The BRAVE Study: Exploring the pathways to a breast cancer diagnosis from the perspectives of young survivors in California

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BRAVE
BREAST CANCER IN YOUNG WOMEN: AWARENESS, VIEWS, EXPERIENCES

BACKGROUND

- Incidence of breast cancer is on the rise in young women (i.e., women under age 40); data from the Surveillance, Epidemiology, and End Results Program (SEER) show a significant 0.68% annual increase in young women versus no significant change in older women.
- Young women are more likely to be diagnosed with advanced stage breast cancer and have poorer prognoses; SEER data indicate that 7.30% of all breast cancers in young women were distant stage versus 4.99% in older women.
- Timely diagnosis is critical, but studies have shown that young women are more likely to experience breast cancer diagnostic delays; Stuver et al (2011) found women ages 18-39 were 39% more likely to experience a delay of more than 90 days, and Partridge et al (2012) found 35.2% of young women experienced a delay of more than 60 days versus 25.2% of older women.
- Understanding the barriers and facilitators to a timely diagnosis in young women is crucial, which no study in the U.S. to our knowledge has explored.
- Since a timely diagnosis stems from the patient as well as the provider, both perspectives need to be explored.
- Young women constitute an important population to study since they currently have limited and conflicting breast cancer screening guidelines and face unique life challenges.
- Objective: To explore the pathways to a breast cancer diagnosis in young women from the perspectives of young survivors.

METHODS

Eligibility
- Female, received a primary breast cancer diagnosis in CA before age 40 and within the last 10 years, current age 18-49, resides in CA, proficient in English.

Recruitment
- Leveraged partnership with The Young Breast Cancer Project (https://www.youngbreastcancer.org/) who outreached to its members and community partners, advertised on social media, and promoted the study at events and conferences.

Study Design
- Conducted two semi-structured focus groups (current age 30-39, 40-49) in March and April 2025 as part of the Breast Cancer in Young Women: Awareness, Views, Experiences (BRAVE) Study.
- Administered questionnaires that included questions about demographics, tumor characteristics, and risk factor profiles (e.g., family history, reproductive factors, lifestyle behaviors).
- Each focus group was 90 minutes and took place on Zoom.

Final Study Population
- 16 young breast cancer survivors

Analysis
- Each focus group was recorded, transcribed, and coded.
- Memos were written by all team members who were present at each focus group.
- Analysis was conducted using NVivo 15 to identify emergent themes, which were then iteratively discussed with the research team.

Table 1. Participant characteristics

	Total (n=16)
Current Age	
Mean (standard deviation)	39 (3.76)
Age at Diagnosis	
Mean (standard deviation)	35 (3.62)
Racial Group	
White/Caucasian	3 (18.75%)
Latina	5 (31.25%)
Asian American	4 (25.00%)
Black/African American	1 (6.25%)
American Indian	1 (6.25%)
Mixed	2 (12.50%)
Education	
Some college/community college	3 (18.75%)
Four-year college	6 (37.50%)
Graduate school or more	7 (43.75%)
Tumor Subtype	
HR+/HER2+	3 (18.75%)
HR+/HER2-	10 (62.50%)
HR-/HER2+	2 (12.50%)
HR-/HER2-	1 (6.25%)
Tumor Stage	
Stage 1	5 (31.25%)
Stage 2	5 (31.25%)
Stage 3	4 (25.00%)
Stage 4	2 (12.50%)
First-degree Family History	
Yes	4 (25.00%)
No	12 (75.00%)
Positive for Genetic Mutation	
Yes	3 (18.75%)
No	12 (75.00%)
Did not receive genetic testing	1 (6.25%)
Physician Talked about Breast Health	
Yes	8 (50.00%)
No	8 (50.00%)
Received Clinical Breast Exam	
Yes	12 (75.00%)
No	4 (25.00%)
Performed Breast Self-Exam	
Yes	13 (81.25%)
No	3 (18.75%)
Used Hormonal Contraceptives	
Yes	11 (68.75%)
No	5 (31.25%)
History of Alcohol Consumption	
Yes	7 (43.75%)
No	9 (56.25%)
History of Smoking	
Yes	1 (6.25%)
No	15 (93.75%)
Body Mass Index	
<25 kg/m^2	9 (56.25%)
25 to <30 kg/m^2	4 (25.00%)
30+ kg/m^2	3 (18.75%)

Three Emergent Themes

1 Survivors consistently felt the need and the sense of urgency to self-advocate

- Self-advocacy was often triggered by provider dismissal.
- Survivors described creative strategies to obtain care (e.g., calling daily for cancellations, going out-of-network, paying out-of-pocket).
- Took an emotional toll on the survivors (e.g., feelings of fear, frustration).

> "Whatever you need to say to get in there…that's what I promote and tell people." (White, 38)

> "So I tried another location, same response. And I even went outside of that network to get an image…these facilities are just not helping me." (Black, 39)

> "If this is something that keeps concerning me, I'm going to have to be the one that says something." (White, 33)

2 Survivors' perception that their initial symptoms were dismissed or minimized

- Survivors linked dismissal to age bias and lack of provider education on young-onset breast cancer.
- Survivors often internalized the dismissals and delayed further action until symptoms worsened.
- Dismissal appeared to be more pronounced when interacting with primary care providers than obstetrics/gynecology (OB/GYN) providers.

> ""I went to an ultrasound [and] the doctor…saw nothing. He literally just threw the wipe at me and said…I'll see you when you're 40." (White, 33)

> ""I was just pretty annoyed with…every doctor [telling me] 'Well, you're young, you're fit',…And I'm just sitting there like 'Okay…well, now what? What else do you want me to say?" (Latina, 33)

> "The nurse practitioner [was] gaslighting me about it. She [said], just wait. It's probably hormonal…" (Latina, 42)

3 OB/GYN providers are gatekeepers for breast health

- OB/GYN visits were often the only point-of-contact for preventive care during reproductive years.
- Survivors expressed that OB/GYN providers should be better trained to recognize breast cancer symptoms in young women and integrate breast health education into annual visits.

> "My primary dismissed it, saying it's hormonal…But then I went to my OB/GYN. Just for a yearly, I expressed my concerns to her and she was my champion." (Latina, 42)

> ""Yes, I heard about it from my OB/GYN about doing like a breast exam, self-exam, but I…didn't really do it. I kind of just expected…my OBGYN to do it." (Latina, 41)

> "I still don't know what I'm checking for, but that's all they ever told me was just…check yourself every month and look for signs of stuff…" (Black, 39)

CONCLUSIONS

- Timely diagnosis of breast cancer in young women appears to be impacted by patients' persistence and ability to self-advocate as well as healthcare providers' receptiveness to take further diagnostic steps despite patients' risk profiles indicating otherwise.
- The role of OB/GYNs when it comes to timely diagnosis may be especially important since they often serve as young women's primary point-of-contact for health concerns.

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