



Published in final edited form as:

J Urol. 2014 January ; 191(1): 48–53. doi:10.1016/j.juro.2013.07.062.

Muscle invasive bladder cancer: Examining survivors' burden and unmet needs

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Abstract

Purpose—Although improvements in perioperative care have decreased surgical morbidity following radical cystectomy for muscle invasive bladder cancer (MIBC), treatment side effects still have a negative impact on patients' quality of life (QOL). This study examines patients' unmet needs along the illness trajectory.

Methods and Materials—Thirty patients (26.7% women) treated with cystectomy and urinary diversion for MIBC participated in the study. Patients were recruited from the Department of Urology at Mount Sinai and through advertisements on the Bladder Cancer Advocacy Network website between December, 2011 and September, 2012. Data were collected through individual interviews. The interviews were audio-taped and transcribed. Qualitative analyses of transcribed data were used to explore key unmet needs.

Results—At time of diagnosis, unmet informational needs were predominant, consisting of insufficient discussions of these topics: urinary diversion options and their side-effects, self-care, recovery process, and medical insurance. Unmet psychological needs related to depression and worries about changes in body image and sexual function were reported. Post-surgical unmet needs revolved around medical (e.g., pain, bowel dysfunction), and instrumental needs (e.g., need of support with use of stomal appliances, catheters, and incontinence). During survivorship (i.e., from 6 to 72 months following surgery), unmet needs centered around psychological (i.e., depression, poor body image, sexual dysfunction) and instrumental support (e.g., difficulty adjusting to changes in daily-living).

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Conclusions—Meeting patients' needs is imperative to ensure patients' adequate involvement in their healthcare, and to enhance post-surgical QOL. An effective support provision plan should follow changes in patients' needs.

Keywords

muscle invasive bladder cancer; treatment side effects; survivors' unmet needs; quality of life

Introduction

It is estimated that there are more than 500,000 bladder cancer (BC) survivors in the United States¹. For patients diagnosed with muscle invasive bladder cancer (MIBC; approximately 30% of newly diagnosed BC patients) and those with high-risk progressive noninvasive disease, radical cystectomy with urinary diversion is the gold standard in treatment, providing excellent local cancer control²⁻⁵. Following cystectomy, urine can either be diverted into: a) an incontinent stoma (ileal conduit procedure); b) a continent urinary reservoir catheterized by the patient; or c) a continent urinary reservoir connected to the urethra (orthotopic neobladder)⁶. The physical and related psychological impact (e.g., urinary incontinence, sexual dysfunction, and poor body image) of these urinary diversion procedures on the patient's quality of life (QOL) has been documented²⁻⁷. However, measures used to assess MIBC patients' QOL fail to distinguish between health-related problems and patients' desire or need to receive professional attention or care for these problems⁸. To optimize the quality of health care provided, MIBC patients' unmet needs should be identified and addressed. However, research that examines MIBC patients' needs is scarce. In this study, we used The Corbin and Straus chronic Illness Trajectory Model (ITM)⁹ as a conceptual framework to understand MIBC patients' needs during the time of diagnosis, following surgery, and at entry into the survivorship phase. The ITM addresses potential changes in patients' needs and challenges due to variations in the medical course of illness^{9, 10}.

An extensive body of research identifying patients' needs in several cancer-related areas (e.g., prostate, breast, and colorectal cancer) has emerged¹¹. These informational needs vary along the illness trajectory, with information about cancer stage, treatment options and side effects emerging as most important during diagnosis and treatment and recovery and surveillance as most important during the post-treatment survivorship phase^{11, 12}. In this study, we propose to explore unmet informational and supportive care needs of MIBC patients along the illness trajectory. *An unmet need for information* is defined as a patient's wish to receive information about cancer, treatment and treatment outcomes; in contrast, *an unmet need for supportive care* is defined as a wish to receive medical, psychological, and emotional support with cancer, treatment, and treatment outcomes. The variation of needs along the illness trajectory as indicated by the ITM framework and the distinction between informational and supportive care needs guided the design of the study^{9, 11}.

Study Design

Selection and Recruitment of Participants

Two strategies were used for patient recruitment. First, patients with MIBC were recruited from the Department of Urology at the Icahn School of Medicine at Mount Sinai (ISMMS) between December, 2011 and September, 2012. We restricted eligibility to those who were (1) treated with cystectomy and urinary diversion, (2) able to communicate fluently in English, and (3) between 18 and 85 years of age. Participants were not eligible if they had a second primary cancer, metastatic disease, or cancer recurrence. Of the 69 patients treated during this time period, 35 were eligible. Of those patients, 19 (54.28%) agreed to participate in the study. Reasons for non-participation include lack of interest or time, and a poor health condition. Second, patients were recruited through the Bladder Cancer Advocacy Network (BCAN) website. The same eligibility criteria were considered using self-reported medical information. Eleven 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 Institutional Review Board of the ISMMS.

Procedures

Data were collected through in-person ($n = 9$) or telephone ($n = 21$) interviews that lasted 1–2 hours (median time = 1 hour), using a semi-structured interview guide. The interviewer (NM) used plain language and explained medical terminology (see Appendix). All interviews were audio-taped and transcribed, and additional written notes were made by a member of the research team (PCH). Medical chart data of patients recruited from ISMMS were also collected to confirm participants' self-reported medical information regarding diagnosis, treatment, and cancer recurrence or metastasis. The interview guide was developed by NM and reviewed by two members of the research team (MAD and CZ). The interviews focused on exploring patients' informational and supportive care needs at three times during the illness trajectory: time of diagnosis (treatment decision making, communication with the physician, emotional impact of diagnosis); following surgery (side effects of MIBC treatments and post-surgical self-care); and the time of survivorship (changes in body image, difficulties in daily living, emotional adjustment, follow-up health care). The protocol allowed the participants to narrate their experiences in chronological order. For example, to examine needs that arose at time of diagnosis, participants were asked to think back to that time, and asked about what information they wish they had had prior to making a treatment decision, how they made their treatment decision (e.g., personal choice of treatment versus physicians' recommendation), and the emotions surrounding that decision.

Data Analyses

Our qualitative analysis used an immersion/crystallization approach. This approach consisted of an iterative process that included cycles of reading, summarizing, and rereading the data¹³. The interview data were coded separately by two members of the research team (NM and PCH) using Atlas.ti software. Differences in codes assigned to specific chunks of data were resolved through discussions between the two members (NM and PCH) and (MAD and TAR) until conflicting codes were resolved. Data collection was completed when

data saturation was reached (i.e., no new or relevant data emerged)¹⁴. Content analysis of participants' responses included checking for representativeness of the data (e.g., checking interpretations against raw data) and data triangulation (i.e., use of multiple methods to interpret data such as comparing coding of interviews with written notes)^{15, 16}. The coding guide identified narrative themes related to the conceptual categories of informational and supportive care needs.

Results

Sample

Data were collected for 30 non-Hispanic White adults with a mean age of 67, nearly three-quarters of them men (22 or 73%). Half of the study sample were treated with ileal conduit (50%), 43.33% with neobladder, and 6.67% with continent reservoir. Table 1 depicts the demographic and clinical characteristics of the study participants. The predominant themes that emerged from the interviews at each time point of the illness trajectory are listed in Tables 2, 3, and 4 respectively.

Unmet needs at time of diagnosis

Unmet needs at this time revolved around patients' understanding of their treatment options and potential side effects (Table 2). Over half of the patients (56.67%) found the information they received from physicians to be insufficient and wished that they had been given more information about self-care after surgery, finances and medical insurance, and the healing process. Of these patients, 26.67% had searched the Internet, joined support groups, or read on-line patients' blogs for more information about treatment options and side effects. Other unmet needs that were mentioned more than a few times included worries about survival, pain, change in body image, and reduced sexual function after surgery. Only 20% of patients reported that their physicians mentioned possible changes in sexual function during the discussion about treatment options. One-third of patients (33.33%) reported feeling severely depressed at the time of diagnosis but did not receive referrals for care.

Unmet needs following surgery

Half the study sample (50%) reported difficulties with post-surgical recovery and almost half (46.67%) reported difficulties related to medical complications (see Table 3). These include urinary tract infections, incisional hernia, deep vein thrombosis, and kidney-related problems. The most frequently reported difficulties encountered following surgery were difficulties in dealing with changes in urinary function (43.33%). Specifically, incontinence was a major concern for patients treated with neobladder and lack of urine control and leakage were frequently reported among patients treated with ileal conduit. Informational needs during this period included a lack of information about recovery and post-treatment self-care. Many patients reported a lack of adequate training on the use of stomal appliances and catheters (i.e., stoma pouch changing, tailoring, cleaning, emptying, and choice of appliances.) Although over half the sample (53.33%) received support with post-surgical self-care from a visiting nurse, 30% of these patients were not satisfied with the support they 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 patients' blogs (e.g., 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 as it influenced patients' selection and use of stomal appliances and catheters (Table 3).

Unmet needs at survivorship

Several unmet needs emerged about 6 months after surgery, when patients and their families are transitioning into the survivorship phase (see Table 4) ¹⁷. Many patients reported that they were unable to resume some of the usual physical or social activities because of treatment sequelae. Changes in sexual function (43.33%) were reported by both men (36.36%) and women (62.50%). Changes in sexual function reported by men included erectile dysfunction and low libido. Women reported difficulties related to vaginal dryness, pain during sexual intercourse, and lost desire for sex because of changes in body image and having a stoma. About 36% of these patients (25% women, 40.91% men) were bothered by these changes and only 16.67% (12.50% women, 18.18% men) received professional advice concerning 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 they would not have changed their decision. One-fifth of the sample (20%; 25% women and 36.36% men) reported difficulties in adjusting to a changed body image. Similar to the time of diagnosis, one-third of the patients (33.33%) reported feeling depressed. Of these patients 50% stayed depressed throughout the time of diagnosis and the survivorship phase. A few patients (6.66%) sought professional assistance for their depressive symptoms. About one-fourth of the sample (23.33%) reported worries about the future and cancer recurrence; some in this group were concerned about their inability to continue using stomal appliances and catheters because of potential age-related declines in manual dexterity and vision.

Discussion

The examination of cancer patients' needs for treatment information, support, and health care are crucial steps in providing high quality health care. Qualitative evaluation of MIBC patients' reports showed several areas of unmet needs that change across the illness trajectory.

Time of diagnosis

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

provided to patients pre- or post-surgery, but they do not substitute for clear communication between patients and medical professionals about these issues. Patients also expressed emotional distress and worries that required reassurance (e.g., worries about change in body image and sexual function)¹⁸ or in some cases, clinical levels of depressive symptoms that might require intervention. None of the patients reported receipt of psychological interventions or even a referral to reduce their emotional distress at the time of diagnosis. This could be the result of a number of factors that were not measured in this study: patients' beliefs that depression and worries are inevitable with cancer and will go away by themselves; patients' beliefs that these issues are not within the physician's realm (as evidenced by the absence of physicians' inquiry about psychological issues¹⁹); or physicians' poor skills or lack of education in how to identify major depression or anxiety from the more transient mood changes associated with major illness²⁰.

These results emphasize the importance of recognition, routine screening, and treatment of distress among MIBC patients. The American College of Surgeon Commission on Cancer (CoC) new accreditation standards for hospital cancer programs include screening all cancer patients for psychological 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 about the evaluation and treatment of distress such as initial and routine evaluation of distress using a validated screening tool (i.e., the single item Distress Thermometer (DT) and a problem list)^{21, 22}. A score of 4 or greater on DT should trigger further evaluation by the physician or nurse and a referral to a psychosocial service, if needed. This screening tool also indicates what type of difficulties patients are experiencing; allowing the physicians to target their referrals to the patients' reported needs. Members of the medical team should also be aware of the services offered by mental health department and psychosocial services in the institution and the community (support groups, help lines, discussion groups for families) and not hesitate to refer patients and families to these in a preventive manner.

Post-surgery

Patients typically receive hands-on training on the use of stomal appliances and catheters following surgery. This type of teaching tends to occur only during initial hospitalization when patients are acutely recovering from surgery with little follow up reinforcement^{23 24, 25}. Although most patients

Survivorship phase

During the survivorship phase, both men and women reported difficulties in adjusting to changes in body image, life style, and sexual function. Men and women reported different profile of changes in sexual function. Men reported erectile dysfunction and low libido. Women reported difficulties related to vaginal dryness, pain during sexual intercourse, and lost desire for sex because of changes in body image and having a stoma. These differences suggest the need for targeted or sex-specific intervention to improve QOL among survivors and their spouses/partners²⁹. Emotional distress and "worries about the future" emerged as strong themes during this period. The majority of patients, however, did not seek professional assistance for emotional support or changes in sexual function. It is possible that patients avoided talking about the emotional distress or sexual dysfunction to avoid

feelings of weakness and vulnerability. A recent study on 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 problems³⁰. This suggests a more pro-active approach to meeting MIBC patients' emotional and information needs for several months after a diagnosis and initial phase of treatment. Follow-up calls from members of the medical team may go a long way to finding out what unmet needs there have and making appropriate referrals. However, we stress the importance of providing information early on and reinforcing that information during the hospital and post-discharge times. We also suggest repeated screening for depression and anxiety and appropriate referrals to prevent long-term psychological distress that may impede recovery.

Study limitations

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

Conclusion

Meeting patients' informational, medical, psychological, and instrumental needs is imperative to ensure patients' adequate involvement in their healthcare and to enhance post-surgical QOL. Because patients' informational and support needs vary along the cancer trajectory, an effective support provision plan should follow changes in patients' needs. Programs and guidelines that target patients' and caregivers' QOL and address their needs such as the NCCN guidelines should be implemented in all medical institutions and community clinics²².

Acknowledgments

Supported by mentored research scholar grants from the American Cancer Society (121193-MRSG-11-103-01-CPPB) and the National Cancer institute (1R03CA165768-01A1)

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Table 1

Participants demographic and clinical characteristics

N=30	Full Sample n (%)
<i>Age</i>	
Age < 60	7 (23.33%)
Age => 60	23 (76.67%)
Median (interquartile range in years)	70 (15)
<i>Gender</i>	
Male	22 (73.33%)
Female	8 (26.67%)
<i>Race</i>	
Caucasian	30 (100%)
<i>Marital Status</i>	
Single	2 (6.66%)
Married/ Living with Partners	27 (90%)
Divorce/Separated/Deceased Partners	1 (3.33%)
<i>Time since Treatment</i>	
0–6 Months	6 (20%)
6–12 Months	7 (23.3%)
12–18 Months	3 (10%)
18+ Months	14 (46.7%)
Median (interquartile range in months)	16.2 (27)
<i>Time between the diagnosis and the interview</i>	
0–6 Months	3 (10%)
6–12 Months	7 (23.3%)
12–18 Months	6 (20%)
18+ Months	14 (46.7)
Median (interquartile range in months)	17.8 (63)
<i>Treatment</i>	
Ileal Conduit	15 (50%)
Continent reservoir	2 (6.67%)
Neobladder	13 (43.33%)
Adjuvant/Neoadjuvant chemotherapy	12 (40%)
<i>Employment</i>	
Employed	10 (33.33%)
Retired	3 (10%)
Unknown/ Not stated	17 (56.67%)
<i>Support provider</i>	
Has a partner/other family member support	23 (76.66%)
Has no partner/other family member support	1 (3.33%)
Unknown/ Not stated	6 (20%)

Table 2

Unmet informational and supportive care needs at the time of diagnosis

Unmet Needs reported during the time of diagnosis	Full Sample (n = 30)	Themes
Information believed to be useful but not offered or fully discussed by the physician	56.67%	<ul style="list-style-type: none"> • Treatment options and side effects • Self-care following surgery • Medical insurance • Recovery rate • Change in sexual function • Preparation for surgery
Searched for information about treatment options and treatment side effects	16.67%	<ul style="list-style-type: none"> • Searched the internet • Talked to other patients • Joined support groups • Joined online patients blogs
Type of information searched about treatment options and treatment side effects	26.67%	<ul style="list-style-type: none"> • Cancer control and recovery rate • Post-surgical self-care • The impact of treatment on sexual function • Satisfaction with treatment outcomes • Chemotherapy and side effects
The physician's provided information about change in the sexual function during counseling	20%	<ul style="list-style-type: none"> • The physician discussed some of the potential impact of treatment on sexual function • The physician discussed erectile dysfunction
Involvement in the treatment decision making	50%	<ul style="list-style-type: none"> • Made their own personal choice of treatment • Made their decision based on physicians' recommendation • Made treatment decision after considering family members recommendations • Getting a second opinion
No active involvement in the treatment decision making	26.67%	<ul style="list-style-type: none"> • Treatment decision was made by the physician • Patients had no other choice but the treatment received because of co- existing comorbidity • Patients had no other choice but the treatment received because of the surgical outcomes
Worries about treatment	23.33%	<ul style="list-style-type: none"> • Worries about the surgical outcomes • Worries about treatment side effects Worries about changes in sexual function • Worries about survival
Emotional distress at time of diagnosis	33.33%	<ul style="list-style-type: none"> • Felt depressed • Had negative emotions • Felt shocked and scared

Unmet Needs reported during the time of diagnosis	Full Sample (n = 30)	Themes
		<ul style="list-style-type: none"><li data-bbox="771 296 899 317">• Felt angry

Table 3

Unmet informational and supportive care needs following surgery

Unmet Needs reported following Surgery	Full Sample (n = 30)	Themes
Received multiple home visits from a visiting nurse	53.33%	<ul style="list-style-type: none"> • A visiting nurse assisted the patient with the use of stomal appliances after discharge • A visiting nurse assisted the patient with the use of catheters after discharge • A visiting nurse assisted the patient with surgery-related complications
Dissatisfaction with supportive care received from visiting nurses	30%	<ul style="list-style-type: none"> • Visiting nurses lacks expertise in stoma care • Visiting nurses lack expertise in use of stoma appliances • Visiting nurses lack expertise in catheter care
Difficulty related to recovery	50%	<ul style="list-style-type: none"> • Difficulty related to physical recovery • Difficulty related to emotional recovery • Difficulties with bowel function
Had complications after treatment	46.67%	<ul style="list-style-type: none"> • Complication from cystectomy • Complication from stoma-related surgeries
Had difficulty after surgery from changes in urinary function	43.33%	<ul style="list-style-type: none"> • Had little or no control of urine • Difficulty with urine leakage • Bother with incontinence • Bother with odor
Had difficulty related to use of stomal appliances	20%	<ul style="list-style-type: none"> • Difficulty with the use of stomal appliances • Had allergic reaction to stomal appliances • Difficulty with changing the stomal bag when away from home
Had difficulty related to neobladder care	20%	<ul style="list-style-type: none"> • Difficulty using public restrooms • Difficulty with irrigation • Difficulty because of infection • Difficulty urinating with a neobladder
Had difficulty related to use of catheters	10%	<ul style="list-style-type: none"> • Difficulty with the use of catheters • Had difficulty emptying the pouch completely
Spouse/partner helped with stomal care	36.67%	<ul style="list-style-type: none"> • Helped with changing the stomal bag • Help with ordering stomal appliances • Provided needed information about stomal care
Spouse/partner helped with catheters	6.67%	<ul style="list-style-type: none"> • Helped with irrigating the pouch • Helped with the use of catheters
Spouse/partner helped with other things related to treatment	13.33%	<ul style="list-style-type: none"> • Helped holding and cleaning appliances • Helped with changing the wet bed-sheets

Unmet Needs reported following Surgery	Full Sample (n = 30)	Themes
		<ul style="list-style-type: none">• Helped with putting cloth on
Patient relied on him/herself in post-treatment self-care	10%	<ul style="list-style-type: none">• Did not receive help from family members or friends with self-care after treatment• Was not satisfied with the support received from family members or friends after treatment

Table 4

Unmet informational and support needs during survivorship

Unmet Needs reported during Survivorship	Full Sample (n = 30)	Themes
Difficulties in daily living	66.67%	<ul style="list-style-type: none"> Limited physical and social activities Could not continue working Stayed closer to home Always on the lookout for public restrooms when away from home Changed clothing style Changed sleep habits
Treatment affected body image	20%	<ul style="list-style-type: none"> Did not like how the stoma looks Did not like having scars Felt less confident because of the altered body image Felt less comfortable around other people
Treatment affected sexual function	43.33%	<ul style="list-style-type: none"> Had erectile dysfunction (men) Lost desire for sex Experience vaginal dryness (women) Low libido Patient believes he developed Peyronie as a result of his treatment
Had difficulty after surgery from sexual dysfunction	36.6%	<ul style="list-style-type: none"> Bother with the inability to ejaculate (men) Painful sexual intercourse (women) Had to learn new ways to sexually satisfy the spouse/partner Difficulty having intercourse with spouse/partner because of body image Intimacy problems with spouse/partner Needed medication to help with sexual dysfunction (men)
Received professional help with sexual dysfunction	16.67%	<ul style="list-style-type: none"> Took Testosterone (men) Took medication for erectile dysfunction(men) Used lubrication (women) Talked to a psychologist about sexual dysfunction
Would not change their decision about the treatment received had they knew that the sexual function would be affected	43.33%	<ul style="list-style-type: none"> Had no other choice therefore would not change their mind about treatment Being alive was more important
Emotional distress after the treatment	33.33%	<ul style="list-style-type: none"> Felt depressed after surgery Had emotional distressed after surgery Felt sad Not feeling "normal"
Received help with emotional distress	6.67%	<ul style="list-style-type: none"> Took medication for depression Had psychological counseling

Unmet Needs reported during Survivorship	Full Sample (n = 30)	Themes
		<ul style="list-style-type: none">• Turned to religion and spirituality to cope with depression
Worried about the future with regards to the treatment they received	23.33%	<ul style="list-style-type: none">• Worries about the future• Worries about cancer recurrence• Worries about self-caring in the future• Worries about urine control in the future