Patient and Caregiver Insight Into the Impact of Non-Muscle Invasive Bladder Cancer and Its Treatments: A Social Media Review

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Conclusions

- Social media (SM) data related to disease and treatment provide an opportunity for patient/caregiver voices to be heard, particularly patients/caregivers who may be difficult to access (i.e., rare diseases or geographically dispersed) or patients underrepresented in the existing published literature (i.e., non- "typical" patients). Therefore, addressing gaps in the existing knowledge of a particular disease and its treatments is important.
- This research provided candid patient/caregiver insights into the burden and unmet needs of patients with non-muscle invasive bladder cancer (NMIBC) and their procedures/treatments.
- While all patients with NMIBC experience similar symptoms and life disruption, these SM data provide insights into the different challenges faced by younger patients who are at the start of their economically productive years and who are establishing themselves as independent individuals.
- Although unsolicited SM posts from patients/caregivers may not be generalizable, the qualitative analysis of SM data can inform future study designs to examine unmet needs and patient preferences.
- Guidance on SM research should be developed to increase methodology consistency across studies.

Background

- NMIBC is a common, heterogeneous disease with high rates of recurrence/progression, often requiring lifelong surveillance.[1] Treatments (i.e., transurethral resection of the bladder tumor [TURBT], intravesical Bacillus Calmette-Guerin [BCG] treatment, intravesical chemotherapy, and/or radical cystectomy) involve invasive procedures with associated side effects and can impact patient/caregiver health-related quality of life (HRQOL).[2-7] Treatment burden is exacerbated by regular maintenance therapy and long-term clinical monitoring. [2,5,8]
- Patient-/caregiver-reported information shared on SM is a nascent data source that provides insights into patients/caregiver physical, emotional, and psychological health outside the formal research context.[9-13]

Objective

- To gain insights into patient/caregiver experience of NMIBC and its treatments (e.g., intravesical BCG/cystectomy) using SM data.

Methods

- RTI International's institutional review board committees determined this study was not research involving human subjects (STUDY00021798).

Data Collection

- A pragmatic Google search using key search terms (Supplemental Table 1) identified websites hosting patient/caregiver-contributed SM data: YouTube, Reddit, Twitter (publicly available SM data used in adherence with site terms and conditions), and Fight Bladder Cancer (permission granted by site owners for use of website content for this study).
- English-language posts were included for review if posts were shared by adult (aged ≥ 18 years) patients or caregivers of patients with a self-reported NMIBC diagnosis and if content was relevant to the patient NMIBC and treatment experience. Video footage and discussion blogs were reviewed manually.

Data Analysis

- Data were extracted from the SM posts, and patient/caregiver narratives were reviewed qualitatively and analyzed thematically. Demographic information (e.g., sex, age) was extracted along with any accompanying disease information where available.

Results

Social Media Posts

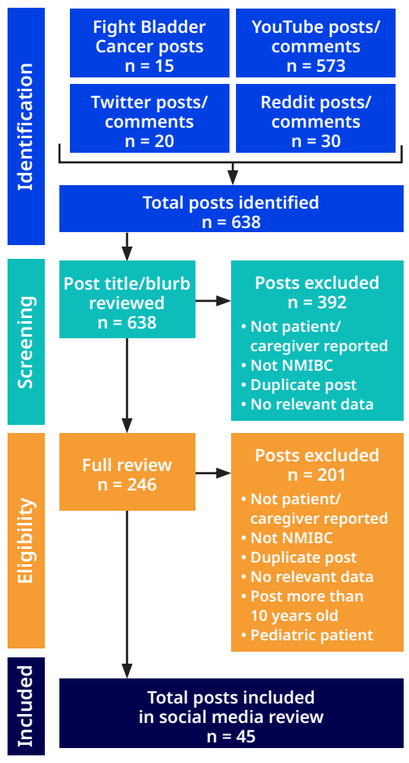
- The SM review was conducted between November and December 2021 using an iterative process (**Figure 1**).
- 45 posts (20 videos, 13 blog/forum posts, 12 comments) uploaded by a total of 38 contributors (31 patients, 7 caregivers) were reviewed. **Table 1** provides contributor sample characteristics. The contributor sample included experience of a range of NMIBC grades and stages. 10 contributors provided more than 1 SM data source.

Table 1. Summary of Social Media Contributor Sample Characteristics

Characteristics	Contributor type		Total contributor sample (N = 38)
	Patient (n = 31)	Caregiver (n = 7)	
Gender, n (%)	**n = 26**	**n = 7**	**n = 33**
Male; female	15 (57.7); 11 (42.3)	1 (14.3); 6 (85.7)	16 (48.5); 17 (51.5)
Age at SM post	**n = 17**	**n = 3**	**n = 20**
< 65 years; ≥ 65 years	14 (82.4); 3 (17.6)	2 (66.7); 1 (33.3)	16 (80.0); 4 (20.0)
Range, years	22-69	60-67	22-69
Age at diagnosis[a]	**n = 11**	—	—
< 65 years; ≥ 65 years	10 (90.9); 1 (9.1)	—	—

Note: Percentages are based on nonmissing data.
[a]Only reported for contributors who self-reported as patients with NMIBC.

Figure 1. Social Media Post Identification Flowchart



NMIBC Patient Symptom Experience

- More than 50% of contributors (n = 21) mentioned NMIBC symptoms (e.g., hematuria [n = 17], urinary urgency [n = 3], dysuria [n = 1]). Hematuria was commonly the first symptom experienced (n = 12, 31.6%) (Supplemental Figure 1).

NMIBC Diagnosis

- Recurrent hematuria misdiagnosed as an infection (e.g., urinary tract) (8 patients [4M/4F], 1 caregiver of female patient).
- Initial symptoms dismissed as gynecological issues (3 female patients).
- Symptoms attributed to anxiety by healthcare provider; cystoscopy later confirmed patient had Ta Grade 3 NMIBC. Patient gender and age considered as key contributory factors in the initial misdiagnosis of anxiety.

"Prior to my GP agreeing to send me for ultrasound, though, they suggested I see a psychologist, saying I likely just had anxiety…and looking back, I do wonder how much of that initial 'diagnosis' had to do with my age and gender. I feel what you said about being [the] only young female in the office. At my cystoscopy, I was [the] youngest by 40 years at least."

Patient, female, age 35 years

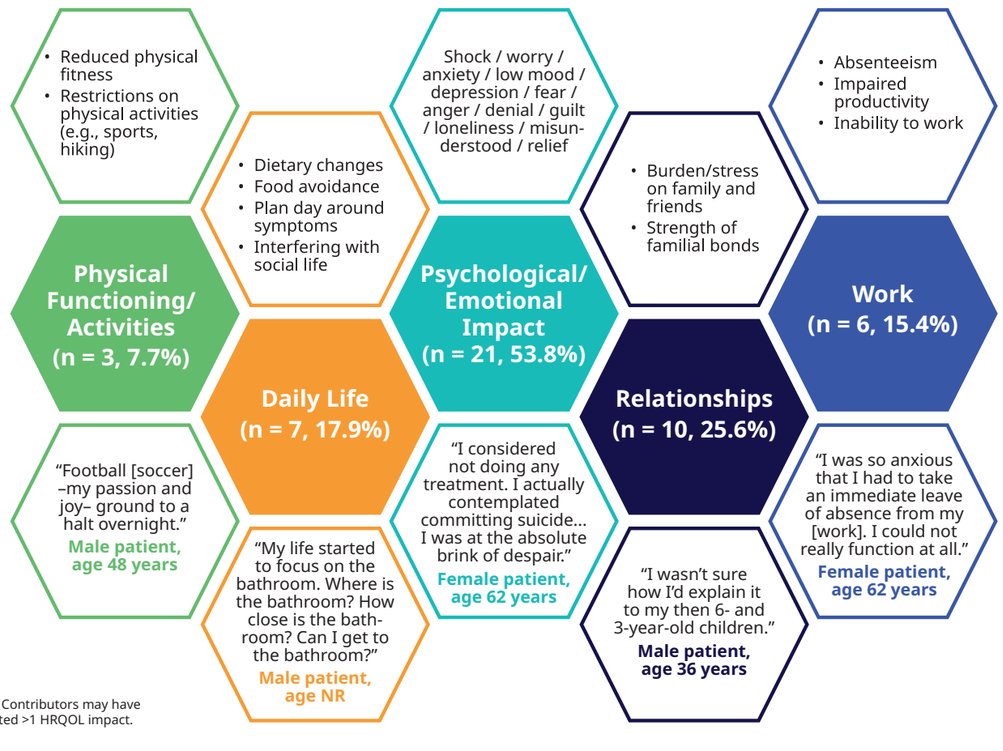
"After 2 years of recurrent UTIs, blood in urine mistaken for gynecological issue. Diagnosed by community urologist."

Patient, female, age NR

Patient Health-Related Quality of Life Impacts

- More than 60% of contributors (n = 25) discussed the detrimental impact of NMIBC on patients' HRQOL (Figure 2).

Figure 2. NMIBC Key Patient HRQOL Impacts (n = 25/38)



Note: Contributors may have reported >1 HRQOL impact.

Caregiver Experience of NMIBC

Impact of NMIBC on Caregivers

- Caregiver emotional and physical well-being impacted by caring for a patient with NMIBC.
- All 7 caregivers discussed impacts, including fear, stress, helplessness, low-mood, worry, feelings of loss, fatigue, and intimacy concerns (i.e., potential risk to caregiver from intercourse with partner during the periods between patient's BCG treatments).

"We both initially found living with the constant reminder of this dreadful disease depressing."

Caregiver, male, age 60 years

"In the end, the cumulative stress manifested itself in both physical and mental health problems for me."

Caregiver, female, age 64 years

"My husband is receiving BCG. How dangerous is it for me in between treatments, in terms of sexual contact, for a female sexual partner?"

Caregiver, female, age NR

NMIBC-Related Procedure and Treatment Experiences

- 32 (84%) contributors reported experience with ≥ 1 NMIBC-related procedure/ treatment (Supplemental Figure 2). BCG treatment length was mentioned by 5 (13%) contributors as ranging from 6 weeks to 2 years.
- 8 (21%) contributors noted they or their family member were in remission (remission period range, 1-15 years). Patients continued to undergo regular procedures/treatments (e.g., cystoscopies [n = 6], maintenance BCG [n = 6]) during remission. 5 patients had experienced ≥ 1 NMIBC recurrence.
- Patient-reported side effects associated with NMIBC procedures/treatments are shown in **Figure 3**.

Impact of NMIBC Treatments

- 21(55%) contributors commented on negative impacts of treatments.
- Long-term implications of NMIBC were particularly salient for younger patients (age < 65 years) for whom NMIBC was perceived as a long-term battle.

Key issues

- Side effects
- Discomfort
- Inconveniences
- Work productivity
- Emotional, physical, and financial burdens

"I feel fortunate because I am retired, and I can deeply appreciate how much it might impact someone's life to set aside the once a week or the days off during weeks of BCG."

Patient, female, age 69 years

"I'll be having annual cystoscopies until the day I croak. The thing with bladder cancer is that it can be so goddamn persistent, and if you don't have good insurance, it is one heck of an expensive disease because of its persistence."

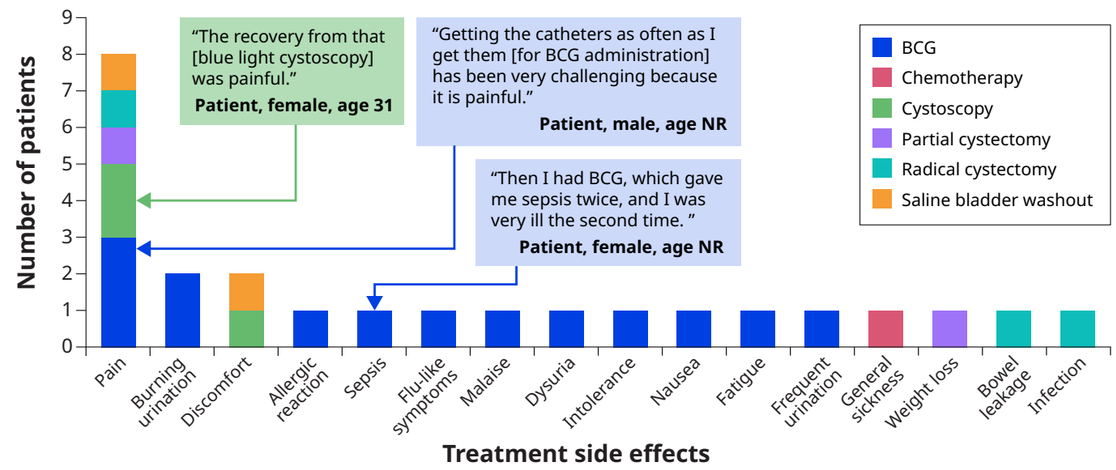
Patient, gender and age NR

- Treatment impact on patients' lives is exacerbated by frequent treatment appointments (BCG), as well as the burden associated with the need to travel long distances for frequent medical appointments.

"I am forced to travel for all maintenance and for induction to either [location deleted], or [location deleted], or [location deleted]. They're about 50 to 70 miles away."

Patient, male, age NR

Figure 3. Patient-Reported NMIBC Procedure and Treatment Adverse Effects (n = 13/38)



Procedure and Treatment Decisions

- 18 (47%) contributors discussed influences on procedure/treatment decisions (Supplemental Figure 3). Key influences included healthcare provider guidance (n = 6), family and friends (n = 3), and patient support groups and/or advocacy websites (n = 3).

Limitations

Limitations and challenges associated with SM data include the inability to verify contributor characteristics (e.g., demographic and clinical information). Additionally, individuals who choose to upload SM posts may not be representative of the broader patient/caregiver population.[13] Thus insights derived from NMIBC SM data should be interpreted in this context. Despite these limitations, SM data can provide a unique perspective on issues of importance to patients/caregivers.

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