

## Original Article

# Depression and anxiety among patients treated for bladder cancer: examining clinical, demographic, and psychosocial predictors

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**Abstract:** Introduction and objective: The significant impact of bladder cancer and treatment on patient health related quality of life (HRQoL) and emotional wellbeing has been documented. Increasing evidence from cancer research emphasizes the importance of examining patients supportive care needs and received social support as factors that could influence their emotional adjustment. The purpose of the study was to assess the demographic and clinical predictors of depression and anxiety among bladder cancer patients and its associations with patient reported supportive care needs and perceived availability of social support. Methods: A cross-sectional design was used to investigate the study questions. Bladder cancer patients were recruited from the Bladder Cancer Advocacy Network (BCAN) to complete a questionnaire that included the Hospital Anxiety and Depression Scale (HADS), bladder cancer patient need survey (BCNAS-32), and the social provisions scale (SPS). The inclusion criteria restricted our sample to include bladder cancer patients who were English speakers, aged 18-85 years, and were able and willing to provide informed consent. Patients who had metastatic disease, cancer recurrence, or other primary cancers at the time of assessment were excluded from the study. Results: Participants included 159 bladder cancer patients. The mean age was 62±9.4 years and 51% were male. Almost two-thirds (62%) of patients reported a diagnosis of muscle invasive bladder cancer (MIBC), 25% patient reported clinically significant levels of anxiety, 17% reported clinically significant levels of depression, and 13% and 17% reported abnormal borderline abnormal levels for anxiety and depression, respectively. Univariate regression analyses revealed significant associations between HADS total score, HADS depression and anxiety subscales, patient age, physical functioning/daily living needs, sexuality needs, and perceived social support with higher total scores, anxiety, and depression scores associated with younger age, higher unmet needs, and lower levels of social support. Multivariate regression analyses, showed similar findings confirming the associations depicted by the univariate regression analyses. Conclusions: Bladder cancer patients experience significant levels of depression and anxiety and these levels are associated with patient age, supportive care unmet needs and lack of social support. Patient focused interventions could be tailored to address these issues with the goal to improve patient HRQoL and emotional adjustment.

**Keywords:** Bladder cancer, psychological distress, anxiety, depression, unmet needs, health related quality of life, radical cystectomy, supportive cancer care

## Introduction

The American Cancer Society estimates that 82,290 individuals will be diagnosed with bladder cancer, and 16,710 patients will not survive their disease in the United States in 2023 [1]. Notably, bladder cancer is the most expensive

malignancy to treat over the lifetime of patients [2]. Bladder cancer is also a disease that primarily affects older individuals, with an average age at diagnosis of ~73 years old. Radical cystectomy (i.e., surgical removal of the bladder) remains the gold standard for muscle invasive and high-risk non-muscle invasive bladder can-

cer (MIBC) refractory to conservative therapy (i.e., approximately 30% of newly diagnosed patients) [2, 3]. Radical cystectomy often includes extended pelvic lymphadenectomy followed by one of three major urinary diversion procedures (Ileal Conduit, Continent Cutaneous Reservoirs, Neobladder). Surgery poses poor outcomes in those not identified as poor candidates and is a detriment to the patient health related quality of life (HRQoL) [4-8]. However, non-muscle invasive bladder cancer (NMIBC) also has its host of detriments of HRQoL. NMIBC has the highest recurrence of any cancer site [9]. Some estimates show NMIBC recurrence rates as high as 75%, with the added risk of transformation to MIBC tumor associated with mortality [10].

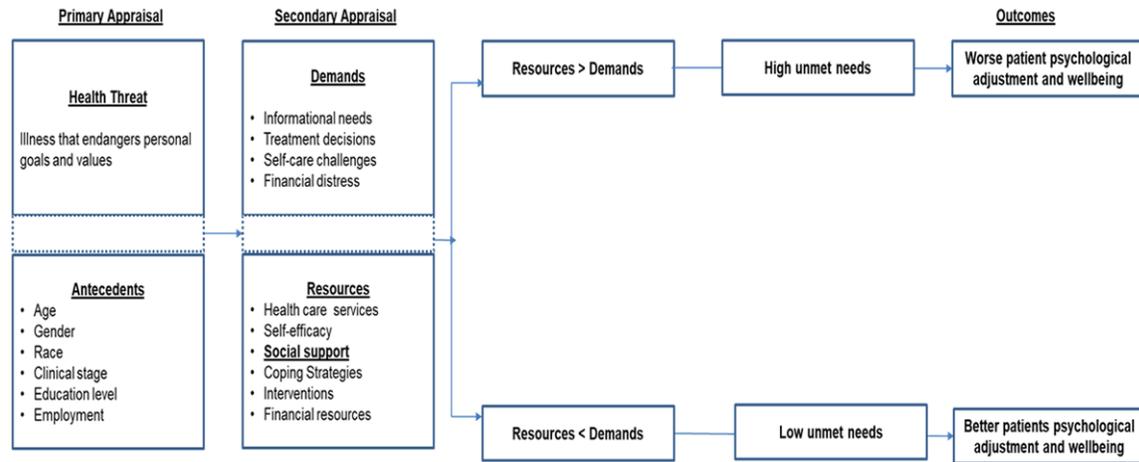
Psychological distress, predominantly experienced as depression and anxiety, is a significant component of poor quality of life in cancer patients as both the disease and treatment are associated with worse clinical outcomes, longer recovery time, post-operative morbidity, and maladaptive coping [11]. Anxiety and depression are risk factors for nonadherence to cancer treatment [12, 13]. Failure to recognize and treat depression and anxiety may lead to several problems: patients' HRQoL may deteriorate; patients may have trouble understanding treatment information or making decisions about treatment; and, patients may make extra visits to the physician's office and emergency room. These negative outcomes place a significant burden on patients and the healthcare system, especially increased stress and burden of care for oncology teams [14-17]. A recent review of the prevalence of depression and anxiety in patients with NMIBC and MIBC showed that depression rates ranged from 4.7 to 78% and anxiety rates range from 12.5 to 71.3% with these ranges varying across the disease and treatment trajectory [18]. Research has also shown that some bladder cancer patients might be at high risk for suicide [19].

Unfortunately, limited support is available for bladder cancer patients for issues related to deteriorated HRQoL and distress. Previous research in other cancer patients confirmed the buffering effects of received social support and the importance of addressing patient informational and supportive care unmet needs in regards to patient emotional adjustment and

wellbeing [20]. The question arises of how patients can be identified early in the diagnosis, treatment, and survivorship phases and how this information may be used to optimize treatment planning and follow-up care. Additionally, a few studies examined the demographic, clinical, and psychosocial factors (e.g., limited access to social network's support) that are associated with significant levels of psychological distress in patients with bladder cancer. In acknowledgement of the high levels of distress in cancer patients the Commission on Cancer requires cancer centers screen patients for psychosocial distress to be accredited [11]. Implementation of distress screening has been slow as institutions have grappled to adapt systems and to identify best practice approaches. Understanding the predictors of bladder cancer patient psychological distress may assist the cancer care team identifying patients most at risk and for whom supportive care interventions (e.g., behavioral activation, cognitive behavioral therapy (CBT), and interpersonal psychotherapy (IPT)) [7, 8] can potentially improve patient quality of life and emotional adjustment.

According to the transactional model of stress and coping, stressful situations experienced by individuals are followed by a subjective process of cognitive appraisals and coping responses. For example, receiving a diagnosis of bladder cancer or managing the treatment-related side-effects can be appraised as threatening, challenging, or harmful (i.e., stressors). The extent to which stressful situations are appraised differs by the individuals' perceived personal and social resources. Perceived social support is one of the most important personal and social resources that may influence patient appraisal and consequently determine the individual ability to cope with cancer and treatment related stress [21]. For examples for a patient diagnosed with bladder cancer, if the disease related demands (i.e., unmet informational and supportive care needs) exceed the patient's resources (i.e., perceived availability of social support), the patient is likely to experience significant unmet needs leading to a worse emotional adjustment to cancer and treatment outcomes (**Figure 1**). Guided by the transactional model of stress and coping, this study aims to examine: 1) patient clinical and demographic characteristics associated

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**Figure 1.** The Transactional Model of Stress and Coping.

with higher levels of psychological distress measured as anxiety and depression; and 2) whether patient perceived unmet needs and social support (i.e., psychosocial characteristics) influence the severity of depression and anxiety.

### Methods

#### Participants

A heterogeneous sample of 159 bladder cancer patients was recruited from the Bladder Cancer Advocacy Network (BCAN) to complete an online survey originally developed to assess unmet needs of patients with bladder cancer (see Leung et al, 2017). Our previous publication describes in details the study population, recruitment method, and standardized measured included in the study [45]. Data collected from the previous study will be used to examine clinical, demographic, and psychosocial predictors on depression and anxiety. Similar to our previous work we restrict the inclusion criteria to include bladder cancer patients who were English speakers, aged 18-85 years, and were able and willing to provide informed consent. Patients who had metastatic disease, cancer recurrence, or other primary cancers at the time of assessment may have other current unmet needs that could potentially bias our study results, therefore, these patients were excluded from the study. Research Electronic Data Capture (REDCap) software is a Health Insurance Portability and Accountability Act (HIPAA) approved browser-

based software. REDCap was used for our online questionnaire [22]. Participants read and signed an online consent form before accessing the questionnaire. Demographic and clinical characteristics of the study participants were collected, as well as the bladder cancer need assessment survey we developed (BCNAS-32), and psychosocial predictors of psychological distress (HADS and SPS).

#### Study measures

*The Hospital Anxiety and Depression Scale (HADS):* The HADS is used to assess medically ill patients for symptoms of anxiety and depression [23, 24]. There are a total of 14 items in the questionnaire, with four response categories, ranging from 0-3. HADS score ranges from 0-42, higher scores on the two subscales (each consisting of 7 items) indicate a higher level of anxiety or depression [25]. The reported internal consistency for this scale is Alpha: 0.78-0.88 [26]. To identify patients with clinically significant levels of depression and anxiety, we followed the HADS manual Scoring. For depression and anxiety; 0-7 = normal; 8-10 = borderline abnormal; and 11-21 = abnormal.

*The Bladder Cancer Needs Assessment Survey (BCNAS-32):* The BCNAS-32 tool measures eight different subscales of bladder cancer patients' unmet needs and has 32 items. These eight subscales include: 1) a psychological need subscale, an eight-item measure of emotional adjustment; 2) a health system need subscale, a five-item subscale of bladder can-

cer specific information and training on self-care strategies; 3) a physical and daily living need subscale, a two-item subscale of the impact of treatment on patients' daily living and lifestyle; 4) a patient care and support need subscale, a four-item subscale of supportive care specific to bladder cancer and treatment side effects; 5) a sexuality need subscale, a six-item subscale of the impact of treatment and side effects on sexual function, body image, and sexual relationships; 6) a logistics need subscale, a two-item subscale of patients' need for support with transportation, access to community-based services, and other logistic issues; 7) a communication with spouse/partner subscale, a three-item subscale measuring communication challenges; and 8) a communication with medical provider subscale, a two-item subscale of difficulties in talking about cancer treatment and concerns with the medical care providers. Each BCNAS-32 scale items utilizes a 1 (no need, not applicable) to 5 (high need) response range with higher scores indicate higher unmet needs. The scale and the subscales have high internal consistency and validity (Alpha range: 0.89-0.97).

*The Social Provisions Scale (SPS):* The SPS is an instrument used to perceived social support. This instrument includes 24 items to assess perceived support provisions including attachment, social integration, reassurance of worth, reliable alliance, guidance, and opportunity for nurturance. The response scale ranges from (strongly disagree: 1) to (strongly agree: 4). A higher score indicates better perceived social support. This scale has moderate-to-high validity and reliability (Alpha: 0.50-0.77) [27]. Social guidance is regarded as informational support, while reliable alliance reflects perceived access tangible/financial/material support. Attachment and social integration signify the presence and degree of "emotional closeness" and integration in an individual's social network's whereas reassurance of worth reflects the individual's perceived value and self-worth based on his/her interactions with the social network. Opportunity for nurturance reflects one's beliefs about his/her ability to provide social support.

### *Data analyses*

Statistical analyses were conducted using R 3.1.3 [28]. The data were first cleaned and

examined for missingness and outliers or extreme values [29]. Data were then summarized as mean  $\pm$  standard deviation (SD) for continuous variables and as frequency (percentage) for categorical variables. Statistical significance for all hypothesis tests was evaluated using a type I error rate of 0.05. Bivariate associations between psychological distress (HADS), unmet needs domains (i.e., including 8 subscales measuring psychological, health system, physical and daily living, patient care and support, sexuality, logistics, communication with partners and provider's needs), and social support domains (i.e., 24 items to assess six subscales of perceived support provisions including attachment, social integration, reassurance of worth, guidance, and opportunity for nurturance) were examined with Pearson or Spearman correlations. Demographic and clinical covariates were examined by using the Mann Whitney U test, the Kruskal-Wallis H test, and Spearman correlations for dichotomous, categorical and continuous variables, respectively. Thereafter, the predictive value of each independent variable was tested with linear regression models for each dependent variable (i.e., anxiety, depression, and HADS total score), separately. Variables with significant associations were incorporated into a stepwise multiple linear regression model to assess associations between dependent and independent variables (i.e., unmet needs and social support domains) and to explore their unique impact controlling for potential covariates (e.g., age, gender, educational levels).

### *Missing data analysis and imputation*

In order to determine the robustness of the data collected, the percentage and the pattern of the missing data of each of the study scales included in the questionnaire were determined. A percentage of 15-20% of missing data in each scale is considered to be reasonable in psychological studies [30]. The number, percentage, and pattern of missing data in each scale were analyzed using the *mice* package in R [28]. Polytomous response logistic regression was used to impute missing values for ordered categorical variables. The mean of the imputed numbers was used for each missing value.

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**Table 1.** Patients' demographics, clinical, and psychosocial characteristics

HADS total score (N = 159)	14.3±12.15
HADS-Anxiety score	
Abnormal (N = 39; 25%)	17.3±4.31
Borderline abnormal (N = 27; 17%)	8.9±0.93
Normal (N = 93; 58%)	3.6±2.10
HADS-Depression score	
Abnormal (N = 27; 17%)	18.6±2.93
Borderline abnormal (N = 21; 13%)	9.0±0.86
Normal (N = 111; 70%)	3.0±2.10
Unmet Need (high-moderate %)	
Psychological needs	29%
Health system info	31%
Physical/daily living	30%
Patient care/support	41%
Sexuality needs	25%
Logistic needs	24%
Communication/caregivers	30%
Communication/providers	44%
Social Support (Total score; M ± SD)	73.25±21.8
Attachment	11.75±4.16
Social integration	12.48±3.33
Reassurance of worth	12.36±3.57
Reliable alliance	12.57±4.08
Guidance	12.43±4.15
Opportunity for nurturance	11.46±3.90
Age (years) (Mean ± SD)	62±9.4
Female (%)	47
Marital status (%)	
Never married	3
Married/living as married	82
Divorced	11
Separated	1
Widowed	2
Number of children (%)	
0	13
1	16
2	42
3	18
4+	9
Education level (%)	
Less than 8 years	0
8-11 years	0
High school graduation (G.E.D.)	6
Vocational/technical school	3
Some college or university	23
Bachelor's degree	29
Graduate degree	37

### *Determination of proportion of moderate/high unmet needs*

The proportion of patients with moderate/high unmet need and no/low unmet need was estimated from the mean value of each subscale after transforming the value to 0-100 score as recommended for the general SCNS-LF59. A mid-point of 50 was used as the cut-off point to separate no/low need and moderate/high need. A score larger than 50 was considered as moderate-high need, otherwise, was considered as no/low need.

### **Results**

#### *Missing data pattern*

There was approximately 6% to 18% missing data in this study for all the original needs assessment survey subscales and between 0% to 19% in the other scales used in this study. No specific pattern of missing values was observed, thus the missingness was assumed to be random.

#### *Sample characteristics*

**Table 1** displays the demographic and clinical characteristics of study participants. Of the 159 study participants, 51% were male and 47% were female. The mean age was 62±9.4 years old. 62% of participating patients received cystectomy. Among these, 28% received ileal conduit, 11% continent reservoir, and 26% neobladder. The majority of the patients were married (82%), with children (85%), and with at least some college education or higher degree (88%). About 43% of patients were retired or unemployed. A significant proportion of these patients reported stage I (T1, 37%) or stage II (T2, 25%) bladder cancer. Fifty-five percent of the patients reported a tumor grade of 3. The average time since cystectomy was 42±37.5 months (range: 3-173 months). On average, the respondents had two comorbidities (**Table 1**). The five most common co-morbidities reported were: hypertension (38%), arthritis (33%), problem with bladder control (27%), hearing loss (17%), and stomach problem (14%) (Data not shown).

Participants were 159 patients diagnosed with muscle invasive bladder cancer (MIBC, 62%) or non-muscle invasive bladder cancer (NMIBC,

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Employment (%)	
Employed	4
Unemployed	43
Retired	43
Other	7
Treatment group (%)	
Ileal conduit	47
Continent reservoir	14
Neobladder	39
Cancer type (%)	
MIBC	62
NMIBC	38
Number of comorbidity (%)	
0	15
1	26
2	28
3	14
4	9
5	4
6	3

38%), 81 (51.9%) were men, 131 (83.4%) were married/with a partner, 141 (90.4%) had college or higher education, 69 (44.2%) were employed, and 149 (98%) were medically insured. The average age was 62.44 (SD = 8.39; range: 34-86 years) Almost two-third (62%) of the patients received cystectomy. Among these, 28% received ileal conduit, 11% continent reservoir, and 26% neobladder. Comorbid diseases reported include arthritis (32.9%), hypertension (37.8%), diabetes (10.1%), and heart disease (9.4%). Participants also reported time since diagnosis ranging between 3 months to 173 months. About 37% reported cancer stage I, 25% reported cancer stage II, and 55% reported cancer stage III.

A significant proportion of bladder cancer patients experience clinically significant levels of anxiety (25%) and depression (17%) requiring immediate psychological interventions. Almost two-third (62%) of patients reported elevated levels of HADS total score (Mean  $\pm$  SD: 14.3 $\pm$ 12.15). HADS total score and HADS anxiety scores were significantly associated with younger age and lower educational levels ( $P < 0.05$ ). Correlation analyses showed significant associations between HADS total score, HADS anxiety and depression scores and all unmet needs and social support subscales and total score (**Table 2**).

Analyses of patient unmet needs showed high-to moderate unmet needs reported by 24% to 44% of survivors across the different domains of unmet needs signifying high unmet needs. Moderate levels of perceived social support were reported across the six measured domains reflecting the availability of social support ties and perceived support resources (**Table 1**).

Univariate regression analyses revealed significant associations between HADS total score, HADS depression and anxiety subscales, patient age, physical functioning/daily living needs, sexuality needs, and perceived social support with higher anxiety, and depression and higher total HADS scores associated with younger age, higher unmet needs, and lower levels of social support (**Table 3**). Multivariate regression analyses showed similar findings confirming the associations depicted by the univariate regression analyses. Younger age, higher physical/daily living needs and sexuality needs, and lower reliable alliance-social support were associated with higher anxiety levels. Physical/daily living needs, and guidance- and reliable alliance-social support were associated with higher depression levels (**Tables 4 and 5**). Younger age, higher physical/daily living needs and sexuality needs, and lower guidance-social support were associated with higher total HADS scores.

### Discussion

Our previous work has shown that patients with bladder cancer experience significant unmet needs across several dimensions of clinical and supportive care including informational, psychological, care and support, communication, and sexuality needs [45]. This manuscript adds to our previous work by: 1) providing evidence for the prevalence of clinically significant levels of depression and anxiety among bladder cancer patients, and 2) the significant associations between depression, anxiety, and patient demographic characteristics, perceived social support, and unmet informational and supportive care needs.

Identifying patient factors associated with depression and anxiety allows health care providers to most effectively allocate scarce resources to improve patient emotional adjustment (i.e., addressing patients' specific unmet

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**Table 2.** Univariate analysis on patient demographics and clinical characteristics

	HADS total score		Anxiety score		Depression score	
	Regression coefficient	p-value	Regression coefficient	p-value	Regression coefficient	p-value
Age	-0.206	0.0451	-0.110	0.0399	-0.096	0.0707
Gender	-1.215	0.5308	-1.200	0.2327	-0.015	0.9878
Marital status		0.2538		0.5737		0.0587
Never married vs. Married	-1.621		-2.534		0.913	
Divorced vs. Married	4.720		1.348		3.372	
Separated vs. Married	4.779		1.466		3.313	
Widowed vs. Married	11.779		4.132		7.646	
Number of children		0.5541		0.3829		0.7802
One child vs. no children	-1.385		-0.596		-0.789	
Two children vs. no children	-0.041		0.221		-0.262	
Three children vs. no children	2.888		1.903		0.985	
Four or more children vs. no children	-3.190		-1.905		-1.286	
Education		0.0488		0.0390		0.0884
Vocation/tech school vs. High school/GED	2.900		3.000		-0.100	
Some college vs. High school/GED	-6.586		-3.108		-3.478	
Bachelor's degree vs. High school/GED	-9.665		-4.543		-5.122	
Graduate degree vs. Some college	-7.600		-3.586		-4.014	
Employment		0.0990		0.0630		0.1989
Unemployed vs. Employed	-5.035		-2.176		-2.859	
Retired vs. Employed	-9.006		-4.582		-4.424	
Other vs. Employed	-5.753		-2.584		-3.169	
Treatment group		0.2816		0.2094		0.4041
Continent reservoir vs. Ileal conduit	6.203		3.607		2.597	
Neobladder vs. Ileal conduit	1.754		0.709		1.046	
MIBC vs. NMIBC	0.011	0.9958	0.447	0.6680	-0.436	0.6711
Number of Comorbidity	-0.9868	0.132	-0.4311	0.208	-0.556	0.099

needs, and provision of social support). Additionally, identifying patients' needs will help improve health care service quality, adherence to treatment recommendation and follow up care, and increase patient involvement and satisfaction with care. Our study findings showed that 25% of bladder cancer patients experienced clinically significant (abnormal) levels of anxiety and 17% had borderline abnormal levels. Regarding depression, 17% had clinically significant (abnormal) levels and 13% had borderline abnormal levels (**Table 6**). These data add to the literature documenting elevated rates of anxiety and depression in bladder cancer patients [19]. Given the negative impact of psychological distress, depression, and anxiety on cancer care and the experience of oncology treatment teams it is imperative that providers screen for anxiety and depression and

connect bladder cancer patients to appropriate mental health care [19].

Anxiety and depression in any clinical setting may stem from uncertainty and patient perception or beliefs surrounding their disease course. Perceptions of the severity of disease may arise from physical symptoms and a psychological paradigm unique to each patient. Previous studies have considered the importance of a patient's perception [31], whether through a formal assessment such as the Brief Illness Perception Questionnaire (B-IPQ) or informal qualitative interviews. Such assessments ought to consider how health literacy plays a role in a patient's perceptions or understanding of disease and, ultimately, how this translates into anxiety and depression and poor quality of life. One possible approach is to

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**Table 3.** Correlation among HADS, anxiety, depression, social support, and unmet need variables

	HADS score	Anxiety score	Depression score	Social support total	Attachment	Social integration	Reassurance of worth	Reliable alliance	Guidance	Opportunity for nurturance	Unmet needs total	Psychological	Health system	Physical & daily living	Patient care	Sexuality	Logistics	Communication (partner)	Communication (provider)	
HADS score	1																			
Anxiety score	0.94***	1																		
Depression score	0.92***	0.75***	1																	
Social support total	-0.61***	-0.54***	-0.63***	1																
Attachment	-0.58***	-0.51***	-0.61***	0.92***	1															
Social integration	-0.60***	-0.55***	-0.59***	0.92***	0.81***	1														
Reassurance of worth	-0.56***	-0.50***	-0.56***	0.86***	0.78***	0.79***	1													
Reliable alliance	-0.63***	-0.58***	-0.62***	0.88***	0.78***	0.82***	0.72***	1												
Guidance	-0.65***	-0.57***	-0.67***	0.92***	0.85***	0.86***	0.76***	0.85***	1											
Opportunity for nurturance	-0.38***	-0.32***	-0.45***	0.76***	0.62***	0.68***	0.56***	0.60***	0.67***	1										
Unmet needs total	0.70***	0.64***	0.69***	-0.51***	-0.49***	-0.50***	-0.52***	-0.56***	-0.51***	-0.35***	1									
Psychological	0.51***	0.49***	0.48***	-0.38***	-0.37***	-0.37***	-0.44***	-0.40***	-0.36***	-0.29***	0.80***	1								
Health system	0.41***	0.37***	0.43***	-0.34***	-0.31***	-0.36***	-0.40***	-0.43***	-0.34***	-0.25**	0.78***	0.72***	1							
Physical & daily living	0.63***	0.54***	0.68***	-0.40***	-0.37***	-0.39***	-0.47***	-0.40***	-0.39***	-0.33**	0.77***	0.59***	0.64***	1						
Patient care	0.53***	0.46***	0.52***	-0.31***	-0.31***	-0.30***	-0.27***	-0.37***	-0.34***	-0.13	0.76***	0.49***	0.49***	0.49***	1					
Sexuality	0.54***	0.55***	0.50***	-0.39***	-0.36***	-0.36***	-0.44***	-0.44***	-0.36***	-0.36***	0.76***	0.67***	0.67***	0.60***	0.38***	1				
Logistics	0.56***	0.54***	0.54***	-0.43***	-0.41***	-0.41***	-0.44***	-0.47***	-0.43***	-0.36***	0.84***	0.63***	0.63***	0.65***	0.63***	0.68***	1			
Communication (partner)	0.54***	0.52***	0.54***	-0.37***	-0.39***	-0.35***	-0.37***	-0.41***	-0.38***	-0.26***	0.75***	0.58***	0.49***	0.54***	0.50***	0.60***	0.64***	1		
Communication (provider)	0.56***	0.51***	0.51***	-0.47***	-0.43***	-0.44***	-0.36***	-0.49***	-0.52***	-0.26***	0.70***	0.41***	0.41***	0.37***	0.70***	0.34***	0.52***	0.44***	1	

Note: \*\*P<0.01; \*\*\*P<0.001.

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**Table 4.** Logistic regression model with all unmet needs and social support subscales

	HADS total score		Anxiety score		Depression score	
	Regression coefficient	p-value	Regression coefficient	p-value	Regression coefficient	p-value
Age	-0.1536	0.005	-0.0777	0.022	NA	
Education level					NA	
Vocation/tech school vs. High school/GED	-0.1536	0.522	2.0360	0.306		
Some college vs. High school/GED	2.0321	0.563	-0.5601	0.678		
Bachelor's degree vs. High school/GED	-1.2476	0.460	0.8248	0.539		
Graduate degree vs. Some college	1.5831	0.876	-0.0341	0.979		
Unmet needs:						
Psychological need	0.0067	0.785	0.010	0.497	0.0015	0.902
Health system & information need	-0.0309	0.175	-0.0227	0.113	-0.0155	0.160
Physical & daily living need	0.1017	<0.001	0.0350	0.005	0.0704	<0.001
Patient care and support need	0.0403	0.118	0.0127	0.430	0.0212	0.084
Sexuality need	0.0903	<0.001	0.0623	<0.001	0.0232	0.037
Logistic/Practical need	-0.0328	0.222	-0.0064	0.705	-0.0220	0.097
Communication (Partner) need	0.0148	0.469	0.0014	0.913	0.0143	0.145
Communication (Provider) need	-0.0083	0.729	0.0058	0.698	-0.0116	0.315
Social support						
Attachment	0.2273	0.497	0.3225	0.125	-0.1333	0.416
Social integration	-0.6918	0.117	-0.5543	0.046	-0.1426	0.504
Reassurance of worth	0.1712	0.616	0.0944	0.659	0.1207	0.453
Reliable alliance	-0.6681	0.075	-0.4582	0.051	-0.2705	0.136
Guidance	-0.7068	0.114	-0.3571	0.201	-0.3884	0.074
Opportunity for nurturance	0.0190	0.938	0.2392	0.119	-0.0910	0.430

**Table 5.** Unmet needs and social support subscales selected from stepwise logistic regression method

	HADS total score		Anxiety score		Depression score	
	Regression coefficient	p-value	Regression coefficient	p-value	Regression coefficient	p-value
Age	-0.1704	<0.001	-0.1021	0.001	-	-
Unmet needs:						
Psychological need	-	-	-	-	-	-
Health system & information need	-	-	-	-	-	-
Physical & daily living need	0.1003	<0.001	0.0342	0.002	0.0738	<0.001
Patient care and support need	-	-	-	-	-	-
Sexuality need	0.0852	<0.001	0.0525	<0.001	-	-
Logistic/Practical need	-	-	-	-	-	-
Communication (Partner) need	-	-	-	-	-	-
Communication (Provider) need	-	-	-	-	-	-
Social support						
Attachment	-	-	-	-	-	-
Social integration	-	-	-	-	-	-
Reassurance of worth	-	-	-	-	-	-
Reliable alliance	-	-	-0.6634	<0.001	-0.3066	0.047
Guidance	-1.3400	<0.001	-	-	-0.5772	<0.001
Opportunity for nurturance	-	-	-	-	-	-

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**Table 6.** Summary of risk factors associated with HADS (total score), and HADS anxiety, and depression scores

HADS score	Anxiety score	Depression score
Social support: Guidance	Social support: Reliable alliance	Social support: Reliable alliance Guidance
Unmet needs: Physical & daily living need Sexuality need	Unmet needs: Physical & daily living need Sexuality need	Unmet needs: Physical & daily living need

have patients write out or draw what they perceive as distress-provoking aspects of their bladder cancer course. The field of Psycho-Oncology has emerged to understand better the interplay between acute and life-changing diseases such as cancer baseline psychological vulnerabilities. Systemic reviews have demonstrated a strong association between health literacy and better quality of life measures [32]. Better health literacy may not only lead to lower anxiety and depression, but by improving health literacy, patients may become more empowered to participate in their care, leading to adherence and better clinical outcomes.

The results of our study suggest that a significant percentage of participants experienced unmet needs during time of the online survey including psychological, health system, physical and daily living, patient care and support, sexuality, logistics, communication with partners and provider's needs. These findings highlight the need of routinely screening patients for their unmet needs throughout their prognosis. Routine screenings would ensure that the patients' needs are addressed promptly and adequately by the available healthcare resources. Previous findings in other cancer populations have shown that psychosocial and health care planning interventions tailored to the patients' unmet needs can improve their quality of life, adherence to cancer treatment, and treatment outcomes [33, 34]. For bladder cancer patients, such interventions could be incorporated into standard care to reduce unmet needs throughout the bladder cancer care-continuum. These interventions may include provision of information about treatment and potential outcomes, telephone calls or home visits by social workers and ostomy nurses to improve self-care skills and symptom management, and, when warranted, provide crisis intervention.

Our study also showed that close to half the sample reporting needs regarding health care, support and communication with providers. Studies have shown that cancer patients who report high unmet needs also report poor HRQoL [35, 36]. High unmet needs were associated with higher depression, anxiety, and the total HADS scores, and with low levels of perceived social support measured as attachment, social integration, reassurance of worth, reliable alliance, guidance, and opportunity for nurturance in line with prior findings in need assessments of other cancer populations [36, 37].

Results from regression analyses indicated that younger age, higher physical/daily living needs and sexuality needs, and lower reliable alliance-social support were associated with higher anxiety levels; whereas physical/daily living needs, guidance-social support and reliable alliance-social support were associated with higher depression levels. These findings underscore the importance of assessing and addressing patient needs and support resources, as specific needs and support resources are uniquely related to the severity of anxiety and depression symptoms. The impact of bladder cancer diagnosis on younger patients' emotional adjustment might be more severe compared to its impact older patients given the changes in sexual and urinary function, reproductive system, and body image. Additionally, younger patients are more likely to be caregivers of small children and older adults, continue working after cancer treatment and thereby experience job related stressors and financial stress xxx.

Comprehensive mind-body treatment programs such as the Stress Management and Resilience Training-Relaxation Response Resiliency Program (SMART/3RP) may be useful for

addressing psychosocial needs of bladder cancer patients and improving resilience and anxiety and depression symptoms [38-41]. Other centers have described bladder cancer specific interdisciplinary collaboration with oncology nurses, wound and ostomy nurses, social workers to improve patient's unmet needs [42, 43]. In a multidisciplinary setting, oncology focused social workers or nurses can utilize our study results to increase awareness of and focus resources towards patient's unmet needs during bladder cancer follow up. Previous studies have also shown the feasibility and low added cost of creating a collaborative care model which includes social workers as care managers [43]. We hope this information is clinically incorporated in the context of any bladder cancer care program as other studies have noted increases in patient satisfaction as their unmet needs are addressed [44].

This study had several limitations. The majority of the study participants were MIBC patients who received cystectomy and urinary diversion. The test-retest validity of the emerging components of BCNAS-32 could not be evaluated because of the cross-sectional design of the study. Additionally, the participants included in the study were members of BCAN who had access to various resources, such as online support groups, patient educational booklets, and online seminars. Future work is needed to evaluate the observed associations over time and in a larger representative sample of bladder cancer patients.

### Conclusions

This study confirms the internal consistency and validity of BCNAS-32. Further research studies are needed to explore how the use of such a tool can be implemented efficiently in clinical practice to contribute to quality patient-centered care.

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### Disclosure of conflict of interest

None.

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