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Patient-reported experience related to aspects of quality of life after cystectomy from an exploratory focus group

Nida Imran[1], Wesley Peters[2], Karen Fixler[1], Priyanka Madireddi[1], Lisa M. Shea[1], Andrea Ireland[1]

[1]Janssen Scientific Affairs, LLC, a Johnson & Johnson company, Horsham, PA, USA; [2]CorEvitas, LLC, part of ThermoFisher Scientific, LLC, Waltham, MA, USA

Conclusions

- Patient experiences with cystectomy highlight negative effects the surgery can have on their mental health, ability to engage in physical intimacy, and ability to perform daily activities
- Social support and care team support are critical throughout the cystectomy process
- Patients expressed the need for improved education about treatment options, a thorough explanation of the ramifications of cystectomy across all aspects of patients' lives, and holistic, long-term support (including emotional support and ostomy care) before, during, and after cystectomy

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Disclosures

NI, KF, PM, LMS, and **AI** disclose that they are employees of Janssen Scientific Affairs, a Johnson & Johnson company, and are Johnson & Johnson stockholders. **WP** is an employee of CorEvitas, LLC, part of ThermoFisher Scientific, LLC, which derives its profits from interactions with pharmaceutical sponsors.

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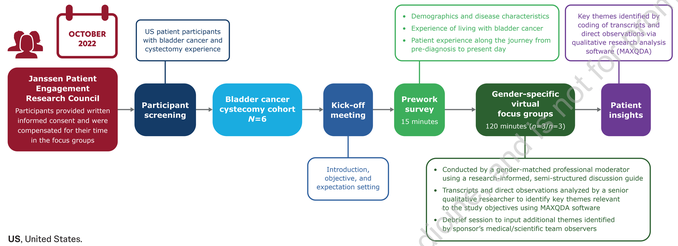
Introduction

- Radical cystectomy is a complex surgical procedure that people with bladder cancer undergo to remove the bladder and can require alteration to bowel, reproductive, and sexual organ systems
- Approximately 10,000 patients undergo radical cystectomy and urinary diversion every year in the United States[1]
- Studies have demonstrated that patient experiences associated with cystectomy are complex and varied, complicated by psychological adjustment, changes in function due to disease factors, and adaption to a new urinary diversion route[2]
- Qualitative research can capture rich data on patient perspectives, experiences, and behavior,[3] and can provide important insights not captured by traditional questionnaires used to measure functioning and quality of life
- This exploratory qualitative focus group set out to understand how patients feel about aspects of their physical function and quality of life before and after cystectomy

Methods

- The methods are outlined in **Figure 1**

Figure 1. Methods

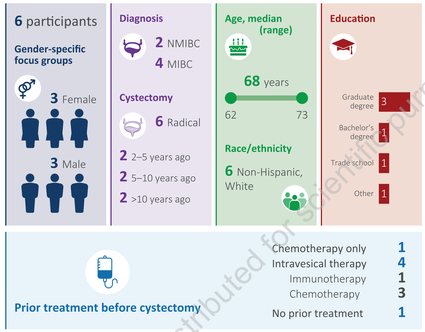


US, United States.

Results

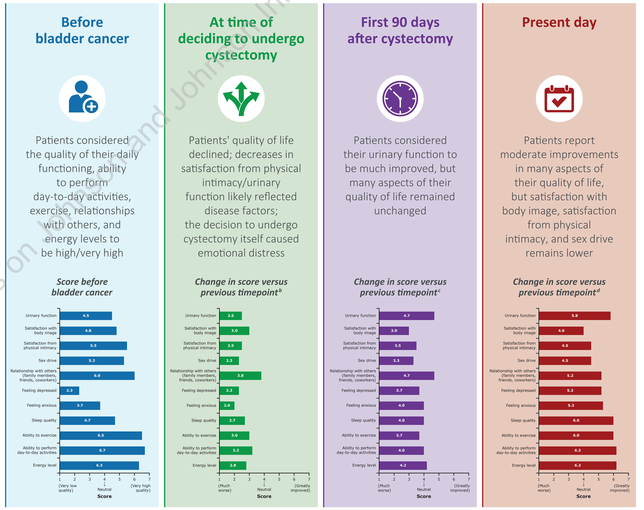
- All patients were White, non-Hispanic adults (female, n=3; male, n=3; median age, 68 years) with non–muscle-invasive bladder cancer (NMIBC; n=2) or muscle-invasive bladder cancer (MIBC; n=4) who underwent radical cystectomy between 2000 and 2020; 50% of patients (n=3) had a graduate degree
- In the first 90 days post-surgery, patients reported that cystectomy negatively affected their ability to perform daily activities, their mental health, and satisfaction from physical intimacy while they adapted to a "new normal." They further cited challenges with urinary diversion routes
- At the time of the focus group, patients reported lower sex drive, lower satisfaction with body image, and lower satisfaction with physical intimacy

Patient Demographics and clinical characteristics



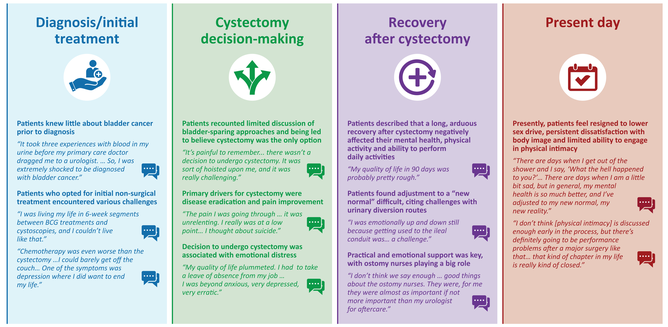
MIBC, muscle-invasive bladder cancer; **NMIBC**, non–muscle-invasive bladder cancer.

Prework survey results: Patients' quality of life during the cystectomy journey[a]



[a]Participants were asked to rate elements of HRQoL before diagnosis on a seven-point numerical scale, where 1=very low, 2=low, 3=somewhat low, 4=neutral, 5=somewhat high, 6=high, and 7=very high. Patients were asked to rate the change in HRQoL before cystectomy, 90 days after cystectomy, and in the present day compared to the previous timepoint on a seven-point numerical scale, where 1=much worse, 2=worse, 3=somewhat worse, 4=neutral, 5=somewhat improved, 6=improved, and 7=greatly improved. HRQoL scores were provided >2 years after cystectomy in all six patients, >5 years in four patients, and >10 years in two patients. [b]Change in score versus before bladder cancer. [c]Change in score versus time of deciding to undergo cystectomy. [d]Change in score versus the first 90 days after cystectomy.

Patient quotes from focus groups: Patients' experiences of the cystectomy journey



BCG, Bacillus Calmette-Guérin.

Female-centric issues

Female patients felt there was a general lack of female-centric support (e.g., education on feminine hygiene and care) and support groups were mostly comprised of male patients focusing on male-centric issues (e.g., erectile dysfunction)

Healing and hygiene	*"Especially for women and bladder cancer, [we comprise] only 20 percent [of patients]. When they take out part of the vagina that's adjacent to the tumors, [physicians] don't really think about it as a problem area for healing."*
Extreme pain	*"No one mentioned it, but they took out more than half of my vagina. That was extremely painful. It was more painful than the other part of the surgery. And that took quite a while to [heal]."*
Lack of female-centric support	*"I first went to the bladder cancer group, but it was all men. We only talked about erectile dysfunction, which is not funny, but just for me, it wasn't really an issue."*
Little privacy and personal space	*"I can't tell you the hundreds of people that have looked at my urethra and everything else down there. And that wasn't an issue for the men. They're like, that didn't bother me. And I'm like, well, it does for me when these men and women keep coming in and looking at the same area. I wish it was on my arm or my leg because you're not always treated with respect. You're not always given that. … It's hard for the women that there's not enough … care that [is] sensitive to our needs."*

Patient recommendations

- **Improved education on**
  - Available treatment options (including bladder preservation)
  - Possible ramifications of cystectomy on all aspects of life (including sexual health)
  - Female-centric needs
- **Increased awareness among HCPs about the struggles patients face throughout their cystectomy journey**
- **Better ostomy care support**
- **More privacy consideration during medical examinations**

HCP, healthcare professional.

References

1. Agency for Healthcare Research and Quality. https://www.ahrq.gov/research/data/hcup/index.html (accessed April 18, 2024).
2. Creta M, et al. *Transl Androl Urol.* 2018;7(Suppl 1):S111–3.
3. Creswell JW, et al. *Research Design.* 5th ed. Los Angeles, CA: Sage Publications; 2018.

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