COGNITIVE APPRAISAL, COPING BEHAVIORS, AND DECISIONAL OUTCOMES IN WOMEN MAKING A TREATMENT DECISION FOR THEIR INCREASED RISK OF BREAST CANCER

A dissertation submitted to the Kent State University Graduate College of Nursing in partial fulfillment of the requirements for the degree of Doctor of Philosophy

by

Jennie M. Wood

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Dissertation written by

Jennie M. Wood

B.S.N., Youngstown State University, 1982

M.S.N., Kent State University, 1986

Ph.D., Kent State University, 2008

Approved by

Co-Chairs, Doctoral Dissertation Committee

______________________  N. Margaret Wineman, Ph.D.

______________________  Diana L. Biordi, Ph.D.

Members, Doctoral Dissertation Committee

______________________  Richard A. Zeller, Ph.D.

______________________  Wendy Lewandowski, Ph.D.

______________________  Herbert Croft, M.D.

______________________  E. Thomas Dowd, Ph.D.

Accepted by

______________________  Karen Budd, Ph.D.
Director, Joint Ph.D. in Nursing Program

______________________  Laura Cox Dzurec, Ph.D.
Dean, College of Nursing
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ABSTRACT

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COGNITIVE APPRAISAL, COPING BEHAVIORS, AND DECISIONAL OUTCOMES IN WOMEN MAKING A TREATMENT DECISION FOR THEIR INCREASED RISK OF BREAST CANCER

Directors of Dissertation: N. Margaret Wineman and Diana L. Biordi

This cross-sectional descriptive correlational study was conducted to examine the relationships between and among the threat of breast cancer (objective and subjective risk), subjective stress, decisional conflict (uncertainty and factors associated with uncertainty), type of coping (approach and avoidance coping behaviors), and decisional outcome (treatment choice and decision effectiveness) in women making a treatment choice for their increased risk of developing breast cancer.

The sample consisted of 105 women who came to a high risk breast cancer clinic for a breast cancer risk assessment. Participants’ ages ranged from 35-72. The majority of the women were married, Caucasian, highly educated, and employed fulltime. A booklet with four self-report questionnaires was used for data collection including a sociodemographic questionnaire developed by the researcher, Horowitz’s Impact of Event Scale, O’Connor’s Decisional Conflict Scale, and Lazarus and Folkman’s Ways of Coping Revised Questionnaire.

Each hypothesis in the study was at least partially supported. Subjective stress and decision uncertainty were significant predictors for using approach coping behavior, but only subjective stress significantly predicted the use of avoidance coping behavior. The
variance in treatment choice was significantly explained by subjective 5-year risk, factors associated with decision uncertainty, and objective risk, while the variance in decision effectiveness was significantly explained by decision uncertainty and factors associated with decision uncertainty. Lastly, approach coping behavior explained a small but significant amount of the variance in decision effectiveness.

Women at risk for developing breast cancer used approach and avoidance coping behaviors to manage the stress associated with their increased risk for breast cancer and consideration of treatment options. Women who used approach coping felt more certain about their treatment choice. Avoidance coping tended to be used by women who were uncertain about their treatment choice with a marginally significant positive relationship between avoidance coping and decision uncertainty. Women who were knowledgeable and clear about their values related to treatment options were more apt to select chemoprevention or prophylactic mastectomy, when appropriate, and felt they made an effective decision.
CHAPTER I
INTRODUCTION
Research Problem and Purpose

Breast cancer is the most commonly occurring cancer and the second leading cause of death in American women (American Cancer Society, 2006). Early detection and improved treatment methods have decreased breast cancer mortality. Despite these advances, approximately one fourth of women who develop breast cancer will die from the disease (Sakorafas & Tsiotou, 2000). Consequently, there is increased emphasis on preventative strategies for decreasing breast cancer incidence. Identifying women at risk provides an opportunity for them to take measures that may prevent breast cancer development or detect its development in the early stages. Treatment options include surveillance (clinical exam, self examination, and imaging studies), chemoprevention (Tamoxifen or Raloxifene), or prophylactic mastectomy (Sakorafas, 2002; Vogel & Bevers, 2003). Prophylactic surgery is generally reserved for women who are identified as being at high risk (National Comprehensive Cancer Network [NCCN], 2006; Vogel, 2000). While national consensus guidelines for breast cancer risk reduction are available (NCCN, 2006), several authors suggest decisions for risk management should be individualized with consideration of the woman’s priorities and goals (Goodwin, 2000; Moller et al., 1999; Rhodes, 2002; Sakarafas & Tsiotou, 2000; et al., 2002). Uncertainty exists as to whether the woman identified at risk will actually develop breast cancer or whether it will be prevented, regardless of the option selected. The threat of breast cancer
coupled with the uncertainty regarding treatment outcomes and increased risk-status result in stress and decisional conflict.

No research is currently available about how women at risk for breast cancer cope with this stress and decisional conflict. This information would provide a theoretical foundation for designing and testing interventions for assisting women to manage threat, deal with the stress, and make the most informed decision possible. The present study examines the relationships between and among the threat of breast cancer, subjective stress, decisional conflict, type of coping, and decisional outcomes in women deciding about treatment options for their increased risk of developing breast cancer.

Conceptual Framework

The conceptual framework for the proposed research is based on Lazarus and Folkman’s theory of Stress, Appraisal, and Coping (Lazarus & Folkman, 1984). Many researchers have used this transactional model as a framework to guide coping research. Related coping research includes evaluation of psychological effects in response to genetic testing (Baum, Friedman, & Zadowski, 1997); adherence to breast self exam in first degree relatives of breast cancer patients (Cohen, 2002a); and coping with breast cancer diagnosis (Anagnostopoulos, Vaslamatzis, Markidis, 2004; Cohen, 2002b; Holland & Holahan, 2003; Stanton & Snider, 1993). In the present study, Lazarus and Folkman’s theory is used to understand the woman’s cognitive and behavioral response to the disclosure of breast cancer risk status and available treatment options. In the next section, an overview of Lazarus and Folkman’s theory is presented followed by a description and diagram of the conceptual model for the current study. Last, a table summarizing the definition of terms proposed for this research is presented.
Lazarus and Folkman’s phenomenological cognitive theory of stress views coping as a process rather than a trait and as a transaction between person and environment rather than a stress-response reaction. According to Lazarus and Folkman, an encounter or event occurs between person and environment which is cognitively appraised by the individual as benign, threatening, or challenging. These theorists assert that after the person evaluates what is at stake and considers coping resources and options, he or she responds by coping with the situation, that is, the person attempts to manage the stress that is appraised as taxing or exceeding his or her resources. Coping behaviors generally include efforts to regulate emotion or distress (emotion-focused coping) and those used to manage the problem underlying the emotions or distress (problem-focused coping).

Analysis of the specific encounter is contextual and is reappraised as the event unfolds. In some situations, both emotion-focused and problem-focused coping are needed for effective coping. For example, a person may manage a problem effectively, yet may not manage negative emotions related to the problem or vice versa. Additionally, the relationship between emotion-focused and problem-focused coping may be complimentary or inhibitory. However, in general, the effectiveness of coping strategies must be evaluated within the specific context in which the stressful encounter occurs and in which it unfolds. These appraisal and coping processes influence a variety of short- and long-term adaptational outcomes for the individual. These adaptational outcomes include three major classes - social functioning, moral health, and somatic health. Social functioning refers to the effect a coping strategy has on managing a specific encounter; moral health is the positive and negative affect an individual experiences during or after the event; and somatic health is the overall physiological changes that occur in response
to a stressful encounter. Lazarus and Folkman purport the outcome of coping is appraised by determining how successful individuals are at achieving their goals and how satisfied they are with their performance.

In this study, the event or encounter between person and environment that is appraised as threatening or challenging is the disclosure of the woman’s increased risk status and treatment options. A conceptual diagram of the relationships among the constructs, concepts, variables, and measures used for this research study appears in Figure 1. Three constructs are depicted: cognitive appraisal, coping and outcomes.

The first construct, cognitive appraisal, includes three concepts: threat, subjective stress, and decisional conflict. Threat refers to the woman’s objective and subjective risk for developing breast cancer. Objective risk is operationalized by documenting the risk estimate provided to the woman by high risk breast cancer clinic health professionals during her breast cancer risk assessment. The Gail model is used to assess the woman’s 5-year and lifetime risk (%) of developing cancer. The model is not used for women with confirmed lobular carcinoma (LCIS) or women with a BRCA gene mutation. Women with LCIS are given a risk of 15% over 20 years and women with a BRCA mutation are given a risk of 60-80% to the age of 70. Subjective risk is operationalized by asking the woman to identify her chances of developing breast cancer over the next five years and over a lifetime. She was asked to indicate the appropriate percentage (e.g. 10%) and the corresponding odds ratio (e.g. 1:10) from those listed on the sociodemographic questionnaire. Subjective stress refers to the woman’s intrusive thoughts, over the past
Figure 1. Conceptual Framework with Substruction based on Lazarus and Folkman's Stress, Appraisal and Coping Theory

- **Event/Encounter**
  - Disclosure of risk & treatment options
- **Cognitive Appraisal**
  - Objective breast cancer risk
  - Subjective breast cancer risk
  - Subjective experience of stress
- **Coping**
  - Decisional conflict
  - Problem-Focused Coping
  - Emotion-Focused Coping
- **Decisional Outcome**
  - Treatment Choice
  - Decision Making Effectiveness

**Constructs**
- Event/Encounter
- Cognitive Appraisal
- Coping
- Decisional Outcome

**Concepts**
- Threat
- Stress
- Decisional Conflict
- Problem-Focused Coping
- Emotion-Focused Coping

**Variables**
- Objective breast cancer risk
- Subjective breast cancer risk
- Subjective experience of stress
- Decisional conflict
- Problem-Focused Coping
- Emotion-Focused Coping

**Measures**
- Estimate: Gail Model, lobular carcinoma in situ, or mutation status
- Perceived risk on socio-demographic questionnaire (odds ratio & %)
- Score on intrusive subscale/impact of Event scale (IES)
- Scores on Uncertainty & Factors Affecting Uncertainty subscales/Decisional Conflict scale (DCS)
- Scores on Confrontive, Seeking Social Support, Planful Problem Solving, & Positive Reappraisal subscales/Ways of Coping revised questionnaire. (WCRQ)
- Scores on Distancing, Self-Controlling, Accepting Responsibility, & Escape-Avoidance subscale/WCRQ
- Choice (surveillance, chemoprevention, prophylactic mastectomy/socio-demographic questionnaire)

**Disclosure of risk & treatment options**
- Perceived risk on socio-demographic questionnaire (odds ratio & %)
- Score on Intrusive subscale/Impact of Event scale (IES)
- Scores on Uncertainty & Factors Affecting Uncertainty subscales/Decisional Conflict scale (DCS)
- Scores on Confrontive, Seeking Social Support, Planful Problem Solving, & Positive Reappraisal subscales/Ways of Coping revised questionnaire. (WCRQ)
- Scores on Distancing, Self-Controlling, Accepting Responsibility, & Escape-Avoidance subscale/WCRQ
- Choice (surveillance, chemoprevention, prophylactic mastectomy/socio-demographic questionnaire)
- Score on Effective Decision subscale/Decisional Conflict Scale
seven days, as she was thinking about her breast cancer risk status and treatment options. Subjective stress is measured using the Intrusive Thought subscale of Horowitz’s Impact of Event Scale (Horowitz, Wilner, & Alvarez, 1979). Decisional conflict is the woman’s perceived difficulty in making a choice among treatment options including the level of uncertainty and modifiable factors contributing to uncertainty. Decisional conflict was measured with the Uncertainty and Factors Contributing to Uncertainty subscales of O’Connor’s Decisional Conflict scale (O’Connor, 1995).

The second construct, coping, refers to the self-reported coping behaviors used by the woman when she considered her increased risk status and treatment options. Two are identified: problem-focused and emotion-focused coping. Problem-focused coping refers to approach behaviors and emotion-focused coping refers to avoidance behaviors. Approach coping behaviors are measured with the Confrontive Coping, Seeking Social Support, Planful Problem Solving, and Positive Reappraisal subscales, and avoidance coping behaviors are measured using the Distancing, Self-Controlling, Accepting Responsibility, and Escape-Avoidance subscales of Lazarus and Folkman’s Ways of Coping Revised Questionnaire (Folkman & Lazarus, 1988).

The third construct, decisional outcome, is the outcome of the appraisal and coping processes. In the this study decisional outcome includes making a choice among treatment options and the women’s perceived decision-making effectiveness (decision effectiveness). The terms decision-making effectiveness and decision effectiveness are used interchangeably in this study. Treatment choice is operationalized by asking the woman to indicate her treatment choice (surveillance, chemoprevention, or prophylactic mastectomy) on the sociodemographic questionnaire. The woman’s perception of her
decision-making effectiveness is operationalized by using the Effective Decision-making subscale on O’Connor’s Decisional Conflict Scale. A summary of construct, concept, and variable definitions is listed in table 1.

In summary, Lazarus and Folkman’s Stress, Appraisal and Coping theory is used as a conceptual framework to examine the relationships between and among cognitive appraisal (threat, subjective stress, and decisional conflict), types of coping (approach and avoidance), and decisional outcomes (treatment choice and decision-making effectiveness) in women who are making a personal treatment choice for their increased risk of developing breast cancer. When the woman is informed of her increased risk status and treatment options, she is faced with many challenges. Sources of these challenges include dealing with the threat of developing breast cancer that is higher than the normal population, dealing with the uncertainty associated with her risk status and treatment outcomes, and considering the risks and benefits associated with each treatment option. The threat of breast cancer and the associated challenges result in stress and decisional conflict. The woman uses problem-focused coping (approach coping behaviors) and emotion-focused coping (avoidance coping behaviors) to manage this stressful situation and the resultant stress and decisional conflict. The outcome of the coping process is a “decisional outcome” which includes the woman’s treatment choice and her subjective effectiveness of decision making.
## Table 1

### Definition of Terms

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<th>Variable</th>
<th>Conceptual Definition</th>
<th>Operational Definition</th>
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<tr>
<td>Threat: objective and subjective risk</td>
<td>Subjective risk: Perceived breast cancer risk over the next five years and over a lifetime.</td>
<td>Subjective: Gambling odds (ratio) and percent responses on sociodemographic questionnaire.</td>
</tr>
<tr>
<td></td>
<td>Objective risk: Estimated breast cancer risk determined by high-risk breast clinic staff.</td>
<td>Objective: Estimate (%) calculated with Gail model or based on confirmed lobular carcinoma in situ (LCIS) or identifiable mutation.</td>
</tr>
<tr>
<td>Stress</td>
<td>“A particular relationship between the person &amp; the environment that is appraised by the person as taxing or exceeding his or her resources &amp; endangering his or her well being” (Lazarus &amp; Folkman, 1984, p.19).</td>
<td>Numerical value (0-35) obtained from a 0-5 Likert-type scale on the Intrusive subscale (items 1, 4, 5, 6, 10, 11, &amp; 14) of the Impact of Event Scale.</td>
</tr>
<tr>
<td>Decisional Conflict</td>
<td>The woman’s perceived difficulty in making a treatment choice for her breast cancer risk, including uncertainty in choosing among options and modifiable factors contributing to this uncertainty.</td>
<td>Numerical value (3-15 for uncertainty &amp; 9-45 for factors associated with uncertainty) obtained from a 1-5 Likert-type scale on the uncertainty (items 10-12) &amp; the Factors Contributing to Uncertainty (items 1-9) subscales of the Decisional Conflict Scale.</td>
</tr>
<tr>
<td>Approach coping behaviors</td>
<td>The woman’s reported use of approach behaviors for managing the stressful encounter of being told she is at an increased risk for breast cancer and making a treatment choice.</td>
<td>Numerical value of 0-75 obtained from a 4-point Likert-type scale of 0-3 on the Confrontive (items 6, 7, 17, 28, 34 &amp; 46); Seeking Social Support (items 8, 18, 22, 31, 42 &amp; 45); Planful Problem Solving (items 1, 26, 39, 48, 49, 52); &amp; Positive Reappraisal (20, 23, 30, 36, 38, 56 &amp; 60) subscales of the Ways of Coping Revised Questionnaire (WCRQ).</td>
</tr>
<tr>
<td>Avoidance coping behaviors</td>
<td>The woman’s reported use of avoidance coping behaviors for managing the stressful encounter of being told she is at an increased risk for breast cancer and making a treatment choice.</td>
<td>Numerical value of 0-75 obtained from a 4-point Likert-type scale of 0-3 on the Distancing (items 12, 13, 15, 21, 41, &amp; 44); Self-controlling (items 10, 14, 35, 43, 54, 63, &amp; 64); Accepting Responsibility (items 9, 25, 29, &amp; 51); and Escape-avoidance (items 11, 16, 33, 40, 47, 50, 58 &amp; 59) subscales of the WCRQ.</td>
</tr>
<tr>
<td>Treatment choice</td>
<td>The woman’s treatment choice among the treatment options offered, after counseling</td>
<td>Self-reported choice for surveillance, chemoprevention, or prophylactic mastectomy on the sociodemographic questionnaire</td>
</tr>
<tr>
<td>Decision making effectiveness</td>
<td>The woman’s self-reported decision-making effectiveness after making a treatment choice</td>
<td>A numerical value (4-20) obtained from a 1-5 Likert-type scale on the Effective Decision subscale (items 13-16) of the DCS.</td>
</tr>
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CHAPTER II
REVIEW OF LITERATURE

The conceptual framework depicted in Figure 1 shows the relationships between and among breast cancer threat, the experience of stress, decisional conflict, problem-focused and emotion-focused coping, treatment choice, and decision-making effectiveness. Literature addressing each of the concepts and relationships among them, where appropriate, is discussed in this section. Each concept is addressed in the order it appears in the model.

Cognitive Appraisal

Cognitive appraisal is a key construct in Lazarus and Folkman’s Transactional Model of Stress and Coping (Lazarus & Folkman, 1984). When a stressful event occurs, the person engages in a series of cognitive processes to assess the level of threat or stress associated with the event (primary appraisal). Once the primary appraisal is made, he or she assesses his or her ability to cope with or manage this threat or stress (secondary appraisal). In this study, the event is disclosure of an increased risk-status for developing breast cancer and consideration of treatment options. Cognitive appraisal includes the woman’s subjective and objective risk of developing breast cancer (threat), the subjective experience of stress related to her breast cancer risk status and treatment options (stress), and the perceived difficulty experienced when making an informed decision about treatment options (decisional conflict). A review of these concepts follows.
Breast Cancer Threat

The threat of developing breast cancer is scary for most women. This threat becomes more salient when a woman is identified as having an increased risk for breast cancer. The differences between objective and subjective risk, the factors associated with inaccurate subjective risk, and the effects of overestimation are discussed below.

Objective vs. Subjective Risk Perception

Objective risk for developing breast cancer can be identified through assessment of personal history, family history, risk factors, and the presence or absence of BRCA 1 and BRCA 2. However, subjective risk is often inconsistent with objective risk. Some women overestimate their risk (Evans, Burnell, Hopwood, & Howell, 1993; Gagnon et al., 1996; Gil et al., 2003; Karp, Brown, Sullivan, & Massie, 1999; Kash & Dabney, 2001; Lerman et al., 1995; Lloyd, Watson, & Waites, 1996; Meiser et al., 2000; Payne, Biggs, Tran, Borgen, & Massie, 2000), while others are more likely to underestimate their risk (Cull et al., 1999). Lancaster (2005) found a curvilinear relationship between actual risk and appraised risk whereby women with high and low levels of subjective risk had low objective breast cancer risk scores, and women with moderate degrees of subjective risk had high objective risk scores. Conversely, Brandberg et al. (2004) reported accurate risk perception by most women.

The above studies were cross-sectional, although misconceptions about risk occurred in long-term follow up studies as well. Cull et al. (1999) found improved but continued overestimation in personal risk after genetic counseling that tended to increase again in long-term follow-up. Hopwood and colleagues (Hopwood, Howell, Lallo, & Evans, 2003) reported a four-fold increase in the proportion of women who could not
recall their objective risk over a period of one year. These women were also unable to put breast cancer risk in perspective when compared to other health threats. However, in Hopwood’s study, genetic counseling did improve the accuracy of personal risk perceptions and this level of accuracy was maintained for one year.

Overall, genetic counseling improves the accuracy of women’s risk perception (Cull et al., 1998; Evans et al., 1999; Hopwood et al., 1998; Hopwood, Shenton, Laloo, Evans, & Howell, 2001; Watson et al., 1999). Nonetheless, many women continue to have inaccurate personal risk perceptions even after genetic counseling (Bish et al., 2002; Cull et al., 1999; Kent, Howie, Fletcher, Newbury-Ecob, & Hosie, 2000; Lerman et al., 1995; Metcalfe & Narod, 2002). These varied outcomes of genetic counseling were also reported in a systematic review and meta-analysis of controlled and prospective studies addressing psychological outcomes of genetic counseling (Braithwaite, Emery, Walter, Prevost, & Sutton, 2004). Braithwaite et al. concluded that genetic counseling had no effect on the accuracy of subjective risk in the controlled trials reviewed. Risk accuracy did improve in five of six prospective studies. In another review, the author concluded that . . . “genetic counseling is successful in improving accuracy of women’s risk perception at least in the short term” (Butow, Lobb, Meiser, Barratt, & Tucker, 2003, p.78).

Factors Associated With Inaccurate Subjective Risk

Several investigators identified factors that may be associated with inaccurate risk perception, including the complex and varied methods used to present risk information, age, family history, and level of anxiety or cancer worry. Highlights of studies addressing these factors are presented in this section.
**Information presentation.** Cull et al. (1999) argued women’s inaccurate risk perceptions may be attributed to the complexity and probabilistic nature of the information presented making it difficult for women to consider and assimilate the information. Women are advised about their personal risk using a variety of terms and/or numbers. For example, statistical information may be presented with words like “lifetime risk”, “10 year risk”, “risk with treatment”, and “risk without treatment”. Hutson (2003) pointed out that women may not accurately translate numerical risk to actual likelihood of developing cancer.

**Age and family history.** Cull et al. (1999) reported older women were more likely to overestimate their risk for breast cancer. Hopwood et al. (2001) compared subjective risk of women in three groups: women whose mother died when they were 10-20 years old, women whose mother died when they were adults, and women who had not lost their mother. Interestingly, although women in the 10-20 year old group had the highest actual risk, they were less likely to overestimate their risk. In another study utilizing a focus group of five women who were undecided about bilateral prophylactic mastectomy, Karp et al. (1999) found all the women believed their risk increased with age and there was a “magical” number (an age) at which they would develop cancer. This age-related number was closely associated with the age they lost a mother or close relative to breast cancer. The influence of family history of breast cancer on a woman’s risk perception also emerged as a common theme among high-risk women participating in a semi-structured interview. The researchers suggested a woman’s risk was more salient when the woman had several affected family members (Kenen, Adern-Jones, & Eeles, 2003).
Anxiety and cancer worry. Lindberg and Wellsah (2001) found a positive correlation between risk perception and trait anxiety scores. Cull et al. (1999) reported women with higher trait anxiety scores were more likely to overestimate their subjective risk as well. Hopwood and colleagues (Hopwood et al., 2001) found overestimators’ mean scores were higher on all items of the Cancer Worry Scale when compared to underestimators and accurate estimators. Furthermore, the cancer worry scores did not change significantly after genetic counseling. The most prevalent item for all groups on the Cancer Worry Scale, irrespective of risk estimation, was the possibility of developing cancer in the future.

Effects of Overestimation

Overestimation of subjective risk is identified as a significant predictor for choosing the most invasive preventative treatment option, bilateral prophylactic mastectomy. This finding is consistent in studies of women who had bilateral prophylactic mastectomy from 1991-2000 in Canada (Metcalfe & Narod, 2002), unaffected women awaiting genetic counseling (Meiser et al., 2000), women with intentions to have bilateral prophylactic mastectomy (Van Dijk et al., 2003), and in a hypothetical vignette presented to women with and without a family history of breast cancer (Stefanek, Enger, Benkendorf, Flamm Honig, & Lerman, 1999). Additionally, VanDijk et al. (2003) and Meiser et al. (2000) reported no significant association between bilateral prophylactic mastectomy choice and objective cancer risk.

Helmes and colleagues (Helmes, Bowen, & Bengel, 2002) found high-risk perception of breast cancer and genetic mutation carrier status led to high levels of fear about breast cancer. Etchegary (2004) comments, “This was a notable finding given that
the study’s sample comprised of women at low to moderate risk for carrier status, precisely the women for whom the BRCA1/2 test is largely uninformative.” (Etchegary, 2004, p. 24). In a controlled group study, Lerman et al. (1995) concluded that inflation of personal risk may be a factor associated with high levels of psychological distress. Lerman et al. opined that subjective stress is a key factor to consider when investigating a woman’s perceived threat of breast cancer.

In summary, studies related to objective and subjective breast cancer risk perception suggest women overestimate their risk, and this overestimation may not be affected by genetic counseling. Inaccurate risk perception may be associated with several factors such as the format of risk presentation, age, family history, anxiety and cancer worry levels. Overestimation of risk is a predictor for choosing bilateral prophylactic mastectomy and is associated with higher levels of fear and psychological distress.

**Subjective Stress**

The threat of breast cancer is stressful for most women especially those who are at risk for hereditary breast cancer. Sources of stress may include the ethical, legal, and family implications of genetic testing, the experience of breast cancer in the family, or the fear of passing the gene to offspring. The relationship between stress and risk perception was discussed earlier. Stress associated with risk for hereditary breast cancer, high-risk status, and other factors are presented in this section.

**Stress and Risk Status**

The possibility of developing breast cancer is stressful for both women with an identifiable mutation for the disease and women who are at-risk based on personal and
family history. Stress associated with mutation carriers followed by a discussion of stress in nonmutation carriers is presented in this section.

Genetic testing for breast cancer has increasingly become more commonplace since the discovery of the BRCA 1 and BRCA 2 genes in 1990 and 1994, respectively. However, knowledge of one’s genetic status may result in major psychosocial concerns such as fear of insurance and work discrimination, passing the mutation to offspring, or the possible negative impact on family relationships. A substantial number of researchers examined the psychosocial impact of genetic testing in these women. A review of some of these studies follows.

Several researchers examined stress levels of women after disclosure of their genetic test results. Statistically significant increases in breast cancer related distress or worry were reported in short-term follow up of mutation carriers at 1-3 weeks using the Impact of Event Scale (Lodder, 2001) and at one month (Watson et al., 2004). Sustained increases in breast cancer distress from 7-10 days to 12 months after disclosure of a positive mutation status were reported as well (Meiser et al., 2002). Conversely, Lodder et al. (2001) reported a decrease in distress at one year.

Braithewaite et al. (2004) conducted a meta-analysis of psychosocial effects of genetic counseling in high-risk women. They reported the pooled effects from short- and long-term controlled group studies, which demonstrated no association between genetic counseling and cancer-specific worry. After conducting a literature review of psychosocial issues in cancer genetics (Bleiker, Hahn, & Aaronson, 2003), the authors concluded the use of a situation-specific instrument like the Impact of Event Scale or Cancer Worry Scale are better at detecting distress related to cancer genetics than general
measures of stress such as the State Trait Anxiety Inventory and Centers for Epidemiological Studies Depression Scale. Stress associated with genetic testing was found to be higher in female carriers who were the first in the family to be tested and whose siblings tested negative (Smith, West, Croyle, & Botkin, 1999).

A comparison of mutation carriers and nonmutation carriers making medical decisions and managing family outcomes revealed higher levels of distress in mutation carriers than noncarriers (Halbert et al., 2004). Conversely, Geirdal and Dahl (2008) found higher levels of anxiety in women who did not have an identified mutation than in those who were BRCA mutation carriers. Rothemund, Paepke, and Flor (2001) reported higher levels of state anxiety and higher scores on the positive symptom distress of the Symptom Checklist in women with a family history of breast cancer when compared to a control group of women. Lastly, higher levels of cancer specific stress, but not general distress, were found in women who were at moderate risk for breast cancer when compared to a control group (Rees, Fry, Cull, & Sutton, 2004).

Factors Associated with Stress

The literature suggests the experience of breast cancer in a family is associated with higher levels of stress. This association is exemplified in the following studies. One group of researchers studied women at-risk for, but unaffected with, breast cancer. The Intrusive subscale of the Impact of Event Scale was used to measure cancer worry in these women. The researchers found being close to the age of the youngest family member diagnosed with breast cancer and experience with breast cancer over the past three years were significant predictors for cancer worry (Price, Butow, Lo, & Wilson, 2007). In another study, breast cancer specific stress using the Impact of Event Scale, was
examined in women at increased risk for hereditary breast cancer and who were participating in a regular surveillance program. The researchers found a significant positive correlation between breast cancer specific distress and women with at least one sister who died of breast cancer; women who were involved in the process of the sister’s breast cancer; and whose sister’s diagnosis was made in the past three years (van Dooren et al., 2005). Similarly, high-risk women whose parent died from cancer (Zakowski et al., 1997) and women who had a relative die of breast cancer (Meiser et al., 2000) had significantly higher levels of intrusive thoughts than those who did not have a parent or relative die from cancer.

One group of investigators (Halbert et al., 2004) examined high-risk women’s perceived stress and confidence levels related to breast cancer risk, communication of risk information to family members, and dealing with the effects of BRCA1/2 results on the family. They found a negative correlation between stress and optimism and a positive relationship between stress, trait anxiety, and a positive BRCA1/2 result. Confidence was negatively associated with trait anxiety.

**Stress and Treatment Choice**

A high level of stress may influence a woman’s treatment choice. This relationship is demonstrated in the following studies.

High levels of breast cancer anxiety as measured with the Impact of Event Scale were strongly correlated with women’s intentions to undergo bilateral prophylactic mastectomy (Meiser et al., 2000). High anxiety levels were also reported by women who actually underwent bilateral prophylactic mastectomy (Stefanek, Helzlsouer, Wilcox, & Houn, 1995).
Lodder et al. (2001) compared distress levels among three groups: mutation carriers choosing surveillance, mutation carriers choosing bilateral prophylactic mastectomy, and noncarriers. The mutation carriers choosing bilateral prophylactic mastectomy had significantly higher distress levels than the surveillance and noncarrier group, but the differences among the groups nearly disappeared at the one-year follow-up. Similarly, Gil et al. (2003) examined surveillance behaviors in women with at least one affected first degree relative and women with a general population risk. A significant difference was found for only one item on the Cancer Worry Scale, “how often do you worry about developing breast cancer?”

In summary, genetic testing and disclosure of mutation status is stressful for the high-risk woman and her family. The stress of genetic counseling is succinctly described in the following quote, “. . . predictive testing brings its own stress: it is a confrontation with the past, the family history of disease and death, and a future that may be one determined by the disease” (DudokdeWit, Tibben, Duivenvoorden, Niermeijer, & Passchier, 1998, p. 63). Vulnerable groups for high levels of stress may include women who are the first in the family to be tested, experienced a breast cancer death in the family, or had siblings whose test was negative. High stress levels or cancer worry may influence a woman’s choice for bilateral prophylactic mastectomy. Stress in women who do not have an identified genetic mutation is also reported. Perceived risk and the experience of breast cancer in the family are associated with higher stress levels in these women. The use of the Impact of Event Scale for measuring subjective stress in the current study is supported in the literature. Stress associated with a woman’s increased risk for breast cancer is prominent in the literature, but limited information is available
about the cognitive processes used by women to deal with this stress. The difficulty
associated with making a treatment choice is also stressful for the at-risk woman and will
be discussed in the next section.

Decisional Conflict

Women identified as being at an increased risk for breast cancer experience stress
and decisional conflict when faced with making a choice between detection and
preventative treatment options. Many risks and benefits are associated with each option.
Models based on personal and family history as well as discovery of the BRCA1 and
BRCA2 genes helped to identify women who are at-risk. However, a high level of
uncertainty continues about whether these at-risk women will actually develop breast
cancer. For example, if a person has a gene mutation for Huntington disease, that person
will develop Huntington’s disease. In contrast, not all women who carry the BRCA1/2
gene mutations will develop breast cancer. Moreover, breast cancer may develop in
women who do not carry the BRCA1/2 genes. In fact, only 5-10% of breast cancer cases
are attributed to identifiable gene mutations (American Cancer Society, 2006). The
remaining hereditary breast cancers are thought to be caused by, as yet, unidentified
breast cancer genes. Also, BRCA testing is only 85% accurate (Mayo Clinic, 2004).
Certain statistical models like the Gail model are widely used to estimate breast cancer
risk in nonmutation carriers. However, researchers who validated the Gail model state
“The Gail et al. model 2 fit well in this sample in terms of predicting numbers of breast
cancer cases in specific risk factor strata but had modest discriminatory accuracy at the
individual level.” (Rockhill, Spiegelman, Bryne, Huner, & Colditz, 2001, p.358). Thus,
even with the best prediction and careful consideration of the risks and benefits, there is a
high level of uncertainty about whether a woman will develop the disease no matter which treatment option is selected.

The Northeastern Diagnosis Association’s definition of decisional conflict is the “state of uncertainty about course of action to take when choice among competing options involves risk, loss, or challenge to personal life values” (Gordon, 2007, p. 246). Defining characteristics or manifestations of decisional conflict include verbalization of uncertainty about choice, concern about undesired outcomes, wavering between choices, decisional delay, questioning personal values, preoccupation with decision, and/or showing signs and symptoms of distress and tension (O’Connor, Jacobson, & Stacey, 2002).

This nursing diagnosis is based on Janis and Mann’s decisional conflict model. Within this model decisional conflict is conceptually defined as the “state of simultaneous opposing tendencies within the individual to accept and reject a given course of action” (Janis & Mann, 1977, p. 46). They suggest manifestations of this conflict include hesitation, vacillation, feelings of uncertainty, and signs of acute emotional stress with unpleasant subjective feelings of distress. Janis and Mann propose that a certain level of stress is necessary to arouse and motivate a person to engage in decision-making behavior. However, when perceived negative outcomes increase stress levels to an extreme level, the person is more apt to utilize nonvigilant decision making rather than vigilant decision making.

Factors contributing to decisional conflict come from two sources: (a) the inherent difficulty in making a choice between options that have both potential advantages and disadvantages and (b) modifiable factors like lack of knowledge, unrealistic expectations,
unclear values, unclear perceptions of others, social pressure, lack of support, lack of skills/confidence and lack of other resources that make the “... inherently difficult decision even more difficult to make” (O’Connor, Jacobsen, & Stacey 2002, p. 2).

Only two studies addressed decisional conflict in this population of women at increased risk for breast cancer. Both studies were intervention studies whereby the effect of a decisional aid on decisional conflict was examined.

Stacey, O’Connor, DeGrasse, and Verma (2003) developed and evaluated a decision aid for women making a decision about the use of Tamoxifen for preventing breast cancer. They used a pre-test/post-test design in a pilot study to elicit acceptability of the decision aid, decisional conflict, knowledge level, expectations of outcomes, decision predisposition, and adoption of healthy life style changes in two groups of women. One group used the decision aid alone and the other group used the decision aid combined with counseling. Comparison of the pre-test/post-test scores revealed the use of the decision aid alone or in combination with counseling decreased some aspects of decisional conflict, improved knowledge (p<.001), and promoted more realistic expectations of outcomes (p<.001). Use of the decisional aid with counseling significantly reduced decisional conflict (p<.001), psychological distress (p<.002), and increased intentions to adopt healthier life-style practices (p<.003). The decision aid was rated as acceptable and both women and practitioners were satisfied with it. While the effect of a decision aid on high-risk women’s decisional conflict was addressed in this study, only one treatment option, Tamoxifen, was included. Close surveillance and bilateral prophylactic mastectomy were not considered.
In a pilot study (Kaufman et al., 2003), an interactive decision aid including all three treatment options was developed for female BRCA1/BRCA2 carriers. The aim of this decision aid is to reduce decisional conflict and psychological distress and to improve knowledge of risk, decisional satisfaction, medical adherence, and quality of life. The efficacy of the decision aid has not yet been determined; but, a randomized clinical trial is planned in the future. Women will be randomized into two groups. The control group will receive standard genetic counseling and the intervention group will receive counseling plus the decision aid.

No studies could be found documenting relationships between decisional conflict and perceived risk or subjective stress in women at increased risk for breast cancer. In addition, studies related to coping with decisional conflict have not been reported. A certain level of stress is needed to motivate the woman to make a decision; however high levels of stress are associated with negative outcomes. Determining at-risk women’s coping behaviors related to stress and decisional conflict will provide valuable information for the health care professional’s assessment of the at-risk woman’s needs for optimum decision making.

Coping

Coping may be conceptualized as a disposition or trait, a style, or a process. Thus, coping-related research may differ based on conceptualization of the term. In this study, Lazarus and Folkman’s “process” approach to coping is used. Clearly, coping is important for at-risk women who are experiencing threat, stress, and decisional conflict. A number of researchers examined coping in women diagnosed with breast cancer, but few studied coping in women who are at risk for breast cancer. Additionally, researchers
have not examined coping behaviors in at-risk women making a choice among treatment options. Research related to coping in women at risk for breast cancer is discussed in the next section.

Lancaster (2005) used Neuman’s Systems Model as a conceptual framework to examine appraisal of and coping with breast cancer risk in women with a family history of breast cancer. The researcher used the Moneyham Threat Index (what is at stake, the outcome, and perceived control) and Champion’s breast cancer susceptibility subscale (perceived risk) to measure appraisal. The Jalowiec’s Coping Scale and an investigator developed instrument, Coping with Breast Cancer Threat Scale (specific behaviors used to deal with breast cancer threat) were used to measure coping behaviors. She found the most commonly used modes of coping included confrontive, optimistic, and early detection behaviors. Evasive, emotive, palliative, and fatalistic modes of coping were not used or viewed as ineffective by 75% of the women. In addition, Lancaster used canonical correlation to determine the relationship between patterns of appraisal and coping behaviors. Five relationship patterns were found: (a) women with higher scores for ability to control risk and positive outcome used confrontive and optimistic behaviors and avoided fatalistic behaviors; (b) women who felt important values were not at risk and had lower susceptibility used avoidance and confrontive coping behaviors; (c) women who felt important values were at risk and had higher levels of susceptibility used evasive and emotive coping, and avoided fatalistic and self reliant coping behaviors; (d) women with low levels for susceptibility, positive outcome, and much at stake used early detection and did not avoid using chemical agents; and (e) women with high levels of susceptibility, much at stake, and some perceived control used early detection and
avoided the use of chemical agents. Lancaster concluded that this analysis “. . . lent support to the premise that the type of coping behaviors used varies with how breast cancer risk is appraised” (Lancaster, p. 144).

Lancaster’s study (2005) provides valuable information about breast cancer appraisal and coping methods. However, the sample consisted of only women with a first- or second-degree relative who was diagnosed with breast cancer and coping was conceptually viewed from a stress-response framework. It is important to study women identified at increased risk for breast cancer through professional evaluation and genetic testing, if indicated, using a transactional framework.

In another study (Tercyak et al., 2001), the investigators used the monitoring process model to examine the effect of BRCA1 and BRCA2 test results and women’s coping style on their level of anxiety. Within this coping model, there are high and low monitors. High monitors focus on threatening cues, seek information, and perseverate on negative outcomes, and thus are more likely to experience heightened stress when faced with a health threat. Conversely, a low monitor avoids information seeking and uses distraction (blunting) when faced with a similar threat. Coping was measured with the Miller Behavioral Style Scale and the level of anxiety was measured with the State Trait Anxiety subscale of the State Trait Anxiety Inventory. Anxiety levels were measured at baseline, immediately prior to disclosure of results (anticipation period), and immediately after results were disclosed (immediate impact period). As predicted by the model, monitors were found to have higher levels of stress during the anticipation period. In addition, younger women, college graduates, and women who were not diagnosed or treated for cancer experienced higher levels of distress during this period. Mutation
carriers were more anxious in the immediate impact period (after disclosure). On the other hand, the researchers’ prediction that coping style moderates the effect of positive mutation status on anxiety was not supported.

Another group of researchers used the monitoring process model to longitudinally examine coping style, psychological distress, and risk perception in women attending genetic counseling for hereditary cancer (Nordin, Liden, Hansson, Rosenquist, & Berglund, 2002). Coping style was measured using both the Miller Behavioral Style Scale coping dispositions and the Threatening Medical Situation Inventory. Psychological distress was measured using the Hospital Anxiety and Depression Scale, and risk assessment was measured by a self report of gambling odds ratio and percentage. There was a positive correlation between coping style (monitors) and psychological distress (depression, anxiety, and worry) both before and after counseling using the Threatening Medical Situation Inventory but not the Miller Behaviors Style Scale. There was no correlation between nonmonitors (blunters) and psychological distress. In addition, there was no significant difference between monitors and nonmonitors using both the Threatening Medical Situation Inventory and Miller Behavioral Style Scale and those who overestimated, underestimated or correctly estimated their breast cancer risk. This study conflicts with Terycak et al. (2001) and Phipps and Zion’s (1986) research findings whereby a positive correlation was found between monitors and psychological distress. All three studies used the Miller Behavioral Style Scale to operationalize coping. However, different scales were used to measure psychological distress (State Trait Anxiety Inventory vs. Hospital Anxiety and Depression Scale) which could account for the discrepant findings.
Bebbington-Hatcher, Fallowfield, and A’Hern (2001) investigated the psychosocial impact and post operative distress factors in high-risk women offered bilateral prophylactic mastectomy. One hundred forty three high-risk women identified by referring physicians were offered bilateral prophylactic mastectomy. Seventy-nine accepted and 64 declined bilateral prophylactic mastectomy. Psychological morbidity (General Health Questionnaire), anxiety (Speilberger State-Trait Anxiety Inventory), coping strategies (Ways of Coping Revised Questionnaire), sexual discomfort and degree of sexual pleasure (Sexual Activity Questionnaire) were measured in both groups (acceptors and decliners of bilateral prophylactic mastectomy) at the initial interview, 6 months, and 18 months. In this study, acceptors of bilateral prophylactic mastectomy most often used a problem-focused approach whereas decliners used a detachment approach to coping.

Kim and colleagues (Kim, Valdimarsdottir, & Bovbjerg, 2003) examined coping styles and psychological adjustments between women with and without family histories of breast cancer. These researchers used 31 items of the Ways of Coping Questionnaire to measure two coping styles (active and passive coping) and the Impact of Event Scale to measure cancer specific distress. They found a positive association between breast cancer specific distress and passive coping in women with a family history, but not in those without a family history.

In summary, approaches for conceptualizing and researching “coping” vary. Some investigators view coping as a style or trait. In this context, information seekers (monitors) may experience higher levels of psychological distress depending on the particular instrument used to measure coping style and psychological distress.
Conversely, Lazarus and Folkman view coping as a dynamic process between the person and environment. Only two studies that were based on Lazarus and Folkman’s conceptual definition of coping was found. In one study, the researchers reported that women who accept bilateral prophylactic mastectomy as a treatment option use the problem-focused approach to coping and those who decline bilateral prophylactic mastectomy use a detachment approach. In the second study, women with a family history of breast cancer and higher levels of stress used passive coping. Moreover, no research was found that examined coping in women who were making decisions among the three treatment options.

Decisional Outcomes

Outcomes in the proposed study include making a choice among treatment options and decision effectiveness. Literature related to available treatment choices and effective decision-making are presented in this section.

Treatment Choice

As mentioned earlier, risk management is individualized with consideration of the woman’s priorities and goals. Treatment options include surveillance, chemoprevention, and prophylactic mastectomy (for those with an identified BRCA1/2 mutation). The efficacy of the options for chemoprevention and prophylactic mastectomy are presented followed by a discussion of studies associated with treatment options.

Treatment Efficacy

Several investigators identified benefits of bilateral prophylactic mastectomy. Two decision analysis studies projected an estimated 85% (Schrag, Kuntz, Garber, & Weeks, 1997) to 90% (Grann, Pangeas, Whang, Antman, & Neught, 1998) reduction in
the incidence of breast cancer in high-risk women who have bilateral prophylactic
mastectomy. These researchers also found gains in life expectancy of 2.9 to 5.3 years
(Schrag et al., 1997) and 2.8 to 3.4 years (Grann et al., 1998). Another group of
researchers, Hartmann et al. (1999) utilized a more rigorous design in their retrospective
study of 639 (214 at high risk and 425 at moderate risk) women who had bilateral
prophylactic mastectomy between 1960 and 1993. Sisters of the bilateral prophylactic
mastectomy women who did not have prophylactic surgery served as the control group.
The Gail model was used to predict the expected number of breast cancers in the two
groups. Comparison between the expected and actual breast cancer incidence in the two
groups demonstrated a 90% (p \leq .001) decrease in the expected incidence and mortality
of breast cancer in those who had bilateral prophylactic mastectomy. In another study of
decisional analysis comparing bilateral prophylactic mastectomy, chemoprevention, and
surveillance, the mean gain in life expectancy with bilateral prophylactic mastectomy was
3.5 years, which was higher than with Tamoxifen (1.8 years). However, the benefits of
bilateral prophylactic mastectomy declined to nearly zero in women over 50 years old
(Grann et al., 2002).

In a randomized controlled trial, The National Surgical Adjuvant Breast and
Bowel Prevention (NSABP) Tamoxifen Prevention Trial, Tamoxifen was shown to
decrease the incidence of breast cancer in high-risk women by 49% (Fisher et al., 1998).
However, this outcome was almost exclusively limited to women who had estrogen
receptor positive tumors. Two other small randomized European studies did not support
this finding. A meta-analysis of these studies indicated an estimated reduction in cancer
risk with Tamoxifen to be about 40% (Cuzick, 2000). Eisinger et al. (2001) predicted the
efficacy of Tamoxifen for BRCA1 positive women by using a model based on biological
predictors: estrogen receptor and pS2 status. A reduction in expected breast cancer
incidence of 10% was demonstrated in these BRCA1 positive women.

Meijers-Heijboer et al. (2001) compared the incidence of breast cancer occurring
in BRCA1 positive women who selected bilateral prophylactic mastectomy or
surveillance. After a mean follow-up of 2.9 years, no cases of breast cancer were found in
the bilateral prophylactic mastectomy group, whereas eight cases of breast cancer were
found in the surveillance group (p = .003). In a review article, Pichert, Bolliger, Buser,
and Pagani (2003) noted that this prospective study supported the retrospective findings
found by Hartmann in 1999.

Using a Markov model to predict outcomes, Grann et al. (2000) compared
chemoprevention (Tamoxifen, Raloxifene, and oral contraceptives) and prophylactic
surgery (bilateral prophylactic mastectomy and/or prophylactic oopherectomy) with
surveillance. They found 30 year old BRCA1 and BRCA2 positive women could expect
an increased life expectancy of 3.4 years with bilateral prophylactic mastectomy, 4.3
years with bilateral prophylactic mastectomy and bilateral prophylactic oopherectomy,
1.6 years with Tamoxifen, and 2.2 years with Raloxifene. However, the quality adjusted
life years for chemotherapy was higher than for bilateral prophylactic mastectomy. All
options were cost effective or saved costs when compared to surveillance. These
investigators updated the analysis again in 2002 (Grann et al., 2002). They found even
higher survival and quality of survival benefits for chemoprevention (1.8 years with
Tamoxifen; 2.2 years with Raloxifene), prophylactic surgery (3.5 years with bilateral
prophylactic mastectomy; 4.3 with bilateral prophylactic mastectomy and bilateral prophylactic oopherectomy), or a combination, than reported in their earlier study.

A clinical double-blind trial (National Surgical Adjuvant Breast and Bowel Project Study [NSABP] Study of Tamoxifen and Raloxifene [STAR] P-2 Trial) comparing the efficacy and safety of Tamoxifen and Raloxifene in postmenopausal women was conducted from 1999-2004. In the initial report of this trial, Vogel et al. (2006) reported similar risk reductions between Tamoxifen and Raloxifene with fewer incidences of cataracts and thrombotic events in the group who received Raloxifene.

Overall, evidence suggests bilateral prophylactic mastectomy is the most effective treatment option for decreasing the high-risk women’s chances of developing breast cancer. However, bilateral prophylactic mastectomy is also a major surgery with inherent surgical risks as well as disfigurement and associated psychological effects (Eisen & Weber, 1998; Simmons & Osborne, 1997). Moreover, Simmons and Osborne (1997) commented that “when one considers the risk and benefits of prophylactic mastectomy, it is ironic and somewhat disturbing that in the hope of preventing a disease, we might perform more extensive surgery than the surgical treatment for the established disease itself” (p. 378).

Chemoprevention is associated with an increased life expectancy and is generally tolerated well. However, Tamoxifen may cause life-threatening endometrial cancer and certain vascular events like deep vein thrombosis that could lead to pulmonary emboli. Although rare, these are significant side effects that need to be considered when the high-risk woman is making decisions about treatment options (Chlebowski, 2002).
Surveillance

Surveillance in at-risk women was examined in a few studies. Botkin and colleagues (Botkin et al., 2003) compared mutation carriers and noncarriers two years after testing with respect to interventions performed for their high risk for breast cancer. They found significant increases of mammography utilization from baseline for both carriers and noncarriers. However, 29% of the women who were mutation carriers had not received a mammogram over the two-year period. Further, no association was found between general distress or test-specific distress and mammography adherence using the State Trait Anxiety Inventory and the Impact of Event Scale, respectively. Lerman and colleagues (Lerman et al., 2000) examined surveillance practices and prophylactic surgery options one year after genetic testing. They found mutation carriers were more likely to obtain a mammogram than noncarriers ($p = 0.02$). However, mutation carrier’s adherence to mammography screening did not change from baseline, rather the difference was attributed to mutation carriers decreased adherence to mammography compared to baseline. The level of intrusive thoughts was positively associated with mutation carriers, but the relationship was not statistically significant ($p \leq 0.07$). A suboptimal level of adherence to mammography was also found in a group of women who had a strong history of breast and ovarian cancer (Isaacs, 2002). Isaacs et al. found mammography adherence was associated with age, income, and number of affected relatives, but not the level of cancer specific distress or cancer worry.

Chemoprevention

Selection of Tamoxifen as a treatment choice is overall low. In one study, a decision guide for Tamoxifen was developed by the researchers. After reviewing the
decision guide, women who were eligible for Tamoxifen were asked about their
ingleness to take this medication. Only 11.8% of the women reported their willingness
to take Tamoxifen (McKay, Martin, & Latosinsky, 2005). The only significant predictor
for taking Tamoxifen in this study was the woman’s perceived health. Women with better
perceptions of their health elected not to take Tamoxifen. Similarly, Melnikow et al.
(2005) studied preferences of women eligible for taking Tamoxifen for risk reduction.
Despite an educational intervention about the risks and benefits, only 17.8% of women
preferred Tamoxifen for their at-risk status. The researchers found no association
between objective risk, age, race, or education and the Tamoxifen decision. A low
perceived risk was associated with not taking Tamoxifen. Women with a lower income,
confidence in the drug’s effectiveness, and fear of fractures secondary to osteoporosis
were more inclined to take Tamoxifen. Concern about side effects like cataracts,
pulmonary embolism, and dyspareunia were associated with the decision not to take
Tamoxifen. In another study, the researchers reported a higher acceptance rate (42%) in
women who were offered Tamoxifen. “Only a history of AM [atypical hyperplasia] and
LCIS [lobular carcinoma in situ] and older age were found to be predictive of tamoxifen

**Prophylactic Mastectomy**

As previously mentioned, vanDijk et al. (2003) found cancer worry and perceived
risk influenced women’s intention to undergo bilateral prophylactic mastectomy. In this
same study, path analysis showed objective risk information presented during counseling
had a corrective effect on perceived risk (beta = 0.38; p = 0.001), but not cancer worry.
Similarly, in a retrospective study investigating predictors and satisfaction with bilateral
prophylactic mastectomy, Stefanek et al. (1995) reported breast-cancer-related worry was the only variable studied that influenced the decision to have bilateral prophylactic mastectomy.

Another group of investigators (Stefanek et al., 1999) examined two groups of women, one with a family history of breast cancer and one without. They found women in the two groups did not differ on their choice for bilateral prophylactic mastectomy after viewing a hypothetical vignette presentation of a high-risk woman (29% vs. 22.1%). However, the group with a family history of breast cancer reported worry as a problem more often than the group with no family history (34.4% vs. 15.7%, respectively). Thus, worry about estimated risk of developing breast cancer was identified as a significant predictor for choosing the bilateral prophylactic mastectomy option (p<.05) (Stefanek et al. 1999).

Meiser et al. (2000) studied 333 women waiting for a breast cancer risk assessment. Participants were hypothetically asked about their choice for bilateral prophylactic mastectomy if their genetic test showed mutation for BRCA genes. Anxiety, generalized psychological distress, breast cancer-related life event, and objective cancer risk were measured using the Impact of Event Scale, General Health Questionnaire 28, two items developed by the investigators, and genetic staff’s clinical judgment of dominate inherited predisposition, respectively. Bivariate analysis revealed the moderate-risk group (25%) would consider bilateral prophylactic mastectomy more often than the high-risk group (16%) (p = .051). Multivariate analysis showed a strong correlation between bilateral prophylactic mastectomy choice and high levels of breast cancer anxiety (p = .0001) and overestimation of breast cancer risk (p = .0036). Conversely,
there was no significant association between bilateral prophylactic mastectomy choice and objective cancer risk ($p = .60$).

Myers (2000) interviewed 17 women who had bilateral prophylactic mastectomy (BPM) to determine how these at-risk women decided to undergo BPM and the impact of having this surgery. One theme was women’s breast cancer worries and vulnerability to breast cancer. Women described increased anxiety when calcifications were found on their mammograms, a relative had died, or if they had a recurrence of breast cancer. The women felt vulnerable and expressed fears associated with finding a new lump or the fear of not finding an existing lump, fear of suffering like relatives had, and the fear of death as they approached the age of a relative who died of breast cancer.

Myers (2000) also described the fear of death, fear of suffering, and fear of leaving a child motherless as powerful motivating factors for bilateral prophylactic mastectomy (BPM). In addition, the women did not think other measures (surveillance, diet, and exercise) would be effective in reducing breast cancer risk because family members who did all these things still developed breast cancer. Similarly, Kenen et al. (2003) reported women with small children who were living with the chronic risk of breast cancer were more open to bilateral prophylactic mastectomy. They stated the participants’ “. . . main concern was staying alive until their children grew up.” (p. 325). Three other studies identified having children as a significant predictor for choosing BPM. These studies included women with a pedigree-based risk of carrying the BRCA 1 and BRCA 2 genes (Meijers-Heijboer et al., 2000), women who were mutation carriers (Lodder et al., 2002), women awaiting DNA test results, and women with proven mutation (Unic, Verhoef, Stalmeier, & Van Daal, 2000).
A woman’s level of education is also associated with the bilateral prophylactic mastectomy choice. Investigators found mutation carriers with an educational level of high school or higher were more likely to have undergone prophylactic mastectomy than those with lower education levels (Metcalfe et al., 2000).

In summary, risks and benefits are associated with both bilateral prophylactic mastectomy and chemoprevention. Bilateral prophylactic mastectomy is the most effective yet most invasive treatment option. Although bilateral prophylactic mastectomy is the least selected option, the majority of research focuses on this option. A heightened perception of risk, anxiety, cancer worry, parenthood, and level of education are predictive of women’s selection of prophylactic mastectomy. Evidence suggests women who select surveillance may not consistently follow recommendations for breast self examination, mammography, and clinical exam and that the level of cancer-related distress is not associated with mammography adherence. Reasons for not taking Tamoxifen include the associated side effects, a perceived good state of health, perceived high risk in one study and a perceived low risk in another study. Lower income status, fear of fractures, confidence in the efficacy of Tamoxifen, older age, and history of lobular carcinoma in situ or atypical hyperplasia were predictive of selecting Tamoxifen for preventative treatment.

**Decision-Making Effectiveness**

Lazarus and Folkman (1984) view coping outcomes as the achievement of an individualized goal and satisfaction with one’s performance in attaining that goal. Similarly, O’Connor (1995) says an appropriate outcome for decisional conflict is a quality decision-making process, not a judgment about the decision choice as “good” or
“bad”. The outcome in the current study is a decisional outcome and is conceptualized as selection of a treatment choice and the woman’s perceived decision-making effectiveness.

Most of the literature focuses on decision satisfaction and regrets associated with bilateral prophylactic mastectomy. Emphasis on this treatment option is likely based on the irreversible nature of this surgery, whereas surveillance and chemoprevention are reversible treatment options that may be temporally changed to include one or both of the two options at some point in their lifetime. Discussion of satisfaction and regrets with the bilateral prophylactic mastectomy choice follows.

Two investigations focused on regrets of women who had bilateral prophylactic mastectomy. One studied women who had contralateral prophylactic mastectomy (Montgomery et al., 1999) and the other, women with bilateral prophylactic mastectomy (Payne et al., 2000). Payne et al. (2000) utilized a mail-in questionnaire to identify women who regretted having bilateral prophylactic mastectomy. Overall, the respondents were satisfied with prophylactic surgery (95%, n = 349). The most commonly reported regret was emotional adjustment, including sexual (n = 6) and body image (n = 6) concerns. The primary influencing factor for bilateral prophylactic mastectomy (n = 12) was initiation of the discussion by the physician followed by fear of cancer (n = 4). Most women reported having psychological distress (n= 15) and anxiety (n = 12) during the decision-making process. Worries postoperatively included postoperative pain (n=2) and physical appearance (n =17). Much of the regret focused on the surgical procedure and reconstruction. In a quantitative study, Montgomery et al. (1999) identified 10 women who regretted contralateral prophylactic mastectomy. Again overall acceptance was high
Regret was defined as “would not have a contralateral prophylactic mastectomy again, nor . . . recommend to another woman with similar risk” (p. 547). Reasons for regret included poor cosmetic result either of the contralateral prophylactic mastectomy or reconstruction (39%), decreased sense of sexuality (22%), little information about surveillance methods or efficacy of contralateral prophylactic mastectomy (22%), and other factors (17%). No research related to decision-making effectiveness in women who select chemoprevention or surveillance was found.

In summary, there is a paucity of literature focusing on the decision-making effectiveness of women who are making a treatment choice for their increased risk of breast cancer. Most available literature focuses on only one treatment option, mastectomy. Most women are satisfied with their decision for bilateral or contralateral prophylactic mastectomy. The factors associated with regret centered on poor outcomes of reconstruction and emotional issues. Distress and anxiety during the decision-making process are reported.

Overall Summary

A woman who is at an increased risk for breast cancer faces many challenges. Once a woman learns her risk-status and treatment options, she must consider the risks and benefits of each option, her personal values, and then make an informed personal choice. Because there are several uncertainties associated with the woman’s risk-status and treatment choices, the woman may experience decisional conflict. A woman’s at-risk status, experiences of breast cancer in the family, and the uncertainties create a stressful situation for the woman. Women tend to exaggerate their risk and this inaccurate risk perception may or may not be affected by genetic counseling. Cancer worry, high levels
of stress, and exaggerated risk perceptions are associated with the most invasive
treatment option, prophylactic mastectomy. On the other hand, the level of cancer
distress is not associated with mammography adherence. Women manage threat, stress,
and decisional conflict using cognitive problem-focused and emotion-focused coping
behaviors. These behaviors may include confrontive coping, seeking social support,
planful problem solving, and positive reappraisal (approach behaviors) and/or distancing,
self-controlling, accepting responsibility, distancing, self-controlling, accepting
responsibility, and escape avoidance (avoidance behaviors). Some or all of these
behaviors may be used. The outcome of this coping process is a decisional outcome that
includes choosing a treatment option and decision-making effectiveness. The available
coping literature indicates women who use the problem-approach to coping are more
likely to select bilateral prophylactic mastectomy. Coping behaviors used by women in
response to their threat of breast cancer, subjective stress, and decisional conflict have not
been studied. It is important to examine the relationships among these concepts to
provide a framework for assisting women to manage threat, deal with stress and
decisional conflict, and make an informed decision using an effective decision-making
process.

Lazarus and Folkman’s model provides a framework for organizing and
testing relationships found to be important. Based on this model and the review of
literature, the following research questions and hypotheses are posed:

Research Question 1. What is the relationship between Cognitive Appraisal and
Coping Behaviors?
H₁: Subjective and objective cancer risk, subjective stress, and decisional conflict will explain a significant amount of the variance in approach and avoidance coping behaviors.

Research Question 2. What is the relationship between Cognitive Appraisal and Decisional Outcome?

H₂: Subjective and objective cancer risk, subjective stress, and decisional conflict will explain a significant amount of the variance in treatment choice and in decision-making effectiveness.

Research Question 3. What is the relationship between Coping Behaviors and Decisional Outcome?

H₃: Approach and avoidance coping behaviors will explain a significant amount of the variance in treatment choice and in decision-making effectiveness.

Research Question 4. What is the relationship between Cognitive Appraisal and Decisional Outcome controlling for Coping Behavior?

H₄: Subjective and objective cancer risk, subjective stress, and decisional conflict will explain a significant amount of the variance in treatment choice and in decision-making effectiveness controlling for approach and avoidance coping behaviors.

Research Question 5. What are the relationships in Research Questions 1-4 controlling for relevant demographic variables?

H₅: Hypotheses 1-4 will be evaluated using outcome measures as residuals from relevant demographic variables.
CHAPTER III

METHODS

Methodology is discussed in this chapter. The study design is presented first followed by a discussion of the setting, sample, measurements, procedures and data analysis plans.

Study Design

A cross-sectional descriptive correlational research design was used to examine the relationships between and among objective risk, subjective risk, subjective experience of stress, decisional conflict, approach coping, avoidance coping, treatment choice, and effectiveness of decision making in women at an increased risk for breast cancer who are making a choice among treatment options.

Setting and Sample

A convenience sample of 105 women was recruited from a high risk breast cancer clinic in southwestern Pennsylvania. This clinic is part of a large university medical center and is staffed with three physicians, a nurse, and two genetic counselors. Women are referred from surrounding areas and some out of state areas to this clinic for breast cancer risk assessment. The researcher met with clinic staff prior to the study. The research proposal was reviewed by the staff and permission for access to patients was obtained from the clinic director.
Power Analysis and Sample Size

Sample size was determined using SamplePower1.0. The goal was to provide an optimal sample size specification given the anticipated number of statistical analyses to be conducted and the anticipated effect sizes. The anticipated effect size for this power analysis was 10% of the variance. With a significance level of .01, the power to detect either an R Squared or a comparison of means accounting for 10% of the variance resulted in a .8 level of power. Because there were many tests for the statistical significance of a correlation coefficient, a .01 power analysis was used as if it represents a .05 level of significance. Hence, the power analysis takes into account the effect of the Bonferroni problem of multiple tests and the likelihood of making a Type I error. Thus, for an anticipated 100 correlations to be examined, one “false positive” Type I error is expected. Under these conditions, a power of .80 is achieved with a universe correlation of .32 (accounting for 10% of the variance) with a sample of N = 105.

Human Subjects Protection and Informed Consent

Approval to conduct this study was sought from Kent State University’s Human Subjects Review Committee and the clinic’s affiliated University Institutional Review Board. The IRB approval letters are presented in Appendix A and B. Participation was strictly voluntary. Potential participants were informed about their right to refuse participation and their right to withdraw at any time without affecting their care at the clinic. Further, the participants were assured of confidentiality and that only aggregate data would be reported. Informed consent was obtained from each participant prior to data collection. The Informed Consent Form is shown in Appendix C.
Measures

Main study variables include subjective 5-year risk, subjective lifetime risk, objective risk, subjective stress, decision uncertainty, factors associated with uncertainty, approach coping behaviors, avoidance coping behaviors, treatment choice and perceived decision-making effectiveness. Sociodemographic data that may be associated with the study variables were also collected. A description of study measures and their reliability and validity follows.

Breast Cancer Threat

Breast cancer threat includes the objective and subjective risk for developing breast cancer. Objective risk was calculated by the clinic staff using the Gail Model calculator, the woman’s history of lobular carcinoma in situ, or mutation status. The Gail model estimates risk based on age, race, age at menarche, age at first live birth, family history, and previous breast biopsies. Questions from the model are presented in Appendix D. The model is based on case-control data from women participating in the Breast Cancer Detection Demonstration Project (BCDDP) and was modified later using data from the Surveillance, Epidemiology, and End Results program (SEER). The Gail model has been validated by researchers (Spiegelman, Colditz, Hunter, Hertzmark, 1994; Costantino, Gail, Pee, Anderson, Redmond, et al., 1999). The calculation results in a percent (%) estimate of the woman’s chance of developing breast cancer over the next five years and over a lifetime. Based on epidemiological research, women with lobular carcinoma in situ (LCIS) were given an estimate of 15% over the next 20 years and women who were BRCA1/2 positive were given an estimate of 60-80% to the age of 70. The subjective risk assessment included two items on the sociodemographic
questionnaire asking participants to estimate their chances of developing breast cancer over the next five years and over a lifetime. Responses included both percentages and odds ratio options.

**Subjective Stress**

Horowitz’s Impact of Event Scale (IES) was used to measure the women’s intrusive thoughts related to breast cancer risk and consideration of treatment options (see Appendix E for permission to use). This scale was developed to measure subjective stress related to a specific event. The instrument is a 15-item, self-report questionnaire. Seven items measure intrusive symptoms (intrusive thoughts, nightmares, intrusive feelings, and imagery) while eight items measure avoidance symptoms like numbing of responsiveness, avoidance of feelings, situations, and ideas. Respondents are asked to select the occurrence of each item over the past seven days on a 4-point scale that includes 0 (*not at all*), 1 (*rarely*), 3 (*sometimes*), and 5 (*often*). The scale is written at a sixth-grade level. Based on the educational reading level and the number of items, approximately 15 minutes is needed to complete the questionnaire.

Known-groups validity was demonstrated by comparing scores of outpatients seeking treatment from bereavement and three field samples. The Impact of Event Scale discriminated between those hypothesized to have lower stress levels than those with high stress levels. Internal consistency using Cronbach’s alpha for the Intrusion subscale was 0.78 and the Avoidance scale 0.82. Test-retest reliability in physical therapy students who were preparing for cadaver dissection was 0.87 for the total stress scores, 0.89 for the Intrusion subscale, and 0.79 for the Avoidance subscale. Split half reliability of the Impact of Event Scale was also high ($r = 0.86$) (Horowitz et al., 1979). The Impact of
Event Scale has been widely used to assess breast cancer related anxiety and high-risk for breast cancer anxiety. The Impact of Event Scale has been recommended for use in high-risk women over general measures of stress (Bleiker et al., 2003). The psychometric properties were examined using a sample of 480 women with hereditary breast cancer (Thewes, Meiser, & Hickie, 2001). The researchers reported acceptable face validity, construct validity, discriminative validity, and convergent validity in this population. Internal consistency coefficients were high with reported Cronbach’s alpha of 0.88, 0.84, and 0.91 for the intrusion, avoidance, and total scores, respectively. Test-retest reliability was calculated by correlating baseline Impact of Event scores with scores obtained 14 days later. Thewes et al. reported satisfactory correlation coefficients of \( r = 0.75 \) (intrusion), \( r = 0.78 \) (avoidance), and \( r = 0.80 \) (total) for the Impact of Event Scale. In the current study, participants were asked to indicate how distressing each item was during the past seven days with respect to their at-risk status and consideration of treatment options.

**Decisional Conflict**

O’Connor’s Decisional Conflict Scale (DCS) was used to measure the woman’s perceived difficulty in making a treatment choice, including decision uncertainty when making a choice among treatment options and factors associated with uncertainty (O’Connor, 1995). The Decisional Conflict Scale is a 16-item self-report questionnaire that elicits a total decisional conflict score and three subscale scores including uncertainty in making health-related decisions, factors contributing to uncertainty, and perceived effective decision-making (see Appendix F for permission letter). According to O’Connor, the first two subscales may be used during deliberation or after a decision is
made, whereas the third subscale (perceived effective decision making) is used only in situations where a decision has already been made. Data from the Factors Contributing to Uncertainty subscales include “being informed about options, risk, and benefits, and feeling clear about values and valued tradeoffs in the decision” (p. 26). Respondents are asked to reflect on health care decisions they are about to make or have just made and respond to each statement using a 5-point Likert-type scale. Participants select a number from 1 (strongly agree) to 5 (strongly disagree) that best expresses how they feel about common comments made by other individuals making health care decisions. In the current study, the health care decision examined was the treatment choice for the increased risk of breast cancer. The Decisional Conflict Scale was developed from Janis and Mann’s decisional conflict model. The scale is at an eighth-grade reading level and requires five to ten minutes for completion (O’Connor, 2005).

Known-groups validity was tested by comparing a group of individuals who delayed or were unsure of their decisions with individuals who accepted or rejected a decision. The Decisional Conflict Scale discriminated significantly between these two groups (p < .0002). Construct validity was evaluated by comparing knowledge about breast cancer risk and decisional conflict scores with an expected inverse relationship between knowledge level and decisional conflict. This comparison resulted in a Pearson r = -0.16 (p < .005). Cronbach’s alpha was used to evaluate internal consistency of the instrument and resulted in alpha coefficients ranging from a 0.78 to 0.92 for the Decisional Conflict Scale total score and from 0.58 to 0.92 for the subscores. O’Connor (1995) also evaluated the reliability of the Decisional Conflict Scale using 909 individuals (health science students, health employees, and cardiac and respiratory
patients) who were making decisions about immunization or breast cancer screening. A subsample of these individuals was tested two weeks later and a test-retest correlation coefficient of 0.81 was found. Participants in the current study were asked to complete the entire instrument. The perceived difficulty in making a decision (decision uncertainty) and the factors associated with uncertainty were measured using the Uncertainty and Factors Contributing to Uncertainty subscales of the Decisional Conflict Scale.

**Coping**

The Ways of Coping Revised Questionnaire (WCRQ) was used to measure the coping process a woman uses to deal with the stressful encounter of being told she is at an increased risk for breast cancer and her treatment options (see Appendix G for permission letter). Two concepts were measured: problem-focused coping and emotion-focused coping. The Ways of Coping Revised Questionnaire is a 66-item self-report questionnaire with a 4-point Likert scale that ranges from (0) *not used* to (3) *used a great deal*. There are eight coping strategy subscales on the WCRQ: Confrontive Coping, Distancing, Self-Controlling, Seeking Social Support, Accepting Responsibility, Escape-Avoidance, Planful Problem Solving, and Positive Reappraisal. Researchers have developed various composites of these eight factors which have been identified through factor analysis. The composites used by Holland and Holahan (2003) were used for the present study. Problem-focused coping refers to approach behaviors and was operationalized by using four subscales (Confrontive Coping, Seeking Social Support, Planful Problem Solving, and Positive Reappraisal) on the Ways of Coping Revised Questionnaire. Emotion-focused coping refers to avoidant behaviors which were measured using the other four subscales (Distancing, Self-Controlling, Accepting...
Responsibility, and Escape-Avoidance) on the Ways of Coping Revised Questionnaire. Some researchers view the accepting responsibility as a problem-focused approach to coping; however, the items on this subscale are based on self-blame (“criticized or lectured myself”, “realized I brought the problem on myself”). This approach to coping would not be constructive for women at an increased risk for breast cancer because of the multicausality and complex nature of breast cancer. Thus, in the present study, this approach to coping is considered an avoidant strategy. These classifications are consistent with the coping literature (Moos, 1992) and were used to study the relationship between social support and the extent to which women utilized each coping strategy from the time their high-risk status and treatment options were presented up to the time they made a choice for treatment (Holland & Holahan, 2003). Adequate face validity and construct validity are reported for the Ways of Coping Revised Questionnaire. Cronbach’s alpha was used to evaluate internal consistency of the instrument. Alpha coefficients ranged from 0.61 to 0.79 for the eight factors (Folkman & Lazarus, 1988). In the current study, participants were asked to indicate the thoughts and actions they used to cope with a specific stressful encounter (increased risk for breast cancer and consideration of treatment options).

**Decisional Outcomes**

Treatment choice was measured by asking the woman to indicate her treatment choice (surveillance, chemoprevention, or prophylactic mastectomy) on the sociodemographic questionnaire. Perceived decision-making effectiveness was measured using the Effective Decision subscale on the Decisional Conflict Scale. Psychometric properties of this instrument were previously addressed under decisional conflict above.
Sociodemographic Questionnaire

Sociodemographic data included age, marital status, ethnic group, occupation, level of education, number and age of children, family members who were affected or died of breast cancer, insurance coverage, and information sources used during the decision-making process. See Appendix H for the sociodemographic form.

Procedure/Data Collection

A researcher-developed pamphlet describing the study was distributed by clinic staff to women who came to the clinic for a breast cancer risk assessment and who met the inclusion criteria. The inclusion criteria consisted of women who were unaffected with breast cancer, had a 5-year risk of 1.7% or greater, could read and write English, and were 18 years or older. Women who met the inclusion criteria were invited to meet the researcher in a private area of the clinic to discuss the study further. The researcher explained the purpose, risks, benefits, and data collection procedures. Informed consent was obtained from women who expressed an interest in participation. A copy of the informed consent was given to each participant. The researcher reviewed the instructions for completing the questionnaire packet. A booklet containing the informed consent form and study instruments were coded and distributed to the woman for completion that day. The total time for instrument completion varied from 15-30 minutes. In instances where the woman had not yet selected a treatment option, a one-page questionnaire with the decision-related items from the questionnaire booklet was given to the woman for her to complete and return after she selected a treatment option. A self-addressed stamped envelope was provided for her to return the questionnaire. Permission for telephone follow-up, along with the woman’s first name and telephone number were attained. In the
event questionnaires were not returned, the researcher called to remind the woman about
the questionnaire or collected the data over the phone. A schematic summary of the
procedure is presented in figure 2.
Figure 2: Summary of Procedure

Disclosure of increased risk-status by clinic staff

Researcher developed pamphlet about study distributed to woman by clinic staff

Clinic staff invite woman to meet with researcher

Researcher explains study purpose, procedures, risks, benefits, & invites woman to participate

Woman consents to participate?

<table>
<thead>
<tr>
<th>Yes</th>
<th>No</th>
</tr>
</thead>
</table>

Treatment decision made?

<table>
<thead>
<tr>
<th>Yes</th>
<th>No</th>
</tr>
</thead>
</table>

Woman completes questionnaire packet: Sociodemographic Questionnaire Impact of Event Scale Decisional Conflict Scale Ways of Coping Questionnaire (takes 35-45 minutes to complete)

Yes

Woman's participation ends

No

Woman returns questionnaire, with decision-related items, in self-addressed stamped

Yes

Woman's participation ends

No

Researcher calls to remind woman about questionnaire or collects data over the phone

Woman returns questionnaire or gives data over the phone

Woman's participation ends
Data Analysis

Data Management and Preliminary Data Analysis

Version 15 of the Statistical Package for the Social Sciences software program (SPSS) was used for data entry and analysis. Nominal data from the sociodemographic questionnaires and interval-like data on the Impact of Event Scale, Decisional Conflict Scale, and Ways of Coping Revised Questionnaire were entered into the database. Data were visually inspected to ensure all values were within range and computer printouts corresponded with the raw data. Descriptive statistics were computed on all variables. This included measures of central tendency and frequencies depending on the level of data. Frequency distributions were evaluated for main study variables, and tested to ensure data met the assumption of normality.

Data from each of the subscales used on the Impact of Event Scale, Decisional Conflict Scale, and Ways of Coping Revised Questionnaire were examined to determine which items were empirically relevant. Factor analyses were conducted to evaluate the consistency between the sets of items and the concepts each was designed to represent. Cronbach’s alpha coefficients were calculated for the scales created from each set of items identified in the factor analyses to represent their respective concepts. Scale scores were calculated for each of the variables measured with the Impact of Event Scale, Decisional Conflict Scale, and the Ways of Coping Revised Questionnaire subscales. Construct validity was evaluated by examining the substantive hypothesis combined with the measurement reliabilities of each of the respective measures.
Statistical Analysis

Hypotheses were tested using regression procedures. Because of the large number of null hypotheses that were tested in this study, the probability of rejecting a true null hypothesis was set at .01 rather than .05. “Statistical significance” was claimed for these associations. Null hypothesis tests with a p value between .01 and .05 were described as “marginally significant”. Relevant variables identified in the literature (e.g. parenthood, age, education, and family history of breast cancer) were statistically controlled during hypothesis testing. Multiple regression was used to evaluate the effects of the predictors on each outcome variable for all of the following hypotheses:

H₁: Subjective and objective cancer risk, subjective stress, and decisional conflict will explain a significant amount of the variance in approach and avoidance coping behaviors.

H₂: Subjective and objective cancer risk, subjective stress, and decisional conflict will explain a significant amount of the variance in treatment choice and in decision-making effectiveness.

H₃: Approach and avoidance coping behaviors will explain a significant amount of the variance in treatment choice and in decision-making effectiveness.

H₄: Subjective and objective cancer risk, subjective stress, and decisional conflict will explain a significant amount of the variance in treatment choice and in decision-making effectiveness controlling for approach and avoidance coping behaviors.

H₅: Hypotheses 1-4 will be evaluated using outcome measures as residuals from relevant demographic variables.
Limitations

The investigator acknowledges several research limitations. The proposed research uses a cross-sectional, descriptive, correlational design. When using a cross-sectional design, the temporal explanations of the data are not possible. Moreover, Folkman and Lazarus view coping as a dynamic process that requires continuous assessment. It follows that a longitudinal design would be preferred over a cross-sectional design (Lazarus, 2000).

Preexisting conditions or extraneous variables may exist which could potentially provide an alternate explanation for the results. To offset this limitation, variables identified in the literature (e.g. parenthood, age, education, and family history of breast cancer) were included on the sociodemographic questionnaire and statistically controlled during data analysis.

Use of a convenience sample, a nonprobability sampling method, limits generalizability of the findings to other populations.
CHAPTER IV
RESULTS

The purpose of this study was to examine the relationships among threat of breast cancer, subjective stress, decisional conflict, type of coping, and decisional outcomes in women deciding about treatment options for their increased risk of breast cancer. It was predicted that subjective and objective cancer risk, subjective stress, and decisional conflict (decision uncertainty and factors associated with decision uncertainty) would explain a significant amount of the variance in approach and avoidance coping behaviors and that subjective and objective cancer risk, subjective stress, and decisional conflict would also explain a significant amount of the variance in treatment choice and in decision-making effectiveness. In addition, it was predicted that approach and avoidance coping behaviors would explain a significant amount of the variance in treatment choice and in decision-making effectiveness.

Data collection occurred from January 2007 to August 2007. The results are presented in the following five sections of this chapter and include preliminary data analysis, description of participants, preliminary results, and hypotheses testing.

Preliminary Data Analysis

A booklet containing four questionnaires was used to gather data. The booklet included Horowitz’s Impact of Event Scale (IES), O’Connor’s Decisional Conflict Scale (DCS), Lazarus and Folkman’s Revised Ways of Coping Revised Questionnaire (WCRQ), and a Sociodemographic Questionnaire developed by the researcher. There
were a total of 127 questions in the booklet and 105 participants, thus 13,345 (127 x 105) responses were expected. All but 20 items were answered resulting in an overall response rate of 99.9%. Data were entered and analyzed using SPSS version 15. Each of the 105 participants represented a case. Frequency distributions for all sociodemographic and study variables were obtained. Measures of central tendency were calculated for all variables measured at the interval level. Data were visually inspected to ensure values were within range and computer printouts corresponded with the raw data. Frequency distributions and histograms were examined for outliers.

**Sociodemographic Variables and Recoding**

The Sociodemographic Questionnaire was used to collect data about age, marital status, ethnic group, occupation, education, number and age of children, family history of breast cancer, insurance coverage, sources of information used for making a decision, subjective risk, and objective risk. Four participants did not respond to employment setting. These four participants were retired or not employed and employment setting was not applicable. One participant did not respond to two items related to information sources used to make a treatment choice. Three items about family members who were affected or died of breast cancer were unanswered. Participants responded to all other items on the Sociodemographic Questionnaire. In summary, 6,579 of 6,615 possible queries were answered. This resulted in a response rate of 99.5% on the entire Sociodemographic Questionnaire. Missing sociodemographic items were left blank for data analysis.
Recoded Age of Youngest Child

Participants were asked the age of the oldest and youngest child. In situations where there was only one child, the age of the only child was entered for both youngest and oldest child. The age of the youngest child variable was then collapsed into dichotomous variables: Women with children ≤ 17 years old and women who did not have children ≤ 17 years old (this included women with no children and women with children older than 17). The decision to group women with children 17 and under was based on the suggestion in the literature that having young children may impact a woman’s stress level and treatment choice (Unic et al., 2000; Meijers-Heijboer et al., 2000; Lodder et al., 2002; & Kenen et al. 2003). This recoded variable was used for data analysis.

Recoded Family Members Who Died and Family Members Who Were Affected With Breast Cancer

Some women indicated they did not know whether specific relatives were affected by breast cancer or died from breast cancer. These “don’t know” responses were recoded to a “no” response. These items were then summed to determine the total number of women with relatives (mother, sister, maternal grandmother, paternal grandmother, maternal aunt, paternal aunt, and others) who were affected with and who died of breast cancer. This recoded variable was used for data analysis. In addition, another variable was created from the data whereby relatives were collapsed into first-degree relative(s) and no first-degree relative(s) who were affected or died of breast cancer. A summary of these and other recoded sociodemographic variables are listed in table 2.
Table 2

Collapsed and Recoded Demographic Categories used in Data Analysis

<table>
<thead>
<tr>
<th>Original Variable</th>
<th>N</th>
<th>%</th>
<th>Recoded Variable</th>
<th>n</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Marital Status</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Married</td>
<td>78</td>
<td>74.3%</td>
<td>Married</td>
<td>78</td>
<td>74.3%</td>
</tr>
<tr>
<td>Divorced</td>
<td>15</td>
<td>14.3%</td>
<td>Unmarried</td>
<td>27</td>
<td>25.7%</td>
</tr>
<tr>
<td>Widowed</td>
<td>4</td>
<td>3.8%</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Never married</td>
<td>7</td>
<td>6.7%</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Racial Identification</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>African American</td>
<td>2</td>
<td>1.9%</td>
<td>Non-Caucasian</td>
<td>3</td>
<td>2.9%</td>
</tr>
<tr>
<td>American Indian</td>
<td>0</td>
<td>0</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Asian/Pacific Islander</td>
<td>0</td>
<td>0</td>
<td>Caucasian</td>
<td>102</td>
<td>97.1%</td>
</tr>
<tr>
<td>Caucasian/NonHispanic</td>
<td>102</td>
<td>97.1%</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Highest Educational Degree</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>&lt;HS diploma/GED</td>
<td>1</td>
<td>1.0%</td>
<td>Diploma/GED</td>
<td>35</td>
<td>33.3%</td>
</tr>
<tr>
<td>HS diploma/GED</td>
<td>34</td>
<td>32.4%</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Associate’s</td>
<td>13</td>
<td>12.4%</td>
<td>Associate/Bachelor</td>
<td>41</td>
<td>39.0%</td>
</tr>
<tr>
<td>Bachelor’s</td>
<td>28</td>
<td>26.7%</td>
<td>Masters/Doctorate</td>
<td>29</td>
<td>27.6%</td>
</tr>
<tr>
<td>Master’s</td>
<td>21</td>
<td>20.0%</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Doctorate</td>
<td>8</td>
<td>7.6%</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Age Youngest Child</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>None</td>
<td>25</td>
<td>23.8%</td>
<td>Children ≤17 Years Old</td>
<td>32</td>
<td>30.5%</td>
</tr>
<tr>
<td>.75-40</td>
<td>80</td>
<td>76.2%</td>
<td>No children ≤17 Years Old</td>
<td>73</td>
<td>69.5%</td>
</tr>
<tr>
<td>Family Members who Died of Breast Cancer</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Mother</td>
<td>32</td>
<td>30.5%</td>
<td>Family Member(s)</td>
<td>70</td>
<td>67.3%</td>
</tr>
<tr>
<td>Sister</td>
<td>23</td>
<td>21.9%</td>
<td>Affected with Breast Cancer</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Paternal Grandmother</td>
<td>5</td>
<td>4.8%</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Maternal Grandmother</td>
<td>9</td>
<td>8.6%</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Maternal Aunt</td>
<td>15</td>
<td>14.3%</td>
<td>No Family Member(s)</td>
<td>34</td>
<td>32.7%</td>
</tr>
<tr>
<td>Paternal Aunt</td>
<td>14</td>
<td>13.3%</td>
<td>Affected with Breast Cancer</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Other Family Member</td>
<td>35</td>
<td>33.3%</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Family Members Affected with Breast Cancer</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Mother</td>
<td>32</td>
<td>30.5%</td>
<td>First-degree Relative</td>
<td>44</td>
<td>41.9%</td>
</tr>
<tr>
<td>Sister</td>
<td>23</td>
<td>21.9%</td>
<td>Affected with Breast Cancer</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Paternal Grandmother</td>
<td>5</td>
<td>4.8%</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Maternal Grandmother</td>
<td>9</td>
<td>8.6%</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Maternal Aunt</td>
<td>15</td>
<td>14.3%</td>
<td>No First-degree</td>
<td>61</td>
<td>58.1%</td>
</tr>
<tr>
<td>Paternal Aunt</td>
<td>14</td>
<td>13.3%</td>
<td>Relative Affected with</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Other Family Member</td>
<td>35</td>
<td>33.3%</td>
<td>Breast Cancer</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Family Members who Died</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Mother</td>
<td>10</td>
<td>9.5%</td>
<td>Family Member(s)</td>
<td>37</td>
<td>35.2%</td>
</tr>
<tr>
<td>Sister(s)</td>
<td>5</td>
<td>4.8%</td>
<td>Died</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Paternal Grandmother</td>
<td>4</td>
<td>3.8%</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Maternal Grandmother</td>
<td>6</td>
<td>5.7%</td>
<td>No Family Member(s)</td>
<td>68</td>
<td>64.8%</td>
</tr>
<tr>
<td>Maternal Aunt</td>
<td>5</td>
<td>4.8%</td>
<td>Died</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Other Family Member</td>
<td>6</td>
<td>5.7%</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
Main Study Variables

Main study variables are discussed in this section. Information about subjective risk, objective risk and treatment choice is presented first followed by factor analysis, scale development and reliability testing for study variables collected using the Impact of Event Scale, Decisional Conflict Scale, and Ways of Coping Revised Questionnaire.

Subjective Risk, Objective Risk, and Treatment Choice

Four questions on the Sociodemographic Questionnaire were used to collect data for subjective risk, objective risk and treatment choice. Subjective risk was measured by asking the participants to indicate their perceived 5-year and lifetime risk (% and odds/ratio) for developing breast cancer. The response rate was 100%. Objective risk was determined by the breast cancer risk clinic staff. The Gail Model was used to calculate an estimate of the woman’s breast cancer risk over the next five years and over a lifetime except in the cases where the woman had confirmed lobular carcinoma in situ or was a documented mutation carrier. In these cases, the risk estimate was based on epidemiological studies. An objective risk was obtained for all 105 participants; however

<table>
<thead>
<tr>
<th>Original Variable</th>
<th>N</th>
<th>%</th>
<th>Recoded Variable</th>
<th>n</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Other Family Member</td>
<td>11</td>
<td>10.5%</td>
<td>First-degree Relative</td>
<td>14</td>
<td>13.3%</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>Died of Breast Cancer</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Mother</td>
<td>10</td>
<td>9.5%</td>
<td>No First-degree Relative</td>
<td>91</td>
<td>86.7%</td>
</tr>
<tr>
<td>Sister(s)</td>
<td>5</td>
<td>4.8%</td>
<td>Relative Died of Breast Cancer</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Paternal Grandmother</td>
<td>4</td>
<td>3.8%</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Maternal Grandmother</td>
<td>6</td>
<td>5.7%</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Maternal Aunt</td>
<td>5</td>
<td>4.8%</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Paternal Aunt</td>
<td>6</td>
<td>5.7%</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Other Family Member</td>
<td>11</td>
<td>10.5%</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
only those women whose risk was determined using the Gail model were given both a 5-year and a lifetime risk factor. Women with lobular carcinoma in situ were given a risk of 15% over 20 years and those who were BRCA1/2 positive were given a 60-80% risk to the age of 70.

Because not all women were given a 5-year and lifetime risk factor by the clinic staff and dissimilar methods were used to calculate their individual risk, objective risk was recoded into three categories. Category 1 included women whose risk was calculated using the Gail model as they generally have the lowest overall risk. Category 2 included women who had a history of lobular carcinoma in situ and were given a risk of 15% over 20 years. Category 3, the highest level of risk, included women who were BRCA1 and/or BRCA2 positive and were given a risk of 60-80% over 70 years. This category system for objective risk was used for hypothesis testing.

All 105 participants indicated their treatment choice (surveillance, medication, prophylactic mastectomy, or unsure) when they completed the questionnaire packet at the clinic. Women who marked “unsure” were given a self-addressed stamped envelope with a one-page questionnaire indicating their treatment choice and other decision-related items like decision effectiveness and information sources used to make a decision. Seventeen women were initially “unsure” about their treatment choice. All but one of these women returned the take-home questionnaire with their treatment choice. The one missing response for treatment choice was left blank for data analysis.

*Factor Analysis, Scale Development, and Reliability Testing*

The Impact of Event Scale, Decisional Conflict Scale, and Ways of Coping Revised Questionnaire were used to collect data for most of the main study variables
(subjective stress, decision uncertainty, factors associated with decision uncertainty, approach coping behaviors, avoidance coping behaviors, and decision effectiveness). Out of 10,500 queries, data were missing for only 2 item responses on the Impact of Event Scale, 4 item responses on the Decisional Conflict Scale, and 4 item responses on the Ways of Coping Revised Questionnaire. This resulted in an excellent overall item response rate of 99.9%. Items from the Impact of Event Scale, Decisional Conflict Scale, and Ways of Coping Revised Questionnaire were recoded for consistency with the author’s recommendations. For example, the Impact of Event Scale responses were changed from 1, 2, 3, and 4 to 0, 1, 3, and 5 respectively. Mean scores for missing items were obtained and substituted for missing values.

A principal components factor analysis using Varimax rotation with Kaiser normalization was used to corroborate the dimensions as theoretically specified for the study variables. The analyses included data from all 105 participants on the Impact of Event Scale, Decisional Conflict Scale, and Ways of Coping Revised Questionnaire items. Cronbach’s alpha coefficients and variable scores were then calculated for each variable. The procedures, results, and decisions are presented for each instrument in this section.

**Impact of Event Scale (subjective stress).** A principal components analysis was conducted on the 15-item Impact of Event Scale. The item means ranged from .43 to 2.66 with standard deviations ranging from .99-1.81. A review of the Scree plot (see Appendix I) suggested a 3-factor structure. This 3-factor structure accounted for 64.5% of the variance in the matrix. However, the 3-factor principal components factor analysis revealed an interpretable 2-factor structure. The 2-factor structure coincided with the
Impact of Event Scale conceptual framework. Item 14 was excluded because the item loading was high for both Factor 1 and Factor 2 (.553 and .610 respectively). The 2-factor structure, rotated to a Varimax solution, and the associated scale items are presented in table 3.

Table 3

*Rotated Component Matrix for Revised 14-item Impact of Event Scale*

<table>
<thead>
<tr>
<th>Item No.</th>
<th>Item</th>
<th>Component 1</th>
<th>Component 2</th>
</tr>
</thead>
<tbody>
<tr>
<td>13</td>
<td>I tried not to think about it.</td>
<td>.836</td>
<td>.179</td>
</tr>
<tr>
<td>12</td>
<td>I was aware that I still had a lot of feelings about it, but I didn’t deal with them.</td>
<td>.781</td>
<td>.231</td>
</tr>
<tr>
<td>9</td>
<td>I tried not to talk about it.</td>
<td>.749</td>
<td>.247</td>
</tr>
<tr>
<td>15</td>
<td>My feelings about it were kind of numb.</td>
<td>.689</td>
<td>.295</td>
</tr>
<tr>
<td>8</td>
<td>I felt as if it hadn’t happened or wasn’t real.</td>
<td>.669</td>
<td>.100</td>
</tr>
<tr>
<td>7</td>
<td>I stayed away from reminders of it.</td>
<td>.629</td>
<td>.333</td>
</tr>
<tr>
<td>3</td>
<td>I tried to remove it from my memory.</td>
<td>.589</td>
<td>.334</td>
</tr>
<tr>
<td>2</td>
<td>I avoided letting myself get upset when I thought about it or was reminded of it.</td>
<td>.564</td>
<td>.102</td>
</tr>
<tr>
<td>4</td>
<td>I had trouble falling asleep or staying asleep because of pictures or thoughts about it that came into my mind.</td>
<td>.165</td>
<td>.785</td>
</tr>
<tr>
<td>5</td>
<td>I had waves of strong feelings about it.</td>
<td>.315</td>
<td>.765</td>
</tr>
<tr>
<td>1</td>
<td>I thought about it when I didn’t mean to.</td>
<td>.263</td>
<td>.750</td>
</tr>
<tr>
<td>10</td>
<td>Pictures about it popped into my mind.</td>
<td>.321</td>
<td>.715</td>
</tr>
<tr>
<td>6</td>
<td>I had dreams about it.</td>
<td>.067</td>
<td>.699</td>
</tr>
<tr>
<td>11</td>
<td>Other things kept making me think about it.</td>
<td>.242</td>
<td>.659</td>
</tr>
</tbody>
</table>

Extraction Method: Principal Component Analysis.
Rotation Method: Varimax with Kaiser Normalization.
Rotation converged in 3 iterations.

Note: Item 14 loaded high on both component 1 and 2 and was eliminated from the revised scale prior to this analysis.

Component 2 (highlighted/underlined) = Subjective stress items

Using a minimum .5 loading to define a factor, an examination of table 3 reveals that Factor 1 was defined by items 2, 3, 7, 8, 9, 12, 13, and 15. Factor 2 was defined by items 1, 4, 5, 6, 10, and 11. Items that loaded on Factor 1 were consistent with the
Avoidance subscale and items that loaded on factor 2 were consistent with the Intrusive subscale of the Impact of Event Scale. The loading plot is presented in Appendix J. The Intrusive subscale was used to measure the variable subjective stress during hypothesis testing. The Avoidance subscale was not used.

A Cronbach’s alpha was calculated for the 6 items on the Intrusive subscale of the Impact of Event Scale. The 6 items had a Cronbach’s alpha of .857. Thus, these items had sufficient equivalence to warrant their inclusion in the model. A Subjective Stress scale was calculated by summing the 6 Impact of Event Scale items and dividing by 6, the number of items.

*Decisional Conflict Scale (factors associated with decision uncertainty, decision uncertainty, and decision effectiveness).* A principal components factor analysis was conducted on the 16-item Decisional Conflict Scale. The item means ranged from 1.42 to 2.37 with a standard deviation ranging from .55 to 1.23. The associated Scree plot (see Appendix K) and rotated component matrix revealed a 3-factor structure. This 3-factor structure explained 69.9% of the variance. A review of the rotated component matrix revealed four items (6, 7, 8, and 9) loaded on both Factor 1 and Factor 2. These items were deleted from the analysis. The explained variance after these items were deleted was 76.9%. The rotated component matrix after eliminating these items is presented in table 4.
Table 4

*Rotated Component Matrix for the Revised 12-item Decisional Conflict Scale*

<table>
<thead>
<tr>
<th>Item No.</th>
<th>Item</th>
<th>Component 1</th>
<th>Component 2</th>
<th>Component 3</th>
</tr>
</thead>
<tbody>
<tr>
<td>2</td>
<td>I know the benefits of each option.</td>
<td>.899</td>
<td>.154</td>
<td>.064</td>
</tr>
<tr>
<td>3</td>
<td>I know the risks and side effects of each option.</td>
<td>.832</td>
<td>.141</td>
<td>.119</td>
</tr>
<tr>
<td>1</td>
<td>I know which options are available to me.</td>
<td>.828</td>
<td>.138</td>
<td>.010</td>
</tr>
<tr>
<td>4</td>
<td>I am clear about which benefits matter most to me.</td>
<td>.698</td>
<td>.112</td>
<td>.442</td>
</tr>
<tr>
<td>5</td>
<td>I am clear about which risks and side effects matter most.</td>
<td>.656</td>
<td>.151</td>
<td>.457</td>
</tr>
<tr>
<td>16</td>
<td>I am satisfied with my decision.</td>
<td>.119</td>
<td>.884</td>
<td>.216</td>
</tr>
<tr>
<td>14</td>
<td>My decision shows what is important to me.</td>
<td>.168</td>
<td>.851</td>
<td>.158</td>
</tr>
<tr>
<td>15</td>
<td>I expect to stick with my decision.</td>
<td>.031</td>
<td>.804</td>
<td>.284</td>
</tr>
<tr>
<td>13</td>
<td>I feel I have made an informed choice.</td>
<td>.338</td>
<td>.740</td>
<td>.174</td>
</tr>
<tr>
<td>11</td>
<td>I feel sure about what to choose.</td>
<td>.275</td>
<td>.268</td>
<td>.859</td>
</tr>
<tr>
<td>12</td>
<td>This decision is easy for me to make.</td>
<td>-.039</td>
<td>.295</td>
<td>.851</td>
</tr>
<tr>
<td>10</td>
<td>I am clear about the best choice for me.</td>
<td>.270</td>
<td>.211</td>
<td>.818</td>
</tr>
</tbody>
</table>

Extraction Method: Principal Component Analysis.
Rotation Method: Varimax with Kaiser Normalization.
Rotation converged in 5 iterations.

Note: Items 6, 7, 8, and 9 loaded on both component 1 and component 2 and were eliminated from the revised scale prior to this analysis.

Component 1 (highlighted/underlined) = Factors Associated with Uncertainty items
Component 2 (highlighted/underlined) = Decision Effectiveness items
Component 3 (highlighted/underlined) = Decision Uncertainty items

Using a .5 factor loading, a review of the remaining 14-item rotation matrix presented in table 4 revealed Factor 1 was defined by items 1, 2, 3, 4, and 5; Factor 2 was defined by items 13, 14, 15, and 16; and Factor 3 was defined by items 10, 11, and 12. Each factor was examined for relevance to the research variables.

Factor 1 represents how informed participants felt and how clear they were about their values as they relate to the risks and benefits associated with treatment choices. This factor was labeled Factors Associated with Decision Uncertainty. A Cronbach’s alpha was calculated on items 1-5 of the Decisional Conflict Scale. These 6 items had a
Cronbach’s alpha of .885. Thus, these items had sufficient equivalence to warrant their inclusion in the model. A Factors Associated with Decision Uncertainty scale was calculated by summing these 5 items and dividing by 5, the number of items.

Factor 2 items were consistent with the Effective Decision subscale of the Decisional Conflict Scale and were labeled Decision Effectiveness. A Cronbach’s alpha was calculated for these items (13-16 of the DCS). These four items had a Cronbach’s alpha of .885. These items also had sufficient equivalence to be included in the model. A Decision Effectiveness scale was calculated by summing the 4 items and dividing by 4, the number of items.

Factor 3 items were consistent with the Uncertainty subscale of the Decisional Conflict Scale and were labeled Decision Uncertainty. A Cronbach’s alpha was then calculated on items 10-12 of the Decisional Conflict Scale. These three items had a Cronbach’s alpha of .886. Cronbach’s alpha of .903. Thus, the decisional uncertainty items had sufficient equivalence to warrant their inclusion in the model. The Decision Uncertainty scale was calculated by summing scores from the 3 Decisional Conflict Scale items and dividing by 3, the number of items.

In summary, based on factor analysis and relevancy to research variables, the Decisional Conflict Scale was used to measure factors associated with decision uncertainty, decision uncertainty, and decision effectiveness. The reliability of each of the scales used to measure factors associated with decision uncertainty, decision uncertainty, and decision effectiveness was high with Cronbach’s alpha above .88 for each scale. These variables were used in all analyses.
Ways of Coping Revised Questionnaire (approach and avoidance coping). A principal components factor analysis was conducted on the 66-item Ways of Coping Revised Questionnaire. An examination of the Scree plot revealed a noticeable descent after the third factor. The Scree plot is shown in Appendix L. The principal components analysis was recalculated limiting the extraction to three factors. This 3-factor structure explained 32.6% of the variance in coping behaviors. The item means ranged from .038 to 2.01 with standard deviations ranging from .038 to 1.18. Items with factor loadings above .55 were retained for each of the three factors. This resulted in a 25-item Ways of Coping Revised Questionnaire. Another principal components factor analysis was conducted on the remaining items. This 3-factor structure accounted for 49.7% of the variance in the matrix. The item means ranged from .105 to 1.77 with standard deviations ranging from .414 to 1.04. The rotated component matrix and the questions representing each component are presented in table 5.
Table 5

Rotated Component Matrix for the revised 25-item Ways of Coping Revised Questionnaire

<table>
<thead>
<tr>
<th>Item No.</th>
<th>Item</th>
<th>Component 1</th>
<th>Component 2</th>
<th>Component 3</th>
</tr>
</thead>
<tbody>
<tr>
<td>23</td>
<td>Changed or grew as a person in a good way.</td>
<td>.776</td>
<td>-.106</td>
<td>.239</td>
</tr>
<tr>
<td>39</td>
<td>Changed something so things would turn out all right.</td>
<td>.746</td>
<td>-.010</td>
<td>-.011</td>
</tr>
<tr>
<td>56</td>
<td>I changed something about myself.</td>
<td>.688</td>
<td>.236</td>
<td>.140</td>
</tr>
<tr>
<td>30</td>
<td>I came out of the experience better than when I went in.</td>
<td>.687</td>
<td>-.050</td>
<td>.086</td>
</tr>
<tr>
<td>20</td>
<td>I was inspired to do something creative.</td>
<td>.664</td>
<td>-.064</td>
<td>.238</td>
</tr>
<tr>
<td>38</td>
<td>Rediscovered what is important in life.</td>
<td>.657</td>
<td>.240</td>
<td>.190</td>
</tr>
<tr>
<td>19</td>
<td>I told myself things that helped me to feel better.</td>
<td>.657</td>
<td>.106</td>
<td>.056</td>
</tr>
<tr>
<td>45</td>
<td>Talked to someone about how I was feeling.</td>
<td>.609</td>
<td>.108</td>
<td>-.135</td>
</tr>
<tr>
<td>28</td>
<td>I let my feelings out somehow.</td>
<td>.588</td>
<td>.316</td>
<td>-.305</td>
</tr>
<tr>
<td>31</td>
<td>Talked to someone who could do something concrete about the problem.</td>
<td>.584</td>
<td>-.016</td>
<td>-.082</td>
</tr>
<tr>
<td>46</td>
<td>Stood my ground and fought for what I wanted.</td>
<td>.554</td>
<td>.043</td>
<td>-.264</td>
</tr>
<tr>
<td>58</td>
<td>Wished that the situation would go away or somehow be over with.</td>
<td>-.038</td>
<td>.754</td>
<td>.234</td>
</tr>
<tr>
<td>12</td>
<td>Went along with fate; sometimes I just have bad luck.</td>
<td>.044</td>
<td>.723</td>
<td>.113</td>
</tr>
<tr>
<td>57</td>
<td>I daydreamed or imagined a better time or place than the one I was in.</td>
<td>.164</td>
<td>.702</td>
<td>.128</td>
</tr>
<tr>
<td>59</td>
<td>Had fantasies or wishes about how things might turn out.</td>
<td>.215</td>
<td>.663</td>
<td>.150</td>
</tr>
<tr>
<td>47</td>
<td>Took it out on other people.</td>
<td>-.079</td>
<td>.651</td>
<td>-.120</td>
</tr>
<tr>
<td>55</td>
<td>Wished that I could change what had happened or how I felt.</td>
<td>.133</td>
<td>.648</td>
<td>.198</td>
</tr>
<tr>
<td>9</td>
<td>Criticized or lectured myself.</td>
<td>.052</td>
<td>.633</td>
<td>-.127</td>
</tr>
<tr>
<td>17</td>
<td>I expressed anger to the person(s) who caused the problem.</td>
<td>.094</td>
<td>.623</td>
<td>-.261</td>
</tr>
<tr>
<td>25</td>
<td>I apologized or did something to make up.</td>
<td>-.024</td>
<td>.583</td>
<td>.285</td>
</tr>
<tr>
<td>50</td>
<td>Refused to believe that it had happened.</td>
<td>-.176</td>
<td>.578</td>
<td>.217</td>
</tr>
<tr>
<td>40</td>
<td>Avoided being with people in general.</td>
<td>.319</td>
<td>.574</td>
<td>-.168</td>
</tr>
<tr>
<td>14</td>
<td>I tried to keep my feelings to myself.</td>
<td>-.083</td>
<td>.206</td>
<td>.794</td>
</tr>
<tr>
<td>54</td>
<td>I tried to keep my feelings from interfering with other things too much.</td>
<td>.023</td>
<td>.256</td>
<td>.667</td>
</tr>
<tr>
<td>43</td>
<td>Kept others from knowing how bad things were.</td>
<td>.314</td>
<td>-.085</td>
<td>.660</td>
</tr>
</tbody>
</table>

Extraction Method: Principal Component Analysis.
Rotation Method: Varimax with Kaiser Normalization.
Rotation converged in 4 iterations.

Component 1 (highlighted/underlined) = Approach Coping Behaviors items
Component 2 (highlighted/underlined) =Avoidance Coping Behaviors items
Component 3 (highlighted) = Excluded from future analyses.

Note: Matrix includes only items from the Ways of Coping revised questionnaire with loadings above .550.
The 3-factor structure was then examined for relevancy to the study variables. All 11 items that loaded on Factor 1 were from the original Approach Coping subscale except for item 19 (“I told myself things that made me feel better”). This item did not factor on any of the original subscales identified by Lazarus and Folkman. Because this item could be interpreted as a positive self-talk and thus an approach coping behavior, the item was retained.

A Cronbach’s alpha was then calculated for items 19, 20, 23, 28, 30, 31, 38, 39, 45, 46, and 56 on the Ways of Coping Revised Questionnaire. These 11 items had a Cronbach’s alpha of .870. Thus, the approach coping items had sufficient equivalence to warrant their inclusion in the model. An Approach Coping scale was calculated by summing these 11 items and dividing by 11, the number of items.

All items that loaded onto Factor 2 were from the original Avoidance Coping subscale except for three items (17, 55, and 57). Item 17 (“I expressed anger to the person(s) who caused the problem”) is identified as an approach coping behavior by Lazarus and Folkman. While in some situations this behavior is consistent with approach behavior, in this population, a person(s) is (are) not the cause of the problem and this behavior is more consistent with avoidance coping behavior. Two of the items 55 and 57 (“Wished that I could change what had happened or how I felt” and “I daydreamed or imagined a better time or place than the one I was in”) were not included in any of the original subscales identified by Lazarus and Folkman. However, wishing and daydreaming are consistent with avoidance coping behaviors. All of the above three items are consistent with the theoretical model and were included in the avoidance coping behavior variable.
A Cronbach’s alpha was calculated for items previously confirmed by factor analysis to represent avoidance coping. The items included numbers 9, 12, 17, 25, 40, 47, 50, 55, 57, 58, and 59 of the Ways of Coping Revised Questionnaire. These 11 items had a Cronbach’s alpha of .870. Thus, these items had sufficient equivalence to warrant their inclusion in the model. An Avoidance Coping scale was calculated by summing these 11 items and dividing by 11, the number of items.

Items that loaded on Factor 3 were reviewed and eliminated. As stated previously, the items included in the first and second components conceptually represent approach- and avoidance-coping behaviors well. In addition, reliability testing of factor 3 revealed a low Cronbach’s alpha (.705). Items from Factor 1 (approach coping behavior) and items from Factor 2 (avoidance coping behavior) were used for hypotheses testing.

In summary, items 1, 4, 5, 6, 10, and 11 of the Impact of Event Scale represent subjective stress; items 1-5 of the Decisional Conflict Scale represent factors associated with decision uncertainty; items 10-12 of the Decisional Conflict Scale represent decision uncertainty, items 13-16 of the Decisional Conflict Scale represent decision effectiveness; items 19, 20, 23, 28, 30, 31, 38, 39, 45, 46, and 56 of the Ways of Coping Revised Questionnaire represent approach coping behaviors, and items 9, 12, 17, 25, 40, 47, 50, 55, 57, 58, and 59 of the Ways of Coping Revised Questionnaire represent avoidance coping behaviors. Using these items, scales were calculated to represent their respective variables and were used for hypothesis testing.

Description of Participants

All participants in this study came to a high risk breast cancer clinic in southwestern Pennsylvania for a breast cancer risk assessment. These women were
unaffected with breast cancer. Each woman’s risk was determined by clinic staff and was estimated to be above 1.7% over the next five years. Of the 107 women who met the inclusion criteria and were referred for potential study participation, 105 participated. This resulted in an excellent total response rate of 98.1%. Most women (88 of 105) completed the questionnaire packet at the clinic. The other 17 women were unsure about their treatment choice. These women also completed all items at the clinic with the exception of selected items related to information sources used, decision effectiveness, and treatment choice. A one-page questionnaire with these items was given to the woman to return after she made a treatment choice. All but one of the 17 women returned this take-home questionnaire.

The ages of the women ranged from 35-72 years with a mean and mode of 52. The majority were married (74.3%), Caucasian (97.1%), highly educated (54.3% had a bachelor’s degree or higher), employed fulltime (64.8%), and employed outside the home (79.1%). Nearly three quarters of the women (76.2%) had children. About a third of the women had a child 17 years old or younger. Several women had at least one first-degree relative who was affected with breast cancer (41.9%) and who died of breast cancer (35.2%). A detailed summary of these and other sociodemographic variables is presented in Appendix M.

Preliminary Results

Description of Main Study Variables

Descriptive information for interval level study variables are presented in table 6. The table is followed by a discussion of each of the main study variables.
Table 6

*Descriptive Information for Interval Level Study Variables (N=105)*

<table>
<thead>
<tr>
<th>Variable</th>
<th>Potential score</th>
<th>Score ranges</th>
<th>Mean</th>
<th>Standard deviation</th>
</tr>
</thead>
<tbody>
<tr>
<td>Subjective 5-year risk</td>
<td>1-14</td>
<td>1-9</td>
<td>2.38</td>
<td>1.56</td>
</tr>
<tr>
<td>Subjective lifetime-risk</td>
<td>1-14</td>
<td>1-12</td>
<td>4.40</td>
<td>2.54</td>
</tr>
<tr>
<td>Subjective stress</td>
<td>0-5</td>
<td>0-4.33</td>
<td>1.35</td>
<td>1.15</td>
</tr>
<tr>
<td>Factors associated with decision uncertainty</td>
<td>1-5</td>
<td>1-3.2</td>
<td>1.65</td>
<td>.56</td>
</tr>
<tr>
<td>Decision uncertainty</td>
<td>1-5</td>
<td>1-4.67</td>
<td>2.11</td>
<td>.93</td>
</tr>
<tr>
<td>Decision effectiveness*</td>
<td>1-5</td>
<td>1-3</td>
<td>1.68</td>
<td>.54</td>
</tr>
</tbody>
</table>

* N = 104

The majority of women (74.3%) perceived their odds for developing breast cancer over the next five years (subjective 5-year risk) as 5 in 100 (5%), or less, and their odds over a lifetime (subjective lifetime-risk) as 30 in 100 (30%), or less. There were 79 women (75.7%) whose objective risk was calculated using the Gail Model, 22 (21%) whose risk was based on having lobular carcinoma in situ, and 4 (3.8%) whose risk was based on having the BRCA gene. The overall stress level was low to moderate. Of a possible mean score range of 0-5 for subjective stress, about one-half (48.6%) of the women had scores of 1 or less. The majority of women (85.7%) had factors associated with decision uncertainty scores of ≤ 2. Considering 1 = *strongly agree* and 2 = *agree* for each item, these scores indicate the majority of women felt knowledgeable and were clear about their values related to the treatment options and their associated risks and benefits. Using this same *strongly agree* and *agree* definition, more than half (60%) of the women had mean decision uncertainty scores of 2 or lower. While this suggests that most women were certain about their decision, the other 40% had mean scores above 2 suggesting they
were not as certain about their decision. The mean approach coping scores were much higher than the avoidance coping scores with means of 1.21 and .48, respectively. The avoidance coping scores were overall low with only 13.3% of the mean scores ≥ 1. Approach coping scores were moderately high with 62.9% of the mean scores ≥ 1. The majority of women (85.7%, n = 104) had mean decision effectiveness scores of ≤ 2. Scores less than 2 indicate the woman strongly agreed or agreed she made an effective decision. Of the 104 women who reported their final treatment choice, 56 (53.8%) opted for surveillance, 45 (43.3%) opted to take Tamoxifen or Roloxifene, and 3 (2.9%) opted for bilateral prophylactic mastectomy. It is important to note that only women who were BRCA positive were given the option of prophylactic mastectomy.

**Associations Between Study Variables**

A Pearson $r$ was used to examine the relationships between main study variables. The following scale was used to interpret the strength of the relationships: <.30 = weak; .30 – .50 = moderate; and > .50 = strong. The level of significance was set at $p < .01$ for all relationships. A summary of the findings are presented in table 7.

Relationships that were strong or moderate included the following. There was a strong positive correlation between subjective 5-year and lifetime risk ($r = .675, p = .000$) and between decision uncertainty and decision effectiveness ($r = .542, p < .000$). A moderate correlation was found between subjective 5-year risk and treatment choice ($r = .323, p = .001$); subjective stress and both approach ($r = .329, p = .001$) and avoidance coping ($r = .385, p = .000$); factors associated with decision uncertainty and both decision uncertainty ($r = .454, p = .000$) and decision effectiveness ($r = .395, p = .000$). A weak relationship was evident between all other study variables. However, some of these
### Table 7

*Pearson Product Moment Correlations Matrix Between Main Study Variables*

<table>
<thead>
<tr>
<th></th>
<th>Subjective 5-year risk</th>
<th>Subjective lifetime risk</th>
<th>Objective risk</th>
<th>Subjective stress</th>
<th>Factors associated w decision uncertainty</th>
<th>Decision uncertainty</th>
<th>Approach coping</th>
<th>Avoidance coping</th>
<th>Decision effectiveness</th>
<th>Treatment choice</th>
</tr>
</thead>
<tbody>
<tr>
<td>Subjective 5-year risk</td>
<td>$r$ 1</td>
<td>.675**</td>
<td>.181</td>
<td>.094</td>
<td>.077</td>
<td>.081</td>
<td>.091</td>
<td>.140</td>
<td>.072</td>
<td>.323**</td>
</tr>
<tr>
<td>$p$</td>
<td>.000</td>
<td>.065</td>
<td>.341</td>
<td>.437</td>
<td>.409</td>
<td>.355</td>
<td>.155</td>
<td>.465</td>
<td>.001</td>
<td></td>
</tr>
<tr>
<td>Subjective lifetime-risk</td>
<td>$r$ 1</td>
<td>.064</td>
<td>.020</td>
<td>-.032</td>
<td>.084</td>
<td>.132</td>
<td>.081</td>
<td>.053</td>
<td>.218*</td>
<td></td>
</tr>
<tr>
<td>Objective risk</td>
<td>$r$ 1</td>
<td>.606</td>
<td>.838</td>
<td>.736</td>
<td>.300</td>
<td>.743</td>
<td>.088</td>
<td>.005</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Subjective stress</td>
<td>$r$ 1</td>
<td>.039</td>
<td>.039</td>
<td></td>
<td>.072</td>
<td>.329**</td>
<td>.385**</td>
<td>-.026</td>
<td>.108</td>
<td></td>
</tr>
<tr>
<td>$p$</td>
<td>.690</td>
<td>.463</td>
<td>.001</td>
<td>.000</td>
<td>.793</td>
<td>.005</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Factors associated w decision uncertainty</td>
<td>$r$ 1</td>
<td></td>
<td></td>
<td>.454**</td>
<td>.264**</td>
<td>.122</td>
<td>.395**</td>
<td>-.255**</td>
<td></td>
<td></td>
</tr>
<tr>
<td>$p$</td>
<td>.000</td>
<td>.007</td>
<td>.215</td>
<td>.000</td>
<td>.793</td>
<td>.005</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Decision uncertainty</td>
<td>$r$ 1</td>
<td></td>
<td></td>
<td></td>
<td>-.265**</td>
<td>.205*</td>
<td>.542**</td>
<td>-.208*</td>
<td></td>
<td></td>
</tr>
<tr>
<td>$p$</td>
<td>.006</td>
<td>.036</td>
<td>.000</td>
<td>.035</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Approach coping</td>
<td>$r$ 1</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>.102</td>
<td>-.291**</td>
<td>.124</td>
<td></td>
<td></td>
</tr>
<tr>
<td>$p$</td>
<td>.300</td>
<td>.003</td>
<td>.209</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Avoidance coping</td>
<td>$r$ 1</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>.102</td>
<td>.086</td>
<td>.385</td>
<td></td>
</tr>
<tr>
<td>$p$</td>
<td>.300</td>
<td>.003</td>
<td>.209</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Decision effectiveness</td>
<td>$r$ 1</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>-.143</td>
<td>.147</td>
<td></td>
</tr>
<tr>
<td>$p$</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Treatment choice</td>
<td>$r$ 1</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
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<td></td>
</tr>
<tr>
<td>$p$</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

*$ = N = 104$, all others $= 105$  
$r = Pearson Product Moment Correlation$  
$* = p \leq .05$  
$** = p \leq .01$
relationships were marginally significant at the .05 level as reported in the next paragraph.

Table 7 was reviewed for significant relationships between the study variables. Relationships that were significant at the .01 level of significance are reported first followed by marginally significant relationships at the .05 level. The following correlations were found at the .01 significance level:

- Treatment choice was positively correlated with subjective 5-year risk ($r = .323, p = .001$) and objective risk ($r = .271, p = .005$); and negatively correlated with factors associated with decision uncertainty ($r = -.255, p = .009$).

- Decision effectiveness was positively correlated with factors associated with decision uncertainty ($r = .395, p = .000$) and decision uncertainty ($r = .542, p = .000$); and negatively correlated with approach coping behavior ($r = -.291, p = .003$).

- Avoidance coping was positively correlated with subjective stress ($r = .385, p = .000$).

- Approach coping was positively correlated with subjective stress ($r = .329, p = .001$) and factors associated with uncertainty ($r = .264, p = .007$); and negatively correlated with decision uncertainty ($r = -.265, p = .006$).

- Decision uncertainty was positively correlated with factors associated with decision uncertainty ($r = .454, p = .000$).

- Subjective lifetime-risk was positively correlated with subjective 5-year risk ($r = .675, p = .000$).
Three relationships were significant at the .05 level of significance and thus are considered marginally significant. These relationships included the following correlations:

- Treatment choice was positively correlated with subjective lifetime-risk (r = .218, p = .026) and negatively correlated with decision uncertainty (r = -.208, p = .035).

- Avoidance coping was positively correlated with decision uncertainty (r = .205, p = .036).

The above findings indicate there is a linear relationship between the variables listed.

A Pearson r correlation coefficient was used to examine relationships between selected demographic variables (age, marital status, race, education, children 17 and under, affected first-degree relative(s), and first-degree relative(s) who died of breast cancer) and the main study variables. The following scale was used to interpret the strength of the relationships: <.30 = weak; .30 – .50 = moderate; and > .50 = strong. The level of significance was set at p <.01 for all relationships. A weak but significant positive relationship was found between women with first-degree relative(s) affected with breast cancer (r = .260, p = .007) and a marginally significant relationship was found between women with first-degree relative(s) who died of breast cancer (r = .222, p = .023) and approach coping behavior. A weak but marginally significant positive relationship was also found between level of education and decision uncertainty (r = .246, p = .011).
Hypothesis Testing

The purpose of this study was to examine the relationships between and among threat of breast cancer, subjective stress, decisional conflict, type of coping, and decisional outcomes in women deciding about treatment options for their increased risk of breast cancer. Study hypotheses are restated in the next section followed by the results for hypothesis testing.

Restated Hypotheses

Hypotheses are restated to include the separation of decisional conflict into two separate variables, decision uncertainty and factors associated with uncertainty.

H$_1$: Subjective and objective cancer risk, subjective stress, decisional conflict (decision uncertainty and factors associated with uncertainty) will explain a significant amount of the variance in approach and avoidance coping behaviors.

H$_2$: Subjective and objective cancer risk, subjective stress, decisional conflict (decision uncertainty and factors associated with uncertainty) will explain a significant amount of the variance in treatment choice and in decision-making effectiveness.

H$_3$: Approach and avoidance coping behaviors will explain a significant amount of the variance in treatment choice and in decision-making effectiveness.

H$_4$: Subjective and objective cancer risk, subjective stress, decisional conflict (decision uncertainty and factors associated with uncertainty) will explain a significant amount of the variance in treatment choice and in decision-
making effectiveness controlling for approach and avoidance coping behaviors.

H5: Hypotheses 1-4 will be evaluated using outcome measures as residuals from relevant demographic variables.

Multiple regression was used for testing study hypotheses. All independent variables were entered as a set to calculate variance accounted for in the dependent variable. Then, nonsignificant predictors were removed from the analysis and the remaining independent variables were regressed on the dependent variable. Hierarchical regression was then used to examine the unique variance in the dependent variable that was accounted for by each independent variable in the model. Each hypothesis, statistical test, and results are presented in this section.

H1: Subjective and objective cancer risk, subjective stress, decision uncertainty and factors associated with uncertainty will explain a significant amount of the variance in approach and avoidance coping behaviors.

Two multiple regression equations were used to test hypothesis 1. The first equation was calculated using approach coping behavior as the dependent variable and the second equation was calculated using avoidance coping as the dependent variable. In the first equation, subjective 5-year risk, subjective lifetime-risk, objective risk, subjective stress, decision uncertainty and factors associated with decision uncertainty were entered simultaneously to determine the variance accounted for in approach coping behavior. This model accounted for 25.2% ($F_{6,98} = 5.51$, $p = .000$) of the variance in approach coping behavior. Only two predictors were significant: subjective stress and decision uncertainty. The four non-significant predictors: subjective 5-year risk,
subjective lifetime-risk, objective risk, and factors associated with decision uncertainty were excluded from the model. Subjective stress and decision uncertainty were then regressed together on approach coping behavior. In this model, 19.2% of the variance in approach coping behavior was explained by subjective stress and decision uncertainty ($F_{2,102} = 12.15, p = .000$). Both subjective stress ($\beta = .350, p = .000$) and decision uncertainty ($\beta = -.291, p = .002$) were significant predictors for approach coping behavior as well.

Hierarchial regression was then used to examine the unique variance in the dependent variable (approach coping) accounted for by each independent variable (subjective stress and decision uncertainty) in the model. Model summaries of these analyses are presented in Table 8.

Table 8

*Model Summaries of the Unique Variance in Approach Coping Behaviors Accounted for by Subjective Stress and Decision Uncertainty*

**Model 1**

<table>
<thead>
<tr>
<th>Order and Variable</th>
<th>R</th>
<th>R square</th>
<th>R square change</th>
<th>F change</th>
<th>df1</th>
<th>df2</th>
<th>Sig F change</th>
</tr>
</thead>
<tbody>
<tr>
<td>1 Subjective stress</td>
<td>.329</td>
<td>.108</td>
<td>.108</td>
<td>12.51</td>
<td>1</td>
<td>103</td>
<td>.001</td>
</tr>
<tr>
<td>2 Decision uncertainty</td>
<td>.439</td>
<td>.192</td>
<td>.084</td>
<td>10.61</td>
<td>1</td>
<td>102</td>
<td>.002</td>
</tr>
</tbody>
</table>

**Model 2**

<table>
<thead>
<tr>
<th>Order and Variable</th>
<th>R</th>
<th>R square</th>
<th>R square change</th>
<th>F change</th>
<th>df1</th>
<th>df2</th>
<th>Sig F change</th>
</tr>
</thead>
<tbody>
<tr>
<td>1 Decision uncertainty</td>
<td>.265</td>
<td>.070</td>
<td>.070</td>
<td>12.51</td>
<td>1</td>
<td>103</td>
<td>.006</td>
</tr>
<tr>
<td>2 Subjective stress</td>
<td>.439</td>
<td>.192</td>
<td>.122</td>
<td>10.61</td>
<td>1</td>
<td>102</td>
<td>.000</td>
</tr>
</tbody>
</table>

Model 1 = subjective stress entered first; Model 2 = decision uncertainty added first
Decision uncertainty uniquely explained 8.4% of the variance in approach coping when subjective stress was entered first. Subjective stress uniquely explained 12.2% of the variance when decision uncertainty was entered first.

In the next equation, the same variables were entered as independent variables and avoidance coping behavior was entered as the dependent variable. This model explained 18.9% of the variance in avoidance coping behavior ($F_{6, 98} = 3.80, p = .002$). Only one variable, subjective stress, was a significant predictor. All other independent variables were excluded from the equation. Subjective stress was then regressed on avoidance coping behavior. In this model, subjective stress explained 14.8% of the variance ($F_{1, 103} = 17.91, p = .000$) in avoidance coping behavior and was a significant predictor ($\beta = .385, p = .000$) of avoidance coping. In summary, the women’s level of subjective stress about their breast cancer risk and treatment options and their level of decision uncertainty were significant predictors for using approach coping behavior. However, the women’s subjective stress level was the only significant predictor for using avoidance coping behavior.

$H_2$: Subjective and objective cancer risk, subjective stress, decision uncertainty and factors associated with uncertainty will explain a significant amount of the variance in treatment choice and in decision-making effectiveness.

Two multiple regression equations were used to test hypothesis 2. The first equation was calculated using treatment choice as the dependent variable and the second equation was calculated using decision effectiveness as the dependent variable. In the first equation, subjective 5-year risk, subjective lifetime-risk, objective risk, subjective stress, decision uncertainty and factors associated with decision uncertainty were entered
as a set to calculate the variance accounted for in treatment choice. This model accounted for 25.6% of the variance in treatment choice ($F_{6, 97} = 5.55, p = .000$). The non-significant predictors were excluded from the model and the three significant predictors (subjective 5-year risk, factors associated with decision uncertainty, and objective risk) were regressed simultaneously on treatment choice. In this model, 23.1% of the variance in treatment choice ($F_{3, 100} = 10.04, p = .000$) was explained. Subjective 5-year risk ($\beta = .306, p = .001$), factors associated with decisional uncertainty ($\beta = -.284, p = .002$), and objective risk ($\beta = .223, p = .014$) significantly contributed to the model at the .05 level. However, only subjective 5-year risk and factors associated with decision uncertainty were significant at the .01 level of significance.

Hierarchical regression was then used to examine the unique variance in the dependent variable (treatment choice) accounted for by each independent variable (subjective 5-year risk, objective risk, and factors associated with uncertainty) in the model. Model summaries of these analyses are presented in table 9.

A review of the models and R square changes in table 9 shows the percent of variance uniquely explained by each of the variables when controlling for the other two predictor variables. Objective risk uniquely explained 4.8%, subjective 5-year risk uniquely explained 9.0%, and factors associated with decision uncertainty uniquely explained 8.0% of the variance when the other two predictor variables were controlled.
Table 9

*Model Summaries of the Unique Variance in Treatment Choice Accounted for by Subjective 5-year Risk, Factors Associated With Decision Uncertainty, and Objective Risk*

**Model 1**

<table>
<thead>
<tr>
<th>Order and Variable</th>
<th>R</th>
<th>R square</th>
<th>R square change</th>
<th>F change</th>
<th>df1</th>
<th>df2</th>
<th>Sig F change</th>
</tr>
</thead>
<tbody>
<tr>
<td>1 Subjective 5-year risk</td>
<td>.323</td>
<td>.104</td>
<td>.104</td>
<td>11.85</td>
<td>1</td>
<td>102</td>
<td>.001</td>
</tr>
<tr>
<td>2 Factors associated with decision uncertainty</td>
<td>.428</td>
<td>.183</td>
<td>.079</td>
<td>9.81</td>
<td>1</td>
<td>101</td>
<td>.002</td>
</tr>
<tr>
<td>3 Objective risk</td>
<td>.481</td>
<td>.231</td>
<td>.048</td>
<td>6.25</td>
<td>1</td>
<td>100</td>
<td>.014</td>
</tr>
</tbody>
</table>

**Model 2**

<table>
<thead>
<tr>
<th>Order and Variable</th>
<th>R</th>
<th>R square</th>
<th>R square change</th>
<th>F change</th>
<th>df1</th>
<th>df2</th>
<th>Sig F change</th>
</tr>
</thead>
<tbody>
<tr>
<td>1 Factors associated with decision uncertainty</td>
<td>.255</td>
<td>.065</td>
<td>.065</td>
<td>7.11</td>
<td>1</td>
<td>102</td>
<td>.009</td>
</tr>
<tr>
<td>2 Objective risk</td>
<td>.376</td>
<td>.141</td>
<td>.076</td>
<td>8.97</td>
<td>1</td>
<td>101</td>
<td>.000</td>
</tr>
<tr>
<td>3 Subjective 5-year risk</td>
<td>.481</td>
<td>.231</td>
<td>.090</td>
<td>11.72</td>
<td>1</td>
<td>100</td>
<td>.000</td>
</tr>
</tbody>
</table>

**Model 3**

<table>
<thead>
<tr>
<th>Order and Variable</th>
<th>R</th>
<th>R square</th>
<th>R square change</th>
<th>F change</th>
<th>df1</th>
<th>df2</th>
<th>Sig F change</th>
</tr>
</thead>
<tbody>
<tr>
<td>1 Objective risk</td>
<td>.271</td>
<td>.073</td>
<td>.073</td>
<td>8.05</td>
<td>1</td>
<td>102</td>
<td>.005</td>
</tr>
<tr>
<td>2 Subjective 5-year risk</td>
<td>.389</td>
<td>.151</td>
<td>.078</td>
<td>9.27</td>
<td>1</td>
<td>101</td>
<td>.003</td>
</tr>
<tr>
<td>3 Factors associated with decision uncertainty</td>
<td>.481</td>
<td>.231</td>
<td>.080</td>
<td>10.45</td>
<td>1</td>
<td>100</td>
<td>.002</td>
</tr>
</tbody>
</table>

Model 1 = Controlling for subjective 5-year risk and factors associated with uncertainty
Model 2 = Controlling for factors associated with uncertainty and objective risk
Model 3 = Controlling for objective risk and subjective 5-year risk

In the second equation, the same independent variables were entered as a set to calculate the variance accounted for in decision effectiveness. The model explained
34.9% of the variance in decision effectiveness ($F_{6, 98} = 8.77, p = .000$). Four variables (subjective 5-year risk, subjective lifetime-risk, objective risk, and subjective stress) were not significant predictors and were excluded from the model. The significant independent variables, factors associated with decision uncertainty and decision uncertainty, were then regressed simultaneously on decision effectiveness.

Decision uncertainty and factors associated with decision uncertainty explained 32.2% of the variance in decision effectiveness ($F_{2,102} = 24.17, p = .000$). The primary predictor for decision effectiveness in this model is decision uncertainty ($β = .456, p = .000$) with factors associated with uncertainty making a smaller, marginally significant, contribution to the overall model ($β = .188, p = .04$).

Hierarchical regression was then used to examine the unique variance in the dependent variable (decision effectiveness) accounted for by each significant independent variable (decision uncertainty and factors associated with uncertainty) in the model. Model summaries of these analyses are presented in table 10.

Factors associated with decision uncertainty uniquely explained 2.8% of the variance when decision uncertainty was controlled. Decision uncertainty uniquely explained 16.5% of the variance when factors associated with uncertainty was controlled. Thus the major predictor for decision effectiveness was decision uncertainty.
Table 10

Model Summaries of the Unique Variance in Decision Effectiveness Accounted for by Decision Uncertainty and Factors Associated With Uncertainty

Model 1

<table>
<thead>
<tr>
<th>Order and Variable</th>
<th>R</th>
<th>R square</th>
<th>R square change</th>
<th>F change</th>
<th>df1</th>
<th>df2</th>
<th>Sig F change</th>
</tr>
</thead>
<tbody>
<tr>
<td>1 Decision uncertainty</td>
<td>.542</td>
<td>.293</td>
<td>.293</td>
<td>42.78</td>
<td>1</td>
<td>103</td>
<td>.000</td>
</tr>
<tr>
<td>2 Factors associated with decision uncertainty</td>
<td>.567</td>
<td>.322</td>
<td>.028</td>
<td>4.23</td>
<td>1</td>
<td>102</td>
<td>.042</td>
</tr>
</tbody>
</table>

Model 2

<table>
<thead>
<tr>
<th>Order and Variable</th>
<th>R</th>
<th>R square</th>
<th>R square change</th>
<th>F change</th>
<th>df1</th>
<th>df2</th>
<th>Sig F change</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Factors associated with decision uncertainty</td>
<td>.395</td>
<td>.156</td>
<td>.156</td>
<td>19.10</td>
<td>1</td>
<td>103</td>
<td>.000</td>
</tr>
<tr>
<td>2. Decision uncertainty</td>
<td>.567</td>
<td>.322</td>
<td>.165</td>
<td>24.83</td>
<td>1</td>
<td>102</td>
<td>.000</td>
</tr>
</tbody>
</table>

Model 1 = Controlling for decision uncertainty
Model 2 = Controlling for factors associated with decision uncertainty

H₃: Approach and avoidance coping behaviors will explain a significant amount of the variance in treatment choice and in decision-making effectiveness.

Two multiple regression equations were used to test hypothesis 3. The first equation was calculated using treatment choice as the dependent variable. The second equation was calculated using decision effectiveness as the dependent variable. Approach and avoidance coping behaviors were entered together to calculate the explained variance in treatment decision.

The model explained only 1.9% of the variance in treatment choice (F₂,₁₀₁ = .985, p = .377). Neither approach coping behaviors nor avoidance coping behaviors were significant predictors for treatment choice.
In the second equation, approach coping behavior and avoidance coping behavior were regressed together on decision effectiveness. The model explained 11.2% of the variance in decision effectiveness ($F_{2,102} = 6.46, p = .002$). Avoidance coping was not a significant predictor and was excluded in the model. Approach coping was then regressed on decision effectiveness. Approach coping behavior explained a small but significant amount of the variance in decision effectiveness with an $R^2$ of .085 ($F_{1,103} = 9.51, p = .003$). In summary, approach coping behavior is a significant predictor of decision effectiveness ($\beta = -.291$, $p = .003$); avoidance coping behavior is not.

H$_4$: Subjective and objective cancer risk, subjective stress, decision uncertainty and factors associated with uncertainty will explain a significant amount of the variance in treatment choice and in decision-making effectiveness controlling for approach and avoidance coping behaviors.

The results from the regression equation used to test hypothesis 3 suggested neither approach nor avoidance coping behavior predicted treatment choice. Thus, a regression equation using treatment choice as the dependent variable was not calculated for hypothesis 4.

Only predictor variables for decision effectiveness from hypothesis 2 (decision uncertainty and factors associated with uncertainty) and hypothesis 3 (approach coping) were included as independent variables in the equation for hypothesis 4. In the first step, approach coping behavior was regressed on decision effectiveness. In the second step, decision uncertainty and factors associated with uncertainty were added to the model as independent variables. The model summary is presented in table 11.
Table 11

Model Summary of Multiple Regression of Decision Uncertainty and Factors Associated with Uncertainty on Decision Effectiveness Controlling for Approach Coping

<table>
<thead>
<tr>
<th>Order and Variable</th>
<th>R</th>
<th>R square</th>
<th>R square change</th>
<th>F</th>
<th>df1</th>
<th>df2</th>
<th>Sig F change</th>
</tr>
</thead>
<tbody>
<tr>
<td>1 Approach coping</td>
<td>.291</td>
<td>.085</td>
<td>.085</td>
<td>9.51</td>
<td>1</td>
<td>103</td>
<td>.003</td>
</tr>
<tr>
<td>2 Factors associated with decision uncertainty</td>
<td>.581</td>
<td>.338</td>
<td>.253</td>
<td>19.29</td>
<td>2</td>
<td>101</td>
<td>.000</td>
</tr>
<tr>
<td>Decision uncertainty</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

In the above model, approach coping behaviors explained 8.5% of the variance in decision effectiveness. Adding decision uncertainty and factors associated with decision uncertainty increased the explained variance to 33.8% with an R² change of .253 (F2, 101, 19.29 = p = .000). However, in this model only decision uncertainty was a significant predictor of decision effectiveness (β = .432, p = .000); factors associated with uncertainty was not a predictor (β = .164, p = .078). Therefore, only decision uncertainty predicted decision effectiveness when controlling for approach coping behavior.

H₅: Hypotheses 1-4 will be evaluated using outcome measures as residuals from relevant demographic variables.

A Pearson r correlation coefficient was calculated on all outcome measures (approach coping, avoidance coping, treatment choice, and decision effectiveness) from hypothesis 1-4 and relevant demographic variables (age, marital status, race, education, children ≤ 17, first degree affected relative, total affected relatives, first degree relative died, and total family members died). A significant relationship was found between first-degree relative affected with breast cancer and approach coping (r = .260, p = .007) and a
marginally significant relationship was found between first-degree relative died of breast cancer and approach coping ($r = .222, p = .023$). Thus, approach coping was the only outcome variable used as the dependent variable to test hypothesis 4. The two sociodemographic variables were then regressed as a set on approach coping and the unstandardized residuals were saved as a variable. This model is presented in table 12.

Table 12

*Model Summary of Multiple Regression of First-degree Relative Affected and First-degree Relative Died on Approach Coping*

<table>
<thead>
<tr>
<th>Variable</th>
<th>R</th>
<th>R square</th>
<th>R square change</th>
<th>F change</th>
<th>df1</th>
<th>df2</th>
<th>Sig F change</th>
</tr>
</thead>
<tbody>
<tr>
<td>First-degree relative affected</td>
<td>.290</td>
<td>.084</td>
<td>.084</td>
<td>4.67</td>
<td>2</td>
<td>102</td>
<td>.012</td>
</tr>
<tr>
<td>First-degree relative died</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

First-degree relative affected and first-degree relative died explained 8.4% of the variance in approach coping behavior ($F_{2, 102} = 4.67 = p = .012$). However, first-degree affected relatives minimally predicted approach coping ($\beta = .203, p = .053$) and first-degree-relative died was not a significant predictor ($\beta = .140, p = .181$) in the model.

In the next step of this analysis the saved residuals from the above equation were treated as the dependent variable. The significant predictors of approach coping from hypothesis 1 (subjective stress and decision uncertainty) were regressed on the saved residuals from the above equation. This model is presented in table 13.
Table 13

Model Summary of Multiple Regression of Subjective Stress and Decision Uncertainty on Sociodemographic Residuals

<table>
<thead>
<tr>
<th>Variable</th>
<th>R</th>
<th>R square</th>
<th>R square change</th>
<th>F change</th>
<th>df1</th>
<th>df2</th>
<th>Sig F change</th>
</tr>
</thead>
<tbody>
<tr>
<td>Subjective Stress</td>
<td>.468</td>
<td>.219</td>
<td>.219</td>
<td>14.31</td>
<td>2</td>
<td>102</td>
<td>.000</td>
</tr>
<tr>
<td>Decision Uncertainty</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Subjective stress and decision uncertainty explained 21.9% of the variance in the residuals ($F_{2, 102}, 14.31 = p = .010$). Both subjective stress ($\beta = .186, p = .000$) and decision uncertainty ($\beta = -.211, p = .000$) explained a significant amount of the variance in the residuals resulting from the regression of first-degree relative affected and first-degree relative died on approach coping behavior. This result indicates that subjective stress and decision uncertainty explained a significant amount of the variance in approach coping after excluding the variance accounted for by first-degree relative affected and first-degree relative died.

In summary, only one outcome variable (approach coping) from hypothesis 1 was significantly related to any of the selected sociodemographic variables. These sociodemographic variables included first-degree relative affected and first-degree relative died. Only two main study variables predicted approach coping (hypothesis 1). These main study variables included subjective stress and decision uncertainty. The two significant sociodemographic variables were regressed on approach coping. The residuals from this equation were treated as the dependent variable and the two predictor study variables (subjective stress and decision uncertainty) for approach coping were regressed on these residuals. The results indicate both subjective stress and decision uncertainty
explained a significant amount of the variance in approach coping after removing the variance explained by first-degree relatives affected and first-degree relatives died.

A second approach was also used to control for first-degree relatives affected and first-degree relatives died. The regression was computed in two steps: in the first step, first-degree relatives affected and first-degree relatives died were entered as control variables and in the second step both subjective stress and decision uncertainty were entered. The model summary is presented in table 14.

Table 14

_Model Summary of Multiple Regression of Subjective Stress and Decision Uncertainty on Decision Effectiveness Controlling for First-Degree Relative Affected and First-Degree Relative Died_

<table>
<thead>
<tr>
<th>Variable</th>
<th>R</th>
<th>R square</th>
<th>R square change</th>
<th>F change</th>
<th>df1</th>
<th>df2</th>
<th>Sig F change</th>
</tr>
</thead>
<tbody>
<tr>
<td>1 First-degree affected</td>
<td>.290</td>
<td>.084</td>
<td>.084</td>
<td>4.67</td>
<td>2</td>
<td>102</td>
<td>.012</td>
</tr>
<tr>
<td>First-degree died</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>2 Subjective stress</td>
<td>.535</td>
<td>.286</td>
<td>.202</td>
<td>14.13</td>
<td>2</td>
<td>101</td>
<td>.000</td>
</tr>
<tr>
<td>Decision uncertainty</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

First-degree relative(s) affected and first-degree relative(s) died explained 8.4% of the variance in approach coping behavior. Adding subjective stress and decision uncertainty resulted in an $R^2$ change of .202 ($F_{2,101} = 14.13$, $p = .000$). Both subjective stress ($\beta = .346$, $p = .000$) and decision uncertainty ($\beta = -.315$, $p = .000$) were significant predictors of approach coping behaviors controlling for first-degree relative(s) affected and first-degree relative(s) who died of breast cancer. In addition, first-degree relative(s)
died of breast cancer was a significant predictor of approach coping behavior ($\beta = .240$, $p = .011$) with the level of significance slightly above .01.

In summary, hypotheses testing revealed significant results for most hypotheses. A summary of the significant findings is presented in table 15.
### Summary of Hypothesis Testing

<table>
<thead>
<tr>
<th>Hypothesis</th>
<th>Significant Findings</th>
</tr>
</thead>
<tbody>
<tr>
<td>H₁: Subjective and objective cancer risk, subjective stress, decision uncertainty and factors associated with uncertainty will explain a significant amount of the variance in approach and avoidance coping behaviors.</td>
<td>Subjective stress and decision uncertainty explained a significant amount of the variance in approach coping behavior. Subjective stress explained a significant amount of the variance in avoidance coping behavior.</td>
</tr>
<tr>
<td>H₂: Subjective and objective cancer risk, subjective stress, decision uncertainty and factors associated with uncertainty will explain a significant amount of the variance in treatment choice and in decision-making effectiveness.</td>
<td>Subjective 5-year risk, factors associated with decision uncertainty, and objective risk explained a significant amount of variance in treatment choice. Decision uncertainty and factors associated with decision uncertainty explained a significant amount of the variance in decision effectiveness.</td>
</tr>
<tr>
<td>H₃: Approach and avoidance coping behaviors will explain a significant amount of the variance in treatment choice and in decision-making effectiveness.</td>
<td>Approach coping explained a small but significant amount of the variance in decision effectiveness.</td>
</tr>
<tr>
<td>H₄: Subjective and objective cancer risk, subjective stress, decision uncertainty and factors associated with uncertainty will explain a significant amount of the variance in treatment choice and in decision-making effectiveness controlling for approach and avoidance coping behaviors.</td>
<td>Decision uncertainty explained a significant amount of the variance in decision effectiveness controlling for approach coping behaviors.</td>
</tr>
<tr>
<td>H₅: Hypotheses 1-4 will be evaluated using outcome measures as residuals from relevant demographic variables.</td>
<td>Both subjective stress and decision uncertainty (from hypothesis 1) significantly explained the variance in the residuals from the sociodemographic variables (first-degree affected and first degree-died) and approach coping behavior equation.</td>
</tr>
</tbody>
</table>
Summary of Findings

The sample in this study consisted of 105 women who came to a high risk breast cancer clinic for a breast cancer risk assessment. More than 98% of the women who met the inclusion criteria participated in the study. There was an outstanding response rate on all of the sociodemographic and study variable items. Participants’ ages ranged from 35 to 72 years old. The majority of the women were married, Caucasian, highly educated, and employed fulltime. About three quarters of the women had children and about a third of the women had at least one child who was 17 years old or younger. Several women had at least one first-degree relative who was affected with breast cancer and who died of breast cancer.

A factor analysis was conducted on items of the Impact of Event Scale, Decisional Conflict Scale, and Ways of Coping Revised Questionnaire. Reliability of the subscales used to measure each variable were examined after factor analysis. There was good reliability for each of the subscales with the standardized Cronbach’s alpha coefficients ranging from .859 - .903.

The majority of women perceived their odds for developing breast cancer over the next five years as 5 in 100 or less and their odds over a lifetime as 30 in 100 or less. There were 79 women whose objective risk was calculated using the Gail Model, 22 whose risk was based on having lobular carcinoma in situ, and 4 whose risk was based on having the BRCA gene. The overall stress level was low to moderate. The majority of women had factors associated with decision uncertainty scores of ≤ 2. More than half of the women had mean decision uncertainty scores of 2 or lower. The mean approach coping scores were much higher than the avoidance coping behavior scores with means
of 1.21 and .48, respectively. The avoidance coping scores were overall low while approach coping scores were moderately high. The majority of women had mean decision effectiveness scores of \( \leq 2 \). Of the 104 women who reported their final treatment choice, 56 opted for surveillance, 45 opted to take Tamoxifen or Roloxifene, and 3 opted for bilateral prophylactic mastectomy.

A Pearson \( r \) was used to examine the relationships between main study variables. Significant positive relationships were found between treatment choice and several other main study variables including subjective 5-year risk, objective risk, and factors associated with decision uncertainty. Decision effectiveness was positively correlated with both decision uncertainty and factors associated with decision uncertainty and negatively correlated with approach coping behavior. Avoidance coping was positively correlated with subjective stress while approach coping was positively correlated with both subjective stress and factors associated with uncertainty and negatively correlated with decision uncertainty. Decision uncertainty and factors associated with decision uncertainty were positively correlated. Lastly, subjective lifetime-risk and subjective 5-year risk were also positively correlated.

Multiple regression was used to test Hypotheses 1 through 4. Each hypothesis was at least partially supported. Subjective stress and decision uncertainty were significant predictors for using approach coping behavior. Only subjective stress significantly predicted the use of avoidance coping behavior. The variance in treatment choice was significantly explained by subjective 5-year risk, factors associated with decision uncertainty, and objective risk, while the variance in decision effectiveness was significantly explained by decision uncertainty and factors associated with decision uncertainty.
uncertainty. Decision uncertainty was a significant predictor for decision effectiveness while factors associated with uncertainty was a marginally significant predictor. Approach coping behavior explained a small but significant amount of the variance in decision effectiveness. When controlling for approach coping behaviors, only decision uncertainty explained a significant amount of the variance in decision effectiveness.

A Pearson Product-moment correlation coefficient was used to examine the relationships between select sociodemographic variables and the main study variables. A weak yet significant positive relationship was found between women with first-degree relative(s) affected with breast cancer and a marginally significant relationship was found between women with first-degree relative(s) who died of breast cancer and approach coping behavior. Using hierarchical regression, both subjective stress and decision uncertainty remained significant predictors of approach coping behaviors controlling for first-degree relative(s) affected and first-degree relative(s) who died of breast cancer. A discussion of these findings as well as limitations and recommendations are presented in the next chapter.
CHAPTER V
DISCUSSION AND CONCLUSIONS

The purpose of this study was to examine the relationships between and among threat of breast cancer, subjective stress, decisional conflict, type of coping, and decisional outcomes in women deciding about treatment options for their increased risk of breast cancer. Variables deriving from these main concepts are described in later sections. Participants were women who came to a breast cancer risk clinic for risk assessment. These 105 women were not affected with breast cancer, but were at an increased risk for developing breast cancer as defined by having a risk of \( \geq 1.7\% \) over the next five years. Data were collected between January, 2007 and August, 2007. A booklet containing Horowitz’s Impact of Event Scale (IES), O’Connor’s Decisional Conflict Scale (DCS), Lazarus and Folkman’s Ways of Coping Revised Questionnaire (WCRQ), and a Sociodemographic questionnaire developed by the researcher was used to gather the data. An overall response rate of 99.9% was obtained on these instruments. This chapter provides a discussion of the findings, implications for nursing and other disciplines, and recommendations for further research.

Measurement Findings

Factor analysis was conducted on all study instruments. Data from this study confirmed a 2-factor structure for the Impact of Event Scale. However, one item was eliminated because it loaded on both factors representing intrusive and avoidance behaviors. This item was part of the original Avoidance subscale. Cronbach’s alphas
were 0.86 for the Intrusive subscale and 0.87 for the Avoidance subscale. These findings are consistent with those reported by Sundin and Horowitz (2002) in their literature review of studies evaluating the psychometric properties of the Impact of Event Scale. They reported a mean Cronbach’s alpha of 0.86 for the Intrusion subscale and a mean of 0.82 for the Avoidance subscale. The current findings are also consistent with those reported in an examination of the psychometric properties of the IES in a group of women who were at-risk for hereditary breast cancer (Thewes et al., 2001) where they reported Cronbach alphas of 0.88 and 0.84 for the Intrusion and Avoidance subscales, respectively. The Avoidance subscale was not used in the current study.

A 3-factor structure was found through factor analysis of the Decisional Conflict Scale (DCS). This finding is consistent with O’Connor’s original validation of the DCS (O’Connor, 1995). However, there were some differences in the items that loaded onto these three factors. Items that loaded on factor 2 and factor 3 were consistent with O’Connor’s Decision Uncertainty subscale and Effective Decision subscale, respectively. But, four items from O’Connor’s Factors Contributing to Uncertainty subscale loaded on both factor 1 and factor 2 and were eliminated from the analyses. Thus, the Factors Contributing to Uncertainty subscale was reduced from nine to five items. Items that loaded on the three factors were used to measure, in factor order, factors associated with decision uncertainty, decision uncertainty, and decision effectiveness. Reliability testing resulted in Cronbach’s alphas of 0.89 for each of the three subscales, whereas O’Connor (1995) reported Cronbach’s alpha coefficients ranging from 0.78 to 0.92 for the total DCS scores and 0.58 to 0.92 for the subscales. The low ends of these alpha ranges are much lower than those found in the current study. The lowest alpha coefficient O’Connor
found (0.58) was for the Factors Contributing to Uncertainty subscale in cardiac/respiratory patients. Interestingly, the items from this same subscale loaded on two separate factors when factor analysis was performed on the current study data.

Factor analysis of the Ways of Coping Revised Questionnaire (WCRQ) revealed an interpretable 3-factor structure. Twenty-five items of the original 66 met the loading criterion of .55 or higher. Items that loaded on factor 1 and factor 2 conceptually represented approach and avoidance coping well. In addition, the third factor had a lower Cronbach’s alpha (0.70) than the other two factors. Consequently, the items that loaded on factor 3 were eliminated. Thus, the Ways of Coping Revised Questionnaire was reduced from a 66-item to a 22-item scale with 11 items representing approach coping and 11 items representing avoidance coping. This scale accounted for 26.3% of the variance in approach and avoidance coping. Internal consistency for these two subscales was good with Cronbach’s alphas of 0.87 for both subscales. In comparison, the factor analyses conducted by Folkman, Lazarus, Dunkel-Schetter, DeLongis, & Gruen (1986) on a community sample revealed an 8-factor structure (8 coping subscales). These eight scales accounted for 46.2% of the variance with Cronbach’s alphas ranging from 0.61 - 0.79 on the eight subscales. Several combinations of these items have been used by other researchers to measure approach (problem-focused) and avoidance (emotion-focused) coping behaviors (Cohen, 2002a; Gencoz, Gencoz, & Bozo, 2006; & Kim et al., 2003). Using the 22-item Ways of Coping Revised Questionnaire identified through factor analysis in the current study may provide a more parsimonious scale for measuring approach and avoidance coping in this population of women at risk for breast cancer.
Discussion of Preliminary Findings

The sociodemographic characteristics of the sample in this research are similar to other studies. That is, the women were primarily married, Caucasian, well educated and employed fulltime (Bober, Hoke, Duda, Regan, & Tung, 2004; Halbert et al., 2004; Lancaster, 2004; & Port, Montgomery, Heerdt, & Borgen, 2001). Having a first-degree relative with breast cancer and/or who died of breast cancer is a common risk factor in this population. Thus, it was not surprising to find 41.9% of the participants had at least one first-degree relative who was affected with breast cancer and that 35.2% had at least one first-degree relative who died of breast cancer.

Main study variables included subjective 5-year risk, subjective lifetime risk, objective risk, subjective stress, decision uncertainty, factors associated with uncertainty, approach and avoidance coping behaviors, treatment choice, and decision effectiveness. Select sociodemographic variables of interest included age, marital status, racial identification, highest educational degree, youngest child \( \leq 17 \) years old, total family members affected and who died with breast cancer, and first-degree relatives who were affected or died of breast cancer. Only two of these sociodemographic variables were related to one outcome variable (approach coping). First-degree relative affected was significant at the .01 level, whereas first-degree relative died approached this level of significance. These women used approach coping behaviors more often than women who did not have a first-degree relative affected with, or who had died from, breast cancer. Although speculative, women with affected family members may have felt more threatened and therefore engaged in problem solving and more actively pursued treatment options.
Contrary to earlier studies (Lodder et al., 2002; Mejers-Heijboer et al., 2000; Myers, 2000; & Unic et al., 2000), having young children did not influence participant’s stress level or treatment choice. Women in these earlier studies were considering bilateral prophylactic mastectomy (BPM). BPM is recommended for those at the highest risk for developing breast cancer. Only four women in the current study were BRCA1/2 positive and were recommended this treatment option. In the previous studies, women were overall at a much higher risk than most of the women in this study; it is conceivable that the threat of death was more salient and immediate to women in these earlier studies. Those women had more worries and were considering a variety of losses including leaving a child behind. The needs of this group, as well as associated interventions, may be quite different from at-risk women who are at a low or moderate level of risk compared to those who are at high risk. Pinpointing the level of risk at which women become concerned about leaving loved ones behind, such as children, may also be important when choosing variables to be included in future studies.

Discussion of Hypotheses Testing

Findings from this study at least partially supported each of the hypotheses. Outcome variables in these hypotheses included coping behaviors (approach and avoidance coping) and decisional outcomes (treatment choice and decision effectiveness). The following discussion is organized by each of these outcome variables. In each section, a discussion of the conceptualized relationships is presented first, followed by findings.
Coping Behaviors

The conceptual framework for this study was based on Lazarus and Folkman’s transactional stress theory. This framework is presented in chapter I, figure 1. According to Lazarus and Folkman, an encounter or event occurs between person and environment which is cognitively appraised by the individual as benign, threatening, or challenging. In the current study, the event was disclosure of the woman’s risk for developing breast cancer that is higher than the normal population and presentation of treatment options. The woman’s cognitive appraisal included evaluation of her threat of breast cancer (subjective 5-year, subjective lifetime, and objective risk), the subjective experience of stress related to her breast cancer risk status and treatment options (subjective stress), and the perceived difficulty in making an informed decision about treatment options (decisional conflict, including decision uncertainty and factors associated with uncertainty). In this framework, the woman uses approach (problem-focused) coping and avoidance (emotion-focused) coping behaviors to manage this stressful situation and the resultant stress and decisional conflict.

In this study, stress was a predictor for using approach and avoidance coping behaviors. This is consistent with Lazarus and Folkman’s model whereby they propose these coping approaches are used to manage stress (Lazarus & Folkman, 1984). Further, Folkman and Lazarus (1985) suggest approach or problem-focused coping behaviors are used over avoidance or emotion-focused coping behaviors when dealing with stressors that can be controlled. A comparison of the mean scores in the current study showed overall, women used approach coping behaviors nearly twice as much as avoidance coping behaviors. Although speculative, women who felt they could control the threat of
developing breast cancer through early detection or preventative measures may have used approach coping behaviors and those who felt less control used avoidance coping behaviors.

Decision uncertainty was a predictor for approach coping behavior. Decision uncertainty was not a predictor for avoidance coping behavior, however it was marginally correlated with avoidance coping. Of interest, was the direction of the correlations between decision uncertainty and coping behaviors used. There was a negative correlation between decision uncertainty and approach coping, but a positive correlation between decision uncertainty and avoidance coping. That is, women who were certain about their decision used approach coping behaviors and women who were more uncertain about their decision used avoidance coping behaviors. The approach coping behaviors used most frequently were related to positive reappraisal (rediscovered what is important in life) and social support (talked to someone who could do something concrete about the problem and talked to someone about how I was feeling). That is, women who had prioritized what was important in life and talked over their feelings and decisions about treatment options were better able to manage uncertainty about these treatment options.

Subjective 5-year risk, subjective lifetime risk, objective risk, and factors associated with decision uncertainty were expected to predict coping behaviors. Interestingly, they did not. A plausible explanation for subjective risk not being predictive of coping behaviors may include the manner in which the event unfolded. Data were collected at a major referral center for breast cancer risk assessment. Being referred to this clinic for a suspected increased risk of breast cancer is cause for worry. In the
months or weeks prior to their appointment, these women likely formulated their own ideas about their risk status. Their ideas or perceptions of risk may have been influenced by their biopsy results, family history, or information they had heard or read, and, may have been much higher than the risk assessment from the referral clinic, which is based on more refined information. After receiving a risk estimate from the clinic staff, their risk may actually have been much lower than they had anticipated. Data were collected soon after their risk assessment. At that time, they may have had a more realistic perception of their risk which was less threatening. This possibility also may influence future research by asking questions to elicit the woman’s perceived risk both before and after obtaining professional risk assessments. An explanation for objective risk not predicting approach coping behaviors may be related to a measurement problem. That is, objective risk was measured at the ordinal level rather than the interval level, and there were only four participants in the highest risk level. This may have resulted in a less robust statistical outcome.

Factors associated with uncertainty were correlated, but not predictive of approach coping behaviors. These scores were overall low suggesting women were knowledgeable and clear about their values related to the risks and benefits of treatment options. Perhaps, armed with knowledge and clarity of their values, use of coping behaviors was not required. Factors that may have contributed to the women’s knowledge and values clarity may have included the format of the risk assessment, the women’s education level, and information sources used. In this clinic, each woman was assessed by a nurse, a physician, and a genetic counselor (if indicated). An individual assessment lasting 30 minutes was planned for each woman. The nurse set the stage by assessing the
woman, clarifying her history, and making her feel at ease. The nurse and the physician then saw the patient together. The physician provided additional information and the woman was given her risk estimate and treatment options. The nurse reinforced information after the woman was seen by the physician. Reinforcement of information from at least two sources and an individualized assessment lasting about 30 minutes may have contributed to women feeling knowledgeable and clear about their values (factors associated with uncertainty) related to the treatment options. Incidentally, women from this study made many positive comments to the researcher about the information they received and the way it was presented. The sample was also well educated and, consequently, women may have attained information and worked through many of their values and beliefs, personally, and with their family, prior to the clinic appointment. Women used a variety of sources to assist with their decision. Sources they considered most important in this study included family as well as health care professionals (breast cancer surgeon, nurse, and oncologist).

**Decisional Outcomes**

According to Lazarus and Folkman, the outcome of the coping process is appraised by how successful individuals are at achieving their goals and how satisfied they are with their performance. In the current study, the outcome of the coping process included selection of a treatment option and the woman’s subjective level of decision effectiveness.

Nearly half of the women in the current study opted for chemoprevention. This number is substantially higher than earlier studies in which 2-18% of women accepted Tamoxifen (McKay et al., 2005; Melnikow et al., 2005; Port et al., 2001; & Taylor &
Taguchi, 2005). These studies examined the acceptance of Tamoxifen only. In the current study, chemoprevention (Tamoxifen or Raloxifene) was listed as a treatment choice on the sociodemographic questionnaire; no differentiation was made between these two chemoprevention options. Some women were taking Raloxifene for osteoporosis with the added benefit of chemoprevention for breast cancer; therefore it is possible that many of the women who checked chemoprevention were taking Raloxifene. This rationale for higher acceptance when the choice includes both Raloxifene and Tamoxifen is validated in another study (Bober et al., 2004). In Bober et al.’s study, the researchers reported 29% of the sample accepted Tamoxifen for treatment and another 27% were enrolled in the STAR trial where women were entered into either a Tamoxifen or Raloxifene treatment group. The sum (56%) of their patients taking either Tamoxifen or Raloxifene is very close to the percentage of women accepting chemoprevention in this study (almost half). Fewer incidences of cataracts and thromboembolic events are reported with Raloxifene compared to Tamoxifen (Vogel et al., 2006) thus, women may be more willing to accept Raloxifene for chemoprevention.

In the current study, significant predictors for treatment choice included subjective 5-year risk, objective risk and factors associated with uncertainty. The higher the women perceived their 5-year risk and the higher their objective risk category, the more apt they were to take medication, or in the situation of the very high-risk woman, the more apt they were to select prophylactic surgery. Conversely, the higher their 5-year perceived risk, the less likely the women were to select surveillance as their treatment option. In contrast, Tchou et al. (2004) and Melnikow et al. (2005) found no association between objective risk and acceptance of Tamoxifen as a treatment option. Meiser et al.
(2000) found no correlation between the choice for prophylactic mastectomy and objective cancer risk, as well. One group of these researchers (Melnikow et al., 2005) focused on women over 55 years of age and assessed all women using the Gail model. Tchou et al. (2004) used the Gail model to assess all women except those with lobular carcinoma in situ (LCIS) and found no association between Gail scores and Tamoxifen acceptance. However, when Tchou et al. examined a subset of this sample (women with atypical hyperplasia or LCIS) they found atypical hyperplasia and LCIS were predictive of Tamoxifen acceptance. Thus, the findings were mixed depending on the subset of the sample being examined. The current study’s sample included all participants regardless of risk estimation either by the Gail model, history of lobular carcinoma in situ, or mutation status. These differences in sample characteristics may account for contrasting findings. Otherwise, the discrepancy between objective risk being a predictor in the current study and not other research is unclear.

Women in this study who felt informed about treatment options and the associated risks, benefits, and side effects and knew which of these factors mattered most to her (factors associated with decision uncertainty) were more likely to select medication, or in the case of high risk, prophylactic mastectomy. In contrast, other studies report a low acceptance level of Tamoxifen even with the use of a decision guide (McKay et al., 2005) and educational interventions (Melnikow et al., 2005). As discussed, this finding may reflect the positive communication pattern used for risk assessment at this clinic. Subjective lifetime risk, subjective stress, and decision uncertainty did not explain a significant amount of the variance in treatment choice. Although subjective lifetime risk and decision uncertainty were not predictive of treatment choice, they were marginally
correlated with treatment choice at the .05 level. Treatment choice was positively correlated with subjective lifetime risk and negatively correlated with decision uncertainty. Women who were more uncertain about their treatment choice tended to select surveillance as their treatment option.

Decision uncertainty was a significant predictor for decision effectiveness. Factors associated with uncertainty approached significance (p=.042) for predicting decision effectiveness as well. Although the interpretation is speculative, at minimum, these variables deserve discussion and further investigation. Both variables are addressed in the following discussion. The more certain women were about their decision and the clearer they were about the risks and benefits of the treatment choices, the more they felt they made an effective decision. These relationships are supported in the decisional conflict literature (O’Connor, 1995; Stacey et al., 2003). Having a low to moderate level of stress is consistent with Janis and Mann’s (1977) view that a certain level of stress is necessary to motivate the person to engage in decision-making behavior and that an extreme level of stress may result in poor decision-making. In this study, women had low to moderate levels of stress and overall felt they had made an effective decision, thus a positive decisional outcome. However, when approach coping behavior was controlled, only decision uncertainty explained a significant amount of the variance in decision effectiveness. Thus, uncertainty may be a significant variable to be included in decision making studies.

The use of approach coping behaviors explained a small but significant amount of the variance in decision effectiveness, but not treatment choice. In contrast, avoidance coping did not explain the variance in either treatment choice or decision effectiveness.
Approach coping is viewed as a more problem-focused type of coping. Women who used this approach felt they made a more effective decision, thus a better outcome. Similarly, other research has also found that approach coping is associated with more positive outcomes compared to avoidance coping (Cohen, 2002a; Holland & Holahan, 2003; & Gilbar, 2005).

In summary, women referred to this high breast cancer risk clinic were threatened with the risk of developing breast cancer. These women had to work through the stress and uncertainties associated with both their chance of developing breast cancer and their treatment options. Approach coping behaviors were used more often by women who had a first-degree relative who was affected or died with breast cancer. Women who used approach coping behaviors tended to be satisfied with the treatment option they selected. Thus, by using these coping behaviors women were able to deal with the stress and uncertainty and make a treatment choice they deemed most appropriate for themselves. Women were more likely to select chemoprevention or prophylactic mastectomy (when appropriate) when they had higher 5-year perceived risk, higher objective risk estimates, and felt informed and clear about the risks, benefits, and side effects of each option.

When considering the above findings and interpretations, the potential threats to external validity need to be considered. Because the data were collected at one facility, the findings may not be generalizable to women seen at other high risk breast cancer clinics.

Implications for Nursing and Other Disciplines

The findings from this study are relevant to health care professionals involved in breast cancer risk assessment. Factor analysis of the Impact of Event Scale (IES)
confirmed the psychometric properties reported by Thewes et al. (2005) in this at-risk population. This finding has both clinical and research implications. Assessment of the at-risk woman’s stress level is an important factor for health care professionals to consider. As mentioned previously, a certain level of stress is necessary to motivate a person to engage in decision-making behavior, however an extreme level of stress may result in poor decision-making. Adding items from the Impact of Event Scale to an intake form is a practical and simplistic method for identifying women who are experiencing high levels of stress prior to their assessment. This information may help guide the plan for providing interventions to meet the stressed woman’s needs for making an optimum treatment choice.

The importance of the at-risk women’s knowledge and values related to the risks and benefits of treatment options (factors associated with decision uncertainty) is exemplified in this study. This variable was predictive of treatment choice and marginally predictive of decision effectiveness whereby women felt they made an effective decision and were more likely to accept chemoprevention. This predictor is modifiable (O’Connor et al., 2002). Health care professionals should assess this area and provide opportunities for women to ask questions and clarify information, perhaps through follow-up calls. While there are several different methods for communicating information about the risks and benefits of treatment options, the mode and quality of this interaction are significant. One possible explanation for the higher acceptance level of chemoprevention and feeling comfortable with their treatment decision, in this study, is the communication network developed in this clinic. The physicians and nurse worked together to provide a variety of opportunities for patients to obtain needed information about the risks and benefits of
both their treatment options as well as the possible side effects. In the opinion and
experience of this researcher, the level, depth, and frequency of communication of risk
and benefits were much higher than the usual approach of health care professionals.
Literature in effective patient-health care professional communication would support the
approach taken in this high specialty, high referral clinic. Although this explanation is
speculative, the patient’s level of decision effectiveness and treatment choice indicates
this area of investigation would be an important area for further study.

The use of avoidance coping is reported to have negative outcomes (Cohen,
2002b; Holland & Holahan, 2003; & Gilbar, 2005). Hence, teaching women who are
using these behaviors more helpful or beneficial ways of coping, like approach coping,
may result in a more positive outcome for these at-risk women making a treatment
choice.

The results also point out the significance of cognitive appraisal, coping
behaviors, and their effect on decisional outcomes in women who are at-risk for breast
cancer. Unlike many other studies that evaluated only the predictive effect of cognitive
appraisal on coping behaviors, this research evaluated this relationship and also evaluated
the predictive effect of cognitive appraisal on decisional outcomes. Nurses may be able to
intervene more effectively if they know how the woman is cognitively appraising the
situation. For example, women who are feeling greatly uncertain about their decision may
not make a decision that is in their own best interest. Nurses and other health care
professionals can intervene by assessing and addressing the modifiable factors associated
with this decision uncertainty.
Future Research

Coping research with the women at risk for breast cancer has mainly focused on those who selected bilateral prophylactic mastectomy as a treatment option. Few have investigated coping in woman who had a history of familial breast/ovarian cancer. The current study has expanded the repertoire of research in this area. This investigation and the results can be complimented in the future by using a qualitative approach. Qualitative methods may elicit a more in-depth understanding of coping and the decision-making process in these at-risk women.

The current literature suggests treatment choice may be biased by the health care professional that presents the information (McKay et al., 2005) and how that information is presented (Port et al., 2001). In this study, patients who had clear information (knowledge levels and clear assessment of risk and benefits) were more likely to be comfortable with their decisions. Therefore, this researcher would argue that, given a robust communication network and information, such as existed in this clinic, the client is more likely to choose chemoprevention and to make an effective decision. Using this clinic as a model, and drawing upon communication literature, a robust model would suggest the inclusion of an interprofessional health team, whose role and contributions are clear and relevant to both the client and each other. Research designed to examine the benefits resulting from the interactions between and among the woman and the physician, nurse, or genetic counselor would make a valuable contribution to the literature.

This study’s sample, like those reported in the literature, was primarily Caucasian and well educated. Questions associated with health disparity, ethnic and other sample differences need to be answered. It is also important for nurses to investigate these
cultural differences in women evaluating the threat of breast cancer and making a
treatment choice. Women from different cultures may evaluate health care situations
differently, particularly when considering factors associated with risk perception and
their interpretations of threat. These differential appraisals may ultimately influence
coping behaviors and decisional outcomes.

Because of the low acceptance of chemoprevention, even after education
interventions, the threshold of a $\geq 1.67\%$ 5-year risk for offering women chemoprevention
has been questioned (Melnikow et al., 2005). Yet, Taylor and Taguchi (2005) point out
that if eligible women identified by the Gail algorithm were to take Tamoxifen, one
million cases of breast cancer could be prevented over the next five years in the United
States. Thus, it is important to continue researching factors that may influence a woman’s
decision for selecting or not selecting preventative treatment options.

Conclusion

The current study provides a theoretical foundation for designing and testing
interventions for assisting at-risk women to manage threat, deal with the stress, and make
the most informed decision possible. Women at risk for developing breast cancer used
approach and avoidance coping behaviors to manage the stress associated with their
increased risk for breast cancer and consideration of treatment options. Women who used
approach coping felt more certain about their treatment choice. Avoidance coping tended
to be used by women who were uncertain about their treatment choice with a marginally
significant positive relationship between avoidance coping and decision uncertainty.
Women who were knowledgeable and clear about their values related to treatment
options were more apt to select chemoprevention or prophylactic mastectomy, when appropriate, and felt they made an effective decision.

This study has added to the stress and coping literature of women at-risk for breast cancer and the results have implications for clinical interventions and future research.
REFERENCES


Lerman, C., Hughes, C., Croyle, R. T., Main, D., Durham, C., Snyder, C., et al. (2000). Prophylactic surgery decisions and surveillance practices one year following BRCA1/2 testing. *Preventive Medicine, 31*(1), 75-80.


Appendix A Kent State University IRB Approval

July 18, 2006

Jennifer Wood, Graduate Student
College of Nursing
Kent State University

Re: 06-581, “Cognitive Appraisal, Coping Behaviors, and Decisional Outcomes in Women Making a Treatment Decision for Their High Risk of Breast Cancer”

Dear Ms. Wood:

I am pleased to inform you that the Kent State University Institutional Review Board (IRB) reviewed your Application for Approval to Use Human Research Participants through the expedited review procedure and your application was approved on July 10, 2006 as Level II research.

This approval is good for one year from July 10, 2006 through July 09, 2007. IRB regulations and Kent State University Institutional Review Board guidelines require that any changes in research methodology, protocol design or principal investigator have the prior approval of the IRB before implementation and continuation of the protocol. The IRB further requests an annual progress report and a final report at the conclusion of the study. A Periodic Review form will be sent prior to the renewal date of July 09, 2007, but please be aware that timely annual reviews are ultimately the responsibility of the Principal Investigator. The University of Akron has accepted, based on regulations set forth per NIH guidelines, Kent State University’s IRB approval of this project. Kent State University will continue to supply the University of Akron with all additional information pertaining to this project.

Kent State University has a Federal Wide Assurance on file with the Office for Human Research Protections (OHRP); FWA Number 00001853.

If you have any questions, please contact me at 330.672.2704 or (klight@kent.edu). You may begin to collect data. Good luck with your research project!

Sincerely,

Katherine Light
IRB Administrator

cc: Diana Biordi, Professor, College of Nursing, Kent State University
    Margaret Wineman, Interim Dean, College of Nursing, University of Akron
TO: Jennie Wood, Graduate Student, College of Nursing

FROM: Katherine Light, Research Subjects Administrator

DATE: November 9, 2006

SUBJECT: 06-581 “Cognitive Appraisal, Coping Behaviors, and Decisional Outcomes in Women Making a Treatment Decision for Their High Risk of Breast Cancer”

I am pleased to inform you that the Project Change was approved by the Kent State University Institutional Review Board (IRB) on November 8, 2006.

HHS regulations and Kent State University Institutional Review Board guidelines require that any further changes in research methodology, protocol design or principal investigator have the prior approval of the IRB before implementation and continuation of the protocol. The IRB further requests an annual progress report, to be filed prior to the original protocol review date, and a final report at the conclusion of the study.

If you have any questions, please contact me at 330.672.2704. (klight@kent.edu)
September 18, 2007

Ms. Jennie Wood
College of Nursing
Henderson Hall

Re: 06-581 – “Cognitive Appraisal, Coping Behaviors, and Decisional Outcomes in Women Making a Treatment Decision for Their High Risk of Breast Cancer”

Dear Ms. Wood:

I am pleased to inform you that the Kent State University Institutional Review Board reviewed the annual progress report and your protocol at the September 12, 2007 meeting for continuing review purposes and has extended the approval of the protocol for an additional year.

HHS regulations and Kent State University Institutional Review Board guidelines require that any changes in research methodology, protocol design or principal investigator have the prior approval of the IRB before implementation and continuation of the protocol. The IRB further requests an annual progress report and a final report at the conclusion of the study.

Kent State University has a Federal Wide Assurance on file with the Office for Human Research Protections (OHRP); FWA Number 00001853.

If you have any questions, please contact me at 330.672.2704 or klight@kent.edu.

Sincerely,

[Signature]

Katherine Light
IRB Administrator

cc: N. Margaret Wineman, University of Akron
    Diana Bioridi, College of Nursing, Kent State University
Appendix B University of Pittsburgh IRB Approval

University of Pittsburgh

Institutional Review Board

MEMORANDUM

TO: Jennie Wood, MSN, RN
FROM: Christopher Ryan, PhD, Vice Chair
DATE: December 7, 2006
SUBJECT: IRB #0610120: Cognitive Appraisal, Coping Behaviors, and Decisional Outcomes in Women Making a Treatment Decision for Their Increased Risk of Breast Cancer

The above-referenced proposal has received expedited review and approval from the Institutional Review Board under 45 CFR 46.110 (5).

Please note that the advertisement that was submitted for review has been approved as written.

If applicable, please include the following information in the upper right-hand corner of all pages of the consent form:

Approval Date: December 7, 2006
Renewal Date: December 6, 2007
University of Pittsburgh
Institutional Review Board
IRB #0610120

Please note that it is the investigator’s responsibility to report to the IRB any unanticipated problems involving risks to subjects or others [see 45 CFR 46.103(b)(5) and 21 CFR 50.108(b)]. The IRB Reference Manual (Chapter 3, Section 3.3) describes the reporting requirements for unanticipated problems which include, but are not limited to, adverse events. If you have any questions about this process, please contact the Adverse Events Coordinator at 412-363-1504.

The protocol and consent forms, along with a brief progress report must be resubmitted at least one month prior to the renewal date noted above as required by FWA00008730 (University of Pittsburgh), FWA00006735 (University of Pittsburgh Medical Center), FWA0000600 (Children’s Hospital of Pittsburgh), FWA0003867 (Magee-Womens Health Corporation), FWA0003338 (University of Pittsburgh Medical Center Cancer Institute).

Please be advised that your research study may be audited periodically by the University of Pittsburgh Research Conduct and Compliance Office.

CR:kh
MEMORANDUM

TO: Jennie Wood, MSN, RN

FROM: Christopher Ryan, PhD, Vice Chair

DATE: January 19, 2007

SUBJECT: IRB #0610120: Cognitive Appraisal, Coping Behaviors, and Decisional Outcomes in Women Making a Treatment Decision for Their Increased Risk of Breast Cancer

The Institutional Review Board reviewed the recent modifications to your protocol and consent form(s) and find them acceptable for expedited review. These changes, noted in your submission of January 4, 2007, are approved.

Please include the following information in the upper right-hand corner of all pages of the consent form(s), if modifications were made to the consent form(s):

Current Approval Date: December 7, 2006
Modification Approval Date: January 19, 2007
Renewal Dates: December 6, 2007
University of Pittsburgh
Institutional Review Board
IRB #0610120

The protocol and consent forms, along with a brief progress report must be resubmitted at least one month prior to the renewal date noted above as required by FWA00006790 (University of Pittsburgh), FWA00006735 (University of Pittsburgh Medical Center), FWA00006600 (Children's Hospital of Pittsburgh), FWA00003357 (Magee-Womens Health Corporation), FWA00003336 (University of Pittsburgh Medical Center Cancer Institute).

If your research proposal involves an investigational drug, please forward a copy of this approval letter along with a copy of the Cover Sheet, protocol, consent form(s) and drug brochure to Investigational Drug Service, PUH Pharmacy.

Please be advised that your research study may be audited periodically by the University of Pittsburgh Research Conduct and Compliance Office.

CR: kh
MEMORANDUM

TO:        Jannie Wood, MSN, RN

FROM:    Christopher Ryan, Ph.D., Vice Chair

DATE:    April 27, 2007

SUBJECT: IRB#0610120: Cognitive Appraisal, Coping Behaviors, and Decisional Outcomes in Women Making a Treatment Decision for Their Increased Risk of Breast Cancer

The Institutional Review Board reviewed the recent modifications to your protocol and consent form(s) and find them acceptable for expedited review. These changes, noted in your submission of April 10, 2007, are approved.

Please include the following information in the upper right-hand corner of all pages of the consent form(s), if modifications were made to the consent form(s):

Current Approval Date: December 7, 2006
Modification Approval Date: April 20, 2007
Renewal Date: December 6, 2007
University of Pittsburgh
Institutional Review Board
IRB #0610120

The protocol and consent forms, along with a brief progress report must be resubmitted at least one month prior to the renewal date noted above as required by FWA00008790 (University of Pittsburgh), FWA00006735 (University of Pittsburgh Medical Center), FWA00006800 (Children's Hospital of Pittsburgh), FWA00003567 (Magee-Womens Health Corporation), FWA00003338 (University of Pittsburgh Medical Center Cancer Institute).

If this research study is subject to FDA regulation, please forward to the IRB all correspondence from the FDA regarding the conduct of this study.

Please be advised that your research study may be audited periodically by the University of Pittsburgh Research Conduct and Compliance Office.

CR:kh
MEMORANDUM

TO: Jennie Wood, MSN, RN
FROM: Christopher Ryan, PhD, Vice Chair
DATE: August 6, 2007
SUBJECT: IRB #: 0610120: Cognitive Appraisal, Coping Behaviors, and Decisional Outcomes in Women Making a Treatment Decision for Their Increased Risk of Breast Cancer

The Institutional Review Board reviewed the recent modifications to your protocol and consent form(s) and found them acceptable for expedited review. These changes, noted in your submission of July 19, 2007, are approved.

Please include the following information in the upper right-hand corner of all pages of the consent form(s), if modifications were made to the consent form(s):

Current Approval Date: December 7, 2006
Modification Approval Date: August 3, 2007
Renewal Date: December 6, 2007

University of Pittsburgh
Institutional Review Board
IRB #0610120

The protocol and consent forms, along with a brief progress report must be resubmitted at least one month prior to the renewal date noted above as required by FWA00006790 (University of Pittsburgh), FWA00006735 (University of Pittsburgh Medical Center), FWA00006520 (Children's Hospital of Pittsburgh), FWA00003567 (Magee-Womens Health Corporation), FWA00003338 (University of Pittsburgh Medical Center Institute).

If this research study is subject to FDA regulation, please forward to the IRB all correspondence from the FDA regarding the conduct of this study.

Please be advised that your research study may be audited periodically by the University of Pittsburgh Research Conduct and Compliance Office.

CR:kh
MEMORANDUM

TO: Jennie Wood, MSN

FROM: Christopher Ryan, PhD, Vice Chair

DATE: November 6, 2007

SUBJECT: IRB #0610120: Cognitive Appraisal, Coping Behaviors and Decisional Outcomes in Women Making a Treatment Decision for Their Increased Risk of Breast Cancer

Your renewal of the above-referenced proposal has received expedited review and approval by the Institutional Review Board under 45 CFR 46.110 (7). This approval is for analysis of data only.

Approval Date: November 5, 2007

Renewal Date: November 4, 2008

The protocol and consent forms, along with a brief progress report must be resubmitted at least one month prior to the renewal date noted above as required by FWA00006790 (University of Pittsburgh), FWA00006735 (University of Pittsburgh Medical Center), FWA00006000 (Children's Hospital of Pittsburgh), FWA00003667 (Magee-Womens Health Corporation), FWA00003338 (University of Pittsburgh Medical Center Cancer Institute).

Please be advised that your research study may be audited periodically by the University of Pittsburgh Research Conduct and Compliance Office.

CR:dj
Appendix C Informed Consent

CONSENT TO ACT AS A PARTICIPANT IN A RESEARCH STUDY

TITLE: Cognitive Appraisal, Coping Behaviors, and Decisional Outcomes in Women Making a Treatment Decision for Their Increased Risk of Breast Cancer

PRINCIPAL INVESTIGATOR: Jennie Wood, MSN, RN, PhD Candidate
JPDN Program, Kent State University and The University of Akron
150-3 Talsman Drive; Canfield, OH  44406
Phone: 330.503.3441; E-mail: jmwood@ysu.edu

COINVESTGATORS: Victor Vogel, MD, Professor of Medicine and Epidemiology,
University of Pittsburgh School of Medicine
Director, Magee-Womens Hospital/University of Pittsburgh Cancer Institute Breast Cancer Prevention Program
UPMC Cancer Center Magee-Womens Hospital
300 Halket Street, Pittsburgh, PA  15213; Phone: 412.641.6500

Patricia Gordon, RN, MSN, Clinical Supervisor - Womens Cancer/Magee Womens Hospital of UPMC
Hillman Cancer Center; 5115 Centre Avenue; Third floor, POD E,
Breast Center; Pittsburgh, PA  15232; Phone: 412.623.3455

FACULTY MENTORS: N. Margaret. Wineman, PhD, RN, Professor and Interim Dean
The University of Akron, College of Nursing
Akron, OH  44325; Phone: 330.972.7552

Diana L. Biordi, PhD, RN, FAAN, Professor
Kent State University College of Nursing
Kent, OH  44242; Phone: 330.672.8762

SOURCE(s) OF SUPPORT: Youngstown State University
Carly Jayne Ensley Award/Akron General Development Foundation

Current Approval Date: 12/7/06
Modification Approval Date: 1/19/07, 4/20/07, 8/4/07
Renewal Date: 12/6/07
University of Pittsburgh
Institutional Review Board
IRB Number: 0610120
Why is this research being done?
The focus of this research is on women making a treatment decision for their increased risk of developing breast cancer. The purpose of this research study is to gain a better understanding of the overall process, the feelings experienced, and the methods used to deal with the stress of making a treatment choice.

Who is being asked to take part in this research study?
Approximately 105 women from two genetic or breast cancer risk assessment clinics will be invited to participate in this research study. These women must be 18 years or older, read and write English, consent to participate, have the ability to read and complete the questionnaires, and have no personal history of breast cancer. You are being invited to take part in this study because you have been identified as being at an increased risk for developing breast cancer. Increased risk means having a 1.7% or greater risk of developing breast cancer over the next five years.

What procedures will be performed for research purposes?
If you agree to participate, you will be asked to complete questionnaires at the clinic. It should take about 35 – 45 minutes of your time to complete all sections of the questionnaire packet. The clinic staff will report your risk for developing breast cancer over the next five years and over a lifetime to the researcher. The researcher will document these numbers (%) on the sociodemographic questionnaire. This is the risk factor they give you as part of your risk assessment. A few questions relate to your treatment decision. If you have not made a decision yet, these questions along with a self-addressed-stamped envelope will be given to you so you can answer and return them after you make a decision. You will also be asked your first name and telephone number and we will give you a follow-up call as a reminder to complete the questionnaire or we may collect the information over the phone.

What are the possible risks, side effects, and discomforts of this research study?
There is little risk involved in this study. The major potential risk is a breach of confidentiality, but we will do everything possible to protect your privacy. No invasive procedures or medications are included. However, some of the questions are personal in nature and there is a possibility that you may experience stress or uncomfortable emotions. We will be available should you wish to discuss any concerns or uncomfortable feelings after completing the questionnaires. Phone numbers are available for professionals that can help you work through any emotions or concerns that surface while you are participating in this study.

What happens if I am injured because I took part in this study?
It is important that you tell the principal investigator if you feel that you have been injured because of taking part in this study. You can tell the principal investigator in person or call her at 330.503.3441. The study will not pay for medical treatment. You and/or your health plan will be charged for any medical treatment that is needed as a result of taking part in this study.

What are possible benefits from taking part in this study?
There may be little value to you as a participant, but the findings may help us to assist other women making a treatment decision in the future.

Will my insurance provider or I be charged for the costs of any procedures performed as part of this research study?
There are no costs to you or your insurance provider for participating in this study.
Will I be paid if I take part in this research study?
Twenty dollars ($20.00) in cash will be given to you as an expression of appreciation for your participation. The money will be distributed to you after you complete all sections of the questionnaire packet.

Who will know about my participation in this research study?
Any information about you from or for this research will be kept as confidential (private) as possible. You will not be asked to identify your last name on the questionnaires. Questionnaires will be stored in a locked cabinet located in the principal investigator’s office. Consent forms will be filed separately from the questionnaires and stored in a locked cabinet or other locked storage area in the Research and Graduate Affairs Office in the College of Nursing at Kent State University. All data will be retained for a minimum of five years after the project is completed. There will be no information reported that could identify you, associate you with your responses, or associate you with the clinic. Findings from this study will be reported or published only as a summary of data from all participants – your personal identity will not be revealed.

Will this research study involve the use or disclosure of my identifiable medical information?
This research study will involve the recording of current and/or future identifiable medical information from your hospital and/or other (e.g., physician office) records. The information that will be recorded will be limited to your risk status that is given to you during your breast cancer risk assessment at the clinic. Your risk-status will be used to determine your objective risk for the study.

Who will have access to my identifiable medical information related to my participation in this research study?
In addition to the investigators listed on the first page of this authorization (consent) form and their research staff, the following individuals will or may have access to identifiable information (which may include your identifiable medical information) related to your participation in this research study:

- Authorized representatives of the University of Pittsburgh Research Conduct and Compliance Office and Kent State University Institutional Review Board may review your identifiable research information (which may include your identifiable medical information) for the purpose of monitoring the appropriate conduct of this research study.

In unusual cases, the investigators may be required to release identifiable information (which may include your identifiable medical information) related to your participation in this research study in response to an order from a court of law. If the investigators learn that you or someone with whom you are involved is in serious danger or potential harm, they will need to inform, as required by Pennsylvania and Ohio law, the appropriate agencies.

For how long will the investigators be permitted to use and disclose identifiable information related to my participation in this research study?
The investigators may continue to use and disclose, for the purposes described above, identifiable information (which may include your identifiable medical information) related to your participation in this research study for a minimum of five years after final reporting or publication of a project.
Is my participation in this research study voluntary?
Taking part in this research study, to include the use and disclosure of identifiable information for the purposes described above, is entirely up to you. No one will hold it against you if you decide not to do it. Whether or not you provide your consent for participation in this research study will have no effect on your current or future relationship with the University of Pittsburgh. Whether or not you provide your consent for participation in this research study will have no effect on your current or future medical care at a UPMC hospital or affiliated health care provider. You do not have to answer any question that makes you feel uncomfortable. You can stop participating in the study at any time without penalty.

May I withdraw, at a future date my authorization (consent) for the use of my identifiable medical record information for the purpose of this research study?
You may withdraw, at any time, your authorization (consent) for the use and disclosure of your identifiable medical record information for the purpose of this research study.

Who should I contact about questions related to this research study?
If you have questions about this research study, you may contact the investigators listed at the beginning of this consent form. If you have questions about your rights as a research subject, please contact the Human Subjects Protection Advocate at the University of Pittsburgh IRB Office, 1.866.212.2668, a committee that reviews all human research at 330.543.3691.

The project has also been approved by Kent State University’s Human Subjects Review Committee. If you have questions about Kent State University's rules for research, please call Dr. John L. West, Vice President and Dean, Division of Research and Graduate Studies, 330.672.2704.

*********************************************************************************************************************************************

SUBJECT’S CERTIFICATION

• I have read the consent form for this study and any questions I had, including explanation of all terminology, have been answered to my satisfaction. A copy of this consent form will be provided to me.
• I understand that I am encouraged to ask questions about any aspect of this research study during the course of this study, and that those questions will be answered by the researchers listed on the first page of this form.
• I understand that my participation in this study is voluntary and that I am free to refuse to participate or to withdraw my consent and discontinue my participation in this study at any time without affecting my future relationship with this institution.
• I agree to participate in this study.

Subject’s Signature ____________________________ Date ____________

Page 4 of 5 Subject’s Initials ______
CERTIFICATION OF INFORMED CONSENT

I certify that I have explained the nature and purpose of this research study to the above-named individual, and I have discussed the potential benefits and possible risks of study participation. Any questions the individual has about this study have been answered, and we will always be available to address future questions as they arise.

Printed Name of Person Obtaining Consent       Role in Research Study

Signature of Person Obtaining Consent         Date
Appendix D *Gail Assessment Model*

A statistical model based on breast cancer risk factors is used to calculate a woman’s five-year and lifetime risk for breast cancer. A woman who has a five-year calculated risk of $\geq 1.67\%$ is considered to be at an increased risk for breast cancer. Answers to the following questions are entered in a handheld calculator:

1. Current age?
2. Race?
3. Age at menarche?
4. Age at first live birth? (or 0 = no children)
5. Number of first-degree relatives (mother, sister, daughter) affected with breast cancer?
6. Number of previous breast biopsies?
7. Biopsy with atypical hyperplasia? (if number 6 is positive)


Appendix E *Impact of Event Scale Permission*

**Mardi Horowitz**

Permission to use the Impact of Event Scale is available on Mardi Horowitz’s Home Page: [http://mardihorowitz.com/index.htm](http://mardihorowitz.com/index.htm)

“RATING SCALES: Copies of, instructions for, and permission to use the IMPACT OF EVENTS SCALE, and the POSITIVE STATES OF MIND SCALE will be found in Treatment of Stress Response Syndromes. People in non-profit research or clinical work have my permission to use this scale. Also the IES can be found by clicking on and then scrolling through the “my works” page of this site.”

Permission is also given in Horowitz’s Treatment of Stress Response Syndromes Book:

“The author holds the copyright for and gives the reader permission to copy and use this scale”, Horowitz, 2003, p. 12

Appendix F Decisional Conflict Scale Permission

April 9, 2008

Jennie Wood, MSN, RN
Associate Professor, Nursing
Youngstown State University
One University Plaza
Youngstown, OH 44509
Email: jnw006@ysu.edu

Dear Ms. Wood,

Thank you for your interest in our Decisional Conflict Scale.

You have permission to use the scale provided you acknowledge its source in your research and in any resulting publications.

Sincerely,

[Signature]

Annette O’Connor, MScN, PhD, FCAHS
Tier 1, Canada Research Chair in Health Care Consumer Decision Support
Professor, School of Nursing and Department of Epidemiology & Community Medicine,
University of Ottawa
Senior Scientist, Clinical Epidemiology Program, Ottawa Health Research Institute

Clinical Epidemiology Program (ASRB 3-008)
Ottawa Health Research Institute, Civic Campus
1053 Carling Avenue, Ottawa ON K1Y 4E9 Canada
Email: aoconnor@ohri.ca
Tel. 613.798.3333 ext. 17158 Fax: 613.761.3402
http://www.ohri.ca/decisionaid
Appendix G Ways of Coping Revised Questionnaire Permission

UNIVERSITY OF CALIFORNIA, SAN FRANCISCO

OSHER CENTER FOR INTEGRATIVE MEDICINE AT UCSF
1711 DIVISADERO STREET, SUITE 100
SAN FRANCISCO, CALIFORNIA 94115

SUZAN FOLKMAN, PH.D.
PROFESSOR OF MEDICINE AND
DIRECTOR

Dear Colleague:

The Ways of Coping that was revised in 1985 is in the public domain and you do not need special permission to use it. In 1988 the Consulting Psychologists Press made minor modifications to a few items. Their version is copyrighted, and has since been purchased by Mind Garden. If you wish to use their version and/or their scoring service, you'll need permission from Mind Garden. You can reach them at http://www.mindgarden.com/ or Mind Garden, Inc., 1690 Woodside Road, Suite 202, Redwood City, CA 94061, USA, (650-261-3500). You might also want the manual for the Ways of Coping. It is available through the same publisher.

Sincerely,

Susan Folkman, Ph.D.
Professor of Medicine
Director, Osher Center for Integrative Medicine at UCSF
Ways of Coping Questionnaire

Duplication Set
Permission to reproduce up to 150 copies from date of purchase:
March 13, 2006

By Susan Folkman, Ph.D.
and
Richard S. Lazarus Ph.D.

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mindgarden@msn.com
www.mindgarden.com

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Appendix H Sociodemographic Questionnaire

Sociodemographic Questionnaire

Responding to the questions is voluntary. Any descriptive data gathered from this questionnaire will be reported in aggregate summary form only. No participant can be identified by her individual responses.

Please indicate your response by placing a check mark (\(\checkmark\)) on the line preceding your answer unless specified otherwise.

1. What is your age? ______ (in years)

2. What best describes your marital status?
   1 ______ Married
   2 ______ Divorced
   3 ______ Widowed
   4 ______ Never Married

3. Which best describes your racial identification?
   1 ______ African American
   2 ______ American Indian
   3 ______ Asian/Pacific Islander
   4 ______ Caucasian/Non Hispanic
   5 ______ Hispanic
   6 ______ Other (please specify):

4. What is your highest level of education attained?
   1 ______ Less than high school diploma or GED
   2 ______ High school diploma or GED
   3 ______ Associate’s degree
   4 ______ Bachelor’s degree
   5 ______ Master’s degree
   6 ______ Doctorate degree

5. What is your employment status?
   1 ______ Not employed/retired
   2 ______ Employed full-time
   3 ______ Employed part-time
   4 ______ Homemaker

6. What best describes the employment setting you work in?
   1 ______ Health care
   2 ______ Educator
   3 ______ Secretary
   4 ______ Homemaker
   5 ______ Sales/Business
   6 ______ Other (please specify):

7. How many children do you have?
   0 ______ None
   1 ______ One
   2 ______ Two
   3 ______ Three
   4 ______ Four
   5 ______ Five
   6 ______ Six or more

8. How old is your oldest child? ______ (in years)

9. How old is your youngest child? ______ (in years)
Have any of the following relatives ever had or died of breast cancer? Please check yes or no.

10. My mother had breast cancer.
   0 _____ No
   1 _____ Yes

   0 _____ No
   1 _____ Yes

12. My sister(s) had breast cancer.
   0 _____ No
   1 _____ Yes (specify number: ___)

13. My sister(s) died of breast cancer.
   0 _____ No
   1 _____ Yes (specify number: ___)

14. My father’s mother had breast cancer.
   0 _____ No
   1 _____ Yes

15. My father’s mother died of breast cancer.
   0 _____ No
   1 _____ Yes

16. My mother’s mother had breast cancer.
   0 _____ No
   1 _____ Yes

17. My mother’s mother died of breast cancer.
   0 _____ No
   1 _____ Yes

18. My mother’s sister(s) had breast cancer.
   0 _____ No
   1 _____ Yes (specify number: ___)

19. My mother’s sister(s) died of breast cancer.
   0 _____ No
   1 _____ Yes (specify number: ___)

20. My father’s sister(s) had breast cancer.
    0 _____ No
    1 _____ Yes (specify number: ___)

21. My father’s sister(s) died of breast cancer.
    0 _____ No
    1 _____ Yes (specify number: ___)

22. Another family member had breast cancer. (Please specify who: ________________)

23. Another family member died of breast cancer. (Please specify who: ________________)

24. Do you have insurance coverage for the following procedures?
   1 _____ Genetic testing
   2 _____ Mammograms
   3 _____ MRI
   4 _____ Medications
   5 _____ Mastectomy surgery
   6 _____ Breast reconstruction surgery

25. What information sources did you use to assist you with your decision? (Check all that apply)
   A ______ Genetic counselor or geneticist
   B ______ Nurse
   C ______ Family physician
   D ______ Oncologist
   E ______ Breast cancer surgeon
   F ______ Other health care professional
       (please specify): ________________
   G ______ Internet
   H ______ Media (TV, radio, newspaper, magazine, etc.)
   I ______ Family
   J ______ Friends
   K ______ Women with breast cancer
   L ______ Other women who have made a treatment decision for their increased risk for breast cancer
   M ______ Source not listed (please specify): ________________
26. Which of the three information sources influenced your decision most? (Make only 3 choices)

A. Genetic counselor or geneticist
B. Nurse
C. Family physician
D. Oncologist
E. Breast cancer surgeon
F. Other health care professional
   (please specify):
   ____________________________

G. Internet
H. Media (TV, radio, newspaper, magazine, etc.)
I. Family
J. Friends
K. Women with breast cancer
L. Other women who have made a treatment decision for their increased risk for breast cancer
M. Source not listed
   (please specify):
   ____________________________

27. What do you think your personal odds are for developing breast cancer over the next 5 years?

   1. 1 in 100 (1%)
   2. 5 in 100 (5%)
   3. 10 in 100 (10%)
   4. 20 in 100 (20%)
   5. 30 in 100 (30%)
   6. 40 in 100 (40%)
   7. 50 in 100 (50%)
   8. 60 in 100 (60%)
   9. 70 in 100 (70%)
   10. 80 in 100 (80%)
   11. 90 in 100 (90%)
   12. 95 in 100 (95%)
   13. 99 in 100 (99%)
   14. 100 in 100 (100% certain)

28. What do you think your personal odds are for developing breast cancer over a lifetime?

   1. 1 in 100 (1%)
   2. 5 in 100 (5%)
   3. 10 in 100 (10%)
   4. 20 in 100 (20%)
   5. 30 in 100 (30%)
   6. 40 in 100 (40%)
   7. 50 in 100 (50%)
   8. 60 in 100 (60%)
   9. 70 in 100 (70%)
   10. 80 in 100 (80%)
   11. 90 in 100 (90%)
   12. 95 in 100 (95%)
   13. 99 in 100 (99%)
   14. 100 in 100 (100% certain)

29. Objective breast cancer risk (to be completed by researcher).

   1. ____________________________
   2. ____________________________

Thank you very much for providing this information for my research study.
Appendix I *Scree Plot for Impact of Event Scale*

Scree Plot

![Scree Plot Image]

Component Number

Eigenvalue
Appendix J Loading Plot for Impact of Event Scale
Appendix K *Scree Plot for Decisional Conflict Scale*

Scree Plot

![Scree Plot Image]

- **Eigenvalue**
- **Component Number**
Appendix L Scree Plot for Ways of Coping Revised Questionnaire
Appendix M  *Detailed Description of Sample Sociodemographic Data*

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<td>45-49</td>
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<td></td>
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<td></td>
<td>Secretary</td>
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<td></td>
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<td>27.6%</td>
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<tr>
<td>Number of Children</td>
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<td></td>
<td>One</td>
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<td></td>
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