The Attitudes, Communication, Treatment, and Support Intervention to Reduce Breast Cancer Treatment Disparity

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Five-year survival after first diagnosis of breast cancer is 13% lower in African American women than in Caucasian American women, an alarming disparity that cannot be explained by stage of disease at presentation (American Cancer Society, 2007; Jemal et al., 2007). U.S. cancer studies have found strong evidence that Caucasian patients receive more aggressive initial treatment for breast cancer than African American patients, resulting in higher mortality among non-Caucasian populations (Blackman & Masi, 2006). In the United States, only half of the African American women eligible for adjuvant breast cancer therapy receive it (Hershman et al., 2005). The treatment disparities also are evident in treatment delay and missed appointments (Hershman et al., 2003). Clinical delays in breast cancer from onset of symptoms until treatment affect ultimate prognosis. Nonadherence to breast cancer treatment and treatment delays from diagnosis to initiation of treatment, specifically adjuvant chemotherapy, may be among the reasons for worse breast cancer outcomes in African American women (Bickell et al., 2006; Blackman & Masi, 2006; Hershman et al., 2003, 2005). This recognition is critical because it suggests that breast cancer survival disparity can be decreased through clinical interventions that increase adherence to chemotherapy.

Distinctive and specific attitudes, perceptions, and stressors among African American women may affect breast cancer treatment adherence (Bickell et al., 2006). Knowledge regarding treatment and its likely outcome is critically important for decision making related to adherence to prescribed therapy (Battaglia, Roloff, Posner, & Freund, 2007; Rosenzweig, Wiehagen, Brufsky, & Arnold, 2007). Several factors are known to contribute to nonadherence to breast cancer treatment among African American women, including (a) perceptions, beliefs, and unique stressors (Ahmed, Fort, Elzey, & Belay, 2005; Bradley, 2006; Lythcott, Green, & Kramer-Brown, 2003; Steinberg et al., 2006); (b) inaccurate knowledge

Purpose/Objectives: To test the effect of a supportive, one-time psychoeducational intervention on treatment adherence among African American women receiving first adjuvant therapy for breast cancer.

Design: A pilot, randomized, controlled clinical trial, two-group design, with one-time intervention and four data collection points.

Setting: Two University of Pittsburgh Cancer Institute clinics.

Sample: 24 African American women.

Methods: The Attitudes, Communication, Treatment, and Support (ACTS) intervention is a 45-minute one-on-one session with an African American woman recommended to have chemotherapy for breast cancer. The interventionist is an African American breast cancer survivor. The intervention consists of a discussion about chemotherapy and the importance of communicating knowledge needs and distress, an explanation of the specific treatment plan according to pathology, and support through the survivor testimonial and video clips from the African American community.

Main Research Variables: Dose of chemotherapy received and dose of chemotherapy prescribed.

Findings: Twenty patients completed chemotherapy, and four chose not to begin or discontinued recommended chemotherapy. The groups were equal in key sociodemographic variables. Compared to usual care, the ACTS intervention participants demonstrated trends toward initiation of chemotherapy (100% versus 82%), overall adherence to chemotherapy (92% versus 73%), and percentage of total dose of chemotherapy received or prescribed (94% versus 74%). Compared to usual care, the ACTS intervention participants demonstrated more rapid initiation of chemotherapy and better overall adherence to chemotherapy.

Conclusions: The pilot ACTS intervention shows promise as a psychoeducational intervention to assist with chemotherapy decision making among African American women.

Implications for Nursing: African American women are at high risk of not receiving the full dose of prescribed chemotherapy for breast cancer for multiple reasons. Nurses must be sensitive to the unique fears and concerns of this population regarding chemotherapy decisions. An intervention addressing these fears and concerns may help to increase adherence.
about personal risk and treatment efficacy (Polacek, Ramos, & Ferrer, 2007); (c) difficulty communicating with predominantly race-discordant clinicians (Cooper, Beach, Johnson, & Inui, 2006); (d) lack of social support (Soler-Vila, Kasl, & Jones, 2003); (e) panic and fear regarding a cancer diagnosis (Reynolds et al., 1994); (f) belief in the power of God to heal (Henderson, Gore, Davis, & Condon, 2003; Holt, Clark, Kreuter, & Rubio, 2003); (g) fatalism (Powe, Hamilton, & Brooks, 2006); (h) silence (“not talking about it”) (Phillips, Cohen, & Moses, 1999; Thomas, 2006); (i) economic vulnerability (Gordon, 2003; Newman et al., 2002); (j) the stress of multiple family roles (Lerman & Schwartz, 1993; Magai, Consedine, Adjei, Hershman, & Neugut, 2008); and (k) an overall pessimism regarding the potential for a cure (Sheppard, Zambrana, & O’Malley, 2004). Rather than being viewed as barriers, these important psychosocial and cultural influences need to be viewed as unique perceptions. The research team sought to accommodate these psychosocial and cultural influences in a psycho-educational intervention to equalize cancer care for African American women.

The purpose of this pilot study was to evaluate the effect of the Attitudes, Communication, Treatment, and Support (ACTS) Intervention versus usual care on adherence to recommended chemotherapy among African American women with breast cancer. Adherence was defined as days from chemotherapy recommendation to first chemotherapy, percentage of total dose prescribed or total dose received, and overall adherence (at least 80%) of recommended chemotherapy in prescribed time frame.

Methods

The study’s design was a pilot, randomized, controlled clinical trial, two-group design, with one-time intervention and four data collection points (at baseline and three time points corresponding to chemotherapy completion: 50%, 75%, and 100%).

Intervention

Guided by Kressin’s (2005) Model of Health Disparity and previous work detailing the African American breast cancer experience (Rosenzweig, Weihagen, Conroy, Sillamen, & Arnold, 2009), the research team devised the psychoeducational ACTS intervention to address factors related to breast cancer treatment non-adherence. Kressin (2005) conceptualized a minority patient’s decision-making process regarding adoption of medical recommendation as influenced by three realms: (a) patient factors such as health-related beliefs, (b) physician factors, and (c) system factors. The intervention was designed to influence only the patient aspect of the model. The resulting patient treatment decision determines whether physician recommendations will be followed. The treatment decision was the focus of the intervention. The intervention was designed to primarily address one (the patient) component of the multietiologic (patient, provider, and institution) model of healthcare disparity. The provider and institutional components of the disparity model were not manipulated nor measured in the analysis. The design was not intended to diminish the role of providers or institutions in decreasing cancer treatment disparity. The ACTS intervention instead focused on the patient centeredness of care and was designed to coach and empower African American women to ensure that they receive appropriate cancer treatment.

The ACTS intervention was developed through an iterative creative process with input from African American survivors to confirm its value and cultural acceptability. African American breast cancer survivors were asked to evaluate the proposed intervention’s content, cultural acceptability, and design during focus groups and one-on-one interviews. Results influenced further refinement of the intervention. More spiritually based content, human pictures with dark skin, more and vibrant pictures, less verbiage, and supportive video testimonials from the African American community were suggested and thus incorporated into the intervention.

Interventionists were recruited from a local African American breast cancer survivors support group. The interventionists were trained in breast cancer education, empathetic communication, cultural sensitivity, and conduct of research studies using didactic lecture, role playing, and online educational modules.

The final intervention for the participants consisted of a 30-minute face-to-face meeting with an African American woman with recently diagnosed breast cancer and recommended to undergo chemotherapy. Inclusion criteria were being African American race by self-report, having any stage of breast cancer, being recommended for chemotherapy, and having no history of previous chemotherapy. Participants were recruited on the day of chemotherapy recommendation from a medical oncology visit with the intervention to be completed immediately to within one week from chemotherapy recommendation. Participants were asked by a treating doctor or nurse if they were willing to be recruited for the study.

Procedure

If participants were willing, they met with a race-matched recruiter who obtained consent. Race-matched recruiters were used based on advice regarding optimal recruiting strategies from the study’s community advisory board, and race-matched interventionists were used based on literature supporting race-matched peers as most supportive to African American women during the breast cancer experience (Lythcott et al., 2003). The interventionist then needed to be in the clinical site at
the time of the patient visit to administer the intervention or make plans to administer within one week.

The ACTS intervention uses a race-matched peer interventionist to address attitudes (including perceptions and stressors) that may affect adherence to clinical visits and treatment; encourage and model patient communication with healthcare providers regarding physical and emotional needs, with attention to race-discordant situations; and provide tailored, understandable information about treatment and its rationale. The support component is threaded throughout the intervention via the presence of a race-matched breast cancer survivor and supportive video messages from the African American community.

The interventionist began with a dialogue asking about the participant’s thoughts related to chemotherapy. The discussion was followed by a video montage of supportive messages from the African American community acknowledging the difficulty of a cancer diagnosis. Then, the interventionist shared her personal story of breast cancer diagnosis, treatment, and survival and reviewed the participant’s individual pathology report. The tumor size, presence or absence of lymph nodes, estrogen status, and HER2/neu status were shared with text and pictorial explanations because all have implications for the therapeutic recommendation. The interventionist confirmed the facts with the clinic nurse or physician before the intervention. The interventionist provided no further clinical information. Any questions regarding staging, prognosis, or treatment were referred back to the clinical care team. Next, the interventionist discussed the importance of communication of physical, emotional, and practical needs to help the participant garner needed support. The intervention ended with a closing video montage of supportive, encouraging messages from the African American community. All intervention sessions were recorded, and the audiotape was reviewed by the principal investigator for protocol fidelity.

The sample was recruited from two urban sites of the Comprehensive Breast Program in the University of Pittsburgh Cancer Institute, a National Cancer Institute-designated comprehensive cancer program. The community from which the sample was recruited has African American poverty rates that are four times higher than Caucasian poverty rates in Allegheny County and three times higher than Caucasian rates in the nation (University of Pittsburgh, Center on Race and Social Problems, 2007). The African American population is not disseminated widely in the community but is primarily urban and located mainly within specific city neighborhoods.

Outcomes

Adherence was defined as days from chemotherapy recommendation to first chemotherapy, percentage of total dose prescribed or total dose received, and overall adherence (at least 80%) of recommended chemotherapy in prescribed time frame.

Results

Twenty-four patients were enrolled; 20 participants completed the recommended chemotherapy, and 4 chose not to begin or discontinued recommended chemotherapy. Key demographic variables were equal across randomized groups. Among reviewed interventions, 100% adhered to the protocol.

Compared to usual care, the ACTS intervention participants demonstrated trends toward initiation of chemotherapy (100% versus 82%), overall adherence to chemotherapy (92% versus 73%), and percentage of total dose of chemotherapy received or prescribed (94% versus 74%). Compared to usual care, the ACTS intervention participants demonstrated more rapid initiation of chemotherapy and better overall adherence to chemotherapy. Nonparametric Wilcoxon test for comparison of medians (percentage of chemotherapy received) and Fisher’s exact test for comparison of categorical variables (initiated chemotherapy, adherence to chemotherapy) revealed no statistical significance between groups (see Table 1). Enrollment and retention were adequate, with enrollment of 24 of 27 (89%)

<table>
<thead>
<tr>
<th>Variable</th>
<th>Intervention (N = 13)</th>
<th>Usual Care (N = 11)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age (years)</td>
<td>X: 50.3 ± 11.1</td>
<td>X: 49.8 ± 11.3</td>
</tr>
<tr>
<td>Days from first oncology visit to start of chemotherapy</td>
<td>21.6 ± 9.4</td>
<td>23.2 ± 13.4</td>
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<table>
<thead>
<tr>
<th>Variable</th>
<th>n</th>
<th>%</th>
<th>n</th>
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</tr>
</thead>
<tbody>
<tr>
<td>Completed high school</td>
<td>13</td>
<td>100</td>
<td>11</td>
<td>100</td>
</tr>
<tr>
<td>Married</td>
<td>2</td>
<td>15</td>
<td>2</td>
<td>18</td>
</tr>
<tr>
<td>Annual income more than $50,000</td>
<td>2</td>
<td>15</td>
<td>2</td>
<td>18</td>
</tr>
<tr>
<td>Religiosity extremely important</td>
<td>13</td>
<td>100</td>
<td>10</td>
<td>91</td>
</tr>
<tr>
<td>Clinical delay of chemotherapy (infection, dental)</td>
<td>2</td>
<td>15</td>
<td>1</td>
<td>9</td>
</tr>
<tr>
<td>Did not begin chemotherapy</td>
<td></td>
<td></td>
<td>2</td>
<td>18</td>
</tr>
<tr>
<td>Overall adherence to chemotherapy</td>
<td>12</td>
<td>92</td>
<td>8</td>
<td>73</td>
</tr>
<tr>
<td>Began recommended chemotherapy</td>
<td>13</td>
<td>100</td>
<td>9</td>
<td>82</td>
</tr>
<tr>
<td>Stopped chemotherapy</td>
<td>1</td>
<td>8</td>
<td>1</td>
<td>9</td>
</tr>
</tbody>
</table>

a U.S. median income is $50,245 (Noss, 2010).
of eligible patients) and retention of 20 of 24 (83% participants).

Of the women who began chemotherapy but did not complete, one woman did not return without a stated reason and, after a few months, became pregnant. The other woman was homeless and, despite social service support, never felt that she had a stable living environment to continue therapy. Two women did not start chemotherapy. One woman chose not to discontinue a contraindicated (for chemotherapy) oral medication that she was prescribed chronically and could not begin treatment. The other woman opted for spiritual and naturalistic therapy.

Discussion

Unlike previous strategies to improve adherence and reduce the racial disparity in breast cancer outcomes, the ACTS intervention was geared to treatment, not specifically screening, and offers promising results. The intervention was developed to address the issues most likely to impact treatment adherence among African American women. The issues of treatment nonadherence in the four women in this study who could improve long-term survival with chemotherapy are compelling and speak to the multiple levels of education and support needed for optimal patient education regarding breast cancer treatment. Every woman should decide whether she will endorse chemotherapy for her personal breast cancer treatment, but nurses must ensure that all treatment decisions are made with adequate information and assurance of physical and emotional support through treatment.

The influence of the ACTS intervention on adherence needs to be evaluated in an appropriately powered, larger study. In addition, the cost to retain an interventionist on staff in a medical oncology clinic needs to be assessed to determine whether the intervention can be integrated into routine clinical practice.

Conclusions

Preliminary data and the literature suggest that African American women have characteristic worries and distress during the breast cancer therapy trajectory, possibly affecting their decision to adhere to chemotherapy and other breast cancer treatment. Unlike previous strategies to improve adherence and reduce the racial disparity in breast cancer outcomes, this intervention is geared toward treatment, not screening. The ACTS intervention was developed to address the issues most likely to affect treatment adherence and is timed to reach women at a vulnerable point in decision making (after medical oncology visit). The ACTS intervention’s influence on chemotherapy adherence and secondary influences on distrust of health care, communication with healthcare providers, and social support will need to be evaluated in a larger study.

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Digital Object Identifier: 10.1188/11.ONF.85-89

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