



# Patients' Evaluation of an Educational and Training Experiential Intervention (ETEI) to Enhance Treatment Decision and Self-Care Following the Diagnosis of Muscle Invasive Bladder Cancer

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## Abstract

**Objectives:** This study examines patients' evaluation of an educational and training experiential intervention (ETEI) developed to enhance muscle invasive bladder cancer (MIBC) patients' treatment decision-making and post-treatment self-care.

**Methods:** Participants were recruited from the Mount Sinai Medical Center and via the National Bladder Cancer Advocacy Network website between December, 2011 and September, 2012. Data were collected via individual interviews and electronic medical record review. Qualitative analysis of patients' reaction and evaluation of the proposed content of the ETEI modules was performed.

**Results:** Data were collected for a total of 30 study participants (26.7% women; 93.0% non-Hispanic White) who underwent cystectomy and urinary diversion for MIBC. Mean age was 66.6 years. 50%, 43.3% and 6.7% of patients were treated with ileal conduit, neobladder and continent reservoir respectively. High satisfaction rate with the educational and training components was reported.

**Conclusion:** The study results emphasize the importance of the proposed ETEI and appropriateness of the informational and training modules for both patients and their caregivers. Such an intervention will help reduce the burden of care on patients, care-givers and care-providers.

**Practice-implications:** There could potentially be an increased need for resources – educational booklets, audio-visuals, trained health care personnel, length +/- number of appointments.

**Keywords:** Urothelial Carcinoma of the Urinary Bladder; Muscle Invasive Bladder Cancer; Radical Cystectomy; Urinary Diversion; Unmet Need; Educational; Training Experiential Intervention

## Introduction

Bladder cancer (BC) is the fifth most common cancer and the fifth leading cause of cancer deaths in the United States (US). According to the Surveillance, Epidemiology, and End Results (SEER) database, it is estimated that 76,960 new cases of BC will be diagnosed in 2016 and 16,390 patient's die of this disease [1]. There has been a decreasing trend in mortality from BC in the US and Europe [2,3], possibly reflecting reduced occupational exposure to carcinogens, reduced incidence of smoking and increased standard of care [4,5].

25% of the newly diagnosed BC are muscle invasive requiring aggressive radical surgery or radiotherapy with or without chemotherapy [6]. The outcomes, however, remain poor despite

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Received Date: 17 Jul 2016

Accepted Date: 01 Sep 2017

Published Date: 18 Sep 2017

### Citation:

Mohamed NE, Pisipati S, Cassara M, Goodman S, Lee CT, Knauer CJ, et al. Patients' Evaluation of an Educational and Training Experiential Intervention (ETEI) to Enhance Treatment Decision and Self-Care Following the Diagnosis of Muscle Invasive Bladder Cancer. *Clin Surg.* 2017; 2: 1617.

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aggressive systemic treatments [7,8]. Muscle invasive bladder cancer (MIBC) is a potentially lethal malignancy and continues to pose an enormous challenge, especially in older patients. The current standard of care for non-metastatic MIBC is radical cystectomy (RC) with lymphadenectomy, followed by urinary diversion (UD) to either a cutaneous stoma or the existing urethra, thus providing excellent local control [9-13]. Neoadjuvant chemotherapy has been proven to enhance survival outcomes in MIBC, by eliminating residual disease, although it is not exempt from side-effects [14].

The three methods of UD currently used are incontinent diversion with a stoma (e.g., ileal conduit, IC), orthotopic continent UD (e.g., neobladder), and continent cutaneous diversion (CCD, e.g., Indiana pouch) [15]. Each of these procedures is associated with a distinct set of challenges and complications, as well as unique psychological burdens [9-13]. The neobladder most closely resembles the native bladder and preserves continence, reducing the need for regular long-term intermittent catheterization associated with CCD [16]. The IC presents shorter recovery time and is largely free of the metabolic complications associated with the orthotopic neobladder procedure. However, the IC requires the use of a stoma and urine collection bags, which patients may find upsetting and obstructive to post-operative lifestyle [16].

RC and UD is associated with high surgical morbidity and mortality [17,18]. Although the incidence of severe complications has shown a declining trend, they are still an issue of great concern in 30% of patients during in-hospital stay and in up-to 60% of patients within 90 days [17-26], thereby prolonging the length of hospital stay and negatively impacting recovery [27,28]. Careful maintenance of the surgical and UD sites is integral to promoting recovery and restoring urinary function. Surgeons must also refine pre- and postoperative strategies to enhance patient recovery following cystectomy. Emphasis must be placed on improving pre-operative nutritional status, educating patients about red-flag symptoms, enhancing recovery protocols, counseling patients, setting realistic goals and expectations, and training patients regarding stoma care [29-32].

RC and UD procedures can significantly alter patients' quality of life (QoL) and psychosocial adjustment. Sexual potency and urinary incontinence are recurring issues, often directly attributable to the diversion process itself [33]. Moreover, no UD technique is clearly better in terms of post-operative QoL and psychosocial adjustment. Preference for a certain procedure is largely based on patient-specific characteristics such as age, comorbidities, physical and manual dexterity, prospective surgical issues, and lifestyle needs [34,35]. Each type of diversion carries its own set of psychological burdens, including negative body image and intrusive nighttime awakenings [34-36]. Poor body image has shown to be more common among patients with conduits, which leads many newly diagnosed patients to opt for the neobladder despite the possibility of reduced urinary continence. Insecurities are mostly due to the stoma's appearance and required continuous care [34-36].

IC is associated with stomal difficulties (prolapse, retraction, stenosis, skin irritation, urinary leakage, difficulty in proper positioning and securing stomal appliance), renal deterioration and recurrent urinary infections [37-40]. Furthermore, depending on the absorptive characteristics of different bowel segments used for reconstruction, IC diversion may lead to one of various metabolic abnormalities such as metabolic acidosis, hypochloremia, hypokalemia, hypocalcemia. These metabolic derangements, however, are more of a concern

with neobladder when compared to an IC. Additionally, neobladder requires life-long monitoring, frequent irrigation of the reservoir for mucus clearance, and urethral surveillance. It also features a higher rate of nocturnal incontinence and metabolic disorders [39,41,42].

Patient-related factors have a significant role in determining the type of UD. Elderly patients typically opt for a conduit as the operation is relatively simpler and takes significantly less time when compared to orthotopic or continent reservoir reconstruction [43], and minimizes incontinence issues. Gender also influences the selection of diversion type; fewer women are eligible candidates for neobladder procedures due to increased chance of voiding dysfunction when compared to men [44]. Women tend to require extensive individual evaluation prior to the procedure to ensure that the tumor is not located at the bladder neck and that there is a clear urethral margin at the time of cystectomy [17]. Patient preference further varies based on treatment-related values, expectations, cultural background, and socioeconomic status [45]. Preoperative continence can reasonably predict post-operative urinary function as preoperative urinary problems may worsen after the orthotopic neobladder procedure (e.g., increased urinary incontinence and higher likelihood of intermittent catheterization).

Lastly, patient preference also plays an important role in procedure decisions. While the IC might offer a less complicated method of bladder evacuation, its impact on body image and the possibility of urine leakage makes it less attractive especially for younger patients. The occasional leakage following the neobladder procedure may seem tolerable to those who fear the conduit's impact on body image and the associated urine collection bag and stoma care. Existing comorbidities (e.g., inflammatory bowel disease, prior radiotherapy) may preclude the use of the bowel for the neobladder, which leads some patients to opt for the IC [46-49]. Physician preference can also influence selection of UD type, as can surgeon-specific characteristics such as age, race, location of practice, surgical volume and surgeon preference [50,51].

The entire process of evaluating disease severity, navigating treatment options, recovering from surgery, and acclimating to postoperative lifestyle changes is undoubtedly rife with difficult and multifaceted decisions. Given the challenges both inherent and specific to MIBC, it is critical to ensure proper support for patients throughout each phase of diagnosis, treatment, and recovery. A recent study by Lee CT et al. found that even among NCI-designated institutions, few treatment centers employ active BC support groups, survivorship clinics, or community resources for education and patient navigation [52]. Patients with MIBC usually receive post-operative educational support regarding self-care strategies such as the utility of stomal appliances and catheterization, yet there remains a lack of research on the actual decision-making process over the course of treatment, as well as on the possible benefits of more extensive educational support for patients prior to surgery. It is therefore critical to investigate BC patients' decision-making processes, which depend upon adequate, ongoing educational support.

In this context, our study evaluated the acceptability of an educational intervention that we developed to enhance MIBC patients' treatment decisions and QoL. Improved knowledge of how patients understand and approach their disease can better inform doctors' care throughout the diagnosis and treatment process. This study therefore explores the merits of a certain BC educational program meant to both inform patients' decision-making and improve their

**Table 1:** Semi-structure Individual In-depth Interview Script.

Theme	Questions
Treatment Information [Brief description about and examples of the planned educational module in provided.]	• What do you think about having full information about invasive bladder cancer treatment options, their side effect, and their pros and cons?
	• What do you think about having a list of questions about treatment options and their pros and cons that a patient can use during his/her consultation with the doctor?
	• What do you think about seeing drawings of different bladder replacements treatments?
	• What do you think about seeing drawings of stoma appliances and catheters?
	• What do you think about talking with a nurse about stoma care and location and use of stoma appliances regardless of your treatment preferences?
Skill learning [Brief description about and examples of the training I module in provided.]	• What do you think about wearing a stoma bag for 24 to 48 hours before your surgery? • What do you think about learning skills needed for your health care after treatment?
Spousal Information	• Would you recommend the same educational materials for patients' spouses? • Are there any other materials/ specific topics you would suggest for spouses?
	• What time should we give the patient this educational tool? Before or after treatment? and why? • When the is best time for spouses to receive these educational materials (before or after treatment)

long-term post-operative satisfaction.

## Study Design

### Study design and methods

This study evaluated patients' acceptability and preliminary evaluation of an educational and training experiential intervention (ETEI), which was designed to enhance treatment decisions and postoperative QoL. As a first step in designing this intervention, we gathered information from patients about their unmet informational and supportive care needs before and after MIBC treatment and held individual, qualitative, semi-structured in-depth interviews. An extensive literature review was conducted to explore additional areas of needs and potential challenges experienced by MIBC patients across the disease trajectory [34,36,53,54]. Iterative reviews of the content of the ETEI were conducted by the research team till an agreement was reached on the content of the ETEI final version [55].

**Description of the educational and training experiential intervention (ETEI):** The development of the content of the ETEI's educational and training components was guided by the traditional model of Self-Regulation Theory (SRT), the Ottawa Decision Support Framework [56-58] results of the qualitative, semi-structured in-depth interviews, literature reviews, and experts' input. The two components of the ETEI were designed to 1) provide accurate information about MIBC treatment and diversion options, 2) create realistic expectations, 3) identify and explore values and goals to provide a context for making "preference sensitive" decisions and choices, 4) validate feeling and concerns and provide emotional support, and 5) provide information and tangible support to enhance skills needed for stoma and pouch care following treatment. The educational components (ETEI information) were designed to be provided as part of a 1-hour nurse-led session and a follow-up call to discuss treatment options and respond to patients' questions and address their worries and concerns. Four booklets were provided to the patients describing BC treatment options and self-care requirements associated with each treatment option, along with a question list for the doctor. The training component involves trying out a stoma bag filled with saline solution for about 24 h - 48 h to get a sense of how it feels to have an IC-related stoma [Table 3] [55].

**Selection and recruitment of participants:** Between January 2010 and January 2012, we recruited patients with MIBC at the Icahn School of Medicine at Mount Sinai's (ISMMS) Urology department.

**Table 2:** Participants demographic and clinical characteristics.

N=30	Full Sample n (%)
<i>Age</i>	
Age < 60	7 (23.3%)
Age => 60	23 (76.7%)
<i>Gender</i>	
Male	22 (73.3%)
Female	8 (26.7%)
<i>Race</i>	
Caucasian	30 (100%)
<i>Marital Status</i>	
Single	2 (6.7%)
Married/ Living with Partners	27 (90%)
Divorce/Separated/Deceased Partners	1 (3.3%)
<i>Time since Treatment</i>	
0-1 year	16 (53.3%)
> 1 year	14 (46.7%)
<i>Treatment Type</i>	
IC	15 (50%)
Continent reservoir	2 (6.7%)
Neobladder	13 (43.3%)
Adjuvant/Neoadjuvant chemotherapy	40%
<i>Employment</i>	
Employed	10 (33.3%)
Retired	3 (10%)
Unknown/ Not stated	17 (56.7%)
<i>Support provider</i>	
Has a partner/other family member Support	23 (76.7%)
Has no partner/other family member support	1 (3.3%)
Unknown/ Not stated	6 (20%)

Patients between 18 and 85 years of age who underwent RC and UD for urothelial carcinoma of the bladder were eligible to participate. Patients with metastatic disease, cancer recurrence, or secondary cancers were excluded from our study. Of the 35 eligible patients, 19 (54.28%) agreed to participate in the study. Reasons for declining to

participate included lack of interest, limited time, and poor health condition. Patients were also recruited via the Bladder Cancer Advocacy Network's (BCAN) online advertisement, which required the same eligibility criteria using self-reported medical information. All 11 of the BCAN advertisement respondents were eligible and agreed to participate. All study participants (N=30) consented and were compensated with a \$50 gift card.

**Ethical issues and approval:** Prior to each interview, patients' verbal and written informed consent was obtained. Participants were given a detailed description about the aim of the study and ensured anonymity and confidentiality of responses. The study was approved by the Institutional Review Board (IRB) of ISMMS and was funded by the American Cancer Society (ACS).

**Data collection:** To facilitate informative discussions with patients about the content and acceptability of the ETEI, we developed a semi-structured interview guide using both expert opinions and results of our prior extensive reviews of cancer patients' and survivors' unmet needs [36]. Data were collected through in-person (N=9) or telephonic (N=21) interviews (median time: 60 min; range: 30 min - 90 min), using a semi-structured interview guide [Table 1]. To maintain uniformity, the same individual (NM) conducted all interviews. Plain language was used to explain all medical terminology. Study participants were asked 11 questions about the type of information and training they wished they had received beforehand, and the best times to have received them [Table 1]. Brief description of the ETEI intervention modules with illustrations depicting different treatment options and examples of self-care strategies were provided and participants were asked to provide their input on these modules and related educational materials [Table 3]. Participants were also asked about their preference for similar educational materials for their spouses. The open-ended interview protocol allowed participants to narrate their experiences and views in broad personal detail. All interviews were audio recorded and transcribed, and a member of the research team made additional written notes. Data was coded during collection and completed upon saturation (i.e., when no new or relevant data emerged).

**Data analysis:** A qualitative analysis using the template analysis approach that involves developing a template/coding guide for sorting narrative data was employed. Content analysis of participants' responses using the template analysis approach also included checking for representativeness of the data, data triangulation (i.e. use of multiple methods to interpret data, such as comparing coding of interviews with written notes) and verification for external validity [59-61]. The coding guide was designed to identify narrative themes related to the acceptability and patients' evaluation of the content of the ETEI. The interview questions directly reflected the template/coding guide's thematic categories of treatment information, skill learning, spousal information, and best time for intervention. Group discussion and negotiation among the members of the research team helped resolve any conflicts regarding which codes should be assigned to certain clusters of data. All data were coded using Atlas.ti software [62]. We obtained ISSMS patients' demographic data such as age, treatment date, and treatment type from medical charts to assist in analysis. For patients recruited from BCAN, we relied on patients' self-reported information [Table 2].

## Results

Data were collected for a total of 30 study participants (26.7%

women; 93% non-Hispanic White) who underwent RC and UD for MIBC. Mean age was 66.6 years (range: 52–82; standard deviation [SD] = 8.99). Half of the study population were treated with IC (50%, N=15), while 43.3% (N=13) were treated with neobladder and the remainder (6.7%, N=2) with the continent reservoir. Table 1 depicts study participants' demographics and clinical characteristics. Table 3 summarizes the results by depicting the acceptability of the ETEI modules. Overall, patients expressed high satisfaction with the educational and training components of the ETEI, as indicated by their reaction to proposed content and plans of intervention delivery.

### The educational module of the ETEI: Treatment information

All participants (100%) desired substantial information about the various UD options available and their outcomes. All agreed that it would have been beneficial to receive full and comparative information about UD options and their side-effects as described by the informational module of the ETEI. 90.5% believed they would have benefited from a prepared list of general questions describing and comparing treatment options during their consultations. 4.8% did not think such a list would have been useful, as they relied solely on their physician's treatment recommendations unique to their situation. Moreover, 86.7% expressed that viewing the ETEI proposed medical illustrations or other visual representations of each treatment option would have enhanced their understanding of how each UD procedure changes the urinary tract's anatomy and functioning. 90.5% felt that seeing the ETEI proposed pictures of stoma appliances and catheters would have helped them prepare for potential challenges following surgical intervention. 85.7% agreed that preoperative discussion with a healthcare professional regarding the stoma's location and care would have been beneficial, even if they ultimately chose another treatment option. About 5% of interviewees felt that they had already received enough information from their physicians.

### The training module of the ETEI: Skill learning

The majority of participants believed that they also would have benefitted from preoperative skills-based education. 71.4% agreed that an opportunity to wear a stoma bag for 24 to 48 hours prior to surgery would have allowed them to preemptively experience stoma-related care issues, while 23.8% felt that this might have raised their anxiety levels. 14% of patients agreed that practicing stoma care skills before surgery (e.g., how to use catheters and stoma appliances) would have effectively prepared them for life after surgery. However, an equal proportion of the study population (14%) also indicated preference for post-surgical training on the stoma care skills, rather than pre-surgical training, largely because the emotional stress of cancer diagnosis and treatment consideration might have affected their ability to understand complicated self-care information at the time.

### Spousal information provided by the ETEI

Most participants (90.5%) recommended that their spouses receive the same educational materials, especially since many of them indicated relying upon their spouses and partners for post-operative health care and support. Participants who cared for themselves post-operatively felt that their spouses would have voluntarily searched for information on their own had they wanted to learn, or otherwise did not recommend the intervention materials for their partners.

### Timing of the ETEI

76.2% preferred to receive an educational intervention

**Table 3:** Acceptability of ETEI.

Acceptability of ETE reported	Full Sample (n = 30)	Themes	Examples
Full information about invasive bladder cancer treatment options, their side effect, and their pros and cons	Yes= 100%	• Information about treatment options	"I think it's great because I didn't know anything about these treatment options when I had mine. I didn't really know, so I think that's perfect because it's something you can take home and you can read and you can meditate on" (Pt.#b7)
	No= 0	• Information about treatment side effect	"I think it would be great, because... me, I know with me, I can only speak for myself, but, for me knowledge is my best friend. So, when I was diagnosed I came home and I spent hours and hours and hours before going to see my cancer doctor on the treatments. And at no time did I find anything about the neobladder." (Pt.# b9)
		• Pros and Cons of each treatment options • Recovery rate	
List of questions about treatment options and their pros and cons that a patient can use during his/her consultation with the doctor	Yes= 90.5%	• List of types of treatments	"Oh yeah. And it should be a list—there should be a pre-list. You should make the list to go with this and then let people add to it. Do you know what I mean? "These are questions everybody should ask and then list your own underneath." (Pt.#b7)
	No= 4.8%	• List of treatments' pro and con	"Well, you know, you wake up and they'll tell you, "OK, you got the neobladder, you didn't get the stoma. Here's the—because it's a urinary thing" (Pt.#27)
		• List of side effects of treatment	
Pictures of different bladder replacements treatments.	Yes= 85.7%	• Anatomical pictures of Bladder and surrounding organs before treatment	"Oh, I think it's really good. I think it's wonderful because sometimes, if you leave it up to your own imagination, [laughs] it's a lot worse than what reality is. And it just kind of shows you where everything is and what they have to do.
	No= 0	• Pictures of each treatment type	And actually, when you see the pictures, and you start thinking about the neobladder, it's pretty incredible what they do." (Pt.#27)
		• Pictures of where the diversion parts come from	"Yeah, I think so. 'Cause it—I didn't know exactly what was done to me until I saw the pictures. After seeing the pictures, I realize now what took place." (Pt.# 46)
Pictures of stoma appliances and catheters	Yes= 90.5%	• Pictures of all appliances to be used with stoma	"Yeah, nothing... I have, I'd love to see that. Most of the time I'm just, because one, I'm curious, but two, I want to learn what, you know, my condition and how I'm going be going forward." (Pt.# 12)
	No= 9.5%	• Pictures of catheters	"Uh, I don't think it's helpful... if the purpose of this is to help people make a decision about options, I don't think it matters, because you need what you need and it's not going to help you make a decision about anything" (Pt.#50)
Talk with a nurse about stoma care and location and use of stoma appliances regardless of treatment preferences	Yes= 85.7%	• Location of Stoma	"I think it's important to kind of know—since you don't know what's going to happen until you wake up, you should kind of have some kind of idea of what this is going to entail." (Pt.#27)
	No= 4.8%	• Stoma Care	"I don't think so, to be honest with you. I think a good description by a doctor of what's going to happen and as he describes the options or someone else having to know—just the fact of having a stoma and knowing that you have to take care of it and it has to be cleaned X numbers of times a week or whatever I think is more than sufficient." (Pt.#20)
Wear a stoma bag for 24 to 48 hours before surgery	Yes= 71.4%	• Wear stoma bag with fluid to get the sense of how it would feel after treatment	"I don't think so, to be honest with you. I think a good description by a doctor of what's going to happen and as he describes the options or someone else having to know—just the fact of having a stoma and knowing that you have to take care of it and it has to be cleaned X numbers of times a week or whatever I think is more than sufficient." (Pt.# 41)
	No= 23.8%		"I really—not having a stoma—I don't have a stoma, so I don't really know. I would say that would—on the continuum, the stoma is kind of the least desirable option. So why make yourself crazy until it happens?" (Pt.#27)
Learn skills needed for health care after treatment	Yes= 14.3%	• Catherization	"Um, I think that's pretty important because people have gone home—I've heard that's a big complaint: people go home and they don't know what the heck they're doing. They don't know what they're doing." (Pt.# b3)
	No= 14.3%	• Stomal bag change	"I don't think so. I don't think I would want to know. I would say "let's deal with that when I wake up, I'll figure it out. You come to me, and we'll figure it out." (Pt.# 27)
Recommendation of the same educational materials for spouses	Yes= 90.5%	• Information	"Absolutely. Absolutely because in many cases, it's the spouse that's doing the changing. And my wife says – I thought it was only a few weeks.
	No= 4.8%	• Training	She says it may be a few months that she helped me. As I say, I don't remember. But she thinks it was a few months that she helped me in the changing process. And – absolutely, because the spouses are very much involved with this, or they should be." (Pt.#b2)
			"Well if she's interested in her husband's problem, then she will read what she wants to read." (Pt.#50)
Patients receive ETE before treatment	Yes= 76.2%	• Receive full ETE before treatment	"Well, after the surgery you have to know what to do, but before the surgery, if you know some of it it might be helpful, but you're not gonna experience it and you're not gonna do it until after the surgery. 'Cause you're gonna be—I, as a patient, am gonna be thinking about the cancer, or this that and this and that and this and that, I'm not gonna be even thinking about the stoma or working with it until after I'm finished. Knowing about it, I don't think would hurt me, though." (Pt.# 39)
	No= 19.1%		"Because I wasn't thinking that clearly. Before the surgery, you're thinking about surgery. Don't ask me to absorb other stuff that I don't need to know at that moment. And then after the surgery, you need a few days to regain your strength and what have you, and I think maybe a few days after the surgery would be time. Which is only a few days before you're leaving. Like halfway into the stay to go over that." (Pt.#50)
Spouses receive ETE before treatment	Yes= 90.5%	• Receive full ETE before treatment	"I would think that when you go for treatment, you know, both of you should be, get as much information as possible, because you know, you're putting... you're going through this together. It's not just the cancer patient; it's the spouse, whether it's the woman or the male". (Pt.#b9)
	No= 19.1%		"[chuckles] I don't know, but I would say it would have to be soon after the operation." (Pt.#52)

immediately upon their diagnosis to help them prepare for the surgery's challenges and the post-operative period. About 19% of the study participants, however, preferred to receive the training module of the intervention following the surgery; they believed that they would have been too emotionally occupied and overwhelmed beforehand to be able to properly learn the needed self-care skills (e.g., changing of stoma appliances and catheters use). Those who agreed that spouses should have received similar educational materials believed that a pre-surgical intervention would have been helpful. However, 19.1% preferred a post-surgical training intervention, as a pre-surgical training intervention might also raise partners' anxiety and distress.

## Discussion

There is a crucial need for educational and training interventions to enhance MIBC patients' treatment decision-making and preparation for self-care after surgery. Qualitative evaluation of reports of patients who participated in this study provides evidence for the importance of such interventions.

Overall, the results of this qualitative study confirm the value of pre-surgical educational materials for MIBC patients and their informal caregivers. Nearly all interviewees expressed belief that they would have made more informed and confident decisions after receiving detailed information, both literary and visual, about each surgical intervention's process, risks, and effects on lifestyle. Those who believed they would have benefitted also believed that their spouses or intimate partners would have as well, given their important caretaking roles.

All participants agreed that receiving the ETEI proposed information about the types of UD procedures, and their side effects would have been helpful prior to surgery. Similarly, the vast majority of patients liked the idea of receiving a prescribed list of questions to ask during their surgical consultation with the physician. Visual information depicting different bladder replacement treatments, stoma appliances, and catheters are perceived as helpful according to more than four-fifths of patients interviewed. Likewise, more than four-fifths of patients believed they would have benefitted from talking to a nurse regarding stoma care, location, and appliances, regardless of treatment preferences.

Patients with MIBC report significant unmet informational and supportive care needs; however very few resources are available to meet these needs [34,36,63,64]. Thus, knowledge of both MIBC treatment options and their consequences is not only empowering the patient, but also fundamental to an individual's decision-making regarding any issue. Our prior studies in MIBC patients showed that patients need information about the likelihood of cure, treatment choices, the benefits and risks of these choices, short- and long-term treatment side effects, as well as self-care skills associated with these choices to help them with the treatment decision-making and to prepare for the unknown [34,36]. Educational tools (e.g., print or Web-based) can provide a vast amount of information [65,66], however, the readability of the language exceeds the national average reading ability [67]. Hence, providing information does not necessarily change the decision-making process or outcomes. Patients need to integrate information about treatment options with their personal values and preferences. When an educational intervention or a patient clinician discussion regarding treatment decision-making are coupled with a personally relevant value clarification, the experience can be much more enhanced for both the patient and the physician [68,69].

According to the US Preventive Services Task Force, a comprehensive decisional tool should: a) provide adequate information about the risks, benefits, and limitations of the procedure; b) enhance the patient's ability to participate in decision-making with providers at a personally desired level; and c) help the patient make a decision that is consistent with his/her personal preferences and values [70]. In line with published data, our studies exploring treatment decision-making in cancer patients showed that patient factors including age, race, values, and preferences are significantly influential and should be addressed during decision-making processes [34,36,71]. Promoting insight and prioritizing personal factors along with medical factors are required in preparation of patients for treatment decisions. By considering these factors, providers can assist patients in making informed choices and prepare for the post treatment self-care requirements.

Anxiety is a normal and well-documented emotional and physiological response to anticipating and awaiting major surgery [72]. While many patients who receive information about their treatment prior to surgery experience relief, others' anxiety may worsen. Our qualitative data also showed that while a large (71.4%) percentage of patients believed that wearing a stoma bag for 24 h to 48 h would have prepared them for this particular operation's post-surgical experience, close to one-third of patients felt that this might have raised their anxiety levels. However, when asked about the best time for patients to learn about the skills needed for self-care, equal number of patients expressed preferences for a pre-surgical hands-on training versus a post-surgical hands-on training. Justifications for patients' preferences of a post-surgical training include reduced stress associated with a cancer diagnosis and better ability to understand complicated self-care information at the post-surgical period due to ongoing coping and adaptation processes. It is therefore very important to customize educational intervention and provide resources based on patients' needs and preferences. Studies in other cancer populations (e.g., prostate cancer) showed that customizing educational and decisional tools based on patients' preferences and values reduced decisional uncertainty and improved values clarity [73].

This study suggests that the great majority of patients recommended that their informal caregivers (e.g., partners and spouses) receive the same information and training suggested for MIBC patients. Our prior qualitative research in MIBC patients' unmet needs [36] showed that many patients relied on family assistance with self-care, although most of the family care-givers did not receive formal training for stoma care and catheter use but rather learned by trial and error and Internet-based resources. Family caregivers need training in post-operative care before discharge from the hospital and follow-up during the weeks after surgery. Part of this education is to provide hands-on training on patient post-surgical care (e.g., use of stoma appliances and catheters), recognize red-flagged symptoms (e.g., fever, discoloration of stoma, and urinary blockage), know when to call the medical team to avoid emergency room visits, and follow-up cancer screening tests. The training module of the ETEI provides detailed information about these issues for MIBC patients. Such materials can benefit both the patient and the family care-givers at multiple levels (e.g., preparation for surgery, improving self-care skills, and providing online resources for patient and caregiver support).

## Study Limitations

First, study participants were MIBC survivors with close to 50% of participants receiving treatment >1 year before the personal interviews. Including newly diagnosed patients who did not receive treatment yet could provide more timely information about perceived usefulness of the intervention and avoid recall bias. Second, our study participants were recruited from ISMMS and via BCAN website. Majority of participants in our study were Caucasians in relationships (partners/spouses). Thus, our sample might not reflect the general characteristics of the study population. Third, although the study participants suggested that the content of the ETEI is appropriate for both the patient and the informal care-giver, we did not access the care-givers perspective or input on the ETEI content. Examining the care-givers evaluation of the ETEI might reveal other issues and challenges relevant to the care-givers (e.g., care-giving burden, sexuality needs, and social support provision). Additional studies are needed to further explore and confirm the unmet needs of MIBC patients' informal care-givers to explore their unmet needs and to confirm the appropriateness of the ETEI for the care-givers.

## Conclusion

In summary, the study results emphasize the importance of the proposed ETEI and appropriateness of the content of the informational and training modules for both patients and their informal care-givers. The next step of our research (ongoing study) is to examine the feasibility and efficacy of implementing the ETEI in traditional clinic setting to enhance both treatment decisions and skills needed for post-surgical care in both patients and their care-givers. Such study will guide further improvement of the content, delivery method, and evaluation of the ETEI (i.e., in person session versus Web-based interventions).

## Practice Implications

Educational and training information in the form of adequate counseling, information booklets and pictorials regarding treatment options, and training for self-care would enable patients to make informed decisions. This could potentially mean an increased need for resources – educational booklets, audio-visuals, trained health care personnel, length +/- number of appointments.

## Acknowledgement

This work was 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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