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Patient and Provider Perception of Transurethral Resection of Bladder Tumor vs Chemoablation for Nonmuscle-invasive Bladder Cancer Treatment

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Full-length article available at https://doi.org/10.1097/JU.0000000000002941.

Study Need and Importance: Given the need for ongoing surveillance with cystoscopy and the high likelihood of recurrence requiring transurethral resection of bladder tumor (TURBT), nonmuscle-invasive bladder cancer (NMIBC) can be burdensome for patients even when compared to other urological malignancies. As such, nonsurgical alternative treatments for NMIBC such as intravesical chemoablation are being explored with promising results. With the increasingly active role of patients in treatment decision making, understanding patient perception of intravesical chemoablation as it relates to TURBT is imperative to achieve value-based care.

What We Found: In this mixed methods study, we elicited both patient and provider perceptions of repeat TURBT as a treatment for NMIBC. Our study demonstrated a significant proportion of patients preferring intravesical chemoablation to conventional TURBT when provided with this alternative as a hypothetical treatment option for NMIBC. Furthermore, we identified differences between the way patients and urologists perceive repeat TURBT for bladder cancer. Specifically, patients but not urologists emphasized the emotional toll of the procedure along with the need for improved counseling regarding recurrence, terminology, and cancer-related signs and symptoms.

Limitations: Identifying our patient sample through an advocacy network and recruiting providers through snowball sampling may introduce selection bias given that respondents may not represent the general population and providers within a similar social network may likewise counsel patients similarly. Furthermore, our sample was homogeneous with a majority of White and male respondents. Other limitations include recall bias inherent to self-reported pathological data, missingness in health-related quality of life data, and selective sampling, which may introduce respondent bias.

Interpretation for Patient Care: As alternative treatment options for NMIBC emerge, shared decision-making becomes increasingly important. Understanding the burden of NMIBC treatment on quality of life is critical when framing these shared decision-making discussions. The discordance between patient and provider TURBT perception highlights the need to expand our understanding to better improve the patient experience through relevant and patient-centered education. Our study provides specific areas of discordance and ways in which they can be addressed through patient educational resources.

https://doi.org/10.1097/JU.0000000000002941
Vol. 209, 150-160, January 2023
Printed in U.S.A.

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www.auajournals.org/journal/juro

Patient and Provider Perception of Transurethral Resection of Bladder Tumor vs Chemoablation for Nonmuscle-invasive Bladder Cancer Treatment

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Purpose: The aim of this mixed methods study was to investigate patient and provider perceptions of repeat transurethral resection of bladder tumors to improve counseling as new nonsurgical treatment modalities for nonmuscle-invasive bladder cancer emerge.

Materials and Methods: Quantitative data were collected via a web-based survey through the Bladder Cancer Advocacy Network of patients with nonmuscle-invasive bladder cancer who had undergone at least 1 transurethral resection of bladder tumor. Bivariable and multivariable analyses were performed to evaluate associations of patient demographics and clinical variables with treatment preference. Qualitative data were collected with 60 in-depth telephone interviews with patients (n=40) and urologists (n=20) to understand experiences with bladder cancer and transurethral resection of bladder tumor. Telephone interviews were conducted by trained qualitative experts. Transcripts were imported into Dedoose to facilitate analysis.

Results: Survey data of 352 patients showed 210 respondents (60%) preferred repeat transurethral resection of bladder tumor while 142 (40%) preferred intravesical chemoablation. Patients who preferred repeat transurethral resection of bladder tumor were more likely to prioritize initial treatment effectiveness (63%), whereas those who preferred chemoablation prioritized risk of recurrence (55%). Variables associated with a preference for intravesical chemoablation included U.S. residence (OR=2; 95% CI 1.1, 3.8), or if they expressed their reason for treatment preference as priority of recurrence risk over effectiveness (OR=14.6; 95% CI 7.4, 28.5). Predominant interview themes varied across participants, with patients but not urologists emphasizing the emotional toll of the procedure along with the need for improved counseling regarding recurrence, terminology, and cancer-related signs and symptoms.

Conclusions: Differences exist in the way patients and urologists perceive repeat transurethral resection of bladder tumor for bladder cancer. Understanding transurethral resection of bladder tumor perception will aid in shared decision making as novel treatments emerge for nonmuscle-invasive bladder cancer.

Key Words: urinary, bladder neoplasms, cystoscopy, patient reported outcome measures

Submitted May 10, 2022; accepted August 12, 2022; published September 6, 2022.

Support: Bladder Cancer Advocacy Network Patient Survey Network Award, sponsored by Urogen Pharma. The funding source for this study had no role in the analyses, interpretation of the data, or decision to submit results.

Conflict of Interest: AS reports work as a consultant for Urogen Pharma and Merck as well as research funding from PCORI, AHRQ, Genetech, and Merck-RTI.

Ethics Statement: This study received Institutional Review Board approval (IRB No. 20-3255).

Author Contributions: The authors confirm contribution to the paper as follows: study conception and design: TP, KR, DM, RT, MV, RL, AS. Data collection: TP, KR, RB, DM, RT, MV, JCA, KS, KG. Analysis and interpretation of results: TP, KR, RB, RT, MV, JCA, KS, KG, RL, AS. Draft manuscript preparation: TP, KR, RT, AS. All authors reviewed the results and approved the final version of the manuscript.

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https://doi.org/10.1097/JU.0000000000002941
Vol. 209, 150-160, January 2023
Printed in U.S.A.

Bladder cancer is the sixth most common malignancy in the United States, and approximately 75% of patients present with nonmuscle-invasive bladder cancer (NMIBC).[1-3] The standard of care for bladder cancer diagnosis and treatment is transurethral resection of bladder tumor (TURBT), followed by chemotherapy or immunotherapy in certain cases.[4] NMIBC has a high rate of recurrence of 30%-40% at 1 year and up to 70% at 5 years.[5] Consequently, NMIBC requires long-term surveillance with cystoscopy and intravesical therapy.

Inherent to the high recurrence rate and long-term management of NMIBC, patients often undergo multiple surgical procedures over their lifetime which can influence health-related quality of life (HRQoL).[6,7] Given the link between HRQoL decline and TURBT, alternative treatments for NMIBC are being explored to lessen the negative impact multiple surgical procedures has on patients. One such alternative to surgical management under investigation is intravesical chemoablation. Several contemporary studies examining chemoablation suggest a complete response rate of approximately 50%-65% with sustained therapeutic effect for at least 2 years.[2,8-10]

Given the promise of chemoablation as a viable alternative to surgical management, patient perception of treatment needs to be defined. Therefore, our objective was to evaluate patient preference for repeat TURBT vs chemoablation for bladder cancer and identify associations between patient and disease characteristics with treatment preferences using a mixed methods approach. Following the administration of a survey to elicit patient preferences, semi-structured interviews were conducted with patients with bladder cancer and urologists who treat bladder cancer, to deepen our understanding of the perception of TURBT and alternative nonsurgical options such as chemoablation.

METHODS

Quantitative

Study Design and Participants. This cross-sectional study was advertised by the Bladder Cancer Advocacy Network Patient Survey Network,[11] through which patients were identified to evaluate patient perception of repeat TURBTs among patients with NMIBC and associated treatment preference (n = 352). Bladder Cancer Advocacy Network Patient Survey Network members were invited by email to participate in a 1-time web-based Qualtrics survey designed by the study team and reviewed and revised by a patient advocate. Inclusion criteria were self-identified patients with NMIBC. Participants were required to have undergone at least 1 TURBT, be at least 18 years of age, be able to read English, and complete a web-based survey. For recruitment, a 1-time web-based survey was distributed via Qualtrics in May 2020 (supplementary Appendix A, https://www.jurology.com). Participants were asked to provide online consent prior to answering questions. Two reminders were sent, and the survey was closed June 2020. The study was exempt from the Institutional Review Board at the University of North Carolina at Chapel Hill.

Data Collection. Patients and caregivers were queried regarding demographics (eg, age, insurance, education, household income, marital status, and country of residence), bladder cancer characteristics (patient/caregiver status, number of TURBTs, years since last TURBT, years since first cancer diagnosis, tumor stage and grade, other bladder cancer treatments received, and the number of additional comorbidities), validated quality of life (QOL) measures, and treatment preference.

We measured bladder cancer–specific QOL with the EORTC (European Organisation For Research and Treatment Of Cancer) NMIBC24, a validated patient-reported outcome measure which assesses HRQoL for patients with NMIBC through 9 symptom scales and 2 functional scales.[12] Responses were scored from 0 to 100, with a higher score representing higher level of functioning whereas a high score for the symptom scales represented a high level of symptomatology or problems.

Patient preferences for treatment were ascertained by providing 2 hypothetical treatments (ie, TURBT vs intravesical chemoablation) which described delivery method, side effects, effectiveness for initial complete response, and risk of subsequent recurrence. Survey respondents were asked about side effects from prior TURBTs, how well informed they were regarding TURBT side effects, if their experience with TURBT was better or worse than their expectation, and information they wished they would have known prior to TURBT.

Analysis. Descriptive statistics were used to report participant demographics, clinical characteristics, and treatment preference. Bivariable analyses (ie, χ^2 or exact tests) were performed to evaluate associations of patient demographics and clinical variables with treatment preference. Overall QOL scores were also analyzed and associations with treatment preference were assessed using a *t*-test. Multivariable logistic regression analysis was performed to examine the relationship of treatment preference with reason for treatment preference and patient characteristics (ie, age, insurance, marital status, and country of residence) and clinical variables (ie, prior intravesical therapy, years since last TURBT, and number of prior TURBTs). Odds ratios and 95% confidence intervals were calculated for variables included in the regression analysis. P value $< .05$ was deemed statistically significant.

Qualitative

Study Design and Participants. Patients who participated in the survey were invited to provide their contact information if they were interested in participating in a follow-up interview. Those who agreed were purposively sampled by age, gender, race, ethnicity, treatment preference, and region. Urologists who agreed to participate in an interview were selected through snowball sampling urologists around the country who treat patients with NMIBC.

Data Collection. A total of 60 individual interviews (40 patients and 20 urologists) were conducted between August-November 2020 (supplementary Appendix D, https://www.jurology.com). A subset of 10 Canadian patients were

included in the overall patient sample, given the differences in results between Canadian and U.S. patients noted in the quantitative analysis. Interviews were conducted by trained qualitative researchers with extensive experience facilitating conversations with health care stakeholders. Interviews were conducted by telephone and lasted approximately 30-60 minutes. The interviewers followed 2 semi-structured interview guides, 1 to guide patient interviews (supplementary Appendix B, https://www.jurology.com) and 1 to guide urologist interviews (supplementary Appendix C, https://www.jurology.com), designed by our study team and patient advocate (R.L.) to elicit insights and descriptive detail from both patient and urologist perspectives. Participants received a $50 gift card for completing the interview.

Analysis. All interviews were digitally recorded and transcribed verbatim. Transcripts were imported into Dedoose, a qualitative research software management tool, to facilitate analysis. A codebook was developed based on the research questions and notes taken during data collection. Standard consensus coding guidelines were followed and iterative meetings were held to resolve code application and reach replicability on coding for all transcripts. Code reports were generated for each code and narrative summaries included a description of the emergent themes and sub-themes, with illustrative quotes highlighting each theme.

RESULTS

Quantitative

Patient Demographics and Clinical Characteristics. A sample of 352 patients with NMIBC were included in the study who provided complete information about treatment preference (Table 1). Respondents were predominantly male (61%) and between the ages of 65-74 years old (43%), consistent with the bladder cancer patient population. The majority of patients (95%) in this sample were non-Hispanic White and married (73%) with at least a college degree (72%) and a total household income greater than $80,000 per year (49%). Respondents were more likely to be insured, with either public (45%) or private (41%) insurance. Nearly all respondents identified as residents of either the United States (59%) or Canada (36%). Nearly half of patients were initially diagnosed more than 5 years prior (49%) and had received their last TURBT within the past 1-5 years (41%; Table 2).

HRQoL. Median scores for symptom and functional scales of the EORTC NMIBC24 were similar among patients who preferred surgery vs chemoablation (Table 3), although patients who preferred chemoablation had slightly more urinary symptoms and slightly worse sexual function, although not statistically significant.

Treatment Preference and Predictors. Overall, 210 respondents (60%) preferred repeat TURBT for treatment of recurrent bladder cancer while 142 (40%) preferred intravesical chemoablation. Important drivers of treatment preference were the respondents' interest in initial effectiveness of treatment and risk of recurrence. Respondents who preferred repeat TURBT selected effectiveness as their reason for treatment preference (63%), whereas those who preferred chemoablation prioritized risk of recurrence (55%).

On bivariable analysis, the only patient demographic associated with a preference for intravesical chemoablation included U.S. residence ($P = .02$; Table 1). Bivariable analysis of clinical variables showed an association of preference for intravesical chemoablation with a more recent TURBT ($P = .03$), high tumor grade ($P = .03$), and priority of recurrence risk ($P < .001$; Table 2). Recognizing that tumor grade and receipt of prior intravesical therapy may be related, patients with high grade were more likely to receive intravesical therapy than those with low grade (87% vs 75%, $P = .003$). However, on multivariable analysis, prior receipt of intravesical therapy was not associated with treatment preference. Similarly, tumor grade was not significant on multivariable analysis and removed from the model to avoid model overfit. On the final

Table 1. *χ^2 Test of Association Between Patient Characteristics and Treatment Preference for Recurrent Bladder Cancer (n=352)*[a]

Characteristic	Preference for repeat TURBT, No. (%) (n=210, 60%)	Preference for intravesical chemoablation, No. (%) (n=142, 40%)	*P* value
Male gender (n=350)	129 (62)	85 (60)	.8
Age, y (n=339)			.4
≤55	18 (9)	8 (5.8)	
56-64	55 (27)	33 (24)	
65-74	82 (40)	68 (49)	
75+	46 (23)	29 (21)	
Highest level of education (n=337)			.3
≤High school	18 (9.1)	9 (6.5)	
Some college	29 (15)	29 (21)	
≥College	152 (76)	100 (72)	
Total income of household, $ (n=310)			.9
≤40,000	21 (11)	13 (10)	
41,000-80,000	62 (33)	44 (35)	
>80,000	103 (55)	67 (54)	
Insurance (n=330)			.9
Public	91 (46)	66 (50)	
Private	88 (45)	56 (42)	
None or missing	14 (7.1)	9 (6.7)	
Other	4 (2)	2 (1.5)	
Marital status (n=334)			.3
Previously married	23 (12)	24 (17)	
Currently married	157 (79)	99 (72)	
Never married	17 (8.7)	14 (10)	
Resident of United States[b] (n=338)	113 (56)	94 (69)	.02[c]

Abbreviation: TURBT, transurethral resection of bladder tumor.
[a] Missing data noted in some categories results in totals <352 and percentages <100. By row, missing values are as follows: gender=2, age=13, education=15, income=42, insurance=22, marital status=18, country=14.
[b] Compared against all other countries combined, including Canada.
[c] Statistically significant at $\alpha = .05$.

Table 2. *χ^2 Test of Association Between Clinical Characteristics and Treatment Preference for Recurrent Bladder Cancer*[a]

Characteristic	Preference for repeat TURBT, No. (%) (n=210, 60%)	Preference for intravesical chemoablation, No. (%) (n=142, 40%)	*P* value
Tumor grade (n=346)			.03[b]
Low	85 (41)	42 (30)	
High	121 (59)	98 (70)	
No. TURBTs (n=351)			.8
1	39 (19)	29 (20)	
2	69 (33)	40 (28)	
3	36 (17)	25 (18)	
>4	65 (31)	48 (34)	
Years since last TURBT (n=352)			.03[b]
In the past year	60 (29)	60 (42)	
1-5	94 (45)	51 (36)	
>5	56 (27)	31 (22)	
Prior receipt of intravesical therapy (n=352)	173 (82.4)	118 (83)	.9
Years since cancer diagnosis (n =352)			.5
In the past year	21 (10)	20 (14)	
1-5 years	85 (40)	53 (37)	
>5 years	104 (50)	69 (49)	
Reason for treatment preference (n=347)			<.001[b]
Effectiveness	130 (63)	22 (16)	
Risk of recurrence	32 (16)	77 (55)	
Treatment type	33 (16)	22 (16)	
Other	11 (5.3)	20 (14)	

Abbreviation: TURBT, transurethral resection of bladder tumor.
[a] Missing data noted in some categories results in totals <352 with number of missing for each row as follows: grade=6, number of TURBTs=1, reason for treatment preference=5.
[b] Statistically significant at $\alpha=0.05$

multivariable analysis (Table 4), patients were more likely to prefer chemoablation if a U.S. resident (OR=2; 95% CI 1.1, 3.8) or if they expressed their reason for treatment preference as priority of recurrence risk over effectiveness (OR=14.6; 95% CI 7.4, 28.5).

Patient Experience. Patients were asked an open-ended question in the survey regarding 1 thing they wished their doctor knew about their experience with TURBT(s). Several common themes emerged from these responses, the most common being inadequate information regarding the discomfort associated with TURBT, risks and complications, catheter expectations, postoperative symptoms, and expected recovery. Less common themes included uncertainty and anxiety surrounding pathology, effectiveness of treatment, and recurrence risks, as well as risks of anesthesia and timing of postoperative information delivered while the patient was sedated. Themes were incorporated in the semi-structured interview guide to explore in more depth.

Qualitative

Similarities of TURBT Views by Patients and Urologists. Patients and urologists both recognized the physical toll of the procedure, including physical discomfort (Table 5). Both groups also shared similar ideas of what aspects of TURBT improved (reduced anxiety, improved communication, acceptance of unknown, tolerability) and worsened (treatment fatigue, anxiety about repeat surgery and recurrence, negative impact on health) over time with repeat procedures (Table 6). Patients and urologists also identified the preoperative setting as the most appropriate time to improve counseling, recognizing the importance of discussion regarding side effects, complications, and catheters (Table 7).

Differences in TURBT Views by Patients and Urologists. While urologists described TURBT as a minor procedure, patients described a major procedure with significant emotional implications (Table 5). Significant differences in the information patients sought preoperatively and the topics urologists routinely discussed in their preoperative counseling included

Table 3. t-*Test of Quality of Life Scores by Treatment Preference*[a]

Patient-reported measure	Preferred surgery, median (IQR) (N=210)	Preferred chemoablation,median (IQR) (N=142)	*P* value[b]
Symptom scales (higher score=higher level of symptomatology or problems)			
Urinary symptoms (N=245)	19 (28.5)	23.8 (23.8)	.12
Malaise (N=246)	0 (0)	0 (0)	.6
Intravesical treatment issues (N=246)	0 (33.3)	0 (33.3)	.5
Future worries (N=247)	33.3 (33.3)	41.7 (41.7)	.2
Bloating and flatulence (N=247)	16.7 (33.3)	16.7 (33.3)	.2
Male sexual problems (N=143)	33.3 (66.7)	33.3 (50)	.9
Sexual intimacy (N=145)	0 (33.3)	0 (33.3)	.6
Risk of contaminating partner (N=148)	0 (0)	0 (33.3)	.07
Female sexual problems (N=59)	33.3 (66.7)	33.3 (33.3)	.14
Functional scales (higher score=higher level of function)			
Sexual function (N=247)	66.7 (33.3)	66.7 (16.6)	.4
Sexual enjoyment (N=142)	33.3 (33.4)	33.3 (33.4)	.7

Abbreviation: IQR, interquartile range.
[a] Missing data for preferences and patient-reported symptom and functional scales results in totals <352; however, some may be due to skip logic. Missing numbers for each row as follows: urinary symptoms=107, malaise=106, intravesical treatment issues=106, future worries=105, bloating/flatulence=105, male sexual problems=71, sexual intimacy=207, risk of contaminating partner=204, female sexual problems=79, sexual function=105, sexual enjoyment=210.
[b] *t*-Tests were run to compare mean scores of 2 treatment preference groups.

Table 4. *Multivariable Logistic Regression Analysis Evaluating Predictors of Treatment Preference*

	Preference for chemoablation treatment (vs repeat TURBT) for bladder cancer recurrence	
Variable	Odds ratio (95% CI)	*P* value
Age, y[a]	1.03 (0.99, 1.06)	.13
Insurance (Ref = public)		
Private	1.52 (0.78, 2.89)	.2
None	1.36 (0.41, 4.48)	.6
Other	1.31 (0.15, 11.8)	.8
Marital status (Ref = currently married)		
Previously married	2.16 (0.96, 4.89)	.06[b]
Never married	1.33 (0.53, 3.37)	.5
U.S. residence (Ref = non-U.S., including Canada)	2 (1.06, 3.8)	.03[b]
No. prior TURBT (Ref = 1-2)		
3-4	0.99 (0.52, 1.9)	.9
≥5	0.93 (0.45, 1.91)	.8
Years since last TURBT (Ref = >5)		
In the past year	1.74 (0.83, 3.64)	.14
1-5	1.38 (0.69, 2.79)	.4
Receipt of prior intravesical treatment	0.96 (0.46, 1.98)	.9
Reason for treatment preference (Ref = no prior intravesical treatment)		
Risk of recurrence	14.6 (7.45, 28.5)	< .001[b]
Treatment type	4.12 (1.94, 8.77)	< .001[b]
Other	12.2 (4.63, 32.3)	< .001[b]

Abbreviations: CI, confidence interval; Ref, reference; TURBT, transurethral resection of bladder tumor.
[a] Continuous scale
[b] Statistically significant at $\alpha = .05$.

a better discussion regarding bladder cancer, recurrence, alternative treatment options, disease terminology, and emotional consequences (Table 7). Although both recognized the need for improved preoperative counseling, patients emphasized emotional challenges with repeat TURBTs along with unrecognized and unaddressed anxiety and depression that coexist with the diagnosis of bladder cancer.

Perceptions Regarding Chemoablative Treatment. Patients and providers noted similarities in perceived benefits and harms of treatment. Benefits included the ability to avoid anesthesia, reduce need for future surgery, provide an option for patients in poor health, avoid long-term side effects from TURBT, reduce cost of repeated surgery, and increase peace of mind regarding recurrence. Perceived concerns regarding chemoablative therapy included the effectiveness of the medication, potential side effects and whether these would increase with multiple treatments, need for future treatment if the medication was ineffective, where (and how) the medication would be administered, and need for transportation and cost.

DISCUSSION

In this mixed method study, we elicited both patient and provider perceptions of repeat TURBT as a treatment for NMIBC, with HRQoL outcomes and perception following treatment of NMIBC only recently reported.[7,13,14] The current literature suggests a link between lower HRQOL and TURBT.[6,7] Given the need for ongoing surveillance with cystoscopy and the high likelihood of recurrence requiring TURBT, NMIBC can be burdensome for patients even when compared to other urological malignancies. As such, nonsurgical alternative treatments for NMIBC such as intravesical chemoablation are being explored with promising results and a reduction rate in recurrence greater than that of surgery alone.[2,8-10] With the increasingly active role of patients in treatment decision making, understanding patient perception of intravesical chemoablation as it relates to TURBT is imperative to achieve value-based care. Our study demonstrated a significant proportion of patients preferring intravesical chemoablation to conventional TURBT when provided with this alternative as a hypothetical treatment option for NMIBC. Specifically, patients were more likely to prefer intravesical chemoablation if they were a U.S. resident, had a recent TURBT experience, or expressed recurrence risk as a priority in decision making. However, current HRQOL was not associated with treatment preference.

The association between country of residence and treatment preference is not well understood with our analysis alone but could be explained by differences in the U.S. and Canadian health care systems. Specifically, Canada is a single-payer, universal health care system while the United States is a nonuniversal publicly and privately funded health care system that can lead to more rapid diffusion of novel treatments. We also found that patients who had a recent TURBT experience were more likely to prefer chemoablation, which could reflect their recall of adverse TURBT experiences more readily. Recurrence risk as a priority also influenced a patient's preference in chemoablation, reflecting the hypothetical scenario that portrayed TURBT as more effective in eradicating the tumor in a single session and chemoablation as more effective in reducing long-term recurrence. These findings were supported by our qualitative results in which patients described treatment fatigue due to cumulative impact of ongoing surveillance and recurring need for TURBTs. Interestingly, we did not find an association between HRQoL and treatment preference. Mixed methodology allowed us to dig deeper into patients' perception of TURBT, which they considered a "major" procedure carrying significant physical, financial, and emotional burden largely related to lack of control regarding the procedure and overall disease status. This perception has recently been confirmed in a mixed methods study which evaluated patients with newly diagnosed NMIBC, noting that patients reported a poor perception of disease control with the belief that they will have continued disease over a prolonged period of time.[14] In

Table 5. *Patient and Urologist Perceptions of TURBTs*

Patient quotes	Urologist quotes
Perception of procedure	
First, getting to the hospital is hard in itself. Then the procedure with general anesthesia can be hard on the body let alone if you need a catheter or you bleed a lot after. Just having the scope in there makes you uncomfortable for days. And then on top of the physical pain, you're worried about what the pathology shows and if you need to have your bladder out. And even if you can keep your bladder they may tell you that you need to have another procedure all over again. And you still might have to have your bladder out.	*They [patients] have this image in their mind that a surgery means a long hospital stay, a long recuperation, and then oftentimes, they're pleasantly surprised that it wasn't that bad*
Most of the nurses and doctors and the doctors' assistants, the PAs, all of 'em that you talk to, all the treatments, nobody has side effects that bad. It's not that bad. They all tell you that you're not gonna be traumatized by the treatments. You're not gonna have downtime. That's a bunch of crap. They should be warning you ahead of time of the reported symptoms that you could have from the lesser part and let you know that you could have severe reactions to it.	*It's a minor procedure, in and out same day* *Usually the smaller of the procedures I'm doing that day*
Emotional impact of procedure	
I think it would have made me feel more normal, and less like I was losing my mind if someone had explained the psychologic toll of the procedure. Any little twinge makes you think something is terribly wrong.	*The patient who's getting it for the first time is anxious.*
…almost like a depression. First you're in shock I guess, and then this like this whole depression thing.	*I think non-muscle invasive bladder cancer is a psychologically difficult cancer. Most patients don't want to lose their bladder but knowing that their chance of cancer coming back is relatively high is the tradeoff.*
It would have been nice to have someone say, "You know what, you're going to have pain and bleeding but you're also probably going to get really sad at some points, and that's normal." But there's none of that, it's all explanation about the physical procedure.	
Financial impact of procedure	
I read online that it's the costliest cancer to have because of the number of tests and treatments over one's lifetime. Yes. That definitely was a concern for me.	*I think probably the bladder cancer is one of the most expensive diseases. I work in a very underserved and underprivileged population. There's a lot of financial need.*
It's not just a question as to the cost of the surgery or treatments themselves. The cost was how long can I afford not to work afterwards. That's where the cost came in for me.	*Very rarely do I hear about financial issues that preclude them from having TURBT*
I swear, it's a sneaky bugger. It's a nasty bugger. It's an expensive cancer.	
No one told me that. This is one of the most expensive cancers to treat 'cause it just comes back and it comes back, and it comes back.	
Educational resources/needs	
Who knows if this bleeding or weird sensation near my bladder is my cancer coming back.	*I think most patients are not naïve to the bladder pain that they may have, the hematuria, irritative voiding symptoms, potential urinary retention, and need for a catheter afterwards.*
I was afraid to look up information on the internet because I was afraid of what I was going to find.	*With pre-operative counseling and the online resources we provide, I think most people have a good idea of what to expect*
He didn't give me any pamphlets, nothing to read about, nada. He may have said the technical name for it, but I didn't even know what a TURBT was.	
Because I don't remember getting any information besides like, "Oh, you're not gonna have a scar. It's minimally invasive. It's two days." I mean, I think being like, "Okay, minimally invasive. I don't have a scar," that was nice. The rest, I didn't have a full understanding of it.	
Perception of repeat TURBT	
How long can I keep doing this? Can I do this for another 20 years? I really don't know.	*I think for patients, they see it as, "Okay. This is something I do periodically." I don't think they look forward to it, but I think they feel comfortable with the process and they know they'll be back to normal soon.*
It doesn't get easier. You worry about what they'll find this time. If this is the one that pushes you into needing your bladder removed.	*The more you have, the more comfortable you get with it, the less anxiety you have about it.*
Suggestions to improve the patient experience	
If something could be done for my emotional state. They were really good at treating my physical body but there was no emotional support throughout the process.	*We should do a better job of going through the process of what a TURBT looks like. Maybe even a video, or an educational sheet about what the experience will entail.*
It would be good to have counseling afterwards, or even just a service where they check in on you to see how you're doing once you get home.	*Setting better expectations of what is normal post operatively and how the disease behaves in general. They should know they'll be back.*
Maybe there could have been someone I could have called. I don't know. It was just so matter-of-fact. I think I would have appreciated if there had been some sort of support or something during that period of time for someone that had just gotten this kind of information, and I didn't get that.	

Abbreviations: PA, physician assistant; TURBT, transurethral resection of bladder tumor.

our study, patients described anxiety regarding the procedure's success, the need for future procedures, whether they would need a ureteral stent or a catheter after the procedure, symptoms to expect post-operatively, and potential pathology.

Patients' perception of TURBT contrasted significantly with those of providers, who perceived TURBT as a minor "smaller, less risky" procedure, especially in comparison to other surgeries performed by urologic oncologists. Providers did agree with patients

Table 6. *Patients' Experiences with Repeat TURBTs: Common Themes Among Patients and Urologists*

How repeat TURBTs improved for patients	How repeat TURBTs worsened for patients
Reduced anxiety from knowing what to expect	Treatment fatigue due to cumulative impact of ongoing surveillance and recurring nature of bladder cancer
Improved ability to communicate, anticipate, and deal with postoperative complications	Increased burden and anxiety about long-term effects of repeat TURBT
Acceptance of the unknown	Anxiety about recurrence
Ability to tolerate postoperative symptoms	Negative impact on other health conditions

Abbreviation: TURBT, transurethral resection of bladder tumor.

Table 7. *Suggested Topics to Include During Preoperative TURBT Counseling*

Topics	Illustrative patient quotation	Education recommendations	Mentioned by patients	Mentioned by urologists
TURBT procedure	Basically, he just told me we were gonna go in, do the same thing as they did when they did the scope to see it. I would be put under. I was in a general anesthetic. They would take it, and I would spend the night in the hospital, which I did the first time. I'd be catheterized, and I'd be able to go home the next day. That was it. He didn't give me any pamphlets, nothing to read about, nada. He may have said the technical name for it, but I didn't even know what a TURBT was.	• Name of the procedure • Technical aspects • Discharge planning • Length of stay • Possible need for hospitalization • Reading materials	X	X
Side effects, complications	Painful, frequent urination all the time. I don't think they had warned me enough. It's probably hard to explain unless you experience it, but how it would feel very not good to urinate right after this procedure. That was shocking, but it was good to be reassured that the symptoms would go away.	• Counsel that LUTS are very common • Frequency • Dysuria • Hematuria • Bladder spasms	X	X
Dealing with catheters	I don't think there was a lot of discussion around the need for catheterization after the procedure. That would've been helpful…I think just being better prepared that there would be—I don't think I've had a good sense for what recovery would look like. I don't know that I was well prepared there, so just giving a better sense of what would come after the surgery.	• Patients may require a catheter • Describe length of need • Describe ways to manage a catheter	X	X
Effects on sexual intercourse and intimacy	One thing that I know they never spoke to me about is intimacy or having sex. I remember thinking after, okay, even with the treatments and then the TURBTs and then the recovery, I'm like, Okay, I don't know. I've asked my nurse if I see them. I think that's the thing 'cause if you have a question, it's not like I have access to my doctor all the time…I think that it definitely—people talking with COVID about the importance of physical connection and the missing of hugs and whatever. I think as a young person with bladder cancer, that has been a major issue for me.	• Provide instructions on when it is safe to resume sexual activity	X	-
Bladder cancer signs, symptoms	I was trying to find out every information—because at that point, I was concerned about, how did I get it? As he stated, I shouldn't be focused on that, but I needed to know for some reason. I wanted to find out everything I could about bladder cancer, the survivability rate, who gets it, all the—everything I could possibly learn from WebMD and anything else that was available at that time so I would know.	• Provide a primer to describe bladder cancer—even before diagnosis is made (eg, BCAN handbook, Urology Care Foundation) • Create timely follow-up for pathology discussion	X	-
Cancer recurrence and repeat TURBTs	As time has gone on, I feel like I am a little bit less in limbo because nobody still is talking about, Well, okay, what is our plan now? I almost wish that I could have another first meeting to say, Okay, well, now that's it been almost three years, and this is what's going— Nobody really talks about the long-term like, Can I have TURBTs forever? I'm only 46. Can I have a TURBT every—two a year, three a year? At what point does the urethra get damaged or the bladder walls get damaged? Each one, I think, is getting worse because I've had way more action down there, like TURBTS, catheters, fulgurations, treatments. I don't know what to expect. I don't know. That's my question now is: How long can I do this? Can I do this for 40 freaking years? Can I do this another three year, even? I don't know.	• Provide information about risks related to repeat TURBT • Explain cystoscopic surveillance and risks related to flexible cystoscopy	X	-
Perioperative chemotherapy information	The effect of the chemo on my bladder. I wish I would have had more information on that. The only thing I knew was I had to be careful that my ureter didn't get blocked with scar tissue. When I had, like, eight weeks afterwards, the blisters and the bleeding, that nobody warned me of it…because I teach, I was actually thinking I was gonna be going back to work, so I only planned to be off for a certain amount of time. Then, when the bleeding started again and the burning with the urination, I'm thinking, Oh, God, it's back. It was worse than it was the first time. Then, when they did the scope and they found blisters, I wish that I would have known about because that really put me into a panic mode.	• Provide detailed information regarding the reason for perioperative chemotherapy • Describe side effects of perioperative chemotherapy (eg, mitomycin or gemcitabine)	X	-
Terminology	Basically, he just told me we were gonna go in, do the same thing as they did when they did the scope to see it. I would be put under. I was in a general anesthetic. They would take it, and I would spend the night in the hospital, which I did the first time. I'd be catheterized, and I'd be able to go home the next day. That was it. He didn't give me any pamphlets, nothing to read about, nada. He may have said the technical name for it, but I didn't even know what a TURBT was.	• Avoid jargon • Spell out and/or define all acronyms such as TURBT or NMIBC	X	-
Emotional consequences	There was no follow-up or no consideration of what the impact of this kind of information is to someone when someone is told they have cancer…I never received that from my health provider. I never really received that from the doctor either. Maybe there could have been someone I could have called. I don't know. It was just so matter-of-fact. I think I would have appreciated if there had been some sort of support or something during that period of time for someone that had just gotten this kind of information, and I didn't get that.	• Provide a follow-up call or visit from health care staff following procedure • Acknowledge emotional toll of procedure • Ask if emotional support would be helpful—and provide resources as needed (eg, BCAN Survivor to Survivor program)	X	-

(continued)

Table 7. (*continued*)

Topics	Illustrative patient quotation	Education recommendations	Mentioned by patients	Mentioned by urologists
Financial consequences	My insurance that I had at time was not covering everything, so each time this had to be done, it was going to be a couple 1000 or more. Usually more by the time they had the pathologist and you had the anesthesiologist. There's just charges and charges…just going in to have the cystoscopy every three months, which is the schedule I'm currently on, there's always a fee. This could be debilitating financially for somebody for sure.	• Provide resources for financial counselor to estimate cost • Describe transportation and other ancillary needs • Provide resources when available (eg, local support, BCAN Support Groups)	X	X

Abbreviations: BCAN, Bladder Cancer Advocacy Network; LUTS, lower urinary tract symptoms; NMIBC, nonmuscle-invasive bladder cancer; TURBT, transurethral resection of bladder tumor.

regarding the physical consequences of the procedure such as effects from general anesthesia, postoperative pain, dysuria, hematuria, and discomfort from catheters. However, the emotional toll on patients was notably missing from provider responses, but strongly emphasized among patients. Patients felt that the chronic nature of disease and need for repeat procedures was not well understood nor explained, magnifying anxiety related to TURBT (beyond physical symptoms).

Regarding the TURBT experience, both patients and providers identified the need for improved preoperative counseling which would serve to improve patient expectations of both TURBT and NMIBC as a chronic (and often recurrent) disease. Patients agreed that providers adequately explained the procedure and general information regarding bladder cancer but wished they had been told about the emotional challenges they could face as a consequence of requiring repeat TURBTs. Anxiety and depression often coexist with the diagnosis of bladder cancer, contributing to a worse prognosis.[15,16]

Our study further supports the growing body of literature that identifies mental health as an undertreated component of bladder cancer.[16] Some suggestions given by the patients in our study included involving family members early in preoperative counseling, stressing the importance of having a support system, discussing pathology results with patients in a timely manner, and warning patients that anxiety may persist well after their immediate postoperative symptoms resolve. Additional suggestions for perioperative education are listed in Table 7.

While our study represents the first to address patient and provider perceptions of TURBT, we recognize several limitations. First, our sample was homogeneous with a majority of White and male respondents. Given the small number of underrepresented minority respondents, and the fact that race is considered a social construct, we did not include race/ethnicity in the analysis as we could not draw meaningful conclusions. However, understanding perceptions among diverse patients is needed to better understand the role of cultural and societal influence on patient perception of TURBT. Additionally, identifying our patient sample through an advocacy network and recruiting providers through snowball sampling may introduce selection bias given that respondents may not represent the general population and providers within a similar social network may likewise counsel patients similarly. Other limitations include recall bias inherent to self-reported pathological data, missingness in HRQOL data although some missingness attributable to skip logic or life-style conditions precluding responses, smaller sample size available for some HRQOL analyses, and selective sampling which may introduce respondent bias. Despite these limitations, our findings do provide valuable and actionable strategies to improve patients' experience with TURBT—and also assist with future shared decision making for patients who will be able to choose between TURBT and chemoablative therapies that may reduce long-term recurrence.

CONCLUSIONS

The results of this mixed methods study highlight differences in patient and provider perceptions of TURBT in the context of emerging nonsurgical treatment modalities for NMIBC. Providers may not recognize the emotional toll patients experience. We hope that better understanding each perspective will result in improved counseling and shared decision making to decrease the overall burden on patients who live with this complex disease.

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EDITORIAL COMMENTS

In this mixed-methods study, Parisse et al compared patient perceptions of hypothetical transurethral resections of bladder tumors (TURBTs) vs intravesical therapies for nonmuscle-invasive bladder cancer. Their multivariable analysis suggested that many factors, including recurrence risk and treatment type, affect treatment preference. Their semi-structured phone interviews with patients and urologists reflected divergent perceived experiences surrounding TURBTs.

TURBTs are common and "one of the smaller procedures" we do as urologists, as reflected in the select quotes from urologists in this study. The routine nature of these cases for us is one cause for the discrepancy between how we vs our patients perceive TURBTs. In the hustle of an operative day, we forget about the full patient experience including fasting, general anesthesia, unfamiliar hospital setting, anxiety related to postoperative hematuria, discomfort, and catheterization. We know TURBTs, especially repeated TURBTs, place a heavy psychological burden on patients.[1]

This study adds to the body of literature on the quality of life burdens nonmuscle-invasive bladder cancer patients face.[2,3] So how do we improve their experience and bridge this gap between us and patients? First step is to acknowledge this burden to our patients as well as within our medical community, as suggested by one patient. Next, we should liberally use patient-friendly resources such as handouts and videos to set general and baseline expectations. We can recruit additional resources to address deeper psychological burdens some patients experience such as palliative care and psychiatric oncology.

Mixed-methods studies such as these are inherently time and resource-intensive to perform, but well-done ones such as this greatly inform and improve the patient experience. The results from this study will certainly inform our own patient counseling in the future, especially with the advent of new treatment options.

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Transurethral resection of bladder tumor (TURBT) forms the cornerstone of initial bladder cancer diagnosis, staging, and treatment. A high-quality, thorough TURBT is associated with improved oncologic outcomes. However, as with any procedure, TURBT is not without morbidity, direct and

indirect financial costs, and decreased health-related quality of life—especially in those patients needing multiple TURBTs.

Alternatives to TURBT remain limited, though include active surveillance and office fulguration in select patients with a known history of low-grade superficial bladder cancer. Recent efforts have focused on the role of chemoablation, an extension from the upper tract space.

With the development of nonsurgical alternatives, (as with chemoablation),[1] shared decision-making must become increasingly emphasized when discussing both treatment options and in the design of studies and direction of new research.

In this important paper, with support from the Bladder Cancer Advocacy Network, Dr Smith and colleagues from North Carolina conducted a rigorous mixed-methods analysis of both patient and provider perspectives on nonmuscle-invasive bladder cancer treatment. While they highlight many important themes, the discordance in perception of TURBT as a "minor" procedure by urologists and major surgery with substantial emotional toll by patients underscores the importance of seeking and critically evaluating patient perspective on treatments. This perception is perhaps reflected in the 40% of patient respondents signaling preference for chemoablation over TURBT, with expanded rationale in the excellent qualitative patient narrative section of the paper, which should be read in detail by any clinician caring for patients with bladder cancer.

There are many take-homes from this project, including the importance of expanding shared decision-making in the bladder cancer space. This work also exemplifies the application of mixed-methods research to provide critical insight into patient experiences and priorities.

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REPLY BY AUTHORS

As suggested by these editorial comments, shared decision making becomes increasingly important as alternative treatment options for nonmuscle-invasive bladder cancer emerge. Understanding the burden of nonmuscle-invasive bladder cancer treatment on quality of life is critical when framing these shared decision-making discussions. The discordance between patient and provider transurethral resection of bladder tumor perception highlights the need to expand our understanding to better improve the patient experience through relevant and patient-centered education. Acknowledging the patient burden as a first step and using patient-friendly resources to bridge this gap are both excellent suggestions by Hougen and Dullea. Furthermore, our paper identifies specific areas of discordance between patients and providers which can be addressed through patient educational resources. We support the suggestion by Zaid et al that clinicians should start by reading the patient narratives surrounding transurethral resection of bladder tumor to better understand the patient perspective and improve future counseling.