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Kristensen, Marianne Boll; Isenring, Elizabeth; Brown, Bena

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Marianne Boll Kristensen RD, MSc.,
Elizabeth Isenring AdvAPD, PhD, Bena Brown BSp Path, PhD

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Title page

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Nutrition and swallowing therapy strategies for head and neck cancer patients

Authors and affiliations

Marianne Boll Kristensen\textsuperscript{a,b,c}, RD, MSc.

Elizabeth Isenring\textsuperscript{c} AdvAPD, PhD

Bena Brown\textsuperscript{d,e,f}, BSp Path, PhD

\textsuperscript{a}Department of Nursing and Nutrition, University College Copenhagen, Copenhagen N, Denmark.

\textsuperscript{b}REHPA, The Danish Knowledge Centre for Rehabilitation and Palliative Care, Odense University Hospital, and Department of Clinical Research, University of Southern Denmark, Nyborg, Denmark.

\textsuperscript{c}Bond Institute of Health and Sport, Bond University, Gold Coast, Australia

\textsuperscript{d}Division of Cancer Services, Princess Alexandra Hospital, Metro South Health, Queensland Health, Australia

\textsuperscript{e}Centre for Functioning and Health Research, Metro South Health, Queensland Health, Australia

\textsuperscript{f}School of Health and Rehabilitation Sciences, The University of Queensland, Australia

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Keywords

Head and neck cancer, nutrition, malnutrition, swallowing, dysphagia

Abbreviations

HNC: head and neck cancer, HPV: human papillomavirus, NIS: nutrition impact symptoms
Introduction

Head and neck cancer (HNC) patients are one of the most vulnerable groups in terms of cancer-related malnutrition and development of nutrition impact symptoms (NIS) before, during and after cancer treatment [1,2]. Globally, approximately 900,000 persons are diagnosed with HNC every year [3]. The incidence has increased during recent years partly due to an increase in the numbers caused by oncogenic viruses such as human papillomavirus (HPV) and Epstein Barr virus [4]. In the same period, the overall survival of the patient group has improved [5,6], and thus the population of HNC patients and survivors is increasing.

Dysphagia, or difficulty in swallowing, is one of the most common and debilitating side effects related to HNC and its treatment. Dysphagia affects up to 30% of patients with HNC pre-treatment, with long-term dysphagia affecting 38-46%, despite improvements in treatment [7,8]. The sequelae of dysphagia include avoidance of eating and/or drinking, poor dietary intake, aspiration leading to pneumonia, reduced psychosocial functioning, and poor social engagement and quality of life [9-11]. Long-term swallowing function is strongly related to the ability to swallow prior to treatment in the population with HNC [12-14]. For this reason, optimizing swallowing function prior to and during treatment is important. Historically, for those patients undergoing radiotherapy +/- chemotherapy treatment, dysphagia has been managed with a reactive approach – waiting for signs and symptoms of difficulty managing oral intake to develop prior to assessment or intervention being recommended.

As such, many HNC patients may present with involuntary weight loss at the time of diagnosis [15], and body composition and function may be affected despite only a modest weight loss. In a population of 65 newly diagnosed HNC patients, Orell-Kotikankas et al. investigated the prevalence of malnutrition, cachexia and sarcopenia defined by different assessment criteria [16]. They categorised 34% of participants as malnourished according to PG-SGA, 31% were categorised as cachectic (defined as low hand grip strength and low mid-arm muscle area) and 46% were categorised as sarcopenic (defined as low mid-arm muscle area)[16]. As the assessment criteria were overlapping, participants could be categorised in more than one category. In an exploratory study, Jager-Wittenaar et al. found a cachexia prevalence of 46% among 26 newly diagnosed HNC patients before treatment was initiated [17]. In this study cachexia was defined by Fearon’s cancer-specific framework [18].
The treatment modalities in HNC include surgery, radiation therapy, chemotherapy and targeted therapy, and often combinations of treatment modalities are used. Frequent side effects to these regimens include development of NIS such as dysphagia, xerostomia, dysgeusia, anorexia and pain on swallowing [19] resulting in decreased dietary intake and malnutrition. Critical weight loss ($\geq 5\%$) during treatment affects up to two thirds of HNC patients [20,21], and weight loss may occur regardless of nutritional status at diagnosis [22]. HNC patients receiving concurrent chemo- and radiation therapy are particularly at risk of involuntary weight loss and development of malnutrition during treatment [20,22]. Malnutrition in HNC patients is a concern, as it is associated with increased treatment toxicity and interruptions in treatment, increased mortality and morbidity [15-16], increased number of admissions and increased health care costs [27]. Furthermore, malnutrition in HNC is associated with depression [28] and reduced quality of life [22,29]. The nutritional challenges in HNC often continue beyond the treatment phase. NIS may persist or occur years after completion of treatment and, in the worst case, become chronic [19]. NIS may lead to social isolation and have great consequences for everyday life [23-26].

Historically, the major risk factors for development of HNC have been alcohol and tobacco use [30]. The proportion of high-risk alcohol and tobacco related cases has decreased and demographics have changed towards a younger population due to early onset of human papilloma virus (HPV)-related HNC [30,31]. However, this change in demographics has not eliminated the problems of NIS and malnutrition. Conversely, Vangelov et al. found that the incidence of critical weight loss during treatment was higher in patients with HPV-positive oropharyngeal carcinoma than in HPV-negative patients even though a larger proportion of the latter group presented with critical weight loss at diagnosis [31].

Newer treatment modalities such as intensity-modulated radiation therapy has reduced the severity of certain NIS in HNC patients, but still has not offset the development of these side effects [32]. Hence, nutritional care in HNC patients is still as important as ever, and interventions to maintain adequate nutritional status, swallowing function and dietary intake are vital throughout the trajectory of care. This article will address nutrition and swallowing therapy strategies in HNC patients from the time of diagnosis to rehabilitation and survivorship.

**Aims of nutritional interventions**

Nutrition interventions in HNC patients should aim to maintain or improve dietary intake and nutritional status including maintenance or build-up of skeletal muscle mass [33]. The adverse effects of malnutrition on physical performance, quality of life and cancer treatment tolerance and
effect should be minimised by appropriate nutrition interventions. Preferably, nutrition interventions should be initiated before malnutrition manifests, as the condition is difficult to reverse in metabolically deranged patients. Food and eating are important in social integration, psychological stabilisation and quality of life for persons with cancer [33].

**Assessment and screening**

To provide early and appropriate nutrition intervention, patients undergoing cancer treatment should have early and regular screening for malnutrition [34]. Validated nutrition screening tools for patients with HNC include the Patient Generated Subjective Global Assessment Short Form (PG-SGA SF) [35], Malnutrition Screening Tool (MST) and Malnutrition Universal Screening Tool (MUST) [36]. Patients identified as at nutritional risk should be referred to a nutrition expert e.g. registered dietitian for full nutrition assessment and early nutrition counselling and intervention as required [34]. As most HNC patients will be at high risk of malnutrition it could be argued that screening may not be necessary and that HNC patients can immediately be referred to a dietitian [37]. The dietitian will use a valid and reliable comprehensive nutritional assessment such as the Subjective Global Assessment (SGA) or PG-SGA and personally tailor appropriate nutrition intervention and follow-up [37]. An electronic system may help facilitate this process. For example, ScreenIT is an electronic screening and triage tool completed by patients with HNC to detect swallowing, nutrition and distress and facilitate clinically appropriate prioritization of multidisciplinary supportive care, and is discussed in more detail below [38].

**Swallowing prehabilitation**

The past decade has seen a shift in clinical priorities, driven by research that investigates a prophylactic approach to swallowing management. Swallowing “prehabilitation” or prophylactic swallowing exercise programs are delivered prior to the onset of dysphagia. Prehabilitation aims to minimize the impact of dysphagia through the maintenance of muscle mass, strength, range of motion, coordination and function, specifically targeting structures of the oral cavity, jaw, tongue base, pharynx and larynx. Prophylactic swallowing protocols have been found to improve functional swallowing outcomes including the ability to manage a wider range of food and drinks, muscle mass maintenance, better mouth opening, improved taste, smell and salivary function, and reduced need for tube feeding [39-43]. Conversely, there are also a number of studies that have shown no difference between swallowing exercises and outcomes related to diet levels [39,44,45] and reliance on alternative feeding [43,44,46]. This discrepancy in outcomes is possibly related to the heterogeneity of exercise programs – with many differing in their intensity, the types of exercises recommended, and the timing and duration of exercises [44,47]. Prophylactic swallowing exercise
programs are typically intensive in nature, with patients educated to complete the battery of exercises multiple times a day, over several weeks prior to or during their (chemo)radiotherapy treatment. To understand the potential benefits of routine prophylactic exercise protocols, large multisite studies examining similar protocols of exercise intensity, frequency and follow-up are required.

Underlying the efficacy of preventative swallowing therapy is patient adherence to these time-intensive programs. During treatment, side effects such as pain, fatigue, thick secretions, and other toxicities related to treatment impact on the ability for patients to complete prophylactic swallowing programs, as prescribed. A number of studies have reported high levels of participant drop-out [39, 46, 48] – over 50% - due to the high treatment burden of radiotherapy and chemotherapy for HNC. Commonly, adherence to swallowing exercises gradually diminishes over the course of (chemo)radiotherapy treatment, and furthermore after the completion of treatment. Adherence is best in the early weeks of (chemo)radiotherapy, with greater attrition towards the end of treatment, when acute toxicity is at its peak [43, 45, 46, 49-52]. The most common reasons for non-adherence have been reported as a lack of understanding as to the rationale for swallowing exercises, the effort required, side effects such as pain, and forgetting to complete the program. The factors found to significantly impact on adherence are smoking at baseline, and the addition of chemotherapy [50, 51]. Alternative models of delivering prophylactic exercises have been explored to determine the impact on adherence [50-51]. Wall et al found face-to-face, clinician-directed therapy yielded significantly higher adherence than patient-directed therapy, with a trend for better adherence using a supported, telepractice model. Furthermore, patients have reported greater comfort, confidence, motivation and increased levels of support to complete their therapy using a technology-enabled application [50] with only 8% of participants reporting a preference for traditional clinician-directed therapy or independent self-directed therapy.

Future exploration of dose effects of swallowing therapy in the provision of prophylactic protocols are required to optimize prescription of, and adherence to, these programs. Study protocols have been published [53] where the impact of exercise load on the tongue is being investigated in a randomized controlled trial. Limited consensus exists regarding the components of prophylactic swallowing programs, the number of repetitions, the number of sets, and the duration of such programs. Furthermore, the long-term outcomes of completing swallowing targeted therapy during (chemo)radiotherapy has not been elucidated fully. Few authors have reported on swallowing
outcomes to 2 years post-treatment [44,54], and found that the effect of exercise diminishes over time, with weight continuing to increase in the exercise group being the only difference.

**Nutritional interventions during treatment**

Nutritional expertise provided by a dietitian as part of the multidisciplinary team for treating patients with HNC has been shown to improve nutrition outcomes and quality of life [37]. Nutrition counselling is a dedicated and repeated professional communication process aiming to provide patients with a thorough understanding of nutritional issues leading to lasting changes in eating habits and should be part of first line nutrition therapy [33].

Nutritional recommendations for patients with HNC should aim for 1.2g protein per kg of body weight per day [37] (1.0-1.5 g/kg/day [33]). Energy intake should be at least 125 kJ/kg/day (30 kcal/kg/day) and it is important to monitor body weight and nutritional status and adjust intake as required [37]. The best way to maintain or increase energy and protein intake is with normal food and fluids. However, in patients with HNC with NIS this may be difficult and, in addition to counselling, oral nutritional supplements may be required to provide extra nutrients in a relatively small volume [33]. For patients with dysphagia having a modified texture diet (e.g. soft, pureed) and thickened fluids as prescribed by a speech pathologist can improve oral intake. It is recommended that vitamins and minerals be supplied in amounts equal to the RDA and discourage the use of high-dose micronutrients in the absence of specific deficiencies as they may interfere with cancer treatments [33].

Psychological techniques have been shown to improve nutritional behaviours in HNC patients undergoing treatment. The “Eating as Treatment” (EAT) trial used motivational interviewing and cognitive behavioral therapy delivered by oncology dietitians and integrated into their clinical practice to improve nutritional outcomes [55]. EAT was a stepped wedge controlled trial and demonstrated that HNC patients receiving the intervention had better nutritional status and were more likely to: be assessed as well-nourished at each time point; lose a smaller percentage of weight have fewer treatment interruptions; present lower depression scores; and report a higher quality of life compared to standard care [55].
Nutrition support via tube feeding is recommended if patients are unable to eat adequately (e.g. no food for more than one week or less than 60% of requirement for more than 1–2 weeks [33]. Enteral nutrition is recommended if the gastrointestinal tract is functional and parenteral nutrition if enteral nutrition is not sufficient or feasible [33]. Consideration can be given to post-operative immunonutrition which may reduce length of stay, although the mechanism is unclear, as other clinical benefits such as reduced complications and infections were not demonstrated [37]. N3 FAs may also be considered useful although the evidence is weak [37].

**Survivorship and post treatment nutritional interventions**

Eating problems and NIS often persist beyond completion of cancer treatment [19] with negative consequences for the HNC survivor’s dietary intake and enjoyment with food and eating [24-26]. The early post treatment phase is particularly challenging as the severity of NIS often peaks within the first weeks after completion of treatment [56,57]. A number of qualitative and mixed methods studies have reported how HNC survivors have felt unprepared to deal with these ongoing challenges post treatment [23,57,58] and have felt left to themselves when the close contact with health professionals during treatment ended [26,56-59]. These studies underpin the importance of continuity in nutritional interventions and supportive care to handle NIS throughout the trajectory of HNC.

Enteral nutrition or oral nutritional supplements are often required in the early post treatment phase and for some HNC survivors the need for enteral nutrition or oral nutritional supplements becomes permanent [60]. However, it is recommended that enteral nutrition is phased out as quickly and safely as possible [33] and for most HNC survivors oral intake and normalcy of the diet can be increased gradually as the severity of the NIS declines and eating ability improves. Hence, for some HNC survivors the early post treatment phase includes the transition from enteral to oral nutrition and for others it involves adding more textures and flavours to the current food repertoire. The tolerance for different textures and flavours is highly individual and the severity of NIS and eating problems may fluctuate from day to day [56]. One of the most frequently reported coping strategies in HNC survivors is the trial-and-error strategy [23,26,57] where HNC survivor perseveres through continuous experiments and testing of their tolerance for foods of different flavours and textures. However, anxiety or fear of choking [11, 60,61] may complicate this process and restrain the individual from experimenting and thus prolong the need for enteral nutrition. Furthermore, errors or unsuccessful experiments leads to feelings of defeat [23] and may discourage the HNC survivor from further food experiments and expansion of their repertoire of tolerated foods.

In addition to the physical and psychological consequences, post treatment NIS often affects the social life as they may lead to social withdrawal and avoidance of social situations involving food
As previously described, nutritional interventions in HNC should recognise the physical, social and psychological functions of nutrition, food and eating [33]. This recommendation still applies post treatment.

In addition to ensuring adequate energy and protein intake, post treatment nutritional interventions should aim at enhancing the HNC survivor’s coping process through support and encouragement of safe experimentation with food and textures for a gradual normalisation of the diet. Post treatment nutritional interventions may include counselling or practical sessions on food preparation, flavour adjustment and texture modification. In a pilot study on the potential effects of a residential multidisciplinary rehabilitation program for HNC survivors, participants benefitted from eating together with peers and health professionals. The supportive eating environment was experienced as a safe place to experiment with different foods and textures [26]. Evidence on the effect of practical dietetic sessions in HNC remains limited but in other groups of cancer survivors, practical cooking sessions have been demonstrated to support dietary changes and thereby improve health-related quality of life [63,64]. Furthermore, other studies have reported how HNC survivors and patients benefit from meeting peers [56,57]. Hence, the potential of practical dietetic sessions and/or group sessions to meet rehabilitation needs in HNC survivors is a relevant area for future research.

Multidisciplinary modal of care

Nutrition and swallowing therapy in HNC is primarily managed by clinical dietitians and speech pathologists (or occupational therapists in certain countries). However, given the complexity of nutrition and swallowing problems in HNC, a close collaboration with other health professionals is recommended [65]. Furthermore, supportive care needs during and after treatment for HNC are multifaceted and go far beyond nutrition and swallowing therapy. Required supportive care to cope with acute or prolonged side effects may include psychological support, management of anxiety and depression, physical training and management of fatigue [66]. In several countries, national clinical guidelines on management of HNC recommend using multidisciplinary teams [67]. Benefits of using multidisciplinary teams include reduced time to treatment and improved outcome [67]. Multidisciplinary teams may improve coordination and contribute to continuity of care [68] and timely identification of challenges in order to initiate the right supportive care. A coordinated multidisciplinary approach may have a synergistic effect and hence be more efficient than the sum of individual strategies.

The multidisciplinary approach should continue post treatment. However, a scoping review published in 2018 on rehabilitation interventions used in clinical studies with HNC survivors only
identified three studies with comprehensive multi/interdisciplinary rehabilitation interventions [69]. Interventions in these studies include an interdisciplinary outpatient rehabilitation program [70] an electronic health information support system [71] and a speech pathology/dietetic service model [72]. Studies have been reported since the review was carried out [26,73] but evidence on the effect of complex multidisciplinary rehabilitations in HNC remains scarce and further research is warranted.

**Technology in HNC management**

Management of swallowing and nutritional sequelae of HNC are predominantly centralized in metropolitan cancer centres, and delivered by a specialist multidisciplinary team, as is best-practice. However, there are barriers to patients accessing accurate information and timely, specialist services including a lack of available and skilled workforce, costs associated with advances in medical and technological services, and a geographical spread of patients [74]. The use of technology to optimize access to specialist health services has been well-investigated in the HNC population. Studies examining the feasibility of using technology to monitor patient status during HNC have been reported [75]. These purpose-built platforms use validated assessments to allow patients to independently record their symptoms during treatment and their health care needs. Of particular interest are “Oncoquest” [76,77], “QUICATOUCH” [78] and “ScreenIT” [38]. The integration of technology into HNC care has also allowed novel models of care for the assessment and management of swallowing and nutrition and during and following treatment to connect patients in need of health care, with the specialist services they require [79-83]. Patients with HNC have been found to have high levels of confidence in using technology to drive their health care [84] and high levels of satisfaction when using telehealth in place of standard face-to-face intervention [79,81]. Furthermore, for patients in geographically diverse locations, the use of telehealth has proffered economic benefits to individuals and to the health service [79,82,85].
Conclusion

Despite the rise in incidence of HNC due to oncogenic viruses rather than heavy alcohol and smoking usage, patients with HNC often still experience NIS requiring nutrition support. Valid screening tools, including electronic triage systems, exist to detect nutrition risk but it can also be argued that HNC patients should automatically be assessed by a registered dietitian and receive appropriate nutrition intervention. Prehabilitation swallowing exercises have demonstrated improved outcomes but adherence decreases during treatment. Ongoing review for nutrition support when dietary intake is inadequate is recommended. Multidisciplinary teams and telehealth have demonstrated improved nutrition and swallowing outcomes for HNC patients and ongoing support is required following the completion of treatment for best patient care.

Conflict of Interest

Liz Isenring, Marianne Boll Kristensen and Bena Brown have no conflicts of interest to declare in relation to their paper, “Nutrition and swallowing therapy strategies for head and neck cancer patients”.
References


