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## Using Expressive Writing to Explore Thoughts and Beliefs about Cancer and Treatment among Chinese American Immigrant Breast Cancer Survivors

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### Introduction

Due to the increasing ethnic diversity in the United States, healthcare providers need to understand the specific needs of minority cancer survivors. The primary goal of this article was to understand beliefs about cancer, its treatment, and relevant concerns among Chinese American breast cancer survivors (BCS). Compared to non-Hispanic White BCS in the United States, Chinese immigrant BCS were less likely to have treatment-related issues (i.e., physical distress) resolved, potentially due to their lower tendency to ask physicians questions, ask for referrals, and make repeated attempts to cope with physical distress [1]. A recent study also highlights that unmet psychosocial needs (e.g., lack of opportunities for open discussions of feelings, needs for medical information, needs for culturally- and linguistically-appropriate support groups) disrupted quality of life among Chinese American BCS [2]. As Chinese American is the largest Asian subgroup in the United States, understanding cancer- and treatment-related beliefs within this population will help to identify informational and medical needs that health care providers can intervene in future services.

Culture can influence how individuals respond to cancer diagnosis and treatment. Standardized tools, however, cannot accurately assess cultural beliefs about cancer. Thus this study used a qualitative and inductive approach. Culture can also influence how individuals disclose their private thoughts or emotions. We have previously argued that expressive writing [3] allows people to privately disclose their deepest thoughts and feelings and thus can help them overcome cultural barriers which prevent them from disclosing. These barriers include stigma related to breast cancer, cultural beliefs of bearing burden alone, and a norm of suppressing emotions. In this study, we used expressive writing as a paradigm to gather qualitative data by allowing in-depth disclosure of thoughts while guaranteeing confidentiality.

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## Method

### Participants and Procedure

Human subject approvals from relevant institutions were obtained. Twenty seven Chinese American BCS participated in an expressive writing study in Southern California. On average, the survivors were 55.1 years old ( $SD = 8.9$ ), being in the United States for 19.6 years ( $SD = 8.6$ ), and 23 months after diagnosis ( $SD=14.0$ ). A majority of them were married (70%), born in mainland China or Taiwan (89%), had (some) college education (74%), and did not have full time employment (67%). About half (41%) had an annual income of less than \$15,000. Most of them were either diagnosed at Stage I (33%) or Stage II (48%) breast cancer. Regarding treatments, 56% had received mastectomy, 52% had received lumpectomy, and 4% had received breast reconstruction surgery. During the study, 82% had received chemotherapy, 48% had received radiation, and 67% were on hormone therapy or medication.

Participants were instructed to write for 20 minutes each week at a convenient time in a comfortable and private setting for three weeks. They were asked to write about their deepest thoughts and feelings regarding cancer diagnosis and treatment (Week 1), the most stressful experience regarding cancer and treatment (Week 2), and positive experiences regarding breast cancer (Week 3). After the last writing exercise, we asked participants to report the extent to which they shared the experience with others before the study. More details of the study were described elsewhere [3].

### Analysis Strategies

The essays were analyzed in three phases. During phase one, a phenomenological research method [4, 5] was employed. First, the investigators read all of the essays to understand the overall experience. Second, meaningful units were identified and translated into psychological language. Third, translated units were synthesized into themes or subthemes. During phase two, line-by-line content analyses were conducted. Two trained bilingual postgraduate students independently coded each essay into the generated subthemes and themes and counted the frequencies. During phase three, cultural meanings or origins of beliefs were extracted to link different subthemes and form a comprehensive story explaining phenomena identified during phase one. The three phases were repeated and reiterated, and any disagreement was discussed until a consensus was reached.

## Results

### Linking breast cancer with imminent death

Eleven participants mentioned that they would die very soon after their diagnosis. Some believed that breast cancer as incurable, and some even did not have any knowledge of breast cancer before diagnosis. The perception of imminent death after diagnosis may cause patients a great deal of distress.

*S07:* Those who got cancer will definitely die soon. It's incurable. Even with medical advances, cancer survivors could die at any moment.

*S09*: I never thought I would get the incurable disease. I knew nothing about cancer and didn't know anyone who had cancer.

*S26*: When I was diagnosed with Stage I breast cancer, I really thought that I was going to die very soon.

### **Undergoing surgery immediately**

Five participants mentioned that they decided to undergo a breast cancer surgery shortly after the diagnosis.

*S08*: “When the surgeon told me that the tumor was malignant, and an immediate surgery was needed. I did the surgery the next morning ...”

*S22*: When I knew the results, I did not think too much. I just wanted to have the surgery as soon as possible for two reasons. First, I was a uterine cancer survivor; I know the importance of having surgery as soon as possible. Second, I have two sisters who are also breast cancer survivors. One of them died two years after diagnosis.

However, two of the participants felt that they were not fully prepared for the surgery.

*S15*: The doctor suggested me having the surgery on the next day. I said, “That soon? I'm not ready yet.” The doctor then said, “You must act quickly if you got this disease.” Then I calmed myself down, “Well, just do it.”

*S19*: I want to get rid of my disease immediately. I requested my physician to arrange my surgery as soon as possible. ...I did not think about the consequences... it was important to treat the disease so I decided to do mastectomy. I now think I was too rushed.

The patients generally trusted the doctors' expertise and followed doctors' recommendations without fully exploring other treatment options. Only three patients mentioned that they had sought a second opinion before the treatments.

*S09*: My sister was concerned about me and thought about the treatment options with me. She went to the physician with me and consulted some experts in other countries for a second opinion. Then she helped me to make a better decision, choosing to have a partial mastectomy.

*S18*: With my friends' help, I got to the specialist from my insurance company. I also consulted a few other specialists for a second opinion, asking for their suggestions for treatments. I decided to have the chemotherapy, and then have the surgery and radiation therapy.

### **Perception that mastectomy is a safer treatment option**

Some participants believed that mastectomy was a safer option for breast cancer treatment and more effective in reducing the risks of recurrence, as they thought mastectomy could remove all the cancer cells. Such a perception may be originated from an old Chinese saying 斬草除根 (*zhan cao chu gen*) (“get rid of the weeds by killing the root”, i.e., radical measures need to be taken to prevent future problems).

*S03:* I finally decided to have a mastectomy. It's safer, just to make sure all the cancer cells were removed.

*S06:* When it comes to cancer, the source of trouble should be removed thoroughly.

*S09:* My husband insisted that I should have a mastectomy. He said that the source of trouble should be removed thoroughly to avoid any future problems.

Despite having a preference for mastectomy, some of our participants still hesitated whether they should choose lumpectomy or mastectomy.

*S03:* When choosing between partial and full mastectomy, I asked people around me (including doctors and friends) and hesitated a lot.

*S09:* I remembered when I was considering whether I should take lumpectomy or mastectomy, I was very hesitant and didn't know how to choose.

### **Body image concerns**

Five participants expressed concerns of losing their breasts. They felt sad about not having a complete body anymore after mastectomy.

*S07:* I got my right breast completely removed, it looks ugly, and I even feel an imbalance while walking. I did not have a breast reconstruction surgery, only wearing a breast prosthesis. I feel so sad. Every woman wants to be pretty, but my body is deformed.

*S15:* Since I got breast cancer, the most overwhelming thing is that I no longer have a complete body.

Body image concerns are not limited to the removal of breasts. Eight participants felt uncomfortable about other aspects of their appearance, for example, loss of hair, increase in body weight, and surgical scars.

*S04:* Like most women, I was also very worried about my appearance. I was not as devastated about losing a breast permanently as I was about not having any hair for six months. I was more conscious about my appearance (hair, skin, weight) and the parts other people can see than the parts that were covered by clothing.

*S07:* I cannot bear seeing my scars. I can't wear short-sleeves, not to mention finding a boyfriend.

### **Discussion**

Using an expressive writing paradigm, this study revealed important beliefs about breast cancer and its treatments among Chinese American BCS. We identified the following themes: 1) myths about imminent death after breast cancer diagnosis, 2) hurried treatment decision making, 3) the perception that mastectomy is a safer way to treat breast cancer, and 4) body image concerns.

Despite the relatively high five-year breast cancer survival rate in the United States [6], many participants believed that breast cancer was incurable and meant imminent death. This

may be due to a lack of knowledge in the prognosis of breast cancer. It suggests that Chinese American BCS should be provided with breast cancer-related medical information that they can understand during the diagnosis. Doing so is important because such cancer-related perceptions may also cause intense distress and feelings of uncertainty after diagnosis [7], which could affect psychosocial well-being among Chinese American BCS.

Regarding treatment decision making, some participants decided to undergo a breast cancer surgery shortly after the diagnosis, whereas several others did not give themselves enough time to consider alternative treatment options carefully. As Chinese people respect the doctors' authority and trust their expertise [8], it is common for the patients to simply follow doctor's recommendations without actively seeking second opinions and information related to treatment alternatives. In line with a previous study on Chinese American women with early-stage breast cancer [9], our participants also believed that mastectomy was a safer way to treat breast cancer and to prevent cancer recurrence. It is important for health care providers to help patients understand the pros and cons about different treatment options so that the patients are more able to choose the optimal treatment.

In contrast to two qualitative interview studies suggesting that Hong Kong Chinese [7] and Chinese American [10] BCS were less concerned with body image issues, our participants did express their concerns about their body image due to the removal of breast(s) and treatment side-effects (e.g., hair loss, drastic weight change). The differences in findings may be due to the data collection methods used. We asked participants to what extent they shared with others before the study about the thoughts and feelings they wrote. We found that 48% of the participants did not tell others about the things they wrote in the writings before the study; 36% of the participants had intentionally withheld their thoughts/feelings from other people and they wrote about these thoughts/feelings in the writing. These results suggest that our participants disclosed something very private and personal in their writings. The use of an expressive writing paradigm may allow Chinese American BCS to express concerns which they feel uncomfortable disclosing in face-to-face interviews.

The non-random sample and self-selection bias in this study may limit the generalizability. Furthermore, the expressive writing paradigm was advantageous in exploring new information but was limited in systematic investigations. However, based on the writings, we were not able to assess if the cancer- and treatment-related beliefs persist throughout the participants' adjustment process. Despite the limitations, this study contributes to the literature by exploring the beliefs about breast cancer and its treatments as well as body image concerns among Chinese American BCS in the United States. The findings shed light on the future research and services promoting a better minority cancer survivorship. Future interventions are recommended to provide Chinese American BCS with more information about breast cancer facts and treatment options (including the option of reconstruction surgery), as well as addressing potential body image issues. Doctors and nurses should help clarify myths about breast cancer, as Chinese patients tend to respect and trust medical experts.

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### 5 key points

- Chinese American breast cancer survivors thought about imminent death when diagnosed with cancer and some rushed to undergo surgery.
- Some Chinese American breast cancer survivors believed that mastectomy was the safest way to treat breast cancer and prevent recurrence.
- In contrast to other studies, it was found that body image issues were salient concerns among Chinese American breast cancer survivors.
- Future interventions should provide Chinese American breast cancer survivors with more information about breast cancer facts and treatment options as well as address potential body image issues.
- Expressive writing can be a good supplement to traditional face-to-face interviews and focus groups in obtaining qualitative data.