Developing Psychosocial and Reproductive Health Support Resources for Young Breast Cancer Survivors in the United States

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 Centers for Disease Control and Prevention

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September 21-23, 2011
Key Provisions of “EARLY ACT”

• Establish an evidence-based education campaign
• Target women between **ages 15 and 44**
• **Target specific at-risk populations**
  – African American women
  – Jewish women of Ashkenazi descent
• Target messages to **health care providers**
• Prevention research
• **Survivor** support
• Establish a Federal Advisory Committee on Breast Cancer in Young Women (ACBCYW)
## Issues faced by breast cancer survivors

<table>
<thead>
<tr>
<th>Category</th>
<th>Issues</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Medical</strong></td>
<td>Recurrence, Late effects</td>
</tr>
<tr>
<td><strong>Physical</strong></td>
<td>Pain, Fatigue, Fertility</td>
</tr>
<tr>
<td><strong>Psychological</strong></td>
<td>Anxiety, Depression, Resilience, Awareness</td>
</tr>
<tr>
<td><strong>Cognitive</strong></td>
<td>Memory, Learning, Attention</td>
</tr>
<tr>
<td><strong>Social</strong></td>
<td>Relationships, Communication, Care giving</td>
</tr>
<tr>
<td><strong>Practical</strong></td>
<td>Access to care, Understanding follow-up</td>
</tr>
<tr>
<td><strong>Economic Issues</strong></td>
<td>Financial burden, Lost income, Insurance</td>
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Project Overview

• The Developing psychosocial and reproductive health support for young breast cancer survivors (YBCS) in the United States project was launched in September 2010.

• Identify, strengthen, and promote real-world, evidence-based interventions providing psychosocial and reproductive health support to young breast cancer survivors (YBCS).

• Provides programmatic support to 2 national organizations that address the needs of and provide psychosocial and reproductive health-related intervention programs for young survivors:
  – African American
  – Ashkenazi Jewish descent
Project Goals

• Identify core programmatic elements of organizations that provide psychosocial and reproductive health support to YBCS

• Identify the best methods to disseminate psychosocial and reproductive health support to YBCS

• Increase the use of evidence-based interventions

• Increase implementation of broader dissemination efforts
Project Tasks

• Assess the capacity of selected organizations to effectively develop, implement, and disseminate interventions providing psychosocial and reproductive health support for YBCS

• Identify and testing of existing programs supporting survivors

• Modify and implement programs (as needed)

• Prepare plan for a process and/or outcomes evaluation for modified/implemented SNI and Sharsheret programs

• Conduct evaluations to assess if modified programs for YBCS yield intended outcomes, are effective, and can be amplified and applied to other survivor audiences.
Key Project Tasks: Years 1, 2 and 3

Evaluation Plan
Develop the evaluation design and protocol to evaluate the selected programs (1 process evaluation and 1 outcome evaluation)

IRB/OMB
Prepare IRB and OMB packages for evaluation of the selected programs and obtain approval for the evaluation

Test selected interventions
Conduct testing to tailor and strengthen select programs to support YBCS psychosocial and reproductive health needs

Organizational case studies
Conduct a case study of 2 select organizations serving YBCS of African American and Ashkenazi Jewish descent

Modify/Tailor selected programs
Facilitate partner organizations tailoring programs based on findings from testing

Implement selected programs
Facilitate partner organizations implementing the tailored programs

Evaluate selected programs
Conduct process evaluation and/or outcome evaluation of programs to support YBCS psychosocial and reproductive health needs

Prepare evaluation report

Year 1 (2010-2011)
Year 2 (2011-2012)
Year 3 (2012-2013)
Selecting Organizations

• Process to **identify** organizations
  – Created an initial list of organizations serving YBCS
  – Conducted an environmental scan to identify other potential organizations

• Process to **select** organizations
  – Establish exclusionary criteria for organizations
  – Review organizations and select six potential organizations
  – Phone calls for brief interviews with representatives from potential organizations
    • Interviews conducted to assess the organization’s (1) capacity to implement project tasks and (2) willingness to participate in the 3 year BCYW project

• Selection of two organizations
  – Sharsharet
  – Sisters Network, Inc.
Organizational Case Studies

• **Purpose**
  – To understand how each organization develops, disseminates, strengthens, and evaluates programs that provide psychosocial and reproductive health support to their target audience.

• **Data collection**
  – Document review
  – 5-6 in depth interviews with organizational staff
  – 5-6 in depth interviews with organizational partners

• **Analysis**
  – Thematic analysis using Atlas.ti software
Case Study Findings: Sharsheret

• Sharsheret is mainly funded by private donations from individuals and foundations, with some corporate sponsorship and Federal funding.

• Sharsheret offers 11 national programs to support YBCS and their loved ones.
  – Primary intervention is the Link Peer Support Network, which matches survivors with peer supporters.

• Sharsheret partners with community organizations and uses social media to recruit survivors to participate in programs. Use of email/Web and word of mouth are the primary communication tool for program promotion.

• Sharsheret monitors and evaluates all of its activities and uses evaluation findings to improve programmatic efforts.
Case Study Findings: Sisters Network, Inc.

- SNI is funded by Federal dollars, grants, and private donations from corporate and other sponsors.

- SNI has **43 affiliate chapters** in the United States. Each offers 2 or more programs to support breast cancer survivors.

- SNI conducts annual events to raise awareness of breast cancer in the African American community; they also partner with community organizations (e.g., churches, sororities) to promote SNI activities.

- SNI’s **newest initiative**, the Young Sisters Initiative, focuses on providing psychosocial health support to YBCS.

- SNI does not currently evaluate implementation or outcomes of its activities, but does **collect monitoring data and plans to evaluate programs in near future**
INTERVENTION TESTING AND MODIFICATION
Choosing Sharsheret Program(s)

- Reviewed Sharsheret programs to select those that:
  - provide psychosocial and reproductive health support to YBCS
  - serve Ashkenazi Jewish YBCS
  - serve women diagnosed with breast cancer before age 45
  - have potential to be “amplified” or “scaled up” to serve more women
  - have existing core elements (e.g., counseling, web support)
  - have modifiable key program characteristics
  - already undergo some level of monitoring and evaluation

- Use case study findings about programming to select programs for testing that meet above criteria:
  - Link Peer Support Network (PSN)
  - Genetics for Life program (GFL)
The Link Peer Support Network

• The Link PSN, Sharsheret’s foundational program, is a matched peer-support network that connects YBCS and women at elevated risk with other Jewish women for support and encouragement.

• The PSN is commonly used by women either recently diagnosed with breast cancer, undergoing treatment, or women who feel that they may be at high risk for breast cancer based on family history.
Genetics for Life

• GFL is a program to provide those at risk, newly diagnosed and survivors a safe, confidential way to receive genetics counseling that supports them in making the decision around testing that is best for them and for their families.

• The program offers women free, anonymous consultation with a certified genetics counselor to discuss testing.

• GFL also offers educational resources regarding breast and ovarian cancer and heredity.
Sharsheret Focus Group testing: Fall 2011

• Purpose
  – To gain a deeper understanding of the health information needs and concerns of Jewish YBCS and gather their feedback on the Link Peer Support Network and Genetics for Life programs.

• Data collection
  – 4 focus groups with Jewish YBCS

• Analysis
  – Thematic notes-based analysis of qualitative focus group data and analysis of pre-focus group questionnaires using SPSS
## Focus Group Segmentation

<table>
<thead>
<tr>
<th>Focus Group Dates</th>
<th>In-person (YBCS &lt;45 years in New Jersey)</th>
<th>Online (YBCS &lt;45 years in other US states)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Target Audience</td>
<td>1 group</td>
<td>1 group</td>
</tr>
<tr>
<td>Focus: Participation in the PSN program</td>
<td>1 group</td>
<td>1 group</td>
</tr>
<tr>
<td>Focus: Participation in the GFL program</td>
<td>1 group</td>
<td>1 group</td>
</tr>
</tbody>
</table>
Next Steps with Sharsheret

• Conduct the focus groups to test PSN and GFL to identify necessary changes to content, graphics, and

• Implement changes to PSN and GFL to prioritize provision of psychosocial and reproductive health support to Jewish YBCS

• Develop the plan to conduct a mixed-methods outcome evaluation of the modified PSN and GFL programs
  – Outcome evaluation questions will focus on the programs’ impact including changes in YBCS’ knowledge, attitudes, skills, behavioral intentions, and/or behaviors.

• Implementation and evaluation of the new program (in year 3)
Choosing Sisters Network, Inc. Programs

- Reviewed programs and resources to select those that:
  - provide psychosocial and reproductive health support to YBCS
  - serve African American YBCS
  - serve or tailored to serve women diagnosed with breast cancer before age 45
  - have potential to be “amplified” or “scaled up” to serve more women
  - have existing core elements (e.g., counseling, web support)
  - have modifiable key program characteristics
  - already undergo some level of monitoring and evaluation

- **Sisters Peer Counseling in Reproductive Issues after Treatment (SPIRIT)**
  - Created by Dr. Leslie Schover, University of Texas M.D. Anderson Cancer Center, in partnership with SNI.
  - To improve knowledge and reduce symptoms related to sexual dysfunction, menopause, and distress about infertility among African American breast cancer survivors.

Schover et al., 2011.
SPIRIT Manual

Sisters Peer Counseling In Reproductive Issues After Treatment

Just Friends by Bettie Eubanks is used with permission of the artist.

THE UNIVERSITY OF TEXAS MD ANDERSON CANCER CENTER
Making Cancer History®
Focus Groups

• **Purpose**
  – To gain a deeper understanding of the health information needs and concerns of African American YBCS
  – To gather YBCS feedback on **SPIRIT**, a workbook tailored for a general African American breast cancer survivor audience

• **Data collection**
  – 4 focus groups with African American YBCS
  – Conducted during the SNI’s 12th Annual National African American Breast Cancer Conference

• **Analysis**
  – Thematic notes-based analysis of qualitative focus group data and analysis of pre focus group questionnaires using SPSS
# Focus Group Segmentation

<table>
<thead>
<tr>
<th>Focus Group Dates</th>
<th>Thursday May 12\textsuperscript{th}</th>
<th>Friday May 13\textsuperscript{th}</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Target Audience</strong></td>
<td>AA YBCS OVER 40 years of age</td>
<td>AA YBCS 40 years of age and UNDER</td>
</tr>
<tr>
<td><strong>Focus: SPIRIT and psychosocial support</strong></td>
<td>1 group (7 women)</td>
<td>1 group (7 women)</td>
</tr>
<tr>
<td><strong>Focus: SPIRIT and reproductive health</strong></td>
<td>1 group (6 women)</td>
<td>1 group (5 women)</td>
</tr>
</tbody>
</table>
Focus Group Demographics

• All participants self identified as African American

• The mean age of all participants was 40.3 years

• The mean age of participants at cancer diagnosis was 35.6 years

• The mean years since diagnosis for participants was 4.3 years

• All participants had 12th grade high school diploma or more education

• 80% of participants were employed full time
Focus Group Demographics con’t.

- 44% of focus group participants were married
- Mean number of children was 1.4 (range 0-4)
- 44% of participants diagnosed with DCIS (ductal carcinoma in situ)
- 44% of participants diagnosed with IDC (invasive ductal carcinoma)
- 72% of participants with stage II or higher tumor diagnosis
- 84% of participants had undergone chemotherapy
- 68% of participants had undergone radiation therapy
Overall Focus Group Findings

• Participants need information about breast cancer types and treatment. In addition, women need information on where to get reliable, up-to-date information about recent advances in breast cancer research.

• Participants do not trust health care providers and were skeptical of providers’ ability and/or willingness to meet their needs for reproductive health information.

• Participants think that providers do not discuss reproductive health issues with African American YBCS because providers perceive such women to lack resources (e.g., insurance) to obtain services to preserve their fertility.
Preliminary Focus Group Findings: “Information Needs”

• Women feel there is little information about breast cancer and treatment tailored for African Americans
  – Existing targeted materials are perceived to be of lower production quality than materials for general audiences

• Participants need more information about early menopause; impact of treatment on intimacy and sexual function; fertility; and mental health issues.

• Women want information about breast cancer directly from other African American breast cancer survivors, especially YBCS.

• All participants (and especially YBCS) want to access psychosocial and reproductive health information in diverse ways, particularly via the Internet sources and from age-group peers.
Preliminary Focus Group Findings: “Message Delivery”

• The *content* of the program workbook available in hard copy and/or online should include:
  – More information on coping with breast cancer symptoms and treatment
  – Testimonials from young breast cancer survivors
  – Frequently asked questions and answers (FAQ) section

• The *graphics* included in the program workbook and any online program should include:
  – Photographs of young African American survivors
  – Bright colors that stand out from the text
  – More tables and text boxes to present textual information

• Offer SPIRIT workbook through multiple channels, especially online
• Complete revamping of SPIRIT to modify it into a program that serves YBCS (in year 2)
  – To be delivered as an online program providing psychosocial and reproductive health support to YBCS

• Development of the process evaluation plan for the new online program (in year 2)

• Implementation and process evaluation of the new program (in year 3) to determine:
  – Is the program implemented as planned?
  – Does it reach the intended audience?
  – What are the barriers to program implementation?
QUESTIONS AND DISCUSSION
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