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LOMA LINDA UNIVERSITY
School of Behavioral Health
in conjunction with the
Faculty of Graduate Studies

Breast Cancer Patients' Perspectives on the
Helpfulness of Supportive Offerings

by

Renee Lauren Jarvis

A Dissertation submitted in partial satisfaction of
the requirements for the degree
Doctor of Philosophy in Social Policy & Social Research

September 2015

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Each person whose signature appears below certifies that this dissertation in his/her opinion is adequate, in scope and quality, as a dissertation for the degree Doctor of Philosophy.

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CONTENT

Approval Page.....	iii
Acknowledgements.....	iv
List of Figures.....	ix
Abstract.....	x
Chapter	
1. Introduction.....	1
Statement of the Problem.....	2
Background and Existing Research.....	3
Definition of Terms & Concepts.....	4
Purpose of the Study.....	4
2. Literature Review.....	6
Worldviews and Paradigms Guiding Conceptualization.....	6
Ontological/Epistemological Perspectives.....	7
Cultural Milieu of the Breast Cancer Experience.....	8
Philosophical Influences on the Research Design.....	10
Existing Research on Social Support for Breast Cancer Patients.....	11
Social Support and Emotional Adjustment.....	12
Measurement of Social Support.....	13
Negative Responses.....	15
Quantitative Studies.....	16
Qualitative Studies.....	16
Ineffectual Supportive Offerings.....	18
Fear/Lack of Skills.....	19
Supportive Mismatch.....	21
Contextual Factors.....	23
Underlying Message of Blame.....	24
Underlying Message to Think Positive.....	28
Constraints to Emotional Expression.....	35
Helpful Support.....	39

Chapter Summary	41
3. Methods.....	43
Study Design.....	43
Sampling Procedures and Recruitment.....	45
Data Collection	46
Procedures.....	49
Risk, Injury, and Protections for Vulnerable Populations	53
Data Analysis	54
Domain Analysis.....	55
Taxonomic Analysis	57
Componential Analysis.....	58
Theme Analysis	59
Techniques to Ensure Rigor.....	59
Chapter Summary	66
4. Results.....	67
Purpose of the Research.....	68
Findings.....	68
Taxonomy of Unhelpful Support	69
Theme #1: Alienation	70
Transitioning to the Identity of a Cancer Patient	70
Cultural Expectations of the “Right Way” to Do Cancer	71
Non-Materialization of Expected Support	72
Speculation Regarding the Cause of the Cancer.....	73
Theme #2: Dismissal/Nonchalance.....	74
Insensitivity.....	74
Downplaying the Seriousness of the Illness	75
Comparison of Illnesses	75
“Looking Great” Observation	76
Negative Stories	77
The Use of Platitudes	77
Theme #3: Unsolicited Advice	78
Advice on Preventing the Recurrence of Cancer.....	78

Lifestyle Changes/Treatment	78
The Curative Effects of Positive Thinking	79
Advice on Coping with Cancer.....	80
Don't Worry/Look on the Bright Side	80
Inspirational Stories	81
Spirituality/Religion.....	82
Be Brave/Strong.....	83
Theme #4: Constraints	84
Obligation to Comfort Others	84
Screening Who You Tell	85
Censoring What You Say.....	86
Theme #5: Pressure for a Positive Outcome.....	87
Get Over It	87
Return to Normal	88
Find a Silver Lining	89
Taxonomy of Helpful Support.....	90
Theme #6: Demonstration of Caring	90
Calls, Cards, Gifts.....	90
Meals/Assistance.....	91
Theme #7: Management of Feelings.....	92
Distraction.....	92
Listening	93
Validation of Feelings.....	94
Chapter Summary	95
5. Conclusion	97
Limitations	97
Discussion.....	98
Measurement of Support.....	100
Context with Previous Research on Unhelpful Support	101
Theme #1: Alienation	101
Theme #2: Dismissal/Nonchalance.....	102
Theme #3: Unsolicited Advice	103

Theme #4: Constraints	104
Theme #5: Pressure for a Positive Outcome.....	104
Context with Previous Research on Helpful Support	105
Theme #6: Demonstration of Caring	105
Theme #7: Management of Feelings.....	105
Recommendations and Implications	106
Recommendations for Future Research	107
Recommendations for Social Policy	109
Implications for Support Providers.....	113
Implications for Clinical Interventions	115
Chapter Summary	116
References.....	117
Appendices	
A. Letter of Support for Interviews	133
B. Letter of Support For Focus Groups	135
C. Interview Recruitment Flyer	137
D. Focus Group Recruitment Flyer.....	139
E. Phone Script for Use with Respondents to Interview Flyer.....	141
F. Phone Script for Use with Respondents to Focus Group Flyer	143
G. Interview Informed Consent Document.....	145
H. Focus Group Informed Consent Document	149
I. Interview Guide	153
J. Demographic Survey	155

FIGURES

Figures	Page
1. Taxonomy #1: Unhelpful Supportive Offerings	60
2. Taxonomy #2: Helpful Supportive Offerings	61
3. Cultural Theme: The Helpfulness of Supportive Offerings.....	62

ABSTRACT OF THE DISSERTATION

Breast Cancer Patients' Perspectives on the Helpfulness of Supportive Offerings

by

Renee Lauren Jarvis

Doctor of Philosophy, Graduate Program in Social Policy & Social Research

Loma Linda University, September 2015

Dr. Jason E. Owen, Chairperson

Research suggests that breast cancer patients seek and benefit from social support that they view as helpful. Previous qualitative studies have explored overtly negative behaviors by family and friends in some depth. Several quantitative studies have explored how support that is viewed as unhelpful constrains, hinders coping, and causes distress to breast cancer patients. The current study differs from previous studies in that it provides an exploration of the perceived helpfulness of support provision that is well-intended.

This study employed a phenomenological approach based on the interpretivist lifeworld perspective. It was conceptualized within the postmodern paradigm which draws from the works of Durkheim and Foucault and emphasizes cultural influences on social phenomena. Ethnography was used as the research method because it is ideal for bringing to light the experiences of social support as perceived by breast cancer patients.

Data collection and analysis was guided by Spradley's (1979) Developmental Research Sequence. Analysis of 20 individual interviews, 2 focus groups, and 20 published writings by breast cancer patients identified 7 main themes that provide an in-depth understanding of the helpfulness of supportive offerings from their perspectives. The results indicate supportive offerings that demonstrate caring and facilitate the management of feelings are helpful. Supportive offerings that alienate, are nonchalant or

dismissive, provide unsolicited advice, are perceived as constraining, or pressure recipients into providing a positive outcome to their experience are perceived as unhelpful.

The findings from this study provide a deeper understanding of the factors that contribute to the salutary effects of support provision. It is expected that these findings will enable support providers, clinicians, and health care practitioners and agencies to determine the extent to which their supportive offerings meet the needs of this target population and to make changes that could benefit future breast cancer patients.

CHAPTER ONE

INTRODUCTION

In the 1950s, two acquaintances, Fanny Rosenow and Terese Lasser, discovered that they were undergoing mastectomies for breast cancer at about the same time (Holland & Lewis, 2001). Afterward, they commiserated with each other and found it to be quite helpful. Because most mastectomy patients at that time were discouraged from openly sharing their feelings with others, the two women decided to create a support system for breast cancer patients to be able to talk to each other about their experiences. As socially prominent New Yorkers, they decided to place an ad in the New York Times for a women's meeting to be held on the subject of breast cancer. The editor responded that, not only would the newspaper not publish the word "breast" - but it would not publish the word "cancer" either. (Holland & Lewis, 2001, pp. 8-9).

It was an era when cancer was a whispered-about disease that was suffered in silence, a painful aspect of social life which was not to be mentioned publicly. With dogged persistence, however, Rosenow and Lasser went on to successfully develop the Reach to Recovery program and, in 1969, the program was incorporated by the American Cancer Society (Holland & Lewis, 2001). By 1974, half of all mastectomy patients nationwide had reportedly received a visit from a Reach to Recovery volunteer (Lerner & Berrie, 2001, p. 144).

Fast forward to 1993, when photographer, Joanne Matuschka, proudly bared her post-mastectomy chest on the cover of the Sunday magazine section of the New York Times (Ferraro, 1993). Times had changed. And the New York Times, in turn, had changed. The photograph was picked up by the Associated Press and was featured in

newspapers worldwide. It generated 12 awards, including a Pulitzer Prize nomination, and it was included in a Life Magazine special edition entitled *100 Photographs That Changed the World* (“Beauty out of damage,” 2011).

Statement of the Problem

The two stories, outlined above, illustrate the influence that societal context has on the experience of illness. Breast cancer patients have led the way in breaking cultural silence about the disease over the past several decades. The topic of breast cancer is now everywhere in our culture: in books, magazine articles, movies, television, and on the internet. Increased public discourse on the topic has had positive benefits in terms of focusing attention on advances in treatment, emphasizing women’s participation in decision-making, and giving breast cancer patients the opportunity to share their experiences with others.

It has also sparked a cultural reconceptualization of how breast cancer should be experienced. In mainstream media, the cancer equals death perspective has given way to the notion that one can overcome and survive breast cancer. In a meta-study of qualitative research, Thorne and Paterson (1998) observe that researchers of serious and chronic illness have changed from a focus on “loss, burden, stigma and disruption” in studies from the 1970s to language of “courage, transformation, wellness and resilience” in the 1990s (p. 175) While this new emphasis can be reassuring to breast cancer patients, it may constrain their expression of negative emotions (Lepore, Silver, Wortman, & Wayment, 1996; Zakowski et al., 2003).

Background and Existing Research

Although an expansive body of research suggests that individuals who experience stressful life events benefit from social support, the evidence for a positive association between social support and well-being among breast cancer patients is equivocal (Cicero, Lo Coco, Gullo, & Lo Verso, 2009; Lepore, Glaser, & Roberts, 2008). The giving and receiving of social support is a complex process. It is important to note that the provision of support and the perception of support by the receiver are relatively independent constructs that are not highly related to each other (Haber, Cohen, Lucas & Baltes, 2007). The current study proposes that the crucial factor in support is not the dosage provided, but the helpfulness of such support. The quality of social support, however, is seldom assessed (Arora, Finney Rutten, Gustafson, Moser, & Hawkins, 2007).

Two hallmark qualitative studies by Dunkel-Schetter (1984) and Peters-Golden (1982) examined social interactions viewed as helpful or unhelpful from breast cancer patients' perspectives. In a subsequent study, researchers found some differences in the perceived helpfulness and unhelpfulness of social support depending on who the support providers were (Dakof & Taylor, 1990). For example, breast cancer patients perceived advice, optimism, and the provision of information to be more helpful when it came from another cancer survivor than from family or friends (Dakof & Taylor, 1990, p. 84). Further qualitative research regarding the experience of social support as perceived by breast cancer patients, however, has been limited since these studies. Because the social and cultural context of the breast cancer experience has changed significantly in the decades following these studies, the current study seeks to reexamine both the positive

and negative aspects of social support in light of a dramatic shift in societal attitudes toward cancer.

Definition of Terms and Concepts

This section includes a discussion of the key concepts to be used in this study. These concepts serve to provide a context for the current research project and are defined according to their application to this study.

Social support: Social support is generally defined as the provision of emotional, informational, or instrumental resources in response to acute or chronic stressful experiences (Cohen, Gottlieb, & Underwood, 2000, p. 4).

Social constraints (Lepore et al., 1996) or social barriers (Zakowski et al., 2003): These terms will be used interchangeably. For the purpose of this study, social constraints are defined as perceived inadequacy of social support resulting in a reluctance to express thoughts and feelings about a specific stressor (Herzer, Zakowski, Flanigan, & Johnson, 2006).

Illness narratives, pathographies or autopathographies (Frank, 1995; Zakowski et al., 2003): In this study, these terms refer to autobiographical accounts of illness.

Purpose of the Study

The purpose of this ethnographic study was to produce a detailed description of the experience of social support from the perspective of breast cancer patients. The overarching question is: What are participants' perceptions regarding the helpfulness and unhelpfulness of supportive offerings? A greater understanding of the aspects of support

that breast cancer patients consider to be helpful and unhelpful will inform both informal and formal providers, enabling them to optimize the salutary nature of their supportive offerings.

CHAPTER TWO

LITERATURE REVIEW

The majority of literature on social support for breast cancer patients views supportive behaviors as universally helpful. Few studies have examined social support qualitatively from the participants' perspectives. This chapter begins by outlining the assumptions, principles, and theories that underpin the current study. It then examines existing studies regarding the quality of social support and researchers' theories about why certain supportive actions are viewed as ineffectual or unwanted by breast cancer patients.

The research reviewed later in this section reveals that, although breast cancer patients seek social support, the benefits of received support are unclear. Studies in which breast cancer patients subjectively self-report satisfaction with their social support show a strong association with psychosocial well-being, whereas studies using quantitative instruments to measure their social support have produced mixed results. This study proposes that current quantitative measures may not effectively tap into the adequacy of support from the perspective of breast cancer patients. Research on this topic underlines the need for the subjective input from a qualitative study to illuminate which supportive actions may be better at providing a quality experience of support for breast cancer patients.

Worldviews and Paradigms Guiding Conceptualization

The theoretical framework for this study is fitting for a qualitative study which

seeks to illuminate the salutary aspects of social support. This section begins by describing the ontological perspective, the epistemological approach, and the theories through which this research is conceptualized. It then explores cultural and philosophical influences on the research design for this study.

Ontological/Epistemological Perspectives

An important ontological assumption providing the foundation for this study is interpretivism which emphasizes the subjective elements in social experience. In line with the aims of this study, interpretivists seek to understand, rather than to predict social phenomena (Lather, 2006). The interpretivist approach contends that people do not react mechanically, like matter, to external stimulus and so it is a more appropriate lens through which to view social phenomena. Social actions are based on, and in many ways confined by, the meanings people attribute to stimuli. Further, these meanings are not static. Through social interaction, they are developed and changed (Erikson, 1986). The emic perspective provided by an interpretivist ontology often contrasts with the etic perspective of other frameworks and, for those dealing with a serious illness, Goodley (2010) points out that, “interpretivism gives voice to those who are often spoken of” (p. 55). Research from this ontological approach provides a more thorough understanding of the breast cancer experience.

The current study was conceptualized within a phenomenological epistemology which is a mode of knowing that focuses on understanding a certain life event through the descriptions of those who experience it. Phenomenological theory asserts that there are multiple realities explaining the way the world works and that the goal is to unveil the

world as experienced by individuals or groups through their life world stories (Heidegger, 1976).

This research draws on the concepts of Durkheim (1933) regarding the notion that the experience of illness is shaped by social processes and that social relationships can be important during the illness experience. Durkheim was a French sociologist who was interested in social ties. He developed the concept of “social solidarity” to refer to the social cohesion that binds individuals together. He theorized that there are two types of social solidarity based on shared beliefs and sentiments (mechanical solidarity) or mutual dependence (organic solidarity) (Durkheim, 1933). Ahmed (2004) explains that: “Solidarity does not assume that our struggles are the same struggles, or that our pain is the same pain, or that our hope is for the same future. Solidarity involves commitment and work, as well as the recognition that even if we do not have the same feelings, or the same lives, or the same bodies, we do live on common ground” (p. 189). The main contention of this study is consistent with Durkheim’s theories on social solidarity, namely that social networks can play a role in the provision of emotional support for those with serious illness (Durkheim, 2001[1912]).

Cultural Milieu of the Breast Cancer Experience

Postmodern thought also has implications for this research because it considers the ways in which social dynamics affect the construction and use of knowledge. Postmodernism draws on some of the concepts of French philosopher, Foucault. Foucault (1998) explored the fluidity and multi-faceted nature of knowledge and proposed that diseases are not just natural events that occur independently, but that the discourses

which reflect the dominant mode of thinking in society both describe and create the disease experience. From this perspective, an illness cannot be understood apart from its social construction. Cultural discourses play a key role in shaping the meaning-making, discussion of, and response to breast cancer. It is important to recognize the way that current social forces have influenced our reactions to illness and to allow breast cancer patients to construct different discourses, from their frame of reference (Turner, 1995).

In his book, *The Illness Narratives: Suffering, Healing and the Human Condition*, Harvard psychiatrist and anthropologist, Kleinman (1988) asserts that the illness experience is culturally shaped and that society has expectations regarding what is appropriately discussed (p. 5). Ehrenreich (2001, 2009), a sociologist and breast cancer survivor, attests that the breast cancer experience does not occur in a vacuum. In her award-winning essay, *Welcome to Cancerland* (2001) and in a subsequent book chapter entitled “Smile or Die” (2009), she describes how cultural and social expectations affect the experience of breast cancer, especially in American culture where individual responsibility for illness is stressed.

Kroll-Smith (2003) notes that the print and broadcast media abound with stories about people triumphing over serious illnesses and that these stories shape the model of how illness should be experienced. Medical sociologist and cancer survivor, Frank (1995), adds that the emphasis is on the sufferer to solve the puzzle of illness (p. 80). The effect of these cultural expectations can add to the stress with which the breast cancer patient must cope.

Philosophical Influences on Research Design

Foucault's (1980) emphasis on actively seeking "subjugated knowledges" or "le savoir des gens" (popular knowledge) provides the basis for the investigation approach in this study. Subjugated knowledges are described as "local, discontinuous, disqualified, illegitimate knowledges" which contrast with the traditional divisions of knowledge that shape the lived experiences and behaviors of individuals in that society. He proposes investigation into these popular or disqualified knowledges in order to transform existing universal knowledge by opening up new possibilities for thought and action (Foucault, 1980, pp. 83-85).

Because ethnography views culture as "shared cognition" and it seeks to understand cultural ideologies, practices and attitudes from the perspective of the participant (Sprenkle & Moon, 1996), it fits with interpretivist, phenomenological, and postmodern aims of this study. It is a methodology particularly suited to providing an understanding of the breast cancer experience. Spradley (1979) notes that ethnographic research ideally uses more than one method to gather information. He outlines three basic sources: what people say/interviews; the way people act/observation; and artifacts/writings (Spradley, 1979, p. 8).

Frank (1995) observes that advances in medicine during postmodern times have enabled patients to survive serious illness and, subsequently, there has been a proliferation of cultural artifacts in the form of illness narratives (or pathographies) that explore illness from the patient's perspective (p. 7). The narrator often tells the illness story within a certain sociohistorical context, illuminating the interplay between the storyteller and his or her world, and informing us about the cultural assumptions which

permeate society (Frank, 1995).

Diedrich (2007) proposes that narratives from patients' perspectives are a form of Foucault's subjugated knowledges which can open up "a space for thinking, being, and doing otherwise in the present and future" (pp.1-2). In his book, *The Wounded Storyteller*, Frank (1995) also advocates for the patient's perspective as a counternarrative to social embeddedness. Sakalys (2000) points out that discourse analysis has focused on how groups with the least power tend to author writings as a means of articulating their own identity (p. 1470). Frank (1995) proposes that pathographies enable the author to "hold her own against forces that threaten to overpower her voice and her text" (pp. 4-5). Scholes (1985) proposes that the texts are "places where power and weakness become visible...where structures that enable and constrain our thoughts and actions become palpable" (p. xi). Murray (2006) asserts that, "Situating illness narratives within relations of power does not obviate their use as a way that selves take care of themselves. On the contrary, bringing Foucault to the study of illness narratives expands our sense of what these stories are and what they can do" (p. 345).

Ethnographic research using a phenomenological approach, based on an interpretivist perspective, and conceptualized within the postmodern paradigm, is proposed for this study. It will provide a rich, in-depth description of the phenomenon of social support as experienced by breast cancer patients, which is lacking in current research.

Existing Research on Social Support for Breast Cancer Patients

This section begins by exploring previous research on associations between social

support and emotional adjustment to the breast cancer experience. Next, it demonstrates some of the difficulties in the measurement of social support. Quantitative research on negative social support is reviewed. Finally, an exploration of the limited amount of qualitative research regarding unwanted support is conducted.

Social Support and Emotional Adjustment

Social support is viewed as an important resource for women coping with a breast cancer diagnosis. Social medicine pioneers, Cassel (1976) and Cobb (1976), argue that individuals with strong social ties are buffered from the harmful effects of stressful events. Other theorists have also posited that social support moderates the relationship between trauma and psychosocial distress (Berkman, Glass, Brisette & Seeman, 2000) and some studies show that individuals in close relationships tend to experience better adjustment to traumatic experiences (Hagedoorn, Sanderman, Bolks, Tuinstra, & Coyne, 2008).

Research shows that female cancer patients often turn to others for support in dealing with their emotional concerns (Figuerido, Fries & Ingram, 2004) and that they tend to reach out to a wider circle of friends and family than their male counterparts (Kiss & Merryn, 2001). The majority of callers to the National Cancer Institute's Cancer Information Service are women and 68% of the callers who are female cancer patients request support services, compared to 18.2% of the male cancer patients (Squiers, Finney Rutten, Treiman & Bright, 2005).

Breast cancer patients, in particular, reach out for emotional support more than other cancer patients. 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 et al., 2005).

Research regarding the beneficial effects of social support for breast cancer patients, however, is mixed. Although friends and family members are generally viewed as a major source of emotional support for cancer patients, the associations between social support and emotional adjustment to the breast cancer experience are complex. While some studies demonstrate a positive association between social support and emotional adjustment to cancer, other studies do not show that they are positively associated (Cicero et al., 2009; Lepore et al., 2008). One study of breast cancer patients showed a positive relationship between level of support and negative affect (Lepore et al., 2008) and Reynolds and Perrin (2004) found unwanted but received support actions to be associated with poor psychosocial adjustment.

Measurement of Social Support

Most studies of social support for cancer patients have measured the quantity of support received (Ganz et al., 2002; Helgeson, Cohen, Schulz, & Yasko, 2000; Martire, Stephens, Druley, & Wojno, 2002; Mellon & Northouse, 2001; Reynolds & Perrin, 2004). Breast cancer patients, however, report that not all behaviors intended by others to be supportive are helpful to them, highlighting the reality that intention does not always correspond to impact (Barker & Pistrang, 2002; Belcher et al., 2011; Dehle, Larsen, & Landers, 2001). Quantitative measures also treat different types of supportive

behaviors offered as equally beneficial to the recipient, assigning them equal point value, when some behaviors may be more helpful than others.

Research shows that breast cancer patients' perceptions of support are often different than the perceptions of the friends and family who provide the support and that it is the patients' perceptions that are associated with their psychological adjustment (Marlow, Cartmill, Ceiplusha, & Lowrie, 2003; Thoits, 2011). A growing body of research suggests that the subjective assessment of support is more important than the objective assessment (Marlow et al., 2003; Thoits, 2011). In these types of assessments, it is breast cancer patients who decide what kind of support they need and whether it is adequate. There are two main ways in which support is measured subjectively: in terms of the recipients' perceptions of support or in terms of their satisfaction with provided support.

Several studies report positive associations between breast cancer patients' perceptions that they are supported and their quality of life (Sammarco, 2001) and psychological well-being (Bloom, Stewart, Johnston, Banks & Fobair, 2001; Kayser & Sormanti, 2002; Marlow et al., 2003; Maly, Umezawa, Leake & Silliman, 2005). In both a cross-sectional and a longitudinal study, breast cancer patients' perceptions of their partners' emotional involvement and understanding of the cancer experience was associated with a decrease in emotional distress and increases in psychosocial adjustment and marital satisfaction (Wimberly, Carver, Laurenceau, Harris, & Antoni, 2005).

Satisfaction with provided social support has also been examined and found to be positively associated with psychological well-being. In a large study with 246 breast cancer patients, researchers found a positive relationship between subjects' satisfaction

with their social support and their health-related quality of life and self-efficacy (Arora et al., 2007). Other researchers have found a relationship between satisfaction with social support and well-being (Ozkan & Ogle, 2008) and decrease in stress (Turner-Cobb, Sephton, Koopman, Blade-Mortimer, & Spiegel, 2000). A qualitative study with focus groups of breast cancer patients underlined the importance of the perception of support and the degree of success in supportive attempts by others (Marlow et al., 2003).

While subjective measures may better tap into the experience of social support than do objective measures, neither inform us about what specific types of support are actually helpful to this particular population. The next section of the literature review focuses on research regarding the relationship between the provision of social support by others and breast cancer patients' emotional adjustment to breast cancer. Studies are reviewed in which participants describe negative responses from others in terms of the non-materialization of support they had anticipated or intentional behaviors that are viewed as insensitive or unsupportive. Next, studies are examined in which breast cancer patients describe supportive behaviors that are intended to be helpful, but are viewed by the recipients as ineffectual.

Negative Responses

Although breast cancer patients may benefit from open discussion of their experience, such disclosure of their thoughts and feelings sometimes elicits negative responses from others. Research indicates that negative support behaviors have more influence on the patient's ability to cope than do positive behaviors (Zakowski et al., 2003). In the following quantitative and qualitative studies, breast cancer patients

reported a non-materialization of the support they had anticipated or responses that they viewed as intentionally unsupportive.

Quantitative Studies

Figueiredo and colleagues conducted a study of 66 breast cancer patients in which the Unsupportive Social Interactions Inventory was used (Figueiredo et al., 2004). Results indicated that “distancing or disengagement” and “minimizing of their concerns” were the most common upsetting or unsupportive responses from others (Figueiredo et al, 2004).

A large, 18-month longitudinal quantitative study of 219 breast cancer patients used the 13-item Perceived Negative Spouse Behavior Scale (Manne, Ostroff, Winkel, Grana, & Fox, 2005). Although both the patients and their partners reported on the supportive partners’ negative behavior, the patients’ perceptions of the negative behavior was the determinant of whether such behavior had detrimental effects in the patients’ psychological well-being. Both intentionally unsupportive reactions (i.e. criticism regarding how the patient was coping with her illness) and subtly insensitive behaviors (i.e. conveying discomfort when the patient attempted to discuss her illness) were associated with patients’ avoidant coping and long-term distress reactions (Manne et al., 2005).

Qualitative Studies

In a few studies with focus groups, negative responses emerged in the main themes. Participants in a focus group of 16 African American breast cancer patients

reported that some family and friends blocked them from talking about their illness, withdrew support, or did not provide the kind of support they needed (Wilmoth & Sanders, 2001). A 2005 Danish study of a 15-member Online breast cancer support group also found post-diagnosis social isolation to be a main theme (Hoybye, Johansen, & Tjornhog-Thomsen, 2005). Researchers identified the word “lonely” in 100% of participants’ narratives (Hoybye et al., 2005). Focus groups in a study by Krigel and colleagues, with 15 breast cancer patients, reported a lack of understanding among their friends and family members who had not experienced breast cancer (Krigel, Meyers, Befort, Krebill, & Klemp, 2014). Isolation was also noted as a theme in this study (Krigel et al., 2014).

Participants in a study that examined the diary entries of 30 breast cancer patients discussed their families both as a source of comfort and also as a source of worry and stress (Curtis, Groarke, McSharry, and Kerin, 2014). They described interactions with some support providers that reduced stress, as well as interactions with others that exacerbated their stress, including the offering of advice and unwanted or inappropriate support (Curtis et al., 2014).

In a study in which 44 breast cancer patients submitted essays on their feelings during the illness experience, 48% of the participants described negative responses from others (Mosher et al., 2013). They reported that others avoided discussion of the illness, showed discomfort during such discussions, and denied the severity of their illness and treatment (Mosher et al., 2013).

Villhauer (2008) conducted a small qualitative study in which 14 breast cancer patients were interviewed regarding their illness experience. Participants reported that

partners, family members, and very close friends reacted with fear or discomfort, minimized their concerns, or seemed disinterested in important illness-related issues (Villhauer, 2008).

Rosedale (2009) interviewed 13 breast cancer patients and invited them to share written and artistic expression in the form of poetry, stories, journal entries, and artwork regarding their illness experience. In one of the main themes of the study, “misunderstanding,” participants related that they felt estranged and lonely because even their closest confidants did not seem to understand their cancer experience. In another main theme, “fragile vital connections,” participants described how, because others were not there for them in the way they had expected, they questioned the reliability and dependability of their relationships (Rosedale, 2009).

Manne and colleagues note that, in studies with cancer patients, there is a greater tendency of partners to withdraw from patients when the patients are female (Manne et al., 2006). In qualitative, open-ended questions from a mixed methods study, one of the four major themes uncovered was termed “communication avoidance” (Walsh, Manuel, & Avis, 2005). The areas of greatest concern to participants, within this theme, were avoidance of communication and lack of partner support. Of the 117 participants, 12% reported that they had separated or ended their relationship with their male partner after their diagnosis. Participants related that the predominant reason for the split was their partner’s inability to cope with the cancer (Walsh et al., 2005).

Ineffectual Supportive Offerings

Research on social support has paid little attention to the recipients’ reactions to

offered support. Breast cancer patients assert that some support behaviors, even if they are well-intended, are not beneficial to them (Figuerido et al., 2004). Researchers refer to these social exchanges as “miscarried helping” (Coyne, Wortman, & Lehman, 1988), “problematic social support” (Revenson, 2003), or “dysfunctional social support” (Semmer et al., 2008). Revenson and colleagues use the metaphor of a “double-edged sword” to describe the positive and negative aspects of social support interactions (Revenson, Schiaffino, Majerovitz, & Gibofsky, 1991). Support that is perceived to be inappropriate may lead breast cancer patients to view their partners as insensitive or patronizing (Dehle et al., 2001). Unwanted but received supportive actions have been associated with breast cancer patients’ poor psychosocial adjustment (Manne et al., 2004).

The remainder of this literature review focuses on studies in which breast cancer patients describe supportive offerings that are sometimes meant to be helpful but are viewed by them as ineffectual. Several theories are presented about why such behaviors are considered unhelpful by the recipients. Lastly, a few studies are reviewed in which breast cancer patients describe helpful support.

Fear/Lack of Skills

Supportive actions that are viewed as unhelpful may be the result of fear or lack of skills on the part of the support provider. In a 2010 survey of 1007 adults, 41% said that cancer is the most feared of diseases (MetLife, 2011). Studies of cancer patients show that the majority of them wanted to openly discuss their fears, thoughts and feelings, however, support providers are often uncomfortable discussing such issues

(Uchino, 2009; Wilmoth & Sanders, 2001). In a mixed methods study, breast cancer patients reported on a quantitative measure that their most common communication problems with others were: talking about death (53%), talking about cancer (37%), discussing cancer-related fears (29%), discussing wills and financial arrangements (29%), talking about the future (26%), and talking about feelings (22%) (Walsh et al., 2005).

Friends and family members commonly experience levels of distress similar to those of the cancer patient and report a lack of skills to provide emotional support for the cancer patient (Lewis, 2006; Petersen, Kruczek, & Shaffner, 2003). Despite their best intentions, they may feel uneasy around those with cancer and their interactions can be awkward, uncomfortable, and tense. The discomfort may contribute to exchanges that are distressing to the cancer patient. In a qualitative study of 29 couples, breast cancer patients described different ways they wanted their spouses to behave that would indicate a better understanding of their experience (Shands, Lewis, Sinsheimer, & Cochrane, 2006). The spouses expressed frustration and irritation at not knowing what to say or do to be supportive (Shands et al., 2006).

Unsupportive interactions may also be the result of misguided attempts to be supportive. When supporters are unsure of what to say or how to act, they tend to rely on cultural norms which dictate appropriate supportive behavior toward those who are ill. Uchino (2009) notes that the interactions tend to be automatic or casual modes of support provision such as visiting, calling, and sending cards. People engage in such behaviors assuming that they are helpful, but they can be perceived as superficial (Uchino, 2009).

A popular cultural notion is that candid discussion of negative emotions will encourage self-pity, undermine the cancer patient's motivation to keep fighting the

disease, and be harmful to the patient's psychosocial adjustment (Petersen et al., 2003). Researchers report that most people think cancer patients will benefit from others behaving in a cheerful, optimistic, and encouraging way. Cancer patients report that they are encouraged to keep conversation superficial and report that others block their attempts to discuss cancer-related concerns or exhort them to use self-restraint (Petersen et al., 2003; Pistrang & Barker, 2005).

Supportive Mismatch

One reason that support attempts may be ineffectual is offered by the stress-support matching hypothesis which proposes that, although a particular action may be supportive in general, it may not be appropriate for a certain stressor (Cohen & McKay, 1984; Cutrona & Russell, 1990). This theory is consistent with the perspective of this study in that it emphasizes that the amount of support is not as crucial as the match between wanted and received support.

The support being offered also may not be a match in terms of the level of stressor. Gremore and colleagues found that, while certain supportive behaviors may have stress buffering effects when breast cancer related emotional and physical concerns are at low levels, those effects are attenuated when concerns reach high levels (Gremore et al., 2011). Vilhauer (2008) noted a cyclical nature to the supportive needs of breast cancer patients. Participants reported that they preferred to be treated as "normal" on days when they felt relatively well but, on other days when they developed new symptoms or received test results, they needed more emotional support (Vilhauer, 2008). In a study with African American breast cancer patients, participants also reported that

loved ones sometimes failed to provide the kind of support that was needed at that time (Wilmoth & Sanders, 2001).

Researchers note that action-facilitating support behaviors, such as giving advice or providing tangible resources, are a better match for controllable stressors (Cutrona & Suhr, 1992). In a qualitative study by Curtis and colleagues, advice from others was one of the responses that participants indicated added to their stress (Curtis et al., 2014). Nurturant types of support behaviors, such as listening or esteem-building, have been found to be a better match for uncontrollable stressors (Cutrona & Suhr, 1992). If the type of support being offered is not a match with the type of stressor, more support might not be desirable.

As part of a study by Reynolds and Perrin (2004), researchers revised a commonly used social support instrument to not only assess whether a breast cancer patient's support person engaged in 40 different possible support actions, but also to assess whether the patient would want a support person to engage in such actions. Four of the items were desired by 100% of the participants and eleven of the items were desired by more than 90% of the women. All of these 15 desired support behaviors reflected the support giver's general care and concern which supports the findings of Cutrona and Suhr (1992) that nurturant types of support behaviors are a better match for uncontrollable stressors.

Two of the items, "tries to interpret or explain why I may have developed cancer" and "tries to show me that something or someone else was responsible for the cancer," were undesired consistently by over 90% of the participants. Although there were some variations among groups of participants, four other items were undesired overall by the

majority of participants: “reminds me that things could be worse” was undesired by 91.5%; “suggests a better way to deal with my situation” was undesired by 81.75%; “suggests I go on as before” was undesired by 80%; “gives philosophical perspective” was undesired by 76.5%; and “encourages me to use religion” was undesired by 64% (Reynolds & Perrin, 2004, p. 427-428). The researchers found that the unwanted but received support actions were solely associated with poor psychosocial adjustment (Reynolds & Perrin, 2004). These findings are in line with the assertions of Cutrona and Suhr (1992) that the giving of advice is better matched with controllable stressors. Participants varied on the remaining action behaviors and the researchers in this study theorized that many of the supportive actions generally viewed as helpful may not necessarily be positively valued by breast cancer patients (Reynolds & Perrin, 2004).

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 (Manne et al, 2005; Reynolds & Perrin, 2004).

Contextual Factors

Uchino (2011) notes that there are also contextual factors that can influence breast cancer patients’ interpretations of supportive offerings (p. 245). In video-recorded conversations between breast cancer patients and their partners, Manne and colleagues found links between communication patterns and distress (Manne et al., 2004). For

example, patients reported less distress when their partners responded to their disclosures with humor (Manne et al., 2004).

Coyne and colleagues note that social support occurs in the context of interdependent relationships in which both the provider and the receiver have their own needs and goals and that, when they are coping with a serious illness, the support provider struggles to disentangle his/her own needs from those of the patient (Coyne, Ellard, & Smith, 1990). One qualitative study of conversations between three couples examined “help-intended” remarks by the husbands which were regarded as unhelpful by their wives, who were breast cancer patients (Pistrang, Barker, & Rutter, 1997). A discussion afterward of the perspectives of the providers and receivers of the supportive offerings yielded some insight into the complexities of the exchange. The researchers posited that the providers’ reassurances may have been somewhat motivated by a need to reduce their own feelings of distress (Pistrang et al., 1997).

Researchers observe that supportive interactions are sometimes laden with underlying messages that undermine the beneficial effects of social support (Semmer et al., 2008). Studies show that certain support behaviors are not seen as helpful by the recipient if the support giver is perceived to be motivated by ulterior motives or if there seem to be underlying messages in the support process (Cohen et al., 2000). Underlying messages can include blaming or pressure to “think positively.”

Underlying Message of Blame

Breast cancer remains an illness with an unknown etiology and, unlike many other illnesses, it has not been shown to have any particular dietary link (Holmes &

Wilett, 2004). Breast cancer patients, however, report that they feel as if they are blamed by others (Fosket, 2000; Hallowell, 2000; Pitts, 2004; Simpson, 2000; Wilkinson, 2001). Krigel and colleagues conducted a study in which breast cancer patients described that much of the supportive offerings of others revolved around the provision of information about “cure-alls” (Krigel et al., 2014). In another study by Sinding and Gray (2005), participants described comments from others like, “If you’re so concerned [about the cancer returning], you should be taking shark cartilage” (p. 152). Such comments left participants feeling blamed and responsible for both the onset of cancer and the possibility of its recurrence (Sinding & Gray, 2005).

In his book, *Blaming the Victim*, Ryan (1976) chronicles the tendency we have in society to attribute a cause to catastrophic events, such as illness, and that, by victim-blaming, we achieve a false sense of security that we can prevent things that are actually beyond our control. This feeds into the popular belief that some illnesses are caused by and can be controlled by a proper emotional response. In her book, *Illness as Metaphor*, Sontag (1990) theorizes that, when a disease is dreaded and poorly understood, theories to blame the patient flourish. She notes the similarity between how, before the discovery of the tubercle bacillus, “TB was once, as cancer is now, thought to be a pathology of energy, a disease of the will” (Sontag, 1990, pp. 61-62).

Several social theorists have examined predominant rhetorical frames and have introduced theories to explain why certain causal explanations become popular. Ryan (1976) observes that people: identify a social problem; study those affected by the problem; look for ways that they are different; and point to the differences as the cause of the problem. Wortman (1976) asserts that people have a need to perceive the world as a

predictable and orderly place, and Lerner and Simmons (1966) similarly propose the “just world theory” in which people believe that we get what we deserve and deserve what we get (p. 209).

Curbow and colleagues observe that, the more frightening a person finds the disease, the more likely they are to perceive the victim as deserving their fate (Curbow, Andrews & Burke, 1986). They point out that drawing negative inferences about cancer patients doubly stigmatizes them, both for having cancer and for causing their cancer (Curbow, et al., 1986). Sontag (1990) agrees, saying that, “psychological disease theories are a powerful means of placing blame on the ill” and “patients who are instructed that they have, unwittingly caused their disease, are also being made to feel that they deserved it” (pp.56-57). Ruthig, Holfield and Hanson (2012) point out that, since cancer patients are confronted with a genuinely stressful experience and their natural inclination is to manifest negative emotions, others are drawn to make negative inferences about the cancer patient and to attribute the cause of the disease to their dispositional weaknesses.

Lerner (1971) notes that, if we believe that people only suffer because something is wrong with them or their behavior, we feel protected from undeserved suffering. Weiner (1985) posits that we are less willing to help others if we perceive their problem as onset controllable and Herbert and Dunkel-Schetter (1992) add that blaming the victim absolves us from feeling guilty for having not helped them. In a study by Buick and Petrie (2002), healthy women were more likely to perceive breast cancer patients as responsible for their cancer and to overestimate breast cancer patients’ feelings of vigor and liveliness during cancer treatment. The researchers speculate that these

misperceptions can place unrealistic expectations on the breast cancer patient and may be a factor in the appropriateness of supportive offerings (Buick & Petrie, 2002).

The media plays an important role in conveying normative lessons for women about how to deal with serious illness. Research shows that magazines are found to be an important source of health information, especially information regarding breast cancer, and that the media is cited as second to the doctor as a patient's primary source of information regarding their illness (Kasper & Ferguson, 2002, p. 304). Magazine articles, such as "Olivia Newton-John: Overcoming Breast Cancer with Grace and Gratitude" (Shipp, 2007), "10 Good Things About Breast Cancer" (*Beyond: Live & Thrive After Breast Cancer*, 2006), "Curly Hair and the Other Gifts Cancer Gave Me" (Donaldson, 2007), "Breast Cancer Made Me Jump for Joy (Gee, 2007), and books, such as *Mind Over Cancer* (Richardson, 1993) or *The Gift of Cancer* (McKeown, 2011), portray the "right way" to respond to the experience of breast cancer, reinforcing the idea that profound optimism is a more appropriate response than anger, fear, or sadness.

Kasper and Ferguson (2002) observe that most personal experience narratives in the media are presented in a "Pollyanna-ish tone and style" in which women experience a "beneficial personal transformation" because of the breast cancer experience (pp. 317-318). Gray, Sinding and Fitch (2001) also note the preponderance of "prettied-up images that deny and obscure complicated, messy realities" of the breast cancer experience (p. 235). Whitehead (2006) proposes that, "For people living with a chronic illness, hearing stories of recovery can be both inspiring... and intimidating if they are unable to see anyway of taking steps to recovery and experience social pressures to overcome illness" (p. 2238).

Kasper and Ferguson (2002) assert that, when the media presents the idea that women have the resources they need within themselves to overcome (and even benefit from) breast cancer, it shapes the way that the disease is thought about and addressed in society. They argue that, “By promoting the idea that women can choose to live, the women’s magazines do a profound disservice to the more than 40,000 women who die from breast cancer each year in the United States. Clearly, these women would have chosen to live if personal choice was simultaneously an alternative and a means to survival” (Kasper & Ferguson, 2002, p. 319).

While acknowledging that stories of courage and triumph over illness can be helpful, Kasper and Ferguson (2002) theorize that the absence of magazine articles on the emotional hardships, suffering, anger and death of women from breast cancer erases the other experiences that also shape the landscape of the disease. They assert that the upbeat genre of women’s magazines is required by advertisers who want readers to view their products in a “feel-good” atmosphere, and also note that advertisers may be “part of giant media corporate conglomerates with financial interests in an array of industries...which may do as much to promote breast cancer as to pacify it” (Kasper & Ferguson, 2002, p. 368).

Underlying Message to Think Positive

Several small qualitative studies have touched on the pressure that cancer patients feel to think positive. In interviews of 11 cancer patients, participants reported that they did not want to be told by others to be positive (O’Baugh, Wilkes, Luke, & George, 2003). One of the themes that emerged in a study by Rosedale (2009) was termed

“inauthentic mirroring,” to describe the pressure breast cancer patients felt to conceal their fears and to act brave. They reported that, even in support groups, they felt pressure to present a “fighting spirit” (Rosedale, 2009). A major theme in a Danish study with breast cancer patients also emphasized the burden participants felt to sustain a heroic survivor narrative (Hoybye et al., 2005). One of the main themes in focus groups with breast cancer patients was termed “managing others” in which participants felt pressure to maintain a “game face” or front to manage the unhelpful expectations and beliefs of family and friends (Beatty, Oxlad, Koczwara & Wade, 2008, pp. 337-338).

A study by Sinding and Gray (2005), with 10 cancer patients (9 of them breast cancer patients), explored contrasts between popular discourse about the experience of cancer and participants’ perceptions of their own experience. Many of the participants were disturbed to receive accolades about their bravery and uncomfortable with their survival being viewed as an accomplishment or positive transformation. They felt that others did not understand the reality of what they had been through and they were uncomfortable with what such comments insinuated about other cancer patients who had died. They felt as though they live under a “shadow” that the cancer will recur while, at the same time, feeling pressure to provide the obligatory success story of the cancer being behind them. Overall, participants described feeling outside the circle of contemporary understanding of the breast cancer experience, abandoned, and separate from others (Sinding & Gray, 2005).

Researchers observe that cancer patients often feel pressure from friends and family to have a positive attitude (Aspinwall & Tedeschi, 2010; Ruthig et al., 2012). Holland and Lewis (2001) refer to such pressure as the “tyranny of positive thinking.”

They propose that, “All this hype claiming that if you don’t have a positive attitude and that if you get depressed you are making your tumor grow faster invalidates people’s natural and understandable reactions to a threat to their lives” (Holland & Lewis, 2001, p. 14). Wilkinson (2001) cautions that, “An even more pernicious aspect of such discourses holds that responsibility for cancer derives not just from who you *are*, or from what you *do* – it depends on how you *think* as well” [italics in original] (p. 273).

Despite its appeal, the evidence for the benefits of positive thinking is equivocal (Petticrew, Bell, & Hunter, 2002; Tod, Wamock, & Allmark, 2011). Trunzo and Pinto (2003) found that attempts by others to raise breast cancer patients’ level of optimism do not decrease the patients’ distress level. Some cancer researchers advise health professionals to exercise caution in prescribing or responding to positive thinking (McGrath, Jordens, Montgomery, & Kerridge, 2006) and in using benefit-finding or post-traumatic growth interventions (Lechner, Tennen, & Affleck, 2009, p. 633). A quote from Carl Jung suggests that there may be something for cancer patients to gain from negative thinking: “One does not become enlightened by imagining figures of light, but by making the darkness conscious. The latter procedure, however, is disagreeable and therefore not popular” (as quoted by McGrath et al., 2006, p. 667).

Wilkinson and Kitsinger (2000) conducted a qualitative study with breast cancer patients in which they raised questions about whether the assessment of thinking positive functions as an accurate report of an internal cognitive state. They note that the phrase “think positive” is an idiom. The Cambridge Dictionary of American Idioms explains that to “think positive” means “to be hopeful that good things will happen” (Think Positive, 2003). Wilkinson and Kitsinger (2000) emphasize that idioms are characterized by

vagueness and generality. They examined how positive thinking is presented in health research, throughout a range of theoretical and methodological perspectives, and found widely varied operational definitions for the concept. The researchers reviewed the ways in which positive thinking is measured and they found many obvious inconsistencies. They also gave examples of how, in some qualitative studies, diverse statements are sometimes coded in similar ways and similar statements are sometimes coded in opposite ways (Wilkinson & Kitsinger, 2000).

In addition to the lack of clarity regarding what is meant by positive thinking, Wilkinson and Kitsinger (2000) question whether “ticking a box on a questionnaire or circling a number on a Likert scale” in a quantitative study, or the mention of positive thinking in a qualitative interview provides an accurate report of a cognitive or psychological state (p. 797-798). They caution that acceptance of such data at face value does not take into account the pervasive cultural pressure on cancer patients to think positively, emphasizing that, while it may be obvious why people might think positively about other major life events, it is not immediately apparent why someone would think positively about a life-threatening disease. They assert that participants responding to an interviewer’s questions or to items on a scale, do so in a cultural context where the media has presented a popular version of social science research on the presumed benefits of positive thinking and in which they feel strong social pressure to have a “fighting spirit” and to “beat cancer with positive thinking” (p. 801). It is within this social context that breast cancer patients’ responses to an interviewer’s questions or to items on a scale must be understood and interpreted (Wilkinson & Kitsinger, 2000).

The researchers were careful in their qualitative study of 77 interviews and 13 focus groups to not directly ask participants about thinking positive (Wilkinson & Kitsinger, 2000). They noted that when the topic cropped up spontaneously, in more than half of the instances, it was phrased as an imperative – as something you “have” to do (2001, p. 806). It was rarely presented as a natural reaction to having cancer or as something participants have found helpful or planned to use in order to cope with cancer (Wilkinson & Kitsinger, 2000).

The researchers note that talk about “thinking positive” serves as a linguistic tool. They point out that idioms are often used to attract endorsement or to shift conversation (Wilkinson & Kitsinger, 2000). In their interviews with breast cancer patients, they found a common juxtaposition of strong negative emotion followed by a statement suggesting a positive outlook. One of the functions of this conversations strategy, they point out, is that it brings an uncomfortable discussion about negative feelings to an “upbeat” end, lightening the interaction and relieving the listeners of their distress. The vagueness of such an idiom also makes it resistant to question or contradiction. It summarizes and shifts the conversation from the “personal” to the “general” to attract agreement and endorsement. In this way, they explain, a breast cancer patient is able to express some negative thoughts and feelings without attracting censure by establishing that she endorses positive thinking (Wilkinson & Kitsinger, 2000).

Frank (1995) outlines different ways that people with serious illness talk about their experience. A “restitution narrative” is characterized by an optimistic perspective and is the type that most people, especially Americans, prefer to hear. The “chaos narrative,” on the other hand, is characterized by lack of control, vulnerability, futility

and impotence. Listeners are often annoyed by the chaotic narrator who feels “sucked into the undertow of illness” because they have difficulty facing the possibility that illness could happen to them (Frank, 1995, p. 115). And so, helpful support, just when the chaotic storyteller needs it, is not there.

Broom (2001) observes that breast cancer patients are burdened with shielding others from the existential realities posed by their liminal status. She emphasizes that “the conventions of autobiography, further shaped by the norms governing illness and breast cancer stories, require the speaker/writer to impose clarity on a disease whose meanings, experiences and prognosis are, in most instances, fundamentally ambiguous, uncertain, and perhaps contradictory” (p. 263). She observes that the pressure to provide a conclusion to the narrative may be in contrast with the tentative and provisional nature of the breast cancer experience (Broom, 2001).

Weingarten (2001), a Harvard psychologist, relates that several years after her experience with breast cancer she came upon Frank’s book on illness narratives which helped her to make sense of her own experience. She states, “When I was first diagnosed with breast cancer, I quickly learned who the people were who wanted to hear a restitution narrative. I was fortunate, ah irony, that breast cancer is a disease that can easily produce a restitution narrative. But I also had another illness narrative and it was this one that consumed me. Like a jewel, I hid this illness narrative, unwrapping it under special trustworthiness. This illness narrative Frank calls a chaos narrative.” She observes that those who do not package their illness narratives in the restitution form experience marginalization from others (Weingarten, 2001, p. 111).

Couser (1997) notes that “bodily dysfunction is perhaps the most common threat to the appealing belief that one controls one’s destiny” (p. 9). Balshem theorizes that “talk about cancer also has been controlled because cancer itself is perceived as uncontrollable” (as cited by Kasper & Ferguson, 2002, p. 171). Weingarten (2001) asserts that, for those who “refuse to package their illness narratives” in the restitution form, there are “micro-processes of withdrawal” from others (p. 116). Frank (1995) agrees that the dominant culture seeks to silence those with a chaos narrative and steer them toward a restitution story. He posits that “the attendant denial of chaos only makes its horror worse” (p. 112) and that “ultimately, chaos is told in the silences that speech cannot penetrate or illuminate” (Frank, 1995, p. 101). Wilkinson (2001) also observes the silences around cancer and emphasizes that “silence and invisibility go hand in hand with powerlessness” (pp. 272-273).

Difficulty talking about cancer is not limited to the provision of support from informal providers. Research also shows that oncologists do not effectively acknowledge or deal with their patients’ emotional needs (Butow, Brown, Cogar, Tattersall, & Dunn, 2002; Kennifer et al., 2009; Morse, Edwardsen, & Gordon, 2008) and that they rarely respond with empathic statements (Pollak et al., 2008). Cancer patients report that they are reluctant to disclose emotional concerns to their oncologist (Butow et al., 2002). Spiegel, a psychiatrist who works primarily with breast cancer patients, explains that “we’re trained to treat crying as bleeding, to apply direct pressure to stop it” (as quoted by Hope, 2005, p. 5). He asserts that it is important for cancer patients to be able to openly discuss a full range of feelings and gives the following instructions: “If you see somebody crying, don’t just do something – stand there” (as quoted by Hope, 2005, p. 5).

Charmaz (2002) points out that people live in multiple worlds which call for different discourses. She observes that people with serious illness learn to read cues from others about their expectations, making general statements instead of expressing genuine feelings, choosing silence to resist dominant views, and only acknowledging suffering in certain relationships. Wortman and Dunkel-Schetter (1979) note that breast cancer patients often feel compelled to “enact a charade” pretending that everything is fine, in order to elicit support from others (p. 143). Abel and Subramanian (2008) point out that “family members, friends, and the medical staff may wish to celebrate the milestone of completion of treatment, but the breast cancer patient knows that for her, life will never be the same” (p. ix).

Constraints to Emotional Expression

Whether unhelpful support is the result of not understanding the breast cancer experience, a mismatch between the supportive offering and the recipient’s particular needs, or is viewed to have underlying messages, such behaviors from friends and family are sometimes perceived by breast cancer patients to constrain their expression of emotions. Social constraints are one way in which social interactions can have detrimental effects on the cancer experience. They result in the individual feeling unsupported or misunderstood by others (Zakowski et al., 2003).

Participants in a qualitative study of 18 breast cancer patients discussed the difficulty they had in talking with others about their feelings, their fears, and their future (Dickerson, Alqaissi, Underhill, & Lally, 2011). They described contemplating and purposefully avoiding certain friends and family members whose responses they

anticipated to be unsupportive (Dickerson et al., 2011). In one qualitative study, 35% of breast cancer patients reported that they did not disclose to anyone their primary cancer-related concern (Kornblith et al., 2006) and in another, among participants who reported having a spouse or partner, only 63% of them identified that partner as their most important confidant (Figueiredo et al., 2004).

In five other qualitative studies with breast cancer patients, social constraints have emerged as a major theme. In the first study, Mosher and colleagues conducted research in which 44 breast cancer patients wrote about their experience, with almost half of them describing constraints to the disclosure of their cancer-related concerns (Mosher et al., 2013).

In the second study, 14 breast cancer patients were interviewed and more than half of the participants reported that they could not confide freely with others because they viewed the responses of others as constraining (Vilhauer, 2008). Some of the participants also reported that they held back their cancer related concerns at social gatherings because they felt like they were in a “reception line” (Vilhauer, 2008, p. 250).

Similarly, participants in a quantitative study of 15 breast cancer patients reported that they screened calls from numerous others, not wanting to “relive” certain experiences with them (Krigel et al., 2014). Participants reported that they culled their support system to create a small “inner circle” of others with whom they could share more about their experience. For those outside the inner circle, participants described the burden of tailoring conversations to avoid unwanted reactions (Krigel et al., 2014).

A fourth study, in which 17 Scandinavian women were interviewed regarding their breast cancer experience, one of the main themes was termed “doubled or multiple

suffering” (Arman, Rehnsfeldt, Lindholm, & Hamrin, 2002, p. 100). Participants described how their suffering was increased when they felt constrained from expressing their “deepest and darkest emotions” (Arman et al., 2002, p. 100).

Lastly, in a case study of a couple, researchers recorded a conversation in which the wife, a breast cancer patient, was asked to reveal a personal concern related to her illness and the husband was instructed to try to be helpful (Pistrang & Barker, 2005). An examination of the 15-minute recording by both the participants and the researchers revealed 10 instances in which the wife talked about her need to express her feelings and the husband responded that it was hazardous to express feelings, encouraging her to be more positive. The wife stated that her husband’s dismissive attitude and optimism discouraged her from expressing her feelings and fueled her distress (Pistrang & Barker, 2005).

Studies of patients with breast and other cancers show that, the more cancer patients interpret their illness as threatening, the more constrained they feel in being able to openly express their thoughts and feelings to their spouses (Herzer et al., 2006). Several studies show an association between higher levels of social constraints and negative affect (Badr, Pasipanodya, & Laurenceau, 2013), increased psychological distress (Figueiredo et al., 2004; Lepore, 2001; Porter, Keefe, Hurwitz, & Faber, 2005), and poorer psychological adjustment (Agustsdottir et al. 2010; Cordova et al. 2007; Figueiredo et al., 2004; Manne et al., 2005; Roberts, Lepore, & Helgeson, 2006; Schmidt & Andrykowski, 2004; Widows, Jacobsen, & Fields, 2000; Wingard et al., 2010; Zakowski, Ramati, Morton, Johnson, & Flanigan, 2004). A large quantitative study with 330 participants found that, when breast cancer patients hold back the sharing of their

concerns, it not only affects their well-being, it also ultimately affects the well-being of their partners (Manne, Kashy, Siegel, & Virtue, 2004).

Researchers theorize that social constraints have an adverse effect on coping because they diminish opportunities for cancer patients to express their feelings, to gain new perspectives from others, and to cognitively process and make sense of their cancer experience (Lepore & Kernan, 2008). Studies with cancer patients show a positive relationship between social constraints and avoidant behavior (Hughes et al., 2010; Manne et al., 2005; Schmidt & Andrykowski, 2004; Zakowski et al., 2004), intrusive thoughts (Cordova, Cunningham, Carlson, & Andrykowski, 2001; Schmidt & Andrykowski, 2004), and the expression of uncertainty words in cancer journals (Cordova et al., 2001).

Some breast cancer patients, who feel constrained and distressed by unhelpful social interactions, use Internet blogs as an outlet to commiserate with others. One such website, ChemoChicks.com, offers a blog section where cancer patients can list unhelpful support behaviors from their “best intention-ers” (Excuse Me?, n.d.). Other sites similarly list “41 Things Not to Say to a Cancer Patient” (Collins, 2005), and “The Stupid Things People Say to Those with Cancer & Their Families” (Adams, 2013).

Orgad (2005) conducted a four-year study with breast cancer patients who used the Internet in the context of their illness. She observes that, while the Internet provides more opportunity than other mass media for breast cancer patients to control how their experience is represented, most forums replicate public discourse and “reproduce similar forms of association, vocabularies, practices, and relations to those that are dominant in the wider culture of breast cancer” (Orgad, 2005, p. 154). She notes that the designers of

such websites significantly shape their communicative spaces by specifying for whom the forums are intended (distinguishing between patients and caregivers) and by framing participants' constructions of their experience into predetermined categories. She gives an example of a breast cancer website which displays an artistic list of words in various fonts on the home page, including "challenge, inform, act, support, question, empower, inspire" and she asserts that it implicitly directs participants to depict themselves in terms that portray a positive attitude and that emphasize personal responsibility for their illness (Orgad, 2005, p. 155). Participants of her study described that, when posts are made to discussion boards expressing negative feelings, they provoke a chain of responses invoking the original poster to reformulate her reactions. She emphasizes that, while computer mediated communication gives voice to breast cancer patients who have historically been silenced, bringing discussion about the experience into the public arena, there remain some constraints to the kind of representation the experiences are afforded in this new communicative space (Orgad, 2005).

Helpful Support

In a quantitative study by Reynolds and Perrin (2004), participants reported that friends and family were, for the most part, successful in their supportive offerings, with 88% of wanted support items from a social support instrument having been provided and only 8% of unwanted items from the instrument having been provided. The top five supportive items from the instrument that participants reported they desired were: "asks if I want to go out"; "lets me direct conversation"; "treats me normally"; "tries to understand situation"; and "identifies with how I feel" (Reynolds & Perrin, 2004).

Two mixed methods studies show that breast cancer patients find it helpful to be able to engage in an open discussion of their cancer-related concerns. In one study, in which 51 breast cancer patients and their spouses wore an audio recorder over a weekend to monitor their conversations about the cancer in a natural setting, spouses' engagement in emotional disclosure was found to predict better patient adjustment at baseline and at a two-month follow-up (Robbins, Lopez Weihs, & Mehl, 2014). These results support a previous study of 98 couples' in-lab breast cancer related discussions in which the spouses' reciprocated emotional disclosure was related to patients' lower distress levels (Manne et al., 2004).

The benefits of social support are complex and influenced by the emotional and relational characteristics of the interaction. Several theories were explored in this section offering explanations as to why certain supportive actions are viewed by breast cancer patients as unhelpful or unwanted. Awkward, inappropriate exchanges may be the result of fear (MetLife, 2011; Uchino, 2009; Wilmoth & Sanders, 2001) or lack of skills (Lewis, 2006; Petersen et al., 2003; Pistrang & Barker, 2005; Shands et al., 2006; Uchino, 2009). Supportive offerings may be viewed by the receiver as motivated by the provider to distance themselves or to reduce their own feelings of distress (Uchino, 2011). Some support attempts may be supportive, in general, but not a match for the particular stressor of breast cancer (Uchino, 2009) or the level of stressor (Gremore et al., 2011; Villhauer, 2008; Wilmoth & Sanders, 2001). Others may be influenced by current cultural trends (Holland & Lewis, 2001; Kasper & Ferguson, 2002; Orgad, 2005; Rosedale, 2009; Sinding & Gray, 2005; Wilkinson & Kitzinger, 2000; Whitehead, 2006). Unwanted supportive actions can leave breast cancer patients feeling misunderstood,

constrained from expressing their feelings, and distressed (Badr et al., 2013; Figuerido et al., 2004; Lepore, 2001; Porter et al., 2005). A greater understanding of the emotional needs of breast cancer patients will help to optimize the helpfulness of supportive offerings.

Chapter Summary

The current study employed a phenomenological approach based on the interpretivist lifeworld perspective. It was conceptualized within the postmodern paradigm which draws from the works of Durkheim and Foucault and emphasizes cultural influences on social phenomena. Ethnography was used because it is an ideal research method to bring to light the experiences of social support as perceived by breast cancer patients.

A review of the research literature on this topic indicates that breast cancer patients seek and benefit from social support that they view as helpful. There is little research, however, on the specific aspects of social support that breast cancer patients, in particular, consider to be helpful or unhelpful.

A few qualitative studies have explored overtly negative behaviors by family and friends in some depth. Several quantitative studies have explored how unhelpful support constrains, hinders coping, and causes distress to breast cancer patients.

Some qualitative studies, although their focus was not on help-intended supportive offerings that were viewed as unhelpful, have uncovered a theme that touched on the subject. Researchers offer several theories about why some well-intended support offerings are viewed by recipients as ineffectual or unwanted.

The current study differs from previous studies in that it provides an in-depth exploration of the perceived helpfulness of support provision that is well-intended. The current body of research suggests that a more thorough understanding of supportive needs during the breast cancer experience would help both informal providers and formally trained providers to maximize their supportive efforts. A qualitative study which elicits information from the participants, specifically about what they have found to be helpful or unhelpful in help-intended supportive actions provided by others, will not only focus attention on the specific support needs of breast cancer patients, but can also be used to provide guidelines or interventions to enhance the experience of support.

CHAPTER THREE

METHODS

This chapter focuses on the design and procedures that were followed during the research process. It begins with a restatement of the purpose of this study. The study design for the project, which used established ethnographic procedures outlined by Spradley (1979, 1980), is then provided.

Factors related to the sampling techniques and recruitment of participants for both the interviews and the focus groups are included in the next section. Data collection was guided by Spradley's (1979) Developmental Research Sequence (DRS) which is detailed along with an overview of the procedures that were used in the study. Provisions that were followed to protect participants from risk and injury are also covered.

The final section of the chapter describes the specific methods of domain analysis, taxonomic analysis, componential analysis, and cultural theme analysis provided by Spradley (1979) that were utilized for analysis of the data. The chapter concludes with techniques that were used to ensure rigor and the framework of understanding the researcher brought to this study.

Study Design

The purpose of this study was to explore and identify, from the participants' perspectives, the provisions of social support that they view as helpful and unhelpful. A qualitative approach was used because it is the most comprehensive way to capture the experience of social support from the breast cancer patient's viewpoint. Ethnography provided the methodology for this investigation. As a research method, ethnography

originated in the field of anthropology but has become popular in the social sciences. Spradley (1979) asserts that, rather than studying people, ethnography seeks to learn from people. The focus is on the emic point of view and this methodology created a framework for honoring the participants in the current study as “expert knowers” about social support during the breast cancer experience. In ethnography, the researcher seeks to discover how participants experience and interpret a problematic circumstance, event, or act (Denzin, 1989). In this study, the problematic circumstance is the experience of breast cancer. The ethnographic approach is ideal for capturing the nuances breast cancer patients can provide about cultural factors that have influenced their experience and for descriptions that fall outside pre-established lines of thinking.

The two main data sources for this research were interviews and focus groups with a total of 20 key informants. Text from 20 insider-written documents, published between 2000 and 2014, were a supplemental data source. All three data sources were used to weave together a richly detailed description, or “bricolage” (Denzin & Washington, 2008, p. 8), of the social support experiences of breast cancer patients in the context of their current cultural environment. Methodological triangulation, using these multiple data sources, was used to increase the credibility and dependability of the results (Guba, 1981).

Data collection included 20 individual, face-to-face interviews approximately 60 minutes in length, 2 in-person focus group sessions, each with 7 participants and approximately 90 minutes in length, and an examination of 20 published autobiographies written by breast cancer patients. An advantage of the individual interviews, focus groups, and autobiographies is that they gathered in-depth information in the participants’

own words. The autobiographies had the advantage of the researcher's absence. The interviews and focus groups had the advantage of allowing the researcher to interact directly with the participants, providing opportunities for clarification and for follow-up questions. An advantage of focus groups is that they benefited from the synergistic effects of group discussion.

A disadvantage of all three data sources was the possible impact of social desirability. Researchers note that cancer patients often feel pressure to project a positive attitude (Holland & Lewis, 2001; Wilkinson & Kitzinger, 2000). A limitation of interviews and focus groups is that they did not allow for naturalistic observation. Focus groups may also have been biased by the moderator or by a strong group member.

It is expected that the participants' expertise will deepen understanding of the salutary aspects of supportive offerings. The research question for this study was: What are breast cancer patients' perceptions regarding the helpfulness and unhelpfulness of supportive offerings?

Sampling Procedures and Recruitment

Because this was a qualitative study, the sampling strategy did not pursue statistical randomness (Guba & Lincoln, 1989). In this study, the commonality was the experience of breast cancer. Purposeful sampling was utilized to locate members of this specific, predefined group who have directly experienced the phenomenon of interest, breast cancer. In ethnographic research, they are called key informants and they were selected for the purpose of describing their experience.

Participants for the individual interviews and focus groups in the study were recruited through flyers (see Appendices C and D) and from subsequent snowball sampling techniques. Participation was limited to adult females who had been diagnosed with invasive breast cancer. Participants were given a small token (\$25 gift card to a local restaurant) for participation in the study. Because this was a qualitative study, the sample size depended on the emergent research process and was not able to be stated at the onset. Recruitment of participants ended when saturation was reached and there were no new themes, categories, or emergence of concepts (Glaser & Strauss, 1967).

Some of the focus group participants were recruited from two local breast cancer peer support groups: the Packinghouse Support Sisters in Redlands and the Breast Cancer Self Help Group at Michelle's Place. These support groups were chosen because the student researcher had an established relationship with the group leaders. They are informal groups led by peers and are comprised of acquaintances who meet at a local church or at a non-profit resource center. The student researcher received verbal support from group members for the distribution of flyers and recruitment for the study.

Additional focus group participants were recruited from the Women's Cancer Support Group, a formal group which meets at the Loma Linda University Behavioral Health Institute. Participants for the individual interviews were recruited from the Loma Linda Breast Cancer Clinic. Letters of support for the study from these two formal sources are provided (see Appendices A & B).

Data Collection

The ethnographic interviewing methodology of Spradley (1979) was used to

discover the participants' perceptions of support during their breast cancer experience from within its social and historical context. Spradley suggests that a conversational communication style conveying empathy or authentic understanding is critical for establishing rapport and retrieving accurate data. An interview guide, based on his seminal work, *The Ethnographic Interview* (Spradley, 1979), was used for both the individual interviews and the focus groups (see Appendix I).

Three main types of questions were used to gather cultural data: descriptive, structural, and contrast. Initially, broad, descriptive questions were used to allow participants to describe their experiences in their own language. Spradley (1979) provides five types of descriptive questions: grand tour, mini tour, example, experience, and native language. The first type of descriptive question was the "grand tour," a very general opening question. The following is an example of a grand tour question that was used: "I am interested to learn about the social support you received during your breast cancer experience. Can you tell me about it?" The conversations moved from broad questions to more focused descriptive questions. "Mini tour" questions were used to obtain more specific information or to provide more depth. Participants were asked to provide examples or talk about specific experiences to help them recall details that would provide a greater depth of understanding. An example of this kind of question was: "Can you give me an example of social support that helped you to cope with your breast cancer experience?" (Spradley, 1979).

Because the ethnographic research process is cyclical, not linear, data analysis occurred concurrently with data collection (Spradley, 1979). As the interviews and focus groups progressed, structural and contrast questions were used to clarify and validate

cultural meanings. Structural questions were used to verify what had been said by the participant or by other participants in order to confirm aspects of emerging categories including their cover terms, included terms, and semantic relationships. These kinds of questions were used to elicit similarities in the meanings of different terms and phrases used by participants (Spradley, 1979).

While structural questions focused on similarities of ideas within categories, contrast questions focused on the differences. Spradley (1980, pp. 125-128) asserts that the meaning of a concept cannot be fully understood without discovering that with which it contrasts. Subsequent questions emerged from the interview or focus group conversations, following information that was provided by the participants (Spradley, 1979).

An example of a dyadic contrast question that was used in this study to make distinctions between two categories asked participants of a focus group meeting about the difference between two examples of supportive offerings. Two informants shared stories in which they had expressed worry about whether they would survive their breast cancer. In each case, the patient's mother attempted to provide encouragement. The mother in one scenario suggested that her daughter should concentrate on the number of breast cancer patients who do survive, adding that doing so might make her one of them. This was shared as an example of unhelpful support. The mother in the second scenario suggested that her daughter should just concentrate on getting through today, which was observed to be helpful. Focus group members were asked about the difference between the two support offerings and it was noted that, in the first example, the mother did not acknowledge the seriousness of the illness and insinuated that the outcome of her cancer

was within the patient's control. In the second example, the patient's feelings and her assessment of the situation were not challenged.

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 were overlooked. This permitted participants to have some flexibility in determining what the salient issues are for this topic while allowing the researcher to formulate additional questions in response to what were viewed as significant replies. Other interview strategies suggested by Spradley (1979, p. 67) were employed including expressing interest, interspersing casual questions, repeating, and creating hypothetical situations. A digital voice recorder was used during the interview which was then transcribed and analyzed for thematic content to provide information on emergent themes.

At the end of the interview or focus group, participants were asked to fill out a brief written questionnaire which elicited demographic information (see Appendix J). Due to the likely diversity of respondents to the study, the researchers were sensitive to participant interaction styles, and the survey used language that is culturally sensitive. The questionnaire did not ask for participants' names to ensure confidentiality. Information received in the questionnaire was held in the strictest of confidence.

Procedures

The two main sources of data for this study were individual face-to-face interviews and in-person focus groups with participants solicited from a flyer (see Appendices C and D) and from further snowball sampling. The interview flyers were provided to the Loma Linda Breast Cancer Clinic. The focus group flyers were provided

to the Women's Cancer Support Group at Loma Linda University Cancer Center, the Breast Cancer Self Help Group at Michelle's Place, and the Packinghouse Support Sisters. Participants were allowed to participate in an interview, a focus group, or both. The flyers briefly described the study and provided the student researcher's phone number to receive more information. Callers were screened to ensure eligibility and were provided with information about the study following a phone script (see Appendices E and F) before they were scheduled for an individual interview or signed up for an upcoming focus group meeting.

In keeping with the qualitative style, individual interviews were conducted by the researcher in the natural setting of each participant's home or in a place of their choosing. A location familiar to participants was used to enhance the participant's comfort level and assist in building rapport. At the beginning of the interview, the researcher reviewed a written consent letter with the participants. The letter informed participants about the purpose of the study, data collection procedures, confidentiality, as well as the risks and benefits of the study. The letter assured participants that all information obtained in the study would be kept strictly confidential by the researcher and that, although some comments might be quoted in the research findings, their anonymity would be kept. It explained 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. It stated that participants were free to opt out of the study at any time without any adverse consequences to them and that they would keep the \$25 gift card to a local restaurant, whether or not they finished the interview (see Appendix G for the interview consent document).

The interview process was approximately 60 minutes in length. At the close of the interview, participants were asked to fill out the brief demographic survey which took approximately five minutes to complete (See Appendix J). They were also given some time for debriefing in which they were asked if they were feeling any discomfort or distress as a result of the interview, in which case they would have been offered a referral to the LLU Behavioral Health Institute. None of the interview participants indicated that they were experiencing any distress or discomfort.

The two focus groups were composed of the same group members who met on two occasions. They were held on a days and times that differed from their normal support group meetings. Only the support group members who had been recruited and screened by the student researcher were in attendance at the focus group meetings. The two focus groups had seven members which fell within the optimum size of six to twelve members as recommended by Sprenkle and Moon (1996). They note that smaller groups have difficulty generating a diversity of ideas and larger groups do not allow everyone to actively participate. The provision of multiple focus group meetings allowed for a “rolling interview guide” with different questions for the subsequent focus group meeting (Steward & Shamdasani, 1990).

Before the focus group meetings began, the researcher reviewed a written consent letter with the participants. The letter informed participants about the purpose of the study, data collection procedures, confidentiality, as well as the risks and benefits of the study. It noted that, by agreeing to participate in the study, participants agreed to not disclose to others outside the event anything said within the context of the focus group, however, it advised participants that there was the possibility that their confidentiality

could be violated. The letter stated that all information obtained by the student researcher in the study would be kept strictly confidential and that, although some comments might be quoted in the research findings, their anonymity would be kept. It stated that participants were free to opt out of the study at any time without any adverse consequences to them and that they would keep the \$25 gift card to a local restaurant, whether or not they finished the focus group meeting (see Appendix H for the focus group consent document).

A digital recorder was used to capture the participants' responses. The focus groups lasted approximately 90 minutes. At the close of each of the focus groups, participants were asked to fill out the brief demographic survey which took approximately five minutes to complete (See Appendix J). Participants were also given a debriefing in which they were asked if they were feeling any discomfort or distress as a result of the interview, in which case they would have been offered a referral to the LLU Behavioral Health Institute. None of the focus group participants indicated that they were experiencing any distress or discomfort.

A supplemental data source for this study was text-based ethnographic artifacts in the form of autobiographies by breast cancer patients which were published since the year 2000. These were "an original or first-hand account of the event or experience" as described by (Wiersma, 1995, p. 234). Autobiographies that met the criteria from two local cancer resource agency libraries, Michelle's Place Temecula and Gilda's Club Desert Cities, were analyzed for content related to helpfulness and unhelpfulness of supportive offerings. This additional data source was used to capture different dimensions

of the same phenomenon and it broadened the research by examining the culture in a larger context.

Risk, Injury, and Protections for Vulnerable Populations

Risks in this study were categorized as minimal. Breach of confidentiality or privacy was identified as a potential risk for the study. However, to prevent this risk, the interview and focus group participants' names and/or identities were kept separate from their demographic questionnaire responses and the names will not appear in any presentation or publication of this research. No participant names were used on the interview or focus group recordings or in the transcripts. During the study, the digital recordings and transcripts remained in a locked cabinet in the Department of Social Work and Social Ecology. At the conclusion of the study, the digital recordings were destroyed, although the de-identified transcripts were saved for future use. A numbering system was utilized for the individual interviews in which participants were assigned a number in the order that they were interviewed. Contact information was provided for the student researcher's faculty advisor in the event that participants had questions regarding the study. Additionally, participating in this study was voluntary, therefore participants were free to withdraw from participating at any time without any harm resulting.

While participation in interviews or focus groups for this study may be of no direct benefit to the participant, the potential contribution to the science of social support is great. The knowledge gained from this study illuminates the salutary effects of specific social support behaviors for breast cancer patients and it is expected to inform

the formal and informal provision of social support for breast cancer patients in terms of quality.

Data Analysis

Spradley's (1979, 1980) DRS method was also used for analysis and interpretation of the data. Interview and focus group recordings were transcribed in full by the researcher. The process of repeatedly listening to, transcribing, and reading the data aided the researcher in gaining a closer understanding of the participants' perspectives. Published autobiographies, written by breast cancer patients, were also examined to supplement the main sources of interview and focus group data and to generate a more comprehensive understanding in the emerging analysis. Each book was read in its entirety by the primary researcher and any mention by the author of social support during her breast cancer experience was noted and collected in written form. The text, from all three sources, was entered into a computer software program, NVivo (Version 10) to facilitate classifying, sorting and arranging the collected data.

Spradley's (1979) techniques of domain analysis, taxonomic analysis, componential analysis, and cultural themes discovery was employed. The researcher and two research assistants, students from the MSW program at Loma Linda University, met periodically in the data analysis process. It was an iterative process with domain and taxonomic analysis used to focus the scope of the research and componential and theme analysis used to provide analysis of the major cultural domains (Spradley, 1979).

Domain Analysis

Ethnography is primarily an inductive method (Spradley, 1979), and an inductive approach was used in which patterns and themes were identified from the data through exploration of all three data sets. The initial goal was to discover similarities in the informants' descriptions. The process began with a preliminary coding to identify key issues described by the informants.

Some of the codes were prompted by the informants' use of certain words or phrases. For example, several informants described scenarios where support providers said, "You look great," "You'll be fine," "You're so strong," or "How are you?" Other codes were triggered by the informants' frequent use of particular words, including: God, positive, TV, normal, meals, distraction, or listen. The code "get over it" was chosen from one of the informants quotes to cover similar terms (i.e. "get on with it," "you're done," or "it's over") that were used by other informants. Some codes were generated as an umbrella term that seemed to capture descriptions using varied terminology. For example, the code "find a silver lining" was not used by any informants but it was chosen to categorize descriptions in which the terms "growth," "life lesson," "meaning," "blessing," or "gift" were used.

Initially, 27 codes were categorized from the data by the primary researcher. As part of the coding process, a codebook was developed from these initial codes. It included the code names, each with a definition and a text example. The two research assistants were then given the task of coding the data. They were asked to read through the data independently, using the codebook to guide them in assigning codes to sections of the

data. The coders were encouraged to collapse, expand, revise, or add to the initial codes to allow for the emergence of new or different codes in the process.

The primary sources of data were the transcripts from the individual interviews and focus groups. These main sources of data were supplemented by text from the published autobiographies written by breast cancer patients. The coders did not read the autobiographical books in entirety but were provided with a list of 67 excerpts in which the authors had mentioned social support during their breast cancer experience.

After completing the coding exercise, the results were analyzed for consistency of responses between the coders. Cohen's Kappa is a statistical formula that takes into account the relationship between the proportion of times when the raters agree on the data and proportion of times when agreement might have been expected by chance (Viera & Garrett, 2005). Cohen's Kappa was calculated separately for the main and supplemental sources of data. Coding of the main data had a score of .77; a score of .83 was achieved with the supplemental data. The overall level of agreement between the two coders on the combined sources of data was .79, indicating substantial agreement (Viera & Garrett, 2005).

These first level codes were compared and consolidated by the primary researcher to generate main themes, or domains. Domains are defined as "a category of cultural meaning that includes other smaller categories" and they are the most basic unit of analysis in Spradley's (1980) DRS for interpreting the data (p. 88). The process involved searching for ideas or concepts that could be categorized into domains by means of semantic relationships. Themes, connections, and patterns within each domain were explored to discover a cover term, included terms, and a description of the semantic

relationship (Spradley, 1979). For example, the codes “cancer patient identity,” “cultural expectations,” “support non-materialization,” and “speculation of cancer cause” described similar experiences and they were categorized under the domain “Alienation.” Inclusion was the semantic relationship that described the connection within the domain.

In this study, a surface analysis approach was used to find as many domains as possible (Spradley, 1980). Seven domains emerged from the data and were given the following cover terms: Alienation, Dismissal/Nonchalance, Unsolicited Advice, Constraints, Pressure for a Positive Outcome, Demonstration of Caring, and Management of Feelings. Each cover term has two or more included terms of components that belong in that domain. There were 16 subcategories identified among the 7 domains.

The semantic relationship is the third component of the domain. Spradley (1980) offers nine suggestions of possible semantic relationships: inclusion, spatial, cause and effect, rationale, location for action, function, means end, sequence and attribution (p. 93). In this study, inclusion was the semantic relationship that described the connections within the seven domains. Domain analysis focuses the data and provides information that can be used for contrast in further analysis (Spradley, 1980).

Taxonomic Analysis

The next analytic step was to identify taxonomies among the domains. Taxonomies pull together the relationships of identified domains (Spradley, 1980, pp. 112-113). This is a deeper analysis of the connections, patterns and themes within and between the domains. It involves regrouping the included terms of a domain into hierarchies and/or the creation of larger domains with domain subsets. A taxonomy is

described as “a set of categories organized on the basis of a single semantic relationship” (Spradley, 1980, p. 112). The first step in taxonomic analysis was to search for as many included terms as possible for the domains. Then, descriptions to elaborate on the included terms were formulated to provide subcategories of meaning.

An additional level of examination of the domains in this study revealed dominant domains that could subsume other domains. An example of this additional level of examination was that “comparison of illnesses” and the “‘looking great’ observation” were initially subcategories of theme #2, “Dismissal/Nonchalance.” After further analysis, they were subsumed under the subcategory “downplaying the seriousness of the illness.”

Spradley (1979) recommends narrowing the focus by organizing the domains to encompass the specified study aims. Two taxonomies were formed in this study: “Unhelpful support” and “Helpful Support.” The taxonomy, “Unhelpful Support,” groups five domains on the basis of the single semantic relationship of inclusion: Alienation, Dismissal/Nonchalance, Unsolicited Advice, Constraints, and Pressure for Positive Outcome. The taxonomy, “Helpful Support,” includes the two domains, “Demonstration of Caring” and “Management of Feelings.” Box diagrams are provided to illustrate these two taxonomies (see Figure 1 and Figure 2).

Componential Analysis

The third preliminary step provides a more in-depth examination of the boundaries of inclusion and exclusion between the domains and taxonomies. Spradley (1980) describes componential analysis as “the entire process of searching for contrasts,

sorting them out, grouping some together as dimensions of contrast, and entering all this information into a paradigm” (p. 133). Attributes are the criteria used by participants to determine whether terms are similar or different. This process helps to clarify the nuances of meaning related to the experience (Spradley, 1980, p. 138). Componential analysis in this study involved grouping the identified domains into the two taxonomies, “Unhelpful Support” and “Helpful Support,” as dimensions of contrast.

Theme Analysis

The final step for analyzing the data was to discover a cultural theme. Spradley (1980) describes a cultural theme as “any principle recurring in a number of domains, tacit or explicit, and serving as a relationship among subsystems of cultural meaning” (p. 141). Theme analysis involved synthesizing the identified major themes within and across the data to pull together the relationships among the domains. “Helpfulness of Supportive Offerings” was used to illustrate the overall cultural theme encompassing all of the domains and taxonomies that emerged this study. A schematic diagram is provided (see Figure 3) to illustrate the relationships among the domains and to show how they are linked to the cultural milieu (Spradley, 1980).

Techniques to Ensure Rigor

This research utilized several techniques to address four criteria proposed by Guba (1981) from which to judge the trustworthiness of a qualitative study. The four criteria are: credibility, transferability, dependability, and confirmability (Guba, 1981).

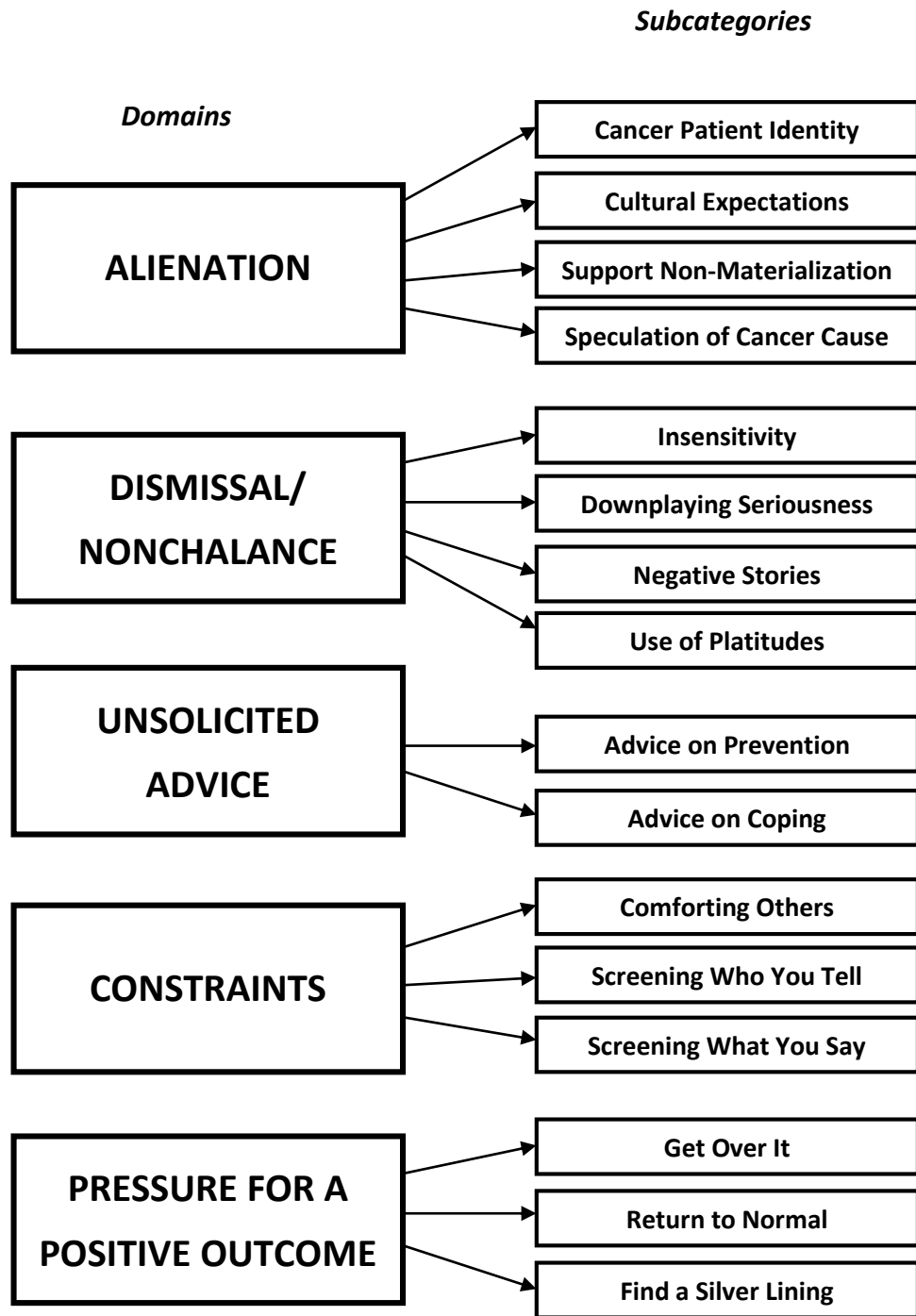


Figure 1. Taxonomy #1: Unhelpful Support

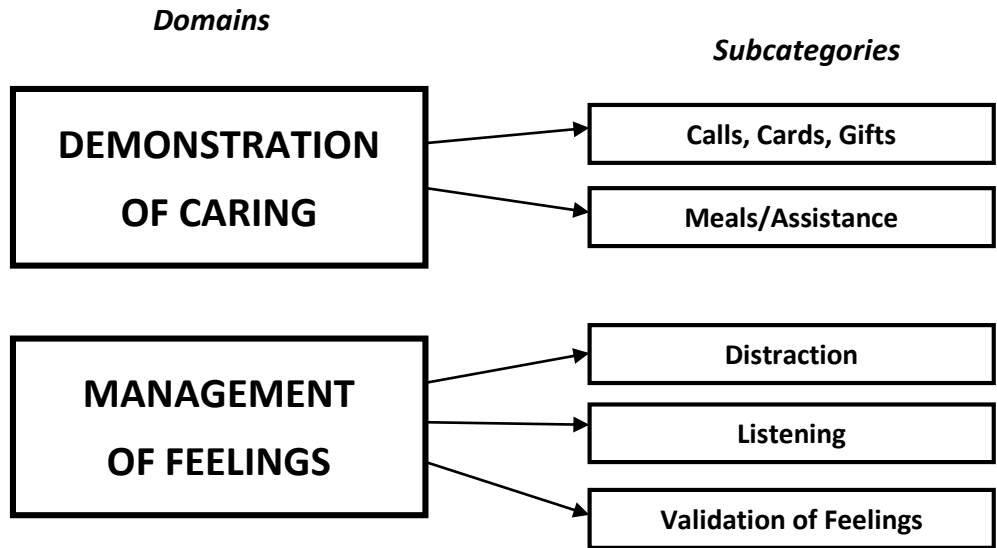


Figure 2. Taxonomy #2: Helpful Support

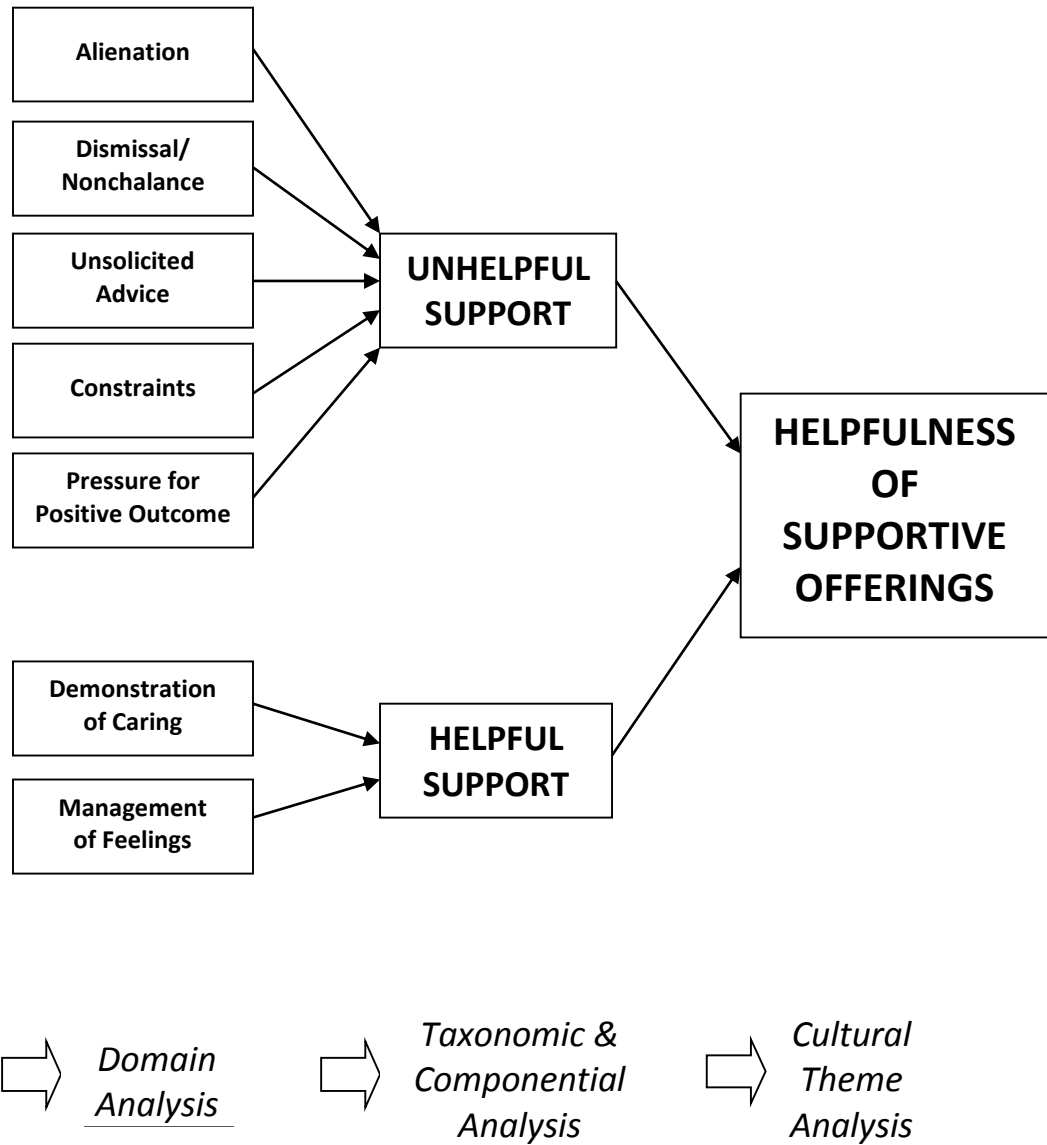


Figure 3. Cultural Theme: The Helpfulness of Supportive Offerings

Credibility refers to the confidence one can have in the truth of the findings from the perspective of the participant (Guba, 1981). Two main techniques were used in this study to establish credibility: triangulation and negative case analysis. Triangulation is a means of corroboration. This study used triangulation in both data collection and data sources. Triangulation of data collection was accomplished with the three methods of data collection: interviews, focus groups, and examination of artifacts. Triangulation was also enhanced with the multiple data sources from which the interview and focus group participants were recruited and from which the artifacts were retrieved. Triangulation provided a richer, more multi-layered data set than would have been provided with one method of data collection from one source. Negative case analysis was the second technique for establishing credibility. After the initial analysis was completed, a reexamination of each of the transcripts was conducted to search for responses that ran contrary to prevailing themes. These negative cases are discussed in the final analysis (Guba, 1981).

Transferability requires the researcher to provide a highly detailed description of their research situation and methods so that readers are able to determine whether the results of the study would transfer to other times, settings, situations or people (Guba, 1981). This was accomplished in the present study with “thick descriptions” of the phenomena of social support, using many quotes from the participants to allow comparisons to be made to another context (Guba, 1981).

Dependability refers to the stability of the findings over time (Guba, 1981). The first technique to enhance dependability in the present study was the use of the “overlapping methods” of interviews, focus groups, and review of artifacts. The second

technique that was used in this study was the detailed reporting, in clear, simple language, of the processes of data collection and analysis that was used in the study. This enables future researchers to repeat the work (Guba, 1981).

Confirmability refers to the degree to which the results could be confirmed by others (Guba, 1981). Investigator triangulation, a technique that was utilized in this study, helps to ensure that the findings are the results of the experiences of the participants rather than the researcher. This study used two research assistants in the analysis of the data to provide multiple perspectives in the interpretation of the data (Guba, 1981)

The credibility of a study includes not only transparency of the analysis used but also reflexivity on the part of the researcher (Guba, 1981. I). The framework of understanding that a researcher brings to a study has a significant effect on the research process. I realize the importance of acknowledging the beliefs I hold that inform this study. The assumptions that underlie the interpretivist ontology, phenomenological epistemology, postmodern influences and use of ethnographic methodology in this project have been addressed in the previous chapter. This section considers how my background and positioning have shaped the research process for this study. It outlines my own epistemological and ontological stance in relation to the present study and my rationale for choosing ethnography as a research method.

It is worth noting that I bring prior knowledge to the subject matter under inquiry. I am Caucasian, female, middle class, heterosexual, married, and an 18-year survivor of locally advanced breast cancer. I have worked with breast cancer patients as a medical social worker for ten years. These personal characteristics, experiences, and lenses have

guided my research interest, the methods judged as most adequate for this investigation, the analysis of the findings, and the framing of the conclusions.

My interest in the topic for this research was sparked about ten years ago when I became a facilitator for a breast cancer support group at a local cancer support agency. During the support group meetings, I observed that group members expressed appreciation for support from others, in general, but they also described support behaviors by family and friends which had aggravated, rather than alleviated, their distress. I was intrigued by their descriptions of such paradoxical effects of social support. Since the descriptions of this phenomenon emanated from their lived experiences, a phenomenological approach, based on the interpretivist perspective, was chosen to guide the research. I selected the research methodology of ethnography as the best way to study this topic because I view what matters to breast cancer patients in terms of social support as important.

This section outlined my personal and professional background with breast cancer, the theoretical framework I operated within, and an awareness of the lenses I brought to the research process. It allows the reader to evaluate how my preconceptions, beliefs, values, and assumptions may have come into play during the research process. An “audit trail” or detailed report of the data collection and analytical steps taken in the study, describing the procedures and the decisions made is provided. This will also allow the reader to judge the potential for bias in the choices underlying the pattern and category foundation for the study (Guba, 1981).

Chapter Summary

The current study used interviews, focus groups, and autobiographies to give voice to breast cancer patients' perspectives regarding the helpfulness of support offerings. This chapter outlined the study design, sampling, data collection, procedures, protection of human subjects, data analysis, and rigor that was utilized in the research project.

CHAPTER FOUR

RESULTS

This chapter begins with a description of the research participants. The research purpose is restated and then the themes and subcategories that were identified from the data are presented. The responses reported in this chapter were obtained from 20 individual interviews, 2 focus groups, and 20 written artifacts in the form of published autobiographies by breast cancer patients.

All of the interview and focus group participants in the study were female. There were a total of 20 participants. All of the participants were individually interviewed and seven of them also participated in both of the focus groups. They ranged in age from 44 to 65 years old, with a mean age of 56. Thirteen of the participants were married, three were single, three were divorced, and one was widowed. Fourteen of the participants were Caucasian, three were Hispanic/Latina, two were Asian, and one was African American. Eleven of the participants reported an education level of some college, five reported a high school education, and four reported a bachelor's degree.

Fourteen of the participants' cancers were at Stage II, five were at Stage III, and one was at Stage IV. Time since initial diagnoses ranged from 2 months to 18 years. In terms of breast cancer treatment, 35% of the participants had undergone lumpectomies. Another 15% initially received lumpectomies and subsequently had mastectomies. At the time of their participation in this study, a total of 65% had ultimately undergone mastectomies, 65% had received chemotherapy treatment, 65% had received radiation therapy, and 50% had received other treatment

Purpose of the Research

The purpose of this research was to understand the experience of social support from the perspective of breast cancer patients. The ethnographic research method was used to move beyond a privileged and authoritarian telling of the experience by giving voice to breast cancer patient's views regarding the helpfulness of supportive offerings. Interviews, focus groups, and autobiographies were used to present a multi-voiced description of their experiences. A central tenet of ethnography is that a culture's knowledge is reflected in its discourse which can be organized into relational categories that make meaning of their world (Spradley, 1979).

Findings

Themes are informed by both individual experience and the contemporary cultural context in which they occur. Themes are often tacit, outside the awareness of the participant, and are explicated by the analysis process (Spradley, 1979). Interview, focus group, and autobiographical excerpts are included extensively in this thematic account, so that the themes are grounded in the verbatim words of the informants. This helps the reader to become engaged in their reality. The findings of this study are presented in a way that illustrates the major thematic elements which were brought to light as the data was read and analyzed. The seven themes that became apparent in the analysis are as follows:

1. Alienation
2. Dismissal/Nonchalance
3. Unsolicited Advice

4. Constraints to Expression
5. Pressure for a Positive Outcome
6. Demonstration of Caring
7. Management of Feelings

While describing their experiences, these seven themes were not necessarily presented by the informants as separate entities. For example, some informants described how certain family members or friends responded with dismissive or nonchalant comments (illustrating Theme 2) and how such behavior was a non-materialization of the support they expected, which left them feeling alienated (illustrating Theme 1). The interaction between these two themes illustrates the complexity of the experience. Even though each theme is explored separately, they are interrelated and woven throughout the descriptions provided by the informants.

The seven general themes were subsumed into the two major taxonomies of “Unhelpful Support” and “Helpful Support.” The themes are reported under these two broad taxonomies and the subcategories of each theme are detailed.

Taxonomy: Unhelpful Supportive Offerings

Spradley (1980) holds that the understanding of a concept is facilitated by discovering that with which it contrasts. Accordingly, informants’ descriptions of what they found to be unhelpful are reported under this first taxonomy to broaden and deepen the understanding of the helpfulness of supportive offerings from their perspectives. Five of the seven themes identified within this taxonomy are described: Alienation,

Dismissal/Nonchalance, Unsolicited Advice, Constraints to Expression, and Pressure for a Positive Outcome. Subcategories within each of the themes are discussed in turn.

Theme #1: Alienation

Within the broad taxonomy of “Unhelpful Support,” the first theme, “Alienation,” included the experience of transitioning to the identity of a cancer patient, cultural expectations of the “right way” to be a cancer patient, the non-materialization of expected support, and speculation about the cause of the cancer. Informants noted social isolation as part of their illness experience. They sensed a divide between those who are healthy and those who have a serious illness. Many of them stopped working during their treatment and lost daily contact with coworkers. Encounters with the medical system, where they donned the requisite gown, were tagged with bar-coded wristbands, and were routinely referred to by their diagnosis or bed number, highlighted their patient status. While they were at home recuperating, friends and family members seemed to be busy with their own lives. Others seemed to have difficulty relating to the breast cancer patient’s new life circumstances.

Transitioning to the Identity of a Cancer Patient

An underpinning in the informants’ descriptions of social interaction was a sense of “otherness” after their diagnosis. The following quotes are a sampling from informants describing their feelings of being an outsider:

You’re normal one day and the next day all the lights are on you. “She’s got cancer.” I remember, I told my mom, because we ran this business and had customers, I said, “I don’t want anybody to know”...It was devastating to me. I

didn't want everybody to look at me and think, "Oh, she's got cancer." (Focus Group Participant)

I was on an airplane flight once and we were where you face each other. And this lady started talking about somebody who had cancer and it was in the lymph nodes. She said, "She's a goner. Isn't it so wonderful to be healthy – that we don't have cancer, you know?" I thought, "What a weird thing to say – 'we don't have cancer.'" So, she was going on about it, assuming the rest of us there were healthy. And then a young lady in her thirties said, "Well, you know, I had Stage IV ovarian cancer three years ago." And I thought, "Okay, I'm going to nail her too." So, I said, "Yeah, I had Stage III breast cancer with 13 positive lymph nodes." You know, you can never assume that somebody hasn't had cancer. (Focus Group Participant)

Bad things never happened to me. But, oh, how life can turn on a dime with just one phone call. One little phone call from that damned surgeon, and I had been ripped from the safety of the sidewalk and pushed onto a concrete ledge overlooking an overpass. I had become one of them, one of *those other types of people* [emphasis in original]. Pitiable. Pitiful. (Roppe, 2012, p. 223)

Cultural Expectations of the "Right Way" to be a Cancer Patient

Informants described how the experience of breast cancer that is portrayed in magazine articles and in movies or on television conveys normative messages that contrasted with their experiences:

The only thing that you see the mention of are things that kind of seem odd to me, things that glorify [breast cancer]. "She's a survivor" kind of thing. Like, they glorify that she was so brave and she went through all this. And you're never really given a true picture of what somebody who's going through this experiences. (Interview Participant)

I don't think you see a realistic portrayal of what to expect... It wasn't in anything that I had seen in the media. (Interview Participant)

You know Stuart Scott of ESPN? When he died, everyone focused in on that part of his speech that said, "You've got to live your life." But nobody focused in on the part – which I found more telling, because I'm a cancer person – was the

statement about how sometimes you have to let other people fight for you... That was the next sentence in his speech, at the ESPY Awards... He talked about how he could call his sister when he just needed to cry... For him to talk about crying, to me, that's the stuff I saw. But that's not what the media picked up at all. It bugged the hell out of me. (Interview Participant)

I watched every single episode of *Sex and the City*, thinking that I could be courageous and stylish like Samantha – you know, a fashion-forward cancer patient. (Grimaldi, 2014)

Not only did their breast cancer experiences contrast with images in the media, but informants also noted that their illness experience was not how they imagined it would be:

I think we have some funny beliefs about how someone should face cancer. The expectation is that you should just breeze right through it. (Interview Participant).

Well, I know before I had cancer, I didn't – I was not going to ever get cancer is what my thoughts were, it would be someone else. And I didn't have anybody that I knew had gone through it. So I really didn't understand the seriousness or what to expect. (Focus Group Participant)

The interesting thing for me was how surprised I was by my behavior. If you had asked me a year ago how I would react to having cancer, my prediction would have been 100% wrong. (Baum, 2014, p. 64)

Non-Materialization of Expected Support

Some informants' expectations about the reactions of others were also not what they expected. The following quotes illustrate how it contributed to their feelings of isolation:

It's very sad when you have a husband or a mom or a family member or friend that you expect a different reaction from, and then you don't get it. Your world just goes upside down in your biggest time of need. (Interview Participant)

[My husband] took care of business in such a way of driving me to my doctor appointments. He sat in on a couple of those. He was there during the surgeries. But he never once, for example, put his arms around me and said, “I’m here with you for this.” I didn’t feel like I could cry on his shoulder or let my defenses down at all – which was difficult because I was scared and I was concerned and worried. I didn’t know what to expect and it was a very frightening, you know, it’s a very frightening situation that you find yourself in. And so, I was very disappointed. And that continued through the whole process. (Interview Participant)

I think [my husband] has been in denial that I have breast cancer. It is too scary for him to comprehend, so he buries it, and escapes by going to the office. His behavior was the one big surprise throughout this whole thing. After being best friends for twenty years I did not expect him to react as he did. To this day I still don’t understand his behavior and I’m still angry. (Stevens, 2000, p. 35)

Speculation Regarding the Cause of the Cancer

Informants described how others’ seemingly benign questions sometimes took on an accusatory tone, insinuating that the onset or outcome of their illness was the result of their lifestyle. They also speculated that, by blaming, others achieved a false sense of security that serious illness would not befall them. The following excerpts describe the alienation that informants felt when conversation turned to a differentiation between each other’s lifestyles:

I have a yoga class that I go to. [The yoga instructor] was really encouraging when my hair started growing out. She didn’t want me to wear the wig to class. It was the first place I went without a wig, because of that encouragement. But then, on the other hand, during our conversations, because we had – during this retreat we would talk about the different things. And it’s her belief that it was something in your life that caused the cancer, which I totally disagree with. It was an uphill battle trying to have people understand that it’s not because of something I had done... So that’s an interesting phenomenon that I think, if I could straighten anybody out, that would be the number one thing on my list, that it is not something that I have done in my life that caused this curse. (Interview Participant)

We had someone at work who was diagnosed with cancer before me and I've heard people at work who would say, "Well, if she hadn't lived the lifestyle that she had." I got all over them. I said, "That is a horrible thing to say. Who are you to say that?" It just made me so angry – it's stupid, too. I think what offended me most about this is that it was a moral judgment. And I found that to be extremely offensive. (Focus Group Participant)

Friends treated me with concern...asking how they could help, and strangely, why I thought I got breast cancer. What did I do, they wanted to know. That question hurt. I know now they were trying to distinguish themselves from me for emotional safety. If they could say I got cancer because of something I did – knowingly or unknowingly – then they could breathe a sigh of relief because they hadn't done that. (LaTour, 2006, p. 14)

Theme #2: Dismissal/Nonchalance

The second theme, "Dismissal/Nonchalance," which was also within the taxonomy of "Unhelpful Support," included the subcategories: insensitivity, downplaying of the seriousness of the illness, negative stories, and the use of platitudes. Informants recognized that certain people had difficulty understanding and relating to their situation which led to uncomfortable exchanges.

Insensitivity

The following excerpts are a sample of some of the thoughtless comments from others that added to informants' distress:

They say, "Oh, you had breast cancer?" Meanwhile, they're looking at your chest trying to figure out which side. I had a customer, a man, he's like, "How are you doing? What's your prognosis?" I thought that was odd. What are you supposed to say to that? It caught me off guard, so I said, "Pretty good." And then he goes, "Which breast was it, your right or left?" (Focus Group Participant)

The one that actually made me mad...was “I know you wouldn’t let anything happen to you. You’d never leave your girls.” That one implies that if I were to succumb to cancer, then I didn’t care enough about my girls to try hard to live. Like, if I were to die, then I was just a bad mother. (Roppe, 2012, p. 253).

Downplaying the Seriousness of the Illness

Informants described how minimization of their breast cancer experience suppressed further discussion and left them feeling that others did not understand or care about what they were going through:

I already did have one person, they’re not close to me, and I know she means well, but she said, “Oh, Stage II, you don’t need to worry at all.” I didn’t say anything to her but I was thinking, “You’re not the one with the cancer.” It confused me in a way. I thought, “Well, yeah, I’m grateful that it’s Stage II, but does that not mean that I need to be concerned? Is it not still serious?” Cancer is cancer. (Focus Group Participant)

“But you know, any one of us could be crossing the street tomorrow and get hit by a bus!” I know this was a genuine effort to make me feel better, to reassure me cancer wasn’t really adding any element of uncertainty to my life. Or else bus-pedestrian accidents have risen to epidemic proportions. Maybe these people are just appallingly lax about looking both ways, but I’m pretty sure that until Stevie Wonder or Ray Charles gives up singing and starts driving a bus, cancer will still be significantly more perilous than crossing the street. (Rodgers, 2001, p. 46)

Comparison of illnesses. A different example of downplaying the seriousness of the illness was that others sometimes responded by making comparisons with their own illnesses. Such comparisons left the breast cancer patients feeling that their concerns were discounted:

I had a friend who has Type II diabetes, and she said, “Oh, I’d much rather have breast cancer than diabetes.” I said, “What?” And she goes, “Well, you know, you have that whole system – Komen and Race for the Cure and all of that.” And I thought, “But with diabetes, you can manage it and get it under control – you can’t do that with cancer.” (Interview Participant)

I think there are so many times that [breast cancer patients] just need to talk. And it doesn't need to be a competition of who was sicker. (Interview Participant)

When I told a relative about my second mastectomy...she acted like I had not even said anything and instead proceeded to tell me about her upcoming possible surgery and a family member's "self-diagnosis" of cancer...I wondered, "When did news about cancer become a competition about who is the sickest person in the family?" (Thompson, 2014, p. 79)

"Looking great" observation. Another example of dismissal that came up repeatedly, and doesn't seem obvious as something that would be distressing, was the comment from others, "You look great!" Informants explained that they felt compelled to enact a charade when such comments were made. The following excerpts describe these encounters:

I remember one day, my husband had taken the trash out to the curb. And I was standing out at the curb. I had a baseball hat on because I was as bald as a cue ball. And these people down the street, you know, our kids had gone to school together since they were in kindergarten, they're walking down the street and they go, "Hey, you look great. What have you been doing lately? You look great." And I look at them and I'm going – you just look at people and you think, "You cannot be this dense." I have no eyebrows or eyelashes. I have no hair, no boobs. I'm sorry – I can't – even if I had on makeup – you could tell under my baseball cap there's no hair...It's like you don't know how to react. I still don't know how to react to people when they say stuff like that. (Interview Participant)

My sister-in-law came over. I had no makeup on. I was in my robe. I wasn't about to play hostess like I always do. I wasn't about to do that. I wasn't feeling up to that. It was a few days after my surgery. My sister-in-law said, "Oh, you look good!" And I'm thinking, "What?" (Focus Group Participant)

I cannot play at social niceties. I am too exposed, too sensitive. Friends and family coddle me, and lie to me, saying I look terrific. (Rakoff, 2010, p. 168)

Negative Stories

Although informants reported that most friends and family members tried to focus conversation on positive topics, some reported that others related tragic stories to them about other breast cancer patients they had known:

When I had my mastectomy, the nurse came in and said, “My aunt had breast cancer. Oh yeah, she died.” We just kind of looked at her like, “Okay, you can leave now.” (Interview Participant)

People come up to you, “Oh, you have breast cancer? My sister just died from that.” Or, “I had an aunt that died from that.” It tripped up my day. This girl I know calls me one day and says, “I’ve just got to tell you, I had a dream. You died, and an angel appeared.” Yeah, thanks. (Focus Group Participant)

Every now and then you get caught unawares, blindsided by someone who means well but is, in the truest sense of the word, thoughtless. I’m thinking of a man I met who had lost his beloved wife to breast cancer about a year earlier, and who, upon hearing that I had just been diagnosed, told me all about her long, sad struggle. (Lewis, 2008, pp. 29-30)

The Use of Platitudes

Informants also related that some friends and family members seemed glib in their responses, ready with an easy answer. Although they were meant to be encouraging, these supportive offerings minimized their situation with a simplistic view of the problem. The following excerpts describe such superficial exchanges:

I was raised Catholic, I went to Catholic school for 12 years, but I’m not practicing now. But, this whole “God has a plan” – I think it’s a crock. I also think, “Really, you think he’s sitting up there and he’s looking at billions of people on Earth and saying ‘I think you need a challenge. I know you can handle this and it will make you better’? (Interview Participant)

Strangers either ignored me or uttered one of about ten stock platitudes... “God has a plan. God doesn’t give you more than you can handle. Everything happens

for a reason. Stay positive.” (Mind you, I don’t actually disagree with any of these statements, and I understand completely that some people don’t know what to say. Still, when you’ve heard the same exact sentiments, however sincerely meant, from fifty people, it’s hard to refrain from checking off a mental box when they’re shared.) (Roppe, 2012, p. 253)

Theme #3: Unsolicited Advice

The third theme “Unsolicited Advice” within the taxonomy of “Unhelpful Support” included advice from others on how to prevent the recurrence of the cancer and how to cope with the illness. Informants observed that others sometimes offered a bromide or quick fix which seemed to underplay their plight.

Advice on Preventing the Recurrence of Cancer

Advice on how to prevent the recurrence of the cancer is presented in two sections: lifestyle changes or alternative therapies that should be pursued and the curative effects of positive thinking.

Lifestyle changes/treatment. Informants described how advice about diet, lifestyle, or alternative cancer treatments was unhelpful. Some felt the advice insinuated that the onset and outcome of their illness is a result of their choices. The following quotes describe the distress that informants felt and the perception that they were being blamed for the cancer:

[My mom is] always trying to look up stuff in books. “Oh, I heard from so-and-so that, if you take such-and-such, it will help you and it will cure the cancer.” And members at church that are in the prayer group have told me that I should try herbs and different things. I am always getting that from my mom. And sometimes it’s overwhelming because, “Did you buy it?” you know, “No, Mom, not yet.” “Did you Google it?” “No, Mom, not yet.” “Well, what have you been doing?” (Interview Participant)

My husband told people at work and someone sent a book home with him, different things to do. I just looked at it and put it aside. I'm like, "No." People suggested different things, little things. But, you know, I knew what I had to do. That other stuff was just hodge podge. (Interview Participant)

My friend in Arizona, I'll give her a 90%. The 10% I have a problem with is when she sends me a text saying, "I'll know how serious you are about fighting this cancer by how many sweets you get out of your diet." (Interview Participant)

My father-in-law thought it was horrible that I was going to have chemotherapy, horrible. He really sympathized with me, but he thought it was just the pharmaceutical companies in cahoots with the doctors. That I didn't need it, I could fight this without it. But everyone else said, "She's got to do this." And I told him I was going to do it. (Interview Participant)

Free health advice was also abounding. There was a Shackley/Magic Herbal Tea/Bolivian Healing Kneesocks salesperson behind every tree, and every one of them had a full presentation to make on the Evils of Chemotherapy (or the Evils of Alternative Medicine or the Evils of Radiation or whatever didn't involve buying large quantities of their particular multilevel marketing product). My sister...sent me a book called *Battle Cancer and Win!*...The battle plan basically consisted of a vegetable juice diet and frequent coffee enemas. I guess maybe I could have dealt with the veggie juice, but hey – Mr. Coffee and I don't have that kind of relationship. (Rodgers, 2001, p. 132)

The curative effects of positive thinking. Many of the informants related that having a positive attitude helped them to be able to cope with their illness. But informants also described that encouragement from others to maintain a positive attitude sometimes insinuated that they were accountable for the onset, progression, and outcome of their breast cancer as a result of their attitude or outlook. Informants found such advice unhelpful:

There's this whole thing out there that we create our own reality, that staying positive can defeat cancer. And if [the cancer] doesn't go away...then it's your own fault. (Interview Participant).

I heard somebody say something along the lines that, if it progresses, then you've failed...But it's out of our control. (Focus Group Participant)

Death by Bad Attitude. Smile or else, baby. I suspect a lot of the positivity pushing is the product of well-meaning but unimaginative friends who don't know what else to say, yet feel obliged to say something. (Hint to those people: Try listening instead of talking.)...Do you really believe any random cancer cells are taking note of your outlook on life before deciding whether to metastasize or die?...If my brain could control my body, I would be five feet eight, a size two, and eat as much fatty food as I wanted. It should be a lot easier to mentally jack up my metabolism than to find and destroy cancer cells...[Breast cancer patients] have enough to worry about without having to feel like a failure at Attitude Camp. (Lewis, 2008, p. 75)

Advice on Coping with Cancer

Support providers also offered advice on how the breast cancer patient could better cope with their illness. These supportive offerings are presented in three sections: encouragement to not worry by looking on the bright side, inspirational stories, spirituality/religion, and pressure to be brave and strong.

Don't worry/look on the bright side. Informants described others' admonitions to not worry or encouragement to focus on the bright side of the situation. Some felt that others emphasized this viewpoint in order to shield themselves from discussion of the negative or serious aspects of the breast cancer experience:

What's not helpful to me is when people go, "Oh, but you could be in the other percentage. Don't listen to statistics." I'm sorry but, to me - for me, I like statistics...Those numbers matter. It might make you, whoever says that to me, uncomfortable that I have a 30%-40% chance of recurrence, but to me, it's reality. So, that's always unhelpful. To me, it's like, "Listen, it's real." And I'm a realist...I've never been in the good numbers with this. I got my very first clear scan in January of this year...for the last 15 months, I've been holding my breath. (Interview Participant)

When I have “scanxiety,” that’s what I call it when I’m waiting for the scan - oh my God, I get so anxious, it’s unbelievable. “Oh, you’ll be fine.” I haven’t been fine yet. I haven’t had one good scan. (Interview Participant)

My husband was more like, “Oh, you’ll be fine. You’re not going to die”...But as a patient, you’re thinking, “Oh, my gosh. You never know.” (Interview Participant)

I had a weird breast cancer, triple negative, so nobody that I knew ever had triple negative. And so everybody would always say, “Oh, but it’s so curable” or “You’ll be cured” or all those things. And I think that’s people’s way of dealing with it. Which is good but it’s not helpful. (Interview Participant)

I don’t want to hear any “Oh, but it’ll be okay” or “Tomorrow’s going to be better” or “Now, it’s not going to come back” or “This is going to take care of it.” If I felt like I was going to have a panic or I was sick and I couldn’t handle it... I just needed to be able to lose it and, if I needed to, be a crazy person and cry. (Interview Participant)

When my family tells me I am going to be fine, I feel as though they are in denial, not facing the reality of the situation. No one, including my doctors can tell me that. Maybe saying it makes them feel better, but I still feel that my cancer is going to kill me one day. (Stevens, 2000, p. 249)

Inspirational stories. Informants described negative stories as unhelpful because they were insensitive, as previously noted. Some informants also found positive stories to be unhelpful because they outlined unrealistic expectations about how one should experience their cancer:

The last thing I wanted to do was read inspirational stuff from somebody else. I just did not want to do that. And this one friend of mine...he sent me this email and it was this journalist who went on this journey and ended up dying. You know I really resented him sending that to me. And I had another friend that sent me a book...about this woman who had cancer and how she started support groups...As far as any inspirational stuff, I was not interested. (Interview Participant)

Octobers past, I was one of those people clipping the stories and passing them along, in this case to Cindy who, being what some term a survivor, certainly would want to read them, right? I saved for her, alerted her, all along the way of the eight years since she was diagnosed and had the mastectomy and the chemotherapy and went on to the great efforts of resuming life in the wake of all that. I felt I was doing her some good. But then I landed on the receiving end of all this. And I realized that, no matter how well-intentioned the piece, most of what was being put out there for Breast Cancer Awareness Month was devoid of information or simply was feel-good material that skirted reality. (Shea, 2002, pp. 72-73)

Spirituality/religion. Several of the informants related that their own spirituality, religious faith, and prayers helped them to cope with their illness. In terms of supportive offerings from others, a few of the informants remarked that they felt touched or were strengthened by the knowledge that others, including strangers, were praying for their recovery. One of the interview participants reported that she found it helpful when members of her bible study group sent her cards with scriptures. The theme of spirituality and religion emerged most often, however, as an example of unhelpful support. In these cases, the insinuation was that the breast cancer patient had lived less righteously than others, that God did not hear her prayers, or that her imminent death might be part of God's plan. The following excerpts describe how conversations about spiritual/religious issues sometimes left them feeling blamed for their illness:

I have a mother-in-law. She lives back east and she's older. And she's very kind. But she always says, "I'll pray for you." And I had the hardest time with her because of just one phrase that she says to me. She says, "You've been on my mind and I've been praying for you. And, if it's God's will, this cancer will be gone"...That it would be God's will that the cancer comes back. I don't have much conversation with her because I know she's going to say that every time we talk...I've avoided her. That's not her place to say that. All you need to say is "I've been praying for you – period." Because it's laying some kind of judgment on me that I've done something to bring this upon myself. (Interview Participant)

Something that really bugs me – and I mean even worse than God screwing up my order – is when people try to tell someone with cancer if their faith is strong enough, they’ll be healed. The obvious implication here is that, if they’re not healed (in the narrowest sense of the word), their faith was somehow lacking. There’s an assumption that if God doesn’t answer our prayer as mandated, he must be screening calls from those of us who lack the spiritual ta-tas to get his attention. (Rodgers, 2001, p. 148)

Be brave/be strong. Informants noted that, when others commented on their strength or bravery, they felt discouraged from freely discussing feelings of fear, anger, depression, or grief. The following quotes describe the pressure they felt to keep a brave front:

They would just say...“You’re strong.” It’s always, “You’re strong.” “You’ve just been so strong though this whole thing.” And inside you’re just crumbling. But you have to have this – I just felt like I had to hold it in. The more they told me I was strong, the more I felt I couldn’t talk about it. I wasn’t as strong as they thought I was. (Interview Participant)

I think comments like, “You’re so strong” or “I just can’t believe how strong you are” – and I’m thinking to myself as I’m lying in bed, “I can’t even get to the bathroom because I’m so tired.” “Oh, you’re so strong.” And I’m thinking to myself, “No.”...And so, that was the expectation. (Interview Participant)

I remember going in for my treatments and I would always have a smile on my face. I’d always be happy when I went. I don’t know why, because you’re going in to hell, you know. You’re going in for this treatment that’s poisoning you. You know what it’s going to do to you after you leave. And I didn’t want to go. But once I got there, I was sometimes a different person, I think. I took on a different persona...And my husband would go with me, and my mom, my daughter, my in-laws. I wanted them to see that I was strong, a smile on my face. And then afterwards I’d take to my bed. I don’t know why I would do that. I don’t know. I think because I didn’t want to let people down, thinking that I wasn’t strong. One day, maybe I’ll tell them, “You know, I wasn’t really as strong as you thought I was.” I think that’s important for people to know. I really do. (Interview Participant)

Luckily, everyone with cancer is issued a Brave Sick Person Face. It comes with the wig. If your prognosis is really bad, you may even be upgraded to Saint Sick Person. She's so brave, people said, as I stumbled through long months of chemotherapy. What a great attitude, what an inspiration...The National Coalition for Cancer Survivorship has published a Patient's Bill of Rights, which states, among other things, that we are not obligated to act any more upbeat than we really feel. And I was so grateful, because really, that big yellow smiley face plastered to the front of my head got a little too heavy sometimes, and I had to sink into the mire. (Rodgers, 2001, pp. 174-175)

Theme #4: Constraints

The fourth theme, "Constraints," which was also within the "Unhelpful Support" taxonomy, included the subcategories of perceived obligation to comfort others, screening who to tell about the diagnosis, and censoring what is said. Although informants reported that they were able to openly discuss their feelings with some of their family and friends, the instances of social constraints to such emotional expression were frequently brought up as having added to their burden.

Obligation to Comfort Others

Informants described how a perceived pressure to provide comfort to other family members and friends felt constraining and added to their distress:

You have to start slowly telling people and I think that's hard because you know that it trickles down to everybody. And you know you're going to have to make a lot of phone calls because you don't want people to be mad like, "How could you tell so-and-so before me?"...And it's just so draining. (Interview Participant)

At first, when I told [my in-laws], I had to comfort them. I had to comfort them and tell them it was going to be okay. It was just weird, you know, because I had to be the strong one for the whole family. So, figure that out! (Interview Participant)

I don't want to have to take care of everybody else. They should be taking care of me... [I'm] the one going through this. (Interview Participant)

You have to be careful who you have around you. You have to say, "I can't pat your back. I need to take care of me." (Focus Group Participant)

On the way to the hospital I'm bothered by something in this bad novel I've been given. The main character, who had breast cancer a couple of years back is advising a friend who's just been diagnosed that she should make a list of things that her friends can do for her. They will want to do things. It'll make them feel better, says the survivor. And I wonder why now, at the worst time of somebody's life should the woman in shock be thinking about finding a pen and a piece of paper and making a list of stuff so other people can feel better. Other people. Other people. What about her? What about me? I know it sounds whiney, but it seems ridiculous to me to go to that effort of worrying about others when the others are totally capable of feeling better if they want to. I rant about this, in the car, aloud, alone. (Shea, 2002, p. 176)

Screening Who You Tell

Most informants related that it took a great deal of time and energy to keep everyone updated about the status of their labs, tests, and treatments. Many of them avoided the emotional difficulty of repeating their story by sending mass e-mails, posting updates on a website, or having someone else serve as an intermediary. Another feature of maintaining a support circle, however, was dealing with others' reactions to news. Some informants related how they kept their support circle small, screened who they told, and limited contact with others:

The fewer people that knew, the fewer I had to deal with as far as getting them through it. (Interview Participant)

Nobody knew. I didn't want the sad looks. I didn't want the devastation of them knowing. So, I just chose to tell about five people. (Interview Participant)

I knew I had to tell my parents and [my husband's] parents, but I didn't want to tell anyone else because I didn't want any fake sympathy. Don't feel sorry for me. Don't act like you feel sorry for me. We were on the outs with my brother-in-law and his wife, for something else... We hadn't talked very much. We used to be very close. I didn't want them to say, "Oh, I feel so bad for you." You know what? You didn't care for two or three years before. Why do you care now? That's what I didn't want. I didn't want to tell them. (Interview Participant)

My biggest fear was telling other people about my cancer because I wasn't sure I could handle their reactions. Initially, it was all I could do to keep myself together emotionally. I just couldn't deal with the concerns or emotional needs of others. (Schwan, 2005, p. 9)

Censoring What You Say

Even though breast cancer patients find it helpful to confide in others, they may feel constrained from doing so. The setting where the question is asked may lack privacy or only allow the time for a quick reply. The seemingly helpful question, "How are you?" can also feel like an invasion of privacy when it is asked by a casual acquaintance. Some informants related that, when they felt good enough to attend a social gathering and wanted to feel "normal" for a few hours, they were inundated with questions. Informants sometimes sensed from others' behavior that, even though some expressed interest, they were not really interested in hearing details of the illness or treatment. Informants describe how they kept disclosures to a minimum and censored their replies:

I guess because you can hear it in people's voices ... So, as a means to protect yourself, I think you just kind of don't offer up a whole lot of things. I would just say, "Yeah, I'm on chemo number whatever." (Interview Participant)

I think for the most part, when people ask, I'm not a hundred percent sure that they want to know. I really don't think they want to know about the long-lasting – the gift that keeps on giving. (Interview Participant)

They'll see me and they'll ask me, "How are you doing?" And I'll tell them, "Oh, I'm doing okay." And that's it. They won't – it's like they don't really want to get involved that much or know too much. I don't know if they have reservations because it's depressing and they feel uncomfortable? (Interview Participant)

If I'm in a lot of pain, or sick, and you say, "How are you doing?" I'm going to say, "I'm fine." Because I don't want to [ruin] your day. Are you really asking me how I'm doing? Say, "But really, I want to know how you're doing." Or are you asking me because you want me to say, "Good! How are you?" So, if you ask me how I'm doing, be prepared for the answer or don't ask. (Interview Participant)

Sometimes when people ask how you're doing and you don't want to tell them, you just say, "Oh, I'm fine." But inside you're crying. (Focus Group Participant)

You also find that the customary greeting of, "How are you?" has suddenly become a loaded question buried in an emotional mine field. You have to muster every ounce of self-control to reply with the anticipated rejoinder of, "Fine, thanks. And you?" instead of collapsing into the other person's arms in a sniveling heap. (Hamilton, 2013, p. 12)

Theme #5: Pressure for a Positive Outcome

The fifth and final theme from the taxonomy of "Unhelpful Support" was "Pressure for a Positive Outcome" and it included others' expectations that one should get over the illness at the end of treatment, return to normal, and find a silver lining to the illness experience. Informants described their indeterminate state after treatment ended which contrasted with others' expectations of a resolution and positive outcome. Each subcategory is described in turn.

Get Over It

Although others tended to view the illness experience as over once the treatment ended, informants described the lasting uncertainty that remained for them and their

reluctance to celebrate milestones. One informant described the difference between her recovery from an injury, which was finite, and the infinite nature of her breast cancer experience – “at least until it kills you.” The following excerpts describe informants’ reluctance to a neat and tidy ending to their story:

They all just say, “You’re fine, you’re done, your cancer’s been removed. You went through treatment and it zapped everything and you’re good.” So, they just think that I’m good to go now. I’m not. You still have fears. That’s how I thought I was going to be. Now that I’m there, it’s not like that. (Interview Participant)

I’ve got a lot of chemo side effects I’m trying to get through. And today is my one-year anniversary of chemo stopping, but, you know, I’m not better. But they’re ready to get on with it, you know... It’s not like you can just say, “Okay, I’m done with chemo, so I’m better.” (Interview Participant)

She and I talk about what the end of treatment means to me. I tell her I know the last day is Thursday, three days away, but that I’m not really spreading the word, because I’m fearful people will do kind things like bake cakes or come to my house with congratulatory banners, and I’ll have to throw things at them. I don’t want to borrow trouble, because I really don’t feel my experience is over. (Shea, 2002, p. 178)

Return to Normal

Some informants reported that they felt pressure from others to return to normal after their treatment was over. They related that others expected them to return to pre-illness routines and roles. They described how they felt changed as a result of their breast cancer experiences and could not return to their “normal” selves.

My sister is trying to plan a trip in June. June, to me, is like, I don’t know. I know June, to her, is around the corner. But to me, I don’t know what is going to happen. So, we will plan this trip, but be prepared if something happens. I guess travel insurance is going to become what you do. (Interview Participant)

You come to a point where you realize that you're never going to be that same person that you were before. Normal is different now. (Focus Group Participant)

I'm sick of reading all this Breast Cancer Awareness Month cheery stuff about how people are diagnosed with breast cancer and then a day after their surgery they're out campaigning for governor again. I'm not exaggerating – that was somebody's story... I'm still not back to resuming “normal activities.” Or feeling anywhere like the normal I once knew. (Shea, 2002, p. 118)

Find a Silver Lining

Although some informants related that they now have a different perspective and have made some positive changes in their lives after their illness, they also described as unhelpful the cultural pressure they felt from others to find some benefit from their cancer experience:

I think there are other ways to get meaning in your life than having a catastrophic disease....It really isn't a gift. Don't go there. I'd pass on it a hundred times. (Interview Participant)

Why does this cancer have such a loaded set of expectations that goes with it? I mean, I feel like I'm supposed to make something out of it – like it somehow improved my life. (Focus Group Participant).

Did you ever hear someone, usually a celebrity with access to, well, everything she could ever want or need, describe breast cancer as a gift?...Of all the maddening ways in which people try to search for meaning in the random meaninglessness that is breast cancer, nothing annoys me more than the women who declare that breast cancer is a gift. It's the social pressure to be the Good, Cheerful Survivor, taken to its extreme...Is diabetes a gift, or heart disease?... I'm not judging the women who say they're thankful that they had it, but I am compelled to point out that those women were given the greatest gift of all – good luck. They were lucky enough to have curable cancer...for tens of thousands of other women every year, it's a journey to tragedy. They're the ones...who fought just as hard, who were just as brave, who deserved to live just as much, but didn't. (Lewis, 2008, pp. 193-193)

Taxonomy: Helpful Support

Two themes are identified within the taxonomy of “Helpful Support”: “Demonstration of Caring” and “Management of Feelings.” Subcategories within each of the themes are discussed in turn.

Theme #6: Demonstration of Caring

The sixth theme, “Demonstration of Caring,” which was in the taxonomy of “Helpful Support,” included the subcategories: provision of calls/cards/gifts and of meals/assistance. Informants appreciated that others showed that they were thinking of them through their acts of kindness. Verbatim quotes from informants are presented in each subcategory to illustrate this theme.

Calls, Cards, Gifts

Several informants mentioned phone calls, cards, and gifts as helpful. One informant related that she made a piece of artwork out of all the cards she received, framed it, and hung over her mantle to remind her of all the good wishes that were sent by friends and family. Another reported that she would sit on the couch with her mom and they would read the cards together, crying. The following are quotes regarding such supportive offerings:

I did feel the love coming from those people from afar. Because I knew that they were thinking about me. And to me, even a card is a small gift. Somebody took the time to go pick one out that applies to you, write something out, mail it or bring it by. That’s a gift. And that all was love to me and I could feel it.
(Interview Participant)

Family members have their own lives, and so they would send me a card...a phone call once in a while, or something...Everyone, even neighbors, would come by and bring me things: gifts, or food, or flowers. Things like that. So, I thought that my outside support was great...Every time I got a card, for example, it stayed up. And I fed off of that love that I was feeling. It was very powerful to me to have those visible. (Interview Participant)

The phone never stopped ringing. I finally gave up answering it and sat there smiling and/or crying while listening to all the wonderful messages. (Brownworth, 2000, p. 100)

Not everyone found cards or flowers to be helpful, however. The following quote offers an alternate viewpoint:

The flowers started arriving – lots of them. My house looked like a morgue because I was getting so many floral arrangements. I hated that. Someone gave me permission to throw them out. I did. (Stevens, 2000, p. 193)

Meals/Assistance

Several informants found it helpful when others brought over meals or assisted with housecleaning or other tasks:

[My friend] would bring me meals and stuff – come and cook at the house. She cooked three or four meals for my family. Then, we’d meet up sometimes and she’d give me meals. (Interview Participant)

I did have a niece and she does work, and she’s a very busy girl. But she did come one day and wash my hair in the utility sink in the laundry room for me, because I couldn’t even wash my hair...I couldn’t get my arms up. (Interview Participant)

[My friend] took me down to my hair dresser so I could make an appointment with him to put color on my hair. And he said, “Well, come on in, I’ll do it right now.” I said, “I have to go get some money first. Let me walk to Wells Fargo first.” He said, “No, no, just come in.” And he colored my hair right there on the spot. Didn’t even charge me for it. Cut it, colored it, blew it dry. That was very supportive. (Interview Participant)

Taking a meal to someone is such a primal act. Even in our microwavable take-out, drive-through world, it survives like a flower pushing through the cracks in the cement...At first I cringed at so much goodwill...I felt as if good will were a bank account that I was depleting, casserole by casserole. I agonized about how I would ever pay it all back. (Nash, 2001, p. 130)

Some of the informants advised support providers to be specific about their offers or expressed appreciation for those who were insistent and didn't wait to be asked for help:

For someone like me, also, what is helpful and what my friends know about me is: just bulldoze me and show up. Don't ask me, "What do you need?" Because I'm going to say, "I'm good, I'm good." But my real good friends are going to know, "Let me bring her some food," "Let me stock her frig." (Interview Participant)

Some people would just say, "I'm coming to do it." I had people do that a couple of times and I appreciated it. (Interview Participant)

Many people asked if they could help, but their question was such a general one that I found it difficult to answer. On the other hand, if somebody called me with a specific offer, such as, "Can I bring over a meal? Or a pot of soup?" I almost invariably said yes, and was truly grateful. (Baum, 2014, p. 72)

Theme #7: Management of Feelings

The seventh theme, "Management of Feelings," is also within the "Helpful Support" taxonomy. It includes the subcategories of distraction, listening, and validation of feelings. The subcategories within the theme are discussed in turn.

Distraction

Several informants described a balance between needing time alone to recuperate

and process what was going on and wanting to forget about cancer for awhile. They related that occasional distractions provided by others helped them to manage their anxiety:

My best friend that would come over, she would just say, "Come on, let's go." She'd make me go do stuff. (Interview Participant)

I had a girlfriend that...drove me around and took me to lunch and, you know, did girl things - which was wonderful, because I wasn't able to do that otherwise. (Interview Participant)

I call the summer that I was in treatment "the summer of distraction." Because the more distracted I was, the better I felt. I would wake up in the morning, and maybe I wasn't feeling that good. I'd go for a walk and I'd feel better. Some friends would come over and we'd do crafting projects, scrapbooking and card-making. And while the people were there, we'd be chatting. And then when they would leave, I would be down, in a real pity party. But as long as I was distracted, I didn't pay attention to what I was feeling...I have a friend that I probably hadn't seen in two years but, when I was in treatment, she came every week. She took me to the library, we'd sit and read magazines. She'd take me out to lunch, take me back home. And I looked forward to it. It distracted me. Distraction really worked for me. (Interview Participant)

One of the things that I always had was my sister and a girlfriend to go with me to doctors' appointments and chemo. After, especially the chemo, we'd go thrift store shopping, just to get my mind off of it. (Focus Group Participant)

You don't want distraction 100% of the time. Sometimes, you need to deal with the reality of it and be able to talk honestly about what's going on and work through it. But certain days, you want to be treated like normal. You go through spurts. (Focus Group Participant)

Listening

Another theme that came up consistently when informants were asked what supportive behaviors were helpful to them was the importance of listening. Being able to

discuss their feelings with an empathetic listener was particularly valuable to them as the following excerpts illustrate:

Just listen. That's the biggest thing. I need you to listen to me. (Interview Participant)

Listen to them. That's all they have to do for the other person to feel better. Let her cry, let her speak, let her be comfortable with you and feel that you love them, feel that you are there for them, that they can depend on you and give you a call at whatever time that they need you. Because you just don't know when you're going to be feeling down. And if they're available for you, then that's a real blessing to be able to have family and friends like that. So, being there for that person and allowing them to speak out and hearing them out, that's awesome right there. (Interview Participant)

Sit and listen to me. Just let me talk. Don't judge me. Let me be weak. Let me cry. (Interview Participant)

One morning when I had just started losing a lot of my hair, a dear friend from Florida called and all I could do was cry. I told her that she didn't call long-distance just to hear me cry and she said if it helped she'd listen to me cry as long as I wanted to. She doesn't judge me when I'm having a bad day and lets me know it's okay. I found that most of my other friends only wanted me to be laughing and joking around like normal. If I got serious or quiet, they were uncomfortable. (Schwan, 2005, p. 95)

Validation of Feelings

Informants related that it was important to them to be able to authentically express their feelings and to feel that others understood their situation. They appreciated some acknowledgement of what they were going through and confirmation of their suffering from others:

I can cry with both of them. They let me have my feelings about things most of the time...they don't try to pooh-pooh me or "Oh, you're going to be fine"...They're the ones that are like, "Oh, my God!" (Interview Participant)

You don't have to say, "You're going to be just fine." Because it's like you're just brushing it off telling them, "You're fine." Validate their feelings. Acknowledge that they're going through something, "It's okay to go through that and have the feelings you have." (Interview Participant)

They'll say, "How are you really doing?" "Oh, my God, I feel like shit today." Whatever, you know. I think that's helpful. Mainly, you've got to be willing to let the patient have their feelings and not try to minimize it because you're scared or you're uncomfortable. (Interview Participant)

Verbal acknowledgement is helpful, like, "I hear what you're saying". If I say, "I'm scared" and they say, "Yeah, I'd be scared too," that is helpful...If they affirm my feelings, then I don't feel like I'm dropping down an elevator shaft. (Interview Participant)

I'm not sitting in judgment here. I have missed several opportunities in the past to speak up when people I care about have been in difficulty. It feels so hard to find the right words. Trust me, though, if you don't acknowledge the elephant at the table, it just gets bigger. "I'm sorry" is a perfectly acceptable thing to say. So is "That really sucks." (Kingston, 2009, p. 10)

Chapter Summary

This chapter began with a description of the interview and focus group participants. The themes that were identified from both the main and supplemental data sources, along with their subcategories, were presented within their representative taxonomies. The main sources of data were the individual interviews and focus groups. Published autobiographies by breast cancer patients were used to supplement the interview and focus group data.

Although there was some thematic variation between the data sources, the supplemental data substantially corroborated the findings of the main sources of data. There were no themes or subcategories that were not present in all three of the data

sources. The subcategories of “insensitivity” and “find a silver lining” were more dominant in the supplemental data source of published autobiographies. The subcategories of “screening who you tell,” “censoring what you say,” “meals/assistance,” “distraction,” and “listening” were more dominant in the primary data sources of interviews and focus groups. Extensive quotes from all three data sources were used to provide the reader with an in-depth understanding of the informants’ perspectives.

CHAPTER FIVE

CONCLUSION

The purpose of this ethnographic study was to produce a detailed description of the experience of social support from the perspective of breast cancer patients. The central question guiding this analysis was: What are participants' perceptions regarding the helpfulness and unhelpfulness of supportive offerings? The self-reported experiences of breast cancer patients were obtained from individual interviews, focus groups, and written artifacts. The data was analyzed using Spradley's (1979) Developmental Research Sequence. A greater understanding of the aspects of support that breast cancer patients consider to be helpful and unhelpful will inform both informal and formal providers, enabling them to optimize the salutary nature of their supportive offerings.

The preceding chapters have provided the literature review, methodology, and results of this study. The present chapter provides the limitations of the study, a discussion of the results, implications for informal and formal support provision, and recommendations for future research.

Limitations

There are important limitations of the study that affect its applicability to larger populations. The purposive sampling may have resulted in the selection of interview and focus group participants that were not representative of breast cancer patients in general. The sample size was small and not reflective of the overall diversity of the larger culture of breast cancer patients. The support groups and breast cancer clinic from which participants were recruited for this study may have attracted populations that differ from

other sources and, because participants self-selected to participate in the study, they may not have provided an accurate representation of the population being researched.

A limitation of interviews and focus groups is that they did not allow for naturalistic observation. Focus groups may also have been biased by the moderator or by a strong group member. A limitation of the written artifacts is that breast cancer patients whose writings have been published may not be representative of other breast cancer patients. The published autobiographies may also have been written with a specific purpose in mind which may not fit with the purpose of this study. A disadvantage of all three data sources was that the informants' views were from a specific group of people, captured at specific points in time and in specific contexts, and they may not be reflective of their perspectives across time or contexts. The data from published autobiographies were also from different points in time and settings than the data from the interviews and focus groups. Another disadvantage is the possible impact of social desirability. Cancer patients, in particular, are noted to feel pressure to project a positive attitude (Holland & Lewis, 2001; Wilkinson & Kitzinger, 2000).

Discussion

The narratives from this ethnographic study were rich in their descriptions of social support during the breast cancer experience. There were more domains categorized within the taxonomy of "Unhelpful Support" than within the taxonomy of "Helpful Support" in the study. One reason for an imbalance in the number of themes between the two taxonomies may be that breast cancer patients, in general, report more unmet supportive needs than other cancer patients (Li et al., 2013). Another reason may be that

many of the research participants were recruited from support groups and breast cancer patients who attend support groups may be less satisfied with the supportive offerings from their social networks. These participants may have been able to provide more examples of unhelpful supportive offerings from their experience than would the larger population of breast cancer patients. Also, the majority of participants in this study received chemotherapy treatment and research shows that cancer patients receiving chemotherapy treatment are more likely to experience unmet supportive needs (Boyes, Irgis, D'Este & Zucca, 2012). While there were a larger variety of unhelpful supportive offerings compared to the smaller range of helpful offerings that were described in this study, it is not necessarily indicative of the number of offerings that were experienced from each category. It is also important to note that supportive offerings may vary in their degree of helpfulness or unhelpfulness and the offerings described, whether helpful or unhelpful, may not have been valued equally by the participants.

Qualitative research is ideal for exploring unexpected findings in quantitative studies and the data from this study sheds light on why, in some studies, the provision of support is not positively associated with emotional adjustment to cancer (Cicero et al., 2009; Lepore et al., 2008). It also corroborates studies which show that even well-meaning support can be unhelpful and distressing to breast cancer patients (Curtis et al., 2014; Manne et al, 2005; Reynolds & Perrin, 2004). The following section places the current study in context by returning to the literature to indicate the relevance of these research findings to those of previous researchers.

Measurement of Social Support

The results of this study provide some insight into why 7 out of 40 support behaviors from the Inventory of Socially Supportive Behavior scale (ISSB) were undesired by the majority of breast cancer patients who participated in a study by Reynolds and Perrin (2004).

The subcategory of “speculation regarding the cause of the cancer,” under the unhelpful theme of “Alienation” in this study, is consistent with the two ISSB items, “tries to interpret or explain why I may have developed cancer” and “tries to show me that something or someone else was responsible for the cancer,” which were undesired consistently by over 90% of the participants in the Reynolds and Perrin (2004) study.

The “downplaying the seriousness of the illness” subcategory under the unhelpful theme of “Dismissal/Nonchalance” in this study concurred with the ISSB item, “reminds me that things could be worse” (undesired by 91.5%) from the Reynolds and Perrin (2004) study. The “return to normal” subcategory under the unhelpful theme of “Pressure for a Positive Outcome” in the current study is consistent with the ISSB item, “suggests I go on as before,” which was undesired by 80% of the participants in the Reynolds and Perrin (2004) study. The “use of platitudes” subcategory, under the unhelpful theme of “Dismissal/Nonchalance” in the current study, is related to the ISSB item, “gives philosophical perspective,” which was undesired by 80% of the participants in the Reynolds and Perrin (2004) study.

The subcategory of “advice on how to cope with cancer” in the unhelpful theme of “Unsolicited Advice” in this study relates to the ISSB item, “suggests a better way to deal with my situation” (undesired by 81.75%). And finally, the “spirituality/religion”

subcategory under the same theme is consistent with the ISSB item, “encourages me to use religion,” which was undesired by 64% of the participants in the Reynolds and Perrin (2004) study.

The top five ISSB supportive items from the Reynolds and Perrin (2004) study were also consistent with some of the helpful support identified in this study under the helpful theme, “Management of Feelings.” The “distraction” subcategory related to the ISSB items, “asks if I want to go out” and “treats me normally.” The “listening” subcategory was consistent with the ISSB item, “lets me direct conversation.” The “validation” subcategory was in agreement with the ISSB items, “tries to understand situation” and “identifies with how I feel.”

Context with Previous Research on Unhelpful Support

The following section discusses the present study findings on unhelpful support as they relate to the results from previous research. Five themes are identified within the taxonomy of unhelpful support: Alienation, Dismissal/Nonchalance, Unsolicited Advice, Constraints, and Pressure for a Positive Outcome. Some subcategories within the themes are also discussed.

Theme #1: Alienation

The findings from this study provided in the subcategory of “cultural expectations” under the unhelpful theme of “Alienation” give credence to theories proposed by Ehrenreich (2009), Kleinman (1988), and Kroll-Smith (2003) about cultural and social expectations shaping the experience of breast cancer. Another subcategory,

“non-materialization of expected support,” from within this theme, supports previous research with breast cancer patients in which they reported a non-materialization of the kind of support that they anticipated or needed (Rosedale, 2009; Shands et al., 2006; Wilmoth & Sanders, 2001).

It has been suggested that supportive behaviors with an underlying message of blame are perceived as unhelpful by the recipient (Cohen et al., 2000) and that such behaviors provide a false sense of security for others (Ryan, 1976). Informants from this study related that others’ questions regarding the cause of their cancer were unhelpful for similar reasons. These were expressed in the subcategory, “speculation regarding the cause of the cancer,” under the unhelpful theme of “Alienation.”

Theme #2: Dismissal/Nonchalance

Informants from this study provided several examples in the unhelpful theme of “Dismissal/Nonchalance” that coincide with previous studies where breast cancer patients related that others avoided discussion of their illness (Mosher et al., 2013), seemed disinterested in important illness-related issues, and minimized their concerns (Villhauer, 2008). Informants cited the use of platitudes, comparison of illnesses, and the observation that they “look great” as methods to keep the conversation superficial which was previously noted in studies by Petersen et al. (2003) and Pistrang and Barker (2005). Informants also wondered, as have Coyne and colleagues (1990), if such reactions served more to reduce the support provider’s own feelings of distress.

Theme #3: Unsolicited Advice

The provision of advice, in general, was mentioned as unhelpful by informants from this study, which is in line with previous research suggesting that advice is a better match for controllable stressors (Curtis et al., 2014). How to prevent the recurrence of the cancer and how to cope with cancer were the two main types of advice noted by informants from this study as unhelpful.

Breast cancer patients in a study by Krigel and colleagues (2014) observed that many of the supportive offerings from others revolved around “cure-alls.” Informants from this study described similar “cure-all” offerings as examples of unhelpful support. Advice about the curative benefits of positive thinking was also noted in this study as unhelpful, which was previously discussed by Holland and Lewis (2001) and Wilkinson (2001). Informants in the present study related that advice about preventing the recurrence of cancer sometimes left them feeling blamed and responsible, an observation which was noted in earlier research by Sinding and Gray (2005).

The unhelpful subcategory of “don’t worry/look on the bright side” in this study lent support to a small qualitative study in which breast cancer patients reported that they did not want to be told by others to be positive (O’Baugh et al., 2003). The subcategory of “inspirational stories” coincided with the results of a previous study by Whitehead (2006) in which researchers assert that inspirational stories can be intimidating if patients experience social pressure to overcome an illness when it is not in their power to determine the outcome. Informants perceived an expectation from some of their friends and family members to be brave or strong. As in previous studies by Rosedale (2009) and Sinding and Gray (2005), they did not find the pressure to be brave helpful.

Theme #4: Constraints

In the subcategory “obligation to comfort others” under the unhelpful theme of “Constraints” in the current study, informants described similar experiences to those in a qualitative study in which participants of focus groups felt pressure to manage others with a “game face” (Beatty et al., 2008). Informants related similar strategies in the “screening who you tell” subcategory to those of previous studies in which participants purposely avoided certain friends and family members (Dickerson et al., 2011), screened calls, and created a small “inner circle” of support providers (Krigel et al., 2014). In the subcategory of “censoring what you say,” informants from this study reported similar experiences to those of previous studies in which participants felt that they couldn’t confide freely with others (Mosher et al., 2013; Villhauer, 2008), remained silent to resist dominant views (Charmaz, 2002), or tailored their responses to avoid unwanted reactions (Krigel et al., 2014).

Theme #5: Pressure for a Positive Outcome

Informants from this study related similar experiences under the subcategory, “get over it,” to those in other studies in which participants perceived pressure to provide a conclusion to their illness narrative (Broom, 2001) and reported difficulty celebrating milestones after the completion of treatment (Abel & Subramanian, 2008) because of their liminal status. In the subcategory, “get back to normal,” also under the unhelpful theme, “Pressure for a Positive Outcome,” the informants from the present study described pressure to put the cancer behind them which was also noted by participants in a study by Sinding and Gray (2005). As in a previous study by Kasper and Ferguson

(2002), informants from this study observed that narratives in the media usually present a beneficial personal transformation because of the breast cancer experience. This is described in the subcategory, “find a silver lining.”

Context with Previous Research on Helpful Support

The present study results on helpful support are discussed as they relate to the research findings from previous research. Two themes are identified within the taxonomy of helpful support: Demonstration of Caring and Management of Feelings. Some subcategories within the themes are also discussed.

Theme #6: Demonstration of Caring

The results of this study did not support the perception of calling and sending cards as superficial support offerings as Uchino (2009) theorized. Most of the informants were touched by the thought behind such offerings.

Theme #7: Management of Feelings

In the subcategory, “distraction,” under the helpful theme, “Management of Feelings,” several of the informants noted that distraction was more effective on days that they were feeling better. This lends credence to Vilhauer’s (2008) observation of a cyclical nature to the supportive needs of breast cancer patients and to the findings of Gremore et al., (2011) that certain supportive behaviors may be more helpful when emotional and physical concerns are at low levels. The subcategory of “listening,” which is also under the helpful theme, “Management of Feelings,” supported the theory that

nurturant types of support behaviors, such as listening, are a better match for uncontrollable stressors (Cutrona & Suhr, 1992).

This section has outlined the relevance of the findings from this study to those of previous studies. The current study adds significantly to the existing body of research by examining the specific aspects of supportive offerings that breast cancer patients view as helpful and unhelpful. While some studies have explored the effects of overtly negative behaviors from friends and family members, the focus of this study, specifically on offerings from others that were intended to be helpful, fills a gap in the literature. The study findings shed light on why some behaviors generally considered to be supportive may not be perceived as helpful by this particular population and why several studies have not been able to demonstrate a positive association between measured social support and emotional adjustment to breast cancer. The results from this research underline the importance of tailoring instruments measuring social support to the population of breast cancer patients. This study also raises awareness around the impact of cultural discourses on expectations about how one should cope with the experience of breast cancer.

The findings from the current study were consistent enough with previous research that some tentative implications can be suggested for both formal and informal support providers, as well as for future research. These implications are presented in the following section.

Recommendations and Implications

The current study makes an important contribution by providing a more thorough understanding of the salutary aspects of social support specific to the experience of breast

cancer. This section provides a discussion of research and social policy recommendations from the study, as well as implications for support providers and clinicians.

Recommendations for Future Research

Spradley (1979) asserts that no ethnography is complete because each describes a culture in a certain place at a certain point in time, highlighting the need for further research. Much of the literature on coping with breast cancer has focused on decontextualized cognitive processes. This study emphasizes the influence and complexity of social exchanges and underlines the need for more studies to identify how social support, and the circumstances in which it occurs, are also relevant to coping with cancer.

In order to do so, improvements need to be made in the measurement of social support. The findings from this study indicate that being in a close relationship, having a large number of support providers, or experiencing a higher frequency of supportive offerings are not necessarily indicative of a higher level of support. Participants in the current study also provided insights into supportive interactions that were not always apparent on the surface. This has implications for measures of supportive offerings which, even if they are determined to be desired by the recipients, typically assign equal point value to each item and don't capture the differences between offerings in terms of the level of their helpfulness.

Research that categorizes social support (e.g. informational, instrumental, tangible, emotional, etc.) has limited utility in illuminating why such support is helpful or unhelpful. The findings from the current study suggest that an approach focusing, instead,

on the interpersonal dynamics involved in the provision and receipt of social support during breast cancer might be more useful. Studies that further examine the process of support rather than the content could propagate new understandings of the complexities of social support and its role in adjustment to breast cancer.

Specifically, this study explored the supportive offerings of breast cancer patients' inner circle of family and friends. Future studies should explore the offerings of a wider support network as well. For example, studies show that cancer patients look to healthcare workers, other cancer patients, and the media for informational types of support (Dubois & Loiselle, 2009).

The participants in this study came from the same geographic area and had similar sociodemographic characteristics. Although the themes that were identified in the current study reached saturation, additional themes might have been identified had there been more diversity among the participants. Research indicates that there may be variance in the supportive care needs of breast cancer patients based on their sociodemographic differences. For example, several studies have shown differences in coping styles among cancer patients of different ethnicities (Ashing-Giwa et al., 2004; Bache, Bhui, Dein & Korszun, 2012; Culver, Arena, Antoni & Carver, 2002), nationalities (Gilbar, 2005; Jingzhi & Lambert, 2007; Taleghani, Yekta & Nasrabadi, 2006), ages (Derks, de Leeuw, Hordijk, & Winnubst, 2004, Link, Robbins, Mancaso & Charlson, 2004), and sexual orientations (Boehmer, Glickman, Winter & Clark, 2014). Other studies show differences in attitudes or outlooks about cancer among patients with different religious or spiritual beliefs (Johannessen-Henry, Deltour, Bidstrup, Dalton & Johansen, 2013; Leyva et al., 2014), ethnicities (Howard, Balneaves & Bottorff, 2007), and cultural assumptions

(Daher, 2012). Follow-up studies should take aspects of cultural identity into consideration, including ethnicity, age, education level, religion/spirituality, sexual orientation, and geographical location, to explore differences in their perceptions of support. A deeper understanding of the specific cultural context of a breast cancer patient's experience is vital for culturally sensitive research and practice.

The present study focused on breast cancer patients who have been diagnosed with invasive breast cancer. The interview and focus group participants ranged from Stage II to Stage IV of the disease and 65% of them had received chemotherapy treatment by the time they participated in the study. Previous research shows that cancer patients have different outlooks on the disease experience depending on their cancer stage, time since diagnosis, and whether or not they are currently undergoing treatment (Kvillemo & Branstrom, 2014). Further research is needed to explore the perceived helpfulness of supportive offerings among breast cancer patients with an earlier stage of the disease than those of the current study. The supportive needs of breast cancer patients may also change over the course of the illness trajectory. Studies exploring perceptions of support at different points of time during the breast cancer experience should be conducted.

Recommendations for Social Policy

There are important policy implications that can be drawn from this study. The field of psychosocial care for cancer patients has undergone some important developments in recent years. It received increased attention in 2008 when the Institute of Medicine (IOM) published a report entitled "Cancer Care for the Whole Patient: Meeting

Psychosocial Health Needs” (Institute of Medicine, 2008). The IOM (subsequently renamed the National Academy of Medicine) is an independent, nonprofit organization that works outside of government to provide advice to decision makers in both government and the private sector regarding health issues. Their report noted a gap between the psychosocial problems of cancer patients and existing services for them. The IOM report recommended that cancer care providers ensure that cancer patients in their practice receive psychosocial care.

This was further advanced when the American College of Surgeons Commission on Cancer (CoC) required over 1,500 accredited cancer centers to begin screening cancer patients for distress by 2015 and provided cancer centers with information about existing community-based support services to address patients’ psychosocial needs. The CoC also required cancer centers to begin providing a survivorship care plan to improve cancer patients’ post-treatment quality of life.

From a social policy perspective, the findings of the present study are important to the IOM’s observation regarding the lack of existing services addressing the emotional needs of cancer patients and to their policy recommendations for the provision of psychosocial care by cancer centers. The participants in this study also indicated that their psychosocial needs continued after they transitioned from active treatment of their cancer to post-treatment surveillance which supports the IOM and CoC suggestions for survivorship care plans to address cancer patients’ needs following treatment.

This study provides a perspective that puts the patient’s voice and needs first and it suggests that the patient experience should influence all aspects of our work with them. It highlights the need for patients to be at the table in the process of developing and

implementing new cancer care models. One way for a cancer center to promote a patient-centered cancer care planning process would be to develop a patient advocacy advisory board. Such an advisory board would increase awareness about the needs of cancer patients, an important step toward influencing policy makers to make changes. One of the barriers to addressing the emotional needs of patients at cancer centers is a financial one because psychosocial care is viewed as a low or non-revenue generating service. These services are typically provided by non-profit agencies which are dependent upon philanthropic donations or grants. The development of new cancer care models, to include billing and reimbursement structures for the provision of psychosocial care, would help to close the gap between the emotional needs of cancer patients and existing services for them.

Cultural identity should also be taken into consideration in service provision to this population. Providers should begin from a place of not knowing, understanding that the breast cancer patient is an expert in their experience. Giving voice to this population allows us to gain insight into their worldview, increase the quality of interactions with them, and develop the kinds of support that are culturally relevant and effective for them.

Medical care coverage and delivery is in the process of transition in this country and it has had an impact on cancer patients. Treatment has been moved increasingly to the outpatient setting and much of patient care has shifted to caregivers. It is recommended that the scope of psychosocial care provided by cancer care centers should be extended to encompass caregivers. The findings from this study can be used to help family members and friends to develop skills necessary for support provision.

The current study also raises awareness of variance in the supportive care needs of breast cancer patients. The results reveal that, in some cases, supportive offerings that are assumed and intended to help the breast cancer patient feel better do not necessarily have the desired impact. It is important for cancer support agencies to have an awareness of their assumptions regarding support and to understand that perceptions of support vary among breast cancer patients. This will enable them to tailor psychosocial services to treat this target population respectfully and effectively.

Consider the following examples of two different non-profit agencies that were created to provide support for cancer patients:

- The Wellness Community (renamed Cancer Support Community in 2009):
Founder, Harold Benjamin, developed what he called the Patient Active Concept, “a powerful connection between emotions and well-being” adding that “people with cancer who participate in their fight for recovery from cancer will improve the quality of their life and may enhance the possibility of their recovery” (Benjamin, 1995).
- Gilda’s Club: A place “to learn how to live with cancer, whatever the outcome.” Their brochure states, “At Gilda’s Club YOU [emphasis in original] are the expert. Your experience is unique and you are encouraged to come as you are; tears, laughter, whatever your life experiences may be” (Gilda’s Club, n.d.).

Based on the results of the current study, the sensitivity to language by Gilda’s Club would have wider appeal to the breast cancer population because it doesn’t insinuate that the outcome of the cancer derives from the patient’s emotions, attitude, or

outlook. The use of the word “wellness” in the first organization’s original name, The Wellness Community, may have discouraged patients with more advanced stages of cancer from seeking social support there. The literature from Gilda’s Club, on the other hand, appears to welcome patients with both negative feelings and outcomes (Bull, 1998).

Implications for Support Providers

The findings of this study highlight areas in which both formal and informal support providers can optimize the social support provided to breast cancer patients. The first suggestion is for support providers to have an awareness of:

- unrealistic cultural expectations about the “right way” to be a cancer patient;
- the potential helpfulness to the patient of screening and limiting the number of persons in her circle of support;
- the potential helpfulness to the patient of censoring her disclosures to avoid emotional difficulty in the retelling of news/updates and having to deal with others’ reactions.

Based on the findings of this study, it would also be important for support providers to let the patient take the lead in conversation, to watch for cues on touchy subjects, and to use caution when:

- speculating about the cause of the cancer;
- making comments that seem to downplay the seriousness of the illness;
- delineating between healthy persons and cancer patients;

- using platitudes or encouraging the person to look on the bright side of their situation;
- sharing stories about other breast cancer patients that have negative outcomes, positives outcomes, or are inspirational;
- suggesting lifestyle changes, alternative/complimentary therapies, or the curative benefits of positive thinking;
- making observations that the patient “looks great” or is brave/strong;
- making spiritual or religious comments that might insinuate blame;
- celebrating of the end of treatment;
- expecting the patient to return to “normal” or to benefit from their experience.

There were a limited number of support behaviors that were described by the informants in this study in terms of their helpfulness. However, there are many other support behaviors that were not mentioned as being particularly helpful or unhelpful. There are presumably individual differences in the perceived helpfulness of such offerings and it cannot be assumed that there are a particular set of specific supportive behaviors that breast cancer patients consistently want from their support providers. There were, however, suggestions for support that were consistently mentioned as being helpful by the informants in this study:

- listen;
- acknowledge the seriousness of the illness;
- validate negative feelings;
- provide occasional distraction;

- show caring with phone calls, cards, gifts, meals, housecleaning, rides to appointments, hair care, etc.

Implications for Clinical Interventions

The present study provides a broad and in-depth understanding of the supportive needs of breast cancer patients and it has important implications for clinicians. It suggests that therapeutic efforts will be more successful when they are guided by a thorough understanding of the experience of breast cancer in its social context.

Treacher and Carpenter (1993) assert that clinicians should be concerned with how psychotherapy is experienced by clients. They suggest that, although it is tempting to make the users fit the service, they should adjust their services to fit the users' needs. The findings of this study can help clinicians examine the underlying cultural influences embedded in their discourse and their assumptions about the experience of breast cancer. The following suggestions are indicated from this study for the practice of psychotherapy with breast cancer patients:

- During intake assessments, be sensitive to insinuations of blame when questioning about lifestyle, history of tobacco/alcohol use, etc.
- It may be helpful to use a social support instrument to guide a discussion of expectations and preferences and to improve the match between support providers' actions and support recipients' desires.
- Use caution in prescribing what is helpful and what is not in terms of coping with cancer.

- A common therapeutic technique is to point out the client's strengths. Care should be taken not to overemphasize the patient's bravery/strength in their cancer experience.
- In family therapy, be careful about obligating the breast cancer patient to tend to the emotional needs of other family members.
- Explore practical ways to lesson anxiety, for example, through activities that provide some distraction.
- Clinicians using Cognitive Behavioral Therapy should be careful not to downplay the seriousness of cancer by challenging what may, in other situations, be considered catastrophizing or magnifying negatives.
- Caution should be used with benefit-finding or post-traumatic growth interventions.

Chapter Summary

This final chapter provided the limitations of the present study, a discussion of the results, implications for informal and formal support provision, and recommendations for future research. The participants in this study made clear the aspects of social support that they found to be helpful and unhelpful.

The findings from this study provide a deeper understanding of the factors that contribute to the salutary effects of support provision. It is expected that these findings will enable support providers, clinicians, and health care agencies/practitioners to determine the extent to which their supportive offerings meet the needs of this target population and to make changes that could benefit future breast cancer patients.

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APPENDIX A

LETTER OF SUPPORT FOR INTERVIEWS

October 30, 2013

Loma Linda University
Office of Sponsored Research
11188 Anderson Street
Loma Linda, CA. 92350

To Whom It May Concern:

I am writing to express my support for the research proposed by Jason E. Own, PhD, MPH and Renee Jarvis, MSW, titled *Breast Cancer Patients' Perceptions of the Helpfulness and Unhelpfulness of Social Support Offerings*. I am happy to assist in identifying and recruiting potential participants through our Women's Cancer Support Group and our medical and surgical breast oncology clinics.

Please contact me with any questions at (909) 558-2262 or via e-mail at tlepale@llu.edu.

Sincerely,

Talolo Lepale, LSCW

APPENDIX B

LETTER OF SUPPORT FOR FOCUS GROUPS

October 30, 2013

Loma Linda University
Office of Sponsored Research
11188 Anderson Street
Loma Linda, CA. 92350

To Whom It May Concern:

I am writing to express my support for the research proposed by Jason E. Own, PhD, MPH and Renee Jarvis, MSW, titled *Breast Cancer Patients' Perceptions of the Helpfulness and Unhelpfulness of Social Support Offerings*. I am happy to assist in identifying and recruiting potential participants through our Women's Cancer Support Group and our medical and surgical breast oncology clinics.

Please contact me with any questions at (909) 558-2262 or via e-mail at tlepale@llu.edu.

Sincerely,

Talolo Lepale, LSCW

APPENDIX C

INTERVIEW RECRUITMENT FLYER

*Breast Cancer Patients' Perceptions of the
Helpfulness and Unhelpfulness of Social Support Offerings*

VOLUNTEERS NEEDED FOR A RESEARCH STUDY

Volunteers are needed to participate in an interview exploring social support for breast cancer patients. The interview will take approximately 60 minutes and involves answering some open-ended questions about the helpfulness or unhelpfulness of supportive actions from others during the breast cancer experience.



Eligibility Criteria
for Participants:

- Age 18 or older
- Diagnosed with invasive breast cancer

This study is being conducted by Renee Jarvis, MSW, a doctoral student at Loma Linda University. Please call (909)754-9921 or e-mail rjarvis@llu.edu if you are interested in volunteering for an interview.

Participants will receive a \$25 gift card to a local restaurant for participation in the study.

APPENDIX D

FOCUS GROUP RECRUITMENT FLYER

*Breast Cancer Patients' Perceptions of the
Helpfulness and Unhelpfulness of Social Support Offerings*

VOLUNTEERS NEEDED FOR A RESEARCH STUDY

Volunteers are needed to participate in a focus group exploring social support for breast cancer patients. The focus group will be approximately 90 minutes in length and involves answering some open-ended questions about the helpfulness or unhelpfulness of supportive actions from others during the breast cancer experience.



**Eligibility Criteria
for Participants:**

- Age 18 or older
- Diagnosed with
invasive breast
cancer

This study is being conducted by Renee Jarvis, MSW, a doctoral student at Loma Linda University. Please call (909)754-9921 or e-mail rjarvis@llu.edu if you are interested in volunteering for an interview.

Participants will receive a \$25 gift card to a local restaurant for participation in the study.

APPENDIX E

PHONE SCRIPT FOR USE WITH RESPONDENTS TO INTERVIEW FLYER

Phone Script for use with Respondents to Interview Flyer

Thank you for your interest in participating in this study about social support for breast cancer patients. My name is Renee Jarvis and I am a doctoral student at Loma Linda University.

First I would like to ask you some questions to determine if you would be eligible to participate. Are you age 18 or older? Have you been diagnosed with invasive breast cancer?

The purpose of the study is to better understand the helpfulness of social support during the breast cancer experience. If you agree to participate in the interview, you will be asked to answer some open-ended questions about the helpfulness or unhelpfulness of supportive actions from others during your breast cancer experience.

The interview will be approximately 60 minutes in length and it will be audio recorded. A code number will be used to identify you instead of your name and no identifying information will be used in any publications or presentations resulting from this study. Your participation is voluntary. You will receive a \$25 gift card to a local restaurant for your participation.

It is also possible that some of the questions may make you feel uncomfortable or that you could become upset in recalling aspects of your breast cancer experience. If this occurs, you may stop the interview at any time.

Although you will not benefit directly from this study, we hope the results will help us to better understand the support needs of breast cancer patients.

Do you have any questions? Would you like to participate in the study?

APPENDIX F

PHONE SCRIPT FOR USE WITH RESPONDENTS TO FOCUS GROUP FLYER

Phone Script for use with Respondents to Focus Group Flyer

Thank you for your interest in participating in this study about social support for breast cancer patients. My name is Renee Jarvis and I am a doctoral student at Loma Linda University.

First I would like to ask you some questions to determine if you would be eligible to participate. Are you age 18 or older? Have you been diagnosed with invasive breast cancer?

The purpose of the study is to better understand the helpfulness of social support during the breast cancer experience. If you agree to participate in the focus group, you will be asked to answer some open-ended questions about the helpfulness or unhelpfulness of supportive actions from others during your breast cancer experience.

The focus group will be approximately 90 minutes in length and it will be audio recorded. All participants will be asked not to disclose anything said within the context of the discussion after the focus group meeting. A code number will be used to identify you instead of your name and no identifying information will be used in any publications or presentations resulting from this study. It is possible that some of the questions may make you feel uncomfortable or that you could become upset in recalling aspects of your breast cancer experience. If this occurs, you may stop the interview at any time.

Your participation is voluntary. You will receive a \$25 gift card to a local restaurant for your participation.

Although you will not benefit directly from this study, we hope the results will help us to better understand the support needs of breast cancer patients.

Do you have any questions? Would you like to participate in the study?

APPENDIX G
INTERVIEW INFORMED CONSENT DOCUMENT

**INTERVIEW
INFORMED CONSENT FORM**

TITLE: Breast Cancer Patients' Perceptions of the Helpfulness and Unhelpfulness of Social Support Offerings.

STUDENT INVESTIGATOR: Renee Jarvis, MSW

Purpose and Procedures

Approximately 20 subjects are expected to participate in the interviews for this study. Participants must meet the following requirements: 1) be 18 year of age or older; and 2) have been diagnosed with invasive breast cancer.

As a breast cancer patient, you are invited to participate in an interview for this research study. The purpose of the study is to better understand the helpfulness of social support during the breast cancer experience. Your answers in the interview will be used for an applied project by doctoral student researcher Renee Jarvis.

As part of the study you will be interviewed by me (Renee Jarvis). The interview will take approximately 60 minutes and it involves answering some open-ended questions about the helpfulness or unhelpfulness of supportive actions from others during your breast cancer experience. Our conversation will be audio-taped to make sure that your answers are correctly recounted.

Initials Date

Risks

The committee at Loma Linda University that reviews human studies (Institutional Review board) has determined that participating in this study exposes you to minimal

risk. There is the possibility that your confidentiality could be violated. It is also possible that some of the questions may make you feel uncomfortable or that you could become upset in recalling aspects of your breast cancer experience. If this occurs, you may stop the interview at any time.

To ensure that your confidentiality remains protected, the following steps will be taken. After the interview, a code number will be used to identify you instead of your name. Interview transcripts and digital recordings will be locked in a file cabinet. Data will be entered in a password-protected computer and only members of the research team will have access to this information. No identifying information will be used in any publications or presentations resulting from this study.

Benefits

Although you will not benefit directly from this study, we hope that the results will help us to better understand the support needs of breast cancer patients.

Participant Rights

Participation in this study is voluntary. Your decision whether or not to participate or withdraw at any time from the study will not affect any services that you may be receiving and will not involve any penalty or loss of benefits to which you are otherwise entitled.

Initials Date

Compensation

You will be given a \$25 gift card to a local restaurant for your participation in this interview.

Impartial Third Party Contact

If you wish to contact an impartial third party not associated with this research regarding any questions or complaints you may have about the study, you may contact the office of Patient Relations, Loma Linda University Medical Center, Loma Linda, CA 92354; phone (909) 558-4647, e-mail patientrelations@llu.edu, for information and assistance.

Informed Consent

I have read this consent form and have listened to the verbal explanation given by the student investigator. My questions concerning this study have been answered to my satisfaction. I hereby agree to participate in this study. Signing this consent document does not waive my rights nor does it release the investigators, institution or sponsors from their responsibilities. I may call Dr. Jason Owen at (909) 558-7705 if I have additional questions or concerns.

I have been given a copy of this consent form.

Participant Signature

Date

I have reviewed the contents of this consent form with the person signed above. I have explained potential risks and benefits of the study.

Investigator Signature

Date

APPENDIX H

FOCUS GROUP INFORMED CONSENT DOCUMENT

**FOCUS GROUP
INFORMED CONSENT FORM**

TITLE: Breast Cancer Patients' Perceptions of the Helpfulness and Unhelpfulness of Social Support Offerings.

STUDENT INVESTIGATOR: Renee Jarvis, MSW

Purpose and Procedures

A total of approximately 24 subjects are expected to participate in focus groups for this study. Participants must meet the following requirements: 1) be 18 year of age or older; and 2) have been diagnosed with invasive breast cancer.

As a breast cancer patient, you are invited to participate in one of the focus groups for this research study. The purpose of the study is to better understand the helpfulness of social support during the breast cancer experience. Your contributions to the focus group will be used for an applied project by doctoral student researcher Renee Jarvis.

As part of the study you will be participating in a focus group with approximately 5 other breast cancer patients. The focus group will be about 90 minutes long and we will explore some open-ended questions about the helpfulness or unhelpfulness of supportive actions from others during the breast cancer experience. The focus group conversation will be audio-taped to make sure that the discussion is accurately documented.

Initials Date

Risks

The committee at Loma Linda University that reviews human studies (Institutional Review board) has determined that participating in this study exposes you to minimal risk. There is the possibility that your confidentiality could be violated. It is also possible

that some of the questions may make you feel uncomfortable or that you could become upset in recalling aspects of your breast cancer experience. If this occurs, you may stop the interview at any time.

All participants in the focus group will be asked not to disclose anything said within the context of the discussion. By agreeing to participate, you agree to not disclose to others outside this event anything said within the context of the focus group discussion.

To ensure that your confidentiality remains protected, the following steps will be taken by the researcher. Focus group transcripts and digital recordings will be locked in a file cabinet. Data will be entered in a password-protected computer and only members of the research team will have access to this information. No identifying information will be used in any publications or presentations resulting from this study.

Benefits

Although you will not benefit directly from this study, we hope that the results will help us to better understand the support needs of breast cancer patients.

Participant Rights

Participation in this study is voluntary. Your decision whether or not to participate or withdraw at any time from the study will not affect any services that you may be receiving and will not involve any penalty or loss of benefits to which you are otherwise entitled.

Initials Date

Compensation

You will be given a \$25 gift card to a local restaurant for your participation in this focus group.

Impartial Third Party Contact

If you wish to contact an impartial third party not associated with this research regarding any questions or complaints you may have about the study, you may contact the office of Patient Relations, Loma Linda University Medical Center, Loma Linda, CA 92354; phone (909) 558-4647, e-mail patientrelations@llu.edu, for information and assistance.

Informed Consent

I have read this consent form and have listened to the verbal explanation given by the student investigator. My questions concerning this study have been answered to my satisfaction. I hereby agree to participate in this study. Signing this consent document does not waive my rights nor does it release the investigators, institution or sponsors from their responsibilities. I may call Dr. Jason Owen at (909) 558-7705 if I have additional questions or concerns.

I have been given a copy of this consent form.

Participant Signature

Date

I have reviewed the contents of this consent form with the person signed above. I have explained potential risks and benefits of the study.

Investigator Signature

Date

APPENDIX I
INTERVIEW GUIDE

Interview Guide

Descriptive Questions

Grand tour question: I am interested to learn about the social support you received during your breast cancer experience. Can you tell me about it?

Mini tour question: Could you give me an example or talk about a specific experience of social support?

Structural Questions

Can you tell me how _____ and _____ are similar?

Contrast Questions

What is the difference between _____ and _____?

Can you rate _____, _____, and _____ in terms of _____?

APPENDIX J
DEMOGRAPHIC SURVEY

DEMOGRAPHIC INFORMATION

Age _____

Marital Status

_____ Single

_____ Married

_____ Separated

_____ Divorced

_____ Widowed

_____ Other

Ethnicity:

_____ African American

_____ Asian

_____ Caucasian

_____ Hispanic/Latina

_____ Pacific Islander

_____ Other

Education Level

_____ Less than High School

_____ High School Graduate

_____ Some College

_____ Bachelor's Degree

_____ Graduate Degree

_____ Other

Stage of Breast Cancer _____

How long ago were you initially diagnosed with invasive breast cancer?

_____ Years _____ Months

What types of treatment have you undergone?

_____ Lumpectomy

_____ Mastectomy

_____ Chemotherapy

_____ Radiation therapy

_____ Other medication/treatment