Turkish Validation and Reliability Study of the Carcinologic Handicap Index for Head and Neck Cancer Patients

Original Investigation

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Abstract

Objective: This study aimed to conduct a Turkish validation study of the Head and Neck Carcinologic Handicap Index (CHI) and investigate its effectiveness in assessing morbidity in head-and-neck tumor patients.

Methods: The original CHI was translated into Turkish after a language validation study based on international standards. The study included 189 patients. Age, gender, primary tumor location, and tumor-node-metastasis stages were recorded. All patients were asked to complete the CHI form. A total of 37 patients completed the CHI form once more within 15 days to examine temporal stability. A control group was also formed to evaluate the validity of the CHI.

Results: The Cronbach's alpha coefficient was 0.898. For temporal validity, the global score showed a statistically significant correlation ($p<0.001$; $r=0.604$). There was a statistically significant difference between the global scores of the patient and the control groups ($p<0.001$). The global score and tumor stage differences were statistically significant ($p=0.012$). Review of the relationship between the tumor location and the scores showed a statistically significant difference in swallowing ($p=0.001$), feeding ($p=0.001$), and hearing ($p=0.015$).

Conclusion: The study adapted the CHI into Turkish and showed that it can be used as a valid and reliable index for the morbidity assessment of head-neck cancer patients. We recommend frequent use of the CHI throughout follow-up.

Keywords: Head and neck cancer, handicap, quality of life, validity study, morbidity

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Cite this article as: *Mengi E, Kara CO, Yavuz A. Turkish validation and reliability study of the carcinologic handicap index for head and neck cancer patients. Turk Arch Otorhinolaryngol. 2025; 63(2): 48-54*

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Received Date: 20.12.2024
Accepted Date: 29.04.2025
Epub: 26.06.2025
Publication Date: 27.06.2025

DOI: 10.4274/tao.2025.2024-12-5

Introduction

Head and neck carcinomas are among the most common cancer types worldwide (1). A multidisciplinary examination is essential when choosing therapy for head and neck carcinomas because the treatment differs depending on the disease's stage, anatomical location, and surgical accessibility. Along with improvements in standard treatment, such as radiation, surgery, and multimodal therapies brought about by immunotherapy advancements, survival has significantly increased in recent years. The five-year survival rate improved from 55% between 1992 and 1996 to 66% between 2002 and 2006 (2). However, as mortality rates decrease, more individuals have to live with treatment-related sequelae. Disruption of the functions of the affected structures may negatively impact life quality.

The head and neck region has essential functions such as swallowing, respiration, feeding, phonation, and hearing. In malignancies in this region, pain, deformities, functional disorders, and psychosocial problems can be observed due to both the effects of the cancer itself and cancer-directed treatments (3). Focusing only on the oncologic process in the follow-up of patients may cause the effects of treatment sequelae on the patient's daily life to be overlooked. Questionnaires or scales for detailed documentation are needed to monitor post-treatment morbidity in patients regularly. Quality-of-life measurements during patient follow-up are crucial for individualizing and coordinating the treatment strategy offered to patients. In addition to problems related to the primary disease, issues related to the function of the affected structures can be identified and prioritized. For example, swallowing problems in patients can be recognized much earlier and treated before they cause more significant issues. Similarly, physiotherapy support can be provided earlier if the patient has limited neck and shoulder movements.

In 2017, Balaguer et al. (4) introduced the head and neck Carcinological Handicap Index (CHI), designed to evaluate the quality of life for head and neck cancers. The CHI's initial version, which focuses on nine sub-domains, has demonstrated strong psychometric properties, validating its application in clinical assessments (4). Nevertheless, during clinical applications, it was found that the domains of neck-shoulder movements and psychosocial impact of physical appearance were missing, which often posed problems for patients. Therefore, an update was made by the same team in 2021 to cover these two new areas (5). Although the CHI is being used by more and more clinicians today, a validity and reliability study of the Turkish version was yet to be conducted. Our study aimed so to conduct a Turkish validation study of the latest CHI version and investigate the effectiveness of this index in evaluating morbidity in head and neck cancer patients and determining patient priorities.

Methods

The Turkish Adaptation Stage

Research approval was received from the Pamukkale University Non-Interventional Clinical Research Ethics Committee (approval date: 18.04.2023; approval number: 60116787-020-358580). First, written permission for the Turkish adaptation was obtained from the original CHI authors, Balaguer M. et al. (4,5). Then, the Turkish language adaptation stage of the scale began. In this stage, two researchers independently translated the original scale into Turkish. Then, the same two researchers combined and converted the scale into a single translated text. This Turkish text was back translated into English by another researcher who was fluent in both native languages. Three researchers then reviewed the original, Turkish, and translated scales to decide on the final Turkish index to be used. After the language validation process, the Turkish text was structured according to the original system (Figure 1).

The CHI evaluates 11 domains related to the primary symptoms experienced by patients with head and neck cancer. Four of these domains focus on sensory functions, four on the functions of the upper respiratory and digestive systems, two on the social effects of the disease, and one on neck and shoulder movements. Each domain consists of four questions, with responses scored on a five-level scale: never, very rarely, occasionally, frequently, and always. This scoring system results in a domain score ranging from 0 to 16 points and a global score. As the score from the handicap index increases, so do the difficulty perceived by patients and the impact of the disease on their life quality.

Data Collection

All head and neck cancer patients admitted to the outpatient clinic between April 2021 and July 2024 were included in the study. We explained the study's purpose to the patients and obtained their consent. Age, gender, primary tumor location, and TNM stages at initial diagnosis were recorded. The patients were then asked to complete the CHI form consisting of 11 domains. The aim was to examine the temporal stability (test-retest reliability) by having 37 patients fill out the CHI form again within 15 days.

A control group was also formed to evaluate the validity of the CHI. The control group was composed of people who matched the patient group in terms of age, gender, and socio-economic status and had no oncologic disease. After being provided information about the study, the control group of healthcare workers and patients' relatives was asked to complete the CHI form once.

Statistical Analysis

Statistical analyses were conducted using SPSS version 25 (IBM Corp.; Armonk, NY, USA). Continuous variables are presented as mean ± standard deviation and minimum (min.) and maximum (max.) values. Categorical variables are presented as count and percentage. Internal consistency was assessed using Cronbach's alpha coefficients. The construct validity of the scale was established by confirmatory factor analysis. The Kaiser-Meyer Olkin test was used to determine the adequacy of the sample size, and Bartlett's test was used to assess its suitability. In confirmatory factor analysis, Goodness of Fit Index (GFI), Comparative Fit Index (CFI), Normed Fit Index (NFI), Root Mean Square Error of Approximation (RMSEA), and χ^2/df goodness of fit indices were evaluated. Standardized factor loadings were obtained to examine how appropriate the scale was to the original scale structure. In statistical evaluation, the normal distribution of the parameters was tested with the

Baş Boyun Kanserli Hastalar için Engellilik Ölçeği						
		Hiçbir zaman	Çok nadir	Ara sıra	Sıklıkla	Sürekli
AĞRI	Ağrılarınız için ağrı kesici kullanıyor musunuz?					
	Ağrılarınız geceleri sizi uykudan uyandırır mı?					
	Ağrılarınız günlük aktivitelerinize engel olur mu?					
	Ağrı nöbetleriniz olur mu?					
YUTMA	Yutma zorluğunuz var mı?					
	Yedikleriniz ya da içtikleriniz boğazınıza kaçıyor mu?					
	Yemeklerden sonra yediklerinizin boğazınıza geri geldiği oluyor mu?					
	Yiyecekleri çiğnerken zorlanıyor musunuz?					
BESLENME	Yediklerinizi yutabilmek için kıvamını değiştirmek zorunda kalıyor musunuz?					
	Yutma güçlüğüne bağlı olarak yemeğinizi yemeniz uzun zaman alıyor mu?					
	Yemeklerinizi güçlendirmek için ek gıda takviyesine ihtiyaç duyuyor musunuz?					
	Kilo kaybediyor musunuz?					
SOLUNUM	İstirahat halindeyken nefes almakta güçlük çekiyor musunuz?					
	Nefes alma problemleriniz fiziksel aktivitelerinizi kısıtlıyor mu?					
	Kendinizi nefes alırken tıkanmış hissediyor musunuz?					
	Uyumak için yarı-oturur pozisyona ihtiyaç duyuyor musunuz?					
KONUŞMA	Konuşmada zorlanıyor musunuz?					
	Dinleyenler sizin konuşmanızı anlamakta zorlanıyor mu?					
	Ailenizle, arkadaşlarınızla, komşularınızla normalden daha mı az konuşuyorsunuz?					
	Kelimeleri çıkarmakta zorlanıyor musunuz?					
İŞİTME	Anlamadığınız için konuşmaları tekrar ettiriyor musunuz?					
	Gürültülü yerlerde konuşulanları anlamakta zorlanıyor musunuz?					
	Telefon konuşmalarını anlamakta zorlanıyor musunuz?					
	Kulaklarınızda uğultu, çınlama gibi sesler oluyor mu?					
GÖRME	Karanlık ortamlarda görmekte zorlanır mısınız?					
	Uzağı veya yakını görmede zorlanıyor musunuz?					
	Gözlerinizde sizi rahatsız eden kamaşma veya uçuşmalar oluyor mu?					
	Görme alanınızda daralma hissediyor musunuz?					
KOKU-TAT	Kokuları almakta zorlanıyor musunuz?					
	Koku alma zorluğunuz nedeniyle kaza geçirmekten korkar mısınız?					
	Yediklerinizin tadını almakta zorluk çeker misiniz?					
	Koku ve tat alma zorluğunuz sebebiyle kendinizi kötü hissettiğiniz oluyor mu?					
FİZİKSEL GÖRÜNÜM	Fiziksel görünümünüzdeki değişiklikler sizi rahatsız ediyor mu?					
	Fiziksel görünümünüzdeki değişiklikler sebebiyle insanların size bakışlarından rahatsız oluyor musunuz?					
	Fiziksel görünümünüzdeki değişiklikler sebebiyle sosyal hayatınız kısıtlanıyor mu?					
	Hastalığınız nedeniyle özel hayatınız değişti mi?					
BOYUN-OMUZ	Boynunuz, omuzlarınız veya kollarınızda his kaybı fark ediyor musunuz?					
	Başınızı çevirmekte zorlanıyor musunuz?					
	Ağırlık taşırken zorlanıyor musunuz?					
	Kollarınızı kaldırmada zorluk çekiyor musunuz?					
PSİKOSOSYAL	Hastalığınız kişisel ve sosyal hayatınızı kısıtlıyor mu?					
	Hastalığınız diğer insanlarla ilişkilerinizi etkiliyor mu?					
	Hastalığınızı sebep olduğu problemler sizi rahatsız ediyor mu?					
	Hastalığınız yüzünden kendinizi engelli hissediyor musun?					

Figure 1. The Turkish version of the head and neck Carcinologic Handicap Index

Shapiro-Wilk test. Independent group t-tests and one-way ANOVAs were performed on those who showed parametric conformity. The Mann-Whitney U and Kruskal-Wallis tests were performed for those who did not conform. In addition, the Spearman's correlation test was applied to evaluate the relationship between numerical data. The statistical significance level was determined as $p<0.05$ in all analyses. The strength of the "r" coefficient in correlation was interpreted as follows: 0.00 to 0.299, weak; 0.300 to 0.599, moderate; 0.600 to 0.799, strong; 0.800 to 0.999, very strong.

Results

The study included 189 head and neck oncology patients. Of these, 159 (84.1%) were male, and 31 (15.9%) were female, with a mean age of 62.53±11.02 (min. 26-max. 87) years. In terms of tumor location, 111 (58.7%) were in the larynx, 34 (18%) in the oral cavity, 18 (9.5%) in the nasopharynx, 12 (6.3%) in the oro-hypopharynx, and 14 (7.4%) were other head and neck tumors (such as salivary gland, paranasal sinus, thyroid). Regarding the stage at the time of initial diagnosis, 73 (38.6%) patients were stage I, 31 (16.4%) were stage II, 47 (24.9%) were stage III, and 38 (20.1%) were stage IV.

The control group included 123 subjects. Their mean age was 61.35±9.22 (min. 44-max. 86) years; 98 (80.3%) were male, and 24 (19.7%) were female.

Internal Consistency

The overall Cronbach's alpha value of the disability index was 0.898. Cronbach's alpha values obtained in the domains of the index are given in Table 1. Internal consistency results in pain, phonation, hearing, vision, physical appearance, and psychosocial domains were considered satisfactory (>0.7). Cronbach's alpha results obtained in other domains were also within acceptable limits (>0.6).

Construct Validity

When the results of the confirmatory factor analysis were analyzed, it was seen that all fit indices showed a good or acceptable level of fit (χ^2/df=1.675, RMSEA=0.06, CFI=0.819, GFI=0.754, NFI=0.654). Further, when the coefficients obtained from the items were examined, it was seen that only one item had a value below 0.3 (Table 2). In order not to disrupt the integrity and structure of the scale and because it was not a very low value, this item did not need to be removed, and the scale structure was preserved. The Bartlett's test result was p=0.0001, and the Kaiser-Meyer-Olkin value was 0.812. According to this coefficient, it was determined that the sample size was very well-compatible with factor analysis.

Temporal validity (Test-retest reliability)

For temporal validity, the relationship between the results of the scale filled in at two different times by 37 patients was evaluated. According to the results obtained, a statistically significant positive correlation was found for the global CHI score ($p<0.001$; $r=0.604$). In the domains of the handicap

Table 1. Results on Cronbach's alpha test

Domain	Cronbach's alpha values
Pain	0.805
Swallowing	0.614
Feeding	0.680
Respiration	0.687
Phonation	0.853
Hearing	0.789
Vision	0.701
Olfaction-gustation	0.689
Physical appearance	0.769
Neck and/or shoulder movements	0.679
Psychosocial	0.835
Global score	0.898

Table 2. Confirmatory factor analysis results

Domain	Item	Coefficient	Domain	Item	Coefficient
Pain	1st	0.706	Vision	1st	0.592
	2nd	0.804		2nd	0.549
	3rd	0.745		3rd	0.571
	4th	0.667		4th	0.675
Swallowing	1st	0.58	Olfaction-gustation	1st	0.675
	2nd	0.383		2nd	0.63
	3rd	0.492		3rd	0.794
	4th	0.675		4th	0.651
Feeding	1st	0.286	Physical appearance	1st	0.454
	2nd	0.522		2nd	0.467
	3rd	0.8		3rd	0.792
	4th	0.711		4th	0.797
Respiration	1st	0.398	Neck/ shoulder movements	1st	0.673
	2nd	0.755		2nd	0.483
	3rd	0.724		3rd	0.595
	4th	0.644		4th	0.439
Phonation	1st	0.857	Psychosocial	1st	0.742
	2nd	0.58		2nd	0.807
	3rd	0.819		3rd	0.76
	4th	0.858		4th	0.697
Hearing	1st	0.519			
	2nd	0.666			
	3rd	0.809			
	4th	0.83			

index, there was a strong correlation (r>0.6) in the domains of phonation, hearing, vision, olfaction-gustation, and psychosocial, and a moderate correlation (0.4<r<0.6) in the domains of pain, swallowing, feeding, respiration, physical appearance, and neck-shoulder movements (Table 3).

Comparison Between Patient and Control Groups

The mean global score in the patient group was 40.06±26.95, while the mean score in the control group was 21.19±15.80. There was a statistically significant difference between the global scores of the two groups (p<0.001).

When the scale's domain scores were analyzed, no significant difference was observed for pain, hearing, and vision (p>0.05), while significant difference was observed for the other seven domains (Table 4).

Results According to Tumor Stage

The study observed that the mean global score obtained on the handicap index increased as the tumor stage increased (Table 5). The difference between the tumor stage and the global score was statistically significant (p=0.012).

When the relationship between the stage of the tumor and the domains of the index was examined, a significant difference was found in the domains of feeding (p=0.028), phonation (p=0.001), olfaction-gustation (p=0.04), and physical appearance (p=0.001). In contrast, no significant difference was found in the other domains (p>0.05).

Results According to Tumor Location

When the relationship between tumor location and the scores obtained in the handicap index was examined, statistically significant difference was found in the domains of swallowing (p=0.001), feeding (p=0.001), and hearing (p=0.015). No significant difference was found between the other domains and tumor location (p>0.05). The mean scores obtained in the domains with statistical differences are summarized in Table 6. As a result of post hoc analysis (Tukey HSD test), in the domains of swallowing and feeding, oral cavity and oro-hypopharyngeal cancer patients had a statistically significant higher rate of disability compared to laryngeal cancer patients, while in the domain of hearing, nasopharyngeal cancer patients had a higher rate of disability compared to other head and neck cancer patients.

Table 3. Temporal validity (correlation between the results of the scale filled in at two different times)

Domains	"r" coefficient	p-value
Pain	0.531	<000.1*
Swallowing	0.558	<000.1*
Feeding	0.532	<000.1*
Respiration	0.419	<000.1*
Phonation	0.639	<000.1*
Hearing	0.661	<000.1*
Vision	0.652	<000.1*
Olfaction-gustation	0.666	<000.1*
Physical appearance	0.540	<000.1*
Neck and/or shoulder movements	0.564	<000.1*
Psychosocial	0.614	<000.1*
Global score	0.604	<000.1*

* p<0.05 statistical significance level

Table 4. Comparison of patient and control groups

Domains	Patients	Controls	p-value
	Mean±SD	Mean±SD	
Pain	2.36±3.26	2.99±2.67	0.75
Swallowing	4.16±3.79	1.67±2.65	<0.001*
Feeding	4.52±4.51	0.75±1.49	<0.001*
Respiration	2.39±3.23	1.33±2.55	0.001*
Phonation	6.24±5.4	0.74±1.73	<0.001*
Hearing	4.48±4.64	3.84±3.63	0.12
Vision	3.45±3.63	4.63±3.27	0.14
Olfaction-gustation	2.85±3.8	0.88±2.17	<0.001*
Physical appearance	2.42±3.72	0.82±1.75	<0.001*
Neck and/or shoulder movements	3.51±4.09	2.43±2.72	0.005*
Psychosocial	3.66±4.58	1.11±2.73	<0.001*
Global score	40.06±26.95	21.19±15.80	<0.001*

* p<0.05 statistical significance level

SD: Standard deviation

Table 5. The relationship between tumor stage and global score

Tumor stage	Number of patients	Mean±SD
Stage I	73	32.33±24.23
Stage II	31	41.19±29.78
Stage III	47	45.08±27.86
Stage IV	38	47.76±25.53

SD: Standard deviation

Table 6. The relationship between tumor location and domains of index

Tumor location	Swallowing Mean±SD	Feeding Mean±SD	Hearing Mean±SD
Larynx	3.26±3.38	3.65±4.18	3.48±4.16
Oral cavity	6.84±4.23*	6.38±4.48*	5.61±5.45
Nasopharynx	5.50±3.74	4.77±4.58	8.06±5.05*
Oro-hypopharynx	6.25±3.64*	8.16±5.01*	4.01±2.44
Other	5.01±4.16	3.50±4.11	4.50±4.34

* p<0.05 statistical significance level

SD: Standard deviation

Discussion

The term quality-of-life was first defined in 1948 by the World Health Organization as "health is not only the absence of disease but a state of complete physical, mental and social well-being of the individual" (6). Knowing the patient's life quality provides the physician with a better understanding of the patient's life from their perspective. Thus, patient-physician communication is strengthened, cooperation is ensured on a realistic basis, the patient's expectations from the physician can be better understood, and patient compliance can increase. The Head and Neck CHI, validated in Turkish in our study, is a quality-of-life scale defined for evaluating morbidity and disability in head-neck cancer patients, and its validity and reliability have been demonstrated (4). The clinical aim of applying this scale is to differentiate the function-limiting factors and to determine patients' needs regarding disease management.

Scales developed in societies from different languages and cultures must be tested in the community to ensure the equivalence of the content in terms of concept and language, test their measurement properties in the community, and conduct reliability and validity studies before they are applied in the society (7). Reliability shows the stability and consistency of test results. In our study, internal consistency was first evaluated to determine the reliability of the Turkish version of the CHI, and high internal consistency was found with a Cronbach's alpha value of 0.898. Although internal consistency was within acceptable limits in all sub-domains of the scale, the lowest value was found in the swallowing domain. Similarly, low internal consistency was found in the swallowing domain on the original CHI scale. When we look at the questions in the swallowing domain, three follow the swallowing stages: oral preparation, pharyngeal, and esophageal; one evaluates all swallowing phases in scope. The relatively low internal consistency in the swallowing domain may be because the questions assess the different phases of swallowing. The authors of the original CHI reported that the questions in the swallowing domain were included in the original scale because of their clinical importance and ability to discriminate between swallowing phases (4).

The results obtained from a reliable scale should also be reproducible. In other words, if a test is applied to the same individuals more than once, the results of the application should be similar (8). In our study, a strong correlation was observed in the global score between the results of the scale completed by the patients at two different times. Although a statistically significant correlation was found in all index domains, the correlation coefficients were lower than the original CHI. In our study, the domains with relatively low correlation coefficients were the functions most exposed to temporal fluctuations, such as pain, swallowing, feeding, and respiration. Head and neck cancer patients with ongoing treatment were also included in the study. The ongoing treatment of the patients, even within two weeks, may have caused the degree of complaints to change, and therefore, the correlation coefficients may have been relatively low. Nevertheless, statistically significant correlations were found in all domains, indicating that the scale is reliable.

Validity is the ability of a scale or test to measure the feature it wants to measure accurately and without confusing it with other features (9). In our study, when the patient and control groups were compared, a statistically significant difference was found in the global score and in the other domains except for pain, hearing, and vision. This result shows the validity of the scale. In general, people frequently have pain, hearing, and vision problems. Given the average age of the patient and control groups, the lack of notable differences in these domains may be explained by the fact that age-related dysfunctions in the domains of pain, hearing, and vision are common in the general population and that head and neck tumors have a relatively small impact on these three areas. Similarly, the original CHI study indicated no significant differences in pain, hearing, and vision domains between the patient and control groups. (4).

In our study, when the relationship between tumor location and the domains of the scale was examined, statistically significant loss of function was found in the areas of swallowing and feeding in oral cavity and oro-hypopharyngeal cancer patients, and in the area of hearing in nasopharyngeal cancer patients. The locations of tumors in the oral cavity and oropharynx impact both the oral and pharyngeal stages of swallowing. Laryngeal structures have less influence on food transportation. Therefore, swallowing and feeding are expected to be affected more in patients with oral cavity or oropharyngeal tumors (9). Similarly, hearing function is more affected in nasopharyngeal cancer patients due to tumor-related Eustachian tube dysfunction, and the radiotherapy area includes the hearing region (10). These results show us the effectiveness of CHI in determining patient priorities.

The CHI is a scale designed for all head and neck cancer patients. However, the functions affected and the degree to which they are affected will vary according to the site of origin and cancer stage. Considering the diversity of the tumor being evaluated and individual psychosocial dynamics, it would be more appropriate to focus on high-scoring domains rather than using an overall cumulative score. The sub-scores for each domain help identify priority functional losses. While patients' needs can vary based on age, gender, treatment method, cancer stage, or tumor location, this scale allows for personalized assessments based on individual circumstances.

The main limitation of our study is that it was conducted at a single center. Future multicenter studies will better assess the

scale's usability for monitoring patients. Another limitation is that a native English-speaking expert did not evaluate the scale during the language validity phase. However, since the scale is not psychological, it does not account for cultural differences and consists of simple sentences that all patients can easily understand, input from a native speaker was not deemed necessary.

Conclusion

In conclusion, the Turkish version of the CHI demonstrated acceptable psychometric properties regarding internal consistency, temporal validity, and content validity. Based on the results of our study, we recommend the regular use of CHI in the follow-up care of patients with head and neck cancer. Considering the life quality measurements during oncological follow-up of patients will help determine the patient's priorities and coordinate the treatment strategy by revealing problems that may be overlooked.

Ethics

Ethics Committee Approval: Research approval was received from the Pamukkale University Non-Interventional Clinical Research Ethics Committee, (approval date: 18.04.2023; approval number: 60116787-020-358580).

Informed Consent: All participants were informed about the purpose of the study, and written informed consent was obtained prior to their inclusion.

Footnotes

Authorship Contributions

Surgical and Medical Practices: E.M., C.O.K., Concept: E.M., C.O.K., Design: E.M., C.O.K., Data Collection and/or Processing: E.M., C.O.K., A.Y., Analysis and/or Interpretation: E.M., C.O.K., A.Y., Literature Search: E.M., C.O.K., A.Y., Writing: E.M., C.O.K., A.Y.

Conflict of Interest: The authors declare that they have no conflict of interest.

Financial Disclosure: The authors declare that this study has received no financial support.

Main Points

- Focusing solely on the oncological aspects in the follow-up care of head and neck cancer patients may result in neglecting the impact of the treatment's side effects on their daily lives.
- The Head and Neck Carcinologic Handicap Index (CHI) is designed to identify the factors that limit function in these patients and assess their disease management needs.
- This study adapted the CHI into Turkish and confirmed its reliability and validity.
- We suggest regularly using the CHI during follow-ups for patients with head and neck cancer.

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