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## Breast cancer survivors' views of how support groups and activism have affected their healing process

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Elizabeth Mary Burnworth  
Breast Cancer Survivors'  
Views of How Support  
Groups and Activism Have  
Affected Their Healing  
Process

ABSTRACT

The purpose of this study was to explore what effects participation in breast cancer support groups and activism had on the lives of breast cancer survivors. The effects of activism and support group participation on healing and the meanings women made of their experiences were documented through women's voices. Themes of general support and outlook on life were also explored.

Through the use of in-depth, open-ended, qualitative interviews, twelve women were invited to tell the stories of their illness, activism, and healing. The findings of this study confirmed previous studies, which document the importance of support for breast cancer survivors in their healing process. The support of family and friends, among others, was vital for study participants. Support groups were particularly helpful because respondents found that other breast cancer survivors had a better understanding of what they were going through. Breast cancer activism had positive effects on participants' healing processes. The importance of supporting other breast cancer survivors and of contributing to efforts to eradicate breast cancer was reflected in each of the women's narratives. The idea of integrating activism into traditional support groups was largely supported. Finally, despite the negative consequences of the disease, the majority of the study participants felt that their breast cancer experiences led them to make positive changes in their lives.

BREAST CANCER SURVIVORS' VIEWS  
OF HOW SUPPORT GROUPS AND ACTIVISM HAVE AFFECTED  
THEIR HEALING PROCESS

A project based upon an independent investigation,  
submitted in partial fulfillment of the requirements  
for the degree of Master of Social Work.

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2007

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I wish to thank my thesis advisor, Joan Laird, for her belief in my ability to complete this project.

Twelve courageous, strong, and inspirational women shared their stories with me for this study. You have each touched my heart. Your hope for a better tomorrow and your commitment to activism today remind us all that we must each do our part. Thank you.

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Smith summers are full of: challenges; amazing moments of insight, learning, and inspiration; frustration; tears; heat and humidity; laughter; and love. I never would have survived Smith without my friends and classmates. To the Wine at Nine folks, my Quiet Dorm mates, my holding environment, and especially Hilary Lynch--thank you with all of my heart. I love you. I know we can change the world, one step at a time. "The best thing you've ever done for me, is to help me take my life less seriously. It's only life after all" (Saliers, 1989).

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## DEDICATION

For my mother, Carolyn P. Burnworth, whose love and gentleness is unparalleled

In memory of my father, Alvin P. Burnworth, whose spirit of kindness lives on



## CHAPTER I

### INTRODUCTION

Breast cancer and mastectomy are not unique experiences, but ones shared by thousands of American women. Each of these women has a particular voice to be raised in what must become a female outcry against all preventable cancers, as well as against the secret fears that allow those cancers to flourish. (Lorde, 1980, p. 10)

One out of every eight women will be diagnosed with breast cancer in her lifetime (National Cancer Institute, 2006). Approximately 175,000 women are diagnosed with breast cancer and approximately 44,000 women die of breast cancer yearly. Therefore, millions of women and their families, friends, and communities are affected by breast cancer (Ferguson & Kasper, 2000). Many women respond to their cancer diagnosis by participating in individual and/or group psychotherapy. A number of women also participate in breast cancer activism. This thesis documents a qualitative research study of women who are breast cancer survivors involved both in breast cancer activism and support groups.

The purpose of this study is to explore what effects participation in breast cancer activism has on the lives of breast cancer survivors who are also involved in support groups, while describing the types of activism and support groups in which breast cancer survivors are engaged. This study documents, through women's voices, the effects of activism and support group participation on healing and the meanings women make of their experiences. (While men also develop breast cancer, this study focuses solely on women because the issues facing men with breast cancer are significantly different and

cannot be covered under the scope of this paper.) Finally, this study documents women's thoughts on the potential effects of the integration of activism into support groups as a treatment intervention for breast cancer survivors. This study has relevance for social work practice and program development.

Through the use of in-depth, open-ended interviews, twelve women were invited to tell the stories of their illness, activism, and healing. A diagnosis of breast cancer inevitably changes the reality of one's life. Robert A. Neimeyer (1997) describes meaning-making as an adaptive process that allows an individual to incorporate the loss that accompanies illness into one's already existing belief system, or a process in which one changes one's life narrative in accordance with one's changed reality. This study will explore the stories that women tell about their changed realities as breast cancer survivors and the meaning-making that women engage in around their illness, activism, and healing.

The effect of activism on the lives of breast cancer survivors or on personal healing in general is not an area that has been extensively researched (Breton, 1995; Israeli & Santor, 2000). Several studies have been done which indicate that there are positive effects of participation in activism on the healing of survivors of sexual assault (Krantz, 1995; Sutton-Ryan, 1998), but similar studies involving breast cancer survivors have not been completed. Gore (1999), in her study of the experiences of women involved in breast cancer support groups, points to the need for further studies on self-advocacy among breast cancer survivors. Therefore, there is a need to study activism participation and its effect on the lives of women who are breast cancer survivors as such a study may have important implications for potential therapeutic interventions for breast

cancer survivors and for feminist therapies which seek to empower women and initiate social change. [For a discussion of feminist therapy see Worell and Remer (2003)].

Feminist standpoint theory provided a starting point for this project. Feminist standpoint theory is based on the idea that oppressed groups experience a different reality than dominant groups. Therefore, in order to have a more complete view of reality, knowledge must be generated from the lived experience of oppressed groups (Swigonski, 1994). Women with breast cancer can be considered an oppressed group whose knowledge, developed from lived experience, has been subordinated by the medical establishment (Fosket, 2000). This study makes central the stories of women living with breast cancer whose knowledge has been previously marginalized.

### Locating Myself

I have been committed to feminist and social justice movements for nearly twenty years. During that time, I have recognized the power of speaking one's truths and telling the stories of one's life, especially if those truths and stories have been previously silenced. My awareness of the need to tell one's cancer narratives is a more recent revelation, which resulted from my father's recent diagnosis, suffering, and death from cancer. My father's cancer experience was too brief for him or me to become involved in cancer activism while he was still alive as there were only 84 days between his diagnosis and death. And so, this research was guided by my passion for feminism, my commitment to women's lives, my vocation as a clinical social worker, and my love for my father, my mother, my sister, and the many women with whom I share this earth.

## CHAPTER II

### LITERATURE REVIEW

This review draws on several bodies of literature including theory on the integration of social action into therapy as well as empirical studies. The first section of this chapter will review the theoretical literature on the integration of social action into psychotherapy. The first section will also review two empirical studies, one that considers women's activism in general and one that considers women's breast cancer activism. In the second section, I will provide an overview of the literature on cancer support groups. In the third section, I will present ideas on breast cancer narratives as a form of consciousness-raising and meaning making. The fourth section of this chapter will review empirical studies on the impact on healing that activism has among survivors of sexual assault. Finally, the implications of the reviewed literature are discussed.

#### Social Action Theory and Practice

Breton (1995), Israeli and Santor (2000), and Donaldson (2004), through theoretical arguments, emphasize the potential for social action/activism in therapy groups. Breton envisions social action as a potential part of psychotherapy groups in general, while Israeli and Santor identify social activism as a part of feminist therapy in particular. Donaldson envisions empowerment-oriented social action groups as a way of bridging micro and macro social work practice because such groups have therapeutic benefits for participants such as increased levels of self-esteem, self-efficacy, and improved personal skills.

Breton (1995) highlights three assumptions that are central to her argument about the potential for social action and empowerment that exists in psychotherapy groups: 1) a dialectical relationship exists between social action and personal healing; working for personal healing can also bring about social change and vice versa; 2) social work practice is political; therefore, how one chooses to allocate one's time and resources whether it be to personal change and/or social change is a political decision; 3) because social justice is a core value of social work, to focus only on the personal consequences of injustice is to blame the victim rather than change unjust conditions. Drawing from feminist theory and examples such as "Take Back the Night" and efforts to end violence against women and change legislation regarding violence against women, Breton argues that in order for personal healing and consciousness-raising to be empowering, a link needs to be made between personal problems and public issues. In order for social justice to become a reality, social work must bridge personal healing and social change. One source of such change is the psychotherapy group itself, which can serve as a location for social action.

Continuing along the theme of bridging personal healing and social change in order to achieve social justice, Israeli and Santor (2000) review the evolution of and the principles for guiding feminist therapy. Feminist therapy is based on a feminist analysis of society where women are seen as an oppressed minority and the "personal is political." Therefore, empowering women to create change in their lives can be beneficial to both the individual and society. Israeli and Santor identify and provide justification for the four core components of feminist therapy: consciousness raising, social and gender role analysis, resocialization, and social activism. Social activism may involve being a

member of a social action group, letter writing, protesting, speaking at rallies, etc. Social change is seen as a crucial part of the improvement of women's mental health, but there is debate about whether social activism should be a part of treatment protocols. Some argue that social change is necessary for real change in women's lives and therefore social activism is vital as a part of the therapeutic process. Others argue that clients who do not want to be part of a political movement might be turned off from therapy and that there is a risk for ethical violations on the part of therapists who impose their political beliefs on others. Systematic research on the impact of social activism in the context of feminist therapy has not been conducted. Therefore, research is needed to determine whether social activism as a part of feminist therapy is beneficial to individual clients and/or societal change. Israeli and Santor hypothesize that engaging in a social endeavor and giving voice to one's thoughts, feelings, and opinions while effecting social change may be empowering and open up new opportunities for women. The strength of Israeli and Santor's work lies in the empirical evidence that they review for the first three components of feminist therapy: consciousness raising, social and gender identity analysis, and resocialization. The limitation of their work is the lack of research done on the applicability of feminist therapy to diverse groups of women such as women of color, women from lower socio economic classes, and lesbian and bisexual women.

Donaldson (2004) uses Bandura's self-efficacy theory to demonstrate how empowerment-oriented social action groups engage members in social action by utilizing the four sources of self-efficacy which are: 1) mastery experiences, such as letter writing campaigns, petitions, recruitment, and/or public testimony; 2) vicarious experiences, such as witnessing peers or group facilitators engaging in the activities described in #1; 3)

social persuasion, such as affirmation and encouragement from group facilitators and participants; 4) physiological arousal, such as teaching and practicing techniques to control debilitating effects of confrontational situations. Self-efficacy has been linked to the development of self-esteem, provides a buffer between stress and depression, improves coping behaviors, and reduces fear arousal. Therefore, Donaldson argues, social action should be incorporated into empowerment-oriented groups.

Donaldson also demonstrates how Yalom's curative factors of therapeutic groups might be present in empowerment-oriented social action groups by detailing each of the relevant curative factors: 1) Social action groups must instill hope in and convey the efficacy of the group. Group facilitators and the group members must all play a part in instilling hope. 2) Social action groups must have an element of universality, i.e., a shared experience and a sense of injustice are necessary for action. 3) People engaged in social action do so in part out of a sense of altruism, or giving back, to those who suffer similarly to themselves. 4) Social skills are developed through social action groups through activities such as consciousness-raising, interacting with public officials, and role-plays. 5) Group members learn from each other and use each other as role models. Group members witness each others' strengths and are therefore empowered to take risks themselves. 6) Interpersonal learning is a source of healing and a vehicle for social action. Therefore, human relationships found in groups are important. 7) Group cohesiveness is critical for social action groups in order to sustain the group beyond their initial focus. Groups also provide a space for catharsis achieved through the expression of emotion. 8) Group members benefit from a shared experience, but also come to learn that they are ultimately responsible for their own lives (Donaldson, 2004). Donaldson

argues that Yalom's curative factors of therapeutic groups apply to psychotherapeutic groups in general, but they also apply to empowerment-oriented social action groups. Donaldson provides a strong argument about the importance of empowerment-oriented social action groups, which could be strengthened by empirical evidence of such groups in action.

It is important to note that Breton (1995), Israeli and Santor (2000), and Donaldson (2004) do not offer empirical evidence to support their arguments for the importance of including social action/activism in psychotherapy. Schwartz (2003) offers an important contribution to the debate through her study of the effects of activism on women's lives.

Schwartz (2003), in her interview study of twelve women activists involved in a variety of social movements (e.g., feminist, Lesbian/Gay/Bisexual/Transgender, civil rights) in the San Francisco Bay Area, found that the development of an activist identity was "a complex phenomenon with multiple determinants that have a powerful and enduring impact in individuals" (p. 75). Women felt that their activism had been influenced by family and other intimate relationships, family and community culture, significant events, felt need, felt responsibility, and individual character traits. These factors created an experience and an understanding of that experience that led participants to become activists, resulting in new behaviors and affiliations as well as new social identities. Motivations for activism came from both negative and positive interactions with the above factors.

All participants reported feeling changed by their activism in positive ways. Personal growth and change were described as experiences of increased internal cohesion



and sense of belonging, enhanced self-confidence and feeling of personal power, transformation of negative emotion states, and increased ownership over the activist process.

Participation in activism also contains painful and challenging dilemmas, which also can contribute to transformation including feelings such as: vulnerability, invisibility, alienation, and disillusionment. Schwartz suggests that, because these negative experiences exist alongside the positive experiences, they might also be factors in one's growth as one resolves the conflict between the positive and negative impacts of one's activist participation.

Personal transformation also resulted from participants' activism participation. Participants' self-concepts and sense of personal power were positively impacted by their work. Some participants challenged the expectation of self-sacrifice that often accompanies activist movements and incorporated self-care, multiple commitments, and limit setting into their lives. Women of color in Schwartz's study also reported "expanding the frame to allow for diversity of voice and experience" (p. 77).

Schwartz suggests that the findings of her study indicate that activism participation can enhance clinical interventions because activism improves the quality of life through access to services, decreases isolation, is empowering for individuals and communities, and increases self-sufficiency.

Schwartz' study is limited in generalizability because of the small sample size, its focus on the San Francisco Bay Area, and a sample of only women. Schwartz acknowledges that her study was biased in that she had a fundamental belief in the power of activism participation before she even began her study and that her belief may have

influenced her participants' responses as well as her study questions. A strength in Schwartz' study lies in the diversity of her sample which included women ranging in age from 26 to 60, heterosexual, bisexual, lesbian, and queer women, women from all social classes, and 7 out of 12 participants were women of color. All of her participants were involved in politically progressive causes. A wide variety of activist activities were represented among her sample including: community organizing, civil rights, women's movement, anti-war/world affairs, children and youth advocacy, and individual acts. Schwartz' study offers interesting ways to conceptualize the impact of activism on women's lives, while Klawiter's (1999) research suggests ways of categorizing breast cancer activism specifically.

Breast cancer activism has been studied in the literature separate from the literature on psychotherapy. Klawiter (1999) completed a participant observation study of three different approaches to activism: the Race for the Cure, the Bay Area Women & Cancer Walk, and the Toxic Tour of the Cancer Industry in the San Francisco Bay Area. Klawiter participated in all three events and interviewed 40 activists across the three events. Subsequently she developed a model to categorize the multiple branches of the breast cancer movement. Klawiter identifies the Breast Cancer Awareness Movement as being based in biomedicine with a focus on survival and feminine appearance. The Breast Cancer Awareness Movement promotes research and early detection and supports such activities as the Race for the Cure. The Women's Cancer Movement draws upon feminism and AIDS activism. It challenges the emphasis that is placed on survival and femininity in the Breast Cancer Awareness Movement, while the Women's Cancer Movement promotes social services, patient empowerment and treatment activism. The

Women's Cancer Movement is best exemplified by small, grassroots organizations founded by local women with breast cancer such as Breast Cancer Action. The Cancer Prevention Movement draws upon the environmental justice movement and emphasizes the responsibility of the cancer industry (i.e., companies such as Astra Zeneca that produces tamoxifen to treat cancer, but is also the parent company of Imperial Chemicals Industry which produces pesticides found to cause cancer). The Cancer Prevention Movement shifts the focus of activism from early detection to cancer prevention. Klawiter found the Women's Cancer Movement and the Cancer Prevention Movement to be more diverse and committed to social justice. The strength of Klawiter's study lies in the deep descriptions that she was able to generate from her participant observation and interviews. The limitation of Klawiter's study is her clear bias in favor of the Women's Cancer Movement and the Cancer Prevention Movement. Klawiter's model of the three branches of the breast cancer movement will be used when considering the various forms of activism in which breast cancer survivors in my study are involved.

### Cancer Support Groups

A significant body of literature has been developed that examines the impact of cancer support groups on the well-being of survivors. Overall, cancer support groups have been found to have positive effects on cancer survivors. Studies show that social support, found in cancer support groups, mitigates the physical and psychological distress that results from cancer.

Spiegel, Bloom, and Yalom (1981), using an experimental design, studied the impact of a therapeutic intervention on women diagnosed with metastatic carcinoma of the breast. Research participants were randomly assigned to either the intervention group

or the control group. Efforts were made to make the groups as similar as possible in terms of age of study participants, average age at the initial diagnosis of breast cancer, the type of surgery, chemotherapy, and radiation treatments received. Thirty-four women who were in the psychotherapy treatment groups finished the study, while 24 women who were in the control group (they received medical treatments but not psychotherapeutic interventions) completed the study. The initial sample started with 86 women, but a number of women dropped out due to weakness, death, and relocation. The researchers found that psychotherapeutic interventions reduced the pain of cancer, which positively affected the emotions and moods of the participants. The support group members experienced significantly less tension, depression, fatigue, confusion, and phobias than control group members. The positive impact of the support groups was attributed to the psychosocial support that members of the intervention group received. This study does raise ethical concerns, as half of the research participants intentionally did not receive psychotherapy at a time of great need in their lives. In fact, more of the control group members died before the study was complete than did the intervention group.

Forester, Kornfeld, Fleiss, and Thompson (1993) completed a similar experimental study to that of Spiegel et al., (1981) in which they studied 24 patients who were receiving radiotherapy treatment for cancer while participating in group psychotherapy and compared them to a control group of 24 patients who were receiving radiotherapy but not participating in psychotherapy. Four weeks after the radiotherapy ended, those patients who had participated in group psychotherapy were found to have fewer symptoms of emotional and physical distress (such as depression, pessimism, hopelessness, worry, social isolation, insomnia, anxiety, anorexia, vomiting, nausea, and

fatigue) than the control group. The authors conclude that group psychotherapy may improve the quality of life of cancer patients by reducing their emotional and physical distress. There was no statistically significant difference based on gender, race, religion, marital or socioeconomic status in the benefit that patients experienced from participating in group psychotherapy. This replicability of this study is limited in that it does not provide the demographic characteristics of the sample population except for age (the average age of the experimental group was 58, while the average age of the control group was 59). While this study provides evidence for the efficacy of psychotherapy for cancer patients, it is not specific to breast cancer as many types of cancer were represented in the psychotherapy groups.

Telch and Telch (1986) compared the relative efficacy of coping skills instruction groups and support group therapy in helping cancer patients adjust to their disease. This experimental study randomly assigned cancer patients to coping skills instruction groups and support groups, while maintaining a control group that received no intervention. There were 14 patients in the control group, and 13 patients in each of the other groups. Twenty-seven women and 14 men, ranging in age from 19 to 64 with a median age of 41.3 participated in the study. A variety of types of cancer were represented. The researchers found the coping skills instruction groups to be more effective than the support groups, while the psychological functioning of the control group participants deteriorated. The researchers found that the coping skills group helped participants “regain a sense of personal control and mastery by learning techniques for coping with stressful thoughts, feelings, and behaviors” (Telch & Telch, 1986, p. 807). One of the limitations of this study was the fact that different varieties of cancer diagnoses were

present in each of the groups. This was especially evident in the support group where group cohesion was hindered because of the lack of commonality among patients. The conclusions of this study are also limited in that 40% of the patients were unavailable for follow-up three months after the end of the groups due to death, hospitalization, moving, or other extenuating circumstances. Therefore, the long-term effects of group participation were unable to be measured. Finally, the conclusions to this study are limited in that there is no mention of race, class, or marital status among other demographic variables.

In a similar study, Helgeson, Cohen, Schulz, and Yasko (2000) studied the effects of participation in an information-based educational and an emotion-focused peer discussion group on women's mental and physical functioning. Women were randomly assigned to groups. Women participating in the educational groups who had greater difficulties (e.g., lacked social support or had fewer resources) benefited more in terms of their physical functioning. Women who participated in the peer discussion groups benefited if they lacked support from their partners or physicians, but the groups were harmful for those women who had such supports. It is suggested that for those women lacking social support, the peer support group provided support. However, for those women who felt they had support before entering the group, the group caused them to question their existing support network. The authors suggest that more research is needed about the needs and resources that women have prior to group participation, how group participation affects women, and which women might benefit most from group participation.

Taylor, Falke, Shoptaw, and Lichtman (1986), in their fixed method descriptive study of 667 cancer patients in Southern California, through the use of a mailed questionnaire sought to determine the factors that lead cancer patients to join support groups. The sample was heavily biased in terms of gender, race, and class. Twenty-two percent of the participants were male and 78% were female. Ninety-three percent of the sample was white, 5% was Hispanic, and 2% identified as Other. The majority of study participants was middle class. Breast cancer was the most common diagnosis. The median age of participants was 58. Sixty percent of the sample had attended a support group, with a median attendance time of 2 years. Support group and non-support group study participants were similar demographically. The authors conclude that the lack of social support from family, friends, and medical personnel is only slightly related to increased support group participation. Those who participated in support groups were also more likely to seek out other types of social support; therefore, support groups are not fulfilling an otherwise unmet need. Support group attendees do report less psychological distress than nonattendees, although support group attendees do report more cancer-related concerns than nonattendees.

In order to evaluate the process, satisfaction and outcome of support group participants at Cancer Care, Inc. in New York City, Glajchen and Magen (1995) evaluated the group process and satisfaction of clients who participated in three types of cancer support groups (patients with cancer, relatives of patients, and bereaved relatives). This evaluation study was done because, although recent studies had shown that support groups improved the quality of life for cancer patients, the development of a conceptual framework to guide practice and research has been slow. Glajchen and Magen evaluated

the surveys of 392 clients representing 63 different groups that were held between August 1992 and June 1993. In addition, from February 1993-June 1993, 77 clients completed the Brief Symptom Inventory prior to participation in the group and at the group's completion. The sample did not include clients who dropped out of treatment (on average, 1 person dropped out of the relatives of patients and patient groups prematurely, while clients did not tend to drop out of the bereavement groups). The average age of members in the patient groups was 56, in the relatives of patients groups it was 47, and in the bereavement groups it was 50 with an overall age range from 20 to 79 years old. Across all three groups there were two to three times more female participants than male participants. Overall, the data showed that support group members were very satisfied with their participation and were less distressed after having participated in the groups. Glajchen and Magen conclude that clients were able to achieve more optimal emotional functioning after having participated in the support groups offered at Cancer Care. The group participants in the patient support group reported the lowest levels of emotional support and universality, while the bereavement groups reported the highest levels. The authors suggest that the short-term nature of the support groups may be most helpful to bereaved group members who are in crisis, while patients are living under the "shadow" of a cancer diagnosis and that this may account for the differences in satisfaction level. It is suggested that "group bonds" are crucial for support groups to be successful and therefore, diagnosis and stage of illness are of great importance when forming patient support groups. Group members also need to learn to transfer the skills they develop in the group for obtaining social support, so that they might find support in their own social networks after the groups end. All three types of support groups were also found to be



significant in reducing psychological distress, promoting coping, and preventing psychological deterioration, highlighting the importance of support groups. Glajchen and Magen recognized several limitations to their study. First, information should be collected from people who drop out of groups who may have had negative experiences. Second, while the surveys were anonymous, they were distributed by the group facilitators and, therefore, may have limited the comfort and honesty level of participants. Third, the Brief Symptom Inventory was not distributed to the entire sample. Fourth, the reliability and validity of the survey instrument needs to be tested. Fifth, while the study was a collaborative effort between the Director of Cancer Care and a Professor of Social Work, it is possible that personal investment in the results may have biased interpretations because one of the researchers worked for the agency being studied.

Gray, Fitch, Davis, and Phillips (1997) completed their qualitative descriptive study of women in four breast cancer self-help groups in order to understand and describe women's perspectives on: "(1) their personal experiences with breast cancer self-help groups, including perceived benefits and limitations; and (2) the processes and structures of groups, including perceived strengths and weaknesses" (p. 280). This study employed an inductive approach to research.

The researchers interviewed 24 women from four community breast cancer self-help groups in Ontario, Canada. A purposive sampling approach was utilized in order to obtain the most heterogeneous sample possible. The respondents ranged in age from 33 to 73, with 15 of the respondents under the age of 50. The respondents were mostly middle class and "well educated." Only 3 of the women had less than a high school education. All of the women were white. Four of the women had been diagnosed with

breast cancer within the last year, 11 within the last 3 years, and the remaining 10 respondents were long-term survivors. Six of the women experienced recurrence of their disease and 2 women died within 6 months of completing their interviews. The researchers acknowledge that their sample was not as heterogeneous as they had hoped, but felt that this was a reflection of group membership.

Three themes emerged from the interviews: emotional support benefits; informational and practical benefits; and group processes and structures. The women found being with other women who were also struggling with breast cancer to be a comfort. The groups also helped the women feel understood because of the shared experiences that emerged through the telling of their stories about their illness experiences. However, some women whose cancer was more advanced did not feel understood. Others felt that the constant talk about cancer was too much. When speaking about informational and practical benefits, the women reported that they learned a lot from the meetings and were able to share information about their illness and treatment which helped them regain a sense of control and allowed them to participate more fully in medical decisions. Many women also spoke about how the groups helped them be more assertive in getting what they needed, especially from health professionals. When speaking about group processes and structures, the women talked about how the group provided a separate space to talk about their illness so that they wouldn't have to burden their family or friends. The most challenging aspect of group membership was when a group member would die. Group members experienced another member's death as overwhelming and threatening to their own healing. There was a difference in opinion among group members about whether a group member's death should be actively grieved

in the group and whether the member's dying process should be honored in the group as opposed to not talking about it so as to not overwhelm newly diagnosed group members. Group members showed ambivalence about whether activism should be a part of the group's purpose or not. Some of the women were very involved in activism, while others felt the group should only be for support and that an activist agenda shouldn't interfere with mutual support.

Gray et al. concluded that breast cancer self-help groups help women overcome the stigma of breast cancer and help women feel less alienated and isolated by providing mutual support. Therefore, such groups are of great value. One of the limitations of this study was that the sample was selected in consultation with the group facilitators. This may have introduced bias into the study findings. The sample also consisted of women who were active members of the group, not those who dropped out of groups or did not participate at all. Therefore, not all women's experiences are represented. The strength of this study was that the benefits and processes of breast cancer self-help groups were described in the participants' own words through qualitative interviews. This allowed women to speak about their experiences using their own terms.

Gore (1999), in her qualitative study of women participating in breast cancer support groups, sought to answer the question: What are the specific variables that enhance the participants' quality of life in a breast cancer support group? Gore interviewed 10 women, between the ages of 41 and 70 with a mean age of 54.6, who had been living with a breast cancer diagnosis for at least one year, who were currently attending at least one breast cancer support group, and had attended at least four sessions. Gore found that participation in breast cancer support groups enhanced the quality of life

for participants in the following ways: by providing encouragement, mutual support, and caring; by providing help for women to deal with and face their fears of dying; to increase the ability of participants to control medical decisions and increase interaction with medical professionals; and by enhancing increased support outside of the family, which allowed the family system to run more smoothly. Gore's study indicates the benefits of support group participation, but it does not capture the experience of women who do not attend support groups. Nine of Gore's participants were white, all but one were heterosexual, seven were married, one was divorced, one was separated, and one was single. Information about social class was incomplete as not all interviewees completed responses for that item. Therefore, Gore's sample was limited in its diversity.

While the positive impact of psychotherapy groups on the well-being of breast cancer survivors has been established, the question remains as to whether participation in activism provides a source of healing that psychotherapy alone cannot/does not. My study will attempt to provide initial insight into this question.

### Breast Cancer Narratives

Very often, the voices and expertise of the women and men who suffer with, live through, and die from the disease are not heard. The story often told about breast cancer is one that is authored by medical personnel who have claimed scientific knowledge and authority about the disease. Rosenbaum and Roos (2000) suggest that three negative ideas about breast cancer have emerged in United States culture: 1) breast cancer equals death; 2) treatment for breast cancer compromises a woman's identity, femininity, and self worth; and 3) breast cancer is an experience that should not be openly discussed. Increasing numbers of women, however, are beginning to tell their breast cancer

narratives. Laura K. Potts (2000) asserts that breast cancer narratives are ways in which women make meaning out of their own breast cancer experiences. Other breast cancer survivors come to understand their own lives and experiences by reading and listening to such narratives.

The telling of one's personal and intimate stories became an important part of feminist consciousness-raising and the Women's Health Movement in the 1970s and 1980s and continues today. By telling the stories of their lives, women are claiming ownership of and authority over their own experiences, rather than succumbing to the dominant discourse. In fact, breast cancer narratives become a form of protest, a form of activism. The telling of stories and breast cancer narratives also allows women to connect with one another. Potts writes, "So while the texts tell a *shared* story, breaking down the isolation of the women's experiences of breast cancer with an assertion of the connective and collective, they also assert the unique and *individualized* self" (2000, p. 104). Potts reminds us that breast cancer can have multiple meanings in women's lives as are represented in women's narratives. Potts resists thinking of breast cancer as just one disease in the way that the Breast Cancer Awareness Month literature suggests. The meanings that women attach to their breast cancer vary according to their social identity (e.g., race, class, sexual orientation, etc.). Yet, breast cancer narratives are also shaped by a common structure: "discovery, diagnosis, decisions about treatment, confronting possible death and life after treatment" (p. 114).

Elizabeth M. Goering (1996) considers the act of storytelling to be empowering. She argues that storytelling is particularly important for women whose voices have often been silenced. Stories, then, become ways to share knowledge and form connections.

Stories transform what can be personally painful into something politically powerful. Storytelling is empowering in three ways: “1) through the stories as texts; 2) through the act of storytelling; and 3) through the act of telling stories about storytelling” (p. 47). As texts, stories document the lived experiences of women’s lives and can be used as political tools. The act of storytelling is a form of sense-making of one’s experiences and confirms one’s power as an agent of change. The telling of stories of storytelling is a self-reflective act, which again allows one to make sense of one’s experiences. Storytelling, the creation of narratives, then becomes an act of meaning making, empowerment, and change.

#### Activism, Healing, and Survivors of Sexual Assault

While no researchers have examined the impact of activism on the mental health of breast cancer survivors, some scholars have explored the impact of activism on the healing of survivors of sexual assault. Researchers have provided useful ideas of how to conceptualize and operationalize activism and mental health in the study of the effects of activism on the mental health of breast cancer survivors.

Krantz (1995) completed a qualitative interview study of adult survivors of sexual assault or child sexual abuse who were also engaged in activism to determine whether activist participation impacted their recovery process and, if so, at what stage of recovery and in what way. Krantz used purposive, convenience, and snowball sampling techniques to select her sample. The following sampling criteria were used: participants were required to be over the age of 20, survivors of sexual assault or child sexual abuse, and engaging in activist work related to sexual abuse or sexual assault. All participants were female (although that was not one of the selection criteria). Nine participants were

Caucasian, two were of mixed Native American-Caucasian descent, and one was African American. The participants ranged from 21 to over 60 (the one participant over 60 did not specify an age), with a median age of 35. All but one of the participants identified themselves as heterosexual; the remaining participant identified herself as bisexual. Ten of the participants identified themselves as either working-middle or middle class; one described herself as working class; and one as upper class. Educational background varied as did religious preference. The sample revealed two types of activists: those who viewed activism as just one part of their lives and those who viewed activism as the central purpose of their lives. Research participants identified the following positive effects of activism upon recovery: actual tasks performed as an activist facilitated the participants' healing and activities augmented their sense of well-being; activism enhanced their self-esteem or promoted self-knowledge; activism allowed them to develop supportive relationships with staff at the rape crisis centers; activism provided them with concrete skills or brought about tangible results; activism was a vehicle for facing one's fears; through activism participants came to view their assault or abuse and their recovery in a new way; activism impacted positively on the actual process of healing. The following negative effects of activism upon recovery were identified: difficulties with the legal system; increased physical danger from the perpetrator; and increase of intrusive symptoms. Krantz concluded that activism has a variety of positive effects upon the recovery process, as well as some negative effects. Those negative effects, including increased PTSD symptoms at the start of activist involvement, suggest new directions for research regarding the stages of recovery such as: whether or not activism is useful during Herman's first stage of recovery (Herman, 1992). However,

most participants reported that activism had positively affected their healing process and emphasized the positive effects over the negative effects. Krantz was unable to make a connection between the stages of recovery and the effects of activism. Krantz suggests that therapists might consider activism as one possible approach to healing from sexual trauma. Krantz's study clearly identified the positive and negative effects of activism upon recovery. However, more exploration into the negative effects is warranted.

Krantz's study was limited by her small sample size, which was non-representative and self-selective. The sample was also fairly homogeneous in terms of race, class, and sexual orientation. The sample also only addressed the recovery process of people involved in activism, while excluding people not involved in activism as a comparison.

Another study to consider in this area is the work of Sutton-Ryan (1998) who found that activism has a positive therapeutic impact on sexual assault survivors. Sutton-Ryan completed qualitative interviews with eleven survivors of childhood or adulthood sexual assault who were also involved in some type of activism. The participants ranged in age from 26-50. Ten were females and one was male. All identified as white. Seven of the research participants identified as heterosexual, three as lesbian, and one as bisexual. Notably, research participants indicated increased self-esteem and empowerment, more positive relationships with others, and the ability to make positive life choices as the result of activism participation. Activism participation also negatively impacted sexual assault survivors, some of whom reported experiencing the triggering of their own issues and emotional strain as a result of their activism. Activism was also found to increase awareness of diversity issues among participants. This study is limited because of the small sample size and the lack of diversity among participants.



Both of these studies indicate the value of activism and its positive impact, as well as raising concerns about possible negative effects on the healing of sexual assault survivors. These studies also illustrate the potential for empowerment and healing in encouraging survivors to tell their stories.

### Summary

The literature reviewed in this proposal clearly indicates that: there is a need for research on the impact of activism on therapy in general; support groups have been found to be beneficial for breast cancer survivors and there is always room for improvement and new interventions; and activism has been found to be healing among other groups of survivors. There is a need for research on the effects of participation in activism on the mental health of breast cancer survivors. The methodology for such a study will be outlined in the next chapter.

## CHAPTER III

### METHODOLOGY

#### Study Purpose and Questions

Therapy and support groups have been found to have positive effects on the well-being of breast cancer survivors. The effects of participation in activism on the lives of breast cancer survivors have not been well researched. Therefore, the purpose of this study is to explore and describe in what ways participation in breast cancer activism affects the lives of breast cancer survivors who are also involved in support groups. This study documents, through women's voices, the effects of activism and support group participation on healing and the meanings women make of their experiences. Finally, this study documents women's thoughts on the potential effects of the integration of activism into support groups as a treatment intervention for breast cancer survivors. This study has relevance for social work practice and program development.

This study asks the research questions: What is the effect that participation in activism has on the lives of breast cancer survivors who are also involved in support groups? What are the meanings that women make of their experiences? Does participation in activism provide a source of healing for breast cancer survivors that support groups alone cannot/do not?

#### Research Method and Design

This research study was conducted using a flexible qualitative interview design. An interview guide containing thematic questions and potential probes allowed research

participants to tell their own stories in their own words. By creating such narratives, women provided in-depth, information-filled descriptions of their experiences. A demographic face sheet was also utilized. This research design was selected because the effect of activism participation on the lives of breast cancer survivors is not an area that has been extensively researched. There is a need to develop a fuller understanding of this phenomenon, from which theory can be developed. Additionally, as a feminist researcher, I have a strong commitment to providing the space for women to tell their own stories in their own voices using their own terms. Finally, as Fosket (2000) has argued, breast cancer survivors are experts on their own experiences with breast cancer and their knowledge is grounded in their lived experiences. Rather than claiming scientific knowledge through the use of fixed methods, as so many medical personnel have done, I chose to employ flexible methods and honor the knowledge of my study participants.

In studying the effect of activism participation on the lives of breast cancer survivors, it is important to formally define and operationalize key concepts in this study. For the purposes of this study, activism is formally defined as “an activity which engages the individual in attempting to effect change in people, institutions or society” (Krantz, 1995, p. 29). Herman’s (1992) work on the role of social action in the recovery of trauma survivors informed my creation of an operational definition of activism. An activity is considered a form of activism if it fits in one of the following categories and relates to breast cancer: 1) Social service (e.g., survivors going to the hospital to be with women who have just had mastectomies, leading a self-help group, providing psychotherapy pro-bono, acting as a hospice volunteer, providing administrative support to a breast cancer

organization); 2) Education (e.g., providing community education about prevention, early detection, and/or treatment options, public speaking); 3) Political change efforts (e.g., lobbying, writing letters to elected officials, participating in demonstrations or political protests); 4) Fundraising (e.g., Race for the Cure, Avon 3-Day Walk, Relay for Life, American Cancer Society Walks); 5) Publication (e.g., research, memoir, poetry, essay, news article, development of educational materials). Activism can also be categorized using Klawiter's (1999) model of the multiple branches of the breast cancer movement. Both ways of categorizing activism are used in this study. Activism is categorized using the model adapted from Herman and the branch of the breast cancer movement that activism fits into is also identified according to Klawiter's model.

#### Types of Data

Participants were asked to complete individual semi-structured interviews for the purpose of sharing their experiences with breast cancer, the effect breast cancer has had on their lives, and their participation in breast cancer activism and psychotherapy. For the purposes of this study, psychotherapy was defined as individual or group therapy with a social worker, psychologist or psychiatrist, counseling, and self-help groups. The majority of participants in the study were members of support groups, and so that is the form of therapy this study focuses on.

Participants were asked to complete demographic questionnaires at the start of the interviews. The demographic questionnaire asked for information such as breast cancer diagnosis and prognosis, type and length of psychotherapy involvement, type and length of breast cancer activism involvement, age, race, national origin, sexual orientation,

education, occupation, approximate income, religious affiliation, family composition, and political affiliation (See Appendix F).

The interviews utilized a semi-structured interview guide which included questions about: the effect that breast cancer has had on the participants' outlook on life, quality of life, and concept of self; their involvement in psychotherapy and what the nature of that work has been; their involvement in breast cancer activism; and the effect, if any, that breast cancer activism has had on their therapy and their lives (See Appendix G).

I am explicit in presenting my methodology and have left an audit trail so that future researchers might reproduce my study to address its trustworthiness. Because of my small sample size, this study is not generalizable to the larger population of breast cancer survivors, but it may offer ideas for breast cancer survivor activists and therapists to apply to their work.

### Sample

This study was conducted using a sample of 12 women who met the following criteria: 1) Participants were women who were 30 years old and older. Although men and younger women do get breast cancer, the issues facing them are significantly different (e.g., breast cancer is often thought of as a woman's disease; stage of life issues) than the issues facing women who are 30 years old and older. 2) Participants ideally would have been diagnosed with breast cancer at least one year prior to participation in the study. This would allow time for the initial shock of a cancer diagnosis to have passed and for women to have integrated the diagnosis and the meaning of the diagnosis into their lives. All but one of the participants were at least one year past their diagnoses.

3) Participants were involved in individual and/or group psychotherapy. The majority of participants were involved in support groups as their primary form of psychotherapy. Participants had attended at least four therapy sessions prior to participating in the study. This hopefully enabled participants to identify the effect (if any) of therapy on their mental health. 4) Participants were involved in breast cancer activism, having participated in at least one form of activism in the past six months (or a year for events that occur annually such as the Race for the Cure).

Important variables also considered were: race, age, social class, sexual orientation, and ability; family constellation; involvement in individual and/or group psychotherapy; the breast cancer diagnosis and prognosis; the length of time that had passed since one was diagnosed; one's remission status; whether one was currently cancer free; involvement in activism (breast cancer or other types) prior to one's breast cancer diagnosis and current breast cancer activism participation; the duration of one's breast cancer activism; sources of social support (e.g., family, friends, community, other activists, other breast cancer survivors); involvement in religious community and/or spirituality; self-care practices; employment status; educational attainment; romantic relationship status; other life stressors (e.g., children, work, finances, access to health care, health insurance, family responsibilities), etc.

Participants for the study were selected using purposive, convenience, and snowball sampling techniques. First, using a purposive sampling technique, I attempted to recruit participants at member organizations of the New York State Breast Cancer Support and Education Network (NYSBCSEN). This was my attempt to reach participants who were a part of what Klawiter (1999) called the Women's Cancer

Movement and the Cancer Prevention Movement. The NYSBCSEN is a statewide coalition of 23 grassroots activist organizations that have created a network and combined efforts to share information and to advocate for comprehensive legislation to improve all aspects of cancer care. Their ultimate goal is to work toward the eradication of breast cancer. The member organizations of NYSBCSEN are a diverse group representing the various regional areas of New York State (e.g., New York City, Long Island, the Hudson Valley Region, the Capital Region, the Adirondacks, Central New York, and Western New York are all represented by various groups), as well as the diversity of women on the basis of race, age, sexual orientation, social class, and ability. Only one of the five member organizations of the NYSBCSEN contacted agreed to allow me to recruit participants through their organization. Letters with an explanation of the study, a statement about the voluntary and confidential nature of participation, and my contact information were distributed to that organization's membership (see Appendix B). I also asked study participants to refer other potential participants to the study, thereby employing the snowball sampling technique.

Two additional recruitment techniques were planned, but not necessary as a sample of 12 women emerged from recruitment efforts through the NYSBCSEN member organization. The other potential recruitment techniques were: 1) the distribution of informational fliers about the study with my contact information at Race for the Cure events and American Cancer Society walks in the Capital Region, the Hudson Valley Region, New York City, and Long Island. This convenience sampling technique may have allowed me to reach potential participants from what Klawiter (1999) called the Breast Cancer Awareness Movement; 2) the distribution of informational fliers about the

study with my contact information to oncologists and members of the New York State Chapter of NASW to be posted in their workplaces. This may have allowed me to reach potential participants involved in the previously cited forms of activism as well as people whose activism might be done on a more individual level.

### Data Collection Methods

Data for this study was collected through in-person, semi-structured intensive interviews conducted in the winter and early spring months of 2007. An interview guide was utilized with a set of thematic open-ended questions and potential probes that allowed research participants to tell their own stories in their own voices, using their own words (see Appendix G). A demographic face sheet was also utilized in order to collect demographic data about each of the participants that might have been missed in the interviews (see Appendix F). The interviews were scheduled at times during daylight hours and places that were convenient and comfortable for both the interviewee and the researcher, such as libraries, coffee shops, and the interviewees' homes.

Participants were mailed the informed consent forms prior to the interviews (see Appendix B). They were able to review those materials before their scheduled interviews and make a decision about their interest in participating. At the beginning of the interviews, I provided an opportunity for questions about the study and the informed consent form, making sure that participants understood their rights, and asked that participants sign the forms before the interviews began. Two copies of the informed consent form were brought to each interview so that both the interviewee and the researcher could have copies. A list of referral sources was also provided to each of the interviewees at the completion of the interviews (see Appendix C).



The interviews were audiotaped. In addition, I kept a journal in which I wrote my impressions and reactions to the women and the interviews as a way of monitoring and reflecting on my own possible reactions and biases. The completed questionnaires, the audiotapes, my notes, and any additional email commentaries that were provided became part of the data collected and analyzed. All data are being stored in a locked file cabinet. I transcribed the interviews using a transcribing machine and analyzed the data using narrative analysis (see the discussion of data analysis below for a detailed description of that process). The interviews were transcribed in private to protect participant confidentiality. Upon completing their interviews, participants were asked to provide pseudonyms, which were used to label their interview tapes and transcripts. A master list matching participant pseudonyms and participant names is being kept in a locked cabinet accessible only to the researcher. All identifying characteristics, quotes, and information gathered during the study have been disguised and data are being presented in the aggregate so they cannot be identified with participants. Finally, all data, audiotapes, notes, emails, and consent forms will be kept secure in a locked cabinet for a period of three years as stipulated by federal guidelines after which time they can be destroyed or continued to be maintained securely.

### Data Analysis

The purpose of this study is to explore the effects that participation in breast cancer activism has on the lives and healing of breast cancer survivors who are also involved in psychotherapy and the meanings that women make of their experiences, while describing the types of activism and psychotherapy in which breast cancer survivors are engaged. This study utilized a flexible qualitative interview design in order

to encourage research participants to tell their own stories in their own words. By creating such narratives, women provided in-depth, information filled descriptions of their experiences with breast cancer, activism, and psychotherapy. In order to fully capture the interviewees' responses, the interview tapes were transcribed verbatim.

The interviews were analyzed using the process of narrative analysis, as described by Catherine Kohler Riessman (1993). The tapes were closely listened to on multiple occasions in order to develop insights and answer the questions: "How is [this narrative] organized? Why does an informant develop her tale *this* way in conversation with *this* listener?" (p. 60). How is the informant making order, making sense of her breast cancer experience through the narrative that she constructs? Riessman describes narrative analysis as a process of beginning inside the narrative and identifying the meanings encoded in the interviewee's speech. The analysis is then expanded outward and the "underlying propositions that make the talk sensible" (Ibid) are identified. That is, how do one's individual experiences, the meaning one has attributed to those experiences in order to understand them, and the language one uses to speak about those experiences inform and reflect or contradict our larger theoretical understanding of that experience. I attempted to give careful attention to how the interviewees' narratives were influenced by larger social and cultural stories and institutions. It is my hope that as I identify events, concepts, meanings, and themes that emerged from the women's narratives, that my analysis honors women's lived experiences. Therefore, when the results of this study are presented, direct quotes from the interviews of breast cancer survivors are incorporated as the stories of the women's experiences are told. When the women's individual narratives are combined, it is possible that new meta-narratives, ones that might replace the

dominant narratives told by the medical establishment, about living with breast cancer, breast cancer activism, psychotherapy, and healing emerge.

In order to ensure the relevance and rigor of this study, I engaged in the process of validation of my interpretations as described by Riessman. Riessman identifies four parts of the validation process: persuasiveness and plausibility; correspondence; coherence; and pragmatic use. In order to address the issues of persuasiveness and plausibility, I include direct quotes from the women's narratives in the analysis, interpretation, and discussion of my findings. This helps to provide evidence for my theoretical claims. My interpretations are also strengthened because I am able to demonstrate coherence in the women's narratives. A narrative is considered to be coherent if the overall goals that the narrator is trying to accomplish in the telling of her story (global coherence) make sense in terms of the structure of an individual's narrative (local coherence) and if there are recurrent themes throughout the entire narrative (thematic coherence). Finally, by demonstrating pragmatic use, i.e., by providing the information necessary for another researcher to build upon or replicate my study and making my interpretations transparent, I am meeting Riessman's fourth criteria for validation (Riessman, 1993, p. 65-67).

#### Strengths, Limitations, Benefits, and Risks of this Study

This study utilized a qualitative, semi-structured interview with open-ended questions as a data collection method. This method has both strengths and limitations. The strengths of qualitative semi-structured interviews are that: Interviewees are able to tell their own stories in their own words and therefore are able to provide a verbal account of their subjective experiences, feelings, memories, interpretations, and the meanings they attach to their lives; the flexibility of semi-structured interviews allows the

interviewer to ask complex questions and open-ended questions; the non-verbal body language, facial expressions, pauses, and hesitations of the interviewee can be observed by the researcher when the interview is done face to face; both the interviewee and the researcher can ask for clarification if a question or response is not understood; and, if rapport is developed, the interviewee may benefit from the feeling of being listened to and be willing to share important and intimate details of their life experiences. The qualitative semi-structured interview also has disadvantages which include: the lack of anonymity for the interviewee, although confidentiality can still be maintained by the researcher; the interviewee may experience the interview as intrusive and it may bring up painful issues for the respondent; the interview is time consuming for both the interviewee and the researcher, while the transcription and data analysis is especially time consuming for the researcher; and the interviewee's responses may be affected by the age, race, social class, gender, sexual orientation, education, and differing cancer status of the interviewer (Anastas, 1999; Padgett, 1998). It was important for me to be aware of how the strengths and limitations of the chosen data collection method impacted the data gathered throughout the entire study. I believe that the strengths of the method outweigh the limitations.

In addition to the strengths and limitations of the method chosen for this study, it is also important to consider methodological biases. My choice of a flexible research method required that I be self-reflective when conducting this study and make explicit my own beliefs and how they impacted my research question, my selection criteria for my sample, the items I included on my interview guide, the questions I chose to ask in my interviews, my analysis of the data, and my interpretations of my findings. My use of

Riessman's validation process helped me address my methodological biases, as did my self-awareness.

When conducting this study, it was important for me to be conscious of and reflective about my personal identity and perspectives and how they may have impacted and potentially biased the study. As a white, middle-class, educated, feminist, woman who is relatively young, and currently cancer free, I needed to be conscious of how my identity may have affected the stories that women participating in the study chose to tell me. I also needed to be aware of how my identity led me to interpret the narratives the women provided. My father died of cancer in 2002. Therefore, it was important for me to be aware of any reactions I had to the stories women were telling me as I interviewed them. It was equally important for me to engage in self-care throughout the course of this research study. As someone who has been involved in feminist activism, been a member of Capital Region Action Against Breast Cancer, participated in the Race for the Cure, and sought individual psychotherapy, I must be conscious of how my own convictions about the importance of activism and my positive experiences with therapy might have impacted my interpretation of the study participants' narratives. It is important to me that the stories of breast cancer survivors involved in activism are genuinely told. It is my hope that my own consciousness and reflection facilitated that process.

There were also ethical issues to consider in this study. There were potential risks and benefits to participants. Participants in this study may have experienced emotional distress while completing their interviews. Participants were informed that if they needed to take a break or end the interview at any point during the interview, that they should let

the researcher know. At the end of the interviews, participants were provided with a list of referral sources should they need assistance (see Appendix C).

One must also consider the benefits of this study. While there was no financial compensation or other tangible benefits, participants in this study may have gained new insights into their breast cancer, therapy, and activism experiences through participation in the interviews. Participants contributed information that helped me write on these topics for my thesis and may help improve therapeutic services offered to breast cancer survivors. This study provided a space for women to tell their stories, through their own voices, about the impacts of breast cancer activism and psychotherapy on healing and the meanings they make of their experiences. In the next chapter, I will present my findings from my completed interviews with breast cancer survivors.

## CHAPTER IV

### FINDINGS

The goal of this study was to provide a space for women to tell the stories of their breast cancer survival; their experiences with support, psychotherapy, and activism; their thoughts on potentially combining support groups and activism; and the impact that breast cancer has had on their outlook on life. This was accomplished through in-depth, open-ended interviews with 12 breast cancer survivors. In this chapter, I review the demographic characteristics of the women who participated in this study and the themes that emerged through the women's narratives.

In order to protect the confidentiality of the women who participated in this study, participants were invited to choose pseudonyms. Pseudonyms have also been created for the names of the various breast cancer activist organizations, support groups, and hospitals with which women were involved.

#### Demographic Profile of Participants

The demographic data gathered on the women in this study were as follows: current age, month and year of first diagnosis, type of psychotherapy involvement and number of sessions attended, number of years in activism, race, sexual orientation, educational attainment, occupation, number of hours worked per week, socio-economic status, relationship status, number and ages of children, religious affiliation, and political party affiliation (see Appendices D and E).

Study participants ranged in age, at the time of the interview, from 43 to 73 with an average age of 57. Participants ranged in age, at the time of their first diagnosis, from 37 to 66 with an average age at first diagnosis of 49. Women’s number of years survived ranged from 7 months to 20 years, with an average of 8 years survived. Table 1 summarizes this data. Three of the women have had recurrences. Four of the women have had multiple types of other cancers in addition to breast cancer including ovarian, lung, bladder, and skin cancers. One woman also has multiple sclerosis.

Table 1—Current Age, Age at Diagnosis, Year of Diagnosis, and Years Survived

<u>Age Now</u>	<u>Age at Diagnosis</u>	<u>Year of Diagnosis</u>	<u>Years Survived</u>
66	46	1987	20
45	43	2005	2
60	43	1990	17
59	46	1994	13
73	59	1993	14
43	37	2001	6
53	51	2005	2
49	45	2003	4
68	66	2005	2
46	45	2006	7 months
61	51	1997	10
69	61	1999	8

For the purposes of this study, psychotherapy was broadly defined to include individual or group therapy with a social worker, psychologist, or psychiatrist, counseling, and self-help groups. The women in this study participated in a variety of forms of psychotherapy. Five women participated in multiple forms of psychotherapy. Nine women participated in self-help groups, including two women who started their own self-help groups. Three women participated in groups facilitated by a social worker, psychologist, or psychiatrist. Two women participated in individual therapy with a social worker or psychologist. Two women participated in online support groups in addition to



in-person self-help groups. One woman facilitated healing retreats. Women have attended from a minimum of 4 to over 75 sessions.

Participants in this study have participated in activism for an average of 6 years with a range from 6 months to 17 years, as indicated in Table 2. All women in the study participated in at least one form of activism within six months of their interviews.

Table 2—Number of Years Survived and Number of Years in Activism

<u># of Years Survived</u>	<u># of Years in Activism</u>
20	10
2	2
17	17
13	12
14	several
6	4
2	2
4	3
2	1
7 months	6 months
10	9
8	7

Eleven Caucasian women and one Pacific Islander woman provided interviews for this research. All twelve women identified as heterosexual. Ten were married and two were single, never married. Three of the women had no children. Four women had one child, four had two children, and one had three children. The children ranged in age from 7 to 44 at the time of the interviews, with the majority 30 years old or older.

Nine participants reported an affiliation to organized religion, while three women reported no religious affiliation. Two women were affiliated with a Protestant religion, six women were Catholic, and one woman was Jewish.

Respondents were also asked to identify themselves politically. Five of the women were Democrats, three were Republicans, three identified as Independent, and

one woman chose not to answer the question on political party affiliation. Two women identified as very liberal, two as liberal, one as moderate and liberal, four as moderate, one as moderate and conservative, one as conservative, and one chose not to answer.

Data on education, employment, and socio-economic status were also gathered. Two of the women held two-year degrees, four women held bachelor's degrees, and six women held master's degrees. Five of the participants were retirees, one woman was a homemaker, and six were employed full time. Among the occupations represented among participants were the following: teacher, museum administrator, bank manager, financial analyst, travel agent, librarian, nurse, health administrator, and project manager for a government agency. Women reported having family incomes of the following: one woman had an income of \$20,000-40,000, one woman had an income of \$60,000-80,000, nine women had incomes of \$80,000+, and one woman chose not to answer.

### Support

Women who participated in this study were asked to speak about the support and/or the lack of support that they received from others during their breast cancer diagnoses, treatment, and survivorship and in relation to their breast cancer activism. When faced with their breast cancer diagnoses, treatment, and survivorship, the women in this study drew on their families, friends, medical personnel, religious communities, co-workers, yoga and other forms of self-care, cancer activist organizations, support groups, resource centers, individual counseling, and friends who also had cancer for support. Varying levels of support were provided for the women in this study.

All of the women found their families--including spouses, children, siblings, parents, and/or in-laws--to be sources of support at varying levels. Among the supports

that these family members provided were: emotional support; accompaniment to medical appointments, treatments, and surgeries; traveling from across the country to be present during the treatments; childcare and driving; grocery shopping, cooking and housecleaning; lymph massage; and medical research.

Angel described the support she received from family as being a lifesaver:

My mom and my dad and my sister actually came. They live in California so they came and stayed a couple of weeks. They took me to treatments and cleaned the house, took care of the kids and did whatever it is that we needed done.... And the times that they weren't there, my two sisters-in-law, they took turns. They live on Long Island. And they took turns, one would come up one week and the next would come up the next week.... So, oh my God, they were lifesavers.... Because I honestly couldn't do it without them. It was huge.

For Angel, Jaws, Maggie, and Easter, the emotional support that they received from their husbands was especially significant.

Angel spoke about her husband's emotional support by saying:

My husband came in [to the doctor's office] and he saw me crying, so he of course knew something was up.... I couldn't help but just cry. And he just hugged me and he said, you know, we are going to get through this. He said it is going to be a rough several months and we're going to get through it. And he said, I am going to be there and we are going to get through it together. And then my son came in and he started hugging me because he knew something was wrong. That was pretty much the day that I found out. Obviously my husband and my son was a big support. My husband just kept telling me, you know you are going to get through this. I know this is rough for you, but you are going to get through this. Look at your kids. You know you want to see them grow up and we want to raise them together. And so that was just, every day I am looking at them and saying, yeah, he is right. You know and that helped me get through it.

Maggie commented on the importance of the emotional support that she received from her husband in terms of the love that he gave her as well as physical affection.

Maggie's husband also felt that it was important for him to be with Maggie during her medical appointments and missed work for her:

My husband was phenomenal. He was very loving. He was very physical. He said this is something we are going to do together. And at his work they were very angry that he insisted on taking the time. He came to every appointment with me. They said you can't take the time off, and he said, no, there is no discussion. I am just going to, and I am not prepared to discuss this. I am going to be there, we are going to make these decisions together.

Jaws found that she was receiving so much support from her husband, daughter, and friends that she initially didn't need a support group:

When cancer comes knocking at your door, it is quite frightening. Oh my God, what do we do? But we jumped into action, basically that is what I did with the aid of my husband who has been such an amazing support as well as my daughter and friends and family. They were my support group from the beginning.

Claire, Flo, and Abigail's husbands provided limited emotional support for various reasons. However, each of their husbands did provide logistical and physical support. Claire's husband learned how to do and provided lymph massage when she developed lymphoedema. Flo's husband, who was typically very quiet, researched breast cancer and its treatments and was active in the decision-making process. Abigail's husband drove her to all of her treatments.

Scottish Queen, Take It Out (TIO), Linda, Angel, and Kate had sisters who were supportive in various ways during their breast cancer diagnoses, treatments, and recoveries. Linda and Scottish Queen's sisters traveled from out of state to be with them during their treatments. TIO, Scottish Queen, and Angel commented on the emotional support they received from their sisters. Finally, Kate and Angel's sisters provided physical support around household tasks.

Flo, Jaws, Claire, Easter, and Angel had children who were especially supportive throughout their breast cancer experiences. Flo reflected upon her surprise when her son arrived for a visit after her surgery:

My kids, my boys live [eight hours away]. We had told them not to come up after the surgery. I woke up the day after the surgery, blurry eyed and I look and I see this person and it looks like he's got a dark shirt and a white collar. And I thought, oh my God, it's a priest. Well, when my eyes cleared I realized it was my son with a dark sweater and a white turtleneck. And I was stunned because we had said not to come up. Well, his wife told me afterwards that he was just in such a state. She said, "I told him, go." He only stayed a day or so, but he had to come up and see me in person, see how I was. When I got out of the hospital, my younger son and his wife came up about a week, ten days, to help me, you know help with all the things around the house and helped me walk.

Claire's daughters became involved in breast cancer activism in the years following Claire's illness. One daughter lived locally and became active in Claire's breast cancer activist organization. Her younger daughter participated in fund-raising events. Both referred other women facing breast cancer to Claire:

I think that my daughters are very proud of the work that I do. My youngest daughter who lives [out of state] got very involved in doing those three-day-walks and doing the Komen walk.... I know that I think that they are proud because they have sent me referrals. And they'll call me up and say, mom, so and so has lymphoedema, can you talk to them?

Angel's story served as a reminder that breast cancer affects all members of one's family and that support can come from even the youngest family members:

It is the things that people do for you while you are going through it also help you along the way.... I'll give you an example, and if I cry, I'm sorry. My son, he was eight at the time. He was in grammar school and I was home. And I was so constantly tired from the chemo so I was resting. He came home from school one day with a big manila envelope and I was like, what's this? And I opened it up and he said, "I told my teacher that you were home sick and that you had breast cancer and that you had surgery." He had all the kids make cards for me. And I just thought that was the sweetest thing that this little eight-year-old was thinking, "I want my whole class to make these cards for me." (crying) And it just gets you through. Things just simple things will get you through what you are going through.

The most common types of support provided by friends were emotional support, meals, and childcare. Jaws recognized that in some ways the support that she received

from her friends was also something that helped her friends cope with their own feelings around her illness:

I've learned as time goes on, you know if somebody wants to do something, they really want to do something and they really need to do something to help. So I let them pick up something at the grocery store or make a meal or you know clean a floor or do something. Because they are helpless. And I understand that feeling. When you do have a sick parent or a sick relative or somebody that you really want to help, and what is it you can do? You need to let them help when they want to help in some way. I have friends that called constantly, came for visits constantly. My husband wouldn't leave my side, which was wonderful except he needed to be on his own. He needed to have time away from me, too.... So, if he had gone out, somebody would be here to hang out with me. They are quite amazing.... But my family, my younger sister, she was my sweet little rock. My parents.

Friends and co-workers were especially important for those women who received limited amounts of support from their families.

Scottish Queen, TIO, Flo, Claire, and Abigail also commented on the importance of the support they received from medical personnel at the time of their diagnoses and during their treatments.

Flo talked about the support that she received from her oncologist this way:

The gynecologic oncologist, when I was diagnosed, when he knew that my sister had died of ovarian, then he would come in every other day and he would sit down with me and he would give me the pep talks. He would say...if one cancer treatment doesn't work, I've got at least a dozen different chemos in my bag. We'll try those and we'll get you through it.

Claire, who was used to having male doctors her whole life, spoke highly of her doctor:

I really liked the idea of being cared for by female doctors, and she was wonderful. I'll never forget how she called me up the night before the surgery and she asked me if I had any questions and was there anything that she could do you know to allay any of my fears. And so we talked awhile. My doctor actually came in on Thanksgiving morning and told me that my lymph nodes were not involved. Which was wonderful news. She actually came in on Thanksgiving.

And I could not believe that she would come in on Thanksgiving, but she said that she wanted to share the news with me...and that I had a very good prognosis.

A spiritual belief system was also an important source of support for Linda, Maggie, and Claire. Claire found support from the priest at her church:

The other very, very nice thing that happened was that during it all—I am a very religious person. And I had gone to see my parish priest do the sacrament of the sick. And it was just he and I in the church and it was after school. I went over there just by myself and I met him. And it is a very big church so only the lights were on by the alter. And he had me come up by the alter and he used the oils and it was the most peaceful moment and I felt very much at peace because of that. And then I knew the next day that the principal of my school had organized everyone to go to my church where my priest would be saying mass. And so while I was being operated on, they were in church. And I know I was very, very relaxed.

Maggie found that her spiritual belief system was strengthened after her breast cancer diagnosis:

One of my biggest support systems has been my yoga. I did yoga most of my life. But it is an immense support first off.... I think the peace, the relaxation. And then the spiritual, you know, I have a spiritual dimension in my life and that has grown and it has become far more loose. I would say that I was a nominal Christian whereas now I think I have a deep belief in God and my Christianity takes me there. I do have a church, but I can sit at a lakeside and find my God in a way that I couldn't before. I think there is a depth that I didn't have that I found.

For all of the women in this study, it was clear that their experiences with breast cancer would have been even more difficult if they had not had the support of others.

Jaws and Scottish Queen spoke to the importance of support that they received during her battles with breast cancer. Jaws said:

I know I was loved before. I just remember writing in my journal, man oh man, I am so loved. And I knew I was loved prior, but it is just amazing the outpouring of support from people that you receive when you are going through something. And I don't ever want to forget those people and they stay important in my life. That is the most important thing, spending time with the people that I like.

Scottish Queen echoed her words by saying:

...what is good about the cancer, you get exposed to all that and feel the love from all those people (friends, family, medical community, activist community), it is pretty amazing.

### Support Group and Psychotherapy Involvement

For all of the women in this study, there came a time when their informal support networks were not completely fulfilling their needs for support. Participants then turned to more formal forms of support from self-help groups, social workers and psychologists who provided individual counseling, group therapy provided by mental health professionals and hospitals, support groups provided by cancer activist organizations, healing retreats, a camp for cancer survivors, and Reach to Recovery sponsored by the American Cancer Society. Several women formed their own support groups, one for people struggling with lymphoedema and one for women with breast cancer. Both of these women later became board members of the member organization of the New York State Breast Cancer Support and Education Network (NYSBCSEN).

The most common source of formal support that women pursued was support groups. Many women found support groups to be particularly helpful because they found that other survivors had a better understanding of what they were going through than even the most well-intentioned family and friends. Women also felt that they were able to share the details of their experiences with other survivors in a way that they could not with others. Flo spoke to the positive impact of support groups in general:

I have this higher threshold of support knowing that there's this community of gals that is with me no matter what happens and I can say anything. We can discuss the most gross topics and nobody is going to blink because they are going through it, or they have been through it, and frankly, for the newer gals who come who don't know a single other person who has ovarian cancer, I am probably at



the stage now, well I am one of the few whose lived the longest in my support group. But they are the pillow underneath your feet, they are the blanket that you can just wrap around yourself because they know what is going on and they will do things for you or send you cards.

Ida spoke to the importance of having a support group of cancer survivors when friends cannot meet one's needs and the positive impact that support groups had on her healing in the following way:

Well, I think it, I'm sure it helped. You know just having somebody else to talk to. But it was like a secret place, a private area of your life. You can't really talk to friends too much. Especially about breast cancer because people who don't have it don't want to hear about it. They really don't want to hear about it. And until their lives are affected, they certainly do not believe they will ever have it even if they have risk. And so the tolerance for listening, you certainly don't want to share uncomfortable things like pain or discomfort or things like that with them. So you wind up joking about it or minimizing it or whatever. So you really do need to talk to other people. They are the only people who know what you've been through. And that helps. And we recognize that that helps, which is why the groups that exist today are willing to talk to one another. We don't give medical advice. We don't give any advice really unless it is practical advice. But if you just want to talk, sometimes all somebody needs to do is tell their whole story and just get it out and then it is over.

Maggie reflected on the understanding that cancer survivors have of each other's experiences and the sisterhood that results:

The sisterhood is actually cancer survivors, I think is amazing. But it is also, you feel their pain with their cancer, they know that you know what it is like. But I think we are the only people who can really help each other really feel what that means. I think other people, I mean you just don't understand. And so particularly, with my one friend, when she died, I don't have anybody when I go for my tests, my friends will say, oh didn't you go? But it is just not the same. They don't have the fear of lymphoedema. You know, why would you? Why should you? I don't want you to have it. I don't want people to feel that. There is something very deep.

One of the realities of long-term support group participation for several of the women was that while they found the support and sisterhood within the support group to be invaluable, the deaths of other women were very painful. Flo was one of the study

participants who was diagnosed with multiple cancers, her first being ovarian cancer. She was very active in an ovarian cancer support group in addition to her breast cancer support group and online support group. She felt that much of her loyalty went to ovarian cancer in large part because there is not as much public awareness and research funding given to ovarian cancer in comparison to breast cancer. Flo found participation in her support groups to be very important, if not bittersweet because of the deaths she has experienced. She said:

I think support groups are very important. I think they give you something that medical people can't give you and sometimes your family can't give you. Even the most supportive family in the world, they are afraid for you and they don't want you to think that you are going to die. And particularly in the ovarian group you know it probably will kill us, but not yet. Sometimes we talk about cancer, but most of the time we just talk about other things. We laugh a lot and you know one of our other gals...has hospice. We've lost a lot of people. And I always wonder what death is going to be the one that is the straw that breaks the camel's back.

Flo was also one of the two women who participated in an online support group. She found the online group to be extremely helpful and read the listserv or signed onto the chat room daily. She said:

And I know with the breast group online, I get that same feeling. And it is really comforting and you just have the sense that they are the closest people in your life. Even with the online group it may sound weird, but I know those people, probably better than some of the gals that I worked with for 20 years. And some people will say, oh, well, I don't want to be defined by cancer, I don't want my cancer to be my definition. Ok, but when you are talking with other cancer patients, you are talking from that frame of reference. And sometimes you have more in common with people because of it.

Not all of the women in this study found support groups to be helpful. For some, they did not consider themselves to be joiners of groups so to participate in a group was

very challenging. Claire commented on the challenge for her of being asked to be introspective in a way that was not comfortable or familiar to her:

I have never been introspective. I mean, I just do things. You know, I don't sit around thinking why am I doing that? What kind of person am I? What drives me? It just doesn't seem to happen. And so to actually sit there and you know, like last week there was this big circle and in the circle, you had to think about the kind of person you are—it is a group thing—so they'd offer things about themselves you know like, so you might be witty and shy. You might be conservative. You might carry hurt. And it took me a long time to find out what is in there. You know, what am I going to say about myself? It's just, it's hard for me. I have to say it is hard. The first time, you know it was like setting your goals. And you know for me, if I set a goal, I admonish myself for not reaching the goal and all of this is about you know maybe trying to let go of some of that, too. So I don't know, but it is challenging. It is challenging for me to participate.

Easter was another one of the women who did not find support groups to be helpful because she does not consider herself to be a joiner of groups. However, she facilitated healing retreats including dream work, creative writing, song writing, and meditation that took place in the mountains. As a breast cancer survivor, while she could identify with the breast cancer survivors that came to her retreats, she did not feel that support groups were her thing, but she did enjoy putting the retreats on for others and admired their strength and courage. She did not consider organizing retreats to be a form of support, but rather a form of activism. About the retreats she said:

I enjoy doing this. I am not a joiner of support groups. In fact, I don't think I would ever have joined a support group. That is not my thing. So this is a way of being, of giving something back, and it is not being quite as oppressive as sitting in a group where what you talk about is your illness. I don't benchmark my life against the illness....Yes, I see women coming in who come for support groups. And that is ok. Because that is apparently what they need. But it is an interesting divide. I guess it is a gift that I have for somebody else. And doing it with people is really a lot of fun. I enjoy working with people who are writing songs and telling stories. I have always grown up with people who were songwriters and storytellers so this is the thing that felt comfortable.

Four of the women participated in support groups that took place at local hospitals. While the women were grateful for the effort that hospitals made in trying to have support groups, the women in this study often found their experiences with the hospital groups to be unhelpful because the groups were often very large, sometimes survivors of multiple types of cancer were present, and often survivors were at vastly different stages with their illnesses and recoveries.

Abigail found participation in large support groups offered by the hospitals in her area to be difficult because they were sometimes monopolized by one person. She said:

They had a pretty good turnout. It was a very central location. It would have been good except for the few times that I went, there was one person who took over the meeting. In both cases, if that person hadn't been there, I think it would have been a really, really wonderful experience. The first meeting that woman was just, she was mad. She was just plain mad. And she had apparently nobody in her life to help her. She used to yell at people. She was at the first one, and she was just like, she couldn't follow a conversation. And finally, if somebody else started to talk, she'd interrupt them and start talking about herself again and yell at the other person. You could just tell she was a stupid person. She ruined the meeting for everybody.

A number of women in this study were also offered support through the American Cancer Society's Reach to Recovery program. Reach to Recovery is a program in which breast cancer survivors visit newly diagnosed women to share their stories of survival and coping. Some of the women in this study found Reach to Recovery to be very helpful and became volunteers themselves. Others found the program to be meaningless and invasive.

Ida was one of the women who did not find Reach to Recovery helpful. She said:

I was feeling pretty lousy and this woman came in and in retrospect I'm sure she meant well, but she wasn't well trained and she didn't know how to handle it. She came in and she said she was from Reach to Recovery and she was here to show me some exercises. They still did them in those days. I don't think they do

it anymore, they don't teach them anymore because there is risk involved and they are very risk averse. So she had a little bag of some sort for me and I started crying. And she got mad and she said, "Well listen, I can't come back just any time.... Why don't we get through this." And I couldn't even talk. I just, I was so upset and she got all upset herself and she left.

Angel was one of the women who found Reach to Recovery to be extremely helpful and she responded by becoming a volunteer herself. She spoke about Reach to Recovery by saying:

The American Cancer Society has someone come from the Reach to Recovery program, which I now volunteer for. So this lady called me up. She gave me her name and her number at home, at work, and said anytime that I can call her, that I needed to call her, just call anytime day or night with any questions, any concerns. So the questions that she answered were helpful and I did end up calling her several times just because you know going through what I went through, she was the person that I could talk to and she could understand it cause she went through similar. So it was helpful. I just feel that having someone to talk to that has gone through it is huge. It is so helpful to people that are in that position that are going to go through it, that I just wanted to be that person. And I've been in contact with about four people and one girl constantly was calling me. And she used to tell me, "I am so glad that you are there for me." I'm sorry I'm crying. It's just really moving to me. It's just you feel that you are helping someone to go through this because it is a rough time. And to have someone there to constantly call and ask questions. It is a great thing to have. Because people around you, not all of them know what you are going through. And you can't really explain it because they don't know what you are feeling, but to talk to someone that has been through it, they will tell you how they felt, and what you are going to go through. It is just a support. And it is just so great to have. It's rough for people to go through something and not have support you know.

For a number of the women, the support that they received from a particular group or organization led them to go on to become active in running, planning, or volunteering for that group or organization. Jaws participated in a summer camp for cancer survivors and she then went on to become one of the planners. The camp provided support for survivors, offered traditional camp activities, as well as activities

meant to challenge participants and helped them realize their emotional and physical strength. Jaws' face completely lit up when she spoke about her experiences at camp:

It was the first summer after I had finished treatment. 2004. It was wonderful, a bunch of women who had been through the same thing. And the connections are just so amazing. For one thing we sleep in a camp, it is like a camp we are all sleeping in bunks together so you get pretty close to people that way anyway. I stayed up all night talking about the funniest things. It works just like camp. You have to sign up for activities. Horseback riding, high ropes, swimming. Lots of stuff to challenge yourself. All I can think of going back to the first camp was you know, live like you are dying. There was no way I was going to do those high ropes. But I did. I was like oh my God, it was so wonderful. But man oh man, all you have to do is just touch somebody who as been through the same thing and it is just such a connection. You just walk up and it is a hug. And you understand on that level. It is just quite wonderful.

#### Breast Cancer Activism

All of the women in this study participated in at least one form of breast cancer activism and were members of at least one breast cancer activist organization. Eleven of the women were involved in two or more organizations. All of the women reported that their activism had a positive impact on their healing process.

The breast cancer activist organizations that women in this study belonged to spanned the three branches of the breast cancer movement as described by Klawiter (1999). Klawiter describes The Breast Cancer Awareness Movement as the branch of the movement that has a focus on survival and feminine appearance while promoting fundraising for research and early detection. The activities/organizations that women participated in under this branch were Reach to Recovery through the American Cancer Society, the Race for the Cure through the Susan G. Komen Foundation, a motorcycle ride to raise money for the American Cancer Society, and the Ovarian Cancer Run/Walk.

Angel was a volunteer for the Reach to Recovery program. She found the support of the Reach to Recovery volunteer who visited her to be essential, and so she wanted to provide that support for others. Angel also started a motorcycle ride to raise money for the American Cancer Society. She spoke of the impact of helping others:

Helping other people, I think that just helps you so much more in healing just because people are going through it now. You are helping someone who is going through it now. Even though you are healing, it makes it so much better to know that they are going to have it a lot easier because of you. And they are in more pain as far as what you are going through. You may still be in some pain, but because you are helping someone else, it just makes it so much better to know that someone out there is going through what you went through and they are seeing you and say, oh my God, I can get through this.

The vast majority of participants' activism efforts were focused in what Klawiter calls The Women's Cancer Movement, which draws on feminism and AIDS activism for inspiration while promoting social services, patient empowerment, and treatment activism. Klawiter argues that The Women's Cancer Movement is best exemplified by small, grassroots organizations founded by local women with breast cancer. The activities that women participated in under this branch included: those sponsored by the member organization of the New York State Breast Cancer Support and Education Network (NYSBCSEN) such as education, lobbying, program development, and support groups; lobbying at New York State Breast Cancer Advocacy Day; founding a Guilda's Club chapter in the region; planning a camp for cancer survivors; participation in the National Breast Cancer Coalition which does advocacy and education; presenting dream workshops at healing retreats; founding support groups; serving as a consultant to the New York State Department of Health; serving as a peer reviewer for breast cancer research projects funded by the Department of Defense; advocating for public policy

changes; serving on a speakers' bureau for medical students; letter writing to officials and newspapers; and participating in the Ovarian Cancer National Alliance Conference.

Claire was a board member for the member organization of the NYSBCSEN and has been extremely active in the organization. She relayed both costs and benefits that resulted from her breast cancer activism:

I would say that the personal cost [time, money, gas, wear and tear on car] to me is worth it because I think the benefits are that we are making strides with the legislature, getting them to see that breast cancer is out there. We have to fight harder because they are moving on to the next disease. But you know, the way it is rewarded is when I do a one on one, when I sit down with someone and I can really help them to see that they don't have to rush right into this. That we're going to tell them about where they can go to look for information. That that information is their friend.

The third branch of Klawiter's model, The Cancer Prevention Movement, which draws upon the environmental justice movement and emphasizes the responsibility of the cancer industry, is best represented in the environmental activism that several women participated in through the member organization of the NYSBCSEN.

Ida was active in the NYSBCSEN and focused many of her efforts through her activist organization on the environment. She first joined the member organization of the NYSBCSEN because of their efforts to stop pesticide use on the public school grounds in her town. She said the following:

I was particularly interested in the environment, which is where we feel it is at as far as prevention. Environment being everything from a person's environment to the environment at large. We had a series. We had people talk about breast cancer in the environment, the general risks that are known, we've had people talk about genetics.

Judith Herman's (1992) work on the role of social action in the recovery of trauma survivors can also be used to categorize the activism that study participants



engaged in. Herman identified social service, education, political change, fundraising, and publication as forms of social action in which trauma survivors might engage. At least one breast cancer survivor in this study was involved in all five categories of social action, the most common being social service and education. Some of the activities that women engaged in that represent the category of social support are: serving as a Reach to Recovery volunteer for newly diagnosed women in the hospital; leading a self-help group; acting as a hospice volunteer; and providing administrative support to a breast cancer organization.

Easter facilitated healing retreats as a part of her activism. She also served on a telephone hotline. She reflected on what she felt she was able to do for others through her activism:

I was briefly on a hotline. And I think that was wonderful. People would call and they were eager to tell their story. Maybe that was all they needed was to tell their story. But some of them needed to find other resources. They want to know where they can find out more information. I like to hear stories. I'd want to hear her story. And I think once you start telling your story, that's half the battle. It changes, it is getting out here, it is not keeping it inside. I think that is important.

Women were also involved in education such as providing community education about prevention and treatment options and serving on the speakers' bureau to educate medical students about the experiences of breast cancer survivors.

Flo spoke to medical students about her cancer experiences and wrote letters to legislators and newspapers. Flo reflected on the impact of her activism on her healing by saying:

I learned more. I know now to be assertive. What I have to do for my activism I think makes me more knowledgeable. It helps I can help other people. I know that it makes me feel good. And anything that makes you feel good can't hurt. I

think it helps people around you if you are personally someone who is not going to get beaten down by the cancer, by the system, by the confusion.

Breast cancer survivors in this study also participated in political change efforts such as lobbying and letter writing to public officials. About lobbying, Scottish Queen said:

It is an outlet. It is definitely an outlet. For me, I think it is probably empowering and a way to feel like you are making a change, you put a face on the disease. You are a person and that certainly is what legislators need to hear and want to hear.

Several research participants engaged in fundraising through their participation in the Race for the Cure, ovarian cancer run/walks, and creating a motorcycle ride to benefit the American Cancer Society. Finally, one breast cancer survivor published her own book about her experiences, one developed an education presentation on alternative treatments, and one wrote for her teacher's magazine.

No matter what form of activism women were involved in, they all found their activism to have a positive effect on their healing process. Ida went so far as to say:

Activism has probably been THE healing process. I've always been a person who wanted to do everything herself, even when it was harder. So it's just working through things yourself, helping other people, it is a way of getting through it.

Breast cancer activists also recognized that the movement was facing some challenges. Scottish Queen highlighted the need to do more outreach to women of color, underserved women, and low-income women. She also worried about the activist community pitting one cancer against another or other illnesses such as HIV in terms of seeking funding for research, etc. She felt that a much more effective strategy would be to combine efforts to improve health care and medical research in general.

The hope and positive attitude that many of the study participants maintained were reflected in the ways women spoke about their activism. Jaws mentored newly diagnosed women. She said:

You say to people, there is no guarantee, but you can get through this. You are going to get through this. And to be able to point out a couple of people that have very similar cancers and you are going to be able to do this. It is going to be hell, you are going to go through hell, there's no denying that, but to be able to say you are going to come out on the other side and you are going to walk and you are going to live, and you are going to laugh, and you are going to cry, and that is the way it should be.

#### Breast Cancer Survivors' Thoughts on Combining Support Groups and Activism

Women who participated in this study were asked to share their thoughts on the idea of consciously creating support groups that combine a traditional support group format with intentional activism. Women held a variety of opinions on this idea. Five women supported the idea of such a combination completely, five felt it might be a good idea for some women and not for others, while one woman completely rejected the idea. (One woman did not respond to the question.)

Claire was the only study participant who did not support the idea of combining support groups and activism. She was also the participant who displayed the most discomfort with support groups, while she was the most active activist. When asked about her thoughts on possibly combining support groups and activism, Claire replied:

I almost see them as two separate things. Because, if you are in a support group, you are going there for that reason because you need support. And then that is to talk about yourself, your cancer. Then you can remove yourself from that and say, I am going to do this activist activity because I have cancer. And this is my activism.

Five women had mixed reactions to the idea of combining activism and support groups. Their reasons for their reactions included: the thought that some women in

support groups felt that activism interfered with the support being offered survivors; concern that some women might not be emotionally or physically able to participate in activism while they needed the support; and the idea that activism might be for some people, but not for all as some women simply want to forget about breast cancer once their treatment is complete. However, all five women felt that if a support group that combined activism had been available to them, they would have joined.

Flo spoke of women who felt that activism sometimes interfered with support saying:

I have to say that our support group, I know gals who say that they feel that sometimes the activism is interfering with the support group. And I think that there are some people along the line decide in their journey that they want to do more than just be a patient.

Kate expressed her concern that some women might not be emotionally or physically ready to engage in activism:

I can see it could be very effective to combine activism with support groups and yet there are always people within support groups who simply need support. They are not, they are either not ready for activism yet, or they are never going to be physically up to it. And it is a way of channeling. There are people who come into a support group who would be interested in advocacy if there was an opportunity for them to become involved. It would be good for them. And they can still be a part of a support group and support the people who simply need support, but then they also have an outlet for going beyond the need for personal individual support into a more active stance.

Maggie reflected on some people's desire to forget about breast cancer once their treatment was over:

I think it would be good for some people, but then I think a lot of people who were diagnosed after me, they don't want to know. They are a total ostrich. They've had their treatment, they are cured, and they don't want to know. I am quite amazed how many people I know that feel like that. But I think for some people it is a great idea.

Five women supported the idea of combining activism and support groups, highlighting how often doing good for others can also be good for one's self.

TIO said:

I think it is a very good idea. I think you are working together for a cause.... Not only does it help other people, it definitely helps yourself. And that is what doing good deeds, doing a mitzvah is doing a good deed. The idea is that you are doing something for somebody else, but basically it helps you and so it is the same thing with activism, advocacy work. You are not only helping others, but you are definitely helping yourself.

Scottish Queen also supported the idea by saying:

I don't know how you separate the two because I think in a way, that is what most people go into activism go in there for because they want to get something out of it, maybe it is for healing or maybe just to help themselves, but that in de facto becomes the supportive thing for them. So for me they are kind of intertwined.

The power of the potential pairing of activism and support groups was highlighted by Jaws:

I think that is what the [member organization of NYSBCSEN] is. [It] definitely works that way. They do a lot of advocacy stuff. Definitely. I think if you feel you are taking this disease by the horns, saying ok sucker, you are here, but we are going to do something about you. We are coming at you in numbers. That is what is really good. That is very empowering.

#### Outlook on Life and Lifestyle Changes

Women who participated in this study were asked to reflect upon their outlook on life prior to and following their breast cancer diagnoses as well as their outlook for the future. Women were also asked about any lifestyle changes they had made since their breast cancer diagnoses. Women provided varying answers to these questions. Some felt that they had positive outlooks on life prior to and following their breast cancer diagnoses. Some felt that their breast cancer diagnoses gave them new appreciations for life. Others felt certain that cancer would ultimately kill them. Some women reported

having made positive lifestyle changes following their diagnoses, while others made no changes. Several women felt that their lifestyle had declined since their diagnoses.

Regardless of one's outlook on life and lifestyle, breast cancer had clearly changed the lives of all of the women interviewed for this study.

At the start of each interview, each participant was invited to tell the story of her breast cancer diagnosis, treatment, and recovery. Breast cancer undeniably influenced the lives of every woman interviewed.

Easter spoke about the impact of breast cancer on her life in this way:

I don't think that there is a woman who is not impacted by losing a breast. And all those things you go through, I'm not so attractive, sexually, physically. I don't wear clothes the same way that I used to wear clothes. And the fear of a recurrence and is this the beginning of my life or the end? The usual concerns that everybody I think goes through when they are faced with that sort of really terrible news.

It was also very important for Easter to reiterate several times throughout her interview, that she did not measure her life in terms of her breast cancer:

Easter: I don't benchmark my life against the illness....Because I will NEVER be known for having a disease and have that as the outcome of my life.

Interviewer: You have said that you don't use the illness as a benchmark for your life. What would you say the benchmarks are in your life?

Easter: Oh, all of the other things that have happened: births of babies, getting a degree in college, doing what I love to do. I don't know if I have a single benchmark in my life. I have never had anything that I sat there and said ok, after this date this happened and before that date the rest of my life happened.

Many of the women who were interviewed spoke of the fear that they experienced upon learning of their diagnoses. Intermingled with that fear, was the worry about what would happen to loved ones, both beloved people and pets. Kate's words reflect that worry:

I would say from the second diagnosis, from the recurrence, my first reaction was really fear. And I can remember saying to my next door neighbor, I have these two cats, I've only had them for two years. They were street cats. And one of them I know had lived on the street for at least five years and the other one for two or three. And they used to come to me every morning to be fed....So I can remember sitting on the back porch sitting with her and saying, you know I feel so bad because these poor cats have just found a home and now they will be back on the street....It is funny that was one of my first reactions. But I did initially feel that you know it was a death sentence. That was going to be it. But it wasn't. Not so far anyways.

The importance of loved ones and families was reiterated in various ways throughout women's narratives. For Angel, Claire, and Jaws, their desire to live was in part a desire to see their children or grandchildren grow up.

Jaws said:

It's like, ok, here [cancer] comes, one, two, three, I'm going to knock you down again. But I keep standing! I'm still standing. I can't let it get me down....I have these two absolutely wonderful grandchildren whom I love. Who I need to see all the time, even to just hug and kiss. And I woke up this other day, and it was like, oh my God, it is a beautiful day. It is really ugly out there today, but is really nice to be here. I'm just not ready to let it get me down. There's days, believe me, there is days. I've got this wonderful doctor. She wrote me this script for Xanax. And I don't take that very often, except when I am having tests and all that good stuff. You know, just to help me get through the rough parts. I have a wonderful life. I have a great life. I'm not ready to let go of it. I have a great life.

When Claire spoke about her grandchildren and her desire to see them grow older, one can also see the impact that breast cancer has on families:

My grandson said to me, Friday in the car, he knows he is going to be in first grade and how old he is going to be, and he said, "And when I am ten Nana, will you be dead?" And I said, "I'm not planning on it." And he said, "So when I am 20, then you will be 81, and will you be dead then?" I said, "I'm not planning on it." And oh, so the future for me is that I would really like to see them grow up and that is, the sports are fine, but they need other things, and I hope that I can help to channel them to other things to see that you need to be a volunteer in life.

Angel, Claire, and Jaws also spoke to how their breast cancer diagnoses led them to reprioritize their lives. All three women were extremely dedicated to their careers at

the time of their diagnoses, to the point where they put their work before everything else.

After their breast cancer diagnoses, they decided that it was time to put their families

first. Claire spoke to the process of shifting priorities:

I was always very, very involved in teaching. I had this outlook that my job had to come first because someone was paying me to do that job and then I was a mother and a wife. And you know, I saw things in that light. And I was well sought out. I mean people wanted children in my class. I did it well. And I am very proud of that. And I got involved in everything school related....And then when I got breast cancer....that is when I knew that my priorities had to shift. That I had to stop making my job the most important thing. And my family, husband, they had to come on the top and the job had to be second. And I also learned to not always volunteer for everything.

Angel echoed Claire's thoughts on the shifting of priorities. She said:

I think that I'm not the person that I was before because my family now is more important than my job, whereas I felt that my job was more important before. Not to say that I'm not a great mom or a wife, because I feel that I am. My family does come first, but it was just huge that I had to do great at work. And I'm not saying that I don't do anymore, I do my job. But unfortunately, if something happened to me, my family is going to be the one to help me out if needed. My job won't be there, you know. And life is short. You don't know if you are going to go one day or the next and you have to do whatever you need to with your family and just enjoy the time you have.

In addition to the shifting of priorities, Claire, Abigail, Kate, Linda, and Scottish Queen also spoke about how their cancer diagnoses led them to develop more relaxed lifestyles in which they were less focused on the details of life and less upset about the smaller things, while they focused on the things that mattered.

Linda spoke about the changes in her lifestyle and her choice of alternative treatments for her breast cancer as a peaceful solution:

I've completely relaxed a lifestyle that was very structured and very rigid, and you know go, go, go from sunup to sundown. And that caused a stress that is also not good. And it is only in the last few years that the medical profession is recognizing that you can't see stress, you can't necessarily diagnose. You find its roots in other diseases and illnesses. So, I've done that. I've become a much



more peaceful person. I'm not trying to say that this is the only way. I don't think that alternative treatments are the only way to go. I think it is another solution, another choice for people to look at before they decide. Prior to my cancer diagnosis, I think I was a little more fixed in my thinking. A little more structured. Not as willing to maybe bend. You know thinking Not as willing to maybe bend. You know thinking that the Holy Grail was what seems to be the typical American dream of having money, having a retirement, you know having, having things. And I think having cancer turned my thinking around into there isn't anything worth having that if you don't have your health, you have nothing.

Scottish Queen felt that dealing with her breast cancer has helped her put life into perspective. She said:

Like if you are having a horrible day, it seems like it is the most important thing you are ever going to deal with, you know in the back of your head, this is really bullshit and it doesn't really matter and life and death stuff is what really matters. This thing will pass, this too will pass. I have a pretty good sense of that. The cancer has helped put a lot in perspective and not get all worked up about you know something at work.... There are things like your health that are much more important. And that is when you should get worked up.

Despite their efforts to maintain a positive outlook on their lives, several women did worry that their cancers would return and ultimately kill them. Abigail, who had an extensive family history of cancers was convinced that she would die from cancer:

I am convinced that my breast cancer is coming back. My body just grows things. I have had cysts and polyps and fibroids....I have this mental image of myself as a terrarium, I am convinced that my cancer is coming back in my breast and I still know that I am going to get colon cancer. So I am waiting for it to happen. I am hoping that it doesn't come back....But in the meantime, I am doing things, like right now I am trying to figure out a health care proxy....For me when I start to go downhill, I want to take steps. I fully expect to die from cancer.

TIO, who has survived multiple types of cancer, also worried about death:

My current outlook on life is that I am taking more positive lectures and workshops, enjoying things more, but I think more about death. Maybe because I am getting older, but also cancer. I don't want to say cancer equals death, but you hear cancer and you hear death as I did. I mean you could either live or die. And we are all going to die, but cancer might bring it sooner. So, I am thinking more about death.

For three of the women, their breast cancer diagnoses created a sense of the temporal nature of life. Jaws, Maggie, and Flo found themselves living more in the moment and while still planning for the future, they plan for the more immediate future rather than the long term.

Jaws expressed how it was important for her to slow down and enjoy life in the present moment:

I don't put things off so much after diagnosis. I leave work early to do something like this [interview]. I'll leave work early to go babysit for my granddaughters. Or to out to lunch with my daughter or go out to lunch with my husband. It is work. And if I am gone in 3 years, what are they going to say? Oh, she was so good, she didn't ever leave this job? That's so silly. I'd much rather have my kid say, mom was so much fun to be with.... I don't ever want to lose the connection to the cancer because it is changes that have occurred, without being specific about any of the changes, it just makes you look at life all so different as far as the day to day with it. Not that it is extreme major changes like I said, I've always lived a healthy life, I haven't changed.... I want to be able to maintain a headset of slow down, enjoy every single day one day at a time. Living much more for the here and now instead of next year. It is much easier doing stuff for the moment.

Maggie, who recently lost a good friend and mentor to breast cancer, held a new appreciation for life following her breast cancer diagnosis, but also spoke of living with an awareness of death and the impact that awareness has had on her sense of the future:

You do think differently. I think not in ten years, I think maybe in three and five years. I don't look too far ahead. And I think that is unconscious. But when I look back, I don't plan on the years from now. That is different from before, absolutely. I don't think I have a death wish, and I don't live with death on my shoulder. But I am also aware it could be. But you know, the longer you live with the disease, but then I look at my friend who died, she was a year out longer than me. I don't know why I am here.

Easter spoke of having a positive outlook on life and planning for the future:

I think [my outlook] is pretty positive. Just having a family, friends, a job, people who have been supportive and have always been there for me. I've never had situations where I've had difficult relationships with anyone.... It has always been

a forward progression.... I will probably be retiring in a couple of years. And there are many more things, in fact the job is getting in the way of all the things I would like to do with the rest of my life. I really love writing and I have a publisher.... We are forming our retreat into a corporation and so we are going to be taking that farther afield.... California, Colorado, and some other places.

Along with their awareness of the fragility of life and fear of death, many of the women spoke of having a new appreciation for life. For Kate, her appreciation for life was magnified by her belief in God:

I think a diagnosis like that, especially when you are treated and believe that you are healed, gives you a new appreciation for the gift of life. You know and it helps you put things in perspective, like things that seemed so terribly important before aren't as important anymore. Like having things for instance become a lot less important than just having the gift of life. I think it has given me a greater appreciation of the positive things in life. I have the presence of God and the care of God. Just a certain amount of wonder at the very reality of life. And all of life, not just human life. But, you know, life is so fragile. And yet it is also very flexible and very durable in a lot of ways.

Scottish Queen, who was the most recently diagnosed woman in the study, also spoke of her new appreciation for life:

I think the change has been, and it is very cliché, when you get cancer, you definitely do smell the coffee better, you do smell the roses, you do have a totally different, better appreciation for today and tomorrow.

### Summary

Millions of women are affected by breast cancer. For the twelve women in this study, breast cancer significantly changed their lives. However, equally important are the effects that support from family, friends, sister activists, support groups, and activism had on the participants' lives.

Scottish Queen, who was at the beginning of her breast cancer journey, spoke about the importance of support:

One thing is the amazing, wonderful people that you meet when you go through a journey like this. You do meet other survivors and other people who are maybe not surviving. I have a friend right now who I knew before this, who is very, very ill with cancer. And you meet people like her and others, just really terrific people. And also the people who are trying to help you, doctors, nurses, and therapists. I said to my oncologist recently, it takes a village to get through cancer...people at support groups, people at Guilda's who work there or volunteer there. It is just, there are some amazing, decent, good-hearted people out there. And you do, what is good about the cancer, you get exposed to all that and feel the love from all those people. It is pretty amazing.

Emotional and physical healing was possible for the women in this study in part because of the support they received and the activism in which they engaged.

In the final chapter, I will summarize the major findings of this study and draw connections to theoretical literature and previous research. I will also discuss the limitations of this study and make recommendations for future research. Finally, I will reflect on the implications of this study for social work practice and policy.

## CHAPTER V

### DISCUSSION

I embarked on this research project with the intent of providing a space for women to tell their breast cancer narratives. In the process, twelve women told their stories of hope, despair, courage, gratitude for the support they received, disappointment in people who did not provide the support they needed, thankfulness for the sisterhood they found in other breast cancer survivors, and their efforts to make change through activism. What was clear in all of the women's stories is that breast cancer changed their lives and each was making an effort in her own way to make the lives of others better and/or work towards eradicating the disease.

This chapter will summarize the major findings of this study. Methodological strengths and limitations will be identified. I will make suggestions for future research. Finally, implications for social work practice and policy will be offered.

#### Summary of Major Findings

The purpose of this study was to explore and describe in what ways participation in breast cancer activism affected the lives of breast cancer survivors who were also in support groups. I sought to document, through women's voices, breast cancer survivors' stories of healing and the meanings they made of their experiences. I was also interested in women's thoughts on the potential effects of the integration of activism into support groups. In order to develop a conceptual understanding of the data presented by the research participants, I used theoretical, empirical, and narrative bodies of literature that

documented the effects of psychotherapy on the healing of breast cancer survivors, explored the potential effects of activism on healing, and highlighted breast cancer narratives as a form of consciousness-raising and meaning-making. The women who shared their stories for this study contributed new knowledge to those bodies of literature through their reflections on their lived experiences.

Twelve women participated in this study and they ranged in age from 43 to 73, with an average age of 57. At the time of their first breast cancer diagnosis, participants ranged in age from 37 to 66, with an average age at first diagnosis of 49. All of the women in this study were participating or had previously participated in some form of psychotherapy, which was broadly defined as individual or group therapy that was professionally facilitated, counseling, or a support group. Nine of the 12 women participated in a support group. All of the women in the study had participated in breast cancer activism within six months of their interviews. Interviewees for this study participated in activism for an average of six years, with a range from 6 months to 17 years. One woman who participated in this study identified as Pacific Islander, while the remaining 11 women identified as Caucasian. All 12 women were heterosexual. Ten were married and two were single, never married. Nine of the 12 women had children.

The findings of this study confirm findings from previous studies, which document the importance of support for breast cancer survivors in their healing process. The women in this study highlighted the emotional, physical, logistical, and household support that they received from family, friends, medical personnel, co-workers, religious communities, cancer activist organizations and support groups, and friends who also had cancer. While the women in this study received varying levels of support, it was clear

that their experiences with breast cancer would have been even more difficult if they had not had the support of others.

Participants in this study turned to more formal forms of support from self-help groups, social workers and psychologists, support groups provided by cancer activist organizations, Reach to Recovery volunteers, healing retreats, and a camp for cancer survivors when their informal support networks were not completely fulfilling their needs for support. The majority of the women who participated in support groups found them to be particularly helpful because they found that other breast cancer survivors had a better understanding of what they were going through than other people in their support system. Support groups provided a place for women to share the details of their experiences with other survivors and an opportunity to learn from each others' experiences.

All of the women who participated in this study were involved in breast cancer activism. Eleven out of the 12 participants were involved in two or more forms of activism. The breast cancer activists in this study were involved in a wide array of forms of social action. All five categories of Judith Herman's (1992) model of social action were represented in the activities of the breast cancer activists. The women were involved in social service, education, political change, fundraising, and publishing. The most commonly represented forms of social action in which women were engaged were social service and education. Herman argued that engagement in social action played an important role in the recovery of trauma survivors. All of the women in this study reported that their activism had a positive effect on their healing process. The vast majority of the study participants' activism efforts were focused in what Klawiter (1999)

called the Women's Cancer Movement, which was exemplified in the study participants' efforts in promoting social services, patient empowerment, prevention, and treatment activism. The importance of having an effect on the world was present in each of the women's narratives about their breast cancer activism.

The women who participated in this study were also asked to share their reactions to the idea of combining a traditional support group for breast cancer survivors with breast cancer activism. Five of the women supported this idea completely, believing that doing good for other people can also be good and healing for one's self. Several of the women felt that the groups that they were already in already combined support and activism. Five of the women supported the idea of combining support and activism for some women, but felt that it might not be appropriate for all women. They were especially concerned about women who might need extensive support and not be able physically or emotionally to participate in social action. However, all five of these women felt that if that a support group that combined activism had been available to them, they would have participated. One woman was opposed to the idea and believed that activism and support groups should remain separate. The twelfth woman interviewed did not respond to the question. Overall, the women's responses suggest that there might be interest among breast cancer survivors in combining support groups and activism, and such groups might contribute positively to healing.

Throughout the stories that women told of their breast cancer experiences, it was remarkably clear that breast cancer had changed each of their lives in some way. Some women reflected on the positive changes that they had made in their lives such as prioritizing family over work, developing a more relaxed lifestyle, and appreciating life



more. For others, the fear of death and the painful physical implications that accompanied their disease were constant reminders of the fragility of their lives. Despite their disease, many women spoke with determination about how they intended to live to see their children and grandchildren grow up and they looked forward to the future. Their vision for a better future was evident in the women's commitments to activism, which reflected their hope and determination to play a part in eradicating breast cancer and their desire to support women who are currently battling the disease.

#### Methodological Strengths and Limitations

Twelve women provided in-depth narratives of their personal experiences with breast cancer, support groups, and activism for this study. The use of open-ended questions in the interviews allowed me to gather stories rich with women's insights, reflections, observations, first-hand experiences, and the meanings breast cancer survivors attributed to their experiences. Therefore, these narratives contribute important knowledge to the literature on women's experiences with breast cancer.

Because this study focuses on 12 women with very similar demographic backgrounds and connections to one breast cancer activist organization in one geographical location, it cannot be generalized to all women with breast cancer who participate in support groups and activism. In particular, this study does not adequately reflect the experiences of women of color, lesbians, women with low-incomes, women living with disabilities, younger women, and women with limited educations.

It is also important to reflect upon how my own identity and belief system may have impacted the development of the research question, the interview questions asked, the stories that women told me, and my interpretations of women's narratives. As a

middle-class, educated, Caucasian woman in my mid-30s, my own convictions about the effectiveness of psychotherapy, my commitment to feminist activism, and my familial history of cancer were certainly filters through which I generated my research questions, listened to women's stories, and interpreted breast cancer survivor's narratives. I do believe that there is powerful potential in the combining of support groups and activism, and that was also reflected in women's narratives.

The strengths of this study and its research design might be expanded upon and the limitations and biases addressed by repeating the study with a larger, more diverse sample. The employment of a second interviewer and analyst of the interviews might address the biases I brought to the study as a researcher. Finally, member checking could be used to check the researcher's interpretations of participants' narratives against women's own understanding of their lived realities and the intentions behind their words.

#### Implications for Future Research

Upon completion of this research, I have a number of recommendations for future study. First, future studies assessing the affects of support group participation and activism on breast cancer survivors' lives that include substantial numbers of women of color, lesbians, women with low-incomes, women living with disabilities, younger women, and women with limited educations would significantly complement the information gathered here. Efforts to diversify by geographical location, support group type, and activist group type would also widen the scope of women's experiences represented.

Second, a case study of a support group that combines traditional support with breast cancer activism might provide interesting information about the processes and

effects of such a group on women's healing. In doing such a study, it would be important to make note of one's previous experiences with psychotherapy, length of time since one's initial breast cancer diagnosis, stage of breast cancer, and previous breast cancer activist involvement among other variables. Certainly, it would also be important to document any outside sources of support women were receiving.

Third, a related study that considered women involved in individual psychotherapy in combination with breast cancer activism might better illuminate the social support women receive from activism participation. Additionally, a study comparing breast cancer activists involved in support groups with breast cancer activists involved in individual psychotherapy might reveal differences in the issues women are facing and addressing in the different types of psychotherapy.

Clearly, there is much more to be learned about breast cancer survivors who are involved in psychotherapy and activism. Such research would contribute important knowledge for clinicians who are seeking to identify women who might benefit from services and clinicians who are developing programs to serve breast cancer survivors.

#### Implications for Social Work Practice and Policy

The findings from this research have important implications for social work practice and policy. First, the majority of women who participated in this study believed that support groups that incorporate breast cancer activism should be provided as an option in the mental health services offered for breast cancer survivors. Such groups might be offered in addition to traditional support groups and individual psychotherapy, but not as a replacement of already existing services. Groups that provide support and

incorporate activism would appeal to some women, but would not be appropriate for all breast cancer survivors.

Second, when creating professionally-facilitated support groups, the breast cancer survivors who participated in this study felt that it was important to keep such groups small. Additionally, groups should be focused on particular stages of breast cancer and length of time since diagnosis and treatment. Study participants felt that groups that varied too much in focus and/or were too large were ineffective.

Third, support groups specifically for breast cancer survivors undergoing alternative treatments were unavailable to the women in this study. The participants who pursued alternative treatments suggested that such groups would be extremely helpful to them as many of their struggles during the treatment phase were quite different from women undergoing traditional treatments for breast cancer.

Fourth, it is important for mental health clinicians to educate themselves about breast cancer resources and activism in their geographic regions. Women who participated in this study found that activism positively affected their healing process. Therefore, suggesting that breast cancer survivors become involved in activism might be an effective treatment intervention for some women.

There are also several important policy issues for social workers to consider. There is a need for advocacy for low cost and free breast cancer screening, treatment, and mental health services for underserved women (e.g., women with low incomes and the uninsured). Additional funding is needed for research on breast cancer prevention, detection, and treatment. The legislative attention given to breast cancer is waning and ongoing advocacy in this area is necessary. Finally, agencies that serve breast cancer

survivors would do well to examine the populations of people currently being served, identify the people they aren't reaching through a study of regional demographics, and alter their outreach efforts accordingly.

### Conclusion

Breast cancer affects the lives of millions of women and their families, friends, and communities. While advances have been made in the prevention, detection, and treatment of breast cancer, more still needs to be done. The stories provided by the breast cancer survivors who participated in this research study demonstrate that support groups and breast cancer activism, in addition to support received from family, friends, and others, positively affected their healing. Until breast cancer is eradicated, social workers might better serve breast cancer survivors through the provision of support groups that incorporate activism.

Melissa Etheridge's song, "I run for life" (Etheridge, 2005, track 17), which she wrote for the Race for the Cure following her own experiences with breast cancer, succinctly expresses breast cancer survivors' motivations for activism, the support they hope to offer to others, and the meanings activism holds for women:

They cut into my skin and they cut into my body, but they will never get a piece of my soul.... If you ask me why I am still running, I'll tell you I run for us all. I run for hope. I run to feel. I run for the truth, for all that is real. I run for your mother, your sister, your wife. I run for you and me my friend. I run for life.

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## Appendix A

### **Human Subjects Application**

**Name:** Liz Burnworth

**Contact Information:** 13 Marshall Drive  
Poughkeepsie, NY 12601  
518-253-5002  
[eburnwor@email.smith.edu](mailto:eburnwor@email.smith.edu)

**Project Title:** Breast Cancer Survivors' Views of How Activism and Psychotherapy have Affected their Healing Process

#### **Background Information**

One out of every eight women will be diagnosed with breast cancer in her lifetime (National Cancer Institute, 2006). Approximately 175,000 women are diagnosed with breast cancer and approximately 44,000 women die of breast cancer yearly. Therefore, millions of women and their families, friends, and communities are affected by breast cancer (Ferguson & Kasper, 2000). Many women respond to their cancer diagnosis by participating in individual and/or group psychotherapy. A number of women also participate in breast cancer activism. The impact that activism has on the lives of breast cancer survivors or on personal healing in general are not areas that have been extensively researched (Breton, 1995; Israeli & Santor, 2000). Several studies have been done which indicate that there are positive effects of participation in activism on the healing of survivors of sexual assault (Krantz, 1995; Sutton-Ryan, 1998), but similar studies involving breast cancer survivors have not been completed. Gore (1999), in her study of the experiences of women involved in breast cancer support groups, points to the need for further studies on self-advocacy among breast cancer survivors. Therefore, there is a need to study activism participation and its impact on the lives of breast cancer survivors as such a study may have important implications for potential therapeutic interventions for breast cancer survivors and for feminist therapies.

#### **Project Purpose and Design**

The purpose of this proposed study is to explore the impact that participation in breast cancer activism has on the lives of breast cancer survivors who are also involved in psychotherapy and the meanings that women make of their experiences. I will also describe the types of activism and psychotherapy in which breast cancer survivors are engaged. For the purposes of this study, psychotherapy includes individual or group therapy with a social worker, psychologist, or psychiatrist, counseling, and self help groups. Participants will be invited to describe the ways in which they believe both activism and psychotherapy have affected their healing process. Finally, this study may point to ways in which activism might be integrated into individual and/or group therapy as a treatment intervention for breast cancer survivors. Not only will this study potentially have relevance for social work practice, it might also have relevance for social work program development. The data from this study will be used for my master's thesis

in partial fulfillment of the Master's in Social Work degree at Smith College School for Social Work and for future professional presentation. I also hope to develop one or more journal articles on this topic.

This research study will be conducted using a flexible qualitative interview design. An interview guide will be utilized with a set of thematic questions and potential probes that will allow research participants to tell their own stories in their own voices, using their own words. It is my hope that by creating such narratives, women will provide in-depth, information filled descriptions of their experiences. A demographic face sheet will also be utilized. This research design was selected because the impact of activism participation on the lives of breast cancer survivors is not an area that has been extensively researched. There is a need to develop a fuller understanding of this phenomenon, from which theory can be developed. Finally, as Fosket (2000) has argued, breast cancer survivors are experts on their own experiences with breast cancer and their knowledge is grounded in their lived experiences. Rather than claiming scientific knowledge through the use of fixed methods, as so many medical personnel have done, I have chosen to employ flexible methods and honor the knowledge of my study participants.

### **Characteristics of the Participants**

This study will be conducted using a sample of approximately 12-15 women that meet the following criteria: 1) Participants must be women who are 30 years old and older. Although men and younger women do get breast cancer, the issues facing them are significantly different (e.g., breast cancer is often thought of as a woman's disease; stage of life issues) than the issues facing women who are 30 years old and older. 2) Participants must have been diagnosed with breast cancer at least one year prior to participation in the study. This will allow time for the initial shock of a cancer diagnosis to have passed and for women to have integrated the diagnosis and the meaning of the diagnosis into their lives. 3) Participants will be currently involved in individual and/or group psychotherapy. Participants will have attended at least four therapy sessions prior to participating in the study. This will hopefully encourage participants to consider how therapy has contributed to their emotional health in the wake of cancer. 4) Participants will be involved in breast cancer activism, having participated in at least one form of activism in the past 6 months (or a year for events that occur annually such as the Race for the Cure). Exclusion criteria will be women under the age of 30, men, women who have been diagnosed with breast cancer for less than a year, women who are not in psychotherapy, and/or women who are not involved in breast cancer activism. Participants must be conversant in English (the language used in these interviews).

### **Recruitment Process**

Participants for the study will be selected using purposive, convenience, and snowball sampling techniques. First, using a purposive sampling technique, potential participants will be recruited at member organizations of the New York State Breast Cancer Support and Education Network (NYSBCSEN), with the organizations' permission. The NYSBCSEN is a statewide coalition of 23 grassroots activist organizations that have

created a network and combined efforts to share information and to advocate for comprehensive legislation to improve all aspects of cancer care. Their ultimate goal is to work toward the eradication of breast cancer. The member organizations of NYSBCSEN are a diverse group representing the various regional areas of New York State (e.g., New York City, Long Island, the Hudson Valley Region, the Capital Region, the Adirondacks, Central New York, and Western New York are all represented by various groups), as well as the diversity of women on the basis of race, age, sexual orientation, social class, and ability. I plan to attend meetings of the member organizations (starting with organizations in the Capital Region, the Hudson Valley Region, New York City, and Long Island and expanding across the state if necessary). At the meetings, I will introduce the study to local membership through a presentation intended to provide the purpose of the project, participant selection criteria, and the potential benefits and risks of participation. I will distribute fliers with an explanation of the study, selection criteria, a statement about the voluntary and confidential nature of participation, and my contact information to all members present at the meetings, along with forms for potential participants to complete with their contact information, and self-addressed, stamped envelopes. Any questions that potential participants have will be welcomed. I will also ask members to refer other potential participants to the study that may not be present at the meetings, thereby employing the snowball sampling technique.

In addition, I will distribute informational fliers about the study with my contact information to oncologists and members of the New York State Chapter of NASW to be posted in their workplaces, with the agencies' permission. Finally, using the snowball sampling technique, I will encourage study participants to refer other eligible potential participants to my study.

If a negative case (i.e., an individual who does not feel that her life has been impacted by her breast cancer activism participation) does not present herself through the above sampling techniques, I may send an additional flier to NYS-NASW members to be hung in their workplaces, with the agencies' permission, advertising for individuals involved in psychotherapy who were formally involved in activism.

Upon receiving contact information from potential participants, I will phone call potential participants to answer any questions that they may have about the study and to make sure they meet the selection criteria for the study. If the potential participant meets the selection criteria and is still interested in participating in the study, I will email or send them through the U.S. Postal service a copy of the informed consent form so that they have an opportunity to read the consent form prior to signing it the day of the interview. I will also bring two copies to be signed at the interview. Interviews will be scheduled at a mutually convenient time and location for the participant and interviewer such as a library, coffee shop, or office.

### **Nature of Participation**

Participants will be asked to complete individual interviews for the purpose of sharing their experiences with breast cancer, the impact breast cancer has had on their lives and mental health, and their participation in breast cancer activism and psychotherapy.

The interview will be scheduled at a time (preferably during daylight hours) and place that is convenient for both the interviewee and the researcher, such as a library, coffee shop, the researcher's office, or as a last resort the interviewee's home.

Participants will be asked to complete a demographic questionnaire at the start of the interview that will take approximately 10-15 minutes to complete. The verbal portion of the interview will take approximately 1 hour to complete.

The demographic questionnaire will ask for information such as breast cancer diagnosis and prognosis, type and length of psychotherapy involvement, type and length of breast cancer activism involvement, age, race, national origin, sexual orientation, education, occupation, approximate income, religious affiliation, family composition, and political affiliation.

During the interviews, among the questions that will be asked are questions about: the impact that breast cancer has had on the participants' outlook on life, quality of life, and concept of self; their involvement in psychotherapy and what the nature of that work has been; their involvement in breast cancer activism; and the impact, if any, that breast cancer activism has had on their therapy and their lives.

### **Recording**

The interviews will be audiotaped. I may also take written notes during the course of the interviews. The completed questionnaires, the audiotapes, my notes, and any additional email commentaries that are provided during the follow-ups will become part of the data collected and analyzed. I will transcribe and analyze the data. Another transcriber, bound by a confidentiality agreement, may also be used.

### **Risks**

Participants in this study may experience emotional distress while completing this interview. Participants will be informed that if they need to take a break or end the interview at any point during the interview, that they should let the researcher know. At the end of the interviews, participants will be encouraged to draw upon the support of their therapist or support group if they should experience any emotional distress following the interview. They will also be provided with a list of breast cancer information and mental health referral sources. Participants may withdraw from the study until April 15, 2007 and all of their records will be destroyed.

**Benefits**

Participants in this study may gain new insights into their breast cancer, therapy, and activism experiences through participation in the interviews. Participants will be contributing information that will help me write on these topics for my thesis and professional presentations and may help improve therapeutic services offered to breast cancer survivors.

Participants will not receive financial compensation for their participation in this study, and no other tangible benefits are anticipated.

**Informed Consent Procedures**

Participants will be emailed the informed consent forms prior to the interviews. They can review those materials before their scheduled interviews and make a decision about their interest in participating. At the beginning of the interviews, I will provide an opportunity for questions about the informed consent form, make sure that participants understand their rights, and ask that participants sign the forms before the interview begins. Two copies of the informed consent form will be brought to each interview so that both the interviewee and the researcher may have copies.

**Precautions to Safeguard Confidentiality**

The audiotapes of the interviews will be listened to and transcribed by me and possibly another transcriber. We will listen to the tapes in private to protect participant confidentiality. The transcriber (if one is used) will be asked to sign a confidentiality pledge. Upon completing their interviews, participants will be asked to provide pseudonyms, which will be used to label their interview tapes and transcripts. A master list matching participant pseudonyms and participant names will be kept in a locked cabinet accessible only to the researcher. All identifying characteristics, quotes, and information gathered during the study will be disguised and data will be presented in the aggregate in professional publications or presentations so that it cannot be identified with participants. Finally, all data, audiotapes, notes, emails, and consent forms will be kept secure in a locked cabinet for a period of three years as stipulated by federal guidelines after which time they can be destroyed or continued to be maintained securely. The consent forms and master list matching pseudonyms with real names will be locked separately from all other research materials.

**Voluntary Nature of Participation**

Participation in this study is voluntary. Participants may withdraw before the study begins. Participants can decline to be involved with this study without repercussion or loss of services. If at any time participants find a question disturbing or if they do not want to answer a question, they are free to do so. Participants may refuse to answer any particular questions and may end the interview at any time. There is no penalty for withdrawal from the study. Until April 15, 2007, participants may also request that their completed interviews be removed from the study and all data will be destroyed.

**Student's Signature:**

**Date:**

**Advisor's Signature:**

**Date:**

## Appendix B

### **Informed Consent Form**

Dear Interview Participant,

My name is Liz Burnworth. I am a master's of social work student at Smith College School for Social Work and I am conducting a study exploring the meanings that breast cancer survivors believe activism and counseling and/or support group participation have on their healing process. Millions of women and their families, friends, and communities are affected by breast cancer. This study of activism participation and its effect on the lives of breast cancer survivors may have important implications for services offered to breast cancer survivors. The data from this study will be used for my thesis in partial fulfillment of the Master's in Social Work degree at Smith College School for Social Work and for future presentation and possible publication on this topic.

The purpose of this study is to provide a space for women to tell the stories of their breast cancer experiences, exploring ideas of how breast cancer activism and counseling have or have not helped in the healing process. This study may point to ways in which individual and/or group counseling, programs, and services for breast cancer survivors might be enhanced.

#### **Nature of Participation**

You are being asked to participate in an individual interview for the purpose of sharing your experiences in breast cancer activism and counseling. Interview participants will be women over the age of 30 who are breast cancer survivors who were diagnosed with breast cancer at least one year ago. Participants will be currently involved in individual and/or group counseling or self help group, having attended at least four sessions prior to participating in the study. Participants will be involved in breast cancer activism, having participated in at least one form of activism in the past six months (or a year for events that occur annually). The ability to be conversant in English (the language used in this interview) is also a criterion of participation. In total, it is anticipated that twelve to fifteen women will be interviewed individually.

You will be asked to complete a 10 to 15 minute demographic questionnaire at the start of the interview. I anticipate that the verbal portion of the interview will take approximately 1 hour to complete. The interview will be scheduled at a time and place that is convenient for both you as the interviewee and me as the researcher.

The demographic questionnaire will ask for information about age, race, national origin, sexual orientation, education, occupation, approximate income, religious affiliation, family composition, and political affiliation. If there are any questions that you don't want to answer, you may leave those questions blank.

During the interview, among the questions that you will be asked are questions about: the impact that breast cancer has had on your outlook on life, your quality of life, and your concept of self; your involvement in counseling and what the nature of that work has been; your involvement in breast cancer activism; the impact, if any, that your breast cancer activism has had on your counseling and your life; and the meanings that you have given to your breast cancer, breast cancer activism, and psychotherapy experiences.

### **Recording**

The interview will be audiotaped. I may also take written notes during the course of the interview. The completed questionnaire, the audiotape, my notes, and any additional email or written commentary that you provide will become part of the data collected and analyzed. I will transcribe and analyze the data. Another transcriber, bound by a confidentiality agreement, may also be used.

### **Confidentiality**

The audiotape of your interview will be listened to and transcribed by me and possibly another transcriber. We will listen to the tapes in private to protect your confidentiality. The transcriber (if one is used) will be asked to sign a confidentiality pledge. Upon completing your interview, you will be asked to provide a pseudonym, which will be used to label your interview tape and transcript. A master list matching participant pseudonyms and participant names will be kept in a locked cabinet accessible only to me as the researcher. All identifying characteristics, quotes, and information gathered during the study will be disguised and data will be presented in the aggregate in professional publications or presentations so that it cannot be identified with you. Finally, all data, audiotapes, notes, emails, and consent forms will be kept secure in a locked cabinet separate from the master list of names for a period of three years as stipulated by federal guidelines after which time they can be destroyed or continued to be maintained securely.

### **Benefits**

Through your participation in this study, you may gain new insights into your breast cancer, counseling, and activism experiences. You will be contributing information that will help me write on these topics for my thesis and for future presentations or publications. In addition, your ideas may help improve therapeutic services offered to breast cancer survivors.

You will not receive financial compensation for your participation in this study, and no other tangible benefits are anticipated.

### **Risks**

You may experience emotional distress while completing this interview. If you need to take a break or end the interview at any point during the interview, please let me know. If you experience emotional distress following the interview, I encourage you to draw upon the support of your individual counselor or support group. At the end of our interview, I will also provide you with a list of referral sources, which you may find helpful in the future.



**Voluntary Nature of Participation**

Your participation in this study is voluntary. You may withdraw before the study begins. You can decline to be involved with this study without repercussion or loss of services. If at any time you find a question disturbing or if you do not want to answer a question, please let me know. You may refuse to answer any particular questions and may end the interview at any time. There is no penalty for withdrawal from the study. Until April 15, 2007, you may also request that your completed interview be removed from the study and all data will be destroyed.

**YOUR SIGNATURE INDICATES THAT YOU HAVE READ AND UNDERSTOOD THE ABOVE INFORMATION AND THAT YOU HAVE HAD THE OPPORTUNITY TO ASK QUESTIONS ABOUT THE STUDY, YOUR PARTICIPATION, AND YOUR RIGHTS AND THAT YOU AGREE TO PARTICIPATE IN THE STUDY.**

Signature of Participant: \_\_\_\_\_ Date: \_\_\_\_\_

Signature of Researcher: \_\_\_\_\_ Date: \_\_\_\_\_

If you have any questions or wish to withdraw your consent, please contact:  
Liz Burnworth  
Box 706  
Vassar College Counseling Service  
124 Raymond Avenue  
Poughkeepsie, New York 12604  
lizburnworth@msn.com  
(518) 253-5002

Please keep this copy for your records so you can contact me or use the referral information!

## Appendix C

### Referrals

**It is possible that completing this interview may stir up a variety of emotions, memories, and responses for you. Please consider drawing upon your therapist, counselor, or support group for support. A list of additional resources is also provided here.**

#### **New York Statewide Breast Cancer Support Hotline**

800-877-8077 or 516-877-4444

9 am- 9 pm, 7 days a week

Staffed by trained and professionally supervised volunteers, most of whom are breast cancer survivors who provide information, referrals and emotional support. Phone counseling with social workers is available for individuals. Relevant literature is mailed at no charge.

#### **National Cancer Institute Cancer Information Services (CIS)**

800-4-CANCER (422-6237), English and Spanish

9 am-4:30 pm, M-F

A nationwide network of cancer information specialists who provide information about treatments, clinical trials, financial and travel assistance, emotional support, among other topics. Pre-recorded information is available 24 hours a day.

#### **CancerCare, Inc.**

800-813-HOPE (4673), English and Spanish

9 am-7 pm, M-Th, and 9am-5 pm F

Social workers provide education, information and community referrals. Brief telephone counseling and teleconferencing services are available. Will mail literature at no charge.

#### **American Cancer Society Resource Center**

800-ACS-2345, English and Spanish

24 hours, 7 days

Provides information and directs callers to ACS and other community services locally.

#### **Stony Brook Cancer Helpline**

800-UMC-2215 (862-2215)

8:30 am-5:00 pm, M-F

Staffed by oncology nurses who provide information on cancer and treatment options. Will send information on current clinical trials, and give referrals to support groups.

### **Online Resources Related to Breast Cancer**

#### **American Cancer Society**

<http://www.cancer.org>

**Cancer Care, Inc.**

<http://www.cancercareinc.org>

**Capital Region Action Against Breast Cancer**

<http://www.CRAAB.org>

**Department of Defense Breast Cancer Decision Guide**

<http://www.bcdg.org>

**Intercultural Cancer Council**

<http://icc.bcm.tmc.edu>

**Living Beyond Breast Cancer**

<http://www.lbbc.org>

**The Mautner Project for Lesbians with Cancer**

<http://www.mautnerproject.org>

**National Alliance of Breast Cancer Organizations**

<http://www.nabco.org>

**National Asian American Women's Health Organization**

<http://nawho.org>

**National Black Leadership Initiative on Cancer**

<http://www.nblic.org>

**The National Breast Cancer Coalition**

<http://www.natlbcc.org>

**National Center for Complimentary and Alternative Medicine**

<http://nccam.nih.gov>

**New York State Breast Cancer Support and Education Network**

<http://www.nysbcse.net>

**OBGYN.net Latina**

<http://latina.obgyn.net/espanol>

**Sisters Network®, Inc.,**

<http://sistersnetworkinc.org>

**Susan G. Komen Breast Cancer Foundation**

<http://www.komen.org> or <http://breastcancerinfo.com>

**Y-ME National Breast Cancer Organization**

<http://www.y-me.org>

Adapted from: Capital Region Action Against Breast Cancer!. (2000). *The CRAAB! breast cancer resource guide*. Albany, New York: CRAAB!.

Appendix D

Recruitment Flier

ARE YOU A BREAST CANCER SURVIVOR?

DO YOU PARTICIPATE IN BREAST CANCER  
ACTIVISM?

IF SO, YOUR HELP IS NEEDED FOR A STUDY  
EXPLORING THE IMPACT OF ACTIVISM ON THE  
EMOTIONAL WELLBEING OF BREAST CANCER  
SURVIVORS

Women, age 30 and over, who are breast cancer survivors, who have participated in breast cancer activism within the past year, and who regularly attend individual or group counseling or support group are eligible to participate.

Participation in this study involves one interview lasting approximately 1 hour at a location convenient to you.

This study is being conducted as part of a Master's Degree in Social Work at the Smith College School for Social Work.

For More Information Please Contact:

Liz Burnworth  
(518) 253-5002  
lizburnworth@msn.com  
Box 706, Vassar College  
124 Raymond Avenue  
Poughkeepsie, NY 12604

## Appendix E

### Screening Questions

Are you a breast cancer survivor?  Yes  
 No

When were you diagnosed with breast cancer? \_\_\_\_\_ Month  
\_\_\_\_\_ Year

Are you currently participating in some form of psychotherapy, counseling, and/or support group?  Yes  
 No

If yes, are you participating in:  Individual counseling  
 Group therapy facilitated by a social worker,  
psychologist, or psychiatrist  
 Self-Help group

Number of therapy sessions attended: \_\_\_\_\_

Do you participate in any form of breast cancer activism?  Yes  
 No

How long have you been participating in breast cancer activism?

Have you participated in breast cancer activism within the past year?  Yes  
 No

Appendix F

Demographic Face Sheet

Please choose a pseudonym by which you will be identified in this study.

\_\_\_\_\_

Age: \_\_\_\_\_

National Origin: \_\_\_\_\_

Race/Ethnicity:  Black/African American  
 Alaskan Native or American Indian  
 Asian or Pacific Islander  
 Spanish/Hispanic/Latina  
 White  
 Other: \_\_\_\_\_

Sexual Orientation:  Heterosexual  
 Lesbian  
 Bisexual  
 Other: \_\_\_\_\_

Education:  Some High School  
 High School Grad or GED  
 Vocational School  
 Some College or 2-Year Degree  
 4 Year College Degree  
 Master's Degree or Equivalent  
 Ph.D. or Other Advanced Degree

Occupation: \_\_\_\_\_

Number of Hours Worked for Pay per Week: \_\_\_\_\_

Number of Hours Worked Without Pay per Week: \_\_\_\_\_

Approximate Family Income:  Less than \$20,000  
 \$20,000-\$40,000  
 \$40,001-\$60,000  
 \$60,001-\$80,000  
 \$80,001+

Marital Status:  Married  
 Committed Same-Sex Relationship  
 Committed, Non-Marital Heterosexual Relationship  
 Divorced  
 Separated  
 Widowed  
 Single, Never Married

Number of Children: \_\_\_\_\_

Ages of Children: \_\_\_\_\_

Religious Affiliation:  Protestant: \_\_\_\_\_  
 Catholic  
 Jewish  
 Buddhist  
 Muslim  
 Other: \_\_\_\_\_  
 None

Please indicate your political party affiliation:  Democrat  
 Republican  
 Independent  
 Green Party  
 Other: \_\_\_\_\_

How would you describe yourself politically:  Very Liberal  
 Liberal  
 Moderate  
 Conservative  
 Very Conservative  
 Other: \_\_\_\_\_

Thank you for completing this questionnaire! Your participation is greatly appreciated.



## Appendix G

### Preliminary Interview Guide

#### **Breast Cancer Diagnosis and Prognosis**

Could you please take some time and tell me about how your breast cancer diagnosis was presented to you and what impact it has had on your life?

--What was your breast cancer diagnosis and prognosis?

--What treatment have you undergone for breast cancer?

--Could you please give me information about the progression of your disease?

--What supports were offered to you after you received your diagnosis?

--Are you able to participate in the same daily activities that you were able to participate in prior to your breast cancer diagnosis?

#### **Breast Cancer Activist Participation**

Please tell me about the breast cancer activism that you are involved in. (Probe: What is your role? What do you do?)

--What role does activism play in your life?

--How did you first come to be involved in breast cancer activism?

--What was your motivation for becoming involved?

--Has your motivation changed over time? If so, how?

--What are the costs and benefits of doing activist work?

--What has it been like working with others in activism efforts?

--How have others in your life responded to your decision to be involved in activism?

--What impact, if any, has participation in breast cancer activism had on your mental health?

--What relationship, if any, exists between your activism and your therapy?

--Are you involved in any other forms of activism?

## **Psychotherapy Involvement**

Please tell me about your involvement in psychotherapy.

--How has your psychotherapy involvement impacted your life?

--Do you participate in breast cancer activism as a part of your psychotherapy?

## **Mental Health**

Please describe your outlook on life prior to your breast cancer diagnosis.

What is your current outlook on life?

--Did your outlook on life change with your breast cancer diagnosis? If yes, how?

--What is your outlook on the future?

--How would you describe yourself?

--Is the way that you see yourself now different from the way you saw yourself in the past? If so, how? What led to the changes?

--What are your favorite qualities about yourself?

--What are the things you like least in yourself?

--What are the forces—events, people, relationships that have influenced you in your life—made you who you are?

--What self-care practices do you engage in?

## Appendix H

### Volunteer or Professional Transcriber's Assurance of Research Confidentiality

#### **STATEMENT OF POLICY:**

This thesis project is firmly committed to the principle that research confidentiality must be protected. This principle holds whether or not any specific guarantee of confidentiality was given by respondents at the time of the interview. When guarantees have been given, they may impose additional requirements which are to be adhered to strictly.

#### **PROCEDURES FOR MAINTAINING CONFIDENTIALITY:**

- All volunteer and professional transcribers for this project shall sign this assurance of confidentiality.
- A volunteer, or professional transcriber should be aware that the identity of participants in research studies is confidential information, as are identifying information about participants and individual responses to questions. Depending on the study, the organizations participating in the study, the geographical location of the study, the method of participant recruitment, the subject matter of the study, and the hypotheses being tested may also be confidential information. Specific research findings and conclusions are also usually confidential until they have been published or presented in public.

It is incumbent on volunteers and professional transcribers to treat information from and about research as privileged information, to be aware of what is confidential in regard to specific studies on which they work or about which they have knowledge, and to preserve the confidentiality of this information. Types of situations where confidentiality can often be compromised include conversations with friends and relatives, conversations with professional colleagues outside the project team, conversations with reporters and the media, and in the use of consultants for computer programs and data analysis.

- Unless specifically instructed otherwise, a volunteer or professional transcriber upon encountering a respondent or information pertaining to a respondent that s/he knows personally, shall not disclose any knowledge of the respondent or any information pertaining to the respondent's testimony or his participation in this thesis project. In other words, volunteer and professional transcribers should not reveal any information or knowledge about or pertaining to a respondent's participation in this project.
- Data containing personal identifiers shall be kept in a locked container or a locked room when not being used each working day in routine activities. Reasonable caution shall be exercised in limiting access to data to only those

persons who are working on this thesis project and who have been instructed in the applicable confidentiality requirements for the project.

- The researcher for this project, Elizabeth Burnworth, shall be responsible for ensuring that all volunteer and professional transcribers involved in handling data are instructed in these procedures, have signed this pledge, and comply with these procedures throughout the duration of the project. At the end of the project, Elizabeth Burnworth, shall arrange for proper storage or disposition of data, in accordance with federal guidelines and Human Subjects Review Committee policies at the Smith College School for Social Work.
- Elizabeth Burnworth must ensure that procedures are established in this study to inform each respondent of the authority for the study, the purpose and use of the study, the voluntary nature of the study, and the effects on the respondents, if any, of not responding.

## **PLEDGE**

I hereby certify that I have carefully read and will cooperate fully with the above procedures. I will maintain the confidentiality of confidential information from all studies with which I have involvement. I will not discuss, disclose, disseminate, or provide access to such information, except directly to the researcher, Elizabeth Burnworth, for this project. I understand that violation of this pledge is sufficient grounds for disciplinary action, including termination of professional or volunteer services with the project, and may make me subject to criminal or civil penalties. I give my personal pledge that I shall abide by this assurance of confidentiality.

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Signature

Date

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Elizabeth Burnworth

Date

## Appendix I

### Human Subjects Review Approval Letter

December 14, 2006

Elizabeth Burnworth  
13 Marshall Drive  
Poughkeepsie, NY 12601

Dear Liz,

Your revised materials have been reviewed. You have done a careful job of their revision and all is now in order, except for one small detail. You changed your language all through the Consent and the Flier to make your study more inclusive, but in your Application, you have continued to say “psychotherapy” which means there is an inconsistency between the Application and the Consent. We will not hold up our acceptance because of this, but request that you make the Application consistent with your other materials and send the revised Application to Laurie Wyman for the permanent file.

You can do this in two ways. You can say in your Application that you include self-help groups and counseling in your definition of psychotherapy, which is the easy way, or, bless the computer, you can go through and change the language, as you have in the Consent.

We are happy to give final approval to your study with the understanding that you will make this minor language adjustment and send the corrected materials to Laurie.

*Please note the following requirements:*

**Consent Forms:** All subjects should be given a copy of the consent form.

**Maintaining Data:** You must retain signed consent documents for at least three (3) years past completion of the research activity.

*In addition, these requirements may also be applicable:*

**Amendments:** If you wish to change any aspect of the study (such as design, procedures, consent forms or subject population), please submit these changes to the Committee.

**Renewal:** You are required to apply for renewal of approval every year for as long as the study is active.

**Completion:** You are required to notify the Chair of the Human Subjects Review Committee when your study is completed (data collection finished). This requirement is met by completion of the thesis project during the Third Summer.

Good luck with this very interesting study.

Sincerely,

Ann Hartman, D.S.W.  
Chair, Human Subjects Review Committee

CC: Joan Laird, Research Advisor