

# Targeted Strategies to Engage Young Breast Cancer Survivors in Education and Support Services

Elana Silber, MBA<sup>1</sup>, Adina Fleischmann, LSW<sup>1</sup>, Andrea C. Johnson, MPH, CHES<sup>2</sup>, Sarah E. Murphy, BA<sup>2</sup>, & Kenneth P. Tercyak, PhD<sup>2</sup>  
<sup>1</sup>Sharsheret, Teaneck, NJ 07666, USA <sup>2</sup>Georgetown Lombardi Comprehensive Cancer Center, Washington, DC 20007, USA

## Background

Young Jewish women are highly susceptible to breast cancer given the prevalence of breast cancer-causing founder mutations in the population. One in 40 Jewish Ashkenazi women carries a BRCA gene mutation, nearly 10 times the rate of the general population. Sharsheret, a non-profit organization dedicated to serving women of all Jewish backgrounds at risk of or surviving cancer, offers education and support programs and services to young breast cancer survivors (YBCS) and other groups, and gathers feedback about its targeted engagement strategies.

## Methods

This is a secondary analysis of resource outcome data collected by Sharsheret as part of a continuous quality improvement initiative for YBCS (age  $\leq 45$ ) programming.

Women who contacted the organization were invited to complete a quantitative survey in 2013 and 2014 about their utilization of Sharsheret's programs and services: respondents were also asked to provide demographic and clinical information, and ratings of resource satisfaction.

There were 9 evaluated resources, including genetic education, peer support, educational materials/seminars, and survivorship interventions. Descriptive statistics were generated, and  $X^2$  tests of association were used to distinguish women who were Low ( $\leq 2$  resources) vs. High users ( $> 2$  resources) of Sharsheret resources.

In follow-up, focus groups were conducted in 2015 with YBCS and their caregivers about their experience utilizing Sharsheret's resources. These sessions were audio-recorded, verbatim transcribed, and subjected to thematic coding to determine key themes of interest.

## Results

Survey respondents (N=296) had a M age of 49.9 years (SD=10.7), 20% were YBCS, 72% were married or in a partnered relationship, 92% affiliated as being Jewish, and 73% were raising children. Of those women with children, 66% were raising minor-age children. Clinically, 70% were breast/ovarian cancer survivors and 28% were carriers of a high risk genetic mutation for breast cancer or self-identified as at-risk. Regarding resource utilization, 24% of respondents utilized only 1 resource, 27% utilized 2 resources (Low=52%), 22% utilized 3 resources, and 26% utilized 4+ resources (High=48%) (See Table 1).

Number of Resources N (%) (N = 296)	Overall	2013 Respondents	2014 Respondents
1 Resource	72 (24.32)	32 (26.67)	40 (22.73)
2 Resources	81 (27.36)	31 (25.83)	50 (28.41)
3 Resources	65 (21.96)	27 (22.50)	38 (21.59)
$\geq 4$ Resources	78 (26.35)	30 (25.00)	48 (27.27)

Table 1: Multiple Resource Utilization, by Year

At the bivariate level, resource utilization did not differ by whether or not women were YBCS, but did differ by referral source and being newly diagnosed with breast cancer at the time of initial contact. Specifically, among High users, 45% were referred to Sharsheret by family/friends or other Sharsheret constituents (33% among Low users;  $X^2[1]=5.08$ ,  $p=.02$ ) and 59% were newly diagnosed (27% among Low users;  $X^2[1]=30.9$ ,  $p=.00$ ) (See Chart 1). Well-utilized and commonly bundled resources were peer support, educational materials/seminars, and survivorship interventions. High users indicated greater satisfaction with several of the resources they utilized. Qualitatively, the N=15 focus group respondents noted enhancing resources and targeted programs and services across the cancer trajectory (from risk to survivorship) as a prominent theme.

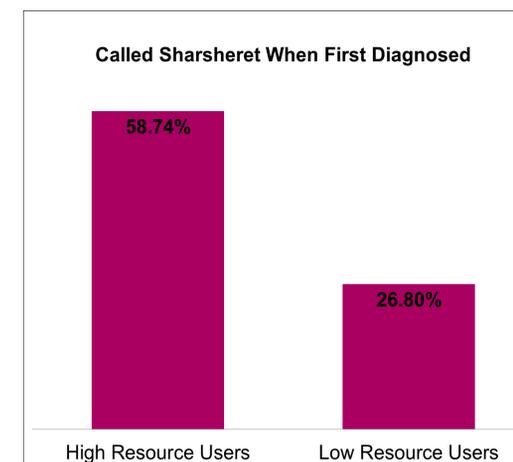
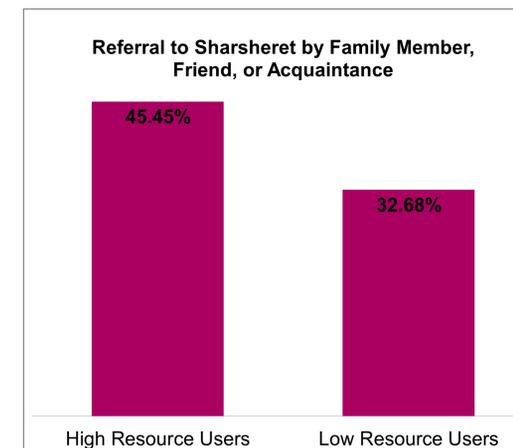


Chart 1: Bivariate Level Resource Utilization

## Conclusion

The results suggest that ~50% of Jewish women seeking culturally-relevant education and support about cancer utilize multiple resources along their journey, and that family/friends are an especially influential source of referral at the time of diagnosis. Scaling-up resources for YBCS can be enhanced by a greater focus on women at different stages in the cancer trajectory, and by reaching them at time of diagnosis. This can be accomplished by bundling closely-related programs and services and anticipating YBCS needs over time as they transition into survivorship.