

The Natural History of Symptoms and Distress in Patients and Families Following Cystectomy for Treatment of Muscle Invasive Bladder Cancer

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Purpose: We characterized the natural history of symptoms with time in patients with bladder cancer undergoing cystectomy.

Materials and Methods: For 6 months we followed 33 participants treated with muscle invasive bladder cancer treatment with cystectomy in this prospective cohort study. Patients and family caregivers completed validated symptom assessment and satisfaction surveys at baseline, and 2, 4 and 6 months later. Primary outcomes were the change from baseline in pain, fatigue, depression, anxiety, quality of life and spiritual well-being. Secondary outcomes included posttraumatic growth, patient satisfaction and family caregiver burden.

Results: Pain increased after radical cystectomy and remained increased 6 months postoperatively based on Brief Pain Inventory scores (baseline and 6-month scores 4.0, 95% CI 0–8.0 and 9.8, 95% CI 1.9–17.6, respectively, $p = 0.03$). Posttraumatic growth showed a trend toward an increase at 2 months ($p = 0.06$). Fatigue peaked at 4 months but did not change significantly with time ($p = 0.12$). There was similarly no significant change with time in depression, anxiety, quality of life, spiritual well-being or satisfaction. Neither family caregiver burden nor satisfaction showed a statistically significant change with time postoperatively.

Conclusions: Pain increased after radical cystectomy and remained increased 6 months postoperatively. There was a trend toward increased posttraumatic growth at 2 months. Otherwise, by 6 months cystectomy was associated with no improvement in preoperative symptoms of fatigue, quality of life, spiritual well-being, depression or anxiety. After cystectomy pain should be assessed and treated more aggressively in patients with bladder cancer and efforts should be made to improve postoperative symptoms.

Key Words: urinary bladder neoplasms, cystectomy, pain, quality of life, questionnaires

PRESERVING quality of life and managing symptoms of cancer and its treatment have become critical aspects of modern oncology. Compared with other common cancers there is limited research on symptoms associated with bladder cancer.^{1,2} As a result, the natural history of

symptoms associated with bladder cancer and its treatment is not well characterized.

Bladder cancer is the fifth most common cancer in the United States. A total of 70,530 new cases were diagnosed in 2010.³ Individuals with bladder cancer experience disease

Abbreviations and Acronyms

BPI = Brief Pain Inventory
FACT-G = Functional Assessment of Cancer Therapy
HADS = Hospital Anxiety and Depression Scale
PTGI = Posttraumatic Growth Inventory

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and treatment related symptoms, including physical, emotional and spiritual distress.⁴ Bleeding, pain, dysuria and urinary obstruction are common physical symptoms.⁵ Limited research has been done to examine these issues and existing studies rarely used prospective designs or validated research tools.^{6,7} Studies to date have shown depression, anxiety and general distress in up to 42%, 55% and 48% of patients with bladder cancer, respectively.^{8,9} Little is known about existential and spiritual distress. Notably, bladder cancer carries a significant economic cost.¹⁰

More than 90% of patients with bladder cancer undergo surgical treatment. A first line definitive treatment for muscle invasive bladder cancer is radical cystectomy with continent diversion or ileal conduit construction. After radical cystectomy patients experience an immediate decrease in daily function.¹¹ Problems with urinary and sexual function, and defecation are the predominant symptoms that affect quality of life.^{1,12-14} Neoadjuvant chemotherapy before definitive surgery can cause fatigue, neuropathy, nausea and anorexia. The impact of postoperative symptoms on daily activity causes significant distress and substantially affects subjective well-being.

Serious illness also creates significant stress, morbidity and even an increased mortality risk in family caregivers.¹⁵ However, research into the experience of family caregivers of bladder cancer patients is limited.

This study was performed to further characterize the natural history of bladder cancer symptoms with time in patients treated with cystectomy, including assessment of pain, fatigue, depression, anxiety, quality of life and spiritual well-being. Secondary outcomes include posttraumatic growth, health care utilization and patient satisfaction. We also investigated the experience and assessed the potential burden of the primary caregivers of patients with bladder cancer after cystectomy.

MATERIALS AND METHODS

In an 11-month period from 2011 to 2012 data were collected from patients undergoing bladder cancer treatment at an academic comprehensive cancer center. All patients with histologically confirmed urothelial carcinoma who were scheduled to undergo radical cystectomy were approached to participate in the study. Those unable to complete study surveys in English, those with psychosis and those with cognitive impairment were excluded from analysis. All study patients were asked to complete validated surveys at baseline before surgery, and 2, 4 and 6 months postoperatively. If participants identified a primary family caregiver at the initial visit, the designated caregiver was also asked to complete surveys at the same intervals.

The primary study outcome measures were the change from baseline in pain, fatigue, depression, anxiety, health related quality of life and spiritual well-being 2, 4 and 6 months after enrollment. Participants completed surveys at each of the 4 time points, including the BPI,¹⁶ Cancer Fatigue Scale (CFS),¹⁷ HADS,¹⁸ Functional Assessment of Chronic Illness Therapy-Spirituality (FACIT-SP-12)¹⁹ and FACT-G.²⁰ These surveys were selected due to brevity and validity in cancer populations. The figure shows the BPI.

Secondary patient outcomes included posttraumatic growth, health care utilization, patient satisfaction and family caregiver burden 2, 4 and 6 months after enrollment. These outcomes were assessed with the PTGI²¹ and Patient Satisfaction Questionnaire III,²² which were validated in populations with cancer.²³ Six-month postoperative health care utilization was assessed at each of the 4 time points by chart and electronic medical record review. The data reviewed included the number of cancer practice and emergency department visits, hospitalizations and hospital days.

In addition to the standard surveys, cystectomy participants were also asked to complete an exit interview performed by a research assistant at the end of the study period. The interviews used open-ended questions about overall quality of care, strengths and weaknesses of care, and the most bothersome symptoms.

Family caregivers completed the Zarit Burden Inventory at the 4 time points.²⁴ This widely used scale, developed to assess the family caregiver burden, has been used extensively for family caregivers of patients with cancer. Caregivers also completed the FAMCARE survey, which was validated as a measure of family satisfaction with advanced cancer care.²⁵⁻²⁷

We also retrospectively reviewed the charts of patients who underwent cystectomy for bladder cancer in 2004. These data were collected to serve as a historical comparison against which the prospective patient data could be assessed. Data were collected on patient sociodemographics, treatment modalities, associated symptoms and health care utilization using information recorded in the chart at the time.

Statistical analysis was performed using generalized estimating equations with a robust SE. All analysis was done using Intercooled Stata®, version 11.0 with statistical significance considered at $p \leq 0.05$. Approval was obtained from the university institutional review board before data collection.

RESULTS

Retrospective Review

We included 23 patients in the retrospective chart review. The supplementary table (<http://jurology.com/>) lists data on sociodemographic characteristics, treatment and health care use. Minimal information was recorded on symptoms related to bladder cancer or treatment. Of the 23 charts reviewed symptoms were assessed and recorded in only 4 patients (17.4%). Reported symptoms in these

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