Published in final edited form as:

Urology. 2017 October ; 108: 122–128. doi:10.1016/j.urology.2017.07.016.

The Burden of Cystoscopic Bladder Cancer Surveillance: Anxiety, Discomfort, and Patient Preferences for Decision Making

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Abstract

Objective—To examine discomfort, anxiety, and preferences for decision-making in patients undergoing surveillance cystoscopy for non-muscle-invasive bladder cancer (NMIBC).

Methods—Veterans with a prior diagnosis of NMIBC completed validated survey instruments assessing procedural discomfort, worry, and satisfaction, and were invited to participate in semi-structured focus groups about their experience and desire to be involved in surveillance decision-making. Focus group transcripts were analyzed qualitatively, using (1) systematic iterative coding, (2) triangulation involving multiple perspectives from urologists and an implementation scientist, and (3) searching and accounting for disconfirming evidence.

Results—Twelve patients participated in three focus groups. Median number of lifetime cystoscopy procedures was 6.5 (interquartile range 4–10). Based on survey responses, two-thirds of participants (64%) experienced some degree of procedural discomfort or worry, and all participants reported improvement in at least two dimensions of overall well-being following cystoscopy. Qualitative analysis of the focus groups indicated that participants experience pre-procedural anxiety and worry about their disease. While many participants did not perceive themselves as having a defined role in decision-making surrounding their surveillance care, their

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preferences to be involved in decision-making varied widely, ranging from acceptance of the physician's recommendation, to uncertainty, to dissatisfaction with not being involved more in determining the intensity of surveillance care.

Conclusions—Many NMIBC patients experience discomfort, anxiety, and worry related to disease progression and not only cystoscopy. While some patients are content to defer surveillance decisions to their physicians, others prefer to be more involved. Future work should focus on defining patient-centered approaches to surveillance decision-making.

Keywords

Bladder cancer; Anxiety; Decision making, shared; Patient preference; Patient satisfaction; Qualitative research

Introduction

Bladder cancer is the third most prevalent non-cutaneous cancer in the United States, its prevalence only being surpassed by prostate cancer in men, breast cancer in women, and colorectal cancer in both sexes.^{1, 2} Because of its high prevalence, bladder cancer is one of the most expensive cancers to manage and treat, estimated at over \$4 billion annually in the U.S. in 2013³ and exceeding the per-patient lifetime expenditures of other common malignancies, including prostate cancer.⁴ Almost three-fourths of bladder cancer patients present with non-muscle-invasive bladder cancer (NMIBC) at initial diagnosis, and half will eventually develop a recurrence.⁵ Due to the high frequency of recurrence, NMIBC patients undergo many years of follow-up testing and procedures, adding to the overall cost of care.

Population cost, however, does not capture the significant burden of disease on individual patients. The standard of care in NMIBC is resection followed by periodic cystoscopic surveillance to detect recurrent disease. While the frequency of cystoscopy varies based on disease characteristics (e.g., pathological grade), these invasive procedures likely exert both physical and psychosocial burdens on patients that may impact adherence to care. Unfortunately, these burdens are not well understood. Specifically, NMIBC patients must weigh episodic procedural discomfort and anxiety against the risk of delayed identification of cancer recurrence. The 2016 American Urological Association/Society of Urologic Oncology guideline on NMIBC⁶ specifically recommends shared decision making for these patients, although evidence on this topic in the context of patients' experience of surveillance and their preferences for decision making is lacking.

We aimed to develop a first understanding of the physical and psychosocial factors that affect patients' experiences and perceptions during bladder cancer surveillance for NMIBC, focusing on discomfort, anxiety, and patients' preferences for decision making.

Methods

We used a cross-sectional, mixed-methods study design. The study setting was the Veterans Affairs Medical Center, White River Junction, Vermont. All patients with a prior bladder cancer diagnosis who were scheduled for surveillance cystoscopy were invited to participate.

Potential participants were contacted prior to their appointments by a research coordinator, who explained the purpose and details of the study. On the day of the appointments, the coordinator again reviewed the study with each participant and obtained written informed consent. The study was approved by the Dartmouth Committee for the Protection of Human Subjects (#28417) and by the Veteran's Institutional Review Board of Northern New England (#897920-1).

Flexible cystoscopy was performed in the following manner. The proceduralist brought each patient to the cystoscopy suite, where the details, risks, and benefits of the procedure were discussed and consent was obtained. The proceduralist was a senior urology resident supervised by an attending urologist. Patients were positioned supine, and nursing staff prepped patients and instilled viscous lidocaine per urethra. Cystoscopy was performed using a 16.5 French flexible cystoscope with camera connected to a large monitor, which patients were invited to watch. At the conclusion of the procedure, the proceduralist interpreted the findings and summarized the management plan with the patient.

Following flexible cystoscopy, participants completed two instruments: the validated psychological consequences of screening questionnaire (PCQ)⁷ and a customer satisfaction survey (CSS).^{8,9} The PCQ includes two sections corresponding to negative and positive subscores. The negative subscore assesses 12 adverse psychological consequences of disease (e.g., worry, anxiety, depression) experienced prior to the cystoscopy, while the positive subscore identifies whether the experience of having the cystoscopy improved 10 domains of psychosocial well-being (e.g., reassurance, self-efficacy, optimism). Questions are scored on a four-point Likert scale. The CSS is based on an instrument that was developed for colonoscopy procedures and was adapted for cystoscopy in this study. The survey uses seven-point Likert scales to probe three experiential domains: satisfaction, worry, and discomfort related to the procedure. Higher scores indicate a higher degree of satisfaction, less worry, or less discomfort.

Upon completion of the instruments, all of the participants having their procedures on a particular day were invited to take part in a 90-minute focus group discussion. Semi-structured focus groups were conducted by a trained facilitator using an interview guide that was prepared to provide depth and consistency based on the Theory of Planned Behavior.¹⁰ The guide included questions and prompts on the following topics: personal attitudes about surveillance cystoscopy procedures; general perceptions and perceived behavioral control regarding surveillance cystoscopy procedures; and the experience of being under cystoscopic surveillance.

Discussions were audio-recorded and transcribed verbatim. Contemporaneous field notes were documented and included in the transcripts and subsequent analysis. Reflective discussions were conducted with each group of participants at the conclusion of the discussion and among the research team afterward. Participants were provided with a small meal; no other financial incentives were offered.

Questionnaire data were summarized descriptively. Transcripts of the focus groups were reviewed in depth and then underwent qualitative thematic content analysis.¹¹ Primary data

was segmented into concept units, iteratively coded using a manual indexing technique and facilitated by NVivo software, and subjected to cross-case analysis for inductive development of explanatory variables, which were then linked to broader themes for contextual interpretation. Triangulation was performed throughout the analyses by (1) evaluating both quantitative and qualitative data, and (2) incorporating different viewpoints into the analyses (from a urologic oncologist, urology resident, and implementation scientist).

Results

Of 28 patients who were eligible and invited to participate in the study, 12 (43%) agreed to participate and completed questionnaires and took part in one of three focus groups. Each focus group consisted of three to five participants, in addition to the facilitator. The majority of the participants were men (10 patients, 83%). Mean age was 71.8 years (interquartile range [IQR] 66–77).

Mean time since first bladder cancer diagnosis was 6.5 years (IQR 4–8). Cancer pathology included low-grade Ta (5 patients, 42%), high-grade Ta (4 patients, 33%), and Tis (1 patient, 8%); two patients' pathology was unknown because their most recent bladder tumor resection had not been performed at our facility. Mean number of lifetime cystoscopy procedures was 6.5 (IQR 4–10). Number of lifetime bladder tumor resections ranged from one to seven; three patients had an unknown total number of resections.

Most participants expressed some degree of pre-procedural anxiety and worry: On the PCQ negative subscore, 64% of participants reported at least two of 12 adverse symptoms due to their bladder cancer, most frequently having trouble sleeping (Table 1). On the CSS, these findings corresponded to a small to moderate amount of “worry about what they would find” (mean item score 5.0; range 3–7; possible range 1–7, 1 indicating maximal worry and 7 indicating no worry) and of discomfort (mean discomfort domain score 55.9; range 25–70; possible range 7–70, 7 indicating maximal discomfort and 70 indicating no discomfort) (Table 2). Following cystoscopy, participants reported experiencing at least a modest post-procedural improvement in well-being as measured by the PCQ positive subscore: all participants indicated improvement in at least two of 10 areas, most commonly feeling more relaxed and more hopeful about the future (Table 1). The mean CSS Satisfaction domain score was 63 out of 70, indicating a relatively high level of satisfaction with the overall experience of the cystoscopy visit (Table 2).

Five primary themes surrounding the experience of surveillance cystoscopy procedures emerged from qualitative analysis of the focus groups: process factors, psychosocial factors, comments about personnel, participants' preferences for decision making regarding follow-up care, and concepts related to self-efficacy. These themes, major explanatory variables, and example quotes are summarized in Table 3.

Process factors

Most participants perceived minimal control over the necessity and frequency of cystoscopy procedures. Several participants made the distinction between exerting self-control outside

the procedure room (e.g., choosing a convenient appointment date, arranging their own transportation) but relinquishing control to their physicians once inside (“It’s not in my hands; I’m just their patient”). The delay between having the cystoscopy and finding out the result of associated tests such as urine cytology was universally noted as a source of anxiety and stress. One factor that improved feelings of control was the ability to watch the procedure in real time (“You’re seeing first-hand that [the bladder] is ‘clean’”).

Psychosocial factors

In parallel with the “worry about what they would find” indicated on the CSS, participants discussed several aspects of psychosocial burden during and surrounding the procedure. Pre-procedural anxiety was commonly cited and rooted in uncertainty about potentially having “good” versus “bad” cancer. Even for participants who were told they had a favorable (i.e., low-grade) cancer, the locus of their anxiety sometimes shifted to the possibility of then developing a more aggressive cancer at the next cystoscopy (Table 3). Another primary psychosocial factor was worry about disease, including recurrence or metastasis. Some participants linked their disease status to their experience of the procedure overall (“And is this going to be a good experience, or is somebody going to tell me [the cancer is] back?”). Between recently-diagnosed participants who had only had a few procedures and those who had undergone many, there was a sense of apprehension at first (“You don’t know what’s really going to happen”) that was in some cases relieved by meeting “experienced” patients in the clinic (“Very helpful for me to see these fellows in here that have been surviving it for 20 years”).

Personnel

Participants expressed mixed feelings about having different proceduralists at each appointment due to rotating staff or trainees. Some participants would have preferred to have the same urologist (“It would be nice to know who it is and [have] the same person every time”), while others found value in having “a different set of eyes look” each time. There were also concerns about not knowing or being asked about having a trainee perform the cystoscopy, although these comments did not appear to be about doubts about competence, but rather the opportunity to know prior to the procedure.

Preferences for decision making

Participants had divided opinions about their involvement in making decisions about surveillance care. Some participants preferred to defer decisions about the intensity of surveillance to the physician and were comfortable accepting the physician’s recommendation (“If the doctor says we need to [undergo surveillance] every three months... We follow through with that, and we’ve let [the doctor] make those decisions.”). These participants tended to refer to the physician as “the boss” or someone who “knows best.” In contrast, other participants were dissatisfied about not having the opportunity to participate in these decisions (“You’re not involved. They tell you [when to return].”). Some patients felt uncertain about the physician’s recommendation and whether it was aligned with their preferences or goals.

Self-efficacy

Participants discussed improved well-being as a result of surveillance care. In particular, several participants referred to feelings of empowerment because undergoing a procedure meant “taking care of it, the best you can.” Empowerment could also be achieved by knowing the status of one’s disease and a plan to manage it: “Even if [the cancer] is still there, at least you know what you’re up against and what you’re gonna do.” Of note, a few participants were motivated by their follow-up care to undertake holistic changes to improve their overall health (“I’ve cleaned up my act considerably... And I think I’m doing all the right things to stay healthy.”).

Discussion

Patients with NMIBC undergo periodic surveillance for many years following control of local disease. Here, we report a mixed-methods study focused on developing an understanding of the physical and psychosocial factors that affect patients’ experience of bladder cancer surveillance care. Quantitative data revealed that patients endorsed high overall satisfaction with care, but most experienced at least some pre-procedural anxiety and worry about disease as well as discomfort associated with the procedure. In-depth qualitative analyses of focus group transcripts revealed five primary themes surrounding the experience of surveillance care: process factors, psychosocial factors, personnel, self-efficacy, and preferences for decision making. Preferences for decision making were highly variable, ranging from acceptance of the physician’s recommendation to uncertainty to dissatisfaction with not being involved more in determining surveillance care.

This is the first mixed-methods study to assess the experience of undergoing cystoscopic procedures in NMIBC from the patients’ perspectives. We add to our understanding of patients’ perceptions and attitudes towards surveillance cystoscopy. We found negative psychological consequences of the procedure, similar to a prior study using the PCQ to assess the consequences of undergoing breast biopsy for the detection of breast cancer.¹² Most of the participants experienced at least some pre-procedural anxiety related to recurrence of disease, which for some was quite substantial, indicating that psychological distress is an important part of patients’ experience prior to an invasive procedure. Participants suggested that their pre-procedural anxiety was due to the potential for detecting disease, rather than having the procedure itself; this is consistent with a study of patients’ anxiety prior to rigid cystoscopy using a visual analogue scale.¹³ The findings are also in line with a study examining women’s experiences prior to colposcopy after a suspicious Pap smear: these women found their anxiety, not the potential for physical side effects, to be most bothersome.¹⁴ For most of our bladder cancer patients, delays in communicating associated test results such as urine cytology was associated with anxiety and stress, very similar to women undergoing diagnostic mammography who did not receive an immediate “all-clear” result or who were referred for additional tests.¹⁵ Finally, the positive subscore of the PCQ and the qualitative data suggest that patients may experience some relief and reassurance following cystoscopy. This is similar to a study of testis cancer survivors, in which follow-up clinical visits appeared to enhance reassurance despite low baseline anxiety.¹⁶ Thus, even for NMIBC patients who have undergone multiple negative

cystoscopies, urologists should neither dismiss the potential for long-term distress of having bladder cancer, nor underestimate the psychological benefits of periodic follow-up discussions surrounding ongoing surveillance and management.

Several limitations should be noted. First, due to the study setting of a single Veterans Affairs Medical Center, the findings may not be generalizable to all Veterans or NMIBC patients. Second, the small sample size limited quantitative evaluation of the PCQ and CSS data. Descriptive analysis of these data, however, enriched and supported our qualitative findings. Furthermore, in the focus groups, the sample size achieved sufficient breadth to identify explanatory variables in each thematic category. Finally, we included both recently-diagnosed and “experienced” patients in the anonymous focus groups, so we were unable to discern whether perceptions of anxiety and discomfort might have differed depending on duration of surveillance. However, by conducting “mixed” focus groups, we were able to gain insights related to self-efficacy and behavioral changes attributed to having and living with bladder cancer over time.

Despite the limitations of this exploratory work, the study has several important implications. First, our exploratory data can inform development of surveys and larger-scale studies focused on obtaining a broader understanding of patients’ perceptions and preferences for decision making across multiple diverse settings. Second, these data may inform strategies to decrease burden of surveillance. Although surveillance cystoscopy is typically a straightforward, in-office procedure, it is nonetheless invasive and may be associated with cumulative physical and psychosocial side effects. Our findings suggest that NMIBC patients may face a multidimensional burden including uncertainty, anxiety, worry, and discomfort. Several strategies to reduce discomfort during cystoscopy have been investigated, and the evidence has been mixed. Patient-reported pain after urethral instillation of lidocaine jelly is no different than that after instillation of plain jelly, based on a recent meta-analysis.¹⁷ Another strategy is to allow patients to watch their cystoscopies on a monitor in real time, which is routinely offered to patients at our study setting. Studies of distraction techniques during flexible cystoscopy have had mixed results; background music during the procedure may reduce anxiety and pain,^{18, 19} while a virtual-reality distraction intervention did not.²⁰ In addition to these peri-procedural interventions to reduce invasiveness, another focus for improving the patient experience should be on pre- and post-procedural counseling that addresses cancer recurrence, given our finding that concern about recurrence contributes substantially to patients’ anxiety and worry.

Finally, our findings demonstrate that NMIBC patients can have highly variable preferences with respect to their involvement in decision making. These results support the need to identify those patients who prefer to be more involved in decision making and thus would benefit from better communication of bladder cancer risk in augmented follow-up discussions. Identifying these patients will require development of tools that help clinicians gauge each patient’s preferences for how involved they wish to be. These tools could then be used to improve the patient experience, potentially enhancing adherence to recommended care.

Conclusions

Many bladder cancer patients undergoing surveillance cystoscopy experience some degree of discomfort, anxiety, and worry related to disease progression. While some are content with deferring surveillance decisions to their physicians, others prefer to be more involved in decision making. Alleviating the psychosocial burden of cystoscopy may also improve overall adherence to follow-up. Future work should focus on defining patient-centered approaches to surveillance decision making and developing effective risk communication and decision support tools.

Acknowledgments

Funding: FRS is supported by the Department of Veterans Affairs, Veterans Health Administration, VISN1 Career Development Award, by a Conquer Cancer Foundation Career Development Award, and by the Dow-Crichlow Award of the Department of Surgery at the Dartmouth-Hitchcock Medical Center. PPG is supported by a grant from the Food and Drug Administration FDA (U01FD005478-01, Sedrakyan = PI).

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Table 1
Summary of responses to the psychological consequences of screening questionnaire

Negative subscore items were rated as follows: 0 = Not at all, 1 = Rarely, 2 = Some of the time, 3 = A lot of the time. Positive subscore items were rated as follows: 0 = Not at all, 1 = A little bit, 2 = Quite a bit, 3 = A great deal. Patients with symptoms were those who responded 1 or greater to a given item.

Item	Mean	Range	Patients with Symptoms (%)
<i>Negative subscore</i> ("Over the past week, how often have you experienced the following symptoms or ideas because of thoughts and feelings about bladder cancer?")	6.8	0–20	64
Had trouble sleeping	0.7	0–2	55
Experienced a change in appetite	0.4	0–2	27
Been unhappy or depressed	0.5	0–2	27
Been scared and panicky	0.6	0–2	36
Felt nervous or strung up	0.6	0–2	46
Felt under strain	0.6	0–2	36
Been keeping things from those who are close to you	0.6	0–3	36
Been taking things out on other people	0.4	0–1	36
Been withdrawing from those who are close to you	0.2	0–1	18
Had difficulty doing things around the house which you normally do	0.7	0–2	36
Had difficulty meeting work or other commitments	0.6	0–3	46
Felt worried about your future	0.8	0–3	36
<i>Positive subscore</i> ("Have your experiences getting cystoscopy procedures at the VA caused any of the following?")	13.5	2–22	100
A sense of reassurance that you do not have bladder cancer	1.5	0–3	82
Feeling more relaxed	1.6	1–3	100
Improved relationship with friends or relations	1.2	0–3	82
Feeling more able to do things which you normally do	1.2	0–2	73
Feeling more able to meet your home and/or work responsibilities	1.0	0–2	73
Feeling more hopeful about the future	1.7	1–3	100
Feeling less anxious about bladder cancer	1.5	0–3	82
Getting on better with those around you	1.2	0–3	73
Been sleeping better	1.0	0–3	64
A greater sense of well being	1.6	0–3	91

Table 2
Summary of responses to the customer satisfaction survey

For each item, participants were presented with a pair of descriptors of their experience and rated each item on a 1-to-7 scale. For instance, for the “Dissatisfied / Satisfied” item, a rating of “1” would represent “Completely dissatisfied” and a rating of “7” would represent “Completely satisfied”.

Item	Mean	Range
<i>Satisfaction domain</i>	62.9	36–70
Dissatisfied / Satisfied	6.1	1–7
Staff were not interested in me / Staff were interested in me	6.5	5–7
I was not pleased with how it went / I was pleased with how it went	6.0	1–7
Staff were cold / Staff were warm	6.6	4–7
Staff were not informative / Staff were informative	5.9	2–7
I felt undignified / I felt dignified	6.2	1–7
I was not interested / I was interested	6.4	3–7
Not confident in staff / Confident in staff	6.6	5–7
Not enough privacy / Enough privacy	6.3	3–7
Loss of modesty / No loss of modesty	6.3	1–7
<i>Worry domain</i>	36.3	38–42
Worried / Not worried	5.8	3–7
Agitated / Calm	6.0	4–7
I was worried about what they would find / Not worried about what they would find	5.0	3–7
I did not understand what was happening / I understood what was happening	6.3	4–7
I felt puzzled / I did not feel puzzled	6.5	5–7
I was confused / I was not confused	6.6	5–7
<i>Discomfort domain</i>	55.9	25–70
Painful / Not painful	5.3	1–7
I wanted to be less awake / I wanted to be more awake	5.0	2–7
Uncomfortable / Comfortable	5.1	1–7
A bad experience / A good experience	5.7	1–7
I felt out of control / I felt in control	5.4	1–7
Soreness / No soreness	5.7	1–7
Afraid of making a fool of myself / Not afraid of making a fool of myself	6.5	4–7
Intrusive / Not intrusive	6.1	3–7
Hard to cope with / Easy to cope with	5.6	1–7
Tired afterwards / Not tired afterwards	5.5	1–7

Table 3

Representative themes and example quotes from focus group discussions.

Themes	Explanatory variables	Examples
Process factors	Perceived control over frequency	"From the time that they determine yes or no on the biopsy, then there will be an amount of time that the doctor will determine that he wants to have another cysto... It's not in my hands; I'm just their patient. [Facilitator: And are you comfortable with that?] Oh, yes. It's because I believe in the doctor."
	Communication of results	"A lot of times [the result] comes back no problem... But in the meantime I do understand that you worry."
Psycho-social factors	Pre-procedural anxiety	"When they [the urologist] called me they said that this is actually good cancer. It's something we can take care of. So it's always in your mind that maybe the next time, it could be bad cancer."
	Worry about disease	"You always worry whether it'll come back or not... So there's a lot of anxiety associated with it. And is this going to be a good experience, or is somebody going to tell me it's back? That's what you worry about."
Personnel	Identity/training of proceduralist	"I feel that if the doctor isn't going to do [the cystoscopy] and you've got a resident or an intern, you should have the option of whether you want them to do it or not. I want to be told. I didn't know [the proceduralist] wasn't a doctor...and I wasn't asked."
Preferences for decision making	Acceptance of physician's recommendations	"If the doctor says we need to see it every three months until we know everything is okay, and then we go to six months. And we follow through with that, and we've let [the doctor] make those decisions."
	Uncertainty	"[The doctor] was saying maybe come back in two years. But I don't know. I'll think about it. I don't know if it's necessary, to tell you the truth."
	Dissatisfaction with not being involved more	"No, you're [the patient] not involved. They [the doctors] tell you."
Self-efficacy	Empowerment	"To take care of yourself, you know what I mean? As much as you can. There's a good sense of satisfaction there, that you're helping yourself, taking care of it, the best you can."
	Holistic effects	"I've changed. I've cleaned up my act considerably, you know what I mean? ... You can set your body up, I think, so that cancer won't live in it. And I've done a lot of changes towards that goal."