Patient and caregiver perception of treatments for locally advanced or metastatic bladder cancer: Insights from social media in the US

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## SCOPE



• This study analyzed patient and caregiver perceptions of chemotherapy or immunotherapy using data from publicly accessible social media

# CONCLUSIONS



- In our study, more patients and caregivers shared their perceptions of chemotherapy (222 posts) than immunotherapy (77 posts) on social media. This was expected, because platinum-based chemotherapy has long been and continues to be the foundational first-line (1L) treatment for patients with locally advanced or metastatic bladder cancer (BC)
- Our findings reveal that caregivers reported negative perceptions of chemotherapy more often than patients, mainly due to side effects and perceived lack of effectiveness. More positive perceptions were noted for immunotherapy among overall posts (patients and caregivers)
- Clinicians may consider increasing support for patients undergoing chemotherapy and their caregivers to help them manage adverse events so that they have a more positive experience, given the survival benefits associated with 1L chemotherapy followed by avelumab maintenance<sup>1,2</sup>

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# BACKGROUND

- In recent times, patient and caregiver involvement on social media has exponentially increased<sup>3</sup>
- Patients with advanced BC and their caregivers may use social media to request information, communicate their experiences, raise concerns, learn about treatments, and connect with others for support.<sup>4</sup> Their posts on social media can include treatment details, as well as their perceived satisfaction with these treatments
- These real-world data can be used as a complementary approach to traditional questionnaire-based studies on patient satisfaction to explore patient and caregiver perspectives on cancer and treatment
- Current standard of care 1L treatment for locally advanced or metastatic BC comprises platinum-based chemotherapy followed by avelumab (immunotherapy) maintenance for nonprogressive disease<sup>1,2</sup>

## METHODS

- This retrospective, real-world study was carried out by collecting public posts written on social media, geolocated in the United States, between January 1, 2015, and March 4, 2021
- Posts were extracted using specific terms for locally advanced or metastatic BC. Testimonies that mentioned a treatment (either chemotherapy or immunotherapy) were identified and analyzed
- Qualitative analysis was based on the manual annotation of caregiver and patient posts by 2 independent analysts
- Guidelines for annotation were agreed upon prior to the analysis
- Analysis aimed to identify the age and sex of patients and caregivers, BC treatments used, treatment modalities, patient and caregiver perceptions of treatments (positive/negative/mixed/without perception), and disadvantages/benefits of the treatments

### RESULTS

- A total of 1902 posts for advanced BC were identified (described in **Table 1**)
- Of these, 299 posts reportedly written by 100 patients and 159 caregivers included an experience with ≥1 mention of chemotherapy or immunotherapy

### Chemotherapy perceptions

- 222 posts mentioned chemotherapy (Figure 1)
- 80 (36%) were posted by patients and 142 (64%) by caregivers
- 71% of patient posts described chemotherapy in a neutral and objective manner as an inevitable part of their healthcare journey
- In contrast, caregivers were more likely to express their opinion of chemotherapy: 44% of their posts were negative, 8% were mixed, and 7% were positive
- Overall perception was more negative (36%) than positive (7%) by both patients and caregivers

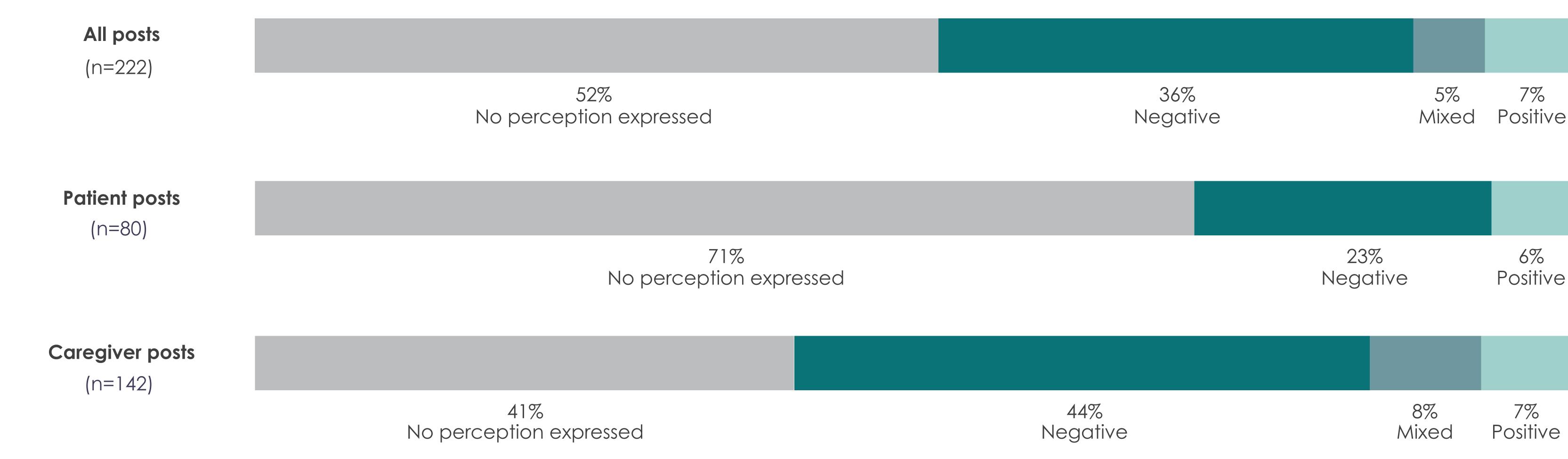
#### Immunotherapy perceptions

- 77 posts mentioned immunotherapy (Figure 2)
- 35 (45%) were posted by patients and 42 (55%) by caregivers
- Among all posts, immunotherapy was perceived positively in 47% of posts and negatively in 22%
- Among all posts, negative perceptions of both chemotherapy and immunotherapy were mainly due to side effects and perceived lack of effectiveness

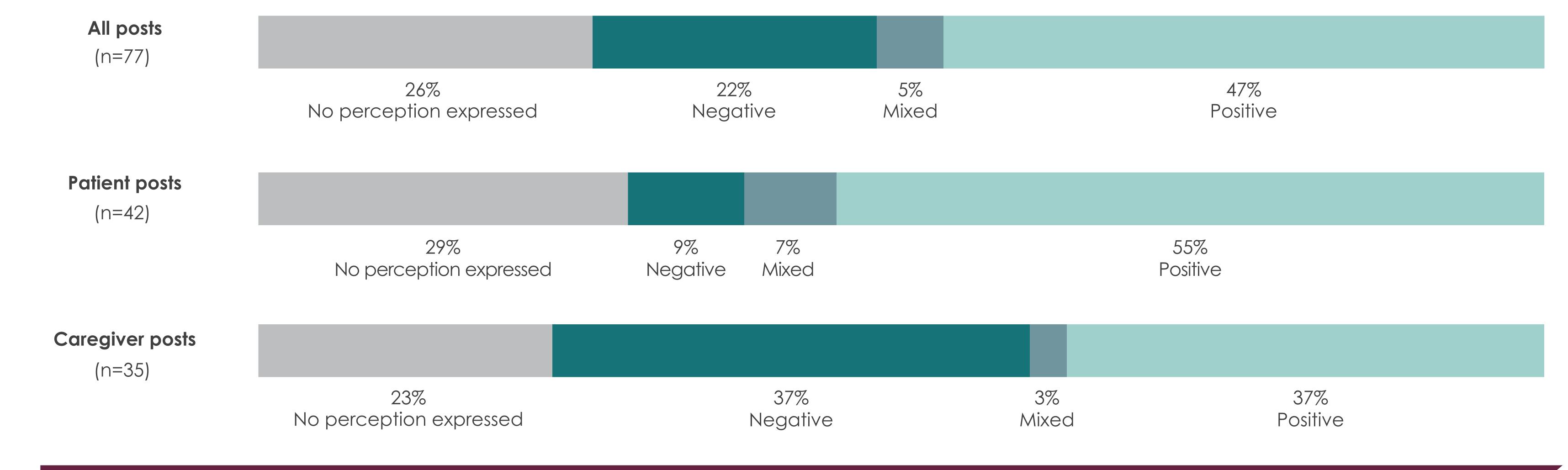
#### Table 1. Characteristics of patients and caregivers

Characteristics	Patients	Caregivers
Users, n	262	679
Users with treatment experience, n	100	159
Social media posts, n	688	1214
Social media used, n (%) Twitter Reddit Inspire.com Bladdercancersupport.org Others	139 (53.1) 16 (6.1) 31 (11.8) 26 (9.9) 50 (19.1)	333 (49.0) 95 (14.0) 27 (4.0) 34 (5.0) 190 (28.0)
Sex, n (%) Female Male Undetermined	54 (20.6) 57 (21.8) 151 (57.6)	88 (13.0) 19 (2.8) 572 (84.2)
Age, n (%), years <40 40-60 ≥60 Undetermined	9 (3.4) 14 (5.3) 19 (7.3) 220 (84.0)	14 (2.1) 2 (0.3) 6 (0.9) 657 (96.8)
Posts by type of treatment, n Chemotherapy Immunotherapy	80 42	142 35

# Figure 1. Chemotherapy perceptions



#### Figure 2. Immunotherapy perceptions



#### LIMITATIONS

- Analysis was based on public social media posts
- Limited information and specificity related to treatments and disease (ie, cannot ascertain lines of treatment, specific stage of cancer, and other details)
- Does not include data from non-public social media platforms such as Facebook non-public groups, etc
- No information available on outcomes to treatments

- Potential selection bias
- May not represent all patients with BC and their caregivers
- Engagement on social media depends on age and sex, ethnicity, socioprofessional class, income, education, and technological and health literacy
- When feedback is unsolicited, as is the case with social media,
   there is the potential for more negative feedback

REFERENCES 1. Powles T, et al. N Engl J Med. 2020;383(13):1218-30. 2. NCCN Guidelines for Patients. Bladder Cancer, 2021. 3. Anampa-Guzmán A, et al. J Med Internet Res 2020;22(7):e16337. DISCLOSURES M. Bharmal is an employee of EMD Serono, Billerica, MA, USA. P. Loussikian, P. Foulquié, A. Mebarki, S. Schück, and S. Renner are employees of Kap Code. A. Marrel, V. Barbier, and B. Arnould are employees of Icon. Black 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.