

Research Communication

The experience of UK patients with bladder cancer during the COVID-19 pandemic: a survey-based snapshot

The COVID-19 pandemic has placed unprecedented strain on healthcare systems worldwide with the requirement to treat large influxes of infected patients, many of whom require respiratory support. Healthcare systems have had to redirect resources and redeploy staff away from routine diagnostic, treatment and follow-up services. The NHS in the UK is no different, and cancer services have undergone significant disruption to create the emergency capacity to tackle the pandemic. As a charity that endeavours to support bladder cancer (BC) patients and improve outcomes, Action Bladder Cancer UK (ABC UK, Tetbury, UK) designed and administered an online survey to investigate the prevalence of such disruption.

Using the SurveyMonkey platform (San Mateo, CA, USA), the survey was launched on 22 April 2020 (approximately 10 days after the peak of UK COVID-19 cases) and closed on 22 July 2020. BC patients were directed to the survey via the ABC UK website (<http://actionbladdercanceruk.org/>), ABC UK Patient Support Groups, and social media platforms. In addition to the collection of anonymized demographic and tumour-specific characteristics, the first three digits of each postcode were converted into area type using Office for National Statistics postcode data and categorized as rural, urban city and town, and urban major conurbation. Associations between area type and disruption were assessed using the chi-squared test. The analysis of these data was approved by the King's College London Research Ethics Office.

In the time from inception to completion, 156 patients with BC responded. Over 94% of respondents lived in England, although there was geographical reach from all of the UK. A total of 34% of patients were from rural areas, 29% were from urban cities and towns, and 22% were from major conurbations such as West Yorkshire, Greater Manchester and Greater London (15% did not submit postcodes). Almost 80% of respondents were aged 60 years or older and more than 68% were men. Approximately 71% of respondents had non-muscle-invasive BC (NMIBC), 22% had muscle-invasive BC (MIBC), and 3% had a diagnosis of advanced/metastatic disease.

Across all groups, 49% of patients described disruption to their treatment or follow-up (delays, postponements, or cancellations/curtailments), while 33% of patients indicated

no change, with treatment and follow-up proceeding as normal. The majority of the remaining 18% of patients were scheduled for follow-up several months in the future and had not yet been informed of any changes. There was no association between area type (rural/urban) and disruption to treatment. This lack of association remained when stratified by NMIBC vs MIBC/advanced disease.

In patients who described disruption, 50% had received a telephone call to inform them, 27% had received a letter, 2% had received a text message, and 21% had contacted the hospital themselves; 33% reported that the pandemic had made it more difficult to communicate with their urology team.

Eight respondents were awaiting their initial transurethral resection of bladder tumour (TURBT); for two of these patients, TURBT had been delayed or postponed (Table 1). Sixteen patients were awaiting a subsequent TURBT (for re-resection or recurrence); for six of these patients, TURBT had been delayed or postponed. Ninety-seven patients described being under cystoscopic surveillance, 85% of whom had NMIBC and 14% MIBC (one patient did not specify their disease status). A total of 51 patients (53%) reported a delay or postponement to their surveillance (Table 1). Of 53 patients with NMIBC undergoing courses of intravesical therapy, 37 (70%) described delays, postponements or curtailments in treatment (Table 1).

Seventeen patients were awaiting cystectomy, of whom nine had been notified of a postponement in their surgery, and three had been notified of cancellation of their surgery (Table 1). Two patients' treatment plans changed from cystectomy to radiotherapy; there were no patients who changed from radiotherapy to cystectomy, and no patients described disruption to radiotherapy or neoadjuvant chemotherapy (Table 1).

Eight patients described undergoing treatment regimens for locally advanced or metastatic disease (adjuvant chemotherapy or chemotherapy only); five of these patients described disruption to the administration of chemotherapy (Table 1).

Regarding COVID-19 itself, 67 respondents (43%) had been advised to shield, and the majority of the remainder felt that they should have been advised to shield and shielded anyway.

Table 1 Changes to treatment due to COVID-19 based on a survey of 156 respondents.

Treatment	Status	n	%
First TURBT (n = 8)	Postponed	2	25.0
	Cancelled	0	0.0
	Going ahead as planned	6	75.0
Subsequent TURBT (n = 16)	Postponed	6	37.5
	Cancelled	3	18.8
	Going ahead as planned	7	43.8
Cystectomy (n = 17)	Postponed	9	52.9
	Cancelled	3	17.7
	Going ahead as planned	5	29.4
Intravesical therapies (BCG and mitomycin; n = 53)	Postponed	28	52.8
	Cancelled	9	17.0
	Going ahead as planned	10	18.9
	Other/missing	6	11.3
Cystoscopic surveillance (n = 97)	Postponed	40	41.2
	Cancelled	11	11.3
	Going ahead as planned	33	34.0
	Other/missing	13	13.4
Neoadjuvant chemotherapy (prior to cystectomy or radiotherapy; n = 3)	Postponed	0	0.0
	Cancelled	0	0.0
	Going ahead as planned	2	66.7
	Other/missing	1	33.3
Adjuvant chemotherapy (after cystectomy or radiotherapy; n = 6)	Postponed	3	50.0
	Cancelled	1	16.7
	Going ahead as planned	2	33.3
	Other/missing	0	0.0
Chemotherapy only (n = 2)	Postponed	0	0.0
	Cancelled	1	50.0
	Going ahead as planned	1	50.0
	Other/missing	0	0.0

TURBT, transurethral resection of bladder tumour.

A total of 76% of patients expressed some concern about attending hospital for their treatment and follow-up appointments, and approximately 64% described that safety precautions for themselves and for staff would make them feel safer when attending.

The outputs of this survey have demonstrated the considerable disruption to the care of BC patients in the UK during the COVID-19 pandemic. Notably, the level of disruption was not significantly different between patients from different types of geographical area (e.g. rural or urban), with the survey capturing a representative sample of the BC population: the majority of respondents were both male and aged >60 years, and approximately 71% were NMIBC patients.

It was also interesting to observe that, although fewer than half of the patients were advised to shield, the majority of patients did so anyway. This response is reflected in the high levels of concern and/or anxiety reported by patients regarding returning to hospital to continue treatment and/or follow-up.

A survey of this nature has a number of limitations. Although the patient demographics accurately reflect those of the UK BC population, this remains a relatively small study using an

unvalidated questionnaire. The survey was more likely to be completed by existing patients with BC who are already engaged with ABC UK, rather than newly diagnosed patients who may not yet be aware of the charity's work.

Furthermore, local or regional patterns have not been captured comprehensively, and more nuanced responses to the survey may have been obtained via telephone interview.

Patients with BC in the UK are not alone in experiencing disruption to their care during the pandemic [1,2]. Some of these disruptions will have been justified in order to protect patients from COVID-19 itself or from additional complications of specific treatments in the environment of the pandemic [2–4]; yet much disruption will have directly resulted from the emergency redeployment of healthcare services to tackle the pandemic. Our survey appears to demonstrate that both MIBC and NMIBC patients have been equally affected by delays, postponements and cancellations during the COVID-19 pandemic. Hence, despite a plethora of recommendations from a number of sources outlining reasonable patient prioritization strategies [2,5–7], these strategies may not have been developed and circulated quickly enough or enacted rapidly enough at or around the peak of the UK pandemic to have made a perceivable difference to patients. Given the overwhelming nature of the pandemic on the whole of society, this is understandable. However, it is critical that the BC clinical and academic community maintains an 'institutional memory' should similar circumstances ensue in the form of a second wave of COVID-19, or as a separate threat. Now is the time to plan effective contingent ways of working and agree upon protocols that minimize the disruption to high-quality bladder cancer care should either scenario become reality; considerable evidence is available to inform such strategies [5,6], including publications available at the following websites:

<https://www.bjuinternational.com/bjui-blog/covid-19-collection-of-urology-papers/>

<https://www.europeanurology.com/covid-19-resource>




<https://uroweb.org/wp-content/uploads/Covid-19-EAU-NMIBC-Recommendations.pdf>

<https://ukcoronaviruscancermonitoring.com/>.

Notwithstanding, the true success of any strategy in the cancer setting can only be appropriately assessed several years downstream in terms of clinical outcomes; potential health-related quality-of-life deficits should not be forgotten, and we are planning follow-up surveys to attempt to capture the physical and psychological burden of the treatment disruptions and postponements. Furthermore, we should be aware that new suspected cancer referrals have also dramatically reduced during the pandemic [8], and so there is a long road to recovery ahead and for none more so than patients with BC.

Conflicts of Interest

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Abbreviations: ABC UK, Action Bladder Cancer UK; BC, bladder cancer; TURBT, transurethral resection of bladder tumour.