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The bladder cancer patient survey: Global perspectives on awareness and treatment of bladder cancer

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ABSTRACT

Introduction: Bladder cancer is the ninth most common cancer globally, but, to date, few studies have examined the personal experience of bladder cancer patients. This study examines three key areas in bladder cancer patient experience: diagnosis, treatment, and support.

Method: An online, multiple-choice questionnaire was designed to collect data regarding bladder cancer patient experience. The study was created, translated, and disseminated electronically via email and social media by the European Cancer Patient Coalition and national bladder cancer organisations and groups. The web-based online survey was conducted between September 2017 and April 2018.

Results: The survey yielded responses from 1615 participants originating from 39 countries. The most common initially reported symptom of bladder cancer was visible blood in the urine (72.8 % of respondents). Three-quarters (74.7 %) of respondents reported that their initial diagnosis was a condition other than bladder cancer. The most popular form of support reported for coping with bladder cancer, for both patients and carers, was friends and family (69.7 %), followed by online support groups (58.3 %). Country comparison showed that awareness of bladder cancer differed widely between countries.

Conclusions: There is a need for greater awareness and understanding of bladder cancer. Further research is warranted to promote early diagnosis and the timely treatment of bladder cancer.

1. Introduction

Bladder cancer is the ninth most common cancer worldwide, with an estimated 430,000 new cases diagnosed each year [1]. Bladder cancer is more common in developed countries. It has a high incidence and a high risk of relapse, which indicates that bladder cancer has a vast impact on healthcare.

The three primary stages of bladder cancer include: non-muscle-invasive bladder cancer, which has not invaded the bladder muscle wall; locally invasive bladder cancer, which has invaded the bladder muscle wall and/or spread to nearby organs and/or lymph nodes [2]; and, metastatic bladder cancer, which has spread to other parts of the body. Of newly diagnosed bladder cancer cases in the US, approximately 75 % were detected at an early stage, with 50 %–70 % of these recurring and 10 %–30 % progressing to advanced disease [2].

For many patients who present with non-muscle-invasive bladder cancer, treatment generally includes transurethral resection of bladder tumour (TURBT). The remaining 25 % of newly diagnosed bladder cancer patients present with locally invasive and metastatic bladder cancer. For these patients, treatment is typically multidisciplinary and

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Table 1
Characteristics of bladder cancer patients reported by either themselves or their carers.

		Number of respondents (% of respondents)	Responses of patients n (%)	Responses of carers and other survey respondents* n (%)
Patient, carer or other		1,247 (100.00 %)	992 (79.55 %)	255 (20.45 %)
Sex of person with bladder cancer	Male	740 (63.52 %)	528 (57.58 %)	212 (85.48 %)
	Female	423 (36.31 %)	389 (42.42 %)	34 (13.71 %)
	Other	2 (0.17 %)	0 (0.00 %)	2 (0.81 %)
Current diagnosis	Non-muscle-invasive bladder cancer	609 (51.01 %)	534 (57.42 %)	75 (28.41 %)
	Locally invasive disease	218 (18.26 %)	175 (18.82 %)	43 (16.29 %)
	Metastatic bladder cancer	68 (5.70 %)	47 (5.05 %)	21 (7.95 %)
	Other	193 (16.16 %)	147 (15.81 %)	46 (17.42 %)
	Diagnosis unknown	37 (3.10 %)	27 (2.90 %)	10 (3.79 %)
	Patient deceased	69 (5.78 %)	0 (0.00 %)	69 (26.14 %)
Smoking status	Current smoker	179 (15.44 %)	111 (12.12 %)	68 (27.98 %)
	Current non-smoker	980 (84.56 %)	805 (87.88 %)	175 (72.02 %)

* Other survey respondents included family members and previous carers.

can include radical cystectomy, radiotherapy, chemotherapy, and/or immuno-oncology therapy [3].

Bladder cancer is more common in men than women, with a 3:1 sex ratio [4]. Women with bladder cancer generally have greater delays in diagnosis [5]. General practitioners refer fewer women to urologists for blood in urine [5], which may be due to higher rates of urinary tract infections in women or because bladder cancer occurs less frequently in women. Women have a higher bladder cancer-related mortality than men [1]. A previous systematic review of bladder cancer patient experience found that inconsistencies in bladder cancer symptoms contributes to delays in diagnosis [6], therefore this survey included research into what initial symptoms patients experienced.

Smoking is the most common risk factor for bladder cancer, and accounts for approximately half of all cases of urothelial bladder cancer [7]; other risk factors include occupational exposure to carcinogens (i.e. plumbers, autoworkers, painters). Some people also have a genetic predisposition for developing bladder cancer [7].

Once a person is diagnosed with bladder cancer, he or she may also face difficulties in accessing appropriate care and treatment. Previous surveys of people with other diseases have found that barriers to care include the high cost, long waiting times, travel difficulties, and a lack of available health services [8]. Previous research has also shown that bladder cancer research is greatly underfunded compared to other malignancies, with the fewest clinical trials of all common cancers [9], despite numerous unanswered research questions [10]. From their own research, Bessa et al. [11] have also noted an 'unmet need' in the long-term support and survivorship resources for bladder cancer patients.

To date, few studies have analysed the experience of bladder cancer patients, with no previous global survey examining bladder cancer awareness. This study addresses three key areas: diagnosis, awareness and support systems.

2. Material and methods

2.1. Survey design

A structured questionnaire was designed to analyse bladder cancer experience. The questionnaire was subdivided into specific areas of interest, including awareness, symptoms and support. All people with bladder cancer and their carers were eligible to answer the questionnaire.

The study was designed and disseminated by the European Cancer Patient Coalition and Fight Bladder Cancer UK, in collaboration with the Norwegian Bladder Cancer Society (Blærekreftforeningen), the Italian Bladder Cancer Society (Pazienti Liberi ale Neoplasie Uroteliali), Bladder Cancer Canada, the Bladder Cancer Advocacy Network USA (BCAN), Bladder Cancer Support Group France (Les Zuros), the Hellenic Cancer Federation Greece (ELLOK), and the Association of Cancer Patients in Finland (Suomen Syöpäpotilaatry).

Surveys were implemented online using a web-based tool (SurveyMonkey tool, SurveyMonkey Inc., Palo Alto, CA USA). In order to capture global perspectives, the survey was disseminated electronically and developed in English with translation into Dutch, Finnish, French, Greek, Italian, Norwegian, and Spanish.

The study population was opportunistic and self-selected. People who completed the survey were predominantly associated with patient organisations concerned with bladder cancer. All responses were anonymous, and the survey was open and available for completion for a period of seven months (September 2017 to April 2018).

2.2. Data preparation and analysis

The survey consisted of 24 multiple-choice questions, with an 'other' option provided, as appropriate, to write in non-listed responses. As there was often overlap between the listed response options and the written answers in the 'other' section, results were also analysed and recalculated to account for overlaps.

Categorical data were summarised using frequency counts and percentages. These summaries were inspected for any general patterns and trends, and exploratory analysis was performed as appropriate. Any written survey answers in French, Finnish, Greek, Italian, Norwegian, Dutch or Spanish were translated into English before analysis.

When a response was missing, it was treated as such and excluded from the summary. Therefore, the denominator for summaries was the number of non-missing responses, and frequencies and percentages were calculated out of the non-missing values.

3. Results

3.1. Respondent characteristics

The survey yielded responses from 1615 participants originating from 39 countries, however, not every responder answered every question. Most respondents were bladder cancer patients (79.55 %; n = 992/1247), with 20.45 % (n = 255/1247) being carers or 'other' respondents, for which 'other' included previous carers and family members of patients (Table 1). Table 2 shows a comparison between the countries which received the greatest number of respondents.

Table 2
Country comparisons.

	Number of patients and carers reported (% respondents)							
Total number of respondents from country who participated in the survey (% of all survey respondents)	Finland 46 (2.85 %)	France 111 (6.87 %)	Greece 172 (10.65 %)	Italy 136 (8.42 %)	Norway 144 (8.92 %)	Spain 62 (3.84 %)	UK 303 (18.76 %)	USA 366 (22.66 %)
Awareness								
Total number of respondents	40	88	141	127	135	39	303	358
Had not heard of bladder cancer prior to diagnosis	23 (57.50 %)	64 (72.73 %)	97 (68.79 %)	64 (50.39 %)	58 (42.96 %)	31 (79.49 %)	187 (61.72 %)	163 (45.53 %)
Diagnosis method								
Total number of respondents	33	58	98	106	123	19	284	358
Cystoscopy	23 (69.70 %)	26 (44.83 %)	63 (64.29 %)	46 (43.40 %)	90 (73.17 %)	9 (47.37 %)	217 (76.41 %)	265 (74.02 %)
Urine test	17 (51.52 %)	15 (25.86 %)	17 (17.35 %)	19 (17.92 %	23 (18.70 %)	5 (26.32 %)	86 (30.28 %)	115 (32.12 %)
Ultrasound scan	16 (48.48 %)	29 (50.00 %)	50 (51.02 %)	44 (41.51 %)	19 (15.45 %)	9 (47.37 %)	101 (35.56 %)	53 (14.80 %)
CT/MRI	9 (27.27 %)	19 (32.76 %)	37 (37.76 %)	21 (19.81 %)	41 (33.33 %)	2 (10.53 %)	70 (24.65 %)	133 (37.15 %)
TURBT	8 (24.24 %)	17 (29.31 %)	35 (35.71 %)	44 (41.51 %	20 (16.26 %)	8 (42.11 %)	120 (42.25 %)	177 (48.44 %)
Other	4 (12.12 %)	4 (6.90 %)	0 (0.00 %)	11 (10.38 %)	10 (8.13 %)	0 (0.00 %)	12 (4.23 %)	17 (4.75 %)
Support								
Total number of respondents	32	51	73	92	116	16	298	354
Family and friends	18 (56.25 %)	31 (60.78 %)	56 (76.71 %)	64 (69.57 %)	81 (69.83 %)	11 (68.75 %)	205 (68.79 %)	248 (70.06 %)
Online support forums	14 (43.75 %)	21 (41.18 %)	5 (6.85 %)	5 (5.43 %)	32 (27.59 %)	2 (12.50 %)	232 (77.85 %)	277 (78.25 %)
Psychologist or psychiatrist	4 (12.50 %)	6 (11.76 %)	3 (4.11 %)	6 (6.52 %)	6 (5.17 %)	1 (6.25 %)	12 (4.03 %)	29 (8.19 %)
Face-to-face support groups	2 (6.25 %)	1 (1.96 %)	4 (5.48 %)	10 (10.87 %)	8 (6.90 %)	1 (6.25 %)	26 (8.72 %)	34 (9.60 %)
Patient advocacy group	1 (3.13 %)	0 (0.00 %)	3 (4.11 %)	5 (5.43 %)	33 (28.45 %)	0 (0.00 %)	15 (5.03 %)	51 (14.41 %)
Financial help	1 (3.13 %)	0 (0.00 %)	6 (8.22 %)	3 (3.26 %)	0 (0.00 %)	2 (12.50 %)	16 (5.37 %)	16 (4.52 %)
Help with sexual issues	1 (3.13 %)	0 (0.00 %)	1 (1.37 %)	0 (0.00 %)	3 (2.59 %)	0 (0.00 %)	7 (2.35 %)	3 (0.85 %)
Spirituality help	0 (0.00 %)	4 (7.84 %)	7 (9.59 %)	10 (10.87 %)	0 (0.00 %)	5 (31.25 %)	11 (3.69 %)	46 (12.99 %)
Other	2 (6.25 %)	13 (25.49 %)	8 (10.96 %)	23 (25.00 %)	18 (15.52 %)	1 (6.25 %)	45 (15.10 %)	43 (12.15 %)

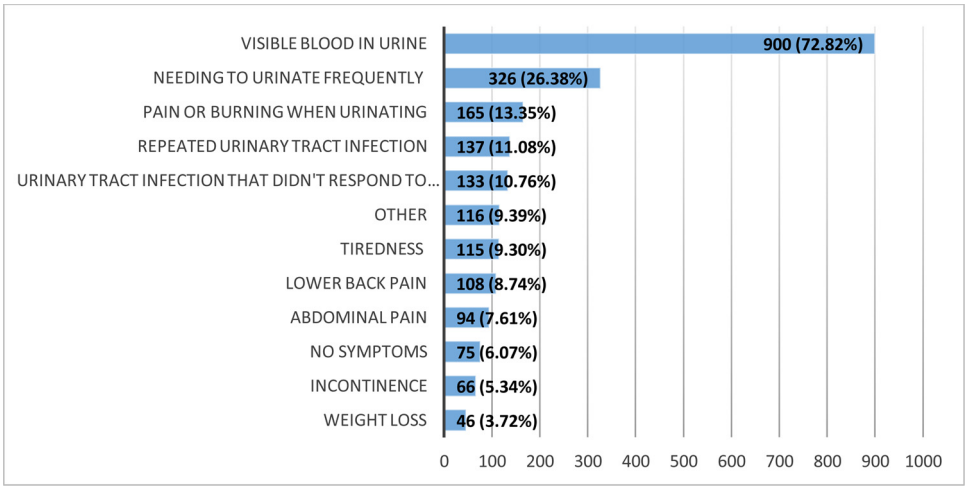

Fig. 1. First symptoms of bladder cancer reported by bladder cancer patients or their carers. Respondents could select more than one response.

3.2. Awareness

Over half of the respondents (55.60 %; n = 745/1340) were unaware of bladder cancer before diagnosis. Of those who had heard of bladder cancer, 44.04 % (n = 266/604) had known someone diagnosed with bladder cancer before their own diagnosis, 53.15 % (n = 321/604) had not known of someone diagnosed with bladder cancer previously, and 2.81 % (n = 17/604) did not know.

3.3. Current diagnoses

The most common current diagnosis was non-muscle-invasive bladder cancer, which 51.01 % (n = 609/1194) of respondents reported. Of the 'other' responses, most answers referred to being in remission after treatment, often due to surgical removal of the bladder (Table 1).

3.4. Symptoms

Many of the participants (72.82 %; n = 900/1236) reported that visible blood in their urine was the first bladder cancer symptom (Fig. 1). For this question, respondents could select multiple answers. The predominant written responses in 'other' (9.39 %; n = 116/1236) referred to microscopic haematuria, which is only detectable upon testing.

3.5. Diagnosis

Nearly two thirds of survey participants (61.88 %; n = 758/1225) reported that the general practitioner (GP) or family doctor was the first health professional sought for the initial bladder cancer symptoms. Other health professionals who were initially consulted were urologists (21.47 %; n = 263/1225), emergency department physicians (8.08 %; n = 99/1225), 'other' (3.76 %; n = 46/1225), gynaecologists (2.86 %; n = 35/1225), nurses (1.71 %; n = 21/1225) and oncologists (0.24 %; n = 3/1225).

The most common initial diagnosis given by health professionals for the presenting symptoms was urinary tract infection (36.03 % of responses; n = 427/1185) (Fig. 2). Of the 24.47 %; (n = 290/1185) 'other' responses, most answers referred to the health professionals not wanting to make assumptions without further testing, or (for females) a potential gynaecological problem.

Most of the respondents (72.17 %; n = 866/1200) were referred to a urologist. The next most common response was that the participant was not referred (12.50 %; n = 150/1200), followed by 'other' (6.33 %; n = 76/1200), of which most respondents reported that they had self-referred themselves to a urologist rather than wait for a formal referral. Other listed referrals from health professionals included: family doctor/GP (3.83 %; n = 46/1200), specialist clinic (3.08 %; n = 37/1200), oncologist (2.92 %; n = 35/1200), gynaecologist (2.08 %; n = 25/1200), and emergency department physician (1.33 %; n = 16/1200). Responses for this question allowed multiple answers.

Most respondents (67.30 %; n = 813/1208) indicated that the bladder cancer diagnoses had been confirmed via cystoscopy (Fig. 3). This question allowed multiple answers and for many individuals multiple diagnostic tests were used.

3.6. Support

Survey participants were asked what support helped them cope with bladder cancer, as either a patient or carer (Fig. 4). This question allowed multiple answers and most participants chose to select more than one answer. The most popular form of support reported was friends and family (69.69 %; n = 798/1145), followed by online support forums (58.25 %; n = 667/1145). Nearly half of the open-ended 'other' responses were reports of how useful their nursing and other medical staff had been in helping them to cope with their diagnosis. Ten of the open-ended 'other' responses (0.87 % of the total respondents) specifically reported receiving no support at all and a desire to have had access to some form of support.

3.7. Country comparisons

Focusing on the three key areas of interest: prior awareness, diagnosis, and methods of coping, the authors analysed country-level data. Awareness of bladder cancer prior to diagnosis was found to vary greatly between countries. In Spain and France, respectively, 79.49 % (n = 31/39) and 72.73 % (n = 64/88) of bladder cancer patients and carers had not heard of bladder cancer prior to the diagnosis. In comparison, just 42.96 % (n = 58/135) of bladder cancer patients and carers in Norway had not heard of bladder cancer prior to the diagnosis (Table 2).

The inter-country analysis showed that a similar range of tests are used to diagnose bladder cancer in the countries. In all countries, except France (where it was the second most common), cystoscopy was the most common test used to diagnose bladder cancer (Table 2). In France, the most common test was ultrasound scan (50.00 %), followed by cystoscopy (44.83 %). Percentage uses of different diagnostic tests did not vary much between countries.

In response to what support system patients and carers used, the

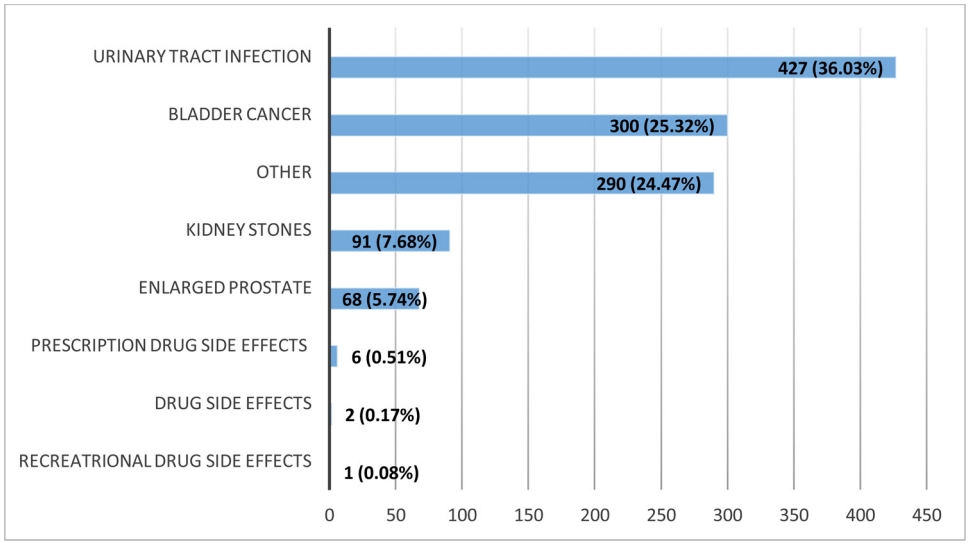

Fig. 2. Initial diagnosis received or interpreted when presenting their symptoms to a health care professional, as reported by bladder cancer patients or their carers.

most common response across all the countries was family and friends, which ranged in frequency from 56.25 % (Finland) to 76.71 % (Greece) (Table 2). In countries where online support forums were more popular, including Finland (43.75 %), and France (41.18 %), face-to-face support groups were found to be less popular (6.25 % and 1.96 % respectively) (Table 2). The inverse was found in Italy, where face-to-face support groups (10.87 %) were found to be twice as popular as online support forums (5.43 %). The UK and the USA were the only countries where the use of online support forums was more popular than the use of friends and family.

4. Discussion

This study is the largest international overview of the global bladder cancer patient experience to date and highlights some key issues. Over half of the respondents were unaware of bladder cancer before diagnosis. For most respondents, the primary bladder cancer symptoms were often initially mistaken for another cause, potentially leading to delays in treatment and possibly worsening prognosis. The survey results also suggest that not all patients were able to access sufficient support.

4.1. Awareness

Most patients were not aware of bladder cancer before their diagnosis, and most initial suspected diagnoses were not of bladder cancer. This lack of awareness of the illness, and hence what symptoms to look out for, could lead to delays in seeking diagnosis and treatment. In their #LiveJournalClub on bladder cancer research, Inarritu et al. [12] found that one of the top five discussion topics was on the need for greater awareness and a specific curriculum for bladder cancer for general practitioners and family doctors. These authors advocate the use of social media, in particular, Twitter, for raising awareness, engaging healthcare professionals globally, and involving patient advocacy groups in meaningful discussions.

At the inter-country level, analysis showed that there were significant differences between countries in the awareness of bladder cancer prior to patient diagnoses. This highlights the need, across all the countries, to raise awareness of bladder cancer symptoms through national campaigns. There needs to be greater awareness of the symptoms of bladder cancer and hence when to seek medical advice if experiencing such symptoms.

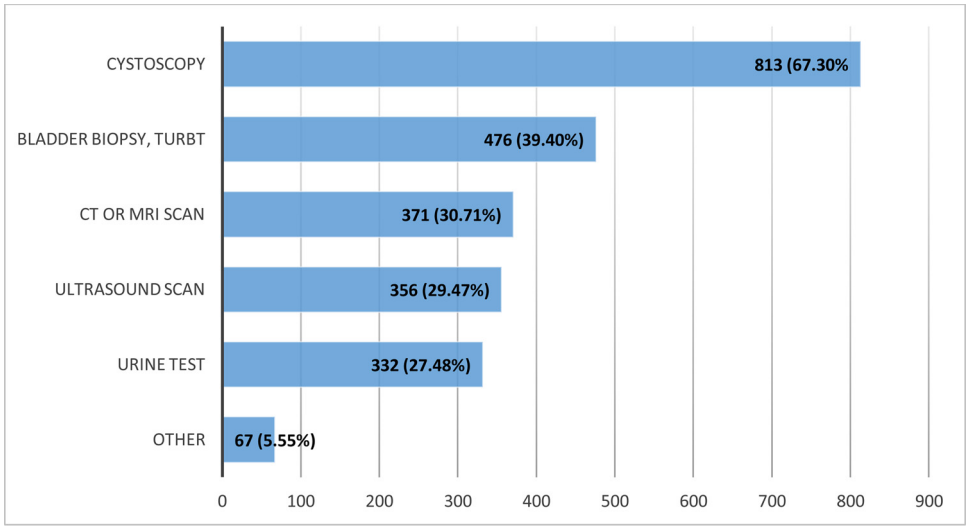

Fig. 3. Diagnostic methods, reported by bladder cancer patients or their carers. Participants could select more than one response.

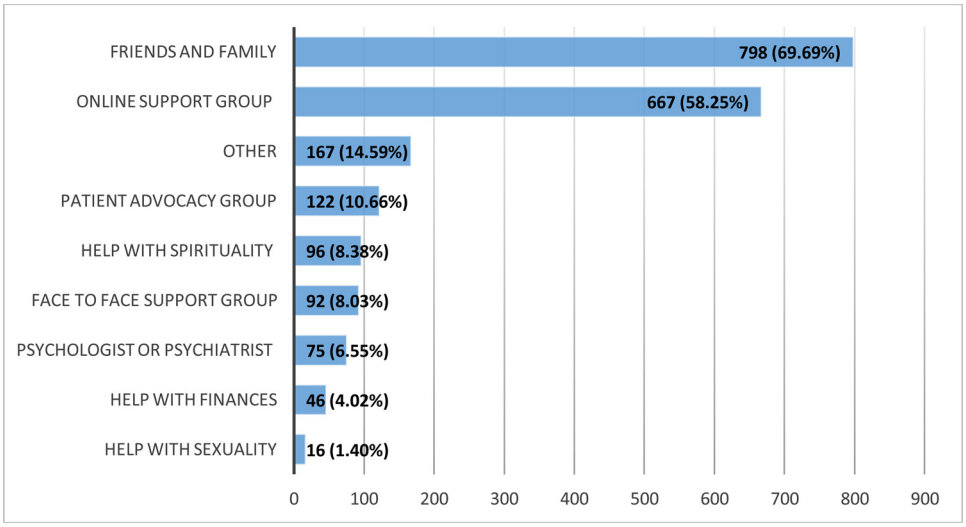

Fig. 4. Support received for bladder cancer, reported by bladder cancer patients or their carers. Participants could select more than one response.

4.2. Support

Previous research at the European level [13] has shown that one out of every three cancer patients experience moderate to severe emotional distress, with one out of four displaying clinically significant maladaptive coping. Previous patient surveys have shown that patients with bladder cancer have a poorer experience compared to most other cancers, with potential reasons cited including a lack of care planning, a lack of emotional support and poor post-discharge care [6]. A cross-sectional study of 365 bladder cancer patients, conducted by Li et al. [14], found that social support was a major determinant for improved quality of life for bladder cancer patients.

Our country-level analysis showed that methods of coping with bladder cancer varied in popularity between different countries (Table 2). Of note, spiritual help was more common in countries known to have a greater religious following, including Spain and Italy, where spiritual help featured in frequency as 31.25 % and 10.87 %, respectively, compared to 0 % in both Finland and Norway. This finding highlights the importance of catering to the sociocultural needs of individuals. Further research could look into the impacts of different coping strategies on bladder cancer patients' wellbeing.

Despite previous research showing that sexual dysfunction is prevalent amongst patients under surveillance for bladder cancer [15], help with sexual issues featured infrequently in all the countries. This could suggest that patients are not receiving the support or information they may need to counter sexual dysfunction, which further research should illuminate. Van der Aa et al. [15] found that bladder cancer patients who were sexually active perceived themselves to have a higher state of general health than their counterparts, hence these authors argue that bladder cancer patients and partners would benefit from proper sexual information in the outpatient clinic.

4.3. Limitations

Not all respondents answered all questions, which may skew the data. In addition, since this survey was conducted online, it had bias that may exclude older people or those with disabilities. As the survey was online, it was more likely to attract respondents whom were active on the internet and may therefore have also led to a bias in the popularity of online support forums. Although bladder cancer is about four times more common in males [4], this survey had only twice the number of male patients than female patients, which suggests there was gender bias.

This study was a self-reported, retrospective study and therefore may have some recall bias. It is possible that patients and carers were not initially told of a physician's suspicions of bladder cancer at their initial presentation, hence the 'initial diagnosis' patients were given may not have taken into account tests their physician were also running to exclude a diagnosis of bladder cancer.

As the number of respondents varied from country to country, comparisons between countries may not be representative of the wider population of bladder cancer patients in each country. For this reason of small sample size, not all countries were included in the country comparisons.

Another limitation of the study is that many of the 'other' written responses did not specifically answer the question, which suggests that in-person interviews could lead to more direct answers and prevent misinterpretation of the questions. Since this initial study provides insight into bladder cancer patient experience from different global regions, future studies would benefit from more qualitative data to enhance understanding of how to improve individual experience with bladder cancer, as well as any barriers to treatment and/or support.

It is also noteworthy that this survey was largely distributed through organisations that offer support for bladder cancer, implying that respondents would likely have had direct association with these organisations. Therefore, the support available to this cohort was possibly over-represented as these bladder cancer patients probably had more access to support than the average bladder cancer patient.

As patients will have been diagnosed and treated over a range of years, country-level differences cannot be taken to reflect current attitudes or public awareness of bladder cancer in these respective countries.

5. Conclusions

The general public awareness of bladder cancer and support available for bladder cancer patients is poor [9]. This study found that, prior to diagnosis, awareness of bladder cancer was low across all countries and only one quarter of the patients represented here were correctly initially diagnosed with bladder cancer. Our survey highlights a range of support mechanisms utilised globally to cope with bladder cancer, as well as highlighting the prevalence of different tests for bladder cancer diagnosis in different countries. Overall, we conclude that there is a need for greater awareness of bladder cancer and its symptoms for both patients and healthcare professionals.

In 2012, the first World Bladder Cancer Awareness Month was celebrated, bringing bladder cancer survivors and families together to increase awareness of early symptoms. The recent establishment of the

World Bladder Cancer Patient Coalition will also enable national bladder cancer patient groups to share resources and best practices. Further initiatives such as these are imperative to promote greater bladder cancer awareness.

The authors have no conflicts of interest to declare.

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