Post-Treatment Symptoms
Among Ethnic Minority Breast Cancer Survivors

Rani Eversley, PhD, Diane Estrin, BS, Suzanne Dibble, DNSc, RN, Linda Wardlaw, DrPH, Maria Pedrosa, MA, and Wendy Favila-Penney, BA

Purpose/Objectives: To determine racial and ethnic differences in the range and number of post-treatment symptoms among women who have undergone surgical and postsurgical treatment for breast cancer.

Design: Retrospective study.
Setting: Community-based social services agency and public health clinic.
Methods: Face-to-face interview of 116 women who had undergone breast cancer surgery.
Sample: Primarily low-income women in an urban area in northern California. Participants were recruited via posted flyers regarding the study.
Main Research Variables: Outcomes (depression, fatigue, pain, and swelling from lymphedema) and demographics (ethnicity, age, income, insurance, education, and marital status).

Findings: The typical participant was 47 years old, had 12 years of education, and was a parent (74%), unmarried (67%), heterosexual (88%), uninsured (68%), and employed (66%). Thirty percent were Caucasian, 30% African American, 25% Latina, and 15% women of other ethnic backgrounds. African American women and Latinas reported increased rates of pain and an increased number of symptoms. Latinas also reported higher rates of fatigue and depression. In multivariate analyses, an increased number of symptoms was associated with decreased income, with receiving chemotherapy, with having a mastectomy, and with Latina ethnicity.

Conclusions: These data suggest an increased rate of post-treatment symptoms experienced by low-income and ethnic minority women.

Implications for Nursing: A need exists for affordable, culturally appropriate symptom management interventions. Nursing will have a vital role in designing, testing, and offering such interventions.

Breast cancer is the most common cancer in women, with 211,240 new invasive cases expected in 2005 (American Cancer Society [ACS], 2005). However, death rates have declined since the 1990s, with the largest decline in younger women (ACS, 2004). Overall five-year relative survival rates from the time of diagnosis are now 97% for localized disease, 79% for regional stage, and 23% for metastatic breast cancer (ACS, 2004). However, only 74% of African American women survive for five years, compared with 88% of Caucasian women (ACS, 2004). These statistics indicate a need to address disparities in survival as well as quality of life among breast cancer survivors.

Post-treatment symptoms, including fatigue, depression, cognitive difficulties, pain, and nausea, are common among women who have undergone treatment for breast cancer (Carpenter et al., 1999; Kakuda, Stuntz, Trivedi, Klein, & Vargas, 1999; Overgard, 2000; Shank, Moughan, Owen, Wilson, & Hanks,

Key Points . . .
➤ Increased levels of post-treatment symptoms exist among minorities.
➤ Increased levels of symptoms also are associated with decreased income.
➤ Affordable symptom management is indicated.

Goal for CE Enrollees:
To examine the racial and ethnic differences in the range and number of post-treatment symptoms of breast cancer survivors.

Objectives for CE Enrollees:
1. Examine the relationship among surgical treatments, adjuvant therapies, and post-treatment symptoms in a multiethnic (Caucasian, African American, and Latina) sample of breast cancer survivors.
2. Identify the proportions of women reporting symptoms in each ethnic group.
3. Discuss the independent associates of reporting multiple symptoms.

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Depression

Although a wide range of rates is reported because of varying degrees in sensitivity of the measures used, depression has been estimated in as many as 57% of patients with breast cancer (Badger, Braden, & Mishel, 2001; Morasso et al., 2001). Women who have a history of trauma are at especially high risk for becoming more severely depressed after breast cancer diagnosis (Green et al., 2000). Depression at breast cancer diagnosis has been associated with younger age (Compas et al., 1999) and late-stage diagnoses (Desai, Bruce, & Kasl, 1999). Walker et al. (1999) demonstrated that psychological factors such as depression are independent prognostic factors of survival among breast cancer survivors undergoing chemotherapy, regardless of size of tumor at diagnosis.

Pain

A large number of patients with breast cancer experiences postsurgical pain at the site of incision (Smith, Bourne, Squair, Phillips, & Chambers, 1999). Postsurgical pain is a chronic neuropathic pain syndrome that manifests in electric shock-like pain, shooting or burning pain, and altered skin sensation prevalent after radical mastectomy, modified radical mastectomy, and lumpectomy (Stevens et al., 1995). Estimates of prevalence range from 20%–27%. Pain also occurs in women who develop lymphedema, an accumulation of protein-rich fluid in soft tissue secondary to interruption of flow of lymphatic fluids. Lymphedema most commonly is found in the extremities but also may occur in the head, neck, abdomen, lungs, and genitals (Loudon & Petrek, 2000). Lymphedema, which generally is progressive, can go from a barely noticeable inflammation to severe impairment of a limb. Lymphedema is estimated to affect as many as 56% of breast cancer survivors and is believed to result from surgical resection of lymphatic vessels and nodes, fibrosis induced by infection, or radiation or surgery around these structures (Erickson, Pearson, Ganz, Adams, & Kahn, 2001).

Fatigue

Fatigue has been cited as the most prevalent and persistent of difficulties and affects up to 75% of cancer survivors (Broeckel, Jacobson, Horton, Balducci, & Lyman, 1998; Okuyama et al., 2000; Woo et al., 1998). Fatigue is a commonly occurring side effect of chemotherapy (Groppman & Itri, 1999; Jacobsen et al., 1999; Richardson, 1995). Moreover, fatigue is associated with the development of other chemotherapy side effects such as nausea and mouth sores (Jacobsen et al.).

Purpose

The purpose of this study was to examine the relationship among surgical treatments, adjuvant therapies, and post-treatment symptoms in a multiethnic (Caucasian, African American, and Latina) sample of breast cancer survivors. Specific questions included “What are the proportions of women reporting symptoms in each ethnic group?” and “What are the independent associates of reporting multiple symptoms?”

Methods

A descriptive survey was designed collaboratively between two community-based organizations and university-based researchers to examine what appeared to be disproportionate suffering of post-treatment symptoms among the ethnic minority breast cancer survivors seeking social services from these community-based organizations.

Design and Sample

Inclusion criteria for this descriptive study were adult women aged 18–60 years who were diagnosed and treated for breast cancer during the past two years, working at least 20 hours weekly at the time of their diagnosis, able to give informed consent, and able to speak either English or Spanish.

Settings

The collaborating agencies included a program that offers advocacy and practical support to women living with cancer and a program to assist patients with cancer attending public hospitals to obtain and adhere to follow-up care. Both programs are located in an urban area in northern California.

Procedures

Participants responded to posted flyers by calling the study coordinator. After receiving informed consent, eligible patients were surveyed using a face-to-face interviewer-administered instrument in Spanish or English that lasted 45–90 minutes. Interviewers estimated the refusal rate to be approximately 15%.

Instruments

Study measures included demographics; disease severity; surgical treatment; post-treatment symptoms measured by the Piper Fatigue Scale (Piper et al., 1998), the Brief Pain Inventory (BPI) (Cleeland, Gonin, Baez, Loehr, & Pandya, 1997), and the Center for Epidemiologic Studies–Depression (CES-D) Scale (Radloff, 1977); and lymphedema-related swelling using a single item on a 1–10 scale. Scale validity had been tested and established in patients with cancer for the Piper Fatigue Scale (Piper et al.), the BPI (Tittle, McMillan, & Hagan, 2003) and the CES-D (Hann, Winter, & Jacobsen, 1999).

The full-scale internal consistency (Cronbach's alpha) for each of the standardized scales ranged from 0.87–0.97, demonstrating good to excellent scale integrity for the study population. Within ethnic groups, less satisfactory results were
found in the pain score and pain interference scores for the Latinas (0.84) and the cognitive or mood scores on the Piper Fatigue Scale for Caucasians (0.79).

Data Analyses

Data were checked, cleaned, entered, and analyzed using SPSS® version 11.0 (SPSS Inc., Chicago, IL) by the study team. Proportions of disease, treatment, and symptom variables were calculated for each ethnic group and compared by chi-square. Mean symptom scores were calculated and compared using analysis of variance. The independent correlates of total number of symptoms were calculated using least-squares regression.

Results

The mean age of the women (N = 116) who participated in this pilot survey was 47 years (range = 29–68). Thirty percent were Caucasian, 30% African American, 25% Latina, and 15% were of other ethnic backgrounds (3 Asians or Pacific Islanders, 14 women who reported mixed-race heritage, and 2 whose ethnicity was not indicated). Thirty-three percent were currently married, and 12% were lesbian or bisexual. The mean years of education was 12 (range = 0–19). The current mean monthly net income was $1,236 (range = $0–$3,500). Latinas, African Americans, and women of other ethnic backgrounds reported lower incomes compared to Caucasians (p ≤ 0.001). Latinas reported the lowest mean years of education, followed by women of other ethnic backgrounds, African Americans, and Caucasians (p ≤ 0.01). Caucasians, women of other ethnic backgrounds, and Latinas were more likely to report being currently married compared to African Americans (p ≤ 0.01). Caucasians were more likely to report being lesbian or bisexual than African Americans, Latinas, and women of other ethnic backgrounds (p ≤ 0.05). Caucasians also were more likely to report having health insurance and to report being diagnosed with stage I breast cancer compared to African Americans, Latinas, and women of other ethnic backgrounds (p ≤ 0.01). Latinas were more likely to not know their breast cancer stage compared to African Americans and Caucasians (p ≤ 0.01). African Americans and Latinas were more likely to report having a mastectomy compared to Caucasians and women of other ethnic backgrounds (p ≤ 0.01). Latinas also were more likely to report receiving chemotherapy (p ≤ 0.01) (see Table 1).

Eighty-four percent of the women reported that they currently suffer from at least one post-treatment symptom. This included 79% with pain, 37% with fatigue, 52% with levels of depressive symptomatology sufficient to be considered clinically depressed (i.e., CES-D score ≥ 16), and 63% with moderate to severe swelling from lymphedema. Latinas reported significantly higher rates of fatigue (p ≤ 0.001) and higher rates of depression (p ≤ 0.001). African Americans and Latinas were more likely to report pain. African Americans, Latinas, and the other women were more likely to report swelling (lymphedema) than Caucasians (p ≤ 0.001).

Ethnicity, education, income, being insured, stage of disease, mastectomy, and chemotherapy were entered into a least-squares regression model to examine independent predictors of number of symptoms. Lower income (p ≤ 0.01), having a mastectomy (p ≤ 0.01), receiving chemotherapy (p ≤ 0.05), and being Latina (p ≤ 0.01) were significantly associated with an increased number of symptoms. No other independent significant relationships existed among demographic, disease or treatment variables, and number of symptoms (see Table 2).

Discussion

This is the first study designed to explore breast cancer-related post-treatment difficulties by ethnicity. African Americans and Latinas reported significantly higher rates of pain and lymphedema. Latinas reported significantly higher rates of depression and fatigue. Post-treatment symptoms have not been explored extensively among minority patients with breast cancer, and these results suggest that substantive ethnic differences exist.

Latinas reported almost twice the rate of depressive symptoms as African Americans and Caucasians. African Americans and Latinas reported higher rates of pain than Caucasians. Reporting lower income, having a mastectomy, having chemotherapy, and being Latina were significant predictors of reporting an increased number of symptoms. This suggests that social and economic factors may play a major role in women being able to access post-treatment rehabilitative care. Although the relationship between social and demographic factors and post-treatment symptoms has not been explored extensively, increased income has been associated with improved quality of life among African American and Caucasian breast cancer survivors (Ashing-Giwa, Ganz, & Petersen, 1999).

These data also suggest that Latina breast cancer survivors are at very high risk for depression and may be in need of targeted psychological support and therapeutic interventions. A possible reason for increased reporting of depression and fatigue among Latinas is an increased rate of receiving chemotherapy. Previous research has shown that depression also has been associated with fatigue and that depression and increased fatigue have been associated with chemotherapy (Jacobsen et al., 1999; Okuyama et al., 2000). Additional factors contributing to depression among Latinas may include low income, decreased access to services, difficulty with finding culturally sensitive services, gender roles, and difficulties with immigration (Amaro & Felipe-Russo, 1987).

Reasons for increased rates of pain among African Americans and Latinas may include more radical treatments (especially increased rates of mastectomy) as a consequence of being diagnosed with more advanced disease and possible disparities in treatment options. Additionally, considerable attention has been given to ethnic and gender disparities in disease screening after pain complaints, interventions offered, and types of pain medications prescribed (Cleeland et al., 1997; MacDonald, 1993; Todd, Deaton, D’Adamo, & Goe, 2000).

Limitations

This study has a number of limitations. A retrospective self-report survey makes attributing causality difficult. The volunteer sample of breast cancer survivors who are enrolled in services at a cancer advocacy or support organization may contribute to a bias toward women who are having more difficulty adapting to cancer or cancer treatment. The psychometrics of the scales, although generally acceptable, are not even across ethnic groups, and the small sample size makes for limited interpretability and generalizability. Finally, this sample was collected in an urban area in northern California, from women who were enrolled in ongoing health care, and may not be representative of a national sample of multiethnic breast cancer survivors.
Strengths of the study include a developing expertise in recruitment of a multiethnic sample of breast cancer survivors. In addition, this experience of melding the community with university-based research was a successful endeavor.

Table 1. Sample Description

<table>
<thead>
<tr>
<th>Variable</th>
<th>Caucasians</th>
<th>African Americans</th>
<th>Latinas</th>
<th>Others</th>
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<td>49</td>
<td>46</td>
<td>49</td>
<td>47</td>
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<tr>
<td>Education (years)</td>
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<td>12**</td>
<td>10</td>
<td>11</td>
<td>12</td>
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<td>Range</td>
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<td>8–19</td>
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<td>–</td>
<td>61</td>
<td>65</td>
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<td>71</td>
<td>93</td>
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<td>74</td>
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<td>Sexual orientation (%)</td>
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<td>Heterosexual</td>
<td>63</td>
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<td>100</td>
<td>94</td>
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<td>8</td>
<td>–</td>
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<td>12*</td>
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<td>Part-time</td>
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<td>Health insurance (%)</td>
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<td>18</td>
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<tr>
<td>Disease stage (%)</td>
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<td></td>
</tr>
<tr>
<td>I</td>
<td>66</td>
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<td>23</td>
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<td>Disease stage unknown (%)</td>
<td>3</td>
<td>–</td>
<td>21</td>
<td>6</td>
<td>7**</td>
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<tr>
<td>Breast cancer procedure (%)</td>
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<td></td>
<td></td>
<td></td>
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<tr>
<td>Lumpectomy</td>
<td>72</td>
<td>44</td>
<td>43</td>
<td>53</td>
<td>44**</td>
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<tr>
<td>Mastectomy</td>
<td>27</td>
<td>66</td>
<td>57</td>
<td>25</td>
<td>56**</td>
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<td>Radiation</td>
<td>92</td>
<td>88</td>
<td>88</td>
<td>38</td>
<td>88</td>
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<tr>
<td>Chemotherapy</td>
<td>41</td>
<td>47</td>
<td>89</td>
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<td>58**</td>
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<td>Postsurgical symptoms</td>
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<td>Number of symptoms (X)</td>
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<td>1.5</td>
<td>2.5</td>
<td>1.1</td>
<td>1.7**</td>
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<tr>
<td>Fatigue (%)</td>
<td>22</td>
<td>27</td>
<td>68</td>
<td>40</td>
<td>37**</td>
</tr>
<tr>
<td>Pain (%)</td>
<td>54</td>
<td>91</td>
<td>93</td>
<td>65</td>
<td>79***</td>
</tr>
<tr>
<td>Swelling (lymphedema) (%)</td>
<td>39</td>
<td>77</td>
<td>75</td>
<td>71</td>
<td>63***</td>
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<tr>
<td>Clinically depressed (%)</td>
<td>40</td>
<td>38</td>
<td>89</td>
<td>47</td>
<td>52***</td>
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<tr>
<td>CES-D score (X)</td>
<td>13.5</td>
<td>14.2</td>
<td>28.3</td>
<td>17.5</td>
<td>18.0***</td>
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<tr>
<td>CES-D score (range)</td>
<td>1–34</td>
<td>1–30</td>
<td>9–53</td>
<td>2–46</td>
<td>1–53</td>
</tr>
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</table>

N = 116
*p < 0.05, **p < 0.01, ***p < 0.001
CES-D—Center for Epidemiologic Studies–Depression Scale
Note. Missing data exist for some variables. Because of rounding, percentages may not total 100.

Conclusions

Data from this survey suggest that, in addition to being associated with breast cancer treatments, post-treatment symptoms may be associated with sociodemographic factors such as ethnicity and income. In the past, social disparities in breast cancer screening and treatment have been associated with decreased chances for survival. These data suggest that social disparities in symptoms also may be associated with disparities in functioning and quality of life. These disparities among breast cancer survivors may result from lack of information regarding therapeutic interventions, inability to afford rehabilitative therapies, language barriers, or lack of information on how to communicate effectively with providers.
Implications for Nursing

Pharmacologic, self-help, and complementary therapy interventions to reduce the impact of post-treatment symptoms are becoming more widespread. These findings suggest a need for these strategies to be affordable and linguistically and culturally appropriate to address the needs of a wider and ethnically inclusive group of breast cancer survivors. Nursing will have a vital role in designing, testing, and offering such interventions.

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References


