

A Systematic Review of Patient-Reported Outcome Measures Assessing Body Image Disturbance in Patients with Head and Neck Cancer

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Abstract

Objective. To synthesize published literature describing the severity of body image disturbance (BID) in patients with head and neck cancer (HNC) over time, its psychosocial and functional associations, and treatment strategies as assessed by patient-reported outcome measures (PROMs).

Data Source. PubMed/MEDLINE, Scopus, PsycINFO, Web of Science, and Google Scholar.

Review Methods. A systematic review of the English-language literature was performed to identify studies of BID in patients with HNC using psychometrically validated PROMs to assess (1) severity of BID over time, (2) psychosocial and functional associations, and (3) management strategies.

Results. A total of 17 studies met inclusion criteria. BID was assessed via 10 different PROMs, none of which were HNC-specific measures of BID. Two of 2 longitudinal studies (100%) reported that BID improved from pretreatment to posttreatment, and 2 of 3 longitudinal studies (67%) showed that the severity of BID decreased over time as survivors got further out from treatment. Seven of 17 studies (41%) described negative functional and psychosocial associations with BID, although study methodology limited conclusions about cause and effect. None of the studies assessing interventions to manage BID (0/2, 0%) demonstrated an improvement in BID relative to control.

Conclusion. BID in patients with HNC has negative functional and psychosocial associations and lacks evidence-based treatment. Research is limited by the lack of an HNC-specific BID PROM. Further research should address knowledge gaps related to the lack of an HNC-specific BID PROM, longitudinal course of BID in patients with HNC, confusion with regards to risk factors and outcomes, and lack of prevention and treatment strategies.

Keywords

systematic review, head and neck cancer, body image disturbance, patient reported outcome measures

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Head and neck cancer (HNC) is the sixth most common cancer worldwide, with 630,000 new diagnoses annually and more than 350,000 deaths per year.¹ Because HNC arises in cosmetically and functionally critical areas, including the face, neck, tongue, pharynx, and larynx, there is commonly significant disfigurement and functional morbidity associated with HNC and/or its treatment.²⁻⁴ Body image disturbance (BID) is a multidimensional phenomenon characterized by a self-perceived change in appearance and/or body-related functional impairments. HNC and its treatment produce changes in highly visible and socially significant portions of the body. As a result, BID is common in patients with HNC, with studies estimating that up to 75% of surgically treated patients with HNC are affected by body image concerns.⁵ In addition to being prevalent, BID is associated with significant psychosocial impairment and decreased quality of life in patients

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with HNC.^{2,3,6-11} For these reasons, managing body image concerns is a key component of HNC survivorship care.¹²

A variety of different strategies exist to measure BID. Although researchers have created objective scales to characterize HNC treatment-related disfigurement,^{13,14} BID is best assessed using patient-reported outcome measures (PROMs) because of its subjective, patient-centric, and multidimensional nature. A PROM is a measurement tool that characterizes the status of a patient's health condition originating directly from the patient.¹⁵ Numerous validated PROMs exist to measure BID in oncology patients, although they have primarily focused on breast cancer.¹⁶⁻¹⁹

Because BID is a critical psychosocial issue for patients with HNC, there has been a proliferation of studies addressing the topic in recent years.²⁰⁻²⁶ These studies have contributed to an improved conceptual framework for understanding BID in patients with HNC, reported on the changes in the severity of BID over time, described risk factors for BID, and characterized different treatment strategies. However, the volume of recent studies, differences in study design, varied patient populations, and heterogeneity of BID assessment tools have made understanding BID in patients with HNC challenging. Prior reviews of BID in patients with HNC have not been systematic in nature,⁶ focus only on psychometric properties of PROMs,²⁷ or require updating due to interval scientific progress.⁸ Therefore, the objective of this systematic review is to evaluate and synthesize the available literature on BID in patients with HNC using PROMs to assess (1) severity of BID over time, (2) psychosocial and functional associations with BID, and (3) management strategies for patients with BID.

Methods

Information Sources, Search Strategy, and Study Selection

A senior medical librarian designed a comprehensive search strategy for published literature to identify English-language articles related to PROMs for BID in patients with HNC. Information sources included PubMed/MEDLINE, Scopus, Web of Science, PsycINFO, and Google Scholar. The database search strategy was performed between July 23, 2018, and December 7, 2018, in an iterative fashion to refine search criteria. The final search strategy employed the following keywords and/or combinations of Medical Subject Headings terms: *head and neck neoplasms, head and neck cancer, head and neck squamous cell, facial neoplasms, facial cancer, mouth neoplasms, oral cancer, nose neoplasms, laryngeal neoplasms, body image, body image disturbance, self-esteem, self-image, self-concept, self-perception, disfigure, appearance change, and appearance concerns*. The search strategy did not limit dates. The Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) guidelines were used for reporting throughout.²⁸

The study inclusion criteria are shown in **Table 1**. Of note, because body image is a multidimensional concept

Table 1. Inclusion Criteria for Article Selection.

1. Patients with cancer of the upper aerodigestive tract, salivary gland, or skin of the head and neck
2. Validated PROM of BID used to assess the severity of, associations with, or treatment strategy for BID in patients with HNC
3. PROM of BID includes more than 1 question related to body image
4. English language

Abbreviations: BID, body image disturbance; HNC, head and neck cancer; PROM, patient-reported outcome measure.

that is not adequately captured by a single question, only studies in which the PROM contained more than 1 question assessing body image were included.^{6,8} In addition, studies were included only if BID was assessed by a previously developed and psychometrically validated PROM. After the initial search, candidate titles and abstracts were reviewed by the first author (M.A.E.) and full-text articles independently assessed for eligibility by the first and senior authors (M.A.E., E.M.G.). Two authors searched the reference lists of the included publications to identify additional articles (M.A.E., E.M.G.).

Data Items and Data Collection Process

Variables to be extracted from each study and categorization definitions were defined a priori. Studies were grouped according to whether they evaluated the severity of BID, psychosocial and functional associations of BID, or strategies for managing BID. We then abstracted the following variables from each article: year of publication, country of study, study design, sample size, sex, head and neck subsite, treatment modality, time of BID measurement (in relation to diagnosis and/or treatment), and measure of BID. To determine what factors are associated with BID, variables were organized into the following categories: demographics, oncologic/treatment characteristics, psychosocial factors, and functional status. Because most of the studies examining the relationship between psychosocial factors, functional status, and BID were cross-sectional in nature, the relationships between these variables are reported as associations instead of risk factors of consequences due to the uncertain temporal and causal relationship. Data collection and analysis were performed between August 22, 2018, and December 10, 2018. No attempts were made to contact investigators to track down or clarify missing or incomplete information.

Data Analysis and Synthesis of Results

Given the heterogeneity in study design and PROMs used to measure BID in patients with HNC, we chose to perform a systematic review instead of a meta-analysis. Reporting meta-regressions for BID in patients with HNC would be limited given the heterogeneity of study type and data included in our review. Furthermore, we were concerned

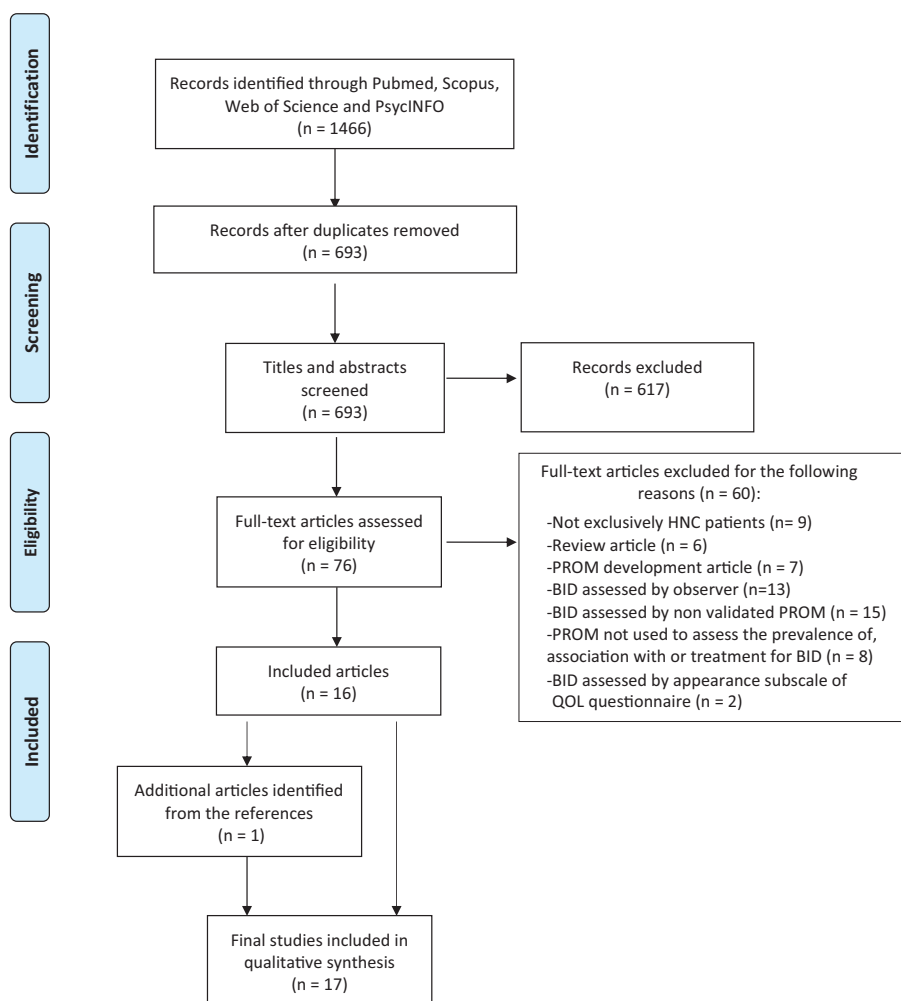


Figure 1. Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) flow diagram. BID, body image disturbance; HNC, head and neck cancer; PROM, patient-reported outcome measure; QOL, quality of life.

that a meta-regression of BID prevalence would be misleading as the PROMs used to characterize BID in patients with HNC lack validated cutoff scores,²⁹ producing definitions of BID that differ between studies. Thus, data are organized and presented but not combined into pooled measures of BID.

Quality Assessment

The National Heart, Lung, and, Blood Institute (NHLBI) Study Quality Assessment Tools were employed to rate the quality of the included articles.³⁰ The NHLBI Study Quality Assessment Tools include 9 to 14 questions (based on study design) and provide an overall quality rating of poor, fair, or good (see Supplemental Table S1, available in the online version of the article). Quality analysis was performed independently by 2 study authors (M.A.E., E.M.G.) and differences in quality ratings were resolved by consensus.

Results

Description of Studies Selected

The PRISMA flow diagram demonstrating derivation of the included articles is shown in **Figure 1**. Using the search

strategy described in the methods, 693 unique abstracts were identified and screened; 76 articles were reviewed in full to assess eligibility, and 16 studies were selected for inclusion. Review of the references from these 16 articles revealed 1 additional article; therefore, 17 articles are included in this systematic review. In terms of article quality, 16 studies were rated as fair and 1 was rated as good. Study designs included cross-sectional ($n = 13$), prospective longitudinal cohort ($n = 2$), randomized controlled trial (RCT) ($n = 1$), and 1 prospective single-blind quasi-experimental study ($n = 1$).

PROMs Used to Assess BID in Patients with HNC

BID was assessed via 10 different PROMs (**Table 2**). Two of 17 studies (12%) used multiple PROMs to assess BID. The Body Image Scale (BIS)¹⁷ ($n = 10$, 59%) and Derriford Appearance Scale (DAS)–24³¹ ($n = 3$, 18%) were the 2 most frequently employed PROMs to assess BID in patients with HNC. Eight other scales were used, each in 1 study.^{32–38} Only 1 PROM was created for and validated in patients with HNC (Body Image Questionnaire [BIQ]); however, it was designed specifically for patients with nonmelanoma

Table 2. PROMs Used to Assess BID in Patients with Head and Neck Cancer.

Name of PROM	Abbreviation of PROM	No. of Questions	Scoring Range	Scoring Method	Validation Population	No. of Studies Using the PROM in This Systematic Review
Body Image Scale ¹⁷	BIS	10	0-30	Higher score associated with more severe BID	Patients with breast cancer, colorectal cancer, testicular cancer, gynecologic cancer, and lymphoma	10
Derriford Appearance Scale-24 ⁵²	DAS-24	24	0-96	Higher score associated with more severe BID	General population and a clinical population with diverse etiologies of disfigurement	3
Body Image Questionnaire ³⁵	BIQ	15	15-75	Higher score associated with more severe BID	Head and neck cutaneous cancer patients treated with Mohs surgery	1
Body Satisfaction Scale ³⁶	BSS	16	16-112	Higher score associated with more severe BID	Females: college and nursing students, overweight subjects, eating disorder patients	1
Fear of Negative Appearance Evaluation ³⁷	FNAES	6	6-30	Higher score associated with more severe BID	Female college students	1
Body Area Satisfaction Scale of the Multidimensional Body-Self Relations Questionnaire ³²	BASS of the MBSRQ	9	1-5	Lower score associated with more severe BID	College students	1
Multidimensional Body-Self Relations Questionnaire Appearance Subscale ³¹	MBSRQ-AS	34	1-5	Lower score associated with more severe BID	College students	1
Body Image Disturbance Questionnaire ³³	BIDQ	7	1-5	Higher score associated with more severe BID	College students	1
Perceived Social Impact Subscale of the Adapted Satisfaction with Appearance Scale ³⁸	PSIS of the ASWAP	7	0-42	Higher score associated with more severe BID	Scleroderma patients	1
Body Image Quality of Life Inventory ³⁴	BIQLI	19	-3-+3	Lower score associated with more severe BID	Female college students	1

Abbreviations: BID, body image disturbance; PROM, patient-reported outcome measure.

head and neck cutaneous malignancies treated with Mohs surgery.³⁵

Severity of BID over Time

Six of 17 studies (35%) reported on the severity of BID in patients with HNC at different points in time following diagnosis and/or treatment (**Table 3**). Of these studies, 4 were longitudinal and 2 were cross-sectional. Of the longitudinal studies, 2 compared pretreatment BID severity to posttreatment BID severity, and 3 assessed BID severity at different posttreatment timepoints. Beal et al³⁵ showed that BID (as measured by the BIQ) was less severe 6 months following Mohs surgery compared to preoperative BID in a cohort of patients with head and neck nonmelanoma skin cancer. Likewise, Chen et al³⁹ showed that BID (as measured by the BIS) was less severe 3 months posttreatment relative to pretreatment in patients with HNC. In contrast, Clarke et al⁴⁰ found that in a cohort of posttreatment patients with HNC, BID severity (as measured by the DAS-24) was unchanged 9 months after initial BID assessment. Rhoten et al⁴¹ showed initial worsening of BID (as measured by the Body Image Quality of Life Inventory [BIQLI]) following treatment for HNC followed by successive improvement in BID at 6 and 12 weeks posttreatment.

Factors Associated with BID

Fourteen of 17 studies (82%) identified factors associated with BID in patients with HNC, including (1) demographics, 10 of 14 (71%); (2) oncologic and treatment characteristics, 7 of 14 (50%); and (3) functional and psychosocial associations, 8 of 14 (57%) (**Table 4**). Of these studies, 3 were prospective in nature and 11 featured a cross-sectional design.

In terms of demographic characteristics associated with BID, in the studies examining the relationship between sex and BID, 29% (2/7) found that female patients were at higher risk for BID. Younger age (4/8 studies) and single relationship status (1/5 studies) also correlated with BID.

Associations between oncologic and treatment characteristics and BID included advanced American Joint Committee on Cancer (AJCC) stage (1/2 studies) and tumor stage (1/1 study). In terms of treatment modality, tumors requiring reconstructive surgery (1/1 study), surgical (vs nonsurgical) treatment (2/2 studies), and surgery plus adjuvant therapy (vs surgery alone) (2/2 studies) were all associated with BID.

Numerous studies examined functional and psychosocial associations with BID: overall quality of life (3/3 studies), depression (2/2 studies), challenges with speaking (2/2 studies), eating impairment (1/1 study), cognitive difficulties (1/1 study), behavioral problems (1/1 study), and lymphedema (1/1 study). Interestingly, Fingeret et al⁴³ quantified the severity of BID in patients with speech/eating functional difficulties relative to appearance-related concerns and showed that BID is more severe in the functional difficulties patient population relative to the appearance concern-related subset.

Treatment of BID in Patients with HNC

Two of 17 studies (12%) focused on the treatment of BID in patients with HNC (**Table 5**). Huang and Liu⁴² performed a prospective single-blind, quasi-experimental design study to assess the impact of a cosmetic rehabilitation program (consisting of makeup education) on BID in patients with HNC following surgery relative to routine care. They found no statistical difference in Multidimensional Body-Self Relationship Questionnaire–Appearance Scales (MBSRQ-AS) scores between the cosmetic rehabilitation program and control cohorts preintervention and at both postintervention time periods (6 weeks and 12 weeks) ($P > .05$).

Chen et al²² conducted an RCT to determine the effect of a skin camouflage program on disfigurement, self-esteem, social interaction, and BID in female patients with HNC following surgery relative to routine care. Their skin camouflage program included a 4-session education program and a supply of cosmetic makeup products for the treatment group. Although patients in the skin camouflage group had less facial disfigurement, depression, and fear/anxiety of social interaction than patients in the control group over time, the intervention did not improve BID as measured by the BIS ($P = .556$).

Discussion

In this systematic review, we identified, analyzed, and synthesized the available literature using PROMs to describe the severity of BID in patients with HNC over time, psychosocial and functional associations with BID, and treatment strategies for patients with BID.

PROMs Used to Assess BID in Patients with HNC

One of the major findings of this systematic review is that there is significant heterogeneity in the measurement of BID in patients with HNC. The 17 studies included in this review used 10 different PROMs. The BIS was the most widely used PROM to assess BID in patients with HNC in this review. The BIS was created for and validated in a cohort of general oncology patients.¹⁷ Although studies employing the BIS to measure BID in patients with HNC have reported high internal reliability, its content validity for patients with HNC remains unknown.^{20,43} Recently, the BIQ was created for and validated in a cohort of patients with nonmelanoma head and neck skin cancer undergoing Mohs surgery; however, this measure lacks content validity for other patients with HNC (mucosal and salivary) given its focus on cutaneous malignancies managed with Mohs surgery.^{25,35} A BID PROM inclusive across the broad spectrum of patients with HNC and treatments is lacking and has been recognized as a major gap preventing advancement of the field.^{6,8} Given the heterogeneity in functional and aesthetic deficits for different subsites and stages of HNC, it is unknown whether a single, global HNC-specific BID PROM will be able to capture the diverse functional and aesthetic differences. Future work will be required to understand the conceptual domains of BID in HNC and whether

Table 3. Severity of Body Image Disturbance in Patients with Head and Neck Cancer over Time.

Author	Year	Country	Design	Time(s) of Measurement	Sample Size	HN Subsite, %	Treatment Modality, %	PROM of BID	Severity of BID	Quality Rating
Beal et al ²⁵	2018	United States	Prospective longitudinal	1. Pre-Mohs surgery AND 2. 6 months post-Mohs surgery	1. 239 2. 80 ^a	Cutaneous: 100	Mohs S: 100	BIQ	1. Pre-Mohs surgery, mean (SD) BIQ: 41.1 (5.3) 2. 6 months post-Mohs surgery, mean (SD) BIQ: 37.6 (7.7)	Fair
Branch et al ²⁶	2017	Canada	Cross-sectional ^b	1. During RT/CRT OR 2. 8-24 weeks post-RT/CRT	1. 13 2. 15	During treatment: OP: 69 HP: 8 NP: 8 Nasal cavity: 15 Posttreatment: OP: 73 NP: 20 Nasal cavity: 7	During treatment: RT: 46 CRT: 54 Posttreatment: RT: 40 CRT: 60	BIS	1. During treatment: BIS 0-9: 77% BIS 10-18: 23% BIS 19-30: 0% 2. Posttreatment: BIS 0-9: 87% BIS 10-18: 13% BIS 19-30: 0%	Fair
Chen et al ²²	2017	Taiwan	RCT	1. Posttreatment (mean 10 months) AND 2. 3-month follow-up after initial evaluation	1. 34 2. 34	OC: 86 Other: 14	S + RT: 20 S + CRT: 80	BIS	1. Posttreatment: mean (SD) BIS: 6.6 (0.9) ^c 2. 3-month follow-up after initial evaluation: mean (SD) BIS: 5.8 (1.4) ^c	Good
Clarke et al ⁴⁰	2014	United Kingdom	Prospective longitudinal	1. Posttreatment (>6 months) AND 2. 9-month follow-up after initial evaluation	1. 49 2. 20 ^a	OC: 25 OP: 6 LX: 35 Cutaneous: 35	S ± RT/CRT: 92 RT/CRT: 8	DAS-24	1. Posttreatment (>6 months), mean (SD) DAS-24: 36.6 (16) 2. 9-month follow-up after initial evaluation, mean (SD) DAS-24: 37.4 (17)	Fair

(continued)

Table 3. (continued)

Author	Year	Country	Design	Time(s) of Measurement	Sample Size	HN Subsite, %	Treatment Modality, %	PROM of BID	Severity of BID	Quality Rating
Rhoten et al ⁴¹	2014	United States	Prospective longitudinal	1. Pretreatment AND 2. Immediately posttreatment AND 3. 6 weeks posttreatment AND 4. 12 weeks posttreatment	1. 43 2. 43 3. 43 4. 43	OC: 21 OP: 42 LX: 12 NP: 7 Other: 19	S ± RT/CRT: 49 RT/CRT: 51	BIQLI	1. Pretreatment, mean (SD) BIQLI: 0.60 (1.13) 2. Immediately posttreatment, mean (SD) BIQLI: 0.43 (1.14) 3. 6 weeks posttreatment, mean (SD) BIQLI: 0.52 (1.36) 4. 12 weeks posttreatment, mean (SD) BIQLI: 0.92 (1.21)	Fair
Fingeret et al ⁵	2012	United States	Cross-sectional ^b	1. Presurgery = >1 year postsurgery	1. 280	OC: 34 Cutaneous: 41 Other: 25	S ± RT/CRT: 82 Pre-S: 18	BIS	1. Presurgery, mean (SD) BIS: 3.2 (5.2) 2. <1 year postsurgery, mean (SD) BIS: 4.7 (5.8) 3. >1 year postsurgery, mean (SD) BIS: 5.8 (6.9)	Fair

Abbreviations: BIQ, Body Image Questionnaire; BIQLI, Body Image Quality of Life Inventory; BIS, Body Image Scale; CRT, chemoradiotherapy; DAS-24, Derriford Appearance Scale–24; HN, head and neck; HP, hypopharynx; LX, larynx; NP, nasopharynx; OC, oral cavity; OP, oropharynx; RCT, randomized controlled trial; RT, radiotherapy; S, surgery.

^aPatients lost to follow-up and/or body image disturbance not assessed at follow-up appointments.

^bCross-sectional study design and measured body image disturbance in different patients at different points in time.

^cBIS scores standardized to the traditional scale by multiplying reported individual item mean and SD by 10.

Table 4. Factors Associated with Body Image Disturbance in Patients with Head and Neck Cancer.^a

Author	Year	Country	Design	Time(s) of Measurement	Sample Size	Sex (Female), %	HN Subsite, %	Treatment Modality, %	PROM of BID	Factors Associated with BID				Quality Rating
										Demographics	Oncologic and Treatment Characteristics	Functional and Psychosocial Associations		
Beal et al ²⁵	2018	United States	Prospective longitudinal	1. Pre-Mohs surgery 2. 6 months post-Mohs surgery	1. 239 2. 80 ^b	40	Cutaneous: 100	Mohs S: 100	BIQ	Female sex (+) Younger age (+)	Preoperative lesion size (–) Repair type (–) Size of scar (+) NP location (–) Advanced AJCC stage (–) Surgical treatment (+) (β, 0.33; 95% CI, 0.06-0.60)		Fair	
Chen et al ²³	2018	Taiwan	Cross-sectional	Posttreatment (mean, 30 months; range, 3-67 months)	105	100	OC: 31 OP: 2 HP: 3 LX: 2 NP: 53 Other: 9	S ± RT/CRT: 29 RT/CRT: 71	BIS	Younger age (–) Single (–)			Fair	
Chen et al ²¹	2015	Taiwan	Cross-sectional	Posttreatment (mean [SD], 17 [1.8] months)	130	3	OC: 59 OP: 4 HP: 14 LX: 24	S ± RT/CRT: 100	BIS ^c		OC location (+) Advanced AJCC stage (+) Requires reconstructive surgery (+)	Speech difficulties (+) (aOR, 21.8; 95% CI, 1.4-350)	Fair	
Clarke et al ⁴⁰	2014	United Kingdom	Prospective longitudinal	1. Posttreatment (>6 months) 2. 9-month follow-up after initial evaluation	1. 49 2. 20 ^b	37	OC: 25 OP: 6 LX: 35 Cutaneous: 35	S ± RT/CRT: 92 RT/CRT: 8	DAS-24	Female sex (+) Younger age (–) Single (–)			Fair	
Deng et al ⁵³	2013	United States	Cross-sectional	Posttreatment (mean, 27 months; range, 3-156 months)	103	31	OC: 15 OP: 48 HP: 4 LX: 18 NP: 3 Other: 14	S ± RT/CRT: 56 RT/CRT: 44	BIS	Single (+) Urban (+)		Lymphedema (+)	Fair	
Fingeret et al ⁴³	2013	United States	Cross-sectional	1. Presurgery = >1 year postsurgery	280	36	OC: 34 Cutaneous: 41 Other: 25	S ± RT or CRT: 82 Before surgery: 18	BIS			Overall QOL (+) Speech difficulties (+) Eating difficulties (+) Cognitive difficulties (+) Behavioral difficulties (+)	Fair	
Fingeret et al ⁵	2012	United States	Cross-sectional	1. Presurgery = >1 year postsurgery	280	36	OC: 34 Cutaneous: 41 Other: 25	S ± RT or CRT: 82 Before surgery: 18	BIS	Female sex (–) Younger age (+) (β, 0.05; 95% CI, 0.01-0.09) ^d	OC location (–)	Overall QOL (+)	Fair	
Fingeret et al ⁴⁴	2010	United States	Cross-sectional	Presurgery	75	44	OC: 100	Presurgery	BIS, BSS, FNAES	Female sex (–) Younger age (–) Single (–) Lower education (–)		Depression (+)	Fair	
Hung et al ²⁴	2017	Taiwan	Cross-sectional	Posttreatment	150	15	OC: 40 NP: 60	S ± RT/CRT: 60 RT/CRT: 40	BIS	Female sex (–) Younger age (–) Single (–) Lower education (+) (β, 3.63; 95% CI, 0.9-6.4) ^e	Surgical treatment (+) (β, 6.9; 95% CI, 4.6-9.2)		Fair	

(continued)

Table 4. (continued)

Author	Year	Country	Design	Time(s) of Measurement	Sample Size	Sex (Female), %	HN Subsite, %	Treatment Modality, %	PROM of BID	Factors Associated with BID			Quality Rating
										Demographics	Oncologic and Treatment Characteristics	Functional and Psychosocial Associations	
Katre et al ⁵⁴	2008	United Kingdom	Cross-sectional	Postsurgery (range, 0-14 years)	252	45	OC: 87 Other: 13	S ± RT/CRT: 100	DAS-24	Younger age (+)	Advanced T stage (+) S + adjuvant treatment (+) S + adjuvant treatment (+)	Overall QOL (+)	Fair
Liu ⁴⁵	2008	Taiwan	Cross-sectional	Postsurgery from 0-6 months	97	9	OC: 87 Other: 13	S ± RT/CRT: 100	BASS of the MBSRQ DAS-24	Female sex (-) Younger age (+) Lower education (-)		PTSD (-) (aOR, 1.04; 95% CI, 0.95-1.14)	Fair
Moschopoulou et al ⁵⁵	2018	United Kingdom	Cross-sectional	Posttreatment	93	42	OC: 56 OP: 24 HP: 2 LX: 2 NP: 4 Other: 12	S ± RT/CRT: 87 RT/CRT: 12 Other: 1					
Rhoten et al ⁴¹	2014	United States	Prospective longitudinal	1. Pretreatment AND 2. Immediately posttreatment AND 3. 6 weeks posttreatment AND 4. 12 weeks posttreatment	1. 43 2. 43 3. 43 4. 43	28	OC: 21 OP: 42 LX: 12 NP: 7 Other: 19	S ± RT/CRT: 49 RT/CRT: 51	BIQLI			Depression (+)	Fair
Teo et al ²⁰	2016	United States	Cross-sectional/ exploratory factor analysis	Pre- and posttreatment	140	32	OC: 54 OP: 4 Cutaneous: 36 Other: 27	S ± RT/CRT: 100	BIS, BIDQ, ASWAP	Female sex (-)			Fair

Abbreviations: AJCC, American Joint Committee on Cancer; aOR, adjusted odds ratio; ASWAP, Adapted Satisfaction with Appearance Scale; BASS, Body Area Satisfaction Scale; BID, body image disturbance; BIDQ, Body Image Disturbance Questionnaire; BIQ, Body Image Questionnaire; BIQLI, Body Image Quality of Life Inventory; BIS, Body Image Scale; BSS, Body Satisfaction Scale; CI, confidence interval; CRT, chemoradiotherapy; DAS-24, Derriford Appearance Scale-24; FNAES, Fear of Negative Appearance Scale; HN, head and neck; HP, hypopharynx; LX, larynx; MBSRQ, Multidimensional Body-Self Relationship Questionnaire; NP, nasopharynx; OC, oral cavity; OP, oropharynx; PROM, patient-reported outcome measure; PTSD, posttraumatic stress disorder; QOL, quality of life; RT, radiotherapy; S, surgery; SD, standard deviation; T, tumor.

^aaOR and β regression coefficients with confidence intervals were reported in the table when available from the study. If no aOR or β regression coefficient was listed in the table, statistical significance was reported by *P* value or regression coefficient alone without associated odds ratios or confidence intervals in the original study.

^bPatients were lost to follow-up and/or BID was not assessed at follow-up appointments.

^cBIS-m was used in the study, which was a 9-question version of the original 10-question BIS.

^dAge reported as a negative association with BID in the study. Thus, β and confidence intervals were adjusted from negative to positive values.

^eEducation reported as a negative association with BID in the study. Thus, β and confidence intervals were adjusted from negative to positive values.

Table 5. Treatment of Body Image Disturbance in Patients with Head and Neck Cancer.

Author	Year	Country	Design	Inclusion Criteria	Time of Measurement	Sample Size	Sex (Female), %	HN Subsite, %	HNC Treatment Modality, %	PROM of BID	Intervention Arms	Study Results	Quality Rating
Chen et al ²²	2017	Taiwan	RCT	1. Patients with HNC 2. Female sex 3. >3 months posttreatment 4. >20 years old 5. Confirmed facial disfigurement by plastic surgeon	Pre- and postintervention (at 3 months)	Intervention: 32 Control: 34	100	OC: 86 Other: 14	S + RT: 20 S + CRT: 80	BIS	Intervention: Skin camouflage program Control: Routine care	Intervention: Preintervention, mean (SE) BIS: 4.8 (0.7) ^a Postintervention, mean (SE) BIS: 2.7 (1.0) ^a Control: Preintervention, mean (SE) BIS: 6.6 (0.9) ^a Postintervention, mean (SE) BIS: 5.8 (1.4) ^a <i>F</i> value interaction between groups and within pre- and postintervention: 2.196 (<i>P</i> = .052)	Good
Huang and Liu ⁴²	2008	Taiwan	Prospective, single-blind, quasi-experimental study	1. OC cancer 2. Free flap reconstruction 3. >2 months posttreatment 4. >18 years old 5. No cosmetic allergies	Pre- and postintervention (at 6 and 12 weeks)	Intervention: 22 Control: 22	7	OC: 100	S ± RT/CRT: 100	MBSRQ-AS	Intervention: Cosmetic rehabilitation program Control: Routine care	No statistical difference in MBSRQ-AS scores between the cosmetic rehabilitation program and control cohorts (<i>P</i> > .05) preintervention and at both postintervention time periods ^b	Fair

Abbreviations: BID, body image disturbance; BIS, Body Image Scale; CRT, chemoradiotherapy; HN, head and neck; HNC, head and neck cancer; MBSRQ-AS, Multidimensional Body-Self Relations Questionnaire–Appearance Scales; OC, oral cavity; PROM, patient-reported outcome measure; RCT, randomized controlled trial; RT, radiotherapy; S, surgery; SE, standard error.

^aBIS scores were standardized to the traditional scale by multiplying reported individual item mean and standard deviation by 10.

^bTotal MBSRQ-AS scores were not reported for the control and intervention groups. Only the subscale scores were reported.

there is sufficient commonality between different types of HNC defects (eg, a laryngectomy and a total maxillectomy) to support a psychometrically sound unified HNC-specific BID PROM.

Severity of BID over Time

There were inconsistent findings with regards to the relationship between the severity of BID and time since treatment. Two studies compared pre- to posttreatment BID severity and found improvement in BID severity for patients following their HNC treatment. In contrast, 1 study showed no change in BID severity 9 months after initial BID assessment in a cohort of posttreatment patients with HNC. In addition, 1 study showed initial worsening of BID severity followed by successive improvement at 6 and 12 weeks posttreatment.

Patients with surgically treated HNC often undergo an additional reconstruction 6 to 12 months after the original reconstruction to shape, contour, and optimize appearance and function. In addition, the perceived importance of non-survival concerns (eg, BID) may increase as survivors become temporally distanced from treatment. It might be hypothesized that BID should worsen over time as longer-term survivors focus less on fear of recurrence and more on late effects and long-term treatment toxicity. Alternatively, BID could remain stable and/or improve over time, especially with continued adjustment and surgical/flap revisions. There were significant methodological limitations to most of the studies assessing BID at different points as most the studies were cross-sectional (featuring patients at different points along treatment continuum). Only 1 study including patients with mucosal HNC followed a cohort longitudinally from pre- to posttreatment but had limited duration of follow-up (12 weeks posttreatment).⁴¹ These methodological limitations preclude knowledge of the longitudinal trajectory of BID in patients with HNC. The knowledge gap about the longitudinal course of BID in patients with HNC, particularly in long-term survivors, precludes delivery of optimally timed, patient-centered preventative and therapeutic interventions for BID.

Factors Associated with BID in Patients with HNC

Numerous studies demonstrated that certain demographic and oncologic/treatment characteristics are potentially risk factors for BID. Younger age, female sex, single relationships status, urban residence, and lower education levels are factors that appear to predispose to BID, but evidence is conflicting regarding these associations. Three studies examined the association between educational attainment and BID: 2 found no association,^{44,45} and 1 found that higher educational attainment was associated with less severe BID.²⁴ One might have hypothesized that patients with higher educational attainment would be more bothered by cosmetic and functional changes following treatment for their HNC. Conversely, one might also hypothesize that patients with higher educational attainment would have better coping strategies and social support, thereby

mitigating the development of BID. Further research is warranted to clarify the relationship between educational attainment and BID. In addition, oral cavity subsite, advanced staged tumors, and cancer that requires reconstructive surgery all appear to be factors associated with BID. Unfortunately, 13 of 17 studies included in our review were cross-sectional in nature, limiting our ability to make causal inferences about the timing of their relationship to BID (eg, prior to treatment, after treatment). Furthermore, cancer treatment modality appears to be associated with BID. Surgery appears to denote an increased “risk” for BID compared to primary radiotherapy/chemoradiotherapy, and surgery plus adjuvant therapy appears to be worse than surgery alone. Whether selection bias based on patient/provider preferences regarding the importance of disfigurement is accounted for in any of the treatment modality relationships is unknown.

Finally, BID is interrelated with numerous functional and psychosocial problems, including lymphedema, challenges with speaking, impaired oral intake, behavioral problems, cognitive difficulties, depression, and decreased quality of life. It is critically important to study the effect of BID on depression and suicide in patients with HNC. Patients with HNC have a 2-fold higher odds of suicide compared to any other cancer type⁴⁶ and an extraordinary high rate of depression that is potentially preventable.⁴⁷ Unfortunately, the majority of studies documenting the association between BID and key psychological outcomes (eg, depression) have been cross-sectional in nature and included a heterogeneous mix of pre- and posttreatment patients. As a result, the relationship between key psychological outcomes and BID remains unknown. Future research that is prospective in nature should seek to clarify the important relationship between BID and key psychological outcomes such as depression and suicide.^{6,8}

Treatment of BID in Patients with HNC

Managing body image concerns remains a key component of HNC survivorship care.¹² We identified 2 studies that described treatment strategies for BID in patients with HNC. These studies implemented cosmetic rehabilitation programs that provided cosmetic education and makeup supplies to patients with HNC with BID; however, both failed to show an improvement in BID for patients with HNC. Currently, there are no evidence-based treatment options specifically for BID in patients with HNC. Future studies are needed to identify effective interventions for the prevention and treatment of BID. Perhaps the most promising of these interventions are time-limited cognitive behavioral therapy and/or web-based psychologic interventions, both of which have been shown to be effective for improving body image concerns in other oncology populations.^{29,48-50} In addition, patients with surgically treated HNC often undergo additional reconstruction 6 to 12 months after the original reconstruction to shape, contour, and optimize appearance and function. The goal of these surgeries is to improve both form and function, which

should result in an improvement in BID. Unfortunately, to date, no studies have assessed changes in BID following additional reconstructive surgeries in patients with HNC.

Limitations

Limitations to this study deserve mention. We excluded articles published in languages other than English, which biases our results. We also did not include unpublished posters, conference proceedings, or other non-peer-reviewed sources, which subjects our findings to the risk of publication bias.^{28,51} The studies analyzed and described herein are heterogeneous in nature with respect to country, study design, population, definition of BID, and PROMs used to assess BID.

The research of BID for HNC has been stated to be in its “infancy” by others,⁶ and the results of this systematic review confirm that statement. This systematic review, which is patient centered in nature, addressed BID, which is conceptually distinct from disfigurement.⁸ Psychometrically sound observer-rated disfigurement scales exist for patients with HNC.^{13,14} They were not the focus of this article, however, and future research should seek to clarify situations in which objective disfigurement and patient-reported BID diverge. In addition, significant gaps in research with regards to BID for HNC identified by this review include the following: (1) the absence of an HNC-specific BID PROM and thus reliance on PROMs developed and validated in different patient populations, (2) heterogeneity of PROMs used to assess BID and a lack of a clear threshold score to differentiate BID from “normal” body image concerns, (3) the unknown longitudinal characterization of BID with regard to time and the inability to distinguish risk factors for BID from consequences of BID, and (4) the lack of evidence-based interventions for the treatment of BID in patients with HNC.

Future studies addressing BID in patients with HNC should address these limitations. Specifically, the development and validation of an HNC-specific PROM assessing BID is needed, followed by the defining of a threshold score distinguishing BID from normal body image concerns. In addition, prospective longitudinal studies are needed to further characterize the relationship of BID with regards to time, treatment variables, and associations to allow for the differentiation of risk factors for and consequences of BID. Finally, given the high prevalence and significant morbidity associated with BID, evidence-based treatments of BID in patients with HNC are greatly needed.

Conclusion

There is considerable heterogeneity in the measurement of BID as no HNC-specific PROMs exist. Many patients with HNC are affected by BID, and there are substantial negative functional and psychosocial associations. Currently, no evidence-based treatment options exist for patients with HNC with BID. Further research should address knowledge gaps related to the lack of an HNC-specific BID PROM, longitudinal course of BID in patients with HNC, confusion

with regards to risk factors and outcomes, and lack of prevention and treatment strategies.

Author Contributions

Mark A. Ellis, project design, data analysis, manuscript drafting, revisions, final approval of the version to be published and agreement to be accountable for all aspects of the work; **Katherine R. Sterba**, project design, data analysis, manuscript drafting, revisions, final approval of the version to be published and agreement to be accountable for all aspects of the work; **Emily A. Brennan**, project design, data analysis, revisions, final approval of the version to be published and agreement to be accountable for all aspects of the work; **Stacey Maurer**, data analysis, revisions, final approval of the version to be published and agreement to be accountable for all aspects of the work; **Elizabeth G. Hill**, data analysis, revisions, final approval of the version to be published and agreement to be accountable for all aspects of the work; **Terry A. Day**, project design, revisions, final approval of the version to be published and agreement to be accountable for all aspects of the work; **Evan M. Graboyes**, project design, data analysis, manuscript drafting, revisions, final approval of the version to be published and agreement to be accountable for all aspects of the work.

Disclosures

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Supplemental Material

Additional supporting information is available in the online version of the article.

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