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The Nature and Extent of Body Image Concerns Among Surgically Treated Patients with Head and Neck Cancer

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Abstract

Objective—The purpose of this study was to describe body image concerns for surgically treated patients with head and neck cancer and evaluate the relationship between body image concerns and quality of life outcomes.

Methods—Data were obtained from 280 patients undergoing surgical treatment for head and neck cancer. We used a cross-sectional design and obtained data from individuals at different time points relative to initiation of surgical treatment. Participants completed the Body Image Scale, the Functional Assessment of Cancer Therapy scale – Head and Neck version, and a survey designed for this study to evaluate disease-specific body image issues, satisfaction with care regarding body image issues, and interest in psychosocial intervention.

Results—Body image concerns were prevalent in the majority of participants with 75% acknowledging concerns or embarrassment about one or more types of bodily changes at some point during treatment. Significant associations were found between body image concerns and all major domains of quality of life. Age, gender, cancer type, time since surgery, and body image variables were significantly associated with psychosocial outcomes. A clear subset of participants expressed dissatisfaction with care received about body image issues and/or indicated they would have liked additional resources to help them cope with body image changes.

Conclusions—These data provide useful information to document wide-ranging body image difficulties for this population and provide important targets for the development of relevant psychosocial interventions.

Body image is a critical psychosocial issue for patients with head and neck cancer, as the disease and its treatment can significantly alter physical appearance and result in functional loss or impairment. Despite the wide variation in treatment-specific issues based on cancer type, location, and stage, an important commonality shared by head and neck patients is that they experience some degree of physical change to a highly visible and socially significant part of their body (i.e., their face) due to cancer. Patients undergoing surgical treatment are at particular risk for experiencing acute disfigurement and functional loss, while those with

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advanced tumors may need to undergo complex means of reconstruction to restore form and function. Multimodal treatment introduces additional body image changes that can further compromise quality of life. While the important role of body image has been discussed in the head and neck literature, limited empirical research has been conducted to obtain an adequate understanding of the nature and extent of body image concerns in this patient group. This work is necessary to establish psychosocial interventions that have the potential to alleviate suffering associated with body image changes.

A significant barrier to conducting conceptually driven research in this area has been the use of inconsistent or simplistic definitions of body image.[1] Body image reflects much more than one's view of his/her physical appearance; it is a multifaceted concept involving perceptions, thoughts, and feelings about the entire body and its functioning.[2] Within this framework, head and neck patients can experience a broad range of body image changes during the process of or following treatment in terms of scarring, swelling, skin discoloration, hair loss, tooth loss, sensory changes, functional loss/alterations (e.g., changes in speech, swallowing, articulation, hearing, eyesight), weight changes, and use of prosthetic devices. A fundamental element of body image experiences is that they are inherently subjective and as such do not necessarily reflect the objective reality of the body.[3] The influence of subjective factors in determining adjustment to bodily changes is demonstrated by a wealth of research on patients with disfiguring conditions, which reports no clear relationship between the degree of disfigurement and psychological reaction to disfigurement.[4–7]

Findings from this study are expected to contribute much needed empirical data on body image adjustment in patients being surgically treated for head and neck cancer. Our initial objective was to obtain descriptive information about the presence of body image concerns, satisfaction with care received about body image issues and interest in psychosocial intervention across a broad range of patients with head and neck cancer undergoing surgical treatment. We were also interested in comparing body image and quality of life (QOL) outcomes for different groups of patients based on disease site. For this study, we selected patients with head and neck cancers that are routinely treated with surgery as a primary treatment modality which includes oral cavity, midface, and cutaneous cancers. Unlike in the oral cancer literature where body image outcomes have been examined and explored to a limited extent[8–10], body image and other psychosocial outcomes are essentially neglected in the empirical literature on cutaneous and other midface cancers. We are aware of no studies describing psychosocial concerns for patients with cancers of the midface such as the maxilla, sinus, and nasal cavity. Previous attempts to describe and evaluate QOL outcomes in patients with cutaneous cancers have been limited to a series of studies by Rhee and colleagues.[11–13] This work resulted in the development of a disease-specific instrument designed to address relevant psychosocial issues for patients with nonmelanoma skin cancer which included a specific focus on appearance-related difficulties.

The current study was also designed to evaluate body image and QOL outcomes for patients at different time points relative to the initiation of surgical treatment (i.e., prior to surgery, within one year of surgical treatment, greater than one year following surgical treatment). These time points were selected to reflect unique phases of the treatment process and to

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obtain estimates of body image distress associated with the anticipation of potentially disfiguring surgery, following initial recovery from surgical treatment, and into the period of survivorship. Previous research supports the influence of preoperative expectations or anticipation of disfigurative surgery on overall distress, anxiety, and coping effectiveness.[9, 14] Greater attention is now being given to evaluating long-term health and psychosocial outcomes for oncology patients due to the growing population of cancer survivors.[15] We have found no published studies evaluating body image issues among head and neck survivors following one year of initial treatment.

Further considerations were given to evaluating the degree to which patients were satisfied with information they received from healthcare providers about how to cope with appearance-related changes, and level of interest in receiving psychosocial services to assist with body image adjustment. The ultimate goal of this research was to determine the need for body image-focused psychosocial interventions which can enhance quality of life and the survivorship experience of head and neck cancer patients. Intervention development must be guided by a clear understanding of the nature and extent of body image concerns, and the association between body image concerns and overall quality of life.

Methods

Our sample included 280 patients being surgically treated for head and neck cancer at the University of Texas MD Anderson Cancer Center. The sample was essentially comprised of three groups of patients: individuals with oral cavity cancer, cutaneous cancer of the head and neck, or other cancer of the midface because these are the largest groups of surgical patients receiving treatment in our center. Patients with cancers in the oropharynx or larynx, which are more typically treated with radiation and/or chemotherapy, were not considered for inclusion. This study used a cross-sectional design to obtain information from patients at different time points relative to the initiation of treatment. Patients were recruited either prior to initiation of surgical treatment, within one year of initial surgical treatment, or greater than one year following initial surgical treatment.

The study protocol was approved by the Institutional Review Board. After providing informed consent, participants completed the following self-report instruments: the Body Image Scale (BIS), The Functional Assessment of Cancer Therapy scale – Head and Neck Version (FACT-HN), and a survey designed for this study. The BIS is a 10-item scale assessing body image/appearance dissatisfaction that was designed to be applicable to patients with any cancer site and form of therapy.[16] This measure has only previously been validated with breast cancer patients. However, it has been used in another study with oral cancer patients where it demonstrated adequate internal consistency and correlated highly with other measures of body image.[8] Higher scores on the BIS are reflective of greater levels of body image dissatisfaction. The FACT-HN is a validated and widely used measure of QOL specifically designed for head and neck patients.[17, 18] This questionnaire is comprised of 5 subscales that include physical well-being, social/family well-being, emotional well-being, functional well-being, and additional head and neck specific concerns. Our analyses focused primarily on the total FACT-HN score (comprised of all 5 subscales). Lower scores on the FACT-HN are reflective of poorer quality of life outcomes.

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To obtain additional useful information about our outcomes of interest, we designed a survey to evaluate disease-specific body image issues relevant to patients with head and neck cancer. Item content was influenced by empirical literature on body image disturbance in various medical populations as well as by a group of interdisciplinary clinicians treating patients with head and neck cancer. The survey, which we will refer to as the Body Image Survey, was divided into four primary content areas: presence of body image concerns, cognitive/behavioral difficulties associated with body image concerns, satisfaction with care received related to body image issues, and interest in psychosocial intervention. The Body Image Survey was designed to gather descriptive information from our participant group and was not designed to be a validated tool. Additional details about survey items can be found in the results section.

We conducted descriptive analyses on demographic variables, disease and treatment-related factors, and responses to our self-report measures. Kruskal-Wallis tests were used to evaluate whether scores on these measures differed by cancer type or time point in treatment. We evaluated the relationship between these two measures using Spearman correlation coefficients. Fisher's exact tests were used to explore whether cancer type and time point in treatment were associated with questions on the Body Image Survey. Multivariate regression models were constructed to evaluate the influence of gender, age, time since diagnosis, and cancer type on body image and quality of life outcomes. Backward selection techniques were used to eliminate terms in the model one at a time until all remaining terms were statistically significant with $p<0.10$.

Results

Data on participant characteristics are presented in Table 1. Participants were considered for inclusion based on their primary cancer site. Oral cavity cancer sites mainly included the retromolar trigone, gingiva, hard palate, tongue, alveolar ridge, floor of mouth, buccal mucosa, and tongue. Cutaneous sites involved the cheek, forehead, nose, ear, eyelid, and temple. Other midface cancer sites were typically comprised of the nasal cavity, maxilla, mandible, and eye.

BIS and FACT-HN

Summary statistics for our two primary self-report scales, the BIS and the FACT-HN, are provided in Table 2. BIS scores ranged from 0–30 with an overall mean of 4.93 (SD=6.21), suggesting relatively low levels of reported body dissatisfaction. FACT-HN scores ranged from 41–148, with an overall mean of 115.60 (SD=22.5). As seen in Table 2, there were some differences for BIS and FACT-HN scores based on cancer type and time point in treatment. These differences were further explored in the multivariate models presented below. Scores on the BIS were found to be significantly correlated with all quality of life domains on the FACT-HN. Spearman's correlation coefficient between the BIS and total FACT-HN score was $r=-0.54$ ($p<0.0001$). On individual subscales of the FACT-HN, correlations with the BIS were $r=-0.43$ for the physical well-being subscale, $r=-0.32$ for the social/family well-being subscale, $r=-0.43$ for the emotional well-being subscale, $r=-0.39$

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for the functional well-being subscale, and r=−0.46 for the additional head and neck specific concerns scale. All p values were <0.0001.

Body Image Survey

Survey findings were initially evaluated for the sample as a whole, and additional analyses were conducted to evaluate results based on disease site and time point in treatment. We used a more stringent p value of $p < 0.01$ to explore group differences due to the large number of tests that were conducted. In contrast to relatively low levels of body image dissatisfaction reported on the BIS, the majority of participants endorsed experiencing body image concerns on our Body Image Survey. Seventy-five percent (N=209) reported feeling concerned or embarrassed by bodily changes related to head and neck cancer and its treatment at some point following diagnosis. Over half the respondents (55.71%, N=152) endorsed some type of body image concern at the time of survey completion. Table 3 presents the type of body image concerns endorsed by patients either currently or at any point following diagnosis. The majority of participants endorsed more than one type of body image concern. The average number of overall body image concerns endorsed (past or present) was 2.72 (SD=2.68) while the average number of current body image concerns endorsed was 1.77 (SD=2.40). Table 3 also presents data on cognitive and/or behavioral difficulties associated with body image concerns for the entire sample. Frequent thoughts about appearance changes were relatively common with over 50% of patients endorsing this potential difficulty at some point in time. When collapsing data across different survey items, there were a total of 106 respondents (38%) who currently or previously avoided social activities, whether due to appearance, speech or eating concerns. A total of 92 respondents (33%) endorsed behavioral difficulties involving reassurance seeking, increased grooming or checking behaviors, or avoidance of grooming at some point following diagnosis.

Data on satisfaction with care regarding body image issues and interest in psychosocial intervention are presented in Table 4. The majority of participants indicated they were satisfied with information received from their healthcare team about how to cope with appearance changes and felt comfortable talking with doctors and nurses about concerns related to their appearance. However, additional data suggest a subset of patients were not satisfied with care in this realm. Twenty-six percent of participants (N=69) indicated they were not satisfied with information received related to body image. When considering subsets of the sample who had already undergone specific forms of cancer treatment: 25% (57 out of 233) reported dissatisfaction with information received about degree of scarring/disfigurement to be expected following surgical treatment, 32% (60 out of 185) reported dissatisfaction with information received about potential effects of radiation treatment on physical appearance and 44% (54 out of 124) reported dissatisfaction with information received about potential effects of chemotherapy on physical appearance.

Consistent with these findings, there was a clear subset of participants who expressed an interest in obtaining additional resources to help them cope with body image changes. A total of 34% participants (N=83) endorsed wanting this assistance either currently or in the past. Moreover, 23% of participants (N=61) indicated they were very likely or somewhat

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likely to utilize counseling resources if made available to them. Most people indicated a preference for obtaining written materials over other forms of intervention. Participants endorsed the need for services to help them cope with appearance-related and body image changes along the entire treatment continuum. Many participants believed psychosocial treatment would be beneficial before treatment begins, during active medical treatment, as well as at the completion of active treatment; however, a clear majority identified the greatest need for these services prior to treatment.

Responses on the Body Image Survey were further examined to explore differences based on disease site and time point in treatment. With respect to disease site, significant group differences emerged on the total number of overall body image concerns endorsed ($p<0.001$) as well as on the total number of current body image concerns ($p=0.006$). Patients with oral cavity cancer had an average of 2.81 overall and 2.16 current concerns, those with cutaneous cancers had an average of 1.41 overall and 1.27 current concerns, while those with other midface cancers had an average of 2.33 overall and 2.07 concerns. Significant between group differences were found for issues related to eating and speaking but not for other appearance-based concerns. Patients with oral cavity and other midface cancers endorsed significantly higher levels of concerns about speaking and eating around others both overall and currently, and they also endorsed higher levels of avoidance due to speech and eating compared to those with cutaneous cancers (all p values <0.001). There were no group differences in level of satisfaction with care or interest in psychosocial intervention. Time point in treatment had very little influence on survey findings. There were no significant differences found in overall level of body image concerns, number of current body image concerns, cognitive/behavioral difficulties associated with body image, satisfaction with care or interest in psychosocial intervention based on time point in treatment.

Multivariate Models

We constructed two separate multivariate models to consider variables that may influence our primary psychosocial outcomes of interest: body image and quality of life. To evaluate the influence of demographic, disease and treatment-related variables on body image dissatisfaction we constructed a multivariate regression model to predict total BIS score. We also included number of current body image concerns reported on the Body Image Survey as a predictor in this model. As can be seen in Table 5, age and time since diagnosis emerged as the only significant disease and treatment-related predictors. Younger patients displayed significantly higher levels of body image dissatisfaction. Level of body image dissatisfaction was found to significantly increase after initial surgical intervention and remained significantly elevated one year following surgery compared to preoperatively. Total number of current body image concerns also emerged as a significant predictor of BIS scores. It is of interest that BIS scores were not found to differ based on gender or cancer type.

We next constructed a multivariate model to predict quality of life outcomes on the FACT-HN (see Table 5) which included demographic, disease and treatment-related variables, as well as two separate body image predictors (i.e., total BIS score and number of current body image concerns). Unlike the previous model, gender and cancer type emerged as significant predictors. Quality of life outcomes were found to be significantly better for women and for

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patients with cutaneous cancers compared to those with other types of cancer. Time since diagnosis also emerged as a significant predictor in this model, though only significant improvement in quality of life scores were found between pre-surgery and greater than one year following surgery. Both body image outcomes emerged as significant predictors indicating that greater body image dissatisfaction and greater number of body image concerns predicted poorer quality of life outcomes.

Discussion

This study provides novel and useful information about disease-specific body image concerns of surgically treated patients with head and neck cancer. In addition to enhancing our understanding of body image difficulties encountered by patients with oral cavity cancer, this is the only study to our knowledge that presents data on body image functioning in patients with cutaneous cancer of the head and neck and other midface cancers. Moreover, this study is the first to document body image difficulties experienced across the cancer treatment trajectory for a group of cancer patients.

The common experience of body image difficulties across a broad range of surgically treated head and neck patients was clearly demonstrated in the Body Image Survey as 75% of participants endorsed experiencing concerns or embarrassment about bodily changes at some point following diagnosis. This fact alone can be used to help normalize and validate body image difficulties for this population and should alert all clinicians working with these patients about the need to directly inquire about body image concerns and familiarize themselves with relevant psychosocial resources for their patients.[19] Our survey data provide useful information about a broad range of body image difficulties experienced by patients with head and neck cancer, some of which extend beyond aspects of physical appearance. We note here that every bodily change inquired about was endorsed by some participants as causing embarrassment or concern at some point following diagnosis. Of particular importance, the number of body image concerns was found to be a significant predictor of behavioral and emotional difficulties with body image as measured by the BIS. These data indicate that those identifying a multitude of concerns are at a greater risk for experiencing difficulties with psychosocial adjustment.

Our survey results identified areas that can be improved upon with regards to psychosocial care of patients with body image difficulties. At least half of the sample endorsed experiencing potential preoccupation with appearance changes at some point following diagnosis and approximately one-third of the sample endorsed behavioral difficulties and social avoidance due to concerns about appearance, speech, or eating changes. Intervention techniques that promote greater body image acceptance while also addressing thought processes and patterns of behaviors (e.g., cognitive-behavioral therapy, acceptance and mindfulness-based approaches) would be ideally suited for this population but need to be tailored to the disease-specific issues of head and neck patients. Further findings revealed significant associations between body image difficulties and quality of life domains involving physical, social, emotional and functional well-being for head and neck cancer patients. This suggests that interventions designed to alleviate distress associated with body

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image concerns will likely enhance overall quality of life and the survivorship experience of head and neck patients and are worthwhile to pursue from this perspective.

While it is true that the majority of patients reported satisfaction with care received about body image issues, there was a clear subset of patients who were not satisfied with information in this realm and specifically wanted assistance in this area. There appears to be particular room for improvement with regards to preparing patients for the effects different treatment modalities can have on physical appearance. Participants recognized the need for psychosocial interventions to address body image concerns all along the cancer treatment trajectory. However, they were particularly attuned to the benefits of providing such care prior to beginning treatment to aid in setting realistic expectations for body image outcomes. Our survey responses provide some initial direction for patient preferences with regard to the format of intervention, suggesting these patients may be most receptive to written materials or counseling interventions provided within the cancer clinic. Our participants were least receptive to being referred to a mental health specialist outside the hospital.

We note that findings from the Body Image Survey contrast with relatively low scores found on the Body Image Scale (BIS). This may be explained by the different content of these instruments. The BIS was designed to be applicable to patients with any form of cancer and contains some items that do not appear relevant for head and neck patients. For example, “Are you dissatisfied with your appearance when dressed?” and “Do you find it difficult to look at yourself when naked?”. There are, however, other items that appear highly relevant related to feeling self-conscious about appearance, being dissatisfied with the appearance of scars, or feeling that treatment has left your body less whole. Unfortunately, there is a limited availability of body image tools for this patient population, which represents an important area for future research. The Body Image Survey was not designed to become a validated tool, its main purpose was for gathering descriptive information on potentially relevant body image concerns for head and neck patients and to help guide the development of psychosocial interventions to target body image distress.

We largely focus on the Body Image Survey results for the entire sample because there were few differences found when exploring body image issues based on cancer type and time point in treatment. Broadly speaking, patients with different types of head and neck cancer experienced many similar types of body image concerns, similar levels of preoccupation with appearance-related changes, and similar levels of satisfaction with care and interest in intervention. It was not surprising to find higher levels of eating and speaking difficulties in patients with oral cavity cancer and to a lesser extent in patients with other midface cancers compared to those with cutaneous cancers. These results may help to explain significant group differences found on the BIS favoring patients with cutaneous cancers, suggesting that functional impairments involving speech and swallowing are important contributing factors to overall body image outcomes. We were surprised to find that time point in treatment had very little influence on our survey findings. Our results suggest that patients experience body image concerns across the entire cancer treatment trajectory and that these concerns can persist well into survivorship. Approximately 14% of the sample included patients who were diagnosed with head and neck cancer greater than 5 years ago; this subset of patients endorsed continued concerns related to feeling embarrassed by bodily changes including but

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not limited to scarring/disfigurement, loss of teeth, skin discoloration, and speech alterations.

Finally, there were several interesting findings resulting from our multivariate regression analyses. A number of different demographic, medical and treatment-related factors were found to predict psychosocial outcomes. Age and time since surgery emerged as significant predictors of behavioral and emotional difficulties with body image as measured by the BIS. Younger participants were found to be at greater risk for experiencing body image difficulties, and these difficulties significantly increased after initial surgery and remained elevated greater than one year following surgery. The latter findings have implications for interventions needed to target cancer survivors. Two variables that were surprisingly not found to predict body image outcomes were gender and cancer type. Gender is widely recognized to be a strong predictor of body image dissatisfaction in the general population,[20] with women clearly experiencing higher levels of difficulties and concerns in this area. Gender failed to contribute to body image scores in this study as well as in two other studies published by our research group (one with oral cancer patients[8] and another with individuals living with HIV[21]). This appears to indicate something unique about the experience of body image concerns for cancer patients as well as other medical groups facing life threatening illnesses. The clinical implications involve recognizing that male cancer patients are at similar risk for experiencing body image difficulties as female cancer patients. It appears reasonable to be concerned that male body image difficulties may be more likely to go undetected and that a more concerted effort needs to be made by clinicians to help normalize these difficulties for their male patients.

With respect to quality of life outcomes, nearly every predictor entered into the model emerged as significant. We were intrigued to find that two separate body image variables (BIS scores and number of current body image concerns) were significant predictors of FACT-HN scores. These results provide additional evidence of the significant association between body image and quality of life outcomes for head and neck patients. We present additional unique findings with regard to cancer site as previous psychosocial literature has not focused on head and neck patients with cutaneous or other midface cancers. In this study, patients with cutaneous cancer were found to have significantly better quality of life outcomes compared to both patients with oral cavity or other midface cancers.

We acknowledge a number of limitations to the present study. A primary limitation is the cross-sectional nature of our design. Though we believe we have obtained much unique and useful information, a greater understanding of the experience of body image difficulties for this patient population would be achieved with a prospective study. Another potential limitation involves the fact that our participants were being treated at a comprehensive cancer center, and it is likely that more aggressive and unusual cases were introduced for treatment. This may limit the ability to generalize our findings. We believe future research will benefit from the work presented here. There is still much to be done with respect to developing and validating appropriate body image assessment tools and establishing empirically validated intervention techniques to address body image difficulties in this patient population. Though we focused on specific groups of surgically treated patients with

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head and neck cancer in this study, it is recognized that body image issues affect patients with oropharynx, larynx, and other cancer types not included here.

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Table 1

Participant Characteristics

Demographics		**Disease/Treatment Characteristics**	
Gender		Cancer Type	
Male	179 (63.90)	Oral Cavity	94 (33.57)
Female	101 (36.07)	Cutaneous	116 (41.43)
		Other Midface	70 (25.00)
Age—mean±SD	59.91±15.11		
		Time Since Diagnosis	
Race		Within last month	26 (9.32)
Caucasian	243 (88.36)	Within last 6 months	79 (28.32)
African American	11 (4.00)	Within last year	46 (16.49)
Asian	8 (2.91)	Within last 2 years	43 (15.41)
Other	13 (4.72)	Within last 5 years	45 (16.13)
		Greater than 5 years	40 (14.34)
Ethnicity			
Hispanic (yes)	18 (8.29)	Treatment Plan	
		Surgical resection	280 (100)
Partnered		Plastics/reconstruction	99 (35.37)
Yes	221 (78.93)	Radiation	172 (61.42)
No	59 (21.07)	Chemotherapy	70 (25.00)
Education Level		Time Point in Treatment	
Less than high school	19 (6.79)	Before surgery	51 (18.21)
High School	65 (30.36)	< 1 year post-surgery	115 (41.07)
Some College	77 (27.50)	> 1 year post-surgery	114 (40.71)
Bachelor Degree +	99 (35.35)		

Note. All values presented as *frequency (percent)*. Total N=280. Percentages were calculated based on the number of participants responding to each individual item.

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Table 2

Summary Statistics for Body Image and Quality of Life Outcomes

	Entire Sample	Cancer Type			Time Point In Treatment		
		Oral Cavity	Cutaneous	Other Midface	Before	<1 year	> 1 year
BIS	4.93± 6.21	4.86 ± 5.91	4.34±6.14	6.01±6.67	3.19±5.17	4.74 ± 5.75	5.82±6.88
FACT-HN	115.60±22.05	110.54 ± 22.45	123.05±18.45	109.80±23.67	109.08±22.72	114.97±21.02	118.88±22.33

Note. BIS=Body Image Scale. FACT-HN=Total score on Functional Assessment of Cancer Therapy—Head and Neck Version. All values are means±SD. Kruskal-Wallis tests were conducted to evaluate scores based on cancer type and time point in treatment. BIS scores by cancer type ($p = 0.0630$) and time point ($p = 0.0140$); FACT-HN scores by cancer type ($p < 0.0001$) and time point ($p = 0.0127$).

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Table 3

Body Image Survey Results for Entire Sample: Participant Concerns and Difficulties

Presence of Body Image Concerns		
Type of Bodily Change	**Currently**	**At some point following diagnosis**
Speaking	70 (25.74)	100 (35.84)
Scarring/disfigurement	65 (23.90)	118 (42.29)
Eating around others	56 (20.59)	70 (25.09)
Loss of teeth	54 (19.85)	84 (30.11)
Swelling	30 (11.03)	49 (17.56)
Drooling	29 (10.66)	49 (17.56)
Hair loss	28 (10.29)	49 (17.56)
Skin discoloration	25 (9.19)	41 (14.70)
Weight loss	21 (7.72)	45 (16.12)
Use of a prosthetic device	20 (7.35)	33 (11.83)
Weight gain	15 (5.51)	17 (6.09)
Removal of nose	14 (5.15)	20 (7.17)
Removal of eye	9 (3.31)	14 (5.02)
Removal of ear	8 (2.94)	10 (3.58)
Presence of stoma/trach	8 (2.94)	15 (5.38)
Other (e.g., hearing loss, eye tearing, loss of smell/taste, dry mouth, numbness, nose drainage)	29 (10.66)	44 (15.77)

Cognitive/Behavioral Difficulties Associated with Body Image Concerns			
	Yes, currently	**Yes, not currently**	**No**
Frequent thoughts about appearance changes	71 (25.91)	72 (26.28)	131 (47.81)
Avoidance of activities due to appearance changes	38 (13.87)	35 (12.77)	201 (73.36)
Avoidance of activities due to speech difficulties	30 (10.95)	28 (10.22)	216 (78.83)
Avoidance of activities due to eating habits	35 (12.77)	32 (11.68)	207 (75.55)
Increased time spent in grooming activities	31 (11.31)	23 (8.39)	220 (80.29)
Avoidance of grooming activities	6 (2.19)	16 (5.84)	252 (91.97)

Cognitive/Behavioral Difficulties Associated with Body Image Concerns			
	Yes, currently	**Yes, not currently**	**No**
Reassurance seeking about appearance	27 (9.85)	35 (12.77)	212 (77.37)

Note. All values presented as *frequency (percent)*. Total N=280. Percentages were calculated based on the number of participants responding to each individual item.

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Table 4

Body Image Survey Results for Entire Sample: Satisfaction and Intervention Interest

Satisfaction with Care/Information Received Healthcare Team					
			Yes	No	N/A
How to cope with appearance-related changes			195 (73.86)	69 (26.14)	
Degree of scarring/disfigurement expected following surgical treatment			176 (66.42)	57 (21.51)	32 (12.08)
Potential effects of radiation on physical appearance			125 (47.17)	60 (22.64)	80 (30.19)
Potential effects of chemotherapy on physical appearance			70 (26.42)	54 (20.38)	141 (53.21)
How comfortable do you feel talking with doctors and nurses about concerns related to your appearance?					
Very comfortable 185 (67.77)	Somewhat comfortable 44 (16.12)	Somewhat uncomfortable 9 (3.30)	Very uncomfortable 2 (0.73)	Not sure 6 (2.20)	N/A 27 (9.89)
Interest in Psychosocial Care/Intervention					
			Yes (I would like this help now)	I would have liked this help previously	No
Would you like to receive additional resources to help you cope with appearance-related changes			32 (12.96)	51 (20.65)	164 (66.40)
What type of resources would you be interested in (whether now or previously?)					
Written materials 74 (30.83)	Face to face counseling 25 (10.42)		Group counseling 11 (4.58)	Telephone counseling 11(4.58)	
Internet-based support group 20 (8.33)	Informational computer CD 28 (11.67)		Referral to mental health specialist 7 (2.92)	Other 13 (5.42)	
How likely would you be to utilize counseling resources in this area if made available to you?					
Very likely 27(10.38)	Somewhat likely 34(13.08)	Unsure 78(30.00)	Somewhat unlikely 25(9.62)		Very unlikely 96(36.92)
Based on your experience, when is the best time to incorporate treatment to help patients cope with appearance-related changes?					

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Before treatment	During active medical treatment	At the completion of active treatment
172 (66.67)	100 (38.67)	81(31.40)

Note. All values presented as *frequency (percent)*. Total N=280. Percentages were calculated based on the number of participants responding to each individual item.

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Table 5

Multivariate Regression Models

Multivariate Linear Regression Model for BIS

	Reduced Model			
			95% CI	
	Estimate	*p*	Lower	Upper
Intercept	2.61	0.0652	0.17	5.38
Female (Ref: Male)				
Age	−0.05	0.0068	−0.09	−0.01
Oral Cavity (Ref: Cutaneous)				
Midface (Ref: Cutaneous)				
<1 Year Following Surgery (Ref: Before Surgery)	2.49	0.0039	0.81	4.18
>1 Year Following Surgery (Ref: Before Surgery)	3.46	<0.0001	1.77	5.14
Number of Current Body Image Concerns	1.71	< 0.0001	1.46	1.96

Multivariate Linear Regression Model for FACT-HN

	Reduced Model			
			95% CI	
	Estimate	*p*	Lower	Upper
Intercept	122.98	<0.0001	116.56	129.40
Female (Ref: Male)	4.81	0.0307	0.45	9.18
Age				
Oral Cavity (Ref: Cutaneous)	−9.84	<0.0001	−14.84	−4.84
Midface (Ref: Cutaneous)	−10.03	0.0003	−15.38	−4.68
< 1 Year of Initial Surgery (Ref: Before Surgery)	5.83	0.0692	−0.46	12.12
> 1 Year Following Surgery (Ref: Before Surgery)	12.43	0.0002	6.06	18.80
BIS score	−1.69	<0.0001	−2.13	−1.26
Number of Current Body Image Concerns	−1.48	0.0144	−2.66	−0.30

Note. BIS=Body Image Scale. FACT—HN=Functional Assessment of Cancer Therapy Scale—Head and Neck Version.