

Research Report

Evaluating Patient-Defined Priorities for Female Patients with Bladder Cancer

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Abstract.

BACKGROUND: Although bladder cancer is much more common in men than in women, female patients with bladder cancer present with more locally advanced tumors and have worse disease-specific outcomes than male patients, even after controlling for biological differences. There is a paucity of research regarding the optimal approach to caring for female patients with bladder cancer in ways that maximize patient satisfaction, preferences, and values.

OBJECTIVE: We sought to explore patient-defined priorities and areas in need of improvement for female patients with bladder cancer from the patient perspective.

METHODS: We conducted focus group sessions and semi-structured interviews of women treated for bladder cancer to identify patient priorities and concerns until reaching topic saturation. Transcripts were analyzed thematically.

RESULTS: Eight patients with muscle-invasive bladder cancer and six patients with non-muscle-invasive bladder cancer participated in two focus groups and seven interviews total. Three themes emerged as significantly affecting the care experience: physical impacts, mental health and emotional wellbeing, and the patient-provider interaction. Each theme included patient-defined specific recommendations on approaches to optimizing the care experience for women with bladder cancer.

CONCLUSIONS: Although most participants were satisfied with the quality of care they received, they identified several opportunities for improvement. These concerns centered around enhancing support for patients' physical and mental needs and strengthening the patient-provider interaction. Efforts to address these needs and reduce gender disparate outcomes via quality improvement initiatives are ongoing.

Keywords: Urinary bladder neoplasms, patient advocacy, quality improvement, qualitative research

INTRODUCTION

Bladder cancer is the sixth most common malignancy and tenth most common cause of cancer death in the United States with an estimated 80,470 new cases and 17,670 deaths in 2019 [1]. Though the diagnosis of bladder cancer is three to four times more common in men than in women, women present with

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more locally advanced tumors and female gender is associated with higher rates of disease recurrence, progression, and mortality following treatment [2, 3]. A combination of molecular and epidemiologic factors including the sex steroid hormone pathway and timeliness of initial diagnostic evaluation contribute to gender disparities. However, discrepancies remain after controlling for these variables, suggesting non-biologic influences such as the patient experience or patient and provider decision-making processes [3, 4].

The patient experience affects medical outcomes, as dissatisfaction with care is associated with lower health-related quality of life, mental well-being, and decreased adherence to care [5–7]. This may be a particularly important area for improvement in bladder cancer, as an English study assessed patient satisfaction with relation to involvement in cancer treatment decision making and found those with bladder cancer to be the least satisfied among almost forty different primary cancers [8]. There is scarce information regarding the optimal approach to care for female patients with bladder cancer and the current literature offers conflicting information. One group found that women more frequently identify family members as emotional support and active participants in decision making compared to men [4], while another found that women rely more on themselves rather than spousal support [9]. To fully address gender disparities in bladder cancer outcomes, priorities and perceived gaps in care for our female patients must be identified to enable clinical practice alignment with patient reported needs, preferences, and values.

In this context, we conducted focus groups and semi-structured interviews with women with bladder cancer to define patient needs and priorities related to diagnosis, treatment, educational and psychosocial resources, survivorship, and the overall care experience. We sought to identify areas in need of improvement from the patient perspective.

MATERIALS AND METHODS

After institutional review board (IRB) approval (IRB number: STU00211118), women receiving treatment for non-muscle-invasive bladder cancer (stage Ta or T1) or muscle-invasive bladder cancer (\geq T2) at a single institution were invited to participate in focus groups to describe their cancer care experience and provide feedback on how to improve care

for female patients with bladder cancer. To identify eligible patients for enrollment, clinic schedules were screened to identify female patients with bladder cancer who were seen in medical oncology or urology clinic over the previous six months or had appointments within the next three months. Exclusion criteria were defined as male sex, patients who did not receive care for bladder cancer at our institution, non-English speakers, and individuals younger than 18 or older than 89 years of age. To enhance feasibility of enrollment, those who were unable to attend in-person focus groups were invited to participate in semi-structured individual interviews by phone. Written consent was obtained from the women participating in in-person focus groups, and verbal consent was obtained from those participating in phone interviews.

Separate in-person focus groups were held for women with muscle-invasive bladder cancer (MIBC) and women with non-muscle-invasive bladder cancer (NMIBC) due to the significant differences in the treatments used in each setting. Focus groups were conducted over approximately 60 minutes and were designed to include no more than five participants to ensure each participant would have an adequate opportunity to engage. Focus groups were overseen by two moderators who were not previously involved in the patients' care, an intentional decision to decrease bias and allow for candid conversation. A moderator guide was used to direct the discussion and included questions about the overall patient experience, impact of bladder cancer on one's quality of life, and resources used during diagnosis and treatment (Appendix 1). Sessions were recorded, transcribed, and analyzed thematically.

The individual phone interviews were structured similarly; questions from the focus group moderator guide were repurposed as interview questions. Interviews lasted 30–45 minutes and were also recorded, transcribed, and analyzed thematically.

Focus group and semi-structured interview responses were coded by two independent raters. In order to adjudicate discrepancies, the reviewers participated in orientation sessions to identify common themes, create definitions and develop coding rules regarding specific group comments. The comments were then compiled and summarized in frequency tables denoting the number of times certain responses were made. Data were organized thematically; responses were grouped into larger categories of mutually agreeable lists of themes and dimensions of major ideas expressed by participants.

All participants also completed an anonymous questionnaire including clinical and demographic data at the time of study registration.

RESULTS

Following the screening process, 26 women met inclusion criteria and were invited to participate; seven of these women attended in-person focus groups. Some of the most common reasons from women who declined to participate in focus groups included no longer living in the area (6), lack of transportation (2), scheduling conflicts (2), and lack of interest (2). Additional in-person focus groups were not possible due to the COVID-19 pandemic. Seven of the 26 women participated in individual semi-structured phone interviews for a total of fourteen participants. 57.1% of participants (8/14) were treated for MIBC and 42.8% (6/14) for NMIBC. Most participants were white (13/14, 92.8%), with a median age of 70.5 years (interquartile range [IQR] 60.3–76.5). Participant demographics are displayed in Table 1.

The majority of participants with MIBC received chemotherapy (6/8, 75.0%) and most, though not necessarily the same participants, underwent a radical cystectomy with urinary diversion (6/8, 75.0%). Other treatments included intravesical bacillus Calmette-Guérin (BCG) therapy (2/8, 25.0%), partial cystectomy (1/8, 12.5%), radiation (1/8, 12.5%), and intravesical chemotherapy (1/8, 12.5%).

All participants (6/6, 100.0%) in the NMIBC group received BCG. Three of these participants (50.0%) received additional treatment including partial cystectomy (1/6, 16.7%), intravesical chemotherapy (1/6, 16.7%) and other intravesical immunotherapy (1/6, 16.7%).

The majority of participants reported overall high satisfaction with the care they received. More than half of the total participants (10/14, 71.4%) consulted with at least one other provider at a separate institution prior to undergoing treatment at our institution. Online research and recommendations from personal contacts in the healthcare industry were the most commonly cited referral sources for an initial visit.

Three themes were identified as significantly impactful of the overall care experience and well-being of female patients with bladder cancer.

Theme 1: Physical impacts

The vast majority of participants (13/14, 92.8%) experienced physical side effects of treatment

Table 1
Participant demographics according to presence of muscle invasion

	MIBC (n = 8)	NMIBC (n = 6)
Median age (IQR)	70 (60.5–73.3)	72.5 (62.5–78)
Race - n (%)		
White	7 (87.5)	6 (100)
African American	1 (12.5)	0 (0)
Highest education completed - n (%)		
High school or less	1 (12.5)	0 (0)
Some college	0 (0)	1 (16.7)
Bachelor's degree	4 (50)	1 (16.7)
Master's degree	1 (12.5)	2 (33.3)
Unknown (did not answer)	2 (25)	2 (33.3)
Marital status - n (%)		
Single	2 (25)	0 (0)
Married	4 (50)	3 (50)
Divorced	1 (12.5)	0 (0)
Widowed	0 (0)	2 (33.3)
Unknown (did not answer)	1 (12.5)	1 (16.7)
Time since treatment - n (%)		
0–12 months	2 (25)	5 (83.3)
12–24 months	2 (25)	1 (16.7)
24+ months	4 (50)	0 (0)
Median time in months (IQR)	23.5 (16.8–30.3)	5.5 (3–9.5)
Time since diagnosis - n (%)		
0–12 months	1 (12.5)	1 (16.7)
12–24 months	2 (25)	1 (16.7)
24+ months	5 (62.5)	4 (66.7)
Median time in months (IQR)	34 (22.8–51.5)	28.5 (19.3–40.8)
Treatment - n (%)		
Radical cystectomy with ileal conduit	4 (50)	0 (0)
Radical cystectomy with neobladder	2 (25)	0 (0)
Partial cystectomy	1 (12.5)	1 (16.7)
Chemotherapy	6 (75)	0 (0)
Radiation	1 (12.5)	0 (0)
BCG	2 (25)	6 (100)
Other intravesical immunotherapy	0 (0)	1 (16.7)
Intravesical chemotherapy	1 (12.5)	1 (16.7)

Abbreviations: MIBC, muscle-invasive bladder cancer; NMIBC, non-muscle-invasive bladder cancer; IQR, interquartile range.

including headache, fever, nausea, urinary frequency/urgency, and/or bladder pain. While some women endorsed only mild symptoms, one woman expressed, “If people heard my story, all they would hear is cancer, but what I went through – the chronic pain – was much worse.” Symptom management strategies explored by participants included dietary modifications, pelvic floor physical therapy and analgesics. Participants undergoing systemic chemotherapy or

195 intravesical BCG also expressed sentiments of mental
196 toughness, perseverance and adjusting expectations
197 to help manage physical side effects.

198 Almost all participants who underwent cystectomy
199 experienced treatment-related complications requir-
200 ing hospital readmission, including infections, fistula
201 formation, blood clots, or ileus (5/6, 83.3%). Some
202 of these participants (2/6 33.3%) suggested the need
203 for additional education about potential postoperative
204 complications in order to better manage their expect-
205 ations. One woman suggested, “It would have been
206 nice to know the consequences. Like, ‘We are tak-
207 ing part of your intestines, and this could end up in
208 a scenario where you have this ileus’ ... Wouldn’t
209 it have been nice for them to say that this could hap-
210 pen? So I know what to expect.” Another participant
211 commented on her experience: “When I went in to
212 see my surgeon, he did not give me a lot of infor-
213 mation... he didn’t tell me anything about getting a
214 neobladder, particularly in terms of the possibilities
215 of what might happen and what you might have to
216 do in terms of catheterizing, infections, etc. I knew
217 nothing about that.”

218 Participants who underwent a cystectomy also
219 emphasized the importance of discussing possible
220 adverse effects on sexual function (notably, partici-
221 pants with NMBIC and those with MIBC who did not
222 pursue radical cystectomy reported no adverse effects
223 in this domain). Most participants who underwent a
224 cystectomy recalled discussing potential sexual side
225 effects with their surgeon prior to treatment (5/6,
226 83.3%), and many sexually active women reported
227 little to no difference in sexual function follow-
228 ing treatment. On the other hand, one participant
229 reported, “I had to find out researching online that
230 in some cases they take your vagina – part of your
231 vagina! And it wasn’t fully disclosed to me so I
232 felt, ‘how can I trust this?’ I’m about full disclosure
233 ... Don’t forget something as important as that.”
234 This participant noted the importance of providers
235 clearly explaining this information prior to surgery
236 with all women, and that this should not be depen-
237 dent on a patient’s reported current sexual activity.
238 The participants also emphasized that strategies for
239 recovery post-surgery should also be explained, with
240 appropriate referrals to sexual medicine services pre-
241 or post-operatively if desired. One woman provided
242 information to the others in the group: “[The hospi-
243 tal] also offers a women’s sexual clinic ... the lady
244 I went to visit was so open with me ... I was ask-
245 ing her, ‘how was the sex thing afterwards?’ That’s
246 what you want to know as a woman. You want to

247 know, ‘Am I going to be the same? Is it going to be
248 different?’ They need counseling for that.”

249 *Theme 2: Mental health and emotional* 250 *wellbeing*

251 Almost all participants recalled feelings of anxiety,
252 stress, fear, and/or depression at the time of diag-
253 nosis and throughout treatment (13/14, 92.8%). One
254 patient described her feelings when she was first diag-
255 nosed: “I have never been so sad in my entire life.
256 I was just floored. I was in a state of shock. I was
257 emotionally done.” Two participants (2/14, 14.3%)
258 reported hiding their diagnoses from their families.
259 One recalled what this experience was like: “My sis-
260 ter tried to ask me ... ‘Are you sick? Is something
261 going on with you? Tell me!’ And I said, ‘I’m fine,
262 I’m fine.’ I didn’t want to worry them.” On the other
263 hand, most participants (12/14, 85.7%) relied heavily
264 on family and friends for emotional and informational
265 support. One woman shared, “I have really good fam-
266 ily support. I have three grandchildren ... they were
267 like, ‘Grammy, you’ll be fine, you’ll get through this!’
268 And they were probably my biggest supporters. They
269 thought it was amazing that I lost my hair, and they
270 would come over and feel my hair and say, ‘It’s com-
271 ing back, it’s coming back!’ And those were the things
272 that kept me going.”

273 Three women (3/14, 21.4%) reported consulting
274 with a therapist or social worker. Seven women
275 (7/14, 50.0%) mentioned the value of talking to other
276 women who also have bladder cancer, specifically to
277 share experiences with decisions regarding types of
278 urinary diversion, recommendations on catheter use,
279 or management strategies for side effects of BCG.
280 One woman commented, “It was also helpful to talk
281 to that woman who had the catheter, because that
282 was what cemented my choice.” Almost all women
283 (13/14, 92.8%) found resources regarding aspects of
284 living with bladder cancer independently from var-
285 ious sources such as online searches (7/14, 50.0%),
286 friends or family who have careers in the medical
287 field (7/14, 50.0%), and Facebook support groups
288 (3/14, 21.4%). Less common but highly regarded
289 resources used by participants included in-person
290 support groups (1/14, 7.1%) and Imerman Angels,
291 a non-profit organization that provides one-on-one
292 support to cancer fighters, survivors, and caregivers
293 through a matching process to pair those facing the
294 same type of cancer (1/14, 7.1%).

295 When asked what advice they would give other
296 women facing bladder cancer, several participants

(5/14, 35.7%) mentioned the importance of strong self-advocacy during all stages of bladder cancer care. A few participants (3/14, 21.4%) stated they regretted not pushing for more aggressive testing at the time of symptom onset. One such participant was initially misdiagnosed and treated for a urinary tract infection for months before she was diagnosed with bladder cancer. When this woman was asked what advice she would give to other women in a similar situation, she said, “Be a little more aggressive – call your internist, do the tests. Speak up. I should have cried out earlier for help.”

Theme 3: The patient-provider interaction

Despite many participants offering some suggestions for improvement, the majority expressed overall high satisfaction with their care and physician. A majority of participants (11/14, 78.6%) reported that clear communication and willingness to answer questions were associated with patient satisfaction and confidence in the treating physician. Participants were more appreciative when they were informed about their cancer prognosis and had aligned expectations about the timeline, side effects and success rates of treatment. Several patients (5/14, 35.7%) specifically endorsed the use of images, including hand-drawn diagrams, to explain the surgical process and outcomes. One patient recalled meeting her urologist: “When my sister and I met him, he was a superstar. He was drawing, ‘We’re going to swing this around’ ... He made me a diagram of what he was going to do. I was so happy ... The option he chose was the one he thought was best for me and he said, ‘If you were my family member, I’d tell you to do this as well.’”

One patient also noted her appreciation for a male surgeon who entered the room accompanied by a female provider each time he examined the patient. On the other hand, one participant experienced a negative interaction, stating that she was “talked down to” by a male provider. Another woman experienced “gruffness” from a male provider who she felt did not view women as “credible.”

Shared and informed decision making was important to participants. Participants stated they were more likely to trust their urologist when they “worked together to come to a decision” and the “provider was at the patient level.” Others (10/14, 71.4%) emphasized that patients should ensure clear articulation of personal treatment goals with their provider before making a treatment decision. One patient described

her relationship with her urologist: “He spent a tremendous amount of time with both me and my family drawing out exactly what was going on and that helped ... giving me my options. It was a team effort. We worked together ... so when it was over I felt very comfortable. I felt very good.” Similarly, participants stressed the importance of asking questions about their condition and treatment plan, and not being afraid to seek help from family, friends, and medical professionals during all stages of care.

DISCUSSION

Female patients with bladder cancer have been shown to have poorer clinical outcomes compared to men even after adjustment for biological differences, suggesting other influences such as variable patient experiences in initial diagnosis and treatment and satisfaction with care. We conducted focus groups and semi-structured interviews of female patients with non-muscle invasive and muscle invasive bladder cancer to explore patient perceptions, preferences, and concerns regarding their experiences throughout diagnosis and treatment. Summarizing the focus group and semi-structured interview data, we identified three themes that affected patient experience: physical impacts, mental health and emotional well-being, and the patient-provider interaction.

Our patients’ recommendations under the theme of physical impacts were disease-specific to bladder cancer, with participants desiring a more thorough discussion regarding potential treatment-related complications to better manage expectations. Participants voiced the importance of discussing potential adverse effects on sexual function regardless of a woman’s sexual activity. Our patients’ feelings were similar to those in a previous study which showed that the majority of patients with bladder cancer felt they did not receive information that might have been useful [9]. Though physicians typically report a commitment to informed decision making prior to any treatment and allow time for any outstanding questions [10, 11], several studies have shown that patients do not always feel that they are part of the decision-making process and often do not recall such conversations with their providers [12–17]. Fortunately, prior research has shown that patient recall and understanding of potential surgical complications can increase with provision of informational pamphlets that describe the surgical procedure and potential risks of the surgery [18]. Consistent with

396 this, several participants in our study endorsed the
397 idea of receiving additional written information to
398 review independently following their appointment,
399 and many stressed the value of images and diagrams.
400 Efforts such as routinely providing a standardized
401 pamphlet of written information describing the risks,
402 benefits, and alternatives of treatment, as well as valid
403 information on additional resources that may meet the
404 specific needs of female patients, may mitigate this
405 shortcoming.

406 The theme of emotional wellbeing among our par-
407 ticipants is similar to existing research describing
408 gender-related preferences in oncologic care. The
409 majority of our participants emphasized the value
410 of emotional support from family and friends, for-
411 mal counseling with a therapist or social worker,
412 or support groups. This is consistent with a study
413 of patients with various cancers which found that
414 women attached more value to psychosocial sup-
415 port than men [19], confirming the importance of
416 providing referrals for mental health and support
417 group information early in the treatment paradigm.
418 Engaging in ongoing discussions regarding patient
419 mental health, ensuring early referrals to psychoso-
420 cial services, providing support group information,
421 and including members of a patient's support net-
422 work in clinical encounters when feasible may reduce
423 psychological burden in this population.

424 Within the theme of the provider-patient interac-
425 tion, our participants placed importance on shared
426 decision making, commenting that this model estab-
427 lished trust and confidence in their physician. These
428 sentiments echo those from a prior study demon-
429 strating that women with colorectal cancer preferred to be
430 actively involved in decision making, and the result-
431 ing trust in their surgeon was fundamental to patient
432 acceptance of treatment decisions [20]. Ensuring
433 effective shared decision making by creating oppor-
434 tunities for bi-directional communication throughout
435 the treatment process is a critical aspect of care
436 for this population.

437 Though the majority of our participants described
438 forming a positive and trustworthy relationship with
439 their treating physicians, some participants described
440 negative experiences with clinical team members.
441 Some attributed these interactions to possible implicit
442 gender biases. Multiple women recounted that their
443 initial diagnosis of bladder cancer was delayed due to
444 treatment for a presumed urinary tract infection prior
445 to primary care teams pursuing cross sectional imag-
446 ing and/or referring to a urologist. These situations
447 are similar to previously published national data that

448 show that women with hematuria can experience a
449 longer time to diagnosis of bladder cancer than men,
450 which may contribute to the higher stage of disease
451 seen at diagnosis in women compared to men [21,
452 22]. Additionally, several participants described the
453 behavior of medical staff as condescending or dismis-
454 sive towards women. There is some data that female
455 patients prefer female urologists [23], though only
456 9.9% of practicing urologists are female [24], and of
457 those female urologists only 4.2% are urologic oncol-
458 ologists [25], greatly limiting the availability of female
459 urologists specializing in bladder cancer. Thus, it is
460 important that clinicians bolster patient self-advocacy
461 by providing reliable patient education materials to
462 ensure thorough patient understanding, encouraging
463 patients to share their own thoughts, values, and opin-
464 ions, and ensuring patients have connectivity to their
465 health care team and are able to easily reach them
466 [26]. Additionally, physicians must take an active
467 role in reducing implicit biases by acknowledging
468 their susceptibility to bias and deliberately focusing
469 on individual patients' information [27].

470 Our study should be considered in the context of
471 several limitations. First, this was a single institu-
472 tion study with a small number of participants, and
473 our identified themes and areas of improvement may
474 not be generalizable. Our participants were predom-
475 inantly white with only one patient self-identified as
476 African American, yielding the possibility that a more
477 diverse group of patients may identify additional
478 priorities. Further research including geographic,
479 socio-economic, and racial diversity is needed to fully
480 explore this topic. Second, this study lacks a direct
481 comparison between male and female bladder cancer
482 survivors, and the ideas expressed by the participants
483 may not be unique to the female gender. Despite this,
484 we believe the voices of our female patients offer
485 perspectives that should be taken into consideration
486 during cancer care. Members of our research team
487 attended a session on sex as a factor influencing blad-
488 der cancer outcomes during the 2019 Bladder Cancer
489 Think Tank Meeting, where several patient advocates
490 commented they felt their voices were less com-
491 monly heard as females. The session concluded with
492 a call to action by advocates to make their concerns
493 and preferences known, and this study is an initial
494 attempt to better serve female patients with bladder
495 cancer. Third, our participants were studied using a
496 combination of in-person focus groups and individ-
497 ual phone interviews rather than a single method.
498 Though the content was similar between the two
499 modalities, we recognize further discussion amongst

participants may have been spurred with additional focus groups. Unfortunately due to the COVID-19 pandemic and the inability to congregate, we ceased in-person focus groups and chose to hold additional individual interviews over the phone to gain further patient perspectives until topic saturation was met.

Acknowledging that non-biologic factors contribute to poorer disease-specific outcomes for female patients with bladder cancer and that female patients with bladder cancer are keen to share their concerns, we present patient-defined priorities at our institution. We hope the experience of our patients can be used as a catalyst to further investigate the needs of bladder cancer patient populations, including women and men, of diverse backgrounds. Developing strategies to optimize the experience for female patients with bladder cancer may improve outcomes and reduce the gender gap in patient outcomes.

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AUTHOR CONTRIBUTIONS

J.M., A.K.M., M.K.K. and A.V. conceived of the presented idea. A.V. and M.K.K. completed the focus groups and theme identification. A.V. interpreted and analyzed the data with support from J.M., A.K.M. and M.K.K. A.V., E.T., M.K.K., J.M. and A.K.M. wrote and revised the manuscript.

CONFLICTS OF INTEREST

Amanda Vo, Mary Kate Keeter, and Emily Tuchman do not have conflicts of interest related to this work to declare. Alicia Morgans has the following honoraria for advisory board activities to report: Janssen, Sanofi, Astellas, AstraZeneca, Bayer, Dendreon, Myovant, Advanced Accelerator Applications, and Clovis. In addition, Alicia Morgans has the following research collaborations to report: Bayer, Seattle Genetics, Astellas, Sanofi, Dendreon. Joshua Meeks does consulting work for Merck, AstraZeneca, Ferring, Cold Genesys, Janssen, Nucleix,

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SUPPLEMENTARY MATERIAL

An organized list of the questions/prompts that were proposed to the participants during the interviews and focus groups is titled "Appendix 1."

The Appendix 1 is available in the electronic version of this article: <https://dx.doi.org/10.3233/BLC-200397>.

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