Factors participants value in breast cancer support groups

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FACTORS PARTICIPANTS VALUE IN BREAST CANCER SUPPORT GROUPS

A Project
Presented to the
Faculty of
California State University,
San Bernardino

In Partial Fulfillment
of the Requirements for the Degree
Master of Social Work

by
Renee Lauren Jarvis
June 2007
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BREAST CANCER SUPPORT GROUPS

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June 2007

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ABSTRACT

Current research reveals that the lifetime risk of breast cancer for women in the United States is 1 in 7.56 women. A diagnosis of cancer has been found to cause severe emotional distress and research has shown that breast cancer patients, in particular, reach out for emotional support. This study used a qualitative research design to explore and identify, from the participants’ perspective, the aspects of a breast cancer support group that facilitate a quality experience of support. Results will help agencies and professionals serving breast cancer patients to determine the extent to which their support groups meet participants’ needs and to make changes that could benefit future participants.
ACKNOWLEDGMENTS

I would like to thank Dr. Rosemary McCaslin, my faculty advisor, for her guidance and Dr. Thomas Davis for his encouragement of this study.

I would also like to extend my deepest gratitude to the breast cancer survivors who generously shared their personal stories in the interviews for this study.
DEDICATION

To my family who have given me their support as I pursue my educational goals. To the 2.3 million breast cancer survivors across the country, an estimated 700,000 more that currently have breast cancer but haven’t yet been diagnosed, and the estimated 40,000 women in this country who die each year from breast cancer.
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CHAPTER ONE
INTRODUCTION

Increasing numbers of women are diagnosed with breast cancer each year and, although research has looked at the efficacy of support groups for breast cancer patients from several different angles, there has been little such research from the breast cancer patients' viewpoints. This study challenges the traditional marginalization of clients' perspectives in outcome research by examining qualitatively what factors breast cancer patients view as valuable in support groups.

Problem Statement

A diagnosis of cancer has a significant impact on the patient and has been found to cause severe emotional distress (Andersen, Andersen, & deProsse, 1989; Moorey & Greer, 1989; Cohen, 1982). Research has shown that cancer patients have a high rate of anxiety and depression (Newell, Sanson-Fisher, Girgis, & Ackland, 1999; Kissane, Clarke, Ikin, Bloch, Smith, Vitetta, et al., 1998; Ford, Lewis, & Fallowfield, 1995), elevated levels of posttraumatic stress symptoms (Cordova, Andrykowski, Kenady, McGrath, Sloan, & Redd, 1995), and chronic sleep
problems (Malone, Harris, & Luscombe, 1994; Cella & Tross, 1986). Mastectomy patients also report problems with sexual functioning and satisfaction (Fobair, Stewart, Chang, D-Onofrio, & Banks, 2006; Farooq, 2005; Avis, Crawford, & Manuel, 2004; Weizner, Hughes, & Schusterman, 1995).

Worldwide

Breast cancer is the most prevalent cancer in the world, and is by far the most frequently diagnosed cancer for women, representing 23% of all female cancers. In 2002, there were an estimated 1.15 million new cases and an estimated 411,000 deaths from breast cancer, accounting for 14% of all female cancer deaths. Breast cancer is the leading cause of cancer death for women worldwide (Parkin, Bray, Ferlay, & Pisani, 2005).

United States

Nationwide, breast cancer is the leading cause of cancer death for women between the ages of 20 and 59. In mortality rate, it ranks second to lung cancer and accounts for 15% of cancer deaths for women of all ages (American Cancer Society [ACS], 2006b). Breast cancer accounts for almost one in three cancers diagnosed in
women and, except for skin cancer, is the most commonly diagnosed female cancer (ACS, 2005a).

Over the past three decades the risk of breast cancer has steadily increased. In 1975, the lifetime risk for breast cancer was 1 in 11 women; in 2005 it was estimated to be 13.22%, or 1 in 7.56 women (ACS, 2005a). It is estimated that 1.5% of the female population has a history of breast cancer (Parkin et al., 2005) and that approximately 2.3 million women with a history of breast cancer were alive in January, 2002. Some of these women were cancer-free and some of them were still undergoing treatment. An estimated 50% of breast cancer patients are 61 years of age or younger at the time of first diagnosis (ACS, 2005a). In 2006, an estimated 274,900 new cases of breast cancer will be diagnosed, and an estimated 41,430 will die of the disease (ACS, 2006b).

California

Statistics for women in the State of California mirror the nationwide rates, with breast cancer accounting for nearly one out of three (31%) cancers diagnosed in women. An estimated 21,200 women in California will be diagnosed with breast cancer in 2006, and 4,080 will die from it (ACS, 2006b). Between 1998 and
2002, the incidence rate for breast cancer was 131.7 per 100,000 and the death rate was 25.1 per 100,000 (ACS, 2006a). An estimated 55% of California women diagnosed with breast cancer are 64 years of age or younger (ACS, 2004).

San Bernardino County and Surrounding Areas

The California Cancer Registry estimates, for 2007, the number of new breast cancer cases in the following California counties to be (ACS, 2006a):

San Bernardino ......................... 860
Riverside ............................. 1,010
Los Angeles ............................ 5,335
Orange ................................. 1,800
San Diego .............................. 1,420

The number of breast cancer deaths in 2007 by county is estimated to be:

San Bernardino ......................... 210
Riverside ............................. 220
Los Angeles ............................ 1,080
Orange ................................. 345
San Diego .............................. 375
Emotional Support

Research shows that breast cancer patients, in particular, reach out for emotional support and counseling. A study of calls to a Cancer Helpline in 2001 showed that the majority of callers were women (68%) and, although breast cancer represented only 14% of the leading cancer sites in the geographical area, 48% of the patients who called had been diagnosed with breast cancer (Jefford, Black, Grogan, Yeoman, White, & Ackerman, 2005). In another study of a volunteer peer support service, the Breast Cancer Support Service, an estimated 90% of all women diagnosed with breast cancer in two distinct urban geographic areas requested and received a visit by a Breast Cancer Support Service volunteer (Dunn, Stegings, Occhipinti, & Wilson, 1999).

Purpose of the Study

Support groups are considered to be helpful in assisting breast cancer patients to cope with their illness. Spira and Reed (2003) consider it the "treatment of choice" and assert that, "nowhere can the power of the group be more beneficially used than with breast cancer patients" (p. 20).
Benefits of Support Groups in General

Yalom (1985) theorized that there are three factors of any group setting that contribute to its salutary effects. The first factor is universality in which participants feel that they are not alone. The second factor, altruism, gives participants an opportunity to support others in the group and provides a sense of meaning and purpose. This factor is supported by the social support model which asserts that reassurance and the ability to confide in others helps patients cope with cancer (Mastrovito, Moynihan, & Parsonnet, 1990). The third factor, hope, comes from the observation that other group members are coping with similar circumstances. This factor is supported by the social comparison model which suggests that it is helpful for breast cancer patients, in particular, to compare themselves to other breast cancer patients in evaluating their emotional responses (Wood, Taylor & Lichtman, 1985).

Benefits of Breast Cancer Support Groups

Researchers are concerned with demonstrating the benefits of support groups for breast cancer patients. Several studies have looked at the efficacy of support groups by trying to determine if the survival of breast
cancer patients is prolonged by participation in a support group. A study of metastatic breast cancer patients at Stanford University found that those who participated in a support group had a better survival rate than the metastatic breast cancer patients in a control group (Spiegel, Bloom, Kraemer, & Gottheil, 1989).

Several subsequent studies, however, including one by the original group of researchers, have been unable to replicate the findings of the study (Goodwin, 2004; Kissane, Love, Hatton, Block, Graeme, Clarke, et al., 2004; Goodwin, Leszcz, Ennis, Koopmans, Vincent, Guther, et al., 2001; Edmonds, Lockwood, & Cunningham, 1999; Edelman, Lemon, Bell, & Kidman, 1999; Cunningham, Edmonds, Jenkins, & Pollack, 1998; Gellert, Maxwell, & Seigel, 1993). One researcher notes that, "even if the study is flawed, like the one that found that women in support groups survived longer [Spiegel et al., 1981], people may want to believe it because it's such an appealing idea" (Holland, 2001 as cited in Spira & Reed, 2003, p. 36). A later study, which examined the Stanford study by comparing the survival curve of the treatment group to the survival curve of the general population of
metastatic breast cancer patients, showed that the treatment group survived no longer than would be expected. The control group from the study, however, was determined to have died at a faster rate than would be expected (Fox, 1998).

Other studies have looked at the efficacy of support groups based on improvement between pre-test and post-test on various measures. Informational and educational approaches have been found to be effective at improving medical knowledge, compliance, and functional adjustment in patients. Behavioral approaches have been found to be effective with managing specific symptoms. Participation in social support groups has been found to be effective in lowering psychiatric symptoms, maladaptive sensitivity, and anxiety (Spira & Reed, 2003).

A study that compared differences in symptom distress, emotional distress or functional status of breast cancer patients in an 8-week support group and a control group, however, found no significant differences (Samarel, Fawcett, Krippendorf, Piacentino, Eliasof, Hughes, et al., 1998). Another study that compared differences in psychosocial adjustment, coping, and
social support, over a 12-week period, between breast cancer patients in a psychotherapy group, in a social support group, and in a waiting list control group also found no significant differences between the groups (Vos, 2004). These studies suggest that the passage of time is a contributing factor in the measured salutary effects of breast cancer support groups.

Quantitative versus Qualitative Research

Studies looking at the efficacy of support groups for breast cancer patients have mainly considered quantitative outcome data. There has been little research to examine qualitatively what the benefits are from the patients’ perspectives. Reamer (2001) notes an “old tension within the therapy field between client satisfaction and measurable outcomes” (p. 48) and describes “a rather uneasy division within the research field between an emphasis on client satisfaction and on measurable outcome” (p. 60).

Treacher and Carpenter (1993) argue that therapists should also be concerned with how therapy is experienced by clients. They suggest that, although it is tempting for an agency to make the users fit the service, agencies should adjust their services to fit the users’ needs.
Reamer (2001) advocates for "involving clients not only as objects of research, but as active participants in developing research, which might include devising the questions" (p. 57).

This study explored and identified, from the participants' perspectives, the aspects of a breast cancer support group that facilitate a quality experience of support. A qualitative approach was used in this study because it is the most comprehensive way to capture the unique experience of participation in a group experience.

Significance of the Project for Social Work

Historically, social workers were the first professionals to assist patients with their psychosocial concerns. The first medical social work department in the United States was initiated in 1905 by Dr. Richard C. Cabot, a physician and educator. He hired social worker, Ida M. Cannon, at Boston's Massachusetts General Hospital. She served there as director of the social services department for 40 years and later founded the American Association of Hospital Social Workers (NASW, 1987). Social workers were in a unique position, by the 1950's, to also be the first "to play a greater role in
both describing the problems of patients and intervening to provide emotional support" (Massie, Holland, & Straker, 1989, p. 445).

It is important to understand the aspects of a support group that breast cancer patients consider to be beneficial. This study will allow agencies and professionals serving breast cancer patients to develop a clearer understanding of the components that facilitate a quality experience of support. Using the generalist intervention process, they will be able to, in the evaluation phase, determine the extent to which their support groups meet participants' needs, and, in the planning phase, to make changes that could benefit future participants.

Participants in the study may have benefited from being able to express their feelings about the support group experience. Sells, Smith, and Moon (1996) reported that clients who participated in research interviews said that it "helped them feel they had become a more equal and active part in the treatment process" (p. 12). Additionally, the information from this study may encourage further research to learn whether the findings could apply to a larger sample of the population.
Methodology

This study utilized individual in-person oral interviews approximately 20 minutes in length. In keeping with the qualitative style, the interviews were conducted in the natural setting of the participant’s home or a place of their choosing.

The method of sampling that was employed for this study was a purposive sampling technique. Since the experience of breast cancer and the salutary aspects of a support group may vary depending on the severity of the illness, the sample for this study was limited to adult, female, stage II breast cancer patients who have undergone chemotherapy. The treatment protocol for breast cancer patients at stage II typically involves chemotherapy (ACS, 2005b). Approximately 31% of breast cancer patients are classified as stage II (ACS, 2005a).

Twenty participants were recruited from the breast cancer support groups at the American Cancer Society in Victorville, Gilda’s Club in Cathedral City, Michelle’s Place in Murrieta, Packinghouse Support Sisters in Redlands, and the Caring and Sharing Support Group in Arrowhead. These support groups were chosen because the
researcher had an established relationship with the groups.

The breast cancer patients who participated in this study did so on a voluntary basis and each received a rhinestone encrusted pink ribbon pin as a gesture of appreciation for their time and effort.

The research question for this study was: What are the factors in a breast cancer support group that participants view as valuable?
CHAPTER TWO

LITERATURE REVIEW

Introduction

The majority of literature on the salutary effects of support groups has focused on their potential survival benefits and the improvement of participants between pre-test and post-test on various quantitative measures. Few studies have examined support qualitatively from the participants' perspectives.

This chapter discusses existing studies on social support and peer support that have examined the experience of support, in general, from the perspective of the breast cancer patient as expert.

This study differs from previous studies in that it focused specifically on the factors of a support group for breast cancer patients that the participants view as contributing to a quality experience of support. The literature review and the theoretical underpinnings for this study that are covered in this chapter supply the grounds for this research project.
Social Support

Non-materialization of Anticipated Social Support

In one study, 100 breast cancer patients were interviewed regarding perceived social support. Their self-reports were compared to the responses of 100 healthy participants regarding their anticipated social support (Peters-Golden, 1982).

While the healthy participants reported their own avoidance behavior toward cancer patients, they anticipated that they would receive strong social support if they were to be diagnosed with cancer. In contrast, the breast cancer patients described a non-materialization of the social support they had anticipated, with over one third of them reporting that they felt avoided by family and friends. They reported that their feelings of isolation and loneliness contributed to a decrease in adjustment to their illness. Researchers attributed the avoidance behavior and withdrawal of support to the stigma associated with cancer (Peters-Golden, 1982).

Inappropriate Social Support

The breast cancer patients also asserted that the attempts of significant others to be supportive were
often inappropriate. More than half deemed the social support attempts inappropriate because they sensed a false cheerfulness. They also reported that healthy individuals mistakenly assume that the loss of a breast is the most salient concern rather than the experience of cancer (Peters-Golden, 1982).

Lack of Social Support Distressful to Patient

Further research indicates that when significant others avoid the cancer patient, refrain from discussing the topic of cancer, fail to express empathy, minimize the negative aspects of their situation, or have an overly cheerful manner, the relationships can be sources of distress rather than support for the person with cancer (Dakof & Taylor, 1990, Wortman & Dunkel-Schetter, 1987).

Helgeson and colleagues (2004) point to these types of behaviors as failures in the cancer patient’s social support system adding that, “one of the rationales behind the peer support group is that peers are unlikely to behave in these ways and may be able to compensate for support deficits from the natural network” (Helgeson, Snyder, & Seltman, 2004, p. 108).
Peer Support

Also missing from the research are studies that examine the benefits of peer support using an approach from the perspective of the breast cancer patient as expert. Two studies were found, however, regarding peer support using a client-centered protocol to evaluate their efficacy.

Evaluation Study of a Peer Support Program

In the first study, Dunn and colleagues (1999) surveyed breast cancer patients to evaluate a volunteer peer support program, Breast Cancer Support Service (BCSS). The program consisted of volunteers who had previously experienced breast cancer offering peer support to women being treated for breast cancer. A two-phase evaluation was conducted (Dunn et al., 1999).

In the first phase, a series of focus groups was held. The focus groups were composed of 57 breast cancer patients who had been visited by a BCSS volunteer. Participants were asked to list how the visit had been helpful or unhelpful. The content of the interviews was evaluated and 16 items were identified and categorized into areas of interest. Within the three categories, eight helpful, five unhelpful, and four social comparison
items were selected to develop a questionnaire to measure ways in which BCSS volunteer’s visit was helpful or unhelpful (Dunn et al., 1999).

In the second phase of the evaluation, the questionnaire was mailed out to 350 breast cancer patients who had been visited by BCSS volunteers during a three month period. Of the 350 women, 245 responded. In general, the respondents most commonly scored the helpful attributes as moderately true to very true and the unhelpful attributes as not true. An analysis was conducted to assess which factors of the visit predicted an overall helpfulness rating (Dunn et al., 1999).

**Helpful Factors of the Peer Support Visit**

The most important helpful factor was the item, “visited me at the time I most needed her;” the most important unhelpful factor was the item, “left me feeling uncertain about my future;” and the most important social comparison factor was the item, “had a similar way of life to me.” The most important factors related to the shared experience of breast cancer (Dunn et al., 1999). One participant from the focus group described this factor with the response, “seeing someone still alive,
well and living normally helped me see there was life after the operation" (Dunn et al., 1999, p. 20).

While this study gave important information about the valuable aspects of a single visit with one other breast cancer survivor, the following study explores the benefits of the group experience with other breast cancer survivors.

**Evaluation Study of Two Support and Education Groups**

Researchers interviewed breast cancer patients who participated in two different 8-week support and education groups to evaluate their efficacy. The groups differed in that one of the groups followed the Roy Adaptation Model (Roy & Andrews, 1991 as cited by Samarel et al., 1998) containing a "more intense focal stimulus" of "coaching" in which a relative or friend attended all group meetings with the patient and was physically and emotionally available to her during the time between meetings.

A 15-minute telephone interview was conducted with participants two months after completion of the support group. Interviews were audio tape-recorded and transcribed verbatim. Of the 122 participants
interviewed, data from 70 were used because content analysis indicated that data saturation had been achieved. A structured interview schedule was developed by the researchers (Samarel et al., 1998).

Interview Questions

The first two questions, designed to determine the participant’s current adaptation level, were: What was your participation in this study like? How do you view your illness? The remaining two questions were based on the four Roy Adaptation model response modes of physiological, self-concept, role function, and interdependence (Samarel et al., 1998, p. 1260).

These two questions were: How does your illness affect you physically, emotionally, in carrying out your activities, and with family and friends? How did your participation in this research help you or not help you physically, emotionally, in carrying out your activities, and with family and friends? Participants’ responses to these questions were categorized as adaptive or ineffective (Samarel et al., 1998, p. 1262).

Beneficial Factors of the Support Group

The study showed no significant differences between the support groups with or without coaching, but, more
important to this research, it also revealed themes about the factors in the support group experience that the participants found beneficial (Samarel et al., 1998).

The most important theme was the feeling of not being alone. One participant expressed this in her response, "It makes you realize that you’re not alone, that it can happen to anyone, and it’s not a death sentence" (Samarel et al., 1998).

A second important theme was the opportunity to verbalize feelings and, in particular, 18.6% of the participants found it beneficial to be able to express feelings with someone who understood the experience of breast cancer. An example of a response with this theme was, "It really helped to talk to people [who] know how you’re feeling and what you’re doing and going through" (Samarel et al., 1998).

A third theme, which was expressed by 15.7% of the participants, was that the group was informative. One participant responded that, "It answered so many questions for me. There were a lot of puzzles in my head and everything just came together" (Samarel et al., 1998).
Theory Guiding Conceptualization

An important theoretical model that provided groundwork for this study was phenomenology and its emphasis on understanding a life event through the descriptions of those who have experienced it. Phenomenological theory asserts that there are multiple realities explaining the way the world works and that the goal is for these realities to be "rendered into words by people who have experienced the phenomenon and the researcher interprets the words" (Annells, 1999, p. 6).

Munhall (1994) theorizes that most researchers have been socialized to develop a proposal before conducting their research and that their studies serve mainly to document these assumptions. Paterson and Zderad (1976) emphasize that, "in order to open the data of experience in using the phenomenological approach, one strives to eliminate 'the a priori,' that which exists in his mind prior to and independent of the experience" (p. 80). Munhall (1994) proposes that the phenomenological approach can provide a fuller understanding of human experiences and that "such understanding could not be attained with the use of quantitative studies" (p. 298).
Summary

This chapter reviewed the few studies on social support and peer support, in general, that have focused on their salutary aspects from the breast cancer patient's perspective. It also explored phenomenology theory, the theory driving this study.

A review of the literature on this topic suggests that there is a lack of research on the aspects of a support group that breast cancer patients, in particular, consider to be beneficial. This research builds on the foundations of previous studies in that it specifically focused on and qualitatively explored the factors in a support group for breast cancer patients that the participants viewed as contributing to a quality experience of support.

A qualitative study that elicits this information from the participants not only contributes to the current literature on the subject, but may also help to focus attention on the need for future research into the efficacy of support groups from the viewpoint of the participants.
CHAPTER THREE

METHODS

Introduction

This research project explored the factors that breast cancer patients view as valuable in support groups. This objective was accomplished using a qualitative study with standardized open-ended face-to-face interviews with individual participants. Core questions addressed the participants' perspectives on the efficacy of support groups. Demographic variables were also taken into consideration.

The study design, sampling, data collection, procedures, protection of human subjects, and data analysis used in this research project are discussed in this chapter.

Study Design

The purpose of this study was to explore and identify, from the participants' perspectives, the factors of a breast cancer support group that facilitate a quality experience of support. This study was qualitative in nature and utilized individual in-person oral interviews approximately 20 minutes in length.
The qualitative approach was used because it was the most comprehensive way to capture the experience of participation in a breast cancer support group. An advantage of the face-to-face interview method was that it gathered in-depth information in the participant's own words. Also advantageous was that it allowed the researcher to interact directly with the participants, providing opportunities for clarification and for follow-up questions.

Use of the interview design had some disadvantages. The most significant limitation is its generalizability. Because the sample was not random, it will not be able to generalize to larger populations. Additionally, the use of preformed groups affected both the external and internal validity of the study. Breast cancer patients who choose to participate in support groups, in general, may not be representative of non-participating breast cancer patients, and the support groups selected for this study may have attracted populations that differ from other support groups in the area. External validity was also affected by selection-treatment interaction from the individuals who self-selected to participate in the study.
Another limitation of the study was the possible impact of social desirability. Researchers note that cancer patients often feel pressure to have a positive attitude (Holland & Lewis, 2001).

It is expected that the participants’ expertise will deepen understanding of the salutary aspects of the breast cancer support group experience.

The research question for the study was: What are the factors of a breast cancer support group that participants view as valuable?

Sampling

The population of interest for this study was breast cancer patients from the Southern California area who have undergone chemotherapy and have participated in a support group. Since the experience of breast cancer and the salutary aspects of a support group may vary depending on the severity of the illness, the sample for this study was limited to adult, female, stage II breast cancer patients. Approximately 31% of breast cancer patients are classified as stage II (ACS, 2005a) and the treatment protocol for breast cancer patients at stage II typically involves chemotherapy (ACS, 2005b).
The method of sampling that was employed for this study was a purposive sampling technique. Twenty participants were recruited from the breast cancer support groups at the American Cancer Society in Victorville, Gilda’s Club in Cathedral City, Michelle's Place in Murrieta, Packinghouse Support Sisters in Redlands, and the Caring and Sharing Support Group in Arrowhead. These support groups were chosen because the researcher had an established relationship with the groups.

Data Collection and Instruments

A semi-structured interview format was followed. The main intent of the questions was to capture each participant’s views on the aspects of the breast cancer support group that are of value. An interview guide was formulated based on preparatory informal discussions with other breast cancer survivors. Participants were prompted by a series of open-ended questions designed to elicit information about the salutary aspects of the breast cancer support group experience (see Appendix A).

Following the qualitative approach, the participants were allowed to elaborate on questions that were
important to them and to bring up topics that they felt had been overlooked. A digital voice recorder was used during the interview. The recorded responses of the interview were transcribed and then analyzed for thematic content to provide information on emergent themes.

At the end of the interview, participants were also asked to fill out a short questionnaire requesting demographic information (see Appendix B). Demographic information obtained from the questionnaire included nominal (sex, race, and marital status), ordinal (education, types of surgery and treatment), and interval-ratio (age, and time since diagnosis) measurements.

Procedures

The data source for this study was personal face-to-face interviews with individual participants solicited from a flyer (see Appendix C) provided to the breast cancer support groups at the American Cancer Society in Victorville, Gilda’s Club in Cathedral City, Michelle’s Place in Murrieta, Packinghouse Support Sisters in Redlands, and the Caring and Sharing Support Group in Arrowhead. Participants volunteered by calling
to schedule an interview. In keeping with the qualitative style, the interviews were arranged by appointment and were conducted by the researcher in the natural setting of each participant's home or a place of their choosing.

Prior to the interview, the researcher explained the nature and purpose of the study. An informed consent (see Appendix D) was read and participants were asked to place a check mark in the appropriate box acknowledging that they understood the informed consent, were at least 18 years of age, and gave their consent to participate. Participants were also asked to place a check mark in the appropriate box giving consent to be audiotaped.

Participants were assured of the anonymity of their participation and the confidentiality of their responses. Participants were told that there were no right or wrong answers, that they could ask for clarification, and that they could stop at any time during the interview process. A debriefing was given to participants at the close of the interview (see Appendix E) and participants were assured that they would not be contacted after the interview.

The breast cancer patients who participated in this study did do so on a voluntary basis and each received a
rhinestone encrusted pink ribbon pin as a gesture of appreciation for their time and effort.

Protection of Human Subjects

Confidentiality and anonymity of the participants were strictly observed. No participant names were used on the recordings or in the transcripts. During the study, the digital recordings and transcripts remained in a locked box in the possession of the researcher. At the conclusion of the study, the digital recordings were destroyed, although the transcripts were saved for future use. A numbering system was utilized in which participants were assigned a number in the order that they were interviewed.

Contact information were made available for the researcher’s faculty advisor in the event that participants had questions regarding the study.

Data Analysis

Digital audio recordings of the interviews were transcribed verbatim. Atlas.ti was used to generate qualitative analysis of the textual data provided by the interview transcripts. The narrative streams were
analyzed for coding, thematic content, and pattern analysis.

Demographic information provided important descriptive information about the characteristics of the sample group in terms of frequencies, percentages, averages, and range, as well their correlations with the emergent themes.

Summary

This study used qualitative interviews to explore the factors of a breast cancer support group that participants deem important and their effect on the quality of the experience of support. This chapter outlined the study design, sampling, data collection, procedures, protection of human subjects, and data analysis that was utilized in the research project.
CHAPTER FOUR

RESULTS

Introduction

In this study, twenty participants were interviewed to explore and identify the factors of breast cancer support groups that facilitate a quality experience of support. This chapter reports the findings of the study.

Presentation of the Findings

All of the participants in this study were female. They ranged in age from 37 to 78 years old, with a mean age of 55. The ethnic makeup was 95% Caucasian and 5% Hispanic/Latino. Education level ranged from less than high school to graduate degree, with 5% of participants reporting an education of less than high school, 15% reporting high school education, 40% reporting some college, and 40% reporting attainment of a graduate degree. The current employment status for participants was 20% employed full time, 15% employed part time, 10% retired, 35% unemployed, and 20% in “other” employment status. At the time of the interview, 70% of the participants were married, 15% were widowed, 10% were single, and 5% were divorced.
In terms of breast cancer treatment, 15% of the participants received lumpectomies. Another 25% initially received lumpectomies, returning for a mastectomy at a later time. A total of 80% of the participants received mastectomies, 75% received chemotherapy, 45% received radiation therapy, and 40% received other adjuvant treatment.

The interview questions were used to gather information about the salutary aspects of the breast cancer support group experience. The responses were recorded, transcribed, and analyzed to provide information on emergent themes. A total of sixteen themes were developed from the responses. They are shown in Figure 1 in order of prominence. The themes are reported under three broad categories: association, emotional support, and assistance. Figure 2 illustrates the subcategories of themes.

Association

Connection

Fourteen participants (70%) described a sense of aloneness following their breast cancer diagnosis. They reported that finding other women who had gone through or
Figure 1. Hierarchy of Emergent Themes
Figure 2. Categories of Emergent Themes
were going through the breast cancer experience was comforting to them.

You just kind of lose hope when you’re by yourself.
I was lost. I was in a fog. And it helps to see other people who are either survivors or are going through it.
It’s healing to know that you’re not the only one out there. You’re not the only one that’s dealing with this cancer.
You just feel this relief. There are other people out here, you’re not alone.

Many of the women described a change after diagnosis in which they felt camaraderie with others who were similarly diagnosed.

I know whenever something would come on TV about cancer, I would flip it as quick as I could and think, “That’s not me. I don’t care about that. I don’t even want to know about that stuff.” And then, once you get it, you want all the information you can get and so now you’re talking to anyone who has been through it. There’s just nothing like getting together with others who have been through it.
It's the club nobody wants to belong to, but once you have joined, we all have that common bond of cancer and, it sounds weird, but I get more warm fuzzies from people who are going through the same thing than I do from my friends and family that are healthy and just don't understand. You feel love from the other ladies that are there, that you're not a stranger, that you're one of them, that you're all going through this together. And you're not alone. It's a sisterhood. We're all the same under the blouse.

One of the women I know that just got diagnosed a few weeks ago sent me an e-mail saying "I'm a new member of the club." You have that clique kind of feeling.

**Commonality**

Another important theme that was mentioned by nine of the participants (45%) was the realization that they shared similar issues with other group members.

At the time I started, there were three of us that were in chemotherapy and one was going into
radiation. And we were all bald. It was nice to be with somebody bald.

Hair loss is emotionally devastating, and to be around other women who have lost their hair is so comforting.

It's that commonality because you have the same experiences and your needs are the same. You have a silly or a dumb thing that you discover is the same as someone else is experiencing.

Not only did the participants find it comforting to discover that they had things in common with the other group members, it also helped allay their fears to learn that their symptoms were normal and to be expected.

I was saying that I was getting more heartburn. I saw a lot of people shaking their heads, "Yes." They got it from the chemo. Other things that your friends wouldn't know anything about. And I was talking about how tired I was, just complete fatigue. And I could see those heads going up and down, "Yes, that's normal." When I found out these things were normal for what I was doing, I was less worried about it. And that's what it is, because they either had been there or were in the same boat.
that I was. And there were a number of them. I found that we had similar symptoms, we had the same worries, we had the same feelings. We all lost our hair during the chemo. We could relate to each other in all of the different ways. That made it good. Loosing my memory was scary. Then you talk to someone and it’s normal. And it’s like, “Oh, thank the Lord, I thought it was just me.” I have lost thoughts. I can be talking and lose thoughts and I know that’s all part of the therapy and everything that I went through. It wasn’t until I came to the group that I discovered that it was normal. It’s being able to look at them and discuss it and say, “I have a scar. Is this normal that my arm is numb?” It threw me for a loop until I talked to several others that said, “Yeah, mine is still that way. It’s normal.” Before I was thinking, “Oh, gosh, something’s terribly wrong.”

Hope

One of the most common themes, reported by fifteen of the participants (75%), was that it gave them hope to
see other women who had survived the breast cancer experience.

It’s awfully nice to have somebody who’s been there and has survived for a long period of time come into the group. There’s hope, we need the hope to know that this can be survivable. You see it walking and talking. It’s such a nice feeling.

If they’re healing, if they’re getting stronger, then you have hope that you’re also going to get better and stronger. And there is a light at the end of the tunnel.

They look fine, they sound fine, they’re functioning, so maybe I’ll be fine. Hope is very important.

I remember that I went to one meeting and there were a couple of older women that were like 20 years out and they had positive lymph node involvement, which is always something that you don’t want. And they were doing fine. And to me, that just made me smile and think, “Why can’t I be one of those. Maybe there’s a chance that I’ll be one of those ladies.” People don’t realize, who are several years out, and they think, “Well, what do I have to contribute?
It’s been so long ago and I’ve forgotten a lot of things.” But when we see somebody that many years out, it’s so encouraging. You think, “That’s going to be me.” You know some of them have chosen different treatments, and to see them it’s very encouraging, it really is.

Perspective

Not only did they find it helpful to be around other group members who seemed to have survived breast cancer, five of the participants (25%) reported that it was also helpful to compare themselves to other group members to gain perspective on their situation.

Being in the group puts your situation in perspective. And even though yours may be dire, you realize that, “You know what, these women have all gone through something, themselves.” And it seems like there’s always somebody who has gone through something worse, or had worse reactions, or harder treatment. It’s a reminder that things could be so much worse.

I was comparing myself in the fact that they were, in my eyes, worse off than me. There was this one woman whose cancer had metastasized and she was
traveling all over the country in her motor home with her friend. She was just an inspiration. That type of thing. Some of them were probably terminal and yet they were still fighting. There was a person at the support group that had been through extensive chemo and had gone to City of Hope and it was more advanced than mine. And so I thought, “Okay, that person had this and went through a lot more. I can do this.” Anytime you get outside your situation or yourself, I think it’s important. Then it’s not all about me, it’s about others. Then you realize, “Oh my gosh, it could be so much worse.” I think that’s one of the main feelings it fosters is getting outside yourself and doing for others and thinking of others, and putting your situation in perspective. A few of the women, however, reported that, especially at their first group meeting, it was frightening to hear from women whose prognosis was not good.

**Ability to Cope**

Twelve of the participants (60%) reported that the opportunity to talk to other group members who were further along in their treatment helped them to be
prepared for and to cope with the effects of upcoming
treatment and surgery.

With all the different stages in the group, I had
people who hadn’t started the treatment, people that
were in treatment, people that had finished
treatment, so they could give me a general idea of
where I was going and what was going to come from
this.

They had been going for many months to the support
group and they were telling me, “You’re going to get
through this” and “Look at my scar and my surgery”
and “It’s not that bad” and “Even if you don’t feel
well now, you’ll feel better later” with the chemo
and stuff. It was just wonderful to meet other
people who had gone through what I was getting ready
to go through.

There was somebody there that I could ask questions
to get real answers... It makes it not so
mysterious. I think you can prepare better that way
for your treatment.

If you’re at least prepared for it, you might be
able to cope better... Preparing you for something
is half the battle, I think. If you know what you’re
going to go through, that helps a lot. It's the things that I haven't been prepared for that have been the most difficult.

The unknown is always scarier than the known. Even though a mastectomy scar isn't beautiful, at least you could see it and say, "Okay, that's probably what I'll look like."

It does so much good to show that, "Yes, your hair does grow back" and "Yeah, you can have the surgery and you're not going to look like you did before, but this is how you can look." It's not so scary if you see what the possibilities are. It's the unknown that is so incredibly scary.

Sustenance

Nine of the participants (45%) described how the encouragement that they received from the other group members helped them to cope between group meetings.

Just about every aspect of the group, I took it in like I was starving for something. When I would leave here, I would leave with a spring in my step. I just could hardly wait for the next Wednesday to come around.
You think, "Oh, I just can't do this anymore" and you go there and you get refreshed. It fills you up. That's how I feel.

Nobody has any idea what this group has brought to me, as far as my own self-worth, my own personal well-being. When I would go to bed at night and turn out the light, there would be dark spots there. I don’t have near the dark spots that I used to have, since I started the group. It's a good place.

For some, the support they received from other group members extended beyond the actual meetings with phone calls, e-mails, and getting together outside of the support group.

It was beyond the actual physical hour and a half we met once a month. I remember crying for more, "I want more!" And we were working on trying to get two a month. At the end of the meeting we were asked to sign a piece of paper and give our phone number. It was voluntary, we didn’t have to if we didn’t want to. But it was the idea that, no matter what time of the week, I could call on any one of these women, whether it was to cry, or to see how they were doing, or to ask a question. We all had such a
strong need to connect with each other, above and beyond the support group. “Support group” is a term that we define as meeting in a place for a certain amount of time, but it went beyond that. I really enjoy my group and I’ve pulled so many good friends out of there. People that I know I could call and say, “I’m just not feeling well. Can I come over and sit with you for awhile.” And they’d say, “yeah, come on over.” I’ve made some friends in the group and sometimes we’ll go to lunch and just sit around and talk. Even though I haven’t known these people for very long, I feel like it’s a pretty deep connection. To be able to attend here and I had phone calls and e-mails and, if I ever want to talk to somebody, I can. That’s very helpful to me. You can talk in between. You know, you get bad days and it lifts you up and you can go on with your days. It’s a scary thing by yourself.
Emotional Support

Acceptance

Four of the participants (20%) related that, after their cancer diagnosis, many of their friends and family members avoided them or seemed uneasy around them. They reported a sense of acceptance among support group members.

It's a relief to be able to talk with support group members because they don't get that look in their eyes when they find out that you have cancer. It's not a pity look, it's almost a horror look. You see it in their face and you don't want to talk about it. I almost feel like I'm hurting them by talking about it. Then they're worrying. Whereas, the women with breast cancer make you feel so much better. It's being able to look at them and discuss it. There's that instant friendship, that bond right away. Because they've been looked at the way that you've been looked at by other people. Other people avoid you, they don't know what to say. People on the outside, even though some were long time friends, were not able to relate... I didn't feel like they understood or they didn't know what
to do, so that seemed kind of curious. They had, kind of, written me off. I felt an alienation. I don’t know if it was on my part, their part, or what.

Knowing that it is survivable, that you can get back to normal, that there are actually people out there that care. I have people out there that care, that understand it completely, and they’re there for me.

Understanding

Many of the participants reported that their friends and family had relatively little understanding of what they were going through emotionally.

Loved ones, friends and family, have not experienced the fear, the confusion, just the day to day thoughts that you really can’t stop thinking about. Breast cancer, while you’re going through it, it consumes your mind, everything in your life. Your friends and family just don’t have that same view. Your family just doesn’t know what you’re really going through. And somebody that has been through it knows exactly what you’re going through. You get withdrawn from your family and they’re upset just as
much as you are, but they don’t feel what you’re
going through.
You say, “I can’t sleep” and your friends and family
say, “Well, just think good thoughts.” But that just
doesn’t work and so their suggestions aren’t very
helpful... I think that with the people in the group
you can say, “I feel like hell.” It’s kind of like a
sounding board, you can just talk and they’re all
willing to listen. And they don’t have suggestions
like, “Just think good thoughts and you’ll be okay.”
They say, “I know that feeling. I understand what
you’re talking about when you say you’ve hit the
wall, how you just can’t take another step.” Friends
and family say, “How are you?” but they really don’t
want to know. But the people in the group, a lot of
times, feel the same way. They say how they feel,
but they can laugh about it, too. But at least you
have met somebody else that understands.
I can talk to a woman who’s been through treatment
easier than I can talk to someone who hasn’t. They
don’t know what I’m talking about. And when they
say, “How are you?” I just tell them, “Fine,...
because I am not going to talk to somebody who hasn’t been through this.

My husband’s reaction when I said I needed to go to a support group was, “Why do you need to do that? You’ve got me. You can talk to me.” Right.

Twelve of the participants (60%) related how reassuring it was to them to be around other group members who had an understanding of what they were experiencing.

The understanding is there. It’s the understanding of going through it. You know, you can’t understand birth until you’ve had a baby, all of those feelings and emotions. It’s the same thing, until you’ve been told that you have cancer.

They went through it, they understand. Other people think they do and they try to be helpful, but unless they have been there they don’t understand.

There are a lot of times when you don’t have to explain everything, because they know what you’re talking about. So that’s comforting.

I can say something and it’s understood because other people have gone through similar emotions. They totally get it. I don’t have to try to explain or justify.
Although everybody feels differently about what they’ve been through or their situation, because some of them are positive and some of them are negative, but there’s understanding. Maybe you didn’t feel that way but you understood how you could feel that way, you really could.

**Fewer Expectations**

In addition to the lack of understanding from family and friends, nine of the participants (45%) related that they felt their loved ones were unable to tolerate the uncertainty and sadness about their situation. They reported that they felt pressure to be strong and stay positive around them.

Even though your husband is very supportive, he doesn’t understand. Your kids are very supportive, but they don’t understand. You can’t talk to them about it. I really felt like they thought it was something that you just get over. You get through it, you get over it, and that’s it.

I was a real basket case and I just needed somebody else to talk to because my family didn’t want to talk to me about it. They were just like, “Oh, she has the flu, she’ll be better tomorrow.” That kind
of thing. And I thought, "This might be my life, you know."

Maybe it's just denial that this can be life-threatening. Whereas, when you go to a support group, they feel the same way, "I might not be here tomorrow." And there are some in that support group that won't be there, that's the fact of it. There can be a lot of expectations, especially if the person is a strong person. I remember one gal sharing that, when she told her kids, all they could do was cry. And she was upset with that because she felt that they should be asking, "How are you feeling?" and "How are you doing with this, Mom?" She thought it was kind of a selfish reaction. I told her, "That's probably all they could do." I tried to encourage her that that was probably all they could give. Where, with the group, she's going to get the understanding, she's going to get the questions, "How are you doing with this?" about her. She doesn't have to be the strong one. You don't have to be there pretending, "I feel like I could crawl in a hole and never come out but I'm here making dinner."
It’s that inner feeling, that you have, that you’re vulnerable. You’re mortal, you’re not immortal. I think many women do so much, and their families count on them, and they think, “I might not be here” and “What’s going to happen?” My son was a sophomore in high school and, even though my husband is a wonderful person, I thought, “How is [my son] going to get to college?” “Who’s going to help him do that?” “I have to be here.” And I think that’s what a lot of women feel, that they have to be there for their family. You want to be strong for your family and that’s what the support group is for. I have a wonderful family and my friends are wonderful. However, I’ve noticed that they take my lead. If I’m having a bad day, they’re having a bad day. If I’m having a really good, day, they’re having a really good day. So it’s better to be positive. I don’t let them know about my aches and pains, otherwise they’d be as miserable as I am. They would hurt, because I hurt everyday. I don’t look sick. I try not to act sick. I try to be as normal as possible.
The participants reported a sense of relief in the support group that they didn’t perceive the expectations to portray themselves as strong and positive.

I let my guard completely down because I know that they’ve let theirs down. And they can understand. I cry with them. At home I don’t do that so much because everybody worries and they think, “What’s wrong with mom?” It overwhelsms me and makes me feel guilty for being sick. Whereas, I don’t feel that way at all in the group. I can come in and say, “I’ve just had a lousy day” and cry about it.

To tell people, “Well, you shouldn’t be angry,” ... I can’t imagine anybody going through this and not having some anger.

You just sit around and you let your hair down and you say what you feel. There’s not the feeling, “Oh, I don’t want to say anything, because then they’ll feel bad.” No.

You don’t have to pretend. You can cry, you can laugh, they understand. They know exactly what you’re saying. You don’t have to explain or defend the feelings.
Discussion of Taboos

In addition to the freedom of being able to express a full range of feelings at the support group, seven participants (35%) reported that it was also helpful to be able to discuss topics in the group that they were not able to discuss anywhere else.

It’s important to feel like you can say anything there. Because some of the things we’d say there, you wouldn’t normally say out in public. No one would ridicule you. No one would say, “Oh, you’re all wrong.

We were all looking at the real possibility of death. And I don’t know too many people in my everyday life that could do that, unless they’ve been a cancer survivor or been in an accident where they were on the brink of death or something. I don’t think I know of anybody who can share that intense and immense fear with you.

It’s a place where you can talk about, let’s say, breast reconstruction. You know, where can you talk about that and have anybody give any kind of input for you? It’s just so far removed from any kind of conversation in society. Even though people have
heard about chemotherapy, “It makes you sick” and “You lose your hair” and they can empathize with that, but still, where can you talk to somebody who’s been through it, and actually laugh about it?

Catharsis

Ten of the participants (50%) reported that the support group was a venue for airing and sorting through their feelings.

My surgeon said, “It’s cancer, let’s do it. Right now. We don’t want to wait.” And zip, zap, zoop, I found myself on my back on the operating table. Which is great, but it’s before you really have a chance to emotionally accept it.

People come in ready to divulge, wanting to be able to vent. The ones that I’ve been in, there’s never been a shortage of things to say. The group is a place where you can let it all out. We all understand.

It’s being able to say anything, or ask anything. Just that you can talk so much more openly and share.

Sometimes people just need to talk. They don’t even need you to say anything back. They just need to
talk because they have a lot to say. They have a lot of feelings and emotions going through them and they just want to talk about it. They don’t even want an opinion. Because once you get it out, you start to make sense of it.

Healing Humor

Nine of the participants (45%) reported that there was humor in their support groups and that it was one of the healing factors of the experience.

It’s amazing the amount of laughter you get with a group like that. I’ve heard some people say, “I don’t want to go to a group like that, everybody crying.” Well, if they needed to cry they did, but there was more laughter than tears.

I think laughing is very healing, being able to laugh at a common experience. But also mixed in with the seriousness of it, sharing things that are common, things you can connect with.

I have to say, the best thing about group, and it still is, we laugh so much. Over silly things. If you hadn’t been in the group and understood the concept of what’s going on, you would say, “How can they laugh about that?” You can find humor if you
look. And group made me realize that. It's not all death and gloom and doom. Even though some of the members are terminal, they're still laughing. I think humor is also a hugely important thing, to be able to find fun and laughter in the scariest situation is really helpful. And I found that in the one support group I went to. They all had funny stories. The first woman was older, I'd say early seventies. And they all tell how they found it. And she said, "Well, my husband and I were fooling around, and yes, at my age we still do!" And we all laughed. I mean, just that kind of stuff. That's important, laughing about it, laughing about having a hot flash with a wig on and how that feels. I had a gal say that her mother went through this. They were in the grocery line and her mother took the wig off and threw it on the floor and said, "I don't care. I'm just so tired of this stupid wig. I'd rather be bald." Everybody just cracked up. That was just so funny to think about when I was going through my treatment. Just to laugh about that
thought. Sometimes I was in the store and it was so hot and I thought about that.

Assistance

Information

Another of the most common themes, reported by fifteen of the participants (75%), was the sharing of information at support groups. Some of the women reported that they did not receive enough information about breast cancer and its treatment from their medical care.

I came right away after I’d had my surgery, because the doctor didn’t tell me anything. I had no information. They say, “Ask a question.” And you don’t know what question to ask if you’ve never had breast cancer.

I looked on the internet, and I found these different things. And I would go to the doctor and he would say, “Well, that doesn’t fit you, you’ve had a hysterectomy.” He would answer my questions, but I didn’t really know which questions to ask next. So, they helped me because they told me what treatments they were having, they told me how it was working for them, and they gave me ideas about
questions I could ask for myself that had to do with me.

Where I went, you were kind of left on your own to figure out whether you wanted a lumpectomy, a mastectomy, what was going on. So, I went online a lot but also I had her as a resource to ask questions. Somebody that had been through it, understood, could give me her input. She understood exactly what I was going through.

The doctors now-a-days do not really talk to you or give you any counseling at all about anything. I wasn’t even given a booklet about it. And they said he should have given me a booklet. And so I knew nothing. I was really at a loss. So, I was very grateful about the support group.

I just wanted to be able to say, “My mouth hurts, can someone tell me why?” without calling the doctor’s office and getting put on hold, and you know, “We’ll get back to you.”

The support group was a place where members could talk to others about the breast cancer experience from the patient’s perspective and learn from them.
You have questions in your mind and you don’t always have the opportunity to ask a doctor and maybe they wouldn’t come at it from the same perspective. So you have a place where you can say, like when I decided that I wanted to start reconstruction, that’s a whole other – you know, clinically they can say blah, blah, blah, but here’s a place where you can ask, “Why did you choose what you chose?” and “What are the up sides?” and “What are the down sides?” from somebody who has lived through it, not just somebody who has performed the procedure. That’s important.

With the shock of being diagnosed that week, I was dying to get information about breast cancer and talk to other people who were going through it who had survived it. I was yearning for information, it was such a shock and all new to me. I got the diagnosis and it was like, “I have breast cancer.” And then you have to find a surgeon and you start that road. It was a matter of, “What do I do next?” I knew what I had to do but it was overwhelming.
I went with a specific goal. I wanted to know what the continuing treatment was for the ladies in the support group. And when I went, that’s what I said, “I’m having a mastectomy. I want to know what you all had to do, what medicine you take, what the continuing treatment is after the surgery.”
I asked everyone, “Did you have radiation?” And it’s helpful to hear that they did generally get radiation after the chemo, because it’s a reinforcement that the treatment that you’re getting is okay.
You will find answers here to your questions at the group that you won’t find anywhere else.

Resources
Six of the participants (30%) found it valuable that there were other members of the support group who were willing to lend a hand.
I know that in our group, I don’t know about all the others, but we bring in hats and wigs that have been used but are no longer needed. A lot of times they get given to the American Cancer Society, Look Good, Feel Better [Program], but we do have them for awhile so that they know that they can get a supply
of those things without having to go look for the wigs and hat.
I know this one lady came in and she had lost a lot of her hair and we said, “We have little hats. You can have one. And how about a wig?”
We pass out catalogs for wigs and hats and things like that for women who are losing their hair. We actually have a stash of wigs right here. At the last meeting there was a woman who was just starting chemo and she knew she was going to lose her hair and so we gave her all the wigs. She just took them with her and said she’d bring back the ones she wasn’t going to use so we’d have them for the next lady.
There was this one woman that was in our group. She had transportation problems just getting to her radiation. And the women all took turns, everybody took a day and we got her there. She didn’t miss one.
If I need a ride to the doctor, they’ll take me to the doctor. When I started this process, I didn’t know how I was going to get to the doctor sometimes because I didn’t want my husband to take a lot of
time off of work. They all say, “family first” until you become an inconvenience. And I was so scared about losing insurance. I drove myself to several things where they told me I had to have a driver and I just never said anything. I drove myself anyway. Until I started going to the support group and then there were people here that were more than willing to take me.

**Empowerment**

One of the benefits nine of the participants (45%) reported about their breast cancer support group experience was that it helped them to feel empowered.

I tell people, “You know you have a right to look at your chart.” People just don’t know that they have a right to get a copy of their pathology report or their scan. They just don’t know this. I love to tell people, to help them be informed… It empowers them. It helps them to realize that they are in charge of some things. I say, “Write a list of your questions so they’ll answer them.”

One thing I had never thought about until I went to the group, they all said, “Get all your records every time you go to the doctor.” And so I started
doing that. Well, when I went to New York for the summer, I had all my records. It’s overwhelming at the time. You’d rather have a straight “yes” or “no” answer, but that isn’t always the case. So, listening to other people’s situations and then considering them for your own situation, I think, is real important. It’s important to feel like you still have choices, you didn’t lose control over everything. Control is a really important issue with most of us.

Reciprocity

An important facet of the assistance offered by support groups is, not only the opportunity to be on the receiving end, but also the opportunity to be on the giving end. Twelve of the participants (60%) shared that giving back to others allowed them to make meaning out their breast cancer experience.

The support group has not only kept me abreast of what’s going on in the field, to my own benefit, but it has given me the opportunity to help other women, which to me, has been the most important part. That’s what gives it perspective for me.
Amazingly enough, I found it healing to help others. That was such an eye-opening experience. And even to this day, if I see somebody and I feel like they’re approachable, I will approach them. I tell them, “You can do this, you can survive it.” That has been such a wonderful, eye-opening discovery.

To me, it’s more giving than receiving. Even though you definitely receive, it’s the ability to give that’s healing.

It made me feel better because, in turn, the ones who came in after me and hadn’t gone through it yet, I could give something back.

I think giving back is so important. Giving back, comforting those with the comfort that you’ve been given, and the support that you can give to another person, going outside yourself. That’s so important. Helping others is more helpful to me as I go on this journey after having the breast cancer. It helps me as much as it helps the people that I talk to.

It’s healing for me, too. The ladies will give you a hug and say, “Oh, you’ve done so much for me.” And I’ll say, “And you’ve done a lot for me, too.”
I get joy out of being able to help somebody, when someone’s going through diagnosis. In my case, if they are very afraid of chemotherapy or losing their hair, I can share with them that I felt the same way.

I’ve done very well and I wouldn’t have believed, in the beginning, that I would have even survived. That’s a lot. It’s great to be there for somebody else who comes and is scared. You can say, “Well, we lived and there’s hope. “I like that part. They see that you have made it. And you start talking. And you just see them taking deep breaths and thinking, “Well, it’s not that bad.” It makes me feel purposeful. It gives my life meaning. It feeds me equally as much as it feeds the person that I’m helping.

Summary

The responses reported in this chapter were obtained from twenty face-to-face interviews of women who had attended breast cancer support groups. Digital recordings were transcribed and analyzed for thematic content. The responses showed some common themes that are factors of
breast cancer support groups the participants value. The salutary aspects of breast cancer support groups were studied in order to develop a clearer understanding, from the participants' perspective, of the components that facilitate a quality experience of support.
CHAPTER FIVE

DISCUSSION

Introduction

After analyzing the responses of the participants involved in this study, three sets of broad thematic categories were developed to report the sixteen common themes that emerged. The first category, association, included the emergent themes of connection, commonality, hope, perspective, ability to cope, and sustenance. The second category, emotional support, included the themes of acceptance, understanding, fewer expectations, catharsis, discussion of taboos, and healing humor. The third category, assistance, included the themes of information, resources, empowerment, and reciprocity.

Discussion

Association with other support group members gave participants a sense of connection, a feeling of commonality, hope, perspective on their situation, an increased ability to cope, and sustenance to help them deal with their illness between support group meetings.
Connection

Participants in this study reported that connecting with other support group members helped them to not feel so alone. This supports research which shows that participation in a group alleviates a sense of loneliness, provides a sense of belonging (Adamsen & Rasmussen, 2001, p. 914), and that members gain a group identity and cohesiveness that is curative in nature (Yalom, 1985, pp. 36-40). According to Steinberg, it is important for group members to feel connected to a common purpose (2004, p. 20). The strength in numbers dynamic says that group members, who may have felt powerless and alone, gain courage and strength from the bond they feel with other group members (Sellars, 1995, p. 139) and Shulman notes that “one’s own courage is strengthened by the courage of others” (as quoted by Steinberg, 2004, p. 4). The strengths perspective also asserts that membership, or a sense of belonging, is therapeutic (Saleeby, 1997, p. 9). Spiegel and Diamond note that the cancer experience, “the very thing that hampers other social relationships is, in fact, the ticket of admission” to the camaraderie of the self-help group (2001, p. 219).
Commonality

Connecting with others helped participants to realize that they shared similar issues with the other support group members. This supports Yalom’s theory that the dialectic process helps group members to explore other’s beliefs and to find common denominators in other members’ viewpoints. He refers to this curative factor as “universality” (1985, pp. 10-11).

Hope

Participants reported that it was helpful for them to meet other women who were further along in their breast cancer diagnosis and seemed to be doing well. This supports Yalom’s curative factor, the “instillation of hope.” Yalom asserts that it is important for support groups to have members at varying stages of recovery so that new participants can observe the improvement of others (1985, p. 9).

Perspective

Some of the participants reported that it was valuable to be able to compare their situation with others in the group, even those whose prognosis was not good. This supports the social comparison model which suggests that it is helpful for breast cancer patients to
compare themselves to other breast cancer patients in evaluating their emotional responses (Wood, Taylor, & Lichtman, 1985, p. 1179). There were a few participants, however, who found that exposure to other members whose prognosis was not good was not helpful, especially at their first support group meeting.

**Ability to Cope**

Participants reported that talking with others about the effects of their treatment helped to prepare them for their own treatment. This supports Steinberg’s theory that the “purposeful use of self,” in which group members share personal stories in order to self-reflect and to be helpful to others, is an important way to utilize the resources of a support group (2004). Yalom refers to this curative factor of groups as “interpersonal learning” (1985, pp. 16-35).

**Sustenance**

Several participants commented on the encouragement they received from the support group that sustained them between group meetings. A few of the participants also reported that they had continued contact with group members outside of the meetings. One of the salutary effects of the support group may be that it offers
prospects for ongoing relationships of support that continue beyond the support group.

The emotional support that participants described included a feeling of acceptance, understanding, fewer expectations, and the opportunity in a support group for catharsis, discussion of taboo topics, and healing humor.

Acceptance

Participants reported that friends and family avoided them and seemed uneasy around them. This supports research in which breast cancer patients report that their family and friends often avoid them (Peters-Golden, 1982), refrain from discussing the topic of cancer, and fail to express empathy (Dakof & Taylor, 1990; Wortman & Dunkel-Schetter, 1987).

The participants in this study reported that, unlike the reactions of some of their friends and family, they felt an acceptance from the other support group members.

Understanding

Participants reported that they found a deeper level of understanding from other support group members than some of their friends and family were able to give.

In several studies, breast cancer patients assert that the attempts of significant others to be supportive
are often inappropriate because of a tendency to minimize the negative and an overly cheerful manner or false cheerfulness (Dakof & Taylor, 1990; Wortman & Dunkel-Schetter, 1987).

Researchers theorize that inappropriate comments from friends and family serve to further isolate the breast cancer patient with her fear and that, when this happens, the relationships can be sources of distress rather than support for the person with cancer (Dakof & Taylor, 1990; Wortman & Dunkel-Schetter, 1987; Peters-Golden, 1982).

Fewer Expectations

Several participants related that they felt an expectation from some of their friends and family members to be strong and have a positive attitude. One researcher observes that there is a "rah-rah-sis-boom-bah, I can beat the odds" tyranny of positive thinking that others place on cancer patients (Holland & Lewis, 2001, p. 16).

Catharsis

Half of the participants commented on the value of being able to talk openly about their feelings in the support group. This supports Yalom’s curative factor of ventilation in which group members are able to express
themselves freely in the group. Yalom also notes that "members who have expressed and worked through the mutual expression of strong feelings will develop more cohesive bonds" (1985, pp. 72).

Discussion of Taboos

A few of the members noted that the group provided them the opportunity to talk about topics that they would not be able to talk about outside the support group setting. This lends support to the strengths perspective which maintains that the members of the group are rich resources for the group. In order to harness the strengths of other group members, Steinberg asserts that it is important for participants to begin by engaging in a dialectic process, including the discussion of taboo topics. Steinberg also notes that "taboo issues are what often bring people to a group in the first place" (2004, p. 41).

Healing Humor

Participants found that humor in the support groups helped them to cope and inspired an esprit de corps. A few of them also commented that humor provided a balance to the seriousness of the cancer experience.
The broad thematic category of assistance includes the themes of information sharing, the allocation of resources, empowering processes, and the opportunity for reciprocity in the support groups.

Information

One of the most common themes brought up by participants was the sharing of information between group members. This coincides with the strengths perspective which holds that group members bring knowledge to the group that is a resource for other members (Steinberg, 2004, p. 36). Yalom also theorizes that this “imparting of information” is an important curative factor of groups, adding that “often it functions as the initial binding force in the group until other curative factors become operative” (1985, p. 7).

Resources

Six of the participants in this study noted that support groups can help in concrete ways, as well. The meetings are places to pass out informational booklets, hats, scarves, wigs, and other donated items. Two participants, from different support groups, also mentioned that group members helped each other with transportation to their medical appointments.
Empowerment

A few participants commented on the loss of control that cancer patients feel, adding that being encouraged by other group members to make choices and advocate for themselves in their medical care gave them a sense of control. Researchers have noted that many breast cancer patients feel oppressed by both the disease and by the medical experience, often describing a perceived loss of power. Cederberg and colleagues fault the health-care system for “sometimes being insensitive and unkind to women with breast cancer” noting that “the system makes you constantly struggle to maintain a leadership role. It is not a consumer-based business” (Cederberg, Davidson, Edwards, Hebestreit, Lambert, Langer et al., 1994, p. 200).

Researchers theorize that one of the salutary effects of self-help groups is that they help participants to feel empowered (Humphreys & Rappaport, 1994, p. 228; Borkman, 1990, p. 329). Saleeby stresses the importance of empowerment, the purpose of which is to help people find and use both internal and external tools and resources to gain some control in their lives. He notes that “the whole group is strengthened by this
process, strengthened by the need to reach for and use whatever skills it has to help a member face a special challenge" (Saleeby, 1997, p. 51). Zebrack also reports that when individuals advocate for others, they often find it to be an empowering experience for themselves as well (2001, p. 285).

**Reciprocity**

Participants reported that they initially came into the group seeking help and after awhile shifted to focus more on helping others. Steinberg calls the mutual support dynamic a group's "primary value" (2004, p. 44). Mutual support is the group's capacity to provide empathy and comfort to its members. This is similar to Yalom's curative factor "altruism" (1985, p. 11-12) and Reissman's "helper therapy" principle (Reissman, 1982, p. 42). Yoak and Chesler stress that "the possibility of assisting someone else, of 'giving back to others the help I received,' reflects a reciprocal and mutually empowering helping relationship" (1985, p. 432).

Yalom describes "existential factors" of a group, in which members develop a sense of meaning to life, as one of the curative factors (1985, p. 69). Taylor, in his theory of cognitive adaptation, points to "validation of
experience" in the search for the meaning of the cancer experience as a method of cognitive adaptation to threatening events (1983, p. 1169). Several of the participants reported that extracting from their experience and using it to help others has given meaning to their own lives.

Limitations

There are important limitations of the study that affect its generalizability to larger populations. The purposive sampling may have resulted in the selection of participants that do not capture the diversity of breast cancer patients. The sample size was small and all but one of the participants were Caucasian. Because participants were recruited from preformed groups, both the external and internal validity of the study were affected. The support groups selected for this study may have attracted populations that differ from other support groups in the area and, because participants from the support groups self-selected to participate in the study, they may not be representative of the non-participating group members. Also, the needs of breast cancer patients who choose not to participate in support groups may be
different than those reported by the participants of this study.

Researchers note that cancer patients often feel pressure to have a positive attitude (Holland, 2001) and the possible impact of social desirability was another limitation of the study.

Recommendations for Social Work Practice, Policy and Research

Social workers should use the information from this study to gain a better understanding of the aspects of a breast cancer support group that facilitate a quality experience of support. Based on the interviews in this study, factors to consider when offering a support group to breast cancer patients include those of association, emotional support, and assistance.

Association factors that should be fostered include a connection with others in a similar situation, commonality of experience, the instillation of hope from others who are improving, perspective to be gained from comparison, the ability to cope from being prepared, and sustenance to help members after they leave the meeting. As support group facilitators, social workers can cultivate these factors of association by forging
connections between group members, initiating discussion that stimulates the emergence of common themes, inviting long term survivors to attend the group, promoting the recounting of members' treatment experiences, and encouraging members to network with each other outside of the group for additional support.

Emotional support factors that should be emphasized include acceptance, understanding, fewer expectations in terms of strength and a positive attitude, catharsis, the opportunity to discuss taboo topics, and humor. Group facilitators can nurture emotional support in breast cancer support groups by creating a safe atmosphere for participation and by encouraging the expression of feelings and nonjudgmental acceptance among group members.

Assistance factors that should be made available to support group participants include the sharing of information, material resources, empowerment through self-advocacy and choices, and reciprocity between members. These elements of assistance can be provided in the group setting or as an adjuvant to the support group. The agency, group facilitator, or group members can procure and disperse educational materials and supplies.
The group facilitator can highlight aspects of the breast cancer experience in which patients have choices, and can promote members' encouragement and assistance of each other.

Conclusion

The participants in this study made clear the association, emotional support, and assistance factors of breast cancer support groups that they found to be valuable.

The most important conclusion from this study is that the breast cancer support group setting can offer factors that contribute to its salutary effects. The results of this study will enable agencies and professionals serving breast cancer patients to determine the extent to which their support groups meet participants' needs and to make changes that could benefit future participants.
APPENDIX A

INTERVIEW GUIDE
INTERVIEW GUIDE

1) What were you hoping to find at a support group?

2) What have you found helpful from the support group?

3) What have you found to be unhelpful from the support group?

4) How has your participation in the support group been beneficial to your life?

5) In what ways have you not benefited by attending the support group?

6) What do you think are the most important aspects of a breast cancer group?

7) What do you think are the least important aspects of a breast cancer group?

8) If you could change anything about your support group, what would that be?
APPENDIX B

DEMOGRAPHIC QUESTIONNAIRE
Demographic Questionnaire

Age_________

Marital Status:
___ Single
___ Married
___ Separated
___ Divorced
___ Widowed
___ Other

Ethnicity:
___ African American
___ Native American
___ Caucasian
___ Asian
___ Pacific Islander
___ Latino Hispanic
___ Other

Education Level:
___ Less than High School
___ High School Graduate
___ Some College
___ Bachelor’s Degree
___ Graduate Degree
___ Other

Employment:
___ Currently unemployed
___ Currently employed part-time
___ Currently employed full-time
___ Other

How long ago were you initially diagnosed with breast cancer?
___ years ___ months

What types of treatment have you undergone?
___ lumpectomy
___ mastectomy
___ chemotherapy
___ radiation therapy
___ other medication/treatment
APPENDIX C

FLYER
Volunteers Needed

Volunteers are needed to participate in a 20-30 minute interview exploring their views about breast cancer support groups. Participants must be breast cancer survivors and at least 18 years of age.

This study is being conducted by Renee Jarvis, a graduate student at California State University, San Bernardino.

Please call Renee at (909)754-9921 to schedule an interview time.

Participants will receive a pink ribbon pin.
APPENDIX D

INFORMED CONSENT
The study in which you are being asked to participate is designed to explore the factors breast cancer patients view as valuable in support groups. This study is being conducted by Renee Jarvis under the supervision of Dr. Rosemary McCaslin, Professor of Social Work. This study has been approved by the Department of Social Work Sub-Committee of the Institutional Review Board, California State University, San Bernardino.

In this study, you will be interviewed regarding your views of breast cancer support groups. The interview should take about 20 to 30 minutes to complete. With your permission, the interview will be audiotaped. All of your responses will be held in the strictest of confidence by the researcher. Your name will not be reported with your responses. All data will be reported in group form only. After the research is completed, the audiotapes will be destroyed. You may receive the group results of this study upon its completion after September 2007 at the following location: John M. Pfau Library, California State University, San Bernardino.

Your participation in this study is totally voluntary. You are free not to answer any questions and to withdraw at any time during this study without penalty. When you have completed the interview, you will receive a debriefing statement describing the study in more detail. Whether or not you decide to finish the interview, you will receive a pink ribbon pin. In order to ensure the validity of the study, we ask that you not discuss this study with other participants.

If you have any questions or concerns about this study, please feel free to call Dr. Rosemary McCaslin at (909) 537-5507. Send correspondence to: Dr. Rosemary McCaslin, California State University, San Bernardino, Department of Social Work, 5500 University Parkway, San Bernardino, California 92407.

By placing a check mark in the box below, I acknowledge that I have been informed of and that I understand the nature and purpose of this study, and I freely consent to participate. I also acknowledge that I am at least 18 years of age.

Place a check mark here □ Today's Date _________

By placing a check mark in the box below, I agree to be audiotaped.

Place a check mark here □ Today's Date _________
APPENDIX E

DEBRIEFING STATEMENT
DEBRIEFING STATEMENT

You have participated in a study that solicited information on the factors participants value in breast cancer support groups. After participating in this study, you may want to further discuss with your support group what we talked about during this interview.

This study was conducted by Renee Jarvis, a graduate student at California State University, San Bernardino. Any concerns about this study may be addressed to Dr. Rosemary McCaslin, Project Advisor, at (909) 537-5507. It is hoped that this study will allow agencies to develop a clearer understanding of the components of a support group that facilitate a quality experience of support. You may view a copy of the study results in the John F. Pfau Library at California State University, San Bernardino after September 2007.
REFERENCES


