Breast Cancer in Women Younger Than 40 Years

Randi Rosenberg*
Roberta Levy-Schwartz†

*President
†Founder and Treasurer
The Young Survival Coalition
New York, NY

INTRODUCTION

BREAST CANCER KNOWS NO boundaries. It is an “equal-opportunity” disease and does not “discriminate” on the basis of age or race. Whereas a diagnosis of breast cancer has serious implications for all patients, some sub-populations present distinct challenges. One such group is young women diagnosed before the age of 40.

Because of a perception of rarity of breast cancer in young women, the resulting lack of screening tools for this population, and the fact that clinicians are often reluctant to use available diagnostic tools on a routine basis, delayed diagnosis is common. This leads to detection of later-stage disease, poorer prognoses, and poorer outcomes [1]. All too often, when a young woman presents with a breast lump, she is told that she “doesn’t fit the profile” or is “too young for breast cancer,” and is sent home to watch and wait, rather than being referred for immediate work-up. The cycle is further delayed because young women themselves often do not believe they are at risk. They are simply unaware of the signs and symptoms of breast cancer and concur with their physicians’ sense that they are indeed “too young” for concern.

The percentage of women under 40 diagnosed with breast cancer constitutes approximately 5% of total cases. When this percentage is viewed as the number of lives affected, however, the estimate is then approximately 11,000 cases a year [2]—not an insignificant number. The number of women diagnosed annually is equal to the total of all annual diagnoses of diseases such as multiple sclerosis or cervical cancer. The U.S. census of 2000 estimates the number of women under 40 living with breast cancer to be more than 250,000 [3]. Because young women are considered a minority among cancer patients, only minimal resources are available to them. At the same time, the dearth of available outcome data for this population makes these individuals particularly challenging for practitioners to treat.

The relatively low perceived incidence of breast cancer in young women is, in all probability, a guiding rationale for the lack of credible screening for this population. Mammography, the “gold standard” for breast cancer screening and diagnostics in women over 40, is typically ineffective in the denser breast tissue common in very young women. In diagnostic use, the combination of mammography and ultrasound has been shown to have greater specificity in dense breasts, however, use as a screening methodology is relegated to women over 40, or younger women considered ‘at-risk’ due to prior breast cancer or suspected genetic predisposition. While the prevalence of genetic predisposition is higher in young women than in older women, it still only accounts for a small percentage of cases—leaving those not ‘at-risk’ without tools beyond the practice of breast self-examination. BSE is hotly
contested as a meaningful tool and evidence does not suggest that it has benefit in saving lives [6].

Given the circumstances cited above, it is not unreasonable to propose that current screening and diagnostic techniques for younger women are inadequate. Because of this, the opportunity for misdiagnosis, underdiagnosis, and undertreatment is particularly pronounced. According to the Physician Insurers Association of America, more than 66% of the breast cancer lawsuits filed between 1995 and 2002 were initiated by women younger than 49, with half of these cases involving women younger than 39 [7]. In the majority of instances, the accusation was "failure to make a timely diagnosis." Certainly, it cannot be suggested that physicians involved in these cases were unaware of breast cancer as a disease entity. Even so, these statistics might lead one to speculate that they at least were unaware of the risk in women under age 40.

The Young Survival Coalition (YSC) was formed in 1998 to address the significant, indeed, specific, lack of information available to young women in an attempt to bridge the gaps in resources and research for early-onset breast cancer patients. It is the only international nonprofit organization dedicated to addressing the critical concerns and issues unique to the problem of young women and breast cancer. Through action, advocacy, and awareness, the YSC seeks to educate and influence the medical, research, breast cancer, and legislative communities to address breast cancer in women 40 and under, and to serve as a point of contact for younger women living with breast cancer.

In seeking to develop a strong vision and advocacy plan for addressing the needs of younger women, the YSC sought to quantify the population of young breast cancer patients, to create a general profile of its membership, and to provide the medical community with insight into the breast cancer experience in young women.

In an attempt to address strategically the lack of research specific to breast cancer in young women, the YSC formulated a plan in 1999 to counter the response heard most frequently from both the medical and scientific communities: "There simply aren't enough young women to warrant study." Our goals were to begin quantifying this population, develop a profile of young breast cancer patients, and utilize the data to provide the scientific community with evidence that these patients could provide hitherto unstudied information. The initial effects in this regard—two of YSC's soon-to-be-published, co-sponsored research studies—had response rates of 45.8% and 43%, respectively [8,9], of all surveyed membership.

**MATERIALS AND METHODS**

The YSC's member database consists of demographic, diagnosis, and treatment information as provided by each breast cancer survivor who decides to join the YSC. Membership is free and provides members with information about YSC activities nationally and in their area, as well as news of specific interest and relevance to breast cancer in young women. The individual member data are immediately added to the database and member statistics are updated in real time on the YSC Website, www.youngsurvival.org. The registration form and the real-time Membership Profile are available for viewing on the Website. The majority of members fill out the questionnaire online. The YSC does not verify the accuracy of self-reported information.

The Membership Registration Form was initially developed as a questionnaire in 1999, in order to establish a database of young breast cancer patient profiles. Since then, it has increased both in terms of information captured and in sophistication. Whereas the original member questionnaire contained six questions—including, for example: "How did you find your cancer?" and "How did you feel about your physician's knowledge about breast cancer in younger women?"—the current version has 25 questions and includes demographic data, such as contact information, age, marital status, number of children, ethnicity, and occupation. The database also includes diagnosis information, such as age at diagnosis, stage at diagnosis, tumor size, number of nodes, estrogen and progesterone status, and Her2Neu status, and treatment information, such as type of surgery, chemotherapy, radiation therapy, tamoxifen use, Herceptin use, existence of local or distant recurrence, location of recurrence, existence of a second primary breast cancer, additional treatment modalities, and clinical trial involvement.

Members who joined before the full 25-question questionnaire was available in January 2002 were asked to re-input their information into the new database and provide answers to all 25 questions. As there is no ability for individuals to update their information on a continuing basis, the database provides a "snapshot" of information at a particular time for a particular set of members. As such, incidence of disease recurrence, metastasis, or death
These survivors range in age from 17 to 68. As depicted in Table I, the majority of the membership reporting ranged from 26 to 34 years old (with >90% over 26 years); the average age at diagnosis was 33 years (not shown). More than 77% of women reporting were Caucasian, and the remainder were almost equally divided among African, Asian, Hispanic, and Other. Almost 70% of respondents were married or had partners, while 28% were single, separated, divorced, or widowed.

**How Cancer Was Found**

Respondents were asked to answer the question “How was your cancer detected?” and were asked to choose from BSE, Primary Care Physician (PCP), OB/GYN, Oncologist, Surgeon, Self, or Other (Table II). Eighty-three percent found their breast lumps themselves. A distinction was made between “BSE” and “Self” to ensure that the membership could distinguish between those masses found during BSE and those found by simply touching/feeling their breast, but not during an actual BSE. Whereas 43% of members found their lumps through BSE, an almost equal number (40%) found their lumps themselves (Self) by touch or feel, not during a BSE. Of those responding “BSE,” it is unclear whether this refers to a rigorously executed, monthly breast self examination, or an “accidental,” unstructured practice that they believed to constitute BSE. Only 10% were found by a PCP or OB/GYN, and 4% were found by a surgeon or oncologist. Although “mammogram” was not a pull-down choice for women to list as a method for finding their cancer, women were able to list “Other” (2%). When developing the form, we determined that mammography was not an option warranting its own category, as it was rarely used as initial screening for young women’s breast lumps or tumors.

**Patient Satisfaction with Doctors’ Knowledge About Breast Cancer in Young Women**

In the original questionnaire, members were asked to rate their satisfaction with their doctors, based upon their experiences when presenting with a suspicious breast lump, receiving the subsequent referral for diagnostic work-up or acquiring an actual diagnosis, or getting overall advisement from their physicians. Sixty-two percent gave their doctors a “Poor” or “Fair/OK” rating, while 20% felt their doctors were “Good”; only 18% felt their physician earned a rating of “Excellent” (Table III).
Stage at Diagnosis

Respondents were also asked to provide information on the stage at diagnosis (Table IV). Only 30% of young women reported identifying their breast cancers at Stages 0 or 1, whereas 57% reported their cancers as being Stage 2 or later. Thirteen percent of women reported having lymph node involvement. These findings might be attributed to the lack of breast cancer screening methodologies available to this population, or suggest that younger women are prone to more aggressive, faster-growing forms of breast cancer.

Type of Surgery

Table V lists the surgical procedures performed on the 2,006 respondents. Women who had more than one surgery counted each of the surgeries (for example, a lumpectomy that failed to remove the cancer followed by a mastectomy counted as two surgeries). More than 50% of survivors reported having a single mastectomy; a further 20% reported having a double mastectomy, either by need or by choice. More than 50% of survivors reported having a lumpectomy or partial mastectomy.

Tumor Size

Table VI shows members' reports of the size of their tumors, demonstrating that more than 56% of total respondents had breast tumors in excess of 2 cm. Almost 42% of these tumors were between 2 and 4.9 cm; 12.5% reported tumors between 5 and 9.9 cm; and 2% actually reported that their tumor was 10 cm or more.

Lymph Node Involvement

The data in Table VII reflect the responses from the 41% of the membership who reported presence of disease in at least one axillary lymph node. Sixty-three percent of those reporting nodal involvement had cancer spread in 1 to 3 nodes; 23% had disease present in 4 to 9 nodes; and 15% reported involvement in 10 or more lymph nodes.

Incidence of Advanced Disease or Recurrence

YSC members also reported the instance of a second primary breast cancer, a recurrence of their breast cancer (including the type of recurrence), and location of distant metastases of their breast cancers (Table VIII). Seven percent reported being diagnosed with a second primary breast cancer. Eleven percent of women reported a local recurrence, and 15% reported distant metastases or recurrence.
TABLE VII
Number of nodes involved.

<table>
<thead>
<tr>
<th>Number of Nodes</th>
<th>Number of Subjects</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>1-3</td>
<td>514</td>
<td>62.42%</td>
</tr>
<tr>
<td>4-9</td>
<td>190</td>
<td>23.02%</td>
</tr>
<tr>
<td>10+</td>
<td>120</td>
<td>14.56%</td>
</tr>
</tbody>
</table>

TABLE VIII
Type of recurrence.

<table>
<thead>
<tr>
<th>Type of Recurrence</th>
<th>Number of Subjects</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>None</td>
<td>1486</td>
<td>74.08%</td>
</tr>
<tr>
<td>Local</td>
<td>211</td>
<td>10.54%</td>
</tr>
<tr>
<td>Distant</td>
<td>309</td>
<td>15.38%</td>
</tr>
</tbody>
</table>

(a) Systemic recurrence.

<table>
<thead>
<tr>
<th>Systemic Recurrence</th>
<th>Number of Subjects</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Single system</td>
<td>283</td>
<td>54.49%</td>
</tr>
<tr>
<td>Multiple systems</td>
<td>237</td>
<td>45.67%</td>
</tr>
</tbody>
</table>

(b) Most common recurrence site(s).

<table>
<thead>
<tr>
<th>Recurrence Site</th>
<th>Number of Subjects</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Axillary</td>
<td>24</td>
<td>4.62%</td>
</tr>
<tr>
<td>Bone</td>
<td>186</td>
<td>35.71%</td>
</tr>
<tr>
<td>Brain</td>
<td>11</td>
<td>2.10%</td>
</tr>
<tr>
<td>Breast/Chest</td>
<td>168</td>
<td>32.35%</td>
</tr>
<tr>
<td>Liver</td>
<td>72</td>
<td>13.87%</td>
</tr>
<tr>
<td>Lung</td>
<td>90</td>
<td>17.23%</td>
</tr>
</tbody>
</table>

Note: Open-ended question allowed for multiple responses.

DISCUSSION

The information obtained from the Young Survival Coalition's (YSC) membership database of young breast cancer survivors shows that younger women are finding their own cancers due to the lack of reliable and/or widely applied screening in this population; are diagnosed in later stages; are greatly dissatisfied with the care they receive from their primary care physicians related to their breast cancer; are opting—or are required to choose—more mastectomies than breast conserving surgeries; have significantly large tumors upon surgical resection. Furthermore, those with lymph node involvement have an extensive number of affected nodes, and almost half of respondents with metastatic breast cancer have disease which spread to multiple organ system.

The data in Table II underscore the fact that most young women's breast cancers are not found via annual screening opportunities, as no such opportunity exists for them. The sad consequence of this is our members' ratings of their physicians' performance, namely, that the majority of young women feel they were not provided with quality care, based upon significant levels of perceived "age discrimination or bias." This finding might lead one to speculate that there is a possible correlation with this pronounced level of dissatisfaction and the increased volume of malpractice cases initiated by younger women. Furthermore, the significant percentage of large tumors is a particular tragedy given the generally accepted 7-year length of time for a tumor to grow to 1 cm. It strongly suggests that breast tumors are growing more aggressively in younger women, given the unlikely circumstance that cancer growth may have begun as early as puberty to the late teen years in some of these women. If screening opportunities had begun at earlier ages for these women, the incidence of such large tumors would almost certainly have been significantly reduced.

Based upon the data the YSC obtained from its members, the YSC believes that current screening and diagnostic tools, their current application, and physicians' attitudes toward suspicious findings in younger patients all may be factors contributing to underdiagnosis of breast cancers in younger women. Such underdiagnosis obviously precedes undertreatment and poorer outcomes. Our findings emphasize a need
to change the priorities for breast cancer screening in younger women in order to include the following:

(1) Improved information for young women of their risk profiles and the importance of appropriate screening and surveillance;

(2) Improved education of frontline physicians, including obstetricians and gynecologists and primary care physicians, regarding possible biases against offering radiologic work-ups for younger patients on the basis of their being "too young" to be at risk for breast cancer;

(3) Development of a new risk-assessment model better suited for use in young women;

(4) Development of new, cost-effective diagnostic tools that can be used to screen younger women (these would ideally involve minimal or no radiation exposure);

(5) Clarification of the insurance issues and obstacles associated with diagnostic [mammographic/sonographic/MRI] screening for breast cancer in younger patients;

(6) Greater advocacy and education regarding the need for public-health screening interventions within the general population of young women, despite the perception that breast cancer is "rare" in this age group.

The YSC also believes that priorities for breast cancer diagnostics in younger women must include the following:

(1) Additional studies to address the relative efficacy of mammography, sonography, and MRI in diagnosing breast cancer in young women, compared to older women;

(2) Improved understanding of the best screening format (e.g., the use of two or three methods in combination) and the necessary frequency, thereby assisting clinicians in achieving the best likelihood of early and timely diagnosis for each patient, which would contribute to improved outcomes;

(3) Expedited development of a biologically based method for early detection of breast cancers that is both cost effective for the general population and does not discriminate on the basis of age.

If these suggestions are implemented, there exists the possibility of reducing delays in diagnosis, performing more breast-conserving surgeries, with reduced morbidities, and improving the prognosis and outcome for women under the age of 40, for whom breast cancer screening is currently unavailable. Addressing these priorities may also help to ensure young women's improved satisfaction with their doctors' care and effect a reduction in the number of malpractice lawsuits arising from misdiagnoses of this population.

REFERENCES