

Body image screening for cancer patients undergoing reconstructive surgery

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Abstract

Objectives: Body image is a critical issue for cancer patients undergoing reconstructive surgery, as they can experience disfigurement and functional impairment. Distress related to appearance changes can lead to various psychosocial difficulties, and patients are often reluctant to discuss these issues with their healthcare team. Our goals were to design and evaluate a screening tool to aid providers in identifying patients who may benefit from referral for specialized psychosocial care to treat body image concerns.

Methods: We designed a brief four-item instrument and administered it at a single time point to cancer patients who were undergoing reconstructive treatment. We used simple and multinomial regression models to evaluate whether survey responses, demographic, or clinical variables predicted interest and enrollment in counseling.

Results: Over 95% of the sample ($n = 248$) endorsed some concerns, preoccupation, or avoidance because of appearance changes. Approximately one-third of patients were interested in obtaining counseling or additional information to assist with body image distress. Each survey item significantly predicted interest and enrollment in counseling. Concern about future appearance changes was the single best predictor of counseling enrollment. Sex, age, and cancer type were not predictive of counseling interest or enrollment.

Conclusions: We present initial data supporting use of the Body Image Screener for Cancer Reconstruction. Our findings suggest benefits of administering this tool to patients presenting for reconstructive surgery. It is argued that screening and treatment for body image distress should be provided to this patient population at the earliest possible time point.

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Introduction

Body image is a multidimensional construct involving perceptions, thoughts, and feelings about the entire body and its functioning [1]. It is recognized as a critical psychosocial issue for cancer patients undergoing reconstructive surgery because they are at high risk of experiencing disfigurement and functional impairment. The process of adjusting to bodily changes during reconstructive treatment is ongoing, as multistaged procedures are often required. Interim outcomes may be particularly bothersome to patients when cosmetic form and function have not been fully restored. Among the adverse psychosocial difficulties linked with body image disturbance in cancer patients include depression and anxiety [2–6], sexual functioning difficulties [7–10], and impairments in overall quality of life [11–13].

High rates of body image concerns have been documented for head and neck and breast cancer patients, two groups who most often undergo reconstructive surgery. Body image disturbance is among the most common psychosocial concern reported by women with breast cancer [14]. Moreover, up to 75% of patients with head and neck cancer have been

found to endorse concerns or embarrassment about bodily changes following diagnosis [15,16]. It is difficult to estimate rates of body image concerns among cancer patients undergoing reconstructive surgery as most research on body image and cancer has been conducted either with disease-specific samples or with a particular subgroup receiving reconstruction (i.e., breast reconstruction). The vast literature reviewing patient-reported outcomes in breast reconstruction identifies various demographic (e.g., age and marital status) [17], psychological (e.g., depression and anxiety) [5,18], medical (e.g., BMI) [19], and disease/treatment related factors (e.g., cancer type, type and timing of reconstruction, and complications) [20–22] associated with body image and quality of life.

Increasing attention is being given to delivering psychosocial care to cancer patients, which specifically targets body image difficulties. Much of this work is based on cognitive-behavioral models of body image disturbance, which highlight the importance of addressing maladaptive thoughts, behaviors, and emotions related to one's appearance [23–25]. For a patient struggling with body image concerns, emphasis is placed on acceptance of body image changes and increasing

self-confidence in social situations. Key treatment strategies for mental health specialists to manage body image issues in the oncology setting have been described elsewhere [26–29], and it is recognized that treatment should be tailored based upon the distinct phase of the cancer journey.

A significant source of distress for cancer patients undergoing reconstructive surgery is related to body image changes they experience during treatment. Unfortunately, much research suggests that physicians are not adept or comfortable with evaluating or managing patient distress. Lack of time is the most frequently reported barrier for medical professionals in being able to identify and manage patient distress [30]. Moreover, patients are reluctant to bring up their distress with their oncologists [31,32], and this may especially be true for those experiencing body image concerns. It is not uncommon for a cancer patient to worry about being seen as ‘vain’ and experience shame and embarrassment about having body image concerns [26]. For these reasons, it is critical to develop a useful screening tool that will facilitate the identification and treatment of patients with body image difficulties in the oncology setting.

Validated tools assessing body image in cancer patients are lacking, and we are not aware of any tools developed for the purpose of screening patients for body image. A systematic review by Annunziata *et al.* found only six questionnaires dedicated to body image assessment for cancer patients. Only one tool was applicable to patients with diverse disease sites, whereas the remaining tools were specific to breast or gastrointestinal cancer [33]. None of these tools were identified as offering a gold standard for evaluating body image in the oncology setting, nor were any specifically developed as a screening tool. More recent advancements have been made with the development of assessment tools for breast cancer patients undergoing reconstructive surgery, focused on satisfaction with outcomes and quality of life. Tools such as the Breast Reconstruction Satisfaction Questionnaire [34] and Breast-Q [35] have gained more widespread use and have undergone extensive validation. However, these tools focus on a specific subset of patients undergoing reconstruction and, again, are not intended for use as a screening measure of body image distress.

Our goals were to design and evaluate a brief body image screening tool for cancer patients undergoing reconstructive surgery that has the potential to be used as part of routine clinical practice. This tool is needed to assist medical professionals in identifying patients with body image distress who may benefit from a referral for specialized psychosocial care.

Methods

Development of the screening tool

Survey items were developed on the basis of knowledge gleaned from the body image literature and clinical expertise

of a multidisciplinary research team. The lead and second authors have considerable experience providing psychological care treating body image difficulties for an array of patients, including those with cancer. The final three authors have expertise as reconstructive surgeons working within a large comprehensive cancer center, highly familiar with the types of body image difficulties of cancer patients report during reconstructive treatment. Key areas of content included distress, preoccupation, and behavioral avoidance. These domains encompass emotional, cognitive, and behavioral aspects of body image disturbance, which are consistently represented in body image assessment tools. Moreover, they reflect core aspects of cognitive-behavioral models of body image disturbance as previously discussed. We generated four items related to concerns about recent changes to appearance, worry about future appearance changes from reconstructive surgery, time spent thinking about appearance, and time spent avoiding activities because of appearance concerns (Table 1). We underwent an iterative process as each member of the team reviewed item content and offered feedback. Language and wording was also reviewed by our institution’s patient education office to ensure an eighth grade reading level. We refer to the instrument as the Body Image Screener for Cancer Reconstruction (BICR).

The BICR was administered as a paper–pencil measure and included a brief introductory paragraph designed to normalize concerns about appearance changes for patients undergoing reconstructive surgery (Table 1). Patients were informed that body image specialists were available to help them cope with appearance concerns. As part of the study, patients were also asked via paper and pencil if they would like to meet with a specialist or would like more information about these services.

This study was approved by our institutional review board. Because information obtained as part of this study was used for clinical purposes (i.e., directing patients to available psychosocial services), a waiver of informed consent was granted.

Evaluation of the screening tool

Body Image Screener for Cancer Reconstruction surveys were administered over a 3-month period (June 2011 to September 2011) to all patients seen by three reconstructive surgeons at The University of Texas MD Anderson Cancer Center. Patients were given the BICR while waiting to see their treating physician. This study employed a cross-sectional design with analyses focused only on the first time point the survey was completed by a given patient. Any patient expressing interest in speaking with a specialist about his or her concerns (regardless of their scores on the BICR) was contacted and offered additional information and a counseling appointment. Those requesting further information received a brief introductory call about available

Table 1. Body Image Screener for Cancer Reconstruction survey

Body Image Screener for Cancer Reconstruction (BICR)				
Many patients have concerns about how cancer treatment will change the way they look. Both men and women worry about changes to their appearance before and after reconstructive surgery.				
Body image specialists are available to help you cope with appearance concerns. Our specialists can help you:				
<ul style="list-style-type: none"> • Discuss difficult treatment decisions that will affect your appearance. • Better prepare for future changes to your appearance. • Adjust to appearance changes during and after reconstructive treatment. 				
Please read each question and circle the number that describes your feelings.				
	Not at all	A little	Quite a bit	Very much
1. How concerned are you about recent changes to your appearance and body?	0	1	2	3
2. How much do you worry about future changes to your appearance from reconstructive surgery?	0	1	2	3
	None of the time	A little of the time	Some of the time	Most of the time
3. How often do you think about your appearance?	0	1	2	3
4. How often do you avoid certain activities because of concerns about your appearance?	0	1	2	3

psychosocial services or a letter providing these details if they could not be reached.

We recorded demographic and clinical characteristics of each participant from a review of medical records and conducted descriptive analyses on these variables and on survey responses. Simple and multinomial logistic regression models were used to evaluate whether demographic, clinical variables, and survey items predicted counseling interest as well as counseling enrollment. We first conducted simple logistic regression analyses to predict interest in body image counseling, where we considered each survey item separately and used the full range of response options. Individual survey items were also analyzed as binary variables reflecting little or no concerns (values <2) versus moderate or extreme concerns (values ≥2). Further analyses summarized survey scores into a single value. We assigned a value of 0 if responses for all four questions were 2 or less and a value of 1 if the score on any question was a 3.

Multiple logistic regression models were used to evaluate all predictor variables in determining counseling outcomes. We conducted simple stepwise variable selection procedures (forward and backward) and report the best model on the basis of maximization of the goodness-of-fit estimate using the Nagelkerke R^2 index.

Results

Table 2 presents demographic and clinical characteristics of our sample, which included 248 patients. The majority of participants were women (87%) and had breast cancer (71%). However, 16% were patients with head and neck cancer, and 13% had other cancers. The other category included patients with various cancers affecting the extremities, abdomen, pelvic, or groin regions. These types of cancers included but were not limited to ovarian, rectal, renal cell, melanoma, sarcoma, and chordoma. Patients were being seen

Table 2. Patient demographic and clinical characteristics (N = 248)

Characteristics	No. of patients/values
Age, years	Mean = 51.86, SD = 13.15 (range, 13–85)
Sex	87% female 13% male
Race	70% white 30% non-white
Marital status	73% married 15% single 9% divorced/separated 3% widowed
Cancer type	71% breast 16% head and neck 13% other
BMI	Mean = 27.40, SD = 5.75 (range, 15.70–46.00)
Clinic visit type	29% consult/preop 71% revision/follow-up
Time since initial reconstructive surgery	Mean = 10.48 months, SD = 1.28 years (range, 0–6.77 years)

SD, standard deviation; preop, preoperative.

either at an initial stage of reconstruction (consult/preop) or for follow-up and/or discussion of revision surgery.

Survey responses revealed that 95% of participants had some degree of concern, preoccupation, or avoidance due to appearance changes. That is, they endorsed at least one item on the BICR at a value other than 'not at all' or 'none of the time'. Table 3 presents information on rate of endorsement of each survey item and shows that depending on the item, approximately 10–24% of the sample endorsed an extreme response ('very much' or 'most of the time'). A total of 35% expressed an interest in counseling or wanted more information related to counseling. Among those interested in speaking with a body image specialist, 35% were seen in person for counseling. Figure 1 presents further data

Table 3. Rate of endorsement on individual items of the Body Image Screener for Cancer Reconstruction

	Not at all	A little	Quite a bit	Very much
Q1: current concerns	51 (20.6%)	98 (39.5%)	55 (22.2%)	44 (17.7%)
Q2: future concerns	60 (24.2%)	79 (31.9%)	62 (25.0%)	47 (19.0%)
Q3: thoughts	None of the time 19 (7.7%)	A little of the time 71 (28.6%)	Some of the time 99 (39.9%)	Most of the time 59 (23.8%)
Q4: avoidance	104 (41.9%)	52 (21.0%)	67 (27.0%)	25 (10.1%)

Q1, question 1; Q2, question 2; Q3, question 3; Q4, question 4.

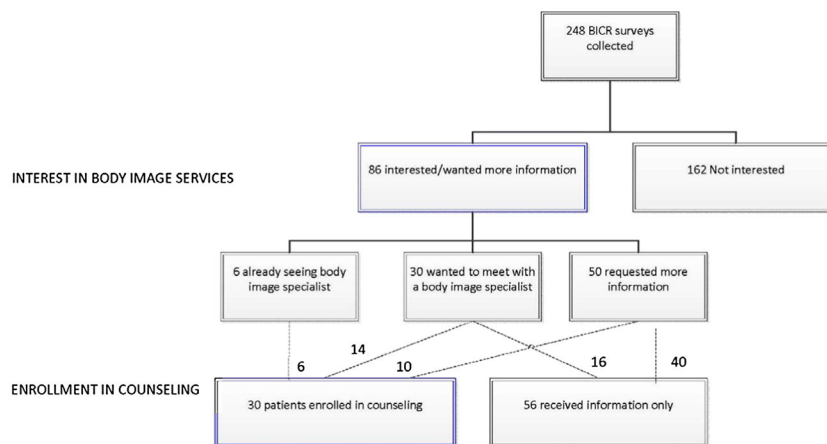


Figure 1. Interest and enrollment in counseling following completion of the Body Image Screener for Cancer Reconstruction (BICR)

on patient interest and subsequent enrollment in body image counseling following completion of the BICR.

Interest in body image counseling

We conducted simple logistic regressions predicting counseling interest on the basis of responses to each survey item. Interest in counseling was defined as requesting more information, requesting to meet with a specialist, or stating that one had already seen a specialist. When considering the full range of response options on the BICR, the odds of being interested in counseling significantly increased with extreme (‘very much’) concerns about recent appearance changes ($OR=4.39$, $p=0.04$, 95% CI 1.06–18.14) and with moderate (‘quite a bit’) and extreme (‘very much’) concerns about future appearance changes ($OR=3.33$, $p=0.04$, 95% CI 1.06–10.49 and $OR=4.67$, $p=0.02$, 95% CI 1.31–6.64, respectively). When considering survey items as binary variables, we found that each survey item significantly predicted counseling interest (Table 4). Age, race, marital status, sex, cancer type, and time since initial reconstructive surgery were not found to significantly predict counseling interest. Type of clinic visit ($p=0.06$) and BMI ($p=0.07$) were associated with marginally significant findings.

Multinomial logistic regression analyses revealed that the odds of requesting more information, with respect to no interest, were 3.26 times higher ($p=0.05$, 95% CI

Table 4. Simple logistic regressions predicting interest in body image counseling

	OR	95% CI		p-value
		Lower	Upper	
BICR survey responses ^a				
BICR 1: current concerns	4.47	2.56	7.81	<.01
BICR 2: future concerns	6.14	3.42	10.95	<.01
BICR 3: preoccupation	3.68	1.99	6.79	<.01
BICR 4: avoidance	3.75	2.16	6.52	<.01
Demographic variables				
Age	0.99	.098	1.01	0.50
Sex	1.49	0.66	3.37	0.34
Race	1.44	0.82	2.52	0.21
Marital status ^b				0.62
Clinical variables				
Cancer type ^c				0.28
BMI	1.04	0.98	1.09	.07
Clinic visit type ^d				0.06
Time since initial surgery	1.00	0.99	1.00	0.32

OR, odds ratio; BICR, Body Image Screener for Cancer Reconstruction.
^aResponse options for each survey item were dichotomized to reflect none/minimal or moderate/high levels.
^bMarital status comprised the following categories: married, single, divorced, separated, and widowed. Each was not significant; p -values > 0.05.
^cCancer type comprised the categories of breast, head and neck, and other. Each was not significant; p -values > 0.05.
^dFor clinic visit type, we defined two types of consult visits (initial consult and follow-up consult), two types of preoperative visits (preop prior to initial surgery and preop prior to revision surgery), and follow-up visits. Significant findings emerged only when comparing follow-up visits with initial consults ($OR=-1.02$, 95% CI 0.18–0.071, $p<0.01$).

1.44–7.38) when a person had extreme concern (value = 3) in at least one area. Similarly, the odds of requesting to meet with a specialist were 16.08 times higher ($p < 0.001$, 95% CI 2.13–121.22) when a person had extreme concern in at least one area versus when a person had no concerns.

Multivariate regression analyses evaluating interest in counseling included survey responses (binary variables) and demographic and clinical variables as predictors. The best model included the following significant predictors: BMI, Q1 (current concerns), and Q2 (future concerns), with a Nagelkerke R^2 index of 0.26. There was a small but significantly greater interest in counseling for those with a higher BMI ($p = 0.03$, $OR = 1.06$, 95% CI 1.01–1.12). In addition, greater interest in counseling was found to be related to higher levels of concern about recent changes in appearance ($p = 0.03$, $OR = 2.17$, 95% CI 1.12–4.21) and future changes in appearance ($p < 0.001$, $OR = 4.45$, 95% CI 2.26–8.75) due to reconstructive surgery.

Enrollment in counseling

Participants were categorized according to whether they were actually seen in counseling, received information only, or expressed no interest in counseling. Results of multinomial regressions predicting enrollment in counseling on the basis of survey responses (binary variable) are presented in Figure 2. The odds of enrolling in counseling and seeking information significantly increased with greater concerns on each survey item. Specifically, the probability of enrolling in counseling increased ninefold whenever the patient was quite a bit or very much concerned about future appearance changes ($OR = 9.5$, 95% CI 3.66–24.72, $p < 0.001$), whereas the probability of seeking information about these services increased fivefold ($OR = 5.02$, 95% CI 2.61–9.65, $p < 0.001$).

Similar to our findings regarding counseling interest, demographic and clinical variables did not significantly predict

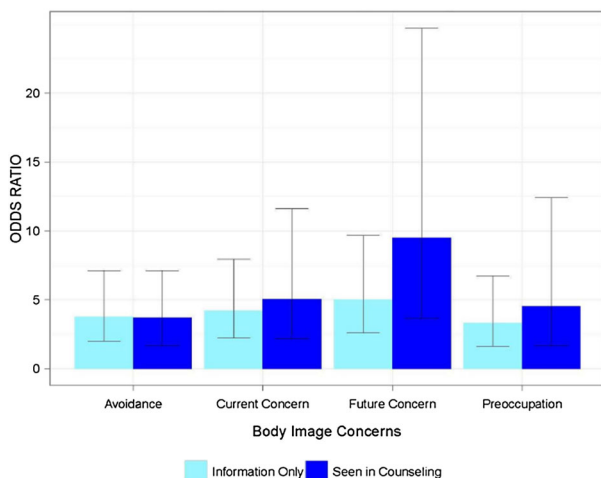
counseling enrollment. Multinomial logistic regression models were not significant for age, race, marital status, sex, or cancer type. There was a marginally significant effect for visit type such that the odds of enrolling in counseling were lower for those seen at follow-up versus consult ($OR = 0.46$, 95% CI 0.20–1.04, $p = 0.06$). The odds of enrolling in counseling also decreased slightly as time passed since initial reconstructive surgery ($OR = 0.99$, 95% CI 0.99–1.00, $p < 0.01$). In contrast to findings regarding counseling interest, higher BMI slightly decreased the probability of counseling enrollment ($OR = 0.94$, 95% CI 0.93–0.95, $p < 0.01$).

Finally, we evaluated counseling enrollment using multiple logistic regression models. We considered a model where survey responses and demographic and clinical variables were included and a model where only the survey responses were considered. The best model had a single predictor, Q2: concerns about future appearance ($p \leq 0.01$, $OR = 6.140$, 95% CI 2.41–15.637). For this model, Nagelkerke R^2 was 0.14.

Discussion

We present initial data supporting the use of the BICR. This screening tool was designed to facilitate the identification of patients who may benefit from a referral for specialized psychosocial care to treat body image concerns. Our findings contribute to the literature on body image and oncologic reconstructive surgery in a number of important ways. To our knowledge, we are among the first to actually document rates of appearance concerns and body image issues for cancer patients undergoing reconstructive surgery. Previous research in this area has typically focused on a single disease site or has examined body image issues only for a specific group of cancer patients undergoing reconstructive surgery. Nearly every patient in our study (95%) endorsed some degree of concern about current and future changes to appearance, preoccupation with appearance, or avoidance due to appearance. Body image concerns were found across all stages of reconstructive treatment and were irrespective of cancer type, sex, age, race, marital status, and BMI. These findings are important in that they underscore the need to normalize and validate body image concerns for cancer patients undergoing reconstructive surgery to help reduce shame, stigma, and embarrassment surrounding these issues [26].

Participants may have been more comfortable with acknowledging their concerns because we deliberately crafted an opening paragraph educating patients about the common nature of body image concerns for those undergoing reconstructive surgery. Although nearly all participants endorsed some concerns related to appearance, it is clear that not all were interested in seeking counseling and many feel equipped to manage their concerns without professional guidance. However, greater than one-third of



Note: Odds ratios for individual items ranged from 3.32 to 9.95, and all p values were < 0.001 .

Figure 2. Multinomial regressions predicting counseling outcome

our sample expressed a desire for counseling or wanted to obtain more information about these services. This reflects interest in counseling or obtaining resources to help cope with body image issues among a substantial portion of this patient population and is consistent with other published findings. In a cross-sectional survey of patients with head and neck cancer, 34% of patients endorsed wanting assistance with body image issues, with the majority indicating that they were very likely or somewhat likely to utilize counseling resources if made available to them [15].

Most of our analyses examined the predictive value of individual items on the BICR because we considered each variable to be categorical. We did not assume that the values necessarily 'sum up' in a quantitatively measurable way. Our findings suggest that a score of 3 on any single item of the BICR could reasonably be used to identify a patient who may benefit from a referral. Participants with these scores were significantly more likely to enroll in body image counseling or desire further resources to assist them in coping with body image concerns. Additional results suggest that a score of 2 or 3 on any single item, but particularly on Q2 (concerns about future appearance changes), could be used as an indicator for a counseling referral.

Although other research has identified age, BMI, and cancer type as potential risk factors for body image distress [25], our study found very few demographic or clinical variables to demonstrate predictive value in identifying patients likely to be interested in or enroll in body image counseling. Contrary to what one might expect, younger age and female sex did not predict interest in counseling and neither did cancer type. Breast cancer, head and neck cancer, and other types of patients undergoing reconstructive surgery were equally likely to seek or be open to learning about body image counseling. We also found no differences based on marital status or race. There were mixed results regarding BMI, with some findings suggesting that a higher BMI is associated with increased odds of being interested in counseling but slightly decreased odds of enrolling in counseling. Although these findings are not clinically meaningful because of the low magnitude of the odds ratios, they suggest that patients with a higher BMI may be reluctant to engage in body image counseling despite having an interest in receiving such assistance. Clearly, further research is needed to explore this issue.

There was consistent evidence that patients in an earlier phase of treatment were more interested in and more likely to enroll in body image counseling. We found that the odds of being interested in counseling and enrolling in counseling were higher for patients seen at consult compared with follow-up. Moreover, concern about future or upcoming appearance changes was clearly the strongest predictor related to counseling. These findings lend support to Cash's cognitive-behavioral model of body image [23],

wherein he posits that certain types of proximal events can serve as a strong trigger for maladaptive thoughts, behaviors, and emotions tied to appearance. Within this context, we consider cancer diagnosis and initiation of reconstructive surgery to be such a trigger.

Our findings suggest a benefit of administering the BICR to patients as early as possible during their treatment, prior to surgical intervention. In previous research, patients with head and neck cancer endorsed the need for services to help them cope with appearance-related and body image changes along the entire treatment continuum. Although many believed that these services would be beneficial before treatment begins, during active treatment, and following completion of treatment, a clear majority identified the greatest need for these services prior to treatment [15]. Taken together, this fits with a model of care focusing on early recognition and treatment of body image difficulties in order to prevent more serious behavioral and psychological problems from arising.

This study can be placed within the larger context of a nationwide movement promoting distress screening in the oncology setting, which is supported by the Institute of Medicine and Commission on Cancer [36–39] and by the American Psychosocial Oncology Society, Association of Oncology Social Work, and Oncology Nursing Society [40]. The American College of Surgeons now requires that patients undergoing treatment for cancer be screened for distress and appropriate referrals be provided for psychosocial care. These standards clearly delineate identification and management of distress as critical for providing high-quality cancer care. As discussed throughout this manuscript, body image concerns are identified as a significant source of distress for cancer patients undergoing reconstructive treatment. As such, conducting screening for body image distress and providing appropriate referrals for psychosocial care would facilitate compliance with accreditation criteria for cancer centers while addressing a highly relevant clinical issue for cancer patients undergoing reconstructive surgery.

This study was developed on the basis of feedback received from reconstructive surgeons in a comprehensive cancer center requesting a screening tool to help them determine when a referral for specialized psychosocial care treating body image difficulties may be warranted. These providers are aware of the depths to which some of their patients struggle to cope with appearance changes resulting from treatment. This type of care would ideally be delivered by a mental health specialist with expertise in treating body image disturbance of cancer patients. The American Cancer Society, American Psychosocial Oncology Society, or Cancer Support Community can assist in locating such professionals locally as well as directing patients to online resources that may be pertinent [26].

Additional consideration could be given to using the BICR as part of clinical query or as a clinical tool for

the treatment team to prompt discussion surrounding appearance concerns identified by patients. For the treatment team to be aware of and to help address the levels of distress, preoccupation with appearance, and avoidance behaviors tied to appearance, further understanding of these is important. Apart from making referrals for body image counseling, this tool could also prompt greater time spent in educating patients about what types of appearance changes to expect from initial reconstruction or revision surgery or to initiate relevant referrals for other psychosocial resources available in their treating facility.

We acknowledge a number of limitations of this study. This study employed a cross-sectional design and evaluated patients at only a single time point. We were unable to consider the influence of body image issues for patients prior to cancer diagnosis. Our findings were limited by our sample size, particularly when evaluating results of regression analyses that divided variables into different categories. Although we were able to evaluate which survey items showed greater predictive value in identifying patients who were interested in and ultimately enrolled in counseling, we did not examine whether patients benefitted from treatment. We note that the fit indices for our multiple regression models were low, suggesting that there is considerable variance not explained in our model. This could be a result of limited power. Alternatively, we may need to consider expanding our screening tool to include additional items.

Although the BICR shows promise in being able to facilitate enhanced psychosocial care for cancer patients undergoing reconstructive surgery, it is clear that further testing and validation of this tool is needed. Although our sample include an array of cancer patients undergoing

reconstructive surgery (breast, head and neck, and others), a large proportion of these patients were women with breast cancer. Further testing with a larger sample is needed, and particular attention must be given to evaluating the psychometric properties of this instrument as related to reliability and validity.

Conclusions

To our knowledge, this is the first effort to design and test a body image screening tool for cancer patients undergoing reconstructive surgery. This tool was developed based upon feedback from healthcare providers who identified a strong desire for being able to recognize which patients are in need of referral for specialized psychosocial care to treat body image concerns. This work further demonstrates that helping cancer patients cope with body image concerns is an important component of high-quality cancer care that can ultimately optimize psychosocial well-being during treatment and into survivorship.

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Conflict of interest

None of the authors has a financial interest in any of the products, devices, or drugs mentioned in this manuscript.

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