

# The Impact of Non–Muscle Invasive Bladder Cancer: Qualitative Research With Patients

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## OBJECTIVE

- To understand disease symptoms experienced by patients with high-risk non–muscle invasive bladder cancer (NMIBC), selected treatment patterns, patients' satisfaction with treatment, and patients' concern regarding future potential treatments.

## METHODS

### Patient Recruitment

- Patients were recruited and screened by urology clinic staff in Denver, CO and San Antonio, TX.
- Patients with high-risk NMIBC (CIS, TaG3, T1G3, or recurrent Ta/T1 of grade 2-3) were eligible to participate based on the following inclusion and exclusion criteria:
  - Aged 18 years or older
  - Met criteria for one of the following NMIBC treatment groups:
    - Group 1: Bacillus Calmette–Guérin (BCG)-naïve, treated with transurethral resection of bladder tumor (TURBT) ± intravesical chemotherapy
    - Group 2: Had current or previous BCG treatment but were refractory or resistant to treatment
    - Group 3: Were BCG refractory or relapsing and next treatment option would be cystectomy (but were prior to cystectomy)
  - Were willing and able to provide informed consent
  - Were willing and able to participate in a 90-minute individual interview
  - Had no physical condition, mental condition, or disorder that would interfere with the patient's ability to effectively complete the interview

### Qualitative Interviews

- Before beginning the patient interviews, informed consent was obtained from each participant.
- All interviews followed a semistructured interview guide, including in-depth and open-ended concept elicitation, and were audio-recorded.
- All study materials were reviewed and approved by RTI International's institutional review board committee.
- Two experienced staff conducted all the patient interviews at the two local clinics where participants were recruited.

## RESULTS

- A total of 10 adults with NMIBC participated in this study:
  - Round 1 (Denver, CO): n = 5
  - Round 2 (San Antonio, TX): n = 5
- Participants were demographically representative of the patient population that seeks treatment for NMIBC (Table 1).

Table 1. Demographic Characteristics For All Patients

Characteristic	Round 1 (n = 5)	Round 2 (n = 5)	All (N = 10)
Sex, n			
Female	2	3	5
Male	3	2	5
Age, years			
Mean	71.8	74.4	73.1
Range	66-80	68-89	66-89
NMIBC classification, n			
Group 1	2	2	4
Group 2	2	2	4
Group 3	1	1	2
Race/ethnicity, n			
White	5	5	10
Education, n			
High school diploma or equivalent	2	1	3
Some college	1	3	4
College degree	1	0	1
Professional or advanced degree	1	1	2
Employment status			
Full-time	0	1	1 (10)
Retired	5	4	9 (90)

### Disease Symptoms

- Nearly all interview participants reported visible hematuria as the symptom which led to their diagnoses.
- Key disease symptoms spontaneously reported by participants that were not related to treatment included the following:
  - One participant reported an on-and-off burning sensation during urination.
  - Two participants reported either needing to urinate frequently, including at night (wakes up every 2 hours) or intermittent urgency to urinate at night (2-3 times per week and then has weeks where this symptom does not occur). One of these 2 participant thought this symptom could be a side effect of blood pressure medications.
  - Two females reported abdominal pain; one noticed pain only when doing strenuous activities prior to diagnosis.
  - One participant experienced flu-like symptoms just prior to diagnosis.
- No participants reported needing a caregiver to assist them regularly due to their NMIBC symptoms; furthermore, 4 participants reported being able to drive themselves to their surgeries and back home afterwards.
  - I don't need any help. Thank God.*
  - Do I need help? No.*

### Treatment or Procedure-Related Symptoms and Effect on Patient Satisfaction

- All participants had received one or more NMIBC drugs (i.e., BCG, mitomycin, valrubicin), a procedure (i.e., TURBT, cystoscopy), or both.
- Key symptoms spontaneously reported that were attributed to a treatment or procedure included the following:
  - Six participants who had received BCG mentioned treatment-related symptoms (e.g., abdominal pain, painful urination, increased urgency to urinate and more frequent urination, passing blood clots, some blood in the urine, flu-like symptoms, chills, burning sensation when urinating, fatigue, soreness at the catheter site). However, these symptoms went away within a few days of treatment and were not reported by participants to affect overall treatment satisfaction.
    - During the treatments when I get the flu like symptoms, I just ache and I get the chills. And I can't get rid of the chills and I feel like I could sleep forever.*
    - I was uncomfortable in my abdomen because of, you know, when you have...when things have been intruding. So then I think there may have been a little blood in my urine after that, which is, I think, normal.*
  - Two participants who had also received either mitomycin or valrubicin [Valstar] following BCG had similar issues (e.g., pain, urgency, discomfort) following treatment.
  - Three participants reported issues with their catheters after TURBT surgery (e.g., painful or burning urination, a constant knife-like sting, urgency to urinate, passing blood clots while urinating, tiny bit of blood in the urine, and catheter-related issues after the surgery), but these symptoms abated after catheter removal.
    - It was just the initial shock when they put that thing in you. And the first time you go to the potty and urinate, that hurt. That hurt like hell. But that was when I was passing, apparently passing little blood clots.*
  - One participant reported issues post-TURBT surgery with a stent placed in the bladder (e.g., painful, burning urination; pelvic discomfort).
    - Yeah. Because one of the tumors was close to the, I think, the tube coming from the kidney. So they put a stent in there just to make sure it stayed open. It's just every time I urinated, it felt like I was getting stabbed in the side. But you know, it was just really a discomfort.*
- The most bothersome aspects of treatment reported by participants were pain related to BCG administration/tube insertion (n = 4), urgency/frequency (tied) (n = 4), the catheter related to BCG administration (n = 2), prepping for surgery/anxiety waiting for results (n = 2), having chills for a few hours after receiving BCG (n = 1), seeing blood in urine (n = 1), and burning/pain during and after urination (n = 1).
  - [Most bothersome after surgery] Oh goodness.... I would say urgency and frequency are tied.*
  - Not being able to put out enough quantity. And that's what causes me to have to get up often. Because I'm down to a tablespoonful when I get up, and then I go back to bed and get up another hour, and another tablespoonful, and this type of thing.*
  - But I would say it's the burning during urination.*
- No participants reported needing a caregiver to assist them regularly due to their NMIBC treatment. All participants were able to continue doing all of their daily routines without help.

- One female participant said she needed a ride home from her partner when the doctor prescribed belladonna/opium suppositories to increase her tolerance for BCG.
- The majority of participants reported that they were satisfied with their treatment and that the side effects they experienced did not impact their satisfaction. This satisfaction may be due to how quickly the side effects resolved.
  - I think they're [bladder cancer treatments] great. I mean if you're going to have to have a treatment for cancer on the bladder, they're very noninvasive.*
  - I was fine with it. I mean, no issues, no problem.*

### Patient Attitudes Towards Cystectomy

- Cystectomy was proposed by the urologist for 2 participants and was mentioned casually (without a full description of benefits/risks) for 1 participant as a treatment option depending on the efficacy of the participant's current treatment.
- All 10 participants reported that they would prefer to avoid bladder removal. Two participants indicated they would not have this procedure, even if it was truly needed (1 due to old age, the other due to preference for quality of life). One participant reported that she would consider bladder removal if her doctor recommended it; however, she indicated that this option was "pretty scary" and that she "would prefer to have her bladder."
  - I don't think that'd be a very good thing. No, I don't think so. No, I don't think that'll be viable. Life after that wouldn't be....*
  - Not good. Because your life would change. Well, you wouldn't be going to void like you used to. And you'd feel different being around people.*

- The most frequently reported concerns with cystectomy were risks due to the age of the patient, concern about the impact on daily life, concerns related to having an ostomy, and not having much information about cystectomy.

### NMIBC Impact

- Less than half of the participants reported a negative emotional impact related to having NMIBC, including anxiety related to their initial diagnosis.
  - [On anxiety] Oh I've got to go do this, you know. Here we go again.*
- All participants reported being generally grateful now that NMIBC was "the ideal cancer to have" and that the cancer was currently contained within the inner lining of their bladders. Participants reported that "it could be worse" and that they were committed to doing what was necessary (e.g., repeated cystoscopies every 3 months, treatment) to make sure the cancer did not metastasize. All participants reported a very positive outlook regarding their diagnosis and prognosis.
  - I'll tell you, it sounds like a broken record, but I'm surprised. It [cancer diagnosis] hasn't affected me in any way.*
  - You say that word cancer and everybody has a tendency to look at it as fatalist. And it is not at all. But you do initially go, all of a sudden you look at your own mortality and go, "Hmm." But it didn't last long. I mean it was, you get used to, once again, realizing that you can live with it. And it's not very invasive. I mean I have more with my arthritic knee than dealing with that than I did with my bladder cancer, so.*

## CONCLUSIONS

- Patients experience disease and treatment-related symptoms; however, the symptoms are not severe enough to impact patients' willingness to undergo intravesical therapy or diagnostic procedures (i.e. cystoscopy); however, proceeding to radical cystectomy uniformly engendered patient avoidance.
- Further research is needed to better characterize the impact of timing and duration of treatment-related symptoms, as well as the patient and caregiver perspectives on additional bladder cancer therapies, especially when bladder sparing may be warranted.

## CONTACT INFORMATION

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