



Urologic oncology patient perspectives during COVID-19 treatment delays

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Abstract

Purpose We sought to describe patient experiences during COVID-19 related delays in urologic cancer treatment.

Methods We conducted a mixed methods study with an explanatory-sequential design. Survey findings are presented here. Patients from a Midwestern Cancer Center and the Bladder Cancer Advocacy Network (BCAN) self-reported via survey their experience of treatment delay, patient-provider communication, and coping strategies. We quantified patient distress with an ordinal scale (0–10), based on the National Comprehensive Cancer Network Distress Thermometer (NCCN-DT).

Results Forty-four patients with bladder, prostate, and kidney cancers consented to the survey. Most individuals were male ($n=29$; 66%) and older than 61 years of age ($n=34$; 77%). Median time since diagnosis was 6 months. Dominant reactions to treatment delay included fear that cancer would progress ($n=22$; 50%) and relief at avoiding COVID-19 exposure ($n=19$; 43%). Most patients reported feeling that their providers acknowledged their emotions ($n=31$; 70%), yet 23 patients (52%) did not receive follow-up phone calls and only 24 (55%) felt continually supported by their providers. Patients' median distress level was 5/10 with 68% ($n=30$) of patients reaching a clinically significant level of distress (≥ 4). Thematically grouped suggestions for providers included better communication, more personalized support, and better patient education.

Conclusion During the COVID-19 pandemic, a high proportion of urologic cancer patients reached a clinically significant level of distress. While they felt concern from providers, they desired more engagement and personalized care.

Keywords COVID-19 · Cancer patients · Stress · Distress · Treatment delay

Introduction

Early in the COVID-19 pandemic, sharp rises in cases overwhelmed health care systems, leading to widespread clinic and procedural cancellations. As resources were reallocated to care for COVID-19 patients, there was growing concern that individuals with other health conditions could not access essential care [1]. The full extent of how the pandemic affected outcomes of patients with other conditions is still uncertain, as reduced screenings may have repercussions for years to come [2]. Even before the pandemic, cancer patients reported

distress related to wait times for diagnostic tests, specialty care referrals, and ultimately scheduling treatment [3]. The pandemic-related disruption only increased delays in care and created greater uncertainty. Patient concerns with delays are valid as prioritizing surgical treatment for many oncologic patients, even during a pandemic, can prevent cancer-related deaths [4].

Urologic oncologists are acutely aware of the need for the timely treatment of conditions such as high-risk urothelial, prostate, testis, penile, and locally advanced renal cancers. Early in the pandemic, individual surgeons had to weigh the risk of delayed care against exposing patients to COVID-19, in addition to responding to institutional cancellations of surgical cases. Perioperative mortality and risks from COVID were deemed especially high for elderly and frail patients [5–8]. The urology community released guidelines to help providers appropriately prioritize such patients at higher risk of disease progression or worse survival outcomes with delayed care [9–12].

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As clinical staff continually stratified patient risk and adjusted clinical schedules, patients were often left wondering if and when they would receive treatment [13]. Several studies have explored cancer patient stress levels, fears of the contracting virus, and the effect of stress on symptom burden [14–16]. However, little is known about patient interactions with their providers in the context of treatment delay. In the current study, our aim was to understand how patients with urologic cancers reacted to delays in their care, how they were informed about care delays, and the consequent impacts on their relationships with providers and their coping. To this end, we surveyed patients with urologic cancers who were poised for treatment during the first wave of the COVID-19 pandemic, in the spring of 2020.

Methods

We conducted an explanatory-sequential, mixed methods study in which patients with urogenital cancers were surveyed. The study was approved by the University of Michigan Institutional Review Board. The survey findings are presented in this manuscript.

Patients were eligible for our study if they had a prostate, muscle-invasive bladder, or advanced renal cancer diagnoses and if they had delay of their surgery initially scheduled between February and April 2020. Patients were recruited from a large Midwestern Comprehensive Cancer Center and from the Bladder Cancer Advocacy Network (BCAN). Patients from the cancer center were contacted via phone by a study coordinator and recruited for the study. Patients from BCAN were recruited by email sent by the Education and Research Director's office with an embedded link to the study. All participants were sent an email with an introduction to the study with a link to the online survey. Patients were contacted for our study between May and June 2020. Prior to entering the survey, participants attested their consent online to enroll in the study.

A Qualtrics survey was designed by the study team and was further reviewed by health experts who care for patients with these cancers. It was determined by our research and clinical experts to have face validity. Some questions were modeled on similar surveys administered to patients by organizations, such as the BCAN and the American Cancer Society. Quantification of distress was modeled on the National Comprehensive Cancer Network Distress Thermometer (NCCN-DT), a validated measure created for cancer patients. The NCCN-DT is an ordinal variable on a scale of 0 to 10, with 0 representing no distress and 10 representing maximal distress. The threshold of 4 or higher is considered to be a clinically significant level of distress [17]. Additional areas covered in the survey include self-reported demographic and clinical information including patient age,

gender, cancer type, date of diagnosis, planned treatment, and prior treatments. Patients were also asked about physician communication, patient understanding of rationale for treatment delay, their emotional reactions, coping strategies, and an assessment of personal and provider-related support. Questions were predominately multiple choice with a final free text answer option for patients to suggest how caregivers could best support patients during delays in treatment. We employed descriptive statistics to analyze the survey data, and results were tabulated. We summarized the open text comments in representative themes.

Results

Twenty-nine of 37 Cancer Center eligible patients agreed to participate in the study (76% response rate). The number of eligible BCAN patients who received a recruitment email could not be determined; however, 15 total patients responded. In total, 44 patients completed the survey. Table 1 describes their demographic and clinical characteristics. Many of the individuals were older than 61 years

Table 1 Patient characteristics and treatment course

	<i>N</i> (%) Median (Q1, Q3)
Age (years)	
25–40	1 (2%)
41–50	1 (2%)
51–60	8 (18%)
≥ 61	34 (77%)
Male	29 (66%)
Time since diagnosis (months)	6 (2, 35)
Diagnosis	
Bladder cancer	20 (45%)
Prostate cancer	13 (30%)
Kidney cancer	9 (20%)
Urachal	1 (2%)
Unknown	1 (2%)
Treatment planned	
Surgery	42 (95%)
Chemotherapy	4 (9%)
Immunotherapy	4 (9%)
Radiation	2 (5%)
Hormonal therapy	2 (5%)
Treatments before March 2020	
None	26 (59%)
Surgery	12 (27%)
Chemotherapy	5 (11%)
Immunotherapy	4 (9%)
Hormonal therapy	2 (5%)
Treatment	
Could not begin	22 (50%)
Had to change	22 (50%)

of age ($n=34$; 77%) and were male ($n=29$; 66%). Most were diagnosed with bladder cancer ($n=20$; 45%), followed by prostate cancer ($n=13$; 30%), and kidney cancer ($n=9$; 20%). Median time since their cancer diagnosis was 6 months. Ninety-five ($n=42$) percent of the sample had a surgical treatment plan, while 59% ($n=26$) had not had any prior treatment. All participants experienced disruptions in treatment due to COVID-19.

The majority of treatment interruptions began in March 2020 ($n=32$; 73%). Most patients were informed by their surgeons over the phone ($n=32$; 72%) about their delay. Explanations for delay included reassurance that they could wait without significant risk of progression ($n=23$; 52%), hospital prioritization of COVID-19 care ($n=18$; 41%), and that risks of contracting COVID-19 outweighed risk of cancer progression ($n=10$; 23%). Eighty percent of patients ($n=35$) were not offered interim or alternative treatments.

Patient self-reported median level of distress was 5 (Fig. 1). Although patients generally felt they understood the reasons for treatment delay ($n=40$; 90%), they had a variety of emotional responses which were not mutually exclusive. They worried about cancer progression ($n=22$; 50%) and reported feelings of sadness ($n=12$; 27%) or anger ($n=7$; 16%) because cancer was not prioritized over the pandemic. On the positive side, some were glad to avoid potential exposure to COVID-19 during cancer treatment ($n=19$; 43%), and others still reported feeling “ok” about the situation ($n=14$; 32%). Apart from reacting to the pandemic in the context of cancer care, many worried about being infected with COVID-19 ($n=15$; 34%), their inability to cope emotionally ($n=12$; 27%), family members being infected ($n=8$; 18%), and loss of income or a job ($n=5$; 9%).

Patients relied on support systems such as family ($n=29$; 66%) and friends ($n=26$; 59%), and employed a variety of coping strategies, such as acceptance of the situation they

cannot change ($n=22$; 50%) and having faith in their providers ($n=20$; 45%) (Table 2).

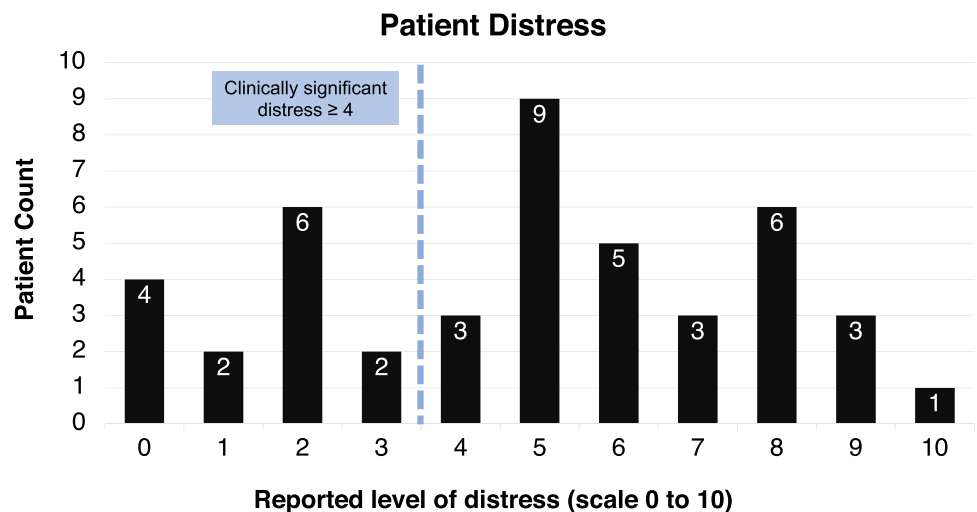
Patients’ experience with provider communication was complicated during this time. Seventy percent of patients ($n=31$) felt that their provider recognized that their feelings of distress were normal and understandable, but 30% ($n=11$) either did not feel that their emotions were addressed or were unsure. Fifty-two percent of patients ($n=23$) reported not having received any follow-up calls from providers, while 43% ($n=19$) received one or two calls. Only 5% ($n=2$) received weekly or more frequent calls. Most of the communication was over phone, while 14% of

Table 2 Patient coping supports

What has helped you cope with the changes in your cancer care?	<i>N</i> =44 <i>N</i> (%)
Support from family	29 (66%)
Support from friends	26 (59%)
Accepting that things are the way they are, what can I do about it	22 (50%)
Having faith in my healthcare providers	20 (44%)
My faith	15 (34%)
Remembering I got through tough times in the past	14 (32%)
Contact with other cancer survivors	9 (20%)
Other*	9 (20%)
Websites that explain my situation	8 (18%)
Reading	8 (18%)
Meditation	7 (16%)
Listening to music	4 (9%)
A counselor	3 (7%)

*Other free text answers included nature and gardening ($n=2$), surgery already completed ($n=2$), time with pets ($n=1$), exercise ($n=1$), support networks, alcohol ($n=1$) and marijuana ($n=1$)

Fig. 1 Patient distress scores. Distribution of patient level of distress on a scale of 0–10 with 0 being no distress and 10 being extremely high distress ($n=44$)



patients ($n=6$) reported having had video visits. Fifty-five percent of patients ($n=24$) felt emotionally supported by their providers, while 27% ($n=12$) felt unsupported and 18% ($n=8$) were unsure.

In an open-ended manner, patients were asked to share what they would like their care teams to know regarding their experience and how to best support them, with 35 individuals (80%) providing a response (Table 3). Many comments reflected themes of praise and gratitude ($n=12$; 27%) for provider support, dedication, and trustworthiness, along with acknowledgement of the risk some providers took during the pandemic. However, another theme was poor communication ($n=8$; 18%) which patients found stressful. Several patients reflected on feeling forgotten. Some patients expressed desire for more personalized support ($n=6$; 14%). One individual requested personalized emails from doctors rather than nurses, while another felt that even a weekly email with a simple update of “no change” would suffice. Three patients at the time of the survey were still hoping for a scheduling update. Patients also wished for better education ($n=5$; 11%), including more in-depth treatment discussions and accurate expectation setting. Overall, patients hoped for personal recognition, further emotional support, and to feel connected to and cared for by team members.

Discussion

Comparing rates of stress among cancer cohorts during the pandemic is challenged by diverse instruments and populations. Our measure of distress was the NCCN-DT, with 68% of patients reporting a score of 4 or greater, qualifying as clinically significant distress. Our cohort of patients was predominately newly diagnosed patients with urologic cancer

anticipating initial treatment. Their cancellations and delays occurred during the first lockdown. Greco et al. examined a comparable group of urologic cancer patients early in the Italian lockdown, surveying those with canceled surgeries yet to be rescheduled. These individuals experienced lower energy, increased anxiety, and a decrease in their perception of their overall health [18]. Broader cohorts with diverse cancers at differing stages of diagnosis, treatment, and surveillance have reported anxiety rates ranging from 17 to 56% [14, 16, 19, 20]. Other studies have identified factors such as how well a patient understands the purpose of their treatment and whether patients were isolated/living alone during the pandemic as influencing distress [21–23].

Our study may be the first to illuminate how patients perceived communication and provider support, and to elicit their suggestions for improvement. Most individuals did receive communication about delay directly from their surgeon (73%), and many felt that their surgeon was one of the most important clinical sources of support (41%). During initial communication, 70% felt that their emotions were acknowledged. However, lower rates of follow-up contact left nearly half of the patients feeling insufficiently supported during this stressful period (45%). It is clear from these results that this decline in provider to patient communication indicates an important area for improvement to mitigate patients' feeling alone during a time of significant distress.

Our findings corroborate studies exploring patients sources of information about COVID-19; while the majority of patients sought information via news and television (78–91%) or social media (43–63%), they still hoped for more personalized information from their providers (35%) [15, 16]. Thus, in the absence of provider communication, patients may seek information elsewhere which can

Table 3 Patient suggestions for support from providers

Theme	N (%) N=44	Example patient quotes
Praise/expression of gratitude	12 (27%)	“I was thankful that Dr. X was honest, sincere, supportive and hopeful about the delay when he called... he promised to pay close attention to any medical changes.” “I will FOREVER be grateful to them risking their necks for me.”
Communication	8 (18%)	“Check in with an email weekly even if there is no change or progress to report on continuing treatment.” “An occasional call during the month and a half I waited for surgery would have been welcome and comforting.” “I was told yes I have cancer, surgery was scheduled then canceled, and I have not heard a word from anyone since.”
Patient education and expectation setting	5 (11%)	“[Discuss]... more on the things I would experience in the weeks post-surgery.” “Explain why they aren't worried the cancer will progress during this time.”
Personalized support and acknowledgement	6 (14%)	“Need to act like they care.” “Explain who you are, and how we can work together. I want to be a participant in my care.” “[Email respondent had] no knowledge of working with the specific patient.”

be misleading and potentially detrimental to appropriate expectations and coping. It must be noted that physicians also experienced distress during this period related to delaying critical cancer care [24].

This may have hindered communication as physicians themselves navigated unpredictable resources and uncertainty on how to support patients. Developing guidelines for how to communicate delays in care and how to provide emotional supports to patients may be helpful. The pandemic is unique, yet treatment delays occur in many circumstances. Screening for support needs and offering mental health resources may also be needed.

Study limitations include a small sample size, lack of denominator for the bladder cancer patients, and lack of longitudinal data points of distress. However, half of our sample came from nationwide recruitment which may offer reassurance that much of what these patients experienced may relate to others with urologic cancers. The somewhat delayed nature of our surveys may have contributed to recall bias. The online survey design may have been prohibitive to those without access to or comfort with technology; however, this format was chosen because during the first phase of the pandemic all research was moved to virtual platforms. The patients of this cohort appeared to be financially secure with low rates of concern for loss of jobs or loss of health insurance, and thus may not accurately represent the nationwide population.

Clinical implications

Our findings provide two important lessons that extend beyond the pandemic: (1) While patient-reported distress is not surprising during delayed urologic cancer care, there is an opportunity to plan for and implement improved patient education regarding anticipated benefits and harms related to postponed treatment. (2) It is critical to establish a system of patient-provider communication that honors the patient's desire for regular updates. Such education and communication can positively enhance patient trust, their sense of inclusion, and confidence in their care.

Author contribution All authors made significant contributions to the conception and design of this project, the data acquisition, and/or the analysis. All listed authors approved the current version to be published.

Data availability All data collected aligns with the published data, and the authors can provide any data if queried.

Code availability Not applicable.

Declarations

Ethics approval Our study's questionnaire and the methodology of the study was approved by the University of Michigan Institutional Review Board and aligns with the ethical standards of the Declaration of Helsinki.

Consent to participate All participants in this study provided informed consent prior to participation.

Consent for publication All participants in this study provided informed consent to publish our findings.

Competing interests The authors declare no competing interests.

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