Innovative Utilization of a State Cancer Registry to Contact Young Breast Cancer Survivors and Their High-Risk Female Relatives to Increase Breast Cancer Screening

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Background
Genetic Predisposition to Breast Cancer

**Personal health history**

- Age of breast cancer onset ≤50 years
- Two primary breast cancers in the same woman
- Breast and ovarian cancer in the same woman

**Family health history**

- 3+ cases of breast or ovarian cancer
- Breast and ovarian cancer in same side of family
- Breast and other cancers in same side of family
- Male breast cancer

**High-risk populations**

- Ashkenazi, French-Canadian, Hungarian, Icelandic, Swedish
Breast Cancer Risk

Risk for a breast cancer survivor

2-fold higher risk

Risk for a relative of a young breast cancer survivor (YBCS)

• First-degree relative has a 2.3 higher risk
• Second-degree relative has a 1.5 higher risk

Determine the feasibility of using a state cancer registry to identify and contact young breast cancer survivors and their high-risk relatives to increase breast cancer screening.

Work was done in conjunction with CDC grant number 5 U48 DP001901-03 which was to develop interventions to increase breast cancer screening in breast cancer survivors and their high risk relatives.
Objectives

• Contact YCBS and recruit into study
• Collect baseline data on screening and risk awareness
• YCBS recruit family members
• Collect baseline data on high risk family members
• Conduct randomized interventions
  • Targeted and Tailored
• Collect follow-up data
# Michigan Cancer Consortium Breast Cancer Screening Guidelines

<table>
<thead>
<tr>
<th>Risk Factor</th>
<th>Screening Method</th>
<th>Frequency</th>
<th>Staging</th>
<th>Notes</th>
</tr>
</thead>
<tbody>
<tr>
<td>3 Strong family history of breast cancer or genetic predisposition (^2) (Hereditary Breast and Ovarian Cancer Patients – HBOC)</td>
<td>CBE</td>
<td>6-12 months</td>
<td>Start at age 25 for HBOC patients</td>
<td>* See Note Breast Self Awareness Consider Risk Reduction Strategies (See NCCN Breast Cancer Risk Reduction Guidelines) Consider referral to genetic counselor</td>
</tr>
<tr>
<td></td>
<td>Mammogram</td>
<td>Annual</td>
<td>5-10 years prior to youngest breast cancer case for strong family history of other genetic predispositions</td>
<td>* See Note Breast Self Awareness</td>
</tr>
<tr>
<td></td>
<td>MRI as adjunct with CBE/Mammogram</td>
<td>Annual</td>
<td></td>
<td>* See Note Breast Self Awareness</td>
</tr>
<tr>
<td>4. Personal History of Breast Cancer (^2)</td>
<td>CBE</td>
<td>6-12 months</td>
<td>Post Diagnosis</td>
<td>* See Note Breast Self Awareness See NCCN Breast Cancer Guidelines- Surveillance Section</td>
</tr>
<tr>
<td></td>
<td>Mammogram</td>
<td>Annual</td>
<td></td>
<td>* See Note Breast Self Awareness</td>
</tr>
<tr>
<td>Women (\geq 35) with 5-year</td>
<td>CBE</td>
<td>6-12 months</td>
<td>After age 35.</td>
<td>* See Note Breast Self Awareness</td>
</tr>
</tbody>
</table>

Interventions to increase screening utilization by young breast cancer survivors and their high risk female relatives

**Intervention**

Adapted from a targeted mammography adherence intervention recommended by the Guide to Community Preventive Services

<table>
<thead>
<tr>
<th>Targeted Mail Intervention</th>
<th>Enhanced Tailored Mail Intervention</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Survivor</strong></td>
<td><strong>Survivor</strong></td>
</tr>
<tr>
<td><strong>Relatives</strong></td>
<td><strong>Relatives</strong></td>
</tr>
<tr>
<td><strong>Letter:</strong></td>
<td><strong>Letter:</strong></td>
</tr>
<tr>
<td>Personalized with:</td>
<td>Personalized with:</td>
</tr>
<tr>
<td>Participant’s name</td>
<td>Participant’s name</td>
</tr>
<tr>
<td>Incl. risk due to breast CA history</td>
<td>Inc. risk due to breast CA history</td>
</tr>
<tr>
<td>MCC guidelines for follow up care</td>
<td>MCC guidelines for follow up care</td>
</tr>
<tr>
<td>Suggest genetic counseling</td>
<td>Suggest genetic counseling</td>
</tr>
<tr>
<td><strong>Brochures:</strong></td>
<td><strong>Brochures:</strong></td>
</tr>
<tr>
<td>Why get a mammogram</td>
<td>Why get a mammogram</td>
</tr>
<tr>
<td>How to get a mammogram</td>
<td>How to get a mammogram</td>
</tr>
<tr>
<td>Finding local low cost mammogram</td>
<td>Finding local low cost mammogram</td>
</tr>
<tr>
<td><strong>Tailored on:</strong></td>
<td><strong>Tailored on:</strong></td>
</tr>
<tr>
<td>Knowledge of genetics</td>
<td>Knowledge of genetics</td>
</tr>
<tr>
<td>Adherence to follow up</td>
<td>Adherence to follow up</td>
</tr>
<tr>
<td>Barriers (if not adherent)</td>
<td>Barriers (if not adherent)</td>
</tr>
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<td>How to get a mammogram</td>
</tr>
<tr>
<td>Finding local low cost mammogram</td>
<td>Finding local low cost mammogram</td>
</tr>
<tr>
<td><strong>Additional Information:</strong></td>
<td><strong>Additional Information:</strong></td>
</tr>
<tr>
<td>Improving your family support</td>
<td>Improving your family support</td>
</tr>
</tbody>
</table>
Enhanced Tailored Booklet

Breast Cancer and Your Family: How to Improve Communication and Support
A guide for young breast cancer survivors and their family members

Breast cancer treatments and follow-up care can be stressful for women and their families. Breast cancer may run in families and it can affect many family members. Talking with your relatives about your family’s risk for breast cancer can be hard to do.

Open family communication can help both survivors and their relatives deal with this stress. It can bring your family closer. It can also help you support one another and work as a team to lower your cancer risk.

This brochure has useful tips on how to
• talk to your relatives about cancer risk
• support each other

Reach out to each other for support because “a shared burden is half a burden”

Enhanced and Targeted Booklet

Breast Cancer and Your Family: How to Improve Screening and Monitoring
A guide for young breast cancer survivors and their female relatives

This booklet was created by the University of Michigan School of Nursing in collaboration with the Michigan Department of Community Health with funding from the Centers for Disease Control and Prevention.
Recruiting Methods
Recruitment of Young Breast Cancer Survivors (YCBS)

Utilize the Michigan Cancer Surveillance Program (MCSP)

- Identify 3,000 YBCS (1,500 black and 1,500 white/other races)

Eligibility Criteria for YBCS:
- Female, 20 years or older, able to read English
- Michigan resident at diagnosis
- Diagnosed with invasive breast cancer or DCIS between 20-45 years
- Not currently pregnant, incarcerated, institutionalized

Contact facility and diagnosing physician before contact with YBCS
Candidate Selection

- Identified 7,886 Michigan cases potentially eligible
  - Diagnosed between 1998-2007
- Cases were screened through Accurint
  - Identify additional deaths
  - Locate current addresses
- Selected random sample for contact
  - 1500 blacks
  - 1500 white or other
  - Anticipated 40% response rate for cases, 35% for relatives
- Recruit survivor following physician contact
  - Physician asked to confirm diagnosis and appropriateness of contact
Relative Recruitment

• YBCS completed a table in their survey on first and second-degree relatives with no history of cancer
• Genetic counselors reviewed the table and selected up to two relatives with the highest risk of cancer based on:
  • Relationship
  • Current Age
  • YBCS family history

FEMALE RELATIVES WITHOUT CANCER

Use these family member titles in your Family History Chart below (do not use names):
- Mom
- Daughter
- Sister
- Niece
- Grandmother (mom’s side)
- Grandmother (dad’s side)
- Aunt (mom’s side)
- Aunt (dad’s side)
- Half-sister (mom’s side)
- Half-sister (dad’s side)

<table>
<thead>
<tr>
<th>Female relative who is living without cancer</th>
<th>Current age?</th>
<th>Does she live in Michigan? (check if yes)</th>
<th>Does she live within 50 miles from you? (check if yes)</th>
<th>Are you willing to contact her for the study? (check if yes)</th>
</tr>
</thead>
<tbody>
<tr>
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</tbody>
</table>
Relative Recruitment

Survey and consent materials were sent to the YBCS to give to the relative. Study team does not know identity until relative enrolls

Female Relative Eligibility

• Female, 25–64 years of age
• *Unaffected* with any type of cancer
• First- or second-degree relatives of the YBCS
• US resident
• Able to read English
• Not currently pregnant, incarcerated, or institutionalized
• YBCS is willing to contact

Up to 2 relatives per YBCS are invited to the study
Results
YBCS Enrollment

- Total Acceptance 883 YBCS
- Reasons not Accepted
  - 274 Declined
  - 66 Deceased
  - 3 Incarcerated
  - 252 No or bad address
  - 22 Do not contact per facility or physician

33.2% Response Rate
Relative Enrollment

- 442 accepted
- 185 units with YBCS and 1 relative
- 123 units with YBCS and 2 relatives

51.6% Response Rate
Recruitment by Race

Total Acceptance (Response Rate):
883 accept participation (33.2%)
- Black: 353 (27.5%)
- Other: 530 (38.6%)

Total Reasons not Accepted:

<table>
<thead>
<tr>
<th>Reason</th>
<th>Black</th>
<th>Other</th>
</tr>
</thead>
<tbody>
<tr>
<td>Deceased</td>
<td>34</td>
<td>32</td>
</tr>
<tr>
<td>Incarcerated</td>
<td>2</td>
<td>1</td>
</tr>
<tr>
<td>No/bad address</td>
<td>175</td>
<td>77</td>
</tr>
<tr>
<td>Do not contact per facility or physician</td>
<td>5</td>
<td>17</td>
</tr>
<tr>
<td>Decline</td>
<td>95</td>
<td>179</td>
</tr>
</tbody>
</table>
## Demographics

<table>
<thead>
<tr>
<th>Metric</th>
<th>YBCS Total</th>
<th>Black</th>
<th>White/Other</th>
<th>Relatives Total</th>
<th>Black</th>
<th>White/Other</th>
</tr>
</thead>
<tbody>
<tr>
<td>Average Age (yrs)</td>
<td>51 ± 6</td>
<td>51 ± 6</td>
<td>51 ± 6</td>
<td>43 ± 12</td>
<td>45 ± 11</td>
<td>43 ± 12</td>
</tr>
<tr>
<td>Time since Diagnosis (yrs)</td>
<td>11 ± 4</td>
<td>11 ± 4</td>
<td>11 ± 4</td>
<td>n/a</td>
<td>n/a</td>
<td>n/a</td>
</tr>
<tr>
<td>White/Other</td>
<td>60.4%</td>
<td>n/a</td>
<td>n/a</td>
<td>79.8%</td>
<td>n/a</td>
<td>n/a</td>
</tr>
<tr>
<td>Black</td>
<td>39.6%</td>
<td>n/a</td>
<td>n/a</td>
<td>20.2%</td>
<td>n/a</td>
<td>n/a</td>
</tr>
<tr>
<td>Married***+++</td>
<td>57.1%</td>
<td>33.1%</td>
<td>72.7%</td>
<td>55.6%</td>
<td>33.3%</td>
<td>61.2%</td>
</tr>
<tr>
<td>Some college or less***++</td>
<td>61.3%</td>
<td>67.5%</td>
<td>57.4%</td>
<td>54.0%</td>
<td>71.9%</td>
<td>49.7%</td>
</tr>
<tr>
<td>Household income &lt;$60,000***+++</td>
<td>52.8%</td>
<td>65.4%</td>
<td>34.3%</td>
<td>52.6%</td>
<td>69.7%</td>
<td>43.6%</td>
</tr>
<tr>
<td>Has medical insurance*++</td>
<td>93.5%</td>
<td>90.6%</td>
<td>95.4%</td>
<td>87.0%</td>
<td>75.9%</td>
<td>89.8%</td>
</tr>
</tbody>
</table>

*p<0.0005 for YBCS
**p<0.0001 for YBCS
***p<0.000 for YBCS
+p<0.0005 for relatives
++p<0.0001 for relatives
+++p<0.000 for relatives
Conclusions
Cancer registries can be used to identify and direct cancer control messages to patients and families at known higher risk

Improving screening in high-risk women can promote earlier detection and awareness of hereditary forms of breast cancer.

As cancer genetics knowledge increases, opportunities for public health interventions will present.
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