Muscle Invasive Bladder Cancer: Examining Survivor Burden and Unmet Needs

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Purpose: Although improvements in perioperative care have decreased surgical morbidity after radical cystectomy for muscle invasive bladder cancer, treatment side effects still have a negative impact on patient quality of life. We examined unmet patient needs along the illness trajectory.

Materials and Methods: A total of 30 patients (26.7% women) treated with cystectomy and urinary diversion for muscle invasive bladder cancer participated in the study. Patients were recruited from the Department of Urology at Mount Sinai and through advertisements on the Bladder Cancer Advocacy Network (BCAN) website between December 2011 and September 2012. Data were collected at individual interviews, which were audiotaped and transcribed. Transcribed data were quantitatively analyzed to explore key unmet needs.

Results: At diagnosis unmet informational needs were predominant, consisting of insufficient discussion of certain topics, including urinary diversion options and their side effects, self-care, the recovery process and medical insurance. Unmet psychological needs related to depression, and worries about changes in body image and sexual function were reported. Postoperative unmet needs revolved around medical needs (eg pain and bowel dysfunction) and instrumental needs (eg need of support for stomal appliances, catheters and incontinence). During survivorship (ie 6 to 72 months postoperatively) unmet needs centered around psychological support (ie depression, poor body image and sexual dysfunction) and instrumental support (eg difficulty adjusting to changes in daily living).

Conclusions: Meeting patient needs is imperative to ensure adequate patient involvement in health care and enhance postoperative quality of life. An effective support provision plan should follow changes in patient needs.

Key Words: urinary bladder neoplasms, neoplasm invasiveness, survivors, health services needs and demands, quality of life

It is estimated that there are more than 500,000 BC survivors in the United States.1 For patients diagnosed with MIBC, who represent approximately 30% of those newly diagnosed with BC, and those with high risk progressive noninvasive disease radical cystectomy with urinary diversion is the gold standard treatment, providing excellent local
cancer control. After cystectomy urine can be diverted into 1) an incontinent stoma (ileal conduit procedure), 2) a continent urinary reservoir catheterized by the patient or 3) a continent urinary reservoir connected to the urethra (orthotopic neobladder). The physical and related psychological impact (eg urinary incontinence, sexual dysfunction and poor body image) of these urinary diversion procedures on patient QOL has been documented. However, measures used to assess QOL in patients with MIBC have failed to distinguish between health related problems and the patient desire or need to receive professional attention or care for these problems.

To optimize the quality of provided health care the unmet needs of patients with MIBC should be identified and addressed. However, there has been sparse research into the needs of patients with MIBC. We used the chronic ITM of Corbin and Strauss as a conceptual framework to understand the needs of patients with MIBC during the time of diagnosis, postoperatively and at entry into the survivorship phase. The ITM addresses potential changes in patient needs and challenges due to variations in the medical course of illness.

Extensive research has emerged that identifies patient needs in several cancer related areas (eg prostate, breast and colorectal cancer). These informational needs vary along the illness trajectory with information on cancer stage, treatment options and side effects emerging as most important during diagnosis and treatment, and recovery and surveillance as most important during the posttreatment survivorship phase. We explored the unmet informational and supportive care needs of patients with MIBC along the illness trajectory. An unmet need for information was defined as the patient wish to receive information about cancer, treatment and treatment outcomes. In contrast, an unmet need for supportive care was defined as a wish to receive medical, psychological and emotional support with cancer, treatment and treatment outcomes. The study design was guided by the variation of needs along the illness trajectory indicated by the ITM framework, and the distinction between informational and supportive care needs.

**MATERIALS AND METHODS**

**Participant Selection and Recruitment**

Two strategies were used for patient recruitment. 1) Patients with MIBC were recruited from the Department of Urology at ISMMS between December 2011 and September 2012. We restricted study eligibility to patients who were treated with cystectomy and urinary diversion, able to communicate fluently in English and between ages 18 and 85 years. Participants were not eligible if they had a second primary cancer, metastatic disease or cancer recurrence. Of the 69 patients treated during this period 35 were eligible, including 19 (54.28%) who agreed to participate in the study. Reasons for nonparticipation included lack of interest or time and a poor health condition. 2) Patients were recruited through the BCAN website. The same eligibility criteria were considered using self-reported medical information. A total of 11 respondents to a BCAN advertisement were eligible and participated in the study. All participants received a $50 gift card. The study was approved by the ISMMS institutional review board.

**Procedures**

Data were collected at an interview in person for 9 patients and via telephone for 21. Interviews lasted 1 to 2 hours (median 1) and used a semistructured interview guide. The interviewer (NEM) used plain language and explained medical terminology (supplementary Appendix, http://jurology.com/). All interviews were audiotaped and transcribed. Additional written notes were made by a research team member (PCH). Medical chart data of patients recruited from ISMMS were also collected to confirm participant self-reported medical information on diagnosis, treatment and cancer recurrence or metastasis. The interview guide was developed by one of us (NEM) and reviewed by 2 research team members (MAD and CZ).

The interviews focused on exploring patient informational and supportive care needs at 3 times during the illness trajectory, including 1) time of diagnosis (treatment decision making, communication with the physician and emotional impact of diagnosis), 2) postoperatively (MIBC treatment side effects and postoperative self-care) and 3) time of survivorship (changes in body image, daily living difficulties, emotional adjustment and followup health care). The protocol allowed participants to narrate their experiences in chronological order. For example, to examine needs that arose at diagnosis participants were asked to think back to that time and asked about what information they wish they had had before making a treatment decision, how they made the treatment decision (eg personal choice of treatment vs physician recommendation) and emotions surrounding that decision.

**Data Analysis**

For qualitative analysis we used an immersion/crystallization approach consisting of an iterative process that included cycles of reading, summarizing and rereading the data. Interview data were coded separately by 2 research team members (NEM and PCH) using Atlas.ti (http://www.atlasti.com/index.html). Differences in codes assigned to specific data chunks were resolved through discussions with 2 research team members (MAD and TAR) until conflicting codes were resolved. Data collection was completed when data saturation was achieved (ie no new or relevant data emerged). Content analysis of participant responses included checking for data representativeness (eg checking interpretations against raw data) and data triangulation (ie using multiple methods to interpret data, such as comparing the coding of interviews vs written notes). The coding guide was used to...
identify narrative themes related to the conceptual categories of informational and supportive care needs.

RESULTS

Sample

Data were collected on 30 non-Hispanic white adults with a mean age of 67 years, of whom 22 (73%) were male. The study sample was treated with an ileal conduit (50%), a neobladder (43.33%) and a continent reservoir (6.67%). The table lists study participant demographic and clinical characteristics. Supplementary tables 1 to 3 (http://jurology.com/) show the predominant themes that emerged from the interviews at each time point of the illness trajectory.

Unmet Needs

At diagnosis. At this time unmet needs revolved around the patient understanding of treatment options and potential side effects (supplementary table 1, http://jurology.com/). Of the patients 56.67% found that the information received from physicians was insufficient. They wished that they had been given more information on postoperative self-care, finances and medical insurance, and the healing process. Of these patients 26.67% had searched the Internet, joined support groups or read patient blogs on line for more information on treatment options and side effects. Other unmet needs that were mentioned more than a few times included worry about survival, pain, body image change and decreased sexual function after surgery. Only 20% of patients reported that their physicians mentioned possible changes in sexual function during the discussion about treatment options. Of the patients 33.33% reported feeling severely depressed at diagnosis but did not receive referral for care.

Postoperatively. Of the study sample 50% reported difficulty with postoperative recovery and 46.67% reported difficulty related to medical complications (supplementary table 2, http://jurology.com/). Complications included urinary tract infections, incisional hernia, deep vein thrombosis and kidney related problems. The most frequently reported postoperative difficulties involved changes in urinary function (43.33% of cases). Specifically, incontinence was a major concern in patients treated with a neobladder, and lack of urine control and leakage were frequently reported by patients treated with an ileal conduit. Informational needs during this period included a lack of information on recovery and posttreatment self-care. Many patients reported a lack of adequate training on the use of stomal appliances and catheters (ie stoma pouch changing, tailoring, cleaning and emptying, and choice of appliances).

Although 53.33% of the sample received support with postoperative self-care from a visiting nurse, 30% of them were not satisfied with the support received. The main complaint was that the visiting nurse was not well trained in stomal or continent reservoir care. Many patients reported that spouses and family members who sought information from the Internet or online patient blogs (eg BCAN) helped with stomal care (36.67%), catheter use (6.6%) or issues related to neobladder care (13.33%). Requests for information about medical insurance also emerged at this time as an important informational need, particularly since it influenced the patient selection and use of stomal appliances and catheters (supplementary table 2, http://jurology.com/).

At survivorship. Several unmet needs emerged about 6 months postoperatively when patients and families were transitioning into the survivorship phase (supplementary table 3, http://jurology.com/). Many patients reported that they were unable to resume some usual physical or social activities because of treatment sequelae. Changes in sexual function were reported by 43.33% of patients,
including men (36.36%) and women (62.50%). Changes in sexual function reported by men included erectile dysfunction and low libido. Women reported difficulty related to vaginal dryness, pain during sexual intercourse and lost desire for sex due to changes in body image and presence of a stoma. About 36% of these patients (25% women and 40.91% men) were bothered by these changes and only 16.67% (12.50% women and 18.18% men) received professional advice on sexual dysfunction. However, when asked whether they would have made a different treatment decision if they had known what they knew now, many patients indicated that they would not have changed the decision.

Of the sample 20% (25% women and 36.36% men) reported difficulty with adjusting to a changed body image. Similar to the time of diagnosis, 33.33% of patients reported feeling depressed, of whom 50% remained depressed throughout the time of diagnosis and the survivorship phase. Of the patients 6.66% sought professional assistance for depressive symptoms. Of the sample 23.33% reported worry about the future and cancer recurrence. Some patients in this group were concerned about the inability to continue using stomal appliances and catheters due to potential age related decreases in manual dexterity and vision.

**DISCUSSION**

The examination of cancer patient needs for treatment information, support and health care is a crucial step in providing high quality health care. Qualitative evaluation of reports of patients with MIBC showed several areas of unmet needs that changed across the illness trajectory.

**Time of Diagnosis**

Unmet needs during the time of MIBC diagnosis revolved around understanding differences among the 3 urinary diversion procedures and their side effects as well as information on the healing process. Although some of these informational concerns were addressed during physician consultations, others, such as the impact of the particular treatment on sexual function, were rarely discussed. Moreover, a fairly large percent of patients reported dissatisfaction with the information received. This is a major area for concern since the initial physician visits not only lay the foundation for trust and open communication but also provide information on critical treatment decisions and planning how the family will cope postoperatively after surgery. This is clearly an area for improvement. Possible modalities include information pamphlets, CDs or websites provided to patients preoperatively or postoperatively but they would not substitute for clear communication between patients and medical professionals about these issues.

Patients also expressed emotional distress and worry that required reassurance (eg about change in body image and sexual function) or in some patients clinical levels of depressive symptoms that might require intervention. At diagnosis no patient reported receiving psychological intervention or even a referral to decrease emotional distress. This could be the result of a number of factors that were not measured in this study, for example patient beliefs that depression and worries are inevitable with cancer and will go away by themselves, patient beliefs that these issues are not within the realm of the physician, as evidenced by the absence of physician inquiry about psychological issues, or physician poor skills or lack of education on how to identify major depression or anxiety from the more transient mood changes associated with major illness.

These results emphasize the importance of recognition, routine screening and treatment of emotional distress in patients with MIBC. The new accreditation standards of the American College of Surgeons (ACS) Commission on Cancer for hospital cancer programs include screening all patients with cancer for emotional distress. The National Comprehensive Cancer Network® (NCCN) Distress Management Guidelines provide standards of care for distress management and specify clinical pathways that provide detailed recommendations on the evaluation and treatment of distress, such as initial and routine evaluation of distress using a validated screening tool (ie the single item Distress Thermometer and a problem list). A score of 4 or greater on the Distress Thermometer should trigger further evaluation by the physician or nurse and referral to a psychosocial service, if needed. This screening tool also indicates the type of difficulty that patients are experiencing, allowing physicians to target referrals to the patient reported needs. Medical team members should also be aware of the services offered by mental health departments and psychosocial services at the institution and in the community (eg support groups and help lines). They should not hesitate to refer patients and families to these departments and community cancer services in a preventive manner.

**Postoperatively**

Patients typically receive hands-on training on the use of stomal appliances and catheters after surgery. This type of teaching tends to occur only during initial hospitalization when patients are acutely recovering from surgery with little followup reinforcement. Although most patients received
some postoperative support from visiting nurses or a family member, many thought that the training received was not sufficient. It is possible that pain, anxiety, fatigue and nausea in the early postoperative period as well as an age related memory problem or senility significantly affect the patient ability to learn about self-care.26 In the context of MIBC this might lead to difficulty with using stomal appliances and catheters after discharge home.27 Other factors that impair learning include shorter postoperative stays during which self-care behavior cannot be practiced adequately before discharge, limited access to stomal care specialists such as enterostomal nurses and difficulty traveling to hospitals or clinics by those who rely heavily on family caregivers.28 The latter is especially true given the regionalization of this type of surgery since patients must travel more than 60 minutes to the hospital, representing a barrier to frequent teaching followups for self-care.

Although many patients relied on family assistance with self-care, most caregivers did not receive formal training for stomal care and catheter use but rather learned by trial and error, often relying on the Internet. Again, there are simple yet elegant solutions. Family caregivers need training in postoperative care before discharge from the hospital and followup during the weeks after surgery. Part of this education is to know when to call the medical team to avoid emergency room visits. We also recommend providing all patients and caregivers with clear but detailed “after your discharge” materials that reinforce the education received from enterostomal nurses in the hospital. Clearly such materials must be developed at multiple levels of health literacy.

Survivorship

During the survivorship phase men and women reported difficulty adjusting to changes in body image, lifestyle and sexual function. Men and women reported different profiles of changes in sexual function. Men reported erectile dysfunction and low libido. Women reported difficulty related to vaginal dryness, pain during sexual intercourse and a lost desire for sex due to changes in body image and having a stoma. These differences suggest the need for targeted or sex specific intervention to improve QOL in survivors and their spouses/partners.29

Emotional distress and worry about the future emerged as strong themes during this period. However, most patients did not seek professional assistance for emotional support or changes in sexual function. It is possible that patients avoided talking about emotional distress or sexual dysfunction to avoid feelings of weakness and vulnerability. A recent study of colorectal cancer patients treated with colostomy showed that patients sought help from nurses only when they experienced stoma related problems but not for psychological or sexual problems.30 This suggests that a more proactive approach is required to meet the emotional and information needs of patients with MIBC for several months after the diagnosis and initial treatment phase. Followup calls from medical team members may go a long way toward determining the unmet needs of survivors and making appropriate referrals. However, we stress the importance of providing information early and reinforcing that information during the hospitalization and post-discharge periods. We also emphasize the importance of repeat screening for emotional distress and appropriate referrals to prevent long-term distress and depression that may impede recovery.

Study Limitations

Our sample was small. Also, many clinical and demographic characteristics were homogeneous, including cancer stage, definitive treatment and age as well as ethnicity and gender since the population was largely composed of nonHispanic white men. This limits the generalizability of our findings. In addition, our patients were survivors of MIBC who were recruited from ISMMS and via the BCAN website. Thus, our study sample might not reflect the general characteristics of the study population. The results also are limited to the patient perspective. Future research should address the unmet needs of family caregivers to further enhance our understanding of patient and caregiver needs. Furthermore, data were collected retrospectively, relying on the recollection of needs or worries, which may be influenced by recall bias. Prospective studies are needed to further explore and confirm the unmet needs reported in this study and examine pathways between perceived unmet needs and potential decrements in patient QOL.

CONCLUSIONS

Meeting patient informational, medical, psychological and instrumental needs is imperative to ensure adequate patient involvement in health care and enhance postoperative QOL. Because patient informational and support needs vary along the cancer trajectory, an effective support provision plan should follow changes in patient needs. Programs and guidelines that target patient and caregiver QOL, and address their needs, such as the NCCN guidelines, should be implemented at all medical institutions and community clinics.22
REFERENCES


