Oral Oncology 51 (2015) 634–642

Contents lists available at ScienceDirect

Oral Oncology

journal homepage: www.elsevier.com/locate/oraloncology

Review

The eating experience after treatment for head and neck cancer: A review of the literature

Heidi Ganzer [a,*], Riva Touger-Decker [a], Laura Byham-Gray [b], Barbara A. Murphy [c], Joel B. Epstein [d,e]

[a] *Department of Nutritional Sciences, Rutgers, The State University of New Jersey, School of Health Related Professions, 65 Bergen Street, Room 157, Newark, NJ 07107-3001, United States*
[b] *Department of Nutritional Sciences, Rutgers, The State University of New Jersey, School of Health Related Professions, 40 E. Laurel Road, Room 2018, Stratford, NJ 08084, United States*
[c] *Division of Hematology and Oncology, Vanderbilt-Ingram Cancer Center, 777 Preston Research Building, Nashville, TN 37215, United States*
[d] *Samuel Oschin Comprehensive Cancer Institute, Cedars-Sinai Medical Center, 8700 Beverly Blvd., Los Angeles, CA 90048, United States*
[e] *Division of Otolaryngology and Head and Neck Surgery, City of Hope National Medical Center, 1500 E. Duarte Road, Duarte, CA 91010, United States*

ARTICLE INFO

Article history:
Received 25 February 2015
Received in revised form 13 April 2015
Accepted 18 April 2015
Available online 29 April 2015

Keywords:
Head and neck cancer
Eating
Eating experience
Changed meaning of food
Qualitative research
Survivorship

SUMMARY

Purpose: Research has identified significant challenges that patients experience following treatment for head and neck cancer (HNC). These include the physical and emotional impacts of the diagnosis and treatment, which compound weight loss and negatively impact eating ability. There is limited research about the lived experience and the changed meaning of food, eating and the eating experience after treatment for patients with HNC. The purpose of this review was to explore available research pertinent to the lived experiences of patients in regards to the changed meaning of food, eating and the eating experience after treatment for HNC. *Principal results:* The review identified a limited number of studies that focused on the eating experience and/or the changed meaning of food after a HNC diagnosis. However, the findings do highlight that there are physical, psychological/emotional and social losses associated with the changed meaning of food and eating within the HNC population. *Conclusions:* The eating experience is impacted after treatment for HNC. Physical, emotional and social losses in regards to the eating experience have been identified. Acknowledging the significance of eating challenges and the changed meaning of food is necessary to ensure patients receive the appropriate management and support to best manage these challenges in a timely manner.

Introduction

Eating, the function of consuming food and liquid is necessary to sustain life, although it is often taken for granted [1]. Diagnosis and the treatment of head and neck cancer (HNC) may result in acute toxicities which impact the ability to eat and the eating experience, during and after treatment [2–6]. Most acute toxicities occur during treatment and generally resolve shortly after treatment completion [7]. Some acute effects may fail to resolve over time, becoming permanent or late effects of therapy. Some late effects may not develop until 90 days following treatment. Regardless of the trajectory, late effects can result in chronic, long term challenges that are potentially devastating physically, emotionally and socially [7]. These include dysphagia, odynophagia, xerostomia, mucosal sensitivity, pain, taste alteration or taste loss, trismus, limited tongue mobility or oral aperture, discontinuous jaw and dental disease [4–8]. Such effects are common in survivors of HNC and impact the ability to eat and drink. As a result, eating and the eating experience may remain problematic for months or years, and for some, eating may never return to normal. The primary aim of this review was to explore the eating experience in survivors of HNC and to identify key themes from the literature and detect gaps, thus highlighting the implications for clinical practice and future research.

The majority of HNC research has focused on the effectiveness of treatment modalities and the assessment and management of acute treatment related side effects and toxicities [9,10]. There is little data dedicated to the impact caused by HNC treatment or the impact these effects have on the meaning of food and the eating experience. Patients that have received treatment for HNC often experience a significant disruption in their lives as it relates to eating and the changed meaning of food. Published studies that assess relationships between nutrition interventions and outcomes in the HNC population are most often quantitative in nature. Several studies have assessed long term (three to 10 years) health

---

[*] Corresponding author. Tel.: +1 973 972 6596; fax: +1 973 972 7403.
E-mail address: ganzerhl@shrp.rutgers.edu (H. Ganzer).

http://dx.doi.org/10.1016/j.oraloncology.2015.04.014
1368-8375/

related quality of life (HRQOL) in HNC survivors [11–14]. The findings suggest that there may be a decline in overall HRQOL in long term survivors and that eating problems related to poor oropharyngeal functioning or persistent pain are prevalent [11–15]. Moreover, patients may underreport their experiences due to fear or the failure to recognize functional losses due to adaptation or compensation over time. The later phenomena may be particularly pertinent to late effects that develop slowly [16,17]. Moore et al. identified that patients with HNC underreported their experience of suffering due to fear of being further diminished by the disease, fear of addiction to opioids, or fear that they will not be able to cope with additional losses associated with the disease [18].

A review of the literature published between 1998 and December 2014 assessing qualitative studies in this distinct population revealed a paucity of data assessing the patient's perspective and/or experiences and the long term impact of treatment as it relates to eating post concurrent chemoradiation (CCR). Terms used for the search included 'head and neck cancer survivors', 'eating experience', 'late effects', symptom burden' 'eating', 'patient experience', 'qualitative', and 'changed meaning of food'. Databases searched included CINAHL, MEDLINE, SumSearch, PubMed, and Cochrane Database. The following inclusion criteria were applied: studies must have included participants with a diagnosis of HNC; participants must have received radiation, chemotherapy, surgery or a combination of modalities. Exclusion criteria included studies not written in English. Level of evidence is also provided for the studies. Studies reviewed assessed patients as early as 4–8 weeks post treatment up to 8 years post treatment [3,4,8,15,18–25]. Although not qualitative, two quantitative articles were included in the review as they assessed quality of life in long term survivors of HNC [11,12]. Although the focus of the studies was not the eating experience, functional challenges in regards to eating were identified [11,12]. The lack of published data describing the patients' experience and the long term challenges in the HNC survivor population may be a result of a gap in knowledge specifically defining the "eating experience", limited long-term follow-up, focus on the primary disease, and lack of background knowledge in nutrition or training of the health care professional.

The total eating experience includes physical, physiological, psychological, social and cultural elements [4]. A person's identity and self-image are based on their daily interactions and life experiences [26,27]. A portion of this identity involves life experiences surrounding food [4,26,28,29]. The eating experience includes psychological and social aspects and involves not only the enjoyment of consuming a meal but also the socialization that occurs during mealtime [3,4,29]. In addition to the physical losses related to a HNC diagnosis and the treatment toxicities, patients' may also identify emotional losses due to reduced satisfaction of food and social losses such as not wanting to accept invitations out to dinner or to partake in meals with co-workers in the event that they appear incompetent (feeling socially marginalized due to eating impairments) [3,4,15,20,22,30]. Although food is fundamentally and physiologically necessary to provide energy and nutrients, the act of eating is both physiological and symbolic [29]. It is through eating we express prosperity, good health, strength and love, obtain psychological comfort and hope and develop new friendships and reconnect with our past [29]. This review provides a summary of the current literature exploring the eating experience following a HNC diagnosis and cancer treatment.

Current research

Qualitative research allows investigators the ability to gain a deeper understanding of HNC survivors' lived experiences of daily life. Table 1 provides a comparison of studies that include assessment of QOL as well as qualitative studies exploring the lived experience of patients after treatment for HNC. The majority of published studies reviewed were qualitative in nature or studies that contained a descriptive component. Additionally, two quantitative articles assess long term QOL in the HNC population [11,12]. Mehanna identified that 10 years following the diagnosis and treatment of HNC ($n = 43$), overall QOL had decreased significantly by an average of 11% (95% CI: -5, -17) when compared to the time period before treatment and 15% when compared with years one and two post treatment [11]. Psychological distress, as measured by the General Health Questionnaire worsened on average by 9% (95% CI: -1, -5) and by 15% when compared with the one and two year scores [11]. All head and neck symptoms (coughing, speaking, head/neck pain, shoulder/arm pain and swallowing) deteriorated by 10–20% compared to baseline with the largest declines occurring for shoulder/arm pain, head and neck pain and coughing [11]. Mehanna indicates that the findings were unexpected considering patient reports for the first two years of QOL data indicated that patient's QOL had recovered and often exceeded baseline [11]. The authors theorized that the results may have been related to the patient's perception of a loss of interest and/or sympathy from medical staff or family after discharge from follow-up care (roughly five years post treatment) [11]. The patients did not report deterioration of their symptoms, likely due to the late effects of treatment and/or increasing co-morbidities with advancing age [11]. These findings are consistent with Funk et al. who examined HRQOL in five year HNC survivors ($n = 337$) [12]. The results identified that although the cohort's long term general health was similar to that of age-matched norms from the general population; over 50% of the long term HNC survivors indicated problems with eating and 28.5% reported depressive symptoms [12]. Funk et al. found that eating problems were related to poor oral and oropharyngeal function and persistent pain. The one year pain and diet scores were the strongest independent predictors of five year HRQOL. The authors suggest that early intervention, addressing eating issues, swallowing problems and pain management may be a crucial component in improving QOL in long term survivors of HNC [12].

Within the qualitative studies, consistent themes emerged in regards to the lived experience post diagnosis and treatment for HNC; disruption to daily life, the diminished self, uncertainty and waiting, sharing the burden/support, psychological wellbeing, and finding a path/uncertain future [8,15,19,20,22–25]. Ottosson, McQuestion and Larsson specifically explored the eating experience in patients post HNC treatment identifying themes that included a long journey, a new way of eating, eating without satisfaction, challenging meals outside the family and the creation and acceptance of a new normal [3,4,21]. These studies identified challenges that impacted physical, emotional and social losses [3,4,21].

Systematic reviews by Lang et al. and Donovan identified the psychological/lived experience after a HNC diagnosis and treatment. Although not specific to the eating experience, the reviews identify the significant impact that HNC treatment had on the eating experience [8,19].

Disruption to daily life

In their systematic review exploring the psychological experience of living with HNC, Lang et al. identified a theme that involves the disruption to daily life particularly focused on eating problems such as the thickening or lack of saliva, changes to taste, pain, fear of choking and feeling of narrowness in the throat impairing the ability and/or desire to eat [8]. A participant interviewed by Roing epitomized the disruption stating "the worst time of the day is when I eat…it is really tough…nothing tastes good anymore. It is hard to eat…it is absolutely the worst time of the day.

Table 1
Literature Review of Studies in Adults with HNC and the Experience with Eating Post Treatment[†].

Investigators	Year	Level	Purpose/aim of study	Sample demographics	Methodology	Main results/findings/themes	Comments
Wells [24]	1998	VI	To examine the lived experience of patients with HNC during recovery post radiation therapy.	$N = 12$ Patients were one month post radiation therapy.	Diary interview method followed by interview and symptom cards. Immediately following radiation completion patients given diaries; interview one month post treatment.	Five themes emerged: "*A hidden experience*" "*The disruption of symptoms*" "*Perceived insignificance*" "*Loss of self*" "*Living with uncertainty*"	Interviews took place one month post treatment. Used three methods within the study to ensure that a full picture was obtained as it related to the physical and emotional experience was grasped. Small sample size. Radiation therapy only. Identified functional issues related to eating but not specific to the experience of eating post treatment.
Rose and Yates [23]	2001	IV	To explore QOL during and after radiation therapy for HNC.	$N = 58$ (41 male, 17 female) Patients post radiation therapy.	Mixed methods. Used QOL instruments and open ended questions. Data collected at three points in time: T1 first week of treatment, T2 last week of treatment and T3 one month post treatment. Used the Functional Assessment of Cancer Therapy: Head and Neck (FACT-H&N) and the Hospital Anxiety and Depression Scale (HADS).	*Physical well-being:* Best at T1, decreased at T2 and T3; improvement between T2 and T3; did not return to functional level noted at T1. *Social well-being:* Lowest scores were at T3: • Sexual life • Social support*Emotional well-being:* • No significant change over the three time points.*Functional well-being:* Lowest scores at each of the three time points: • Being able to work • Enjoying usual leisure pursuitsThere was a significant increase in functional well-being between T2 and T3 (t [57] = −2.11; $p < .039$).HN subscale: Low scores related to: • "I am able to eat the foods I like" • "I can eat solid food" • "Dryness of the mouth, and swallowing difficulties."Mean scores significantly increased between T2 and T3 (t [57] = −6.86; $p = <.001$). Overall well-being scores for FACT-H&N: Decreased overall QOL over the three time points; although some improvement was seen between T2 and T3 the increase did not reach the level of functioning at treatment initiation. Open ended questions at T3: "*What was the worst part or radiation treatment?*" • Sore dry mouth and throat • Skin breakdown Dysphagia • Loss of taste Fatigue • Nausea "What worries you most at the moment?"Physical concerns: • Sore dry throat and mouth • Coughing and swallowing • Loss of taste • Pain • Eating difficulties Fatigue Emotional concerns: • Concerns about the future • Concerns about recurrence	Used mixed methods. Larger sample size for qualitative study. Not specifically addressing nutritional concerns, however, items identified by patients in the qualitative information indicated that these issues were significant to the patients. The study was only 4 months post treatment; does not address long term late effects of treatment.

Table 1 (*continued*)

Investigators	Year	Level	Purpose/aim of study	Sample demographics	Methodology	Main results/findings/themes	Comments
Moore et al. [18]	2004	VI	To explore why patients with HNC tend to under-report their experiences of pain and suffering.	*N* = 18 Patients with HNC, newly diagnosed and long-term HNC survivors (both disease free and recurrent cancer; treatment information not included).	Used in-depth, semi- structured and open-ended interviews to allow for a full exploration of the participants' experiences as it relates to pain and suffering.	Three themes emerged: “A self diminished by cancer.” “The fear of addiction to pain medication.” “The hopelessness and the loss of meaning after HNC.”	Assessed patients longer term (i.e. 4 years out). Small sample size. Not specific to the experience of eating post treatment but does identify concerns functional concerns including swallowing difficulty, emotional, psychological and existential components which affect QOL.
Mehanna and Morton [11]	2006	IV	To report QOL from a prospective 10 year follow-up of a cohort of patients with HNC and to examine the potential predictors of late QOL.	Cohort *N* = 200 HNC patients post surgery, radiation or possibly combined surgery/radiation therapy.10 year survivors *N* = 43.	The Auckland QOL questionnaire was completed at diagnosis, 3, 12, 24 months as part of the 2 year prospective QOL study. At 10 years surviving patients completed the Auckland QOL questionnaire again.	At 10 years: • QOL had decreased significantly by an average of seven points (95% CI: −3, −11) (i.e. a drop of 11% for the 10 year survivors compared with baseline before treatment and a decline of 15% when compared with scores of years 1 and 2). • Psychological distress had worsened on average by 3 points (95% CI: −1, −5) or a 9% decrease, and by more (15%) when compared with the 1 and 2 year scores. • All HN symptoms deteriorated by 0.4–0.8 points, or a 10–20% change when compared with baseline. • Pre-treatment QOL significantly predicted late QOL, while QOL 1 year after treatment did not predict long term QOL, psychological distress after had a significant association with poorer long term QOL. • Pre-treatment speech was the only symptom measure to significantly predict long term health related QOL; those with better speech pre- treatment showed larger deteriorations in their long term health related QOL.	Most survivors in this study had early stage disease controlled by single modality treatment; therefore findings may be biased by this factor. Only 25% of patients were alive by 10 years. This was a longer term study; it did not specifically address nutrition, however, it did note that QOL as it related to functional status (i.e. coughing, speaking and swallowing) had decreased over time (representing a 10–20% change). Not a qualitative study.
Röing et al. [22]	2006	VI	To describe how patients with HNC experience their illness and treatment.	*N* = 7 Patients post treatment (median 16 months post treatment). All had undergone radiation therapy; 5 also had surgical treatment.	Qualitative method based on existential phenomenology; open ended interviews were used.	The life of patients changed drastically during treatment. Experience at treatment initiation: “The invaded body”Experience of treatment: “No escape from the wounded mouth.” Experience at treatment completion: “The disabled mouth.”	Small sample size. Looked at longer term survivors versus immediately after treatment. Was not looking specifically at nutrition, however, each question with treatment starting and after treatment noted challenges as it related to eating, speaking, weight status, taste, the impact on social status and the lack of enjoyment in eating. Findings gave insight into the life world of the oral cancer patient and how the mouth became “inescapable” as it was felt with every attempt to speak, eat and swallow. Identified the goal of rehabilitation after treatment is a mouth that functions as normally as possible.

(*continued on next page*)

Table 1 (*continued*)

Investigators	Year	Level	Purpose/aim of study	Sample demographics	Methodology	Main results/findings/themes	Comments
Larsson et al. [21]	2007	VI	To acquire a deeper understanding of HNC patients' lived experiences of daily life during the trajectory of care, with a focus on eating problems.	$N = 9$ Patients 6–8 weeks treatment which may have included radiation therapy, surgery or a combination of radiation therapy and surgery.	Qualitative study using open dialog and interpretative phenomenology.	Three themes emerged: "Disruption of daily life." "Waiting in suspense." "Left to one's own devices."The study identified patients missed the taste of foods, and that they were anxious/self-conscious when eating/drinking with company.	Small sample size. Focused specifically on the eating challenges post treatment. Participants were very recently post treatment. Did not assess symptom severity.
Semple et al. [20]	2008	VI	To explore the changes and challenges to patients' lifestyles following treatment for HNC.	$N = 10$ Patients 6–12 months post treatment which may have involved radiation therapy, surgery or a combination of both radiation therapy and surgery.	Qualitative approach using a semi-structured interview; thematic analysis was used to interpret findings.	Seven themes emerged: "Physical changes" "Concerns about cancer." "Work tasks and day-to-day tasks." "Interpersonal relationships." "Social functioning."The two remaining themes were personal attributes that facilitated and inhibited coping after treatment. "Coping with cancer following treatment for HNC" Information needs in the post-treatment phase"	Small sample size. Only 6–12 months post treatment. Each theme included challenges related to eating. Findings highlight the complexity and spectrum of lifestyle challenges following HNC treatment.
McQuestion et al. [3]	2011	VI	To provide an in- depth analysis of the changed meaning of food after radiation therapy for the treatment of HNC.	$N = 17$ Patients three months post radiation therapy.	Qualitative approach via interview; an inductive process was use for descriptive analysis.	The changed meaning of food was evident in three areas of the participant lives: Physical loss Emotional loss Social loss	Smaller sample size Did not look at long term survivors; only 3 months post treatment.
Mortensen and Paaske [15]	2012	VI	To determine the QOL effects on cancer in the tonsillar region at a time when the acute effects after treatment had receded and the long-term effects had appeared.	$N = 7$ Patients post treatment which may have included radiation therapy, chemotherapy, surgery or a combination of modalities.Minimum of 2 years post treatment (maximum 8 years post treatment).	Qualitative approach using a semi-structured interview.	Identified: • Psycho-social impact of eating difficulties • The impact of reduced communication skills and changed appearances on QOL • Consequences on the psychological QOL All participants identified a disrupted sense of taste and varying degrees of difficulty eating/drinking. Decreased mobility of the tongue and jaw resulted in minor speech difficulties for some patients. Within 1–2 years post treatment most had regained the ability to consume food/drinks however, not necessarily easily. The mouth was still sensitive. Meals were noted to be significant in regards to identity. Participants felt socially marginalized due to eating impairments and missed the enjoyment of meals, talking about food or getting a drink with others. Many avoided eating and drinking in professional contexts from fear of seeming incompetent.	Small sample size. Includes longer term survivors. Notes psychosocial aspects of eating.
Funk et al. [12]	2012	IV	To examine HRQOL reported by 5 year HNC survivors and factors that predicted long-term scores.	$N = 337$ Patients were treated with a variety of modalities; surgery, chemotherapy, radiation therapy or a combination of treatment.	HRQOL surveys completed at diagnosis and at 3, 6, 9, 12 months after diagnosis. The protocol was revised to include data collected at 2, 3, 4, 5, 10, 15, and 20 years post treatment. Used the Medical Outcomes Study Short-Form 36 (SF-36), the	Of the 4 HNC specific outcomes, eating had the lowest mean scores with less than half of the patients having scores in the high functioning category. Survivors of HNC may be confronted with deficits in functional and facial appearance. Poor oral and oropharyngeal function was a persistent problem in long term survivors with	Larger study. Not specifically looking at nutritional issues, however, findings did identify significant challenges with oral and oropharyngeal functioning impacting eating. Looked at long term survivors.

Table 1 (*continued*)

Investigators	Year	Level	Purpose/aim of study	Sample demographics	Methodology	Main results/findings/themes	Comments
					Head and Neck Cancer Inventory, the Beck Depression Inventory and the Social Provision Scale.	greater than 50% reporting problems with eating.The best predictors of 5 year outcomes: • Level of pain • Type of diet reported by patients at one year.-Pain and diet at 1 year post treatment accounted for more of the variance in long term outcomes than pretreatment variables (i.e. stage, site and/or age). Another significant predictor of long-term eating functioning for survivors was dental status at 1 year.	Not a qualitative study.
Molassiotis and Rogers [25]	2012	VI	To explore and understand the experience of receiving treatment for HNC with the focus on symptom experiences over a one year period from diagnosis.	*N* = 16 Patients treated with either radiation therapy alone or chemoradiation therapy or surgery alone.	Qualitative approach using semis-structured interviews prospectively over a period of one year. Four time frames: T1 at the beginning of treatment, T2 3–5 months after diagnosis, T3 six to eight months and T4 12–14 months.	Four themes emerged: "Nutritional concerns" "Tiredness or lack of energy" "The mask used for radiation therapy" "Regaining "normality" Nutritional issues were identified in regards to weight loss, malnutrition, dysphagia, xerostomia, and taste changes. These were present and substantially affected life during the first six months with some improvement over time. Taste changes were still evident at 12 months. Swallowing difficulties were present in 51–85% of patients, some as long as 28 months post-surgery.	Smaller sample size. Time frame greater than one year. Identified significant issues with eating post treatment that related to taste, xerostomia, swallowing.
Donovan and Glackin [19]	2012	V	To find and analyze papers pertaining to the lived experiences of patients with HNC receiving radiotherapy.	Studies included if they involved HNC patients that had received radiation therapy as part of their disease management, focused on the patients' experience of perspective.	10 studies met inclusion; 5 qualitative, 5 quantitative.	Six themes emerged: "Waiting and uncertainty" "Disruption of daily life" "Radiotherapy environment and treatment process" "Side-effects from radiotherapy" "Psychological well-being" "Support"HNC and the treatment can be devastating as it may profoundly affect the fundamental activities of daily living. A holistic approach is needed into this population.	Systematic review of the literature. Includes HNC studies at varying time points. Patient experience.
Lang et al. [8]	2013	V	To summarize patients' experience of HNC by examining the findings of existing qualitative studies.	Inclusion criteria: Primary qualitative studies, focusing on any aspect of the experience of HNC. Treatment included radiation therapy, chemotherapy and/or surgery.	Twenty-nine papers met inclusion criteria and were included in the meta-synthesis.	Six core concepts were identified. In addition, further dimensions to five of them were noted. "Uncertainty and waiting." "Disruption to daily life." "The diminished self." "Making sense of the experience." "Sharing the burden." "Finding a path."	Large systematic review and meta-synthesis. Looked at patients at varying time points. Identifies concerns regarding functional status as it relates to eating.
Ottosson et al. [4]	2013	VI	To describe the experience of food, eating and meals following radiotherapy.	*N* = 13 Patients were nine months post radiation therapy.	Qualitative approach using in-depth semi-structured interviews.	Six themes emerged: "A long journey, taking small steps to an uncertain future." "A new way of eating." "Eating without satisfaction." "Challenging meals outside the family." "Support and information—the key to a successful journey." "The creation and acceptance of a new normal."	Small sample size. Only nine months post treatment. Study by an RD. Looked exclusively at the eating experience.

† Levels of Evidence—IV Evidence from well-designed case-control or cohort studies, V Evidence from systematic reviews of descriptive or qualitative studies, VI Evidence from a single descriptive or qualitative study.

Yet you have to eat…it just takes so long" [8,22]. The pleasure of eating was also impacted as a result of the length of time required to eat, the embarrassment of eating in front of others and the resulting anxiety [8]. The family structure was also altered as meals were no longer a social occasion. One study participant identified the following, "Friday night and Saturday would have been a big family thing for us—video, pizza, whatever and great conversation. That all stopped straight away, even the conversation. Mealtimes in general were stressful. The whole thing, it is woeful" [8,20]. McQuestion identified that participants indicated the need to concentrate on food selection, consistency and the volume of food eaten. Additionally, there was a heightened awareness of what could not be eaten [3].

In their qualitative study Larsson et al. explored the lived experience of patients with HNC 6–8 weeks post radiation therapy [21]. Consistent with Lang et al. and McQuestion, Larsson also identified the theme disruption to daily life, specifically throughout the trajectory of care, from cancer diagnosis through treatment and after treatment [3,8,21]. Participants revealed that the severity of side effects and eating problems fluctuated on a daily basis, thus the unpredictability contributed to worries about treatment success and doubts about getting through the ordeal [21]. Larsson noted that study participants played down the impact of the cancer and resulting treatment. This was also noted by Wells, Molassiotis and Moore in their study of patients (from 4 weeks to 4 years) post treatment for HNC [18,21,24,25]. One participant interviewed by Wells described the distress that was experienced, "everybody says I look well, but I feel like the placid duck pointing upstream—it looks quiet and serene, but under the water line it's paddling like hell…" [24]. Data from the Well's study (which included diaries and interviews) revealed a common tendency to downplay the treatment experience, however, what was concerning to the author as a health care practitioner, was that health care professionals appear to accept the "brave face" that is shown and rarely look beneath the surface [24].

The diminished self

HNC survivors may experience temporary or longer lasting functional, social and existential losses, which may alter their life expectation [8]. Challenges may impact confidence, self-esteem, self-image and sense of self [8]. One participant reported the following, "my husband is really thoughtful, but he finds it difficult to touch me, and I feel that's a big minus. Both he and our son have been affected more by my disease than I've been, and we never go to restaurants anymore since they think it's hard to see that I can't eat…" [8,31]. Functional impairments that result from HNC treatment may further erode self-image and self-confidence. The actual physical problems may be constant reminders of the cancer and the general lack of "normality". Difficulty with speaking and eating and a change in appearance may result in a diminished body image and social withdrawal [8]. Lang et al. found that many patients recover or adapt to the change in their life and self, however, others continue to view their future as diminished [8]. Wells also identified a "loss of self" that results from "bodily disruption" signifies more than the presence of symptoms or the effect on body image [24]. The physical changes signal a rite of passage from good health to illness and body change is a constant reminder of a "disrupted feeling of fit" [24]. This disruption impacts every aspect of life; work, hobbies, and relationships with friends and family [24]. Losses of self-confidence and self-worth were described by patients. One participant stated "I dribble at the corner of my mouth and this upsets me. I've never quite got full control; the whole thing makes me feel that I'm not functioning properly" [24]. Similarly, McQuestion revealed patients identified the loss of return to expected normal functioning of their body (physically and emotionally) related to side effects [3]. Although acute effects (e.g. weight loss, skin changes related to radiation therapy) resolve, changes associated with eating, swallowing and managing food are often hidden [3].

Uncertainty and waiting

Uncertainty and waiting was noted to be a significant feeling in regards to the diagnosis, start of treatment, treatment period or after treatment, wondering if the cancer would return [4,8,19–21]. Lang et al. reports patients feeling uncertain, as though they were in limbo, dealing with the uncertainty of living with the disease and the future; living between hope and despair [8]. Larsson found that after completion of treatment, participants identified a new waiting in regards to functional status and the ability to eat as usual [21]. Pain, loss of taste and a diminished appetite were identified as concerns. The participants longed for the taste of certain foods and eating for enjoyment [21]. Participants identified that the experiences continued for a longer period of time than they had anticipated. One participant revealed how this uncertainty drained strength, "this period has been a lot worse than I had expected. It has taken much, much longer for my mouth and throat to heal than I believed it would…" [21]. Roing et al. found that patients with HNC had an increasing need for both physical and emotional support as treatment progressed, and that their need may be greatest at the end of treatment as they attempt to return to some sense of normality [22]. McQuestion recognized the need to ensure patients are educated and well prepared post treatment so that expectations about recovery are grounded in reality [3].

Sharing the Burden

The need to develop supportive connections with family, friends and their wider social network, health care providers and other HNC survivors to help cope emotionally and practically with their illness was identified by Lang et al. [8]. Roing reported that care and understanding from doctors and hospital staff was greatly appreciated with one participant commenting, "it is quite important…the way I felt I was cared for by everybody…it is worth a lot…it really helped me" [22]. Additionally, having an understanding from friends and family was imperative to HNC survivors with one participant stating "with good friends I eat what I can…I usually joke with them and say be prepared for the fact that I might drool" [22]. McQuestion also concluded that there was a need for social support as losses were described by participants in regards to eating, food choice and social interactions [3].

Psychological wellbeing

HNC treatments may have severe psychological consequences including anxiety, depression, distress, feelings of shame and guilt as well as changes in body image and self-esteem [19]. The ability to eat and drink is associated with the ability to uphold life and general health [15,29]. Mortensen concluded that participants felt socially marginalized due to their eating impairment and they had missed enjoying meals, talking about food or getting a drink with others [15]. Thus, a social meeting over coffee, a dinner with friends or a professional lunch had become linked to embarrassment and self-consciousness [15]. In general, challenges with respect to communication, enjoying meals, socializing and engaging in other pleasurable activities may contribute to a reduced level of psychological wellbeing [15].

Finding a path/uncertain future

This theme identifies a concept that reflects how HNC survivors characterized life beyond HNC [8]. Physical symptoms may disrupt every day activities, including eating, working, relationships and socializing [8]. Establishing contact with health care professionals which involve a multidisciplinary team that includes medical and dental teams, psychosocial experts, dietitians and speech language pathologists is necessary to enable patients to access advice and information on how to manage their physical and psychological problems [3,8,22].

The majority of studies reviewed and discussed herein have not focused specifically on the eating experience; however, participants in most of the studies identified challenges that impacted their ability to eat as well as the eating experience (psychological and social aspects) [11,12,15,18,20,22–25,31]. Ottosson utilized an in-depth, semi-structured interview to explore eating problems in survivors of HNC [4]. Although the acute phase of treatment was demanding (during treatment and the time period adjacent to treatment) participants continued to experience sequelae of the treatment nine months after treatment completion. Xerostomia, dysphagia, dysgeusia, mucosal sensitivity and fatigue were common symptoms identified. Participants indicated that the changes from the acute phase to the nine month time frame were subtle, with only "small steps towards improvement" [4]. McQuestion et al. similarly found that participants described the difficulty of not knowing how long challenges may persist or if they would become permanent [3]. Participants persevered using a trial and error approach to eating, focusing on the small improvements that were made and looking towards the future [3].

A new way of eating

Ottosson and McQuestion both identified participants reported that meals took longer to eat related to dysphagia and the need to chew food more carefully [3,4]. Meals also took longer in regards to the need to use trial and error strategies to manage the physical act of eating and the need to concentrate on food selection [3]. Food sticking in the mouth and the need to clear the mouth during and after eating lead to stressful meal experiences [3,4]. One respondent stated "you are always unclean in the mouth, food sticks, around your tongue, you have to clean and rinse, it is almost like a full time job..." [4]. Similarly, one participant commented that "there are a lot of things that I can't eat. I could have a little bit of soup, some cream soups...I tried mashed potatoes. I can't eat mashed potatoes anymore, it is just like glue" [3].

Eating without satisfaction

In regards to eating without satisfaction, which may be a result of xerostomia, taste loss or taste change and pain, Ottosson et al. found that participants had adapted to their eating challenges. Respondents could eat sufficiently, however, alterations were required that resulted in less variety in food choices and participants struggled to find anything new and/or exciting to eat [4]. Taste alterations were present and closely related to being able to enjoy food and eating [4]. Respondents who had a diminished taste or taste alterations reported that this was challenging to adjust to; conversely those that had taste return felt as though it was a victory. Taste alterations lead to a loss of variety in food choices and changed the experience of food and eating which resulted in the feeling that eating was only done to obtain energy and nutrients versus eating for pleasure [4]. Similarly, subjects in the McQuestion study reported taste alterations, "I'm Italian, a lot of tomato-based (food). Well, tomato was gone and it tasted terrible when I did have it. So there was that and the sweet tooth that I had. Well, sweets tasted horrible too. My two favorite things" [3]. Additionally, the following summarized a lack of eating for enjoyment, "the enjoyment of food and the pleasure of food is different... I have to eat for nutrition. I have to eat for calories" [3].

Creating and acceptance of a new normal

Ottosson noted that respondents identified that they were coping with their eating challenges by selectively choosing food. The use of water or milk with meals was used to facilitate eating and/or swallowing if xerostomia was present (adaptive behavior) [4]. Participants indicated that many aspects related to food, eating and meals had been altered due to the disease and treatment, however, participants had adapted in order to cope with the new way of living and reasoned that this was "the price to be paid for survival" [4]. This concept is consistent with findings by Semple and Wells who indicate that patients with a history of HNC seem to accept eating problems as an unavoidable part of the disease and treatment [4,20,24].

Implications for practice

The research evaluated within this review summarizes the significant impact that treatment for HNC has on eating and the eating experience. The recognition and acknowledgment of the significance of eating problems post treatment is necessary. Nutrition assessment should include the assessment of macro and micronutrient intake and should explore the psychological, physical, social and cultural elements related to eating and the eating experience. Ensuring that patients are properly prepared and educated throughout the trajectory of care, including long term survivors of HNC, will ensure that patient expectations are grounded in reality. This has been shown to be helpful in patients with cancer [3]. Providing strategies and interventions to assist patients and their caregivers in navigating a "new normal" related to potential changes and/or losses that may be associated with food and eating is imperative.

Although the findings of the review highlight and contribute to the understanding of the eating experience in survivors of HNC there are some limitations to the review. Studies included involved a variety of treatment modalities (chemotherapy, radiation therapy and/or surgery or a combination of modalities). Recognizing that the long term consequences for radiation alone versus surgery versus chemoradiation may be quite different, mixed method studies were included due to the limited number of studies available. Additionally, studies conducted in the 1990s or early 2000s may have different experiences with the advancement in treatment options. Further, studies often were of sample size or with limited follow-up.

Conclusion

Eating is an act that is often taken for granted. This complex and necessary function is commonly affected in HNC due to the primary disease and its therapy. Individuals with a history of HNC may face a long journey where physical, sensory, psychological and social dimensions of eating and the eating experience may be impacted. It is imperative that health care practitioners, including medical, dental and nutrition professionals, understand and talk with patients that have gone through HNC treatment about their eating experience. The discussion should include exploration of the social impact of eating, possible disruptions and/or losses associated with treatment and the impact on the eating experience. The use of a holistic, interdisciplinary approach will best support patients in regards to the functional, physiological, psychological and social aspects of eating which will maximize the eating experience within this population. Further research is needed to explore the eating experience in patients with HNC throughout the trajectory of care. Research should also involve caregivers and family that support patients. Studies should explore not only the functional impact associated with treatment for HNC but also the social and emotional context of eating. Future research might also involve effects based on specific treatment modalities and management of specific cancer or treatment related side effects which may lead to improved management and would allow for a more efficient dialog with patients at follow-up.

Funding source

This review was funded by the Academy of Nutrition and Dietetics Foundation Grant: Colgate Palmolive Fellowship in Nutrition, Oral Health/Dental Education.

Conflict of interest statement

None declared.

References

[1] Carlsson E, Ehrenberg A, Ehnfors M. Stroke and eating difficulties: long-term experiences. J Clin Nurs 2004;13:825–34.
[2] Larsson M, Hedelin B, Athlin E. Lived experiences of eating problems for patients with head and neck cancer during radiotherapy. J Clin Nurs 2003;12:562–70.
[3] McQuestion M, Fitch M, Howell D. The changed meaning of food: physical, social and emotional loss for patients having received radiation treatment for head and neck cancer. Eur J Oncol Nurs 2011;15:145–51.
[4] Ottosson S, Laurell G, Olsson C. The experience of food, eating and meals following radiotherapy for head and neck cancer: a qualitative study. J Clin Nurs 2013;22:1034–43.
[5] Ganzer H, Touger-Decker R, Parrot J, Murphy B, Epstein J, Huhmann M. Symptom burden in head and neck cancer: impact on energy and protein. Support Care Cancer 2013;21:495–503.
[6] Epstein JB, Thariat J, Bensadoun RJ, Barasch A, Murphy BA, Kolnick L, et al. Oral complications of cancer and cancer therapy: from cancer treatment to survivorship. CA Cancer J Clin 2012;62:400–22.
[7] Vissink A, Jansma J, Spijkervet F, Burlage F, Coppes R. Oral sequelae of head and neck radiotherapy. Crit Rev Oral Biol Med 2003;14:199–212.
[8] 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. Psycho Oncol 2013;22:2648–63.
[9] George J, Yom S, Wang S. Improved outcomes in adjuvant radiotherapy for oral cavity carcinoma at an academic center: a matched-pair analysis. Laryngoscope 2014;124:1603–8.
[10] Pimentel M, Filho M, Araujo M, Gomes D, Costa DAL. Evaluation of radioprotective effect of pilocarpine ingestion on salivary glands. Anticancer Res 2014;34:1993–9.
[11] Mehanna H, Morton R. Deterioration in quality of life of late (10-year) survivors of head and neck cancer. Clin Otolaryngol 2006;31:204–11.
[12] Funk G, Hynds-Karnell L, Christensen A. Long-term health-related quality of life in survivors of head and neck cancer. Arch Otolaryngol Head Neck Surg 2012;138:123–33.
[13] Bjordal K, Kaasa S, Mastekaasa A. Quality of life in patients with pharyngeal carcinoma: a five year follow-up. Head Neck 1994;28:847–56.
[14] Abendstein H, Nordgren M, Boysen M, Jannert M, Silander E, Ahlener-Elmqvist M, et al. Quality of life and head and neck cancer: a 5 year prospective study. Laryngoscope 2005;115:2183–92.
[15] Mortensen G, Paaske P. Patients perceive tonsil cancer as a strike at psycho-socially "vital organs". Dan Med J 2012;59:A4504.
[16] Murphy B. Late treatment effects: reframing the questions. The Lancet 2009;10:530.
[17] Murphy B, Ridner S, Wells N, Dietrich M. Quality of life research in head and neck cancer: a review of the current state of science. Crit Rev Oncol Hematol 2007;62:251–67.
[18] Moore R, Chamberlain R, Khuri F. A qualitative study of head and neck cancer. Support Care Cancer 2004;12:338.
[19] Donovan M, Glackin M. The lived experience of patients receiving radiotherapy for head and neck cancer: a review of the literature. Int J Palliat Nurs 2012;18:448.
[20] Semple C, Dunwoody L, Kernohan W, McCaughan E, Sullivan K. Changes and challenges to patients' lifestyle patterns following treatment for head and neck cancer. J Adv Nurs 2008;63:85–93.
[21] Larsson M, Hedelin B, Athlin E. Needing a hand to hold: lived experiences during the trajectory of care for patients with head and neck cancer treated with radiotherapy. Cancer Nurs 2007;30:324–34.
[22] Roing M, Hirsch J, Holmstrom I. The uncanny mouth – a phenomenological approach to oral cancer. Patient Edu Counsel 2007;67:301–6.
[23] Rose P, Yates P. Quality of life experienced by patients receiving radiation treatment for cancers of the head and neck. Cancer Nurs 2001;24:255.
[24] Wells M. The hidden experience of radiotherapy to the head and neck: a qualitative study of patients after completion of treatment. J Adv Nurs 1998;28:840–8.
[25] Molassiotis A, Rogers M. Symptom experience and regaining normality in the first year following a diagnosis of head and neck cancer: a qualitative longitudinal study. Palliat Supp Care 2012;10:197–204.
[26] Winkler M, Wetle T, Smith C, Hagan E, O'Sullivan-Maillet J, Touger-Decker R. The meaning of food and eating among home parenteral nutrition-dependent adults with intestinal failure: a qualitative inquiry. J Am Diet Assoc 2010;110:1676–83.
[27] Robinson C. Managing life with a chronic condition: the story of normalization. Qual Health Res 1993;3:6–28.
[28] Bisogni C, Connors M, Devine C, Sobal J. Who we are and how we eat: a qualitative study of identities in food choice. J Nutr Edu 2002;34:128–39.
[29] Winkler M. 2009 Lenna Frances Cooper memorial lecture: living with enteral and parenteral nutrition: how food and eating contribute to quality of life. J Am Diet Assoc 2010;110:169–77.
[30] Swore-Fletcher B, Cohen M, Schumacher K, Lydiatt W. A blessing and a curse: head and neck cancer survivors experience. Cancer Nurs 2012;35:126–32.
[31] Bjorklund M, Sarvimaki A, Berg A. Living with head and neck cancer: a profile of captivity. J Nurs Healthcare Chronic Illness 2010;2:22–31.