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

- Young breast cancer survivors (YBCS) and their first- and second-degree relatives are at increased risk for cancer
- Breast cancer diagnosed at a young age indicates a possible hereditary cause
- Because of this increased risk, genetic counseling, earlier screening and prevention services are recommended for these high-risk women

PURPOSE OF STUDY

To examine the feasibility of using a statewide cancer registry to recruit YBCS and their high-risk female relatives in a randomized efficacy trial aiming to increase cancer screening and use of genetic services

METHODS

- Enrolled YBCS reported in the baseline survey first- and second-degree female relatives, with no history of cancer, who were willing to invite in the study
- Genetic counselors reviewed the information and selected up to two relatives per YBCS
- YBCS were notified of the selected relatives and were asked to contact them for study participation
- Relatives were enrolled once they returned a signed informed consent and a completed baseline survey

RESULTS – DEMOGRAPHICS (TABLE 1)

<table>
<thead>
<tr>
<th>YBCS</th>
<th>Relatives</th>
</tr>
</thead>
<tbody>
<tr>
<td>Total</td>
<td>Black</td>
</tr>
<tr>
<td>Average Age (yrs)</td>
<td>51 ± 6</td>
</tr>
<tr>
<td>Time since Diagnosis (yrs)</td>
<td>11 ± 4</td>
</tr>
<tr>
<td>White/Other</td>
<td>60.4%</td>
</tr>
<tr>
<td>Black</td>
<td>39.6%</td>
</tr>
<tr>
<td>Married*</td>
<td>57.1%</td>
</tr>
<tr>
<td>High school grad or less’</td>
<td>23.4%</td>
</tr>
<tr>
<td>Household income &lt;$86,000’</td>
<td>52.8%</td>
</tr>
<tr>
<td>Has medical insurance</td>
<td>93.5%</td>
</tr>
</tbody>
</table>

RESULTS – RECRUITMENT OF YBCS (FIGURE 1)

- 883 YBCS accepted participation in the study (33.2% response rate)
- Most common reason for not taking part was no known address for YBCS
- Black YBCS had a higher percentage of bad addresses than Whites/Other
- 281 YBCS had no eligible relatives

METHODS – RECRUITMENT OF RELATIVES (FIGURE 2)

- Genetic counselors identified 1,875 eligible first- and second-degree female relatives
- YBCS were willing to contact 1,360 relatives
- Recruitment materials were provided to 522 YBCS to distribute to 856 relatives
- 442 relatives who accepted participation in the study (51.6% response rate)
- 185 family units that included the YBCS with 1 relatives and 123 family units that included the YBCS with 2 relatives

RESULTS – RECRUITMENT OF RELATIVES (FIGURE 2)

- 290 relatives were contacted for this study
- 164 relatives (56.6%) were successfully contacted
- 76 relatives accepted participation

CONCLUSIONS

- The enrollment and follow-up response rates indicate that using a state cancer registry to contact cancer survivors and high-risk relatives is a feasible recruitment method
- Using a state cancer registry allows for increased outreach to a unique population that has high cancer risk and needs increased cancer surveillance and screening
- The study took an innovative approach to using family health history and is suggested as a method of recruitment for cancer survivors and relatives

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