

Delayed Urologic Cancer Care in the COVID-19 Pandemic: Patients' Experiences

Key Words: COVID-19, treatment delay, genitourinary cancer, psychological distress

Abstract

Objective: To understand experiences of patients with genitourinary cancer who experienced delayed cancer care due to the COVID-19 pandemic.

Methods: We conducted a mixed-methods study with an explanatory sequential design.

Qualitative findings are reported here. Patients with muscle invasive bladder, advanced prostate, or kidney cancer were eligible. Participants were selected for interviews if they self-reported low (0-3/10) or high (6-10/10) levels of distress on a previous survey. Participants were interviewed about their experiences. Interviews were transcribed, coded and categorized using thematic data analysis methodology.

Results: 18 patients were interviewed. Seven had prostate cancer, six bladder cancer, and five kidney cancer. Six themes were derived from the interviews: 1) arriving at cancer diagnosis was hard enough, 2) response to treatment delay, 3) labeling cancer surgery as elective, 4) fear of COVID-19 infection, 5) quality of patient-provider relationship and communication, and 6) what could have been done differently.

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Conclusion: These findings offer insight into the concerns of patients with genitourinary cancers who experienced treatment delays due to COVID-19. This information can be applied to support patients with cancers more broadly, should treatment delays occur in the future.

Introduction:

Since its first case in December of 2019, the COVID-19 pandemic has greatly affected healthcare delivery. During the winter of 2020, hospitals and health systems adapted to handle the effects of the pandemic by restructuring physical spaces, including operating and recovery rooms, to accommodate patients with COVID-19. Cancer surgeries were deemed ‘elective’ and were delayed if the risk of contracting a potentially lethal infection in the hospital outweighed the risk of delay (American College of Surgeons, 2020). As a result, many patients with cancer experienced delays in their treatment (Rosenbaum, 2020).

The urologic oncologic community quickly developed guidelines for treatment deferrals of genitourinary (GU) cancers, suggesting that those with low-grade non-muscle invasive bladder cancer, low, intermediate, and high risk prostate cancer, and T1 renal masses were unlikely to suffer from treatment delay (Campi, 2020; Russell, 2019; Tachibana, 2020; Wallis, 2020). While these decisions may have been oncologically safe, they added stress to patients’ already stressful experience of being diagnosed with cancer.

Even prior to the pandemic, cancer patients reported psychological distress related to diagnostic testing, wait times, navigating the challenges of specialty care referrals and scheduling treatment (Paul, 2012). Patients with GU cancers are not immune to these issues; the psychological distress of these patients has been well studied. For example, studies found that up to 20% of patients with localized prostate cancer developed a mental health disorder after their diagnosis (Ravi, 2014). For patients with renal masses undergoing active surveillance, those with biopsy-proven renal cancer had high levels of psychological distress (Goldberg, 2020). A systematic review of patients with bladder cancer found that patients with bladder cancer have rates of depression up to 23% (pre-treatment) and up to 78% (post-treatment), with post-treatment anxiety rates reaching up to 71% (Vartolomei, 2018).

During the COVID-19 pandemic, cancer patients reported in surveys added stressors, such as fear of infection, treatment delays and social isolation (Han, 2021; Koinig, 2021; Ng, 2020; Wang, 2020). The goal of our study was to understand the impact of treatment delay during the COVID-19 pandemic on patients with GU cancers. We conducted a mixed methods study with a sequential-explanatory design in order to deeply understand the experiences of patients with kidney, bladder and prostate cancers. In this report, we present findings from the qualitative portion of the study.

Methods:

Study Setting

The data being presently reported are the qualitative component of a sequential-explanatory mixed methods study. Quantitative findings were reported in an earlier publication (Faris, 2022).

Participants

Patients were eligible for the original study if they had a prostate, muscle-invasive bladder or advanced renal cancer diagnosis and if their surgeries were initially scheduled in the spring of 2020. They were eligible for the qualitative portion of the study if they gave their consent to be interviewed.

Recruitment

Patients were recruited from a large Midwestern Comprehensive Cancer Center and from a national support organization, the Bladder Cancer Advocacy Network (BCAN), for the mixed methods study. In the first phase of the study (May-June, 2020), patients completed a survey and were asked to rate their level of distress on a 0-10 scale. The scale was modeled after the National Cancer Care Network's Distress Thermometer (NCCN-DT) (Jacobsen, 2005). Based on this scale, a score of 4 and higher is considered clinically significant. At the end of the survey, patients were asked if they would be willing to be interviewed. Those who agreed and reported low (0-3) or high (6-10) levels of distress were contacted.

The Interview

Participants were interviewed in November and December of 2020 via telephone for approximately 30-60 minutes. Interviews were conducted by three members of the study team

(HG, DW, AS), based on an interview guide. The interview guide was developed by the study team that included two urologists and a social worker with extensive experience caring for patients with urologic conditions. Patients were asked about their experience of cancer diagnosis and treatment decision making, how they found out about treatment delay, their response to the delay and reasons given, their concerns as they related to the delay and to the COVID-19 pandemic, their communication with their providers and their thoughts about how treatment delay could be managed better in the future.

Data Analysis

Interviews were transcribed verbatim. Thematic data analysis was adopted to analyze the data (Braun, 2006). Data were coded for interview utterances that reflected patients' experiences of treatment delay during the pandemic. Individual interview coding was conducted by six team members (HG, DW, AS, LM, MM, IVW). Coding was reviewed by the first author (HG) and the principal investigator (DW) who has expertise in qualitative research. Codes were grouped into higher level concepts and further categorized into themes to best reflect findings.

Trustworthiness of the data analysis was secured by the study team's prolonged exposure to the subjects of the study, study team consensus discussions led by the principal investigator, iterative review of the code book, based on new findings, and discussions of interviewers' reactions to the interviews (memoing).

The study was approved by the University of Michigan Institutional Review Board (IRB), with permission to be conducted only virtually, per COVID-19 IRB research guidance.

Results:

Forty-four patients were invited to participate in interviews. Of those, 37 agreed to be interviewed. Due to scheduling and timing constraints, 18 patients in total were interviewed by phone in November and December of 2020. Patients were not asked to disclose reasons for declining an interview. The majority of participants were male (66%). All patients who were interviewed had some aspect of their oncologic care disrupted by the COVID-19 pandemic. Participant diagnoses and distress levels reported in surveys in May and June of 2020 are reported in Table 1. While we did not quantitatively measure the levels of distress in interviews, 13 patients described feelings of high levels of distress upon interviews, as compared to the 8 patients who self-reported high levels of distress in the survey. For example, one patient described the experience of going into a ‘downward spiral’, while another described themselves as ‘feeling abandoned medically’. This type of terminology was used as a qualitative marker for high levels of distress.

Thematic analysis revealed six areas of focus: 1) arriving at cancer diagnosis was hard enough, 2) response to treatment delay, 3) labeling cancer surgery as elective, 4) fear of COVID-19 infection, 5) quality of patient-provider relationship and communication, and 6) what could have been done differently.

Arriving at Cancer Diagnosis was Hard Enough

Participants described feeling distress well before the COVID-19 pandemic because of the difficulties they experienced during the diagnostic process and the way in which their diagnosis

was delivered. They cited factors such as poor communication with providers, scheduling delays, and having to advocate to receive appropriate referrals to multiple providers and/or specialties as major difficulties.

Participant 9: "...I guess when the biopsy results came in, the urologist called me and said well, the results of the tests are back and it looks like you do have prostate cancer. I'm going on vacation for Christmas. You know, it's a slow-growing cancer so there shouldn't be any concern about it, and I'll call you back when I'm back. That was my phone call. So, you know, that started all me being in a really bad downward spiral..."

Participant 22: "So I went to gynecology, and with gynecology, since the blood was continuing to be in my urine, and they would not listen to me that I said I know it's my urine. It's not coming from my vaginal area...so I had a hysteroscopy...and I had a biopsy, and then I had a sonogram. And in the sonogram...a tumor was found in my bladder, even though the sonogram was supposedly a sonogram of my uterus and, you know, my female organs. So, then gynecology referred me back to urology."

Response to Treatment Delay

a. Stress of Treatment Delay

There was a mixed reaction to the stress of the delay. Some participants used humor to cope with the delay or felt reassured by their provider, but many were distressed. For those who were stressed by the delay, a commonly cited source of stress was fear of cancer progression.

Low stress

Participant 1: "No, no. We joked about it a little bit, you know. I mean, not much else you could do. It was just normal until you get the call. You keep waiting, oh, you say, oh, it's a week, this is two weeks, you know, it's three weeks, it's a month. Five weeks later, maybe six maybe they'll call me, but they won't. Who knows? But then sooner or later they'll call."

Participant 8: "I wasn't too concerned because I had been informed that mine was actually very slow growing and that it wasn't really going much further at the time. And I was reassured by [doctor] and the person in charge of the radiation treatment,

[doctor]. They both told me, you know, this is not a runaway cancer and anything like that. It's very slow, and it's not going to be such a big deal in your life."

High stress

Participant 9: "But it's just, you know, you've got this, you know. You've got this issue. It's not going away. You get to worry about it for another six weeks, you know. It's the unknown aspect of it that I think bothered me the most, that, you know, it's still there. I haven't done anything about it. It could be getting worse."

Participant 17: "...but, the whole thing was very nightmare-ish...I suddenly became very aware, of my kidney...it's like you have this alien in you and it, could be growing, and you really want to get rid of it, but you can't and...so it was a tough period there."

b. Understanding of Treatment Delay

Although several participants noted being stressed because of the circumstances of the delay, nearly every participant understood the reason for the delay and understood the implications of the pandemic.

Participant 24: "I understand, because of the pandemic, it's going like crazy. I understand that, so they wanted me to wait, and that I am, you know, they don't want to take a chance of catching the pandemic, you know. So they wanted to wait. I understand that. So I don't mind. You know, as long as they keep an eye on me and know what they are doing, you've got to trust the doctor."

Labeling Cancer Surgery as Elective

Participants were frustrated by the label 'elective' for cancer surgeries. This verbiage was seen as insulting to those who were undergoing cancer treatment, as this treatment was life-saving and therefore was not elective in their minds.

Participant 21: "I remember the first time I heard that, you know, quote unquote, you know, elective surgery wasn't being allowed and then reading all these things about how they defined it...I had some sense, you know, that maybe it would apply to me. On the other hand, I thought, if people, if they're cancer patients who need these things uh that

would presumably come in, a different category than someone who'd had plastic surgery”

Participant 20: “...that was the dimension that frustrated me. You know, it, the-the... presumably we shouldn't have done elective surgery. That's-that's the word. You-you know if it was cosmetic or...but [Gleason] 9 [prostate]cancer, that-that's not elective.”

Fear of COVID-19 Infection

Participants were not fearful of contracting COVID-19 in the hospital, and many cited robust hospital protocols and testing requirements as reasons for not being fearful of infection.

Participant 16: “No, they were very strict in terms of, they tested me twice. I had to, we got to [city] on Wednesday, because they wanted to test two days prior to the surgery, so we did the test there on Wednesday. And then we had another test, another rapid test at the hospital on the same day of the surgery. . . But they were, I mean, [hospital] is, they're top notch. They're very good.”

Participant 22: “...I trusted all the protocols that [health system] put in place...every member was notified these are the protocols. And when I showed up for [treatment], I was very pleased with all the protocols...And so I felt that [health system] did a really good job”

Quality of Provider Relationship and Communication

a. A Strong Provider Relationship was Protective from Distress

Patients described positive relationships or interactions with a provider as diminishing their distress. Many noted that their urologist was the one to deliver the news that their surgery needed to be delayed, which made them feel supported. Participants also noted faith and trust in their provider when discussing a positive outlook on the success of their treatment even when it had to be deferred.

Participant 3: “I felt it was explained well, especially [doctor]. I really felt good with him, you know, and he was very good at that, and he told me what I needed to know. I

didn't ask a whole lot of questions, but I got my questions answered...I feel as though I got the best. And that was very comforting to know that."

Participant 9: "...after I talked to the doctor for about ten minutes, I was fine, because he, you know, he's a pro and he knows what he's doing, and he had the, he had all the information...So after he talked for a few minutes, I felt pretty comfortable that he was good."

b. A Poor Provider Relationship Added to Distress

Communication with providers, if negative, led to a more distressing experience. Patients who experienced poor delivery of diagnosis or had difficulty communicating with their providers felt more alone and this increased psychological distress.

Participant 4: "...my feelings on that experience was, when I was informed of my prostate cancer, it was through an office staff person through a telephone call... I just felt abandoned medically by an individual who decided that I can just tell my staff to give you a call, to give you what could be perceived as really devastating information."

Participant 22: "But I think if I could talk to anybody in the urology department, I would just say that a little bit of kindness along the way would've been appreciated...a little bit of understanding, a little bit of trying to understand my viewpoint in addition to their view point, but they seemed very focused that, you know, it's COVID-19, and we're trying the best we can, and we've got to do what we got to do. That could be said in a kinder, more gentle way that would be much more comforting."

What Could Have Been Done Differently

a. More Frequent Communication

Patients desired ongoing communication with their provider during the delay. Even when there was no new information, regular check-ins would have helped patients feel more supported.

Participant 8: "I actually feel that maybe it would've been nice if we would've had a few updates, you know, sent us some, the virus is still raging, it's not a good idea to go ahead with the treatment now because we have your safety concerns. And then as it's getting better, it would've been nicer too, because I never had a date, and I kept on thinking,

when is this going to happen? Is anybody going to give me a date or anything like that? And that became a little bit concerning.”

Participant 9: “You know, and I would have liked them to call me and say, hey, we're working on it, but we don't have an answer...it would have been better if I had more constant communication, even if the communication was to say we don't know...that would have been a little bit more reassuring.”

b. Acknowledging and Supporting Emotions

Patients desired a stronger acknowledgement and support for their distressed emotions. In addition to support from providers, they wished that they could have had assistance in connecting with patient support networks.

Participant 22: “I think an acknowledgement of, I hear you, and I understand that you're frightened. You're scared. This is overwhelming. We're going to work on this together, you know, that together. We're going to work on this together. And I think also if the doctor just had said to me that there is a Bladder Cancer Advocacy Network that you can connect with to connect with people who are going through what you're going through, who have already gone through it, and can really give you good advice to, let me see, how... to make me feel like I've been seen as a person.”

Discussion:

The findings of this study support the existing literature on cancer patients' experiences with COVID-19. Patients in our cohort were already distressed prior to the COVID-19 pandemic as they navigated a path to their cancer diagnosis. They cited a number of worrisome experiences, such as coping with wait times between diagnosis and treatment, and making difficult treatment decisions. These experiences have previously been shown to contribute to patient distress (Paul, 2012). In addition, convincing physicians that their symptoms were concerning and getting to the correct provider also presented a frustration. Facing COVID-19-

related restrictions represented added uncertainty about how they could access treatment for life-threatening conditions. Similar distress was reported in patients with varying types of cancers (Koinig, 2021). Being able to use humor and feeling reassured by their physician that their treatment could wait mitigated patients' distress. Generally, throughout their treatment delay, participants cited faith in their providers as a coping mechanism. Previous studies have highlighted how provider communication and support was crucial for cancer patients prior to the pandemic (Mazor, 2016) and that this support became more important in the context of COVID-19 (Bowman, 2020; Klassen, 2021). Lack of that support led to feelings of abandonment.

There are several novel findings from our study. First, consistent communication with providers was widely desired. A previous study conducted by our team of urologic oncologists showed that providers were hesitant to continuously contact their patients throughout the delay because they were concerned that they had no new information to share and could not reassure them (Wittmann, 2021). This was contrary to what patients in our study desired from their physicians. Patients in our study wanted communication with physicians regardless of specific information as a way of feeling cared for. They also wanted physicians to acknowledge their emotional stress associated with the treatment delay. Second, patients in our study were not fearful of acquiring COVID-19 while in the hospital. We hypothesized that fear of COVID-19 infection may have delayed participants' presentation for treatment, and that the risk and fear of contracting COVID-19 in the hospital may have increased participant distress in general. On the contrary, participants in this study perceived their hospitals as providing comprehensive and

well-communicated safety guidelines and fear of contracting the COVID-19 infection while in the hospital for treatment did not contribute to participant distress. The third novel outcome was patients' frustration with the label of 'elective' for their cancer surgeries which they considered necessary and life-saving. It appeared to add to their feeling of not being taken seriously or supported.

Studies since the COVID-19 pandemic predict that more patients will have delays in cancer diagnosis, and that cancer mortality will rise as COVID-19 continues to impact healthcare delivery (Chen, 2021; London, 2020; Maringe, 2020; Patt, 2020). This suggests that patients with urological and other cancers could continue to experience distress related to diagnosis and/or treatment delays. The desire for more consistent communication as an aspect of the provider-patient relationship, regardless of the ability to provide factual updates offers an opportunity to improve practice. Although not specific to cancer communication, Wittenberg et al. conducted a systematic review to identify opportunities to improve provider communication in the context of COVID-19. They found that communication resources and guidelines should involve interdisciplinary teams, engage patient families, utilize telehealth platforms, and focus on identifying and offering support for psychological distress (Wittenberg, 2021). These findings can be adapted to develop consistent communication guidelines for urologic oncologists and other oncology providers to use should future delays in care occur for any reason.

This study has several strengths. To our knowledge, this is the first study to utilize the voices of patients with urological cancers to understand their experiences related to treatment

deferrals in the context of COVID-19. Second, although this is a qualitative report that does not aim to make an inference about urological cancer patients in general, patients in our sample were broadly recruited from geographic locations across the U.S. which gives a sense that patients in a variety of parts of the country might have had similar experiences. Finally, our study demonstrated the psychological importance of patient-provider communication even in the absence of information exchange. This insight can enable providers to create a pathway to improving patient care, utilizing the patient perspective.

Our study has several limitations. First, interviews were conducted nearly five months after the initial survey was conducted, after most participants successfully continued their treatment. As a result, participants were subject to recall bias when describing past experiences. In addition, they may have minimized their concerns about COVID-19 infection because they had already been treated without becoming infected. Second, interview transcripts were not double coded which limits the validity of our qualitative results.

Future studies can use our findings to create more nuanced surveys to be used with a larger sample to determine whether the experience reported by patients in our study is more universal. Future findings can lead to developing improvements in care that will assure appropriate support capable of mitigating the distress related to diagnosis and treatment delays.

Clinical Implications:

This study provides insight into the experiences of patients with genitourinary cancers who experienced treatment delays due to the COVID-19 pandemic, such as fear of cancer

progression, need for consistent communication with providers and frustration with cancer surgeries being deemed ‘elective’. The study findings can be used to develop guidelines for providers on how to best participate in continuous communication utilizing the entire care team during diagnosis and treatment delays.

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