



A Not-For-Profit Model of Survivorship Care and Navigation to Facilitate Care Planning for Young Breast Cancer Survivors

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SHARSHERET: Your Jewish Community Facing Breast Cancer



INTRODUCTION

About 11% of new breast cancer cases in the United States are found in women younger than 45. Young breast cancer survivors face challenges impacting their quality of life, psychosocial functioning, and reproductive health outcomes, and often lack care plans to address these challenges. By 2015, the American College of Surgeons Commission on Cancer's accreditation standards will call for certified cancer centers to provide a treatment summary and follow-up plan to all cancer survivors. There is a pressing need for the development of collaborative and cost-effective tools to facilitate the implementation of these survivorship care plans for a growing population of survivors. With funding from the Centers for Disease Control and Prevention, Sharsheret developed Thriving Again, a breast cancer support program that includes survivorship care plans and personalized navigation for young breast cancer survivors (YBCS) diagnosed age <45.

METHODS

In developing Thriving Again, staff clinicians engaged in a comprehensive assessment of YBCS and available resources to identify the support and education needs of Jewish YBCS. Methods included:

- **Literature Review** of more than 120 articles on programming, research, and best practices to address the needs of Jewish YBCS or survivors of specific cultural and religious backgrounds.
- **Key Informant Interviews** with organizational and community leaders who work with YBCS and identified emerging trends in the field, as well YBCS needs. Key informants represented non-profit breast cancer professionals, surgeons, researchers, oncologists, oncology nurses, oncology social workers, and YBCS.
- **Focus Groups** of 45 YBCS.
- **National Survey** in print and online of more than 1,400 breast cancer survivors across the 50 states who highlighted and prioritized survivorship needs, including information gaps and preferred resources.

Sharsheret collaborated with more than 40 national partners to distribute the survey, including non-profits, hospitals, support groups, and national organizations. Surveys were available to complete in written form, online, via Facebook, QR code, and by telephone.

National Survey of Breast Cancer Survivors:
Priority Needs of YBCS

Information or Support Needs	% Respondents Rated "Very Important" or "Important"
Information about bone health	82.7%
Understanding breast cancer medical terminology	79.9%
Understanding and managing fear of recurrence	78.6%
Understanding my "new normal"	77.2%
Understanding the genetic component to some breast cancers	76.2%
Understanding the importance of weight management as a survivor	75.9%
Processing my breast cancer experience	75.5%
Understanding what "survivorship" means to me	74.2%
Understanding and managing fatigue	72.3%
Understanding pre-existing conditions and insurance	72%

Exhibit A: Priority Needs of YBCS

RESULTS

A review of the literature addressing YBCS revealed a gap in research addressing the information and support needs of young survivors, and further gaps in resources specific to Jewish YBCS at increased risk of mutations in the BRCA1 and BRCA2 genes. Key informant interviews, focus groups, and a survey of more than 1,400 YBCS identified the priority information needs of Jewish YBCS (Exhibit A). With that information, Sharsheret developed Thriving Again, a culturally-relevant survivorship program for Jewish YBCS that provides clinical support and education resources for survivors and their families.

The Thriving Again program includes three core components:

1. A **customizable survivorship kit** of tools mailed to YBCS, including a survivorship care plan, tailored resources, choice of fitness DVD, and choice of cookbook (kosher or non-kosher) (Exhibit B). Tailored resources include information addressing genetics, employment/insurance, parenting, health and well-being, relationships and intimacy, nutrition, smoking and alcohol cessation, fear of recurrence, lymphedema, fertility and pregnancy, using the Mikvah (Jewish ritual bath) during treatment, and exercise after chemotherapy, radiation and/or hormonal therapy.
2. **Survivor navigation** with a member of Sharsheret's clinical staff.
3. **Teleconferences** addressing key survivorship issues.

Through Thriving Again, YBCS can also access Sharsheret's core support and education programs, including:

- **Genetics For Life**, a support and education program for those at risk for hereditary breast, ovarian cancer, or related cancers.
- **Peer Support Network**, a national network of more than 3,000 YBCS with whom participants can connect to share experiences confidentially.

Through Thriving Again, Sharsheret has, to date:

- Distributed more than **1,200 Thriving Again kits** to breast cancer survivors in 48 states.
- Conducted more than **700 individual navigation appointments** with YBCS, guiding them through survivorship care plans and customizing their kits with tailored information and resources.
- Presented **four teleconferences** addressing YBCS needs identified during the comprehensive assessment, including:
 - Am I a Survivor? What You Need to Know About Breast Cancer Survivorship (January 2013)
 - It's Complicated: Understanding and Managing Relationships as a Breast Cancer Survivor (May 2013)
 - Breast Cancer Survivors: What You Need to Know About Recent Developments in Genetics (October 2013)
 - Breast Cancer Survivors and the Long Term Effects of Breast Cancer Treatment (May 2014)

RESULTS (continued)



Exhibit B: Thriving Again Survivorship Kit

Sharsheret has and will continue to present its findings regarding YBCS needs to healthcare professionals seeking to establish survivorship programs. Healthcare professionals have begun to utilize the survivorship needs identified during the comprehensive assessment and the methods Sharsheret employed in developing Thriving Again to develop their own proprietary survivorship programs. Sharsheret now offers consulting services to breast centers and cancer centers, and the option for those centers to co-brand survivorship programs based on the Thriving Again model and to refer YBCS to Sharsheret's core support and education programs.

CONCLUSION

New standards in cancer care and the growing population of YBCS require health care professionals and cancer centers to identify collaborative and cost-effective tools to address the psychosocial and information needs of YBCS. Using the data gleaned from Sharsheret's comprehensive assessment of YBCS and the development of Thriving Again, researchers, clinicians, policymakers, and public health experts can collaborate to develop additional survivorship programs and materials that address the information and support needs of this unique survivor population.

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