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Social Media Listening for Early Breast Cancer in Italy: Framework for Social Media-Based Insights

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KEY FINDINGS

- Patients were active on social media platforms to share their experiences and to seek advice
- Patients used forums and blogs primarily to discuss topics such as coping with drug side effects and impact of the disease on overall well-being
- Twitter/X was used more by the HCPs to raise disease awareness highlighting the risk factors and shared updates on research/clinical trials
- Facebook community pages had plethora of patient conversations seeking advice from peers and sharing their experiences for disease management
- Instagram was used for raising awareness through expert interviews on topics such as mental well-being
- Local patient support groups shared patient testimonials on YouTube highlighting aspects such as delayed diagnosis, multiple diagnostic tests

INTRODUCTION

- In 2022, female breast cancer is predicted to be the top cancer worldwide, with 2.3 million new cases (11.6% of all cancers)[1]. It is also the leading cause of death for women and the fourth highest cause of cancer-related mortality globally[1]. Breast cancer patients face a multitude of challenges throughout their disease journey, starting from the initial symptom identification and continuing through diagnosis, treatment and disease management[2-4]. To comprehend these diverse challenges, conventional approaches such as questionnaires, interviews, and patient-reported outcome measures are frequently utilized to gather qualitative data. Nevertheless, these studies often involve a limited number of participants or necessitate longer durations to conduct, ultimately failing to fully grasp the distinctive obstacles experienced by patients in their individual journeys[5-8]. To gain a deeper understanding of these challenges, the approach of social media listening has recently gained significant prominence and importance[9-11].
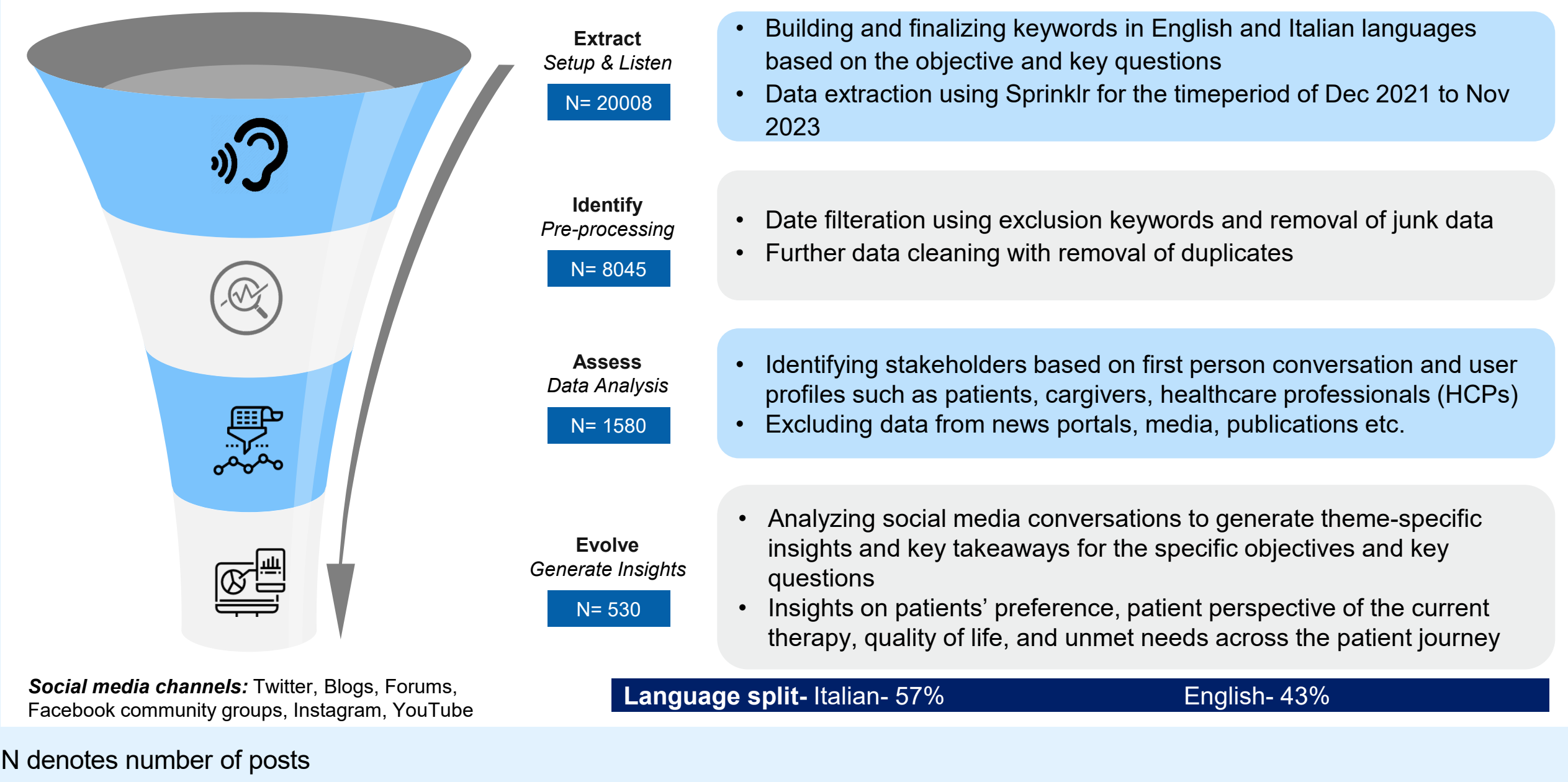
OBJECTIVE

- This study aimed to harness the power of social media listening (SML) to gain insights on patients' journey in early breast cancer (eBC) in Italy.

METHODS

- A comprehensive search was conducted on social media platforms (Twitter/X, Blogs, Forums, Facebook community groups, Instagram, and YouTube) from December 2021 to November 2023, using relevant keywords of 'breast cancer' both in Italian and English language. Data collection was performed using Sprinklr, an online SML tool. Natural language processing and manual screening were employed to preprocess and analyze the data. Details of methodology are depicted in **Figure 1**.
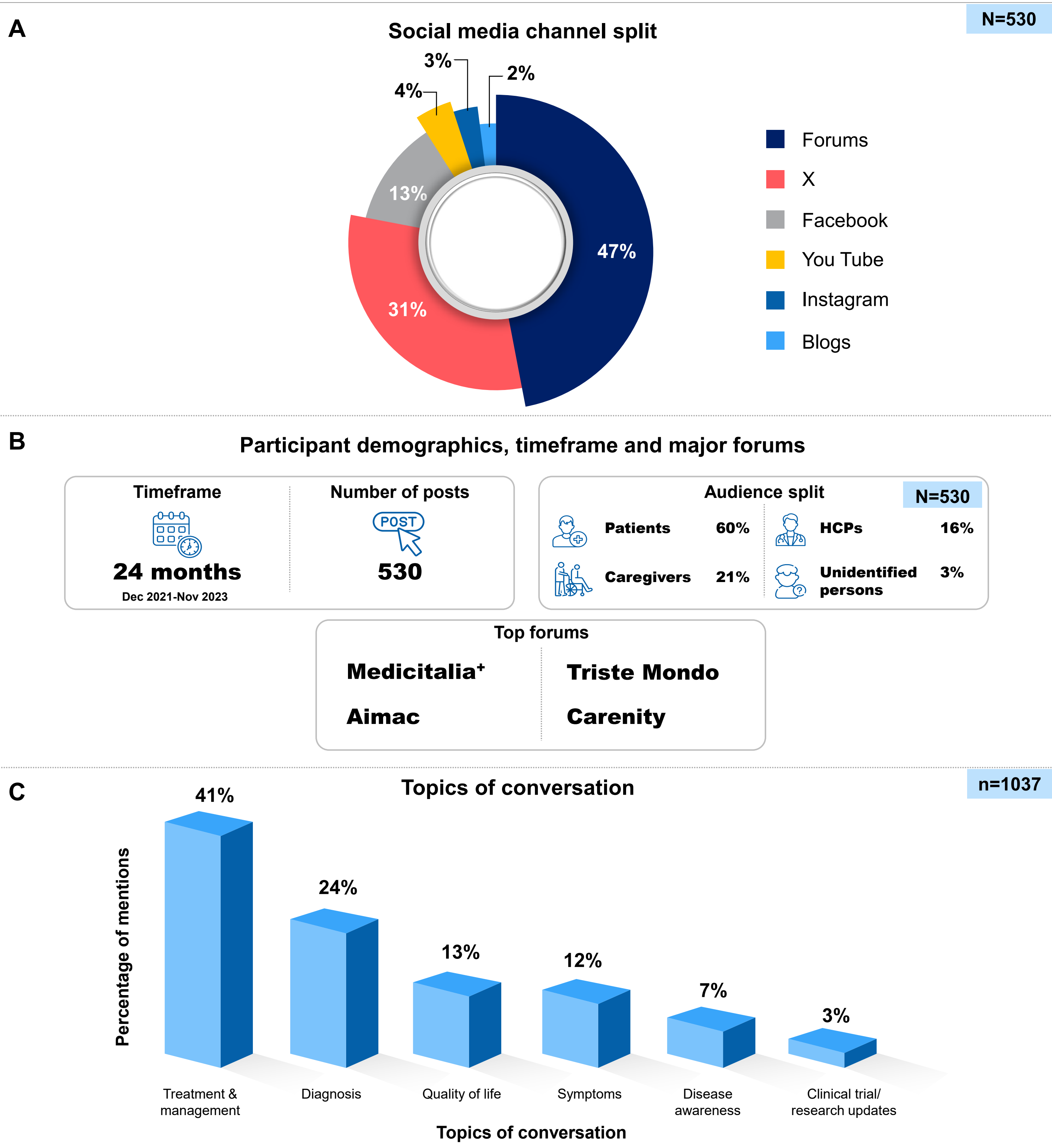
Figure 1. Social media listening methodology

Stage		Details
Extract Setup & Listen N= 20008		• Building and finalizing keywords in English and Italian languages based on the objective and key questions • Data extraction using Sprinklr for the timeperiod of Dec 2021 to Nov 2023
Identify Pre-processing N= 8045		• Date filteration using exclusion keywords and removal of junk data • Further data cleaning with removal of duplicates
Assess Data Analysis N= 1580		• Identifying stakeholders based on first person conversation and user profiles such as patients, carigivers, healthcare professionals (HCPs) • Excluding data from news portals, media, publications etc.
Evolve Generate Insights N= 530		• Analyzing social media conversations to generate theme-specific insights and key takeaways for the specific objectives and key questions • Insights on patients' preference, patient perspective of the current therapy, quality of life, and unmet needs across the patient journey

Social media channels: Twitter, Blogs, Forums, Facebook community groups, Instagram, YouTube

Language split- Italian- 57% English- 43%

N denotes number of posts

RESULTS

A total of 1580 posts were screened, and 530 posts were included in the final analysis after excluding irrelevant posts

Social media channel landscape

Prominently used social media platforms were forums (47%) and Twitter/X (31%). Around 60% of the total posts were contributed by patients. Most of the conversations were related to treatment and management of disease followed by diagnosis (**Figure 2**).

Figure 2. (A) Percentage of posts from various social media platforms, (B) Participant demographics, timeframe, and major forums and (C) Type of conversations/themes identified
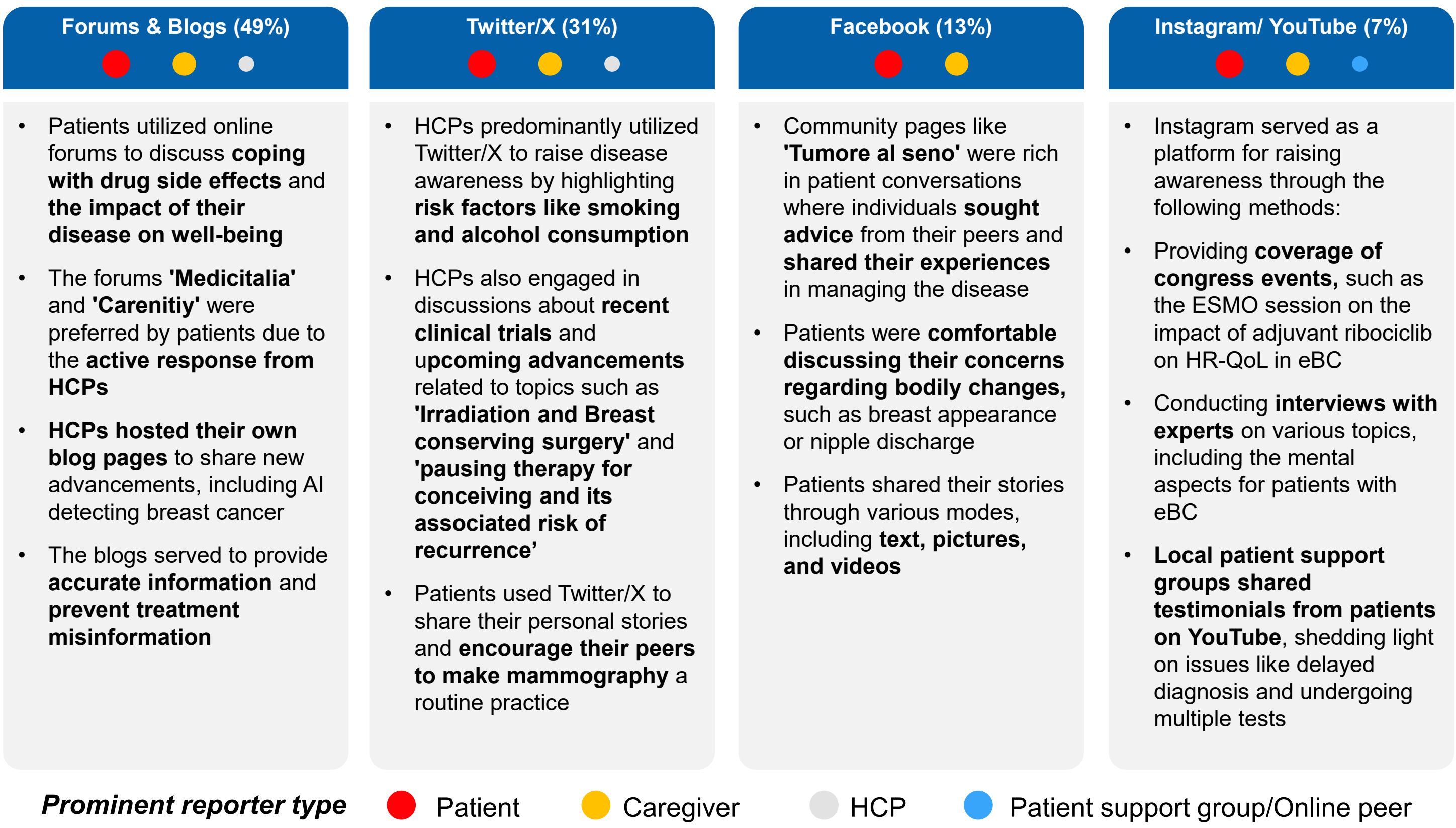

A — Social media channel split — N=530
- Forums 47%
- X 31%
- Facebook 13%
- You Tube 4%
- Instagram 3%
- Blogs 2%

B — Participant demographics, timeframe and major forums — N=530

Timeframe	Number of posts	Audience split	
24 months Dec 2021-Nov 2023	POST **530**	Patients 60%	HCPs 16%
		Caregivers 21%	Unidentified persons 3%

Top forums
- Medicitalia[+]
- Aimac
- Triste Mondo
- Carenity

C — Topics of conversation — n=1037
- Treatment & management 41%
- Diagnosis 24%
- Quality of life 13%
- Symptoms 12%
- Disease awareness 7%
- Clinical trial/ research updates 3%

(y-axis: Percentage of mentions; x-axis: Topics of conversation)

'N' denotes the number of posts; 'n' denotes the number of mentions of the specific attribute; HCP: Healthcare professional

Insights from analysis of social media channels

Patients used mainly forums and Facebook community pages for discussing their diagnosis and treatment journey. Healthcare professionals (HCPs) also actively participated on these forums and answered patient queries. Insights from various social media channels are provide in **Figure 3**.

Figure 3. Insights from various social media channels

Forums & Blogs (49%)
- Patients utilized online forums to discuss **coping with drug side effects and the impact of their disease on well-being**
- The forums **'Medicitalia'** and **'Carenitiy'** were preferred by patients due to the **active response from HCPs**
- **HCPs hosted their own blog pages** to share new advancements, including AI detecting breast cancer
- The blogs served to provide **accurate information and prevent treatment misinformation**

Twitter/X (31%)
- HCPs predominantly utilized Twitter/X to raise disease awareness by highlighting **risk factors like smoking and alcohol consumption**
- HCPs also engaged in discussions about **recent clinical trials** and upcoming advancements related to topics such as **'Irradiation and Breast conserving surgery'** and **'pausing therapy for conceiving and its associated risk of recurrence'**
- Patients used Twitter/X to share their personal stories and **encourage their peers to make mammography** a routine practice

Facebook (13%)
- Community pages like **'Tumore al seno'** were rich in patient conversations where individuals **sought advice** from their peers and **shared their experiences** in managing the disease
- Patients were **comfortable discussing their concerns regarding bodily changes,** such as breast appearance or nipple discharge
- Patients shared their stories through various modes, including **text, pictures, and videos**

Instagram/ YouTube (7%)
- Instagram served as a platform for raising awareness through the following methods:
- Providing **coverage of congress events,** such as the ESMO session on the impact of adjuvant ribociclib on HR-QoL in eBC
- Conducting **interviews with experts** on various topics, including the mental aspects for patients with eBC
- **Local patient support groups shared testimonials from patients on YouTube,** shedding light on issues like delayed diagnosis and undergoing multiple tests

Prominent reporter type — 🔴 Patient — 🟡 Caregiver — ⚪ HCP — 🔵 Patient support group/Online peer
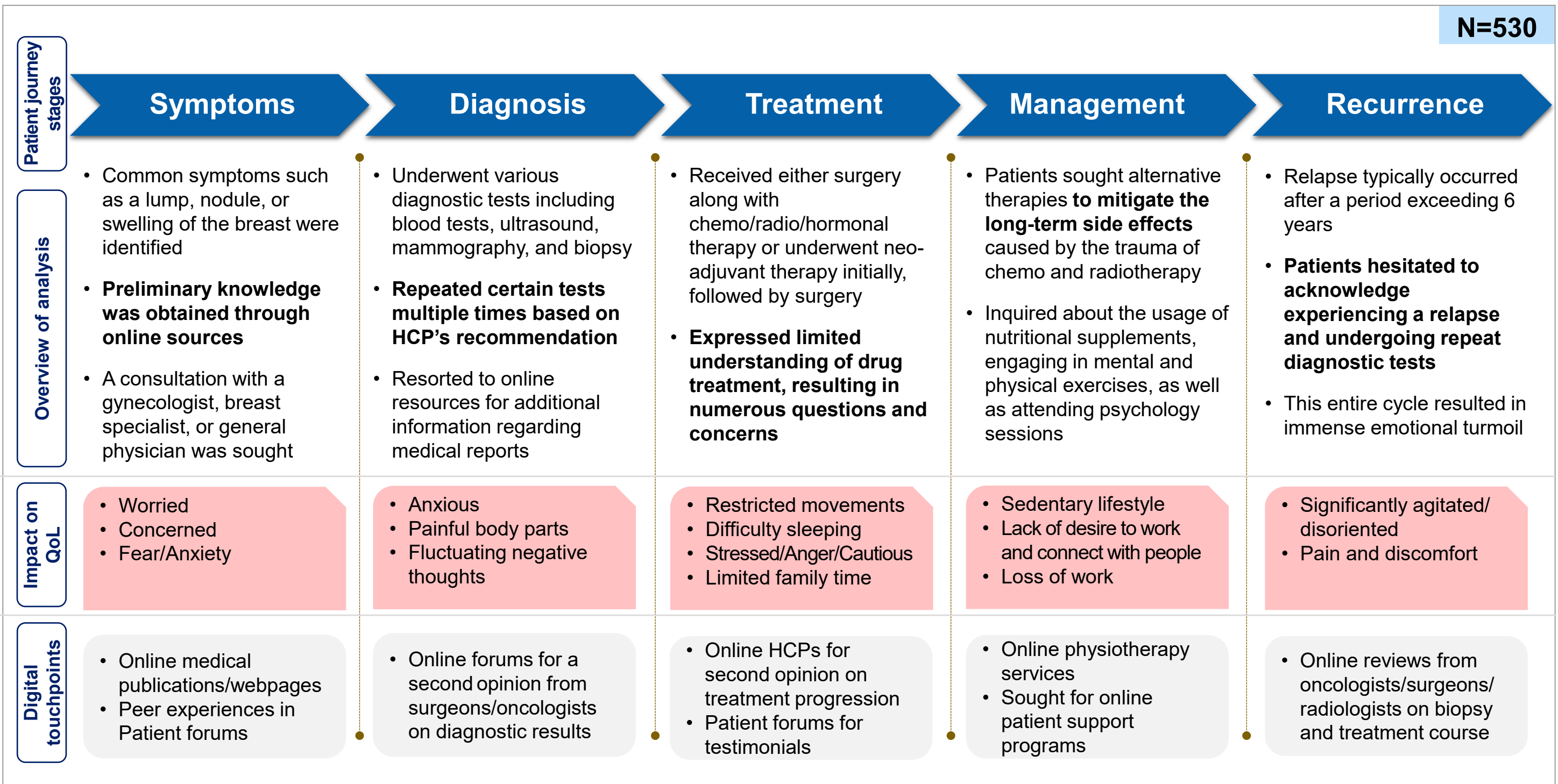
The size of the circle indicates the prominence of reporter types within respective social media channels. A larger circle size represents a greater number of posts

Insights from SML at various stages of eBC patient journey

Patients had limited depth in their knowledge to navigate the disease journey. They were active on online channels to seek peer experiences to overcome the challenges. Analysis of SML data helped to uncover the insights at various stages of patient journey starting from symptom identification to diagnosis, treatment, management and recurrence of the disease (**Figure 4**).

Figure 4. Patient journey with eBC

N=530

Patient journey stages	Symptoms	Diagnosis	Treatment	Management	Recurrence
Overview of analysis	• Common symptoms such as a lump, nodule, or swelling of the breast were identified • **Preliminary knowledge was obtained through online sources** • A consultation with a gynecologist, breast specialist, or general physician was sought	• Underwent various diagnostic tests including blood tests, ultrasound, mammography, and biopsy • **Repeated certain tests multiple times based on HCP's recommendation** • Resorted to online resources for additional information regarding medical reports	• Received either surgery along with chemo/radio/hormonal therapy or underwent neo-adjuvant therapy initially, followed by surgery • **Expressed limited understanding of drug treatment, resulting in numerous questions and concerns**	• Patients sought alternative therapies **to mitigate the long-term side effects** caused by the trauma of chemo and radiotherapy • Inquired about the usage of nutritional supplements, engaging in mental and physical exercises, as well as attending psychology sessions	• Relapse typically occurred after a period exceeding 6 years • **Patients hesitated to acknowledge experiencing a relapse and undergoing repeat diagnostic tests** • This entire cycle resulted in immense emotional turmoil
Impact on QoL	• Worried • Concerned • Fear/Anxiety	• Anxious • Painful body parts • Fluctuating negative thoughts	• Restricted movements • Difficulty sleeping • Stressed/Anger/Cautious • Limited family time	• Sedentary lifestyle • Lack of desire to work and connect with people • Loss of work	• Significantly agitated/ disoriented • Pain and discomfort
Digital touchpoints	• Online medical publications/webpages • Peer experiences in Patient forums	• Online forums for a second opinion from surgeons/oncologists on diagnostic results	• Online HCPs for second opinion on treatment progression • Patient forums for testimonials	• Online physiotherapy services • Sought for online patient support programs	• Online reviews from oncologists/surgeons/ radiologists on biopsy and treatment course

'N' denotes the number of posts; HCP: Healthcare professional; QoL: Quality of life

CONCLUSION

SML as a research methodology provided a unique opportunity for deeper understanding of experiences and concerns of patients with eBC, their caregivers, and HCPs. The findings will empower HCPs and researchers for enabling more patient-centric care and improved health outcomes.

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