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Reliability and Preliminary Validation of a Body Image Scale Survey for Use in Bladder Cancer Patients

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Abstract

Introduction Extirpative bladder surgery for bladder cancer requires urinary diversion which causes cosmetic and functional changes that affect a patient's body image and quality of life. Current health-related quality of life (HRQOL) surveys validated for use in bladder cancer patients have no dedicated domain evaluating body image. We sought to validate the ten-item Body Image Scale (BIS) for use in bladder cancer patients. The BIS is scored on a 4-point Likert scale with a maximum score of 30. Higher scores represent increasing distress.

Methods With Institutional Review Board approval, native English or Spanish speaking patients who had undergone radical cystectomy and urinary diversion with either ileal conduit formation or orthotopic neobladder creation within the past 5 years for muscle-invasive bladder cancer were identified. The survey was conducted via telephone or e-mail. Surveys were scored and analyzed for reliability and validity.

Results 32 patients were identified (22 men, 10 women). 25 patients had ileal conduits and 7 had orthotopic neobladders. Cronbach's alpha reliability coefficient measuring internal consistency for the BIS instrument in this group was 0.926. All ten items met the response criteria (score of >0 by >30% respondents) in our study population. Though the ileal conduit group mean (17.4) and median (16) scores were lower than the neobladder (mean=19.1 and median=22), there was no statistically significant difference in BIS scores between the two cohorts (p=0.755).

Conclusions We present a validation study for use of BIS in bladder cancer patients to be utilized in future clinical trials or psycho-oncology research.

Key words body image, bladder cancer, urinary diversion, ileal conduit, neobladder, quality of life surveys

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Introduction

Surgical management of localized and locally advanced muscle invasive bladder cancer is extirpation with radical cystectomy and creation of a urinary diversion [1, 2]. In men, radical cystectomy involves removal of the bladder, prostate, neurovascular bundles, and seminal vesicles. In women, it traditionally entails removal of the bladder, uterus, ovaries, and anterior vaginal wall [3, 4]. Several options for urinary diversions exist, including ileal conduit, continent cutaneous diversion, bilateral ureteral skin stomas, and orthotopic neobladder [5]. While radical cystectomy imparts oncologic benefit, the cosmetic and functional changes incurred after urinary diversion represent an important source of survivorship burden that can significantly affect patients' quality of life [6].

Ileal conduit and orthotopic neobladder are the most performed urinary diversions, with the incidence of ileal conduits increasing with the rise of robotic cystectomies [7]. The diversions each have distinct advantages and many patient-specific factors (personal preference, stage of disease, comorbidities, and surgical history) must be considered when selecting which diversion is most appropriate. Ileal conduit creation has a shorter operative time, making it advantageous for older, high risk surgical candidates who do not desire a continent diversion. Ileal conduits require a urostomy bag that may negatively affect body image. Neobladders are ideally a continent diversion, with 90% of patients achieving daytime continence with voiding and pelvic floor rehabilitation [7]. Body image is hypothesized to be less affected by neobladder creation due to lack of urostomy and regaining of continence. With longer operative time and commitment to reestablishing continence, neobladders are often created for younger patients with fewer comorbidities [7].

As radical cystectomy with urinary diversion is potentially disfiguring, body image is an important aspect of quality-of-life in bladder cancer patients. However, accurate assessment of body image is limited by lack of dedicated domains in current health related quality of life surveys (HRQOL) validated in bladder cancer [8]. Though previous studies report body image differences between neobladder and ileal conduit cohorts, the instruments used to elucidate these findings were either not validated for use in bladder cancer or consisted of three or less scaled items [9].

We sought to validate the previously developed, ten-item Body Image Scale (BIS) for use in bladder cancer patients. Developed in 1993 by Hopwood et al., the BIS is scored on a 4-point Likert scale towards a maximum total score of thirty, with higher scores representing increasing symptoms or distress [10]. The BIS has previously been validated for use in colorectal and breast cancers, but has not been validated for use in bladder cancer patients in the United States [11, 12]. In this study, we aimed to assess the body image of patients after radical cystectomy followed by ileal conduit or orthotopic neobladder for muscle-invasive bladder cancer and establish the BIS as both a reliable and valid measurement tool in this patient population.

Materials and methods

Patient population

Included patients were native English or Spanish speakers who had undergone radical cystectomy with urinary diversion within the past 5 years for muscle invasive bladder cancer. Patients were greater than 18 years of age. Institutional Review Board approval was obtained by the University of California –San Diego IRB, registration number: 804652. Eligible patients were identified via an EPIC electronic medical records system search.

Data collection

Patient reported data was gathered using the BIS, a 10-item scale developed under EORTC Study Group guidelines. The instrument is scored on a 4-point Liker scale with points towards a maximum total score of 30 ranging from 0 ("not at all"), 1 ("a little"), 2 ("quite a bit"), to 3 ("very much"). Higher scores represent increasing symptoms or distress.

Eligible patients were contacted by the clinical research coordinator to determine interest in participation. Interested patients completed the survey via telephone or e-mail in either English or Spanish depending on individual preference. Patients who completed the study were compensated for their involvement.

RedCap was utilized to store survey data with access available only to authorized study personnel.

Data analysis

The survey was scored and analyzed for reliability and validity. Mann-Whitney U test was employed to elucidate differences in BIS scores by type of urinary diversion.

Results

Eighty eligible patients were identified. Thirty-one (twenty-one men, ten women; twenty-eight native English speakers, three native Spanish speakers) patients completed the survey (**Table 1**). Twenty-four patients underwent cystectomy with ileal conduit, while seven patients received orthotopic neobladders. Mean age of the cohort was 73.0 years.

Reliability

Table 1. Demographics.

Items	Overall (n=31)	Ileal conduit (n=24)	Neobladder (n=7)
Mean age (years)	73 ±8.5	74.8± 7.4	66.4 ± 9.7
Male	21	16	5
Female	10	8	2
English	28	21	7
Spanish	3	3	0

Table 2a. Body image scale results for ileal conduit.

Ileal conduit n=24	Not at all	A little	Quite a bit	Very much
Have you been feeling self-conscious about your appearance?	8 (33.3%)	14 (58.3%)	1 (4.1%)	1 (4.1%)
Have you felt less physically attractive as a result of your disease or treatment?	6 (25.0%)	13 (54.2%)	3 (12.5%)	2 (8.3%)
Have you been dissatisfied with your appearance when dressed?	10 (41.7%)	13 (54.2%)	1 (4.1%)	0 (0.0%)
Have you been feeling less feminine/masculine as a result of your disease or treatment?	10 (41.7%)	9 (37.55%)	3 (12.5%)	2 (8.3%)
Did you find it difficult to look at yourself naked?	13 (54.2%)	8 (33.3%)	3 (12.5%)	0 (0.0%)
Have you been feeling less sexually attractive as a result of your disease or treatment?	10 (41.7%)	5 (20.8%)	7 (29.2%)	2 (8.3%)
Did you avoid people because of the way you felt about your appearance?	18 (75.0%)	5 (20.8%)	1 (4.1%)	0 (0.0%)
Have you been feeling the treatment has left your body less whole?	8 (33.3%)	10 (41.7%)	6 (25.0%)	0 (0.0%)
Have you felt dissatisfied with your body?	8 (33.3%)	13 (54.2%)	3 (12.5%)	0 (0.0%)
Have you been dissatisfied with the appearance of your scar?	15 (62.5%)	7 (29.2%)	2 (8.3%)	0 (0.0%)

Cronbach's alpha reliability coefficient measuring internal consistency for the BIS instrument in this group was 0.917. No item had a value less than 0.903, and item alphas ranged between 0.903 and 0.922.

Face validity

The questionnaire was discussed during one-on-one interviews with eight individual patients, who felt that the survey questions appropriately measured self-image.

Content validity

The BIS measures a subjective construct. However, two urologic oncologists at our institution were polled and agreed that the BIS is inclusive of all aspects of body image in relation to treatment for bladder cancer, with a higher score relating to lower body image perception.

Clinical validity

A body image instrument with ideal clinical validity would be able to determine a subject's body image disturbance post-treatment with high accuracy. We sought to establish this with discriminant validity testing, as there is no established clinical threshold score for body image disturbance.

Discriminant validity

We compared the BIS scores between patients with neobladder and ileal conduits (**Table 2**). As the distribution curve between the two cohorts was not normal nor similarly shaped by visual inspection, we are unable to make inferences about the differences in medians between groups. A Mann-Whitney U test was run to determine if there were differences in BIS scores between cohorts (**Table 3**). Though the ileal conduit group mean (17.5) and median (17) scores were lower than the neobladder mean (19.1) and median (22), there was no statistically significant difference in BIS scores between the two cohorts (U=82.5, z=0.281, p=0.784).

Response prevalence

EORTC guidelines for scale development recommend response prevalence (the frequency of scores >0 in any item) be greater or equal to 30%. All ten items met the response criteria (score of >0 by >30% of respondents) in our study population.

Construct validity

To determine construct validity, there would need to be a theoretic model based on published data by which to compare the BIS data from our institution. However, there is insufficient existing quantitative data in the urologic literature regarding post-operative body image. Therefore, construct validity cannot be determined at this time due to the inability to compare our data to a theoretical model.

Discussion

Post-surgical body image is an important yet underrecognized source of treatment burden for patients following radical cystectomy. In this study, we sought to validate the BIS in a cohort of patients with muscle invasive bladder cancer who underwent radical cystectomy followed by ileal conduit or orthotopic neobladder. We chose not to include patients who had undergone cutaneous ureterostomy urinary diversions as these are not commonly performed, making it difficult to have an adequate sample size for study of this group. We found that the BIS is reliable and valid in patients with ileal conduit or orthotopic neobladder. While patients who underwent ileal conduit had lower average BIS scores compared to patients who underwent orthotopic

Table 2b. Body image scale results for neobladder.

Neobladder n=7	Not at all	A little	Quite a bit	Very much
Have you been feeling self-conscious about your appearance?	3 (42.9%)	3 (42.9%)	1 (14.3%)	0 (0.0%)
Have you felt less physically attractive as a result of your disease or treatment?	3 (42.9%)	1 (14.3%)	2 (28.6%)	1 (14.3%)
Have you been dissatisfied with your appearance when dressed?	4 (57.1%)	2 (28.6%)	0 (0.0%)	1 (14.3%)
Have you been feeling less feminine/masculine as a result of your disease or treatment?	3 (42.9%)	2 (28.6%)	1 (14.3%)	1 (14.3%)
Did you find it difficult to look at yourself naked?	3 (42.9%)	3 (42.9%)	1 (14.3%)	0 (0.0%)
Have you been feeling less sexually attractive as a result of your disease or treatment?	3 (42.9%)	1 (14.3%)	1 (14.3%)	2 (28.6%)
Did you avoid people because of the way you felt about your appearance?	3 (42.9%)	4 (57.1%)	0 (0.0%)	0 (0.0%)
Have you been feeling the treatment has left your body less whole?	2 (28.6%)	3 (42.9%)	0 (0.0%)	2 (28.6%)
Have you felt dissatisfied with your body?	3 (42.9%)	3 (42.9%)	0 (0.0%)	1 (14.3%)
Have you been dissatisfied with the appearance of your scar?	4 (57.1%)	1 (14.3%)	1 (14.3%)	1 (14.3%)

neobladder, there was no statistically significant difference in BIS between type of urinary diversion. Clinical validity was not able to be established.

There is conflicting evidence regarding the importance of body image for bladder cancer survivors [13-16]. In a qualitative interview of thirty patients with bladder cancer undergoing urinary diversion, Somani et al. found that no patient mentioned body image as an important factor for quality of life [14]. In contrast, in a semi structured interview of sixteen women who underwent radical cystectomy, Gupta et al. found that while body image improved with time after surgery there was significant distress associated with post-operative body perception [17]. Differences in outcomes may be due to non-standardized measurement methods (i.e. open versus semi-structured interview, multiple inventories).

Several studies have attempted to elucidate differences in body image with respect to modality of urinary diversion. Most have hypothesized that patients who receive orthotopic neobladders will have superior body image due to lack of disfigurement associated with urostomy [9]. In our study, we did not note a statistically significant difference between ileal conduit and orthotopic neobladder. However, it should be noted that direct comparison between these groups is challenging without randomization as factors influencing surgical selection may also impact body image. Furthermore, as a preliminary validation study our sample size is small.

Table 3. BIS scores.

Urinary diversion	Median	Mean
Ileal conduit	17.0	17.5
Neobladder	22.0	19.1

BIS = body image scale.

Hedgepeth et al. compared the effects of ileal conduit diversion and neobladder diversion on body image using 10 items from the BIS that assess aspects of body image that are pertinent to all cancer patients. Patients were evaluated at baseline, 1 month, 6 month, 1 year, 2 years and every other year until 8 years after surgery. They hypothesized that patients with neobladder diversion would have better body image compared to ileal conduit patients. Patients who underwent cystoscopy with or without intravesical chemotherapy served as a control group. The three groups had no difference in body image scores before surgery. After surgery, neobladder and ileal conduit patients had a decline in body image, whereas cystoscopy patients remained the same. However, there was no difference between the mean BIS scores for the 2 diversion groups. Both groups' scores improved over time, but only the ileal conduit group had scores that returned to baseline and had no difference compared to cystoscopy. Gender did not impact BIS scores, but age did, with older patients having better BIS scores. Patients who received neobladder diversion were younger in age which could explain these results [9].

This study has several important limitations. Due to its retrospective nature, this study is subject to confounding biases. Additionally, the completion rate of 40% (32/80) may introduce selection bias. We do not have pre-operative body image measurements to serve as a baseline assessment. Nevertheless, in this study we establish that the BIS is both valid and reliable assessment of body image in a US cohort of bladder cancer patients. Further efforts must focus on validation in a larger sample size and valid prospective setting.

Conclusion

We present a validation study for use of BIS in bladder cancer patients. Patients and urologic oncologists felt that the BIS scale adequately assessed body image after cystectomy. As advances in surgical technique and systemic treatment increase the life expectancy of patients with bladder cancer, recognizing the potential psychological distress associated with interventions becomes increasingly important for counseling patients and can be implanted into future clinical trials and psycho-oncology research. Further validation with a larger and more diverse sample is requisite.

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Ethical policy

All procedures performed in this study were in accordance with the ethical standards of the institutional and/or national research committee and with the 1964 Helsinki declaration and its later amendments or comparable ethical standards. Informed consent was obtained from all individual participants included in the study. Approval from institutional ethical committee was taken. Institutional Review Board approval was obtained by the University of California –San Diego IRB(804652).

Availability of data and materials

That data is available from the corresponding author on request.

Author contributions

AS conceived of the study, and participated in its design and coordination and helped to draft the manuscript as well as edit the manuscript and coordinate with authors. HGH helped to draft and edit the manuscript, coordinate with authors, and submit for publication. MFM participated in its design and coordination and helped to draft the manuscript. MES carried out participant recruitment, survey conduction, and data analysis. KLY participated in its design and coordination and helped to draft the manuscript. TS participated in its design and coordination and helped to draft the manuscript. JTA participated in its design and coordination and helped to draft the manuscript. YASL participated in its design and coordination and helped to draft the manuscript. AS participated in its design and coordination and helped to draft the manuscript. All authors read and approved the final manuscript.

Competing interests

All authors declare no competing interests.

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