

Patient and caregiver perceptions of systemic anticancer treatments in advanced bladder cancer: results of a social media listening study conducted in 5 European countries (Eu5)

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SCOPE

- Although recent therapeutic progress has been made in advanced bladder cancer (aBC), little is known about patient and caregiver perceptions of different systemic anticancer treatments
- To further explore this, we conducted a social media listening (SML) study to assess patient and caregiver perceptions of chemotherapy and immunotherapy for aBC using data from social media posts in Eu5 (France, Germany, Spain, Italy, and the UK)

CONCLUSIONS

- To our knowledge, this is the first study in Eu5 to examine perceptions of aBC systemic anticancer treatments in social media posts by patients and their caregivers
- This qualitative observational study provides valuable insights on areas in which to improve the treatment experience for patients with aBC and their caregivers
- Strengthening support for patients receiving platinum-based chemotherapy may help them and their caregivers manage side effects and improve their perceptions of treatment; this could enable more patients to achieve disease control on chemotherapy and become eligible to receive avelumab first-line (1L) maintenance treatment to achieve improved survival

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BACKGROUND

- Bladder cancer is the tenth most common malignancy worldwide, accounting for approximately 573,000 new cases and 213,000 deaths in 2020^{1,2}
- Bladder cancer is predominantly diagnosed in older adults; is approximately 4 times more common in men^{2,3}; and ranks as the fourth most commonly diagnosed cancer among men in France, Germany, Spain, and Italy, and the sixth most common in the UK⁴
- Urothelial cancer (UC) is the most common type of bladder cancer, accounting for 90% of cases⁵; current standard-of-care 1L treatment for locally advanced or metastatic UC comprises platinum-based chemotherapy followed by avelumab maintenance for patients with nonprogressive disease^{5,6}

METHODS

General study design and data source

- This retrospective real-world study evaluated written public posts on geolocated social media in Eu5 (France, Germany, Spain, Italy, and the UK) posted from October 2017 to January 2022⁷ (Figure 1)
- To extract data from social media and public forums, extraction terms were identified in several languages and extraction sources were verified with the help of native linguists. After formatting and automatic filtering of the extracted data, posts were translated and a user profile algorithm was applied to identify patients and caregivers. The translation and algorithm predictions were validated and corrected by linguists. Data from users who were not patients or caregivers and irrelevant messages (ie, not relevant to aBC) were removed. Finally, after redistributing the language-specific corpora by country of interest, segmentation according to the treatments mentioned was carried out

Treatment segmentation design

- Lexical fields related to chemotherapy and immunotherapy were established for each language with the help of native linguists. Messages were then classified into 2 subgroups (chemotherapy and immunotherapy) based on the lexical field associations identified above (Figure 2)
- Messages mentioning a line of chemotherapy or immunotherapy were qualitatively analyzed by 2 researchers to classify treatment perceptions (positive, negative, mixed, or no perception), as well as the advantages and drawbacks of each type of treatment mentioned by patients and caregivers

Statistical analysis

- For the anonymized content, only aggregated qualitative findings are reported
- Manual curation was used to analyze the perception expressed by users (patients and caregivers) of the systemic treatments used in the treatment of aBC, as well as the drawbacks and advantages. These treatments were divided into 2 categories: chemotherapy and immunotherapy
- All data were analyzed using descriptive statistics. Categorical data were described using number of posts and/or percentages

Ethical considerations

- All data utilized and presented in this study were obtained from publicly accessible sources without accessing password-protected information
- All social media research assumes that the information provided by patients and caregivers is authentic and was voluntarily shared publicly by the patient and caregiver community

Figure 1. Social media post identification flowchart

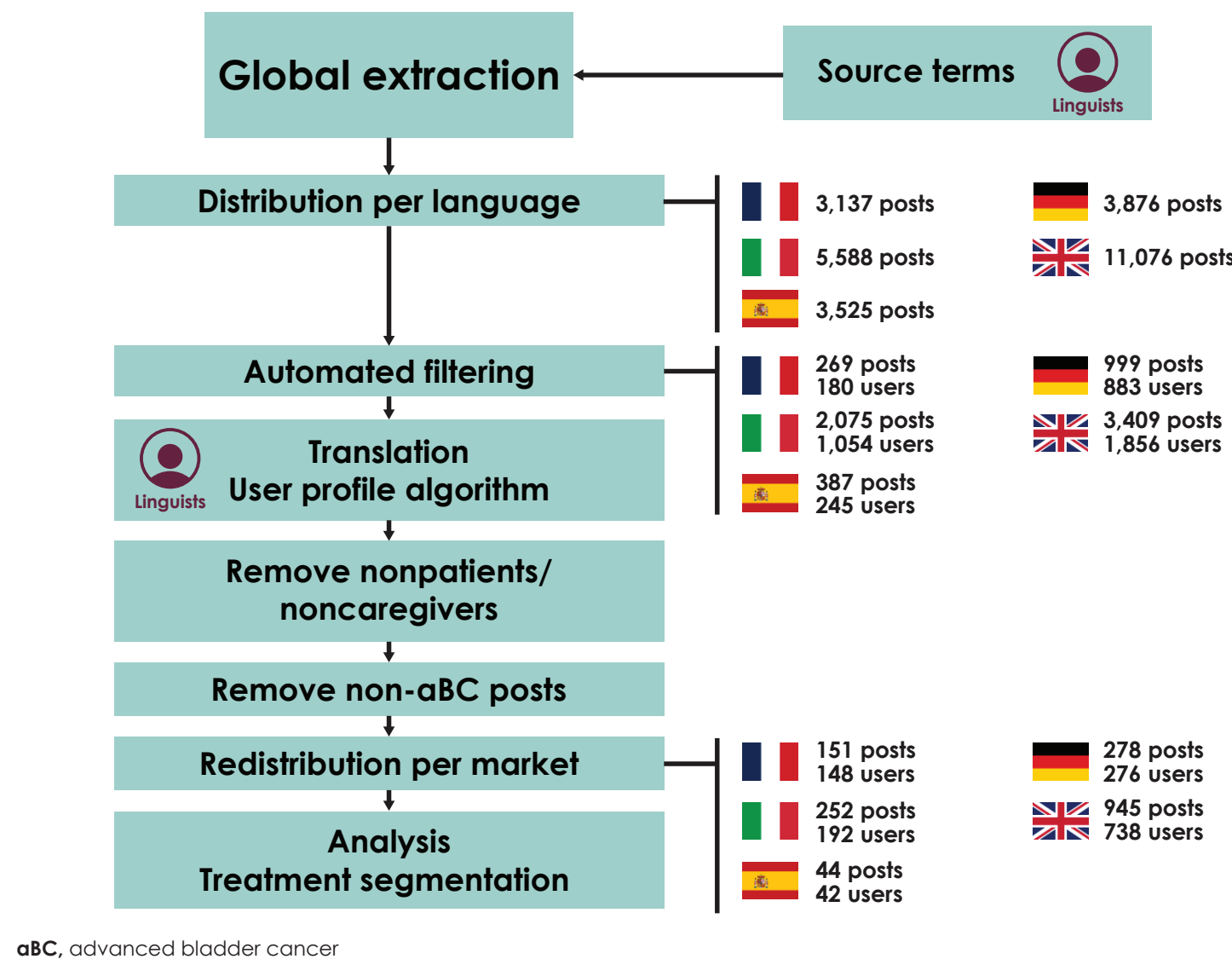
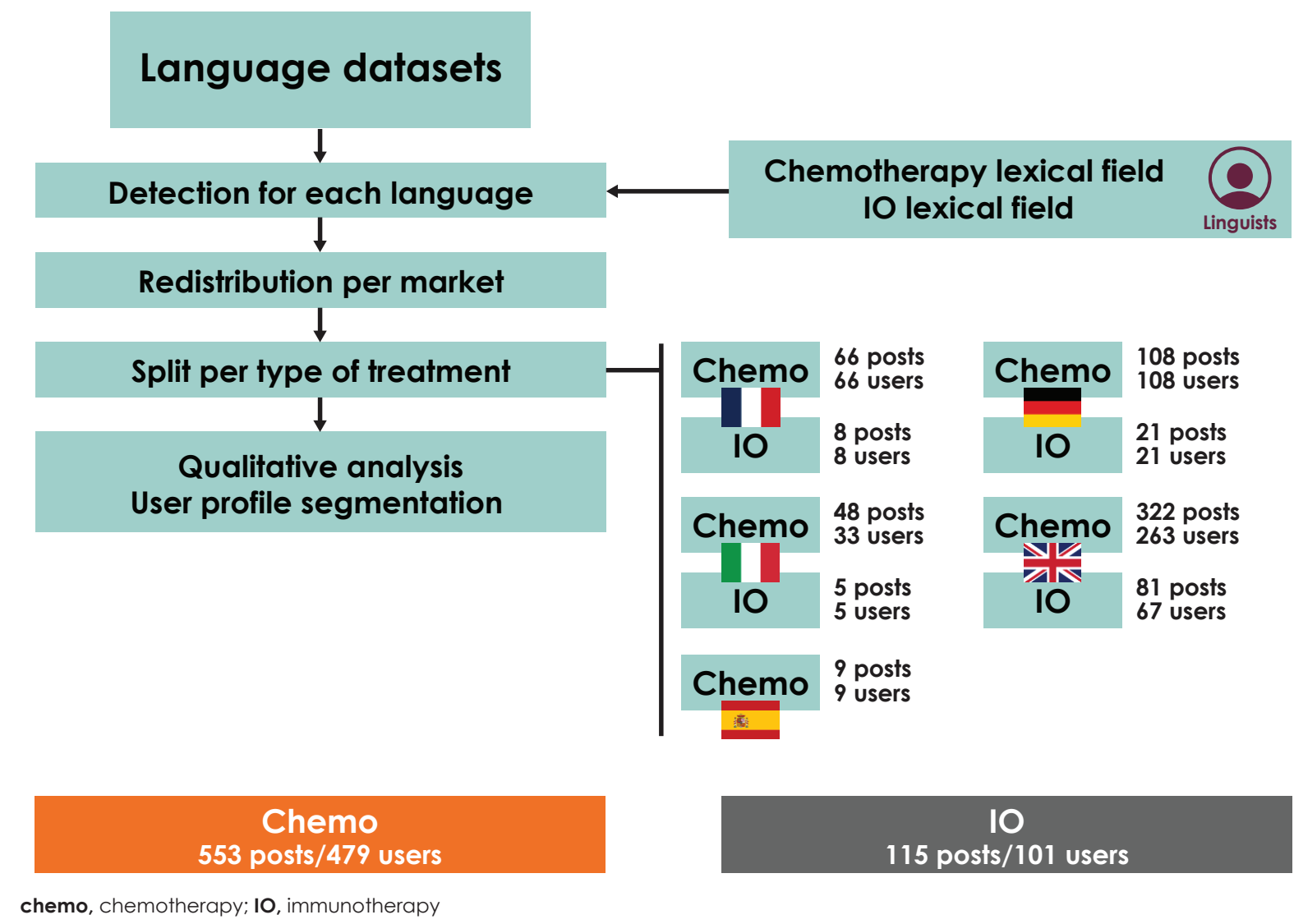


Figure 2. Treatment segmentation flowchart



RESULTS

Source and geographic distribution

- A total of 1,670 posts written by 1,396 users discussing aBC in 91 publicly available online sources were identified (699 posts from 546 patients and 971 posts from 850 caregivers). A large proportion of posts were geotagged in the UK (945 [56.6%]), while Spain had the fewest (44 [2.6%])
- Among all of the posts, a total of 514 users reported experience of systemic treatment (219 patients and 295 caregivers)
 - Among the 514 users, chemotherapy treatment was the most commonly mentioned (553 posts), followed by immunotherapy (115 posts), and both (73 posts)
- Data sources included both global social media and country-specific health forums (Tables 1 and 2)

Patient and caregiver demographics

- For posts written by patients, the average patient age was 52.8 years and half were male (272 [49.8%]). For posts written by caregivers, the average caregiver age was 35.2 years and more than half were female (474 [55.8%])
- Furthermore, the majority of patients mentioned in caregiver posts (average age, 67.7 years) were male (577 [67.9%]) (Table 3)

Table 1. Characteristics of patients and caregivers who posted social media messages

Characteristics	Total	Patients	Caregivers
Users, n	1,396	546	850
Social media posts, n	1,670	699	971
Posts by country, n (%)			
UK	945 (56.6)	419 (59.9)	526 (54.2)
Germany	278 (16.7)	150 (21.5)	128 (13.2)
Italy	252 (15.1)	82 (11.7)	170 (17.5)
France	151 (9.0)	40 (5.7)	111 (11.4)
Spain	44 (2.6)	8 (1.2)	36 (3.7)
Top 5 social media platforms by posts, n (%)			
Macmillan Cancer Support	390 (23.4)	180 (25.8)	210 (21.6)
X (formerly Twitter)	261 (15.6)	87 (12.4)	174 (17.9)
Blasenkrebs Online-Selbsthilfegruppe	202 (12.1)	126 (18.0)	76 (7.8)
HealthUnlocked	170 (10.2)	124 (17.7)	46 (4.7)
Cancer Research UK	156 (9.3)	40 (5.7)	116 (11.9)
Users with treatment experience, n	514	219	295
Posts by type of treatment, n			
Mention of chemotherapy	553	230	323
Mention of immunotherapy	115	56	59
Mention of both	73	29	44

Table 2. Forums and social media where users mentioned specific bladder cancer treatments

Social media used with mention of treatment	Country	Total posts, n (%)	Total users, n (%)	Patient posts, n (%)	Patients, n (%)	Caregiver posts, n (%)	Caregivers, n (%)
Total	–	595 (100)	514 (100)	257 (100)	219 (100)	338 (100)	295 (100)
Macmillan Cancer Support	UK	195 (32.8)	144 (28.0)	91 (35.4)	59 (26.9)	104 (30.8)	85 (28.8)
Blasenkrebs Online-Selbsthilfegruppe	Germany	93 (15.6)	93 (18.1)	54 (21.0)	54 (24.6)	39 (11.5)	39 (13.2)
HealthUnlocked	UK	62 (10.4)	61 (11.9)	50 (19.5)	49 (22.4)	12 (3.6)	12 (4.1)
Cancer Research UK	UK	60 (10.1)	48 (9.4)	16 (6.2)	14 (6.4)	44 (13.0)	34 (11.5)
Doctissimo	France	49 (8.2)	49 (9.5)	10 (3.9)	10 (4.6)	39 (11.5)	39 (13.2)
Aimac	Italy	27 (4.6)	16 (3.1)	5 (2.0)	3 (1.4)	22 (6.5)	13 (4.4)
X (formerly Twitter)	Global	23 (3.9)	19 (3.7)	7 (2.7)	6 (2.7)	16 (4.7)	13 (4.4)
Ligue contre le cancer	France	12 (2.0)	12 (2.3)	0 (0)	0 (0)	12 (3.6)	12 (4.1)
Others	–	74 (12.4)	72 (14.0)	24 (9.3)	24 (11.0)	50 (14.8)	48 (16.3)

Table 3. Demographics of patients and caregivers

Demographics	Patients, n (%)	Caregivers, n (%)
Sex		
Female	158 (28.9)	474 (55.8)
Male	272 (49.8)	198 (23.3)
Not mentioned	116 (21.3)	178 (20.9)
Age group		
0-20 years	0	7 (0.8)
21-30 years	1 (0.2)	14 (1.7)
31-40 years	18 (3.3)	13 (1.5)
41-50 years	30 (5.5)	9 (1.1)
51-60 years	46 (8.4)	4 (0.5)
>60 years	58 (10.6)	2 (0.2)
Not mentioned	393 (72.0)	801 (94.2)
Average age, years	52.8	35.2

Chemotherapy perceptions

- Among the 553 posts mentioning chemotherapy (Figure 3), 58.6% did not express any opinion; in posts that did, negative perceptions (23.2%) were more commonly reported than positive (9.2%) based on the total 553 posts
- More negative (25.4%) and more mixed (10.8%) discourses were observed in caregiver posts mentioning chemotherapy (n=323) compared with patient posts (20.0% and 6.5%, respectively) discussing chemotherapy (n=230). Furthermore, patients expressed more positivity toward chemotherapy treatments (13.5%) than caregivers (6.2%)
- The main perceived chemotherapy benefits, as identified in 69 patient and caregiver posts, were effectiveness (35.4%), tumor reduction (14.5%), and treatment tolerance (13.0%)
- The main drawbacks of chemotherapy cited within 154 posts were side effects (38.3%), perceived lack of effectiveness (16.9%), and general fatigue (13.0%)

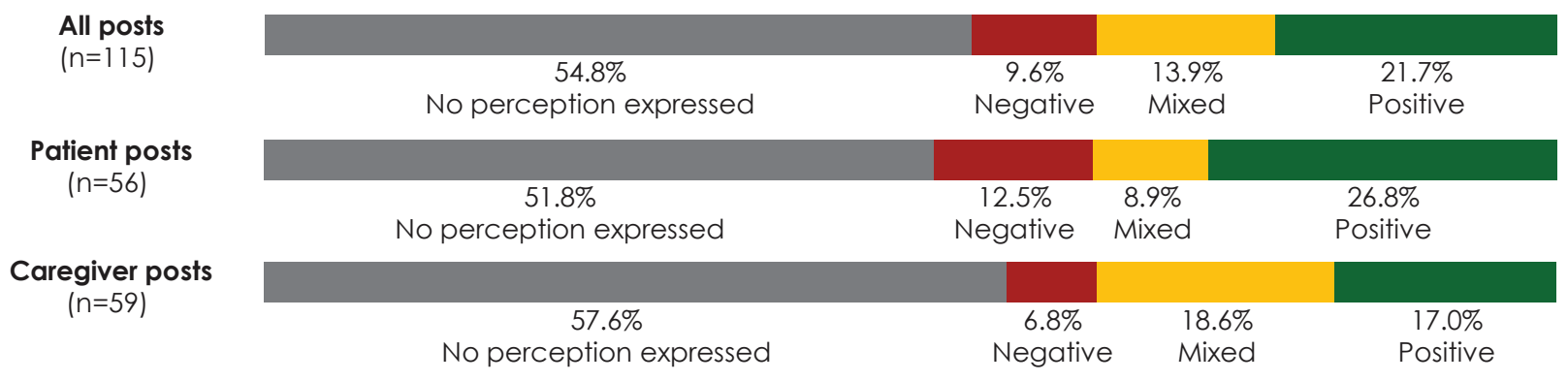
Immunotherapy perceptions

- 115 posts written by 48 patients and 53 caregivers mentioned immunotherapy as part of aBC management. Among posts (Figure 4), immunotherapy treatments were perceived more positively (21.7%) than negatively (9.6%). Caregivers, when they had an opinion on the subject, seemed hesitant in their perception of immunotherapy treatments, reacting most commonly in a mixed manner (18.6%)
- 20 posts described the benefits of immunotherapy as a treatment for aBC, with 50.0% highlighting its perceived effectiveness
- Drawbacks were described in 22 posts. Almost half (45.5%) of these concerned perceived side effects that were difficult to manage on a daily basis

Figure 3. Overall perception of chemotherapy



Figure 4. Overall perception of immunotherapy



LIMITATIONS

- Limitations and challenges associated with SML data include the inability to verify contributor characteristics (eg, demographic and clinical information). Thus, the accuracy of testimonials cannot be confirmed and may not reflect clinical reality
- There was limited information and specificity related to treatments and disease (ie, cannot ascertain lines of treatment, specific stage of cancer, and other details) and no information available on clinical outcomes of treatments
- There was also potential selection bias as individuals who choose to upload social media posts may not be representative of the broader patient population with aBC and their caregivers
- Engagement on social media depends on age, sex, ethnicity, socioprofessional class, income, education, and technological and health literacy. When feedback is unsolicited, as is the case with social media, there is potential for more negative feedback^{8,9}
- Analysis was based on publicly available social media posts; as such, data from nonpublic social media platforms such as nonpublic groups on Facebook were not included

REFERENCES 1. Sung H, et al. CA Cancer J Clin. 2021;71(3):209-49. 2. Saginala K, et al. Med Sci (Basel). 2020;8(1):15. 3. Patel VG, et al. CA Cancer J Clin. 2020;70(5):404-23. 4. European Cancer Information System. Accessed 23 August 2023. <https://ecis.jrc.ec.europa.eu/index.php>. 5. Powles T, et al. Ann Oncol. 2022;33(3):244-58. 6. Cathomas R, et al. Eur Urol. 2021;81(1):95-103. 7. Schuck S, et al. ESMO 2023: Poster No. 2381P. 8. Jalonen H. Online J Commun Media Technol. 2014;4:53-70. 9. Robertson SP, et al. Inf Polity. 2013;18(2):107-26. DISCLOSURES S. Schuck, P. Loussikian, A. Mebarki, J. Malaab, P. Foulquié, and M. Talmatkadi report employment with Kap Code. M. Kearney reports employment with Merck, and reports stock and other ownership interests in Merck, Novartis, and UCB. ACKNOWLEDGMENTS The study was sponsored by Merck (CrossRef Funder ID: 10.13039/100009945). Editorial support was provided by Clinical Thinking and was funded by Merck.