



## Original article

## Unmet informational and supportive care needs of patients following cystectomy for bladder cancer based on age, sex, and treatment choices

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## Abstract

**Purpose:** Assessing the unmet needs of cancer patients can help providers tailor health care services to patients' specific needs. This study examines whether the unmet informational and supportive care needs of the patients with muscle-invasive bladder cancer vary by the patients' age, sex, or individual treatment choices.

**Methods and materials:** Participants ( $N = 30$  survivors; 73.3% men) were recruited from the Mount Sinai Medical Center and through advertisements posted on a national Bladder Cancer Advocacy Network website between December 2011 and September 2012. Data were collected through individual interviews and electronic medical record review. A prior qualitative study of this cohort, using immersion/crystallization approach, confirmed the prevalence of unmet needs across the disease trajectory. This is a secondary quantitative analysis of the initial interview data we collected (i.e., quantitative analyses of transformed qualitative data using Chi-square and Fisher exact tests) to examine differences in unmet needs based on the patient's age, sex, and treatment choices.

**Results:** Younger patients ( $<60$  y) were less satisfied with the treatment information received presurgery and more likely to report posttreatment complications, choose a neobladder, and seek and receive professional support regarding sexual function, than were older patients ( $P < 0.05$ ). More women than men reported difficulties with self-care and relied on themselves in disease self-management as opposed to relying on spousal support ( $P < 0.05$ ). Patients with neobladder were more likely to report difficulties with urinary incontinence and deterioration in sexual function, whereas patients with ileal conduit were more likely to require spousal help with self-care. Patients who received chemotherapy were significantly more likely to report changes in everyday life ( $P < 0.05$ ). Lastly, regardless of age, sex, or treatment choice, up to 50% of patients reported feeling depressed before or after treatment.

**Conclusions:** Unmet informational and supportive needs of patients with muscle-invasive bladder cancer during survivorship, and vary by age, sex, and treatment choices. Educational and psychological assessments as well as clinical interventions should be tailored to a patient's specific unmet needs, and to specific clinical and demographic characteristics. © 2016 Elsevier Inc. All rights reserved.

**Keywords:** Urothelial carcinoma of the urinary bladder; Muscle-invasive bladder cancer; Cystectomy; Urinary diversion; Unmet need

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## 1. Introduction

A current standard of care for muscle-invasive bladder cancer (MIBC) and high-risk non-muscle-invasive bladder

cancer (NMIBC) is radical cystectomy (RC) with lymphadenectomy, followed by a form of incontinent diversion (IC) or continent urinary diversion (UD) (Indiana pouch or orthotopic neobladder) [1–5]. Each type of UD is associated with individual challenges and complications in addition to unique psychological burdens [1–5]. Additionally, neoadjuvant chemotherapy is recommended to enhance survival outcomes in patients with MIBC [6]. Adjuvant chemotherapy appears to be increasing in use, though the current data to support such use is not high level as that for neoadjuvant chemotherapy [7]. Chemotherapy, however, is associated with toxicity that could increase patients' physiological and psychological burdens, and reduce quality of life (QoL) [6,7]. Given the significant effect of urothelial cancer of the bladder (UCB) and its treatment, assessing patients' unmet needs is important in helping health care professionals tailor limited resources and professional practices to address those needs more effectively. Furthermore, identifying differences in unmet needs by patients' sociodemographic and clinical characteristics allow for better targeting and tailoring of resources and health care services.

Previous studies on other cancer populations showed that younger age, female sex, type of treatment received, late-stage disease, and rural habitation were associated with greater unmet informational and supportive care needs among survivors [8]. It is likely that differences in UCB severity and treatment burden are associated with differences in informational and supportive care needs experienced by patients and survivors. In a previous study [9] we identified patients with MIBC unmet informational and supportive care needs across 5 domains: health system and information needs, patient care and support, physical/daily living, psychological well-being, and sexuality. These unmet needs varied across the disease trajectory. Employing a secondary quantitative analysis of the data, this study examines whether unmet needs reported at the time of diagnosis, following surgery and during survivorship (6–72 months postoperatively) vary by the patient's age, sex, UD type and the receipt of neoadjuvant/adjuvant chemotherapy. We hypothesize, based on the literature in other cancer populations, that older age, female sex, and receipt of chemotherapy would be associated with significant unmet informational and supportive care needs along the disease trajectory.

## 2. Study design

Of the 35 eligible patients (i.e., treatment of UCB with RC and UD and no metastasis or recurrence) recruited from the MSMC, 19 (54.28%) agreed to participate in the study. Additionally, 11 eligible patients were respondents to a Bladder Cancer Advocacy Network online advertisement inviting UCB patients to join the study. All participants consented and each received a \$50 gift card. The study was approved by the institutional review board of Icahn School

of Medicine at Mount Sinai (ISMMS). Data were collected through 60 minute, semistructured, in-person ( $N = 9$ ) or telephonic ( $N = 21$ ) interviews (median time: 60 minutes; range: 30–90 min), as previously described using a semistructured interview guide [9] (Appendix 1). The interview guide explored patients' unmet needs at time of diagnosis, following surgery and during survivorship [9].

Our qualitative analysis used an immersion/crystallization approach [10]. This approach consisted of an iterative process (i.e., immersion) that included cycles of reading, summarizing, and rereading the data [10–12]. Crystallization is the process of identifying and articulating patterns or themes noticed during the immersion process [10–12]. These dual processes continue until all the data have been examined and patterns or themes emerge from the data that are meaningful and can be well articulated and substantiated. The interview data were coded using Atlas.ti software [13]. Content analysis of participants' responses included checking for representativeness of the data and data triangulation [10–12]. A coding guide we developed identified narrative themes related to the conceptual categories of unmet needs. The quantification of the qualitative data and the proposed comparative analysis was informed by general recommendations on “cross-over” mixed methods research [14]. Quantification of qualitative data was performed by exporting text categories and their frequencies as dichotomies (need reported = 1 and need not reported = 0) to SAS (Release 9.1; SAS Institute) [15]. Similarly, sociodemographic characteristics were dichotomized into binary variables (e.g., sex: ♀ = 0, ♂ = 1; age: <60 y = 0, and ≥60 y = 1). Treatment was coded into (1) 3 categorical “surgery” variables (IC-1, Indiana pouch-2, and orthotopic neobladder-3) and (2) 2 categorical “chemotherapy” variables (receipt of neoadjuvant/adjuvant chemotherapy-1 and no chemotherapy-0). The continent cutaneous reservoir (CCR) group was excluded from the choice UD comparative analyses because of small cell size ( $N = 2$ ).

Proportion comparison analyses were conducted using Chi-square test. Given the small sample size ( $N = 30$ ), the Fisher exact test—a more conservative proportion—comparison test, was used to verify and confirm the Chi-square test results [16]. Significant differences were confirmed using a 2-tailed Fisher probability ( $P_{\text{Fisher}} < 0.05$ ) [16].

## 3. Results

Data were collected for 30 survivors (93% non-Hispanic White; 73.3% men). Mean age was 67 years (standard deviation [SD] = 8.99; range: 52–82 years). Bladder Cancer Advocacy Network's participants were significantly more likely to be younger and female (mean age = 60.8; SD = 8.532; 75% ♀) compared with patients recruited from MSMC (mean age = 70.6; SD = 7.267; 25% ♀;  $P < 0.05$ ). Table 1 represents clinical and sociodemographic characteristics. Tables 2 and 3 represent age and sex related

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