JAMA Otolaryngology-Head & Neck Surgery | Original Investigation | FROM THE AMERICAN HEAD AND NECK SOCIETY

# Factors Associated With Risk of Body Image-Related Distress in Patients With Head and Neck Cancer

David Macias, MD; Brittany N. Hand, PhD, OTR/L; Stacey Maurer, PhD; Wendy Balliet, PhD; Mark A. Ellis, MD; Patrik Pipkorn, MD, MSCI; Andrew T. Huang, MD; Marci L. Nilsen, PhD, RN; Kenneth J. Ruggiero, PhD; Amy M. Williams, PhD; Courtney H. Marsh, BS; Hong Li, PhD; Bethany A. Rhoten, PhD, RN; Katherine R. Sterba, PhD, MPH; Evan M. Graboyes, MD, MPH

**IMPORTANCE** Body image-related distress (BID) is common among head and neck cancer (HNC) survivors and associated with significant morbidity. Risk factors for HNC-related BID remain poorly characterized because prior research has used outcome measures that fail to fully capture BID as experienced by HNC survivors.

**OBJECTIVE** To assess the association of demographic and oncologic characteristics with HNC-related BID using the Inventory to Measure and Assess imaGe disturbancE-Head & Neck (IMAGE-HN), a validated, multidomain, patient-reported outcome measure of HNC-related BID.

**DESIGN, SETTING, AND PARTICIPANTS** This cross-sectional study assessed 301 adult survivors of surgically managed HNC at 4 academic medical centers.

MAIN OUTCOMES AND MEASURES The primary outcome measure was IMAGE-HN scores, for which higher scores reflect more severe HNC-related BID. Multivariable linear regression analyses were performed to evaluate the association of patient characteristics with IMAGE-HN global and 4 subdomain (other-oriented appearance concerns, personal dissatisfaction with appearance, distress with functional impairments, and social avoidance) scores.

**RESULTS** Of the 301 participants (212 [70.4%] male; mean [SD] age, 65.3 [11.7] years), 181 (60.1%) underwent free flap reconstruction. Graduation from college ( $\beta = -9.6$ ; 95% CI, -17.5 to -1.7) or graduate school ( $\beta$  = -12.6; 95% CI, -21.2 to -3.8) was associated with lower IMAGE-HN social avoidance scores compared with less than a high school education. Compared with paid work, unemployment was associated with higher IMAGE-HN other-oriented appearance ( $\beta$  = 10.7; 95% CI, 2.0-19.3), personal dissatisfaction with appearance ( $\beta$  = 12.5; 95% Cl, 1.2-23.7), and global ( $\beta$  = 8.0; 95% Cl, 0.6-15.4) scores. Compared with no reconstruction, free flap reconstruction was associated with higher IMAGE-HN global scores ( $\beta$  = 11.5; 95% CI, 7.9-15.0) and all subdomain scores (other-oriented appearance:  $\beta$  = 13.1; 95% Cl, 8.6-17.6; personal dissatisfaction with appearance:  $\beta$  = 15.4; 95% CI, 10.0-20.7; distress with functional impairment:  $\beta$  = 12.8; 95% CI, 8.1-17.4; and social avoidance and isolation:  $\beta$  = 10.2; 95% CI, 5.8-14.6). Higher IMAGE-HN distress with functional impairment scores were found in those who received surgery and adjuvant radiation ( $\beta$  = 7.8; 95% CI, 2.9-12.7) or chemoradiotherapy ( $\beta$  = 6.5; 95% CI, 1.8-11.3) compared with surgery alone. The multivariable regression model accounted for a modest proportion of variance in IMAGE-HN global ( $R^2 = 0.18$ ) and subdomain scores ( $R^2 = 0.20$ for other-oriented appearance, 0.14 for personal dissatisfaction with appearance, 0.21 for distress with functional impairment, and 0.13 for social avoidance and isolation).

**CONCLUSIONS AND RELEVANCE** In this cross-sectional study, factors associated with risk of HNC-related BID included free flap reconstruction, lower educational attainment, unemployment, and multiple treatment modalities. These characteristics explain a modest proportion of variance in IMAGE-HN scores, suggesting that other characteristics may be the major risk factors for HNC-related BID and should be explored in future studies.

*JAMA Otolaryngol Head Neck Surg.* 2021;147(12):1019-1026. doi:10.1001/jamaoto.2021.1378 Published online July 8, 2021. Author Affiliations: Author affiliations are listed at the end of this article.

#### **Corresponding Author:**

David Macias, MD, Department of Otolaryngology–Head & Neck Surgery, Medical University of South Carolina, 135 Rutledge Ave, MSC 550, Charleston, SC 29425 (maciasd@musc.edu).

ead and neck cancer (HNC) is the sixth most common cancer worldwide, and the number of HNC survivors is increasing sharply in the US.<sup>1,2</sup> Both HNC and its treatment result in highly visible disfigurement and functionally critical impairments, including challenges speaking, difficulty swallowing, and impaired smiling.<sup>3,4</sup> When severe, these impairments have significant negative effects on psychosocial well-being and physical function and result in body imagerelated distress (BID), a disorder characterized by selfperceived displeasing change in appearance and/or function and the resultant psychosocial distress.4-8 Body imagerelated distress is common among HNC survivors because of the visible nature of the head and neck and its association with personal identity and communication<sup>3,9</sup> and is an important contributor to social isolation, stigmatization, depression, decreased intimacy, and worse quality of life.<sup>4,10-12</sup>

Multiple studies<sup>5</sup> have sought to identify pretreatment risk factors for HNC-related BID. These studies<sup>13,14</sup> relied on patientreported outcome measures (PROMs) to assess HNC-related BID because of its subjective nature and poor correlation with objective measures of disfigurement. Unfortunately, the PROMs used in these studies<sup>5</sup> were developed for non-HNC populations (eg, breast cancer) and do not fully capture the spectrum of body image concerns experienced by HNC survivors. As a result, risk factors for HNC-related BID remain poorly characterized. The Inventory to Measure and Assess imaGe disturbancE-Head & Neck (IMAGE-HN) is a psychometrically sound PROM of HNC-related BID that was validated in a multiinstitutional study.<sup>15</sup> Through its comprehensive assessment of key aspects of HNC-related BID using 4 individual domains and a global domain, the IMAGE-HN can more precisely identify factors associated with BID among HNC survivors. Therefore, this study aims to assess the association between sociodemographic and oncologic characteristics and HNC-related BID using the IMAGE-HN.

# Methods

## **Study Design and Participants**

This cross-sectional study is a secondary analysis of data collected for the IMAGE-HN validation. The description of the validation cohort and results of the psychometric validation have been previously published.<sup>15</sup> Individuals 18 years or older with a history of surgically managed HNC and no known active disease were included. Participants were enrolled from multidisciplinary HNC clinics at 4 academic medical centers (Medical University of South Carolina, Baylor College of Medicine, University of Pittsburgh Medical Center, and Washington University School of Medicine). After enrollment during a posttreatment or survivorship clinic visit, participants completed the IMAGE-HN and a self-reported sociodemographic and oncologic questionnaire using an electronic tablet. Of 309 patients approached for participation, 4 declined, and 4 did not provide demographic or oncologic data, leaving a sample of 301 patients. The study was approved by the Medical University of South Carolina institutional review board. The patients provided verbal consent, and a waiver of written informed con-

## **Key Points**

Question What are the factors associated with risk of body image-related distress (BID) among survivors of head and neck cancer (HNC)?

Findings In this cross-sectional study of 301 adult HNC survivors, lower educational attainment, unemployment, complex reconstructive surgery, and higher number of treatment modalities were associated with more severe HNC-related BID as measured by a validated patient-reported outcome measure of HNC-related BID. However, these associations explained only a modest proportion of variance in scores on the Inventory to Measure and Assess imaGe disturbancE-Head & Neck.

Meaning These findings suggest that although certain demographic and oncologic characteristics are associated with HNC-related BID, other risk factors appear to exist and should be explored in future studies.

sent was granted for the study because the research involved no more than minimal risk to the participants. Patient data were deidentified. This study followed the Strengthening the Reporting of Observational Studies in Epidemiology (STROBE) reporting guideline.

#### **IMAGE-HN**

Details regarding the development and validation of IMAGE-HN have been previously published,<sup>15</sup> and the instrument and scoring manual are publicly available.<sup>16</sup> In brief, the IMAGE-HN is a psychometrically sound, 24-item, multidomain PROM of HNC-related BID that consists of 4 subdomains and a global domain. The 4 subdomains are (1) other-oriented appearance concerns (perceived verbal and nonverbal reactions by others to the appearance of patients with HNC), (2) personal dissatisfaction with appearance (dissatisfaction with their appearance by patients with HNC), (3) distress with functional impairments (challenges related to speaking, swallowing, oral competence, and so on), and (4) social avoidance and isolation (avoidance of social interaction because of image concerns). Raw IMAGE-HN scores for each subdomain and the global domain can be converted to scaled scores ranging from 0 to 100, with higher scores reflecting more severe HNC-related BID.15

#### Variables

Self-reported sociodemographic characteristics included age, sex, race/ethnicity, marital status, living situation, educational attainment, employment, rurality, and insurance coverage. Self-reported oncologic characteristics include tumor subsite, cancer treatment, and type of reconstructive surgery. Time since completion of treatment was collected as a categorical variable.

#### Statistical Analysis

Descriptive statistics (eg, frequencies for categorical variables and mean [SD] or median [range] for continuous variables) were used to characterize the sample. Multivariable linear regression was used to identify characteristics associated with scores on the IMAGE-HN global domain and 4 subdomains. Patient characteristics were considered for inclusion in the multivariable linear regression models on the basis of bivariate analyses assessing the association with each of the 4 subdomains and global domain. The associations between categorical variables and IMAGE-HN domain scores were analyzed with 1-way analyses of variance, whereas continuous variables were examined with correlations. Categorical variables were included in the multivariable regression model if analysis of variance revealed P < .10 for the association with IMAGE-HN domain scores; continuous variables were included in the multivariable model if there was a linear correlation of at least 0.1 with IMAGE-HN domain scores. To evaluate the presence of multicollinearity among tumor location, reconstructive surgery type, and cancer treatment, we evaluated all possible 2-way associations. All correlations were weak to moderate (Cohen d = 0.12-0.43), suggesting no significant degree of multicollinearity among any of these 3 variables. We then included interaction terms for these variables in the multivariable regression models when any of the main effects were significant; none of the interaction terms were significant (P > .05 for each). The final multivariable models were identified using backward elimination. A 2-sided P < .05 was considered statistically significant for all variables and interaction terms. Statistical analyses were performed using SAS statistical software (SAS Institute Inc).

## Results

## **Sample Characteristics**

A total of 301 participants (212 [70.4%] male; mean [SD] age, 65.3 [11.7] years) with sociodemographic and oncologic information were included in the study (**Table 1**). The most common HNC subsites were oral cavity (129 [42.9%]), oropharynx (50 [16.6%]), and facial cutaneous (50 [16.6%]); 186 patients (61.8%) underwent adjuvant therapy, and 181 patients (60.1%) underwent free flap reconstruction.

## Associations of Demographic Characteristics With HNC-Related BID

Table 2 gives the results of the multivariable linear regression models, demonstrating the association of demographic characteristics with HNC-related BID. Higher educational attainment was associated with lower social avoidance and isolation subdomain scores. Graduation from college ( $\beta = -9.6$ ; 95% CI, -17.5 to -1.7) or graduate school ( $\beta = -12.6$ ; 95% CI, -21.2 to -3.8) was associated with 9.6-point and 12.6-point lower IM-AGE-HN social avoidance and isolation subdomain scores compared with non-high school graduates.

Employment status was also associated with IMAGE-HN scores. Disability was associated with an increased IMAGE-HN global ( $\beta$  = 5.1; 95% CI, 0.1-10.0) score compared with part-time or full-time paid work. Unemployment had a positive association with IMAGE-HN global ( $\beta$  = 8.0; 95% CI, 0.6-15.4) scores as well as other-oriented appearance concerns ( $\beta$  = 10.7; 95% CI, 2.0-19.3) and personal dissatisfaction with appearance ( $\beta$  = 12.5; 95% CI, 1.2-23.7) subdomain

haracteristic	Finding (N = 301) <sup>a</sup>
Age, mean (SD), y	65.3 (11.7)
2X	. ,
Female	89 (29.6)
Male	212 (70.4)
ace	222 (7 01 1)
White	251 (83.4)
African American	34 (11.3)
Other <sup>b</sup>	
thnicity	16 (5.3)
,	(۲ ۲)
Hispanic	8 (2.7)
Non-Hispanic	278 (92.4)
Prefer not to answer	15 (5.0)
larital status (n = 300)	204 (66.6)
Married or current partner	204 (68.0)
Single, separated, divorced, or widowed	96 (32.0)
iving situation (n = 300)	
Spouse	196 (65.3)
Parents, children, friends, or other	49 (16.3)
Self	55 (18.3)
ducational attainment (n = 299)	
Less than high school	27 (9.0)
High school graduate	85 (28.4)
Some college	77 (25.8)
College graduate	69 (23.1)
Graduate school	41 (13.7)
mployment (n = 299)	
Part-time or full-time paid work	75 (25.1)
Unemployed	17 (5.7)
Disability	54 (18.1)
Retired	153 (51.2)
urality (n = 300)	. ,
Rural	117 (39.0)
Suburban	147 (49.0)
Urban	36 (12.0)
Insurance	(-=-0)
Private	104 (34.6)
Medicare	162 (53.8)
Medicaid, self-pay, or other	35 (11.6)
umor location	55 (11.0)
	120 (42.0)
Oral cavity	129 (42.9)
Oropharynx	50 (16.6)
Larynx/hypopharynx	38 (12.6)
Unknown/other	14 (4.7)
Major salivary gland	20 (6.6)
Facial cutaneous malignancy	50 (16.6)
ancer treatment	
Surgery	115 (38.2)
Surgery and adjuvant radiation	98 (32.6)
Surgery and adjuvant chemoradiation	88 (29.2)
econstructive surgery	
None	102 (33.9)
Other (including local or regional flap)	18 (6.0)
Microvascular free flap	181 (60.1)

(continued)

Table 1. Participant Characteristics (continued)				
Characteristic	Finding (N = 301) <sup>a</sup>			
Osseous microvascular free flap reconstruc	tion			
No	259 (86.0)			
Yes	42 (14.0)			
Time since completion of treatment, mo <sup>c</sup>				
0-6	119 (39.5)			
6-12	49 (16.3)			
12-24	52 (17.3)			
>24	81 (26.9)			

<sup>a</sup> Data are presented as number (percentage) of patients unless otherwise indicated. Some sample sizes are smaller because of missing information.

<sup>b</sup> Other includes those who self-reported as Asian, self-reported as more than 1 race, and preferred not to answer.

<sup>c</sup> Categories as used in the original data set.

scores when compared with paid employment. IMAGE-HN scores were not associated with the remainder of the demographic characteristics (age, sex, race/ethnicity, marital status, rurality, or insurance), and there were no significant interaction terms.

# Associations of Oncologic Characteristics With HNC-Related BID

Table 2 gives the results of the multivariable linear regression models, demonstrating the association of oncologic characteristics with HNC-related BID. Compared with patients with oral cavity cancer, patients with laryngeal/hypopharyngeal cancer had increased scores on the other-oriented appearance concerns subdomain ( $\beta = 9.6$ ; 95% CI, 3.3-15.8). Patients with facial cutaneous malignant tumors had lower distress with functional impairments subdomain scores ( $\beta = -14.5$ ; 95% CI, -20.1 to -8.9).

Microvascular free flap surgery had a large, positive association with the IMAGE-HN global domain and all 4 subdomains. Compared with no reconstructive surgery, free flap surgery was associated with an 11.5-point higher IMAGE-HN global score ( $\beta$  = 11.5; 95% CI, 7.9-15.0) and elevated scores across all subdomains (other-oriented appearance:  $\beta$  = 13.1; 95% CI, 8.6-17.6; personal dissatisfaction with appearance:  $\beta$  = 15.4; 95% CI, 10.0-20.7; distress with functional impairment:  $\beta$  = 12.8; 95% CI, 8.1-17.4; and social avoidance and isolation:  $\beta$  = 10.2; 95% CI, 5.8-14.6). IMAGE-HN scores were not associated with time since completion of treatment as a categorical variable or osseous flap reconstruction compared with nonosseous reconstruction.

#### **Explanation of Variance in HNC-Related BID**

The coefficients of multiple determination ( $R^2$ ) for the multivariable linear regression models (Table 2) accounted for a modest proportion of the variance in global IMAGE-HN scores ( $R^2 = 0.18$ ), as well as scores on each of the IMAGE-HN subdomains ( $R^2 = 0.20$  for other-oriented appearance, 0.14 for personal dissatisfaction with appearance, 0.21 for distress with functional impairment, and 0.13 for social avoidance and isolation).

# Discussion

This cross-sectional study of a large, multi-institutional cohort of surgically treated HNC survivors describes demographic and oncologic characteristics associated with HNCrelated BID, including (1) reconstructive surgery, (2) educational attainment, (3) employment, (4) tumor subsite, and (5) adjuvant therapy. In addition to identifying factors associated with HNC-related BID, this study also adds to the increasing body of literature that suggests that age, <sup>5,17,18</sup> sex, <sup>5,7,9</sup> and duration of treatment<sup>17</sup> are not associated with BID among HNC survivors. Although factors associated with BID among HNC survivors have been explored in previous studies,<sup>5</sup> these studies were limited by the use of measures of BID developed for patient populations without HNC. Therefore, risk factors for HNC-related BID remain poorly characterized.<sup>4-6</sup> This study addresses this knowledge gap by using an HNC-specific BID PROM to assess the associations between patient characteristics and HNC-related BID.

## **Reconstructive Surgery**

Patients undergoing microvascular free flap surgery appear to be at very high risk for developing HNC-related BID. Free flap reconstructions are the standard of care for complex ablative defects in HNC in terms of functional and cosmetic outcomes,19 yet the use of a free flap does not appear to mitigate BID induced by the associated surgical resection. The finding of a strong association between extent of reconstructive surgery and HNC-related BID is in accordance with prior studies.<sup>5,20,21</sup> This association between free flap reconstruction and HNCrelated BID, although not surprising, is potentially confounded by a complex association among cancer stage, extent of surgical resection, need for adjuvant therapy, and free flap reconstruction. Although these associations may be difficult to disentangle because of challenges quantifying the extent of surgical resection and nonrandom allocation of patients to type of reconstruction,<sup>22</sup> future studies could consider exploring the interplay between these variables and HNC-related BID. Further complicating this association is that free flaps are a heterogenous group that consists of different types of flaps (eg, osseous or nonosseous), tissue characteristics, donor sites, and other characteristics that vary widely. For example, some studies have found that patients undergoing osseous free flap reconstruction are at higher risk for BID compared with those undergoing a nonosseous reconstruction, 23,24 although other studies, <sup>17</sup> including the current one, have not. This discrepancy could be explained by a number of factors, including small sample size or differences in measures of BID. It is nevertheless clear that much work remains to be done to understand the mechanisms by which free flap reconstructions are associated with HNC-related BID.

## **Educational Attainment**

This study found that higher levels of educational attainment are protective against image-related social avoidance and isolation among HNC survivors. Although the findings of this study are consistent with numerous prior studies,<sup>5,20,25</sup> a re-

Fable 2. Association of Demographic and Oncologic Characteristics With the 4 Subdomains and Global Domain of the IMAGE-HN
---

	β (95% CI)					
Characteristic	00A	PDA	DFI	SA	Global	
Educational attainment						
Less than high school	NA	NA	NA	1 [Reference]	NA	
High school graduate	NA	NA	NA	-2.1 (-9.7 to 5.6)	NA	
Some college	NA	NA	NA	-5.4 (-13.1 to 2.4)	NA	
College graduate	NA	NA	NA	-9.6 (-17.5 to -1.7)	NA	
Graduate school	NA	NA	NA	-12.6 (-21.2 to -3.8)	NA	
Employment						
Part-time or full-time paid work	1 [Reference]	1 [Reference]	NA	NA	1 [Reference]	
Disability	5.3 (-0.5 to 11.2)	5.0 (-2.6 to 12.5)	NA	NA	5.1 (0.1 to 10.0)	
Retired	-1.4 (-6.0 to 3.1)	-3.1 (-9.0 to 2.8)	NA	NA	-2.4 (-6.3 to 1.4)	
Unemployed	10.7 (2.0 to 19.3)	12.5 (1.2 to 23.7)	NA	NA	8.0 (0.6 to 15.4)	
Tumor location						
Oral cavity	1 [Reference]	NA	1 [Reference]	NA	NA	
Oropharynx	-2.3 (-8.0 to 3.5)	NA	-0.2 (-6.2 to 5.9)	NA	NA	
Larynx/hypopharynx	9.6 (3.3 to 15.8)	NA	1.3 (-5.1 to 7.7)	NA	NA	
Unknown/other	12.0 (2.8 to 21.2)	NA	2.2 (-7.7 to 12.0)	NA	NA	
Major salivary gland	6.5 (-1.4 to 14.4)	NA	-4.1 (-12.3 to 4.1)	NA	NA	
Facial cutaneous	3.9 (-1.5 to 9.2)	NA	-14.5 (-20.1 to -8.9)	NA	NA	
Cancer treatment						
Surgery	NA	NA	1 [Reference]	NA	NA	
Surgery and RT	NA	NA	7.8 (2.9 to 12.7)	NA	NA	
Surgery and CRT	NA	NA	6.5 (1.8 to 11.3)	NA	NA	
Reconstructive surgery						
None	1 [Reference]	1 [Reference]	1 [Reference]	1 [Reference]	1 [Reference]	
Microvascular free flap	13.1 (8.6 to 17.6)	15.4 (10.0 to 20.7)	12.8 (8.1 to 17.4)	10.2 (5.8 to 14.6)	11.5 (7.9 to 15.0)	
Other	1.5 (-6.2 to 9.2)	1.9 (-7.9 to 11.8)	5.1 (-2.9 to 13.2)	0.3 (-7.9 to 8.5)	1.1 (-5.5 to 7.6)	
Model R <sup>2</sup>	0.20	0.14	0.21	0.13	0.18	

Abbreviations: CRT, chemoradiotherapy; DFI, distress with functional impairments; IMAGE-HN, Inventory to Measure and Assess imaGe disturbancE-Head & Neck; NA, not applicable (variable not associated with scores in bivariate analysis and not included in the final regression model); OOA, other-oriented appearance concerns; PDA, personal dissatisfaction with appearance; RT, radiotherapy; SA, social avoidance and isolation.

cent study<sup>26</sup> in a Chinese cohort describes that higher education is associated with more severe BID among surgically treated patients with HNC. Potential explanations for their divergent results may be (1) differences in oncologic characteristics, (2) the categorization of education, or (3) cultural differences in how BID among patients with HNC in China may be internalized compared with patients with HNC in the US. Although the mechanism by which more education offers protection against HNC-related BID is not known, it is hypothesized that more education provides patients with improved coping abilities, psychological insight, and a better understanding of their cancer and its effects, thus allowing for healthier responses to changes in appearance and function.<sup>27,28</sup>

#### Employment

The HNC survivors with an employment status of disability or unemployed had higher IMAGE-HN scores. Employment may protect against BID through social support in the workplace and a sense of normalcy and routine.<sup>29</sup> However, the temporal association between employment and HNC-related BID may be reversed, and unemployment is possibly the consequence of more severe BID among HNC survivors. After HNC and its treatment, survivors struggling with body image concerns may feel unable to return to the workforce because of negative reactions or avoidance by others to changes in appearance or function.<sup>4,30</sup> Furthermore, HNC survivors are potentially unable to retire because of the substantial financial burden of HNC treatment<sup>31</sup> coupled with negative reactions to disfigurement by potential employers.<sup>32</sup> Half of HNC survivors do not return to work after treatment,<sup>33,34</sup> and appearance is one of the most common reasons. Future studies that longitudinally track employment and HNC-related BID from diagnosis through survivorship are necessary to disentangle the association between employment and HNC-related BID and determine whether unemployment is a cause or effect of BID among HNC survivors.

# **Tumor Subsite**

No associations were found between tumor location and higher BID except for the larynx/hypopharynx and other/ unknown subsites, which were associated with the otheroriented appearance concerns subdomain only. A reasonable

jamaotolaryngology.com

assumption is that facial cutaneous cancers would have a strong association with higher appearance-related concerns, but the findings of this study do not support this conclusion, perhaps in part because the study was not powered to detect subtle differences among subsites. The only tumor location reported as having an association with higher BID in the literature is the oral cavity, yet prior research is limited by use of BID measurement tools not validated for the HNC population and low numbers of patients with facial cutaneous tumors. Two studies<sup>9,35</sup> composed of large numbers of patients with facial cutaneous cancer did not find an association with this subsite and increased BID compared with the oral cavity subsite. In fact, 1 study<sup>35</sup> describes how patients with functional difficulties (eg, speech and swallowing) reported equal or even greater BID compared with those with exclusively appearancerelated concerns. These findings point to the multidimensionality of BID. Because objective measures of disfigurement are poorly associated with patient-reported measures of BID, inferences by practitioners on how HNC and its treatment affects BID can be misleading.

## **Practical Implications**

One practical implication of this study is that the demographic and oncologic characteristics associated with HNCrelated BID may be used to help counsel patients about their risk of developing HNC-related BID after treatment. Highrisk patients are those with lower educational attainment who are unemployed or have disabilities and will be expected to undergo surgery with free flap reconstruction and adjuvant therapy. Whether these patients will benefit from preemptive discussions about expectations associated with posttreatment BID is unknown and should be explored in future studies. In addition to targeted counseling, these risk factors could also help identify patients at risk for HNC-related BID for preventive interventions implemented in the pretreatment period. Unfortunately, pretreatment interventions to prevent posttreatment BID among patients with cancer are poorly characterized. Although no such treatments have been described specifically for patients with HNC, a prehysterectomy educational intervention appeared to protect against the development of BID in a small pilot study.<sup>36</sup> The lack of a preventive intervention for patients at risk for HNC-related BID represents a major gap in clinical care and a potentially significant opportunity to minimize long-term psychosocial toxic effects. For preventive interventions to be effective before treatment, highly predictive risk tools must be available; however, such tools remain elusive because many risk factors for developing HNC-related BID remain unknown. The value of effective early posttreatment interventions should be emphasized as well. Although research on specific interventions targeting BID in HNC survivors is limited, 2 recent studies<sup>37,38</sup> have produced mixed results. One study<sup>37</sup> used an expressive writing activity based on self-compassion to reduce BID in HNC survivors. Despite this method's success in breast cancer survivors, 38 it was not efficacious in the HNC population. Another intervention using a telemedicine-based cognitivebehavioral intervention to manage BID in HNC survivors showed promise in a small cohort.<sup>18</sup> Ultimately, it is hoped

that the data from the current study can inform the development of patient-centered interventions in the pretreatment and posttreatment settings targeted to those at highest risk of developing BID.

Although this study identified a number of demographic and oncologic characteristics associated with HNC-related BID, the models explained only a modest proportion of the overall variance in IMAGE-HN scores, suggesting that additional variables explain differences in the risk of developing BID after HNC treatment. The finding that most of the variability in IMAGE-HN scores is not explained by oncologic characteristics agrees with prior literature<sup>4,5</sup> suggesting poor correlation between disfigurement and BID. Other potentially important characteristics that may explain variability in BID among HNC survivors but were not analyzed in this study include functional outcomes (eg, swallowing impairment and speech production or intelligibility<sup>35,39</sup>), psychosocial factors (eg, image investment; body image coping strategies; social support; and mental health history, including pretreatment depression and/or anxiety<sup>7,21,40,41</sup>), and neurobiological factors (eg, attentional networks<sup>42,43</sup>). Future research on risk factors for HNC-related BID should explore these characteristics using validated PROMs of HNC-related BID.

## **Strengths and Limitations**

This study has strengths and limitations. It is a rigorously conducted study with a large number of patients from across 4 diverse academic medical centers, giving the results robust external validity in a population of a typical academic HNC practice. This is also the first study, to our knowledge, to describe the associations between patient characteristics and HNC-related BID using a PROM specific to HNC-related BID. Despite these strengths, the study possesses a number of important limitations. The study used a cross-sectional design, which prevents evaluation of how the severity of HNC-related BID changes after treatment. Because the study cohort was composed entirely of patients treated with a primary surgical paradigm, it was not possible to evaluate whether surgical approaches result in higher HNC-related BID than nonsurgical paradigms. The association of surgical-based approaches with HNC-related BID should thus be explored in future studies that include nonsurgical patients. This study relies on selfreported oncologic data, and although the administered questionnaires used patient-appropriate language complexity, the data are subject to recall or response bias. Significantly larger sample sizes are required to detect interaction effects compared with main effects, and the study was not powered to detect interaction terms; therefore, it is possible that an interaction between certain variables with a priori relevance to HNC-related BID (eg, subsite and treatment or subsite and reconstruction) exists and the study was underpowered to detect it.<sup>44</sup> In addition, the clinical relevance of a specific IMAGE-HN score remains unknown, preventing us from accurately identifying patients with HNC with clinically meaningful BID and determining the prevalence of HNC-related BID among different at-risk populations. Future research should define the utility of the IMAGE-HN by describing cutoff points and score ranges to better characterize the disorder.

# Conclusions

This multi-institutional study using a validated, multidomain PROM of HNC-related BID identified a number of demographic and oncologic characteristics associated with HNC-related BID, including educational attainment, employment, tumor subsite, free flap reconstruction, and adjuvant therapy. These demographic and oncologic characteristics,

ARTICLE INFORMATION

Accepted for Publication: May 11, 2021. Published Online: July 8, 2021.

doi:10.1001/jamaoto.2021.1378

Author Affiliations: Department of Otolaryngology-Head & Neck Surgery, Medical University of South Carolina, Charleston (Macias, Ellis. Marsh. Graboves): School of Health and Rehabilitation Sciences, The Ohio State University, Columbus (Hand); Department of Psychiatry and Behavioral Sciences, Medical University of South Carolina, Charleston (Maurer, Balliet); Department of Otolaryngology-Head and Neck Surgery, Washington University School of Medicine in St Louis, St Louis, Missouri (Pipkorn); Bobby R. Alford Department of Otolaryngology-Head and Neck Surgery, Baylor College of Medicine, Houston, Texas (Huang); Department of Otolaryngology-Head and Neck Surgery, University of Pittsburgh School of Medicine, Pittsburgh, Pennsylvania (Nilsen); College of Nursing, Medical University of South Carolina, Charleston (Ruggiero); Department of Otolaryngology-Head and Neck Surgery, Henry Ford Health System, Detroit, Michigan (Williams); Department of Public Health Sciences, Medical University of South Carolina, Charleston (Li, Sterba, Graboyes); Vanderbilt University School of Nursing, Nashville, Tennessee (Rhoten).

Author Contributions: Drs Macias and Hand had full access to the data in the study and take responsibility for the integrity of the data and accuracy of the data analysis.

*Concept and design:* Macias, Balliet, Ellis, Ruggiero, Marsh, Graboyes.

Acquisition, analysis, or interpretation of data: Macias, Hand, Maurer, Balliet, Pipkorn, Huang, Nilsen, Williams, Marsh, Li, Rhoten, Sterba, Graboyes.

Drafting of the manuscript: Macias, Hand, Balliet. Critical revision of the manuscript for important intellectual content: Macias, Hand, Maurer, Ellis, Pipkorn, Huang, Nilsen, Ruggiero, Williams, Marsh, Li, Rhoten, Sterba, Graboyes.

Statistical analysis: Hand, Li. Obtained funding: Macias, Ellis, Graboyes. Administrative, technical, or material support: Maurer, Balliet, Huang, Marsh, Sterba. Supervision: Macias, Ellis, Pipkorn, Nilsen, Ruggiero,

**Conflict of Interest Disclosures:** Dr Ruggiero reported receiving grants from the National Institutes of Health during the conduct of the study. Dr Graboyes reported receiving grants from the National Cancer Institute during the conduct of the study, receiving grants from the National Cancer Institute and the Doris Duke Charitable Foundation outside the submitted work, and being an editorial board member for JAMA Otolaryngology-Head & Neck Surgery. No other disclosures were reported.

tients with HNC.

#### REFERENCES

1. Howlader N, Noone, AM, Krapcho, M, eds. *SEER Cancer Statistics Review (CSR) 1975-2017*. National Cancer Institute; 2018.

2. Cohen EE, LaMonte SJ, Erb NL, et al. American Cancer Society head and neck cancer survivorship care guideline. *CA Cancer J Clin*. 2016;66(3):203-239. doi:10.3322/caac.21343

3. Ellis MA, Sterba KR, Day TA, et al. Body image disturbance in surgically treated head and neck cancer patients: a patient-centered approach. *Otolaryngol Head Neck Surg.* 2019;161(2):278-287. doi:10.1177/0194599819837621

4. Rhoten BA, Murphy B, Ridner SH. Body image in patients with head and neck cancer: a review of the literature. *Oral Oncol.* 2013;49(8):753-760. doi:10. 1016/j.oraloncology.2013.04.005

5. Ellis MA, Sterba KR, Brennan EA, et al. A systematic review of patient-reported outcome measures assessing body image disturbance in patients with head and neck cancer. *Otolaryngol Head Neck Surg.* 2019;160(6):941-954. doi:10.1177/ 0194599819829018

6. Shunmuga Sundaram C, Dhillon HM, Butow PN, Sundaresan P, Rutherford C. A systematic review of body image measures for people diagnosed with head and neck cancer (HNC). *Support Care Cancer*. 2019;27(10):3657-3666. doi:10.1007/s00520-019-04919-6

7. Clarke SA, Newell R, Thompson A, Harcourt D, Lindenmeyer A. Appearance concerns and psychosocial adjustment following head and neck cancer: a cross-sectional study and nine-month follow-up. *Psychol Health Med*. 2014;19(5):505-518. doi:10.1080/13548506.2013.855319

**8**. Rhoten BA. Body image disturbance in adults treated for cancer - a concept analysis. *J Adv Nurs*. 2016;72(5):1001-1011. doi:10.1111/jan.12892

**9**. Fingeret MC, Yuan Y, Urbauer D, Weston J, Nipomnick S, Weber R. The nature and extent of body image concerns among surgically treated patients with head and neck cancer. *Psychooncology*. 2012;21(8):836-844. doi:10.1002/pon.1990

 Wu YS, Lin PY, Chien CY, et al. Anxiety and depression in patients with head and neck cancer:
6-month follow-up study. *Neuropsychiatr Dis Treat*.
2016;12:1029-1036. doi:10.2147/NDT.S103203

**11.** Fingeret MC, Teo I, Goettsch K. Body image: a critical psychosocial issue for patients with head and neck cancer. *Curr Oncol Rep*. 2015;17(1):422. doi:10.1007/s11912-014-0422-0

**12**. Fingeret MC, Vidrine DJ, Reece GP, Gillenwater AM, Gritz ER. Multidimensional analysis

of body image concerns among newly diagnosed patients with oral cavity cancer. *Head Neck*. 2010;32(3):301-309. doi:10.1002/hed.21181

which are likely known in the pretreatment setting, may be

used to identify those at greatest risk of HNC-related BID. However, these associations explain a modest proportion of

variance in IMAGE-HN scores, suggesting that other patient-

specific characteristics contribute to HNC-related BID as well.

Future studies should continue to explore other factors asso-

ciated with HNC-related BID that were not accounted for in

the current study using a validated BID PROM specific to pa-

 Sneeuw KC, Aaronson NK, Yarnold JR, et al. Cosmetic and functional outcomes of breast conserving treatment for early stage breast cancer, 1: comparison of patients' ratings, observers' ratings, and objective assessments. *Radiother Oncol.* 1992;25(3):153-159. doi:10.1016/0167-8140(92) 90261-R

14. Pezner RD, Lipsett JA, Vora NL, Desai KR. Limited usefulness of observer-based cosmesis scales employed to evaluate patients treated conservatively for breast cancer. *Int J Radiat Oncol Biol Phys.* 1985;11(6):1117-1119. doi:10.1016/0360-3016(85)90058-6

**15.** Graboyes EM, Hand BN, Ellis MA, et al. Validation of a novel, multidomain head and neck cancer appearance- and function-distress patient-reported outcome measure. *Otolaryngol Head Neck Surg.* 2020;163(5):979-985. doi:10.1177/ 0194599820927364

16. Graboyes EM. IMAGE-HN. Medical University of South Carolina College of Medicine. Accessed January 6, 2021. https://medicine.musc.edu/ departments/otolaryngology/research/bodyimage/image-hn

17. Graboyes EM, Hill EG, Marsh CH, et al. Temporal trajectory of body image disturbance in patients with surgically treated head and neck cancer. *Otolaryngol Head Neck Surg.* 2020;162(3):304-312. doi:10.1177/0194599819898861

**18**. Graboyes EM, Maurer S, Park Y, et al. Evaluation of a novel telemedicine-based intervention to manage body image disturbance in head and neck cancer survivors. *Psychooncology*. 2020;29(12): 1988-1994. doi:10.1002/pon.5399

**19**. Gilbert RW. Reconstruction of the oral cavity; past, present and future. *Oral Oncol*. 2020;108: 104683. doi:10.1016/j.oraloncology.2020.104683

**20**. Hung TM, Lin CR, Chi YC, et al. Body image in head and neck cancer patients treated with radiotherapy: the impact of surgical procedures. *Health Qual Life Outcomes*. 2017;15(1):165. doi:10. 1186/s12955-017-0740-7

**21**. Melissant HC, Jansen F, Eerenstein SE, et al. Body image distress in head and neck cancer patients: what are we looking at? *Support Care Cancer*. 2021;29(4):2161-2169. doi:10.1007/ s00520-020-05725-1

**22**. Akakpo KE, Varvares MA, Richmon JD, et al. The tipping point in oral cavity reconstruction: a multi-institutional survey of choice between flap and non-flap reconstruction. *Oral Oncol*. 2021;105267. doi:10.1016/j.oraloncology.2021.105267

jamaotolaryngology.com

Williams, Graboyes.

23. Zebolsky AL, Ochoa E, Badran KW, et al. Appearance-related distress and social functioning after head and neck microvascular reconstruction. *Laryngoscope*. Published online April 2, 2021. doi:10. 1002/lary.29548

24. Graboyes EM, Hill EG, Marsh CH, Maurer S, Day TA, Sterba KR. Body image disturbance in surgically treated head and neck cancer patients: a prospective cohort pilot study. *Otolaryngol Head Neck Surg.* 2019;161(1):105-110. doi:10.1177/ 0194599819835534

**25.** Raggio GA, Naik AD, Moye J. Body image satisfaction among male military veterans with cancer. *J Health Psychol*. 2019;24(7):909-917. doi:10.1177/1359105317690035

26. Chen C, Cao J, Wang L, Zhang R, Li H, Peng J. Body image and its associated factors among Chinese head and neck cancer patients undergoing surgical treatment: a cross-sectional survey. *Support Care Cancer*. 2020;28(3):1233-1239. doi:10. 1007/s00520-019-04940-9

27. Vartanian JG, Carvalho AL, Toyota J, Kowalski IS, Kowalski LP. Socioeconomic effects of and risk factors for disability in long-term survivors of head and neck cancer. *Arch Otolaryngol Head Neck Surg.* 2006;132 (1):32-35. doi:10.1001/archotol.132.1.32

28. Llewellyn CD, Horney DJ, McGurk M, et al. Assessing the psychological predictors of benefit finding in patients with head and neck cancer. *Psychooncology*. 2013;22(1):97-105. doi:10.1002/pon. 2065

**29**. Peteet JR. Cancer and the meaning of work. *Gen Hosp Psychiatry*. 2000;22(3):200-205. doi:10. 1016/S0163-8343(00)00076-1

**30**. Houston V, Bull R. Do people avoid sitting next to someone who is facially disfigured. *Eur J Soc Psychol*. 1994;24:279-284. doi:10.1002/ejsp. 2420240205

**31.** Massa ST, Osazuwa-Peters N, Adjei Boakye E, Walker RJ, Ward GM. Comparison of the financial burden of survivors of head and neck cancer with other cancer survivors. *JAMA Otolaryngol Head Neck Surg*. 2019;145(3):239-249. doi:10.1001/ jamaoto.2018.3982

**32**. Stevenage S, McKay Y. Model applicants: the effect of facial appearance on recruitment decisions. *Br J Psychol.* 1999;90:221-234. doi:10. 1348/000712699161369

**33**. Osazuwa-Peters N, Simpson MC, Zhao L, et al. Suicide risk among cancer survivors: head and neck versus other cancers. *Cancer*. 2018;124(20): 4072-4079. doi:10.1002/cncr.31675

**34**. Buckwalter AE, Karnell LH, Smith RB, Christensen AJ, Funk GF. Patient-reported factors associated with discontinuing employment following head and neck cancer treatment. *Arch Otolaryngol Head Neck Surg*. 2007;133(5):464-470. doi:10.1001/archotol.133.5.464

**35.** Fingeret MC, Hutcheson KA, Jensen K, Yuan Y, Urbauer D, Lewin JS. Associations among speech, eating, and body image concerns for surgical patients with head and neck cancer. *Head Neck*. 2013;35(3):354-360. doi:10.1002/hed.22980

**36**. Yaman Ş, Ayaz S. The effect of education given before surgery on self-esteem and body image in women undergoing hysterectomy. *Turk J Obstet Gynecol.* 2015;12(4):211-214. doi:10.4274/tjod.95770

**37**. Melissant HC, Jansen F, Eerenstein SEJ, et al. A structured expressive writing activity targeting body image-related distress among head and neck cancer survivors: who do we reach and what are the effects? *Support Care Cancer*. Published online March 18, 2021. doi:10.1007/s00520-021-06114-y

**38**. Sherman KA, Przezdziecki A, Alcorso J, et al. Reducing body image-related distress in women

with breast cancer using a structured online writing exercise: results from the My Changed Body Randomized Controlled Trial. *J Clin Oncol*. 2018;36 (19):1930-1940. doi:10.1200/JCO.2017.76.3318

**39**. Chen SC, Yu PJ, Hong MY, et al. Communication dysfunction, body image, and symptom severity in postoperative head and neck cancer patients: factors associated with the amount of speaking after treatment. *Support Care Cancer*. 2015;23(8): 2375-2382. doi:10.1007/s00520-014-2587-3

**40**. Rhoten BA, Deng J, Dietrich MS, Murphy B, Ridner SH. Body image and depressive symptoms in patients with head and neck cancer: an important relationship. *Support Care Cancer*. 2014;22(11): 3053-3060. doi:10.1007/s00520-014-2312-2

**41**. Dropkin MJ. Anxiety, coping strategies, and coping behaviors in patients undergoing head and neck cancer surgery. *Cancer Nurs*. 2001;24(2): 143-148. doi:10.1097/00002820-200104000-00010

**42**. Castellini G, Polito C, Bolognesi E, et al. Looking at my body: similarities and differences between anorexia nervosa patients and controls in body image visual processing. *Eur Psychiatry*. 2013;28(7): 427-435. doi:10.1016/j.eurpsy.2012.06.006

**43.** Gaudio S, Wiemerslage L, Brooks SJ, Schiöth HB. A systematic review of resting-state functional-MRI studies in anorexia nervosa: evidence for functional connectivity impairment in cognitive control and visuospatial and body-signal integration. *Neurosci Biobehav Rev.* 2016;71:578-589. doi:10.1016/j. neubiorev.2016.09.032

**44**. Leon AC, Heo M. Sample sizes required to detect interactions between two binary fixed-effects in a mixed-effects linear regression model. *Comput Stat Data Anal*. 2009;53(3):603-608. doi:10.1016/j.csda.2008.06.010