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A Pilot Study of Expressive Writing Intervention among Chinese Speaking Breast Cancer Survivors

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Abstract

Objective—Little attention has been focused on Asian American breast cancer survivor's psychological needs. No outcome based psychosocial interventions have been reported to target at this population. Expressive writing interventions have been previously shown to improve health outcomes among non-Hispanic white breast cancer populations. This pilot study aimed to test the cultural sensitivity, feasibility, and potential health benefits of an expressive writing intervention among Chinese-speaking breast cancer survivors.

Methods—Participants (N=19) were asked to write about their deepest thoughts and feelings, their coping efforts, and positive thoughts and feelings regarding their experience with breast cancer each week for three weeks. Health outcomes were assessed at baseline, three, and six months after the intervention. A Community-Based Participatory Research Approach (CBPR) is used.

Results—Expressive writing was associated with medium and large effect sizes ($\eta_p^2=0.066\sim0.208$) in improving multiple health outcomes (quality of life, fatigue, posttraumatic stress, intrusive thoughts, and positive affect) at follow-ups. Participants perceived the study to be valuable. The study yielded high compliance and completion rates.

Conclusion—Expressive writing is associated with long-term improvement of health outcomes among Chinese breast cancer survivors and has the potential to be utilized as a support strategy for minority cancer survivors. In addition, CBPR is valuable in improving feasibility and cultural sensitivity of the intervention in understudied populations. Future studies employing randomized controlled trial designs are warranted.

Keywords

Expressive Writing; Asian/Chinese Breast Cancer Survivors; Community Based Participatory Research (CBPR); Psychosocial Intervention; Quality of Life

Cancer is the leading cause of death for Asian Americans and breast cancer is the most common cancer in Asian women (Kwong, Chen, Snipes, Bal, & Wright, 2005). Despite that currently an estimated 17.3 million U.S. residents identify themselves as Asian (U.S. Census Bureau, 2010), their quality of life and overall health during cancer survivorship have been

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overlooked (Yoo, Levine, Aviv, Ewing, & Au, 2010). Due to social, cultural, and linguistic factors, culturally competent mental health care is largely unavailable for these women (Tu et al., 2005), constituting unnecessary health disparities.

Studies with Asian American breast cancer survivors revealed unmet emotional needs and sources of distress, such as feeling stigmatized and shame associated with cancer (Wong-Kim, Sun, Merighi, & Chow, 2005) in addition to being self-sacrificing to avoid disrupting harmony (Kagawa-Singer & Wellisch, 2003). However, no intervention studies have been reported in this population to test psychosocial support to improve cancer survivorship. In order to develop culturally sensitive interventions, we first recognize culturally specific obstacles that prevent Asians American breast cancer patients from seeking emotional support to relieve their distress. Those obstacles consist of stigma related to breast cancer (Wong-Kim, et al., 2005), cultural beliefs of bearing the burden alone (Kagawa-Singer & Wellisch, 2003), a norm of suppressing emotions to avoid disrupting harmony with others, the lack of trained mental health professionals with cultural and linguistic competency, and linguistic barriers (Sue & Sue, 1999).

Expressive writing is a *private and guided* writing exercise designed to improve health by prompting emotional and cognitive processes. It has the potential to be suitable to Asian American communities as it has the capacity to overcome cultural and linguistic barriers. With the assurance of privacy, expressive writing may provide a culturally sensitive way to disclose emotional events without being stigmatized. Through intrapersonal disclosure, expressive writing might facilitate emotional expression for Asian American cancer survivors without damaging harmony with others. By disclosing emotions privately in one's preferred language, expressive writing has the promise to overcome linguistic barriers and to be easily adapted to serve those with limited English proficiency.

A recent meta-analysis of 146 randomized controlled trials reveals that expressive writing confers a variety of benefits, including increased physical and psychological well-being (Frattaroli, 2006). Expressive writing has reduced physical symptoms among early stage non-Hispanic white breast cancer survivors (Stanton et al., 2002). Healthy Asian adults benefited more from expressive writing than Caucasians (Lu & Stanton, 2010). As the first step in evaluating potential health benefits of expressive writing intervention among Asian cancer survivors, we implemented this pilot study among Chinese-speaking breast cancer survivors. We hypothesized that expressive writing would be associated with improvement in quality of life, physical health (i.e., fatigue and physical symptoms) and psychological adjustment (i.e., affect, intrusive thoughts, post-traumatic stress, and post-traumatic growth). The goal of this paper is to document the methodology and report the feasibility, cultural sensitivity, and potential effectiveness of the intervention.

Methods

Community Based Participatory Research Approach (CBPR)

Recruiting minority cancer survivors for psychosocial intervention studies or clinical trials is particularly challenging. Due to the fact that few psychosocial interventions have been successfully conducted with this underserved population, the study used a Community Based Participatory Research (CBPR) model (Kagawa-Singer, 2000) to fully involve communities where cancer survivors live. Following the CBPR model, the research team built collaborations with community partners to integrate their assistance in every step of the research process: study design, recruitment, implementation, data collection, interpretation, publication, and dissemination. The community members provided particularly valuable input in modifying study design, recruitment strategies, and study materials to be culturally appropriate and acceptable.

Participants and Recruitment

Human Subjects approval was obtained from relevant institutions. Inclusion criteria were: 1) self-identified as being comfortable writing and speaking in Chinese (i.e., Mandarin and/or Cantonese); 2) women within 5 years post breast cancer diagnosis, and 3) having a diagnosis of Stages 0-III breast cancer. Recruitment was conducted between January 2008 and May 2008. Participants were primarily recruited through the community partner, the Chinese Herald Cancer Association (HCA), a local community based organization in Southern California. The study was announced at cultural events, educational conferences, and support groups organized for cancer survivors by the HCA. Potential participants were told that the study involved writing about their cancer experience and answering questions about their health. Twenty-three breast cancer survivors interested in the study were screened; one was ineligible due to her limited ability in writing in Chinese. Among the 22 breast cancer survivors who were eligible and invited to participate, one declined due to a busy travel schedule. Thus 21 (95%) enrolled and gave written consent. Two women dropped out due to lack of time after completing the baseline questionnaire. The remaining 19 women (90%) completed the study.

Procedure

Participants completed standardized health outcome measures and reported demographic and medical information in Chinese at baseline and returned the questionnaires by mail. After the completion of baseline assessment, participants received three sealed envelopes mailed simultaneously, labeled “week 1”, “week 2”, and “week 3”. Each envelope contained different writing instructions for the corresponding week. Participants were asked to write about their deepest feelings and thoughts regarding their experience with breast cancer, their coping strategies to deal with stressors associated with cancer, and positive thoughts and feelings regarding their experience with breast cancer during week 1, 2, and 3, respectively. This writing task aimed to facilitate emotional disclosure, effective coping, and finding benefit, which would work together to bring stressors and personal goals into awareness and regulate thoughts and emotions relevant to the cancer experience. Participants were instructed to write for 20 minutes each week at a convenient time in a comfortable and private setting. They were assured that their writing was confidential and anonymous. After each writing session, participants mailed their essays to the research office. All participants completed all three writing sessions, yielding a compliance rate of 100%. After the last writing exercise, survey items were given to assess participants' reaction to the study. Questionnaires assessing health outcomes were mailed to participants at three and six months after the completion of the writing assignments. Semi-structured phone interviews were conducted after the six-month follow-up.

Health Outcomes Assessment

We assessed outcomes including quality of life, fatigue, physical symptoms, intrusive thoughts, and mood, which were commonly assessed in previous expressive writing studies with cancer survivors (de Moor et al., 2002; Stanton, et al., 2002). In addition, we also assessed perceived benefit and post-traumatic stress symptoms. The Functional Assessment of Cancer Therapy-Breast Cancer (FACT-B) measured quality of life in physical, social, emotional, functional domains, and breast cancer concerns during the past week (Brady et al., 1997). The Functional Assessment of Chronic Illness Therapy-Fatigue scale (FACIT-F) assessed fatigue (e.g., “I feel tired”). Physical symptoms were assessed using the Physical Symptom Checklist (PSC)(Pennebaker, 1982) which asked participants to report the number of days in the past month on which they experienced each of ten somatic symptoms (e.g., coughing/sore throat). Positive and negative affect during the past week were assessed through a 20-item version of the PANAS (Watson, Clark, & Tellegen, 1988) which provided largely independent measures of Positive Affect (PA) and Negative Affect (NA) (e.g.,

“cheerful”, “afraid”). The Posttraumatic Growth Inventory (PTGI) (Tedeschi & Calhoun, 1996) was administered to assess perceptions of growth in relating to others, new possibilities, personal strength, spiritual changes, and appreciation of life (e.g., “I discovered that I’m stronger than I thought I was”). The PTSD Symptom Scale (PSS) (Foa, Riggs, Dancu, & Rothbaum, 1993) was modified to assess the severity of post-traumatic stress symptoms related to cancer during the past week (e.g., having bad dreams or nightmares about the illness). The 7-item Intrusion subscale of the Impact of Events Scale (IES) (Horowitz, Wilner, & Alvarez, 1979) was administered to assess how distressing cancer-related intrusive thoughts had been over the past week (e.g., “Other things kept making me think about it.”). The FACT-B, IES, and PTGI have been previously validated in Chinese. The FACT-F, PSC, PANAS, PSS were translated into Chinese and back-translated into English by bilingual researchers in our group through an iterative process to insure that the items in the two language versions were the same or sufficiently close in meaning. A focus group interview was then conducted with breast cancer survivors to improve the clarity of the questionnaires. As shown in Table 1, all questionnaires had acceptable reliabilities in the current study (Cronbach’s α ranging from 0.76 to 0.96).

Results

Sample Characteristics and Preliminary Analysis

Participants had a mean age of 54 years (SD, 11 years; range, 31 to 83 years). The average number of years in the U.S. was 19 (SD, 8; range, 8 to 35). About half of the participants (47.6%) had an annual household income less than \$15,000. The majority of participants had completed high school or more (95.2%), were married (76.2%), and had stage I or II diagnosis (80.9%). The average diagnosis duration was 2 years (SD, 1.1 years, range 1 to 5 years), and the majority (80.9%) were within 1 to 4 years post diagnosis.

Immediately after the writing, participants reported that they found the writing task to be easy (Mean=4.63, SD=1.34), revealed their emotions (Mean=4.47, SD=1.22), and disclosed experiences in writing that they had not previously told others (Mean=4.11, SD=2.05) (“0” being “not at all” and “6” being “extremely”). Thematic line-by-line analysis of the phone interview and answers to the open-ended questions after the last writing session revealed that participants were quite positive about the implementation of the study overall. Participants reported that they wrote down whatever they thought and felt, commented that the study was meaningful for Chinese women, and appreciated the opportunity to participate in such a study. Findings suggest that participants perceived the intervention to be appropriate and valuable.

Health Outcomes

The descriptive statistics of the outcomes are shown in Table 1. General linear models were conducted using SPSS (SPSS, 2010) to compare values of the outcomes at the three time points. The goal of this pilot study was to estimate effect sizes associated with the intervention and thus we reported estimated effect sizes rather than significance level, as the significance level would not be meaningful for studies with small sample sizes (Schmidt, 1996). Effect sizes (ES) were estimated using partial Eta squared (η_p^2) to describe the amount of variance in outcomes accounted for by the intervention. The values were judged using Cohen’s criteria (Cohen, 1988) for small, medium, and large effect for behavioral science with $\eta_p^2 = 0.01, 0.059, \text{ and } 0.138$ respectively (corresponding to Cohen $d = 0.2, 0.5, 0.8$). The effect size estimation is reported in Table 1 and medium and large effects are highlighted in the text below.

The intervention was associated with medium to large effects on the decrease of fatigue and intrusive thoughts and a large effect on reducing posttraumatic stress at the three-month follow-up. The intervention was also associated with medium to large effects on the decrease of fatigue and post-traumatic stress, and the increase of quality of life and positive affect at the six-month follow-up. Overall, findings suggest that expressive writing was associated with long-term physical and psychological health benefits.

Discussion

Previous expressive writing literature largely focuses on non-Hispanic white samples. This study contributes to the growing literature of expressive writing by illustrating its feasibility and potential benefits among Chinese-speaking breast cancer survivors using a community-based participatory research approach and mixed method design. Although the one group design did not allow for causal inferences, it was suggestive that expressive writing was associated with improved health outcomes at long-term follow-ups. The medium and large effect sizes ($\eta_p^2 = 0.066\sim 0.208$) associated with multiple important health outcomes are encouraging, compared with the small effect size ($\eta_p^2 = 0.009$) revealed from a meta-analysis of expressive writing studies (Frattaroli, 2006). A previous expressive writing study among breast cancer patients revealed reduced physical symptoms ($\eta_p^2 = 0.042$) and mixed results for psychological outcomes (Stanton, et al., 2002). The current study revealed comparable effect sizes associated with reduction in physical symptoms ($\eta_p^2 = 0.057$). More importantly, the current study demonstrated that writing was associated with improvement in fatigue, quality of life, and psychological adjustment (posttraumatic stress, intrusive thoughts, and positive affect). In previous studies, these health benefits were not associated with expressive writing among non-Hispanic white cancer survivors (de Moor, et al., 2002; Low, Stanton, Bower, & Gyllenhammer, 2010; Stanton, et al., 2002; Zakowski, Ramati, Morton, Johnson, & Flanigan, 2004). Our results suggest that Asian cancer survivors experience increased benefits from expressive writing, consistent with findings from a prior study with healthy Asian adults (Lu & Stanton, 2010). Future randomized controlled trials of expressive writing with larger samples are warranted to test the efficacy, moderators, and underlying mechanisms of the intervention among minority cancer survivors.

The study yielded high compliance and completion rates, suggesting that CBPR can improve study feasibility by incorporating community input and reaching out to the targeted population. Participants perceived the study to be valuable, suggesting that the CBPR process is an effective method of enhancing cultural sensitivity. In addition, the CBPR enabled the development of true partnership between researchers and the community, which paved the way for designing culturally relevant and appropriate research, promoting the program's sustainability and dissemination, and facilitating further collaboration between community and researchers. These improvements are in contrast to interventions that fail to focus on the social and cultural environments of the community and thus lack acceptability in the population of focus.

The study has some limitations worth mentioning. The pilot intervention does not allow for causal inferences because the positive outcomes could be the result of other confounding factors, such as the natural course of recovery of breast cancer survivors. The non-random sample and self-selection bias may reduce the generalizability. Several questionnaires also need further validation in a larger sample. Despite the limitations, the study revealed health benefits associated with the intervention at long-term follow-ups and demonstrated how to adapt and utilize expressive writing intervention for minorities.

Few intervention studies have been targeted at improving cancer survivorship among Asian American breast cancer survivors. Our pilot study suggests that the expressive writing

intervention is culturally sensitive in an Asian American population and is associated with long-term improvement of health outcomes among Chinese breast cancer survivors. Expressive writing interventions may have the potential to be utilized by other underserved populations with limited English fluency and cultural backgrounds that differ from non-Hispanic white groups.

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Table 1

Descriptive Statistics and Effect Sizes Associated with Outcomes

Variable	Cronbach's α	Baseline	Month 3	Partial η^2	Month 6	Partial η^2
		Mean (SD)	Mean (SD)		Mean (SD)	
Quality of Life	.94	98.82 (23.25)	103.09 (21.88)	0.03	102.71 (23.5)	.087
Fatigue	.93	14.30 (10.72)	11.63 (8.97)	.066	12.06(7.91)	.066
Physical Symptoms	.76	31.65 (41.26)	31.33(33.02)	.057	29.24 (37.37)	.004
Positive Affect	.92	2.66 (0.89)	2.83(0.66)	.027	2.86 (0.99)	.099
Negative Affect	.94	1.62 (0.67)	1.54 (0.57)	.001	1.66 (0.71)	.004
Intrusive Thoughts	.87	1.19(0.77)	.93(0.53)	.124	1.10 (0.83)	.043
Post-traumatic Growth	.86	72.00(23.05)	76.01(15.77)	.053	75.73 (19.53)	.035
Post-traumatic Stress	.94	13.90 (10.12)	11.63(7.72)	.208	11.75 (7.23)	.100