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# Perceived unmet needs and challenges faced by patients with advanced bladder cancer and their caregivers: results of a social media listening study conducted in 5 European countries

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## SCOPE

- This observational study aimed to gain insights into patient and caregiver experience with advanced bladder cancer (aBC) and its treatments using social media listening (SML) data from 5 European countries (Eu5)

## CONCLUSIONS

- Our findings demonstrate that patients with aBC and their caregivers actively share experiences and seek information on social media platforms. They have an unmet need for support and to express their challenges, especially regarding disease management
- The results indicate that the challenges faced by patients and caregivers were similar across Eu5 countries
- SML reveals that there is a need for improved patient and caregiver education and for effective and tolerable systemic anticancer treatments and palliative care options for patients with aBC
- This study illustrates how SML is a powerful tool that can be used to explore different elements of patient and caregiver perceptions, providing key insights not typically captured by patient-centered research
- Additional studies on patients with aBC and their caregivers are required to quantitatively explore the impact of this disease and its treatments on quality of life

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## BACKGROUND

- BC is the tenth most common malignancy worldwide, accounting for approximately 573,000 new cases and 213,000 deaths in 2020<sup>1,2</sup>
- It is predominantly diagnosed in older adults and is approximately 4 times more common in men<sup>2,3</sup>
  - Among men, bladder cancer is the fourth most commonly diagnosed cancer in France, Germany, Italy, and Spain, and the sixth in the UK<sup>4</sup>
- aBC has a very poor prognosis and is associated with physical, emotional, and social challenges that patients and caregivers are increasingly expressing on social media platforms<sup>5</sup>
- SML presents a new approach to derive unfiltered and uninfluenced insights on patient and caregiver experiences with diseases such as aBC. Thus, SML data can provide a unique perspective on issues of importance to patients and caregivers<sup>6-8</sup>

## METHODS

### Study design and data source

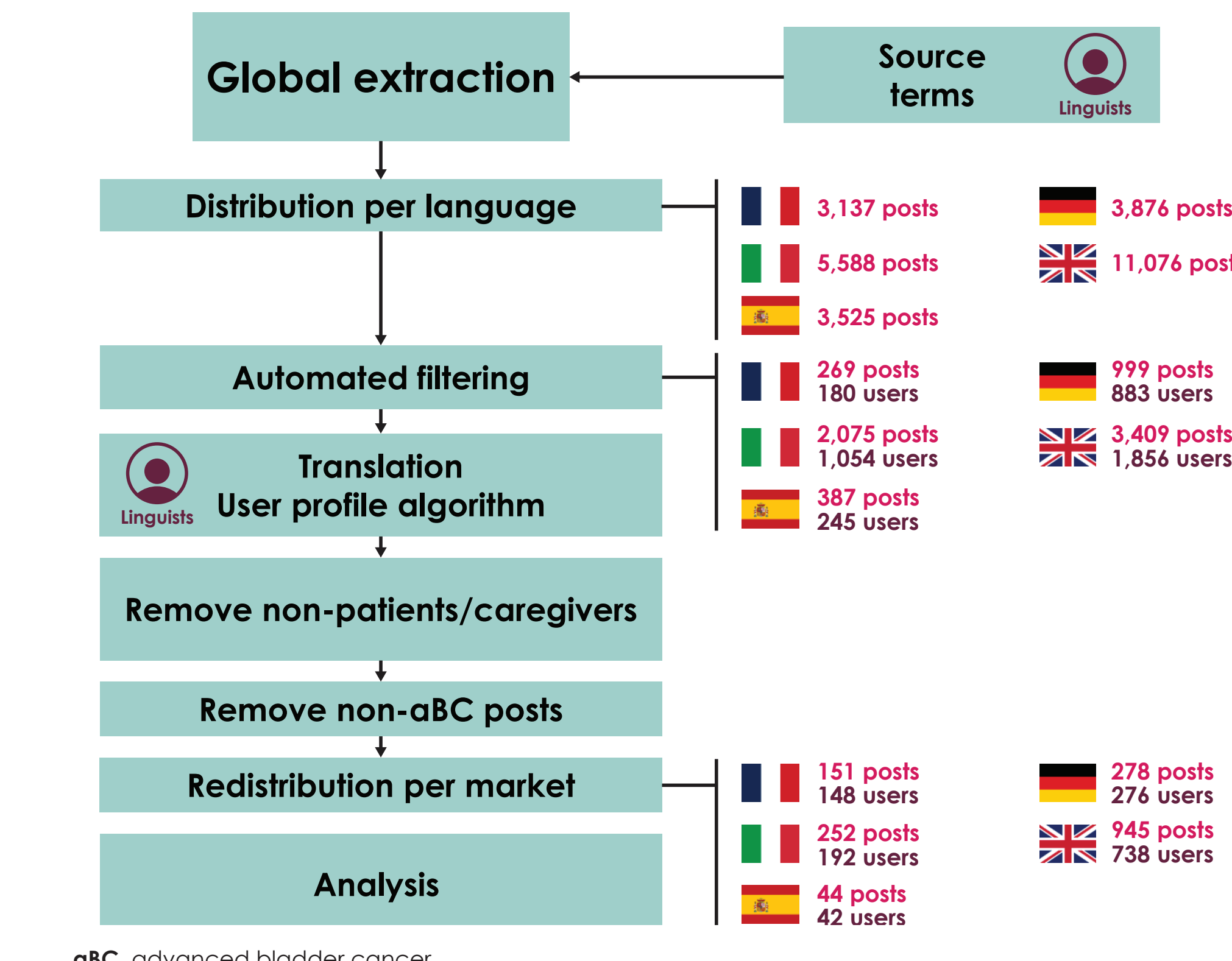
- This retrospective real-world study evaluated written public posts on geolocated social media in the Eu5 (France, Germany, Spain, Italy, and the UK) posted from October 2017 to January 2022 (Figure 1)
- To extract data from social media and public forums, extraction terms were identified in several 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. Users who were not patients or caregivers and messages not relevant to aBC were

removed. Finally, language-specific corpora were redistributed by country of interest

### Data analysis

- Natural language processing methods were used to filter out irrelevant content and identify posts from patients and caregivers. Specific algorithms (Kap Code proprietary information) were applied for quantitative analysis of the posts. Then, a deep learning algorithm was applied to identify the main categories of challenges. A qualitative analysis (ie, annotation) and saturation method were then used to qualify these challenges and unmet needs in detail. Demographic information (eg, sex and age) was extracted, along with any accompanying disease information where available

Figure 1. Social media post identification flowchart



aBC, advanced bladder cancer.

## 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 was the country with the fewest (44 [2.6%]) social media posts. The sources include both global social media and country-specific health forums (Tables 1 and 2)

### Patient and caregiver demographics

- For posts written by patients (average age, 52.8 years), half were male (272 [49.8%])
- For posts written by caregivers (average age, 35.2 years), the majority 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. Top 10 data sources

Forum/social media	Forum country	Posts, n (%)
Macmillan Cancer Support	UK	390 (23.4)
X (formerly Twitter)	Global	261 (15.6)
Blasenkrebs Online-Selbsthilfegruppe	Germany	202 (12.1)
HealthUnlocked	UK	170 (10.2)
Cancer Research UK	UK	156 (9.3)
Doctissimo	France	94 (5.6)
Aimac	Italy	89 (5.3)
Medicitalia	Italy	44 (2.6)
Ligue contre le cancer	France	30 (1.8)
Facebook	Global	14 (0.8)
Others	Global	220 (13.2)

Table 2. Geographic distribution of posts and users

Country	Total posts, n (%)	Total users, n (%)	Patient posts, n (%)	Patients, n (%)	Caregiver posts, n (%)	Caregivers, n (%)
UK	945 (56.6)	738 (52.9)	419 (59.9)	291 (53.3)	526 (54.2)	447 (52.6)
Germany	278 (16.7)	276 (19.8)	150 (21.5)	150 (27.5)	128 (13.2)	126 (14.8)
Italy	252 (15.1)	192 (13.7)	82 (11.7)	57 (10.4)	170 (17.5)	135 (15.9)
France	151 (9.0)	148 (10.6)	40 (5.7)	40 (7.3)	111 (11.4)	108 (12.7)
Spain	44 (2.6)	42 (3.0)	8 (1.2)	8 (1.5)	36 (3.7)	34 (4.0)
TOTAL	1,670 (100.0)	1,396 (100.0)	699 (100.0)	546 (100.0)	971 (100.0)	850 (100.0)

Table 3. Demographic characteristics of patients and caregivers

Characteristic	Patients, n (%)	Caregivers, n (%)	
		Posts mentioning caregivers	Posts mentioning patients
<b>Sex</b>			
Female	158 (28.9)	474 (55.8)	241 (28.4)
Male	272 (49.8)	198 (23.3)	577 (67.9)
Not mentioned	116 (21.3)	178 (20.9)	32 (3.7)
<b>Age group, years</b>			
0-20	0	7 (0.8)	0
20-30	1 (0.2)	14 (1.7)	1 (0.1)
30-40	18 (3.3)	13 (1.5)	4 (0.5)
40-50	30 (5.5)	9 (1.1)	5 (0.6)
50-60	46 (8.4)	4 (0.5)	29 (3.4)
≥60	58 (10.6)	2 (0.2)	77 (9.1)
Not mentioned	393 (72.0)	801 (94.2)	734 (86.3)
<b>Average age, years</b>	52.8	35.2	67.7

### Main categories identified

- The combination of the categorization algorithm and the manual annotation of challenges enabled us to identify 1,092 occurrences of challenges and unmet needs in all posts combined: 382 for patients and 710 for caregivers
- No significant differences were found in terms of challenges faced by patients and their caregivers in the Eu5 countries
- Most unmet needs and challenges identified belonged to 2 main categories: transversal, that is, arising throughout the patient's care pathway (307 [28.1%]), and disease specific (295 [27.0%])

### Main challenges and unmet needs identified

- Across all posts, the main challenges included disease worsening (141 [12.9%]), psychological impact (112 [10.3%]), and the need to share experiences and seek support (94 [8.6%])
- Table 4 describes the top 8 challenges and unmet needs found in patient and caregiver posts, which constituted more than half of all occurrences identified in these posts (608 [55.7%])
- The need for experience sharing and support was mainly expressed in the form of questions from patients (42 [11.0%]) and their caregivers (52 [7.3%])
- In addition, Figure 2 shows that a lack of information and knowledge was expressed, with more specific questions about the management of aBC being asked by patients (16 [4.2%]) and their caregivers (12 [2.1%])
- Questions specific to the treatments indicated for aBC were also found in some of the posts (12 [3.1%] for patients and 19 [2.7%] for their caregivers)
- In addition to challenges and unmet needs concerning patients, challenges concerning caregivers exclusively, or even both patients and caregivers, were identified in caregivers' posts
- Among the main challenges described in Figure 2, there were 3 challenges affecting mostly caregivers: psychological impact (74 [10.4%]), burden of caring for terminally ill patients and grieving (22 [3.1%]), and concerns about the future, with difficulties projecting ahead (32 [4.5%])

Table 4. Top 8 challenges identified in posts from patients and caregivers

Challenge	Occurrence in all posts combined, n (%)	Occurrence in patient posts, n (%)	Occurrence in caregiver posts, n (%)	Category
Progression/worsening/complication/recurrence of disease	141 (12.9)	40 (10.5)	101 (14.2)	Disease specific
Psychological impact	112 (10.3)	38 (10.0)	74 (10.4)	Transversal
Need for sharing experiences/support	94 (8.6)	42 (11.0)	52 (7.3)	Transversal
Fear and management of aBC symptoms	82 (7.5)	31 (8.1)	51 (7.2)	Disease specific
Sequelae of aBC or care	60 (5.5)	34 (8.9)	26 (3.7)	Remission phase specific
Worried about future and difficulties to project oneself	46 (4.2)	14 (3.7)	32 (4.5)	Transversal
Difficulty or delay in accessing treatment	40 (3.7)	13 (3.4)	27 (3.8)	Treatment specific
Consideration and management of pain	33 (3.0)	11 (2.9)	22 (3.1)	Disease specific
<b>TOTAL</b>	<b>608 (55.7)</b>	<b>223 (58.4)</b>	<b>385 (54.2)</b>	

aBC, advanced bladder cancer.

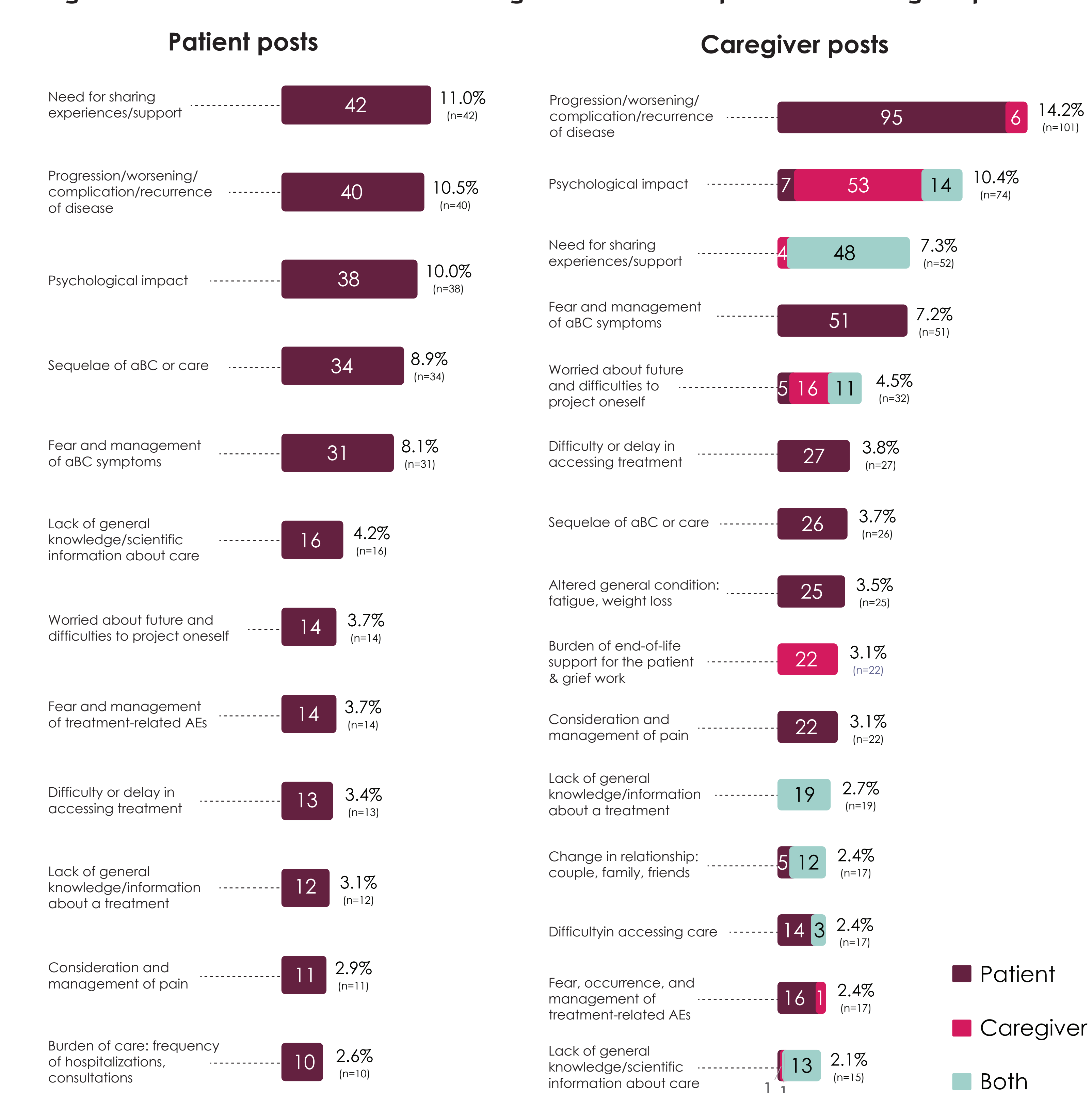
## Statistical analysis

- For the anonymized content, only aggregated qualitative findings are reported
- Manual curation was used to analyze and map detailed challenges and unmet needs expressed by users
- 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
- The privacy of patients was respected, and caution was taken in using the information posted (all online content was anonymized)
- All social media research assumes that the information provided by patients and caregivers is authentic and was voluntarily shared with the patient and caregiver community publicly

Figure 2. Main unmet needs and challenges mentioned in patient and caregiver posts



aBC, advanced bladder cancer; AE, adverse event.

## 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
- Additionally, individuals who choose to upload social media posts may not be representative of the broader patient population with aBC and their caregivers
- Analysis was based on publicly available social media posts; as such, data from nonpublic social media platforms such as Facebook nonpublic groups were not included
- Quality of insights gathered from the analysis of digital conversations was dependent on the richness of patient and caregiver input, that is, the details shared by patients/caregivers about their health condition, unmet needs, disease management challenges, and quality of life