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RESEARCH LETTER

Association Between Observer-Rated Disfigurement and Body Image–Related Distress Among Head and Neck Cancer Survivors

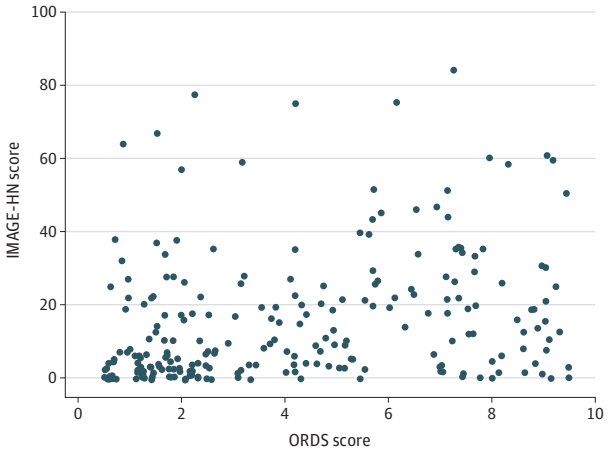
Head and neck cancer (HNC) is associated with a high rate of body image–related distress (BID),[1] a disorder characterized by a distressing self-perceived change in appearance and/or function that can lead to devastating psychosocial morbidity. Prior studies have characterized demographic, clinical, and psychosocial factors associated with HNC-related BID in an attempt to identify high-risk patients and understand the mechanisms underlying this disorder.[2] However, the contribution of observer-rated disfigurement to BID among HNC survivors remains poorly characterized.[3] Therefore, this study's objective is to assess the association between observer-rated disfigurement and BID in HNC survivors.

Supplemental content

Methods | This cross-sectional study analyzed data for HNC survivors from 6 institutions from November 2020 to August 2021.[1] The study included 250 patients (see the eTable in the Supplement for demographic and clinical characteristics), was approved by the institutional review board at each participating institution, and followed the STROBE reporting guideline. Written informed consent was obtained from participants. Observer-rated disfigurement was assessed by a clinician using the validated observer-rated disfigurement scale (ORDS; score range, 1-9; higher scores reflecting greater disfigurement).[4] Interrater reliability for ORDS scores is 0.91 to 0.98.[3,4] Head and neck cancer–related BID was measured using the Inventory to Measure and Assess imaGe disturbancE-Head & Neck (IMAGE-HN), a validated patient-reported outcome measure of HNC-related BID (score range, 0-84; higher scores reflect more severe HNC-related BID).[5] To characterize the association of ORDS with IMAGE-HN scores, we constructed an unadjusted linear regression model and a multivariable linear regression model adjusted for sex, education, years since treatment completion, and employment (variables associated with IMAGE-HN scores).[2] Statistical analyses were performed using SAS statistical software, version 9.4 (SAS Institute). Data were analyzed between January 3 and March 14, 2022.

Results | The **Figure** depicts the ORDS and IMAGE-HN score for each patient. The associations between ORDS and IMAGE-HN scores from the unadjusted and adjusted models are shown in the **Table**. The unadjusted model shows a positive association between ORDS and IMAGE-HN scores (β = 1.8; 95% CI, 1.0-2.6). The coefficients of multiple determination (R^2) for the unadjusted model accounted for a minimal proportion of variance (R^2, 0.08). After adjusting for variables associated with IMAGE-HN scores, there was no association between ORDS and IMAGE-HN scores (β = 1.6; 95% CI, 0.8-2.3).

Figure. Observer-Rated Disfigurement Scale (ORDS) vs Inventory to Measure and Assess imaGe disturbancE–Head & Neck (IMAGE-HN) Scores



This scatterplot shows the association between observer-rated disfigurement (measured by ORDS scores) and body image–related distress (measured by IMAGE-HN scores) for 250 survivors of head and neck cancer. Each participant's ORDS value has been jittered horizontally by adding a random number between −0.5 and 0.5 to prevent overlap of data points along the x-axis. For a given level of observer-rated disfigurement (ORDS score), there is significant variability in the corresponding level of body image–related distress (IMAGE-HN score).

Table. Results From Unadjusted and Adjusted Linear Regression Models Estimating IMAGE-HN Scores From ORDS Scores

	β (95% CI)	
Variable	Unadjusted model	Adjusted model
ORDS	1.8 (1.0 to 2.6)	1.6 (0.8 to 2.3)
Post treatment, y	NA	−0.1 (−1.1 to 0.9)
Sex	NA	
Male	NA	1 [Reference]
Female	NA	5.4 (0.6 to 10.1)
Education	NA	
Less than high school	NA	1 [Reference]
Some college	NA	−1.5 (−7.1 to 4.1)
College graduate	NA	−3.9 (−9.8 to 2.0)
Graduate school	NA	−6.6 (−13.3 to 0.4)
Employment	NA	
Employed[a]	NA	1 [Reference]
Not employed[b]	NA	4.4 (−2.0 to 10.7)
Retired	NA	−6.6 (−11.4 to −1.8)
Model R^2	0.08	0.19

Abbreviations: IMAGE-HN, Inventory to Measure and Assess imaGe disturbancE–Head & Neck; NA, not applicable; ORDS, observer-rated disfigurement scale.

[a] Either part- or full-time or homemaker.

[b] Disability or unemployed.

Discussion | Using a clinically valid measure of HNC-related BID, we found that observer-rated disfigurement correlated poorly with BID among HNC survivors. This finding adds to prior studies showing minimal association between observer-rated disfigurement and BID among HNC survivors[3] as well as other cancer survivor populations (eg, breast cancer).[5] With its large sample size, multi-institutional nature, and use of an HNC-specific BID patient-reported outcome measure, our study also improves upon methodological limitations of prior studies.[3]

There is significant heterogeneity in the severity of BID among HNC survivors. As demonstrated in the Figure, for a given level of observer-rated disfigurement, there is a wide range of BID severity. This variability in BID severity, as well as the lack of association with observer-rated disfigurement, is inadequately explained by existing models of HNC-related BID, which have focused on clinical, demographic, and a limited number of psychosocial factors.[2] Future research should identify factors that moderate the association between disfigurement and BID among HNC survivors.

An important implication of our study is that observer-rated disfigurement should not be used to identify HNC survivors for referral for management of their BID. It may be necessary to develop formal screening protocols and instruments that can be implemented into clinical workflow to accurately identify HNC survivors with BID who may benefit from psychosocial interventions such as cognitive behavioral therapy.[6] A limitation of this study includes the potential for bias from using 1 observer at each site to rate ORDS, although prior studies indicate excellent interrater reliability.[3,4] In conclusion, this study shows that among HNC survivors, observer-rated measures of disfigurement correlate poorly with patient-reported BID.

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Concept and design: Macias, Pipkorn, Graboyes.
Acquisition, analysis, or interpretation of data: All authors.
Drafting of the manuscript: Macias.
Critical revision of the manuscript for important intellectual content: All authors.
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