

Divergent Experiences of Bladder Cancer Patients: A Focus on Advanced and Metastatic Disease Stages

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BACKGROUND

Bladder cancer patients encounter a diverse range of challenges across different stages of diagnosis and treatment. This study investigated the specific experiences of patients with advanced or metastatic bladder cancer, highlighting the disparities in diagnosis, treatment accessibility, psychological impact, and quality of life.

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 and was disseminated online in Arabic, English, French, Hindi, Italian, Japanese, Norwegian, Polish, Portuguese, Russian, and Spanish.

Data were extracted from the World Bladder Cancer Patient Coalition Survey, focusing on responses from patients across different stages of bladder cancer, with a particular emphasis on patients with advanced/metastatic disease. Variables analysed include time to diagnosis, treatment modalities and side effects, financial impact, support systems, and expectations for the future.

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. There were few responses from low- and middle-income countries.

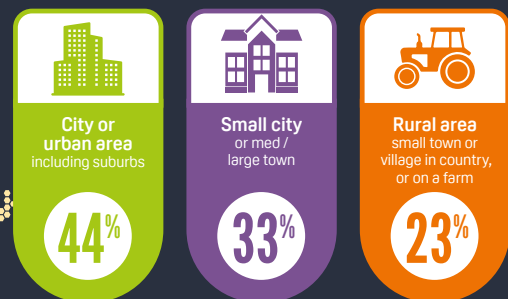
RESPONDENT CHARACTERISTICS

Respondents came from a total of 45 countries



1,198 Survey responses

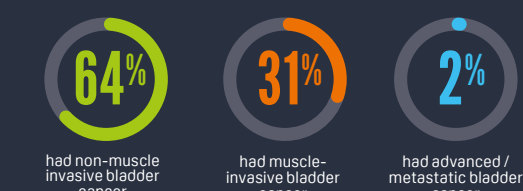
Percentage of respondents by geographic area:



Breakdown of respondents by country %, (n)

20%	United Kingdom (227)	3%	Argentina (29) Poland (34)	<1%	Algeria (4) Bahamas (1) Colombia (4) Cyprus (1) Denmark (1) Ecuador (3) Georgia (1) Germany (3) India (4) Iraq (1) Israel (3) Jordan (1) Kuwait (1) Lebanon (1) Netherlands (6) Peru (3) Portugal (1)	(4)	Russia (4) Senegal (2) Slovenia (1) Switzerland (3) Turkey (2) UAE (4)
13%	United States of America (150)	2%	Chile (21) Ireland (24) Japan (24) Spain (22)	64%	had non-muscle invasive bladder cancer	31%	had muscle-invasive bladder cancer
10%	Australia (112)	1%	Belgium (9) Finland (7) Mexico (6) New Zealand (10) Sweden (7) Pakistan (7) Tunisia (8) Venezuela (8)	2%	had advanced/metastatic bladder cancer		
9%	France (103) Italy (104) Norway (103)						
7%	Canada (1)						

Initial bladder cancer diagnoses for survey respondents

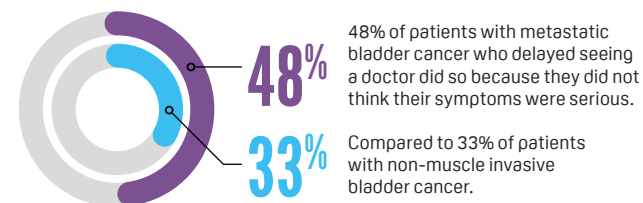


RESULTS

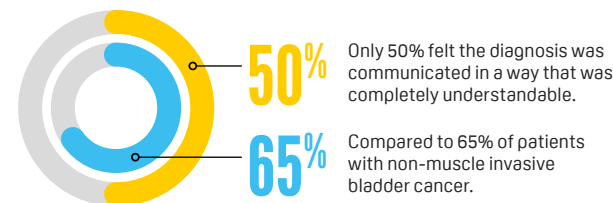
People with advanced/metastatic bladder cancer face challenges in diagnosis and understanding their condition.

Key findings include:

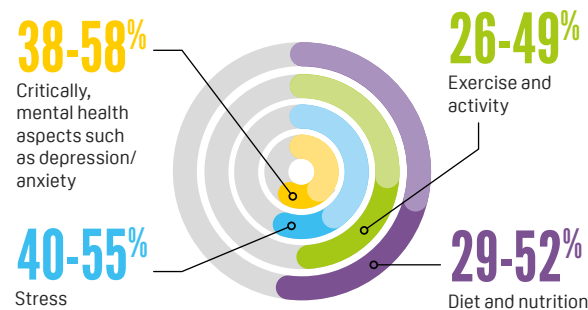
Delay in seeing a doctor



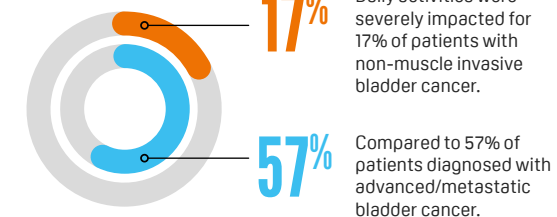
How diagnosis communicated



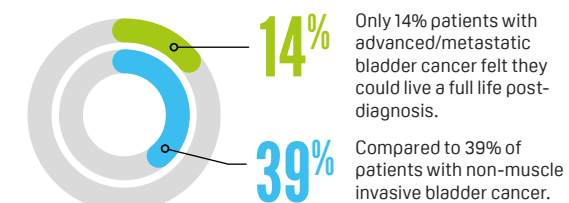
A lack of needed support was reported across all bladder cancer stages for:



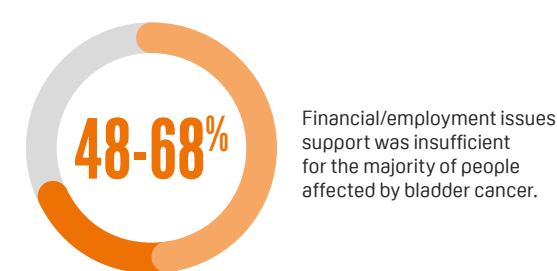
Daily activities



Living a full life post-diagnosis



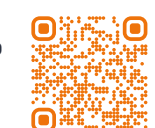
Financial / Employment issues



KEYWORDS

Bladder Cancer, Patient Experience, Advanced Cancer, Metastatic Cancer, Treatment Challenges, Quality of Life.

Scan the QR code to read the full report here.



BLADDER CANCER PATIENT GROUPS



CONCLUSION

The findings underscore the urgent need for tailored interventions to address the multifaceted challenges faced by patients with advanced/metastatic bladder cancer. Improving diagnostic pathways, expanding treatment options, enhancing patient support systems, and offering psychological counselling are critical to ameliorating the burden of this disease. Additionally, this study calls for further research into the experiences of this patient cohort to inform policy and practice in oncology care.

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