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Feasibility and impact of a dedicated multidisciplinary rehabilitation program on health-related quality of life in advanced head and neck cancer patients

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Abstract In an observational prospective study, feasibility and outcomes of a dedicated multidisciplinary rehabilitation program (HNR) for head and neck cancer (HNC) patients were evaluated. HRQoL was assessed before and after HNR with EORTC C30 and H&N-35 QoL questionnaires in 52 consecutive patients. Initial HRQoL scores were compared with EORTC reference scores for HNC patients and post-HNR with those available for the general healthy population. Distress was assessed before and after HNR with the distress thermometer (DT). At completion of HNR with a mean duration of 7 months, overall HRQoL was significantly improved ($p < 0.001$). Role, Emotional, and Social function scales and most EORTC C30 and H&N35 symptom scale items showed a statistically

significant ($p < 0.01$) and clinically relevant improvement. Mean distress score before HNR was above the cutoff value of 5, suggesting the need for referral to rehabilitation. After completing HNR, distress decreased significantly to 3.0 ($p < 0.001$). HRQoL pretreatment was poorer than that of the EORTC reference HNC population, whereas at the completion of the HNR program, the HRQoL was comparable to that of the general population reference level. We conclude that a dedicated multidisciplinary HNR program is feasible and suggest that it has a positive impact on HRQoL. The multidisciplinary approach may have added value over mono-disciplinary interventions. However, our results should be judged cautiously due to the observational nature of the study.

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Keywords Head and neck cancer · Multidisciplinary rehabilitation · Health-related quality of life · Distress

Introduction

The incidence of head and neck cancer (HNC) in the Netherlands is 17/100,000, almost 5 % of the total cancer incidence. This makes HNC part of the top 10 most registered cancers in the Netherlands (Netherlands Cancer registry). Treatment options for HNC are surgery, radiotherapy (RT), concomitant chemo-radiotherapy (CRT), photodynamic therapy, or a combination of these modalities [1, 2]. Survival rates for HNC are slowly increasing, and the impact of the treatment of HNC on health-related quality of life (HRQoL) is receiving more and more attention [3–5]. In general, the focus is changing toward long-term QoL and late side effects of HNC treatment and how to cope in life after treatment. Many patients remain restricted in daily activity and functioning after treatment

for HNC because of dysphagia, altered speech, shoulder disability, facial and/or physical disfigurement, psychosocial problems, and/or fatigue [6–9].

Studies on the effects of rehabilitation after treatment for HNC mainly focus on mono-disciplinary interventions, such as speech and language therapy, interventions for nutritional problems, psychosocial support, physical therapy, and/or exercise [10–13]. There is little information though on the effects and possible added value of combining these mono-disciplinary interventions into a multidisciplinary rehabilitation program, especially with respect to HRQoL [14–16]. Based on existing supportive care before, during and after treatment for HNC in our institute, such a multidisciplinary rehabilitation program was set up in collaboration with one of the local rehabilitation institutes. Based on the WHO definition of health [17], this Head and Neck Rehabilitation program (HNR) aimed to optimize all aspects of physical and social functioning after treatment for HNC. The rationale of multidisciplinary rehabilitation was that a coordinated approach is often more effective than separate treatments by the involved disciplines. Considering that, in patients with HNC, physical and psychosocial rehabilitation needs are often interrelated, this integrated approach might achieve larger improvements on functioning, social participation, and quality of life, compared to conventional, multiple mono-disciplinary interventions.

In this paper, the structure and feasibility of the program is described and the changes in HRQoL outcomes are evaluated in a prospective series of patients who were treated in our comprehensive cancer center between 2011 and 2014.

The Head and Neck Rehabilitation program (HNR)

Patients become eligible for rehabilitation if there are extensive function disorders, and prolonged and/or incomplete recovery is expected. Patients with multiple interrelated problems (impairments, activity, and/or participation limitations), who are expectedly not able to resolve these problems themselves, are also eligible for a multidisciplinary rehabilitation program [18]. Eligible patients are identified by the head and neck surgeon, radiotherapist, head and neck nurse, allied health professionals, or by the case manager of the HNR program (a specialized HNC nurse). All potentially eligible patients are screened for rehabilitation needs by the case manager under supervision of a rehabilitation physician. Eligibility (that is, the presence of complex and multiple rehabilitation needs) is assessed in an interview and with the help of the Dutch Distress thermometer [18, 19]. If patients have needs that most likely can be resolved by a mono-disciplinary intervention, patients are referred to in-hospital or primary

allied health care, mostly after consulting the relevant allied health professional or psychosocial team member(s). The rehabilitation physician sees all eligible patients with multiple or complex rehabilitation needs for intake. The intake consists of identifying the main health problem(s), mapping out the complaints and problems in day-to-day functioning that result from the condition and/or treatment, checking for contra-indications, and estimating the suitability for rehabilitation treatment. The rehabilitation physician decides which rehabilitation interventions are required and refers to the allied health disciplines involved. Baseline measurements of HRQoL are done and of additional measures (by involved disciplines) that are relevant to the identified problems. Each involved discipline draws up individual SMART rehabilitation goals (SMART criteria: specific, measurable, attainable, relevant, and time-bound) in consultation with the patient. In a multidisciplinary team meeting, the main rehabilitation goal is determined and SMART goals are adjusted if needed. Progress on the goals is evaluated every 6–8 weeks during rehabilitation in team meetings. Progress is monitored with the help of validated instruments, with each allied health discipline using their own clinimetrics. The outline of the HNR program is shown in the flowchart provided as “Online supplement 1,” and a summary of the allied health modules used in the present study is provided as “Online supplement 2.” Full details on the evidence, content, and clinimetrics used of all modules are available in the HNR protocol on request [20].

The multidisciplinary team consists of a head and neck surgical oncologist, radiotherapist, rehabilitation physician, physical therapist, occupational therapist, speech language pathologist, social worker, community psychiatric nurse, nutritionist, psychologist, and the oncology nurse/case manager. Main goal of HNR program is to treat/assist patients to participate in society taken into account their capabilities. The modular program is tailored specifically to patients’ individual needs and goals. The program has been set up based on the International Classification of Functioning, Disability and Health (ICF) model [21]. Where possible the Head and Neck ICF core set for classification of the treatment modules was used [22–24], and results of the rehabilitation will be considered as improvements in the functioning of the ICF components (functional and anatomical properties, activity, and participation), see also “Online supplement 2.” Treatment modules are evidence based to the best possible extent, and encompass speech therapy, (preventive) swallowing rehabilitation, mime-therapy, trismus treatment, shoulder/neck exercise and/or therapy, physical exercises, energy conservation techniques, guidance in return to work, general and specific nutritional advice, and guidance in coping and adjustment. The choice of modules as well as the duration and

frequency of treatment depends on the need for help, and is determined (SMART) prior to starting the program for each individual patient.

A pilot started in 2010, and from the end of 2011 till present, the HNR program was offered to patients. The National Health Insurance Institute [Zorginstituut Nederland, formerly CVZ (College van Zorgverzekeraars)] has recognized this HNR program as a multidisciplinary rehabilitation program entitled to reimbursement under the basic medical insurance package approved in the Netherlands. There is no restriction on disease stage or location, age, or gender for inclusion in the HNR program. Exclusion criteria for the HNR program are interfering co-morbidity, interfering psychiatric illness, or severe drug/alcohol abuse. Patients must be teachable, trainable, and able to understand the Dutch language.

Materials and methods

Study population

Between October 2011 and March 2014, 156 patients were screened for eligibility/inclusion in the HNR program. 59 patients were not included in the HNR program because there was no rehabilitation need ($n = 17$), because of an indicated or expected lack of compliance ($n = 12$), referral to a primary care facility ($n = 9$), or mono-disciplinary support needs only ($n = 8$). Moreover, there were 13 patients who followed a preventive swallowing rehabilitation program during combined chemo-radiotherapy (CRT). This preventive rehabilitation module starts prior to and is continued during CRT with swallowing exercises in order to minimize dysphagia and/or trismus, and provides nutritional guidance in monitoring intake and weight [10]. These 13 patients no longer had complex function or rehabilitation needs after treatment, and therefore were not included in this HNR program assessment. This left 97 patients for inclusion in the HNR program. Of this cohort, 32 patients were excluded from the analyses because of progressive disease, 8 patients because of incomplete questionnaires, and 5 due to premature ending of the HNR program (2 due to non-compliance after all, and 3 due to a prohibitive travel distance to the Institute). These patients did not differ with respect to their initial epidemiologic and HRQoL data with the 52 evaluable patients (data not shown). This resulted in 52 patients, who completed the HNR program, and who were available for analysis (see flow chart—Fig. 1). The majority of these 52 patients (71.2 %) had stage IV disease. All patients included in this prospective series had curative treatment for HNC in our institute, with the exception of two patients who were treated in another Dutch Head and Neck Cancer Centre.

Data collection

Socio-demographic and clinical data

Socio-demographic data collected were age, gender, marital stage, socio-economic status, smoking, and alcohol use. Disease characteristics included tumor location, tumor stage, treatment type, time after treatment, and rehabilitation duration. All data were collected prospectively and/or withdrawn from medical files.

Patient reported outcome measures

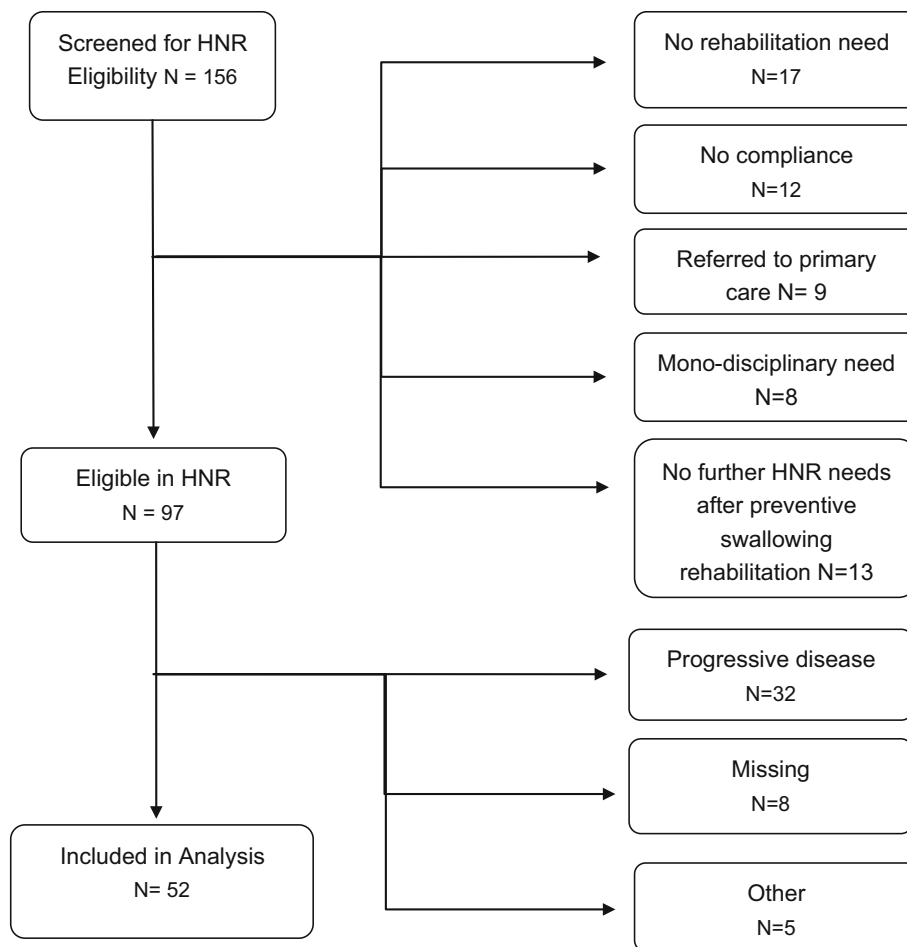
Since the main goal of the HNR program is to optimize QoL, overall HRQoL was used as the primary outcome measure, with the addition of functional and symptom scales. The European Organisation of Research and Treatment of Cancer (EORTC) describe Health-Related Quality of life as the impact of cancer and cancer treatment on the ‘whole well-being of a person.’ For over 30 years, EORTC questionnaires have been used in studies and psychometric properties have been proven in several studies [25–28].

The EORTC QLQ-C30 is a questionnaire developed to assess the quality of life of cancer patients and consists of five functional scales (physical, role, emotional, cognitive, social), nine symptom scales (fatigue, nausea/vomiting, pain, dyspnea, insomnia, appetite loss, constipation, diarrhea, financial difficulties), and a global health status/quality of life (QoL) scale. All of these scales range in score from 0 to 100. A high score represents a higher response level; thus, a high score for a functional scale represents a high/healthy level of functioning, and a high score on global health status/QoL represents a high QoL, but a high score for a symptom scales represents a high level of symptomatology/problems [29]. A difference of ten points in QoL scores is generally considered to be clinically relevant [30, 31].

The additional EORTC QLQ H&N35 is a disease-specific module for HNC that consists of seven multiitem scales that assess pain, swallowing, senses (taste and smell), speech, social eating, social contact, and sexuality. There are also eleven single items concerning teeth, opening mouth, dry mouth, sticky saliva, coughing, feeling ill, painkillers, nutritional supplements, feeding tube, weight loss, and weight gain. Higher scores for symptoms in this H&N-35 questionnaire indicate more problems.

These questionnaires are self-reported and were filled in at onset and at completion of the rehabilitation program. Data were compared to EORTC reference scores for the HNC population and those available for the general population. All EORTC HNC reference data are based on pretreatment HRQoL. Comparison with the HNC

Fig. 1 Flowchart: eligibility and inclusion in Head and Neck Rehabilitation program (HNR) and inclusion in assessment analysis. 156 patients were screened for eligibility for HNR; after intake with the rehabilitation physician, 97 patients were included in HNR. 52 patients remained available for analysis, exclusion from analysis was caused by progressive disease ($n = 32$), incomplete questionnaires ($n = 8$), and other reasons like traveling distance ($n = 5$)



population provides insight in baseline HRQoL of our HNR population. Comparison with the general healthy population may give insight in the attainability of HRQoL after rehabilitation [32].

Distress (defined as an unpleasant state that might affect how one feels, thinks, or acts) was assessed with the distress thermometer (DT) as developed by the National Comprehensive Cancer Network (NCCN) [33]. This is a self-reported and validated questionnaire, reporting the level of distress on a Visual Analogue Scale from 0 (no distress) to 10 (extreme distress). Attached to this ‘thermometer’ is a Problem List (PL) with 47 questions about practical, social, emotional, spiritual, and physical problems. Two Dutch national guidelines (screening for psychosocial care and oncological rehabilitation) recommend the use of the DT with a cutoff value of ≥ 5 for referral to psychosocial care or further screening for multidisciplinary needs (by multiple items/domains on PL) during or after cancer treatment [18, 19]. Therefore, we applied the distress thermometer in all eligible patients before and after HNR [34].

Data were coded before analysis, and the code was only accessible to the principal investigator and the coordinating

investigator to maintain patient confidentiality. Original data are kept in archive.

Statistical analysis

Descriptive statistics of the HNR patients were generated to characterize the study population. Sum scores for the EORTC questionnaires were calculated in accordance with the respective manuals [35]. Paired t tests were used to compare baseline and end-of-program overall HRQoL, function, and (H&N35) symptom scales. The level of significance was set at $p = 0.01$ with a 99 % confidence interval. All analyses were performed using IBM Statistics Package SPSS for Windows version 22.

Results

HNR population

The male to female ratio (3:1) is comparable to most HNC studies. Most of the HNR participants are married with or without children, or living together (total 69 %). The

majority of patients participating in the HNR program is working (57 %) or retired (28.8 %). Mean age of patients is 59 years (range 31–79). The majority of patients have a history of smoking (64 %) and (social) alcohol use (50 %). Although surgical patients may have major function loss, and are therefore more eligible for HNR, most patients (61.5 %) included in HNR program were treated with concomitant chemo-radiotherapy (CRT). Median start of HNR after treatment was at 1 month (IQR 2, range 0–208); most patients treated with CRT started preventive swallowing rehabilitation prior to treatment. Mean duration of rehabilitation program (including preventive swallowing rehabilitation during treatment) is 7 months (median 6 months). All patients ($N = 23$), who required feeding tube support during treatment, were freed of that at completion of the HNR program. Patients characteristics are presented in Table 1.

HNR program outcomes

Choice of interventions in the program was based on individual patients' rehabilitation needs. The speech pathologist was involved in 83 % of cases, the nutritionist in 52 %, the physical therapist in 51.9 %, the occupational therapist in 50 %, and the social work in 46 %; the frequencies of modular interventions by allied health professionals in HNR are presented in Table 2. Overall attainment of the main rehabilitation goal was accomplished in 47 out of 52 patients (90 %).

Results on HRQOL and symptoms are presented below and shown in Table 3.

Health-related quality of life and functional scales

After HNR, a statistically significant and clinically relevant improvement in Global Health status and overall Quality of life was observed [$+16.3$ points ($p < 0.001$, 99 % CI 8.9–23.8)]. Except for Cognitive functioning, all function scales had significantly and positively changed after HNR. Besides a significant improvement in functional scales, also Role functioning ($+25.8/p < 0.001$, 99 % CI 14.2–37.4), Emotional functioning ($+11.3/p = 0.001$, 99 % CI 2.8–19.7), and Social functioning ($+25.6/p < 0.001$, 99 % CI 16.3–35) showed significant, clinically relevant improvements (Table 3).

Symptom scales

In five of nine EORTC C30 symptom scales, significant and clinically relevant (>10 points) improvements were observed, meaning fewer symptoms: fatigue ($-13.5/p < 0.001$, 99 % CI -21.6 to -5.5), pain ($-13.5/$

Table 1 Socio-demographic and clinical data in Head and Neck Rehabilitation population

	HNR population ($N = 52$)
Gender frequency (%)	
Male	39 (75 %)
Female	13 (25 %)
Marital stage frequency (%)	
Alone	12 (23 %)
Married	19 (36 %)
Widowed	3 (6 %)
Living with partner	2 (4 %)
Married with children	15 (29 %)
Alone with children	1 (2 %)
Economic stage frequency (%)	
Unemployed	3 (6 %)
Employed	30 (57 %)
Fulltime	18 (34 %)
Part-time	12 (23 %)
Disabled	2 (4 %)
Reintegration	2 (4 %)
Retired	15 (29 %)
Smoking frequency (%)	
No never	15 (29 %)
Smoking	3 (6 %)
Stopped smoking	30 (58 %)
Missing	4 (7 %)
Alcohol frequency (%)	
None	11 (21 %)
Social (<2 daily)	26 (50 %)
Mild (2–4 daily)	9 (17 %)
Severe (>4 daily)	2 (4 %)
Missing	4 (8 %)
Age years	
Mean (median)	59.3 (59)
Range	31–79
Tumor Location frequency (%)	
Hypopharynx	2 (4 %)
Larynx	7 (13 %)
Oral cavity	14 (27 %)
Oropharynx	18 (35 %)
Other	11 (21 %)
Stage frequency (%)	
Stage 1	2 (3.8 %)
Stage 2	1 (1.9 %)
Stage 3	12 (23.1 %)
Stage 4	37 (71.2 %)
Status frequency (%)	
First primary	38 (73 %)
Recurrence/residue	9/1 (19 %)
Second primary	4 (8 %)

Table 1 continued

	HNR population (<i>N</i> = 52)
Treatment frequency (%)	
Chemo-radiotherapy	32 (61 %)
Total Laryngectomy	2 (4 %)
Commando	1 (2 %)
Radiotherapy	4 (8 %)
Other surgery	2 (4 %)
Surgery +(chemo-) radiotherapy	11 (21 %)
Time since treatment in months	
Median (range)	1 (0 ^a –208)
IQR	2
Rehabilitation duration in months	
Mean (median/range)	7.02 (6/2 to 19)

^a Start HNR for patients treated with CRT starts during treatment—preventive swallowing rehabilitation

$p = 0.001$, 99 % CI -23.3 to -3.6), insomnia ($-15.3/p < 0.001$, 99 % CI -26.2 to -4.4), appetite loss ($-14.0/p = 0.002$, 99 % CI -25.4 to -2.6), and constipation $-18.3/p < 0.001$, 99 % CI -29 to -7.6).

Ten items of the EORTC H&N35 show a significant and clinically relevant symptom score decrease meaning fewer problems. The symptom scale pain decreased ($-12.1/p < 0.001$, 99 % CI -20 to -4.2), swallowing scores decreased ($-10.5/p = 0.005$, 99 % CI -20 to -0.9), speech scores decreased ($-13.1/p < 0.001$, 99 % CI -21.5 to -4.8), social eating decreased ($-10/p = 0.006$, 99 % CI

-19.4 to -0.6), sexuality improved ($-15/p < 0.001$, 99 % CI -25.5 to -4.3), opening mouth scores decreased ($-11.1/p = 0.008$, 99 % CI 21.9 to -0.3), coughing scores decreased ($-14.7/p = 0.001$, 99 % CI -26.3 to -3.1), feeling ill scores decreased meaning fewer problems ($-12.2/p = 0.001$, 99 % CI -21.4 to -3), painkillers scores decreased meaningless usage (-40.4 , $p < 0.001$, 99 % CI -60.2 to -20.6), and feeding tube use decreased ($-17.6/p = 0.002$, 99 % CI -32.1 to -3.2). No significant differences were found for the symptoms dyspnea, financial difficulties, senses, teeth, dry mouth, sticky saliva, nutritional supplements, weight loss, and weight gain.

Distress

Mean distress score before HNR was 5.4 out of 10 (median 6.0), which is above the cutoff value of ≥ 5 suggesting the need for referral to psychosocial care or further screening. There was a significant mean difference of -2.3 comparing Distress Thermometer scores before and after completion of the HNR program ($p < 0.001$, 99 % CI -3.1 to -1.5).

Comparison of QoL outcomes with EORTC reference groups

HNR QoL scores were compared to EORTC reference scores for the Head and Neck population and the General population. Results are presented in Table 4.

Table 2 Frequencies (%) of modular interventions applied by allied health professionals in Head and Neck Rehabilitation Program (HNR)

HNR allied health professionals	Nutritionist	Occupational therapist	Physical therapist	Speech and language pathologist	Social worker
Modular intervention	41 (78.8 %)	26 (50 %)	27 (51.9 %)	43 (82.7 %)	24 (46.2 %)
No modular intervention	10 (19.2 %)	26 (50 %)	13 (25 %)	9 (17.3 %)	27 (51.9 %)
Referred to primary care	1 (2 %)	–	12 (23.1 %)	–	1 (1.9 %)
Modular interventions applied	Feeding tube 23 (44.2 %)	Daily functioning 20 (38.5 %)	Preventive or curative shoulder rehabilitation 17 (32.7 %)	Voice and Speech rehabilitation 22 (52.3 %)	Guidance coping and adjustment 24 (46.2 %)
	Weight monitoring 41 (78.8 %)	Return to work 12 (23.1 %)	Exercise tolerance 28 (53.8 %)	Swallowing rehabilitation 38 (73.1 %)	
	Additional Nutrition 38 (73.1 %)	Energy conservation 22(42.4 %)	Lymphedema 10 (19.2 %)	Smell rehabilitation 3 (5.8 %)	
	Nutritional Advice 32 (61.5 %)			Trismus treatment 28 (53.8 %)	
				Hearing training/ advice 1(1.9 %)	

Table 3 EORTC–C30 and H&N 35 mean differences on health-related quality of life

	Before HNR		After HNR		Comparison		
	Mean (SD)	<i>n</i>	Mean (SD)	<i>n</i>	Mean difference before/after	<i>n</i>	<i>p</i> value (99 % CI)
EORTC QLQ-C30							
Functional scales							
Global health status/QoL	55 (20.3)	52	71.3 (17.5)	52	+16.3	52	<0.001 (8.9 to 23.8)
Physical functioning	77.1 (17.5)	52	85.4 (12.8)	51	+8.8	51	<0.001 (3.6 to 14)
Role functioning	50 (31.3)	52	75.5 (22.7)	51	+25.8	51	<0.001 (14.2 to 37.4)
Emotional functioning	67.7 (23.9)	52	79 (24.4)	52	+11.3	52	0.001 (2.8 to 19.7)
Cognitive functioning	78.5 (20.2)	52	84.3 (18.5)	52	+5.7	52	0.025 (−0.9 to 12.5)
Social functioning	56.7 (29.2)	52	82.4 (22.5)	52	+25.6	52	<0.001 (16.3 to 35)
Symptom scales							
Fatigue	43.6 (25)	52	30.3 (21.8)	51	−13.5	51	<0.001 (−21.6 to −5.5)
Nausea/vomiting	11.9 (22.2)	52	2.6 (6.1)	51	−9.2	51	0.004 (−17.1 to −1.1)
Pain	30.4 (27.8)	52	17 (25)	52	−13.5	52	0.001 (−23.3 to −3.6)
Dyspnea	19.9 (25.8)	52	16.3 (24.4)	51	−3.9	51	0.182 (−11.7 to 3.8)
Insomnia	36.6 (30.7)	51	22.2 (26.4)	51	−15.3	50	<0.001 (−26.2 to −4.4)
Appetite loss	28.1 (33.6)	51	13.7 (22.3)	51	−14.0	50	0.002 (−25.4 to −2.6)
Constipation	23.7 (28.3)	52	4.6 (11.6)	51	−18.3	51	0.001 (−29 to −7.6)
Diarrhea	10.3 (16.9)	52	2.6 (11.2)	51	−7.8	51	0.006 (−15.1 to −0.5)
Financial difficulties	15.4 (29.1)	52	14.7 (29.8)	52	−0.6	52	0.859 (−10.2 to 8.9)
EORTC H&N 35							
Pain	30.8 (25.6)	52	18.6 (19.3)	52	−12.1	52	<0.001 (−20 to −4.2)
Swallowing	28.6 (27.1)	52	18.1 (20.1)	52	−10.5	52	0.005 (−20 to −0.9)
Senses	30.8 (31.2)	52	25.3 (22.5)	52	−5.4	52	0.174 (−16 to 5.1)
Speech	28.1 (25.7)	52	15 (17)	52	−13.1	52	0.001 (−21.5 to −4.8)
Social eating	34.2 (28.1)	52	24.3 (23.7)	52	−10	52	0.006 (−19.4 to −0.6)
Social contact	18.3 (24.7)	52	9.6 (15.6)	52	−8.7	52	0.001 (−15.3 to −1.9)
Sexuality	38.4 (37)	49	24.3 (30)	48	−15	48	0.001 (−25.5 to −4.3)
Teeth	19.2 (29)	52	21.6 (28.9)	51	+2.6	51	0.569 (−9.6 to 14.8)
Opening mouth	28.8 (33)	52	18.3 (26.9)	51	−11.1	51	0.008 (21.9 to −0.3)
Dry mouth	43.6 (33.4)	52	52.6 (33.9)	52	9.0	52	0.095 (−5.1 to 23.6)
Sticky saliva	41.7 (34.9)	52	35.9 (31.2)	51	−5.9	51	0.202 (−18.1 to 6.3)
Coughing	34.6 (33)	52	19.9 (20.1)	52	−14.7	52	0.001 (−26.3 to −3.1)
Feeling ill	24.4 (27.3)	52	12.2 (20.9)	52	−12.2	52	0.001 (−21.4 to −3)
Pain killers	71.2 (45.7)	52	30.8 (46.6)	52	−40.4	52	<0.001 (−60.2 to −20.6)
Nutritional supplements	50 (50.5)	52	36.5 (48.6)	52	−13.5	52	0.164 (−38.9 to 12)
Feeding tube	19.2 (39.8)	52	0 (0)	51	−17.6	51	0.002 (−32.1 to −3.2)
Weight loss	25 (43.7)	52	21.2 (41.2)	52	−3.8	52	0.598 (−23.2 to 15.5)
Weight gain	34.6 (48)	52	27.5 (45.1)	51	−5.9	51	0.411 (−24.9 to 13.1)
Distress thermometer mean	5.4 (2.2)	50	3.0 (2.2)	52	−2.3	50	<0.001 (−3.1 to −1.5)

Functional and Symptom scales. Mean difference on distress thermometer (DT) compared before/after Head and Neck Rehabilitation (HNR). A higher mean on functional scores represents a better QoL; a higher score on Symptom scales and HN 35 represents lower QoL. Clinically relevant differences are printed in bold

Comparison of our patient cohort with the EORTC HNC reference population, based on baseline measurements, shows that the present HNR population had a clinically relevant lower HRQoL on functioning scales (role −28.9, social −25.9) at baseline. Global health status and HRQoL

were −9.1 points lower in the HNR population. Except for financial problems, the HNR participants had higher symptom scales than the EORTC HNC reference population; the differences for fatigue +16.7, appetite loss +10.4, and constipation +12.6 are clinically relevant as well.

Table 4 Differences in health-related quality of life scores on EORTC–C30 and H&N 35 global health status/quality of life

	Before HNR Mean (SD)	H&N population <i>N</i> = 2929 Mean (SD)	Difference before HNR—H&N Ref. population	After HNR Mean (SD)	General population <i>N</i> = 7802 Mean (SD)	Difference after HNR—General population
EORTC QLQ-C30						
Functional scales						
Global health status/QoL	55 (20.3)	64.1 (22.7)	−9.1	71.3 (17.5)	71.2 (22.4)	0.1
Physical functioning	77.1 (17.5)	81.2 (20.4)	−4.1	85.4 (12.8)	89.8 (16.2)	−4.4
Role functioning	50 (31.3)	78.9 (28.1)	−28.9	75.5 (22.7)	84.7 (25.4)	−9.2
Emotional functioning	67.7 (23.9)	72.5 (24.1)	−4.8	79 (24.4)	76.3 (22.8)	2.7
Cognitive functioning	78.5 (20.2)	85.9 (19.7)	−7.4	84.3 (18.5)	86.1 (20)	−1.8
Social functioning	56.7 (29.2)	82.6 (24.7)	−25.9	82.4 (22.5)	87.5 (22.9)	−5.1
Symptom scales						
Fatigue	43.6 (25)	26.9 (24.9)	16.7	30.3 (21.8)	24.1 (24)	6.2
Nausea/vomiting	11.9 (22.2)	5.3 (13.7)	6.6	2.6 (6.1)	3.7 (11.7)	−1.1
Pain	30.4 (27.8)	23.2 (26.1)	7.2	17 (25)	20.9 (27.6)	−3.9
Dyspnea	19.9 (25.8)	18.2 (26.9)	1.7	16.3 (24.4)	11.8 (22.8)	4.5
Insomnia	36.6 (30.7)	27.3 (31.8)	9.3	22.2 (26.4)	21.8 (29.7)	0.4
Appetite loss	28.1 (33.6)	17.7 (28.2)	10.4	13.7 (22.3)	6.7 (18.3)	7.0
Constipation	23.7 (28.3)	11.1 (22.6)	12.6	4.6 (11.6)	6.7 (18.4)	−2.1
Diarrhea	10.3 (16.9)	6.1 (16.9)	4.2	2.6 (11.2)	7.0 (18)	−4.4
Financial difficulties	15.4 (29.1)	18.2 (29.6)	−2.8	14.7 (29.8)	9.5 (23.3)	5.2
EORTC H&N 35						
Pain	30.8 (25.6)	27.1 (24)	3.7	18.6 (19.3)		
Swallowing	28.6 (27.1)	23.9 (25.3)	4.7	18.1 (20.1)		
Senses	30.8 (31.2)	19.3 (28.8)	11.5	25.3 (22.5)		
Speech	28.1 (25.7)	28.0 (27.6)	0.1	15 (17)		
Social eating	34.2 (28.1)	20.9 (25.1)	13.3	24.3 (23.7)		
Social contact	18.3 (24.7)	13.0 (18.9)	5.3	9.6 (15.6)		
Sexuality	38.4 (37)	31.3 (35.2)	7.1	24.3 (30)		
Teeth	19.2 (29)	25.5 (33.2)	−6.3	21.6 (28.9)		
Opening mouth	28.8 (33)	19.5 (29.5)	9.3	18.3 (26.9)		
Dry mouth	43.6 (33.4)	30.7 (33.4)	12.9	52.6 (33.9)		
Sticky saliva	41.7 (34.9)	30.5 (33.9)	11.2	35.9 (31.2)		
Coughing	34.6 (33)	33.9 (32.2)	0.7	19.9 (20.1)		
Feeling ill	24.4 (27.3)	21.6 (28.9)	2.8	12.2 (20.9)		
Pain killers	71.2 (45.7)	49.5 (50)	21.7	30.8 (46.6)		
Nutritional supplements	50 (50.5)	26.7 (44.2)	23.3	36.5 (48.6)		
Feeding tube	19.2 (39.8)	19.7 (39.8)	−0.5	0 (0)		
Weight loss	25 (43.7)	38.9 (48.8)	−13.9	21.2 (41.2)		
Weight gain	34.6 (48)	27.3 (44.6)	7.3	27.5 (45.1)		

Functional and Symptom scales compared Head and Neck Rehabilitation population (before HNR) with Head and Neck EORTC reference scores (H&N population) and after rehabilitation (after HNR) compared with EORTC reference scores of the General healthy population (general population)

A higher mean on functional scores represents a better QoL; a higher score on Symptom scales and HN 35 represents lower QoL. Clinically relevant differences are printed in bold

When comparing H&N35 symptom scales, relevant clinical differences between HNR and EORTC HNC reference population in senses, +11.5, social eating +13.3, dry mouth +12.9, sticky saliva +11.2, painkillers +21.7,

nutritional supplements +23.3, and weight loss—13.9 were observed.

There were no clinically relevant differences (>10 points) between our HNR population after completion of

the HNR program and the EORTC general population. Global health status and quality of life are almost equal, or even slightly better, in our sample, i.e., 71.3 in the HNR population versus 71.2 in the general healthy population.

Discussion

The purpose of this study was to assess the feasibility and outcomes of a multidisciplinary head and neck cancer rehabilitation (HNR) program and its impact on HRQoL. Our analyses suggest that there is a significant improvement of HRQoL after HNR. Moreover, on most functional and symptom scales, there was also a significant and clinically relevant improvement. To set these results into perspective, the baseline measurements were compared with EORTC reference scores for HNC and the scores after rehabilitation with the EORTC reference scores for the general population. These comparisons show that at baseline HRQoL in the present HNR population is low(er) in comparison with the reference group of HNC patients. The available patient characteristics of the EORTC HNC reference data were comparable with our HNR cohort, except that the HNR cohort had significant higher stages (94.3 versus 59 % stage III–IV), which, in part, may account for the lower HRQoL. This suggests that our patient selection indeed has identified a subgroup of patients with complex and/or multiple limitations and/or impairments requiring dedicated HNC rehabilitation. The HNR program turns out to be feasible, considering the goal attainment rate of 90 %. Comparing HRQoL after rehabilitation with the general healthy population reveals no clinically relevant differences. This suggests that, despite the selection of a ‘more complex/impaired’ patient population, most participants to the HNR program achieve the main goals of HNR, improve functioning, social participation, and optimize quality of life. Furthermore, aside from improvements in most of the relevant symptoms and function scales, it is worth noting that all HNR participants starting the program with a feeding tube completed the rehabilitation program without requiring a feeding tube. This confirms results from prior studies in our department implying that dedicated preventive swallowing rehabilitation is effective, as is also illustrated by the 13 patients who did not have further rehabilitation needs after this intervention [36]. Mean duration of the HNR program is 7 months. The literature indicates that it takes up to 1 year to regain HRQoL after treatment for HNC [37–42]. In accordance with national guidelines, HNC treatment preferably starts within a month after diagnosis [43, 44]. Even taking into account the delay from diagnosis till treatment, this suggests that our multidisciplinary HNR program may shorten the recovery period

needed to accomplish optimal functioning and HRQoL after treatment.

Limitations

Surgically treated patients are underrepresented in this series, despite the presence of well-known functional impairments in this group. This is due to selective referral of these patients, who are (still) not prospectively screened in our Institution. This is also true for the lower stage HNC patients, who are treated with RT only. The number of dropouts (approximately one-third) caused by progressive disease or metastasis was relatively high. This number is not high from an oncological perspective, but it may have biased the results on HRQoL due to differential loss to follow-up of those patients with the lowest HRQoL. The 13 (missing) patients not included in analysis could also have influenced study results. But as already mentioned, we have checked whether these 13 excluded patients are different from the 52 in their initial epidemiologic and HRQoL data, and they are not.

Nevertheless, this study is limited by its observational nature. The observed positive outcome of this HNR program would warrant further investigation in a controlled design, keeping in mind that provision of rehabilitation could be considered ‘best practice,’ which deems randomization questionable from an ethical perspective.

Conclusion

The presented data support the feasibility of multidisciplinary head and neck rehabilitation. The results suggest a positive impact on HRQoL. Results show a significant and clinically relevant improvement in HRQoL after rehabilitation. Moreover, the HRQoL pretreatment was lower/poorer than that of the EORTC reference HNC population, whereas at completion of the HNR program, the HRQoL was comparable to that of the general population reference level.

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