

Meeting the Information and Psychosocial Needs of Young Jewish Women at Increased Risk for or Diagnosed with Breast Cancer

Elana Silber¹, MBA; Adina Fleischmann¹, LSW; Rochelle Shoretz¹, JD; Andrea C. Johnson, MPH²; Sarah E. Murphy, BA²; Darren Mays, PhD, MPH²; Suzanne C. O'Neill, PhD²; Kenneth P. Tercyak, PhD²

¹Sharsheret and ²Division of Population Sciences, Lombardi Comprehensive Cancer Center, Georgetown University Medical Center

San Antonio Breast Cancer Symposium – December 8-12, 2015

Abstract

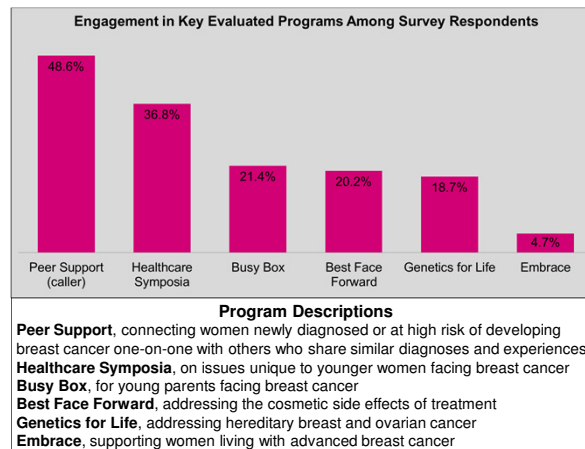
Approximately 12% of women living in the United States will be diagnosed with breast cancer during their lifetimes. Although breast cancer survival rates are improving, there remain significant impacts upon women's length and quality of life. This includes women already diagnosed with the disease, as well as those who are at increased risk owing to hereditary breast cancer-causing mutations (e.g., *BRCA1/2* genes). While all women face formidable challenges posed by the threat of living with or being at increased risk for breast cancer, those of Ashkenazi and Central or Eastern European Jewish descent face additional challenges owing to higher *BRCA1/2* mutation prevalence in this population. Amidst calls for population-based screening for hereditary breast cancer risk, much can be learned from the experiences of young Jewish women at risk for and surviving with breast cancer about their information and psychosocial needs.

Methods

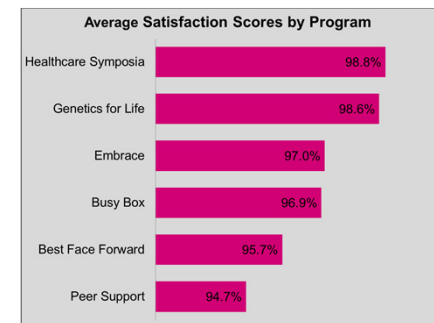
The present study is a secondary analysis of survey data from 2010 to 2014 originally collected by Sharsheret, a non-profit organization dedicated to serving women of all Jewish backgrounds facing or at risk for breast cancer. The evaluation included measures and metrics of community referral practices, social service/program engagement and satisfaction, and resource needs among the target population (*N*=555). Only survey items administered across all data collection years were analyzed.

Results

Respondents had a *M* age of 50 years and ~90% identified as Jewish. Over 1/3 were referred to the organization by family or friends, most often after a breast cancer diagnosis. Within the surveyed population, 25% reported being at risk or confirmed carriers of a *BRCA1/2* mutation. Of the education and support programs offered, the greatest level of engagement occurred in the 1-on-1 peer emotional support and health care symposia education programs. Women reported very high levels of satisfaction with the programs and services available, sought additional information and social support services, and noted a strong desire to give back to the community by participating as a peer supporter.



Importantly for this high-risk population, women who participated in the organization's breast cancer genetics program were >98% satisfied (on average) with the various evaluated components of the program. Women identified genetic risk information as one of their top needs for future engagement.



Conclusions

These data affirm success of the organization's programs, especially in educating Jewish women about breast cancer genetics. Genetic information is increasingly salient among members of the Jewish community, extending to their cultural needs and need for peer support. Women likely responded well to Sharsheret's peer support program as it connects women to those with similar backgrounds, including culture, lifestyle, and medical similarities. Implications of these findings assert that culturally-relevant information and psychosocial services for young Jewish women living with or at risk for breast cancer can be enhanced for larger dissemination to meet the expected growing demand in this high risk community.