

ORIGINAL ARTICLE

Nutritional experiences in head and neck cancer patients

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Extra Foundation for Health and
Rehabilitation (2015/FO4654).**Abstract****Objective:** Extensive research has documented the negative nutritional impact of head neck cancer (HNC) treatment, but few studies have addressed the patients' experiences. The purpose of this study was to describe how patients with HNC experience the nutritional situation and perceive nutritional support from diagnosis to the post-treatment phase.**Methods:** Patients with HNC were recruited from a randomised pilot study. Individual interviews were conducted after radiotherapy with 10 participants aged 49 – 70 years and analysed by qualitative content analysis.**Results:** Undergoing surgery was experienced as a poor nutritional starting point for the upcoming radiotherapy. During radiotherapy, increasing side effects made the participants customise their meals to improve food intake. About halfway through radiotherapy, virtually no food intake was experienced and hospital admissions and initiations of tube-feeding occurred in this period. Oral nutritional supplements were recommended for all, but eventually became unbearable to ingest. When radiotherapy was finally completed, the participants felt discouraged about the persistent side effects preventing them from resume eating. The participants missed tailored information about development of side effects and involvement of a dietitian when reflecting on the treatment-period.**Conclusion:** The comprehensive nutritional problems experienced by patients with HNC require early nutritional assessments and improved individually tailored nutritional support.**KEYWORDS**

adverse effects, diet, food, and nutrition, head and neck cancer, qualitative research

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1 | INTRODUCTION

Patients with head and neck cancer (HNC) may already experience reduced food intake before the start of radiotherapy, due to consequences of the diagnostic procedures, the psychological stress of a cancer diagnosis and location of the tumour (Chencharick & Mossman, 1983; Cunningham & Bell, 2000; Harrison, Sessions, & Kies, 2013). After the start of radiotherapy, increasing side effects such as mucositis, pain and swallowing difficulties further aggravate the food intake (De Sanctis et al., 2016; Schindler et al., 2015; van der Laan et al., 2015). Malnutrition is common (>70%), often leading to severe weight loss, impaired immune function, interrupted or incomplete treatment and decreased quality of life (Hebuterne et al., 2014; Jellema, Slotman, Doornaert, Leemans, & Langendijk, 2007; Kruijenga et al., 2003; Unsal et al., 2006). Thus, the maintenance of an optimal nutritional status is vital for improved patient outcomes, treatment tolerance and survival for patients receiving tumour-directed treatment (Odelli et al., 2005; Paccagnella et al., 2010; Pressoir et al., 2010).

To date, most clinical research in patients with HNC has focused on the efficacy of anti-cancer treatments and identification and documentation of side effects during and after treatment (Gregoire, Langendijk, & Nuyts, 2015; Schindler et al., 2015). Various nutritional interventions have been tested, and individualised nutritional counselling has shown particular beneficial effects on nutritional status during radiotherapy (Langius et al., 2013). In addition, numerous qualitative studies have been conducted to explore the psychological experiences of a HNC diagnosis (Lang, France, Williams, Humphris, & Wells, 2013). However, although oral and eating problems have been identified as the most common concerns and unmet needs during the first 5 years following HNC treatment, only a few studies have been conducted to obtain a deeper understanding of the patients' nutritional experiences following a HNC diagnosis (Wells et al., 2015).

Two older qualitative studies have specifically addressed how patients with HNC cope with the decreased nutritional intake, which were found to cause a number of severe negative consequences in daily life (Larsson, Hedelin, & Athlin, 2003; Wilson, Herman, & Chubon, 1991). A later published study has highlighted the physical, emotional and social losses associated with decreased nutritional intake in patients with HNC (McQuestion, Fitch, & Howell, 2011). A recently published study explored the experiences from participating in a dietitian-delivered health behaviour intervention during radiotherapy, by focusing on the patient's working relationship with the dietitian, specific components of the intervention and suggestions for improving the intervention (McCarter et al., 2018).

However, none of the previous qualitative studies have involved experiences from the entire clinical pathway of HNC (i.e., from diagnosis to the acute post-treatment phase), and neither of the studies have specifically addressed the patients' perceptions of nutritional support delivered as part of the standardised care. Clinical experience indicates that nutritional support for patients with HNC shows considerable variation within the specialised

health care in Norway. As an example, the involvement of nutrition experts or dietitians seems to be somewhat inconsistent across hospitals, although international clinical nutritional guidelines recommend that oncology dietitians play a central role in the supportive care within this patient group (Arends, Baracos, et al., 2017). A more thorough understanding of the patients' subjective experiences of the nutritional situation is vital to ensure a more patient-centred nutritional care that meets the patients' individual needs and preferences.

Therefore, the aim of this study was to describe how patients with HNC experience the nutritional situation and perceive nutritional support in the period from diagnosis to the acute post-treatment phase.

2 | METHODS

A qualitative study with individual interviews was conducted to describe the patients' experiences and perceptions. The interviews were planned to be completed after the end of radiotherapy, if possible on the same day as the standard physician consultation about 2 weeks post-treatment.

2.1 | Recruitment and participants

Patients with HNC were recruited from a randomised pilot study ($n = 41$) that investigated the feasibility of a rehabilitation intervention during versus after radiotherapy consisting of physical exercise and nutritional support. Enrolment in the pilot study was carried out at St. Olavs hospital, Trondheim University Hospital (Norway) from April 2015 to April 2016. Only patients with HNC who were scheduled for radiotherapy towards the affected area for the first time were included in the pilot study. The oncologic treatment was intended to be provided according to national and international guidelines. The need for nutritional support (e.g., oral nutritional supplements and nasogastric tube-feeding) was continuously monitored by the responsible multidisciplinary team.

The intervention during treatment was carried out at a meeting place and retreat for cancer patients and their families close by the hospital, where the patients conducted resistance training twice a week and were provided with daily oral nutritional supplements ("E+" by Tine SA, Norway) during the 6 weeks radiotherapy period. The patients randomised to the post-treatment intervention received standard care during radiotherapy and were scheduled for a 3-week stay at a rehabilitation clinic 2–4 weeks after the end of radiotherapy.

The patients had received both oral and written information about the qualitative study prior to the start of treatment and agreed to be contacted about participation in the study. Towards the end of treatment, some of the patients were invited either face-to-face or by phone/SMS to complete an interview. Efforts were made to ensure participants were representative of the HNC population, including both genders, younger and older, and those living

in rural and urban areas. A selection was also made based on the availability of the patients with regard to conflicting appointments at the hospital.

A total of 10 participants equally distributed between men and women and with a median age of 59 years (range 49–70 years) participated in the present study (see Table 1). Six patients participated in the rehabilitation intervention during treatment and four patients in the intervention after treatment (controls during treatment). More than half of the participants were employed while others either retired or on disability benefits. The majority had a Karnofsky performance status of 70% at the end of treatment (scored by a physiotherapist), indicating that they were able to care for themselves but unable to carry out normal activities or do active work (Yates, Chalmer, & McKegney, 1980). Seven of the participants attended the interview as scheduled, while the others were unable to attend the interview until 4 weeks after treatment due to severe side effects. About half of the participants had a feeding tube in place at the time of the interview.

2.2 | Interviews and interview guide

Individual interviews were completed from November 2015 to April 2016. The interviews were carried out at a meeting place and retreat for cancer patients and their families near the hospital, unless the participants preferred another localisation. One participant chose to complete the interview in her home on another day than the post-treatment consultation. The interviews lasted from 30 to 98 min (48 min on average) and were carried out by a research nurse (VV) with experience from the clinical HNC field who did not take part in the treatment of the participants. The research nurse was at the time working in the research department of the involved hospital's cancer clinic and had experience from conducting clinical trials in cancer patients utilising both quantitative and qualitative methods. Three participants were accompanied by their partners, who did not have an active role in the interview.

A semi-structured interview guide (Appendix 1) was used to ensure open-ended questions about the participants' nutrition-related experiences and needs for nutritional support from diagnosis to the current situation after treatment. The interviewer used broad questions and made reflections of content and feelings to encourage the patients to elaborate, and relevant topics that emerged were pursued by follow-up questions. The interviews were audio-recorded and transcribed verbatim after all interviews were completed. The texts were managed and systematised by Microsoft Word® and by working manually with printouts and pen and paper. Quotations from the texts were translated from Norwegian to English by the first author of the present paper (JAS).

2.3 | Ethical considerations

The present qualitative study was approved by the Regional Committee for Medical and Health Research Ethics in Central Norway (REK midt 2013/2098) as a sub-study of the previously

described pilot study. The written study information and informed consent included both the pilot study and the qualitative sub-study. All participants that were invited for the qualitative study after treatment renewed their consent before the interview. The interviewer strived to create trust with the participants, by recognising their situation and the experiences from the treatment-period. All participants were offered to read the transcribed interviews and to know more about the analysis process, but none of them expressed any interest.

2.4 | Analysis

The transcribed interviews were analysed by qualitative content analysis. This is a method mainly focusing on the subject and context, emphasising differences and similarities within codes and categories (Graneheim & Lundman, 2004). The manifest content analysis, rather than latent content analysis, was chosen to describe visible and clear components from the interviews (Downe-Wamboldt, 1992; Kondracki, Wellman, & Amundson, 2002).

Initially, all the interviews were read and reread by the core analysing team (JAS, ASH, and KS) to get a general overview and a sense of topics. The topics were discussed, leading to a consensus among all of the authors regarding the focus of the analysis. Next, all relevant meaning units (i.e., the constellation of words or statements that relate to the same central meaning) were extracted, and meaning units that deviated from the focus of the study were excluded (Graneheim & Lundman, 2004). The meaning units were then sorted into the preliminary categories "before treatment," "symptoms/side effects," "consequences," "supportive actions," and "after treatment." Based on these preliminary categories, codes were created to label all meaning units (e.g., "nutritional preparations," "mucous, nausea and vomiting," "swallowing difficulties," "coping strategies," "hospital admission and tube-feeding," "hope and expectations" and "thoughts and reflections"). Sub-categories were then abstracted, combining one or more of the codes within the preliminary categories to cover the time periods from diagnosis to the acute recovery phase after treatment. Finally, new category names were created and narrative descriptions were written. The phases of developing codes, sub-categories and categories were continuously reflected on and discussed between the core analysing team throughout the process. The core analysing team continuously returned to the original text to ensure that the core meaning was preserved, and this process was maintained throughout the entire analysis.

3 | RESULTS

The patients' nutritional experiences and needs for nutritional support evolved within the four categories Waiting to get started, Undergoing daily radiotherapy turns everyday life upside down, Finally done but still troubling and Reflecting on the treatment trajectory.

TABLE 1 Characteristics of the participants

	Number of participants
Gender	
Males	5
Females	5
Age distribution	
40–49	1
50–59	4
60–69	4
70–79	1
Civil status	
Married/cohabiting	7
Single	3
Education	
Primary/secondary school	7
College/university	3
Employment status	
Employed	6
Disability benefits	2
Retired	2
Tumour site	
Oropharynx	7
Salivary glands	2
Unknown origin	1
Tumour stage	
Stage I-II	2
Stage III	2
Stage IVA	5
Not assessed	1
Treatment modality	
Surgery + chemoradiotherapy	4
Surgery + radiotherapy	3
Chemoradiotherapy	2
Radiotherapy	1
Hospital admissions	7
No hospital admission	5
Staying at home	2
Staying at outpatient accommodation	1
Nasogastric tube	6
Still in place at the time of the interview	5
Karnofsky performance status (0–100) ^a	
Score = 80%	3
Score = 70%	7
Symptoms (0–100) ^b	
Fatigue score ≥ 50	7

(Continues)

TABLE 1 (Continued)

	Number of participants
Nausea/vomiting score ≥ 50	5
Pain score ≥ 50	9
Nutritional status (0–36) ^c	
Score ≥ 9	9
Score 2–8	1

^aScored by a physiotherapist at the end of radiotherapy, 0 = dead and 100 = normal no complaints (80%: able to do normal activity/work with some effort, some signs or symptoms, 70%: cares for self, but unable to carry on normal activity or to do active work (Yates et al., 1980).

^bSelf-reported by the European Organization for Research and Treatment of Cancer Quality of Life Questionnaire (EORTC QLQ-C30) at the end of radiotherapy, 0 = no symptoms and 100 = maximal symptoms (Aaronson et al., 1993).

^cSelf-reported by the Patient-Generated Subjective Global Assessment (PG-SGA) Short Form at the end of radiotherapy, 0 = no problems and 36 = severe problems (0–1: no interventions needed, 2–8: require nutritional interventions, ≥ 9: critical need for improved symptom management and/or nutrient intervention options) (Detsky et al., 1987; Gabrielson et al., 2013).

3.1 | Waiting to get started

3.1.1 | Preparing for radiotherapy

Except from following generalised advice to increase the caloric intake and acquire nutritional drinks, the participants did not highlight any specific nutritional preparations before starting radiotherapy. Living as normal as possible and maintaining everyday routines, including their dietary pattern, was the way they coped with the situation. However, the participants who underwent surgery prior to radiotherapy described commonly soreness, pain and swallowing difficulties. It was experienced as difficult to eat and drink as normal, and initial weight loss started. Also, fatigue and appetite loss was mentioned, and the situation was described as not the most ideal for the upcoming radiotherapy:

My starting point for radiotherapy was really bad. I had gone through surgery with removal of the tumour and tonsils, and then biopsies from different locations in my throat 14 days after that. I felt exhausted already at the first day, and I think that was the reason I got so sick and dehydrated during the initial days of radiotherapy.

Participant 4

3.1.2 | Receiving information

The participants received both oral and written information about the expected nutrition-related consequences of treatment, but preferred different delivery methods. One participant stated "I'm a craftsman and a man, and you have to tell these things to idiots

like me and not just deliver a stack of papers," while another found the written information really relevant and "read it all." The participants appreciated to have someone among the treatment staff to ask questions as they appeared.

3.2 | Undergoing daily radiotherapy turns everyday life upside down

3.2.1 | Increasing side effects and diminishing food intake

The participants described that side effects started slowly in the first week of radiotherapy and "just increased as the weeks went by," and included soreness, pain, nausea, increased mucous production, alterations of taste and smell, swallowing difficulties and mouth dryness:

But in the second week, the side-effects became more evident, and in the third week they really struck [...]. It was just painful to swallow, pain and soreness [...]. The taste disappeared completely, and everything tasted crap, metal, like in a weird way [...]. And then the increased mucous production on top of that, which was the worst part.

Participant 5

It was indicated that a combination of soreness, pain and increased mucous production represented the main cause of the swallowing difficulties, and most participants suffered from a decreased nutritional intake. "The feeling of being really sick" was also highlighted, and loss of appetite was evident. Some participants gave detailed descriptions of their weight development, while others made rough estimates.

3.2.2 | Coping with increasing nutritional problems

The participants expressed different strategies to manage their increasing nutritional problems during radiotherapy. "To live like normal at home" and "avoid losing too much weight" were highlighted as a motivation for keeping up the nutritional intake, and actions were taken like "I squeezed the potatoes in the sauce, I even used a knife and fork to cut the crust from a slice of bread." One participant stated "I just forced myself to eat because I knew I needed food," and made several active efforts to make this possible:

The next week I brought a blender back to the outpatient accommodation and mashed all the food in my room, and then I was able to ingest some [...]. During the weekends at home, I made it a bit more advanced by blending for example broth, meat and vegetables into a drinkable soup, which I brought back to the outpatient accommodation.

Participant 3

3.2.3 | Using oral nutritional supplements as nutritional first aid

All participants were introduced to oral nutritional supplements prior to or during radiotherapy. Those tasting the nutritional drinks from the start of radiotherapy, found them "really good when testing the different flavours." All participants expressed that it became gradually more difficult to ingest the drinks as the intensity of the side effects increased, and most participants had to quit the drinks about halfway through radiotherapy:

I tried to continue with the nutritional drinks, but it was becoming increasingly unbearable. The taste of it just got more nasty, it became more and more difficult to swallow and I got really nauseous [...]. It tasted of metal and cardboard, I don't know how else to put it.

Participant 1

3.2.4 | Deciding hospitalisation and starting tube-feeding

Hospital admissions occurred in the third or fourth week of radiotherapy. It was expressed that the side effects affected the nutritional intake to such an extent that "I just wasn't able to swallow anymore." Although the participants highlighted that it was the treatment staff's suggestion and decision to admit them to the hospital, the participants regarded hospitalisation as a necessary way out of an unbearable nutritional situation.

Tube-feeding was started in virtually all participants just after hospitalisation, and was described as "I felt much better already the day after I started the tube-feeding" and "my body weight was stabilised after I got the tube." However, the tube was tolerated differently among the participants. One expressed "I barely managed the tube in my throat because I easily throw up," while another, that had to change the tube several times, stated "it was not a problem because they do it in a really smooth and quick way."

Most of the participants that did not start tube-feeding were not hospitalised, and were able to ingest food although "smaller and smaller portions of dinner" and despite that "it was very painful to eat and everything tasted the same." One participant really wanted to avoid the tube, even if it was recommended by the treatment staff:

But I really didn't want to install a tube, because from that moment on you really mark the transition from a person to a patient.

Participant 4

3.3 | Finally done but still troubling

3.3.1 | Persisting side effects and altered senses

After treatment, side effects like pain, nausea, altered or loss of taste and increased mucous production were still troubling the

participants. Decreased saliva secretion was also addressed, and it was stated that "some of the saliva secretion has returned, but it's not like it used to be, it's stickier." Most participants expressed they were still unable to achieve a normal intake, and it was stated that "the food still needs to have a smooth texture and definitely not any sharp edges to slide down." Pain and sticky saliva were highlighted as the main causes for the swallowing difficulties. Food they normally enjoyed now tasted awful, or the taste was totally or partly missing:

Now I can feel a hint of flavour when I start to eat some food like soft-boiled eggs and maybe tomato sauce. But the flavour is gone already after a couple of spoons. So it doesn't matter what I eat, it all tastes the same.

Participant 3

The three participants who completed the interviews about 4 weeks after treatment expressed improvements of the side effects but still troubled to eat adequately: "The soreness in my throat has improved some, and I try to ingest some porridge, soup and half a slice of bread." It was also described eating problems despite being able to swallow:

Now I'm able to swallow, but the thing is that nothing tastes anything and I get nauseous from it [...]. It's such a pity because I really want to eat, but it's so disgusting in a way.

Participant 10

3.3.2 | Moving towards the usual life

The participants expressed different strategies to cope with their deteriorated nutritional situation after radiotherapy, mainly by focusing on maximising the food intake either through the tube, orally or a combination of both. With regard to the tube-feeding, the participants expressed concern regarding their ability to get enough calories and about "getting nauseous again if I take too much at once." To optimise oral intake, patients referred to strategies such as finding the best time during the day for eating and adjusting the consistency of the food.

Patients tried to use nutritional drinks "as a snack meal in between the tube-feeding," and tried to take these drinks on a regular basis. The importance of living as normal as possible was also expressed as a way of maintaining the food intake:

I have tried to live as normal as possible from diagnosis and until now, also when it comes to nutrition and food. So, now I blend the ingredients separately, not making one soup out of it, and serve it separately on the plate like a normal dinner.

Participant 3

The participants hoped for a gradual increase in their food intake in the upcoming period. One explicitly stated "that's what I'm hoping for now, to be able to eat, you know, and get rid of the tube," while it was recognised that "the recovery will take some time" and "I guess it's different from person to person how long time it takes to be able to eat again." It was pointed out some specific expectations related to the type of food, like "I expect to be able to ingest some soup or porridge from now on."

3.4 | Reflecting on the treatment trajectory

3.4.1 | Highlighting tailored information and specialised nutritional support

When looking back at the entire treatment trajectory, the participants questioned their ability to absorb the provided information prior to start of radiotherapy:

I'm not sure I was able to absorb the information at that time. It's something completely different when you actually experience the side-effects compared to hearing or reading about them.

Participant 5

The participants requested more information about "what is normal and not" regarding the time aspect of the side effects, and stated "it's still unclear when I can expect to start eating again" and "nobody has told me when it is expected that the mucous and saliva production will normalise." It was suggested that "the treatment staff could have informed a little bit more in detail about when it is expected to start chewing and eating again," and it was also suggested to introduce peer support in the period before radiotherapy. The absence of nutritional support from a dietitian was specifically addressed:

A doctor, nurse and dental hygienist were all present at the weekly status meetings. But a dietitian was never present, and I was never offered a referral for dietary counselling.

Participant 4

4 | DISCUSSION

While waiting to get started with radiotherapy, the reduced food intake after surgery was experienced as a poor starting point. When undergoing daily radiotherapy, the side effects caused increasing difficulties with eating and drinking, and loss of appetite was evident. The participants had to customise their meals to improve the food intake. Using oral nutritional supplements as nutritional first aid only made sense during the initial weeks of radiotherapy, since it eventually got unbearable to ingest them. Hospital admissions occurred about halfway through radiotherapy, and tube-feeding was

initiated just after being hospitalised. Although finally done with radiotherapy, the participants felt discouraged about the persistent side effects, preventing them from eating and drinking as desired. When reflecting on the course of treatment, the participants questioned their ability to absorb the pre-treatment information about nutritional side effects. They missed specific information regarding the expected recovery from side effects and when to resume eating, and the absence of a dietitian as part of the multidisciplinary team was highlighted.

Being exposed to the side effects of radiotherapy was experienced as quite different from just hearing and reading about them in the present study. Even though the participants received standard information before the treatment started, it is a well-known challenge for patients to realise the practical implications of medical information, and in particular for patients with HNC that are exposed to extensive information from various healthcare professionals (Diefenbach et al., 2009; Ishikawa, Hashimoto, & Kiuchi, 2013; Ziegler, Newell, Stafford, & Lewin, 2004). This could be caused by the lack of time to assimilate the information, and the fact that traumatic experiences are indescribable until they have been experienced (Llewellyn, McGurk, & Weinman, 2005). Also, the shock of diagnosis in conjunction with the tumour morbidity may reduce the patients' ability to absorb the information adequately despite careful explanations. The latter is in line with research documenting that many patients with HNC suffer from psychological distress already from diagnosis, which may interfere with the patients' ability to absorb and process relevant information (Chen et al., 2009; Williams, 2017). Ensuring that key messages are repeated continuously, and preferably coupled with written materials, may facilitate for an improved understanding of the information. In addition, as highlighted in the present study, utilising former patients with similar experiences to provide relevant information may improve the credibility and thus the absorption of the information.

The participants called for more specific information about the nutritional consequences of the side effects and stressed the need to provide an approximate timeline of recovery in the post-treatment phase. This is in line with the findings from a survey of information needs and preferences in patients with HNC, which showed that information about treatment and recovery time frames was considered most important, in addition to signs and symptoms of recurrence, cure rates, post-treatment rehabilitation and financial support (Saroa et al., 2018).

Medical information provided to patients with HNC is typically generic and intended to apply for all patients. However, the duration of recovery varies greatly between patients with HNC, and information provided on a group level may not fit with the progress of the individual patient's recovery. Several studies have shown that a generic provision of information is not sensitive enough to capture the variation that exists between patients in their desire for and understanding of information (Fujimori & Uchitomi, 2009; Kreuter, Strecher, & Glassman, 1999; Rodin et al., 2009). In addition, a recently published qualitative study that described HNC patients' perceptions of information delivery indicates that comprehensive verbal information and audio visuals may prepare the patients in a

better way compared to providing only verbal information in an ad-hoc manner (D'Souza et al., 2018).

Providing individually tailored information, and involving the patients in the decision-making by requesting values and preferences with regard to food, has been found to result in higher levels of cancer knowledge and satisfaction with information, and lower levels of anxiety, compared to providing generic information (D'Souza, Blouin, Zeitouni, Muller, & Allison, 2013a, 2013b). This indicates that an assessment of HNC patient's needs for information is vital before deciding information strategies, although the findings need to be confirmed with a randomised approach. However, such a patient-centred approach of providing information and nutritional interventions may not fit the current streamlined cancer pathways in Norway, and we therefore suggest that individually tailored nutritional support forms a part of the clinical pathway of HNC treatment. Clinical nurse specialists are recommended to act as gatekeepers to the patients' cancer pathway to provide a seamless journey; they therefore form a vital part of the multidisciplinary team to support implementation of more patient-centred nutritional support in all phases of the treatment trajectory (Dempsey, Orr, Lane, & Scott, 2016).

The absence of a dietitian as part of the multidisciplinary team was highlighted. Both after surgery and during the initial weeks of radiotherapy, the participants had to customise their meals to the best of their ability. Nutritional drinks were recommended for all on a general basis. The majority of the participants were hospitalised about halfway through radiotherapy, and tube-feeding was then initiated. Since patients with HNC are at a high risk of malnutrition already from diagnosis, specific nutritional strategies are required to minimise the negative consequences of surgery, radiotherapy and chemotherapy (Hebuterne et al., 2014; Silva, de Oliveira, Souza, Figueroa, & Santos, 2015; Weimann et al., 2017). Specialised nutrition competencies and skills are needed to make early detections of patients in need of nutritional support and to assess and initiate relevant nutritional support. Hospital stays are longer and costs per hospitalisation are higher in malnourished cancer patients, thus actions that may delay or prevent hospital admissions during treatment are desired (Maasberg et al., 2017; Planas et al., 2016; Pressoir et al., 2010). Updated international clinical guidelines on nutritional support in cancer patients recommend that dietitians play a central role in the multidisciplinary team responsible for the supportive care of HNC patients (Arends, Bachmann, et al., 2017; Thompson et al., 2017). The reasons for the inconsistent provision of dietitian-delivered nutritional support to Norwegian HNC patients need to be clarified in order to improve the quality of patient care. Not only may a dietitian improve the nutritional support through direct contact with HNC patients, but also through increasing the nutritional expertise of the involved healthcare professionals.

4.1 | Strengths, limitations and trustworthiness

Qualitative methods may contribute with a deeper understanding of the nutritional impact of a HNC diagnosis and treatment, and is an excellent fit to quantitative data documenting the occurrence of side effects and effective nutritional interventions. The use of

a semi-structured interview guide allowed for unexpected aspects and themes to arise. All interviews were carried out by a research nurse with experiences clinical trials utilising both quantitative and qualitative methods, and with clinical experience from the field of HNC.

The included participants were invited from a randomised rehabilitation study that involved the majority of all HNC patients scheduled for curative treatment within the health region of central Norway (2015–2016). The participants represent the heterogeneity of HNC patients, including both genders, younger and older than 60 years and living in rural and urban areas. Most of the participants (7 out of 10) were diagnosed with pharyngeal cancer in the present sample, and patients with oral cavity and laryngeal cancer were not represented. While the treatment modalities of oral and laryngeal cancer are similar to that of pharyngeal cancer (i.e., radiotherapy ± chemotherapy), patients with laryngeal cancer often experience less side effects compared to oral and pharyngeal cancer due to much smaller irradiated areas, depending on stage (Evensen, 2015). Since more than half of the participants (6 out of 10) participated in the rehabilitation intervention during radiotherapy, while the other participants received standard care in the same period, the intervention may have influenced the perceptions of supportive care and the provision of nutritional drinks. However, the interviewer experienced that the participants did not distinguish between the study-specific and standard care, since nutritional drinks also were recommended as part of the standard care.

Since the interviews were conducted about 2 weeks after the end of radiotherapy, and even about 4 weeks after treatment for three participants, oversights and recall biases of relevant events cannot be ruled out. Repeating the interviews during the different treatment phases would result in more accurate snapshots of the patients' experiences and will be conducted in a planned follow-up study within this patient group.

4.2 | Clinical implications

The findings from the present study stress the importance of dietitian led nutritional care during all phases of the clinical pathway in patients with HNC. Addressing nutritional issues immediately following diagnosis enables appropriate interventions on time (Larsson, Hedelin, Johansson, & Athlin, 2005; Sanson-Fisher et al., 2000). A nutritional screening is recommended for all patients with HNC, followed by a full assessment if nutritional risk is present (Arends, Baracos, et al., 2017). Subsequent nutritional support should be initiated before treatment start, since nutritional interventions are most successful if initiated early (Capra, Ferguson, & Ried, 2001; Langius et al., 2013; Ottery, 1995; Piquet et al., 2002). Nutritional counselling is recommended as the first line of nutritional support and should consist of a patient-centred and repeated communication process to provide the patients with a thorough understanding of nutritional topics, as distinct from brief and casual dietary advice (Arends, Bachmann, et al., 2017). Such counselling will ensure that relevant nutrition-related information is provided. Since

radiotherapy and chemotherapy are intended to be carried out on an outpatient basis in patients with HNC, it is necessary to co-ordinate and adjust nutritional interventions to the patients' hospital visits. Finally, the interventions should meet the patients' changing needs in order to enhance coping and self-care in the home situation (Wells, 1998).

In addition to the importance of early detection and initiation of nutritional support, the present study also revealed the need for individual strategies for providing medical information during the different treatment phases. Continuous assessments of health status and side effects are essential to be able to provide meaningful information to each patient, which may enhance self-care (Larsson et al., 2003).

5 | CONCLUSION

The comprehensive nutritional problems that patients with HNC experience from diagnosis to the recovery phase after treatment indicate a need for dietitian led individually tailored nutritional care to improve patient outcomes. This implies early individual assessments of needs for information and nutritional support for all patients, including continuous reassessments of the changing needs. In this way, individualised nutritional care may become an integrated part of the clinical HNC pathway.

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CONFLICT OF INTEREST

The authors declare that they have no competing interests.

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APPENDIX 1

INTERVIEW-GUIDE "NUTRITIONAL EXPERIENCES IN HEAD & NECK CANCER PATIENTS" (TRANSLATED FROM NORWEGIAN BY THE FIRST AUTHOR OF THE PRESENT PAPER)

How did you experience the time from diagnosis to the start of treatment (i.e., about 2 weeks for most patients)?

- Reception at the hospital, information, use of time, waiting-time, help from the staff member if needed.
- Did you prepare yourself in any specific way prior to treatment start (food/nutrition, mentally, physically, socially or in other areas)?

How did you experience conducting daily radiotherapy for 6 weeks?

- Attendance and reception radiotherapy unit, use of time, the treatment itself, co-ordination between different departments, predictability.
- Several involved departments and personnel, who is responsible for me, who to contact during treatment, who to contact after treatment (at home) etc.
- Nutritional situation—development, coping, needs, supportive care
- How to cope mentally?
- Physical function—status at the start of treatment, development, loss of function.
- Side effects—coping, supportive care, information etc.
- Social functioning and support from family and friends.

Did you miss any kind of follow-up during radiotherapy?

- Diet/nutrition and meals—what to eat and not.
- Physically—what is recommended and not.
- Mentally—somebody to talk to, support from personnel, peer-support.
- Side effects—information, coping, use of drugs.

Finally, is there anything you find relevant to talk about that we didn't address?

(If the participant provides short and imprecise answers to any question, try to make the participant elaborate by asking follow-up questions such as "can you give any examples", "could you please elaborate more about that" and "please tell more about that").