PHASE Intern Report:
Development of a Survey to Assess Disparities in Breast Cancer Care on the Eastern Shore of Maryland

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MPH advisor: Yin Yao
Background

- Breast cancer is the most commonly diagnosed cancer among women in the US and the state of MD

Despite the improvement in outcome of breast cancer over decades, disparities in breast cancer care exists

*MD rates from 2002   ** SEER, 2000 - 2003
Barriers to quality breast cancer care

MD DHMH identified following contributing factors to cancer disparities

- Risk factors and exposures
- Socioeconomic status
- Discrimination
- Attitudes and behaviors
- Access to quality care
- Delay in seeking diagnosis and treatment
- Culture and language

Social, economic, and public health environment
- Race/ethnicity, socioeconomic status, poverty, education, age, language, geography

*Modified from Blackman DJ, Masi CM. J Clin Oncol. 2006*
Eastern Shore and Worcester County

- The largest rural region in MD
- High proportion of population over 50
- Rapid increase in population due to in-migration of retirees
- Designated “medically underserved area” by HRSA since 1978
- Most common cause of death: cancer
Comprehensive Cancer Control Plans by CDC

“an integrated and coordinated approach to reducing cancer incidence, morbidity, and mortality through prevention (primary prevention), early detection (secondary prevention), treatment, rehabilitation, and palliation.”

1) Enhancing infrastructure
2) Mobilizing support
3) Using data and research
4) Building partnership
5) Assess and address cancer burden
6) Conduct evaluation
Data and research

- Existing sources of data
  - Local Health Plan
  - Tri-County Community Adult Health Survey
  - MD Cancer Registry

- Limitations
  - Not sufficient for assessing cancer burden or identifying service needs
  - Small number of cases
  - Lack of individual socioeconomic data
  - Uneven quality of data from smaller populations
Community partnership

- **Worcester County Cancer Coalition Meetings**
  - Primary prevention and early detection of cancer in Worcester county
  - Smoking cessation programs, recruiting community members to BCCP, community education
  - Members include:
    - Local health department officials
    - ACS liaison
    - Community-based organizations
    - Local hospital representatives
Project goal

- Mobilize a community partnership in developing survey to establish public health data that can be used to assess the cancer burden in the area

*Source: Public Health Functions Steering Committee*
More about the partnership…

- Worcester County Health Department
  - Linkage between the PHASE program and the community-based organization
  - Structural meetings and resources

- Women Supporting Women
  - Local breast cancer support group
  - Serves over 1000 breast cancer survivors in the Eastern Shore
  - Links to the mailing list of breast cancer survivors
  - Further distribution and collection of the surveys

- PHASE intern
Developing the survey content

- Intended to collect comprehensive information along the breast cancer care continuum from screening to diagnosis, treatment, and post-treatment care and support, at both individual and systematic levels

- Initial template: the intake form previously used by WSW to collect basic demographic and clinical data

- Specific question and answer formats from various existing surveys
  - National Action Plan on Breast Cancer, Comprehensive Questionnaire
  - Health Information National Trends Survey
  - US Census categories for income and education categories
Contents of the survey

- Part I. Use of the support group resources and potential supporting group needs

Q1. What services have you used that were provided by Women Supporting Women? (Check all that apply)
  - Support group meetings
  - Information totes
  - Cards
  - Phone calls
  - Piglet pillows
  - Wigs/ hats
  - Other:

Q2. What other assistance would you like?

_________________________ ____________________________
_________________________ ____________________________
_________________________ ____________________________
_________________________ ____________________________
Part II. Tumor characteristics and treatment received

- Timing of screening, diagnosis, and initial treatment
- Method of tumor detection
- Tumor characteristics: stage, recurrence, hormone receptors, genetic tests
- Types of treatment received
- Distance and method of transportation to the treatment facility
Part III. Individual demographics and socioeconomic status

- Age at diagnosis
- Race/ethnicity
- Marital status
- Language
- Area of residence
- Employment status
- Income
- Education
- Insurance status
- Family history

<table>
<thead>
<tr>
<th>Question</th>
<th>Answer Options</th>
</tr>
</thead>
<tbody>
<tr>
<td>Q22. What is your date of birth?</td>
<td>__ __ __ __ (mm/yyyy)</td>
</tr>
<tr>
<td>Q23. What is your gender?</td>
<td>Female</td>
</tr>
<tr>
<td>Q24. Which one of these groups would you say best represents your race?</td>
<td>White</td>
</tr>
<tr>
<td>Q25. What is your marital status?</td>
<td>Married</td>
</tr>
<tr>
<td>Q26. Do you speak a language other than English at home?</td>
<td>Yes: (what language)</td>
</tr>
<tr>
<td>Q27. What is the zip code of your current address?</td>
<td>__ __ __ __ (mm/yy)</td>
</tr>
<tr>
<td>Q28. What is the zip code of your last address?</td>
<td>__ __ __ __</td>
</tr>
<tr>
<td>Q29. Are you currently employed?</td>
<td>Employed for wages</td>
</tr>
<tr>
<td>Q30. What is your annual household income from all sources?</td>
<td>Less than $10,000</td>
</tr>
<tr>
<td>Q31. What is the highest grade or year of school you completed?</td>
<td>Never attended school or only attended kindergarten</td>
</tr>
<tr>
<td>Q32. Do you have any kind of health care coverage, including health insurance, prepaid plans such as HMOs, or government plans such as Medicare?</td>
<td>Yes: Please specify</td>
</tr>
<tr>
<td>Q33. During the past 12 months, not counting times you went to an emergency room or for cancer treatment, how many times did you go to a doctor, nurse or other health care provider to get care for yourself?</td>
<td></td>
</tr>
</tbody>
</table>
Pilot study with 19 survivors

- 19 WSW members who attended the support group meetings in Berlin or Salisbury

- Revision of answer categories and sub-questions

<table>
<thead>
<tr>
<th>DEMOGRAPHICS</th>
<th>Race, No. (%)</th>
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</thead>
<tbody>
<tr>
<td>White</td>
<td>19 (100)</td>
</tr>
<tr>
<td>Median age (years)</td>
<td>63</td>
</tr>
<tr>
<td>Age at diagnosis, No. (%)</td>
<td></td>
</tr>
<tr>
<td>less than 50</td>
<td>9 (47.4)</td>
</tr>
<tr>
<td>50 ≤ 59</td>
<td>2 (10.5)</td>
</tr>
<tr>
<td>60 ≤ 69</td>
<td>5 (26.3)</td>
</tr>
<tr>
<td>older than 70</td>
<td>2 (10.5)</td>
</tr>
<tr>
<td>Marital Status, No. (%)*</td>
<td></td>
</tr>
<tr>
<td>Married</td>
<td>14 (73.7)</td>
</tr>
<tr>
<td>Widowed</td>
<td>3 (15.8)</td>
</tr>
<tr>
<td>Other</td>
<td>2 (10.5)</td>
</tr>
<tr>
<td>Current zip code, No. (%)*</td>
<td></td>
</tr>
<tr>
<td>21811</td>
<td>13 (68.4)</td>
</tr>
<tr>
<td>Others</td>
<td>6 (31.6)</td>
</tr>
<tr>
<td>Income, No. (%)*</td>
<td></td>
</tr>
<tr>
<td>20000 ≤ 34999</td>
<td>3 (15.8)</td>
</tr>
<tr>
<td>35000 ≤ 75000</td>
<td>5 (26.3)</td>
</tr>
<tr>
<td>75000 ≤ 99999</td>
<td>3 (15.8)</td>
</tr>
<tr>
<td>100000 ≤ 199999</td>
<td>3 (15.8)</td>
</tr>
<tr>
<td>No response</td>
<td>6 (31.6)</td>
</tr>
<tr>
<td>Insurance, No. (%)</td>
<td></td>
</tr>
<tr>
<td>Employment-based private or military</td>
<td>10 (52.6)</td>
</tr>
<tr>
<td>Direct private</td>
<td>5 (26.3)</td>
</tr>
<tr>
<td>Medicare only</td>
<td>4 (21.1)</td>
</tr>
<tr>
<td>Education, No. (%) *</td>
<td></td>
</tr>
<tr>
<td>High school graduate or less</td>
<td>8 (42.1)</td>
</tr>
<tr>
<td>Some college</td>
<td>3 (15.8)</td>
</tr>
<tr>
<td>College graduate</td>
<td>8 (42.1)</td>
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</tbody>
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<table>
<thead>
<tr>
<th>TUMOR CHARACTERISTICS</th>
<th>Stage at diagnosis, No. (%)</th>
</tr>
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<tbody>
<tr>
<td>Invasive</td>
<td>11 (57.9)</td>
</tr>
<tr>
<td>Non-invasive</td>
<td>7 (36.8)</td>
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<thead>
<tr>
<th>Initial treatment, No. (%)</th>
</tr>
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<tbody>
<tr>
<td>Surgery</td>
</tr>
<tr>
<td>Non-surgical treatment</td>
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Future plans

- Data collection by WSW during the summer of 2007

- Target population: WSW members in the mailing list who have voluntarily contacted the support group for assistance or information

- Information obtained will be used to assess and address the cancer burden and disparities of the Eastern Shore Area
Strengths and limitations

- Focused on collecting both clinical data and individual socioeconomic information
- More appropriate in assessing cancer burden and disparities in smaller geographical area
- Self-selected nature of the survey participants
- Self-reported information
Thank you

- Worcester County Health Department
- Women Supporting Women
- Dr. Yin Yao
- PHASE interns, Dipti and Dr. Ibrahim