PCR92

Renal Cell Carcinoma and Muscle Invasive Bladder Cancer Patients' Perception of Risk and Fear of Recurrence

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Background

- Renal cell carcinoma (RCC) and muscle invasive bladder cancer (MIBC) are aggressive urological malignancies of epithelial origin associated with poor survival rates[1,2]
- For patients with non-metastatic RCC or MIBC, surgery is the standard of care: nephrectomy for RCC and radical cystectomy for MIBC
- However, both cancers commonly recur post-surgery, with 5-year recurrence rates of up to 62% for RCC and 45% for MIBC[3,4]
- Fear of cancer recurrence (FCR) is a common clinical issue across cancer survivors that is associated with substantial impacts on quality of life, including emotional well-being and daily functioning[5,6]
- For patients with RCC or MIBC, FCR after surgery is a major source of anxiety and emotional distress[7,8]
- Understanding FCR in patients with RCC or MIBC can help physicians recognize patient psychological distress and engage in shared decision-making on neoadjuvant or adjuvant treatment options

Objectives

- To explore post-surgery FCR and associated quality of life impacts in patients with non-metastatic RCC or MIBC
- To inform development of a future quantitative survey study

Methods

Study design

- A qualitative, observational, concept elicitation study was designed to involve a small number of patients with RCC or MIBC (around n=10 each)
- One-on-one, semi-structured, virtual interviews were conducted in the US from March to May 2024
- Adult patients with RCC were recruited who:
  - Had a clinically confirmed diagnosis of early-stage RCC (T2G4 N0 M0, T3 N0 M0, or T4 N0/N1 M0)
  - Had undergone nephrectomy in the past 6 months or had begun post-surgical adjuvant therapy in the past month
- Adult patients with MIBC were recruited who:
  - Had a clinically confirmed diagnosis of early-stage MIBC (stage II, IIIA, or IIIB)
  - Had undergone radical cystectomy in the past 12 months or planned to undergo in the next 6 months
- During concept elicitation, patients were asked open-ended questions about their experiences after surgery and perspectives on cancer recurrence or progression
- Interviewers probed with specific questions to identify and summarize patient understanding of key concepts, including language and terminology used to describe cancer recurrence
- As interviews were semi-structured, not all patients answered all questions
- Interview transcripts were reviewed systematically, and quotations from each participant were extracted and tabularized into summary tables organized by interview questions and concepts of interest
- Interview data were analyzed qualitatively, and key themes were identified

Results

Study participants

- All RCC and MIBC patients had undergone nephrectomy or radical cystectomy (**Table 1**)
- Both groups had a mean age of around 50 years (RCC: 51.5 ± 5.5 years; MIBC: 54.0 ± 5.7 years), were evenly split between male and female patients, and were mostly White (RCC: n=8, 80%; MIBC: n=10, 100%)
- Some patients (RCC: n=4, 40%; MIBC: n=2, 20%) were currently receiving adjuvant immunotherapy
- Two (20%) patients with MIBC had received neoadjuvant therapy before surgery: one received chemotherapy, while the other received an unspecified infusion

Patient understanding of cancer recurrence

- All patients defined cancer recurrence as the cancer "coming back," "returning," or "happening again"; several patients did not clearly distinguish between the terms "recurrence" and "progression"
- Most patients with RCC (n=7/8, 88%) and all 10 with MIBC believed their cancer could come back after surgery
- Among patients receiving adjuvant immunotherapy, most (RCC, n=3/4, 75%; MIBC, n=1/2, 50%) believed their cancer could come back despite postoperative treatment

FCR and impact on quality of life

- Most patients (RCC: n=5/7, 71%; MIBC: n=6/9, 67%) reported FCR, using phrases such as "scared," "worried," "devastating," and "stressed out" (**Table 2**, **Table 3**)
- Some patients (RCC: n=2/7, 29%; MIBC: n=3/9, 33%) did not directly describe negative feelings about cancer recurrence, instead mentioning that they did not want to think about recurrence, that it was too soon to be fearful, or that they were staying positive and hoping their cancer would not come back (**Table 2**, **Table 3**)
- Patients described impacts of FCR on emotional well-being (RCC: n=4/6, 67%; MIBC: n=10/10, 100%) and relationships/social activities (RCC: n=2/6, 33%; MIBC: n=2/10, 20%)

Limitations

- The small sample size (10 RCC and 10 MIBC patients) limits generalizability of findings to the broader population of urological cancer survivors
- The cross-sectional study design captured patient perceptions at a single time point, whereas FCR may fluctuate over the survivorship trajectory, particularly around surveillance visits
- The retrospective nature of patient reporting may have introduced recall bias, particularly for patients further from their surgery date
- The virtual interview format may have limited rapport-building and depth of emotional disclosure
- Selection bias may exist, as patients experiencing severe psychological distress may be less likely to participate in research studies
- Moreover, hard-to-reach patients, more ill patients, or patients with less leisure time may also be less likely to participate
- Variability in time since surgery (ranging up to 12 months post-procedure) introduces heterogeneity in patients' recovery experiences

Table 1. Self-reported demographic and clinical characteristics

Characteristic	Patients with RCC (n=10)	Patients with MIBC (n=10)
Age (years)		
Mean (SD)	51.5 (5.5)	54.0 (5.7)
Range	45–61	49–64
Sex, n (%)		
Male	5 (50)	5 (50)
Race, n (%)		
White	8 (80)	10 (100)
Black or African American	2 (20)	0 (0)
Marital status, n (%)		
Married and living with spouse	10 (100)	10 (100)
Current adjuvant treatment, n (%)		
Immunotherapy	4 (40)	2 (20)
None	6 (60)	8 (80)
General health status, n (%)		
Very good	0 (0)	1 (10)
Good	4 (40)	5 (50)
Fair	6 (60)	4 (40)
Current severity of disease, n (%)		
Mild	6 (60)	7 (70)
Moderate	4 (40)	3 (30)
Severe	0 (0)	0 (0)

MIBC, muscle invasive bladder cancer; RCC, renal cell carcinoma; SD, standard deviation.

Table 2. Illustrative quotes from patients with RCC

Experiences of FCR	Impacts of FCR on quality of life
RCC-002: It almost paralyzes me. I want to do a lot of stuff, but on the other hand, I don't want to do anything. So, it gets depressing, you know?	RCC-002: I don't really feel doing a whole lot. I try to minimize my activity. I just do the bare minimum.
RCC-008: It's not consistent or like permanent that it's on my mind every second, but it definitely runs through my brain every day, of the fear, yes.	RCC-010: Yeah, because I'm trying to be a lot more healthier. You know, eat healthy, exercise.
RCC-005: It's too soon for that. No, I don't, I can't have fear like that, because that's not going to do anything, do any good. I would be careful, you know, I honestly can say no I don't have any fear of that.	**RCC-007: I go about my life, but it's something that's in the back of my mind all the time that I have to be more or less pro-aggressive way of exercise, diet, eat in a certain way that doesn't promote my cancer cell growth. Or at least enhance it, you know.**
RCC-001: I was diagnosed, and [the chance to become metastatic] seemed to be minimal compared to what it could be. […] Once you have cancer, your life is upside down. And then you kind of get your thoughts together and realize "okay, I have some options because it isn't at that point."	**RCC-008: I would just say that I've really opened up as a person, with my husband. Sometimes with stress and things, you don't necessarily share everything. But I've learned through this that it's important to communicate better and share my fears versus holding them in.**

FCR, fear of cancer recurrence; RCC, renal cell carcinoma.

Table 3. Illustrative quotes from patients with MIBC

Experiences of FCR	Impacts of FCR on quality of life
MIBC-002: I'm very high risk now for it, because the cancer, very highly likely to come back, be in a different place […] So, I don't feel free. I don't feel away from it. I don't feel—I'm still scared. I'm still fearful.	**MIBC-002: I don't feel free. I don't feel away from it.**
MIBC-006: Yes [I feel afraid of the cancer coming back] […] I'm hopeful that they can prevent it or if not, then treat it if it does come back.	**MIBC-004: I wasn't happy, felt upset and worried, but also knew I had to do something to kind of remove the cancer, and move on with my life, and try to get back to proper health.**
MIBC-007: I would be lying if I said I didn't [feel afraid of the cancer coming back] […] I try not to think about it because I feel like if I think about it, then it's just going to bring me down […] I just have to take each day by day.	**MIBC-009: So you're worried, trepidation, depression, anxiety, denial […] I am a victim of having cancer. […] I don't want to let that overwhelm me. All I can do is hope and be vigilant.**
MIBC-008: I hope it doesn't [come back]. […] There's all sorts of what if, what if, what if […] I'd rather not go down that path. I try to stay, you know, it's not a good thing to dwell on it. I'd rather try to stay positive in my thinking.	**MIBC-010: [The fear] affects my energy levels […] dealing with the bladder cancer, which also debilitates you, and also stress out. It even lowers my energy levels […] My social life for the most part [is impacted] […] I just don't go out as often. I don't socialize.**

FCR, fear of cancer recurrence; MIBC, muscle invasive bladder cancer.

Conclusions

- This qualitative study found that FCR post-surgery was common among patients with RCC or MIBC
- While a lack of clarity between the terms "recurrence" and "progression" was noted for several patients, the majority of patients believed their cancer could come back after the surgery
- These results highlighted the importance of cancer recurrence as a patient-relevant endpoint and illustrated the impacts of FCR on patient quality of life
- The results also illuminated perspectives and behaviors of patients with RCC or MIBC to aid physicians in counseling patients on long-term treatment options and support services
- Additional quantitative survey work with larger sample size is ongoing to fully understand FCR and its impacts on quality of life among patients with RCC or MIBC

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