



Head and neck cancer patients' perceptions of quality of life and how it is affected by the disease and enteral tube feeding during treatment

Ylva Tiblom Ehrsson, Kay Sundberg, Göran Laurell & Ann Langius-Eklöf

To cite this article: Ylva Tiblom Ehrsson, Kay Sundberg, Göran Laurell & Ann Langius-Eklöf (2015) Head and neck cancer patients' perceptions of quality of life and how it is affected by the disease and enteral tube feeding during treatment, Upsala Journal of Medical Sciences, 120:4, 280-289, DOI: [10.3109/03009734.2015.1075630](https://doi.org/10.3109/03009734.2015.1075630)

To link to this article: <https://doi.org/10.3109/03009734.2015.1075630>



Informa Healthcare



Published online: 20 Oct 2015.



Submit your article to this journal [↗](#)



Article views: 1942



View related articles [↗](#)



View Crossmark data [↗](#)



Citing articles: 13 View citing articles [↗](#)

ORIGINAL ARTICLE

Head and neck cancer patients' perceptions of quality of life and how it is affected by the disease and enteral tube feeding during treatment

Ylva Tiblom Ehrsson^{1,2}, Kay Sundberg³, Göran Laurell¹ & Ann Langius-Eklöf³

¹Department of Surgical Sciences, Section of Otorhinolaryngology and Head & Neck Surgery, Uppsala University, Uppsala, Sweden, ²Department of Public Health and Caring Sciences, Uppsala University, Uppsala, Sweden, ³Department of Neurobiology, Care Sciences and Society, Karolinska Institutet, Stockholm, Sweden

Abstract

Aim. To explore individual quality of life in patients with head and neck cancer from diagnosis up to 3 months after termination of radiotherapy. Research questions: 1) Which areas in life are important to quality of life, and which are influenced by the disease and by having oral or enteral nutrition; and 2) Which areas in life are influenced by having a nasogastric feeding tube (NGT) or a percutaneous endoscopic gastrostomy (PEG) tube?

Material and methods. Data were collected in 36 patients. Semi-structured interviews were conducted using an extended version of the Schedule for the Evaluation of Individual Quality of Life (SEIQoL) and analysed with content analysis.

Results. Negative and positive experiences of quality of life in general were about relation to family, own health, and leisure activities. Negative impacts on physical, psychological, existential and social problems, but also positive experiences are described by the patients related to the disease. More than half expressed eating-related problems. Enteral nutrition entailed negative and positive experiences, and no greater variations were described by the patients with NGT or PEG tube. Overall, there were interindividual variations.

Conclusions. The patients' perception of general or disease-related quality of life was not affected by whether they had enteral nutrition or not. From the patients' perspective neither of the two feeding tubes (NGT or PEG) was clearly in favour. We suggest that more studies are needed on how the choice of enteral feeding tube can be evidence-based, and incorporating the patients' perspective.

Key words: : Enteral nutrition, head and neck cancer, nasogastric feeding tube, patient perspective, percutaneous endoscopic gastrostomy, quality of life, radiotherapy, SEIQoL

Introduction

Head and neck (H&N) cancer includes malignant tumours of the lip, oral cavity, nasal cavity and sinuses, pharynx, larynx, salivary glands, and ear. The most common treatment modalities for H&N cancer are external beam radiotherapy and surgery, although an increasing role for chemotherapy can be seen. Radiotherapy and surgery are used either as single-modality therapy or in combination (1). One important component of clinical care is to consider the patients' quality of life (QoL) in order to be able

to identify their different needs during the disease trajectory. The longitudinal pattern of changes in QoL has been reported in a number of studies. From the time of diagnosis to discharge from hospital after surgery, patients with oral cancer showed marked deterioration in physical functioning (2). In addition, symptoms and problems increased in the domains of swallowing, taste and smell, sticky saliva, body weight loss, and speech. However, at the end of a 12-month follow-up, a significant overall improvement of QoL has been reported (3). The improvement was especially noted in patients with tumours

with lower T stage, whereas patients with a feeding tube had lower and slower improvement in QoL (3). A follow-up study 5 years after diagnosis of patients with H&N cancer reported improvements in insomnia, pain, global health status, and emotional function, whereas problems with dry mouth, teeth, and sense of smell and taste worsened over time (4).

Eating-related problems, usually appearing early in the disease and often even before diagnosis, are frequent and reported to have major effects on many patients with H&N cancer (5-8). Problems with oral continence, mastication, and swallowing are examples of common dysfunctions often seen after single-modality or combined-modality treatment. In addition, unhealthy habits such as alcohol and tobacco abuse can aggravate body weight loss and nutritional decline (5,9-11). Nutritional surveillance is an important component of clinical care for identifying patients at risk for malnutrition. When required, nutritional treatment often initially involves food enrichment and oral supplements. If the patient cannot swallow but has a functioning gastrointestinal tract, enteral tube feeding is preferred (5,12). The two most common methods for enteral feeding are the polyurethane nasogastric feeding tube (NGT) and the percutaneous endoscopic gastrostomy (PEG) tube. Risks and benefits are associated with both methods. NGT is mainly used on a short-term basis (8). Examples of NGT complications include pharyngeal ulceration, altered body image, tube blockages, and tube dislodgements (8). PEG is used on a short- and long-term basis and is preferred because of the assumption that it provides higher subjective and social acceptance (13). Complications that can arise from PEG use are pain (especially in the first days/weeks), leakage, wound infections, bleeding, gastric/esophageal perforation, pneumoperitoneum, and peritonitis (5,8,14,15). Early PEG insertions (before or within 1 month of treatment) have shown a smaller decrease in patients' body mass index (BMI) at 12 months compared with receiving PEG after 1 month or more of treatment (16). Corry et al. (17) compared NGT and PEG in a group of patients with H&N cancer and found no differences regarding general physical condition and overall QoL. Patients with PEG lost less body weight 6 weeks after treatment, but 6 months after treatment there were no differences in body weight loss (17). However, patients with NGT had significantly more complications related to tube dislodgements, and patients with PEG had significantly more infections. Moreover, the costs for PEG were higher than for NGT (17). Today there is an ongoing clinical and academic debate about when enteral nutrition should

be initiated and which enteral nutrition method to use, NGT or PEG. In this debate, the patients' experiences of having NGT or PEG, and the positive or negative aspects, are seldom included.

The concept of QoL pertains to general well-being and is multidimensional, including physical, psychological/emotional, and social functioning, disease- and treatment-related symptoms, and perceived health status (18). The definition 'health-related QoL' (HRQoL) is sometimes preferred, as it is not as broad and focuses on health status and disease-related issues, such as symptoms and functions (19,20). Instruments measuring QoL issues are mainly generic or condition/disease-specific (18), although several instruments combine generic with condition/disease-specific issues. Well-known questionnaires used in studies of QoL and HRQoL in patients with H&N cancer include The European Organisation for Research and Treatment of Cancer Quality of Life Questionnaire-Core 30 (EORTC QLQ-C30) (21), with the H&N cancer-specific module (EORTC QLQ-H&N35) (22), and The University of Washington Quality of Life Scale (UW-QoL) version 4 (23,24). Standardized questionnaires focus on predefined problems and may therefore overlook many QoL aspects important on an individual level (18,25). Consequently, these questionnaires may fail to consider the individual's own perspective of what is negatively (or positively) affected by the disease. The Schedule for the Evaluation of Individual Quality of Life-Direct Weighting (SEIQoL-DW) is an individual-based instrument without predefined items, thus allowing identification of both negative and positive values in life (26,27). There is a body of knowledge showing that patients with H&N cancer experience emotional and physical distress during treatment and that problems related to nutritional state are prominent. However, there is less knowledge about how relevant these problems are on an individual level, whether there are any positive consequences following the disease, and if enteral nutrition influences patients' daily lives.

The aim of this study was to explore individual quality of life in a sample of patients with head and neck cancer from the time of diagnosis up to 3 months after termination of radiotherapy with the specific research questions: 1) Which areas in life are important to quality of life, and which are influenced by the disease and by having oral or enteral nutrition; and 2) Which areas in life are influenced by having a nasogastric feeding tube (NGT) or a percutaneous endoscopic gastrostomy (PEG) tube?

Material and methods

Patients were interviewed at three time points: the start of radiotherapy (T1), 2 weeks after termination of radiotherapy (T2), and 3 months after termination of radiotherapy (T3).

Setting and sample

Over a period of 6 months, 73 patients at a university hospital in Sweden were consecutively allocated at a weekly multi-disciplinary team conference where treatment modality was decided. Patients were included if they were planned to receive radiotherapy (duration 6–7 weeks) with a curative intention either as a single-modality treatment or in combination with other treatment modalities. Exclusion criteria were inability to participate in the interviews (i.e. being unable to speak fluent Swedish, having dementia, or having psychiatric disorders). Based on these criteria, 9 were excluded, leaving 64 eligible patients. Twenty-three declined participation, leaving 41 patients enrolled, of whom 36 completed the whole study. The 5 patients who did not take part in all the interviews either declined further participation ($n = 3$), or died during the study ($n = 2$). The number of participants at the three interview occasions was 41, 38, and 36 at study times T1, T2, and T3, respectively. The patients were divided into two groups at T2 and T3, depending on whether they maintained oral feeding (OF group) or needed enteral nutrition (EN group). Patients were given enteral nutrition if they lost >5% of their initial body weight, or if they had a stage IV tumour and swallowing problems (14). The choice of NGT or PEG was mainly based on the clinical and traditional decision by the physician.

Data collection

The Schedule for the Evaluation of Individual Quality of Life–Direct Weighting (SEIQoL-DW) is an interview-based questionnaire developed to describe individual QoL without using predefined variables (26,27). The original SEIQoL included only a generic part (henceforth SEIQoL-G), but in the Swedish modified and extended version a disease-related (SEIQoL-DR) part was added (28). The generic part generates areas that patients describe as important for their general QoL, and the disease-related part generates aspect that the patients describe to be specifically affected by the disease. The extended disease-related part has been previously shown to be feasible and valid when used in patients with cancer (29). For the purpose of the present study, a third part was developed and added

to capture patients' descriptions of perceptions and problems related to enteral nutrition (SEIQoL-EN).

The interviews included all three parts at the same time for each patient. Firstly, the patients were asked the question according to the SEIQoL-G, 'If you think about your life as a whole, what are the most important things, both good and bad, in your life at present that are crucial for your QoL?' Secondly, they were asked the question according to the SEIQoL-DR part, 'If you think about the fact that you will be/are being/have been treated for cancer, what things in your life are influenced, both positively and negatively, by the disease?' Finally, the patients that had any type of feeding tube were asked the question according to the SEIQoL-EN part, 'If you think about the feeding tube (NGT or PEG), what things in your life are influenced, both positively and negatively, by this experience?' In all three parts of the interview the respondents could freely identify as many areas as they wanted.

Demographic data (sex, age, marital status, and educational level) were collected at the first interview. Clinical data (diagnosis, TNM classification, stage, and treatment) were collected from the patients' medical records.

Procedure

All patients were given oral and written information about the study, and those who agreed to participate gave their written informed consent. In total, 115 interviews were performed mainly at the hospital (81%), while some interviews at T2 and T3 (19%) were performed by telephone due to prohibitively long distances to the hospital. Interviews ranged from 10 to 60 minutes (mean = 26 minutes). Three persons trained to use the instrument conducted the interviews: two of the authors, and a registered nurse at the clinic.

Analyses

The interviewer took verbatim notes of patient answers in accordance with the interview protocol, i.e. different notes were made under each of the three different parts. To make sure that their intentions and feelings were fully described, the patients were asked to verify their statements. The notes were then transcribed into three consolidated texts for SEIQoL-G, SEIQoL-DR, and SEIQoL-EN, respectively. These three text transcriptions were analysed separately from each other. All three transcriptions were analysed according to Elo and Kyngäs (30), using inductive qualitative content analysis. Content

Table I. Demographic and clinical characteristics of patients with head and neck cancer ($n = 41$).

Characteristic	Number of patients (%)
Sex	
Male	28 (68)
Female	13 (32)
Age	
Mean age, years	62.3
30–39 years	1 (3)
40–49 years	3 (7)
50–59 years	10 (24)
60–69 years	18 (44)
70–79 years	7 (17)
80–89 years	2 (5)
Marital status	
Married, cohabiting	31 (76)
Single, divorced, or widowed	10 (24)
Educational status (highest level)	
Mandatory	13 (32)
High school/college	12 (29)
University	13 (32)
Other	3 (7)
Diagnosis	
Oropharynx	15 (37)
Oral cavity	8 (20)
Larynx	5 (12)
Unknown primary	4 (10)
Nasopharynx	3 (7)
Salivary glands	3 (7)
Hypopharynx	2 (5)
Oral cavity and oropharynx	1 (2)
Tumour stage (I–IV)	
I	6 (14)
II	5 (12)
III	4 (10)
IV	22 (54)
No stage	4 (10)
Treatment	
Radiotherapy	16 (39)
Radiotherapy and surgery	9 (22)
Surgery and radiotherapy	3 (7)
Combination treatment ^a	13 (32)

^aRadiotherapy and chemotherapy, and/or brachytherapy, and sometimes surgery.

analysis is a method that can be used to draw valid conclusions about a manifest message in a communication by systematic identification of specified communication characteristics. Data from the open-ended questionnaires are suitable for this technique. The analysis was first performed with the text from the SEIQoL-G followed by SEIQoL-DR and finally SEIQoL-EN. The transcriptions were read through several times, and subsequently words and sentences that shared the same meaning from the transcripts were coded. The codes were then transferred to a coding sheet, one for each part, where similar codes were grouped together; by comparing differences and similarities, main

categories and sub-categories were created. Codes that were worded in a positive sense were grouped together within each category. The first author carried out this first step of the analysis. Thereafter, two of the other authors read the material and compared the main categories and sub-categories within each part with the codes by defining their boundaries. In repeated meetings, the research group discussed and modified the categories within each part until consensus was achieved. Appropriate quotations are used in the results to illustrate the categories. Frequencies and per cent with which each category is mentioned by patients are presented (31). To assess differences in the proportion of the categories and number of patients, regarding all three parts, Fisher's exact test was calculated.

Ethical approval

The Regional Ethical Review Board in Stockholm, Sweden, reviewed and approved the study (entry no: 04-456/3).

Results

Descriptive data

Demographic and clinical characteristics of the 41 participating patients with H&N cancer are presented in Table I.

In total, 18 patients (44%) maintained oral feeding (OF group, $n = 18$) during the entire study period, and 23 patients (56%) received enteral nutrition (EN group, $n = 23$), of whom 14 were given PEG, and 9 NGT.

Areas of general QoL and relation to enteral nutrition

The patients' descriptions of important areas of general QoL were wide-ranging but consistent from the time of diagnosis and up to 3 months after the termination of radiotherapy, and could be organized in 13 general categories (Table II). In the interviews patients described the family to be of most importance. Those who had a partner said that he/she was the most important person in their lives, and this was also the person they turned to for support. The patients who had children and grandchildren described that they were a joy and of great importance for them. Other important areas brought up by the patients were related to their own health, of wanting to be healthy and wishes to be like other people including, for example, people with normal physical appearance, not suffering from pain, being

Table II. Categories of most important areas in life (SEIQoL-G) found from interviews of patients with head and neck cancer over time: at start of radiotherapy (T1), 2 weeks (T2) and 3 months (T3) after the termination of radiotherapy, divided into two groups—oral feeding (OF) and enteral nutrition (EN). Numbers and percentages show frequencies of nominations in each category.

Main categories	T1 ^a	T2 ^b		T3 ^b	
	<i>n</i> (%)	OF <i>n</i> (%)	EN <i>n</i> (%)	OF <i>n</i> (%)	EN <i>n</i> (%)
Total number of participants	41	17	21	18	18
Family/relation to family	35 (85)	10 (59)	16 (76)	11 (61)	15 (83)
Own health	18 (44)	9 (53)	11 (52)	8 (44)	14 (78)
Interest/leisure activities	30 (73)	7 (41)	5 (24)	7 (39)	6 (33)
Friends/relations to other people	19 (46)	6 (35)	8 (38)	6 (33)	6 (33)
Work	18 (44)	6 (35)	4 (19)	5 (28)	6 (33)
Housing/living conditions	17 (41)	3 (18)	1 (5)	9 (50) ^c	3 (17) ^c
Psychological impact	3 (7)	2 (12)	4 (19)	1 (6)	4 (22)
Finances	6 (15)	1 (6)	0 (0)	2 (11)	0 (0)
Pets	3 (7)	1 (6)	1 (5)	2 (11)	1 (6)
Health of someone close	2 (5)	1 (6)	0 (0)	2 (11)	0 (0)
Environment	1 (2)	0 (0)	1 (5)	0 (0)	0 (0)
Society/politics	1 (2)	1 (6)	0 (0)	0 (0)	0 (0)
Religion/spirituality	1 (2)	0 (0)	0 (0)	0 (0)	0 (0)

^aAt T1, 4/41 had EN.

^bThere were no differences between the OF and EN groups (Fisher's exact test).

^cExcept for statements regarding housing/living conditions where a statistically significant difference was seen at T3 (Fisher's exact test).

able to eat and drink orally, and also to be able to eat and drink together with other people. The patients also described how they in different ways liked to perform different leisure activities like being outdoors in nature, walking, exercising, and reading. There were no differences in frequencies of the different categories between the patients in the OF and EN groups, except for housing/living conditions at T3 ($p < 0.01$). Thus, patients in the OF group described housing/living conditions more often.

Areas of disease-specific QoL and relation to enteral nutrition

Negative impacts on physical, psychological, existential, and social problems were described by the patients related to the disease, but also positive experiences emerged from the interviews (Table III). The most common physical health problems concerned fatigue, pain, and eating problems. Psychological issues were described in the interviews by the patients as a worrying feeling and some patients also felt depressed. In addition, the patients also described existential problems: they had thoughts and worries about their disease, and some patients' thoughts occupied and affected them a lot and were time-consuming as they could not stop thinking about their disease and what would happen in the future. Positive aspects were also described by the patients, mostly of a social character, about family and friends and the relationship to them. How family and friends were there for them, helped them,

visited, or telephoned them. Some patients also described how they themselves tried to make the best of their life situation. There were no differences in the number of statements made with regard to areas influenced by disease between the OF and EN groups at T2 and T3 (Table IV).

Areas in life related to having NGT or PEG

The patients with NGT ($n = 9$) or PEG ($n = 14$) described in the interviews both positive and negative feelings about having a feeding tube (Table V). Many of the patients expressed in the interviews positive aspects about receiving enteral nutrition. They did not have to battle with each meal and to worry about not getting beverage and food, they received calories, and realized they would have lost body weight without it. The negative aspects described in the interviews by the patients concerned problems with the feeding procedure as it was time-consuming and for some patients it was difficult to manage to take all the planned nutritional bags per day. They also described practical difficulties with handling the tube and in connection to the feeding procedure. Other negative problems described by the patients were about having the tube (NGT or PEG), how it was irritating to have the NGT in the nose and throat, and that the stomach area around the PEG tube hurt. They felt unhygienic, for example, as the tube was disturbing when they tried to sleep, and they felt embarrassed being around other people. Some patients also described that they missed eating and

Table III. Examples of quotes describing the different categories influenced by the disease (SEIQoL-DR) as reported by patients with head and neck cancer (*n* = 41).

Main categories	Sub-categories	<i>n</i>	Examples of quotes	
<i>Negative aspects</i>				
Health aspects:				
Symptoms	Fatigue/loss of energy	24	I'm not recovering in the way I expected. I'm getting impatient. It affects my daily life—cleaning the house, and so on, is difficult. I'm tired both psychologically and physiologically. I get tired when I'm walking.	
	Pain	20	It hurts inside my mouth and throat, and the skin on my neck also hurts.	
	Xerostomia	14	My mouth is very dry because of the radiotherapy.	
	Skin/mucous impairment	10	I'm sore in my mouth as I've got blisters, and the skin on my neck is red and itchy.	
	Viscous phlegm	6	I have problems with stiff, viscous phlegm.	
	Loss of hair	3	I have hair loss around my ears after the radiotherapy treatment.	
	Function restrictions	Psychological impact	18	I'm psychologically affected and I feel worried. I feel slightly depressed sometimes.
		Sleeping problems	11	I have sleeping problems and I wake up many times during the night. It's hard to fall asleep again.
		Speaking problems	6	I'm wheezing, have hoarseness, my voice is affected, and mainly in the morning I've got lots of viscous phlegm.
		Hearing problems	4	After treatment, my hearing capacity is reduced in my right ear.
Tooth extraction		4	It's been horrible to take out good teeth before treatment.	
Altered body appearance		3	My face looks different and I feel strange.	
Nutrition	Impact on sexual life	2	I don't have a normal sex life.	
	Eating problems/dysphagia	20	I've got problems with chewing and swallowing food.	
	Eating habits/taste changes	14	I have no taste. I'm eating normal food again but feel it is boring when there is no taste, except for sometimes the first bite having taste.	
	Loss of appetite	9	I have problems with my appetite.	
	Enteral nutrition	5	I'm bored with enteral food. I really wish I could eat normal food.	
Social restrictions	Losing weight	5	I haven't been able to eat, and have lost between 10 and 12 kg. I'm pleased with my weight reduction.	
	Social life	14	Restrictions in my social life, especially in contacts with other people and friends.	
	Family life	13	I'm worried about my family—what they think about the situation.	
Thoughts about disease	Work/financial	13	My economy is affected because of the cancer. The money I get when I am sick doesn't cover our expenses, I have to take from our savings and it affects the whole family. We can't do fun things with the children that are costly.	
		22	My whole life is affected by the cancer. I'm thinking about it all the time, even though I'm trying not to.	
Treatment-related concerns		17	The disease changes your entire life. My life is now about treatment, the intake of calories, and killing time in between. It's a full-time job.	
Opinions on health care		9	The rehabilitation has taken much longer than what they said it would take, and I am surprised over the fact of having 12 meetings with 9 doctors during my radiotherapy treatment. Insufficient information about side-effects and that everything takes such a long time. Also, the appointments with different doctors each time is so frustrating.	
<i>Positive aspects</i>				
Social improvements	Family life	8	My wife and daughter are very engaged in my situation.	
	Social life	8	People—friends and relatives have been in contact with me. They care.	

(continued)

Table III. Continued

Main categories	Sub-categories	n	Examples of quotes
View of life and oneself		11	I'm living in the present and trying to enjoy life (e.g. the spring, flowers, and grandchildren).
Thoughts about disease and treatment		11	I'm very happy and at ease now since I've talked to the doctor who told me the cancer is cured.
Opinions on health care		9	A good continuity of the nurses. Both the staff and doctors have been answering my questions.
Miscellaneous		5	Smoking is both positive and negative. I don't want to quit.

Table IV. Categories of areas influenced by the disease (SEIQoL-DR) found from interviews of patients with head and neck cancer over time: at start of radiotherapy (T1), 2 weeks (T2) and 3 months (T3) after the termination of radiotherapy, divided into two groups—oral feeding (OF) and enteral nutrition (EN). Numbers and percentages show frequencies of nominations in each category.

Main categories	T1 ^a	T2 ^b		T3 ^b	
	n (%)	OF n (%)	EN n (%)	OF n (%)	EN n (%)
Total number of participants	41	17	21	18	18
<i>Negative aspects</i>					
Health aspects	30 (73)	15 (88)	17 (81)	14 (78)	16 (89)
Social restrictions	19 (46)	5 (29)	4 (19)	4 (22)	5 (28)
Thoughts about disease	15 (37)	6 (35)	4 (19)	6 (33)	3 (17)
Treatment-related concerns	9 (22)	5 (29)	4 (17)	1 (6)	0 (0)
Opinions on health care	0 (0)	2 (12)	2 (10)	3 (17)	2 (11)
<i>Positive aspects</i>					
Social improvements	10 (24)	0 (0)	2 (10)	2 (11)	1 (6)
View of life and oneself	5 (12)	0 (0)	4 (19)	3 (17)	1 (6)
Thoughts about disease and treatment	1 (2)	2 (12)	3 (14)	4 (22)	2 (11)
Opinions on health care	2 (5)	1 (6)	2 (10)	3 (17)	1 (6)
Miscellaneous	2 (5)	0 (0)	1 (5)	2 (11)	0 (0)

^aAt T1, 4/41 had EN.

^bThere were no statistically significant differences between the OF and EN groups (Fisher's exact test).

drinking orally. The categories found from the interviews are presented with quotes from the interviews (Table V). The greatest variations of number of statements were noticed in the categories 'Confined to a tube' and 'Social limitations'. In comparison with patients with NGT, patients with PEG more often stated that the manner of insertion of the PEG tube was a negative experience, yet stated less often that it was embarrassing.

Discussion

The areas nominated by the patients as important to their general QoL were close to the findings from other studies in patients diagnosed with cancer (32,33). In these and the present study, the areas of importance were also similar to what the general population proclaim are important in life (28).

Overall, our results confirm that eating is a fundamental aspect of life that is often affected by the disease and treatment in patients with H&N

cancer. More than half of the areas that the patients mentioned as influenced by the disease had some connection with nutritional problems. Eating problems, such as difficulty in chewing or opening the mouth, loss of taste, and experience of pain, for example, may affect patients in many ways, leading to prolonged eating time, reduced eating pleasure, and not being able to eat with family and friends. However, except for statements on housing and living there seemed to be no differences related to all aspects affected by general QoL and disease in patients with oral eating versus enteral nutrition. This finding is in contrast to that of Ringash et al. (3), who found that patients with H&N cancer receiving enteral nutrition had significantly less improvement in physical and functional well-being 6 months after treatment compared to patients that did not need enteral nutrition. However, prolonged use of enteral nutrition may be related to having a more advanced stage of disease, which could explain the decline in QoL (9).

Table V. Category descriptions and examples of quotes found from interviews (SEIQoL-EN) of patients with head and neck cancer receiving enteral nutrition by either the polyurethane nasogastric feeding tube (NGT) or the percutaneous endoscopic gastrostomy (PEG) tube. Numbers and percentages show frequencies of nominations in each category.

Main categories	Sub-categories	Examples of codes	Number of patients (%)		p value ^a
			NGT (n = 9)	PEG (n = 14)	
Nutrition	Nutritional comfort	It is positive. I do not have to panic about meals. I get nutrition without having to worry about not being able to swallow	6 (67)	13 (93)	0.26
	Maintaining and gaining weight	Positive as I realize that I would have lost weight without it	4 (44)	5 (36)	1.00
	Long feeding time	It takes lots of time. To take all three bags in one day is hard to manage	3 (30)	6 (43)	1.00
	Missing oral eating	I cannot eat. I miss eating orally. It is hard. I cannot chew	3 (30)	4 (29)	1.00
	Losing weight	It is hard to maintain my weight	0 (0)	2 (14)	0.50
Function	Functioning well	I have learned to live with tube feeding	5 (56)	9 (64)	1.00
	Difficult to handle	Practically, it is difficult to handle the tube, the syringe, and tube feeding	2 (22)	4 (29)	1.00
	Gastrointestinal problems	I easily feel nauseous in connection to tube feeding	4 (44)	2 (14)	0.16
	Nose and throat problems	My nose feels irritated by the NGT	2 (22)	1 (7)	0.54
	Pain	It hurts around the PEG tube	0 (0)	5 (36)	0.12
Limitations	Feel unhygienic	I feel unhygienic—it smells bad	1 (11)	6 (43)	0.18
	Confined to a tube	It is negative because the tube is in the way. The tube disturbs my sleep. I feel confined to the tube when feeding	1 (11)	8 (57)	<0.05
	Social limitations	I feel embarrassed to have the NGT in my nose	6 (67)	1 (7)	<0.01
Miscellaneous		I only use the PEG in the mornings, so I am hoping to get rid of it soon	0 (0)	4 (29)	0.13

^aFisher's exact test.

A typical experience for patients having PEG was that the tube was disturbing and uncomfortable, causing sleeping problems and forcing them to stay at home. Typical for patients with NGT was that they felt embarrassed because part of the tube is visible, which in turn hindered social activities. Patients with NGT talked more about irritation in the nose and throat, drooling, viscous phlegm, and feelings of nausea when eating than did patients with PEG. Similar problems, such as pharyngeal ulceration, inconvenience in using NGT, and altered body image, interference in family and social life, were described by Corry et al. (17) when they compared NGT with PEG in a group of patients with H&N cancer. Furthermore, they did not find any differences in overall QoL between the two methods 1 week after enteral nutrition insertion or 6 weeks after completion of treatment. At this time point, many patients treated with radiotherapy are still

experiencing treatment side-effects that affect swallowing. In another study on patients with H&N cancer, significant differences were noted regarding QoL in favour of PEG at 6 weeks post-insertion as well as for weight (34). In our study, patients with PEG more frequently reported problems with the unhygienic feeling of the PEG tube with regard to leakage and a bad odour, for example, as well as pain around the stoma compared to patients with NGT. Stomach pain is a known complication in connection with and after PEG insertion (14,17). The problem of leakage has previously been addressed as a disturbing complication associated with the PEG procedure (5,14,15).

The version of the SEIQoL instrument used in this study proved to be a good method to capture areas in life that are affected by disease and treatment in patients with H&N cancer. It allowed the patients to express their present life situation in their own

words. When comparing the statements from the interviews, several areas emerged that are not included in frequently used instruments (e.g. the EORTC QLQ-C30, EORTC-H&N35, and UW-QoL) in this patient group. The patients in our study gave their opinions on health care and mentioned their concerns about treatment. Questions regarding these matters are not included in these questionnaires. Most importantly, the patients in our study often referred to nutrition-related problems influencing their life situation, but only a few questions on nutritional problems are included in the EORTC questionnaires, and none in the UW-QoL. Finally, the patients noted some positive areas not captured in the standardized questionnaires. Applying the SEIQoL questionnaire is rather time-consuming, as it is generally used in face-to-face interviews. In this case, 19% of the interviews were conducted by telephone due to long distances. For the future, telephone interviews alone might be a good option (35,36). Although shorter and self-reported questionnaires save time, they might miss areas of importance to individual patients. One way to solve this dilemma is to add open-ended questions to standardized questionnaires, which would allow patients to report personal concerns.

Limitations in our study were the rather small sample size, and that the patients did not have homogeneous types of H&N cancer, or the same treatment modalities; all patients received radiotherapy, but some also receiving surgery, chemotherapy, or brachytherapy, which could have influenced the results. However, in a long-term follow-up study (25 months), different treatment modalities for advanced oropharynx cancer did not affect specific problem areas (37). In this study and especially when comparing patients with NGT and PEG, the sample size is too small for generalizations; it only provides indications. A larger study is needed to confirm the result concerning the comparison between NGT and PEG.

In conclusion, eating aspects are fundamental in life for patients with head and neck cancer, but the perception of general or disease-related quality of life did not differ between patients receiving enteral nutrition and patients who did not. Patients receiving enteral nutrition regarded that type of treatment as something positive and necessary. However, both NGT and PEG were associated with restrictions with different spectra. From the patients' perspective neither of the two feeding tubes was clearly in favour. We suggest that more studies are needed on how the choice of enteral feeding tube can be evidence-based, and incorporating the patients' perspective.

Acknowledgements

We wish to thank Lena Wettergren for help with the interview instruments and Anna-Maria Svensson for help with the interviews, as well as all the patients who participated in this study.

Funding: This study was sponsored by the Swedish Cancer Society (049503), the Swedish Larynx Foundation (30/06) and the Fund of Goldi and Ludvig Berglund, Sweden.

Declaration of interest: The authors report no conflicts of interest. The authors alone are responsible for the content and writing of the paper.

References

1. Argiris A, Karamouzis MV, Raben D, Ferris RL. Head and neck cancer. *Lancet*. 2008;371:1695-709.
2. Lee HF, Liu HE. Prospective changes of the quality of life for patients newly diagnosed with oral cancer during the acute stage. *Eur J Oncol Nurs*. 2010;14:310-15.
3. Ringash J, Lockwood G, O'Sullivan B, Warde P, Bayley A, Cummings B, et al. Hyperfractionated, accelerated radiotherapy for locally advanced head and neck cancer: quality of life in a prospective phase I/II trial. *Radiother Oncol*. 2008;87:181-7.
4. Nordgren M, Jannert M, Boysen M, Ahlner-Elmqvist M, Silander E, Bjordal K, et al. Health-related quality of life in patients with pharyngeal carcinoma: a five-year follow-up. *Head Neck*. 2006;28:339-49.
5. Batty J. Nutrition. In Feber T, editor. *Head and neck oncology nursing*. London: Whurr Publishers; 2000. p 171-88.
6. Larsson M, Hedelin B, Johansson I, Athlin E. Eating problems and weight loss for patients with head and neck cancer: a chart review from diagnosis until one year after treatment. *Cancer Nurs*. 2005;28:425-35.
7. Ravasco P, Monteiro-Grillo I, Vidal PM, Camilo ME. Nutritional deterioration in cancer: the role of disease and diet. *Clin Oncol (R Coll Radiol)*. 2003;15:443-50.
8. Lees J. Nasogastric and percutaneous endoscopic gastrostomy feeding in head and neck cancer patients receiving radiotherapy treatment at a regional oncology unit: a two year study. *Eur J Cancer Care (Engl)*. 1997;6:45-9.
9. Ehrsson YT, Langius-Eklof A, Laurell G. Nutritional surveillance and weight loss in head and neck cancer patients. *Support Care Cancer*. 2012;20:757-65.
10. Gillison ML. Current topics in the epidemiology of oral cavity and oropharyngeal cancers. *Head Neck*. 2007;29:779-92.
11. Hofstra EI, Hofer SO, Nauta JM, Roodenburg JL, Lichtendahl DH. Oral functional outcome after intraoral reconstruction with nasolabial flaps. *Br J Plast Surg*. 2004;57:150-5.
12. Lochs H, Allison SP, Meier R, Pirlich M, Kondrup J, Schneider S, et al. Introductory to the ESPEN Guidelines on Enteral Nutrition: terminology, definitions and general topics. *Clin Nutr*. 2006;25:180-6.
13. Löser C, Aschl G, Hebuterne X, Mathus-Vliegen EM, Muscaritoli M, Niv Y, et al. ESPEN guidelines on artificial enteral nutrition-percutaneous endoscopic gastrostomy (PEG). *Clin Nutr*. 2005;24:848-61.

14. Ehrsson YT, Langius-Eklof A, Bark T, Laurell G. Percutaneous endoscopic gastrostomy (PEG) - a long-term follow-up study in head and neck cancer patients. *Clin Otolaryngol Allied Sci.* 2004;29:740–6.
15. Zuercher BF, Grosjean P, Monnier P. Percutaneous endoscopic gastrostomy in head and neck cancer patients: indications, techniques, complications and results. *Eur Arch Otorhinolaryngol.* 2011;268:623–9.
16. Morton RP, Crowder VL, Mawdsley R, Ong E, Izzard M. Elective gastrostomy, nutritional status and quality of life in advanced head and neck cancer patients receiving chemoradiotherapy. *ANZ J Surg.* 2009;79:713–18.
17. Corry J, Poon W, McPhee N, Milner AD, Cruickshank D, Porceddu SV, et al. Prospective study of percutaneous endoscopic gastrostomy tubes versus nasogastric tubes for enteral feeding in patients with head and neck cancer undergoing (chemo)radiation. *Head Neck.* 2009;31:867–76.
18. Haberman M, Bush N. Quality of life methodological and measurement issues. In King C, Hinds P, editors. *Quality of life from nursing and patients perspectives. Theory, research, practice.* 3rd edition. London: Jones and Bartlett Learning; 2012. p 167–95.
19. Doward LC, McKenna SP. Defining patient-reported outcomes. *Value Health.* 2004;7:S4–8.
20. Naughton MJ, Shumaker SA. The case for domains of function in quality of life assessment. *Qual Life Res.* 2003;12:73–80.
21. Aaronson NK, Ahmedzai S, Bergman B, Bullinger M, Cull A, Duez NJ, et al. The European Organization for Research and Treatment of Cancer QLQ-C30: a quality-of-life instrument for use in international clinical trials in oncology. *J Natl Cancer Inst.* 1993;85:365–76.
22. Bjordal K, Hammerlid E, Ahlner-Elmqvist M, de Graeff A, Boysen M, Evensen JF, et al. Quality of life in head and neck cancer patients: validation of the European Organization for Research and Treatment of Cancer Quality of Life Questionnaire-H&N35. *J Clin Oncol.* 1999;17:1008–19.
23. Hassan SJ, Weymuller EA. Assessment of quality of life in head and neck cancer patients. *Head Neck.* 1993;15:485–96.
24. Rogers SN, Gwanne S, Lowe D, Humphris G, Yueh B, Weymuller EA. The addition of mood and anxiety domains to the University of Washington quality of life scale. *Head Neck.* 2002;24:521–9.
25. Lang H, France E, Williams B, Humphris G, Wells M. The psychological experience of living with head and neck cancer: a systematic review and meta-synthesis. *Psychooncology.* 2013;22:2648–63.
26. Browne JP, O’Boyle CA, McGee HM, McDonald NJ, Joyce CR. Development of a direct weighting procedure for quality of life domains. *Qual Life Res.* 1997;6:301–9.
27. Hickey AM, Bury G, O’Boyle CA, Bradley F, O’Kelly FD, Shannon W. A new short form individual quality of life measure (SEIQoL-DW): application in a cohort of individuals with HIV/AIDS. *BMJ.* 1996;313:29–33.
28. Wettergren L, Bjorkholm M, Axdorph U, Bowling A, Langius-Eklof A. Individual quality of life in long-term survivors of Hodgkin’s lymphoma—a comparative study. *Qual Life Res.* 2003;12:545–54.
29. Wettergren L, Bjorkholm M, Langius-Eklof A. Validation of an extended version of the SEIQoL-DW in a cohort of Hodgkin lymphoma’ survivors. *Qual Life Res.* 2005;14:2329–33.
30. Elo S, Kyngäs H. The qualitative content analysis process. *J Adv Nurs.* 2008;62:107–15.
31. Sandelowski M. Real qualitative researchers do not count: the use of numbers in qualitative research. *Res Nurs Health.* 2001;24:230–40.
32. Stone PC, Murphy RF, Matar HE, Almerie MQ. Measuring the individual quality of life of patients with prostate cancer. *Prostate Cancer Prostatic Dis.* 2008;11:390–6.
33. Wettergren L, Sprangers M, Bjorkholm M, Langius-Eklof A. Quality of life before and one year following stem cell transplantation using an individualized and a standardized instrument. *Psychooncology.* 2008;17:338–46.
34. Sadasivan A, Faizal B, Kumar M. Nasogastric and percutaneous endoscopic gastrostomy tube use in advanced head and neck cancer patients: a comparative study. *J Pain Palliat Care Pharmacother.* 2012;26:226–32.
35. Sundberg KK, Doukkali E, Lampic C, Eriksson LE, Arvidson J, Wettergren L. Long-term survivors of childhood cancer report quality of life and health status in parity with a comparison group. *Pediatr Blood Cancer.* 2010;55:337–43.
36. Sundberg KK, Lampic C, Bjork O, Arvidson J, Wettergren L. Positive and negative consequences of childhood cancer influencing the lives of young adults. *Eur J Oncol Nurs.* 2009;13:164–70.
37. Mowry SE, Ho A, Lotempio MM, Sadeghi A, Blackwell KE, Wang MB. Quality of life in advanced oropharyngeal carcinoma after chemoradiation versus surgery and radiation. *Laryngoscope.* 2006;116:1589–93.