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Disparities in Dysphagia Care Among Head and Neck Cancer Patients: A Retrospective Cohort Study

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Abstract

Objective. To investigate the incidence of dysphagia among head and neck cancer (HNC) patients and assess disparities in utilization of speech-language pathology (SLP) services across different demographic groups.

Study Design. Retrospective cohort study.

Setting. Analysis of data from the TriNetX global health network, comprising over 125 million deidentified electronic health records worldwide.

Methods. HNC patients diagnosed with oral, oropharyngeal, laryngeal, or nasopharyngeal cancer with and without dysphagia between January 1, 2004 and October 30, 2024 were identified. Patients were divided into two cohorts for comparison: those who received SLP services after dysphagia diagnosis and those who did not. The association of demographic characteristics (sex, ethnicity, and race) with SLP services were analyzed.

Results. Of 269,629 HNC patients, 28.8% (n = 77,562) were diagnosed with dysphagia. Significant disparities were found: female and non-White patients were less likely to be diagnosed with dysphagia. Once diagnosed, female, Hispanic/Latino, and non-White patients were also significantly less likely to receive SLP services compared to female, Hispanic/Latino, and non-White patients. Overall, only 38.8% of patients with dysphagia received SLP services.

Conclusion. This study highlights significant sex, ethnic, and racial disparities in dysphagia diagnosis and SLP service utilization among HNC patients. Furthermore, SLP services are underutilized. There is a need for targeted interventions to increase dysphagia prevention and surveillance and ensure equitable access to dysphagia care, improving outcomes for all HNC survivors.

Keywords

disparities, dysphagia, head and neck cancer, speech-language pathology, swallowing

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Head and neck cancers (HNC) encompass a wide range of malignancies originating from the squamous epithelium regions within the head and neck, accounting for roughly 5% of cancer diagnoses and deaths in the United States.[1] These cancers often lead to significant and lasting morbidities, among which dysphagia, or difficulty swallowing, is particularly prevalent and debilitating. Dysphagia affects more than 55% of HNC patients, and the consequences are severe, including depression, anxiety, malnutrition, aspiration pneumonia, and death.[2-7] Notably, the onset of dysphagia is not limited to the immediate post-operative or post-treatment period; instead, it can arise before or more than ten years after treatment, particularly in patients who have undergone radiation and chemotherapy.[3,7-10] Thus, dysphagia and its associated complications continue to pose significant challenges to both patients and healthcare providers over an extended timeframe.

The etiology of dysphagia in HNC patients is multifactorial, encompassing anatomical changes secondary to the disease itself, the loss of structures due to surgery, and radiation-induced complications such as trismus, xerostomia, fibrosis, and strictures, all of which contribute to the complexity of evaluation and treatment.[11-15] Management of dysphagia in HNC survivors is inherently multidisciplinary, with speech-language pathologists (SLPs) playing a crucial role in addition to other professionals such as physicians, nurses, and dieticians.[16,17] The SLP's role includes

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educating patients about anticipated functional loss, preemptively initiating pre-rehabilitative exercises, and following patients during and after treatment to help maintain and restore swallowing function as much as possible.[16,18-20] Although there are few published guidelines or standardized protocols in place for SLPs managing dysphagia in patients with HNC, studies have described improvements in the quality of life of patients who work with SLPs.[20-22] Furthermore, studies have shown that early intervention by SLP in HNC patients leads to reduced treatment burden, reduced morbidity, increased treatment tolerance, lower healthcare costs, improved long-term swallowing functionality, and overall better patient outcomes.[19,23-26]

Despite the critical role of SLPs in managing dysphagia for HNC patients, it is unclear if access to these services is uniform across patient populations. Although some studies have indicated there may be disparities in dysphagia care, there is a clear gap in the literature surrounding this topic.[27] Recent studies have revealed disparities in the treatment of HNC; therefore, similar patterns of inequities may also exist in post-HNC dysphagia care.[28,29] It is well established that social determinants of health, such as race, socioeconomic status, and geographic location, are closely linked to healthcare outcomes. Variances in access and outcomes within healthcare not only affect the physical well-being of survivors but also place a considerable strain on the healthcare system.[30-33] A deeper exploration of the scope of disparities in post-HNC dysphagia care is foundational for developing targeted solutions to address barriers faced by underserved populations.

Given the profound impact of dysphagia on the quality of life among HNC survivors and the limited amount of research on disparities in dysphagia care, our study aims to bridge this gap by examining potential inequities in this population. Specifically, our study sought to investigate the incidence of dysphagia in patients diagnosed with HNC and to assess differences in the rate of subsequent SLP services across patient populations. These data could ultimately be used to inform clinical practice and policy changes, improving access to dysphagia treatment and swallowing care for HNC patients and survivors.

Methods

Study Design

This retrospective cohort study utilized data from TriNetX, a global health research network comprising over 125 million deidentified electronic health records from 92 healthcare organizations worldwide. The data is aggregated for secondary analysis and does not involve intervention or interaction with human subjects. This study used de-identified data obtained through TriNetX, which does not require review or approval by an Institutional Review Board or ethics committee as outlined in the University Hospitals Clinical Research Standard Operating Procedures (SS-308).

Data Collection

The database was queried for HNC patients diagnosed with oral, oropharyngeal, laryngeal, or nasopharyngeal cancer using International Classification of Diseases-10 (ICD-10) codes C00-C14 and C32 between January 1, 2004 and October 30, 2024. Patients with dysphagia after HNC were then identified via the presence of a new diagnosis of dysphagia (ICD-10 code R13.1*) after the diagnosis of HNC. For any data coded with older classifications, such as ICD-9, TriNetX automatically maps the corresponding ICD-10 codes. Patients were included if they had dysphagia-related Current Procedural Terminology (CPT) codes (92610, 92611, 92612, and 92526) recorded following their HNC diagnosis, regardless of which provider performed the assessment. This approach allowed us to focus on the utilization of SLP services for dysphagia management post-HNC diagnosis.

Patients were divided into two cohorts for comparison: (1) HNC patients with a diagnosis of dysphagia and subsequent SLP services and (2) HNC patients with a diagnosis of dysphagia but without subsequent SLP services. The timing of SLP services relative to the diagnosis of dysphagia was categorized as dysphagia diagnosis within 1 year, between 1-5 years, and more than 5 years after HNC diagnosis.

To examine the frequency of other diagnoses associated with dysphagia, a separate query was performed, excluding patients with concomitant diagnoses with high risk for dysphagia, such as stroke (ICD-10 I63, I63.50), cervical neck trauma (ICD-10 S12.9XXA), Parkinson's Disease (ICD-10 G20), amyotrophic lateral sclerosis (ALS) (ICD-10 G12.21), and other neuromuscular diseases (ICD-10 G99.2).

Statistical Analysis

All data was exported from TriNetX into Microsoft Excel (Microsoft® Excel for Mac, Version 16.86; Microsoft Corporation) for statistical analysis. Descriptive statistics were performed to determine the number of patients with a diagnosis of dysphagia and subsequent SLP services in different demographic groups (sex, ethnicity, and race). χ^2 tests were used to examine differences between groups, with statistical significance set at $P < .05$. The odds ratio (OR) with 95% confidence intervals (CI) was calculated for each demographic variable. Given the small relative number of other race categories compared to White patients, all other races were combined into a single non-White group for analysis.

Results

Incidence and Timing of Dysphagia Diagnosis and First SLP Service

Out of 269,629 patients diagnosed with HNC, 28.7% (n = 77,276) had a subsequent diagnosis of dysphagia. Of those diagnosed with dysphagia, 75.8% (n = 60,278) occurred within one year, 16.5% between one to five years (n = 13,085), and 7.7% more than five years (n = 6,115) after HNC diagnosis (**Figure 1**).

A separate query revealed that 10.4% (n = 8,045) of the total HNC cohort also had other diagnoses with a risk of dysphagia, including stroke, cervical neck trauma, Parkinson's Disease, amyotrophic lateral sclerosis, and other neuromuscular diseases. Ultimately, these patients were not excluded from the analysis, given their dysphagia was diagnosed after HNC, and these diagnoses would not preclude their referral to SLP.

Of the HNC patients diagnosed with dysphagia, 38.8% (n = 30,006) received one or more swallowing-specific SLP services. 94.8% (n = 28,447) of those patients received services within the first year of dysphagia diagnosis, 9.2% (n = 2773) between 1 and 5 years, and 4.1% (n = 1220) more than 5 years after their dysphagia diagnosis (**Figure 1**).

Demographic Characteristics of HNC Patients With Dysphagia

Table 1 shows the demographic characteristics of the entire cohort of HNC patients with and without a dysphagia diagnosis. Out of the total cohort, 28.8% (n = 77,562) had a diagnosis of dysphagia. Patients in the dysphagia cohort were predominantly male and White, constituting 72.1% (n = 55,930) and 74.7% (n = 57,951) of the study population, respectively. Patients with a dysphagia diagnosis had a higher average age (mean ± SD) than patients without a dysphagia diagnosis (62.9 ± 11.0 years vs 60.3 ± 13.1 years; *P* < .0001). Females were significantly less likely than males to be diagnosed with dysphagia (26.0% vs 29.9%, OR = 0.825, 95% CI [0.812-0.838], *P* < .0001). Hispanic or Latino patients were less likely than non-Hispanic or Latino patients to be diagnosed with dysphagia, though this did not reach statistical significance (34.8% vs 35.2%, OR = 0.983, 95% CI [0.944-1.023], *P* = .4055). Non-White patients were significantly less likely than White patients to be diagnosed with dysphagia (18.1% vs 35.9%, OR = 0.393, 95% CI [0.391-0.396], *P* < .0001).

Disparities in SLP Services After Dysphagia Diagnosis

Table 2 shows the demographic composition of those receiving SLP evaluation or treatment within the subgroup of patients diagnosed with dysphagia after HNC diagnosis. Due to inherent TriNetX database characteristics, the total number of patients with dysphagia in this subgroup analysis does not equal the number of patients with dysphagia in the entire HNC cohort. Although there was a statistically significant difference in average age (mean ± SD) between patients with SLP services compared to patients without SLP services (63.5 ± 10.8 years vs 62.8 ± 11.0 years; *P* < .0001), this difference is likely not clinically significant. Further analysis revealed significant sex, ethnic, and racial disparities in terms of receiving SLP services among HNC patients with dysphagia. Female patients were significantly less likely to receive SLP services than male patients (37.8% vs 39.1%, OR = 0.942, 95% CI [0.913-0.972], *P* = .0004). Hispanic or Latino patients were significantly less likely to receive SLP services than non-Hispanic or Latino patients (30.3% vs 41.8%, OR = 0.623,

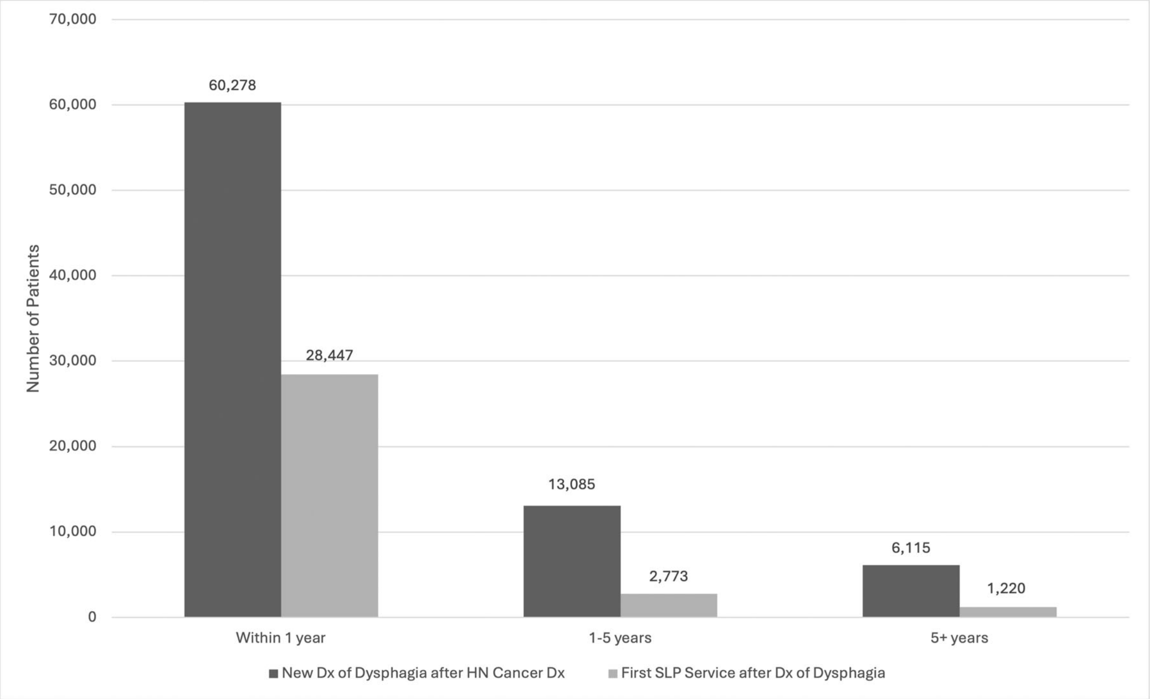

Figure 1. Dysphagia diagnosis (dx) after head and neck cancer (HNC) diagnosis, compared to speech-language pathology (SLP) service utilization after HNC and dysphagia diagnosis.

Table 1. Demographic Characteristics of Head and Neck Cancer Patients with and without Dysphagia

	Total	Dysphagia	No dysphagia	% with dysphagia	Odds ratio (95% CI)	*P* value
Total	269,629	77,562	192,067	28.8%		
Average age (years ± SD)		62.9 ± 11.0	60.3 ± 13.1		—	<.0001
Sex						
Male	187,280	55,930	131,350	29.9%	1.00	
Female	76,934	20,002	56,932	26.0%	0.825 (0.812-0.838)	<.0001
Unknown	5,415	1,630	3,785	30.1%	—	
Ethnicity						
Not Hispanic or Latino	158,498	55,718	102,780	35.2%	1.00	
Hispanic or Latino	10,720	3,726	6,994	34.8%	0.983 (0.944-1.023)	.4055
Unknown	100,411	18,118	82,293	18.0%	—	
Race						
White	161,201	57,951	103,250	35.9%	1.00	
Non-White	53,897	13,074	40,823	24.3%	0.393 (0.391-0.396)	<.0001
Black or African American	19,864	7,016	12,848	35.3%		
Asian	20,495	2,845	17,650	13.9%		
Native Hawaiian or Other Pacific Islander	1,632	704	928	43.1%		
American Indian or Alaska Native	662	243	419	36.7%		
Other Race	11,244	2,266	8,978	20.2%		
Unknown	65,775	8,803	56,972	13.4%	—	

Table 2. Demographic Characteristics of Head and Neck Cancer Patients by Speech Language and Pathology (SLP) Service Utilization

	Total	SLP services	No SLP services	% with SLP services	Odds ratio (95% CI)	*P* value
Total	77,276	30,006	47,270	38.8%		
Age (years ± SD)		63.5 ± 10.8	62.8 ± 11.0		—	<.0001
Sex						
Male	55,684	21,874	33,810	39.3%	1.00	
Female	19,986	7,567	12,419	37.9%	0.942 (0.913-0.972)	.0004
Unknown	1,606	565	1,041	35.2%	—	
Ethnicity						
Not Hispanic or Latino	55,845	23,288	32,557	41.7%	1.00	
Hispanic or Latino	3,664	1,129	2,535	30.8%	0.623 (0.595-0.651)	<.0001
Unknown	17,767	5,589	12,178	31.5%	—	
Race						
White	58,015	23,587	34,428	40.7%	1.00	
Non-White	12,829	4,566	8,263	35.6%	0.807 (0.781-0.833)	<.0001
Black or African American	7,008	2,531	4,477	36.1%		
Asian	2,696	1,004	1,692	37.2%		
Native Hawaiian or Other Pacific Islander	667	214	453	32.1%		
American Indian or Alaska Native	238	83	155	34.9%		
Other Race	2,220	734	1,486	33.1%		
Unknown	8,652	2,587	6,065	29.9%	—	

95% CI [0.595-0.651], $P < .0001$). Non-White patients were significantly less likely to receive SLP services than White patients (35.6% vs 40.7%, OR = 0.807, 95% CI [0.781-0.833], $P < .0001$).

Discussion

This study aimed to investigate the incidence of dysphagia in HNC patients and to assess disparities in the utilization of SLP services among different demographic groups. The analysis uncovered significant differences in the rates of dysphagia diagnosis and subsequent SLP services among demographic groups. HNC patients identified as non-White, Hispanic or Latino, or female were not only less likely to be diagnosed with dysphagia, but once diagnosed with dysphagia, they were also less likely to receive SLP services. In addition, the results indicated that overall SLP care is likely underutilized, with less than half of those diagnosed with dysphagia having evidence of swallowing-specific SLP CPT codes. Therefore, there is both a need for targeted interventions to improve equitable access to dysphagia care as well as a general necessity to enhance awareness and utilization of SLP services among all HNC patients.

In our study, male HNC patients were more likely to be diagnosed with dysphagia. Interestingly, this finding contrasts with some studies, such as Shune et al, which found that females with HNC are at greater risk of developing dysphagia, although their sample size was limited to their institution.[34] Other studies have indicated that female HNC patients experience worse swallowing outcomes and report a lower overall quality of life compared to male HNC patients.[35-37] In addition to sex differences, our results suggest that Hispanic or Latino and non-White patients were also less likely to be diagnosed with dysphagia than their non-Hispanic or Latino and White counterparts. Although one interpretation of the data is that these groups may be less likely to develop dysphagia after HNC diagnosis, it is more likely that they are being underdiagnosed. Ensuring that all patients receive appropriate dysphagia diagnosis and management is crucial for improving their quality-of-life post-HNC diagnosis.

Our analysis further demonstrated significant differences in the utilization of SLP services in HNC patients diagnosed with dysphagia based on sex, ethnicity, and race. Female, Hispanic, and non-White patients were significantly less likely to receive SLP services than male, non-Hispanic or Latino, and White patients, respectively. These observed disparities align with existing literature on racial inequities in HNC treatment. For instance, studies have shown that compared to White patients, Black or African American patients not only lack access to care and have higher tumor burdens at diagnosis but also are less frequently recommended for surgery, more likely to refuse surgery, and have higher mortality rates.[38-40] Education, screening, and better healthcare coverage have been suggested to reduce these differences.[40] Our findings further underscore the need for continued research to address inequities in both treatment and rehabilitation for HNC patients.

Beyond disparities, we found that overall utilization of SLP services following dysphagia diagnosis after HNC diagnosis was only 38.8%. The underutilization of rehabilitation services, including SLP, has also been noted by other prior studies, some of which report an even lower rate of SLP utilization than our study.[41,42] Although there are multiple treatment pathways for dysphagia after HNC, studies have shown a significant positive impact on patient morbidity and overall outcomes.[43,44] Early intervention by SLPs in HNC patients can lead to a quicker return to oral diets, reduced need for feeding tubes, and lower healthcare expenses, among a myriad of other benefits.[19,22-26] These advantages highlight the essential role of SLPs in addressing dysphagia and enhancing patient outcomes, underscoring the importance of expanding the use of SLP services for all patient groups. Improving education for both patients and clinicians about dysphagia prevention, developing dysphagia surveillance protocols for early diagnosis and management, and addressing systemic barriers such as financial and geographic constraints are essential steps toward ensuring comprehensive and equitable care for all HNC patients.

To our knowledge, this study is the largest and only retrospective study to focus on the disparities in receiving SLP services following dysphagia diagnosis in HNC patients. However, inherent to our study are several key limitations. The data extracted from the database was limited to proportional demographic data lacking granular patient information; as a result, we could not adjust for additional confounding factors. The reliance on ICD codes for identifying dysphagia and SLP service utilization likely results in misclassification or underreporting. Additionally, as TriNetX data primarily reflects larger health care organizations (HCOs), the generalizability of our findings to the broader HNC population may be limited. For instance, some patients may have been diagnosed with dysphagia at larger centers but subsequently received SLP services at regional hospitals or through home care, which may not report data to the TriNetX network. Still, although actual SLP service utilization may be higher than reported in our study, our findings still suggest an overall underutilization of services.

In addition, temporal relationships between ICD-10 and CPT codes were used to construct the queries to create the patient cohorts, which may not accurately reflect true diagnostic or procedural timing. Furthermore, we were unable to determine if the SLP services were directly linked to dysphagia from an HNC etiology; however, less than 10% of our cohort were found to have other diagnoses commonly associated with dysphagia. It is also noteworthy that the non-White demographic group primarily consists of Black or African American patients; therefore, future work should strive to collect data from other minority populations to ensure representation in research. Further research that incorporates data from diverse healthcare settings, including community and regional hospitals, as well as studies with more granular patient information will be essential to comprehensively uncover and address disparities in dysphagia diagnosis and access to SLP care.

Conclusion

The results of this large retrospective cohort study highlighted significant sex, ethnic, and racial disparities in the diagnosis and management of dysphagia, as well as overall underutilization of SLP dysphagia services among HNC patients. These findings emphasize the need for targeted interventions to ensure equitable access to dysphagia care and improve the quality of life for all HNC survivors. Increasing awareness among healthcare providers and patients about the importance of dysphagia prevention, diagnosis, and management, implementing standardized screening protocols, and addressing systemic barriers such as financial constraints and geographic disparities are essential steps. Future research should focus on identifying and addressing the specific obstacles that contribute to these disparities and evaluating the effectiveness of interventions designed to improve access to dysphagia management services.

Author Contributions

Daniel Karasik, conceptualization, methodology, data curation, formal analysis, visualization, project administration writing—original draft, writing—review and editing; **Gillian Michaelson**, writing—review and editing; **Claudia I. Cabrera**, validation, writing—review and editing; **Alexis Nahra**, validation, writing—review and editing; **Nina W. Zhao**, conceptualization, methodology, supervision, validation, writing—review and editing.

Disclosures

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