theory (Deci & Ryan, 1991, 1995, 2000; Kim et al., 2010; Moss, 2016), a caregiving need will decrease when caregivers receive satisfactory support in that category of need, namely that needs are being fulfilled; unfulfilled or unmet needs have a negative impact on social well-being and quality of life. Although information needs are high early in the cancer trajectory, they begin to decline in the post-treatment period as caregivers accumulate information from healthcare providers and the Internet. On the other hand, if caregivers did not receive sufficient support, that category of need remains unfulfilled or unmet (Kim et al., 2010). For instance, because very few support programs are available to support caregivers' psychological needs, there is often no decrease in psychological needs along the disease trajectory, indicating that psychological needs are highly unmet. Therefore, to improve caregiving, it is important to distinguish between caregivers' needs and their unmet needs, so that unmet needs can be prioritized.

After the analysis of caregiver needs for patients with head and neck cancer, the authors found that it is of paramount importance to recognize these needs from a systematic perspective so that an optimal time to introduce the most needed support can be identified. Three main areas for future improvement in this realm of scientific evidence have been identified:

- Encourage the use of homogeneous evaluative instruments and longitudinal study design.
- Integrate theoretical frameworks when analyzing care needs and designing interventions.
- Develop more interventions targeting caregivers' psychological and skill-training needs.

First, only a few measurements used in the literature review were shared in more than one study in the systematic review. The heterogeneity of scales makes it difficult to do comparisons of their findings. This review provides a summary of the instruments in the literature. Future researchers should be aware of the existing instruments while designing studies. Having a consensus of instruments and outcomes is essential to conduct a meta-analysis, which will help to guide future study designs and determine sample sizes. From this systematic review, it is clear that caregivers' needs vary along the disease trajectory. Therefore, it is important to design studies with a longitudinal approach to have a thorough understanding of the variations in needs.

Second, only 6 of the 19 quantitative descriptive studies analyzed multiple perspectives in caregiving for patients with head and neck cancer, such as information, psychological, and social needs. The rest only focused on a single perspective. To help researchers analyze multiple perspectives pertaining to caregiving, the authors of the current study suggest using a theoretical framework to map out the relationships among the needs and their predictors. Using theoretical frameworks to describe the phenomenon of unsupported caregivers of patients with head and neck

cancer yields a broader and in-depth understanding of the caregiving experience and how the quality of caregiving affects patients' outcomes. In addition, with multiple perspectives in the study designs, advanced statistical analysis can be applied to explore the factors associated with unmet needs. This evidence will assist healthcare providers to anticipate caregivers who are more vulnerable in caregiving.

Third, early skills and psychological supportive interventions to improve and assess caregivers' psychological wellness are needed. In contrast to the decreasing pattern in informational needs, caregivers' psychological needs remain high throughout the disease trajectory. Caregivers tend to be overwhelmed with the tasks and information in caregiving. They also feel guilty when expressing their feelings and, therefore, prioritize patients' feelings before their own. Consequently, stressed caregivers are more likely to have difficulty in providing care to their loved ones. However, there is a lack of attention and interventions from healthcare providers related to caregivers' psychological wellness. Early and repeated assessments should also be implemented to identify populations who are more vulnerable in their role of caregiving. Future studies are needed to test new interventions to address caregivers' unmet psychological needs.

Implications for Nursing

The review shows that the trajectory of informal caregiving for patients with head and neck cancer is a long-term commitment for both patients and caregivers. During different stages, caregivers experience different aspects of caregiving needs. The rehabilitation from head and neck cancer treatments does not end when patients and caregivers leave the hospital; recovery from treatment may take as long as one year or more. A qualitative study in Sweden by Isaksson et al. (2016) involving 56 patients with head and neck cancer without tracheostomy found that only 27% were able to resume their normal activities in 2.5 years after completion of treatment. In the treatment stage, caregivers' information needs regarding treatment and prognosis are high. In the post-treatment stage, caregivers' social needs remain high. During the significant transitions between treatment areas, nurses play a primary role in educating and preparing caregivers for treatment transitions and post-treatment survivorship. A more proactive approach in meeting psychological needs throughout the survivorship trajectory is needed.

There are several recommendations for nurses interacting with caregivers of patients with head and neck cancer based on this review. First, because caregivers play critical roles in supporting patients with head and neck cancer, healthcare providers need to include them more in providing care and avoiding complications. Oncology nurses are encouraged to provide an environment that is conducive for patients and their caregivers to express their needs freely. Oncology nurses, particularly those treating patients with head and neck cancer, should be more vigilant in educating and preparing informal caregivers on the proceeding needs in the disease trajectory. Second, the review shows that patients' and their family caregivers' information needs are poorly addressed by healthcare providers. The implication in clinical nursing is that nurses need to recognize their nurse-as-teacher role (Wang, 2020) in patients' and caregivers' education, beyond performing technical tasks in taking care of patients with head and neck cancer. Unfortunately, these early educational initiatives often do not get much attention in the clinical setting (Farahani et al., 2013). Third, when healthcare providers could not support the caregivers in a timely manner, patients with head and neck cancer were at risk for impaired quality of care and more complications, such as respiratory infection from poor tracheostomy care and mucositis from lack of oral care education (Ward et al., 2018). Beyond information needs, caregivers also need skills training and psychological support throughout survivorship. Systematic institutional services to support caregivers should be tested and implemented to improve education outcomes and quality of life for both caregivers and their loved ones, particularly for those sustaining high psychological needs.

There are several implications for nursing research as well. More evidence is needed regarding factors associated with caregiving burden in caregivers of patients with head and neck cancer. Longitudinal studies are needed to assess the needs of caregivers of patients at different time points along the disease

KNOWLEDGE TRANSLATION

- Caregivers for patients with head and neck cancer are at high risk for experiencing caregiving burden as patients experience high treatment toxicity.
- Nurses should recognize informal caregivers as an integral part of the caregiving team for patients with head and neck cancer.
- Informal caregivers' psychological and emotional needs are consistently high during cancer treatment and survivorship.

trajectory and in different treatment modalities (i.e., comparisons between the caring needs for single and multiple treatment modalities). In addition, investigators should also be encouraged to investigate the full spectrum of caregiving needs with consistent instruments examining information, psychological, social, healthcare service, and financial needs. Skill training and psychological support intervention studies with bigger sample sizes are needed to calculate the intervention's effect sizes. Promising interventions conducted in countries with different cultural backgrounds require further testing to validate effectiveness in the United States.

Limitations

Although studies were categorized based on different time points on the disease trajectory, the lack of consideration for different types of treatments and the location of tumor site might also affect the caregiver's need for support. Other needs, such as financial and medical, were less studied and reported in the reviewed studies. In addition, some pertinent articles may have been omitted related to limiting the search to CINAHL, MEDLINE/PubMed, and PsycINFO. Not including the specific components of all of the reviewed studies may also challenge the reproducibility of the search results.

Conclusion

Informal caregivers of patients with head and neck cancer are critical to patients and face a number of challenges along the trajectory, specifically related to skill training and psychological and social needs. During the treatment period, studies have found that caregivers have high informational and psychological needs related to their worries, fatigue, lack of sleep, and other uncertainties (Badr et al., 2014; Chen et al., 2014). Later in the survivorship period, specifically during the post-treatment period, caregivers' social and psychological needs peak as they require the most help in adjusting to their new normalized life of taking care of patients with head and neck cancer. Therefore, the increase in social demands after treatment has resulted in an increase in the importance of assisting caregivers' psychological and social adjustment to long-term caregiving (Balfe et al., 2016; Hanly et al., 2016). However, caregivers are often neglected in the healthcare arena (Sherman, 2019). The systematic approach in analyzing informal needs of caregivers of patients with head and neck cancer reveals that a gap exists between clinical practice and caregivers' needs, particularly in supporting their psychological needs. Nurses can play a crucial role in preparing and equipping caregivers to manage their informational, psychological, and social needs.

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QUESTION GUIDE FOR A JOURNAL CLUB

Journal clubs can help to increase and translate findings to clinical practice, education, administration, and research. Use the following questions to start discussion at your next journal club meeting. Then, take time to recap the discussion and make plans to proceed with suggested strategies.

1. What are some of the identified needs of informal caregivers of patients with head and neck cancer?
2. How might these needs differ or show similarities across different cancer types?
3. What are some different ways in which oncology nurses can assess the needs of informal caregivers as part of traditional cancer care in inpatient settings? In home environments? Other settings?

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