Beliefs in Chemotherapy and Knowledge of Cancer and Treatment Among African American Women With Newly Diagnosed Breast Cancer

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Purpose/Objectives: To examine beliefs regarding the necessity of chemotherapy and knowledge of breast cancer and its treatment in African American women with newly diagnosed breast cancer, and to explore factors associated with women’s beliefs and knowledge.

Design: Descriptive, cross-sectional study.

Setting: Six urban cancer centers in Western Pennsylvania and Eastern Ohio.

Sample: 101 African American women with newly diagnosed breast cancer.

Methods: Secondary analysis using baseline data collected from participants in a randomized, controlled trial at their first medical oncology visit before the first cycle of chemotherapy.

Main Research Variables: Belief in chemotherapy, knowledge of cancer and recommended treatment, self-efficacy, healthcare system distrust, interpersonal processes of care, symptom distress, and quality of life.

Findings: African American women endorsed the necessity of chemotherapy. Most women did not know their tumor size, hormone receptors, specific therapy, or why chemotherapy was recommended to them. Women who perceived better interpersonal communication with physicians, less self-efficacy, or were less involved in their own treatment decision making held stronger beliefs about the necessity of chemotherapy. Women without financial difficulty or having stronger social functioning had more knowledge of their cancer and recommended chemotherapy.

Conclusions: African American women with newly diagnosed breast cancer generally agreed with the necessity of chemotherapy. Knowledge of breast cancer, treatment, and risk reduction through adjuvant therapy was limited.

Implications for Nursing: Oncology nurses could help advocate for tailored educational programs to support informed decision making regarding chemotherapy acceptance for African American women.

Breast cancer is the most common cancer among American women and the second-leading cause of cancer death in the United States (American Cancer Society, 2015). Although survival is improving for all women with breast cancer, African American women with newly diagnosed breast cancer have overall lower five-year survival rates (78%) than Caucasian women (90%) (National Cancer Institute, 2014). Biologic differences do not explain all racial variation in breast cancer survival (Danforth, 2013; Martin et al., 2009). Historically, explanations for such disparities in survivorship include late-stage presentation in African American women related to poor adherence to breast cancer screening (Fedewa et al., 2011; Tariq, Latif, Zaiden, Jasani, & Rana, 2013). In addition, some social, economic, and cultural barriers to screening and treatment, such as social injustice, poverty, and a general mistrust of the healthcare system, may disproportionately affect African American women (Gerend & Pai, 2008).
Evidence shows that systemic chemotherapy and hormonal therapy improve survival after a diagnosis of breast cancer (Early Breast Cancer Trialists’ Collaborative, 2005; Peto et al., 2012). However, African American women are more likely to discontinue the treatment early or have treatment delays as compared to Caucasian women (Fedewa, Ward, Stewart, & Edge, 2010; Hershman et al., 2009). Previous studies (Martin et al., 2014; Nurgalieva et al., 2013; Sheppard et al., 2013) have explored factors associated with chemotherapy treatment delays and early treatment cessation and indicated that the patient–physician relationship and patients’ spiritual beliefs may be associated with treatment disparities (Sheppard et al., 2013) in addition to other factors, such as age; marital status; insurance coverage (Jansen, Otten, & Stiggelbout, 2006; Jorgensen, Young, & Solomon, 2013); cognitive, emotional, and social network variables (Magai, Consedine, Adjei, Hershman, & Neugut, 2008); and disease- or treatment-associated factors. Research also suggests that additional unknown sociocultural factors may influence treatment disparities (Nurgalieva et al., 2013).

Distinctive attitudes, perceptions, and stressors may affect breast cancer treatment adherence among African American women (Allicock, Graves, Gray, & Troester, 2013; Jansen et al., 2006; Jassem et al., 2013; Johnson, Elbert-Avila, & Tulsky, 2005; Thune-Boyle, Myers, & Newman, 2006). Medication nonadherence can be a reasoned decision for patients when they perceive limited benefits about the medication. Leventhal’s well-known self-regulatory theory suggests that patients are more likely to adhere to a prescribed medication regimen if they believe that the regimen makes common sense in the context of health beliefs and the likelihood of benefit (Leventhal, Meyer, & Nerenz, 1980). To ensure that consent for chemotherapy in African American women with newly diagnosed breast cancer is informed, it is necessary to explore and understand their perceptions regarding the necessity of chemotherapy.

Knowledge about cancer, treatment, and likely treatment outcomes is critically important for decision making regarding adherence to prescribed therapy (Sadler et al., 2007). African Americans traditionally are less active in seeking generic health information than other ethnic groups (Matthews, Sellergren, Manfredi, & Williams, 2002). In general, they have less knowledge about their bodies and lack awareness about cancer prevention (Ashing-Giwa et al., 2004). In a survey of women with breast cancer, African American women were found to be less likely than Caucasian women to correctly answer questions about their tumor characteristics, including stage and receptor status (Freedman, Kouri, West, & Keating, 2015). African Americans report a preference for cancer information tailored to individual risk (Darnell, Chang, & Calhoun, 2006) and health communication to be personally relevant and culturally appropriate (Allicock et al., 2013). How best to address the preferences for communication and education in African American patients with cancer requires a great deal of attention from healthcare providers. In addition, because of the disproportionate number of African Americans living at or below poverty levels, African Americans may have lower levels of health literacy than Caucasians and are less likely to question physicians (Gordon, Street, Sharf, & Souchek, 2006; Rust & Davis, 2011; Shea et al., 2004), limiting the amount of information they receive (Skalla, Bakitas, Furstenberg, Ahles, & Henderson, 2004). Breast cancer treatment is increasingly tailored and complex. Options for individual patients with breast cancer may differ from those of other patients based on the person’s tumor pathology (Olopade, Grushko, Nanda, & Huo, 2008), tumor subtype, treatment options, and associated treatment effects, making these discussions even more challenging (Nehls et al., 2013). Because the information is critically important for an informed decision, clinicians must understand the risk factors for lack of understanding among all women, work to increase clarity and relevance in information presentation, and subsequently improve patient understanding (Royak-Schaler et al., 2008). The healthcare system in general and individual providers may also play a role in influencing understanding (Lennes, Temel, Hoedt, Meilleur, & Lamont, 2013; Matthews et al., 2002). Few studies have specifically reported on African American women’s knowledge of cancer pathology and treatment effects (Ashing-Giwa et al., 2004; Hofman et al., 2004).

The purpose of the current study was to examine beliefs regarding the necessity of chemotherapy in African American women with newly diagnosed breast cancer, as well as their knowledge of their cancer pathology, the treatment recommended to them, and likely treatment outcomes. In addition, factors associated with African American women’s beliefs in chemotherapy and knowledge were also explored. It was expected that belief in chemotherapy was associated with physician communication and perceived relationship to the healthcare system. An additional hypothesis was that knowledge of cancer and recommended treatment was associated with sociodemographics, such as age, education, income, and communication with physicians. Findings from this study are expected to guide development of tailored interventions for African American women to improve patient counseling regarding understanding of chemotherapy recommendations.
Methods

This study was a secondary analysis using baseline data from 101 African American women who participated in a parent study at six urban cancer centers in Western Pennsylvania and Eastern Ohio. The parent study was a nonblinded, repeated-measures, intent-to-treat randomized, controlled trial comparing the efficacy of a psychoeducational intervention with that of usual care on percentage of prescribed dose of breast cancer chemotherapy received (Rosenzweig et al., 2011). Preliminary findings of the parent study revealed that the psychoeducational group demonstrated more rapid initiation of chemotherapy and better overall adherence to chemotherapy (Rosenzweig et al., 2011).

Sample

Participants in the study were African American women from southwestern Pennsylvania and eastern Ohio newly diagnosed with breast cancer. Informed consent was signed by all participants after the physician confirmed that chemotherapy was recommended. Inclusion criteria were (a) being African American, as determined by patient self-report, (b) aged 18 years or older, (c) being diagnosed with invasive breast cancer, (d) being of female gender, and (e) being recommended for chemotherapy. Exclusion criteria were (a) impaired cognition, as determined by clinician performing the initial history and physical examination, (b) inability to read and understand English, and (c) receiving hormonal therapy alone. Baseline data were collected before first therapy at the patient’s first visit to medical oncology or at a subsequent visit for prechemotherapy testing within one week of recommendation. Standard chemotherapy teaching about chemotherapy toxicity and potential side effects was completed by the RN in the clinic after the chemotherapy recommendation was made. Chemotherapy teaching did not include why the recommendation for chemotherapy was made. Questions to the nurse about the need for chemotherapy were referred back to the physician, per clinic policy.

Measures

Baseline questionnaires were administered by the research staff in a private conference room adjacent to the clinic area, free of distraction. It took about 40 minutes to complete all questionnaires.

Belief in chemotherapy: Belief in the necessity of chemotherapy was assessed using a subscale adapted with permission from the Beliefs about Medicines Questionnaire (BMQ). The subscale consisted of six items assessing African American women’s beliefs about the necessity of chemotherapy, such as “Chemotherapy is effective,” and “My health, at present, depends on chemotherapy.” Respondents indicated their degree of agreement with each statement on a five-point Likert-type scale, ranging from 1 (strongly disagree) to 5 (strongly agree). Scores for this subscale could range from 6–36. Higher scores indicated stronger beliefs in the necessity of chemotherapy. A Cronbach alpha of 0.86 was reported for the necessity scale of the original BMQ (Horne, Weinman, & Hankins, 1999).

Understanding of tumor and treatment: The Tumor and Treatment Knowledge Assessment is an investigator-created questionnaire and is deliberately brief because of the researcher’s reluctance to “test” patients in a clinical setting. Six questions, including size of tumor(s), lymph node status, status of hormone receptors, HER2 status, the name of specific therapy, and the reason that the chemotherapy recommendation was made, were asked in a conversational manner. The accuracy of the responses was then determined by study personnel against the medical record.

Demographic and medical variables: Sociodemographic variables included age, income, years of education, employment, insurance status, and spiritual beliefs. Clinical variables included comorbidities, previous medical history, current medications, current cancer treatment, and course of illness. Both were measured by the standard demographic and medical variable questionnaires from the University of Pittsburgh School of Nursing in Pennsylvania.

Health beliefs and distrust: The Health Care System Distrust Scale was constructed to measure a patient’s perceptions of the healthcare system. This 10-item, five-point Likert-type scale ranging from 1 (strongly disagree) to 5 (strongly agree) measures patient’s perceptions of healthcare honesty (four items), confidentiality (two items), competence (two items), and fidelity (two items) (Rose, Peters, Shea, & Armstrong, 2004). Higher scores indicate stronger healthcare system distrust. The internal consistency of the scale was 0.75 in a sample population with 43% African Americans and 45% Caucasians (Rose et al., 2004).

Communication satisfaction: The Medical Effectiveness Research Center Interpersonal Processes of Care (MERC IPC) questionnaire is a 29-item measure to assess interpersonal processes of care from the perspective of diverse racial/ethnic groups into a framework for investigating how processes of communication, decision making, and interpersonal style might account for observed ethnic and socioeconomic differences in health care (Stewart, Napoles-Springer, & Perez-Stable, 1999). For each item, respondents were asked how often that type of care had been provided
during the past 12 months using a five-point scale (1 = always, 2 = often, 3 = sometimes, 4 = rarely, 5 = never). An example of a question from the communication subscale is, “How often did doctors speak too fast?” Other example questions include, “How often did you and your doctors work out a treatment plan together?” for the decision-making subscale and, “How often were doctors concerned about your feelings?” for the interpersonal style subscale. Higher subscale scores indicate better perception of the process of care. The instrument was validated with internal consistency reliability ranging from 0.64–0.93 in ethnically diverse populations (Stewart et al., 1999; Wong, Korenbrot, & Stewart, 2004).

**Self-efficacy:** The General Self-Efficacy Scale (GSE) is a 10-item scale with a score for each question ranging from 1 (“not at all true”) to 4 (“exactly true”) assessing optimistic self-beliefs used to cope with a variety of demands in life (Schwarzer & Jerusalem, 1995). Higher scores indicate stronger patient belief in self-efficacy. Several studies have shown that the GSE has high reliability, stability, and construct validity (Bosscher & Smit, 1998; Luszczynska, Scholz, & Schwarzer, 2005).

**Quality of life:** The Functional Assessment of Cancer Therapy is a 27-item Likert-type self-report questionnaire yielding four subscales (physical well-being, social well-being, functional well-being, and emotional well-being) measuring health-related quality of life for patients with cancer (Brady et al., 1997; Cella et al., 1993). Each item is rated on a scale from 0 (not at all) to 4 (very much). This questionnaire has been determined to be appropriate for use in clinical oncology settings and shown to have good validity and reliability, with a Cronbach alpha of 0.89 for the total scale and 0.69–0.82 for the subscales (Cella et al., 1993).

**Symptom distress:** The McCorkle Symptom Distress Scale (SDS) was developed based on interviews with patients about their symptom experiences, with scores ranging from 1–5 on a Likert-type scale, with 5 indicating most severe (McCorkle & Quint-Benoliel, 1983). Total symptom distress can be obtained as the unweighted sum of 13 items. A cumulative score greater than 33 indicates severe distress, necessitating immediate intervention. Psychometric testing among patients with cancer using the SDS revealed high reliability with a Cronbach alpha of 0.97 (McCorkle & Quint-Benoliel, 1983).

**Data Management and Analysis**

Study data were collected and managed using REDCap electronic data capture tools hosted at the University of Pittsburgh (Harris et al., 2009). Data analysis was conducted using SPSS®, version 22.0. Descriptive statistics were used to describe the sample sociodemographics and summarize participants’ beliefs in chemotherapy and knowledge of cancer and treatment. For continuous variables, means and SDs were calculated. Categorical variables were described using frequencies and percentages. Correlation analyses, Mann–Whitney U tests, and multiple linear regression were used to assess relationships of sociodemographics, health system distrust, communication satisfaction, self-efficacy, quality of life, and symptom distress with beliefs in chemotherapy and knowledge of tumor and treatment. Both bivariate analysis results (significance level of p < 0.25) and literature reports were considered for selection of potential predictors in regression models (significance level of p < 0.05).

**Results**

The sample for this secondary analysis included 101 African American women with newly diagnosed breast cancer. Table 1 summarizes the personal characteristics of women in this study.

**Beliefs in Chemotherapy**

Prior to chemotherapy, African American women with newly diagnosed breast cancer had a mean score...
of 21.8 (SD = 4.6, range = 6–36) regarding their beliefs about the necessity of chemotherapy. Most women agreed or strongly agreed that their health depended on chemotherapy (n = 79), chemotherapy protected them from getting worse (n = 74), and chemotherapy was effective (n = 66) (see Table 2).

Bivariate correlation analyses demonstrated that women’s stronger beliefs about the necessity of chemotherapy medication were significantly associated with less distrust in the healthcare system (r = –0.217, p = 0.03), better interpersonal communication with physicians (r = 0.301, p = 0.002), and better interpersonal style of care experience with physicians (such as being respected, not discriminated against, and being emotionally supported) (r = 0.201, p = 0.045). Women’s sociodemographic characteristics were not found to be associated with their beliefs in necessity of chemotherapy. Women who had perceived economic distress (some or extreme difficulty to pay for basic needs) tended to believe more in necessity of chemotherapy than women of higher income, but the difference was marginally significant (p = 0.081).

The multiple linear regression model included age, income, self-efficacy, social support, health system distrust, interpersonal processes of care (communication, decision making, and interpersonal style), symptom distress, and knowledge of tumor and treatment. These variables significantly predicted the necessity of chemotherapy (F[10, 84] = 2.659, p = 0.007, R² = 0.24). After controlling for the other variables in the model, women who perceived receiving better interpersonal communication with their physician had greater beliefs in necessity of chemotherapy (b = 0.057, p = 0.007); woman with higher self-efficacy (b = –0.159, p = 0.044) and women who were more involved in their own treatment decision making (b = –0.079, p = 0.02) had fewer beliefs in the necessity of chemotherapy (see Table 3).

**Knowledge of Tumor and Chemotherapy**

More than half of African American women with newly diagnosed breast cancer did not know the size of their tumor (n = 57), the status of their hormone receptors (n = 65), the name of their specific recommended therapy (n = 66), or why chemotherapy was recommended to them (n = 80) (see Table 4). Higher knowledge of tumor and recommended chemotherapy was found to be significantly associated with higher quality of social function (r = 0.213, p = 0.034), some or all coverage of medication by insurance (U = 166, p = 0.027), and having no difficulty paying for basic needs by income (U = 773.5, p = 0.008). The multiple linear regression model includes sociodemographics (age, education, income, insurance, and marital status), self-efficacy, social support, health system distrust, interpersonal processes of care, and quality of life (physical and social function), which significantly predicted knowledge of tumor and chemotherapy (F[12, 81] = 2.634, p = 0.005, R² = 0.281). After controlling for the other variables in the model, income and quality of social function significantly predicted that women with no difficulty at all paying for basic needs (b = 1.197, p = 0.012) and women having better social function (b = 0.147, p = 0.012) had more knowledge of their tumor and recommended chemotherapy.

**Discussion**

African American women with newly diagnosed breast cancer believed that chemotherapy was necessary. However, they lacked knowledge about their disease and why chemotherapy was recommended to them. Lack of knowledge about breast cancer among minority women is supported by previous studies (Aashing-Giwa et al., 2004; Freedman et al., 2015). In particular, gaps were found in information provided from physicians to African American women with breast cancer about treatment, side effects, and follow-up care, including long-term effects of their treatment (Royak-Schaler et al., 2008). Lack of understanding of treatment recommendations can increase patients’ concerns and may affect their decision making about treatment (Cowley, Heyman, Stanton, & Milner, 2000). To improve patients’ understanding of information about the treatment goal, long-term effects, and side effects of the treatment, clinicians may need to be more culturally competent in communication and integrate appropriate communication skills when providing patient education and support (Nehls et al., 2013). The role of lay or professional navigators

<table>
<thead>
<tr>
<th>Belief Statement</th>
<th>n</th>
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<tbody>
<tr>
<td>My health, at present, depends on chemotherapy. (N = 100)</td>
<td>79</td>
</tr>
<tr>
<td>Chemotherapy protects me from becoming worse. (N = 100)</td>
<td>74</td>
</tr>
<tr>
<td>Chemotherapy is effective. (N = 101)</td>
<td>66</td>
</tr>
<tr>
<td>My health in the future will depend on chemotherapy. (N = 101)</td>
<td>56</td>
</tr>
<tr>
<td>I sometimes worry about the long-term effects of chemotherapy. (N = 100)</td>
<td>50</td>
</tr>
<tr>
<td>Without chemotherapy, I would be very ill. (N = 99)</td>
<td>41</td>
</tr>
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may mitigate communication difficulties between clinicians and patients in breast cancer care (Robinson-
White, Conroy, Slavish, & Rosenzweig, 2010).

The current study also found that African American women’s beliefs in the necessity of chemotherapy were highly associated with their relationship with the healthcare system, particularly their trust in hospital care and their communication with healthcare providers. Women reporting poor relationships with the healthcare system and their physicians are expected to have less belief in the necessity of chemotherapy. This finding is consistent with previous studies that suggest that physician trust and patient–physician communication were critically important factors for patients with cancer in deciding whether to accept chemotherapy (Jorgensen et al., 2013; Kreling, Figueiredo, Sheppard, & Mandelblatt, 2006). Medical mistrust and less physician communication were found to be common among minority patients with cancer (Bergamo et al., 2013; Kreling et al., 2006). African American patients reported fewer encounters with physicians, asked fewer questions, and received less information about cancer treatment than Caucasian patients (Baldwin et al., 2005; Gordon et al., 2006). In this current study, a high percentage of women reported misunderstanding of cancer and recommended treatment, indicating possible ineffective patient–physician communication.

Greater self-efficacy and perceived shared decision making can increase the sense of control and engagement in health care (Andersen, Bowen, Morea, Stein, & Baker, 2009; Jones et al., 2010). However, both factors were found in the current analysis to signifi-
cantly predict less belief on the part of the patient in the necessity of chemotherapy. It is possible that women feel confident that other options are available to treat breast cancer. It also is possible that a confidence in the ability to engage in one’s own health care, coupled with a lack of understanding of tumor, treatment, and potential benefit of adjuvant chemotherapy, encourages a woman to challenge the belief that chemotherapy is of benefit or the only option. Therefore, healthcare providers should combine efforts at improving healthcare empowerment with concrete, understandable information about the importance of chemotherapy within the context of the individual presenting with breast cancer. Jansen et al. (2006) reported that women who preferred less involvement in decision making were more likely to perceive that they had no choice and accepted recommended treatment (such as adjuvant chemotherapy). An additional concern with women who believe they have no choice is that they may follow the treatment recommendation and start chemotherapy but, when they begin to experience side effects and do not communicate this information to physicians, continuous adherence and persistence to chemotherapy can be difficult (Chawla & Arora, 2013).

Because of a lack of information and understanding of cancer and treatment effects, patients with cancer can heavily rely on their physician to make treatment decisions for them (Arora & McHorney, 2000; Seror et
Many African American women with newly diagnosed breast cancer believe that chemotherapy is necessary but have limited knowledge of their cancer and the treatment recommended to them. Providing better interpersonal communication with African American women may increase women’s belief in chemotherapy. Women who are low income and are less socially connected may have less knowledge regarding the tumor and resultant need for chemotherapy.

Because interpersonal communication was measured by the manner of communication, such as whether the doctor talks too fast, whether the doctor uses medical jargon, or how often the doctor cares about the patient’s concerns. The measure did not actually assess how the patient understood the information delivered. Patient-centered communication should ensure not only that adequate information is delivered to the patient, but also that the patient fully understands what she may want to know regarding her newly diagnosed illness (Mazor et al., 2013).

African American women’s social function also is an important predictor of knowledge gained about cancer and treatment. Social support affects African American women seeking medical care and adherence to treatment (Fowler, 2007; Paschal, Ablah, Wetta-Hall, Molgaard, & Liow, 2005). Women with stronger social support are more likely to actively seek health information, such as information from the Internet (Guillory et al., 2014), from their social networks, or from participating in support programs (Kent et al., 2013). After their diagnosis, African American women with breast cancer may experience a decline in social support (Thompson, Rodebaugh, Perez, Schootman, & Jeffe, 2013). They are less likely than other groups of women to use healthcare services and may rely more frequently on informal sources of support, such as family members and/or social support networks (Copeland, Scholle, & Binko, 2003). Social networking and interaction may help women better communicate with their healthcare providers, enhancing their ability to obtain accurate cancer and treatment knowledge.

A few limitations can be identified in the current study. Questionnaires were completed by African American women who came to the clinic for chemotherapy consultation based on surgical referral. Women who decided not to come to the clinic were not able to be included. Therefore, it is possible that the current study excluded African American women who are at high risk for nonadherence to cancer treatment, which may cause sampling bias and affect the generalization of the findings. In addition, as a secondary analysis, only baseline factors from the questionnaires were included in regression models. Finally, because only African American women with newly diagnosed breast cancer were included in the study, comparison to a Caucasian population was not done but would be of interest.

Conclusion

African American women with newly diagnosed breast cancer and recommended for chemotherapy
believe that chemotherapy is necessary. African American women with better communication with their healthcare providers and less involvement in treatment decision making are expected to have stronger beliefs regarding the necessity of chemotherapy. Low income and low socially connected African American women have less knowledge regarding their tumors and resultant needs for chemotherapy.

A foundational element of informed consent is the provision of information to make the consent truly informed. The information must be provided in accordance with the patient’s ability to understand the information and in a manner that the patient finds the information to be necessary. Findings from this study may help design targeted interventions to better guide clinicians in providing information to aid in the decisions regarding chemotherapy. Interventions to improve understanding of tumor and treatment among minority patients are necessary to ensure informed consent for all women.

References


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**Question Guide for a Journal Club**

Journal clubs can help to increase your ability to evaluate literature and translate findings to clinical practice, education, administration, and research. Use the following questions to start discussion at your next journal club meeting. Then, take time to recap the discussion and make plans to proceed with suggested strategies.

1. What factors could be associated with the relatively low levels of knowledge shown by these women?
2. The beliefs of these women were strong and, at times, not in line with the evidence. How can we bridge the gap between beliefs and knowledge in such women?
3. The authors asked about patient–physician communication; how could nurses provide clearer messages to women and overcome the mistrust that some women felt?
4. The authors question whether the consent to treatment for these women was truly informed based on their lack of knowledge. What can be done to improve this?

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