

# Patient and caregiver experiences in metastatic prostate cancer: social media analysis in the United States

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## KEY FINDINGS & CONCLUSIONS

- Social media posts provide insights regarding the lived experiences of US patients with mPC and their caregivers, revealing unmet needs, emotional and QoL burdens (e.g., effect on daily living), and barriers to care that may be underappreciated by healthcare professionals and underrepresented in traditional research
- Patients mainly expressed needs for better side effect management; caregivers primarily focused on QoL, including the burden of providing emotional support
- Both patients and caregivers expressed desires for accessible education on upcoming treatment and clinical trials via improved communication, continuous listening, psychosocial support, and empathy
- Collaboration between patient advocacy groups, providers, and pharmaceutical companies could serve to help address these needs

## INTRODUCTION

- Prostate cancer (PC), the most commonly diagnosed cancer in men in the U.S., accounts for 29% of male cancer diagnoses and is the second most common cause of cancer-related death in men<sup>1</sup>
- As treatment options for metastatic PC (mPC) evolve, gaining insight into patient and caregiver perspectives is increasingly important to understand real-world experiences, quality of life (QoL; including health-related aspects), and unmet needs<sup>2</sup>
- Social media platforms are a widely used form of communication among patients and caregivers sharing experiences and seeking support,<sup>3-5</sup> and are also recognized by the U.S. Food and Drug Administration as legitimate sources of real-world evidence<sup>4</sup>
- This analysis explored the trending topics, sentiments, and unmet needs of patients with mPC and their caregivers using social media data

## METHODS

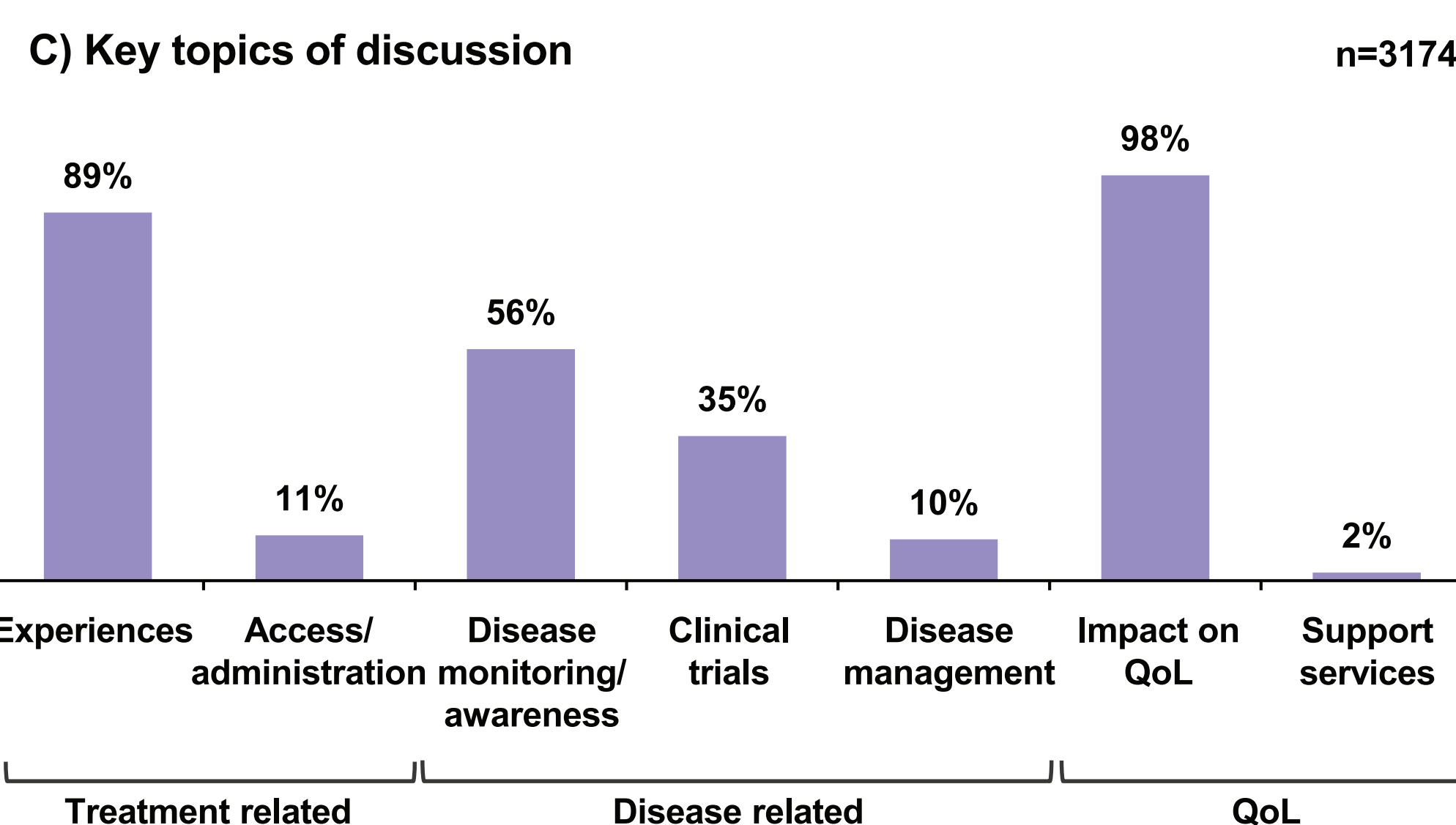
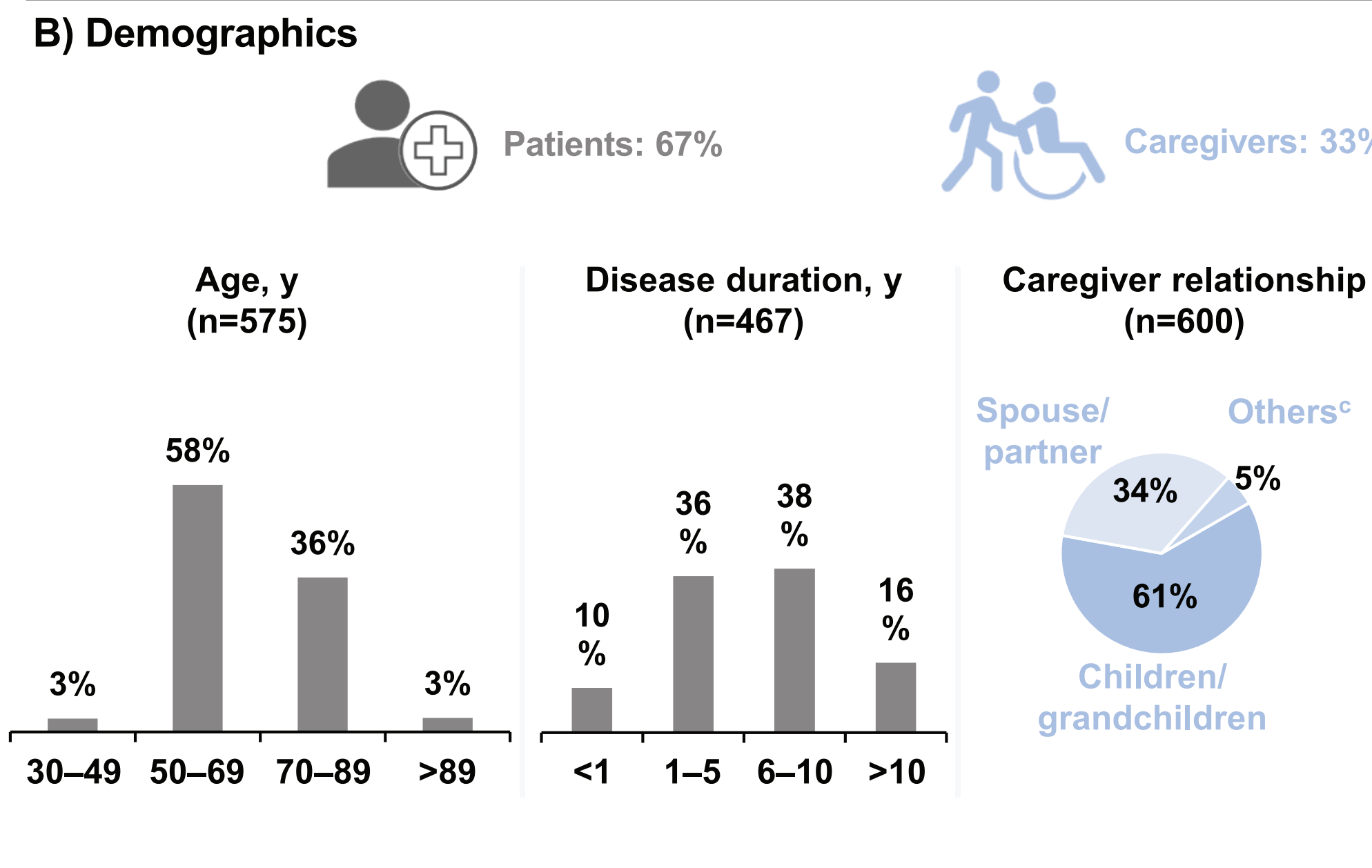
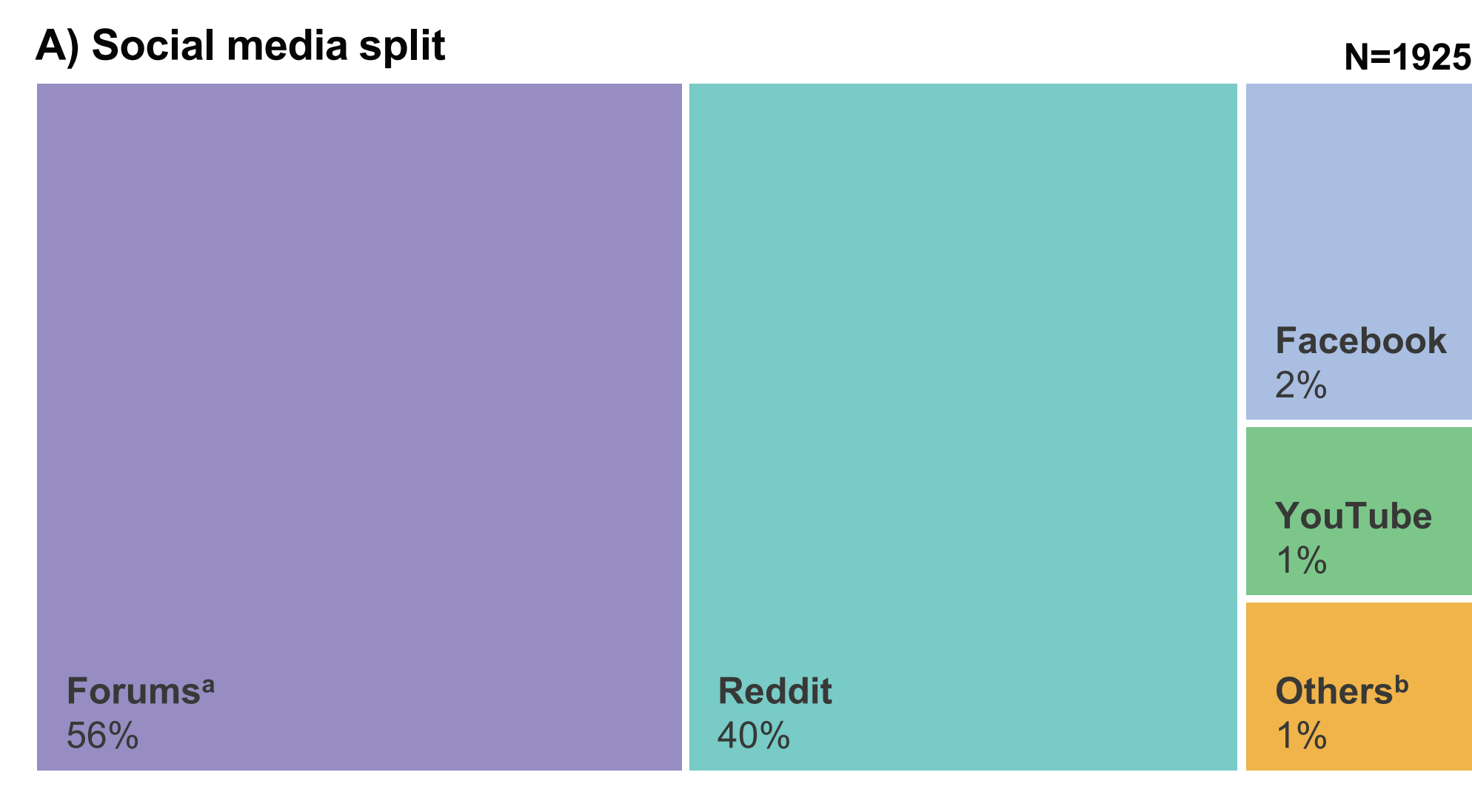
- This was a retrospective, real-world analysis
- Data from forums (e.g. Malecare), Reddit, Facebook, YouTube, Instagram, X, and Quora were collected using predefined keywords related to mPC via the licensed Sprinklr tool (English language) from 01/2023–07/2025
- Relevant datasets were identified via manual screening and automated algorithms
- U.S.-specific data were filtered, and thematic analysis was conducted to generate qualitative insights on demographics, unmet needs, current therapy experiences, and QoL from patient and caregiver perspectives

## RESULTS

### Study overview, demographics, and digital behavior

- Overall, 1925 relevant posts were identified from social media platforms, the majority from forums (e.g. Malecare) and Reddit (Figure 1)

Figure 1. A) Percentage of posts from social media platforms. B) Audience split and population demographics. C) Type of conversations/themes identified.



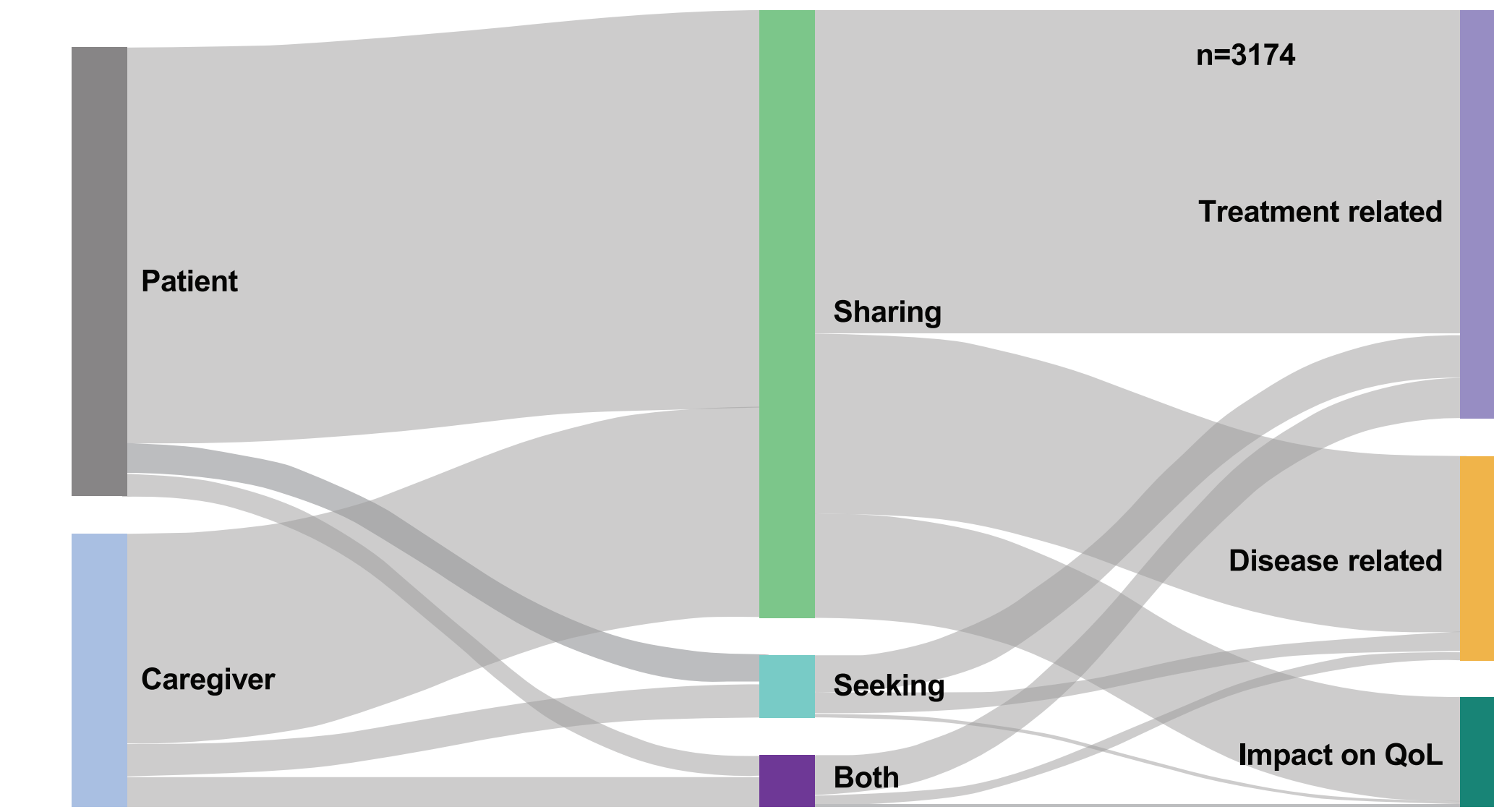
<sup>a</sup>n indicates total number of posts. <sup>b</sup>n indicates mentions of identifiable age or total number of mentions. <sup>c</sup>Top forums included malecare, healingwell.com, and inspire.com; <sup>d</sup>Others included Instagram, X, and Quora. <sup>e</sup>Others included siblings, friends, and parents. QoL, quality of life; y, years.

- Patients mainly shared their personal experiences, while caregivers actively sought advice on disease management and safety (Figure 2)

### Sentiment analysis

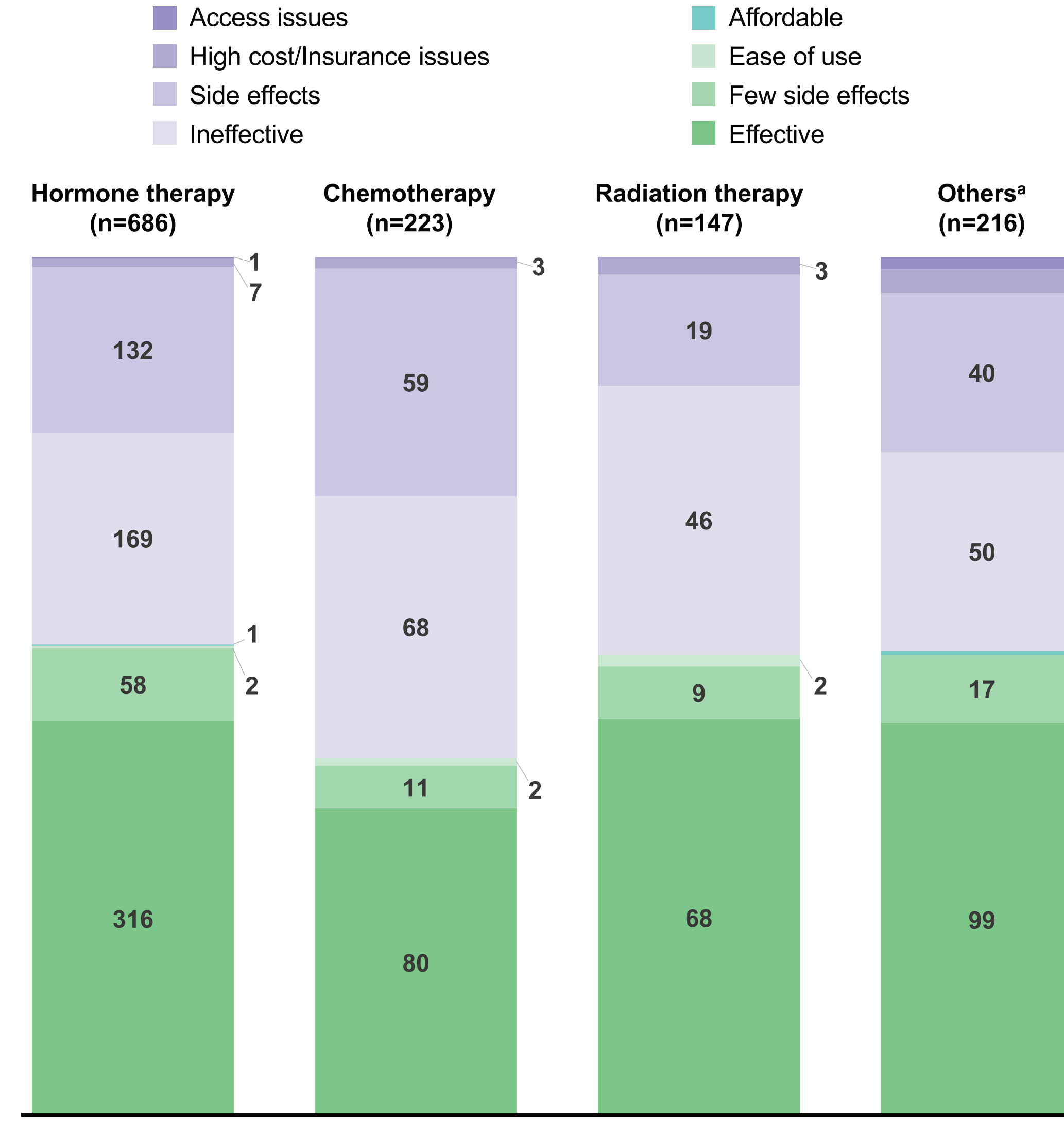
- Hormone therapy and chemotherapy were the most frequently mentioned treatment classes; chemotherapy had the highest proportion of negative sentiments (58%)
- Negative sentiments were mainly driven by ineffectiveness and side effects (Figure 3)

Figure 2. Digital behavior of patients and caregivers.



<sup>a</sup>n indicates total number of mentions. One post can have more than one discussion. QoL, quality of life.

Figure 3. Sentiment and its drivers.

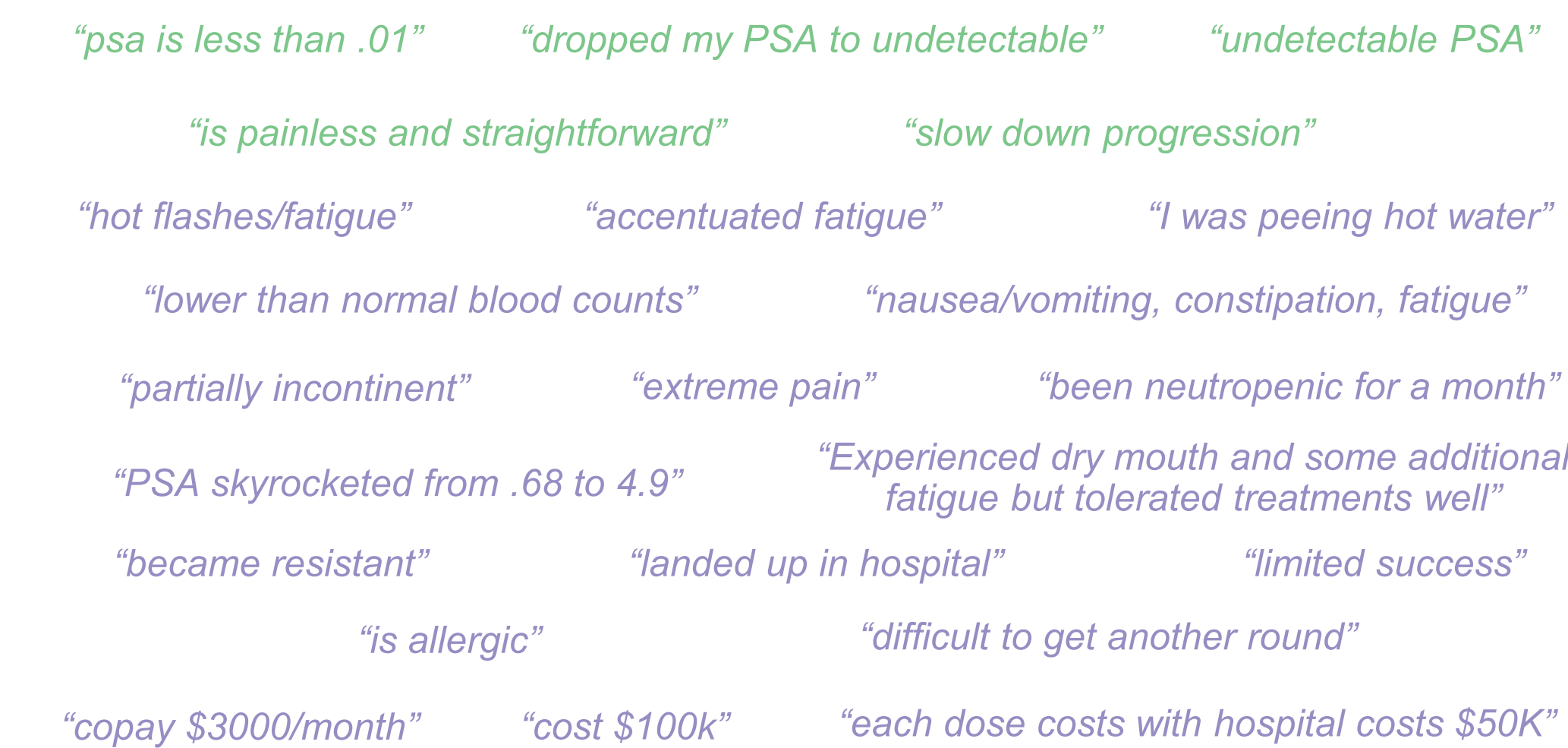


<sup>a</sup>worked best  
 "tumors appeared to have shrunk"  
 "working some miracles"  
 "treated symptomatic metastases"  
 "psa is less than .01"  
 "is painless and straightforward"  
 "hot flashes/fatigue"  
 "lower than normal blood counts"  
 "partially incontinent"  
 "PSA skyrocketed from .68 to 4.9"  
 "became resistant"  
 "is allergic"  
 "copy \$3000/month"

<sup>b</sup>got very mild side effects  
 "making great progress"  
 "totally in remission"  
 "changed the course of my life"  
 "dropped my PSA to undetectable"  
 "undetectable PSA"  
 "slow down progression"  
 "accentuated fatigue"  
 "nausea/vomiting, constipation, fatigue"  
 "extreme pain"  
 "Experienced dry mouth and some additional fatigue but tolerated treatments well"  
 "landed up in hospital"  
 "difficult to get another round"

<sup>c</sup>far less side effects  
 "psa dropped back to 0.1"  
 "changed the course of my life"  
 "undetectable PSA"  
 "I was peeing hot water"  
 "been neutropenic for a month"  
 "limited success"

<sup>a</sup> 531 posts had 651 mentions of different aspects of QoL. One post might have multiple mentions. PSA, prostate-specific antigen; QoL, quality of life.



<sup>a</sup>For patients and caregivers, includes risk of radiation exposure, difficulty in identifying symptoms and dose and administration; for caregivers, includes limited information. QoL, quality of life.

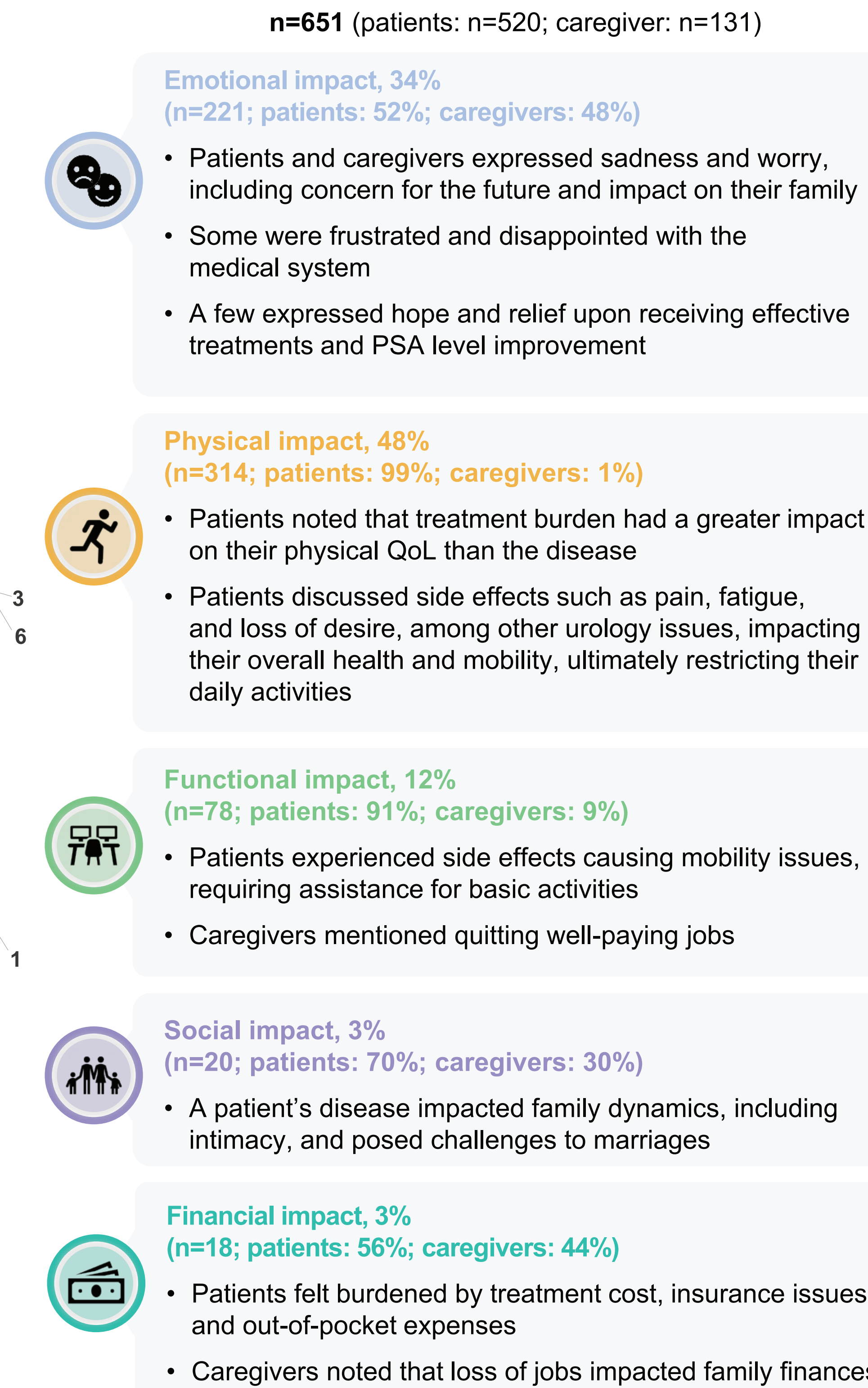
Figure 4. Impact on patient and caregiver QoL.

<sup>a</sup>n indicates total number of mentions; numbers within the figure indicate the number of mentions covering each topic. One post can have more than one discussion. <sup>b</sup>Includes RLT (exclusive RLT mentions were removed to avoid bias; only RLT mentions in combination with other classes were considered), surgery, immunotherapy, and targeted therapy. PSA, prostate-specific antigen; RLT, radioligand therapy.

### QoL

- QoL was highlighted in 651 mentions and was mainly discussed by patients (80%; caregivers: 20%) (Figure 4)
- Patients mainly described physical limitations and impact on functional well-being; caregivers were emotionally drained and discussed financial challenges

Figure 4. Impact on patient and caregiver QoL.



<sup>a</sup>For patients and caregivers, includes risk of radiation exposure, difficulty in identifying symptoms and dose and administration; for caregivers, includes limited information. QoL, quality of life.

### Unmet needs

- Key concerns included lack of effective and safe treatment, reduced QoL, and access issues (Figure 5)
- Regarding QoL, patients were mainly concerned about treatment burden, and described the impacts on their physical and emotional health, as well as impacts on mobility and employment
- When caregivers discussed QoL, they mainly focused on disease burden and emotional health, such as the toll of a loved one suffering and concerns for their family's future

### Educational needs

- Patients and caregivers mostly looked for treatment-related information, i.e. personal experiences and possible side effects before initiating a particular treatment (Figure 6)
- Caregivers sought ways to better support patients so as to make better decisions on their behalf
- Caregivers also asked about disease prognosis, interpreting test results, and ways to manage QoL

### Disclosures

EIH: Advisory Board: Bayer, Sanofi, AstraZeneca, Gilead Sciences, Novartis, EMD Serono, Pfizer, Genzyme, Seagen, Sumitomo, Petauri Kinect, Janssen Biotech, Inc.; Consultancy: Bayer, Sanofi, AstraZeneca, Astellas Pharma, Novartis, IDECology Health, LLC, Curio Science LLC, Education/Meeting Faculty: IDECology Health, LLC, Speakers' Bureau: Sanofi, Research Funding: Seagen, Merck, AstraZeneca, Oncology Biopharma, Bristol Myers Squibb, Fortis, Astellas Pharma, Caris Life Sciences, GlaxoSmithKline, Merck Sharp & Dohme, Concept Therapeutics, Infinity Pharmaceuticals, Bayer, Moderna Pharmaceuticals, Novartis, Janssen Research & Development, Mirati Therapeutics, Peloton Therapeutics, Daiichi Sankyo Inc., Calibr, Eisai, Pharmacyclics, Five Prime Therapeutics, Arvinas, BioXcel Therapeutics, Calithera Biosciences, Corvus Pharmaceuticals, Exelixis, Gilead Sciences, Harpoon Therapeutics, Roche, ITeos Therapeutics, Pfizer, POINT Biopharma, Clarify Pharmaceuticals Ltd, Janssen Scientific Affairs, LLC, Genentech, Prostate Cancer Foundation, Exelixis, Inc., Novartis Pharmaceuticals, AstraZeneca AB, MacroGenics, Inc., Regeneron Pharmaceuticals, Inc., ImmunBio, Inc., Xenor, Inc., Janux Therapeutics, Janssen Research & Development, LLC, Merck Sharp & Dohme LLC, K36 Therapeutics, Inc., Travel, Accommodations, Expenses: IDECology Health, LLC; Other Relationship: Caris Centers of Excellence.

### References

- Siegel RL, et al. *CA Cancer J Clin* 2024;74:12-49. 2. U.S. Food & Drug Administration. Available at: CDER Patient-Focused Drug Development. <https://www.fda.gov/drugs/development-approval-process-drugs/cder-patient-focused-drug-development>. Accessed November 2025. 3. Loeb S, et al. *CA Cancer J Clin* 2024;74:453-464. 4. Frank PP, et al. *Adv Ther* 2023;40:159-173. 5. Cimiano P, et al. *Front Med (Lausanne)* 2024;11:1274688.

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