# Unmet needs of caregivers in locally advanced or metastatic bladder cancer from social media in the US

S. Renner,[1] P. Loussikian,[1] A. Marrel,[2] V. Barbier,[2] P. Foulquié,[1] A. Mebarki,[1] S. Schück,[1] M. Bharmal[3]

[1]Kap Code, Paris, France; [2]Icon, Lyon, France; [3]EMD Serono, Billerica, MA, USA

Presentation No. P36. Presented at Virtual ISPOR Europe 2021, November 30 – December 3, 2021.

# Disclosures

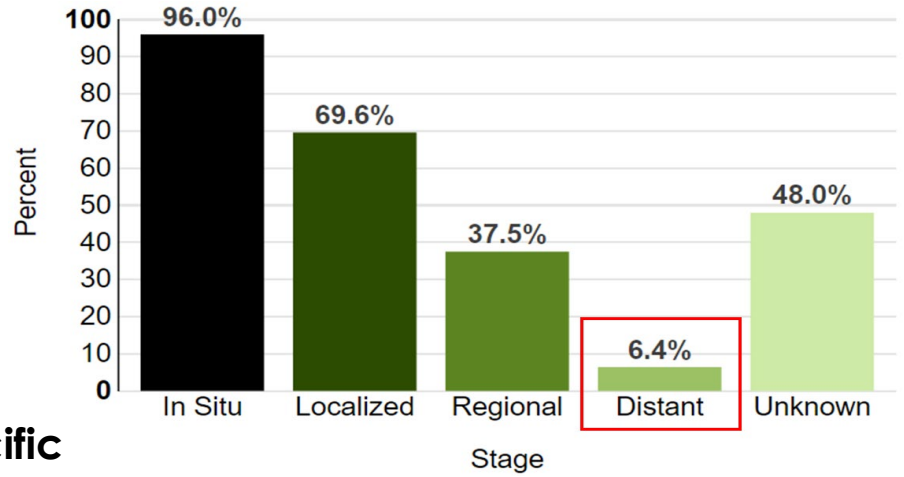
I have the following disclosures:

- **M Bharmal** is an employee of EMD Serono, Billerica, MA, USA

# Bladder cancer in the United States & social media listening

- In the US, bladder cancer is the **6th most common** cancer
  - An estimated **84,000 new cases** and **17,000 deaths** from bladder cancer will occur **in 2021**[1,2]
- Bladder cancer has a negative impact on the quality of life of patients,[3,4] however, **few studies have assessed the burden on caregivers**

**5-year survival by bladder cancer stage at diagnosis**[2]




## Patient/caregiver involvement on social media

- New way of sharing and communicating: **disease-specific Twitter hashtags**, **online patient groups**, and **forum conversations** between patients, caregivers, practitioners, and advocacy groups[5,6]

## Objective

- This study aimed to characterize the unmet needs of caregivers of patients with locally advanced or metastatic bladder cancer using social media data in the US

1. Siegel RL, et al. CA Cancer J Clin. 2021;71:7-33.
2. SEER Research Data 1975-2018. https://seer.cancer.gov/statfacts/html/urinb.html. Accessed July 5, 2021
3. Singer S, et al. Support Care Cancer. 2013;21:1383-93.
4. Smith AB, et al. BJU Int. 2018;121:549-57.
5. Leveridge MJ. World J Urol. 2016;34(1):57-62.
6. Borgmann H, et al. Urol Oncol. 2016;34:377-83.

# Methodology

A **3-step extraction and filtration strategy** was used to obtain data for caregiver testimonies.
A **qualitative analysis** was then carried out to deepen understanding of the challenges and unmet needs experienced by both caregivers and patients.

**WEB**

**Extraction**

1 ***Removal of nonmedical sources*** → Exit

2 ***Identification of caregivers' experiences*** → Exit

3 ***Focus on testimonies discussing advanced urothelial/bladder cancer*** → Exit

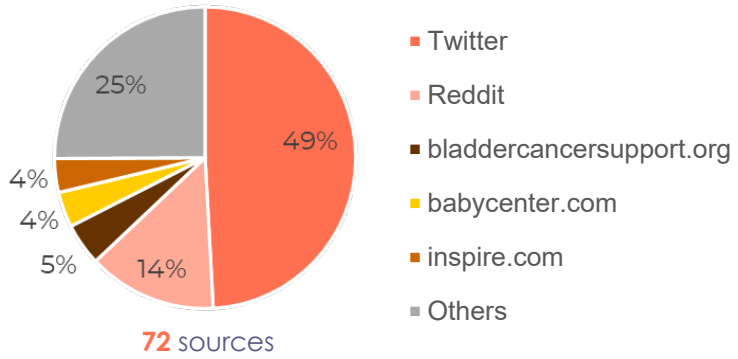
"My husband had **stage 4 bladder cancer** treated with removal of bladder and prostate and construction of neobladder."

**Caregiver CORPUS**

- 1,214 testimonies
- Average age 35.4 years (2.9%)*
- 679 caregivers
- Men 16.8% / Women 83.2% (14.3%)*

**Qualitative analysis** focusing on the challenges and unmet needs mentioned in caregiver testimonies

Distribution of testimonies volume by source (%)



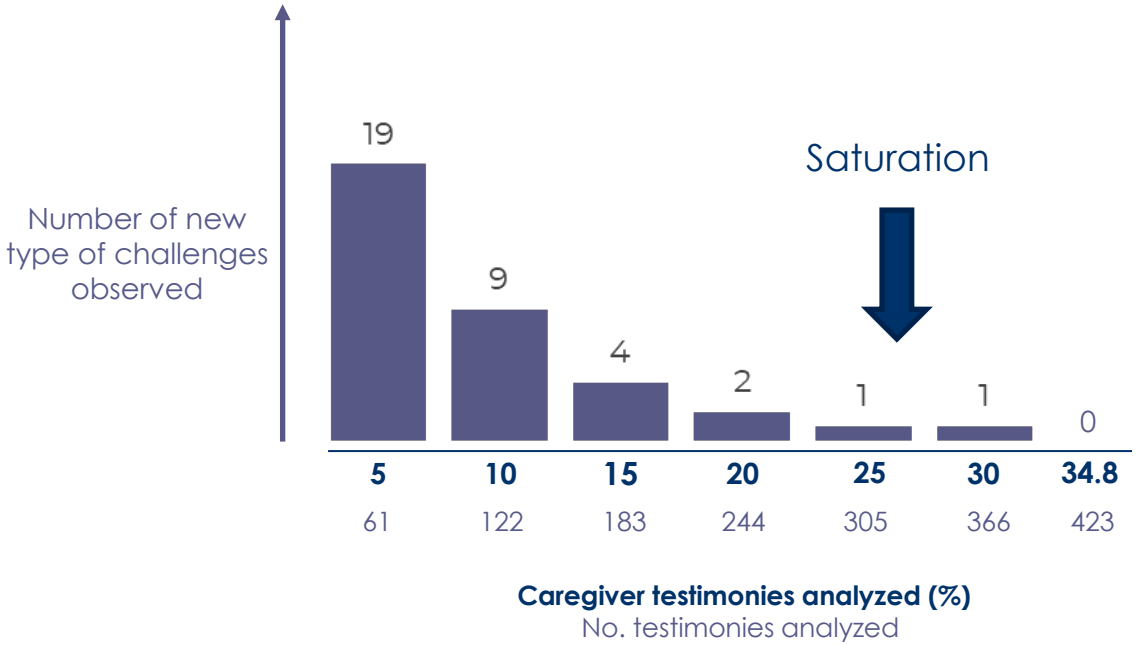

72 sources

*(xx%): percentage of testimonies in which the information is mentioned.

# Qualitative analysis of caregiver testimonies to identify unmet needs

## Qualitative Analysis

- Manual annotation of **1,214** caregiver testimonies by 2 independent researchers
- A subset of **423** caregiver testimonies was randomly identified from the testimonies to check for saturation of new unmet need concepts
- A total of **36** unmet need categories were identified




"**I just burst into tears.** My dad had bladder cancer—stage 4 at diagnosis **with mets in the bones of his legs, skull, etc**. He survived 3 months after diagnosis. **I knew he was in pain** but he didn't seem in agony and took as little pain med as possible (less than we encouraged him too). Hearing this..... **He must have endured more pain than he showed us**. But that is my dad for you—taking the brunt of things if it meant making it easier for us. **I miss him so much**."

## Coding of the unmet needs/challenges

- Testimonies were coded based on challenges concerning either the **patient** or the **caregiver** or in some cases **both**
- Each of these difficulties was grouped, according to their similarities, into broader categories using a coded annotation chart
  *Example: "I feel depressed" or "I'm feeling a bit down" was coded into the category "Psychological impact"*

# Unmet need categories: patient-centered, caregiver-centered, or both*

| | | | | |
|---|---|---|---|---|
| 1 | **Psychological impact** Loneliness, depression, anxiety, fear, distress, personality change... | 34 | 5 | 7 | n=46 | 26.0% |
| 2 | **Need to share experiences and gain support** discussion groups, social networks | 11 | 1 | 16 | n=28 | 15.8% |
| 3 | **Fear, occurrence, and management of treatment-related AEs and special situations** | 1 | 21 | | n=22 | 12.4% |
| 4 | **Burden of end-of-life support for the patient or loved ones & grief work** | 18 | | | n=18 | 10.2% |
| 5 | **Impact of being a caregiver:** energy-consuming support for caregivers, time-consuming, moving... | 16 | | 1 | n=17 | 9.6% |
| 6 | **Screening/diagnostic delay or lateness** | 11 | 2 | | n=13 | 7.3% |
| 7 | **Wandering, therapeutic dead ends, or ineffective treatments** | | 11 | | n=11 | 6.2% |
| 8 | **Consideration and management of symptoms characteristic of bladder cancer** | | 11 | | n=11 | 6.2% |
| 9 | **Difficulty or delay in accessing treatment** | 1 | 7 | 2 | n=10 | 5.6% |
| 10 | **Change in relationship:** couple, family, friends | 3 | | 6 | n=9 | 5.1% |
| 11 | **Progression/worsening complication/recurrence of disease** | | 6 | 2 | n=9 | 5.1% |
| 12 | **Financial impact of the care:** insurance, social coverage, cost... | 5 | | 3 | n=8 | 4.5% |
| 13 | **Fear/shock of the diagnosis disclosure** | 4 | | 3 | n=7 | 4.0% |
| 14 | **Altered general condition:** fatigue, weight loss | | 6 | | n=6 | 3.4% |
| 15 | **General knowledge/information about a treatment** | 3 | | 3 | n=6 | 3.4% |
| 16 | **Misdiagnosis/prognosis error** | | 6 | | n=6 | 3.4% |
| 17 | **Communication problems:** lack of empathy, lack of information transmission | 3 | | 3 | n=6 | 3.4% |
| 18 | **Sequelae of illness or care** | | 6 | | n=6 | 3.4% |
| 19 | **Acceptance of the disease** | 3 | | 1 | n=5 | 2.8% |
| 20 | **Aggressiveness of the disease** | | 4 | 1 | n=5 | 2.8% |

Caregiver Patient Both

*423 testimonies analyzed, of which (N=177) included challenges or unmet needs.

# Deep dive into the 3 most frequently mentioned unmet need categories

## Psychological impact — 26.0%

- Mentioned also as patient-centered challenge, but most frequently mentioned as caregiver unmet need
- Across the life cycle of the disease, from the diagnosis to the potential death of the patient, through the care and management stages
- Insights that the caregiver's life changes along with the patient's, resulting in stress, fear, and loneliness

"I just wanted to introduce myself. I lost my husband on May 4, 2018 to metastatic bladder cancer. He was only sick for 6 months. **I cry daily. I don't know how to live without him.** My prayers to all of you."

## Need to share experiences and gain support — 15.8%

- Caregivers seek support or sharing group for the patient, but also in many cases for themselves
- A lot of credit is given to feedback from experienced users; caregivers are looking to learn from people who have been through this journey of care and have experienced these challenges
- Some testimonies are general, concerning more spontaneous requests for support, such as requests for prayers

"**Is there a cancer support group on Twitter?** My father has stage 4 bladder cancer and has metastasized and would love to get more info from other patients and survivors"

## Fear, occurrence & management of treatment-related AEs — 12.4%

- Centered on the patient and ranged from the simple notification of one (or more) adverse event (AE) and its potential management, to the fear, generated by these AEs, that is felt by the patient, the caregiver, or both
- Some caregivers want to inform others that these AEs lead some patients to change their treatment. This allows to prevent but also to get answers, advice, or comfort for them and their relatives

"When I was 13, my dad was diagnosed with stage 3 bladder cancer. Things looked very grim for him, **especially with how his body reacted to chemo and radiation. It made him very weak, turned him into a husk of who he was**."

# Limitations

## Representativeness bias

- Social media use varies according to **socioprofessional class, income, and level of education,** as well as **familiarity with technological tools**[1]
- As patients with bladder cancer are often elderly men, electronic literacy may be low[2]
- Caregivers, **directly representing** patients on social networks, may **alter** or **not accurately convey** the patients' journey

## Extraction bias

- The analyses are based only on **public data**, ie, testimonies of patients who have shared on a forum or social network **in an open way**

## Other biases

- Internet users (and therefore caregivers) often **tend to verbalize a negative experience rather than a positive one** (negativity bias), which can lead to an over-representation of negative observations (notification bias)[3]
- Testimonies analyzed are **unstructured free texts**, not designed for research purposes. The quality of testimonials can be **heterogeneous** according to the caregiver knowledge (literacy, spelling mistakes, etc). In addition, sociodemographic or specific clinical data (eg, mutation, type of cancer, etc) **are not always clearly specified**[4]
- The accuracy of testimonials **cannot be confirmed and may not reflect clinical reality**[4-5]


1. Donegan K, et al. Social Media and M-Health Data. Heads of Medicines Agencies. European Medicines Agency. Accessed [October 19, 2021]. https://www.ema.europa.eu/en/documents/report/social-media-m-health-data-subgroup-report_en.pdf
2. Tariq A, et al. BJU Int. 2019;123(suppl 5):10-8.
3. Kätsyri J, et al. PLoS One. 2016;11(5),e0153712.
4. Nabhan C, et al. JAMA Oncol. 2019;5(6):781-3.
5. Moorhead SA, et al. J Med Internet Res. 2013;15(4):e85.

# Conclusion

Social media allows caregivers of patients with advanced bladder cancer to speak out, and represents an emerging source of real-world insights, which otherwise are not directed to, but relevant for the treating physicians

This study found substantial psychological impact and burden of care on caregivers related to accompanying the patient on a daily basis and at the end of life

Future research may explore bladder cancer caregiver well-being and quality of life as outcomes in quantitative studies and possible interventions to improve these outcomes

# Acknowledgments

This work was supported by the healthcare business of Merck KGaA, Darmstadt, Germany (CrossRef Funder ID: 10.13039/100009945), as part of an alliance between the healthcare business of Merck KGaA, Darmstadt, Germany and Pfizer.

**PRESENTATION PDF**

Copies of this presentation obtained through this hyperlink or quick response (QR) code are for personal use only and may not be reproduced without permission from ISPOR Europe and the author of this poster.

Correspondence: Murtuza Bharmal, murtuza.bharmal@emdserono.com