

Title: Patient and carer experiences with bladder cancer: results of a global survey in 45 countries

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Patient and carer experience data are vital to improving patient outcomes. Few global studies exist detailing the lived experiences of bladder cancer (BC) patients and their carers [1,2]. To collect these real-world experiences, a comprehensive survey was developed by the World Bladder Cancer Patient Coalition (WBCPC) in collaboration with an international expert steering committee (Table 1 in supplementary material). The survey was administered from October 2021 to February 2022 and a total of 1198 patients and 67 carers from 45 countries responded (Tables 2 and 3 in supplementary material).

The majority of patients (91%) had one or more signs and symptoms of BC prior to diagnosis (Figure 1a). However, consistent with previous research [2,3], 54% were not aware of BC signs and symptoms before their diagnosis (Figure 1b). Also, misdiagnoses prior to a BC diagnosis were common, particularly among women and younger patients (Table 4 in supplementary material).

At the time of diagnosis, the majority of patients did not receive any information about patient organisations (73%; n=714/980) or clinical trials (84%; n=941/1117). Information and supportive services were also lacking across various areas (Figures 1 and 2 in supplementary material). Almost half of patients who underwent cystectomy (45%; n=145/322) reported not being counselled on sexual side effects prior to surgery.

Compared to other common cancers, the emotional impact of BC has been greatly overlooked [1,4]. In our survey, the emotional impact of BC was felt across many aspects of life, with younger patients being more

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severely impacted across all domains examined (Table 5 in supplementary material). Over half of patients (58%, n=660/1135) were not offered emotional support to help them cope with their diagnosis, and 46% (n=509/1102) indicated that the long-term emotional impact of their BC treatment was not addressed. Financial toxicity is another major concern for BC patients; 49% (n=577/1176) of surveyed patients indicated that having BC impacted them financially, with the burden being highest for younger patients (68%; n=107/157) and those with advanced/metastatic BC (57%; n=16/28).

To date, research focused on the impact of BC on carers has been sparse [3,5]. In our survey, 91% (n=61/67) of carers indicated that they were impacted emotionally by caring for someone with BC. Carers also took on critical and diverse roles (Figure 3 in supplementary material), but the majority (79%; n=46/58) lacked sufficient information to effectively take on these roles.

Our study has some limitations. Given the online nature of the survey, older patients, people with disabilities or those without internet access may have been excluded. Also, there were few patients from low- and middle-income countries; more research is needed to better understand the experiences of these patients.

Despite these limitations, our survey identifies clear areas for improvement across the BC patient pathway – from awareness of BC signs and symptoms, to early disease detection, and access to information and supportive services for both patients and their carers. These findings provide an evidence-base to guide the

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development of future initiatives that address the unmet needs of patients and their carers.

To view the full report of this global survey, please visit: <https://worldbladdercancer.org/wp-content/uploads/2023/06/WBCPC-Patient-Survey-Report.pdf>

Author Contributions:

L.E. Makaroff, A. Filicevas and S. Boldon had full access to all the survey data and take responsibility for the integrity of the data and the accuracy of the data analysis.

Study concept and design: All authors

Data collection: L.E. Makaroff, A. Filicevas and S. Boldon

Analyses and interpretation of data: L.E. Makaroff, A. Filicevas, S. Boldon, P. Hensley, P. Black, S. Chisolm, S.

Demkiw, M.I. Fernandez, M. Sugimoto, B. Thoft Jensen, W. Witjes, A.M. Kamat

Drafting of the manuscript: A.M. Kamat, L.E. Makaroff, A. Filicevas

Critical revision of the manuscript for important intellectual content: All authors

Obtaining funding: A. Filicevas

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Financial Disclosures:

Dr. Ashish Kamat has participated in clinical trials with FGD, Merck, Bristol Myers Squibb, Photocure, SWOG, Adolor, Heat Biologics, Janssen, Taro, Seattle Genetics; he has participated in laboratory research with: NIH, SPORE, AIBCCR, PCORI; he has acted as an advisory board member or consultant for: TMC Innovation, Arquer Diagnostics, Asieris, Astellas, Biological Dynamics, BMS, CG Oncology, Cystotech, Eisai, Engene, Ferring, InCyte, Imvax, Imagin Medical, Janssen, Medac, Merck, Nonagen, Photocure, ProTara, Pfizer, Roche, Seattle Genetics, Sessen Bio, Theralase, US Biotest, Urogen Inc; he is a member of the Editorial Board of European Urology Oncology, the Journal of Urology, and UroToday; Dr. Kamat is President of the International Bladder Cancer Network (IBCN) and the International Bladder Cancer Group (IBCG); he holds patent(s) with CyPRIT (Cytokine Predictors of Response to Intravesical Therapy) – joint with UT MD Anderson Cancer Center. Lydia Makaroff is an employee of Fight Bladder Cancer, which has received financial support from Astellas, AstraZeneca, Bayer, BMS, Ferring, Janssen, Medtec, Merck, MSD, Pfizer, Prokarium, Roche, Sanofi, and Seagen. Lydia Makaroff is a volunteer board member of the World Bladder Cancer Patient Coalition, which has received financial support from Astellas, AstraZeneca, BMS, Janssen, Merck, MSD, Pfizer, Roche, and Seagen. Alex Filicevas is an employee of the World Bladder Cancer Patient Coalition, which receives funding from Astellas, AstraZeneca, Bristol Myers Squibb, Janssen, Merck, MSD, Pfizer, Roche and Seagen. Alex Filicevas is a volunteer board member of All.Can International, which receives funding from Amgen, Bristol Myers Squibb, Johnson & Johnson, Illumina and Roche. Shannon Boldon is a health policy consultant and was paid for her role as a researcher in the survey. She contributed pro-bono to the development of this manuscript. Dr. Mikio Sugimoto has received honoraria from Janssen, AstraZeneca, Takeda and Astellas; Mario I. Fernández has acted as a

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References:

1. Edmondson AJ, Birtwistle JC, Catto JWF, Twiddy M. The patients' experience of a bladder cancer diagnosis: a systematic review of the qualitative evidence. J Cancer Surviv 2017;11(4):453-61.
2. Elliott J, Rotterud R, Maddox-Smith A, et al. The bladder cancer patient survey: Global perspectives on awareness and treatment of bladder cancer. Journal of Cancer Policy 2019;22:100207.
3. Fight Bladder Cancer UK. Exemplar research report - striving for exceptional services for people affected by bladder cancer. 2021.
4. Bessa A, Martin R, Häggström C, et al. Unmet needs in sexual health in bladder cancer patients: a systematic review of the evidence. BMC Urology 2020;20:NA.
5. Renner S, Loussikian P, Foulquié P, et al. Perceived Unmet Needs in Patients Living With Advanced Bladder Cancer and Their Caregivers: Infodemiology Study Using Data From Social Media in the United States. JMIR Cancer 2022;8(3):e37518.

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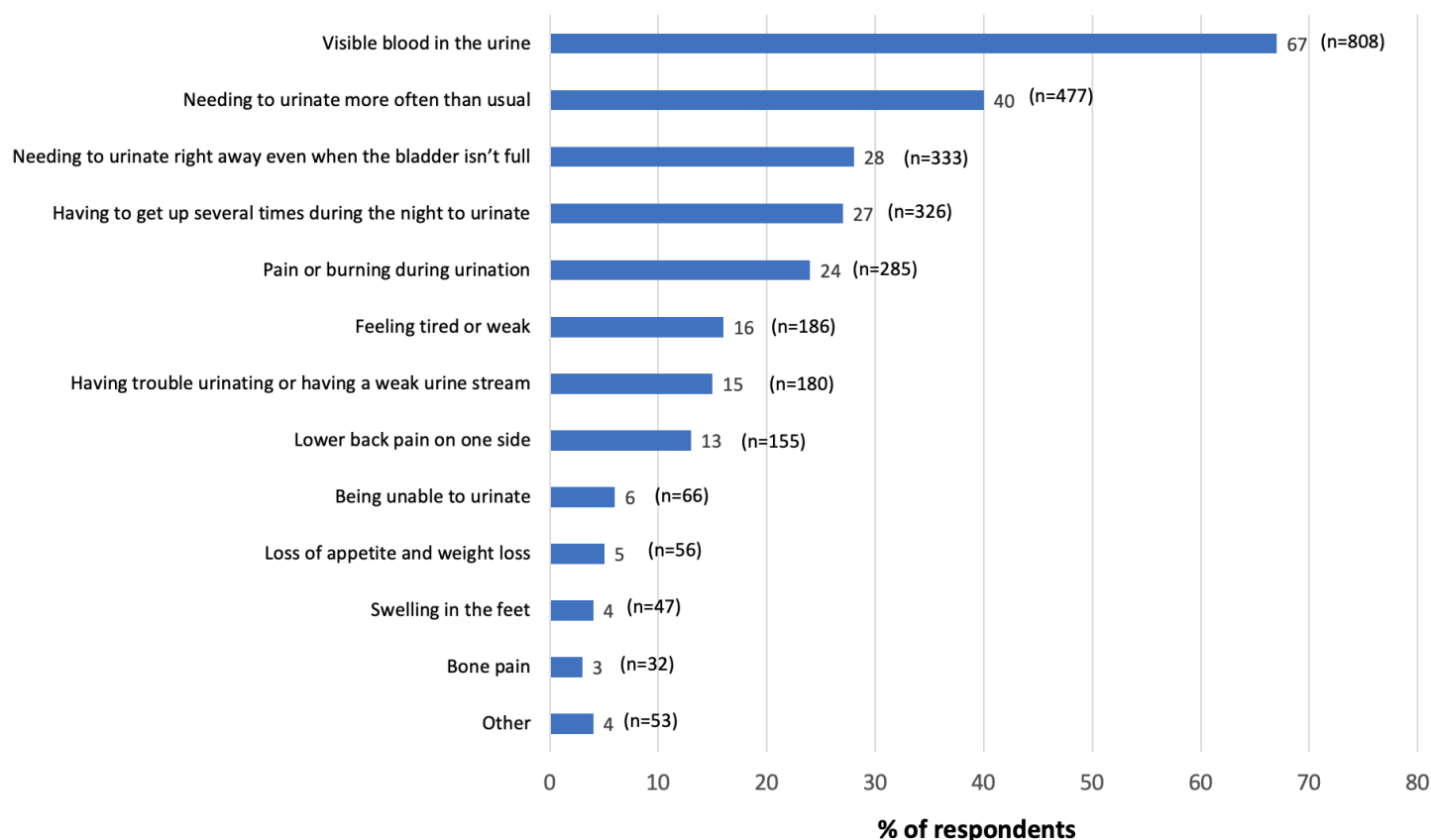
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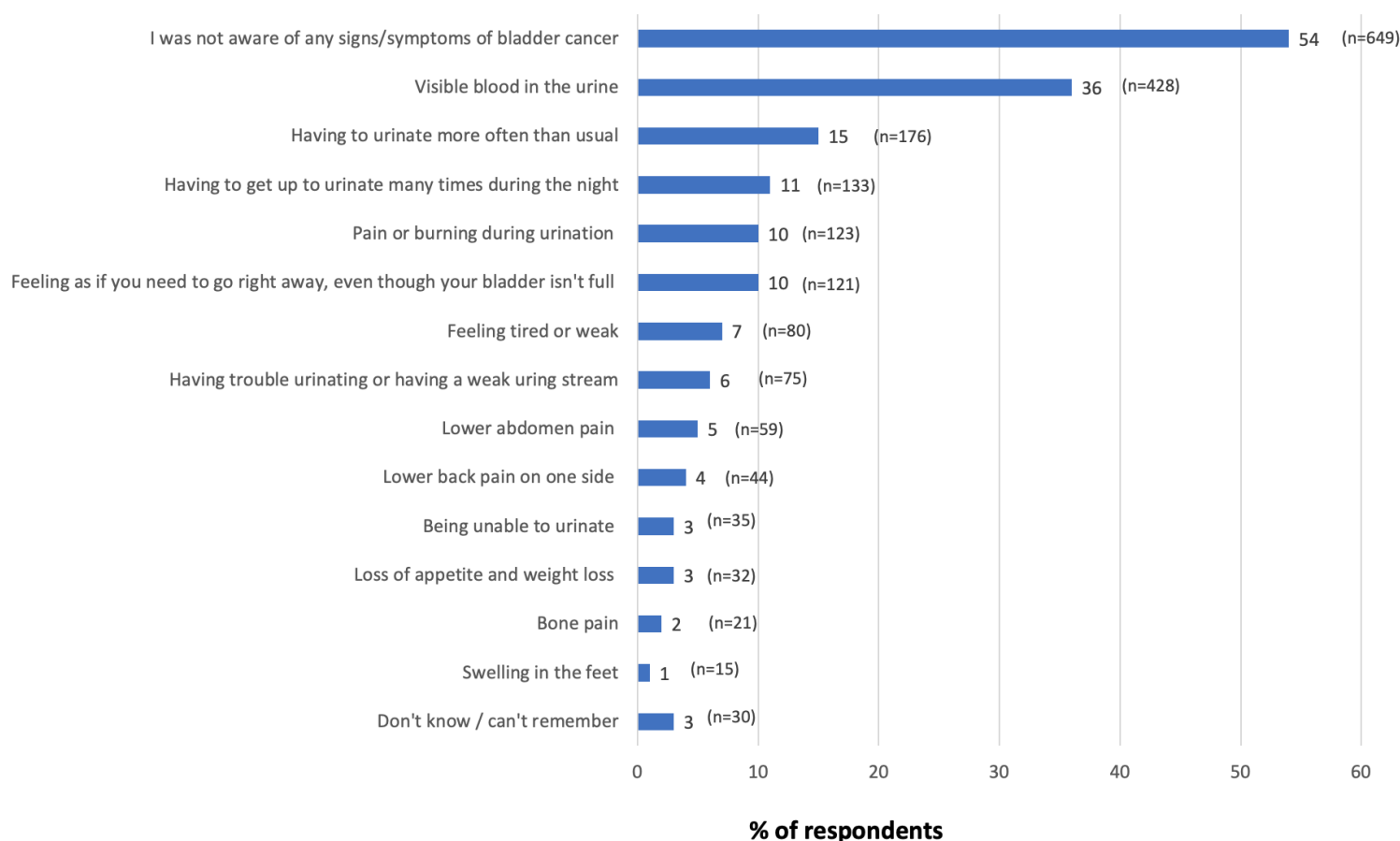
Figure 1a. Initial signs and symptoms experienced by BC patients*



*Patients' answer to the following question: "Before you were diagnosed with bladder cancer, which signs, or symptoms were you experiencing?". Patients could select more than one option. Missing responses were excluded from analyses.

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Figure 1b. Patient awareness of signs of symptoms of BC prior to diagnosis*



*Patients' answer to the following question "Before you were diagnosed with bladder cancer, did you know about any signs and symptoms of bladder cancer?". Patients could select more than one option. Missing responses were excluded from analyses.

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Supplementary Appendix. Supplementary Tables and Figures

Table 1.

Project Expert Advisory Committee
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Dr Mario I. Fernandez, Clínica Alemana Universidad del Desarrollo; International Bladder Cancer Group (Chile)
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Supplementary Table 2.

	Patients (n=1198)
Sex, % (n)	
Male	60 (697)
Female	40 (464)
Age Category, % (n) ^{††}	
Under 55 years	14 (157)
55-74 years	66 (746)
Over 74 years	20 (231)
Year of Diagnosis, % (n) ^{††}	
2021	19 (215)
2020	18 (206)
2019	15 (176)
2018	10 (116)
2017	8 (91)
More than five years ago	30 (341)
Bladder cancer stage at initial diagnosis, % (n) ^{††}	
NMIBC	64 (746)
MIBC	31 (364)
Advanced and/or metastatic BC	2 (28)
Unknown	3 (36)
Current bladder cancer stage, % (n) ^{††}	
NMIBC	60 (661)
MIBC	28 (315)
Advanced and/or metastatic BC	7 (73)
Unknown	5 (57)
World Region*, % (n) ^{††}	
African region (AFRO)	<1 (6)
Region of the Americas (AMRO)	27 (306)
Western Pacific Region (WPRO)	13 (146)
European Region (EURO)	58 (667)
Eastern Mediterranean Region (EMRO)	1 (17)
South-East Asia Region (SEARO)	<1 (4)
Country economy[†], % (n) ^{††}	
Low income	0 (0)
Middle income	7 (80)
High income	93 (1066)

NMIBC, non-muscle-invasive bladder cancer; MIBC, muscle-invasive bladder cancer

^{††}Note that missing responses were excluded from analyses.

*Defined according to World Health Organization (WHO) world region; AFRO included: Algeria, Senegal, AMRO included: Argentina, Bahamas, Canada, Chile, Colombia, Ecuador, Mexico, Peru, United States, Venezuela; WPRO included: Australia, Japan, New Zealand; EURO included: Belgium, Denmark, Cyprus, Finland, France, Georgia, Germany, Greece, Ireland, Israel, Italy, Netherlands, Norway, Poland, Portugal, Russia, Slovenia, Spain, Sweden, Switzerland, Turkey, United Kingdom; EMRO included: Iraq, Tunisia, Jordan, Kuwait, Lebanon, Pakistan, United Arab Emirates (UAE); SEARO included: India

[†]Low-income economies are defined as those with a GNI per capita of USD \$1,045 or less; middle-income defined as USD \$1,046 to \$12,695; and high-income defined as USD \$12,696 or more (2020 figures) (Definitions from <https://datahelpdesk.worldbank.org/knowledgebase/articles/906519-world-bank-country-and-lending-groups>)

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Supplementary Table 3.

Breakdown of respondents by country %, (n)			
Algeria :	<1 (4)	Kuwait :	<1 (1)
Argentina :	3 (29)	Lebanon :	<1 (1)
Australia :	10 (112)	Mexico :	1 (6)
Bahamas :	<1 (1)	Netherlands :	<1 (4)
Belgium :	1 (9)	New Zealand :	1 (10)
Canada :	7 (81)	Norway :	9 (103)
Chile :	2 (21)	Pakistan :	<1 (1)
Columbia :	<1 (4)	Peru :	<1 (3)
Cyprus :	<1 (1)	Poland :	3 (34)
Denmark :	<1 (1)	Portugal :	<1 (1)
Ecuador :	<1 (3)	Russia :	<1 (4)
Finland :	1 (7)	Senegal :	<1 (2)
France :	9 (103)	Slovenia :	<1 (1)
Georgia :	<1 (1)	Spain :	2 (22)
Germany :	<1 (1)	Sweden :	1 (7)
Greece :	<1 (3)	Switzerland :	<1 (3)
India :	<1 (4)	Tunisia :	1 (8)
Iraq :	<1 (1)	Turkey :	<1 (2)
Ireland :	2 (24)	UAE :	<1 (4)
Israel :	<1 (3)	UK :	20 (227)
Italy :	9 (106)	USA :	13 (150)
Japan :	2 (24)	Venezuela :	1 (8)
Jordan :	<1 (1)		

UAE, United Arab Emirates; UK, United Kingdom;
USA: United States of America

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Supplementary Table 4.

Responses to the question: “Were you diagnosed with another condition before you were diagnosed with bladder cancer?”						
	Sex		Age			All Survey (n=1198)
	Male (n=697)	Female (n=464)	< 55 years (n=157)	55-74 years (n=746)	>74 Years (n=231)	
No, only bladder cancer, % (n)	52 (362)	31 (146)	33 (52)	45 (337)	48 (112)	43 (519)
Yes - urinary tract infection, % (n)	21 (143)	39 (183)	41 (64)	26 (197)	24 (55)	28 (334)
Yes – cystitis, % (n)	4 (29)	12 (55)	13 (20)	7 (50)	5 (12)	7 (84)
Yes - overactive / underactive bladder, % (n)	4 (25)	6 (29)	4 (7)	5 (34)	5 (11)	5 (56)
Yes - kidney or bladder stone, % (n)	6 (45)	9 (43)	13 (20)	7 (50)	6 (13)	7 (88)
Yes - prostate problem, % (n)	14 (100)	0.2 (1)	8 (12)	8 (58)	11 (26)	9 (106)
Yes - gynaecological problem, % (n)	0.1 (1)	13 (58)	6 (10)	5 (39)	4 (9)	5 (59)
Yes - another cancer, % (n)	2 (12)	2 (8)	1 (1)	2 (12)	2 (5)	2 (20)
Yes – other, % (n)	6 (44)	9 (40)	11 (17)	7 (53)	6 (14)	7 (86)
Don't know / can't remember, % (n)	2 (13)	2 (7)	1 (2)	2 (13)	2 (4)	2 (20)

Missing responses were excluded from analyses.

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Supplementary Table 5.

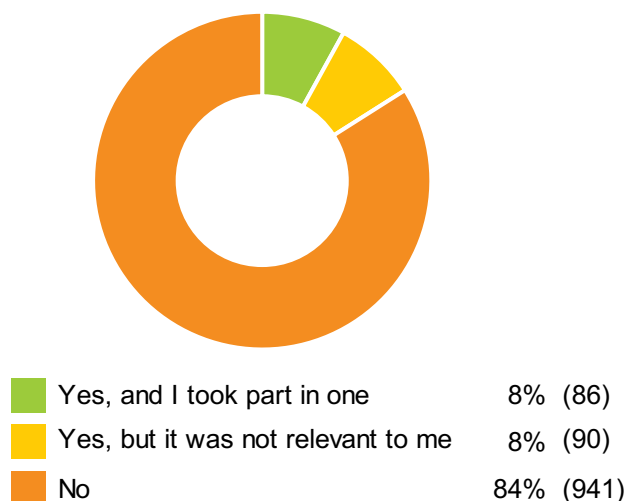
Has the emotional impact of your bladder cancer diagnosis affected any of the following? - Respondents answering 'Severely'				
	< 55 years	55-74 years	>74 years	Total survey
Your relationships, % (n/N)	16% (23/148)	8% (54/648)	9% (17/185)	10% (102/1012)
Your ability to carry out day-to-day activities, % (n/N)	18% (27/147)	10% (62/650)	10% (18/186)	11% (114/1017)
Your ability to enjoy life, % (n/N)	21% (31/149)	16% (107/668)	14% (27/193)	17% (176/1045)
Your happiness, % (n/N)	26% (38/147)	17% (112/656)	14% (26/188)	18% (184/1024)
Your confidence, % (n/N)	26% (38/145)	17% (105/634)	13% (23/180)	18% (176/992)
Stress/anxiety levels, % (n/N)	41% (61/147)	26% (176/680)	19% (36/189)	27% (289/1055)
Hopes for the future / future plans, % (n/N)	34% (50/148)	25% (165/664)	20% (37/186)	26% (266/1033)
Trouble/inability to sleep, % (n/N)	26% (38/146)	20% (133/652)	14% (25/177)	20% (204/1005)
Your body image, % (n/N)	24% (35/143)	18% (110/619)	11% (19/170)	18% (172/961)
Sexual performance, % (n/N)	35% (50/142)	36% (228/625)	33% (56/168)	36% (347/964)
Your work, % (n/N)	25% (35/142)	15% (87/574)	9% (12/132)	16% (138/870)

Missing responses or respondents answering "Don't know/can't remember" were excluded from analyses.

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Supplementary Figure 1.

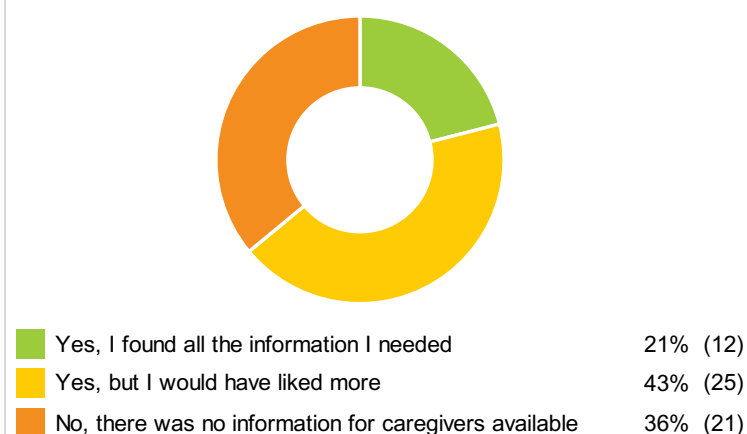
When you were diagnosed, did you receive any information about clinical trials?



Missing responses were excluded from analyses.

Supplementary Figure 2.

Were you able to find information specifically for carers of bladder cancer patients?

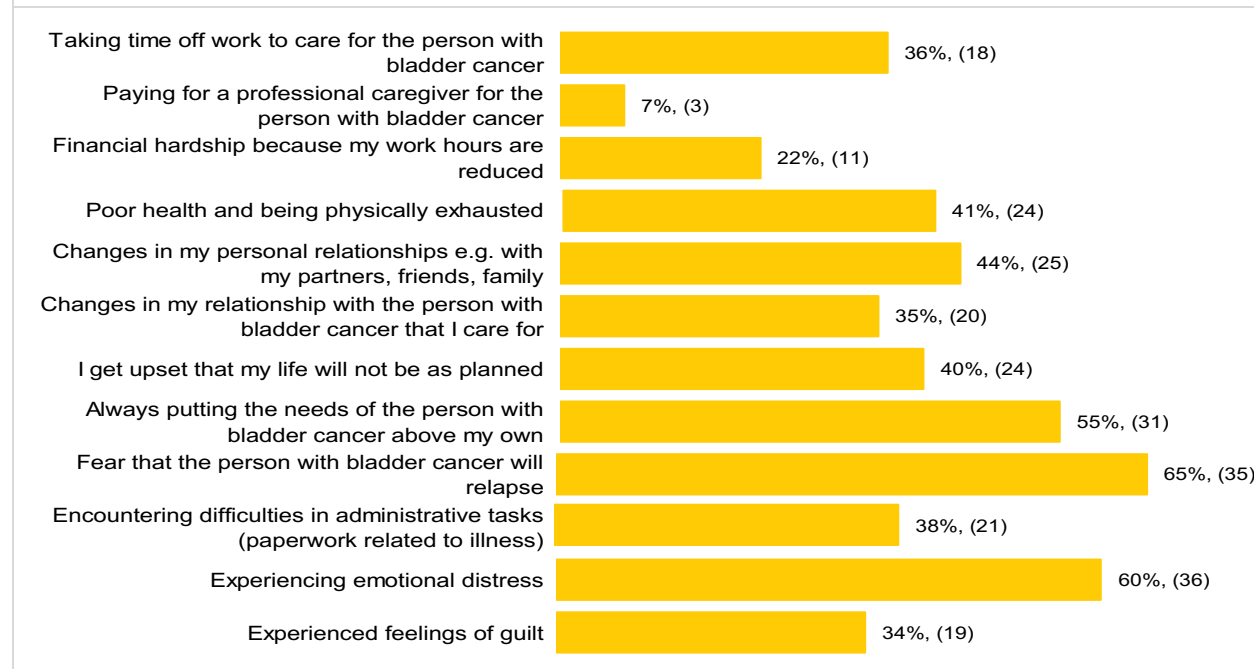


Missing responses were excluded from analyses.

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Supplementary Figure 3.

To what extent have each of the following issues affected you as a carer? - Respondents answering 'Often/Always'



Missing responses

were excluded from analyses.

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