

Effective Practices in Bladder Cancer Care: ENGAGING PATIENTS IN THEIR CARE

Goals-of-Care Conversations

As with all cancers, a bladder cancer diagnosis can be scary and overwhelming for both patients and their caregivers. Compared to other cancer types, however, patient experience of bladder cancer care is especially poor.¹ For people with non-muscle invasive bladder cancer (NMIBC), discomfort from procedures and psychological stress diminish quality of life in terms of fatigue, physical functions, and mental health.^{1,2} Beyond treatment, side effects such as urinary incontinence, waking during the night to urinate, changes to sexual function, and altered body image, all contribute to psychological stress.³⁻⁶ Additionally, a bladder cancer diagnosis can affect a person's quality of life because it requires life-long care such as stoma care, catheterization, or ensuring access to bathrooms.

Because of the long-term care needed following bladder cancer treatment, it is important for health care providers to educate patients at the start. Goals-of-care conversations are used with people facing serious illness.⁷ The purpose is to identify what matters most to them and what they would like to see throughout their medical care. Results of this conversation can be used to build a care plan that includes their values and preferences. Heather Honoré Goltz, PhD, LCSW, MEd, Research Investigator, at the Michael E. DeBakey VA Medical Center and Professor of Social Work at the University of Houston-Downtown, Texas, emphasizes the important role that oncology nurses and social workers play in fostering shared decision-making. Says Dr. Goltz,

“It is important to lay out what is possible for the patient given their unique patient profile so that they have the most comprehensive information possible to be able to look at their unique circumstances, their spiritual and religious needs, their cultural values, their family circumstances and dynamics to make a decision that is going to try to give the best clinical and personal outcomes possible.”

Health Literacy Practices

Health literacy refers to the ability to find, understand, and use information to make informed decisions about care.⁸ Stated simply, people need information they can understand in order to make informed decisions about their health. People of all socio-economic and educational levels are affected by health literacy.⁹ In fact, the U.S. Department of Education reports that only 12 percent of adults in the U.S. are proficient when it comes to health literacy.

Health literacy encompasses more than just reading materials, it also includes calculating the right dose of medication, following directions before surgery, or checking a nutrition facts label for food allergies. Individuals with lower health literacy skills tend to have poorer health outcomes, face errors with medication management, and skip preventive services such as vaccines and health screenings.¹⁰

In recent years, health literacy strategies have become the focus of many fields such as communication, adult education, health care, and public health.⁹ Evidence has shown that successful interventions typically include simplifying language in written materials, using video to provide patient education, and improving patient-provider communication. Another validated method is to include your target audience in the development and testing of any materials.⁹ Allowing your audience to participate improves future participation.

Patient Information and Supportive Care Needs

Patients have informational and supportive care needs across all phases of the bladder cancer continuum that are informed by bladder cancer type (NMIBC vs MIBC), stage, and treatment.^{5,11}

Many patients struggle to comprehend the range of treatment options across the bladder cancer spectrum and need support to recognize and manage potential disease- and treatment-related side effects.¹¹ Patients specifically report interest in information about strategies to manage urinary frequency, pain, bowel function changes, sexual function, diet, exercise, stoma care, locating and using medical supplies for ostomy care, and self-catheterization.¹²

Patients have also identified the following informational needs as especially important:

- General information about cancer
- Medical tests
- Risks and benefits of treatment, including options for systemic therapy such as neoadjuvant chemotherapy, immunotherapy, and maintenance therapy
- Treatment side effect recognition and management
- Clinical trial eligibility
- Financial toxicity and out-of-pocket expenses
- When to see a healthcare provider
- The expected pace of recovery following treatment

Many people are uncertain where to go for clear information and education about medical treatment options, practical strategies for managing bladder cancer, and supportive care across the disease trajectory.⁵ The National Comprehensive Cancer Network's (NCCN) Guidelines for Patients®: Bladder Cancer provides information on testing, treatment options, and supportive care.

The *Bladder Cancer Advocacy Network* details a range of resources for patients including what to expect following a diagnosis of bladder cancer, an interactive state-by-state map with information on National Cancer Institute (NCI)-designated Cancer Centers, and tips on living well with bladder cancer.

Another resource is Cancer Support Community's *Frankly Speaking about Cancer: Maintenance Therapy for Advanced and Metastatic Bladder Cancer*. This publication helps patients better understand their diagnosis and how to engage with their care team.

References

1. Garg T, Connors JN, Ladd IG, Bogaczyk TL, Larson SL. Defining Priorities to Improve Patient Experience in Non-Muscle Invasive Bladder Cancer. *Bladder cancer (Amsterdam, Netherlands)* 2018; 4(1): 121-8.
2. Jung A, Nielsen ME, Crandell JL, et al. Quality of Life in Non-Muscle-Invasive Bladder Cancer Survivors: A Systematic Review. *Cancer Nurs* 2019; 42(3): E21-e33.
3. MacLennan SJ, MacLennan S. How Do We Meet the Supportive Care and Information Needs of Those Living With and Beyond Bladder Cancer? *Front Oncol* 2020; 10: 465.
4. Mohamed NE, Pisipati S, Lee CT, et al. Unmet informational and supportive care needs of patients following cystectomy for bladder cancer based on age, sex, and treatment choices. *Urol Oncol* 2016; 34(12): 531.e7-.e14.
5. Chung J, Kulkarni GS, Morash R, et al. Assessment of quality of life, information, and supportive care needs in patients with muscle and non-muscle invasive bladder cancer across the illness trajectory. *Support Care Cancer* 2019; 27(10): 3877-85.
6. Mohamed NE, Chaoprang Herrera P, Hudson S, et al. Muscle invasive bladder cancer: examining survivor burden and unmet needs. *J Urol* 2014; 191(1): 48-53.
7. "The Goals-of-Care Conversation: A Best-Practice, Step-by-Step Approach." *Advance Care Planning (ACP) Decisions*, April 23, 2021. <https://acpdecisions.org/goals-of-care-conversations-a-best-practice-step-by-step-approach/>.
8. "What Is Health Literacy?" Centers for Disease Control and Prevention. Centers for Disease Control and Prevention, February 2, 2022. <https://www.cdc.gov/healthliteracy/learn/index.html>.
9. U.S. Department of Health and Human Services, Office of Disease Prevention and Health Promotion. (2010). *National Action Plan to Improve Health Literacy*. Washington, DC: Author.
10. "An Introduction to Health Literacy." NNLM. Accessed June 8, 2022. <https://nmlm.gov/guides/intro-health-literacy>.

In partnership with Bladder Cancer Advocacy Network. Sponsored by EMD Serono and Pfizer Oncology.



A publication from the ACCC education program, "Multidisciplinary Bladder Cancer Care." Learn more at acc-cancer.org/bladder-cancer-care or scan this QR code.

The Association of Community Cancer Centers (ACCC) is the leading education and advocacy organization for the cancer care community. For more information, visit acc-cancer.org.

© 2022. Association of Community Cancer Centers. All rights reserved. No part of this publication may be reproduced or transmitted in any form or by any means without written permission.



Association of Community Cancer Centers