

Research Report

Factors Influencing Patient Decision-Making in the Treatment of Muscle-Invasive Bladder Cancer

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Abstract.

BACKGROUND: In 2023, an estimated 82,290 individuals were diagnosed with bladder cancer in the United States. For muscle-invasive bladder cancer (MIBC), the American Urological Association recommends offering radical cystectomy with cisplatin-based neoadjuvant chemotherapy. However, patients are increasingly requesting alternative treatments.

OBJECTIVE: To describe factors influencing selection of radical cystectomy with cisplatin-based neoadjuvant chemotherapy (NAC + RC), radical cystectomy monotherapy (RC), or tri-modality therapy (TMT) among patients with MIBC.

METHODS: Individual, semi-structured phone interviews were conducted with 18 adults who underwent MIBC treatment at the University of North Carolina, recruiting six patients each from three treatment groups: 1) NAC + RC, 2) RC, and 3) TMT. Interview transcriptions were qualitatively analyzed using QSR NVivo, with major themes and sub-themes extracted. Patients also completed the Shared Decision-Making Questionnaire (SDM-Q-9; range 0–100).

RESULTS: Concern for survival and risks, quality of life, and varied patient preferences for involvement influenced the decision-making process. Concern surrounding sexual function, bladder preservation, and urostomy bags drove patients towards TMT. High levels of shared decision-making were observed overall, with a median SDM-Q-9 score of 95 (IQR 89–100). Patients undergoing TMT reported the highest median SDM-Q-9 score (97, IQR 94–100), while those receiving radical cystectomy alone had the lowest (66, IQR 37–96).

CONCLUSIONS: Patients with MIBC described a multifaceted treatment decision-making process, highlighting key influences, concerns, and unmet needs. Understanding this process can help address misconceptions and align treatment choices with patient goals. Physicians can use these insights to engage in shared decision-making, ultimately improving patient experiences and outcomes.

Keywords: Bladder cancer, cystectomy, chemoradiotherapy, decision making, quality of life, patient-centered care

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INTRODUCTION

In 2023, an estimated 82,290 individuals were newly diagnosed with bladder cancer in the United States. This contributes to the over 725,000 individuals living with a bladder cancer diagnosis, making bladder cancer the sixth most common cancer in the United States [1]. Approximately 25% of these patients have muscle-invasive bladder cancer (MIBC) [2]. American Urological Association (AUA) guidelines strongly recommend offering radical cystectomy to patients with MIBC who are eligible for surgery, with the addition of cisplatin-based neoadjuvant chemotherapy to radical cystectomy as the standard treatment [2]. Patients are increasingly pursuing alternate treatment with tri-modality therapy, fostering the need for thoughtful conversation and shared decision-making regarding the most suitable treatment approach [3, 4].

Radical cystectomy involves the removal of the bladder, prostate, and seminal vesicles for males and the removal of the bladder, uterus, fallopian tubes, ovaries, and anterior vaginal wall in females, ultimately resulting in placement of urinary diversions [2]. While it is supported by a long-standing body of evidence, it can also significantly impact patients' quality of life, particularly with regard to urination, sexual dysfunction, and functional independence [5, 6]. The addition of cisplatin-based neoadjuvant chemotherapy is shown to further improve outcomes after radical cystectomy; however, its application is restricted by patients' eligibility and tolerance [7]. Alternatively, tri-modality therapy is a bladder-sparing treatment that appears to have similar outcomes in selected patients with MIBC [4]. It consists of maximum transurethral resection of the bladder tumor followed by concurrent chemotherapy and radiation therapy [2]. It is primarily associated with acute gastrointestinal, hematologic, and genitourinary toxicities, as well as mild long-term toxicities on pelvic organs [6, 8]. Treatment is followed by long-term cystoscopic surveillance, with 11–16% of patients needing salvage cystectomy for recurrence [6, 9, 10].

This treatment decision is a complex and highly personal process for each patient that necessitates shared decision-making, in which patients and their physicians integrate clinical evidence with patients' values and preferences to make choices about care plans [11–13]. Evidence suggests that patient involvement in care decisions increases patient satisfaction, improves knowledge, and reduces distress

[12]. Studies have investigated patient decision-making in the choice of urinary diversion with cystectomy [14–16], gender differences in patient decision-making when pursuing bladder cancer treatment [17], and treatment decisions among patients with bladder cancer generally [18]. While there are numerous studies focused on improving clinical decision-making in bladder cancer treatment, there have been few studies designed to better understand patient decision-making regarding whether to pursue radical cystectomy with or without neoadjuvant chemotherapy or tri-modality therapy.

This study aims to identify reasons for which patients with non-metastatic MIBC choose specific treatment options. Specifically, we will qualitatively analyze semi-structured interviews with patients with MIBC to assess the factors that influence the pursuit of radical cystectomy with neoadjuvant chemotherapy (NAC + RC), radical cystectomy monotherapy (RC), and tri-modality therapy (TMT).

MATERIALS AND METHODS

Study design

This was a qualitative study consisting of in-depth semi-structured interviews to identify factors influencing treatment decision-making in patients with MIBC and to compare these factors across treatment groups.

Participants

Participants were recruited from the multidisciplinary genitourinary oncology clinic in the Lineberger Comprehensive Cancer Center at the University of North Carolina (UNC). Eligible participants were 18 years or older, English-speaking, and had a diagnosis of and treatment for MIBC. The UNC Cancer Registry was reviewed to identify eligible patients who underwent treatment for MIBC between December 2018 and July 2020. Eighteen participants were recruited through purposive sampling, consisting of six from each of the following treatment groups: 1) NAC + RC, 2) RC, and 3) TMT. All new patients with MIBC at UNC are scheduled for a new patient visit with urology, medical oncology, and radiology oncology.

All participants provided informed consent verbally by phone due to the COVID-19 pandemic and the potential risk of face-to-face contact during these

interviews. All participants were offered the ability to withdraw from the study at any time. This study was approved by the Institutional Review Board at UNC (approval number: 20-0398).

Data collection

Demographic and clinical characteristics regarding each patient's bladder cancer diagnosis and treatment were abstracted from medical records. Interviews were conducted by phone by one study team member (LB) from July 2020 to August 2020 using a semi-structured interview guide (Appendix A).

All interviews began with the nine-item Shared Decision-Making Questionnaire (SDM-Q-9), a brief self-assessment tool for measuring patients' perceived level of involvement in decision-making related to their own treatment and care [19]. This initial step, recommended by the embedded patient advocate, was intended to stimulate initial reflection and prime patients for the remainder of the interview. This was followed by open-ended questions about each participant's MIBC treatment and factors most important to their decision-making. Topics discussed included but were not limited to: factors driving the treatment decision, factors that discouraged the choice of alternate MIBC treatments, the participant's understanding of their MIBC diagnosis and treatment options, the influence of lifestyle preferences, the anticipation of the impact of treatment on quality of life, and experiences with recovery. Patients were interviewed independently to capture their individual reflections. The median interview length was approximately 16 minutes. All interviews were audio-recorded and transcribed.

Data analysis

Interview transcriptions were uploaded into NVivo for analysis (QSR International, Version 1.7.1). Two team members (AD, ABS) performed consensus coding to analyze the interview transcripts. Each line was coded and reviewed to derive common themes and sub-themes. Themes and sub-themes were compared across all collected patient characteristics and treatment groups using NVivo queries, as well as cross-referenced with other themes. Themes were then reviewed and revised by the research team. Thematic saturation was largely achieved, with repetition of similar qualitative themes and progressively lower

return of novel insights as interviews proceeded. Patient quotes were selected to highlight identified themes and sub-themes.

Each item in the SDM-Q-9 was scored on a six-point Likert scale from 1 (completely disagree) to 6 (completely agree). Summing all responses for each patient produced a raw score between 9 and 54. These raw scores were then linearly transformed to a composite percentage score, with 0 representing no SDM behavior and 100 representing ideal SDM behavior.

RESULTS

Of the 18 patients interviewed, six received NAC + RC, six received RC, and six received TMT. The average age of participants was 69 years (range 49–82). The majority were men (83%) and white (83%) (Table 1).

Three primary themes surrounding factors influencing the treatment decision for patients emerged: concern for survival and risks, quality of life, and varied preferences for involvement. Three themes also emerged around unmet needs: varied levels of understanding before treatment, unforeseen outcomes, and desired initial discussions (Table 2).

Key priorities in decision-making

Concern for survival and risks

Almost all patients (88%) noted that the probability of survival influenced their decision. While all NAC + RC and 80% of RC patients identified this as a factor, only 50% of TMT patients did. Patients often acknowledged that there could be significant quality-of-life changes associated with their treatment, but they felt that these costs were worth the increased odds of survival. Anxiety about cancer and the fear of its spread often contributed to this factor, driving the treatment decision and urgency with which the treatment was selected. Furthermore, the lack of a guaranteed outcome factored into patients' risk assessment. Three TMT patients felt that although NAC + RC was the standard option, it was not guaranteed to eradicate disease and thus could not justify its invasive nature without first trying other options.

All patients who underwent RC alone and one patient receiving TMT were recommended against pursuing NAC + RC, primarily due to risks from chemotherapy and surgery, respectively. Most of these patients had comorbidities, including compromised renal or pulmonary function, that increased their risk of poor outcomes with these treatments.

Table 1
Summary of participant characteristics (N = 18)

Characteristics	Treatment Group		
	Neoadjuvant chemotherapy + radical cystectomy (n = 6)	Tri-modality therapy (n = 6)	Radical cystectomy monotherapy (n = 6)
Age, years, mean (range)	70 (63–81)	68 (49–82)	68 (57–79)
Gender, n (%)			
Male	4 (67%)	5 (83%)	6 (100%)
Female	2 (33%)	1 (17%)	0 (0%)
Race, n (%)			
White	6 (100%)	6 (100%)	3 (50%)
Black or African American	0 (0%)	0 (0%)	3 (50%)
Months since treatment, mean (range)	3 (0–6)	16 (7–20)	6 (2–14)

Variant tumor histology also contributed to recommendations to exclude NAC + RC.

Quality of life

Twelve patients (67%) reported various quality-of-life and personal attributes that influenced their treatment decision. Most commonly, patients noted a positive attitude and willingness to persevere, which imparted a greater willingness to take on perceived challenges of treatment. Some older patients also noted an increased willingness to compromise on their quality of life due to a less active lifestyle, fewer commitments, and reduced prioritization of appearance. However, this attitude was not universal across all older patients.

Among several male NAC + RC and RC only patients, sexual function was a consideration and increased the difficulty of the decision, but it did not ultimately alter the decision made. Some patients reported initially having hope for some degree of preserved sexual function following cystectomy.

The majority of TMT patients (67%) brought up their desire for bladder preservation during the interview. Patients were less familiar with cystectomy, finding it confusing and perceiving it to be an extreme decision that they did not want to pursue until absolutely necessary. Similarly, many TMT patients (50%) were averse to the removal of the bladder because of the consequent need for a urostomy bag. One NAC + RC patient felt similarly, noting this significantly factored into their decision but ultimately did not outweigh other priorities. Patients reported concerns that the urostomy would lower overall quality of life, particularly by reducing activity levels and adding inconvenience.

Varied preferences for involvement

Participants discussed different preferences regarding their involvement in the treatment decision-making process. Nine patients (50%) described a shared-decision making approach in which they considered physician recommendations in the context of personal desires and external sources of information. External sources most commonly included loved ones and independent research, followed by experiences of other bladder cancer patients. Notably, most TMT patients (80%) preferred shared decision-making, often assuming an active role in steering treatment conversations.

Alternatively, nine patients (50%) deferred to the recommendation of their physicians. Six of these patients were comfortable with and preferred this approach, viewing physicians as the experts and better suited to make treatment decisions. However, three of these patients, all of whom received RC, felt that this passive approach was involuntary. They reported feeling that they did not have any agency or options beyond the physician's recommendation.

To quantitatively assess the extent of shared-decision making, patients reported their experiences using the SDM-Q-9 scale. The overall median scaled SDM-Q-9 score was 95 (IQR 89–100). TMT patients reported the highest average perception of SDM, while patients receiving RC reported the lowest (Table 3). Of the nine items on the SDM-Q-9, four received responses averaging lower than 5.0 out of 6.0: “My doctor told me that there are different options for treating my medical condition” (4.3), “My doctor asked me which treatment option I prefer” (4.7), “My doctor and I thoroughly weighed the different treatment options” (4.9), and “My doctor and I selected a treatment option together” (4.9).

Table 2
Themes and subthemes with representative quotations

Themes and subthemes	Representative quotations
Concern for survival and risks	
Chance for survival	<ul style="list-style-type: none"> • “I knew that it was gonna make me sick and I was gonna lose my hair, but that was minor in comparison to how I believed it would help me just survive.” –NAC + RC
Lack of guaranteed outcome	<ul style="list-style-type: none"> • “The options were to be even if I had the bladder removed, it may not be completely effective. And the cancer could return... so it was a gamble.” –TMT
Quality of life	
Positive attitude, willingness to persevere	<ul style="list-style-type: none"> • “I was just optimistic. I understood that there were going to be things that would affect me from the treatment... But I realize that you have to have a certain amount of persistence, and you can’t expect it to be the same as taking a couple of Aspirin and your headache going away.” –TMT • “I thought well, you know, ‘Here they go. They’re gonna take it out. They’re gonna create a different channel. I’m gonna have to wear an appliance.’ Okay, big deal. When you’re faced with something like that, you just do what you have to do.” –RC
Older age	<ul style="list-style-type: none"> • “You realize that okay, so you’re gonna have an ostomy bag... I’m 79 years old. I got no vanity left, so it’s no big deal!” –RC
Sexual function	<ul style="list-style-type: none"> • “I’m glad I was single at the time because the sex life part was difficult, you know.” –NAC + RC • “We discussed [that] there’s a 50/50 chance that I could have [sexual function]. That’s the understanding I took... I don’t know where his 50 went. My 50 was still hoping I’d get it, but I didn’t.” –RC
Desire for bladder preservation	<ul style="list-style-type: none"> • “Oh, having the bladder removed seemed very drastic... I felt like that was jumping to the end, and I didn’t want to jump to the end if I didn’t have to.” –TMT
Urostomy bag avoidance	<ul style="list-style-type: none"> • “I said, well, look, after we exhaust all other things, then maybe we’ll do the bag, but I doubt it [laughs].” –TMT
Varied preferences for involvement	
Preferred shared decision-making	<ul style="list-style-type: none"> • “My father and I said, ‘What if we don’t want to do [the standard treatment], what happens?’ Then [the doctor] talked about other decisions people have made.” –TMT
Deferred to physician recommendation	<ul style="list-style-type: none"> • “I just go along with what my doctors say... I’m not the expert in the field.” –NAC + RC • “I didn’t even go online and research anything. I really didn’t want to... I was in complete confidence with the doctors, everybody. I was happy with everything.” –NAC + RC
Felt lack of agency in decision-making	<ul style="list-style-type: none"> • “I basically didn’t make the decision. They told me there wasn’t nothin’ they could do to then catch it... They told me it was just one option. They had to take my bladder.” –RC
Varied levels of understanding before treatment	
Felt that they understood well	<ul style="list-style-type: none"> • “I really didn’t have a lot of confusion about it. It was explained to me pretty well I would say.” –NAC + RC
Reported confusion	<ul style="list-style-type: none"> • “I wanna know why it was so urgent to take my bladder out and my prostate.” –RC

(Continued)

Table 2
(Continued)

Themes and subthemes	Representative quotations
Unforeseen outcomes	
Positive surprises	<ul style="list-style-type: none"> • “I still was sick... but it wasn’t as awful as I thought it was. As far as the recovery from the surgery, I was amazed at how quickly I was recovering, or how good I felt that I could get up that day and walk, that kind of thing.” –NAC + RC • “I was worried about wearing the bag and all that stuff. It was like, ‘Wow, this is gonna be crazy,’ but again, I was pleasantly surprised that it really hasn’t changed anything. It has its positive things.” –NAC + RC • “The [chemoradiation] was pretty tough while it was goin’ on... but after it was all said and done, I lost some weight and feel 20 years younger.” –TMT
Negative surprises	<ul style="list-style-type: none"> • “I change the bag about three times a day and it still leaks... everything is full of pee and smells like urine, and it’s coming straight out of my belly... I didn’t think it [would] have such a negative impact on my life.” –RC • “Erectile dysfunction really had a very bad, negative impact on my social life... It was after the operation I’ve become aware of all these things... I didn’t know until after the surgery that nothing should ever come out of my penis again.” –RC • “Now when I get the urge that I have to go [urinate], I really need to go... I really didn’t expect that.” –TMT
Desired initial discussions	
Treatment consequences	<ul style="list-style-type: none"> • “I didn’t even know they would take the prostate out. They told me that afterward... [I wish they had] given more information about the consequences because I had no idea.” –RC • “Something that they may need to do in the future with future patients is to explain some of these little oddities that are gonna happen.” –RC
Additional desired changes (e.g., alternative treatment options, more time with physicians, referrals to peer support)	<ul style="list-style-type: none"> • “I wish they had told me all the options and... tried the basic ones before they removed my bladder.” –RC • “[Physicians are] awful busy and things get glossed over a little bit. I don’t need to know every darn thing, but a couple things extra might have been good to know.” –RC • “I really wanted to talk to someone who had been through it. Even if it’s for what to prepare for if I decided to do this. I would really like that.” –TMT

Abbreviations: NAC + RC = patient who received neoadjuvant chemotherapy + radical cystectomy, TMT = patient who received tri-modality therapy, RC = patient who received radical cystectomy monotherapy.

Table 3

Average responses to Shared Decision-Making Questionnaire (SDM-Q-9) stratified by treatment group ($N = 18$)

Treatment Group	<i>N</i>	Median scaled score (IQR)
Overall	18	95 (89–100)
Tri-modality therapy	6	97 (94–100)
Neoadjuvant chemotherapy + radical cystectomy	6	94 (89–100)
Radical cystectomy monotherapy	6	66 (37–96)

Unmet needs

Varied levels of understanding before treatment

Participants had different levels of understanding about their diagnosis and treatment options. All NAC+RC and 50% of RC and TMT patients felt that they understood their conditions well before making a decision. Patients felt that the situation was explained clearly, with medical teams answering questions comprehensively. However, six patients (33%) reported confusion about their conditions, particularly about the need to pursue bladder removal, post-treatment outcomes and plans, and sexual function. Notably, four of these patients were younger (<65 years). Among the lowest quartile of SDM-Q-9 scores ($SDM-Q-9 \leq 89$), most patients (67%) reported a poorer understanding of their condition and care plan before treatment.

Unforeseen outcomes

Almost all patients (83%) experienced surprises after the treatment, both positive (53%) and negative (80%). Positive surprises were evenly distributed across all treatments; only one patient in the lowest quartile of SDM-Q-9 scores reported positive surprises, however. Positive outcomes included a better recovery experience with regard to speed, efficacy, and general feelings of wellness, less debilitating side effects, and urostomy benefits.

Negative surprises were reported by all RC patients, as well as 50% of NAC+RC and TMT patients. Most commonly, patients found their recovery experience to be more challenging than expected, particularly in terms of recovery length, complications, and resulting bowel and urinary dysfunction. Two TMT patients felt surprised at the intensity of the chemoradiation. Furthermore, four patients noted challenges with the urostomy bag, particularly inconvenience, odor, and anxiety about leakage. Similarly, four patients, all who received RC, expressed frustration at their resulting sexual dysfunction.

Desired initial discussions

Eleven patients (61%) noted topics that they wish their physicians had initially discussed (Table 4). This population consisted of all RC, four TMT, and one NAC+RC patient. Eight of these patients, six of whom received RC, desired a more comprehensive discussion of treatment consequences, specifically the impact on urination and bowel habits (88%), sexual function (63%), and the general recovery process (25%). Furthermore, patients sought more initial information on alternative treatments (45%), longer consultations with their doctors (36%), and referrals to peer support (27%). Patients in the lowest quartile of SDM-Q-9 scores in particular desired more initial discussions on alternative treatments and the impact of sexual function. Patients noted that counseling on these elements, particularly additional time with the doctors, would have facilitated more informed and easier treatment decisions.

DISCUSSION

Patients with MIBC undergo a multifaceted treatment decision-making process. Here, we report a qualitative evaluation of factors influencing treatment decision-making among patients with MIBC. Qualitative analysis of in-depth semi-structured interviews revealed key priorities in the decision-making process, specifically concern for survival and risks, quality of life, and varied patient preferences for involvement. Additionally, patients provided insight into unmet needs along the treatment journey, particularly varied levels of understanding before treatments, unforeseen outcomes, and desired initial discussions.

Our findings suggest that many patients are driven towards NAC+RC, the more aggressive and invasive treatment, due to their prioritization of survival and fear of cancer. This is consistent with previous research that establishes the chance for survival as a priority for patients with bladder cancer, significantly influencing their treatment journey [18, 20]. A recent qualitative study reported that patients perceive RC treatments as more curative than TMT due to the invasiveness and rapid tumor removal, supporting our observation that survival-focused patients largely prefer NAC+RC [21]. Similar decision-making patterns have also been documented among some groups of patients with prostate cancer [22, 23–25]. In addition, we found that several patients pursuing NAC+RC noted quality-of-life considerations, such as sexual function and changes to urination. However,

Table 4
Desired initial discussions by treatment based on reported patient concerns

Treatment group	Desired initial discussions
Radical cystectomy (with or without neoadjuvant chemotherapy)	<ul style="list-style-type: none"> ● Rationale for treatment recommendations ● Other treatment options ● Risk of complications and anticipated recovery ● Sexual dysfunction ● Urostomy bag challenges and care ● Peer support options
Tri-modality therapy	<ul style="list-style-type: none"> ● Rationale for treatment recommendations ● Impact on urination and bowel movements ● Intensity of chemotherapy and radiation

these concerns did not outweigh the focus on survival or impact the ultimate treatment decision. This finding builds upon literature in prostate cancer in which patients getting radical prostatectomy reported concerns for similar side effects that ultimately did not influence the treatment choice [25].

Conversely, we found that patients with strong wishes for bladder preservation and urostomy bag avoidance opted for TMT, despite recommendations by the AUA and often their physicians for NAC + RC [2]. Several of these patients found that treatments involving RC were excessively invasive as an initial step. This preference is consistent with a similar qualitative study in Belgium that found patients pursued TMT because they felt it would preserve their physical integrity and activity levels [21]. Our findings also extend phenomena seen among other populations of prostate cancer patients, where a greater aversion to side effects pushed them away from more aggressive treatments, even though this was against physicians' recommendations in many cases [23].

We saw that patients who underwent TMT sought greater involvement in the treatment decision process, which was reflected by higher SDM-Q-9 scores. This suggests that patients opting for TMT largely prefer more involved shared decision-making, whereas other patients were satisfied with deferring entirely to physician recommendations. Previous qualitative research exploring decision-making for treatment among patients with prostate cancer [22, 26], bladder cancer surveillance [27], and various types of bladder cancer [18, 21] report that patients have differing opinions on their involvement in care and treatment choices. We corroborate these findings, as well as expand upon them to provide insight into processes among patients receiving TMT.

In contrast, all patients who underwent RC received this treatment due to recommendations against pursuing NAC + RC. We found that half of these patients reported poorer understanding of their

conditions and that this cohort had the lowest SDM-Q-9 scores, indicating lower feelings of engagement in the decision-making process. All patients receiving RC also reported negative surprises and would have preferred a more comprehensive discussion of treatment consequences earlier, especially regarding changes in urinary, bowel, and sexual function. These themes were less commonly noted by patients receiving NAC + RC and TMT. Of note, because patients receiving NAC + RC and TMT have more appointments to receive their non-surgical therapies, these patients interface with their care team more frequently than patients who undergo RC. As such, it is more likely that patients receiving RC alone have fewer opportunities for discussion and patient learning. Altogether, these findings suggest that an initial lack of understanding may decrease feelings of agency and satisfaction throughout the treatment process. This could indicate that patients with exclusionary criteria and comorbidities in particular require more detailed information about their treatment options and enhanced engagement strategies.

This study highlights several unmet needs in the treatment decision-making process for patients with MIBC. Despite physicians discussing side effects and treatment plans, many patients still experienced unforeseen outcomes and expressed a desire for more comprehensive information prior to treatment. Patients with lower SDM-Q-9 scores especially reported these gaps, suggesting a close link between perception of adequate information provided and sense of agency in their treatment decisions. In particular, patients felt that there was insufficient discussion of all treatment options, recovery, potential sexual dysfunction, and urostomy bag challenges. These findings build upon those from a qualitative review of information needs in patients with bladder cancer undergoing radical cystectomy, which similarly highlight how patients felt that they did not receive enough

information about side effects, recovery times, and post-operative care prior to treatment [28]. Though providing this information earlier may not change patient decisions, it may improve the patient experience and mitigate disparities in unexpected outcomes.

The present study has several limitations. First, the study was conducted at a single academic medical center, with the majority of patients identifying as white (83%) and male (83%) and an average age of 69 years. This distribution is similar to the documented incidence rates of MIBC, with 90% of patients identifying as white and 74% as male and an average age of 68 years [29]. Nonetheless, the findings may not be generalizable to all MIBC patients, particularly those who are not white, identify with other genders, or are younger. Additionally, comprehensive data were not available on patient education or support systems, preventing analysis of these potential influences on decision-making. The smaller, non-random sample also limited the quantitative analysis of the SDM-Q-9 data. However, we found that the sample largely achieved thematic saturation.

This study has several important implications. First, this data can inform the development of larger, multi-institutional studies that explore perceptions of a broader and more diverse patient population. Additionally, this study provides insight into the complex treatment decisions of patients with MIBC, providing a basis on which to develop more accessible and effective patient-centered resources. Physicians should appreciate key factors and concerns in each patient's decision-making process and their perceptions about treatment options. With this knowledge, physicians can address treatment misconceptions and better equip patients to navigate complex decisions regarding choice of therapy. This understanding can improve the alignment of treatment choices with patient goals, ultimately advancing patient experiences, satisfaction, and outcomes.

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AUTHOR CONTRIBUTIONS

Avani Desai: performance of work, interpretation of data, writing the article.

Lucas Bouknight: performance of work.

Thomas Reed: interpretation of data, writing the article.

Dana Mueller: writing the article.

Chelsea Osterman: interpretation of data, writing the article.

Michael Repka: interpretation of data, writing the article.

Tracy Rose: interpretation of data, writing the article.

Angela B. Smith: conception, performance of work, interpretation of data, writing the article.

All authors had access to the data.

CONFLICT OF INTEREST

Angela B. Smith is an Editorial Board member of this journal, but was not involved in the peer-review process nor had access to any information regarding its peer-review. She also reports research funding support from PCORI, AHRQ, Genentech, and Merck-RTI, as well as membership on the Society of Women in Urology (SWIU) Board of Directors, American Urological Association (AUA) Science and Quality Council, Journal of Urology Editorial Board, and Bladder Cancer Advocacy Network (BCAN) Scientific Advisory Board. Thomas Reed reports personal holdings in Pfizer and Abbott stock.

Avani Desai, Lucas Bouknight, Dana Mueller, Chelsea Osterman, Michael Repka, and Tracy Rose have no conflicts of interest to report.

DATA AVAILABILITY

The data supporting the findings of this study are available on request from the corresponding author. The data are not publicly available due to privacy or ethical considerations.

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APPENDIX A

Interview Questions

SDM-Q-9

With each statement that I read, I would like you to tell me if you completely disagree, strongly disagree, somewhat disagree, somewhat agree, strongly agree, or completely agree.

1. My doctor made it clear that a decision needs to be made regarding treatment of bladder cancer.
2. My doctor wanted to know exactly how I want to be involved in making that decision.
3. My doctor told me that there are different options for treating my medical condition.
4. My doctor precisely explained the advantages and disadvantages of the treatment options.
5. My doctor helped me understand all the information.
6. My doctor asked me which treatment option I prefer.
7. My doctor and I thoroughly weighed the different treatment options.
8. My doctor and I selected a treatment option together.
9. My doctor and I reached an agreement on how to proceed.

Open-Ended Questions

1. What factors led you to choose to undergo <treatment> for your bladder cancer?
2. What factors made you decide not to undergo <alternative treatments>?
3. Do you feel that there were any aspects of your diagnosis and/or treatment that you did not fully understand? If so, what were those aspects?
4. How did your lifestyle preferences impact your choice in treatment?
5. How did you envision that treatment would impact your quality of life?
6. How did changes in your bowel habits impact your treatment decision?
7. Were there any factors that your doctor did not discuss but wish that they would have discussed before treatment?
8. What would have helped you in your treatment decision making?
9. Is there anything else you would like us to know about your treatment decision for bladder cancer?