

# PROVIDING EQUITABLE CARE TO PATIENTS WITH BLADDER CANCER

Patients face many challenges and roadblocks on their treatment path, which can be exacerbated by social determinants of health and health disparities. Cancer care team members can take evidence-based steps to improve quality care and minimize disparities for patients with bladder cancer.

Diagnosis, Evaluation, Treatment

**Common Challenges**

- Delays in diagnosis, evaluation, and treatment are common for women and Black patients<sup>1,2</sup>
- Patients are often overwhelmed by a diagnosis of bladder cancer
- Patients may not know or understand treatment options<sup>3</sup>
- Black patients are less likely to receive guideline-concordant care than White patients with the same disease characteristics treated at the same institution<sup>4</sup>
- Tobacco smoking and exposure to occupational carcinogens are key risk factors for bladder cancer

**Real-Life Perspective**

The intersection of gender and race compounds disparities. Black women are diagnosed at later stages than either White women or Black men.<sup>5</sup>

*"The doctor let me know the mass was four by two centimeters and a grade T4. I had no idea what that meant."*

- PATIENT<sup>6</sup>

*"I didn't know immunotherapy was an option for me."*

- PATIENT<sup>6</sup>

**Recommended Actions**

- Consider concurrent consultation with urology throughout oncology evaluation
- Engage patients in discussions about goals of care
- Practice shared decision-making with patients, aligning treatment to their goals
- Present guideline-concordant treatment options to patients
- Direct patients and caregivers to resources from Bladder Cancer Advocacy Network (BCAN) and other patient support organizations
- Share information with patients about potential clinical trial options
- Connect patients with oncology nurses who can help them understand their diagnosis and treatment options
- Advise patients to stop smoking as a modifiable risk factor and connect them with resources

Accessing Care

**Common Challenges**

- Limited access to timely care leads to delays in treatment
- Travel burden, including taking time off of work or finding childcare, is high for patients and their caregivers, especially for patients treated in specialized oncology centers<sup>7</sup>
- Many patients have limited transportation

**Real-Life Perspective**

Being female, Black, older, uninsured/Medicaid-insured or living in rural areas contributes to less timely access to specialist treatment<sup>8,9</sup>

*"It's a win if patients make it to a cancer program."*

- PATIENT ADVOCATE

*"How will I get time off work?"*

- PATIENT

*"I don't have transportation. How will I get to my treatment?"*

- PATIENT

**Recommended Actions**

- Liaise with urology specialists to enhance timely patient access to oncology care
- Refer patients to oncology social workers to ensure access to social support
- Implement adaptive scheduling and flexible clinic hours
- Direct patients toward travel assistance resources during treatment and follow-up

Affording Care

**Common Challenges**

- Costs of care are high and lead to financial hardship for many patients<sup>10</sup>

**Real-Life Perspective**

Patients diagnosed at late-stage incur 90% more out-of-pocket costs (co-pays, co-insurance, deductibles) in the first year following diagnosis than early-stage treated patients (\$9,970 vs \$5,225).<sup>11</sup>

*"How will I pay for treatment?"*

- PATIENT

**Recommended Actions**

- Screen patients for financial distress at diagnosis and throughout treatment
- Refer patients to financial navigators for assessment and support in accessing assistance
- Reduce orders for unnecessary tests or imaging

\* ACCC analysis of claims data. \*\* MIBC = muscle invasive bladder cancer; NMIBC = non-muscle invasive bladder cancer.

**Common Challenges**

- Dealing with fears of recurrence<sup>12</sup>
- Negative impact of cancer and treatment on mental health<sup>12</sup>
- Impact of treatment on relationship with partner<sup>3</sup>
- Adjustment to altered body image post-surgery<sup>3,11</sup>

**Real-Life Perspective**

The risk for suicide is high among bladder cancer patients, especially among men, older patients, and patients with aggressive disease.<sup>13</sup> Patients treated with radical cystectomy are at higher risk of poor mental health and having a post-treatment psychiatric illness compared to patients who receive radiation and/or chemotherapy.<sup>14</sup>

*"I'm not sure I can face being intimate again with my wife."*

- PATIENT

*"I used to go to the gym and play racquetball and exercise. I don't ride my bike as much. I mean, most of the stuff that I used to do."*

- PATIENT

**Recommended Actions**

- Acknowledge the emotional impact of diagnosis
- Set expectations for patients by discussing treatment side effects, self-care, and the recovery process
- Refer patients to mental health specialists for evaluation and support
- Develop a survivorship care plan
- Compile information about supportive care resources in your area
- Direct patients and caregivers to resources from BCAN and other patient support organizations

**Common Challenges**

- Patients are under-prepared to live with stoma after ostomy surgery<sup>15</sup>
- Long-term treatment- and disease-related side effects include urinary incontinence and disrupted sleep due to increased nocturia<sup>15</sup>

**Real-Life Perspective**

*"I had a hard time adjusting to the stoma, because in the beginning, I wasn't touching it."*

- PATIENT<sup>15</sup>

*"What happens if the stoma gets red and rashy?"*

- PATIENT<sup>15</sup>

*"I was taking sleeping pills because my sleep was very bad. I'd be up the whole night. I wouldn't be sleeping."*

- PATIENT<sup>15</sup>

*"Nobody talks to me about changes I could make in diet or lifestyle."*

- PATIENT<sup>16</sup>

**Recommended Actions**

- Involve caregivers in education about side effect management to bridge the gap between patients and care teams
- Provide symptom management information in plain language
- Connect patients with oncology and wound ostomy and continence nurses to help them navigate stoma management and the emotional consequences of treatment
- Develop a plan to provide supportive care across the treatment trajectory

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