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

Nihal E Mohamed1,*, Sailaja Pisipati2, Mario Cassara3, Sarah Goodman3, Cheryl T Lee4, Cynthia J Knauer RN1, Reza Mehrzad1, John P Szakianos1, Barbara Given5, Diane Z Quale6 and Simon J Hall7

1Department of Urology and Oncological Sciences, Icahn School of Medicine at Mount Sinai, USA
2University of Nevada Reno School of Medicine, USA
3Department of Public Health, Icahn School of Medicine at Mount Sinai, USA
4Department of Urology, The Ohio State University, Columbus, USA
5College of Nursing, Michigan State University, USA
6Bladder Cancer Advocacy Network, USA
7Smith Institute for Urology, North Shore/LIJ Health System, USA

Submission: October 30, 2017; Published: November 21, 2017
*Corresponding author: Nihal E Mohamed, Department of Urology and Oncological Sciences, Icahn School of Medicine, USA, Tel: (212) 241-8858; Fax: (212) 876-3246; E-mail: nihal.mohamed@mountsinai.org

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, caregivers and caregivers.

Keywords: Urothelial carcinoma of the urinary bladder; Muscle invasive bladder cancer; Radical cystectomy; Urinary diversion; Unmet need; Educational and training experiential intervention

Abbreviations: BC: Bladder Cancer; SEER: Surveillance, Epidemiology, and End Results; MIBC: Muscle Invasive Bladder Cancer; RC: Radical Cystectomy; UD: Urinary Diversion; CCD: Continent Cutaneous Diversion; QoL: Quality of Life; ETEI: Educational and Training Experiential Intervention; BCAN: Bladder Cancer Advocacy Network's; IRB: Institutional Review Board; ACS: American Cancer Society; SRT: Self-Regulation Theory

Practice-Implications

There could potentially be an increased need for resources - educational booklets, audio-visuals, trained health care personnel, length ± number of appointments.

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
25% of the newly diagnosed cases of BC are muscle invasive requiring aggressive radical surgery or radiotherapy with or without chemotherapy [6]. The outcomes, however, remain poor despite 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 with UD is associated with high surgical morbidity and mortality [17,18]. Although the incidence there of has declined, severe complications remain a great concern to 30% of patients during in-hospital stay, and to 60% of patients within 90 days of surgery [17-26], thereby resulting in prolonged 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. Reduced 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].

ICs 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, and hypocalcemia. These metabolic derangements, however, are more of a concern with neobladder when compared to an IC. Additionally, neobladder requires lifelong monitoring including urethral surveillance, as well as frequent irrigation of the reservoir for mucus clearance. It also features a higher rate of nocturnal incontinence and metabolic disorders [39,41,42].

Patient-related factors play a significant role in determining the type of UD. For instance, elderly patients typically opt for a conduit, as the operation itself is relatively simpler and quicker than both orthotopic and continent reservoir reconstruction [43], and it minimizes incontinence issues. Gender also influences the selection of diversion type; fewer women are eligible candidates for the neobladder procedures due to increased chance of voiding dysfunction when compared to men [44]. Women also 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 postoperative urinary function as preexisting urinary problems may worsen after the orthotopic neobladder procedure (e.g., preexisting urinary problems may predict or produce increased urinary incontinence and greater likelihood of intermittent catheterization).

Lastly, patient preference also plays an important role in procedure decisions. While 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 urinary collection bag and stoma care. Existing comorbidities (e.g., inflammatory bowel disease, effects of 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. [52], 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 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. Via individual, qualitative, semi-structured interviews, researchers gathered patients’ information about unmet informational and supportive care needs both before and after MIBC treatment to inform the study’s overall design. They also conducted an extensive literature review to explore additional challenges and areas of need that MIBC patients experience across the disease trajectory [34, 36, 53, 54]. The research team conducted iterative reviews of the ETEI until agreeing upon the final version’s content [55].

Description of the educational and training experiential intervention (ETEI)

The traditional model of Self-Regulation Theory (SRT), the Ottawa Decision Support Framework [56-58], results of the aforementioned in-depth interviews, literature, reviews, and other expert’s input each helped guide the development of the ETEI’s educational and training content.

a. Provide accurate information about MIBC treatment and diversion options;

b. Create realistic expectations;

c. Identify and explore values and goals to provide a context for making “preference sensitive” decisions and choices;

d. Provide emotional support, such as via validation of feelings and concerns

e. Provide information and tangible support to enhance skills needed for postoperative stoma and pouch care. Researchers intended that the ETEI’s educational components be delivered via a 1-hour nurse-led session and a follow-up call, both of which involved discussion of treatment options and patients’ concerns. Each patient also received four booklets describing each BC treatment option, respective 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 24-48 hours 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, researchers recruited patients with MIBC at the Icahn School of Medicine at Mount Sinai’s Urology department. Eligible participants included patients between the ages of 18 and 85 who underwent RC and UD for urothelial carcinoma of the bladder. Patients with metastatic disease, cancer recurrence, or secondary cancers were excluded. 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

Patients provided verbal and written informed consent prior to each interview. Each received a detailed description of the study’s aim and the confidential nature of their 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 ETEI’s content and acceptability, researchers developed...
a semi-structured interview guide using experts’ opinions, as well as results of prior extensive reviews examining patients’ and survivors’ unmet needs. [36]. Data were collected through in-person (N=9) or telephonic (N=21) interviews (median time: 60 minutes; range: 30-90 minutes), 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). The coding guide identified narrative themes related to the ETEI's acceptability and patients' evaluations thereof. The interview questions directly reflected the template and coding guide’s thematic categories of treatment information, skill learning, spousal information, and best time for intervention. 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).

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

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

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 identified narrative themes related to the ETEI’s acceptability and patients’ evaluations thereof. The interview questions directly reflected the template and 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).

Table 2: Participants demographic and clinical characteristics.

<table>
<thead>
<tr>
<th>N=30</th>
<th>Full Sample n (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age</td>
<td></td>
</tr>
<tr>
<td>Age &lt; 60</td>
<td>7 (23.3%)</td>
</tr>
<tr>
<td>Age =&gt; 60</td>
<td>23 (76.7%)</td>
</tr>
<tr>
<td>Gender</td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>22 (73.30%)</td>
</tr>
<tr>
<td>Female</td>
<td>8 (26.7%)</td>
</tr>
<tr>
<td>Race</td>
<td></td>
</tr>
<tr>
<td>Caucasian</td>
<td>30 (100%)</td>
</tr>
</tbody>
</table>

Table 3: Acceptability of ETEI.

<table>
<thead>
<tr>
<th>Acceptability of ETEI Reported</th>
<th>Full Sample (n=30%)</th>
<th>Themes</th>
<th>Examples</th>
</tr>
</thead>
<tbody>
<tr>
<td>Full information about invasive bladder cancer treatment options, their side effect, and their pros and cons</td>
<td>Yes=100% No=0</td>
<td>o Information about treatment options.</td>
<td>“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)</td>
</tr>
<tr>
<td></td>
<td></td>
<td>o Information about treatment side effect</td>
<td>“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)</td>
</tr>
<tr>
<td></td>
<td></td>
<td>o Pros and Cons of each treatment options</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>o Recovery rate</td>
<td></td>
</tr>
<tr>
<td>List of questions about treatment options and their pros and cons that a patient can use during his/her consultation with the doctor</td>
<td>Yes=90.5% No=4.8%</td>
<td>o List of types of treatments</td>
<td>“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)</td>
</tr>
<tr>
<td></td>
<td></td>
<td>o List of treatments’ pros and cons</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>o List of side effects of treatment</td>
<td>“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)</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Recommendation of the same educational materials for spouses</th>
<th>Yes=71.4%  No=23.8%</th>
</tr>
</thead>
<tbody>
<tr>
<td>o Information Training</td>
<td>&quot;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. 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.&quot; (Pt.#b2)</td>
</tr>
<tr>
<td>Spouses receive ETE before treatment</td>
<td>Yes=90.5%  No=19.1%</td>
</tr>
<tr>
<td>o Receive full ETE before treatment</td>
<td>&quot;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.&quot; (Pt.#b9)</td>
</tr>
<tr>
<td>Patients receive ETE before treatment</td>
<td>Yes=71.4%  No=23.8%</td>
</tr>
<tr>
<td>o Receive full ETE before treatment</td>
<td>&quot;Well, after the surgery you have to know what to do, but before the surgery, if you know some of 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, I wanna know 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.&quot; (Pt.# 39)</td>
</tr>
<tr>
<td>Wear a stoma bag for 24 to 48 hours before surgery</td>
<td>Yes=71.4%  No=23.8%</td>
</tr>
<tr>
<td>o Wear stoma bag with fluid to get the sense of how it would feel after treatment</td>
<td>&quot;I think it’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.&quot; (Pt.# 41)</td>
</tr>
<tr>
<td>Talk with a nurse about stoma care and location and use of stoma appliances regardless of treatment preferences</td>
<td>Yes=85.7%  No=4.8%</td>
</tr>
<tr>
<td>o Pictures of stoma care</td>
<td>&quot;Uh, I don’t think it’s helpful... if the purpose of the 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.&quot; (Pt.#12)</td>
</tr>
<tr>
<td>Learn skills needed for health care after treatment</td>
<td>Yes=14.3%  No=14.3%</td>
</tr>
<tr>
<td>o Catherization Stomal bag change</td>
<td>&quot;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.&quot; (Pt.# 83)</td>
</tr>
<tr>
<td>Pictures of different bladder replacements treatments</td>
<td>Yes=85.7%  No=0</td>
</tr>
<tr>
<td>o Anatomical pictures of Bladder and surrounding organs before treatment</td>
<td>&quot;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. And actually, when you see the pictures, and you start thinking about the neobladder, it’s pretty incredible what they do.&quot; (Pt.#27)</td>
</tr>
<tr>
<td>Pictures of stoma appliances and catheters</td>
<td>Yes=90.5%  No=9.5%</td>
</tr>
<tr>
<td>o Pictures of all appliances to be used with stoma</td>
<td>&quot;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.&quot; (Pt.# 12)</td>
</tr>
<tr>
<td>&quot;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.&quot; (Pt.# 46)</td>
<td></td>
</tr>
</tbody>
</table>

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 comprehensive information about each UD option and its side effects, as described in the ETEI's informational module. 90.5% believed they would have benefited from a prepared list of general questions describing and comparing treatment options during their consultations. 48% 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’s medical illustrations (or other similar visual representations of each treatment option) would have enhanced their preoperative understanding of how each UD procedure changes the urinary tract’s anatomy and functioning.

with 90.5% felt that seeing the ETEI’s pictures of stomal appliances and catheters would have helped them prepare for potential postoperative challenges. 85.7% agreed that preoperative discussion with a healthcare professional about 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 benefited 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 have received an educational intervention immediately upon their diagnosis to help them prepare for the surgery’s challenges and postoperative period. About 1 About 19% of the study participants, however, preferred to have received the training module following surgery; they believed that they would have been too emotionally occupied and overwhelmed before hand to be able to properly learn the needed self-care skills (e.g., changing of stomal 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 postsurgical 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. with Qualitative evaluation of participants’ reports provides evidence of such interventions’ necessity.

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...
Patients with MIBC report significant unmet informational and supportive care needs. Yet very few resources are currently available to meet them [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 of MIBC patients have also shown that they need information regarding each operation’s likelihood of effectiveness, risks, benefits, and side effects (both short and long term). Additional knowledge of the self-care skills associated with each treatment choice further facilitates treatment-related decision-making and helps patients 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 typically exceeds the national average reading ability [67]. Hence, mere information of any kind or level of complexity does not necessarily influence the decision-making process. Patients also benefit from integrating treatment option information with their own personal values and preferences. When an educational intervention or patient-clinician discussion regarding treatment options is coupled with clarification of personally relevant values, the exchange of information is much more productive for both the patient and provider alike [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 to 48 hours 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, an equal number of patients expressed preferences for a pre-surgical, rather than post-surgical, hands-on training. Patients’ preference for post-surgical training involved anticipated lower stress levels after surgery. Not only would reduced stress allow for easier learning, these patients believed that newly emerging, post-surgical coping and adaptation processes would have enabled better understanding of complicated self-care information. It is therefore very important to customize educational intervention and provide resources based on patients’ needs and preferences. Studies conducted among other cancer populations (e.g. prostate cancer) have shown that customizing educational tools reduces decisional uncertainty and enhances patients’ understanding of their own values [73].

As our study also suggests, most patients would prefer that their informal caregivers (e.g., partners and spouses) receive the same information and training, particularly before surgery. Our prior qualitative research of MIBC patients showed that many rely on family assistance with self-care [36]. However, most of these family caregivers do not receive formal training for stoma care or catheter use; rather, they learn by trial and error or via internet-based resources. Family caregivers need training in post-operative care both before discharge from the hospital and during the weeks after surgery. The ETEI is meant to a) Provide patients and informal caregivers hands-on post-surgical care training (e.g., for use of catheters and stomal appliances), b) Empower patients to recognize troubling red flag symptoms such as fever, stoma discoloration, and urinary blockage, c) Further inform patients of when to call the medical team to avoid emergency room visits, and d) Instruct patients on when to pursue 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 caregivers 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 eETEI is appropriate for both the patient and the informal care-giver, we did not access the caregiver’s perspective or input on the ETEI content. Examining the
Care-giver’s 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 caregivers.

**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 clinical 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.

**Acknowledgements**

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).

**References**


68. Institute OHR. Ottawa decision support framework: Update, gaps and research priorities.


