THE RELATIONSHIP OF INVOLVEMENT IN A SUPPORT GROUP, COMMUNICATION PATTERNS, AND MARITAL SATISFACTION IN COUPLES WITH A GENETIC MUTATION FOR BREAST AND OVARIAN CANCER (BRCA)

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THE RELATIONSHIP OF INVOLVEMENT IN A SUPPORT GROUP, COMMUNICATION PATTERNS, AND MARITAL SATISFACTION IN COUPLES WITH A GENETIC MUTATION FOR BREAST AND OVARIAN CANCER (BRCA)

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Dissertation

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ABSTRACT

The purpose of this study was to gain a better understanding of the relationship between couples’ communication, marital satisfaction, and involvement in a support group for couples where one partner has a genetic mutation that places him/her at a significant risk for developing cancer. Researchers have investigated marital satisfaction in couples with illness, the role of support groups for couples with illness, and communication about illness. Research looking at genetic risk for illness, however, is limited, especially as it relates to couples’ relationships.

Breast cancer is the second most diagnosed cancer in women and ovarian cancer is the fifth most diagnosed cancer in women. About 10% of breast cancers and about 10% of ovarian cancers are related to a deleterious mutation, referred to as BRCA (Breast Cancer), that can be detected through a blood test. There are many decisions facing individuals and families in dealing with this BRCA mutation, and this stress can cause a great deal of strain on the couple relationship. Support groups are available to help wade through the vast amount of information. However, the role of these support groups on relationship satisfaction has not been studied.

A correlational research design examined data from 62 couples who were recruited through a support group called FORCE (Facing Our Risk of Cancer Empowered). The couples recruited for the study required that at least one partner be
diagnosed with the BRCA mutation. The couples were in a marital or co-habitating relationship. The couples were asked to complete a standardized instrument, the Marital Satisfaction Inventory-Revised, to examine issues impacting their relationship satisfaction. They also completed a demographic questionnaire that included several Likert scale questions regarding support for their BRCA status and involvement in a support group.

John Rolland’s Family Systems-Illness Model (1994) was the lens used in examining the data reported by the participants. The results from this study may provide some information about issues couples with a genetic risk for disease may be facing, how support groups impact coping with this genetic knowledge, and how communication patterns are impacted for these couples. The present study looked at the relationship of the level of involvement in a support group on communication patterns and marital satisfaction in couples where one partner has the BRCA mutation.
DEDICATION

This dissertation is dedicated to the author’s family members who have faced their BRCA status with great courage and empowerment, especially to the author’s cousin Linda Varvaro Pedraza whose tireless efforts to make some meaning of hereditary cancer, who were the inspiration for this research. While Linda, her mother Judy Sadowski Varvaro, and her aunt Josephine Sadowski Zelsky, left this world way too soon, their sacrifices gave power to her sister Lisa Varvaro Carden, brother Gary Varvaro, and her cousin Marie Zelsky Gasser to confront their risk and cancer illnesses with grace and determination.
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The author’s advisor, Dr. Patricia Parr, saw from the beginning of this project its importance and has offered support and encouragement to see it to completion. The dissertation committee, Dr. John Gabrosek, Dr. Karin Jordan, Dr. Cynthia Reynolds, and Dr. Sandra Spickard-Prettyman, offered great advice and flexibility in the completion of this dissertation.

The patience and love of the author’s huge family, especially husband Michael, also aided in the finishing of this adventure. Data entry, data management and output, assistance in mailings, proofreading, meals, housekeeping, and humor was appreciated from all. The author’s amazing support group of friends, mentors, and fellow classmates also need to be recognized and appreciated for their contributions in support, walks, encouragement, work sessions, play sessions, and the overall provision of balance to this journey’s finish.
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CHAPTER I
THE PROBLEM

Introduction

Technological advances in medicine can be overwhelming to patients and their family members as they attempt to make decisions and cope with serious illness. The ill member of the family may feel a need to protect loved ones from the pain of disease, or may feel alone in trying to make decisions about their medical treatment. When the disease is genetic, there may be an increased sense of guilt or worry about the disease impacting other family members, frustrations about not being able to control the outcome, or decisions to consider altering the possible course of the disease. It is clear however, that illness and genetic knowledge impacts relationships. Professionals working with families dealing with genetic illnesses need knowledge and resources to assist these families in coping with the stressors of illness.

One genetic marker that has been identified in the last 15 years is the BRCA (Breast Cancer) mutation for breast and ovarian cancers. Carriers of these genetic mutations have as high as an 80% lifetime risk of developing breast cancer, and/or a 35-70% lifetime risk of developing ovarian cancer (American Cancer Society, 2009a & 2009b). Genetic knowledge can inform the patient of their risk of disease and can be helpful in making some decisions about reducing the risk of the disease. The choices
involved for risk reduction in BRCA include prophylactic surgeries (mastectomies, hysterectomies) of non-diseased tissue, life style monitoring, and/or enhanced medical surveillance. Decisions regarding childbearing (the possibility of passing the genetic mutation to offspring), and how and when to share information with children or significant others can be influenced by and can impact the couple relationship. Some relationships may grow stronger as a result of this crisis, while others may crumble. One purpose of this study is an initial examination of relationship issues in couples in which one partner has had confirmed the BRCA genetic marker.

A number of studies have examined relationship concerns related to illness. Research studies have examined relationships and chronic illness (Abbey, Andrews, & Halman, 1995; Badr, 2002; Badr & Acitelli, 2005; Baider, 2008; Bluman et. al., 2003; Carter & Carter, 1994; Ellenwood & Jenkins, 2007; Fekete, Stephens, Mickelson, & Druley, 2007; Peyrot, McMurray, & Hedges, 1988; Pfeiffer, 1991; Pruchno, Wilson-Genderson, & Cartwright, 2009; Rohrer, 2001; Samelson & Hanon, 1999; Skerrett, 2003). Other studies have examined relationship issues and cancer (Badr & Carmack Taylor, 2006; Carmack Taylor et. al., 2008; Hagedoorn, et. al., 2000; Hinnen, Hagedoorn, Ranchor, & Sanderman, 2008; Kayser, Sormanti, & Strainchamps, 1999; Kayser, Watson, & Andrade, 2007; Maciel, 2009; Manne & Badr, 2008; Rodrigue & Park, 1996). Genetic testing (Bowen, Bourcier, Press, Lewis, & Burke, 2004), and well spouses’ issues (Bottorff et.al., 2008; Bultz, Specia, Brasher, Geggies, & Page, 2008) related to couples and families have also been researched.

A few studies have looked specifically at psychosocial issues of individuals with the BRCA mutation (Brédart, Autier, Audisio, & Garacthy, 1998; Vadaparampil, Ropka, 2
& Stefanek, 2005; van Oostrom, et. al., 2007), while some studies have examined BRCA mutation issues related to families (Barsevick et. al., 2008; Clarke, Butler, & Esplen, 2008; Coyne & Anderson, 1999; Coyne, Benazon, Gaba, Calzone, & Weber, 2000; DeMarco & McKinnon, 2006, 2007; Weber, 2009; Werner-Lin & Gardner, 2009; Wilson, et.al., 2004). Some research has also looked at the impact of support groups on coping with illness (Carmack Taylor, et. al., 2007; van Uden-Kraan, Drossaert, Taal, Seydel, & van de Laar, 2009; Vilhauser, 2009). This literature has indicated that there are benefits to having support systems in place when dealing with disease. Research is lacking, however, in looking at couples with the BRCA mutation and their communication skills and relationship satisfaction, as well as research concerning the impact of support groups on couples dealing with BRCA issues.

Research has shown that one of the benefits of finding out about the BRCA mutation is being able to have some control over decisions that could alter the outcome of the disease (Morris & Gordon, 2010). There is no research, however, concerning the impact of “knowing” about the BRCA mutation on significant others. It is important to consider the impact of this genetic risk knowledge on the family. From a systemic framework, a couple can be viewed as an emotional, physical, and psychological system. What impacts one person in the system (the illness or threat of illness) impacts the system as a whole. Medicine is typically focused on the patient, and the rest of the system (spouse/partner) is not typically considered.

There is some research emerging about BRCA, but relational studies are very limited. Brédert, Autier, Audiscio, and Geragthy (1998) reviewed some of the psychosocial stressors individuals face when they begin to first wonder about the
possibility of carrying a genetic mutation, and the need for ongoing research to provide support at the different stages of dealing with genetic testing and its results. The researchers reviewed research that examined the psychological impact on individuals at risk for hereditary breast and ovarian cancers, attitudes toward genetic testing, and the psychological impact of genetic testing. The authors reported that more research needs to be conducted with individuals at risk for hereditary cancers to increase information and support to aid in decision making. The present study examined how another level of support (involvement in a support group) was related to relationship satisfaction and to communication in coping with a BRCA diagnosis.

One of the great challenges with illness is to find some control. Being out of control may come from the dependency on caregivers. Some outside supports can be helpful to the couple facing disease, however it has not been determined which types or how much outside support is most helpful. Baider, Cooper, and De-Nour (2004) wrote extensively on the complexities of assessing couples dealing with cancer. The authors emphasized the importance of looking at families’ developmental stage, their past experiences with illness, and their current difficulties with the present illness. Coyle and Fiske (1992) discussed the impact that marriage can have on couples’ health and stated, “Marriage is associated with psychological well-being, good physical health, and lower mortality, although the benefits of marriage may be limited to those in satisfactory marriages” (p. 130). In addition, couples reported lower marital satisfaction when stress was higher than average (Revenson, Kayser, & Bodenmann, 2005). When exposed to adequate resources, stress can become an opportunity to support one another. “The
quality of relationships thus plays an important role in helping individuals and families cope with, adapt to, and perhaps even survive chronic illness” (Revenson, Kayser, & Bodenmann, 2005, p. 131).

The current research examined the relationships of communication patterns, marital satisfaction, and the level of involvement in a support group through the lens of a Family Systems-Illness Model (Rolland, 1994a) in couples when one partner has an identified genetic risk for breast/ovarian cancers. It was hoped that the research might provide some tools for professionals working with genetic diseases.

**BRCA**

With the genetic advancements in the last 15 years, a gene mutation has been identified that puts carriers of the BRCA mutation at a 35-80% lifetime risk of developing breast or ovarian cancer. Although only 5-10% of all cases of breast cancer are linked to the identified mutation (Gibbon, 2007), the knowledge of being genetically at risk opens a Pandora’s box of questions, decisions, and choices with which to deal. The BRCA genes for hereditary breast and ovarian cancers were isolated in 1994 and 1995 by Dr. Mary Claire King (Davies & White, 1995). Since that time, genetic screenings have been developed to determine whether the testing is indicated. If two or more first degree relatives have been diagnosed with breast or ovarian cancer, the test for the mutation would be indicated. BRCA is a tumor suppressor so mutation of this gene increases the carrier’s risk of ovarian and breast cancer.

Several documentaries have been published in the last few years that draw attention to the difficulties the BRCA mutation can have on relationships. Joanna Rudnick (2008) put the camera on herself and discussed the difficulties that her search to
understand her genetic risks had on her relationship. Other families highlighted in the film showed how the family was involved in supporting the BRCA diagnosed individual. There have also been several personal written accounts of women’s experiences with the BRCA mutation (Winn, 1990; Queller, 2008; Greene, 2007; Morris & Gordon, 2010).

The importance of these personal stories identifies the need to examine what communication and supports are beneficial to this population. There is little research examining the issues facing these families. Some marital support research has been done with illness (Carter & Carter, 1994; Fekete, Stephens, Mickelson, & Druley, 2007) and with cancer (Hagedoorn Kuijer, Buunk, DeJong, Wobbes, & Sanderman, 2000; Kayser, Sormanti, & Strainchamps, 1999), but very little research has been done with marital issues and the BRCA mutation. Years ago, cancer might have been a private illness with some embarrassment about the treatment especially involving mastectomies. Some areas that have been examined with communication and hereditary risk for cancer are barriers to communication, intentions to communicate, stages of disclosing genetic risk, and the impact of disclosure on unmarried couples (Barsevick, et. al., 2008; Hoskins, Roy, Peters, Loud, & Greene, 2008; Wilson, et. al., 2004). It is important to be able to discuss genetic illness with family members as it is difficult to determine genetic risk if family members fail to communicate with one another about the disease. The present study examined the relationship of communication patterns to coping with a genetic risk for disease and to marital satisfaction in couples dealing with hereditary cancer risk.

Miller, et. al (2006) pointed out that as new medical information is learned through the study of genetics, there is a need to develop new psychosocial approaches and techniques to assist families with coping skills, decision making strategies, and
accessing accurate information. Since the biological implications extend beyond the at-risk individual, the interplay of coping processes across family members needs to be considered by examining the developmental phase, multigenerational history of coping, family belief systems, and the meaning of illness to the family. The inclusion of the couple at consultation may be helpful in identifying families at high risk for dysfunctional coping and adaptation who may benefit from family counseling. One goal of the current study was to provide some information about issues that may impact relationships in couples dealing with the BRCA mutation.

Theoretical Framework

Families dealing with an illness or disability are unique and therefore it is important to look at these families through a unique framework. Rolland’s (1994a) Family Systems–Illness Model takes into consideration how psychological, social, and medical factors impact families faced with illness. This biopsychosocial approach is based on the interaction between the illness, the family, and other systems, such as medical personnel, which evolves over time. Since illness can impose stress on more than just the identified patient, it is important to examine the impact and the interaction of coping processes in the family. The Family Systems–Illness Model (FSIM) is therefore a relevant model to use as the theoretical frame for this study.

Rolland developed the FSIM as a way to assist mental health practitioners to view illness in psychosocial terms. As a systemic model, this model takes into account potential sources of benefit and of stress for the patient dealing with an illness, as well as the potential sources of benefit and of stress for the family.
The FSIM considers the developmental time phases of the family in combination with the psychosocial demands imposed by the illness. Rolland discusses 32 potential psychosocial “types” of illness to consider. The typology of the illness needs to be considered in terms of its onset being acute or gradual. The progressive, constant, or relapsing course of the illness is also important in evaluating the demands of the illness. Some illnesses are nonfatal, others shorten the life span or result in sudden death, while others are considered fatal. Consideration of these outcomes is also important in FSIM. Whether the illness has no incapacitation, or results in a mild, moderate, or severe incapacitation, also helps to categorize the demands of the illness.

In addition, the predictability of the course of the illness is important to consider. Some diseases have a fairly predictable course, while most have varying degrees of uncertainty. The FSIM also considers the family’s belief system, the meaning of the illness to the family, the culture in which the family is embedded, and the family’s multigenerational experiences with illness (Rolland, 1994a). The attention to the multigenerational experiences with illness is particularly important when considering genetic diseases. “Chronic conditions need to be conceptualized in a manner that organizes similarities and differences over the course of the disease so that the type and degree of demands relevant to psychosocial research and clinical practice are highlighted in a more useful way” (Rolland, 1994a, p.19).

The Family Systems Illness Model looks at the developmental stages of a family who is dealing with illness. The model provides a structure for psychoeducation, assessment, and interventions and is grounded in systems theory (Miller, McDaniel, Rolland, & Feetham, 2004). The framework for assessment in the model is based on the
evaluation of the family structural/organizational patterns, the communication processes, the multigenerational patterns and family life cycle, and the family belief systems (Rolland, 1994a; Rolland, 1994b; Rolland, 2004; Rolland, 2005b). The communication processes of this model were examined in couples coping with hereditary risk for breast and ovarian cancer using the Affective Communication and the Problem-Solving Communication subscales of the Marital Satisfaction Inventory-Revised.

Rolland and Williams (2005) further discussed the role of genetic risk and how it adds new dimensions to the FSIM. Rolland and Williams referred to this as the Family System Genetic Illness Model, and add the dimensions of the likelihood of developing a disease, the overall severity of the disease, the timing of the disease in the life cycle, and whether or not treatment is available for the disease. Family myths, beliefs, and multigenerational experiences take on new meaning. The genetics of illness is more complex as it adds a crisis point of knowing genetic risk, and can add another layer of issues with which to deal. In addition, new knowledge, more research, and advanced treatments are presented at an overwhelming rate.

It is important that research in the mental health areas related to genetics and illness address the impact of these medical advances. The ways in which individuals cope with genetic illness and where these individuals find support and knowledge need to be examined. The focus of this study was about couples’ communication patterns and overall marital satisfaction in dealing with a genetic issue that has many complex attributes. The study was also interested in looking at the role that support groups play in supporting the marital relationship. Rolland highlights the importance of communication between couples regarding the possible impact of genetic disorder as “couples develop
their relationship with the factor of possible loss overtly acknowledge or covertly overshadowing their commitment” (1994a, p. 188). Examining communication patterns may aid therapists in understanding how communication patterns are impacted and how they impact couples dealing with a genetic anomaly. Examining issues such as when in the life cycle the genetic anomaly is diagnosed, the phases of the possible illness (genetic mutation found before illness onset, during illness, or in a period of recovery from the illness), and the impact of systems outside the family, may aid therapists’ understanding of issues facing couples dealing with a genetic illness. The Family Systems Illness Model highlights the importance of communication and assessing the phases of illness and can be helpful in guiding family therapists who work with these couples.

Communication Patterns

Patterns of communication in a family with a genetic risk for disease can take on immense importance as the genetic information of one person can impact other members of the family. “Because a great many emotionally supportive behaviors are communicative in nature (e.g. talking, listening, etc.) everyday communication between spouses facing chronic illness becomes key to creating positive relationship outcomes by restoring emotional equity between partners” (Badr, 2002, p. 21). Family communication has been found to be an important factor in overall family functioning. Vangelisti (2004) advises looking at each family uniquely when assessing communication in families as what works for some families in terms of communication, may be dysfunctional for another family. When a family deals with the difficulties of an illness, communication patterns can influence how the family makes sense of the disease and navigates their way
through the course of the illness. Rolland discusses how an illness diagnosis can “reverberate throughout a family system, leaving no one untouched,” (1994a, p. 1). Imagine the additional repercussions for a disease that has a genetic basis.

Family communication is a difficult construct to define. When the communication is related to illness, the family often feels a need to protect one another from the difficulties associated with dealing with the disease. One coping mechanism that they may use is to choose not to talk about the illness. However, research has indicated that one powerful tool in dealing with disease is feeling social support (Baider, 2008; Barsevick, et.al. 2008; Rolland, 1994b; Miller, McDaniel, Rolland, & Feetham, 2006). By studying patterns of communication about disease, therapists may begin to understand how to facilitate communication and work through the barriers to good family communication. “Effective communication is absolutely vital to family mastery of illness and disability” (Rolland, 1994a, p.71).

Marital Satisfaction

Effective communication skills are critical to good marital relationships, and therefore communication is one of the factors considered in research on marital satisfaction (Snyder, 1997). There has been some research on marital satisfaction related to illness and several assessment devices have been developed to measure it (Abby, Andrews, & Halman, 1995; Badr, 2004; Carter & Carter, 1994; Coyne & Anderson, 1999; Hagedoorn, et. al., 2000; Peyrot, McMurray, & Hedges, 1988; Pruchno, Wilson-Genderson, & Cartwright, 2009; Rodrigue & Park, 1996; Thoman-Touet, 1992; Yeh, Lorenz, Conger, & Elder, 2006). Several of these studies have looked at the level of health in married couples and looked at the relationship of marital satisfaction on health.
Some of the studies have begun to look at the relationship between marital satisfaction and coping with illness. These studies have suggested that positive relationships have positive health benefits for individuals in these relationships. Few studies, however, have looked at the relationship between marital satisfaction and genetic risk for disease. As more genetic anomalies are identified, how marital satisfaction impacts the coping and decision making involved in learning of genetic risk may be important in helping couples struggling with this issue.

Support Groups

The marital relationship can offer great support to an ill spouse, and Rolland’s (1994a) FSIM encourages awareness of other possible sources of supports such as the medical community, church community, and other individuals experiencing the same illness. Support groups are one example of another source of support and are available in a variety of formats. There are support groups connected to treatment centers that meet on a regular basis. Some of these are facilitated, some are on line through the internet, and some are formed by members to serve a need for support. Family and friends can be great support, but they don’t always understand what difficulties a patient is facing. Support groups are organized around a particular topic, illness, or condition. Members of a support group can share their thoughts and experiences or just vent frustrations. Research has looked at support groups’ impact on patients’ coping with illness (Avis, et. al., 2008; Bottorff, et. al., 2008; Bultz, Speca, Brasher, Geggies, & Page, 2008; Carmack Taylor, et. al., 2007; Flexman, Berke, & Settles, 1999; Gottlieb & Wachala, 2007; Han, et. al., 2008; Matthews, Baker, Hann, Denniston, & Smith, 2002; Sandaunet, 2008; Stang & Mittlemark, 2009; Ussher, Kirsten, Butow, & Sandoval, 2008; van Uden-Kraan,
Dorssart, Taal, Seydel, & van de Laar, 2009; Vilhauser, 2009). These research studies have shown that patients reported better coping skills, better moods, and a sense of empowerment when involved in a support group. However, research was not found on the impact of the support group on the patient’s spouse.

A support group that is specific to individuals with the BRCA genetic marker is FORCE (Facing Our Risk of Cancer Empowered, 2010). This organization offers support to individuals dealing with hereditary risks for breast and ovarian cancers. FORCE is web-based and offers message boards, educational tools, and other resources to find more information about hereditary cancer (specifically BRCA), and also offers a national conference yearly that brings in medical professionals and other speakers on topics pertinent to the BRCA population. Several regional face-to-face support groups for those diagnosed with the BRCA have emerged as well. The organization also serves as a catalyst for researchers studying individuals impacted by BRCA, and therefore was utilized as the support group for this study and as a place to recruit volunteers for this study.

There were several reasons for using members of FORCE as participants in the current study. FORCE can be accessed by individuals from any geographic area through its website, and therefore participants were recruited from varied geographic locations. FORCE supports local face-to-face support groups as well as on-line support. These different levels of support were variables important to the current study. It was important to examine if a patient’s involvement in a support group is helpful in relieving some of the pressure for support off the spouse who is dealing with emotional turmoil as well. It was also important to examine if over involvement in a support group neglects the
spouse’s needs. This research looked at levels of involvement in a support group related to communication patterns and overall marital satisfaction.

Subjectivity Statement

The Health Insurance Portability and Accountability Act (HIPAA) privacy laws in medical and mental health treatment have certainly highlighted the right to privacy for individuals regarding their health status and treatment. However, many individuals find support from others by sharing some of their health issues, especially with family and friends. My personal experience with BRCA is one that suggests communication is important.

In September, 1970, my mother’s Aunt Judy (who was only 13 years older than my mother) was diagnosed with an advanced stage of ovarian cancer. She died 13 months later. During my aunt’s illness, my mother (who was a registered nurse) cared for her. My cousins were 13 (Gary), 11 (Linda), and 7 (Lisa) years of age at the time, and I was 9 years old. My aunt was a very proud and beautiful woman, and she did not want anyone to know about her disease. She died without ever talking about it. My mother vowed that as long as she was involved with someone, there would be communication about every stage of life. In April 1974, my maternal grandmother (Aunt Judy’s much older sister) was diagnosed with the same disease, and she died in October 1974. Her disease and death was a much different experience for our family, partly because she was older and had grown children, but in part, I believe, because we all had the chance to say our goodbyes and process the experience. In the early 1980’s, my cousin, Linda, entered the medical field and sent research studies to all of us discussing the possible heredity of ovarian cancer. Her younger sister, Lisa, questioned why she was getting this
information, as she thought their mother had died of lung cancer! Over the next decade, there were only brief references to the disease as our generation began careers and families.

In December, 1995, my mother’s youngest sister was diagnosed with breast cancer, and about that same time, researchers were isolating the BRCA genes associated with breast and ovarian cancers in families. However, genetic testing was quite expensive, and insurance companies of course were not quick to pick up the tab. Women in our family were all talking about this genetic testing, and unsure what to do to find out who was at risk. Medical professionals were as unaware as we were. In 2002, Lisa received her first breast cancer diagnosis. Her second diagnosis came in April 2004, the same time Linda’s ovarian cancer was diagnosed. The family finally began getting tested for the gene. Communication about genetic testing, needed surgeries, and health surveillance ensued. In the last few months of completing this research project, my mother’s youngest sister is again dealing with breast cancer. Initially, the radiologists did not see conclusive indications of cancer. However, armed with BRCA knowledge, my aunt was able to have treatment in the very earliest stage of the cancer, and her prognosis is good.

It is clear that all of the women in our family communicated about their genetic risk and cancer diagnoses to each other and how they were impacted by the diagnoses. In the meantime, there were spouses for all of the women involved, but no one communicated about what this meant for the spouses. The spouses were supportive to their wives, but it is not clear how the BRCA and cancer diagnoses impacted them.
This research study sought to examine patterns of communication between spouses and overall marital satisfaction. The study was also concerned with the relationship of involvement in a support group with communication and marital satisfaction.

Purpose of the Study

The purpose of this research was to examine the relationships between communication patterns and marital satisfaction, and involvement in a support group in couples dealing with an identified genetic risk for breast/ovarian cancer from a Family Systems–Illness Model. This information may be beneficial to therapists working with individuals with genetic risk for disease in identifying helpful supports and enhancing communication for couples. This study utilized Rolland’s Family System – Illness Model of looking at genetic risk for disease from a system approach considering support from a spouse and from an outside resource (support group).

Statement of the Problem

This study was concerned with investigating the relationships of marital satisfaction, communication, and involvement in a support group in couples dealing with the BRCA genetic marker. The specific objectives of this investigation were:

1. To assess the relationship between marital satisfaction and communication.
2. To assess the relationship between marital satisfaction and partner support.
3. To assess the relationship between involvement in a support group and marital satisfaction.
General Research Questions

1. Is marital satisfaction higher for couples who also report good communication skills? Are low scores on the Marital Satisfaction Inventory-Revised positively correlated with low scores on the Affective and Problem-Solving subtests on the Marital Satisfaction Inventory-Revised?

2. Is marital satisfaction will be higher for couples where the ill spouse has a high level of partner support? Are low scores on the Marital Satisfaction Inventory-Revised positively correlated with low scores measuring partner support?

3. Do couples who report high marital satisfaction also report a high level of involvement in a support group? Are low scores on the Marital Satisfaction Inventory-Revised positively correlated with low scores measuring high involvement in a support group?

Delimitations

There are several delimitations to this study. Participants for this investigation were involved in a support group for individuals with hereditary cancer and a variety of demographic areas were represented. The participants were recruited on a voluntary basis. Self-report measures were utilized for this study, which may be subject to participants responding in socially desirable ways. This investigation only assessed communication, marital satisfaction, and involvement in a support group.

Instruments Used in Study

The Marital Satisfaction Inventory-Revised (MSR-I) was used to measure marital satisfaction (Snyder, 1997). The MSI-R assesses several dimensions of the marital relationship through self-report by responding to 150 true-false questions.
definitions are Affective Communication, Role Orientation, Problem-Solving Communication, Aggression, Family History of Distress, Time Together, Dissatisfaction with Children, Disagreement about Finances, Conflict over Child Rearing, and Sexual Dissatisfaction. High scores are indicative of high levels of distress, with the exception of the Role Orientation scale. The Affective Communication and Problem-Solving subtests were used to measure communication patterns. A demographic instrument was developed with several 4-point Likert scale statements assessing levels of involvement in a support group.

Definitions and Operational Terms

**BRCA**. The acronym given to the genetic mutations that put individuals at risk for developing breast and ovarian cancer

**BRCA Carrier.** The partner in the couple relationship who has been diagnosed as having the BRCA genetic mutation

**Communication.** The ability to solve problems and express affection/intimacy with a partner as measured by the Marital Satisfaction Inventory-Revised

**FORCE.** Facing Our Risk of Cancer Empowered is an organization that was established to provide information, support, and resources for individuals who are at risk for hereditary breast and ovarian cancers

**Marital Satisfaction.** Overall rating of satisfaction in a relationship as measured by the Marital Satisfaction Inventory-Revised, used interchangeably with relationship satisfaction for the purpose of this study

**Partner.** The partner in the couple relationship without the BRCA genetic mutation
Assumptions Underlying the Study

In this study, there are several assumptions:

1. Utilizing the Family Systems-Illness Model will add to the research by providing a systemic lens that looks at the relationship of illness on the couple relationship and the relationship of a support group on the couple relationship. This will be done by using information from the demographic questionnaire to tap into the timing of the diagnosis, history of illness, implications of illness for the couple, the developmental stage of the couple, and the involvement of outside supports.

2. Variables of involvement in a support group and communication patterns impact marital satisfaction.

3. Self reported information is error free.

4. The instruments used in this study represent the concepts they purport to measure.

5. Participants in the study were assumed by the researcher to be representative of subjects that experience a BRCA diagnosis.

Summary

Overwhelming amounts of new information are available almost daily, and the genetic technology has potential to increase knowledge and power about one’s health. Numerous studies have indicated that support from a spouse and from others can be beneficial to sorting out information and making decisions about illnesses. On-line support and information groups are one way to get knowledge, share frustrations, and learn about others’ experiences. In some relationships, this may ease the burden on the
spouse, while others may feel left of out the information loop. The effect on marital satisfaction in couples with BRCA has not been examined, nor has the relationship with involvement in a support groups and marital satisfaction been studied.

The purpose of the present study is to enhance the understanding of the relationships between communication and involvement in a support group with marital satisfaction in couples dealing with a BRCA genetic marker that puts and individual at risk for developing breast and/or ovarian cancers. In particular, this investigation utilized Rolland’s Family Systems-Illness Model (Rolland, 1994a) by providing a systemic lens to examine communication patterns and involvement in a support group to study marital satisfaction in couples with a genetic illness risk. The systemic lens looks at both couples in the relationship and the influence of the involvement in a support group. Ultimately, the intent of this research was to identify possible supports to strengthen relationships when genetic risk for disease is known.
CHAPTER II
REVIEW OF THE LITERATURE

Introduction

The literature review examines the following topics in relation to illness: communication patterns, marital satisfaction, and support groups. This review of the literature summarizes important research related to the variables measured in this study. The framework for this investigation is the Family Systems-Illness model.

Family Systems-Illness Model (FSIM)

An important emphasis of the FSIM is the view of the family as a resource in coping with illness rather than “pathologizing” the family system. Rolland and others (Abby, Andrews, & Halman, 1995; Badr, 2002; Rolland, 1994b; McDaniel & Rolland, 2006) discuss how the illness of a family member can provide an opportunity for growth in relationships, or pose a threat of distancing the relationships. What is functional and beneficial for coping for one family may be different for another family. The same functional behaviors may no longer be functional at a different stage in the illness. It is important to consider that no specific family pattern is viewed as healthier than another, but rather the emphasis is on what degree of family functioning is optimal while considering the different kinds of illnesses and how the functioning may be different at each of the phases of an the illness (Rolland, 2003).
Rolland’s (1994a) Family Systems Illness Model (FSIM) is a biopsychosocial systems approach to help families dealing with illness. The model considers the possible resources that the family can bring to assist the ill member, how the illness is impacting other family members, and how the interaction of the coping processes affects the overall functioning of the family. Rolland discusses different psychosocial types of illnesses by categorizing them into the course of the illness, the predictability of the illness, and the outcome of the illness. The 32 different “types” of illnesses categorized in this typology are then considered in reference to the family’s developmental stage.

Rolland (1994a) describes illness as an “uninvited guest” with a variety of demands that needs to “find its place” in the family. He emphasizes the importance of the family not becoming completely identified with or over-organized around the illness. The family may need some time to grieve the loss of the health or pre-illness state of the individual, and they need to develop some strategies to keep the illness in its place. It is particularly important that the patient is not defined as the problem, as this can skew the couple relationship. The couple relationship is of particular interest in the current study, and Rolland addresses concerns specific to the couple relationship.

The vows of supporting one another “in sickness and in health” have huge implications when one of the partners is faced with a BRCA diagnosis (Rolland, 1994a). When a couple is faced with anticipatory loss, they may withdraw from one another or they may cling to one another in a fused way. The couple may need to discuss how to live with a threatened loss, which may include loss of life, loss of body parts or functions, or loss of future dreams. Rolland (1994a) stated that it is important to address the couples’ fears and to give them confidence to face making difficult decisions.
Rolland (1994a) emphasizes the importance of addressing communication with couples. He states that the couple should become aware of the illness demands over time, and of their own beliefs about the causes of the disease and what can affect its course. In addition, it is important for couples to set personal and relationship priorities. The couple may need to clarify roles of patient and caregiver and work to maintain a balanced marital relationship. Rolland stresses that not all thoughts need to be communicated between the couple. An individual may have shameful thoughts and feelings that impede open communication, and therefore it is important to normalize these feelings so individuals can understand and forgive these thoughts. The FSIM stresses that past problem solving skills and problematic communication patterns will be challenged in the face of the mounting demands of the illness.

Communication Patterns

Understanding communication patterns affecting marital satisfaction when dealing with an illness can be beneficial in working with couples with genetic risk for disease. While communication is a difficult construct to define, a search of the literature provided some research with couples and families which reported that existing communication patterns in couples and families impact communication about genetic illness (Barsevick, et. al., 2008). Several studies have looked at communication between married couples who are dealing with other illnesses such as lung cancer, diabetes, heart disease, Parkinson’s disease, and autoimmune disorders. In addition, several studies have examined some of the issues involved with families dealing with cancer and genetic testing (Anderson, Bowen, Yasui, & McTiernan, 2003; Bluman et.al., 2003; Bowen, Bourcier, Press, Lewis, & Burke, 2004; Brédert, Autier, Audisio, & Garachy, 1998;
These studies highlight the need for effective screening tools to assist physicians in identifying and referring families who may need assistance with better communication skills as they deal with the complicated issues involved with genetic testing for disease. Following are some specific articles which examined how communication impacts couples dealing with illness, and how the BRCA impacts communication. The dearth of research draws attention to the need to further study the impact of communication in couples dealing with the BRCA diagnosis.

Badr and Carmack Taylor (2006) examined communication in lung cancer patients and their spouses. These researchers studied 13 patients and 12 spouses (participants were recruited from separate dyads) utilizing grounded theory methods. The investigators interviewed the couples about their communication regarding the ill spouse’s lung cancer. The researchers found that the spouses of patients who were dealing with a lung cancer diagnosis experienced social constraints that were detrimental to open communication and spousal support. These constraints included denying the severity of the illness, avoiding talking about the illness, and increased conflict. The research indicated that couples coping with disease may benefit from interventions to increase communication to better adapt to the demands of chronic illness together.

Badr also examined the concept of “relationship talk” with Acitelli (2005) in married couples where one spouse had a chronic illness. The researchers examined how couples talked about the aspects of a relationship in relational terms. One hundred eighty-two couples were given Spanier’s 1976 Dyadic Adjustment Scale, a questionnaire rating eight factors associated with relationship talk, and a physical symptoms rating scale.
Factors associated with relationship talk were how often spouses talked about their relationship, about their feelings for one another, and about everyday and important events. There were an equal number of couples with illness as there were couples where both were healthy. The researchers examined the value of talking about relationship issues in couples dealing with chronic illness, and found that couples who talked about their relationship (higher score on the relationship talk measure), reported stronger dyadic adjustment, as indicated by the Dyadic Adjustment Scale. The researchers also found that these scores were higher for the couples dealing with chronic illness. The findings of the study suggested the importance of the couple relationship in working with individuals with chronic illness.

These studies highlight some of the issues of couples’ communication patterns in dealing with illness in a spouse. Both research studies emphasized the need for more research in the area of couples’ communication about illness and the complex nature of conducting relationship research. The studies also illuminated the lack of standardized assessment tools to examine these issues.

Another area of communication that has been studied has been communication about the BRCA mutation. The Theory of Planned Behavior was discussed by Barsevick and her colleagues (2008) as a way to look at intentions to communicate information about BRCA genetic risk to family members. The Theory of Planned Behavior assumes that an individual is influenced by social factors and attitudes in intending to act in a particular health behavior. The study participants were 329 women who were seeking genetic testing for the BRCA mutation. The participants completed surveys constructed for the study to measure attitudes and social influences about genetic disclosure to family
members. The data analysis showed that 83.9% of the participants intended to share their genetic test results, while 63% intended to share their test results with all relatives. Using the Theory of Planned Behavior to measure the influences regarding the decision to disclose genetic information, the researchers found that attitude, social influence, and perceived control were significantly related to intention to disclose. The researchers discussed that most people want to share their genetic information with others, but distant or difficult relationships can be a barrier to communication. The researchers also discussed that people may feel the information won’t be helpful to others or that the family members will reject the information, and therefore choose not to share the information. The researchers found that the attitudes, social factors, and perceived control of their intention to tell (factors in the theory of planned behavior) were helpful in understanding barriers to communication in families with a genetic anomaly.

Speice, McDaniel, Rowley, and Loader (2002) used a psychoeducational group as a way to improve communication between family members about genetic risk for disease. The researchers met with nine women for six 90-minute sessions. The researchers studied themes that developed during the group regarding family issues. Participants in the group expressed concern about passing the gene to their children, disclosing their genetic information to others, family disagreements about genetic testing, unresolved grief and family conflict issues, and coping and decision making strategies. The groups made several recommendations to assist families with dealing with the BRCA mutation. Family communication, family functioning, conflict, and strengths and weaknesses need to be assessed as part of the pretesting for the genetic anomaly. Based on this research, it might
be important to examine existing communication assessments that may be useful with this population.

Clarke, Butler, and Esplen (2008) addressed the issue of women disclosing their BRCA genetic information to their children. A qualitative study was conducted utilizing a constant comparison technique with 24 participants who were randomly selected from one of five support groups for BRCA over several sessions. During the sessions, participants shared their experiences with making decisions about disclosing their BRCA status, their experiences about disclosing their BRCA status, and their reflections following the disclosure. The researchers categorized these experiences into several distinct stages of disclosure that occur as a process over time, and labeled the phases as the pre-disclosure phase, the disclosure phase, and the impact of disclosure phase. Some experiences that the participants shared during the pre-disclosure stage were perceived consequences of not telling, possible impact of sharing the information, and the possible contexts for disclosure. The participants shared the actual events of the disclosure, feeling unprepared, and feeling a need to support others during the disclosure phase. In the impact of disclosure phase, participants shared concerns about life plans being altered, determining if and when relatives will be tested, and fears and worries of relatives test results. The researchers stressed that family context can affect the communication in the family in discussing cancer risks at each of these phases. They also suggested that there is a need to provide counseling for families before, during, and following genetic testing to provide support, education, and interventions.

Wilson et. al. (2004) also discussed factors that influence people sharing genetic information. The authors reviewed current literature and highlighted the importance of
the communication of genetic information in regards to the accuracy of the information. The review of the literature highlighted concerns that there may only be a limited number of family members with the genetic anomaly, and sharing the information is important for awareness of hereditary risk. The literature also indicated that family members do not always have a clear understanding of genetic risk and inherited genetic patterns. The emotional distress brought on by talking about or not talking about the genetic risk was another area of concern the authors found in the literature. Wilson and colleagues also discussed the literature about the impact on others by choosing not to disclose genetic information. The article also discussed how the literature has addressed disease factors, individual factors, family factors, and socio-cultural factors.

Mesters et. al. (1997) tested a scale (Openness to Discuss Cancer in the Family, ODCF) to assess openness in a family to communicate about cancer. The researchers used interview data of 282 patients with either breast cancer or Hodgkin’s disease from one study to develop the ODCF scale. The ODCF had nine items and an internal consistency of 0.81 (Cronbach’s alpha). The researchers then used the ODCF scale in a second longitudinal study to confirm and test the ODCF on a new population. In the second study, 133 patients with head/neck cancers completed the ODCF at home. An internal consistency of 0.84 was found in the second study, as well as test-retest stability measures over four time periods with correlations above .59. Significant correlations of r = 0.37, p < .01 and r = 0.23, p < .01 for discussion of cancer and perceived support were also found at two time periods. As a result of these studies, the researchers pointed out that families tend not to want to discuss cancer because of the negative feelings associated with cancer such as uncertainty, sadness, depression, loneliness, anxiety, and
loss of control. The researchers also found preliminary support for adequate reliability of the scale. The ODCF scale may be of benefit in screening the needs of families dealing with genetic cancers and the communication patterns within their families, but several attempts to contact the developers of the scale and the researchers who have used the ODCF were not successful.

DeMarco and McKinnon (2006, 2007) reviewed the literature about communication issues in families with BRCA and highlighted different factors such as cultural differences, gender, and emotional issues that can impact communication regarding a BRCA status. The authors also discussed different means of support for individuals with the BRCA mutation that counselors working with this population should be aware of such as written materials, support groups, internet, and one-day retreats. The authors discussed the complex nature of genetic testing and the need to respect patient privacy, while at the same time stress the implications of communicating genetic information to family members. The authors encouraged professionals working with this population to be knowledgeable of family communication issues as well as available resources to these families.

A study conducted in the Netherlands examined family system characteristics’ influence on the psychological adjustment of dealing with hereditary cancer susceptibility (van Oostrom, et. al., 2007). Open communication about hereditary cancer and the support of a partner was found to be important in coping with distress. The participants in the study were at risk of having a genetic mutation, but had not yet had genetic testing at the initiation of the study. One hundred seventy-five of the participants were to be tested for the BRCA gene and 96 of the participants were to be tested for HNPCC (hereditary
nonpolyposis colorectal cancer). The researchers obtained demographic and medical history information, and utilized the Family Adaptability and Cohesion Evaluation Scales, Differentiation in the Family Scale, Openness to Discuss Hereditary Cancer in the Family Scale, Impact of Event Scale Revised, Cancer Worry Scale, and questions assessing perceived support. The researchers had the participants rate their level of distress prior to genetic testing, immediately after receiving their genetic results, and six months later. The participants also rated the amount of family support that they received. The participants reported more distress about the hereditary cancer (as measured by the Impact of Event Scale Revised and the Cancer Worry Scale) when they perceived their family to be maladaptive (i.e. enmeshed, disengaged as measured by the Family Adaptability and Cohesion Scale and the Differentiation in the Family Scale) compared to those participants who perceived their family as cohesive and adaptive. The results of this research study indicated that patients with better communication and family support experienced less psychological distress related to their cancer risk susceptibility. The researchers recommended that genetic counselors be aware of communication patterns and family supports in families dealing with hereditary cancer risks.

Green, Richards, Murton, Statham, and Hallowell (1997) examined communication issues in women seeking genetic counseling for hereditary breast/ovarian cancer in a longitudinal qualitative study. Forty-six women participated in the study and were interviewed before and after genetic testing to assess how genetic information is shared with family members. The initial interviews occurred prior to genetic testing and were open ended questions about who the women had spoken to in their family and who in their family they would have liked to have spoken to regarding genetic testing. The
women were then interviewed after genetic testing and the open ended questions were about with which family members the women had shared the genetic test results. The researchers identified some issues regarding communication patterns and barriers in the discussion of genetic cancer with the patients’ mothers, sisters, children, fathers, and brothers. The longitudinal study was designed to gather information from the women regarding communication of genetic risk for cancer, and pre and post test measures were not obtained. These information gathered included the perceived taboo of talking about cancer and reproductive body parts, information needing to come from elderly, ill, or grieving relatives, and the need to balance the giving of information without creating a panic in the family. Issues were also discussed about the women being the historians in the families, and if they were deceased, information was not obtainable, and the misconception that only women can pass on the BRCA gene, and therefore the paternal family history is ignored. However, no communication concerns with spouses/partners about BRCA were addressed in this study.

It is important that research has identified the importance of communication regarding disclosure of the BRCA mutation within families, as awareness of who is affected by the genetic marker is critical to the testing process. The importance of evaluating relationships in families, identifying barriers to communication in these families, and guiding families to be more effective communicators has also been discussed. Research is sparse, however, on communicating disclosure in non-genetic family members.

Hoskins, Roy, Peters, Loud, and Greene (2008) examined young couples’ communication of their BRCA positive status. The researchers interviewed 11 women
between the ages of 26 and 35 whose knowledge of the genetic mutation came before marriage. Semi-structure open-ended interview questions were analyzed using grounded theory qualitative methods. Several themes emerged before, during, and after the participants disclosed their BRCA status to their partners. Being aware of the themes at each of these stages may be important in working with couples dealing with the BRCA disclosure process. Before the disclosure, the participants expressed concerns of feeling vulnerable, and having self-doubt, fear, and anxiety. The participants also expressed concern of their partner’s reaction, the timing of the disclosure, and integrating their partner’s reaction with their own ways of dealing with the information. During disclosure, participants expressed feeling the disclosure was a process that had been occurring over time, and feeling supported by their partner. Several of the participants indicated a closer relationship with their partner in disclosing their BRCA status. After the disclosure, participants discussed ways of feeling supported by their partner that included listening, helping to reduce anxiety and stress, and exploring options in dealing with the cancer risk. The researchers emphasized the need for more research in looking at the relationship between BRCA and couple relationships. The researchers also provided some insight to issues with which this population may be struggling such as managing anxiety, remaining hopeful, maintaining sufficient concern without increasing anxiety, and maintaining partner responsiveness.

Marital Satisfaction

The quality of a marriage can have a great impact on coping with illness. A review of the literature highlights several studies that show the impact of a couple’s relationship on overall health and coping skills. Many of these studies looked at cancer
and the couple relationship (Carmack Taylor et. al., 2008; Pruchno, Wilson-Genderson, and Cartwright, 2009; Hagedoorn et. al., 2000; & Coyne and Anderson, 1999), but none were found specific to the couple relationship and BRCA other than the previously discussed study by Hoskins, et. al. (2008) on communication and the disclosure of the genetic marker. One study by Coyne and Anderson (1999) looked at women with a risk of hereditary cancer based on family history, but did not measure the spouse’s perceptions. Following is a more detailed discussion of these studies.

Carmack Taylor et. al. (2008) examined the relationship function of lung cancer patients and their spouses. One hundred sixty-nine lung cancer patients and their spouses completed demographic questionnaires, the Dyadic Adjustment Scale, the Brief Symptom Inventory, the COPE, and a social support scale. The researchers found that both spouses reported psychosocial stress associated with lung cancer, but the rates of psychological distress in both the patients and their spouses, was lower for those who reported higher marital satisfaction. The researchers also noted that couples who reported the most adaptive coping skills may provide mutual support to one another. The researchers noted the importance of gathering data from both spouses at the same time, as few studies have, and that the results of the study support that the couple should be the focus of psychosocial intervention.

Pruchno, Wilson-Genderson, and Cartwright (2009) studied marital satisfaction and depression in end-stage renal disease of 315 patients and their spouses over a two year period of time. The couples completed the Center for Epidemiologic Studies Depression Scale, the Dyadic Adjustment Scale, and the CHOICE Health Experience Questionnaire. The researchers found that patients were more satisfied with their
marriage than spouses of the patient, and that the spouse’s marital satisfaction decreased over time. The researchers suggest that working with the spouse of the patient and addressing the marital relationship is important in chronic illness.

Hagedoorn et al. (2000) examined marital satisfaction in patients with cancer. Sixty-eight patients and their partners completed the Ways of Giving Support Questionnaire, the Center for Epidemiologic Studies Depression Scale, the Physical Functioning Subscale, and the Marital Quality Scale. The researchers looked at how spouses supported the patient with cancer with questionnaires for both partners. The patient’s level of distress, physical impairment, and perceived marital satisfaction was measured in the patient, but not the spouse. The researchers found that some types of support (i.e. active engagement) were positively correlated with marital satisfaction, while other support (i.e. overprotection and protective buffering) were negatively associated with marital satisfaction. The researchers also noted that the more distress that the patient reported, the higher the need for active engagement support, and a possible negative effect of buffering or overprotecting for the highly distressed patient. The results of the study emphasized the importance of working with couples on communication issues about support that is needed in dealing with cancer.

Coyne and Anderson (1999) studied women at high risk for breast cancer and their perception of marital support. Four hundred sixty-four women with a family history of breast or ovarian cancer completed questions selected from the Inventory of Social Support Behaviors that were related to spousal support, the Hopkins Symptom Checklist, and the Dyadic Adjustment Scale. Sixty-seven percent of the women reported being in a satisfying marriage. A significant correlation (20.06, p<.001) was found between reported
high levels of psychological distress for the married women who reported dissatisfying marriages, but not for unmarried women or married women who reported satisfying marriages. The researchers discussed that some women are supported by their husbands in coping with chronic illness, while other women’s husbands avoid discussing the illness which causes more stress for the woman. Coyne and Anderson examined the positive and negative aspects of being married in coping with hereditary breast and ovarian cancers. The researchers found that women dealing with hereditary cancer expressed more psychological distress with a lack of support from their husbands. In addition, the researchers found that married women in a dissatisfying marriage reported more distress then unmarried women. This researcher suggested that spouses may have a critical role in the psychological well being of a patient dealing with genetic risk for cancer.

Support Groups

Support groups are established to offer mutual support to others dealing with a similar concern (Stang & Mittlemark, 2010; Carmack Taylor, et. al., 2007). Several studies have examined the use of support groups for women with breast cancer. Some support groups have face to face interaction while the internet has offered some innovative ways of connecting that may be important for people too ill to leave home.

Vilhauer (2008) noted that it is often difficult for women to share their concerns and problems with family members and friends despite the patients’ need for emotional support, and suggested that support groups can be of help to these patients. Vilhauer looked at the perceived benefits of involvement in an online support group for women with metastatic breast (MBC). Eighteen women with MBC completed monthly questionnaires about their experience in an online support group. Eighty-five percent of
the women involved in the study were married. Vihauer examined the areas of group cohesiveness, exchange of information, hope, altruism, catharsis, and universality and found that the patients reported that involvement in the support group had a positive impact on how they coped with cancer. In the open-ended interviews, the participants indicated that they trusted and cared about the members of their group. The participants also reported feeling that they were able to get better medical care because of the support and encouragement offered by their group co-members. The women in the study also reported less need to focus on their illness when dealing with the people in their everyday life because of the ability to discuss illness concerns in the group, that they were more open in seeking support from others, including friends, therapists, and face-to-face support groups. Being able to share information about the illness and treatment of the illness was an important attribute of the support group reported by the study participants. The support group members also felt a sense of hope in hearing about the daily activities of other members of the group and felt that they were helpful to others in the group. The participants also reported that they felt that their spouses, family, and friends did not thoroughly understand what they were experiencing with a cancer diagnosis, while support group members had a better understanding.

Carmack Taylor and her colleagues (2007) discussed the benefits of participation in a support group for cancer patients with limited psychosocial resources compared to patients who had more psychosocial resources. The authors highlighted the current research on the benefits of support groups for cancer patients with a high level of distress. Themes that emerged from the research suggested that cancer patients who had limited psychosocial supports benefited from support groups because they obtained helpful
information, received support from others in the group, and shared common experiences with the group members. The authors discussed understanding the effectiveness of support groups by utilizing the social comparison theory, in which people assess their own abilities by comparing themselves with others. The authors also stressed the need for theory-based research on support group involvement.

Van Uden-Kraan, Dorsssaert, Taal, Seydel, and van de Laar (2009) examined the impact of a support group on empowerment. The researchers looked at 19 online support groups for patients with breast cancer, fibromyalgia, and arthritis in this qualitative study. The support group participants completed the Short Form-12 Health Survey (version 2) to assess quality of life, and questionnaires about online support group involvement, empowering processes (i.e. helping others, exchanging information, getting emotional support), and empowering outcomes (i.e. increased optimism, being better informed, feeling more confident). The empowering processes were significantly correlated with the outcomes of participating in a support group (<.30). The researchers found that patients reported being more comfortable discussing concerns with their physician and more in control of their treatment as a result of being involved in a support group. The researchers emphasized the importance of medical practitioners being aware of existing support groups to share with their patients.

Norwegian researchers, Stang and Mittelmark (2009), studied several support groups and the use of empowerment techniques as a tool to help patients gain some control and to improve relationships with professionals and family members. These empowerment techniques included facilitation of in-depth questions to encourage participants to share their stories, focusing on strengths and resources, and having a sense
of control in their lives. One significant outcome for the participants was more confidence in speaking up for themselves with medical professionals. The researchers gathered their data from 18 women with breast cancer who were involved in three different support groups that met for 90 minutes every other week for approximately four months. The researchers emphasized the importance of the patients becoming aware of their strengths and abilities that contributed to their functioning and sense of empowerment.

From reviewing this research on outcomes of involvement in support groups, it appears that patients feel more control over their illness, feel more confident in speaking up for themselves with medical professionals, and feel more comfortable talking to others about their illness. These outcomes are seen for groups that meet online or face-to-face and were found for a variety of illness varying in chronicity and level of debilitation. These studies focused on outcomes for the patient, and some studies have looked at the outcomes of support groups for partners of these patients.

Bultz, Speca, Brasher, Geggie, and Page (2000) studied support groups for the spouses of breast cancer patients. Thirty-four couples participated in the study. The patients and their partners were randomly assigned into either a support group or a control group. The partners assigned to the support group met once a week for 6 weeks to provide psychoeducation and allow partners to discuss their feelings, fears, and their relationships. Participants completed the Mental Adjustment to Cancer Scale, the Profile of Mood States, the Index of Marital Satisfaction, and the Functional Social Support Scale. The researchers found that spouses reported high marital satisfaction from those who participated in a support group, and a decline in marital satisfaction from those who
did not participate. In addition, patients reported that the spouses who participated in support groups were better caregivers and had increased communication with their partners about the illness.

Baider, Cooper, and De-Nour (2004), in their book and trauma and families, discussed illness as a threat to the life course of the family and that social support can be a resource to deal with the “trauma” to the patient and other family members. The authors stated that support can be tangible, informational, or emotional, and can be provided by family or others. Support groups provide the opportunity to interact with “similar others”.

Sandaunet (2008) examined why individuals drop out of online support groups. The researcher interviewed and gathered data through an action-oriented qualitative study of 21 breast cancer patients who began participation in an online self-help group, but then dropped out. In this qualitative study, Sandaunet identified five factors that appeared to be related to dropping out of the support group. Some participants discussed the need to avoid the details of their disease, some did not consider themselves “ill enough” for the group, while others had difficulty finding their position in the group. Some women stated that they didn’t have time for a support group due to their everyday responsibilities and dealing with the disease, while others stated that their disease was at a phase where the group did not meet their needs. It is important to note that this support group was very beneficial to half of the women who participated, and that the uniqueness of each individual needs to be taken into consideration when examining possible sources of support for individuals dealing with disease.
BRCA

Vadaparamil, Ropka, and Stefanek (2005) reviewed the literature regarding psychological factors associated with hereditary cancers. The researchers expressed concern about the lack of consistency of self-report measures and reports of psychometric properties of instruments used. The researchers emphasized that as genetic testing becomes more prevalent it will become more important to utilize standardized assessments to measure psychological distress.

Anderson, Bowen, Yasui, and McTiernan (2003) surveyed 1,366 women between the ages of 18 and 74 about their family history of breast cancer, about their knowledge about genetic cancers, about their awareness of and interest in genetic testing, and about their perceived risk of getting cancer. Twelve percent of the participants were considered to be at high risk of getting cancer, and the high risk group reported having a lot of knowledge about cancer, but not about testing, and perceived themselves as being at high risk for getting cancer.

While little research has been done in relation to family issues with the BRCA mutations, there have been several personal documentaries that have highlighted some issues facing families at genetic risk for cancer. The film “In the Family” (Rudnick, 2008) highlighted several women dealing with the BRCA mutation. One spouse of a BRCA patient stated how angry and hopeless he felt that there was nothing he could do. Another spouse showed his support to his wife and her sisters when their BRCA status was revealed. Several BRCA patients stated they were just looking for someone to tell them what to do. Winn (1990) shared her story of her BRCA status and choices she made. She discussed the fears of changes in her relationship with her husband and how he
suffered with fear of losing her to cancer. Queller (2008) wrote about women she encountered on her journey of decision making after her BRCA diagnosis. She discussed a woman who relied on a support group (FORCE) to gain information as she made her decisions, and through the process her husband was “shell-shocked” about what was happening. Conversely, Greene (2007) wrote when discussing her husband’s support “I realized then that with him by my side, we would get through this” (p. 50). Valverde (2006) wrote about the difficulties of discussing her decision to test for the mutation until she knew the results. She shared only her decision to test with her husband. Valverde works as a genetic counselor and suggested that other counselors consider how patients are coping with the stressors and losses involved with genetic cancer risks. Morris and Gordon (2010) offered a resource book for those with hereditary risks of breast and ovarian cancer. Morris discussed the importance of the support and communication she shared with her husband, and the benefits of the support group, FORCE.

Summary

The preceding discussion explored some of the research done with couples impacted by illness regarding communication patterns, marital satisfaction, and involvement in a support group. While several aspects of illness have been studied from a relational perspective, genetic risk for illness, specifically the BRCA gene mutation, have not been studied in couples from a relational perspective.

The Family Systems-Illness Model (Rolland, 1994a) was presented as a framework to look at genetic risk for illness from a systemic lens to consider the impact of genetic risk on communication in the couple relationship. Rolland’s (1994a) model emphasizes the importance of utilizing the family system, the medical system, and other
systems such as community, church, and support groups to strengthen the coping skills of the individual affected by illness and his/her family.
CHAPTER III

METHODOLOGY

An explanation of the research methodology that was used to address whether there is a relationship between the involvement in a support group, communication patterns, and marital satisfaction in couples with a BRCA mutation is presented in Chapter III. The research setting, data collection process, hypotheses, and statistical analyses are described. The research sample, instrumentation, research design, and limitations are also presented.

Restatement of the Problem

This study examined the relationships between marital satisfaction, communication patterns, and involvement in a support group in couples with a BRCA genetic mutation. The theoretical framework in this study was the Family Systems-Illness Model (Rolland, 1994a) which looks at the developmental stages of a family who is dealing with illness by providing a structure for psychoeducation, assessment, and interventions.

Research Design

The research design for this investigation was a survey research design to examine the relationships between the variables of marital satisfaction, communication, and involvement in a support group. A correlational research design was used to describe relationships between multiple characteristics in the research (Heppner, Kivlinghan, &
Wampold, 2008). According to Heppner, Kivlinghan, & Wampold (2008), one advantage of using a survey study is possible high external validity because of sampling from a real-life setting. They also state that external validity suggests that the study’s results are able to be generalized to other similar situations. The current investigation attempted to gather study participants from various geographic areas, across age ranges, and from diverse religious, ethnic, and socioeconomic backgrounds. Heppner, Kivlinghan, & Wampold (2008) caution that survey studies are low in internal validity because the variables are not manipulated. In addition, they state that internal validity suggests that there is confidence in inferring causal relationships between variables. They report that another limitation of a survey study is that relationships can only be determined, but not underlying causal mechanisms. The reason for this is that variables that are not of primary interest but may affect marital satisfaction are not controlled for by the study design. Random assignment and control group conditions were not appropriate for this type of investigation because the variables being investigated were already present in the population. Participants decided on their own whether or not they would participate in the present study, and how much participation they chose to have in the FORCE (Facing Our Risk of Cancer Empowered) support group.

Description of the Research Setting and Data Collection Procedures

The participants for this study included individuals who have been identified as having a BRCA mutation and their partners. Couples were recruited from the annual FORCE convention and through the FORCE website message board. Recruited couples were from diverse geographic areas. The couples responded to either a flyer that was
given to participants at the annual FORCE conference, to postings on the message board on the FORCE website, or through their local support group contact person.

The couples completed an informed consent and were sent a packet that included information about the purpose of the study, instructions for completing the packet, and two sets of questionnaires. The couples were asked to complete the questionnaire and MSI-R without consulting with one another. The completed forms/questionnaires were then mailed back to the researcher. The participants were asked to return the questionnaire package within two weeks of receiving them. Those couples who did not return the package within the two weeks were given a reminder call.

Procedure

This research project was approved by the Institutional Review Board at The University of Akron. All participants read and signed an Informed Consent document. The sample of participants may not be representative of the BRCA population, as those who participated were recruited through a support group for BRCA and therefore have sought out some type of information or support.

Participants

The participants were couples in which one partner had a BRCA mutation. In 60 of the couples, a female carried the BRCA mutation, while in two couples, a male partner was the BRCA carrier. The couples were recruited through a support and advocacy group, FORCE. FORCE holds an annual conference to provide information about current research, procedures, and options available to individuals and families faced with hereditary breast and ovarian cancers. Flyers about the study were distributed to participants at this annual conference and information was posted about the study on the
FORCE website (www.facingourrisk.org). Volunteers contacted the researcher and study packages were mailed to the volunteers.

Participants were recruited from the FORCE organization as there are no other known support groups for individuals with the BRCA mutation.

The participants ranged in age from 25 to 83 years of age, with the mean age of 43.19 years old. Sixty-two couples participated, with two of the couples in same sex relationships, 56 of the couples in married relationships, and four of the couples in cohabitating relationships. Overall, 60 males and 64 females participated in the research study. Married couples ranged from one year of marriage to 52 years of marriage, with a mean of 15.76 years of marriage. Same sex couples reported seven and ten years in current relationships, and cohabitating couples reported one, 4.5, 5.5, and nine years in current relationships. BRCA diagnoses ranged from 13 years ago to just this year, with a mean of 3.10 years since BRCA diagnosis.

Other demographic information included race, religion, education, geographic location. One hundred eighteen participants reported being Caucasian, six reported being Asian or Pacific Islander, and one reported being Middle Eastern. Nineteen participants reported religious affiliation of Jewish, 29 participants reported religious affiliation of Protestant or Christian, 26 participants reported religious affiliation of Catholic, seven participants reported religious affiliation of other, and 44 participants reported no religious affiliation. Within the category of education, 97 participants reported having a college education, with 54 of them also having advanced degrees in their field. Ten participants resided outside of the United States, while the other 114 participants were from 21 of the 50 states, thus representing a wide geographic area.
Additional demographic information included information on children, previous relationships, and household income. Eighty-four participants reported having children, and children ranged in age from 1 to 47 years of age. Twenty-one participants reported a previous marriage and six participants reported a previous significant relationship.

Instruments

Marital satisfaction was measured utilizing Douglas Snyder’s Marital Satisfaction Inventory-Revised (1997). The Marital Satisfaction Inventory-Revised (MSI-R) is a multidimensional self-report instrument used to measure marital interaction (Scheer & Snyder, 1984; Snyder, 1979, 1997). The MSI-R consists of two validity scales, Inconsistency (INC) and Conventionalization (CNV), a Global Distress scale (GDS), and ten scales measuring various aspects of marital interaction that are assessed through 150 true-false questions. The validity scales on the instrument are designed to assess if individuals are consistent with their responses on the instrument and not providing random responses. These validity scales were checked on the participants MSI-R profiles, and excluded if the responses were seen as invalid or random. The ten dimensions measured on the MSI-R are Affective Communication (AFC), Role Orientation (ROR), Problem-Solving Communication (PSC), Aggression (AGG), Family History of Distress (FAM), Time Together (TTO), Dissatisfaction with Children (DSC), Disagreement about Finances (FIN), Conflict over Child Rearing (CCR), and Sexual Dissatisfaction (SEX). Affective Communication measures dissatisfaction with the amount of understanding and affection expressed by partner, while Problem-Solving Communication assesses the couple’s ineffectiveness in resolving difficulties. Aggression measures physical aggression and intimidation, Family History of Distress assesses the disruption of
relationships from family of origin, and Time Together measures companionship by amount of time spent together. Dissatisfaction with Children evaluates concerns regarding child rearing, Disagreement about Finances assesses discord regarding finances, and Conflict over Child Rearing measure disagreements about how to raise the children. Sexual Dissatisfaction measures the level of the couple’s discontent with the frequency and quality of their sexual activity. High scores on these nine scales are indicative of high levels of distress. The Role Orientation scale measures preference for nontraditional family roles, where decision making, child care responsibility, and work outside the home are shared, and it is more important that couples have similar ratings on this scale, then whether the score is high or low.

The MSI-R takes about 20-25 minutes to complete and is given to each partner separately. Numerous studies have supported the reliability (test–retest at 6 weeks, 0.79) and validity (both criterion and discriminant) of the MSI-R and the interpretive value of its sub-scales (Burnett, 1987; Snyder & Regts, 1990). Criterion validity for the MSI-R was found to range from .70 to .93, while the discriminant validity ranged from 0.43 to .75 (p<.001). The MSI-R has been extensively researched (Snyder & Alkman, 1999). Coefficients of internal consistency average .82, and temporal stability coefficients average .79. The research has also shown the MSI-R scales relate to a broad range of external criteria that is consistent with what they are intended to measure. For the purpose of this study, the affective (AFC) and problem solving communication (PSC) sub-scales were used to measure perceived communication patterns. The Cronbach Alphas for the AFC and PSC research version were 0.85 and 0.89, respectively (Snyder, 1997). Normalized T-scores are plotted on a profile and based on gender-specific norms.
The MSI-R has also been used in research on couples with illness. Harper and Sandberg’s (2009) research indicated that when husbands or wives are more depressed, both affective communication and problem solving processes are impaired for the couple. Affective communication and problem solving communication are worse when both spouses are depressed, compared to when only one spouse is depressed. When one or both partners are depressed, both husband and wife communication scores are worse than when neither husband nor wife is depressed. Harper and Sandberg suggested implications for providing mental health services or couple based education groups as supports to these couples.

Other research looking at specific populations utilizing the MSI-R is reported by Snyder (1997). Couples who were preparing for divorce obtained similar scores on the MSI-R when compared to couples entering therapy. In pre- and post-treatment measures for couples entering therapy, scores on the MSI-R were sensitive to the effectiveness of the treatment interventions. Snyder (1997) reported that abused partners reported elevated scores on the Aggression subscale and less satisfying relationships as indicated by elevated Global Distress scores. Couples where one partner had had psychiatric treatment (inpatient or outpatient) showed general marital discord (elevated Global Distress scores) and deficits in communication skills (elevated scores on Affective Communication and Problem Solving Communication subtests), when compared to non-clinical couples.

Self report questionnaires can be helpful in assessing overall communication (Vangelisti, 2004). The participants in the present study also completed a demographic questionnaire assessing age, race, culture, religion, number of years married, number of children, number of marriages, state of residence, amount of time since BRCA diagnosis,
and several questions assessing perceived support from spouse, family, and others, and involvement in a support group for those at risk of hereditary breast and ovarian cancers.

Derivation of General Research Hypotheses

Rolland’s (1994a) Family Systems-Illness Model (FSIM) was used as the framework to examine the hypotheses tested in this study. This study examined affective and problem solving communication, spousal support during illness, and support from a focused support group. The FSIM emphasizes the importance of communication during illness and the collaboration of others outside of the family (i.e. health care providers, support groups, institutions such as health care agencies, churches). The implications of a genetic anomaly can be recurrent and can pass through several of Rolland’s phases. Attempting to gain information about the BRCA gene and making decisions about what to do with the information can fall into Rolland’s initial phase of diagnosis. During this phase, the individual and their partner may feel overwhelmed with the information and this may impact their relationship. Partners may turn toward or away from one another as they deal with the implications of the diagnosis. When the couple has children, they are faced with how to pass information about the possibilities of illness and genetic ramifications to the children. If a couple is considering having children, the genetic information may alter their original plans. For a couple who has already faced a disease, and a family history of the genetic disease, the genetic information may help to provide some answers and purpose to the disease struggle. These issues and others are all considered when utilizing Rolland’s Family-Illness Model as a theoretical framework.
General Research Hypothesis One

Marital satisfaction as measured by the total score on the Marital Satisfaction Inventory-Revised (MSI-R) will be higher for couples with BRCA who report good affective and problem solving communication as measured by the MSI-R subscales of Affective Communication and Problem Solving Communication scores.

General Research Hypothesis Two

Marital satisfaction as measured by the total score on the MSI-R will be higher for couples with BRCA who report high levels of support by their partner as measured by a self-report 6 point Likert rating scale.

General Research Hypothesis Three

Marital satisfaction as measured by the total score on the MSI-R will be higher for couples with BRCA who report high levels of involvement in a BRCA support group as measured by a self-report 6 point Likert rating scale.

Variable List

The following are the response and predictor variables in this study:

<table>
<thead>
<tr>
<th>Response Variable</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>Y1 Marital Satisfaction</td>
<td>As measured by the Marital Satisfaction Inventory-Revised, Global Distress Scale, where T scores below 50 are indicative of satisfying relationships, T scores between 50 and 60 are indicative of moderate relationship dissatisfaction, and T scores above 60 are indicative of high relationship dissatisfaction</td>
</tr>
</tbody>
</table>

51
### Predictor Variables

<table>
<thead>
<tr>
<th>X1</th>
<th>Affective Communication</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>As measured by the Marital Satisfaction Inventory-Revised, Affective Communication Scale, where T scores below 50 are indicative of partners being loving, supportive, understanding, and able to share intimate feelings, T scores between 50 and 60 are indicative of often feeling distant emotionally from partners, and T scores above 60 are indicative of more extensive feelings of distance emotionally from partners</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>X2</th>
<th>Problem Solving Communication</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>As measured by the Marital Satisfaction Inventory-Revised, Problem Solving Communication Scale, where T scores below 50 are indicative of partners committed to solving conflict/differences when they occur, and being relatively effective at doing so, T scores between 50 and 60 are indicative of partners’ difficulties in dealing with disagreements, and T scores above 60 are indicative of more extensive</td>
</tr>
<tr>
<td>X3</td>
<td>Partner Support with BRCA</td>
</tr>
<tr>
<td>------</td>
<td>---------------------------</td>
</tr>
<tr>
<td>X4</td>
<td>Partner Support in general</td>
</tr>
<tr>
<td>X5</td>
<td>Comfort level with BRCA</td>
</tr>
<tr>
<td>X6</td>
<td>Amount of Time</td>
</tr>
<tr>
<td>X7</td>
<td>Years in Relationship</td>
</tr>
<tr>
<td>X8</td>
<td>Years since BRCA diagnosis</td>
</tr>
<tr>
<td>X9</td>
<td>Age</td>
</tr>
<tr>
<td>X10a</td>
<td>Marital Status</td>
</tr>
<tr>
<td>X10b</td>
<td>Marital Status</td>
</tr>
<tr>
<td>X11</td>
<td>Sex</td>
</tr>
</tbody>
</table>
Statistical Analysis

Descriptive and inferential statistics were used in this research study. Descriptive statistics included means, standard deviations, frequencies, reliability coefficients, and correlations for the data set variables. Multiple linear regression was used to develop a model that relates the response variable Y1 to the potential predictor variables X1, X2, …, X11. Because one of the goals of a multiple regression analysis is to determine which predictor variables provide statistically significant information about the response variable, it is not possible to state which predictor variables will ultimately be included in a final regression model for a particular data set. However, it is possible to write out a full model that includes separate terms for each predictor variable. This full model will quite likely not be the final regression model indicated by the data. First, the necessary “dummy” variables for categorical (i.e. qualitative) predictor variables are defined. For variable X3 define 3 dummy variables as:

\[
X_{3a} = \begin{cases} 
1, & \text{if } X3 = 1 \\
0, & \text{otherwise}
\end{cases} \quad X_{3b} = \begin{cases} 
1, & \text{if } X3 = 2 \\
0, & \text{otherwise}
\end{cases} \quad X_{3c} = \begin{cases} 
1, & \text{if } X3 = 3 \\
0, & \text{otherwise}
\end{cases}
\]

Similarly, for variables X4, X5, and X6. For variable X10 define 1 dummy variables as:

\[
X_{10a} = \begin{cases} 
1, & \text{if } X10 = \text{married} \\
0, & \text{otherwise}
\end{cases}
\]

For variable X11 define 1 dummy variables as:

\[
X_{11a} = \begin{cases} 
1, & \text{if } X11 = \text{female} \\
0, & \text{otherwise}
\end{cases}
\]
With these variable definitions a full regression model relating the predictors to the response variable is:

\[
Y_1 = \beta_0 + \beta_1 X_1 + \beta_2 X_2 + \beta_3 a X_3 a + \beta_4 b X_3 b + \beta_5 c X_3 c + \\
\beta_6 a X_4 a + \beta_7 b X_4 b + \beta_8 c X_4 c + \beta_9 a X_5 a + \beta_10 b X_5 b + \beta_11 c X_5 c + \\
\beta_{12} a X_6 a + \beta_{13} b X_6 b + \beta_{14} c X_6 c + \beta_{15} a X_7 + \beta_{16} b X_8 + \beta_{17} c X_9 + \\
\beta_{18} a X_{10} a + \beta_{19} b X_{10} b + \beta_{20} c X_{11} a + \epsilon,
\]

where \( \epsilon \) is the error term that encompasses the difference between the predicted value for \( Y_1 \) and the actual value for \( Y_1 \).

Post hoc analyses were also conducted on some of the subscales after the initial analysis to determine any relationships that were significant. A significance level of .05 was utilized throughout the study to determine the rejection of the null hypothesis. This alpha level was determined to be appropriate in this investigation because it is conservative and the consequences of rejecting a true null hypothesis are not serious enough to justify a more stringent confidence level. For this study, power is based on an alpha level of .05 and an N of 100.

Limitations

There were several limitations to this research investigation. Consideration of these limitations should be given when interpreting the results of the statistical analysis.

1. The study utilized an observational design, and therefore causation cannot be inferred.

2. The participants were recruited from a support group (FORCE) and may not be representative of the population dealing with a BRCA diagnosis, which limits the ability to generalize the research results.
3. The participants chose to participate in the study and it is difficult to determine if those who did not respond to the request differed in some way from those who did participate, and therefore caution needs to be taken in generalizing to the larger population.

4. This study only examined the involvement in one support group, and therefore cannot be generalized to other support group involvement.

5. The reliability and validity of the instruments used in this investigation limit the results.

Summary

The research design, research setting, and data collection procedures were described in this chapter. The selection of participants, the basic demographics of participants, and descriptions of the instruments were also presented. This chapter also explained the research methodology that was used to address the research questions.

Previous research has not addressed marital satisfaction, communication, and involvement in a support group with couples dealing with a BRCA genetic mutation. Therefore, this study will provide much needed research on the relationship of these variables that impact couples dealing with a BRCA diagnosis. It is anticipated that this research will also clarify different types of treatment interventions for these couples.
CHAPTER IV
RESULTS

The purpose of Chapter IV is to present the findings from the data analyses and to show how the interview data correspond to the central research questions noted in Chapter III. This study examined the relationships between marital satisfaction, communication patterns, and involvement in a support group in couples with a BRCA genetic mutation. Chapter IV has been divided into two major sections to present the results of this investigation. The first section reports the demographic descriptive statistics and the second section presents the results of testing the research hypotheses. A summary of the results concludes this chapter.

Descriptive Statistics

The descriptive statistics and a preliminary analysis of the data are presented in this section. One hundred and ninety six questionnaires were mailed, and 130 were returned, with a return rate of 66.3%. Of the 130 questionnaires that were returned, six were not completed. The present sample represents 62 participants who identified as carrying the BRCA genetic marker, and their 62 partners.

Demographic information was obtained by having each participant with the BRCA marker and his/her partner complete separate demographic questionnaires (see Appendices C and D).
The demographic descriptive statistics are presented in Tables 1 through 17. Two same sex couples participated in the study, with a total of 64 (51.6%) participants being female, and 60 (48.4%) participants being male. The participants with BRCA were predominantly female (96.8%). The partners were predominantly male (93.5%). The average age of the BRCA participants was 42.15 years old, and the average age of their partners was 44.24 years old (SD = 10.88 and 12.06; see Tables 1, 2, 3, and 4).

Table 1

*Gender of the Participants*

<table>
<thead>
<tr>
<th>Variable</th>
<th>Frequency</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Female</td>
<td>64</td>
<td>51.6</td>
</tr>
<tr>
<td>Male</td>
<td>60</td>
<td>48.4</td>
</tr>
<tr>
<td>Total</td>
<td>124</td>
<td>100%</td>
</tr>
</tbody>
</table>

Table 2

*Gender of the BRCA Participants*

<table>
<thead>
<tr>
<th>Variable</th>
<th>Frequency</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Female</td>
<td>60</td>
<td>96.8</td>
</tr>
<tr>
<td>Male</td>
<td>2</td>
<td>3.2</td>
</tr>
<tr>
<td>Total</td>
<td>62</td>
<td>100%</td>
</tr>
</tbody>
</table>
Table 3

*Gender of the Partners*

<table>
<thead>
<tr>
<th>Variable</th>
<th>Frequency</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Female</td>
<td>4</td>
<td>6.5</td>
</tr>
<tr>
<td>Male</td>
<td>58</td>
<td>93.5</td>
</tr>
</tbody>
</table>
| Total    | 62        | 100%

Table 4

*Participant’s Age by BRCA Status*

<table>
<thead>
<tr>
<th>Variable</th>
<th>Mean</th>
<th>SD</th>
</tr>
</thead>
<tbody>
<tr>
<td>BRCA carrier</td>
<td>42.15</td>
<td>10.88</td>
</tr>
<tr>
<td>Partner</td>
<td>44.24</td>
<td>12.06</td>
</tr>
<tr>
<td>Total</td>
<td>43.19</td>
<td>11.48</td>
</tr>
</tbody>
</table>

The relationship status of the participants is presented in Table 5. One hundred twelve of the participants were married, eight were co-habitating, and four were in same sex partner relationships. For married couples, the mean length of marriage was 16.79 years, while co-habitating partners reported a mean of 5.00 years in their relationship and same sex couples reported a mean of 8.50 years in current relationship. The mean length of relationship status is presented in Table 6. Twenty-one of the participants (16.9%) reported a previous marriage, while 12 (9.7%) of the participants reported a previous significant relationship, and the mean length of these previous relationships was 8.31
years for marriages, 2.91 years for co-habitating, and 3.33 years for other previous significant relationships (see Tables 7 and 8).

Table 5

*Relationship Status of Participants*

<table>
<thead>
<tr>
<th>Variable</th>
<th>Frequency</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Married</td>
<td>112</td>
<td>90.3</td>
</tr>
<tr>
<td>Co-habitating</td>
<td>8</td>
<td>6.5</td>
</tr>
<tr>
<td>Same Sex Union</td>
<td>4</td>
<td>3.2</td>
</tr>
<tr>
<td>Total</td>
<td>124</td>
<td>100%</td>
</tr>
</tbody>
</table>

Table 6

*Length of Relationship in Years*

<table>
<thead>
<tr>
<th>Variable</th>
<th>Mean</th>
<th>SD</th>
</tr>
</thead>
<tbody>
<tr>
<td>Married</td>
<td>16.79</td>
<td>11.90</td>
</tr>
<tr>
<td>Co-habitating</td>
<td>5.00</td>
<td>1.73</td>
</tr>
<tr>
<td>Same Sex Union</td>
<td>8.50</td>
<td>3.04</td>
</tr>
</tbody>
</table>
Eighty-four of the participants reported having children, and the children ranged in age from one year to 47 years of age. The mean age of the children was 15.3, and mean number of children was 2.15 children. There were a total of 183 children reported among
the 84 participants, and 117 (63.9\%) of the children were minors (age 17 or under) while 66 (36.1\%) of the children were adults. This information is presented in Tables 9 and 10.

Table 9

*Number of Participants' Children*

<table>
<thead>
<tr>
<th>Variable</th>
<th>Frequency</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Minor Children</td>
<td>117</td>
<td>63.9</td>
</tr>
<tr>
<td>Adult Children</td>
<td>66</td>
<td>36.1</td>
</tr>
<tr>
<td>Total</td>
<td>183</td>
<td>100%</td>
</tr>
</tbody>
</table>

Table 10

*Age Ranges of Participants' Children*

<table>
<thead>
<tr>
<th>Variable</th>
<th>Frequency</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>1-5 years old</td>
<td>39</td>
<td>21.3</td>
</tr>
<tr>
<td>6-13 years old</td>
<td>63</td>
<td>34.4</td>
</tr>
<tr>
<td>14-17 years old</td>
<td>15</td>
<td>8.2</td>
</tr>
<tr>
<td>18-22 years old</td>
<td>25</td>
<td>13.7</td>
</tr>
<tr>
<td>23 years old and above</td>
<td>41</td>
<td>22.4</td>
</tr>
<tr>
<td>Total</td>
<td>183</td>
<td>100%</td>
</tr>
</tbody>
</table>

Table 11 presents the ethnic representation of the participants. One hundred eighteen (95.2\%) participants were Caucasian, five (4.0\%) Asian/Pacific Islander, and
one (0.8%) Middle Eastern. Four (3.2%) of the participants reported their highest level of education to be high school, five (4.0%) reported technical school training, 17 (13.5%) reported some college, 47 (37.9%) reported a college degree, 25 (20.2%) reported a master’s degree, and 25 (20.2%) reported a doctorate degree (see Table 12). Seventy-eight (62.9%) of the participants reported a household income over $100,000; twelve (9.7%) reported an income between $80,000-$99,999; twelve (9.7%) reported an income between $60,000-$79,999; thirteen (10.5%) reported an income between $40,000-$59,999; and nine (7.3%) reported an income between $20,000-$39,999 (see Table 13).

Table 1

*Ethnic Representation of Participants*

<table>
<thead>
<tr>
<th>Variable</th>
<th>Frequency</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Caucasian</td>
<td>118</td>
<td>95.2</td>
</tr>
<tr>
<td>Asian/Pacific Islander</td>
<td>5</td>
<td>4.0</td>
</tr>
<tr>
<td>Middle Eastern</td>
<td>1</td>
<td>0.8</td>
</tr>
<tr>
<td>Total</td>
<td>124</td>
<td>100%</td>
</tr>
<tr>
<td>Variable</td>
<td>Frequency</td>
<td>%</td>
</tr>
<tr>
<td>--------------------</td>
<td>-----------</td>
<td>------</td>
</tr>
<tr>
<td>High School</td>
<td>4</td>
<td>3.2</td>
</tr>
<tr>
<td>Technical School</td>
<td>5</td>
<td>4.0</td>
</tr>
<tr>
<td>Some College</td>
<td>17</td>
<td>13.5</td>
</tr>
<tr>
<td>College Degree</td>
<td>47</td>
<td>37.9</td>
</tr>
<tr>
<td>Master’s Degree</td>
<td>25</td>
<td>20.2</td>
</tr>
<tr>
<td>Ph.D./M.D./J.D.</td>
<td>25</td>
<td>20.2</td>
</tr>
<tr>
<td>Total</td>
<td>124</td>
<td>100%</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Variable</th>
<th>Frequency</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>$20,000-$39,999</td>
<td>9</td>
<td>7.3</td>
</tr>
<tr>
<td>$40,000-$59,999</td>
<td>13</td>
<td>10.5</td>
</tr>
<tr>
<td>$60,000-$79,999</td>
<td>12</td>
<td>9.7</td>
</tr>
<tr>
<td>$80,000-$99,999</td>
<td>12</td>
<td>9.7</td>
</tr>
<tr>
<td>$100,000 or more</td>
<td>78</td>
<td>62.9</td>
</tr>
<tr>
<td>Total</td>
<td>124</td>
<td>100%</td>
</tr>
</tbody>
</table>
The geographic locations of the participants were categorized using the US Census Bureau (U.S. Census Bureau, 2011) designations and are presented in Table 14. Ten (8.1%) participants resided outside of the United States. Twenty-one of the 50 states were represented, with 28 (22.6%) participants from the Northeast Region of the United States, 28 (22.6%) from the Midwest Region, 28 (22.6%) from the South Region, and 30 (24.2%) from the West Region.

Table 14

Geographic Location of Participants

<table>
<thead>
<tr>
<th>Variable</th>
<th>Frequency</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Another country</td>
<td>10</td>
<td>8.1</td>
</tr>
<tr>
<td>Northeast</td>
<td>28</td>
<td>22.6</td>
</tr>
<tr>
<td>Midwest</td>
<td>28</td>
<td>22.6</td>
</tr>
<tr>
<td>South</td>
<td>28</td>
<td>22.6</td>
</tr>
<tr>
<td>West</td>
<td>30</td>
<td>24.2</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td><strong>124</strong></td>
<td><strong>100%</strong></td>
</tr>
</tbody>
</table>

The mean number of years since the BRCA diagnosis was 3.10, with year of diagnosis ranging from 1998 to 2011 (see Table 15). Forty-seven (37.9%) of the participants reported a family history of breast or ovarian cancer, and 16 (12.9%) of the participants reported a breast or ovarian cancer in themselves. Fifty-five (88.7%) of the participants who are BRCA carriers reported a family history of illness, while 37 (59.7%)
of the partners reported a family history of illness (see Tables 16 and 17). Thirty-seven (29.8%) participants also reported a personal illness and a list of personal illnesses is presented in Table 18.

Table 15

*Year of BRCA Diagnosis*

<table>
<thead>
<tr>
<th>Variable</th>
<th>Frequency</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>1998</td>
<td>2</td>
<td>1.6</td>
</tr>
<tr>
<td>2001</td>
<td>3</td>
<td>2.4</td>
</tr>
<tr>
<td>2002</td>
<td>5</td>
<td>4.0</td>
</tr>
<tr>
<td>2003</td>
<td>4</td>
<td>3.2</td>
</tr>
<tr>
<td>2004</td>
<td>2</td>
<td>1.6</td>
</tr>
<tr>
<td>2005</td>
<td>2</td>
<td>1.6</td>
</tr>
<tr>
<td>2006</td>
<td>8</td>
<td>6.5</td>
</tr>
<tr>
<td>2007</td>
<td>8</td>
<td>6.5</td>
</tr>
<tr>
<td>2008</td>
<td>18</td>
<td>12.9</td>
</tr>
<tr>
<td>2009</td>
<td>22</td>
<td>17.7</td>
</tr>
<tr>
<td>2010</td>
<td>30</td>
<td>24.2</td>
</tr>
<tr>
<td>2011</td>
<td>20</td>
<td>16.1</td>
</tr>
<tr>
<td>Total</td>
<td>124</td>
<td>100%</td>
</tr>
</tbody>
</table>
Table 16

*Incidence of Illness by Type and BRCA Status*

<table>
<thead>
<tr>
<th>Variable</th>
<th>Frequency</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Breast/Ovarian Cancer in BRCA Carrier</td>
<td>16</td>
<td>12.9</td>
</tr>
<tr>
<td>Breast/Ovarian Cancer in Partner</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>Other Illness in BRCA Carrier</td>
<td>7</td>
<td>5.6</td>
</tr>
<tr>
<td>Other Illness in Partner</td>
<td>14</td>
<td>11.3</td>
</tr>
<tr>
<td>No Personal Illness</td>
<td>87</td>
<td>70.2</td>
</tr>
<tr>
<td>Total</td>
<td>124</td>
<td>100%</td>
</tr>
</tbody>
</table>

Table 17

*Incidence of Family History of Illness by Type and BRCA Status*

<table>
<thead>
<tr>
<th>Variable</th>
<th>Frequency</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Breast/Ovarian Cancer BRCA Carrier</td>
<td>43</td>
<td>34.7</td>
</tr>
<tr>
<td>Breast/Ovarian Partner</td>
<td>4</td>
<td>3.2</td>
</tr>
<tr>
<td>Other Illness BRCA Carrier</td>
<td>13</td>
<td>10.5</td>
</tr>
<tr>
<td>Other Illness Partner</td>
<td>30</td>
<td>24.2</td>
</tr>
<tr>
<td>No Family Illness History</td>
<td>34</td>
<td>27.4</td>
</tr>
<tr>
<td>Total</td>
<td>124</td>
<td>100%</td>
</tr>
</tbody>
</table>
Table 18  

*Personal Illnesses of Participants*

<table>
<thead>
<tr>
<th>Illness</th>
<th>Frequency</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Anxiety</td>
<td>1</td>
<td>.8</td>
</tr>
<tr>
<td>Asthma</td>
<td>1</td>
<td>.8</td>
</tr>
<tr>
<td>Bladder Cancer</td>
<td>1</td>
<td>.8</td>
</tr>
<tr>
<td>Breast Cancer</td>
<td>15</td>
<td>12.1</td>
</tr>
<tr>
<td>Crohn's Disease</td>
<td>1</td>
<td>.8</td>
</tr>
<tr>
<td>Detached Retina/Hernia/Chicken Pox</td>
<td>3</td>
<td>2.4</td>
</tr>
<tr>
<td>Fibromyalgia</td>
<td>1</td>
<td>.8</td>
</tr>
<tr>
<td>Heart Issues</td>
<td>1</td>
<td>.8</td>
</tr>
<tr>
<td>High Blood Pressure</td>
<td>1</td>
<td>.8</td>
</tr>
<tr>
<td>Intussusception</td>
<td>1</td>
<td>.8</td>
</tr>
<tr>
<td>Melanoma/Other cancer</td>
<td>3</td>
<td>2.4</td>
</tr>
<tr>
<td>Orthopedic Issues</td>
<td>4</td>
<td>4.8</td>
</tr>
<tr>
<td>Ovarian Cancer</td>
<td>1</td>
<td>.8</td>
</tr>
<tr>
<td>Sarcoidosis</td>
<td>1</td>
<td>.8</td>
</tr>
<tr>
<td>TIA</td>
<td>1</td>
<td>.8</td>
</tr>
<tr>
<td>Testicular Cancer</td>
<td>1</td>
<td>.8</td>
</tr>
<tr>
<td>None Reported</td>
<td>87</td>
<td>70.2</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td><strong>124</strong></td>
<td><strong>100%</strong></td>
</tr>
</tbody>
</table>

68
Overall, the mean scores on the Marital Satisfaction Inventory-Revised indicated that most of the participants reported satisfactory relationships (Global Distress Scale scores < 50). The overall Global Distress Scale (GDS) mean was 46.75. BRCA carriers’ mean on the GDS was 46.34, and their partners’ mean score was 47.16. Table 19 presents the mean scores overall for the total score and for each of the subtests, and a breakdown of mean scores for BRCA carriers and for their partners.

Table 19

Mean Scores for Total Score and Subtests for Marital Satisfaction Inventory-Revised

<table>
<thead>
<tr>
<th>Scale</th>
<th>Overall</th>
<th>BRCA Carrier</th>
<th>Partner</th>
</tr>
</thead>
<tbody>
<tr>
<td>Global Distress Scale*</td>
<td>46.75</td>
<td>46.34</td>
<td>47.16</td>
</tr>
<tr>
<td>Affective Communication*</td>
<td>46.82</td>
<td>46.65</td>
<td>47.00</td>
</tr>
<tr>
<td>Problem Solving Communication*</td>
<td>45.67</td>
<td>46.11</td>
<td>45.24</td>
</tr>
<tr>
<td>Aggression*</td>
<td>46.75</td>
<td>46.10</td>
<td>47.40</td>
</tr>
<tr>
<td>Time Together*</td>
<td>44.99</td>
<td>44.81</td>
<td>45.18</td>
</tr>
<tr>
<td>Disagreement About Finances*</td>
<td>44.77</td>
<td>45.13</td>
<td>44.42</td>
</tr>
<tr>
<td>Sexual Dissatisfaction*</td>
<td>48.99</td>
<td>49.15</td>
<td>48.84</td>
</tr>
<tr>
<td>Role Orientation</td>
<td>56.01</td>
<td>55.42</td>
<td>56.60</td>
</tr>
<tr>
<td>Family History of Distress**</td>
<td>48.60</td>
<td>49.00</td>
<td>48.21</td>
</tr>
<tr>
<td>Dissatisfaction With Children*</td>
<td>46.33</td>
<td>45.79</td>
<td>46.90</td>
</tr>
<tr>
<td>Conflict Over Child Rearing*</td>
<td>47.29</td>
<td>47.71</td>
<td>46.86</td>
</tr>
</tbody>
</table>

*Scores above 50 and **scores above 45 indicative of dissatisfaction
Research Hypothesis Test Results

The research questions were tested using multiple regression with an alpha error rate of .05 level of significance set for each research question. The research questions and hypothesis testing results are presented in this section.

This study was exploratory in nature based on Rolland’s Family Systems-Illness Model (1994a) and examined the relationships between communication, relationship satisfaction, and support group involvement in couples. Figure 1 shows Rolland’s Interface of Family and Illness, and the variables used in this study and the general research hypotheses are superimposed on the model.

In this study three general hypotheses were tested. The first hypothesis examined the relationship between marital satisfaction and communication. It was hypothesized that marital satisfaction as measured by the Global Distress Scale (GDS) on the Marital Satisfaction Inventory-Revised (MSI-R) would be low (indicating a satisfactory relationship) for couples who also scored low on the Problem Solving Communication (PSC) and the Affective Communication (AFC) subscales of the MSI-R. The second general hypothesis examined the relationship between marital satisfaction and partner support. It was hypothesized that marital satisfaction as measured by the GDS on the MSI-R would be low (indicating a satisfactory relationship) for couples who indicated that their partner provided a great deal of support on the demographic questionnaire (score of 1 or 2 on the Likert rating scale). The third general hypothesis examined the relationship between marital satisfaction and level of involvement in a support group. It was hypothesized that marital satisfaction as measured by the GDS on the MSI-R would be low (indicating a satisfactory relationship) for couples who indicated that they had a
high level of involvement in a support group on the demographic questionnaire (score of 1 or 2 on the Likert rating scale).

**General Hypothesis One**

There is a significant relationship between marital satisfaction and communication. Data related to these findings are presented in Table 20. The findings support the research hypothesis that there was a significant relationship between marital satisfaction and communication, where $R^2 = 0.540$, $F = 46.872$, df = 3, 120 and $p < .001$. There is a significant interaction between AFC and PSC scores, and these scores account for about half of the variance in GDS scores. Communication did account for a significant amount of marital satisfaction, as measured by the GDS. The regression equation is: $predicted \ GDS = 50.189 - 0.454AFC - 0.410PSC + 0.017(AFCxPSC)$.

Because the regression model includes an interaction term $(AFCxPSC)$ that involves AFC and PSC, one cannot simply look at the sign of the regression coefficients for AFC and PSC to determine the relationship between these factors and GDS. The situation is complicated by the presence of the interaction term which suggests that the relationship between AFC and GDS depends on the value of PSC. Similarly, the relationship between PSC and GDS depends on the value of AFC. As an example, suppose that a person had a PSC score of 45 and an AFC score of 45. The predicted GDS would be: $predicted \ GDS = 50.189 - 0.454(45) - 0.410(45) + 0.017(45\times45) = 45.734$. If the PSC score were held constant and the AFC score increased by 10 from 45 to 55, then the predicted GDS would be: $predicted \ GDS = 50.189 - 0.454(55) - 0.410(45) + 0.017(55\times45) = 48.844$. Thus, when $(AFC = 45, \ PSC = 45)$ then a ten-point increase in AFC would result in about a three-point increase in GDS. Because of the interaction term this relationship of GDS to
changes in AFC is not constant and how GDS changes as AFC changes depends on the value of PSC.

Table 20

*Regression Coefficients for Global Distress Scale and Communication*

<table>
<thead>
<tr>
<th></th>
<th>B</th>
<th>Std. Error</th>
<th>P</th>
</tr>
</thead>
<tbody>
<tr>
<td>Constant</td>
<td>50.189</td>
<td>15.495</td>
<td>.002</td>
</tr>
<tr>
<td>AFC</td>
<td>-0.454</td>
<td>0.323</td>
<td>.162</td>
</tr>
<tr>
<td>PSC</td>
<td>-0.410</td>
<td>0.331</td>
<td>.218</td>
</tr>
<tr>
<td>PFC* AFC</td>
<td>0.017</td>
<td>0.00646</td>
<td>.0011</td>
</tr>
</tbody>
</table>

**General Hypothesis Two**

There is a significant relationship between marital satisfaction and partner support. Data related to these findings are presented in Table 21 and the findings support the research hypothesis that there was a significant relationship between marital satisfaction and partner support where $R^2 = 0.182$, $F = 27.234$, df = 1, 122 and $p < .001$. Table 21 presents the mean scores for partner support. BRCA carriers reported much support from their partner about their BRCA issues, with a mean of 1.32. Partners reported giving their BRCA partner much support, with a mean of 1.58. Overall, partner support was also high with a mean of 1.21 (see Table 22). Partner support did account for a significant amount of marital satisfaction. Specifically, the slope of 5.561 indicates that as the partner support increases by 1 it can be estimated that the GDS will increase by 5.561. This relationship is positive indicating that low scores on the Global Distress Scale were related to low scores on partner support. Higher scores indicate high levels of
distress and low partner support. However, it should be noted that partner support only accounted for 18.2% of the variation in GDS scores.

Table 21

*Regression Coefficients for Global Distress Scale and Partner Support*

<table>
<thead>
<tr>
<th></th>
<th>B</th>
<th>Std. Error</th>
<th>P</th>
</tr>
</thead>
<tbody>
<tr>
<td>Constant</td>
<td>39.709</td>
<td>1.510</td>
<td>&lt; .001</td>
</tr>
<tr>
<td>Partner Support</td>
<td>5.561</td>
<td>1.066</td>
<td>&lt; .001</td>
</tr>
</tbody>
</table>

Table 22

*Mean Scores for Partner Support*

<table>
<thead>
<tr>
<th></th>
<th>Mean</th>
<th>SD</th>
</tr>
</thead>
<tbody>
<tr>
<td>BRCA Carrier</td>
<td>1.32</td>
<td>.78</td>
</tr>
<tr>
<td>Partner</td>
<td>1.21</td>
<td>.45</td>
</tr>
<tr>
<td>Overall</td>
<td>1.26</td>
<td>.64</td>
</tr>
</tbody>
</table>

Participants were asked where they received support about their concerns about the BRCA. Multiple sources of support were identified by participants. Seventy-seven percent of the BRCA participants stated they received support from their partner, while 81% of the partners stated they received support from their BRCA partner. In addition, 28% of the BRCA participants stated that they received support from another family member, while 14% of the partners reported receiving support from another family member. Eighteen percent of the BRCA participants stated that they also received
support from friends, while 4% of the partners reported receiving support from friends. Twenty-three percent of the BRCA participants stated that they also received support from a support group, while none of the partners reported receiving support from a support group. Two percent of the BRCA participants stated that they also received support from church, while 5% of the partners reported receiving support from church.

Twelve percent of the BRCA participants stated that they also received support from a medical professional, while 12% of the partners reported receiving support from a medical professional. Five percent of the BRCA participants stated that they also received support from another source, while 7% of the partners reported receiving support from another source. These results are presented in Table 23.

Table 23

*Source of Support for BRCA by BRCA Status*

<table>
<thead>
<tr>
<th>Variable</th>
<th>BRCA Carrier Frequency</th>
<th>BRCA Carrier %</th>
<th>Non BRCA Carrier (Partner) Frequency</th>
<th>Non BRCA Carrier %</th>
</tr>
</thead>
<tbody>
<tr>
<td>Partner</td>
<td>47</td>
<td>75.8</td>
<td>49</td>
<td>79</td>
</tr>
<tr>
<td>Other Family Member</td>
<td>17</td>
<td>27.4</td>
<td>8</td>
<td>12.9</td>
</tr>
<tr>
<td>Friend</td>
<td>10</td>
<td>16.1</td>
<td>3</td>
<td>4.8</td>
</tr>
<tr>
<td>Support Group</td>
<td>14</td>
<td>22.6</td>
<td>1</td>
<td>1.6</td>
</tr>
<tr>
<td>Church</td>
<td>1</td>
<td>1.6</td>
<td>3</td>
<td>4.8</td>
</tr>
<tr>
<td>Medical Professional</td>
<td>8</td>
<td>12.9</td>
<td>7</td>
<td>11.3</td>
</tr>
<tr>
<td>Other</td>
<td>3</td>
<td>4.8</td>
<td>4</td>
<td>6.5</td>
</tr>
</tbody>
</table>
**General Hypothesis Three**

The third general hypothesis states that there is a significant relationship between marital satisfaction and involvement in a support group. Data related to these findings are presented in Table 24. The findings did not support the research hypothesis that there was a significant relationship between marital satisfaction and involvement in a support group, where $R^2 = 0.005$, $F = 0.628$, df = 1, 121 and $p = .430$. Support group involvement not did account for a significant amount of the variation in marital satisfaction.

Table 24

*Regression Coefficients for Global Distress Scale and Support Group Involvement*

<table>
<thead>
<tr>
<th></th>
<th>B</th>
<th>Std. Error</th>
<th>P</th>
</tr>
</thead>
<tbody>
<tr>
<td>Constant</td>
<td>45.204</td>
<td>2.164</td>
<td>&lt; .001</td>
</tr>
<tr>
<td>Support Group Involvement</td>
<td>0.369</td>
<td>0.466</td>
<td>.430</td>
</tr>
</tbody>
</table>

Figures 2-7 provide visual representations of comparisons of each couple’s Global Distress Scale score and level of support group involvement. BRCA carriers reported their own level of support group involvement, while their partners reported their perception of the BRCA partners’ level of support group involvement. These figures are divided into four quadrants. Quadrant I represents couples where both the partner and BRCA carrier reported high relationship distress. Quadrant II represents couples where the partner reported high relationship distress, while the BRCA carrier reported low relationship distress. Quadrant III represents couples where both the partner and BRCA
carrier reported low relationship distress. Quadrant IV represents couples where the partner reported low relationship distress and the BRCA carrier reported high relationship distress. The level of reported support group involvement reported by the BRCA carrier was plotted based on high (scores of 1 or 2), medium (scores of 3 or 4), or low (scores of 5 or 6) levels of support group involvement, and the partner’s perception of the BRCA carriers’ level of support group involvement was also plotted on these graphs by high, medium, and low levels of support group involvement.

Quadrants II and IV are of particular interest as they indicate discrepancies between couples’ relationship satisfaction. Couples reported level of support group involvement whose point falls in quadrant II are partners who have high relationship distress, while their BRCA carrier partner reports low relationship distress. Couples reported level of support group involvement whose point falls in quadrant IV are partners who have low relationship distress, while their BRCA carrier partner reports high relationship distress. Where high and medium levels of support group involvement were reported by both the partner and the BRCA carrier, partners tended to be more dissatisfied in the relationship then the BRCA carrier.

BRCA carriers reported a mean of 3.25 for level of support group involvement, where 1 was indicative of spending several hours a day with support group involvement, 2 being several hours a week, and 3 being several hours a month. Partners reported a mean of 2.90 in their perception of the level of support group involvement of their BRCA partner. BRCA carriers reported a mean of 5.58 for their perception of their partners’ level of involvement in a support group, while partners reported a mean of 5.39 for their level of support group involvement where 4 was indicative of several hours a year, 5
being several hours ever, and 6 being never. Table 25 presents the reported levels of support group involvement.

Table 25

<table>
<thead>
<tr>
<th></th>
<th>Mean</th>
<th>SD</th>
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<tbody>
<tr>
<td>BRCA Carrier Self-Report</td>
<td>3.25</td>
<td>1.25</td>
</tr>
<tr>
<td>Partner Self-Report</td>
<td>5.39</td>
<td>1.30</td>
</tr>
<tr>
<td>BRCA Carrier Perception of Partner</td>
<td>5.58</td>
<td>0.90</td>
</tr>
<tr>
<td>Partner Perception of BRCA Carrier</td>
<td>2.90</td>
<td>1.49</td>
</tr>
</tbody>
</table>

Summary

This chapter summarized the demographics of the sample as well as the results of the hypothesis testing. The overall sample consisted of 124 participants.

General Research Hypothesis One tested whether marital satisfaction as measured by the total score (Global Distress Scale) on the Marital Satisfaction Inventory-Revised (MSI-R) was lower for couples with BRCA who reported good affective and problem solving communication as measured by the MSI-R subscales of Affective Communication and Problem Solving Communication scores. This hypothesis was supported by the research findings.

General Research Hypothesis Two tested whether marital satisfaction as measured by the total score on the MSI-R was higher for couples with BRCA who
reported high levels of support by their partner as measured by a self-report 6 point Likert rating scale. This hypothesis was also supported by the research findings.

General Research Hypothesis Three tested whether marital satisfaction as measured by the total score on the MSI-R was higher for couples with BRCA who reported high levels of involvement in a BRCA support group as measured by a self-report 6 point Likert rating scale. This hypothesis was not supported by the research findings.
CHAPTER V
DISCUSSION

Introduction

This final chapter is focused on the analysis of the results of this investigation and is organized into six sections. The first section includes a summary of the problem, review of the procedures, and a summary briefly reviewing the hypotheses that were tested. A discussion of the research findings as they relate to each hypothesis is presented in the second section. The third section presents some implications of the research findings. Suggestions for future research are discussed in section four. There were several limitations of the study, and these are presented in the fifth section. Finally, section six summarizes the current study and concludes the chapter.

Summary of the Study

Statement of the Problem

Illness impacts couples’ relationships, but little information is available about the impact of genetic illness on the couple relationship (Rolland, 1994a; Abby, Andrews, & Halman, 1995; Badr, 2002; McDaniel & Rolland, 2006). Two important factors that influence the relationship of the couple dealing with illness are communication and support (Rolland, 1994a; Badr & Carmack Taylor, 2006; Stang & Mittlemark, 2010). In order for mental health and medical professionals to better serve their clients and patients,
it is important to understand how communication and support about illness impacts relationships. In particular, this study adds empirical support to the constructs identified in Rolland’s (1994a) Family Systems-Illness Model when looking at couples with genetic risk for illness. Family therapists can be beneficial to couples struggling with the issues involved with genetic risk for disease by helping couples improve communication and support for one another.

The purpose of the present investigation was to increase understanding of the impact of a genetic illness, communication skills, and the use of a support group on relationship satisfaction. The study was an exploratory investigation utilizing Rolland’s (1994a) Family Systems-Illness Model as a guide to examine these constructs. Very little research has studied the impact of genetic risk for disease on the couple relationship (Vadaparamil, Ropka, & Stefanek, 2005; Queller, 2008).

The participants were 62 individuals who carry the BRCA gene mutation and their 62 partners. The participants were representative of a wide geographic area, and included some participants living outside of the United States. Each participant completed a demographic questionnaire, a questionnaire about support group involvement and support from others, and the Marital Satisfaction Inventory-Revised (MSI-R). An ex post facto research design was used to analyze the obtained data using descriptive statistics and multiple regression analyses.

**Research Hypotheses**

Three general hypotheses were investigated in this study. The first general hypothesis proposed that marital satisfaction as measured by the total score on the Marital Satisfaction Inventory-Revised (MSI-R) would be higher for couples with BRCA
who reported good affective and problem solving communication as measured by the
MSI-R subscales of Affective Communication and Problem Solving Communication
scores. The second general research hypothesis proposed that marital satisfaction as
measured by the total score on the MSI-R would be higher for couples with BRCA who
reported high levels of support by their partner as measured by a self-report 6 point Likert
rating scale. The third general research hypothesis proposed that marital satisfaction as
measured by the total score on the MSI-R would be higher for couples with BRCA who
reported high levels of involvement in a BRCA support group as measured by a self-
report 6 point Likert rating scale.

Conclusions

General Research Hypothesis One

Marital satisfaction as measured by the total score on the Marital Satisfaction
Inventory-Revised (MSI-R) will be higher for couples with BRCA who report good
affective and problem solving communication as measured by the MSI-R subscales of
Affective Communication and Problem Solving Communication scores. A significant
relationship between marital satisfaction and communication was found in the current
study. Regression results indicated that communication as measured by the Problem
Solving Communication and the Affective Communication Scales on the MSI-R, did
account for a significant amount of marital satisfaction, as measured by the Global
Distress Scale (GDS) on the MSI-R.

Implications of Hypothesis One

Overall, the participants reported satisfactory relationships with a GDS mean of
46.75, where scores below 50 are indicative of satisfaction in relationship. The
participants reported good affective communication and problem solving communication with means of 46.82 and 45.67, respectively, where scores below 50 are indicative of good affective communication and problem solving communication skills. These results support the importance of communication in a relationship, and specifically, are indicative of the importance of communication in satisfying relationships for couples facing a genetic risk for illness. Rolland’s (1994a) Family Systems-Illness Model emphasizes the importance of good communication in couples coping with illness.

Hypothesis one’s findings are consistent with research done with patients with chronic illness (Badr & Acitelli, 2005) and their spouses, where those who talked about their illness experiences also experienced better adjustment. Another study also found open communication to be important in coping with the stress of dealing with hereditary cancer (van Oostrom, et. al., 2007). A qualitative study on young couples also found open communication between couples about the BRCA reduced anxiety (Hoskins, Roy, Peters, Loud, & Greene, 2008).

General Research Hypothesis Two

Marital satisfaction as measured by the total score on the MSI-R will be higher for couples with BRCA who report high levels of support by their partner as measured by a self-report 6 point Likert rating scale. There is a significant relationship between marital satisfaction and partner support. Regression results indicated that partner support as measured by a self-report Likert rating score did account for a significant amount of marital satisfaction as measured by the GDS on the MSI-R.
Implications of Hypothesis Two

Overall, the participants reported satisfactory relationships with a GDS mean of 46.75, where scores below 50 are indicative of satisfaction in relationship. The participants reported good partner support regarding BRCA with a mean of 1.32 for BRCA carriers and a mean of 1.21 for partners where a score of 1 indicated a partner who’s always supportive of issues about BRCA, and a score of 2 indicated a partner who’s mostly supportive of issues about BRCA as indicated on a 6 point Likert scale rating. These results support the importance of providing partner support for a genetic illness in having a satisfying relationship. The Family Systems-Illness Model emphasizes the importance of support (cohesion) in couples coping with illness (Rolland, 1994a).

Hypothesis two’s findings are consistent with research done with lung cancer patients (Carmack Taylor, et. al., 2008) and their spouses, where higher marital satisfaction and support was found to be related to less psychological distress in both the patients and their spouses.

General Research Hypothesis Three

Marital satisfaction as measured by the total score on the MSI-R will be higher for couples with BRCA who report high levels of involvement in a BRCA support group as measured by a self-report 6 point Likert rating scale. A significant relationship was not found between marital satisfaction and level of involvement in a support group. The findings did not support the research hypothesis that there was a significant relationship between marital satisfaction and level of involvement in a support group. High support group involvement did not account for a significant amount of marital satisfaction.

Regression results indicated that level of support group involvement where a score of 1
indicated several hours a day of support group involvement, 2 indicated several hours per week, 3 several hours per month, 4 several hours per year, 5 several hours ever, and 6 never, as indicated on a 6 point Likert scale rating did not account for a significant amount of marital satisfaction as measured by the Global Distress Scale on the Marital Satisfaction Inventory-Revised.

Implications of Hypothesis Three

Overall, the participants reported satisfactory relationships with a GDS mean of 46.75, where scores below 50 are indicative of satisfaction in relationship. The BRCA carrier participants reported a medium level of support group involvement with a mean of 3.25. Their partners perceived slightly higher level of support group involvement by the BRCA carriers with a mean of 2.90. Both the self-report of the partner and the BRCA carrier perception of the partners’ level of support group involvement was reported as low, with means of 5.39 and 5.58, respectively. The partners indicated that they were less likely to seek support though a support group. Despite the fact that the BRCA carriers were recruited through an online support group, their overall level of involvement was medium, rather than high as this researcher had hypothesized.

Although General Research Hypothesis Three was not significant, there are some possible explanations for the findings. The participants generally reported satisfactory relationships. The participants had some level of involvement with support groups, and therefore appeared to be somewhat motivated to find more information and support regarding relationship implications about their BRCA. Some level of support group may be positive for marital satisfaction, and no involvement in support groups as a control variable may have supported this hypothesis better. The results may have differed if
participants were recruited from a therapy clinic or a physician’s office. The participants varied greatly in age, length of marriage, and whether or not they had children. These factors were not controlled for in the study due to the limited number of participants. The length of time since the BRCA diagnosis also varied greatly, which was also not considered in the study.

While research has indicated that support groups can be beneficial to those with limited resources (Carmack Taylor, et. al., 2007), the participants in the present study may have several resources as per the analysis of the demographics of the participants (see Tables 12, 13, and 19), such as education, financial comfort, and satisfying relationships, so that it may be difficult to see what benefit support group involvement alone would have for this particular population.

Additional Examination of Scales

The scatter plots in Figures 2-7 indicated the level of involvement in a support group and the partners Global Distress Scores compared to one another. The scatter plots are divided into four quadrants BRCA carriers reported their own level of support group involvement, while their partners reported their perception of the BRCA partners’ level of support group involvement. Quadrant I represents couples where both the partner and BRCA carrier reported high relationship distress. Quadrant II represents couples where the partner reported high relationship distress, while the BRCA carrier reported low relationship distress. Quadrant III represents couples where both the partner and BRCA carrier reported low relationship distress. Quadrant IV represents couples where the partner reported low relationship distress and the BRCA carrier reported high relationship distress. The level of reported support group involvement reported by the BRCA carrier
was plotted based on high (scores of 1 or 2), medium (scores of 3 or 4), or low (scores of 5 or 6) levels of support group involvement, and the partner’s perception of the BRCA carriers’ level of support group involvement was also plotted on these graphs by high, medium, and low levels of support group involvement.

Quadrants II and IV are of particular interest as they indicate discrepancies between couples’ relationship satisfaction. Couples reported level of support group involvement whose plot point falls in quadrant II are partners who have high relationship distress, while their BRCA carrier partner reports low relationship distress. Couples reported level of support group involvement whose point falls in quadrant IV are partners who have low relationship distress, while their BRCA carrier partner reports high relationship distress. Where high and medium levels of support group involvement were reported by both the partner and the BRCA carrier, partners tended to be more dissatisfied in the relationship then the BRCA carrier. Although not statistically significant in the present study, these findings may suggest that partners may feel somewhat disconnected from their BRCA partner when there are higher levels of support group involvement. Most partners reported low levels of support group participation for themselves. Examining the responses of partners who had high levels of support group involvement could also add to this area of research.

Pruchno, Wilson-Genderson, and Cartwright (2009) found that marital satisfaction decreased over time in their study of renal patients’ and their partners. However, their study did not indicate the amount of time. Many of the participants in the current study had recent diagnoses of the BRCA gene, for which this variable was not controlled. It may be that at the initial diagnosis, there is much support and invested
energy while information is being sought, and this support may wane after a time. This area needs to be further investigated as well.

Overall, participants reported very satisfying relationships, good communication skills, and good support from their partners. Histograms in figures 8-11 indicated that most participants’ scores on these constructs were positive (scores below 50). The histogram in figure 8 shows the frequency of GDS scores, where scores below 50 are indicative of satisfying relationships. The histogram in figure 9 shows the frequency of Affective Communication scores, where scores below 50 are indicative of relationships that are loving, supportive, understanding, and where couples are able to share intimate feelings. The histogram in figure 10 shows the frequency of Problem Solving Communication scores, where scores below 50 are indicative of relationships that are committed to and successful at solving conflicts when they occur. The histogram in figure 11 shows the frequency of level of partner support for BRCA concerns, where a score of 1 is indicative of partners who are always supportive, 2 where partners are mostly supportive, 3 moderately supportive, 4 sometimes supportive, 5 seldom supportive, and 6 never supportive. Again these trends in the data suggest a research population that has relatively satisfying relationships with good communication and support, and therefore it is impossible to generalize what variables may influence a dissatisfying relationship.

Research Contributions and Implications

The findings of this research study contribute to the field of marriage and family therapy in several ways. First, the research frames the constructs facing couples with genetic risk for illness in a model, through the use of Rolland’s (1994a) Family Illness-
Medical Model lens. The research findings also suggest that the Marital Satisfaction Inventory-Revised may be a useful tool in assessing relationship satisfaction and communication patterns in couples dealing with the BRCA mutation. More information is needed from couples expressing distress to examine how support group involvement may impact their relationship satisfaction. No other studies have examined the couple relationship in BRCA couples, and therefore this exploratory study began an examination of relationship satisfaction, communication, and support in BRCA couples. The study sampled participants from a large geographic area and from a wide age span, and therefore is somewhat representative of the general population.

This study also examined the impact of a support group on couple relationship satisfaction, which has not been done for couples dealing with BRCA. There was some variance to the level of involvement in a BRCA support group in the participants, even though all participants reported some level of participation. This study also examined the level of involvement in a support group for the partner of the BRCA carrier. Most partners have had very little involvement in a support group. While the research has suggested benefits for support groups for individuals impacted by disease, there is little research that examines the impact of support group for the partner of an individual with disease.

This study also heightened the importance of the impact of disease on the couple relationship. Many of the couples in this study reported good communication and support, and relatively satisfying relationships. The FORCE organization, from where the couples were recruited, has also recognized the need for supporting the partner, and is
now offering support groups for partners. Rolland’s (1994a) Family Systems-Illness Model emphasizes the need to consider how illness impacts the whole family.

The results of this study also provide implications for marriage and family therapists who are working with couples who are impacted by disease risk, especially where many decisions about the disease can impact the couple relationship. Therapists need to highlight fostering the couple’s open communication with one another and encouraging the couple to support one another in treatment.

The researcher in this study had much prior knowledge about the implications of BRCA and decisions which couples may face. Therapists also need to be aware of the implications of working with couples who are at risk for a genetic disease such as BRCA, and this study provided some examples of areas to address in therapy. Marriage and family therapists are increasing their presence in family systems medicine, and this study highlighted the importance of marriage and family therapists’ work with couples facing medical issues.

Anecdotally, participants in the study indicated a heightened awareness of the importance of communication in their relationships about the BRCA. Participants expressed gratification that the researcher was investigating relationships and BRCA, as many partners have indicated frustration of being left out of the BRCA implications despite the impact of the BRCA on relationships and families. Some individuals who returned the incomplete study materials or withdrew after initially volunteering shared stories about surgeries, mental health issues, difficulties with their partner acknowledging or communicating about the BRCA implications, and relationships ending due to issues
related to their BRCA status. They also expressed encouragement about the need to conduct research in couples with BRCA.

Future Research Recommendations

As medical research discovers new genetic relationships with disease, mental health professionals need to increase research on the psychological, emotional, and relational impact this knowledge may have on individuals, couples, and families. Collaboration between medical and mental health professionals is critical to complete and integrated care for couples, families, and individuals. Further research needs to assess the emotional needs of couples and families impacted by genetic diseases, and the effectiveness of treatment for them.

Couples who present to clinics for treatment need to also participate in empirical research studies that examine the impact of genetic disease on the couple relationship, communication, and support. The usefulness of treatment to improve communication and support in couples with genetic disease also needs to be examined.

Research by Hagedoorn, et. al. (2000) indicated that some types of support were beneficial (active engagement), while other types of support were detrimental to the relationship (overprotective, protective buffering). The current investigation did not clarify the types of partner support about the BRCA, and further research needs to investigate whether this construct is applicable to this population. It would be valuable to the marriage and family therapist to understand what types of supports are helpful and what types of supports by a partner are not helpful, or may even damage the partner relationship.
This study tapped into other constructs of Rolland’s FSIM (1994a) such as family and individual developmental stages by assessing children’s ages, years of marriage, and conflict over child rearing, but these variables were not evaluated statistically due to the wide range of developmental stages in the small population in the study. Further investigation should examine these variables with a larger sample size to examine this construct. Another construct that this study tapped into was family history of distress and multigenerational loss. This area may be best investigated through a qualitative examination of the stories of multigenerational loss that exist with inherited genetic disease. Specifically, there is a lack of research in regard to the needs of partners of individuals with genetic risk for disease, and more investigation needs to be done.

Research with spouses of cancer patients has indicated higher marital satisfaction where spouses had an opportunity to participate in a support group, and patients reported better communication and care giving from these spouses (Bultz, Speca, Brasher, Geggie, & Page, 2000).

Limitations of the Study

As with all research investigations, the present study has limitations that can potentially influence the conclusions. The following limitations exist for this study and should be considered when interpreting the results:

1. The study employed an ex post factor design, and therefore causal inferences should not be made.

2. The results of the study were based on participants who consulted an online support group, and therefore cannot be generalized to those who have not sought support from the FORCE organization.
3. This study only assessed communication, relationship satisfaction, and level of involvement in a support group in couples dealing with BRCA. Other factors such as illness history, length of marriage, and years since BRCA diagnosis were not examined in this study, and may have an impact on the variables studied.

4. The participants were predominantly Caucasian (95.2%), thereby limiting the generalizability of the study’s findings to couples of other races.

5. The participants were predominately married heterosexual couples in which the female was the BRCA carrier. The sample size underrepresented same-sex couples, co-habitating couples, and couples where the male is the BRCA carrier, and therefore caution should be taken in generalizing the study’s findings to these couples.

6. The participants were well educated (19.3% with a doctorate level degree, 21.9% with a masters degree, and 36.8% with a bachelors degree) and this may also impact the ability to generalize the study’s findings.

7. The reliability and validity of the instruments that were used to measure the constructs of the study also limit the results of the research. While the MSI-R has demonstrated good validity and reliability, the rating assessments for support only had face validity, as they had not been used in previous research.

8. The participants actively volunteered for the project and may not be representative of all couples dealing with the BRCA diagnosis.
9. The participants were not assessed about previous counseling experiences or other interventions that may have contributed to the high level of satisfaction.

Summary

This chapter included a review of the research problem and a summary of the research procedures and methods. The hypotheses were briefly summarized and the implications of these results were presented. Implications of the research findings and suggestions for future research were also discussed. Finally, the limitations of the study were presented in the last section.

The goal of this research study was to empirically examine issues facing couples dealing with a genetic risk for disease utilizing the constructs in the Family Systems – Illness Model (Rolland, 1994a). In general, this study investigated the relationship of marital satisfaction, communication, and involvement in a support group in couples with the BRCA genetic mutation. Descriptive statistics and multiple regression measures were utilized to analyze the data. The research supported a significant relationship between communication and marital satisfaction, and a significant relationship between marital satisfaction, but did not support a significant relationship between marital satisfaction and level of involvement in a support group.

Given the difficulties facing couples dealing with genetic risk for disease, it is important that attention be given to identifying variables that contribute to relationship satisfaction. Therefore, future research may need to explore couples at genetic risk for disease who are in relationship distress. The results of this study provide a basis to begin to examine these relationships in more detail.


APPENDICES
APPENDIX A

Informed Consent Form

Thank you for your interest in participating in a study investigating marital satisfaction and communication in coping with a BRCA diagnosis and the impact of involvement in a support group conducted by Joanne Holbert, Ed.S. from the University of Akron, Ohio as a part of her doctoral research. Her research supervisor is Dr. Patricia Parr, Professor, at the University of Akron. This study will help to gain a better understanding of the factors related to how marital communication and support groups impact coping with the BRCA diagnosis. Couples dealing with the BRCA diagnosis are being asked to complete several confidential questionnaires about communication and marital satisfaction. In addition you will be asked to provide basic demographic information (ethnic background, age, education, etc). Completing the questionnaires should take about 45 minutes to one hour.

It is hoped that you will answer all the questions; you are not required to do so. You may refuse to answer any question. Your participation is voluntary, and you may refuse to participate or withdraw at any time. Every effort will be made to maintain the confidentiality of your participation in this project. Each participant’s name will be paired with a code number by the research investigator. This code number will appear on all written materials. The list pairing people’s names to the assigned code numbers will be kept separate from all research materials and will be available only to the principal investigator and the research supervisor. Confidentiality will be maintained within legal limits.

While there are no personal benefits to you for participation in this study, your responses will benefit the aims of this research project. There are no serious risks involved in participating in this study. However, due to the personal nature of some questions you may feel some discomfort. Should any question come up that makes you feel uncomfortable in any way, you are free not to answer it. If this discomfort causes undue stress, counseling may be beneficial to work through these concerns. Therapists can be located in your area through http://www.therapistlocator.net

The results of this study may be published in professional and/or scientific journals. They may also be used for educational purposes or for professional presentations. However, the information reported will be general and apply only to groups of couples - your name will never be revealed in any of these publications. If you are interested in obtaining the study results, please indicate this on the next page.
If you and your partner are willing to help, each of you should fill out the enclosed consent form. You will then be asked to complete two questionnaires in the privacy of your own home. Please do not share your answers with your spouse while completing the forms. Upon completion of the questionnaires, please return them in the envelope provided within the next two weeks.

If I do not hear from you within two weeks, I may contact you once by email or postcard. If I do not hear from you after that, I will not attempt to contact you again, and will assume that you no longer wish to participate in the study. Your participation is greatly appreciated. Thank you for taking the time to consider this request.

PARTICIPANT RIGHTS

1. I understand that informed consent is required of all persons participating in this project.
2. All procedures have been explained to me and all my questions have been answered to my satisfaction.
3. Any risks and/or discomforts have been explained to me.
4. Any benefits have been explained to me.
5. I understand that if have any questions. I may contact those listed below.
6. I have been told that I may refuse to participate or stop my participation in this project at any time before or during the project.
7. All information that is obtained in connection with this project and that can be identified with me will remain confidential as far as possible within legal limits. Information gained from this study that can be identified with me may be released to no one other than the principal investigator. The results may be published in scientific journals, professional publications, or educational presentations without identifying me by name.

I HAVE READ (OR HAVE HAD READ TO ME) THE CONTENTS OF THIS CONSENT FORM AND HAVE BEEN ENCOURAGED TO ASK QUESTIONS. I HAVE RECEIVED ANSWERS TO MY QUESTIONS. I GIVE MY CONSENT TO PARTICIPATE IN THIS STUDY. I HAVE RECEIVED (OR WILL RECEIVE) A COPY OF THE INFORMED CONSENT FORM FOR MY RECORDS AND FUTURE REFERENCE.

Participant’s Name (Please Print)______________________________________
Signature__________________________________ Date__________________
Telephone/Email___________________________________________________
Mailing Address ____________________________________________

Please note: If you are interested in receiving the summary results of the study, please check ‘Yes’ below. If you are not interested in receiving the results of the study please check ‘No.’

___ Yes, I would like a copy of the results
___ No, I would not like a copy of the results

Contact People: Joanne Holbert, 330-730-7353, jmh93@zips.uakron.edu
                        Dr. Patricia Parr, 330-972-8151, pparr@uakron.edu
APPENDIX B

DEMOGRAPHIC QUESTIONNAIRE (BRCA positive)

Last Name: ________________________ First Name: ________________________

Address: ________________________

_______________________

Date of Birth: _______________________

Age: ___

Sex: □ Female □ Male

Current Relationship Status: □ Married □ Co-habitating □ Other _________

Years with current partner:_____

Previous relationships (yrs.): Married________ Co-habitating________

Other significant (explain)__________________________

Number of Children: _____ Ages: ____________________________

Race/ethnicity: □ Caucasian □ African-American □ Hispanic

□ Native American □ Asian or Pacific Islander □ Other _________

Highest level of education: □ Less than high school □ High school/GED

□ Technical school □ Some college □ Bachelor’s degree □ Master’s degree

□ Doctoral degree □ Other _________
Occupation: _______________________________

**Household income:** □ Under $20,000 □ $20,000-39,999 □ $40,000-59,999
□ $60,000-79,999 □ $80,000-99,999 □ $100,000 or more

**Religious preference:** □ No affiliation □ Jewish □ Protestant □ Catholic
□ Christian □ Islamic □ Other__________

Year of BRCA diagnosis: __________________________

Have you experienced illness in your family? ___ Who?________________
What type? _______________________________________

Have you personally experienced illness in yourself? ___ When?______________
What type? _______________________________________

106
Please circle the number that best describes your feelings:

1. Regarding my BRCA diagnosis, my partner is:
   1 2 3 4 5 6
   always mostly moderately sometimes seldom never
   supportive supportive supportive supportive supportive supportive

2. When problems arise, I am:
   1 2 3 4 5 6
   always mostly moderately sometimes seldom never
   supportive supportive supportive supportive supportive supportive

3. When problems arise, my partner is:
   1 2 3 4 5 6
   always mostly moderately sometimes seldom never
   supportive supportive supportive supportive supportive supportive

4. When talking to my partner about how BRCA impacts me personally, I am:
   1 2 3 4 5 6
   always very mostly sometimes sometimes seldom would never
   very comfortable comfortable comfortable uncomfortable comfortable discuss
   comfortable but will talk

5. Amount of time my partner and I spend discussing BRCA and its implications:
   1 2 3 4 5 6
   once or so once or so once or so once or so once never
   a day   a week   a month   a year

6. Amount of time I spend with support group activities (i.e. meetings, message board review/discussions, conference):
   1 2 3 4 5 6
   several hours several hours several hours several hours several hours never
   a day   a week   a month   a year

7. Amount of time I feel my partner spends with support group activities (i.e. meetings, message board review/discussions, conference):
   1 2 3 4 5 6
   several hours several hours several hours several hours several hours never
   a day   a week   a month   a year
8. From whom or where have you felt the most support about the BRCA?

☐ Partner  ☐ Other family member ________  ☐ Friend  ☐ Support group
☐ Church  ☐ Medical professional ________  ☐ Other__________

9. From whom or where do you feel that your partner has received the most support about the BRCA?  ☐ Partner  ☐ Other family member ________  ☐ Friend
 ☐ Support group  ☐ Church  ☐ Medical professional ________
 ☐ Other__________
APPENDIX C

DEMOGRAPHIC QUESTIONNAIRE (partner)

Last Name: ______________________  First Name: ______________________

Address: ______________________

_______________________

Date of Birth: ______________________

Age: ___

Sex:  □ Female      □ Male

Current Relationship Status:  □ Married  □ Co-habitating  □ Other _________

Years with current partner:______

Previous relationships (yrs.): Married_______ Co-habitating________

Other significant (explain)______________________________

Number of Children: _____ Ages: __________________________

Race/ethnicity: □ Caucasian    □ African-American    □ Hispanic

□ Native American □ Asian or Pacific Islander □ Other _________

Highest level of education: □ Less than high school □ High school/GED

□ Technical school □ Some college □ Bachelor’s degree □ Master’s degree

□ Doctoral degree □ Other __________
Occupation:______________________________

**Household income:**  
☐ Under $20,000  ☐ $20,000-39,999  ☐ $40,000-59,999  
☐ $60,000-79,999  ☐ $80,000-99,999  ☐ $100,000 or more

**Religious preference:**  
☐ No affiliation  ☐ Jewish  ☐ Protestant  ☐ Catholic  
☐ Christian  ☐ Islamic  ☐ Other____________

**Year of partner’s BRCA diagnosis:**______________________________

Have you experienced illness in your family? ___ Who?______________  
What type? ____________________________________________________

Have you personally experienced illness in yourself? ___ When?______________  
What type? ____________________________________________________
Please circle the number that best describes your feelings:

1. Regarding my partner’s BRCA diagnosis, I am:
   |   | 1 | 2 | 3 | 4 | 5 | 6 |
   |   | always | mostly | moderately | sometimes | seldom | never |
   | supportive | supportive | supportive | supportive | supportive | supportive |

2. When problems arise, I am:
   |   | 1 | 2 | 3 | 4 | 5 | 6 |
   |   | always | mostly | moderately | sometimes | seldom | never |
   | supportive | supportive | supportive | supportive | supportive | supportive |

3. When problems arise, my partner is:
   |   | 1 | 2 | 3 | 4 | 5 | 6 |
   |   | always | mostly | moderately | sometimes | seldom | never |
   | supportive | supportive | supportive | supportive | supportive | supportive |

4. When talking to my partner about how their BRCA impacts me personally, I am:
   |   | 1 | 2 | 3 | 4 | 5 | 6 |
   |   | always | mostly | sometimes | sometimes | seldom | would never discuss but will talk |
   | very comfortable | comfortable | uncomfortable | comfortable | discuss |

5. Amount of time my partner and I spend discussing BRCA and its implications:
   |   | 1 | 2 | 3 | 4 | 5 | 6 |
   |   | once or so | once or so | once or so | once or so | once | never |
   | a day | a week | a month | a year |

6. Amount of time I spend with support group activities (i.e. meetings, message board review/discussions, conference):
   |   | 1 | 2 | 3 | 4 | 5 | 6 |
   |   | several hours | several hours | several hours | several hours | several hours | never |
   | a day | a week | a month | a year |

7. Amount of time I feel my partner spends with support group activities (i.e. meetings, message board review/discussions, conference):
   |   | 1 | 2 | 3 | 4 | 5 | 6 |
   |   | several hours | several hours | several hours | several hours | several hours | never |
   | a day | a week | a month | a year |
8. From whom or where have you felt the most support about the BRCA?
☐ Partner    ☐ Other family member ________  ☐ Friend    ☐ Support group
☐ Church    ☐ Medical professional ________  ☐ Other__________

9. From whom or where do you feel that your partner has received the most support about the BRCA?
☐ Partner    ☐ Other family member ________  ☐ Friend
☐ Support group    ☐ Church    ☐ Medical professional ________
☐ Other__________
APPENDIX D

NOTICE OF APPROVAL

April 8, 2011

Joanne Holbert
15448 Hatfield Road
Rittman, Ohio 44270

From: Sharon McWhorter, IRB Administrator

Re: IRB Number 20110324 "The Relationship of Involvement in a Support Group, Communication Patterns and Marital Satisfaction in Couples with a Genetic Mutation for Breast and Ovarian Cancer (BRCA)"

Thank you for submitting an IRB Application for Review of Research Involving Human Subjects for the referenced project. Your protocol represents minimal risk to subjects and has been approved under Expedited Category #7.

Approval Date: April 7, 2011
Expiration Date: April 7, 2012
Continuation Application Due: March 24, 2012

In addition, the following is/are approved:

☐ Waiver of documentation of consent
☐ Waiver or alteration of consent
☐ Research involving children
☐ Research involving prisoners

Please adhere to the following IRB policies:

- IRB approval is given for not more than 12 months. If your project will be active for longer than one year, it is your responsibility to submit a continuation application prior to the expiration date. We request submission two weeks prior to expiration to insure sufficient time for review.
- A copy of the approved consent form must be submitted with any continuation application.
- If you plan to make any changes to the approved protocol you must submit a continuation application for change and it must be approved by the IRB before being implemented.
- Any adverse reactions/incidents must be reported immediately to the IRB.
- If this research is being conducted for a master's thesis or doctoral dissertation, you must file a copy of this letter with the thesis or dissertation.
- When your project terminates you must submit a Final Report Form in order to close your IRB file.

Additional information and all IRB forms can be accessed on the IRB web site at: http://www.uakron.edu/research/orssp/compliance/IRBHome.php

Cc: Patricia Parr- Advisor
Cc: Stephanie Woods - IRB Chair

☐ Approved consent form/s enclosed

Office of Research Services and Sponsored Programs
Akron, OH 44325-2102
330-972-7666 • 330-972-6281 Fax
The University of Akron is an Equal Education and Employment Institution

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APPENDIX E

CITI Collaborative Institutional Training Initiative
Human Research Gradebooks Curriculum Completion Report
Printed on 9/25/2011

Learner: Joanne Holbert (username: joanneholbert)
Institution: The University of Akron
Contact Information
15448 Hatfield Rd
Rittman, OH 44270 USA
Department: counselor education
Phone: 3309274530
Email: jmh93@zips.uakron.edu

SBR Researchers:
Stage 1. Basic Course Passed on 10/23/09 (Ref # 3675470)

<table>
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<tr>
<th>Required Modules</th>
<th>Date Completed</th>
<th>Score</th>
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<tbody>
<tr>
<td>Introduction</td>
<td>10/23/09</td>
<td>no quiz</td>
</tr>
<tr>
<td>Belmont Report and CITI Course Introduction</td>
<td>10/23/09</td>
<td>3/3 (100%)</td>
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<tr>
<td>History and Ethical Principles - SBR</td>
<td>10/23/09</td>
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<td>The Regulations and The Social and Behavioral Sciences - SBR</td>
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<tr>
<td>Assessing Risk in Social and Behavioral Sciences - SBR</td>
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<td>10/23/09</td>
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<td>Privacy and Confidentiality - SBR</td>
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<tr>
<td>The University of Akron - HSR</td>
<td>10/23/09</td>
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For this Completion Report to be valid, the learner listed above must be affiliated with a CITI participating institution. Falsified information and unauthorized use of the CITI course site is unethical, and may be considered scientific misconduct by your institution.
Paul Braunschweiger Ph.D.
Professor, University of Miami, Director Office of Research Education
CITI Course Coordinator
Dear Graduate Student:

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We appreciate your interest in our material, as well as your consideration for its copyright. Please contact me if you have any questions.

Sincerely yours,

Susan Dunn Weinberg
Assistant to the President
WPS Rights and Permissions
e-mail: weinberg@wpspublish.com

SDW:se
Figure 1. Rolland’s (1994a) Interface of Family and Illness with Study Variables and General Research Hypotheses One and Two Imposed
Figure 2. BRCA Carrier Self-Report of High Level of BRCA Carrier’s Support Group Involvement
Figure 3. Partner Report of High Level of BRCA Carrier’s Support Group Involvement
Figure 4. BRCA Carrier Self-Report of Medium Level of BRCA Carrier’s Support Group Involvement
Figure 5. Partner Report of Medium Level of BRCA Carrier’s Support Group Involvement
Figure 6. BRCA Carrier Self-Report of Low Level of BRCA Carrier’s Support Group Involvement
Figure 7. Partner Report of Low Level of BRCA Carrier’s Support Group Involvement
Figure 8. Frequency of Global Distress Scores (Scores below 50 indicative of Marital Satisfaction)
Figure 9. Frequency of Affective Communication Scores (Scores below 50 indicative of Good Affective Communication)
Figure 10. Frequency of Problem Solving Communication Scores (Scores below 50 indicative of Good Problem Solving Communication)
Figure 11. Frequency of Level of Partner Support for BRCA Concerns (Scores of 1 and 2 indicative of High Levels of Support)