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Exploratory study of functional and psychological factors associated with employment status in patients with head and neck cancer

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Abstract

Background: Compared with other malignancies, head and neck cancer (HNC) increases the risk of not returning to work (RTW).

Methods: Within a cross-sectional study, patients with HNC filled out the OncoFunction questionnaire, a version of the International Classification of Functioning Core Sets for HNC. In 231 patients below 65 years of age, associations of sociodemographic, clinical, functional, and psychological factors with employment and participation in rehabilitation program were explored.

Results: Unemployed patients reported more swallowing difficulties and speaking problems. Being unemployed was associated with higher levels of depressive and anxiety symptoms, fatigue, and lower global health. Rehabilitation participation was not significantly associated with any of the assessed factors except for smoking.

Conclusions: Unemployed patients with HNC are more burdened than employed patients with HNC regarding clinical, psychological, and functional factors. These differences are more evident later in recovery. Rehabilitation participation was not associated with psychological and functional burden which indicates the need for tailored HNC rehabilitation programs.

KEYWORDS

employment, functional impairment, head and neck cancer, rehabilitation, return to work

1 | INTRODUCTION

The survival rate of patients with cancer has increased considerably due to improved screening methods and treatment regimes. This necessitates increased attention to issues that cancer survivors have to face, such as return to work (RTW): employment creates a sense of normality and appreciation through social participation, and it can positively impact patients' psychological wellbeing.[1] On the other hand, loss of employment disrupts daily routine and can lead to social isolation and lack of confidence.[2] For patients with diverse types of cancer, the

risk of not returning to work after cancer treatment is associated with older age, sex (women), comorbidity, advanced disease stage, and chemotherapy.[3-7] Fatigue, sleeping problems, physical complaints, anxiety, and depression may further complicate RTW.

Whereas many studies investigate the RTW in patients with more common cancers, only a few studies are focusing on RTW in patients with head and neck cancer (HNC). However, several studies suggest that patients with HNC have an increased risk of disability and early retirement and take longer to RTW compared to other patients with cancer.[7-10] This is associated with a higher prevalence of sociodemographic and psychological risk factors such as low educational level, social withdrawal, depression, and anxiety.[11-13] It is important to keep in mind that most studies addressing patients with HNC had a cross-sectional study design, while studies including more cancer entities and locations often had a longitudinal design.

RTW in patients with HNC might be further complicated by the impairment of relevant functional variables: swallowing and breathing problems are a frequent consequence of the tumor and its therapy, as are communication problems and impaired social functioning when the voice function has been affected.[14] A cross-sectional study by Verdonck-de Leeuw et al.[11] reported that anxiety and oral dysfunctions such as trismus, xerostomia, sticky saliva, dental problems, loss of appetite, and problems with social eating and social contacts are associated with the risk of not returning to work. In another cross-sectional study by Buckwalter et al.,[15] patients with HNC reported that they discontinued work because of fatigue, speech, and eating problems. RTW and quality of life are also associated in patients with HNC.[16] Furthermore, alcoholism and tobacco smoking are prevalent before the diagnosis of HNC and increase the risk of recurrence.[17-19] The surgical removal of the tumor and its surrounding tissue often causes visible disfigurement of the face and neck and can lead to a sense of shame and social withdrawal.[20,21] Together with the use of multimodality therapy, commonly applied in patients with HNC, the likelihood of RTW might further decrease. Thus, it can be assumed that patients with HNC face several additional problems concerning RTW in comparison to other patients with cancer. The RTW issue may become even more socioeconomically relevant in the light of the increasing incidence of HPV-related oropharyngeal cancers and the younger age of patients at the time of diagnosis.[22,23]

Information on RTW in patients with HNC in Germany is scarce. The goals of this exploratory study were to assess employment status and RTW in patients with HNC in Germany within the first and second year after diagnosis and to investigate associations between employment status and sociodemographic, clinical, functional, and psychological factors. In order to obtain preliminary impressions regarding the effectiveness of existing rehabilitation programs that may or may not exert an impact on RTW, we performed secondary exploratory analyses comparing those patients who had attended a rehabilitation program with patients who had not attended a rehabilitation program. To assess these factors, we used the OncoFunction questionnaire system, which allows for a reliable assessment of patient-reported outcomes.[24] Results may contribute to better understanding (re)employment in patients with HNC in Germany and possible barriers to RTW and help to design HNC-specific rehabilitation programs.

2 | MATERIAL AND METHODS

2.1 | Patients

The study was designed in the framework of the cohort study LIFE B7 head and neck cancer (approved by the ethics committee of the Medical Faculty Leipzig) and focused on functional and psychological aspects. The clinic adheres to NCCN guidelines (2.2011 FOLL-A) regarding recommendations of aftercare intervals. Patients were invited to participate in the study at time of diagnosis and invited to participate in the substudy OncoFunction if they completed curative treatment and were attending the tumor aftercare consultation of our clinic between July 2013 and June 2018. Patients who gave written informed consent according to the Helsinki Declaration II and with HNC diagnosed after April 2013 were included in the study reporting data obtained from July 2013 to June 2018. The first examination date coincided with the first aftercare consultation. Only patients younger than 65 years at the time of both examinations were included in the analysis. Older patients were excluded, as they were most likely already retired. Patients with less than 50% missing data and examination dates between 3 and 12 months after diagnosis (t1) and between 15 and 24 months (t2) were selected for analysis. If more than one examination occurred during this time, the first available examination date was used for analysis. Further exclusion criteria were severe cognitive impairment, reading problems, and lack of understanding of the German language.

2.2 | Data collection

After registering for the aftercare consultation, patients were asked by the nursing staff to fill out a questionnaire on a tablet computer before the consultation. Collected data were sent online to and stored on a secure server.

After the consultation attending physicians entered the clinically assessed data and selected therapies into the patient's electronic health record. When patients refused to participate, only the clinical data assessed by the physician was collected. Zebralla et al.[24] demonstrated the usability of the OncoFunction system for improved recording of patient data and that nonparticipants did not differ from participants concerning tumor size and localization.

2.3 | Outcome measures

2.3.1 | Patient-reported outcomes

The OncoFunction questionnaire system was derived from the International Classification of Functioning (ICF) developed by the World Health Organisation. The ICF was adapted for patients with HNC by defining and evaluating HNC-related symptoms.[25] The adapted version (ICF Core Sets for head and neck cancer [ICF-HNC]) was validated by Tschiesner et al.[26] The ICF-HNC was developed further and is described in more detail by Harréus et al.,[27] who additionally presented guidelines for clinical practice that help identify individual aftercare and rehabilitation needs. Patients were administered these assessments at both t1 and t2. The patient-reported outcomes selected for analysis were:

Functional characteristics: Functional assessments included self-reported questions concerning laryngectomy ("Did you have a laryngectomy?"), tracheostomy tube ("Do you have a tracheotomy tube at this time?"), a feeding tube ("Do you have a feeding tube?"), voice difficulties (two speech items from the EORTC QLQ-H&N35), swallowing difficulties (all 10 items from the German version of the EAT-10), and pain level (numeric analog scale from "0: no pain" to "10: worst imaginable pain"). The EAT-10 is a 10-item questionnaire to assess dysphagia and has been validated in a German HNC sample by Zaretsky et al.[28] The EORTC QLQ-H&N35 is a disease-specific questionnaire module belonging to the European Organization for Research and Treatment of Cancer Quality of Life Questionnaire Core 30 (EORTC QLQ-C30). This module is intended for use among patients with HNC and assesses HNC-specific symptoms.

Psychological characteristics: Psychological assessments included questions regarding health risk behavior ("Do you smoke currently?" and "Do you drink alcohol currently?"), fatigue (fatigue subscale of the EORTC QLQ-C30), anxiety symptoms (GAD-2), depressive symptoms (PHQ-9), and global quality of life (global quality of life subscale from the EORTC QLQ-C30). The fatigue subscale composed of three items from the EORTC QLQ-C30 measures physical fatigue over the past week in patients with cancer.[29] The GAD-2 is a validated two-item screening tool for detecting generalized anxiety disorder in primary care patients.[30] The PHQ-9 is a well-established nine-item screening instrument to assess depressive symptoms in clinical populations.[31] The global quality of life subscale from the EORTC QLQ-30 is composed of two items.[32] The global quality of life subscale assesses functioning in the past week, and both the PHQ9 and GAD-2 assess symptoms over the past 2 weeks.

Employment status: The current employment status was assessed with one question ("Are you currently employed?").

Rehabilitation status: The attendance in a rehabilitation program was assessed with one question ("Have you attended a rehabilitation program?").

Physician-reported outcomes: The following clinically assessed characteristics were analyzed for this study: tumor site (oropharynx, larynx/hypopharynx, oral cavity, other), treatment modality (surgery, radiotherapy, chemotherapy), the occurrence of metastases, recurrence of cancer, the occurrence of secondary tumor, and tumor stage.

2.4 | Statistical analyses

The dependent variable was employment status (employed vs. unemployed) in our primary analyses, and rehabilitation status (did participate in rehabilitation vs. did not participate in rehabilitation) in ancillary analyses. Univariate cross-sectional analysis explored t1 and t2 variables associated with employment status at t1 and t2, respectively. An additional cross-sectional analysis explored associations between rehabilitation status and variables at t1.

Sociodemographic variables included sex (men vs. women) and age (years). Clinical variables included tumor site (oropharynx vs. larynx/hypopharynx vs. oral cavity vs. other), treatment modality (surgery only vs. chemotherapy and radiotherapy vs. multimodal therapy), the occurrence of metastases (yes vs. no), recurrence of cancer (yes vs. no), the occurrence of a secondary tumor (yes vs. no), and tumor stage (UICC stage I vs. II vs. III vs. IV). Functional variables described presence of laryngectomy (yes vs. no), tracheotomy tube (yes vs. no), a feeding tube (yes vs. no), swallowing difficulties (range 0–40), pain level (range 1–10), and voice difficulties (difficulty speaking to people and difficulty speaking on the phone, both range 0–3). Psychological variables included smoking (yes vs. no), drinking alcohol (yes vs. no), fatigue (range 0–100), anxiety symptoms (range 0–6), depressive symptoms (range 0–27), and global quality of life subscale (range 0–100).

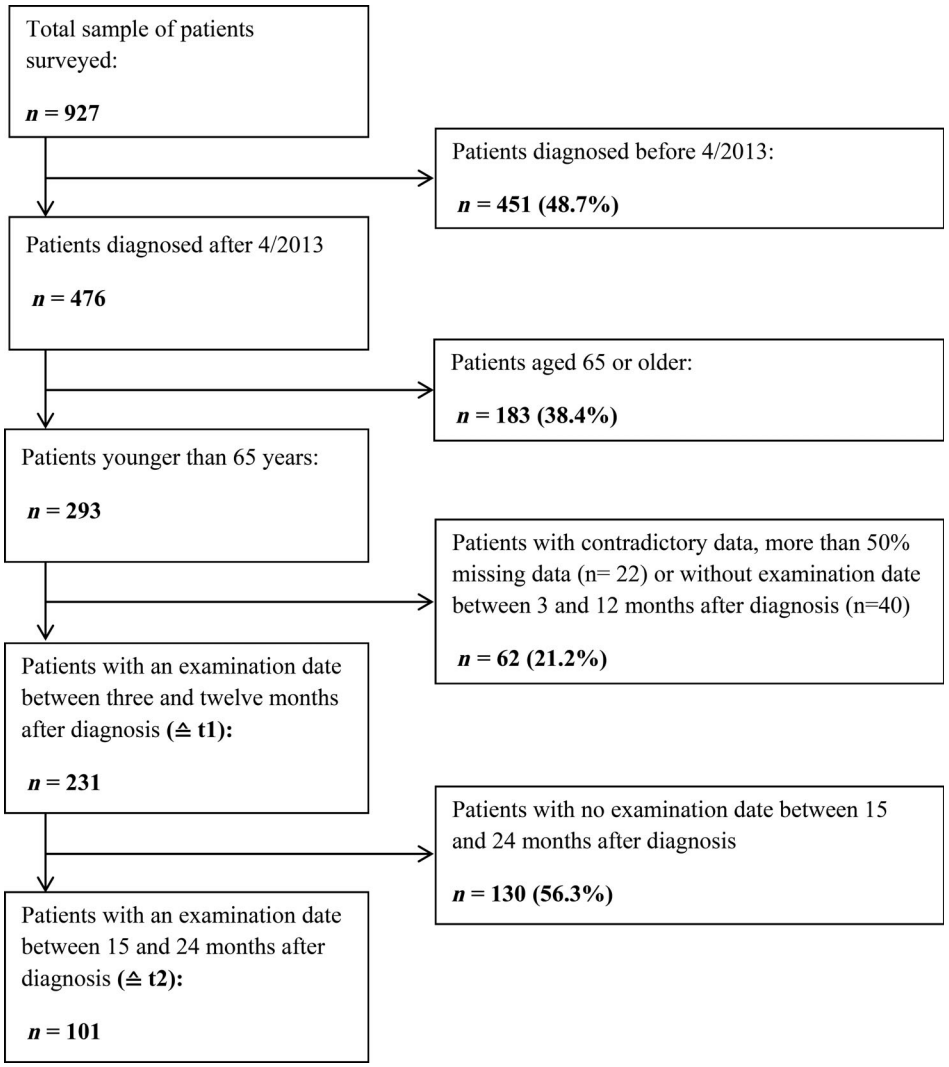

FIGURE 1 CONSORT-diagram specifying the selection of study population

We performed statistical analyses using IBM SPSS Statistics, Version 24. Descriptive statistics are used to compare unemployed with employed patients at t1 and t2. We report frequencies (n) and column percentages (%) for categorical characteristics and means (M) and SD for continuous characteristics. Chi-square tests were used to explore associations of the categorical characteristics with the study outcome (i.e., employment status, rehabilitation participation). Whenever chi-square test assumptions were violated (20% of cells had expected cell counts <5), Fisher's exact test was used.

For contingency tables of variables with more than two categories, we performed an overall test (mostly Pearson's chi-square and Cramer's V) and additional tests using dummy variables for each category separately. As a measure of effect size, we present Cramer's V. For tests with one degree of freedom (df) effects of $V \geq 0.1$ are interpreted as small, $V \geq 0.3$ as a medium, and $V \geq 0.5$ as large. With increasing degrees of freedom, these boundaries have to be adjusted by dividing them by the square root of df.[33] To examine associations between employment status or rehabilitation status and continuous variables, we used heteroscedastic t tests and present Hedges' g as a measure of effect size. It corrects the value of Cohen's d for bias due to sample size.[34] The following boundaries classify the magnitude: $g \geq 0.2$ small, $g \geq 0.5$ medium, and $g \geq 0.8$ large. For all statistical tests, the result is considered as statistically significant with a 2-sided type-I error probability $\alpha < 0.05$.

3 | RESULTS

3.1 | Patients

Out of 293 effectively cured and potentially eligible patients attending an aftercare consultation at t1, 231 (78.8%) provided informed consent, participated in the study, and completed data recording at t1. The

TABLE 1 Sociodemographic, clinical, functional, and psychological characteristics with employment status as group variable (*N* = number of patients)

		Employment at t1 (3–12 months after diagnosis)					Employment at t2 (15–24 months after diagnosis)				
Characteristic	**Statistic**	**Total (*N* = 231)**	**No (*N* = 147)**	**Yes (*N* = 84)**	**Test[a]**	**ES[b]**	**Total (*N* = 101)**	**No (*N* = 57)**	**Yes (*N* = 44)**	**Test[a]**	**ES[b]**
Sociodemographic											
Sex					3.3 (1), 0.071	0.12				1.3 (1), 0.246	0.11
Women (yes)	*N* (%)	61 (26.4)	33 (22.4)	28 (33.3)			35 (34.7)	17 (29.8)	18 (40.9)		
Men (yes)	*N* (%)	170 (73.6)	114 (77.6)	56 (66.7)			66 (65.3)	40 (70.2)	26 (59.1)		
Time related characteristics											
Age at diagnosis (years)	M (SD)	54.63 (6.99)	54.84 (7.32)	54.26 (6.41)	0.6 (229), 0.082	0.08	53.65 (6.97)	54.84 (7.05)	52.11 (6.62)	2.0 (99), 0.051	0.39
Time since diagnosis (months)	M (SD)	5.77 (1.89)	5.87 (1.91)	5.60 (1.84)	1.0 (229), 0.300	0.14	17.45 (2.16)	17.20 (2.03)	17.78 (2.31)	−1.3 (99), 0.223	−0.27
Clinical											
Diagnosis (overall)					5.9 (3), 0.115	0.16				0.6 (3), 0.902	0.08
Oropharynx (yes)	*N* (%)	96 (41.6)	63 (42.9)	33 (39.3)	0.3 (1), 0.596	0.11	45 (44.6)	24 (42.1)	21 (47.7)	0.3 (1), 0.573	0.06
Larynx/hypopharynx (yes)	*N* (%)	59 (25.5)	43 (29.3)	16 (19.0)	2.9 (1), 0.087	0.11	27 (26.7)	15 (26.3)	12 (27.3)	0.0 (1), 0.914	0.05
Oral cavity (yes)	*N* (%)	38 (16.5)	22 (15.0)	16 (19.0)	0.6 (1), 0.421	0.13	11 (10.9)	7 (12.3)	4 (9.1)	0.3 (1), 0.752[c]	0.05
Other (yes)	*N* (%)	38 (16.5)	19 (12.9)	19 (22.6)	3.7 (1), 0.056	0.13	18 (17.8)	11 (19.3)	7 (15.9)	0.2 (1), 0.659	0.04
Therapy (overall)					1.5 (2), 0.476	0.04				3.7 (2), 0.161	0.19
Surgery only (yes)	*N* (%)	47 (20.3)	28 (19.0)	19 (22.6)	0.4 (1), 0.517	0.04	20 (19.8)	15 (26.3)	5 (11.4)	3.5 (1), 0.062	0.19
Radio-and/or chemotherapy (yes)	*N* (%)	48 (20.8)	34 (23.1)	14 (16.7)	1.4 (1), 0.244	0.08	16 (15.8)	9 (15.8)	7 (15.9)	0.0 (1), 0.987	<0.01
Multimodal treatment (yes)	*N* (%)	136 (58.9)	85 (57.8)	51 (60.7)	0.2 (1), 0.668	0.03	65 (64.4)	33 (57.9)	32 (72.7)	2.4 (1), 0.123	0.22
Additional disease burden (m, r or s yes)	*N* (%)	80 (34.6)	52 (35.4)	28 (33.3)	0.1 (1), 0.754	0.02	30 (29.7)	22 (38.6)	8 (18.2)	**5.0 (1), 0.026**	0.22
Metastases (m)	*N* (%)	13 (6.0)	9 (6.5)	4 (5.1)	0.2 (1), 0.773[c]	0.03	2 (2.1)	2 (3.6)	0 (0.0)	1.5 (1), 0.507[c]	0.12
Recurrence (r)	*N* (%)	42 (18.2)	25 (17.0)	17 (20.2)	0.4 (1), 0.540	0.04	12 (11.9)	9 (15.8)	3 (6.8)	1.9 (1), 0.167	0.14
Secondary tumor (s)	*N* (%)	36 (15.6)	27 (18.4)	9 (10.7)	2.4 (1), 0.123	0.10	17 (16.8)	12 (21.1)	5 (11.4)	1.7 (1), 0.197	0.13
UICC classification (overall)[d]					**10.0 (3), 0.019**	0.21				1.9 (3), 0.599	
UICC I	*N* (%)	36 (15.8)	16 (11.0)	20 (24.4)	**7.1 (1), 0.008**	0.18	17 (17.0)	10 (17.5)	7 (16.3)	0.0 (1), 0.868	0.02
UICC II	*N* (%)	15 (6.6)	13 (8.9)	2 (2.4)	3.6 (1), 0.059	0.13	5 (5.0)	4 (7.0)	1 (2.3)	1.2 (1), 0.384[c]	0.11
UICC III	*N* (%)	40 (17.5)	25 (17.1)	15 (18.3)	0.1 (1), 0.824	0.02	21 (21.0)	10 (17.5)	11 (25.6)	1.0 (1), 0.329	0.10
UICC IV	*N* (%)	137 (60.1)	92 (63.0)	45 (54.9)	1.4 (1), 0.229	0.08	57 (57.0)	33 (57.9)	24 (55.8)	0.0 (1), 0.835	0.02

(Continues)

TABLE 1 (Continued)

Characteristic	Statistic	Employment at t1 (3–12 months after diagnosis)					Employment at t2 (15–24 months after diagnosis)				
		Total ($N = 231$)	No ($N = 147$)	Yes ($N = 84$)	Test[a]	ES[b]	Total ($N = 101$)	No ($N = 57$)	Yes ($N = 44$)	Test[a]	ES[b]
Functional											
Laryngectomy (yes)	*N* (%)	20 (8.7)	17 (11.6)	3 (3.6)	**4.3 (1), 0.038**	0.14	9 (8.9)	8 (14.0)	1 (2.3)	4.2 (1), 0.074[c]	0.21
Tracheotom tube (yes)	*N* (%)	75 (32.5)	62 (42.2)	13 (15.5)	**17.4 (1), <0.001**	0.27	12 (12.0)	11 (19.6)	1 (2.3)	**7.0 (1), 0.008**	0.27
Feeding tube (yes)	*N* (%)	96 (41.6)	72 (49.0)	24 (28.6)	**9.2 (1), 0.002**	0.20	11 (10.9)	10 (17.5)	1 (2.3)	**6.0 (1), 0.021**[c]	0.24
Difficulties swallowing (0–40)	M (SD)	8.06 (7.38)	9.18 (7.83)	6.11 (6.09)	**3.3 (208.5), 0.001**	0.42	6.44 (8.24)	8.82 (9.49)	3.34 (4.85)	**3.8 (87.3), <0.001**	0.70
Pain level (0–10)	M (SD)	2.53 (2.40)	2.68 (2.59)	2.26 (2.01)	1.4 (208.5), 0.174	0.17	1.97 (2.25)	2.47 (2.28)	1.32 (2.04)	**2.6 (99), 0.010**	0.53
Voice difficulties on the phone (0–3)	M (SD)	1.52 (1.07)	1.66 (1.06)	1.26 (1.04)	**2.8 (229), 0.006**	0.38	1.00 (1.08)	1.21 (1.10)	0.73 (1.00)	**2.3 (99), 0.025**	0.45
Voice difficulties with other people (0–3)	M (SD)	1.39 (0.99)	1.50 (0.99)	1.21 (0.97)	**2.1 (229), 0.037**	0.29	0.95 (1.04)	1.11 (1.03)	0.75 (1.04)	1.7 (99), 0.090	0.34
Psychological											
Smoking (yes)	*N* (%)	82 (35.5)	63 (42.9)	19 (22.6)	**9.6 (1), 0.002**	0.20	38 (37.6)	26 (45.6)	12 (27.3)	3.6 (1), 0.059	0.19
Drinking alcohol (yes)	*N* (%)	54 (23.4)	34 (23.1)	20 (23.8)	0.0 (1), 0.906	0.01	33 (32.7)	23 (40.4)	10 (22.7)	3.5 (1), 0.061	0.19
Fatigue (0–100)	M (SD)	50.46 (27.45)	53.29 (27.62)	45.50 (26.59)	**2.1 (229), 0.038**	0.28	37.07 (27.72)	45.03 (28.52)	26.77 (23.15)	**3.5 (99), <0.001**	0.69
Anxiety symptoms (0–6)	M (SD)	1.50 (1.74)	1.67 (1.86)	1.20 (1.47)	**2.1 (206.0), 0.035**	0.27	1.14 (1.51)	1.40 (1.60)	0.80 (1.32)	**2.0 (99), 0.044**	0.41
Depressive symptoms (0–27)	M (SD)	6.45 (5.71)	7.31 (6.16)	4.94 (4.48)	**3.4 (216.0), <0.001**	0.42	5.02 (5.08)	6.79 (5.45)	2.73 (3.43)	**4.6 (95.5), <0.001**	0.86
Global quality of life subscale (0–100)	M (SD)	51.47 (19.98)	49.15 (20.41)	55.56 (15.81)	**−2.5 (229), 0.014**	−0.34	61.14 (21.22)	52.92 (20.32)	71.78 (17.44)	**−4.9 (99), <0.001**	−0.98

[a]Chi-square test for categorical characteristics: chi-square (df), *p*-value; *t* test for continuous characteristics: *t*-value (df), *p*-value; bold: significant difference ($p < 0.05$).

[b]Effect size for categorical characteristics: Cramer's *V* (small: ≥0.1, medium: ≥0.3, large: ≥0.5), for continuous characteristics: Hedges' *g* (small: ≥0.2, medium: ≥0.5, large: ≥0.8).

[c]Chi-square test assumptions violated: ≥20% of cells showed expected cell counts <5, therefore Fisher's exact *p*-value is reported.

[d]Missing values excluded: t1: $n = 3$, t2: $n = 1$.

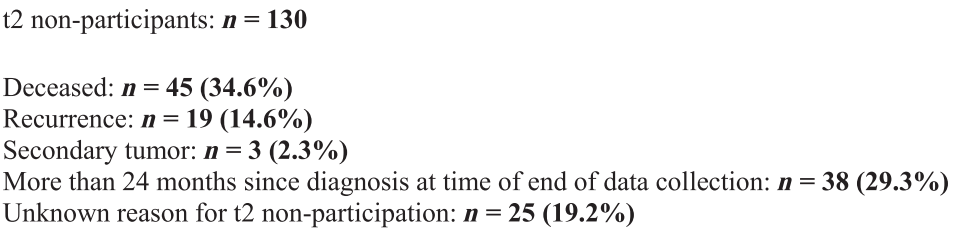

FIGURE 2 Follow-up of t2 nonparticipants

number of recruited patients, who were retained in the analysis at t1 and t2, is depicted in Figure 1. The sociodemographic, clinical, functional, and psychological characteristics of these 231 patients with HNC and a sample of 101 patients who had attended an aftercare consultation at both t1 and t2 are shown in Table 1.

Two out of five patients ($n = 101$, 43.7%) attended an aftercare consultation at t2 between 15 and 24 months after diagnosis (see Figure 1 for reasons for attrition between t1 and t2). These patients differed from those who did not attend a t2 aftercare consultation: They were more often women (chi-square (df) = 6.3 (1), $p = 0.012$), had less often a diagnosis of oral cavity cancer (chi-square (df) = 4.0 (1), $p = 0.045$), less often metastases (chi-square (df) = 4.8 (1), $p = 0.028$), less often recurrence of cancer (chi-square (df) = 4.8 (1), $p = 0.029$), and a higher global quality of life at t1 ($t = -2.0$, $p < 0.05$) than the 130 patients who did not attend an aftercare consultation at t2. No difference was found in employment status (chi-square (df) = 0.81 (1), $p = 0.367$).

Follow-up information on t2 nonparticipants is presented in Figure 2.

3.2 | Employment status at about 6 months after diagnosis

At an average of 6 months after diagnosis (t1), 147 of the 231 patients (63.6%) reported being unemployed, and 84 patients (36.4%) reported being employed (Table 1).

In univariate analyses, employment status was significantly associated with lower tumor stage, absence of laryngectomy, tracheostomy, and feeding tube. Also, functional problems like difficulties in swallowing and voice difficulties, as well as psychosocial problems such as fatigue, anxiety symptoms, depressive symptoms, and diminished global QoL were significantly associated with reduced employment rates. The magnitude of the effect sizes was small (Table 1).

3.3 | Employment status at about 17 months after diagnosis

At an average of 17 months after diagnosis (t2), 57 of the 101 patients (56.4%) reported to be unemployed, and 44 (43.6%) reported to be employed (see Table 1). Employment status at t2 was strongly associated with employment status at t1 (chi-square (df) = 26.6 (1), $p < 0.001$, Cramer's $V = 0.51$, large effect). Of the 57 patients who were unemployed at t2, 47 (82.5%) were already unemployed at t1. Of the 44 patients who were employed at t2, 30 (68.2%) were employed at t1 as well. No other sociodemographic characteristics were significantly associated with employment status.

Regarding clinical characteristics, patients with an additional disease burden (metastases, recurrence of cancer, and secondary tumor) were less likely to be employed at t2 (see Table 1). Employment status was significantly associated with most functional variables. These included an absence of tracheostomy or feeding tube as well as fewer difficulties with pain, swallowing, or speaking on the phone, but not with laryngectomy or speaking with other people (see Table 1). The reported effects were small to medium. Regarding psychological variables, being unemployed was significantly associated with higher levels of depressive symptoms (large effect), anxiety symptoms, fatigue (medium effect), and a lower global quality of life (large effect). With regard to tobacco smoking and drinking alcohol, the difference between employed and unemployed patients was not significant.

For some functional variables, especially swallowing, voice, and pain, effect sizes appeared to be larger at t2 than at t1. For psychological variables, larger effect sizes at t2 are shown for fatigue, anxiety symptoms, depressive symptoms, and reduced global quality of life status.

3.4 | Rehabilitation status within the first year after diagnosis

Secondary analyses revealed that patients who had attended a rehabilitation program did not differ significantly from those who did not regarding functional and psychological characteristics, except smoking at t1 (see Table 2) and time since diagnosis. Only a weak nonsignificant association of participation in rehabilitation programs with employment was observed ($p = 0.226$). Differences between patients who had participated in rehabilitation and those who had not are shown in Table 2.

TABLE 2 Sociodemographic, clinical, functional, and psychological characteristics with rehabilitation status at t1 as group variable (N = number of patients)

		Rehabilitation at t1				
Characteristic	**Statistic**	**Total (N = 231)**	**No (N = 165)**	**Yes (N = 66)**	**Test[a]**	**ES[b]**
Sociodemographic						
Sex					0.7 (1), 0.396	0.06
Women (yes)	N (%)	61 (26.4)	41 (24.8)	20 (30.3)		
Men (yes)	N (%)	170 (73.6)	124 (75.2)	46 (69.7)		
Employment					1.5 (1), 0.226	0.08
No	N (%)	147 (63.6)	109 (66.1)	38 (57.6)		
Yes	N (%)	84 (36.4)	56 (33.9)	28 (42.4)		
Time related characteristics						
Age at diagnosis (years)	M (SD)	54.63 (6.99)	54.77 (6.89)	54.29 (7.27)	−0.5 (229), 0.637	−0.07
Time since diagnosis (months)	M (SD)	5.77 (1.89)	5.40 (1.79)	6.71 (1.81)	**5.0 (229), <0.001**	0.73
Clinical						
Diagnosis (overall)					5.7 (3), 0.128	0.16
Oropharynx (yes)	N (%)	96 (41.6)	62 (37.6)	34 (51.5)	3.8 (1), 0.052	0.13
Larynx/hypopharynx (yes)	N (%)	59 (25.5)	42 (25.5)	17 (25.8)	0.0 (1), 0.962	<0.01
Oral cavity (yes)	N (%)	38 (16.5)	32 (19.4)	6 (9.1)	3.6 (1), 0.056	0.13
Other (yes)	N (%)	38 (16.5)	29 (17.6)	9 (13.6)	0.5 (1), 0.466	0.05
Therapy (overall)					1.5 (2), 0.476	0.04
Surgery only (yes)	N (%)	47 (20.3)	41 (24.8)	6 (9.1)	**7.2 (1), 0.007**	0.18
Radio- and/or chemotherapy (yes)	N (%)	48 (20.8)	37 (22.4)	11 (16.7)	0.9 (1), 0.330	0.06
Multimodal treatment (yes)	N (%)	136 (58.9)	87 (52.7)	49 (74.2)	**9.0 (1), 0.003**	0.20
Additional disease burden (m, r or s yes)	N (%)	80 (34.6)	63 (38.2)	17 (25.8)	3.2 (1), 0.073	0.12
Metastases (m)	N (%)	13 (6.0)	9 (5.8)	4 (6.3)	0.0 (1), 1.000[c]	0.01
Recurrence (r)	N (%)	42 (18.2)	33 (20.0)	9 (13.6)	1.3 (1), 0.257	0.08
Secondary tumor (s)	N (%)	36 (15.6)	31 (18.8)	5 (7.6)	**4.5 (1), 0.034**	0.14
UICC classification (overall)[d]					4.8 (3), 0.184	0.15
UICC I	N (%)	36 (15.8)	31 (19.0)	5 (7.7)	**4.5 (1), 0.034**	0.14
UICC II	N (%)	15 (6.6)	10 (6.1)	5 (7.7)	0.2 (1), 0.668	0.03
UICC III	N (%)	40 (17.5)	29 (17.8)	11 (16.9)	0.0 (1), 0.876	0.01
UICC IV	N (%)	137 (60.1)	93 (57.1)	44 (67.7)	2.2 (1), 0.139	0.10
Functional						
Laryngectomy (yes)	N (%)	20 (8.7)	15 (9.1)	5 (7.6)	0.1 (1), 0.711	0.02
Tracheotomy tube (yes)	N (%)	75 (32.5)	55 (33.3)	20 (30.3)	0.2 (1), 0.657	0.03
Feeding tube (yes)	N (%)	96 (41.6)	72 (43.6)	24 (36.4)	1.0 (1), 0.311	0.07
Difficulties swallowing (0–40)	M (SD)	8.06 (7.38)	8.09 (7.47)	7.98 (7.21)	−0.1 (229), 0.922	−0.01
Pain level (0–10)	M (SD)	2.53 (2.40)	2.54 (2.43)	2.50 (2.36)	−0.1 (229), 0.911	−0.02
Voice difficulties on the phone (0–3)	M (SD)	1.52 (1.07)	1.54 (1.10)	1.45 (1.00)	−0.5 (229), 0.587	−0.08
Voice difficulties with other people (0–3)	M (SD)	1.39 (0.99)	1.39 (1.02)	1.41 (0.93)	0.1 (229), 0.883	0.02

TABLE 2 (Continued)

Characteristic	Statistic	Rehabilitation at t1				
		Total ($N = 231$)	No ($N = 165$)	Yes ($N = 66$)	Test[a]	ES[b]
Psychological						
Smoking (yes)	*N* (%)	82 (35.5)	63 (42.9)	19 (22.6)	**9.6 (1), 0.002**	0.20
Drinking alcohol (yes)	*N* (%)	54 (23.4)	34 (23.1)	20 (23.8)	0.0 (1), 0.906	0.01
Fatigue (0–100)	M (SD)	50.46 (27.45)	49.90 (28.24)	51.85 (25.51)	0.5 (229), 0.626	0.07
Anxiety symptoms (0–6)	M (SD)	1.50 (1.74)	1.47 (1.81)	1.59 (1.57)	0.5 (229), 0.625	0.07
Depressive symptoms (0–27)	M (SD)	6.45 (5.71)	6.75 (6.01)	5.70 (4.83)	−1.3 (229), 0.205	−0.18
Global quality of life subscale (0–100)	M (SD)	51.48 (19.08)	51.62 (19.76)	51.14 (17.41)	−0.8 (229), 0.863	−0.03

[a]Chi-square test for categorical characteristics: chi-square (df), *p*-value; *t* test for continuous characteristics: *t*-value (df), *p*-value; bold: significant difference ($p < 0.05$).

[b]Effect size: Cramer's *V* for categorical characteristics (small: ≥0.1, medium: ≥0.3, large: ≥0.5), Hedges' *g* for continuous characteristics (small: ≥0.2, medium: ≥0.5, large: ≥0.8).

[c]Chi-square test assumptions violated: ≥20% of cells showed expected cell counts <5; therefore Fisher's exact *p*-value is reported.

[d]$n = 3$ missing values excluded.

4 | DISCUSSION

In our sample of HNC survivors, 63.5% of the patients reported that they were not working when assessed an average of 6 months after diagnosis, and 56.4% of patients reported that they were unemployed when evaluated an average of 17 months after diagnosis. Verdonck-de Leeuw et al.[11] reported that only 48% of patients with HNC were unemployed 2 years or more after diagnosis. However, their data collection took place much later to diagnosis than in our study. The rates of discontinuing work among individuals with HNC reported in other studies range from 34% to 53% of patients who were employed at the time of diagnosis.[15,35,36] It has to be mentioned that in these studies the follow-up range differs from 12 months[15] to greater than 4 years.[36] A study by Terrell et al. did not specify the follow-up period but reported that all patients were at least 1 month after treatment, and more than 80% of the patients were more than 6 months after treatment.[35] However, since employment status at the time of diagnosis is unknown in our sample, our findings are difficult to compare to those studies.

There was little change in employment status from the first to the second year after diagnosis: Only 14 patients found employment between t1 and t2, whereas 10 lost or quit employment. Some patients who reported being unemployed at both t1 and t2 might still be recovering from disease- and treatment-related symptoms: health-related quality of life is often still severely impaired even 3 years after a diagnosis of HNC[14] and RTW following HNC can take more than 5 years in some cases.[37] Therefore, those patients might need more time to RTW. On the other hand, many of them are approaching retirement age, making it more unlikely for them to RTW at a later time.[7] Future research is needed to explore the employment pathways of patients with HNC for a longer period after diagnosis.

More than half of the patients who attended an aftercare consultation within the first year did not attend an aftercare consultation within the second year. These t2 nonparticipants were more burdened with both metastases and recurrence of cancer than t2 participants. Both factors are likely to complicate or even impede the recovery process. Follow-up of t2 nonparticipants revealed that reasons for not attending aftercare and providing t2 data were multiple: one third of these patients had died, 17% experienced a recurrence or secondary tumor, 29% had below 15 months of follow-up, and 19% were missing due to unknown reasons. Inpatient care without access to the electronic recording and re-treatment, causing delayed re-entry of data, is likely the most prominent reason why these patients did not attend further aftercare consultations during the predefined time frames. Therefore, it is to be expected that the t2 nonparticipants would have a lower employment rate at this time than t2 participants. This fact would render the 43.6% employment rate at t2 and overestimation due to systematic dropout. On the other hand, t2 non-participants were not unemployed more often at t1 than t2 participants. Additionally, the characteristics that were associated with t2 non-participation were not the characteristics associated with employment status, except the quality of life. This suggests that our findings regarding factors associated with employment status at t2 may still be valid despite the reduced sample. The reduced quality of life in t2 nonparticipants is likely related to the increased disease burden.[38] Additionally, more men than women patients did not attend an aftercare consultation within the second

year. This finding is in line with several studies in the general population that report consultation rates in men being lower than in women.[39,40]

In univariate analyses unemployed patients reported higher levels of anxiety symptoms, depressive symptoms, and fatigue and had a lower quality of life than employed patients at both times of data collection. Several studies confirm these associations both for the general cancer population[41,42] and for patients with HNC.[11,13,15,16] A causal direction cannot be derived, since each of these factors may have an impact on employment status or vice versa. However, it is suggested that fatigue, anxiety, and depressive symptoms are conditions that might possibly contribute to impaired employment status.[3] On the other hand, difficulties in RTW and in sustaining employment may significantly contribute to anxiety and depressive symptoms resulting in reduced quality of life, probably exerting negative feedback regarding the inability to pursue employment. Our exploratory analyses of potentially modifying effects of participation in rehabilitation programs on (earlier) RTW and sustaining employment revealed no significant effect and especially no demonstrable benefit. In this respect, however, it has to be kept in mind that our study was not designed and was not powered to assess such effects; only hypothesis-generating information was gained. We believe that in order to support RTW in HNC patients rehabilitation programs targeting fatigue, depressive and anxiety symptoms are needed, particularly because 25%–50% of the patients with HNC are affected by anxiety and depression.[43-45]

Smoking, but not drinking alcohol was associated with employment status at t1. At t2, both factors showed the same tendency but were not significant. Koch et al.[13] found, also in a cross-sectional study, that risky alcohol consumption after cancer treatment, but not smoking, was associated with unemployment in HNC survivors. Thus, results in the literature are inconsistent but provide hints that risky health behaviors might be related to RTW. The influence of drinking alcohol and smoking on employment status has to be examined in further studies to answer questions about the inconsistent findings. Nevertheless, alcohol consumption and smoking should be addressed in programs aiming to support RTW in patients with HNC, especially because continuing drinking alcohol and smoking after HNC are risk factors for tumor recurrence and survival.[17,18,46]

This study revealed that all functional factors were associated with employment status, at least at one of the examination dates. Only pain was not significantly associated with employment status at t1 (but significant at t2), and laryngectomy and speech problems showed marginally significant associations with employment status at t2 (but significant at t1). Oral dysfunction, speech problems, and pain as potential barriers to RTW in patients with HNC were also reported in other cross-sectional studies.[11,16,47] Despite the recent improvement in surgical reconstruction techniques and the increase of non-surgical treatment options, patients with HNC often experience oral dysfunction and speech and swallowing problems.[48,49] Many of these problems persist for several years after treatment.[14] These problems seem to be even more pronounced in unemployed patients with HNC cancer, rendering them relevant issues in potential HNC rehabilitation programs.

Differences between employed and unemployed patients in both psychological and functional characteristics were even more pronounced within the second year compared to the first year. This might be traced back to the better functional and psychological status in employed patients, whereas unemployed patients more often suffered from psychological and functional impairments within the second year after diagnosis. This indicates that there is a group of patients who are not only more burdened with the disease- and treatment-related symptoms and reduced quality of life for a long time after diagnosis, but who are also at a higher risk of unemployment.

Patients who had attended a rehabilitation program and those who had not did not differ from each other concerning psychological and functional characteristics, except for smoking: Smokers had attended rehabilitation less often than nonsmokers, possibly due to anticipated limited opportunities for smoking at rehabilitation programs. The finding that more time had elapsed between diagnosis and t1 with patients who had attended a rehabilitation program is most likely due to the duration of the rehabilitation program, delaying the first aftercare visit for approximately 1 month as compared to those patients who did not attend a rehabilitation program. This lack of significant differences in employment, functional, or psychological variables after rehabilitation tentatively implies that patients with HNC are rather unlikely to benefit from existing rehabilitation programs and demonstrates the need for rehabilitation programs that are tailored to the needs of patients with HNC. To define such programs, further research is required. These tailored programs should address functional issues such as communication problems and swallowing difficulties, and also psychological issues such as health-related risk behavior and depression. So far, there are no established rehabilitation programs in Germany that aim to support this patient group. HNC-specific rehabilitation programs could be integrated into existing inpatient rehabilitation programs for patients with cancer. Another option would be to develop outpatient rehabilitation programs for

HNC that could complement standard rehabilitation programs.

This study is exploratory by nature and subject to several limitations: Patients attended aftercare consultations at varying times and at varying frequencies making it difficult to select a specific date for data collection. Moreover, the employment status of patients before the cancer diagnosis was not assessed. Another limitation of this study was not having assessed certain variables that have been reported to be associated with RTW, such as education level and job requirements.[50] These variables will be integrated into the OncoFunction questionnaire in the future. Other aspects that could have relevance to RTW after HNC and were not included in the evaluation are comorbidity, change of work, and the effect of the shift to part-time jobs. Our results must be interpreted with caution as the study design was not confirmatory; our findings, however, are relevant from a clinical point of view, since data collection was an integrative part of the routine aftercare consultation providing real-world data. The sample might be more representative of HNC patients in a clinical setting than the samples in other questionnaire-based studies since patients were strongly encouraged to complete the questionnaire on-site. The distribution and collection of questionnaires via mail are more prone to self-selection bias. Whereas other studies reported response rates of 59%–75%,[11,15,37] the OncoFunction questionnaire was completed by 82% of patients who had attended the aftercare consultation in a previous feasibility study.[24] This feasibility study was conducted in the same clinic, but the number of participants was not assessed in detail for this study. Nevertheless, no changes in the clinical setting and software were made, so we assume that the response rates were similar to those we reported previously. The relatively small proportion of self-selected nonparticipants supposed by the feasibility study is also a strong point of this study. However, we do not have information about the number of eligible patients who declined to participate in this study. It is to mention that the patient-reported outcomes were not only collected for research purposes but were consulted by the attending physician and used to select suitable therapies for the patient.[24]

The reader might have missed a presentation of a longitudinal analysis. However, we had to resist such approach as we had to face statistical limitations based on the too low number of events allowing to perform longitudinal analyses, although the study design would have made such analyses possible. This is mainly because only a small number of patients changed their employment status from t1 to t2. Among 61 patients who were not employed at t1, 14 (23%) were employed at t2, and among 40 patients who were employed at t1, 10 (25%) were unemployed at t2. It can, therefore, be expected that longitudinal tests, such as a binary logistic regression, would not have enough strength to identify trustworthy effects. Hosmer et al. suggest that such a regression model should contain no more than $p \leq \min(n1, n0)/10–1$ parameters (p = parameters, n1 = positive events of the outcome, n0 = negative events), and when having "as few as 5–9 events per parameter one must be careful when interpreting results."[51] In our study (with n = 44 employed at t2, n = 57 unemployed at t2), we have less than four events per parameter. Hence it is not recommended to perform a multivariable longitudinal analysis addressing the main outcome of this study (employment status).

Despite our cross-sectional study design, the data suggest a consistent association of specific functional and psychological variables with patients' employment status and RTW. Further research ought to look into this underreported but highly relevant topic. The effect of health-related risk behavior on employment is not yet evident and our data are in some respect contradictory to other data. The direction of the effects, especially psychological effects, is not clear and has to be explored further in large longitudinal studies. A high number of patients must be included in further studies because the dropout rate and loss to follow up at t2 were high, so there is a need for multicenter studies. Even though 927 patients were recorded in our database, less than one third of these could be included in our analysis mainly due to restrictions in the eligibility criteria.

5 | CONCLUSION

Unemployed patients with HNC are more burdened than employed patients with HNC regarding psychological and functional factors. These factors include both HNC-specific areas of concern such as voice difficulties and swallowing problems as well as issues that affect patients with cancer in general, such as depression and fatigue. These differences become even more pronounced over time. Although this was not a clinical trial, our preliminary, impressionistic findings do not offer much support for the value of existing rehabilitation programs to affect these psychological and functional impairments. These hypothesis-generating findings can guide future research exploring the implied need for specific rehabilitation programs in HNC.

DATA AVAILABILITY STATEMENT

The data that support the findings of this study are available on request from the corresponding author. The data are not publicly available due to privacy or ethical restrictions.

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