# **Body Image Disturbance in Surgically Treated Head and Neck Cancer Patients:** A Prospective Cohort Pilot Study

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Evan M. Graboyes, MD<sup>1,2</sup>, Elizabeth G. Hill, PhD<sup>2,3</sup>, Courtney H. Marsh<sup>1</sup>, Stacey Maurer, PhD<sup>2,4</sup>, Terry A. Day, MD<sup>1</sup>, and Katherine R. Sterba, PhD, MPH<sup>2,3</sup>

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### Abstract

This prospective cohort pilot study sought to characterize the short-term temporal trajectory of, and risk factors for, body image disturbance (BID) in patients with head and neck cancer (HNC). Most patients were male (35/56), had oral cavity cancer (33/56), and underwent microvascular reconstruction (37/56). Using the Body Image Scale (BIS), a validated patient-reported outcome measure of BID, the prevalence of BID (BIS  $\geq$  10) increased from 11% preoperatively to 25% at 1 month postoperatively and 27% at 3 months posttreatment (P < .001 and P = .0014 relative to baseline, respectively). Risk factors for BID included female sex (odds ratio [OR], 4.8; 95% confidence interval [CI], 1.3-19.8), pT 3 to 4 tumors (OR, 8.9; 95% Cl, 2.0-63.7), and more severe baseline shame and stigma (OR, 1.06; 95% CI, 1.01-1.13), depression (OR, 1.25; 95% CI, 1.06-1.51), and social isolation (OR, 1.21; 95% Cl, 1.01-1.49). The prevalence and severity of BID increase immediately posttreatment. Demographic, oncologic, and psychosocial characteristics identify high-risk patients for targeted interventions.

### **Keywords**

head and neck cancer, body image, patient reported outcomes, survivorship, disfigurement, quality of life

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ead and neck cancer (HNC) arises in cosmetically and functionally critical areas, resulting in life-altering disfigurement, difficulty swallowing, and challenges speaking.<sup>1,2</sup> As a result, HNC survivors express high rates of body image disturbance (BID), a multidimensional construct characterized by a displeasing self-perceived change in appearance and/or function.<sup>3-6</sup> Although BID is associated with significant psychosocial morbidity and decreased quality of life,<sup>7,8</sup> significant gaps about its epidemiology remain. This knowledge gap about the temporal trajectory of, and risk factors for, BID in surgically managed HNC patients<sup>7,8</sup> precludes delivery of optimally timed, preventative, and therapeutic interventions targeted to high-risk patients. This pilot study aims to test the hypotheses that (1) BID increases in prevalence and severity in the short term following treatment, and (2) demographic, oncologic, and psychosocial characteristics identify a high-risk subset of patients.

### Methods

This prospective cohort study was approved by the Medical University of South Carolina Institutional Review Board. Included patients were >18 years old with surgically treated HNC. Participants were recruited from a multidisciplinary HNC clinic at a single academic medical center using a purposive enrollment strategy to stratify across hypothesized risk factors. Seventy patients enrolled; mortality (n = 7) and lost to follow-up (n = 7) resulted in a final cohort of 56 patients.

Sociodemographic,<sup>9</sup> comorbidity,<sup>10</sup> and oncologic data were collected. Psychological, emotional, social, and functional characteristics were assessed with the following validated patient-reported outcome measures (PROMs): Shame and Stigma Scale,11 PROMIS-SF v1.0-Depression 4a and Anxiety 4a,<sup>12</sup> PROMIS-SF v2.0–Social Isolation and Satisfaction with Social Roles and Activities 4a and 4a,<sup>13</sup> and Performance Status Scale-Head and Neck.14 The primary outcome measure was the Body Image Scale (BIS), a

<sup>1</sup>Department of Otolaryngology–Head and Neck Surgery, Medical University of South Carolina, Charleston, South Carolina, USA

<sup>2</sup>Hollings Cancer Center, Medical University of South Carolina, Charleston, South Carolina, USA

<sup>3</sup>Department of Public Health Sciences, Medical University of South Carolina, Charleston, South Carolina, USA

<sup>4</sup>Department of Psychiatry and Behavioral Sciences, Medical University of South Carolina, Charleston, South Carolina, USA

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#### **Corresponding Author:**

Evan M. Graboyes, MD, Department of Otolaryngology–Head & Neck Surgery, 135 Rutledge Ave, MSC 550, Charleston, SC 29425, USA Email: graboyes@musc.edu

validated PROM of BID in oncology patients<sup>4</sup> that has been widely used to study BID in HNC<sup>5,6,15-18</sup>; BIS scores of  $\geq 10$  are considered clinically significant.<sup>19,20</sup> Data were collected at enrollment, 1 month postoperatively, and 3

therapy). Statistical analyses were performed using R version 3.2.2. Summary statistics for demographics, clinical measures, and PROMs included frequencies and percentages for categorical variables and median and interquartile range (IQR) for continuous measures. Changes in BIS scores over time were analyzed using a Wilcoxon sign-rank test. Associations between demographics, clinical characteristics, psychosocial and head and neck function, and BID (BIS score  $\geq 10$  vs <10) were summarized using odds ratios (ORs) based on fitted simple logistic regression models. Models were adjusted for pretreatment BIS scores (treated as a continuous variable) using multiple logistic regression models. Ninety-five percent confidence intervals for ORs were constructed using a profile likelihood approach to improve interval coverage.<sup>21</sup> Summed scores for all PROMs were treated as missing if any individual question for that instrument was missing.

months after treatment completion (surgery or adjuvant

## Results

**Table I** shows the cohort characteristics. The prevalence of BID (BIS  $\geq 10$ ) increased from 11% (6/53) preoperatively to 25% (13/53) at 1 month after surgery and 27% (14/52) at 3 months after the completion of treatment (P < .001 and P = .0014 for values relative to baseline, respectively). The median pretreatment BIS was 2 (IQR, 0-6), increasing to 4 (IQR, 2-9) at 1 month postoperatively, then 3.5 (IQR, 1.75-10) 3 months after treatment completion (**Figure 1**). Increases in BIS scores of more than 5 points occurred in 22% of patients (11/51) from baseline to 1 month postoperatively and 23% of patients (11/49) from baseline to 3 months posttreatment. Relative to baseline, 63% of patients (32/51) had higher BIS scores at 1 month postoperatively and 57% (28/49) had higher BIS scores at 3 months posttreatment.

The logistic regression analysis demonstrating the relationship between demographic, clinical, and psychosocial risk factors and BID (BIS  $\geq 10$ ) at 1 month postoperatively and 3 months after treatment is shown in **Table 2**. Risk factors for BID included female sex, pT 3 to 4 tumors, and higher baseline levels of shame and stigma, depression, and social isolation.

### Discussion

As the importance of delivering patient-centered HNC care grows, it is imperative to move beyond clinician ratings of disfigurement<sup>22,23</sup> to patient-reported assessments of how HNC affects body image.<sup>24,25</sup> A landmark study by Krouse et al<sup>26</sup> analyzing adaptation following HNC treatment analyzed longitudinal changes in BID, although it employed a nonvalidated outcome measure. Other studies of BID in surgically-treated HNC patients have been cross-sectional in

**Table 1.** Sociodemographic, Clinical, Oncologic, and Psychosocial Characteristics of the Study Cohort (N = 56).

Characteristic	No. (%) <sup>a</sup>
Age, median (IQR), y	61 (51.75-71)
Sex, No. (%)	
Female	21 (38)
Male	35 (63)
Race, No. (%)	
White	48 (86)
African American	7 (13)
Other	I (2)
Insurance, No. (%)	
Private	25 (45)
Medicare	24 (43)
Medicaid/self-pay/other	7 (13)
Marital status, No. (%)	
Married/current partner	33 (59)
Single/separated/divorced/widowed	23 (41)
Living situation, No. (%) <sup>b</sup>	~ /
Spouse/partner	36 (64)
Self	9 (16)
Parents/children/friends/other	16 (28)
Educational attainment, No. (%)	( )
High school or less	20 (36)
College attendee or graduate	27 (48)
Graduate school	9 (16)
Occupational status, No. (%)	. ()
Employed <sup>c</sup>	15 (27)
Not employed <sup>d</sup>	18 (32)
Retired	23 (41)
Body mass index (kg/m <sup>2</sup> ), No. (%)	
Underweight	2 (4)
Normal weight	19 (34)
Overweight/obese	35 (63)
Charlson Comorbidity Score No. (%)	33 (83)
	33 (59)
	9 (16)
> <b>?</b>	14 (25)
Tumor location and histology No. (%)	(23)
Oral cavity SCC	33 (59)
Oropharynx SCC/SCC of unknown primary	8 (14)
Larvny SCC	4 (7)
Facial cutaneous malignancy	(7)
n l 6 status (oronbaryny cases only) No. (%)	11 (20)
p16 negative	3 (38)
p16 nositive	5 (63)
AICC pathologic T classification No. (%)	5 (05)
	30 (54)
3.46	30 (34) 26 (46)
Ablative surgery Ne. $(%)^{b}$	20 (40)
Mandibulactomy	
	24 (61)
Maxillactomy	(۱۵) ۲۰ (۲)
Padical tonsillatomy/shammestamy	י) ד ( <i>ד</i> )
Radical tonsillectomy/pnaryngectomy	+ (/)

(continued)



**Figure I.** Short-term temporal trajectory of body image disturbance in patients with surgically treated head and neck cancer. Box-and-whisker plot showing the severity of body image disturbance (as determined by Body Image Scale [BIS] scores) prior to treatment, I month after surgery, and 3 months after completion of treatment.

nature.<sup>5,15,27</sup> Our prospective cohort design using a validated PROM of BID thus represents a methodological improvement over prior research. Using this rigorous approach, we expand upon prior work<sup>5,6,27-30</sup> to provide preliminary data that demographic (female sex), oncologic (T-stage, free flap), and baseline psychological, emotional, and social characteristics identify a subset of patients at high risk for BID.

This prospective cohort study using a validated PROM was methodologically sound and conducted with low levels of missing data. Limitations include the single-institution design and lack of long-term follow-up, which should be addressed in future work. The small sample size, which was not determined a priori to measure prespecified changes in BID, limits power to detect small but clinically significant differences. We attempted to maintain high external validity by employing a purposive enrollment strategy and creating a cohort representative of a standard academic HNC practice. However, the heterogeneous inclusion criteria limit internal validity relative to a study with narrowly defined inclusion criteria (eg, T4 oral cavity cancer undergoing free flap reconstruction).

In this prospective cohort pilot study of surgically treated patients with HNC, the prevalence and severity of BID increased at 1 month postoperatively and 3 months posttreatment relative to pretreatment. Demographic, oncologic, and psychosocial characteristics identified high-risk patients. These data will inform the delivery of optimally timed, targeted, preventative, and therapeutic interventions.

### **Author Contributions**

**Evan M. Graboyes**, substantial contributions to the conception and design of the work, drafting the work and revising it critically for important intellectual content, final approval of the version to be published, agreement to be accountable for all aspects of the

Table	Ι. (	(continued)	
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Characteristic	No. (%) <sup>a</sup>			
Total laryngectomy	2 (4)			
Partial laryngectomy	2 (4)			
Skin/soft tissue resection	14 (25)			
Parotidectomy	3 (5)			
Neck dissection	49 (88)			
Other	3 (5)			
Reconstructive surgery, No. (%)				
None or dermal substitute	15 (27)			
Regional flap	4 (7)			
Microvascular free flap	37 (66)			
Osseous microvascular free flap				
reconstruction, No. (%)				
No	46 (82)			
Yes	10 (18)			
Adjuvant therapy, No. (%)				
None	22 (39)			
Radiation	20 (36)			
Chemoradiation	14 (25)			
	Median (IQR)			
Shame and Stigma Scale	14 (10-21.75)			
PROMIS Anxiety–SF 4a	10 (5.5-12.5)			
PROMIS Depression–SF 4a	6 (4-9.5)			
PROMIS Satisfaction with Social	16 (11.75-20)			
Roles and Activities–SF 4a				
PROMIS Social Isolation–SF 4a	4 (4-8)			
Performance Status Scale–Head and	92 (69-100)			
Neck, average score across subscales				
Normalcy of Diet	100 (50-100)			
Public Eating	100 (75-100)			
Understandability of speech	100 (75-100)			

Abbreviations: AJCC, American Joint Committee on Cancer; IQR, interquartile range; SCC, squamous cell carcinoma.

<sup>a</sup>Percentages may not sum to 1 due to rounding.

<sup>b</sup>Number sums to more than 56 as patients may belong to more than I category concurrently.

<sup>c</sup>Includes full-time employment and part-time employment.

<sup>d</sup>Includes unemployed, work disability, homemaker.

work in ensuring that questions related to the accuracy or integrity of any part of the work are appropriately investigated and resolved; Elizabeth G. Hill, analysis and interpretation of data for the work, drafting the work and revising it critically for important intellectual content, final approval of the version to be published, agreement to be accountable for all aspects of the work in ensuring that questions related to the accuracy or integrity of any part of the work are appropriately investigated and resolved; Courtney H. Marsh, the acquisition and interpretation of data for the work, drafting the work and revising it critically for important intellectual content, final approval of the version to be published, agreement to be accountable for all aspects of the work in ensuring that questions related to the accuracy or integrity of any part of the work are appropriately investigated; Stacey Maurer, the analysis and interpretation of data for the work, revising the work critically for important intellectual content,

Table	2.	Risk Factors f	or Body Im	age Disturbance	(Body Image	Scale Score	>10) at 1 Mont	h Postoperatively a	and 3 Mont	hs Posttreatment. <sup>a</sup>
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		BIS Score at I Month Post	$\geq$ 10 coperatively	BIS Score ≥10 at 3 Months Posttreatment			
Characteristic	n <sup>b</sup>	Unadjusted OR (95% CI)	Adjusted <sup>c</sup> OR (95% CI)	n <sup>b</sup>	Unadjusted OR (95% CI)	Adjusted <sup>c</sup> OR (95% CI)	
Sex	51			49			
Male		Reference	Reference		Reference	Reference	
Female		2.25 (0.59-8.7)	2.20 (0.48-10.6)		4.8 (1.3-19.8)	4.3 (0.88-23.9)	
Age, y	51			49		(,	
40+		Reference	Reference		Reference	Reference	
<40		7.6 (0.66-173.7)	4.9 (0.24-142.7)		6.4 (0.56-144.9)	3.9 (0.15-124.4)	
Marital status	51	· · · · · ·	( , , , , , , , , , , , , , , , , , , ,	49	· · · · ·	· · · · ·	
Married/current partner		Reference	Reference		Reference	Reference	
Single, divorced, separated, widowed		0.43 (0.09-1.7)	0.32 (0.04-1.6)		0.38 (0.07-1.5)	0.23 (0.03-1.3)	
BMI	51			49			
Overweight or obese		Reference	Reference		Reference	Reference	
Underweight or normal		1.6 (0.41-6.1).	1.9 (0.39-9.5)		0.68 (0.13-2.8)	0.99 (0.16-5.1)	
AJCC Pathologic T Classification	51	· · · ·	, , , , , , , , , , , , , , , , , , ,	49	· · · ·	· · · · ·	
0, 1, or 2		Reference	Reference		Reference	Reference	
3 or 4a		8.9 (2.0-63.7)	19.6 (2.8-352.3)		3.15 (0.85-13.5)	3.8 (0.8-24.2)	
Reconstructive surgery	51			49			
None or dermal		Reference	Reference		Reference	Reference	
Substitute rotational flap		4.7 (0.16-144.5)	11.1 (0.25-832.8)		1.8 (0.07-27.2)	I.3 (0.04-23.2)	
Microvascular free flap		6.4 (1.0-123.3)	21.5 (1.7-1341.8)		2.5 (0.54-18.1)	2.3 (0.39-20.8)	
Osseous microvascular free flap reconstruction	51			49			
No		Reference	Reference		Reference	Reference	
Yes		2.9 (0.50-15.7)	22.3 (2.4-304.5)		1.1 (0.15-6.1)	4.7 (0.49-42.4)	
Pretreatment Shame and Stigma Scale	50	1.06 (1.01-1.13)	1.06 (0.19-6.07)	48	1.11 (1.04-1.21)	1.02 (0.91-1.15)	
Pretreatment PROMIS Emotional Distress–Anxiety SF4a	50	1.15 (0.98-1.39)	1.00 (0.80-1.25)	48	1.19 (1.00-1.46)	0.98 (0.75-1.26)	
Pretreatment PROMIS Emotional Distress–Depression SF4a	50	1.25 (1.06-1.51)	1.08 (0.85-1.36)	48	1.13 (0.96-1.34)	0.80 (0.54-1.07)	
Pretreatment PROMIS Satisfaction with Social Roles and Activities SF4a	51	0.88 (0.77-0.98)	0.94 (0.82-1.10)	49	0.90 (0.79-1.01)	0.98 (0.84-1.15)	
Pretreatment PROMIS Social Isolation SF4a	51	1.21 (1.01-1.49)	1.05 (0.79-1.34)	49	1.13 (0.92-1.39)	0.88 (0.58-1.18)	
Pretreatment Performance Status– Head and Neck, average across subscales	50	0.98 (0.95-1.02)	1.00 (0.97-1.05)	48	0.97 (0.94-1.00)	0.98 (0.95-1.02)	
Performance Status Scale–Head and Neck, Normalcy of Diet	50			48			
90, 100		Reference	Reference		Reference	Reference	
0, 10,, 80		1.09 (0.21-4.65)	0.79 (0.11-4.31)		2.11 (0.52-8.34)	2.75 (0.46-17.14)	
Performance Status Scale–Head and Neck, Public Eating	50			48			
75, 100		Reference	Reference		Reference	Reference	
0, 25, 50		2.06 (0.37-9.81)	1.00 (0.12-6.14)		1.45 (0.27-6.67)	0.86 (0.10-5.35)	
Performance Status Scale–Head and Neck, Understandability of Speech	51			49			
75, 100		Reference	Reference		Reference	Reference	
0, 25, 50		2.27 (0.40-11.18)	1.22 (0.12-8.35)		2.76 (0.58-12.73)	1.78 (0.23-11.49)	

Abbreviations: AJCC, American Joint Committee on Cancer; BIS, Body Image Scale; BMI, body mass index; CI, confidence interval; OR, odds ratio. <sup>a</sup>Bold values are statistically significant.

 $^{b}N < 56$  for certain patient-reported outcome measures (PROMs; PROMs were treated as missing if any individual question for that instrument was missing). <sup>c</sup>Adjusted for pretreatment Body Image Scale scores (treated as a continuous variable) using multiple logistic regression models. final approval of the version to be published, agreement to be accountable for all aspects of the work in ensuring that questions related to the accuracy or integrity of any part of the work are appropriately investigated and; **Terry A. Day**, the analysis and interpretation of data for the work, revising the work critically for important intellectual content, final approval of the version to be published, agreement to be accountable for all aspects of the work in ensuring that questions related to the accuracy or integrity of any part of the work are appropriately investigated; **Katherine R. Sterba**, the acquisition, analysis, and interpretation of data for the work, revising the work critically for important intellectual content, final approval of the version to be published, agreement to be accountable for all aspects of the work in ensuring that questions related to the accuracy or integrity of any part of the work are appropriately investigated.

### Disclosures

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