

A Comprehensive Summary of Patient And Caregiver Experiences with Bladder Cancer: Results of a Survey from 45 Countries

A. Filicevas (1) ; PJ. Hensley, (2) ; AM. Kamat, (3) ; LE. Makaroff, (4)
(1) World Bladder Cancer Patient Coalition, Bruxelles, Belgium; (2) University of Kentucky, Lexington, United States of America; (3) MD Anderson Cancer Center, Houston, United States of America; (4) Fight Bladder Cancer, Cambridge, United Kingdom

Background

Patient-reported experiences of their bladder cancer diagnosis can provide unique insights. Few global studies exist detailing the lived experiences of bladder cancer patients.

Aim

To collect the views and experiences of patients with bladder cancer from a worldwide cohort.

Methods

A comprehensive survey consisting of 65 questions was administered by the World Bladder Cancer Patient Coalition and Quality Health, an IQVIA business, from October 2021 to February 2022 in English, Arabic, French, Hindi, Italian, Japanese, Norwegian, Polish, Portuguese, Russian, and Spanish. Responses were received from Algeria, Argentina, Australia, Bahamas, Belgium, Canada, Chile, Colombia, Cyprus, Denmark, Ecuador, Finland, France, Georgia, Germany, Greece, India, Iraq, Ireland, Israel, Italy, Japan, Jordan, Kuwait, Lebanon, Mexico, Netherlands, New Zealand, Norway, Pakistan, Peru, Poland, Portugal, Russia, Senegal, Slovenia, Spain, Sweden, Switzerland, Tunisia, Turkey, UAE, United Kingdom, United States of America, and Venezuela.

The survey results were cleaned by removing duplicates and incorrectly formatted data. The dataset was analysed using the statistical software package SPSS to produce descriptive and comparative statistics. The percentage responses were calculated after excluding respondents that did not answer that question. Sub-analyses were conducted for sex, time to diagnosis, age, geographic region, and stage.

Our survey was distributed online via social media and patient support organisations. While stage distribution and sociodemographic characteristics in this cohort reflect real-world bladder cancer patients, there may be disproportionately represented patient populations. The online nature of the survey means that older people, people without internet access, and disabled people may have been excluded.

Results

There were 1,198 responses from 45 countries. Almost half (54%) of patients reported not knowing the signs and symptoms of bladder cancer before their diagnosis, including 64%, who were not aware that blood in urine was a symptom of bladder cancer. More than half reported having 'another' diagnosis before being correctly diagnosed with bladder cancer. Women were almost twice as likely to be misdiagnosed with a UTI (39%) than men (21%). Respondents under 55 years were less likely to be diagnosed in a timely fashion (3 months): (66%) compared to 55-74 years (79%) and over 74 years (81%). Almost half (45%) of patients undergoing radical cystectomy were not counselled on sexual side effects.

Conclusion

Before diagnosis, awareness of the signs and symptoms of bladder cancer was low. Women were twice as likely to be misdiagnosed with a UTI than men. More women and younger respondents had delays in diagnosis.

Image(s):

Number: **001321**

Speaker: **A. Filicevas**

Category of abstract : **Scientific study**

Theme : **6. People living with cancer**

Topic : **Improving care delivery**

Preferred Presentation Type : **Oral poster Presentation in Geneva and inclusion in the digital library**

UICC Member Organisation : **Yes**

Member Organisation : **World Bladder Cancer Patient Coalition**

Travel Grant : **No**

Official congress language acceptance

Presenting author needs to be registered

All information correct

Abstract not previously presented

Corresponding author

Authority to act

Original author

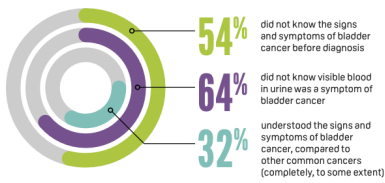
Privacy policy

Declaration of conflict of interest

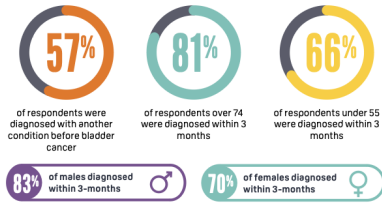
Conflicts of interest : **No**

Updated on: **Thursday, April 4, 2024 10:03 PM**

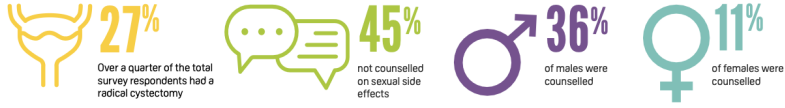
RESULTS - AWARENESS



RESULTS - DIAGNOSIS



RESULTS - CYSTECTOMIES



RESULTS - SUPPORT

