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Real-World Patient and Caregiver Experiences With Breast Cancer Risk of Recurrence in the US: Results of an Online Survey and Social Media Analysis

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KEY FINDINGS & CONCLUSIONS

- These analyses demonstrate that patients prioritize reducing ROR yet lack sufficient information and understanding about ROR
  - Understanding of ROR is especially important for patients with HR+/HER2− EBC whose risk includes early and late recurrence, a majority of which are metastatic recurrences[1]
- Patients express concern about ROR and rank limiting the risk of metastasis and living as long as possible as their highest expectations of breast cancer treatment
- When ranking expectations of BC therapies, patients also prioritize reducing ROR and receiving treatments with well-managed side effects with minimal impact of their daily life
  - Patients with HR+/HER2− EBC feel that they have less access to support services that could potentially help build their knowledge and understanding of ROR
- These analyses further elucidate the need for educating patients about ROR within shared decision-making conversations with HCPs along with the need for more emotional support services, which will aid in providing a better balance between patients' fear and empowerment

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INTRODUCTION

- Patients with hormone receptor–positive (HR+)/human epidermal growth factor receptor 2–negative (HER2−) early breast cancer (EBC) remain at risk of early (≤5 years) and late (>5 years) disease recurrences despite standard-of-care adjuvant endocrine therapy[1-3]
  - Up to 27% of all patients with BC will recur within 10 years of diagnosis, particularly if initially diagnosed at stage II or III where recurrence rates are 41% and 63%, respectively[1,4]
- Currently, there is little published evidence related to the concerns of patients and caregivers concerning risk of recurrence (ROR)
- Lack of awareness about ROR has considerable impact on patient and caregiver quality of life, which may result in emotional distress from being unprepared about the true ROR
- Here, we present important insights on ROR through the combined results of an online patient survey and subsequent social media analysis (SMA) of patients and caregivers

RESULTS

- Of the 220 US patients who responded to the Carenity online patient and caregiver community survey, 57 (26%) reported being diagnosed with HR+/HER2− BC, 86 (39%) with HER2+ BC, and 49 (22%) with triple-negative BC (TNBC) (**Table 1**)
  - Among patients with HR+/HER2− BC, 38 (67%) were initially diagnosed with EBC (stage I-III)
  - Of those patients initially diagnosed with EBC, 11 (29%) recurred as metastatic BC
- A screen of 3440 posts in the SMA found 1622 relevant to EBC and ROR (**Figure 1**); 279 (36%) reported a diagnosis of HR+/HER2− BC, 5% HER2+ BC, and 20% TNBC
  - 82% of online conversations were driven by patients (**Table 2**)

Table 1. Survey: US Patient Sociodemographic and Clinical Profile

Participant characteristics, n (%)	Female patients with BC in the US N = 220
Age, n (%)	
<41 years	16 (7)
41-50 years	47 (21)
51-60 years	39 (18)
61-70 years	49 (22)
>70 years	7 (3)
Age of diagnosis, n (%)	
<41 years	72 (33)
41-50 years	55 (25)
51-60 years	33 (15)
>60 years	53 (24)
Menopausal status, n (%)	
Premenopausal	110 (50)
Postmenopausal[a]	110 (50)
Stage at diagnosis, n (%)	
I/II	114 (52)
III	63 (29)
IV	41 (19)
Don't know	2 (1)
Breast cancer subtype at diagnosis, n (%)	
HR+/HER2−	57 (26)
HR−/HER2+	13 (6)
HR+/HER2+	73 (33)
HR−/HER2−	49 (22)
Don't know[b]	28 (13)
Treatments previously received, n (%)	
Radiotherapy	106 (48)
Chemotherapy	87 (40)
Endocrine therapy	64 (29)
Immunotherapy	39 (18)
CDK4/6 inhibitor therapy	34 (15)
Anti-HER2 targeted therapy	56 (25)
Other targeted therapy	20 (9)
Treatments currently received, n (%)	
Radiotherapy	72 (33)
Chemotherapy	54 (25)
Endocrine therapy	91 (41)
Immunotherapy	32 (15)
CDK4/6 inhibitor therapy	32 (15)
Anti-HER2 targeted therapy	22 (10)
Other targeted therapy	28 (13)

[a] Includes 55 patients with chemically induced menopause. [b] Includes 3 patients with unknown HR status, 9 with unknown HER status, and 16 with unknown status for each biomarker.

Table 2. US Patient Demographics in the SMA

Demographics as reported in online posts	Patients and caregivers who posted online N = 1886
Reporter type	N = 1622
Patients	1330 (82)
Caregivers	292 (18)
Posts with age mentioned, n	n = 189
Age, n (%)	
20-30 years	28 (15)
31-40 years	148 (78)
41-50 years	114 (60)
51-60 years	74 (39)
61-70 years	39 (21)
>70 years	18 (10)
Posts with cancer subtype mentioned, n	n = 781
Breast cancer subtype at diagnosis, n (%)	
HR+/HER2−	279 (36)
TNBC	154 (20)
HR+	102 (13)
ER+	97 (12)
TPBC	62 (8)
HER2+	36 (5)
ER+/HER2−	14 (2)
Others	37 (5)
Posts with current disease stage mentioned, n	n = 681
Current disease stage, n (%)	
0	13 (2)
0/I	2 (0.3)
I	180 (26)
I/II	4 (1)
II	129 (19)
II/III	3 (0.4)
III	109 (16)
IV	156 (23)
Relapse (unidentified stage)	85 (12)
Tumor grade and nodal status mentioned, n	n = 145
Tumor grade and nodal status, n (%)	
Grade 1	21 (14)
Grade 2	30 (21)
Grade 2/3	4 (3)
Grade 3	46 (32)
N0	38 (26)
N1	2 (1)
N negative	4 (3)

ER, estrogen receptor; TPBC, triple-positive breast cancer.

Information on ROR Provided to Patients

- In the Carenity survey, patients responded to questions on whether they received relevant information from their healthcare provider (HCP) at the time of their initial diagnosis (**Figure 2**)
  - Many of the 57 patients initially diagnosed with HR+/HER2− EBC wished they had received more relevant information on chances/duration of survival (18/57 [32%]) or emotional support options (15/57 [26%])

METHODS

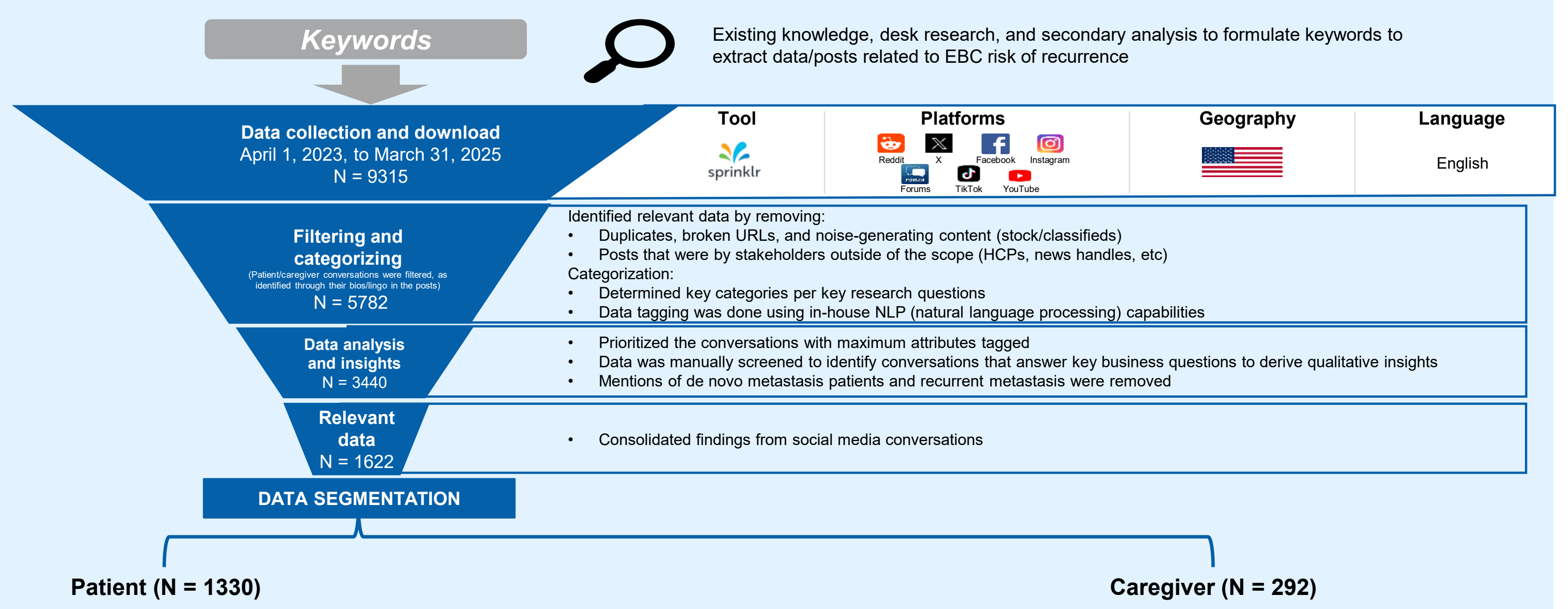
Online Patient Survey

- The patient questionnaire was developed with input from the authors (including medical experts and patient advocates); and the methodology was locally approved in each participating country and approved by an institutional review board
- Patients with BC from the Carenity BC online patient and caregiver community and other BC focus groups were invited to participate in the online survey on the Carenity platform
- Female patients (age, >18 years) with BC and disease stage knowledge (early or metastatic) living in France, Germany, Italy, UK, or the US were eligible to participate.100% of respondents were from developed countries, and most had access to places of care
- The survey was conducted between December 1, 2021, and January 24, 2022

SMA

- Deidentified data from publicly available social media posts by US patients and caregivers on social media sites, forums, and blogs between April 1, 2023, and March 31, 2025, were analyzed using the Sprinklr social media aggregator (**Figure 1**)

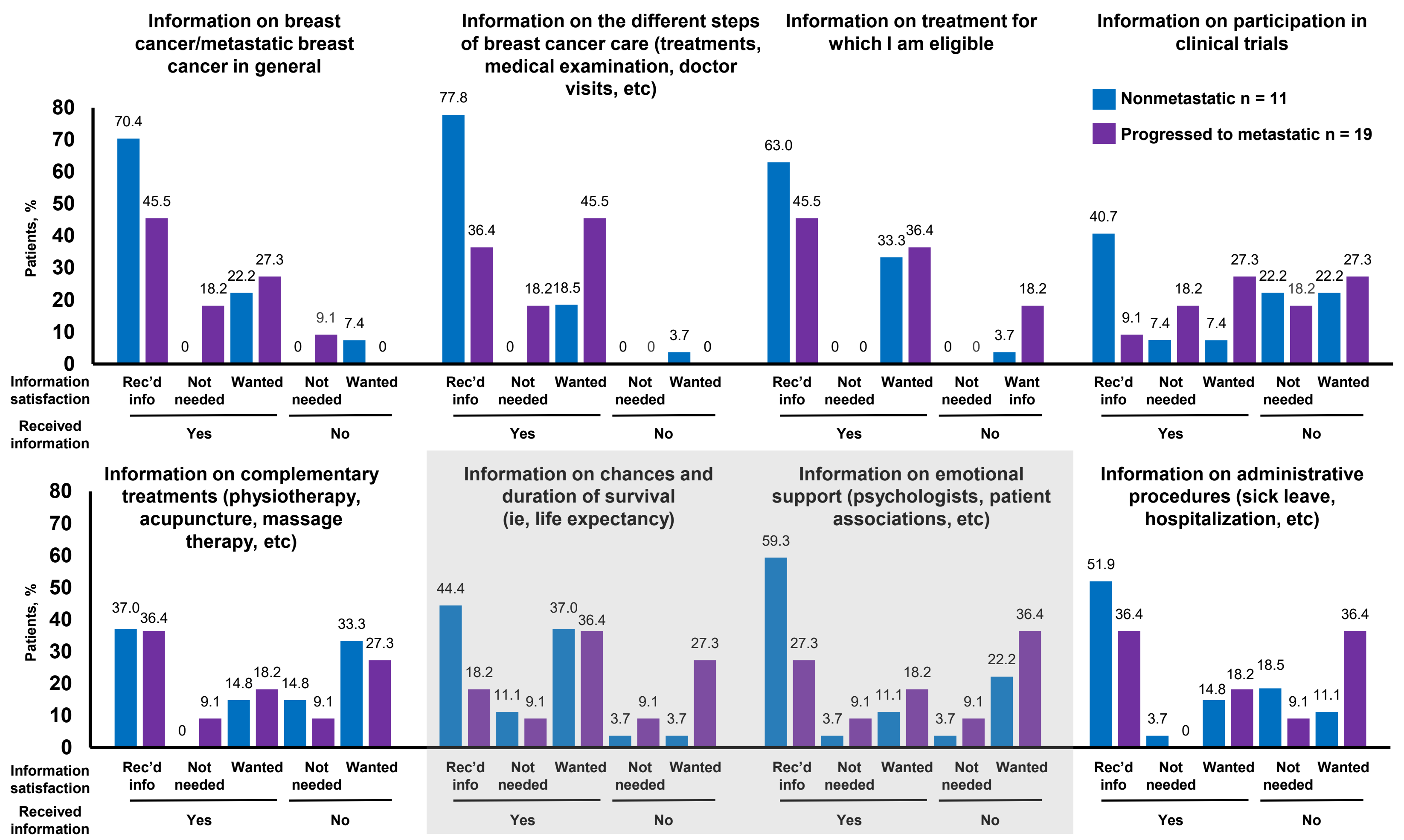
Figure 1. SMA Methodology



Information on ROR Provided to Patients (cont)

- Of the patients initially diagnosed with HR+/HER2− EBC who wanted more information at diagnosis, some indicated they received no information at diagnosis on chances/duration of survival (4/18 [22%]) and emotional support options (10/15 [67%])
- Many patients who went on to experience a metastatic recurrence indicated that they had not received information on chances/duration of survival (3/4 [75%]) or emotional support options (4/10 [40%]) at the time of their initial diagnosis but would have liked to have received more information at that time
- The findings of the survey were reinforced by the SMA, which identified recurrence rate and peer support as topics patients wanted to receive more information on

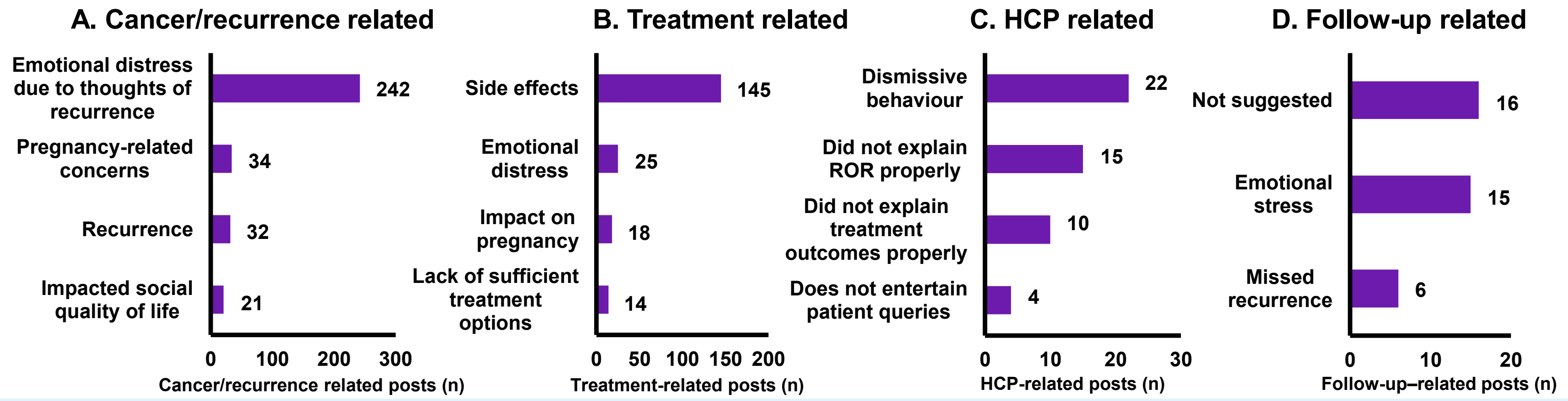
Figure 2. Survey: Information Given to US Patients with HR+/HER2− EBC at First Diagnosis



Patient Concerns Identified in the SMA

- The SMA identified posts that highlighted patient and caregiver concerns about late recurrences, limited long-term monitoring, and persistent worries about unexpected recurrences (**Figure 3**)
  - Patients also expressed feelings of being overwhelmed by the fear of BC recurrence in their posts

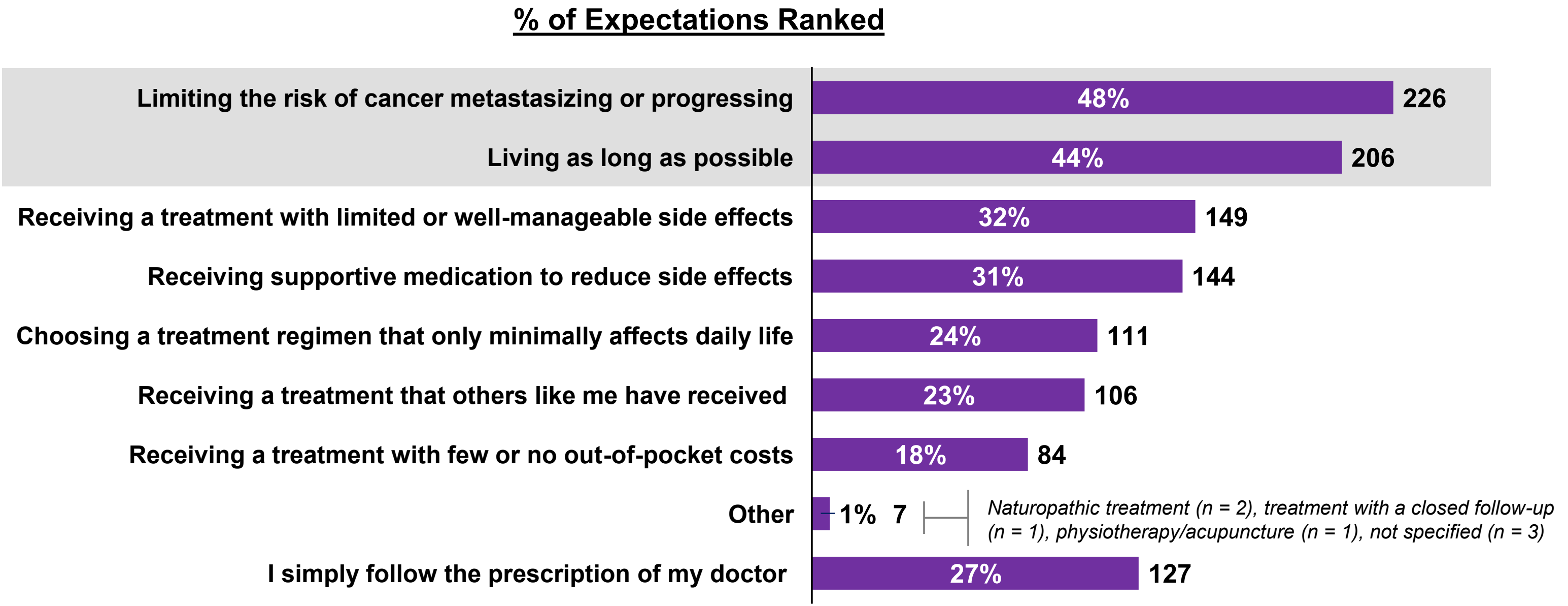
Figure 3. Concerns Expressed in Social Media Posts



Patient Expectations Regarding BC Treatment

- Limiting risk of cancer metastasis (mean rank, 1.8) and living as long as possible (mean rank, 1.9) ranked high among treatment expectations of patients who responded to the Carenity survey (**Figure 4**)
- Similar themes emerged from the SMA, in which lowering ROR was identified as one of the top aspects that lead to a positive perception of available treatments

Figure 4. Survey: Ranking of Patients' Expectations Regarding BC Treatment[a]



[a] Sample size: 467 respondents who have received at least one treatment for their breast cancer.

Access to Services and Support Programs

- Patients with HR+/HER2− BC responding to the Carenity survey felt they had less access overall to services and support programs compared with access reported by patients with HER2+ BC or TNBC (**Table 3**)

Table 3. Survey: Access to Services and Support Programs

	Lifestyle and nutrition programs	Emotional and psychological well-being	Self-image	Access to complementary/ alternative therapies	Interaction with other patients	Support from a professional caregiver	Apps/ wearables	Access to BC resources
HR+/HER2− (n = 57)								
Access, n (%)	41 (71.9)	33 (57.9)	32 (56.1)	23 (40.4)	40 (70.2)	22 (38.6)	24 (42.1)	46 (80.7)
No access, n (%)	16 (28.1)	24 (42.1)	25 (43.9)	34 (59.6)	17 (29.8)	35 (61.4)	33 (57.9)	11 (19.3)
HER2+ (n = 86)								
Access, n (%)	68 (79.1)	64 (74.4)	52 (60.5)	42 (48.8)	55 (64.0)	46 (53.5)	38 (44.2)	73 (84.9)
No access, n (%)	18 (20.9)	22 (25.6)	34 (39.5)	44 (51.2)	31 (36.0)	40 (46.5)	48 (55.8)	13 (15.1)
HR−/HER2− (n = 49)								
Access, n (%)	40 (81.6)	39 (79.6)	38 (77.6)	37 (75.5)	36 (73.5)	34 (69.4)	34 (69.4)	45 (91.8)
No access, n (%)	9 (18.4)	10 (20.4)	11 (22.4)	12 (24.5)	13 (26.5)	15 (30.6)	15 (30.6)	4 (8.2)

Patients' Concerns Regarding ROR

- In online posts, patients discussed challenges and stressors associated with the lack of ROR knowledge within their existing support systems (**Figure 5**)

Figure 5. Examples of Patients' Concerns Regarding ROR in Social Media Posts

> *"How many years has it been, did it ever come back? It's so hard to find research about recurrence without chemo."*

> *"Honestly, I did not know how common a recurrence was. I only thought that it was breast cancer, then metastatic breast cancer."*

> *"I have also recently found out that ER+ has a lower recurrence in the first 5 years but after that increases each year. I was never told this before."*

> *"I have recently read anywhere from 20% to 40% recurrence. No one talked to me about this stuff years ago, only survival rates.*

References 1. Early Breast Cancer Trialists' Collaborative Group. *Lancet.* 2024;404(10461):1407-1418. 2. Pederson RN, et al. *J Natl Cancer Inst*. 2022;114(3):391-399. 3. Curigliano G, et al. *J Clin Oncol*. 2023;42(16 suppl). 4. O'Shaughnessy J et al. Cancer Res (2023) 83 (5_Supplement): P3-03-12.

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