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A New Look at Survivorship: Female Cancer Survivors' Experience of Resilience in the Face of Adversity

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A NEW LOOK AT SURVIVORSHIP:
FEMALE CANCER SURVIVORS' EXPERIENCE OF RESILIENCE
IN THE FACE OF ADVERSITY

PROFESSIONAL DISSERTATION

SUBMITTED TO THE FACULTY

OF

THE SCHOOL OF PROFESSIONAL PSYCHOLOGY
WRIGHT STATE UNIVERSITY

BY

CHRISTINE MARIE VALENTI, Psy.M.

IN PARTIAL FULFILLMENT OF THE
REQUIREMENTS FOR THE DEGREE
OF
DOCTOR OF PSYCHOLOGY

Dayton, Ohio

September, 2012

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July 25, 2011

I HEREBY RECOMMEND THAT THE DISSERTATION PREPARED UNDER MY SUPERVISION BY **CHRISTINE MARIE VALENTI** ENTITLED **A NEW LOOK AT SURVIVORSHIP: FEMALE CANCER SURVIVORS' EXPERIENCE OF RESILIENCE IN THE FACE OF ADVERSITY** BE ACCEPTED IN PARTIAL FULFILLMENT OF THE REQUIREMENTS FOR THE DEGREE OF DOCTOR OF PSYCHOLOGY.

Julie Williams, Psy.D., ABPP
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Abstract

The present study examined the lived experience of adult female cancer survivors to discover common protective resilience factors that enabled them to cope with their cancer experience and to identify potential barriers to resilience. Nine female cancer survivors, age 18 years and older whose cancer was in remission or currently active, who were members of a cancer support group and who volunteered to participate in this study were interviewed. They were asked open-ended questions regarding the biological, social, psychological and spiritual factors that helped them to cope with, heal and thrive with their cancer experience. The participants identified resilience protective factors and barriers within the biological, social, psychological, and spiritual domains that assisted them to cope with the impact of cancer. The results of this study can better inform cancer survivors, care takers and the medical community regarding holistically meeting the needs of females diagnosed with cancer.

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Dedication

This Professional Dissertation is dedicated to my beloved family who joined me on my cancer journey and assisted me with my biological, social, psychological, and spiritual resilience.

CHAPTER 1

Statement of the Problem

An estimated 713,220 women will be diagnosed with cancer in the United States in 2009 (Homer et al., 2008). The 5-year survival rate of women diagnosed with cancer in 2001 was 69.7% (Homer et al., 2008). Clearly, cancer directly touches the lives of many women. This raises the question, how do women diagnosed with cancer cope with their diagnosis? The diagnosis of a life-threatening illness such as cancer is a traumatic experience. Women are faced with a new reality as they venture into the uncharted, uncertain territory of their cancer experience. These women must face their new cancer reality, which typically includes harsh chemotherapy, medications, radiation, invasive medical procedures, questions regarding their quality of life and body image, concerns about continuing to fulfill social and family roles, and concerns about social and financial support.

Much research has focused on the negative impact of the cancer experience such as feelings of depression, isolation, anxiety, and fears of death and dying. Additionally, research on cancer survivorship is often limited to those individuals whose cancer has entered into remission. The tendency to define survivors in terms of remission status is likely influenced by the social construction of disability. Persons currently living with a disability are not considered “whole” or “complete” if they do not fit society’s socially constructed standards of able-bodied (Shapiro, 2003).

This limited view of survivorship excludes the lived experience of cancer survivors who are currently living *with* cancer and *thriving* in the face of cancer. This dissertation seeks to present a new view of cancer survivorship—a more inclusive view that considers the lived experience of women currently living with cancer and the experiences of those survivors whose cancer has gone into remission. Specifically, this study seeks to identify the strengths and resources that enabled adult female cancer survivors to cope with the stress and adversity of their cancer experience such that they live it rather than suffer it. This study also seeks to identify the barriers female cancer survivors experience that impede their ability to cope with their cancer experience.

The research questions addressed in this dissertation are in line with the mission of the Noble Circle Project, a cancer support group in Dayton, Ohio. The Noble Circle Project was founded in 2002 at the Heartwood Institute in northern California by Anne Burns, a breast cancer survivor of 14 years (Noble Circle Project, 2011). The mission of Noble Circle is “to help women diagnosed with cancer to reclaim their health using simple, natural, and low-cost methods of self-healing including a whole foods diet, qigong, and group support” (Noble Circle Project, 2011, “Mission,” para.1). The Noble Circle Project strives to empower persons living with and surviving cancer.

Purpose of the Study

This study seeks to (a) examine the lived experience of adult female cancer survivors to discover common protective factors that enabled them to be resilient as they experienced the adversity of their cancer experience; (b) identify potential barriers to resilience; (c) inform other cancer survivors, caretakers and the medical community regarding holistically meeting the needs of females diagnosed with cancer; and (d)

expand the research literature on resilience and female cancer survivors to include adult female cancer survivors living in the United States.

Adult female cancer survivors were interviewed one-on-one and asked open-ended questions regarding their cancer experience to ascertain the resilience factors that they perceived enabled them to cope, heal, and live their cancer experience. This study is based on the premise that female cancer survivors are the most informed regarding their personal narratives and their needs. Thus, this study seeks to empower female cancer survivors and provide them with a collective voice by providing them with a forum to give voice to the resilience protective factors that enabled them to cope, heal, and thrive as cancer survivors.

This premise is in line with the principles of Participatory Action Research (PAR) that will guide this study. Bradbury and Reason (2003) stated “Action research is grounded in lived experience, developed in partnership, addresses significant problems, works with (rather than simply studies) people, develops new ways of seeing/interpreting the world (i.e., theory), and leaving infrastructure in its wake” (p. 156).

With a better understanding of the resilience protective factors that have enabled female cancer survivors to cope with their cancer experience, cancer survivors, researchers, and the medical community will gain a better understanding of female cancer survivors’ lived experience. This will better inform individuals diagnosed with cancer, their families and the medical community to develop more effective ways to intervene to assist female cancer survivors to successfully cope with the various aspects of their cancer experience.

CHAPTER 2

Literature Review

This chapter presents an overview of resilience research that informed this study. Specifically, this chapter provides an overview of the definitions of resilience and an outline of the three phases of resilience research: (a) identification of resilience qualities; (b) a model of resilience; and (c) resilience reintegration. This chapter also includes an overview of research on resilience and persons with illness and measurements of resilience as well as an overview of the theoretical framework, rationale and methodology for the study which was based on Participatory Action Research (PAR) and Grounded Theory. The chapter concludes with an overview of the potential benefits and risks of this research.

Overview of Definitions of Resilience

Resilience is a positive psychology concept (Pan & Chan, 2007). Resilience does not have a precise definition. Rather, researchers offer various definitions of resilience. The American Psychological Association (2009) defined resilience as “the process of adapting well in the face of adversity, trauma, tragedy, threats, or even significant sources of stress.” Resilience “involves behaviors, thoughts, and actions that can be learned and developed in anyone” (“The Road to Resilience,” para. 1). Conner and Davidson (2003) suggested that resilience is the personal qualities that enable a person to thrive despite adversity.

Richardson (2002) defined resilience as a process that encompasses the development and implementation of a variety of personal qualities. Resiliency is “the processes of coping with adversity, change, or opportunity in a manner that results in the identification, fortification and enrichment of resilient qualities or protective factors” (p. 308). In regard to the cancer experience, Denz-Penhey and Murdoch (2008) suggested that resiliency is a “way of being and acting in the world that has the person strongly connected to life through relationships and a quality-of-life experience that made their illness secondary to their living” (p. 391). These definitions of resilience have features in common, including: (a) resilience is a set of qualities that are at least in part learned, (b) developing resilient qualities is a process that enables persons to cope with adversity, and (c) resilience is a cognitive and behavioral process.

Identifying Resilience Qualities

Richardson (2002) presented a metatheory of resilience that categorizes the history of the research on resilience into three distinct phases. During phase one of resilience research, researchers sought to answer the question, what are the resilient qualities? Researchers focused their attention on the phenomenological description of resilient qualities of individuals that forecast social and personal success. The outcome of this first line of research was the development of lists of qualities or “protective factors” that enable people to cope with adversity (Richardson, 2002).

Early researchers who examined resilience protective factors formulated a triad classification system of resilient protective mechanisms. These categories are (a) individual dispositional attributes, (b) family support and coherence, and (c) external support systems (Masten & Garmezy, 1985). Research on resilience began in the 1960s

and 1970s. Researchers identified resilient qualities in children who were considered at risk for developing psychopathology due to living in poverty. These researchers identified a set of resilient protective factors that enabled “at risk” children to flourish despite the adversity of economic disadvantage. These resilient qualities include good communication skills, an internal locus of control, high self-esteem and self-efficacy, and an ability to manage strong emotions and impulses, a sense of humor, secure attachment, supportive family relationships, a cohesive family unit, positive role models, socialization and external support networks such as church, school, or work (Masten & Garnezy, 1985; Rutter, 1985; 1987).

Kobasa (1979) identified the concept of hardiness, which is closely related to the concept of resilience. She identified the protective factors which enabled male business executives to better cope with stress. She termed these protective factors hardiness. Hardiness is personality characteristics that buffer the negative impact of stress on illness. Hardiness is composed of three characteristics: commitment, control and challenge (Kobasa, 1979; Kobasa, Maddi, & Courington 1981; Kobasa, Maddib & Kahn, 1982). The concept of hardiness can be classified under the resilience category of individual dispositional attributes.

Commitment is a sense of one’s values, goals, and capabilities, the belief in the importance of one’s self, and active engagement with the environment (Kobasa, 1979). Control is the ability to make one’s own choices and to handle stress and the ability to incorporate stressful events into an “ongoing life plan thereby creating meaningfulness in one’s life” (p. 3). Challenge is a way of framing stressful life events as an expected change rather than a threat to one’s well-being (Kobasa, 1979). These three

characteristics of hardiness enable people to experience empowerment because they are able to control and manage events.

Denz-Penhey and Mordoch (2008) studied personal resilience in persons in Australia who were diagnosed with a life threatening illness, but who unexpectedly recovered despite a less than a 10% chance of living. These life threatening illnesses included cancer, a life-threatening congenital condition, and multiple organ failure. Through personal interviews with 26 participants, the researchers found the narratives of the participants held five common dimensions of resilience: “Connectedness to their social environment, to family [and] to their physical environment, to their sense of inner wisdom (experiential spirituality), and a personal psychology with a supportive mindset and way of living which supported their values” (Denz-Penhey & Murdoch, 2008, p. 391).

Model of Resilience

Phase two of resilience research attempted to identify the process by which persons cope with life stressors and develop, utilize, and strengthen their resilient qualities when they face adversity (Richardson, 2002). Researchers sought to answer the question, how are the resilience qualities acquired? Richardson (2002) provided a model of resilience. This is a linear model in which individuals pass through the stages of biopsychospiritual homeostasis. During biopsychospiritual homeostasis, a person is able to effectively adapt his or her mind, body, and spirit to current life experiences.

Resilience qualities come into play when the person is presented with internal or external life stressors, adversity, or life events that disrupt their biopsychospiritual homeostasis (Richardson, 2002). Through coping with a variety of life stressors, a person

develops and utilizes a variety of resilience protective factors such as those identified in the first phase of resilience research. These resilience protective qualities include social support, spirituality, and perceived control (Kobasa, 1979; Masten & Garmezy, 1985).

A diagnosis of cancer is a significant life stressor that disrupts and throws a person's biopsychospiritual homeostasis out of balance. The resilience protective qualities that the individual typically uses to cope with everyday concerns may not be sufficient to handle a significant life crisis such as a diagnosis of cancer (Richardson, 2002). A disruption in biopsychospiritual homeostasis typically results in a person experiencing strong emotions, such as "Why did this happen to me?" Over time, the person faces the question "What am I going to do?" At this time, the person begins the reintegration process (Richardson, 2002).

Richardson (2002) suggested that a person can reintegrate biopsychospiritually in four ways: (a) A person can reintegrate resiliently in which he or she "experiences some insight or growth through disruption" (p. 312). The person identifies, utilizes, and strengthens his or her resilient qualities; (b) a person can reintegrate back to homeostasis in which he or she does not experience growth and strengthening of resilient qualities, but simply "heals and gets past the disruption" (p. 312); (c) the person can reintegrate with loss in which he or she "gives up some motivation, hope, or drive because of the demands of life prompts" (p. 312); and (d) the person can experience dysfunction reintegration in which he or she resorts to substance abuse or destructive behavior to cope with life stressors (Richardson, 2002). Richardson (2002) suggested that people can develop resilience qualities by developing an awareness of the different pathways of resilience integration and by consciously choosing to move toward the path of resilient reintegration

Resilient Reintegration

Phase three of resilience research examines “spiritual/innate resilience” and attempts to answer the question, “What and where within us is the energy source to reintegrate resiliently?” (Richardson, 2002, p. 313). Richardson (2002) contended that resilience “is a force within everyone that drives them to seek self-actualization, altruism, wisdom, and harmony with a spiritual source of strength” (p. 313). The source of the resilience force comes from internal forces, a person’s environment, Eastern medicine, and a belief in God or a creative force. The goal of this third phase of resilience research is to help people identify their resilience forces so they can utilize these forces to move towards self-actualization and resilient reintegration after a disruption (Richardson, 2002).

Two scales have been developed to quantify an individual’s resilience qualities. The first is *Resilience Scale for Adults* (RSA; Friborg, Hjemdal, Rosenvinge, & Martinussen, 2002). The RSA consists of 33 items with a 5-point semantic differential scale that measures five factors of resilience. These factors are personal strength/perception of self, structured style, social competence, family cohesion, and social resources.

The second is the Conner-Davidson Resilience Scale (CD-RISC ; Conner & Davidson, 2003) and is based on Richardson’s model of resilience. The CD-RISC was developed as a brief self-administered measure of resilience. The scale consists of 25 items that are measured on a 5-point likert scale. Items measure factors of resilience including control, commitment, and challenge (Kobasa, 1979). Other factors include developing clear goals, an action orientation, high self-esteem/confidence, adaptability to

change, problem solving skills, humor, strengthening effects of stress, secure/stable affectionate bonds, and previous experiences of achievement and success. Other factors assessed are patience and faith (Rutter, 1985).

Because quantitative resilience measures cannot completely capture the lived experience of cancer survivors, these resilience scales will not be used in this research study. This study seeks to capture resilience factors in the survivor's own words.

Rationale and Theoretical Framework of Study

This section provides a description of the rationale and theoretical framework of this study which was based on Participatory Action Research (PAR) and grounded theory.

Participatory Action Research.

The study is based on the principles of Participatory Action Research (PAR). PAR is an "orientation to inquiry" rather than a specific research method (Bradbury & Reason, 2008). PAR has its roots in the social and political movements in Latin America during the 1970s. Researchers sought to move social, philosophical, and psychological research from the sole, objective domain of traditional academia into the community (Fals-Borda, 1991). Action research is defined as:

A participatory, democratic process concerned with developing practical knowing in the pursuit of worthwhile human purposes and grounded in a participatory worldview. It seeks to reconnect action and reflection, theory and practice, in participation with others, in the pursuit of practical solutions to issues of pressing concern to people. More generally, it grows out of concern for the

flourishing of individuals and their communities. (Bradbury & Reason, 2008, p. 226)

There are five prominent features of action research: (a) a focus on practical issues, (b) participation and democracy, (c) focus on human flourishing, (d) knowledge in action, and (e) an emergent developmental form.

Reason and Bradbury (2006; 2008) summarized the purposes of PAR research. PAR creates practical knowledge based on lived experiences and is useful to people during their everyday lives and it is participatory research in that individuals and communities construct meaning in their lives (the social construction of reality). Thus, PAR research involves the “stakeholders,” including researchers and community participants, in all stages of the research process, such as the development of research questions and the implementation of action. It seeks to raise the critical consciousness of researchers and participants, empowers those in the research process, and utilizes their resources.

PAR contributes practical knowledge to increase the economic, political, psychological, and spiritual well-being of people and communities to establish a more equitable and sustainable relationship with the world. Also, PAR research is action research in that it seeks to create theory *and* activism. Action research develops over time to work towards practical outcomes to create new forms of understanding, because “action without reflection and understanding is blind, just as theory without action is meaningless” (Bradbury and Reason, 2008, p. 227). PAR also seeks to improve living conditions, empower people and change the power dynamics between individuals and social institutions.

Grounded Theory.

Grounded theory is an inductive qualitative research methodology developed by Glaser and Strauss (1969). Grounded theory includes a set of theoretical guidelines for gathering, synthesizing, analyzing, and conceptualizing qualitative data to construct theory (Charmaz, 2001). A grounded theory methodological design begins with general, open-ended questions about a research topic (Charmaz, 2008). In this study, the general questions are based on resilience factors and cancer survivorship and the questions are informed by past research on resilience qualities and/or protective factors. The data generated by these open-ended questions are coded and categorized by emergent themes. Theory emerges from the data collection and coding process (Charmaz, 2008).

Contributions to Resilience Research

This research study supports the principle of PAR that encourages the active participation and collaboration of researcher and participants in the discovery of new knowledge and action (Bradbury & Reason, 2006). The “stakeholders” including researchers and community members were involved in all stages of the research process. Two of the three dissertation committee members were cancer survivors and the third committee member was a woman with a disability with an interest in resilience and cancer survivorship. The committee members had personal experience and interest in learning about the resilience factors that enable cancer survivors to thrive in the face of cancer. They had input regarding the research design, question development and the gathering and analysis of the data.

As the primary investigator in this study is a female cancer survivor, I am not only the researcher, but a cancer survivor with a personal, vested interest in the study of

resilience factors of female cancer survivors. As I experience by own cancer journey with Hodgkin's Lymphoma, I have been intrigued by the questions: "How did *I* get through this daunting, often scary cancer experience, and how did I thrive in the face of adversity?" I was once told that a positive attitude was essential in the battle against cancer. I wondered if this was true. Through the knowledge of my own experience, and that of other female cancer survivors, I seek to identify common protective resilience factors that enabled us to flourish despite the challenges of our cancer experiences.

This dissertation intends to expand the definition of cancer survivor. Rather than defining cancer survivors in terms of remission status, this study seeks to broaden the definition of survivor to include females who are currently living with cancer, as well as female survivors whose cancer is in remission. This study holds that surviving cancer is not simply an experience to "overcome." This commonly held socially constructed view of illness and disability may lead to cancer survivors' disempowerment. This study is built on the premise that survivorship is an ongoing process and an identity that should be recognized and celebrated.

This dissertation seeks to expand the scope of previous research on resilience in terms of demographics. Denz-Penhey and Murdoch (2008) studied personal resilience in persons in Australia who were diagnosed with a life threatening illness, but who unexpectedly recovered despite a less than a 10% chance of living. These resilience factors may not generalize to other demographic groups. This study will focus on the resilience protective factors of adult female cancer survivors in the United States and will not be limited to those survivors with spontaneous remission.

Definition of Terms

Several terms and concepts used in the following chapters need to be defined for clarity.

Cancer Survivor.

Cancer survivors are women who are currently living with cancer and women whose cancer is currently in remission.

Resilience.

This study will define resilience in accordance with the definition provided by Richardson (2002): Resilience is “the processes of coping with adversity, change, or opportunity in a manner that result in the identification, fortification and enrichment of resilient qualities or protective factors” (p. 308).

Model of Resilience.

Richardson’s (2002) process model of resilience will be utilized as an organizing model. When faced with adversity, an individual can identify, develop, and strengthen resilience protective factors to reintegrate resiliently, reintegrate back to homeostasis, reintegrate with loss, or reintegrate with dysfunction.

Self-efficacy.

Self-efficacy is defined as peoples’ beliefs about their capabilities to produce designated levels of performance that exercise influence over events that affect their lives.

Benefits and Risks

With a better understanding of the resilience protective factors that have enabled female cancer survivors to cope with their cancer experience, cancer survivors,

caretakers, researchers, and the medical community will gain a better understanding of female cancer survivors' lived experience. This will better inform individuals diagnosed with cancer, their families and the medical community to develop more effective ways to intervene to assist female cancer survivors to successfully cope with their cancer experience. A potential risk to participants was mild psychological distress from discussing their cancer experience. Participants were provided with a list of local psychologists.

Summary

This dissertation seeks to examine the lived experience of adult female cancer survivors to (a) discover common protective factors that enabled them to be resilient as they experienced the adversity of their cancer experience; (b) identify potential barriers to resilience; (c) inform other cancer survivors, caretakers and the medical community regarding holistically meeting the needs of females diagnosed with cancer; and (d) to expand the definition of cancer survivor to individuals living with cancer and to extend resilience research to a sample of adult female cancer survivors living in the United States. This dissertation is based on the principles of PAR, which focuses on practical issues, participation and democracy, human flourishing, knowledge in action, and an emergent developmental form (Reason & Bradbury, 2008). This study seeks to empower female cancer survivors and provide them with a forum to give collective voice to the resilience protective factors that enabled them to cope with, heal, and thrive as cancer survivors. A grounded methodological design will be utilized to allow the themes of resilience to emerge from the data provided by the participants.

CHAPTER 3

Methods

This chapter includes criterion regarding participants, inclusion and exclusion, the procedure, and the question protocol development.

Participants

A letter from Dr. Irma Johnston of the Noble Circle Project was obtained, indicating her agreement in allowing this study to be conducted using the members of Noble Circle. Dr. Johnston agreed to allow the researcher to supply Noble Circle members with a recruitment letter and e-mail (Appendix A). Contact information for the researcher was provided in the e-mail. Participants were recruited via an advertisement sent through the Noble Circle Project internet listserv. Individuals meeting the inclusion criteria outlined in the recruitment material were encouraged to contact the researcher. At the start of each interview, the participant was asked to complete a demographic sheet which asked them their current age, ethnicity, annual income, and level of education (Appendix B).

Table 1

Demographics of Participants

Participant	Age	Ethnicity	Annual Income	Level of Education
Helen	57	Hispanic	>\$100,000	Master's Degree
Anne	69	Caucasian	\$20-\$30,000	Doctorate

Janice	52	Caucasian	\$10,000	Bachelor
Loretta	61	Hispanic	\$20-\$25,000	Post
Rosa	61	Caucasian	\$60,000 Joint \$30,000	Graduate 2 Bachelor's Degrees
Candace	41	Caucasian	\$20,000	2 Years College
Beverly	60	Caucasian	\$80,000	Master's Degree
Marisa	45	African American	\$49,000	Master's Degree
Sara	37	Caucasian	\$20,000 \$90,000 joint	Bachelors and Masters level Courses

Inclusion and Exclusions Criteria

To be included in this study, participants needed to be adult females who were currently living with cancer for at least three months or their cancer had gone into remission. Participants needed to be members of Noble Circle. Exclusion criteria included males, persons without a history of a cancer diagnosis, persons with a history of cancer who were not members of Noble Circle, and persons who were under age 18.

Procedure

In this study nine adult female cancer survivors who are members of Noble Circle were individually interviewed and asked open-ended questions regarding their cancer experience to ascertain the resilience factors that they perceived enabled them to cope, heal, and live their cancer experience (Appendix C). The topic of these questions pertained to their cancer diagnosis and treatment, and the organizational, social, individual and spiritual resources that helped facilitate their resilience during their cancer experience.

Human Subjects approval was obtained through the Wright State University Institutional Review Board Panel (IRB), and permission was granted by the executive board of the Noble Circle Project as this organization does not have its own IRB. Participants contacted the researcher to set up an hour-long meeting with the researcher at a location of the participant's choosing: either at a Noble Circle meeting, or in a private room at Wright State University. Each of these locations ensured confidentiality of the participant.

At the time of the interview, participants were provided two identical consent forms to sign, stating their willingness to participate in the current study (Appendix D). Each participant kept one consent form to document her informed consent to be interviewed, and the researcher kept one consent form to document the participant's informed consent. Once the participant consented, she was given a brief demographic information sheet, which gathered information including her ethnicity, diagnosis, and date of diagnosis, remission status, and social economic status.

The participant then engaged in an individual interview that consisted of 13 open-ended questions that asked her to reflect on the medical aspects, and the community, social, individual, and spiritual resilience factors that enabled her to cope with her cancer experience. The interviews lasted approximately one hour, and each interview was audio-taped and transcribed to code for themes that emerged regarding resilience protective factors that enabled the participants to cope with their cancer experience as well as their perceived barriers to resilience.

Following the interviews, the tapes were transcribed and sanitized by the primary researcher to remove any identifying information. Analysis of the data followed the

phenomenological grounded qualitative method to allow the themes of resilience to emerge and evolve from the data as the data analysis process progressed. Analysis of the data responses were grouped into “clusters of meaning” to determine and identify both a “textural description” and “structural description.” These descriptions, according to phenomenological methods, lead to an understanding of the essence of the resilience of female cancer survivors (Creswell, 1998). All data were sanitized and kept in a locked cabinet in the office of the dissertation committee chair, Dr. Julie Williams.

Question Protocol Development

The development of the research questions for this study was informed by the three phases of research on resilience outlined in the Introduction to this study. Questions were divided into five sections: (a) demographic characteristics of the participants; (b) community organizations; (c) others; (d) self; and (e) closing thoughts. The aim of these open ended questions was to provide the participants an opportunity to identify resilience protective factors in several areas of their lives. In line with the principles of PAR research, the dissertation committee members which included three cancer survivors, and a woman with a disability had input into the development and the research questions.

CHAPTER 4

Results

This chapter presents the research findings in two parts. The first part provides a table displaying the demographic information regarding the participants, including their age at diagnosis, ethnicity, and annual income, level of education, date of diagnosis, type of cancer, stage of cancer, notification, and cancer status.

The second part of this chapter presents the findings of the study in a table that clusters the resilience protective factors by biological, social, psychological, and spiritual identified factors, and the perceived barriers to resilience that the participants identified.

Findings

Demographics.

The first set of interview questions was intended to gain demographic information and basic information about the medical aspects of the participant's cancer experience including the type and stage of cancer with which they were each diagnosed, date of diagnosis, age at diagnosis and who first notified each of them of their cancer diagnosis.

Table 2 provides this diagnostic information:

Table 2

Diagnostic Variables of Participants

Participant	Date of Diagnosis	Type of Cancer	Stage of Cancer	Notification	Cancer Status
Helen	2003	Breast	IIA	Surgeon	Remission

		Cancer			
Anne	2003	Breast Cancer	IIA	GYN	Remission
Janice	2006	Breast Cancer	II	Surgeon	Remission
Loretta	2006	Breast Cancer	IV	GYN	Active
Rosa	2008	Breast Cancer	I	GYN	Remission
Candace	2004	Breast Cancer	III	General Practitioner	Remission
Beverly	2005	Breast Cancer	IIB	GYN	Remission
Marisa	2008	Breast Cancer	IIB	General Practitioner	Remission
Sara	2007	Melanoma	IIB	Surgeon	Active

Of the nine participants, two were diagnosed with cancer in 2003. One participant was diagnosed in 2004 and one participant was diagnosed in 2005. Two participants were diagnosed in 2006. One participant was diagnosed in 2007 and two participants were diagnosed in 2008. All participants were diagnosed within the past eight years. With regard to type of cancer, eight of the participants were diagnosed with breast cancer and one participant was diagnosed with Melanoma. Participants' stage of cancer ranged from stage I to stage IV. One participant was diagnosed with stage I cancer. Two participants had a diagnosis of stage IIA. One participant had a diagnosis of stage II cancer. Two participants reported a diagnosis of stage IIB. Two participants were diagnosed with stage III cancer and one participant was diagnosed with stage IV.

Participants' notification of the cancer diagnosis came from three types of medical doctors: gynecologists, surgeons, and general practitioners. Four participants were

notified of their cancer diagnosis by their gynecologists. Three participants were notified by their surgeon and two participants were notified by their general practitioner. Of the nine participants, seven participants' cancer was in remission and currently, two participants' had active cancer.

The interview questions were designed to be open-ended, so in answer to these questions, participants were asked to expound and expand on the question and provided significant detail. Each interview was transcribed and coded by the primary investigator. Each participant's interview was first coded by going line by line and coding for identified resilience factors that emerged from the interview text. Next, themes that were the same from each participant were grouped together. The resilience protective factors clustered into four areas: biological, social, psychological, and spiritual aspects of their cancer experience (Table 2).

Table 3

Biological, Social, Psychological and Spiritual Resilience Factors

Resilience Factor	Facilitating Resilience: Efforts to Reestablish Control	Potential Barriers to Resilience
Biological/Medical	Self perceived manageable side effects of cancer treatment Seeking early detection	Late stage diagnosis
	Utilization of complementary/alternative methods (CAM): massage, qigong, whole foods nutrition, Asian energy work	Not taking a holistic approach to cancer diagnosis and treatment
	Acknowledgement of sexual response issues	Not acknowledging the impact of cancer on sexual response
Social/ Environmental	Supportive notification	Insensitive or Impersonal notification

	Lack of clear communication among medical professionals
Family and friends as social support	Feeling like a burden to friends and family
	Not having access to a social support network
	Over-emphasis on disease over living life
Social bond with other cancer survivors	Non-cancer survivors not being open to or able to relate to the cancer experience
Supportive, validating, and competent medical professionals (physicians, nurses, psychologists) who offer a holistic approach to cancer treatment	Not feeling heard and validated by the medical community
	The medical community not addressing the biological, social, psychological, and spiritual needs of the survivor
Proactively advocating for ones' self: Obtaining education/information regarding cancer diagnosis, treatment, and prognosis	Lack of informational resources related to the cancer experience
Utilizing cancer support groups as a source of psychological, social, and biological support	

	and information	
	Access to economic resources, i.e. access to affordable healthcare	Lack of affordable healthcare for early prevention and cancer treatment
		experiencing the social stigma of being uninsured
Psychological	Acknowledgment of sexuality/ body image concerns	Feeling less attractive and sexually undesirable as a result of cancer treatment
	Control	Feeling a lack of self-efficacy to cope with and manage cancer experience
	Self-Advocacy Optimism Self-determination Independence Perseverance Humor Stubbornness Creative expression Stoicism Avoidance End of life planning Reframing Accepting reality, but not giving up	Fear Anxiety
		Depression
Spiritual	Energy work/ belief in higher power	
	Faith in a God	Feeling angry/ abandoned by God
	Utilization of a spiritual community as social support.	

Participants consistently identified the importance of reestablishing a sense of “control” over their cancer experience as a means for them to experience resilience during their cancer experience. The participants defined control in terms of biological/medical, social/environmental/psychological and spiritual resilience factors. They established a sense of control and empowerment over their cancer experience by advocating for themselves by seeking out medical professionals who could meet their needs in a caring and compassionate manner.

The participants gained a sense of control by seeking out information and education regarding their treatment options and methods of self care such as the utilization of complementary and alternative medicine. They also sought to gain a sense of control over their cancer experience by actively seeking out social support from friends, family and from the members of a cancer support group. Key to their sense of resilience and control over their cancer experience were the supportive and validating relationships the participants formed with other cancer survivors.

Participants also defined control in terms of psychological and spiritual resilience factors. Psychological resilience factors that facilitated a sense of control included optimism, humor, reframing, stoicism, avoidance, acceptance, goal setting, and end of life planning. Spiritual resilience factors that facilitated a sense of control included energy work and belief in a higher power and God. The participants gained control over their cancer experience by utilizing the identified resilience factors to set their own terms by which they would cope with cancer.

Factors that impeded the participant's sense of control and resilience over their cancer experience included a late stage diagnosis, an invalidating medical community, and a lack of social support, self efficacy, informational resources, and health insurance.

CHAPTER 5

Discussion

This chapter provides a discussion of the biological/medical, social/environmental, psychological, and spiritual resilience factors that the participants identified as helpful to them as they coped, healed, and lived their cancer experience. The resilience protective factors are presented in the participant's own words to honor their right to give voice to their lived experience with cancer. This discussion of the resilience protective factors is organized by interview question and the resilience factors that emerged from each research question are identified in the participants own words

The participants identified biological/medical, social/environmental, psychological, and spiritual resilience protective factors across all questions. The first two questions focused on the biological resilience factors of the cancer experience.

Interview Questions 1 and 2

- 1. With what type of cancer and at what stage of cancer where you diagnosed?*
- 2. What was the date of your cancer diagnosis and at what age were you diagnosed with cancer?*

In response to these first two questions regarding the medical aspects of the cancer experience, the participants shared their type, stage, date and age at diagnosis. Each participant also individually engaged in a discussion with the researcher regarding her reaction to her diagnosis. Participants' responses to questions included specifics

regarding the type of medical treatment they received including chemotherapy, radiation, mastectomy, and the chronic side effects of their cancer treatment.

Control.

The participants identified the importance of establishing control over one's cancer experience by (a) taking a proactive stance toward cancer treatment decisions; (b) becoming educated regarding one's diagnosis, prognosis and treatment; and (c) becoming a self-advocate. Other resilience protective factors that emerged included the impact of a mastectomy on one's sexual identity and sexuality and the importance of having doctors who are supportive, understanding, direct, and validating during the cancer notification and treatment process.

Proactive Stance.

Participants noted how a proactive stance regarding cancer treatment increased their sense of control over their cancer experiences. For some participants, a means of controlling the cancer treatment experience was self-advocating for aggressive cancer treatment. One participant reflected on the importance she placed on taking control by seeking a double mastectomy. Helen:

I mean, my first reaction when I heard that I had breast cancer, aside from crying, was 'I need to get this off. This is not good for me. I need to get this breast off.' It was like my instinct to protect myself. 'We need it OFF as soon as we can.'

Education.

Participants also took steps to educate themselves about their diagnosis. This included reading literature, seeking information on the internet and on help lines, and seeking advice from other cancer survivors. Marisa:

Yeah, anything else you think I need to know. So, I'm a feverish researcher. I mean I read books like you wouldn't believe. I was on the internet and signed into every site that you can think of. [I was] on the American Cancer Society, on the hotline at 2:30 in the morning when you can't sleep and you are thinking about all of this and they have a 24-hour hotline. Other participants expressed the value they found in seeking medical knowledge from other survivors. Anne: So my friend, she says, 'Well, I really like the one I go to.' So I said, 'Okay, fine.' So when we talked to the surgeon we gave him the name, he said, 'That's fine.' So I just went there. I didn't shop around—I don't know anything about that sort of stuff, you know, my friend said she's good. I really trust her.'

Self-Advocacy.

Another participant spoke of maintaining control over her cancer treatment by advocating for herself by taking the time to find a surgeon that would meet her biological needs by being conservative regarding her breast cancer surgery. Beverly:

I was really concerned about them taking all the lymph nodes and, in fact, wouldn't agree to that. I finally found a surgeon...She was wonderful. She understood my concerns. She did something called sentinel node biopsy rather than taking all the lymph nodes like the first two surgeons wanted to do; she took as few as she could.

Sexual Identity and Sexuality.

Another resilience protective factor that emerged from the interviews was the impact of a mastectomy on the participants' sexual identity and sexuality. One

participant spoke of her emotional/psychological reaction to having a mastectomy and losing her breast. Janice:

So, anyway, I just, my breasts are kind of important to me. They're part of my sexuality. You know, I was the little girl who wanted to grow breasts, and didn't for a long time. And you know, it was just like, I was just devastated that they wanted to remove my breast. So anyway, they did.

Reframing.

To cope with the loss of her breast and maintain her sense of sexual identity, she reframed the loss of her breast as a loss that is significant, yet not self-defining. Janice:

I don't know, it's odd now, because now I think, I look at myself and think, oh yeah, I only have one breast. I'm glad that I have one breast, you know, but, and I miss the other one, but you know, it's like I'm alive and my breast isn't who I am.

Interview Questions 3 to 5

This set of questions asked the participants to reflect on any community organizations or people that positively influenced their coping with cancer.

3. Who first informed you of your cancer experience?

Supportive Medical Professionals.

With regard to the third question, participants had a variety of reactions to their cancer notification experience. Some participants reported an empowering experience in which their doctors and surgeons were supportive and validating during the notification process and cancer treatment, which increased their sense of self-efficacy. One

participant noted the value she found in having a doctor who notified her of her cancer diagnosis in a direct, straightforward manner. Helen:

Well, before he told me, I could hear it in his voice. You know he had a kind of somber voice. He was calm and he was very direct. I like doctors that are direct. I don't like them to beat around the bush. I just like to know the facts. So, I thought he was fine. He did a nice job.

Participants also identified psychologists as an important resilience factor because the psychologist provided a safe place to self-disclose one's feelings about the cancer experience. Sara:

You know people don't share most of what's on their mind. They do in the psychologist's office because that is a safe place. But typically, if someone is putting something emotional out there that's just the tip of the iceberg. They're not sharing all the other thoughts and mind chatter and everything else that comes up.

Self-Advocacy.

The participants' spoke of the importance of finding doctors who were willing to listen to and address their biological, psychological, and social needs and validate them as they engage in their cancer experience. Rosa:

I think that the woman who was my second surgeon was wonderful in many ways, but part of it was that she was a woman and had an understanding of how a woman might feel towards her breasts. But, I think she was just a better surgeon to begin with and just a wonderful person that she listened and validated. She didn't talk down to you in anyway. She used terms and if you didn't

understand a term you could ask for clarification, yet she didn't carry on a conversation and try to dumb down like the other doctor.

The participants highlighted the need for cancer diagnostic notification and treatment information that is delivered in a personalized, clear, direct, yet sensitive and validating manner in that the medical professional recognizes and considers the potential holistic impact of a cancer diagnosis on the patient's biological, psychological and social well-being.

4. Are there any community organizations that have helped you with your emotional, physical, social, and spiritual coping with cancer? Explain.

5. How did you utilize these organizations?

Resilience protective factors that emerged from these questions involved the importance the participants placed on their membership in cancer support groups, such as Noble Circle, which offers holistic, and alternative and complementary healing and also provides a supportive environment of women coping and living with cancer.

Benefits of Cancer Support Groups.

Participants placed significance in their membership in the Noble Circle Project, as a means to promote their resilience. Unlike some cancer support groups which only provide practical information focused on the cancer medical treatment process and drug side effects, Noble Circle offered these participants a sense of community. The participants explained that Noble Circle is a sisterhood of other cancer survivors whose cancer is active and in remission, who provide each other with psychological/emotional, social, and biological support and information.

Bond with Other Survivors.

The participants identified that a bond with other cancer survivors was a key resilience protective factor. They experienced universality in that they had a sisterhood of cancer survivors who understood the holistic significance and impact of the cancer experience. The participants noted that they felt safe to self-disclose information, concerns, and worries among the members of the group. They shared their cancer experience, but were not defined by it. Together, the sisters of Noble Circle created a bond in which they drew on their collective strength which enabled them to *live* with cancer rather than *suffer* it. Rosa:

Then everyone is just so nice and understanding and all of these women are dealing with cancer in some way. They don't say 'oh, her cancer is much worse because she's got this and yours isn't much.' Everyone is taken very seriously and listened to and there were sessions where we would just talk about our worst fears and our hopes and just that sort of thing, just with our new group of sisters just starting. Very open and we could say anything and it was heard and it was listened to and it was taken seriously. Everyone just listened. They didn't come back with their experience of it, you know how just sometimes in conversations people will say 'well if you think that is bad, listen to this!' It was none of that at all. So, it was just very nurturing.

Complementary and Alternative Medicine (CAM).

Another resiliency factors that the participants highlighted was the importance they placed on using Complementary and Alternative Medicine (CAM) as a means to enhance their sense of control over their cancer experiences, to become spiritually

reconnected, and to holistically improve their health and well-being. CAM is defined as “diagnosis, treatment, and/or prevention which complements mainstream medicine by contributing to a common whole, by satisfying a demand not met by orthodoxy or by diversifying the conceptual framework of medicine” (Mckenzie, Pinger, & kotecki 2005, p. 389). A CAM practice that the participants highlighted as being particularly helpful to them as they coped with and healed from their cancer experience is qigong, an exercise and healing movement that strengthens one’s qi, or “life energy.” Other CAM practices that the participants found beneficial included massage and whole foods nutrition. One participant reflected on the benefits she found in her practice of CAM. Anne:

I think that the medical model is a way, but not the only way, and within the medical model, it’s not an either/or question. It can be a both/and question-- in terms of you do the medical treatment and you do other things to help yourself. And if you’re just submissive, you know, accepting XYZ drug, XYZ surgery, XYZ whatever, you’re potentially powerless. But if you are combining the medical model, which I believe is very good when you have an acute issue, it can be enhanced with what is now called CAM, complementary and alternative medicine, which you know, covers a very large variety of things.

I think you have to choose judiciously, but I think things like improved nutrition is very relevant. I think learning about energy is very relevant. For me, learning about movement has been very relevant. And none of those things contradict or counteract the medical model. But the medical model isn’t the whole story. I think that’s what I would say: The medical model isn’t the whole story. It’s an important part to get things kind of under control, but then it’s not the whole story

anymore. And if you are aware of the alternatives, it needn't be the whole story even in the most intense phases of treatment.

Questions 6 and 7

Questions six and seven were intended to help identify people who served as supportive resiliency protective factors. These questions asked the participants to reflect on whom, if anyone, was helpful to them as they experienced cancer and how these people were helpful.

6. Who was helpful to you during your cancer experience? Explain.

7. How were they helpful? Explain.

The participants indicated that several people were socially supportive and served as protective resilience factors, including family members, especially their husbands, children and siblings. Also identified as helpful were friends, including Noble Circle sisters, and religious community members. The participants valued the support of these individuals because they stood by them, provided motivation and a sense of humor during difficult times. Several participants identified the usefulness of humor. Participants also noted the importance of their spirituality as a resilience factor.

Family Members.

Participants identified their husband as a significant source of support. Beverly: My husband was the only person while I was going through chemo who could make me laugh. He has a really dry sense of humor. Laughter is a really important part of our relationship and as bad as I felt when I was going through chemo, he could still make me laugh. So, he would be at the top of my list of people who helped get me through it.

Janice identified her husband as someone who motivated her to stay active during her cancer treatment. Janice:

And my husband—he was a significant, you know, pillar for me. He made me do things that I was really pissed off about, that he was making me do stuff, and I was like just leave me alone, I don't want to go out there and do that.

Other participants identified siblings and close friends as key supports. Speaking of her brother, Rosa identified the importance of having caretakers who were not overbearing, and listened to and addressed her needs at the same time they took care of their own well-being. Rosa:

He didn't come with his own preconceived ideas of what I needed. He would ask me what I needed and he would take time for himself. He would go for a walk to take a break. He wouldn't let himself get worn out. He would take care of himself, too. I thought that was wonderful because then when I did need something and I asked him, he would take it seriously. If he could do it, he would; and if he couldn't, he didn't. He wouldn't feel put upon, he would just honestly help if he could. I think that went very well.

Friends.

Other participants who did not have a family social support network highlighted the importance of proactively seeking support from friends. Anne:

I think the biggest help for me was a woman I knew, but you know, not intimately, from my church, who had breast cancer probably six or seven years before I was diagnosed and has been doing really well. She was the one who stood by me all the time. You know, like she went with me to the meeting with

the surgeon...She was my basic support system because I don't have any local family.

Spirituality.

Participants found spiritual support within their mainstream religious communities and in their faith in a higher power. Marisa:

There's too many times when God just pulled through when I was just like I can't take anymore of this.' You know the scripture says he'll never give you more than you can handle. He lived up to that for me. That was really a wonderful, wonderful support.

Candace also found her faith as a source of resilience. Candace:

I've been going to church and they teach me that my spirit is eternal and that helped me. I don't fear dying anymore because part of me will live on some way or other in the next dimension or what have you. Whatever it is. That gave me the peace that I need to continue living and if I don't get to live then I can accept it.

Questions 8 to 11

Questions 8 through 11 asked the participants to identify personal qualities and skills that they felt have helped them cope with their cancer experience.

8. What personal qualities and skills do you feel have helped you cope with your cancer experience?

Personal resilience qualities that the participants identified as assets to them during their cancer experience included: self advocacy and a proactive stance, optimism, self-determination, perseverance, independence, humor, faith, setting goals, creative

expression, stoicism, stubbornness, avoidance, and acceptance without giving up. A resilience factor that was consistently present was proactively seeking information to make informed treatment decisions:

Self-Advocacy.

Participants spoke of the importance of self-advocacy. Helen:

I guess I'm the kind of person that when faced with a challenge I rise to the occasion and I try to be as rational as possible and I have faith that things are going to work. I don't shy back. So being open minded trying different things-- trying to reach out to different institutions to help me instead of just kind of getting back into my little shell and not trying to think about it. I want to be proactive.

Optimism.

Other participants spoke of maintaining an optimistic attitude. Janice:

Well, I do think that basically I've always been optimistic. I've had people try to drill that out of me by pointing out all the pessimistic things in life, but I've always had that little voice that's like, 'You know, it'll be okay. It'll be okay.'

So I think that makes a huge difference in how you move through the process, the process of the journey.

Self-Determination.

Self-determination was a resilience protective factor that participants reflected on using:

Beverly: “Well, I think my dogged determination has kept me fighting to maintain as much independence as I can. As bleak as things seemed during that time, I am not someone who is going to throw up my hands and quit.”

Independence.

Participants spoke of independence as a resilience protective factor that was useful to them during their cancer experience. Anne:

A great deal of independence, you know, not depending on others to make decisions for me, not expecting others to be there for me, knowing that if it was gonna get done, it was up to me. I don't have a family support system, so I've always been—you know, if it gets done, I do it.

Humor.

The use of humor was also a resilience protective factor that the participants used to cope with cancer. Loretta:

I think the humor, when it got really bad, that really resonated with me because I think that was a mechanism that I used too, because it was so terrible that it becomes funny when it's really not funny at all. But I think you have to—it may not be funny at the time, but you have to have some of that humor.

Marisa also found value in using humor to manage some of the more challenging side effects of her cancer treatment. Marisa:

Wow, I'm a glass half full girl. I have a really good sense of humor.

‘You've lost weight. I'm like it's the chemo goddess!’ ...look, I can either joke about it or I can cry. No bad hair days. No bad hair days. Whoo! I have a

wicked sense of humor. All of that and add my faith to it and sheer stubborn will.

Goal Setting.

The participants noted goal setting as a key resilience protective factor. Sara:

The one that I identify with the most right now is having things in the future to pull me forward. I don't mean living in the future because I do believe that I have a pretty good capability of living in the present. I mean a lot of exuberance and excitement and enthusiasm about the future version of myself that I am in the process of creating... So the excitement of getting me up to speed with what my dreams and goals and hopes are.

Creative Expression.

Participants also used creative expression such as poetry, painting, and jewelry making as a means to reestablish control, experience joy in their lives, and cope with their cancer. Candace:

What I do know is that while I was painting, I felt powerful because it was my world and I could create it anyway that I chose. While I was being engaged I just felt connected to something. It was a relief to get away from all of my crazy internal dialogue. It was a form of meditation.”

Stoicism.

Cancer treatment is a challenging experience and participants reflected that stoicism assisted them to cope with cancer treatment. Loretta:

And I think there's also a certain stoicism. When I was in treatment, there was a certain stoicism where you just went every week, regardless of how you felt. You

just went...So I think that also has a bearing because if you tend towards those ups and downs and highs and lows, this will get to you really easily.”

Avoidance.

For some participants, at times, minimizing the seriousness of their medical condition was a useful and necessary resilience protective factor:

Loretta: “Denial and blinders work wonderfully. Cause I just couldn’t understand why my entire family was in my hospital room, while I was in ICU, when everything was perfectly all right.”

9. Do you think that these qualities were learned or always present? Explain.

In response to this question, the participants acknowledged that the resiliency factors they have and used are both innate qualities and learned behavior, a combination of nature and nurture.

10. From where do you draw personal strength?

The participants indicated that they drew personal strength from the support of their friends and family, Noble Circle, from within themselves, and through the practice of qigong and CAM and through their spirituality. Rosa:

I think when I do qigong, it’s pulling in energy from the universe and I do feel that when I do that. So, I’m also a spiritual person and I think God is not a man sitting on a mountain top or anything but it is energy inside and so when we are doing qigong and pulling in the universal energy, it’s energy from God. I get a lot of energy from my children and friends and Noble Circle sisters that’s what nourishes me.

11. *Overall, how do you think you have coped with cancer? Below average/ average/ above average? Explain.*

The participants indicated that they believe they have dealt with cancer in the “average” to the “above-average” range. One participant emphasized that the cancer experience is an individual journey that cannot be arbitrarily rated.

Questions 12 and 13

The last two interview questions were designed to provide the participants with an opportunity to express their views of survivorship and to provide an open forum to express any final thoughts that they would like to share regarding their cancer experience. Participants shared their view that they wanted to feel empowered in the cancer experience and did not want to be defined by the disease. They also highlighted the need for early cancer detection and the value they found in the support of other cancer survivors. They emphasized a goal of not being defined by cancer, but choosing to make one’s own definition of her lived experience with cancer.

12. *What does the term “cancer survivor” mean to you?*

Empowerment.

Beverly summed up the prevailing view of the participants in this study: They want to *live* with cancer and *thrive*. Beverly:

Well, I’m not really crazy about the word survivor. At Noble Circle our tag line was ‘Women Thriving Beyond Cancer.’ It was surviving, we changed it to thriving. A lot of the cancer terminology is war related: ‘battle cancer,’ ‘disease,’ ‘fight.’ I don’t like that terminology so much, although I find myself

using it. I'm not a cancer survivor. To me, that defines me that way and that's not all of who I am. It's a part of me and it has definitely impacted my life.

Anne reflected on how her use of "thriving" was an empowering term that implies action and resilience which is counter to the socially constructed view of cancer as an illness and disability that must be suffered: Anne:

Well I think it's the idea of thriving beyond cancer. It's like the difference you see in the evolution in terms of speaking about different kinds of disabilities, for example, 'that person is a schizophrenic,' as opposed to 'this is a person who has schizophrenia.' Or 'this person is a diabetic,' rather than 'this is a person with diabetes.' You know, this is a person dealing with cancer. And quite frankly, I'd rather language like 'dealing with' than 'fighting' because 'dealing with' involves things like getting support, doing things.

13. What would you like others to know about your cancer experience?

Early Detection.

Participants' advocated for seeking preventative healthcare. Helen:

As long as you can get an early diagnosis it can really make your life better because it will be a wake-up call for you to improve many aspects of your life: your emotional life, your spiritual life, your physical health and exercise and food. It's basically that.

Support of Other Survivors/Reframing.

Beverly reflected on how the biological, social, psychological and spiritual support she received from her sisters at Noble Circle enabled her to have a more positive outlook on life and her cancer experience. Beverly:

One of the things that I learned from Noble Circle is that I want to live my life in a place of joy and I don't want to focus my attention on fear and poor me. I have met some of the most courageous women who, when they are desperately ill, they are going through God awful treatment and when you say to them 'How are you?' they say, 'I'm well.' I have really been exposed to the power of intentions. Putting out that you are well, believing that you are well, maybe doesn't change the fact that you have cancer and you may die, but you are certainly going to be happier. A lot of the women have been huge inspirations to me.

Not Defined by Cancer.

Marisa highlighted the importance of *living* life with cancer rather than suffering it. Marisa:

Don't allow cancer to define you. Take the opportunity when you have cancer to make your own definition of what your life is going to be like that you don't want it to define you. It's not who I am. It's not who I am. And go through the journey. Go through the journey. Remember what is important, prioritize your life. It's all about giving and receiving love that's why we are here. When you take it down to that base level, it makes everything seem a little bit different.

Barriers to Resilience

As the participants spoke of the biological, social, psychological, and spiritual protective factors that promoted and enhanced their resilience, they also noted some barriers to resilience that they had to overcome. These barriers included perceived

impersonal and insensitive cancer notification, the hardship and stigma associated with not having adequate healthcare coverage, social withdrawal from friends who could not relate to the cancer experience, feeling like a burden to others, and fear and anxiety.

Impersonal Notification.

Participants spoke of the negative psychological impact of their notification of their cancer diagnosis and they emphasized the need for a sensitive, supportive, and validating notification process. Janice:

My surgeon--she was pretty blunt. And, um I come off as the really pretty strong woman, and she felt that I was strong and that it wasn't gonna bother me. And I fell apart in her office. And she came back later and apologized. She felt badly that she wasn't more sensitive about it."

Anne spoke of the impersonal nature of her cancer notification and she expressed the need for a more personal, face to face communication during the notification process.

Anne:

In terms of how the diagnosis was handled, I would say rather poorly, in the sense that, you know, I did the mammogram and then I got the little letter from the place that did the mammogram, and you know the last sentence was 'highly suggestive of malignancy.' You get this in a letter? On a Saturday in your mail? What are you supposed to do on a Saturday with this information? You know, so anyway, I didn't have a choice but to wait till Monday...I think it should been handled with some kind of face to face communication, rather than, you just open your mail and Wham-O, there it is. I felt as if that was kind of cold and mechanical.

Lack of Health Insurance.

The lack of affordable healthcare coverage, the burden of paying extravagant medical bills, and the social stigma of discussing disparities in healthcare coverage was another barrier to resilience that the participants identified. Rosa:

I think if you either have no medical insurance or you have bad insurance because you are self-insured, the financial worry was probably just as much of a worry as the cancer. I had two major worries going on and a lot of the women who had good insurance just had the one to focus on that was something that I felt that even with the support group it was hard to talk about because people didn't really understand how it feels like to have the doctor not want you because of the insurance you have. It's difficult.

Sexuality and Sexual Identity.

Participants spoke of the silence around the negative social and psychological impact of a mastectomy on their sexuality and sexual identity. They spoke of feeling less feminine:

Janice: "And it hadn't really dawned on me, you know, that I hadn't been flirting. And when we were talking to these younger women, it was like 'yeah, that's definitely something that has changed in my life.' My sex drive is not there."

Anger/Questioning Faith.

Some participants indicated that when they were first diagnosed with cancer they experienced intense anger and questioned their faith. Beverly:

The idea of starting this whole new diagnosis, this new journey was just too much. I just sort of folded inwards. Got really angry at God again, you know

‘this just isn’t fair’ and I stayed that way for a long time. Honestly, Noble Circle is what brought me out of it.

Fear/Depression.

Fear was also an emotion that the participants reflected on experiencing. Marisa: Oh, it was a lot of things, a lot of things. You are afraid to die. You are afraid to live through. All the stuff you hear about chemo. You know that whole expression ‘that which doesn’t kill you makes you stronger?’ I think that expression came about chemo, I really do. Seriously, chemo invented that expression. That stuff is nasty. It’s really nasty and [you] really believe at certain points that you’re just not going to live through this chemo. It’s sad. So, there are fears of everything. Fear of leaving your kids, leaving your husband. Fear of how all of it is going to work out.

Burden.

Participants spoke about not wanting to be a burden on their family and friends and the support they found from the members of the support group. Rosa:

I think what was the most helpful was having other women who had a similar experience because I didn’t have family around that I could talk with--just having people who have had that experience to be able to talk openly about it. With my kids I felt like I needed to protect them from it and I didn’t really want to worry too much and just go on about it around them a lot. I didn’t want to worry them. With these other women I could be very open with it and talk. I found myself talking a whole lot, and it was very good.

Summary

This chapter presented the results of the study. The demographic variables of the participants were identified including the participants' age at diagnosis, ethnicity, and annual income, level of education, date of diagnosis, type of cancer, stage of cancer, notification, and cancer status. Also presented were the biological/medical, social/environmental, psychological, and spiritual protective factors that the participants identified they utilized as they coped with their cancer experience. In line with the philosophy of Participatory Action Research, the participants identified bio-social-psycho-spiritual resilience factors and these were presented in the participants' own words to provide them with a forum to give voice to the resilience factors that assisted them to cope, to heal, and *live* their cancer experience.

CHAPTER 6

Conclusion

In this study, nine adult female cancer survivors who were members of the Noble Circle Project were individually interviewed and asked open-ended questions regarding their cancer experience to ascertain the resilience factors that they perceived enabled them to cope, heal, and live their cancer experience. Specifically, this study sought to (a) identify the resilience protective factors that are strengths and resources that enabled adult female cancer survivors to cope with the stress and adversity of their cancer experience such that they live with cancer rather than suffer it; (b) identify the perceived barriers female cancer survivors experience that impedes their ability to cope with their cancer experience; (c) expand the research literature on resilience and cancer survivors to include adult female cancer survivors from the United States; and (d) inform other cancer survivors, caretakers, and the medical community regarding the identified resilience protective factors to assist them to facilitate resilience following a cancer diagnosis.

Connection to Prior Cancer Research

The biological/medical, social/environmental, psychological and spiritual resilience factors that the participants identified were supported by past research on resilience and cancer survivorship. This section provides a discussion of this connec

Identified Biological/ Medical Resilience Factors.

The biological, social, psychological, and spiritual resilience factors identified by the participants in this study were consistent with prior research on resilience. The participants in this study identified resilience protective factors, which were organized into four domains: biological/medical, social/environmental, psychological and spiritual resilience protective factors. Biological resilience protective factors that the participants identified as significant to their well-being included (a) perceived manageable side effects of the cancer treatment, (b) utilization of complementary and alternative health methods, and (c) acknowledgement of sexual response issues.

The participants in the study indicated that early cancer detection and a manageable physical impact of their cancer treatment were important resilience protective factors. This is consistent with prior research that suggested that low-income women who did not receive early cancer detection were more dissatisfied with their cancer treatment (Thind, Hoq, Diamant, & Maly, 2009).

The participants in the present study highlighted the importance of breaking the silence around cancer and women's sexuality by speaking to other cancer survivors and medical professions. They identified silence around sexuality and body image as a barrier to resilience. In regard to acknowledgment of sexual response issues, Katz (2011) found that cancer treatment can impact cancer survivor's sexual identity and sexual response by causing fatigue, loss of libido, decreased physiologic signs of arousal, and pain during intercourse. Also, cancer treatment can create body image concerns including feeling less attractive as a result of hair loss or a mastectomy.

The PLISSIT Model for Discussing Breast Cancer and Sexuality offered by Annon (1979) provided healthcare professionals practical information regarding discussing sexuality and body image concerns with cancer survivors. The elements of this model are: (a) permission, (b) limited information, (c), specific suggestions, and (d) intensive therapy. This model for discussing sexuality highlights the need for medical professionals to take the initiative to address and educate clients regarding cancer and sexuality. The participants' emphasis on the use of Complementary and Alternative Medicine (CAM) as a resilience protective factor was consistent with the finding by Crammer, Kaw, Gansler, and Stein (2011) that CAM utilization was associated with being female, younger, more educated and having poorer physical or mental health (p. 99). These researchers also discovered that CAM use was positively associated with spiritual well-being. Similar to these findings, the participants in the present study were female, well educated, and dealing with the impact of cancer. They also identified their use of CAM practices such as massage and qigong as a means to facilitate a spiritual connection to the energy in the universe.

Identified Social Resilience Factors.

Social resilience protective factors that the participants identified as helpful in facilitating their coping with cancer were: (a) supportive and sensitive notification; (b) socially supportive friends and family; (c) a bond with other cancer survivors; (d) supportive, validating and competent medical professionals; (e) proactively self advocating for ones' self by obtaining information regarding ones' cancer diagnosis, prognosis and treatment; (e) using cancer support groups as a source of biological, social,

psychological and spiritual support and; and (f) having access to economic resources such as affordable healthcare.

The participants in this study identified that supportive, sensitive notification, competent medical professionals and proactively self-advocating for ones' self were key protective factors and that invaliding interactions with medical professionals were a significant barrier to resilience. This is consistent with findings by Thind et al. (2009) who found that women with breast cancer reported a higher satisfaction with their cancer treatment when they received more information, had greater physician emotional support, and were participatory in the treatment decision process.

The participant's identification of family, friends, and other cancer survivors as key resilience protective factors is also consistent with past research. Schroevers, Helgeson, Sanderman and Ranchor (2010) reported that cancer survivors who receive social support characterized by reassuring, comforting, and problem solving 3 months after diagnosis had greater post-traumatic growth eight years post diagnosis (p. 50-52). Also, perceived social support from friends and family assisted the cancer survivor to frame cancer as a life challenge and to engage in stoic acceptance (Cicero, Coco, Gullo, Lo Verso, 2009).

In regard to healthcare insurance, the participants recognized having adequate healthcare insurance as a resilience protective factors and a lack of these resources as a barrier to resilience. In a study of 1,767 cancer patients 39% of individuals with a yearly income of less than \$40,000 dollars reported that the financial costs of their cancer treatment caused a "great amount of distress" and 9% of patients stated that they decided not to have a recommended cancer treatment because it was too expensive. This figure

increased to 25% for those individual who have an annual income of less than 40,000 (Markman & Luce, 2010).

Identified Psychological Resilience Factors.

Psychological resilience protective factors that the participants identified as key to their living with cancer included (a) acknowledgment of sexuality and body image concerns; (b) a sense of control; (c) self advocacy; (d) optimism; (e) self determination; (f) Independence; (g) perseverance; (h) humor; (i) stubbornness; (j) creative expression; (k) stoicism, (l) avoidance; (m) end of life planning; (n) reframing; and (o) accepting reality, but not giving up. They identified fear and depression and a lack of self-efficacy as barriers to resilience. The participants' use of humor as a resilience protective factor is consistent with the results of a literature review regarding the impact of humor on patients with cancer. Christie and Moore (2005) reported that cancer patient's use of humor increased their general well-being by increasing immune functioning and by reducing stress, anxiety, fear, and discomfort. The participants in this study also identified a range of psychological resilience factors that they use to increase their self-efficacy. Past research supported the association between greater self-efficacy and emotional well-being (Rottmann, Dalton, Christensen, Frederiksen, Johanson, 2010).

Identified Spiritual Resilience Factors.

Spiritual resilience protective factors that the participants identified as important during their cancer journey included: Asian energy work, a belief in a higher power or God, and utilization of a supportive spiritual community. Prior research by Yanez et al. (2009) found that cancer patients who had a greater spiritual-well being, defined as a sense of meaning/peace and faith, had decreased depressive symptoms and lower cancer

related stress. The participants in the present study also reported that they received social support from their spiritual community, which was also supported by past research (Howsepan & Merluzzi, 2009).

Connection to Prior Resilience Research

The bio-social-psycho-spiritual resilience protective factors identified by the participants were consistent with past research on resilience and hardiness. The resilience protective factors that the participants identified were consistent with Masten and Germezy's (1985) triad classification system of resilience protective factors. These included (a) individual disposition attributes, (b) family support and coherence, and (c) external support systems. Specific resilience factors within this classification system were good communication skills, an internal locus of control, high self-esteem, and self-efficacy, and the ability to manage strong impulses, a sense of humor, secure attachment, supportive family relationships, a cohesive family unit, positive role models, and socialization and external support networks such as church, school or work (Masten & Garnezy, 1985; Rutter, 1985; 1987). The participants in this study identified utilizing these resilience protective factors as they coped with their cancer experience.

In regard to the concept of hardiness which is composed of three characteristics: commitment, control, and challenge, the participants in this study also identified these factors as key to managing their cancer experience (Kobasa, 1979; Kobasa, Maddi & Courington, 1981; Dobasa, Maddi & Kahn, 1982). The participants expressed a commitment to their values, goals and capabilities, and the belief in the importance of their selves, and active engagement with the community through their involvement with a cancer support group, friends and family and spirituality. They also placed emphasis on

reestablishing control and facing the challenges of their cancer experience by self-advocating for their biological, psychological, social and spiritual needs to be met. Also, through their active involvement in a cancer support group, the participants spoke of making meaning of their illness and cancer experience such that they were inspired by other cancer survivors and not defined by cancer (Kabosa, 1979).

Implications and Recommendations

This study of resilience in female cancer survivors has implications for cancer survivors, caretakers and medical professionals. In line with the principles of Participatory Action Research (PAR) which focuses on practical issues, participation and democracy, human flourishing, knowledge in action, and an emergent developmental form, this study highlighted the biological, social, psychological and spiritual resilience protective factors that adult female cancer survivors identified as helpful to them as they coped with and healed from and lived their cancer experience.

This research adds to the literature on female cancer survivors and resilience and offers other cancer survivors and caretakers practical knowledge regarding the bio-social-psycho-spiritual resilience factors that they can utilize during the journey with cancer. Also, this research can help inform the medical community regarding holistically meeting the needs of women diagnosed with cancer. Specifically, the participants highlighted the need for competent, compassionate medical professionals who communicate cancer notification in a sensitive, informative and validating manner and involve their patient in treatment decisions.

This research has implications for mental health professionals interested in facilitating group work. Contrary to the group counseling literature that suggests that

groups should not include person who are at differing stages of illness due to concern that persons with a “manifestation of an illness at an advanced stage can be very disheartening for people in its early stage” (Pollin, 1995, p.140), the participants emphasized the importance of the social support they received from cancer survivors at all stages of the disease. The tendency to want to limit the interactions of persons living with chronic disease may reflect the social construction of disability and illness (Shapiro, 1994). Finally, this research has implications for social policy. The participants highlighted the need for better access to quality, affordable healthcare.

Limitation and Future Directions

One potential limitation to this study was that the participants were diagnosed with different types and stages of cancer. People may use different resilience protective factors based on their stage or type of cancer. Future research should study resilience factors of specific populations with specific types or stages of cancer.

A second limitation to this study is that only adult female cancer survivors who were members of the Noble Circle Project participated in this study. The participants in this group were highly educated women who were actively interested in complementary and alternative medicine. These participants may possess and utilize resilience protective factors that are not utilized by other segments of society. The results of the study do not reflect the lived experience of all adult female cancer survivors living in the United States. Future research should examine the resilience factors utilized by cancer survivors living in the United States who have other diversity variables based on gender, ethnicity, race, sexual orientation, and socio-economic status.

Another limitation to this research was that only the primary investigator who was a cancer survivor coded the data for resilience themes, and thus unintended bias may have impacted this research process. Future research PAR research regarding resilience and cancer survivors should utilize multiple coders to help ensure that the data is not subject to unintended bias.

Appendix A
Advertisement

TO: the Noble Circle Project

Are you a female currently living with cancer or whose cancer has gone into remission?

Would you be willing to discuss your experience as a female cancer survivor?

If so, please consider participating in the following research study:

Christine Valenti, a doctoral student in the School of Professional Psychology at Wright State University in Dayton, OH, is conducting a research study on the resilience factors that help female cancer survivors cope with their cancer experience. This research is being conducted under the supervision and advisement of Dr. Julie Williams, faculty advisor and Dr. Irma Johnston.

The first 8-10 eligible volunteers will be asked to complete a brief demographic information sheet and engage in an in-person interview with Christine Valenti. It is estimated that the entire process will take approximately one hour. If you are willing to participate, please contact Christine Valenti at (440) 479-5482 or valenti.5@wright.edu.

For further information about this research study, please contact Christine Valenti at valenti.5@wright.edu, or Dr. Julie Williams, faculty advisor, at 937-775-3407 or julie.williams@wright.edu.



Appendix B: Demographic Information Sheet

Thank you for your participation in this study. The purpose of this study is to examine the experience of female cancer survivors and to identify factors that help female cancer survivors cope with their cancer experience. The information collected in this study is strictly confidential and will not be used to identify you in any report or dissertation. Participation in this study is voluntary; therefore, you are free to decline to be in this study at any time.

- 1.) Age of Participant_____
- 2.) Ethnicity of Participant_____
- 3.) Annual Income of Participant_____
- 4.) Level of Education of Participant_____

Appendix C

Interview Protocol

Thank you for your participation in this study. Your responses are appreciated and valued. The purpose of this study is to gain a greater understanding of the resilience factors that help female cancer survivors cope with their cancer experience.

While a great deal of research has been conducted on cancer survivors, the voice of female cancer survivors in this research is sorely missing. I am going to ask you some questions regarding your lived experience as a female diagnosed with cancer.

Research Questions

This set of questions is intended to gain some basic information about your cancer experience.

1. With what type of cancer and what stage of cancer were you diagnosed?
2. What was the date of your cancer diagnosis and at what age were you diagnosed with cancer?
3. Who first informed you of your cancer diagnosis?

The next set of questions asks about how you have coped with her cancer experience.

Organizations

4. Are there any community organizations that have helped you with your emotional, physical, social, and spiritual coping with cancer? Explain.
5. How did you utilize these organizations? Explain.

Others

6. Who was helpful to you during your cancer experience? Explain.
7. How were they helpful? Explain.

Self

8. What personal qualities and skills do you feel have helped you cope with your cancer experience? Explain.
9. Do you think that these qualities were learned or always present? Explain
10. From where do you draw personal strength?
11. Overall, how do you think you have coped with cancer? Below average/ average/ above average. Explain?

Closing

12. What does the term “cancer survivor” mean to you?
13. What would you like others to know about your cancer experience?

Appendix D

Consent Form

A New Look at Survivorship:

Female Cancer Survivors' Experience of Resilience in the Face of Adversity

This consent form is to certify my willingness to participate in this research study.

Christine Valenti, a doctoral student in the School of Professional Psychology at Wright State University in Dayton, OH, is conducting a research study of resilience factors that enable female survivors to thrive in the face of their cancer diagnosis. In this study, survivorship is defined as adult females who are currently living with cancer and females whose cancer has gone into remission. I am being asked to participate in this study because I am a female cancer survivor.

My participation in this study will involve engaging in an open-ended interview with the primary investigator, Christine Valenti. I will be asked a series of open-ended questions regarding how I have coped with my cancer experience. I will also be asked some demographic questions about my age and ethnicity, and some questions about my diagnosis. This information will not be used in any way to identify me. Information that I provide will be kept strictly confidential and all responses I provide will not be associated with my identity in any way.

It is possible that my participation in this study may elicit mild psychological distress related to the disclosure of information of a personal and potentially difficult nature. If I experience psychological distress that is beyond what I expect, I may discontinue participation and/or I may choose to contact a mental health professional to address my concerns by asking my primary care physician for a referral. The researcher can also provide a list of mental health referrals if needed.

There will be no direct benefit to me from participating in this study. However, the information that I provide may help health professionals to better understand the lived experience of female cancer survivors and help to inform health professionals of the resilience factors that assist female cancer survivors to cope with their cancer experience. My participation or non-participation in this study will in no way impact my standing as a member of Noble Circle Project.

Any information about me obtained from this study will be kept strictly confidential and I will not be identified in any report or publication. **PARTICIPATION IN THIS RESEARCH IS VOLUNTARY.** I am free to decline to be in this study, or to withdraw from it at any point.

If I have questions about this research study, I can contact the researcher, Christine Valenti at valenti.5@wright.edu, or Dr. Julie Williams, faculty advisor, at 937-775-3407 or julie.williams@wright.edu. If I have general questions about giving consent or my rights as a research participant, I can call the Wright State University Institutional Review Board at 937-775-4462. If I would like a copy of the group (not individual) results of this study, I can contact Christine Valenti at the phone number or email address provided above. Estimated completion time of the study is December, 2010 for those interested in obtaining a copy of the results.

I have read and understand the above statements, and by signing on the line below, I indicate my consent to participate in this study.

Signature

Date

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