9-1-2013

Screening Adherence and Emotional Adjustment of Daughters of Breast Cancer Patients

Sarah R. Ormseth
Loma Linda University

Recommended Citation

Ormseth, Sarah R., "Screening Adherence and Emotional Adjustment of Daughters of Breast Cancer Patients" (2013). *Loma Linda University Electronic Theses, Dissertations & Projects*. 141.
http://scholarsrepository.llu.edu/etd/141

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

Screening Adherence and Emotional Adjustment of Daughters of Breast Cancer Patients

by

Sarah R. Ormseth

A Dissertation submitted in partial satisfaction of
the requirements for the degree
Doctor of Philosophy in Clinical Psychology

September 2013

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

, Chairperson

Adam Aréchiga, Associate Professor of Psychology

Kauser Ahmed, Clinical Psychologist and Training Director, The Simms/Mann–UCLA Center for Integrative Oncology

David Vermeersch, Professor of Psychology

David Wellisch, Professor in Residence, University of California, Los Angeles

ACKNOWLEDGEMENTS

Thank you to Dr. Aréchiga, my committee chair, advocate and mentor who somehow never fails to recognize my potential. Deepest thanks as well to Dr. Wellisch for his continual support, optimism and enthusiasm. To Drs. Vermeersch and Ahmed, thank you for valued insight and advice about this research, and even more so for the guidance, wisdom and hope shared over the past many years.

Thank you to my friends, especially to Taylor Draper… your intellect, creativity, perspective, and perceptiveness make you an ingenuous work partner but more importantly a true friend.

Dad and Mom, your love, support and encouragement throughout graduate school and life is awe-inspiring. Your confidence inspires me to trust in my strengths and potential and see and appreciate the good in others. I love you so much and want to do my best as a daughter and to lead a life that is reflective of what amazing parents you are.

To Kelly, thank you for your love and support. I love you very much, you are a great sister, and I’m excited to be able to spend more time with you and for us to share more of our lives with each other.

CONTENT

Chapter

FIGURES

Figures Page

TABLES

Tables Page

ABSTRACT OF THE DISSERTATION

Screening Adherence and Emotional Adjustment of Daughters of Breast Cancer Patients

by

Sarah R. Ormseth

Doctor of Philosophy, Graduate Program in Clinical Psychology
Loma Linda University, September 2013
Dr. Adam Aréchiga, Chairperson

Women at high risk for breast cancer oftentimes also experience psychological vulnerably related to experiences of cancer in their family, high bereavement rates and their own uncertainties regarding if and when they may develop the disease. This research sought to evaluate psychological adjustment and examine reattendance among a sample of women adhering to regular breast cancer surveillance, with a specific focus on daughters of breast cancer patients. The study described in Chapter 2 longitudinally profiled anxiety and depressive symptoms among these high-risk daughters across three consecutive surveillance appointments, and also evaluated the effects of a set of hypothesized predictors on change in symptomatology. The results showed an overall decrease in anxiety over the course of the three surveillance visits, as well as a marginally significant decrease in depressive symptoms. When the effects of moderating variables on symptom change were examined, results demonstrated that some subgroups of daughters differentially benefited from the high-risk program, with daughters whose mothers died who were older at the time of their mother's diagnosis being the only group that did not appear to experience decreases in symptomatology. The study presented in Chapter 3 investigated psychosocial correlates of reattendance at the high-risk clinic, again focusing on daughters of breast cancer patients. Results showed that greater likelihood of reattendance was associated with hypothesized predictors, including older age, lower depressive symptoms and maternal loss to breast cancer. Moreover, mother's survival status was found to moderate the effect of perceived risk on likelihood of reattendance such that higher perceived risk predicted increased reattendance for daughters whose mothers survived, but not those whose mothers died. Additionally, results indicated that the association between anxiety and likelihood of reattendance was non-linear in nature (inverted "U"); reattendance was more likely among daughters with moderate anxiety compared to those with low or high anxiety. Findings from these studies contribute to a greater understanding of psychological adjustment and screening adherence of women at high-risk for breast cancer and may inform the development of targeted interventions to promote screening adherence and psychosocial wellbeing among this and other vulnerable high-risk populations.

CHAPTER ONE

INTRODUCTION

Despite recent progress in early detection and treatment, breast cancer remains a serious health concern. Excluding skin cancer, breast cancer is the most frequently diagnosed cancer in women and ranks second as a cause of cancer death, with 234,580 new cases and 40,030 breast cancer deaths expected in 2013 in the United States (Siegel, Naishadham, & Jemal, 2013). Family history of breast cancer is a significant risk factor for development of the disease, particularly for women with first-degree relatives diagnosed with breast cancer (Calle, Martin, Thun, Miracle, & Heath, 1993; Sattin et al., 1985; Sellers et al., 1999; Slattery & Kerber, 1993). A woman's breast cancer risk approximately doubles if a first-degree relative, such as a mother, has been diagnosed. Women with a family history of breast cancer are at higher risk for breast cancer than the general population because of shared genetic factors and possibly because of shared exposures to environmental and lifestyle risk factors (Easton, 2002; Slattery & Kerber, 1993).

A number of general and cancer-related psychosocial difficulties may also be associated with high-risk status. Many women at high risk for breast cancer experience elevated levels of general anxiety (Lindberg & Wellisch, 2001) and report levels of distress significant enough to warrant psychological counseling (Kash, Holland, Osborne, & Miller, 1995), which can negatively affect quality of life. Furthermore, research has shown that high-risk women overestimate their risk of developing breast cancer (Katapodi, Lee, Facione, & Dodd, 2004), experience higher levels of anxiety related to cancer screening (Lindberg & Wellisch, 2001), express greater concern about breast cancer, and endorse less confidence in available treatment methods for the illness (Cappelli et al., 2005; Wellisch et al., 1999). Psychosocial distress among women at high risk for breast cancer warrants concern given its influence on quality of life, as well as its negative impact on cancer screening adherence (Hay, McCaul, & Magnan, 2006).

Screening for breast cancer in high-risk women may include mammography, clinical breast examination, breast self-examination, and more recently, magnetic resonance imaging. While research is mixed regarding which of the various screening methods and technologies is most effective, some form of regular screening is necessary to permit early breast cancer detection in women at higher familial risk of breast cancer. While regular screening for high risk women is important, the importance of the setting in which screening occurs is also receiving increasing recognition. The need for centralized multidisciplinary care of women at high risk for breast cancer has resulted in recommendations for, and the development of, such clinics (Kuschel, Lux, Goecke, & Beckmann, 2000). This stems from recognition of some problems that may be associated with ongoing cancer surveillance through individual private specialists in a non-multidisciplinary context (Antill, Shanahan, & Phillips, 2005). For example, it may be inconvenient for a woman to attend multiple specialists and diagnostic facilities on different days and in different locations. A decentralized arrangement may also hinder coordination of care. Additionally, it may be difficult for some women to independently locate breast specialists with particular expertise in high-risk populations.

The UCLA Revlon Breast Center High Risk Clinic is a multidisciplinary center that setting that serves patients at familial risk for breast cancer. Patients are seen once or twice a year for a personalized surveillance program, based on individual risk factors. A multidisciplinary team manages patient care, including a nurse practitioner to perform a breast exam, teach breast self-examination, and order same day diagnostic tests such as a mammogram, ultrasound or MRI as needed. A medical oncologist will offer counsel about breast cancer risks risk reduction strategies. A Genetic counselor will also provide education and counseling.

Additionally, patients are seen by specialists whose services may be more difficult to obtain outside the context of a multidisciplinary clinic. A physician nutritionist, who specializes in cancer risk, makes recommendations for modifying diet. This is important because research is increasingly showing the association between diet and lifestyle and risk for developing breast cancer. Significantly, patients are also seen by a psychologist to discuss the feelings associated with being at high risk, and about coping with illness and loss of family members to breast cancer. Psychologists and other mental health professionals are uniquely qualified to help address many potential barriers to care among high-risk women.

Drawing on data from the UCLA-Revlon High Risk Program, two papers were conceptualized and written focusing on important yet understudied aspects of psychological adjustment and healthcare utilization among women at high risk for breast cancer, namely daughters of breast cancer patients. In a longitudinal study of the psychological adjustment of these women across consecutive high risk clinic appointments, the first study (Chapter 2) sought to determine the pattern of anxiety and depressive symptoms of these daughters across the clinic visits, particularly decreases (or increases) in symptom severity which may be reflective of positive (or negative) outcomes related to adhering to regular surveillance appointments. In a second study

(Chapter 3), predictors of reattendance to the high risk clinic were explored in an effort to profile patients who may be at greater risk for not returning for follow-up appointments for continued surveillance given their high risk status.

To the best of our knowledge, no other studies have examined predictors of reattendance to a high-risk clinic, or long term psychological adjustment of women at high risk for breast cancer across multiple surveillance appointments. The utility of focusing on and striving to better understand issues of relevance to daughters of breast cancer patients is evident in its potential to enhance the health, wellbeing and quality of life in this population, women with a family history of breast cancer, and individuals who are at increased hereditary risk for other cancers and diseases.

CHAPTER TWO

EVOLUTION OF EMOTIONAL SYMPTOMS OF DAUGHTERS OF BREAST CANCER PATIENTS

Sarah Ormseth, M.A., David Wellisch, Ph.D., Adam Aréchiga, Psy.D., DrPH

Abstract

This study longitudinally profiled anxiety and depressive symptoms of daughters of breast cancer patients, and examined mother's survival status, daughter age at time of mother's diagnosis, and style of family communication about breast cancer as moderators of change in symptomatology across participants' first three appointments at the UCLA Revlon Breast Center High Risk Clinic. To evaluate the effects of hypothesized predictors on change in anxiety and depressive symptoms, 3 (symptomatology at first, second, and third clinic visits) × 2 (mother survived or died) × 2 (< 20 years or ≥ 20 years old at diagnosis) × 2 (open or closed family communication) repeated measures ANOVAs were employed. Results showed a main effect for time on state anxiety, demonstrating a significant reduction in anxiety across clinic visits overall ($p < .001$). There were also significant 3-way interactions. For state anxiety, mother's survival status moderated the Time × Age at Diagnosis and Time × Family Communication interaction effects. For daughters whose mothers died, decreased anxiety was observed in those who were younger at the time of diagnosis ($p = .001$). For daughters whose mothers survived, anxiety was decreased for those with closed family communication styles ($p = .001$). The Time × Mother's Survival × Age at Diagnosis interaction was also significant for

depressive symptoms (*p* = .001). Among daughters whose mothers died, those who were younger showed decreases in symptoms (*p* = .004). Overall, these daughters appeared to benefit from the high-risk program as demonstrated by decreased symptomatology, particularly daughters whose mothers died who were younger at the time of diagnosis.

Introduction

In addition to the psychological distress often experienced by children of cancer patients (Visser, Huizinga, van der Graaf, Hoekstra, & Hoekstra-Weebers, 2004; Watson et al., 2005), daughters whose mothers are diagnosed with breast cancer must also cope with learning of their own heightened susceptibility to the disease (Facione, 2002; Raveis & Pretter, 2005). These daughters and other women with a strong family history of breast cancer face ambiguity and threat about if and when cancer will develop, as well as decisions about how to manage this increased risk. Risk-reducing surgery and chemoprevention significantly reduce breast cancer risk, but uptake of these strategies is low (Schwartz et al., 2012). Screening and surveillance remain the mainstay of management for most women at increased breast cancer risk (Field & Phillips, 2007). Because women at high risk for breast cancer experience greater levels of general and cancer-specific distress (Baider, Ever-Hadani, & Kaplan De-Nour, 1999; Bovbjerg & Valdimarsdottir, 2001; Gilbar, 1998; Zakowski et al., 1997), some concern exists about the potential psychological burden of long term breast cancer surveillance.

Increased distress is common for many high-risk women the day of screening appointments (Valdimarsdottir et al., 1995; Zakowski et al., 1997). In general though, research has not evidenced lasting adverse psychological outcomes related to breast cancer screening among high-risk women (Brédart et al., 2012; Rijnsburger et al., 2004; Watson, Henderson, Brett, Bankhead, & Austoker, 2005). Findings from a large, prospective cohort study of women with a family history of breast cancer showed significant decreases in distress six months after mammography (Brain et al., 2008; Tyndel et al., 2007). Although research of the effects of adhering to a breast cancer surveillance program is more limited, findings from the Dutch magnetic resonance imaging screening (MRISC) study of women at increased breast cancer risk have demonstrated short term reductions in distress following two successive screening appointments (van Dooren et al., 2005), as well as long term reductions in intrusion and avoidance (den Heijer et al., 2013).

While most women with a family history do not appear to experience significant distress associated with breast cancer surveillance, some are more prone to persistent adjustment difficulties and may benefit from additional psychosocial support. Research suggests that several demographic, clinical and psychological factors may influence adjustment to breast cancer surveillance (den Heijer et al., 2013; Gopie, Vasen, & Tibben, 2012; van Dooren et al., 2005). Mother's breast cancer diagnosis and/or death from breast cancer are well-established risk factors for maladaptation among high-risk women (Erblich, Bovbjerg, & Valdimarsdottir, 2000; Thewes, Meiser, Tucker, & Schnieden, 2003; Wellisch, Gritz, Schain, Wang, & Siau, 1991; Wellisch, Ormseth, Hartoonian, & Owen, 2012). In studies of psychological adjustment in the context of breast cancer screening, death of a close relative to breast cancer has been found to be associated with increased levels of cancer-specific distress (Brain et al., 2008; den Heijer et al., 2013). Given the unique psychosocial burden faced by daughters whose mothers have been diagnosed with breast cancer (Raveis & Pretter, 2005; Thewes et al., 2003), it seems important for research to further examine the specific impact of maternal loss to breast cancer on emotional response to surveillance.

For women with a family history of breast cancer, other aspects of their experiences of breast cancer in their family may moderate the psychological effects of surveillance. The salience of specific risk factors varies according to the developmental phase of a woman at the time of the diagnosis of a parent and/or loss of a first degree relative. Studies of daughters of breast cancer patients have shown greater adjustment difficulties among women who were younger at the time mother's diagnosis (van Oostrom et al., 2006; Wellisch, Gritz, Schain, Wang, & Siau, 1992), and whose mothers died of breast cancer at a younger age (Erblich et al., 2000; Esplen & Hunter, 2002). Previous research has also shown that that open family communication regarding breast cancer has a positive effect on general and breast cancer specific distress (den Heijer et al., 2011), as well as short- and long-term adjustment to genetic testing (van Oostrom et al., 2007; van Oostrom et al., 2003). To our knowledge however, no previous study has investigated the impact of factors related to women's experiences of breast cancer in their family on adjustment to breast cancer surveillance among daughters whose mothers have been diagnosed with breast cancer.

The main aim of this study was to longitudinally profile the course of depression and anxiety symptoms of daughters of breast cancer patients across three consecutive biannual surveillance appointments at a high risk breast cancer clinic. It also was the intent of this study to examine potential moderators of change in symptomatology over time. To accomplish these goals, four hypotheses are proposed. We expected that a higher level of depressive symptomatology would be observed among daughters whose mothers died from breast cancer at baseline. Second, it was anticipated that a significant reduction in anxiety symptoms, but not depressive symptomatology, would be observed over the span of the clinic visits. Third, it was hypothesized that daughter's age at the time of her mother's breast cancer diagnosis would relate to the pattern of change in symptoms across clinic visits such that a greater decrease in anxiety and depressive symptomatology would be observed among daughters who were older at the time of their mother's diagnosis. Fourth, we expected that style of family communication about breast cancer would be related to the pattern of change in symptoms across clinic visits such that an open style of communication would be associated with a greater decrease in in anxiety and depressive symptomatology. The potential interactive effects of mother's survival status, age at time of mother's diagnosis and style of family communication about breast cancer were explored, though no specific hypotheses were proposed.

Method

Institutional Review Board approval was granted prior to data collection. Study data were obtained during participants' first three visits to the UCLA Revlon Breast Center High Risk Clinic. The High Risk Clinic is a multidisciplinary setting that serves patients at familial risk for breast cancer. Patients are individually seen and counseled by an oncologist, a genetics counselor, a nurse practitioner, a nutritionist, and a psychologist. Women were eligible for participation if their biological mother had been diagnosed with breast cancer, were at least 18 years old, were English-speaking, and had never themselves been diagnosed with breast cancer. Following informed consent, participants completed baseline questionnaires assessing depression and anxiety symptoms and a semi-structured clinical interview in which psychosocial background information was obtained. The depression and anxiety symptoms questionnaires were also administered to participants at subsequent follow-up appointments. Data for 73 patients from the High Risk Clinic from were available for analyses for the current study.

Measures

Information was obtained regarding the survival status of the participants' mothers (survived or passed away from breast cancer), developmental stage at the time of their mother's breast cancer diagnosis (less than 20 years old and 20 years of age and older), and whether participants felt they could talk openly about their mothers' breast cancer with their families (open or closed communication).

The State Anxiety subscale of the State-Trait Anxiety Inventory (STAI; (Spielberger, Gorsuch, & Lushene, 1970) was used to evaluate anxiety experienced at the time of assessment ("state anxiety"). The State Anxiety subscale contains 20 items and responses are measured on a 4-point Likert scale, with higher scores signifying the presence of higher levels of anxiety. The STAI manual reports high internal consistency for the State subscale ($\alpha = .92$). For the current study, Cronbach's alpha ranged from .86 to .92 for the three time points.

The Center for Epidemiologic Studies Depression Scale (CES-D;(Radloff, 1977) was used to assess current depressive symptomatology. It has 20 items that measure the frequency and intensity of depressive symptoms during the past week. Scores may range from of 0 to 60, with higher scores signifying the presence of more symptomatology. The test has adequate internal consistency ($\alpha = .85$ for general population; $\alpha = .90$ for clinical population); the Cronbach's alpha in this study varied from .89 to .93.

Additionally, a number of variables were considered as potential covariates including age in years at interview**,** ethnicity (Caucasian or non-Caucasian), marital status (unmarried or married), educational attainment (high school, some college, college graduate, or graduate school), employment status (currently employed or unemployed), number of years since mother's diagnosis, number of relatives with a past or present breast cancer diagnosis, and objective breast cancer risk based on the Gail model (Gail et al., 1989).

Statistical Analyses

Repeated-measures analysis of variance (ANOVA) was used to assess the effects of survival status of the mother and a group of selected predictors on changes in anxiety and depressive symptomatology across participants' first, second and third appointments at the high risk clinic. A number of potential covariates were considered, and any shown to be significantly associated with either of the outcome variables would have been included the multivariate models. Two 3 × 2 × 2 × 2 repeated measures ANOVAs were conducted with time (first, second and third clinic appointments) as the within subjects variable, mother's survival status (survived or died from breast cancer), participant's age at the time of her mother's breast cancer diagnosis (< 20 years or ≥ 20 years old), and style of family communication about breast cancer (open or closed family communication style) as between subjects factors, and state anxiety (STAI State Anxiety subtest percentile) and depressive symptomatology (CES-D score) as the dependent variables. The assumption of sphericity was evaluated using Mauchly's test and, if violated, degrees of freedom were corrected using the Greenhouse-Geisser correction factor. A full-factorial design was employed, therefore each model included main effects as well as all two, three and four-way interactions. Significant interaction effects were decomposed using simple effects post hoc analyses.

Results

A total of 73 participants were included in the study. Table 1 shows background characteristics of the sample. The sample was balanced between women whose mothers died from breast cancer and those whose mother survived ($n = 34$ and $n = 39$, respectively). The majority of participants were Caucasian (83.56%, $n = 61$) and married (67.12%, $n = 49$), with an average age of 41.14 years. Additionally, the sample was largely employed (75.34%, $n = 55$) and had a college or advanced degree (76.71%, $n = 56$). Participants exhibited absolute breast cancer risks moderately higher than that in the general population (18.72% mean calculated lifetime risk), and the average time since the mother's breast cancer diagnosis was 16.44 years. With regard to the assessment of potential covariates, none were used as control variables in the multivariate models given their lack of association with either outcome variable. Moreover, significant differences in baseline CES-D scores were not observed between daughters whose mothers died from breast cancer ($M = 11.40$, $SE = 1.84$) and those whose mothers survived ($M =13.64$, $SE = 2.04$), $t(71) = 0.80$, $p = .425$.

An overall main effect for time on state anxiety was observed, $F(1.69, 109.94) = 12.45$, $p < .001$. Specifically, participants showed significantly less anxiety at the first follow-up ($M = 53.42$, $SE = 3.83$) and second follow-up ($M = 51.50$, $SE = 3.91$) as compared to the initial visit ($M = 65.88$, $SE = 2.94$), $ps < .001$. Moreover, there was a significant three-way interaction between time, mother's survival and age at diagnosis, $F(1.69, 109.94) = 3.77$, $p = .033$ (see Figure 1). To facilitate interpretation of this significant interaction, the association between time and age at diagnosis was examined separately among daughters whose mothers died and daughters whose mothers survived.

Table 1

Summary statistics for sample and model variables (N = 73)

Variable	Mean ± SD or *N* (%)	Range
Sample characteristics		
Age in years	41.14 ± 9.33	20–66
Ethnicity		
Caucasian	61 (83.56)	
Non-Caucasian	12 (16.44)	
Education		
High school	5 (6.85)	
Some college	12 (16.43)	
College graduate	28 (38.36)	
Graduate school	28 (38.36)	
Married	49 (67.12)	
Employed	55 (75.34)	
Years since mother's diagnosis	16.44 ± 10.80	0–44.00
Computed risk of breast cancer	18.72 ± 8.22	6.80–57.40
Personal estimate breast cancer risk	56.29 ± 26.30	0–100
Number of family with breast cancer	2.19 ± 1.22	1–7
Model variables		
Mother's survival status		
Survived	39 (53.42)	
Died from breast cancer	34 (46.58)	
Age at mother's diagnosis		
Younger (< 20 years old)	30 (41.10)	
Older (> 20 years old)	43 (58.90)	
Family communication about breast cancer		
Open communication style	33 (45.21)	
Closed communication style	40 (54.79)	
State anxiety percentile		
Initial appointment	65.29 ± 24.10	10–100
First return visit	52.81 ± 30.85	2–100
Second return visit	52.43 ± 30.56	2–100
CES-D score (depressive symptoms)		
Initial appointment	12.60 ± 11.83	0–52
First return visit	10.12 ± 11.61	0–51
Second return visit	9.97 ± 10.08	0–44

Table 2

F values for repeated measures analyses of variance models

	df	State Anxiety Percentile		*df*	Depressive Symptoms	
		F	*p*		*F*	*p*
Main effects						
Time (A)	1.69, 109.94	12.45	<.001	2, 130	2.63	.076
Mother survival (B)	1, 65	0.17	.686	1, 65	0.13	.718
Age at mother's diagnosis (C)	1, 65	3.26	.076	1, 65	0.05	.829
Family communication about BC (D)	1, 65	0.50	.484	1, 65	2.16	.147
Two-way interactions						
A × B	1.69, 109.94	0.19	.793	2, 130	1.80	.170
A × C	1.69, 109.94	1.82	.173	2, 130	1.61	.204
A × D	1.69, 109.94	2.77	.076	2, 130	0.33	.721
B × C	1, 65	0.75	.388	1, 65	1.44	.235
B × D	1, 65	0.46	.500	1, 65	5.77	.019
C × D	1, 65	0.19	.663	1, 65	1.94	.168
Three-way interactions						
A × B × C	1.69, 109.94	3.77	.033	2, 130	6.91	.001
A × B × D	1.69, 109.94	4.10	.025	2, 130	1.42	.245
A × C × D	1.69, 109.94	0.98	.366	2, 130	1.88	.157
B × C × D	1, 65	0.24	.624	1, 65	0.39	.535
Four-way interaction						
A × B × C × D	1.69, 109.94	0.05	.927	2, 130	0.50	.606

The interaction effect stems from a significant Time × Age at Diagnosis interaction among participants whose mothers died from breast cancer, *F*(1.43, 43.01) = 5.15, *p* =.018. Participants whose mothers died who were younger at the time of diagnosis demonstrated a significant decrease in anxiety, *F*(1.24, 18.67) = 11.77, *p* = .001 (see Figure 1a), namely from the first visit (*M* = 64.89, *SE* = 4.39) to the second visit (*M* =

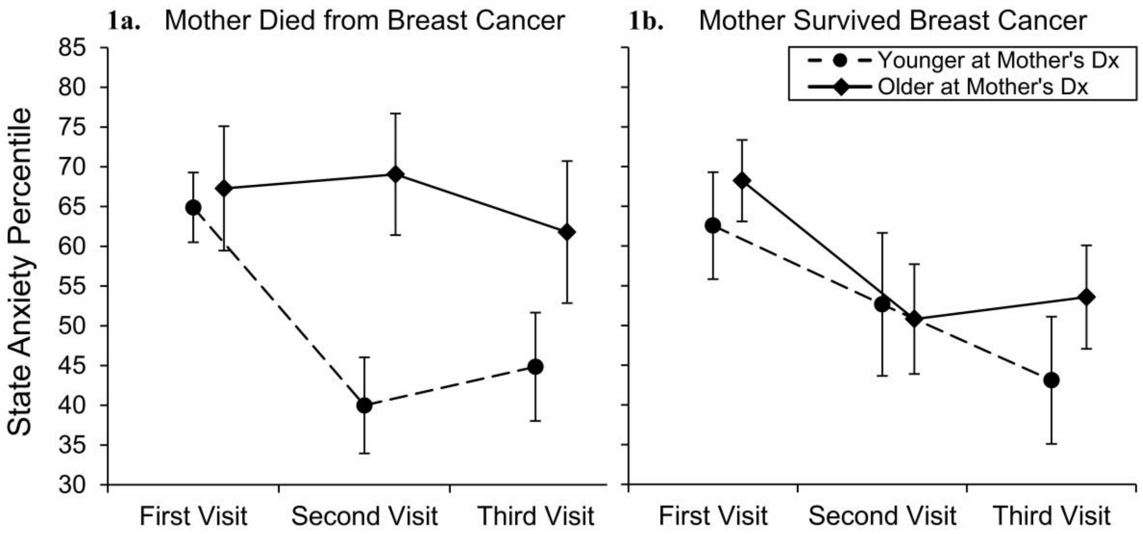


Figure 1. Means plot of change in state anxiety percentile across time based on age at mother's diagnosis.

39.99, *SE* = 6.04, *p* = .001) as well as from the first visit to the third visit (*M* = 44.84, *SE* = 6.81, *p* = .005). For participants whose mothers survived, only the main effect of time emerged as significant, *F*(2, 70) = 6.87, *p* = .002, with significant decreases in anxiety from the first visit (*M* = 66.22, *SE* = 3.33) to the second visit (*M* = 52.04, *SE* = 4.97), *p* = .005, and from the first visit to the third visit (*M* = 49.93, *SE* = 4.88), *p* = .001.

There was also a significant three-way interaction between time, mother's survival and style of family communication about breast cancer, *F*(1.69, 109.94) = 4.10, *p* = .025 (see Figure 2). Further analyses revealed that the interaction effect was only present only among participants whose mothers survived breast cancer, *F*(2, 70) = 6.10, *p* = .004 (see Figure 2b). Follow-up contrasts showed a significant change in anxiety over time among participants whose mothers survived who reported a closed style of family communication, *F*(2, 28) = 9.30, *p* = .001, with decreases in symptomatology from the first visit (*M* = 78.86, *SE* = 4.37) to the second visit (*M* = 54.31, *SE* = 9.25, *p* = .012),

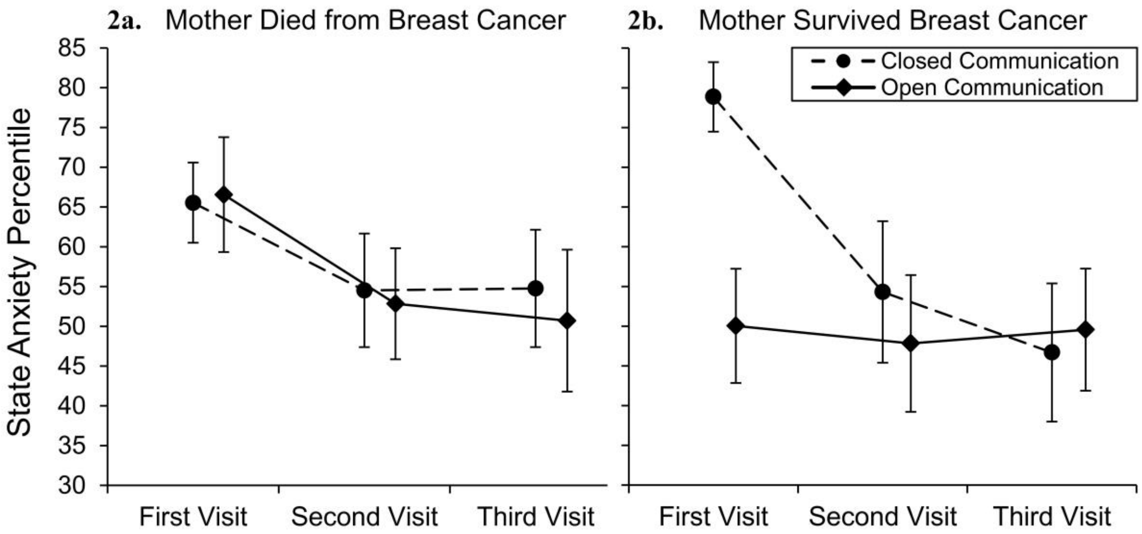


Figure 2. Means plot of change in state anxiety percentile across time based on style of family communication about breast cancer.

and from the first visit to the third visit (*M* = 46.69, *SE* = 9.24, *p* = .001). In contrast, style of family communication did not moderate change in anxiety among participants whose mothers died, *F*(1.43, 43.01) = 0.09, *p* = .855 (see Figure 2a).

With regard to depressive symptoms, there was a marginally significant overall main effect for time on change in symptomatology, *F*(2, 130) = 2.63, *p* = .076, with a significant decrease in depressive symptoms from the initial clinic visit (*M* = 12.85, *SE* = 1.46) to the third visit (*M* = 10.40, *SE* = 1.24), *p* = .032. There was also a significant three-way interaction between time, mother's survival and age at diagnosis, *F*(2, 130) = 6.91, *p* = .001 (see Figure 3). To facilitate interpretation of this interaction effect, the association between time and age at diagnosis was examined separately among daughters whose mothers died from breast cancer and daughters whose mothers survived. Follow-up analyses indicated a significant Time × Age at Diagnosis interaction among participants whose mothers died, *F*(2, 60) = 8.26, *p* = .001. The effect was significant

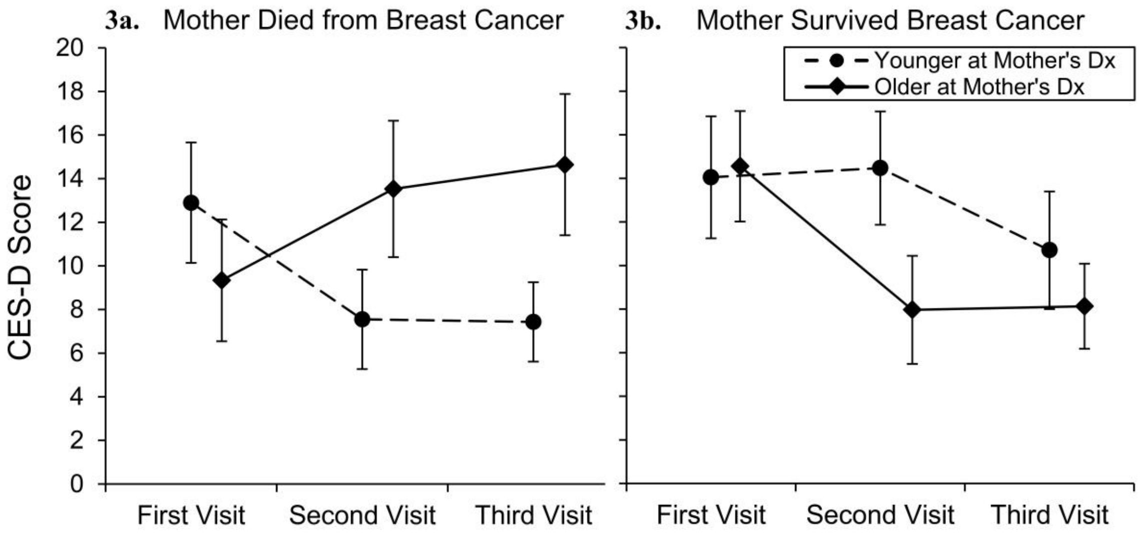


Figure 3. Means plot of change in depressive symptoms across time based on age at mother's diagnosis.

among participants whose mothers died who were younger at the time of diagnosis, *F*(2, 34) = 6.63, *p* = .004 (see Figure 3a). Specifically, there were significant decreases in depressive symptoms from the first visit (*M* = 12.90, *SE* = 2.76) to the second visit (*M* = 7.55, *SE* = 2.28, *p* = .015) as well as from the first visit to the third visit (*M* = 7.43, *SE* = 1.82, *p* = .004). For participants whose mothers survived, only the main effect of time emerged as significant, *F*(2, 70) = 3.58, *p* = .033, with a significant decrease in depressive symptoms from the first visit (*M* = 14.31, *SE* = 2.18) to the third visit (*M* = 9.76, *SE* = 1.77), *p* = .014. With regard to the effect of style of family communication on depressive symptoms, no main or interaction effects were shown.

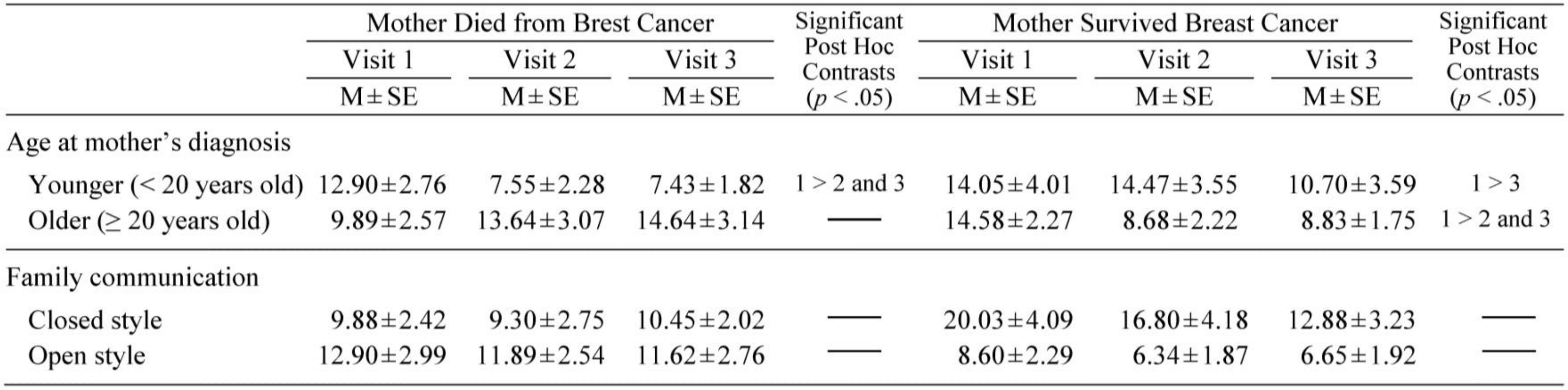
Table 3

Mean State Anxiety Percentile Across High Risk Clinic Visits as a Function of Mother's Survival Status, Age at Mother's Breast Cancer Diagnosis, and Style of Family Communication About Breast Cancer

	Mother Died from Brest Cancer			Significant Post Hoc Contrasts ($p < .05$)	Mother Survived Breast Cancer			Significant Post Hoc Contrasts ($p < .05$)
	Visit 1	Visit 2	Visit 3		Visit 1	Visit 2	Visit 3	
	M ± SE	M ± SE	M ± SE		M ± SE	M ± SE	M ± SE	
Age at mother's diagnosis								
Younger (< 20 years old)	64.89 ± 4.39	39.99 ± 6.04	44.84 ± 6.81	1 > 2 and 3	62.57 ± 6.73	52.65 ± 11.02	43.10 ± 10.31	1 and 2 > 3
Older (≥ 20 years old)	67.58 ± 7.49	69.17 ± 7.41	62.67 ± 8.75	——	68.48 ± 4.59	51.88 ± 6.19	55.36 ± 5.83	1 > 2 and 3
Family communication								
Closed style	65.54 ± 5.04	54.52 ± 7.14	54.76 ± 7.38	——	78.86 ± 4.37	54.31 ± 9.25	46.69 ± 9.24	1 > 2 and 3
Open style	66.94 ± 6.47	54.65 ± 6.25	52.75 ± 7.99	——	52.20 ± 6.44	50.22 ± 7.70	51.77 ± 6.88	——

Table 4

Mean CES-D Score Across High Risk Clinic Visits as a Function of Mother's Survival Status, Age at Mother's Breast Cancer Diagnosis, and Style of Family Communication About Breast Cancer



	Mother Died from Brest Cancer			Significant Post Hoc Contrasts ($p < .05$)	Mother Survived Breast Cancer			Significant Post Hoc Contrasts ($p < .05$)
	Visit 1	Visit 2	Visit 3		Visit 1	Visit 2	Visit 3	
	M ± SE	M ± SE	M ± SE		M ± SE	M ± SE	M ± SE	
Age at mother's diagnosis								
Younger (< 20 years old)	12.90±2.76	7.55±2.28	7.43±1.82	1 > 2 and 3	14.05±4.01	14.47±3.55	10.70±3.59	1 > 3
Older (≥ 20 years old)	9.89±2.57	13.64±3.07	14.64±3.14	—	14.58±2.27	8.68±2.22	8.83±1.75	1 > 2 and 3
Family communication								
Closed style	9.88±2.42	9.30±2.75	10.45±2.02	—	20.03±4.09	16.80±4.18	12.88±3.23	—
Open style	12.90±2.99	11.89±2.54	11.62±2.76	—	8.60±2.29	6.34±1.87	6.65±1.92	—

Discussion

This study was an attempt to longitudinally profile anxiety and depressive symptoms of daughters of breast cancer patients attending a high-risk breast cancer clinic. A number of specific effects emerged that lend further understanding to the influence of mother's survival, daughter's age at time of mother's diagnosis, and style of family communication about breast cancer and their relationship to the long-term emotional functioning of these high-risk daughters. While results confirmed some significant main effects, the interaction effects were more significantly and consistently associated with changes in anxiety and depressive symptomatology. Overall, the findings underscore the importance of moderating variables in understanding the long-term adjustment of women with a family history of breast cancer adhering to a high-risk surveillance program.

In regard to the first hypothesis, it was not the case that depressive symptomatology was higher at baseline, or for that matter at follow-up, among women whose mothers died from breast cancer. This finding may appear to fly in the face of "reasonable" clinical expectations. It seems reasonable to expect that women whose mothers died from breast cancer will enter the clinic with significantly higher levels of depressive symptomatology. That the baseline CES-D scores were essentially identical for daughters whose mothers died and daughters whose mothers survived suggests that the depressing and emotionally impactful aspect of the experience involves witnessing the mother going through the disease process. Maternal loss, therefore, is not necessarily the only depressing stressor in this experience.

The second hypothesis was supported in that a significant reduction in anxiety, but not depressive symptoms, was observed over the span of the three clinic visits. This was not unanticipated by the investigators. Anxiety is an emotional state which we are used to seeing dramatically changed over a brief period of time in the clinic. These daughters oftentimes enter the clinic with significant anxiety related to concerns about their own vulnerability to breast cancer and memories of their mother's experience with the disease. It appears however that emotional support for women to process these issues facilitates a rapid and significant reduction in symptoms of anxiety. This would reinforce the notion elsewhere in the literature of the potential of single-session interventions to affect significant changes in emotional states (Hymmen, Stalker, & Cait, 2013).

The third hypothesis was not confirmed as age at time of mother's diagnosis, by itself as a predictor, was not associated with change in anxiety or depressive symptomatology. Significant effects were observed when age at the time of diagnosis was considered in terms of the moderating effects of mother's survival status. For daughters whose mothers survived, the main effect for time was significant as reflected by decreased anxiety and depressive symptomatology. The interaction between time and age at mother's diagnosis was significant among daughters whose mothers died from breast cancer. In particular, and contrary to our expectations, a pronounced reduction in anxiety symptoms was observed from the first to second clinic visits among daughters whose mothers died who were younger at the time of diagnosis. It appears that the opportunity to talk openly in the clinic context was less beneficial in reduction of anxiety symptoms for daughters whose mothers died who were older at the time of diagnosis. Research has shown that women who were older at the time of their mother's diagnosis and death experience greater role strain and caretaking responsibilities (Wellisch et al., 1991), while women who were younger during this experience were more protected (Compas et al., 1994; Wellisch et al., 1992). Perhaps the women who were older require more intensive and supportive interventions beyond what might be possible in the context of the clinic visits.

In regard to hypothesis 4, by itself as a predictor, style of family communication was not found to be associated with change in anxiety or depressive symptomatology across clinic visits. It was only when style of family communication was considered in interaction with mother's survival status that it proved decisive in the data. Specifically, the results demonstrated that daughters whose mothers survived but whose families had a closed style of communication about breast cancer entered the clinic with significantly elevated levels of anxiety compared to daughters whose mothers survived with an open style of family communication and daughters with mothers who died regardless of family communication style. This suggests that hampered family communication about breast cancer, in the face of the continued presence of the mother in the household, may be reflective of a particularly dysfunctional dynamic. While it is fortunate that this group of daughters appears to derive significant benefit from the opportunity to talk about their experiences in their first clinic visit, this finding reminds us to more carefully consider the emotional experience of the daughter whose mother survived breast cancer. As previously discussed, adaptive versus less adaptive adjustment and functioning on the part of high-risk women should not be inferred solely on the basis of maternal survival versus maternal death from breast cancer (Wellisch et al., 2012).

The findings of this study should be considered in light of some limitations. The sample was comprised of women adhering to regular breast cancer surveillance and may not be generalizable to high-risk women in the community or those with limited access to healthcare. Additionally, the sample was predominantly Caucasian, well-educated urban women. Larger studies with more demographically representative samples would add clarity regarding the robustness of these results. Additional research to expand on the results of this study will further enable healthcare professionals to identify and offer additional support to high-risk women most vulnerable to maladjustment.

References

Baider, L., Ever-Hadani, P., & Kaplan De-Nour, A. (1999). Psychological distress in healthy women with familial breast cancer: Like mother, like daughter? *International Journal of Psychiatry in Medicine, 29*(4), 411-420.

Bovbjerg, D. H., & Valdimarsdottir, H. B. (2001). Interventions for healthy individuals at familial risk for cancer. In A. Baum & B. L. Andersen (Eds.), *Psychosocial Interventions for Cancer* (pp. 305-320). Washington, DC: American Psychological Association.

Brain, K., Henderson, B. J., Tyndel, S., Bankhead, C., Watson, E., Clements, A., . . . Group, P. S. M. (2008). Predictors of breast cancer-related distress following mammography screening in younger women on a family history breast screening programme. *Psycho-Oncology, 17*(12), 1180-1188.

Brédart, A., Kop, J. L., Fall, M., Pelissier, S., Simondi, C., Dolbeault, S., . . . Tardivon, A. (2012). Anxiety and specific distress in women at intermediate and high risk of breast cancer before and after surveillance by magnetic resonance imaging and mammography versus standard mammography. *Psycho-Oncology, 21*(11), 1185-1194.

Compas, B. E., Worsham, N. L., Epping-Jordan, J. E., Grant, K. E., Mireault, G., Howell, D. C., & Malcarne, V. L. (1994). When Mom or Dad has cancer: Markers of psychological distress in cancer patients, spouses, and children. *Health Psychology, 13*(6), 507.

den Heijer, M., Seynaeve, C., Vanheusden, K., Duivenvoorden, H. J., Bartels, C. C., Menke-Pluymers, M. B., & Tibben, A. (2011). Psychological distress in women at risk for hereditary breast cancer: The role of family communication and perceived social support. *Psycho-Oncology, 20*(12), 1317-1323.

den Heijer, M., Seynaeve, C., Vanheusden, K., Timman, R., Duivenvoorden, H. J., Tilanus-Linthorst, M., . . . Tibben, A. (2013). Long-term psychological distress in women at risk for hereditary breast cancer adhering to regular surveillance: A risk profile. *Psycho-Oncology, 22*(3), 598-604.

Erblich, J., Bovbjerg, D. H., & Valdimarsdottir, H. B. (2000). Looking forward and back: Distress among women at familial risk for breast cancer. *Annals of Behavioral Medicine, 22*(1), 53-59.

Esplen, M. J., & Hunter, J. (2002). Grief in women with a family history of breast cancer. *Primary Psychiatry, 9*(5), 57-64.

Facione, N. C. (2002). Perceived risk of breast cancer. *Cancer Practice, 10*(5), 256-261.

Field, K. M., & Phillips, K. (2007). Management of women at high familial risk for breast and ovarian cancer. *Cancer Forum, 31*(3), 141-149.

Gail, M. H., Brinton, L. A., Byar, D. P., Corle, D. K., Green, S. B., Schairer, C., & Mulvihill, J. J. (1989). Projecting individualized probabilities of developing breast cancer for white females who are being examined annually. *Journal of the National Cancer Institute, 81*(24), 1879-1886.

Gilbar, O. (1998). Coping with threat. Implications for women with a family history of breast cancer. *Psychosomatics, 39*(4), 329-339.

Gopie, J. P., Vasen, H. F., & Tibben, A. (2012). Surveillance for hereditary cancer: does the benefit outweigh the psychological burden? A systematic review. [Review]. *Crit Rev Oncol Hematol, 83*(3), 329-340.

Hymmen, P., Stalker, C. A., & Cait, C.-A. (2013). The case for single-session therapy: Does the empirical evidence support the increased prevalence of this service delivery model? *Journal of Mental Health, 22*(1), 60-71.

Radloff, L. S. (1977). The CES-D Scale. *Applied Psychological Measurement, 1*(3), 385-401.

Raveis, V. H., & Pretter, S. (2005). Existential plight of adult daughters following their mother's breast cancer diagnosis. *Psycho-Oncology, 14*(1), 49-60.

Rijnsburger, A. J., Essink-Bot, M. L., van Dooren, S., Borsboom, G. J., Seynaeve, C., Bartels, C. C., . . . de Koning, H. J. (2004). Impact of screening for breast cancer in high-risk women on health-related quality of life. *British Journal of Cancer, 91*(1), 69-76.

Schwartz, M. D., Isaacs, C., Graves, K. D., Poggi, E., Peshkin, B. N., Gell, C., . . . Perley, L. (2012). Long-term outcomes of BRCA1/BRCA2 testing: Risk reduction and surveillance. *Cancer, 118*(2), 510-517.

Spielberger, C. D., Gorsuch, R. L., & Lushene, R. E. (1970). *Manual for the State-Trait Anxiety Inventory*. Palo Alto, CA: Consulting Psychologists Press.

Thewes, B., Meiser, B., Tucker, K., & Schnieden, V. (2003). Screening for psychological distress and vulnerability factors in women at increased risk for breast cancer: A review of the literature. *Psychology, Health & Medicine, 8*(3), 289-304.

Tyndel, S., Austoker, J., Henderson, B. J., Brain, K., Bankhead, C., Clements, A., & Watson, E. K. (2007). What is the psychological impact of mammographic screening on younger women with a family history of breast cancer? Findings from a prospective cohort study by the PIMMS Management Group. *Journal of Clinical Oncology, 25*(25), 3823-3830.

Valdimarsdottir, H. B., Bovbjerg, D. H., Kash, K. M., Holland, J. C., Osborne, M. P., & Miller, D. G. (1995). Psychological distress in women with a familial risk of breast cancer. *Psycho-Oncology*, *4*(2), 133-141.

van Dooren, S., Seynaeve, C., Rijnsburger, A. J., Duivenvoorden, H. J., Essink-Bot, M. L., Tilanus-Linthorst, M. M., . . . Tibben, A. (2005). Exploring the course of psychological distress around two successive control visits in women at hereditary risk of breast cancer. *European Journal of Cancer, 41*(10), 1416-1425.

van Oostrom, I., Meijers-Heijboer, H., Duivenvoorden, H. J., Brocker-Vriends, A. H., van Asperen, C. J., Sijmons, R. H., . . . Tibben, A. (2006). Experience of parental cancer in childhood is a risk factor for psychological distress during genetic cancer susceptibility testing. *Annals of Oncology, 17*(7), 1090-1095.

van Oostrom, I., Meijers-Heijboer, H., Duivenvoorden, H. J., Brocker-Vriends, A. H., van Asperen, C. J., Sijmons, R. H., . . . Tibben, A. (2007). Family system characteristics and psychological adjustment to cancer susceptibility genetic testing: A prospective study. *Clinical Genetics, 71*(1), 35-42.

van Oostrom, I., Meijers-Heijboer, H., Lodder, L. N., Duivenvoorden, H. J., van Gool, A. R., Seynaeve, C., . . . Tibben, A. (2003). Long-term psychological impact of carrying a BRCA1/2 mutation and prophylactic surgery: A 5-year follow-up study. *Journal of Clinical Oncology, 21*(20), 3867-3874.

Visser, A., Huizinga, G. A., van der Graaf, W. T., Hoekstra, H. J., & Hoekstra-Weebers, J. E. (2004). The impact of parental cancer on children and the family: A review of the literature. *Cancer Treatment Reviews, 30*(8), 683-694.

Watson, E. K., Henderson, B. J., Brett, J., Bankhead, C., & Austoker, J. (2005). The psychological impact of mammographic screening on women with a family history of breast cancer-A systematic review. *Psycho-Oncology*, *14*(11), 939-948.

Watson, M., James-Roberts, I., Ashley, S., Tilney, C., Brougham, B., Edwards, L., . . . Romer, B. (2005). Factors associated with emotional and behavioural problems among school age children of breast cancer patients. *British Journal of Cancer, 94*(1), 43-50.

Wellisch, D. K., Gritz, E. R., Schain, W., Wang, H. J., & Siau, J. (1991). Psychological functioning of daughters of breast cancer patients. Part I: Daughters and comparison subjects. *Psychosomatics, 32*(3), 324-336.

Wellisch, D. K., Gritz, E. R., Schain, W., Wang, H. J., & Siau, J. (1992). Psychological functioning of daughters of breast cancer patients. Part II: Characterizing the distressed daughter of the breast cancer patient. *Psychosomatics*, *33*(2), 171-179.

Wellisch, D. K., Ormseth, S. R., Hartoonian, N., & Owen, J. E. (2012). A retrospective study predicting psychological vulnerability in adult daughters of breast cancer patients. *Families, Systems & Health, 30*(3), 253-264.

Zakowski, S. G., Valdimarsdottir, H. B., Bovbjerg, D. H., Borgen, P., Holland, J., Kash, K., . . . Van Zee, K. (1997). Predictors of intrusive thoughts and avoidance in women with family histories of breast cancer. *Annals of Behavioral Medicine, 19*(4), 362-369.

CHAPTER THREE

PREDICTING REATTENDANCE TO A HIGH-RISK BREAST CANCER CLINIC

Sarah Ormseth, M.A., David Wellisch, Ph.D.,
Adam Aréchiga, Psy.D., DrPH, Taylor Draper, M.A.

Abstract

Research about follow-up patterns of women attending high-risk breast cancer clinics is limited. The objective of this study is to profile daughters of breast cancer patients who are likely to return versus those unlikely to return for follow-up care in a high-risk clinic. This longitudinal investigation included 131 patients attending the UCLA Revlon Breast Center High Risk Clinic. Predictor variables included age, computed breast cancer risk, participants' perceived personal risk, clinically significant depressive symptomatology (CES-D score ≥ 16), current level of anxiety (State-Trait Anxiety Inventory), and survival status of participants' mothers (survived or passed away from breast cancer). Results showed that a greater likelihood of reattendance was associated with older age (adjusted odds ratio [AOR] = 1.07, $p = .004$), computed breast cancer risk (AOR = 1.10, $p = .017$), absence of significant depressive symptomatology (AOR = 0.25, $p = .009$), past psychiatric diagnosis (AOR = 3.14, $p = .029$), and maternal loss to breast cancer (AOR = 2.59, p=.034). Also, an interaction was found between mother's survival status and perceived risk ($p = .019$), such that reattendance was associated with higher perceived risk among participants whose mothers survived, (AOR

= 1.04, *p* = .002), but not those whose mothers died (AOR = 0.99, *p* = .685). Furthermore, a non-linear inverted “U” relationship was observed between state anxiety and reattendance (*p* = .037); participants with moderate anxiety were more likely to reattend than those with either low or high anxiety levels. Findings highlight the importance of psychological factors in predicting reattendance to a high-risk breast cancer clinic. Explication of profiles of women who may or may not follow-up offers the possibility of intervention from the first visit to increase the likelihood of follow-up care.

Introduction

For women at high risk for breast cancer, screening is the mainstay of risk management. Given that evidence-based cancer screening and risk reduction strategies for women with a family history of breast cancer are complex and dynamic, optimal risk management is likely to be in the context of a multidisciplinary setting (Field & Phillips, 2007). The advantages of multidisciplinary high-risk care has resulted in recommendations for, and the development of, such clinics (Kuschel, Lux, Goecke, & Beckmann, 2000). High risk clinics provide continual surveillance, screening, and management for high-risk women in a centralized context. Despite the benefits of multidisciplinary high-risk cancer surveillance programs, many women with a family history of breast cancer do not attend or re-attend for continued screening and risk management (Hailey, Carter, & Burnett, 2000).

While extant research has identified a number of barriers and facilitators of screening adherence among women at high risk for breast cancer, few studies have examined factors related to re-attendance. Previous studies have primarily focused on prior screening experiences and a limited set of demographic variables and have shown an association between a decreased likelihood of reattendance and reluctance at initial attendance, negative past screening experiences, prior mammography screening, a foreign language background, and greater rurality (Bulliard, De Landtsheer, & Levi, 2003; Cockburn, Schofield, White, Hill, & Russell, 1997; Katapodi, Lee, Facione, & Dodd, 2004; Price et al., 2010; Tatla et al., 2003). Research on reattendance is particularly important considering that attendance rates tend to decline with successive screening (Fink, Shapiro, & Roester, 1972; Taylor, Taplin, Urban, White, & Peacock, 1995).

Therefore, research examining additional factors related to reattendance is essential for increasing rates of reattendance (Cockburn et al., 1997).

Among high-risk women, some evidence suggests that elevated levels of distress and depressive symptoms relate to decreased screening adherence (Kash, Holland, Halper, & Miller, 1992; Price et al., 2010; Wellisch & Lindberg, 2001). While anxiety has been found to be related with both screening avoidance and adherence (Consedine, Magai, Krivoshekova, Ryzewicz, & Neugut, 2004; Hailey, 1991; Kash et al., 1992; Lerman et al., 1993; Lerman, Kash, & Stefanek, 1994; Lindberg & Wellisch, 2001; Meiser et al., 2000), there is some evidence that the anxiety-adherence relationship may be non-linear with likelihood of adherence declining both with increasing or decreasing levels of anxiety (Meiser et al., 2000; Zhang et al., 2012). Literature evaluating the effect of lifetime psychiatric history on reattendance behavior is more limited. However, consistent with the kindling hypothesis (Kendler, Karkowski, & Prescott, 1999), it might be expected that high-risk women with a history of depression or anxiety may be sensitized to stressful life events such as maternal illness and death and experience subsequent maladaptation. Indeed, previous research has demonstrated an association between past psychiatric illness and current affective difficulties among women at high risk for breast cancer (Hopwood et al., 1998).

Studies have also examined perceived risk as a correlate of breast cancer screening among high-risk women, though findings have been inconsistent. Perceived risk has shown a positive association with breast cancer screening (Consedine et al., 2004; Lerman et al., 1993; McCaul, Branstetter, O'Donnell, Jacobson, & Quinlan, 1998; McCaul, Schroeder, & Reid, 1996; Zhang et al., 2011), and has also been shown to be unassociated with screening (Diefenbach, Miller, & Daly, 1999; Gorin & Albert, 2003; Isaacs et al., 2002; Martin & Degner, 2006). However, a recent comprehensive review about perceived risk and adherence to breast cancer screening among women with familial breast cancer risk reported a weak to moderate positive relationship between perceived breast cancer risk and mammography adherence (Walker et al., 2013).

Demographic characteristics also likely affect screening re-attendance. Research indicates that older age and being married/partnered predicts screening uptake (Price et al., 2010; Rahman, Dignan, & Shelton, 2005), as well as reattendance for breast cancer screening (Pakenham, Pruss, & Clutton, 2000). Reattendance may also be related to aspects of women's experiences of breast cancer in their families. Research has shown that women with a breast cancer death in the family were more likely to have had a recent mammogram compared with women with only a breast cancer survivor in the family (Tracy et al., 2008). However, the association between mothers' survival from breast cancer and daughters' reattendance rates to high-risk clinics has not yet been examined.

The main aim of this study was to profile women who are likely to return versus those unlikely to return for follow-up care in a high risk breast cancer clinic, with a specific focus on daughters of breast cancer patients. A set of hypotheses emerge from the literature that this study can help evaluate. It was expected that demographic characteristics would be associated with an increased likelihood of reattendance, including older age and being married/partnered. Next, it was hypothesized that depressive symptomatology, lifetime psychiatric diagnoses, perceived breast cancer risk, and survival status of the mother will be associated with likelihood of reattendance. Specifically, an increased likelihood of reattendance was expected to be associated with higher levels of perceived risk and maternal loss to breast cancer, while a decreased likelihood of reattendance was expected to be associated with clinically significant depressive symptoms and having a previous diagnosis of a psychiatric disorder. It was also hypothesized that the relationship between state anxiety and reattendance will be curvilinear in nature such that reattendance will be more strongly associated with moderate levels of anxiety than milder anxiety or more severe anxiety. Finally, it was hypothesized that survival status of the mother will moderate the effects of the aforementioned hypothesized predictors on likelihood of reattendance.

Method

The data for the present study were obtained during the patients' first three appointments at the UCLA Revlon Breast Center High Risk Clinic. The High Risk Clinic is a multidisciplinary center that setting that serves patients at familial risk for breast cancer. During their initial visit to the clinic, patients are individually seen and counseled by an oncologist, a genetics counselor, a nurse practitioner, a nutritionist, and a psychologist; most patients also receive a mammogram. During follow-up visits, patients are seen by specific members of the team according to the patient's needs.

Institutional Review Board approval was granted prior to data collection. Women were eligible for participation if their biological mother had been diagnosed with breast cancer, were at least 18 years old, were English-speaking, and had never themselves been diagnosed with breast cancer. Data for 131 patients from the High Risk Clinic from were available for analyses for the current study. A psychologist conducted a semi-structured clinical interview with participants during their first appointment, in which psychosocial background information was obtained. Participants also completed questionnaires assessing depression and anxiety symptoms during their initial appointment.

Measures

The primary outcome variable was reattendance to the high-risk clinic, defined as a dichotomous measure of whether patients returned for a follow-up appointment (reattendance coded as 1, did not follow-up as 0).

To ascertain their mothers' survival from breast cancer, participants were asked whether their mothers were still alive, and cause of death if deceased (died from breast cancer coded as 1, alive or non-breast cancer death as 0). Perceived risk was assessed by having participants rate from 0 (not at all likely) to 100 (extremely likely) the likelihood that they would ever develop breast cancer. Participants were also asked about their lifetime history of any diagnosed psychiatric condition (previous psychiatric diagnosis coded as 1, no psychiatric history as 0).

The State-Trait Anxiety Inventory (STAI; (Spielberger, Gorsuch, & Lushene, 1970) was used to evaluate current level of anxiety ("state anxiety"). The State scale contains 20 items and responses are measured on a 4-point Likert scale, with higher scores signifying the presence of higher levels of anxiety. The STAI manual reports high internal consistency State scale ($\alpha = .92$), which was replicated in this study ($\alpha = .90$).

The Center for Epidemiologic Studies Depression Scale (CES-D;(Radloff, 1977) was used to assess current depressive symptomatology. The CES-D consists of 20 items and scores may range from of 0 to 60, with higher scores signifying the presence of more symptomatology. The test has good reliability ($\alpha = .85$ for general population; $\alpha = .90$ for clinical population); the reliability of the scale was strong in the current study ($\alpha = .95$). Although not constituting a clinical diagnosis of depression, scores at or above 16 on the CES-D are considered indicative of clinically significant symptoms of depression.

Additionally, a number of variables were considered as potential covariates including age in years at interview, ethnicity (Caucasian or non-Caucasian), marital status (married/partnered or never married/partnered), educational attainment (high school, some college, college graduate, or graduate school), employment status (currently employed or unemployed), participant age at the time of mother's breast cancer diagnosis, mother's age at the time of diagnosis, number of relatives with a past or present breast cancer diagnosis, and computed breast cancer risk using the Gail model (Gail et al., 1989).

Statistical Analyses

Analyses were conducted using SPSS 19.0. Associations between reattendance and potential control variables were examined using **χ^2 *and* t *tests*** for categorical and ***continuous variables, respectively.*** Variables that had a significant association reattendance were included as covariates in the multivariate models to ascertain unbiased point estimates. Three multivariate logistic regression models were used to predict reattendance as a dependent variable, with results expressed in adjusted odds ratio (AORs) with 95% confidence intervals (CIs). The first model assessed likelihood of reattendance based on the focal main effects, after controlling for relevant covariates. Perceived breast cancer risk, depressive symptomatology, state anxiety percentile score, personal history of a psychiatric diagnosis, and survival status of participants' mothers were included in the model as main effects.

Next, to test the moderating effects of mother's survival status, the two-way interactions of survival status with perceived risk and the other focal predictors were considered. Continuous predictors were mean centered prior to creating interaction terms (Aiken & West, 1991). Preliminary analyses revealed three non-significant interaction terms (survival × state anxiety, survival × depression, and survival × past psychopathology, *F*s < 1). Thus, these terms were trimmed, and the significance of the survival status × perceived risk interaction effect was tested in the multivariate model. In may be non-linear. Quadratic anxiety scores were computed by squaring the centered state anxiety scores. Likelihood ratio tests were used to determine whether the increment in the proportion of variance accounted for by addition of the higher-order terms was statistically significant. Statistically significant interaction and quadratic effects were depicted graphically using locally weighted scatterplot smoothing (Lowess) to facilitate the visual interpretation of the plots (Cleveland, 1979).

Results

A total of 131 (65 reattended; 66 did not return) participants were included in the study. Table 5 shows background characteristics of the sample. With respect to age, the overall sample was relatively young (*M* = 39.85, *SD* = 10.10) and exhibited absolute breast cancer risks moderately higher than that in the general population (18.24 percent calculated lifetime risk). Additionally, the majority of participants were Caucasian (81.68%, *n* = 107), married (61.07%, *n* = 80), and had a college or advanced degree

Table 5

Demographic characteristics of participants who returned for a follow-up appointment compared to those who did not

Variable	Total Sample (N = 131)	Attended Follow-up Appointment Yes (n = 65)	Attended Follow-up Appointment No (n = 66)
	M ± SD or *n* (%)	M ± SD or *n* (%)	M ± SD or *n* (%)
Age in years*	39.85 ± 10.10	42.75 ± 9.23	36.99 ± 10.17
Marital status*			
Married or partnered	82 (62.60)	50 (76.92)	32 (48.49)
Not married or partnered	49 (47.40)	15 (23.08)	34 (51.51)
Ethnicity			
Caucasian	107 (81.68)	54 (83.08)	53 (80.30)
Non-Caucasian	24 (18.32)	11 (16.92)	13 (19.70)
Education			
High school	8 (6.11)	3 (4.62)	5 (7.58)
Some college	18 (13.74)	12 (18.46)	6 (9.10)
College graduate	48 (36.64)	21 (32.31)	27 (40.91)
Graduate school	57 (43.51)	29 (44.62)	28 (42.42)
Employment status			
Unemployed	30 (22.90)	13 (20.00)	17 (25.76)
Employed	101 (77.10)	52 (80.00)	49 (74.24)
Computed breast cancer risk*	18.24 ± 7.15	19.62 ± 9.20	16.87 ± 3.88
Number of relatives with BC	2.12 ±1.21	2.15 ± 1.29	2.08 ± 1.27
Age at mother's diagnosis	24.18 ± 11.80	24.98 ±11.69	23.40 ± 11.94
Mother's age at diagnosis	51.35 ± 11.94	50.32 ±12.87	52.40 ±10.90

*p < .05 for differences between participants who did and did not reattend.

(80.15%, n = 105). The background characteristics of these two groups were generally similar. However, compared to participants who returned for a follow-up appointment, participants who did not reattend were younger ($t(129) = -3.40$, $p = .001$), less likely to be married ($\chi^2(1)=11.31$, $p = .001$) and had a lower computed breast cancer risk ($t(129) = -2.22$, $p = .029$). Given these findings, age, marital status and computed breast cancer risk were used as control variables.

The main effects model discriminated well between patients who did and did not return for follow-up, $\chi^2(8) = 45.89$, $p < .001$, and accounted for 39.4% of the variance in reattendance (Nagelkerke $R^2 = 0.39$). The coefficients for seven of the eight hypothesized predictors were statistically significant ($p < .05$). Odds ratios for the independent variables are presented in Table 6. When holding other variables constant, this model suggests that likelihood of reattendance increased by eight percent for each one year increase in age, and each one standardized unit increment in computed breast cancer risk was associated with an 11 percent rise in likelihood of reattendance. For each one standardized unit increment in perceived breast cancer risk, likelihood of reattendance increased by two percent. Participants with clinically significant distress were only about 21 percent as likely to reattend as those did not demonstrate marked depressive

Table 6

Sample characteristics and multivariate logistic regression predicting reattendance

Variable	Attended Follow-up Appointment		Multivaraite Logistic Regression	
	Yes (*n* = 65)	No (*n* = 66)		
	M ± SD or *n* (%)	M ± SD or *n* (%)	AOR (95% CI)	*p*
Age in years	42.75 ± 9.23	36.99 ± 10.17	1.07 (1.02–1.13)	.004
Computed breast cancer risk	19.62 ± 9.20	16.87 ± 3.88	1.10 (1.02–1.20)	.017
Married or partnered	50 (76.92)	32 (48.49)	1.98 (0.80–4.88)	.141
Significant distress (CES-D)	12 (18.46)	23 (34.85)	0.25 (0.09–0.71)	.009
Prior psychiatric diagnosis	22 (33.85)	14 (21.21)	3.14 (1.13–8.74)	.029
State Anxiety percentile	64.24 ± 7.70	66.08 ± 9.50	0.95 (0.90–1.00)	.049
Perceived breast cancer risk	56.77 ± 24.81	48.27 ± 24.99	1.02 (1.00–1.04)	.035
Maternal breast cancer loss	35 (53.85)	23 (34.85)	2.59 (1.08–6.23)	.034

symptomatology. For each one percentile increase in state anxiety, likelihood of reattendance decreased by five percent. Finally, the likelihood of reattendance among participants who reported a past psychiatric diagnosis was over three times as large as those without a psychiatric history, and the likelihood of reattendance among participants whose mothers died from breast cancer was almost three times that of participants whose mothers survived breast cancer.

In addition to main effects, the interaction of survival status and perceived risk was also assessed. While the significance of all other previously present predictors remained virtually unchanged, entry of this interaction term into the multivariate model significantly improved the fit over the main effects only model, $\chi^2_{\text{inc}}(1) = 5.53$, $p = .019$, Nagelkerke $R^2 = 0.43$. This suggests that the association between perceived risk and likelihood of reattendance was moderated by mother's survival status. To facilitate interpretation of this significant interaction effect, the association between perceived risk and likelihood of reattendance was examined separately among daughters whose mothers died from breast cancer and daughters whose mothers survived (see Figure 4). Analyses revealed that higher perceived risk was associated with a greater likelihood of reattendance among participants whose mothers survived breast cancer ($p = .002$, AOR = 1.04, 95% CI: 1.01–1.07). In contrast, no association was shown between perceived risk and reattendance among participants whose mothers died ($p = .685$, AOR = 0.99, 95% CI: 0.97–1.02). This interaction effect is illustrated in Figure 4, which shows predicted probabilities of reattendance based on perceived breast cancer risk, stratified by mother's survival status.

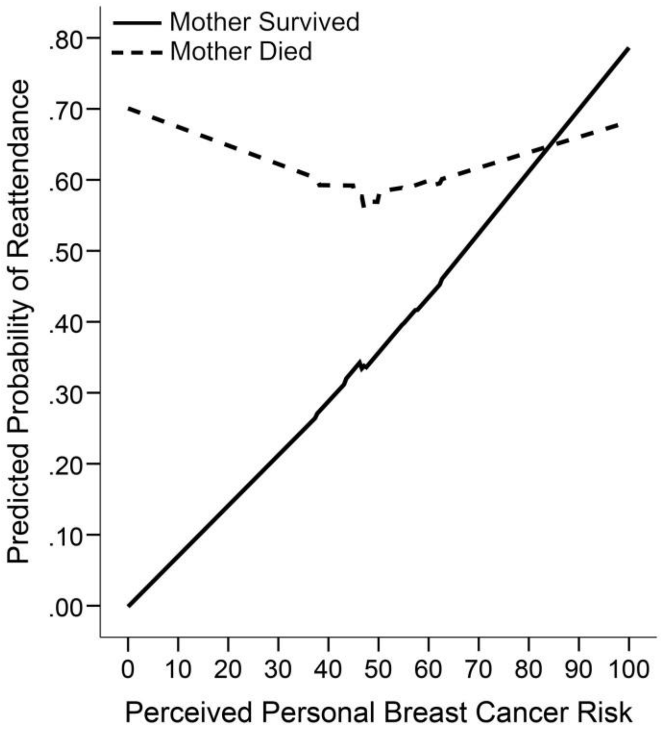


Figure 4. Predicted probability of reattendance as function of perceived breast cancer risk for daughters whose mothers survived and died from breast cancer (plotted using Lowess smoothing with bandwidth 0.8).

To assess nonlinearity in the association between state anxiety and likelihood of reattendance, a quadratic effect for state anxiety term was introduced to the multivariate logistic regression model. As previously discussed, the linear state anxiety term was significantly associated with reattendance in the main effects model (see Table 6). When the quadratic term was entered into the model, all previously significant main effects remained as such, including the linear state anxiety term (p = .049, AOR = 0.95, 95% CI: 0.90–0.99). The quadratic state anxiety term was also shown to be significant (p = .037, AOR = .99, 95% CI: 0.99–1.00), and the addition of this term resulted in a significant model improvement, $\chi^2_{\text{inc}}(1) = 6.26$, p = .012, Nagelkerke R^2 = 0.44, demonstrating that a

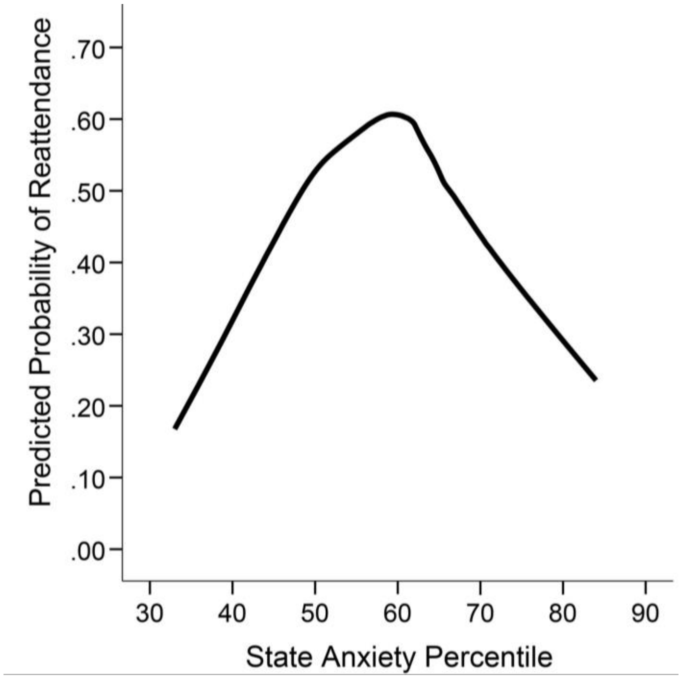


Figure 5. Estimated predicted probability of reattendance as function of state anxiety percentile scores (plotted using Lowess smoothing with bandwidth 0.8).

nonlinear relationship better described the data. A figure examining the association between state anxiety and likelihood of reattendance plotted the predicted probability of reattendance as a function of state anxiety. As shown in Figure 5, the peak probability of reattendance implied by the model occurs at a state anxiety percentile of about 60, with reattendance declining both with increasing or decreasing levels of state anxiety.

Discussion

As predicted, demographic characteristics were found to be related to clinic attendance. Specifically, our hypothesis that increased age and being married/partnered would be associated with reattendance was in fact borne out by the data. Though not significant in in multivariate analyses, the finding that greater reattendance was observed among participants who were married/partnered supports the results of previous studies (Pakenham et al., 2000). Some suggest that a stable relationship provides the social support that is often related to higher levels of adherence with health recommendations (Lerman, Rimer, Trock, Balshem, & Engstrom, 1990). Age was significant in the multivariate model and, holding all other variables constant, it was found that each year of increased age was associated with a seven percent greater likelihood of reattendance; likelihood of reattendance doubled with each decade of age. This agrees with the thrust of the literature that older age is predictive of greater reattendance as well as adherence to breast cancer screening practices such as mammography (Pakenham et al., 2000; Price et al., 2010; Rahman et al., 2005). We view this as logical because older patients would have more stability and security in their lives personified by long-term committed relationships, having children, and more established career patterns. These life issues help support such older patients in facing the anxiety of high risk status and clinic attendance, and offer more reason to live, thus reinforcing the possibility of clinic reattendance. We have often been told by patients in the clinic that a key reason for them to keep reattending is to identify any possible breast cancer early to allow them to be there for their children and grandchildren.

Clinically significant depressive symptoms turned out to be among the most significant predictors of non-reattendance to the clinic. Our hypothesis was supported in that those patients with clinically significant depressive symptomatology (CES-D score of 16 or higher) were only 25 percent as likely to return for follow-up. In our view, reattendance to the clinic requires motivation, energy, cognitive organization, emotional resilience and other factors that are depleted by the existence of significant depressive symptomatology. This begins to make a case for measuring depression at baseline in clinics such as this, and with patients found to have CES-D scores above 16, to be given additional attention. This might be characterized by offering them more emotional support, time with a clinic mental health professional in the first visit, and more diligent call backs to ensure that patients schedule and attend follow-up appointments. Additionally, efforts can be made to link them up with outside mental health systems to so as not to take a wait and see approach but to take action on day one given such a clinical finding.

For patients with a CES-D score of 16 or greater, clinicians may consider reviewing the endorsed items with the patient in the first consultation session. For example, if a patient is endorsing significant sleep difficulties, we recommend attempting to understand what is occurring, why this is occurring, and discussing with the patient about pragmatic interventions and even strategies she can take home from the first clinic consultation visit. We view this kind of collaborative problem solving as useful in creating a bond with the patient and helping to instill hope that her concerns will be heard and addressed, thus leading to increased motivation to return for future visits.

With regard to our hypothesis about a previous diagnosis of a psychiatric condition, we appear to have been dramatically mistaken in our prediction. Unexpectedly, a history of a psychiatric diagnosis proved to be predictive of substantially greater likelihood of clinic reattendance. The data showed that having one or more previous psychiatric diagnoses increased likelihood of clinic reattendance by a factor of three. This is in sharp contrast to the finding that current clinically significant symptoms of depression eventuated in significantly less likelihood of reattendance. However, it is important to note that having a previous psychiatric diagnosis does not equate necessarily to having a current psychiatric diagnosis. Moreover, the presence of anxiety and significant depressive symptomatology were statistically controlled for in consideration of the effects of this variable. It is possible that having had a previous diagnosis sensitizes one to the value and need for clinical care, and that such patients are likely to be more motivated and more accepting of clinical care in a situation such as the high risk clinic. This is not to imply that we take these past diagnoses lightly, but view them as being a potential positive prognostic factor in the formation of the treatment alliance with the clinic. These findings suggest that such history should not be considered as a rule out factor that would preclude continuity of care, but perhaps as an asset and motivating factor in continuity of care.

The hypothesis that maternal loss to breast cancer would predict higher likelihood of compliance with clinic attendance was basically borne out in the data analysis. This finding is consistent with existing research showing that loss of a close family member to breast cancer may motivate reattendance and adherence to cancer screening recommendations (Tracy et al., 2008). By itself, it is a powerful predictor with results indicating that participants who lost their mothers to breast cancer were over 2.5 times more likely to attend a follow-up appointment. However, and as posited in the final hypothesis, the data in this study reflect the fact that this variable cannot be considered in isolation but should be considered in an interactional context with other relevant predictors.

We considered this variable in relation to perceived risk and in doing so discovered that perceived risk differentially impacts on reattendance according to maternal loss. Results demonstrated that mother’s survival status moderated the relationship between reattendance and perceived risk such that a higher level of perceived risk was associated with a greater likelihood of reattendance only for participants whose mothers survived breast cancer. This finding has sensitized us to be more attentive to patients whose mothers survived who perceive themselves at lower risk. The data show that these daughters are significantly less likely to return, even though their actual risk may be higher than they perceive. For the women whose mothers died from breast cancer, perceived risk become somewhat of a moot point in predicting clinic return. They are more likely to reattend regardless of level of perceived risk. It appears that the fact their mothers died from breast cancer is decisive in their patterns of reattendance.

With regard to the hypothesis that the association between anxiety and reattendance will be curvilinear, this was robustly supported by the data. It was clearly shown that when anxiety reaches a clinically elevated level, it profoundly affects the likelihood of clinic reattendance. Previous literature has shown anxiety to negatively affect breast cancer surveillance (Kash et al., 1992). However, we felt it was necessary to examine the role of anxiety in a curvilinear fashion in regard to the complexity of issues of reattendance. It is evident, in our data, that a certain level of anxiety is motivating and facilitative of clinic attendance and reattendance. There is literature which shows that the effects of anxiety on adherence to recommended screening practices is best considered as an inverted “U” (Zhang et al., 2012).

Similar to the data we found and discussed earlier on depressive symptoms, this data on state anxiety symptoms has sensitized us to the need to carefully identify and consider immediate intervention with the patient showing significant clinical anxiety on a screening measure such as the State Trait Anxiety Inventory. At the middle part of the anxiety curve, we have learned to perceive anxiety as a motivating and facilitating feature in regard to clinic reattendance. Too little anxiety and too much anxiety appear to place patients at an increased risk for non-reattendance. Therefore, in addition to identifying patients who are overwhelmed with anxiety, we have learned to be equally concerned with identification of patients with seemingly too little anxiety appropriate to the context of our clinical situation. It may be that patients endorsing minimal levels of anxiety are utilizing the defense mechanisms of denial, suppression, or repression in ways that do not facilitate the optimal adherence with their clinical care. With regard to the patients with clearly identifiable severe anxiety, we see the necessity of extra and intensive interventions starting from the point of the initial visit. Anxiety may be related to post-traumatic stress disorder which has been previously identified in women at high risk who have witnessed fatal breast cancer in their mother or other close family relatives (Lindberg & Wellisch, 2001). It is essential that such patients be offered anxiety management interventions starting from the baseline visit to the clinic. This may be particularly necessary in helping such patients deal with issues such as breast self-examination, mammography, and integration of risk information (Kash et al., 1992).

It is important to take some limitations into consideration when interpreting the findings from the present study. The demographics of the study sample were weighted toward Caucasian, highly educated, married women, thus limiting generalizability to other populations. Additionally, it cannot be assumed that the subset of patients who did not return to the high risk clinic did not get other types of surveillance in another clinical setting. In future studies, the assessment of depression, anxiety, and past psychiatric history should be strengthened through use of the Structured Clinical Interview for the Diagnostic Statistical Manual modules for Major Depressive Disorder, Generalized Anxiety Disorder, and Post-Traumatic Stress Disorder, at a minimum, as well as a more detailed questionnaire regarding general past psychiatric history.

References

Aiken, L. S., & West, S. G. (1991). *Multiple regression: Testing and interpreting interactions*. Newbury Park, CA: Sage Publications.

Bulliard, J. L., De Landtsheer, J. P., & Levi, F. (2003). Results from the Swiss mammography screening pilot programme. *European Journal of Cancer, 39*(12), 1761-1769.

Cleveland, W. S. (1979). Robust locally weighted regression and smoothing scatterplots. *Journal of the American Statistical Association, 74*(368), 829-836.

Cockburn, J., Schofield, P., White, V., Hill, D., & Russell, I. (1997). Predictors of returning for second round screening at a population based mammographic screening programme in Melbourne, Australia. *Journal of Epidemiology and Community Health, 51*(1), 62-66.

Consedine, N. S., Magai, C., Krivoshekova, Y. S., Ryzewicz, L., & Neugut, A. I. (2004). Fear, anxiety, worry, and breast cancer screening behavior: A critical review. *Cancer Epidemiology Biomarkers & Prevention, 13*(4), 501-510.

Diefenbach, M. A., Miller, S. M., & Daly, M. B. (1999). Specific worry about breast cancer predicts mammography use in women at risk for breast and ovarian cancer. *Health Psychology, 18*(5), 532-536.

Field, K. M., & Phillips, K. (2007). Management of women at high familial risk for breast and ovarian cancer. *Cancer Forum, 31*(3), 141-149.

Fink, R., Shapiro, S., & Roester, R. (1972). Impact of efforts to increase participation in repetitive screenings for early breast cancer detection. *American Journal of Public Health, 62*(3), 328-336.

Gail, M. H., Brinton, L. A., Byar, D. P., Corle, D. K., Green, S. B., Schairer, C., & Mulvihill, J. J. (1989). Projecting individualized probabilities of developing breast cancer for white females who are being examined annually. *Journal of the National Cancer Institute, 81*(24), 1879-1886.

Gorin, S. S., & Albert, S. M. (2003). The meaning of risk to first degree relatives of women with breast cancer. *Women & Health, 37*(3), 97-117.

Hailey, B. J. (1991). Family history of breast cancer and screening behavior: An inverted U-shaped curve? *Medical Hypotheses, 36*(4), 397-403.

Hailey, B. J., Carter, C. L., & Burnett, D. R. (2000). Breast cancer attitudes, knowledge, and screening behavior in women with and without a family history of breast cancer. *Health Care for Women International, 21*(8), 701-715.

Hopwood, P., Keeling, F., Long, A., Pool, C., Evans, G., & Howell, A. (1998). Psychological support needs for women at high genetic risk of breast cancer: Some preliminary indicators. *Psycho-Oncology, 7*(5), 402-412.

Isaacs, C., Peshkin, B. N., Schwartz, M., DeMarco, T. A., Main, D., & Lerman, C. (2002). Breast and ovarian cancer screening practices in healthy women with a strong family history of breast or ovarian cancer. *Breast Cancer Research and Treatment, 71*(2), 103-112.

Kash, K. M., Holland, J. C., Halper, M. S., & Miller, D. G. (1992). Psychological distress and surveillance behaviors of women with a family history of breast cancer. *Journal of the National Cancer Institute, 84*(1), 24-30.

Katapodi, M. C., Lee, K. A., Facione, N. C., & Dodd, M. J. (2004). Predictors of perceived breast cancer risk and the relation between perceived risk and breast cancer screening: A meta-analytic review. *Preventive Medicine, 38*(4), 388-402.

Kendler, K. S., Karkowski, L. M., & Prescott, C. A. (1999). Causal relationship between stressful life events and the onset of major depression. *American Journal of Psychiatry, 156*(6), 837-841.

Kuschel, B., Lux, M., Goecke, T., & Beckmann, M. (2000). Prevention and therapy for BRCA1/2 mutation carriers and women at high risk for breast and ovarian cancer. *European Journal of Cancer Prevention, 9*(3), 139-150.

Lerman, C., Daly, M., Sands, C., Balshem, A., Lustbader, E., Heggan, T., . . . Engstrom, P. (1993). Mammography adherence and psychological distress among women at risk for breast cancer. *Journal of the National Cancer Institute, 85*(13), 1074-1080.

Lerman, C., Kash, K., & Stefanek, M. (1994). Younger women at increased risk for breast cancer: Perceived risk, psychological well-being, and surveillance behavior. *Journal of the National Cancer Institute*(16), 171-176.

Lerman, C., Rimer, B., Trock, B., Balshem, A., & Engstrom, P. F. (1990). Factors associated with repeat adherence to breast cancer screening. *Preventive Medicine, 19*(3), 279-290.

Lindberg, N. M., & Wellisch, D. (2001). Anxiety and compliance among women at high risk for breast cancer. *Annals of Behavioral Medicine, 23*(4), 298-303.

Martin, W., & Degner, L. (2006). Perception of risk and surveillance practices of women with a family history of breast cancer. *Cancer Nursing, 29*(3), 227-235.

McCaul, K. D., Branstetter, A. D., O'Donnell, S. M., Jacobson, K., & Quinlan, K. B. (1998). A descriptive study of breast cancer worry. *Journal of Behavioral Medicine, 21*(6), 565-579.

McCaul, K. D., Schroeder, D. M., & Reid, P. A. (1996). Breast cancer worry and screening: Some prospective data. *Health Psychology, 15*(6), 430-433.

Meiser, B., Butow, P., Barratt, A., Friedlander, M., Kirk, J., Gaff, C., . . . Tucker, K. (2000). Breast cancer screening uptake in women at increased risk of developing hereditary breast cancer. *Breast Cancer Research and Treatment, 59*(2), 101-111.

Pakenham, K. I., Pruss, M., & Clutton, S. (2000). The utility of socio-demographics, knowledge and health belief model variables in predicting reattendance for mammography screening: A brief report. *Psychology and Health, 15*(5), 585-591.

Price, M. A., Butow, P. N., Charles, M., Bullen, T., Meiser, B., McKinley, J. M., . . . Phillips, K. A. (2010). Predictors of breast cancer screening behavior in women with a strong family history of the disease. *Breast Cancer Research and Treatment, 124*(2), 509-519.

Radloff, L. S. (1977). The CES-D Scale. *Applied Psychological Measurement, 1*(3), 385-401.

Rahman, S. M., Dignan, M. B., & Shelton, B. J. (2005). A theory-based model for predicting adherence to guidelines for screening mammography among women age 40 and older. *International Journal of Cancer Prevention, 2*(3), 169-179.

Spielberger, C. D., Gorsuch, R. L., & Lushene, R. E. (1970). *Manual for the State-Trait Anxiety Inventory*. Palo Alto, CA: Consulting Psychologists Press.

Tatla, R., Paszat, L., Bondy, S., Chen, Z., Chiarelli, A., & Mai, V. (2003). Socioeconomic status & returning for a second screen in the Ontario breast screening program. *The Breast, 12*(4), 237-246.

Taylor, V. M., Taplin, S. H., Urban, N., White, E., & Peacock, S. (1995). Repeat mammography use among women ages 50-75. *Cancer Epidemiology Biomarkers & Prevention, 4*(4), 409-413.

Tracy, K. A., Quillin, J. M., Wilson, D. B., Borzelleca, J., Jones, R. M., McClish, D., . . . Bodurtha, J. (2008). The impact of family history of breast cancer and cancer death on women's mammography practices and beliefs. *Genetics in Medicine, 10*(8), 621-625.

Walker, M. J., Chiarelli, A. M., Knight, J. A., Mirea, L., Glendon, G., & Ritvo, P. (2013). Perceived risk and adherence to breast cancer screening guidelines among women with a familial history of breast cancer: A review of the literature. *The Breast*.

Wellisch, D. K., & Lindberg, N. M. (2001). A psychological profile of depressed and nondepressed women at high risk for breast cancer. *Psychosomatics, 42*(4), 330-336.

Zhang, L. R., Chiarelli, A. M., Glendon, G., Mirea, L., Edwards, S., Knight, J. A., . . . Ritvo, P. (2011). Influence of perceived breast cancer risk on screening behaviors of female relatives from the Ontario site of the Breast Cancer Family Registry. *European Journal of Cancer Prevention, 20*(4), 255-262.

Zhang, L. R., Chiarelli, A. M., Glendon, G., Mirea, L., Knight, J. A., Andrulis, I. L., & Ritvo, P. (2012). Worry Is Good for Breast Cancer Screening: A Study of Female Relatives from the Ontario Site of the Breast Cancer Family Registry. *Journal of Cancer Epidemiology, 2012,* Article ID 545062.

CHAPTER FOUR

CONCLUSION

The emergence of multidisciplinary high risk clinics offer significant promise for women with a familial risk for breast cancer. Familial risk is especially high for women with first-degree relatives, such as those with mothers diagnosed with breast cancer (Calle et al., 1993; Sattin et al., 1985; Sellers et al., 1999; Slattery & Kerber, 1993). High risk clinics provide continual surveillance, screening, and management for these women using a multidisciplinary approach that integrates services from oncologists, nurse practitioners, nutritionists, clinical psychologists, and genetics counselors according to the patient’s needs (Antill et al., 2005). Regular screening (mammography, MRI, CBE, ultrasound, and BSE), as well as integrated services are useful in detecting breast cancer in women with a familial risk of breast cancer (Chart & Franssen, 1997; Kuhl et al., 2010; Larsson et al., 1996; Tabar et al., 1985). Although believed to provide benefit, extant research has not established the psychological effects of attending regular surveillance appointments. Additionally, existing research has not shed light on why some high-risk women do not return for even a second visit in spite of the significant upside of adhering to regular surveillance.

One of the more significant appreciations to be gained from this research is that while some similarities may be shared, as a population, women at high risk for breast cancer are enormously complex. This was evident among a group of women limited to daughters of breast cancer patients, a study sample some might be considered as less heterogeneous in nature. An approach that proved useful in this research may also be useful in future studies in efforts to disentangle the complexities that will likely be encountered. In particular, insight afforded by the results of these studies is the value and need to consider moderating variables when examining predictors of a phenomena. Much of the previous literature in this area, examining reattendance as well as adjustment among high-risk women, has not yielded robust results. It might be the case that from the same data that originally provided finding best described as equivocal, if it were reanalyzed with consideration of moderating factors, perhaps the results would be something theoretically and clinically meaningful. In both studies, mother's survival status was modeled in interaction terms with other predictors, and this alone led to interesting and useful results. This dataset, and most others as well, likely have not yet been fully potentiated and a small bit of additional work and creative thinking to identify potential moderators could lead to remarkable findings.

Taken together, the findings from these studies also underscore the need for clinicians to attend to those patients who we would not expect to be distressed, and even those who deny feeling distress whatsoever. For example, as discussed in Chapter 2, despite what "reasonable" expectations may dictate, it is sometimes the case that daughters whose mothers survived experience greater distress. In Chapter 3, the curvilinear relationship between anxiety and reattendance showed high levels of distress to be associated with a decreased likelihood of reattendance. Given the effectiveness of surveillance programs are contingent on continued attendance, this is concerning, and points towards the usefulness of screening measures to identify patients in immediate psychological need. While patients reporting elevated levels of anxiety are a matter of concern for physicians and psychologists alike, the quadratic, inverted "U" pattern of the association between anxiety and reattendance also helps to bring attention to another subgroup of at risk women represented on the opposite side of the graph who should be of equal if not perhaps greater concern.

These patients are in some ways at greater risk because they do not demonstrate distress or convey a need for support that oftentimes catches the attention of mental health clinicians. To block or deny anxiety in a setting where at least moderate feelings of anxiety are normative is troubling but a challenge to deal with because these patients will not be as receptive to offers of support. Because women endorsing very minimal anxiety appear at risk for not returning for follow-up, support in the form of a phone call from the office staff to schedule timely follow-ups or provide reminders of upcoming appointments may is a good starting place. Another underserved but at risk patient group highlighted by this research is the half of women not returning for a follow-up visit at the high-risk clinic. It is unfortunate that many of these women, who appear to be experiencing significant distress, perhaps to a greater degree than patients who reattend, are also those least accessible to mental health clinicians by virtue of their absence.

Beyond empirical, academic and theoretical contributions, an equally if not more important contribution of these studies is to resensitize clinicians and health professionals to the reality that the patients most in need of support and healing oftentimes are those who do not voice their distress or appear to be experiencing difficulty. As with the half of the sample of high-risk women who did not reattend, there are opportunities to identify and offer support to the distressed who are less visible, and even just having a renewed appreciation of the potential need of such patients will allow to be better clinicians to more of the patients who really need us.

REFERENCES

Antill, Y., Shanahan, M., & Phillips, K. (2005). The integrated, multidisciplinary clinic: for the ongoing management of women at high genetic risk for breast and ovarian cancer. *Cancer Forum, 29*(2), 107-110.

Calle, E. E., Martin, L. M., Thun, M. J., Miracle, H. L., & Heath, C. W. (1993). Family history, age, and risk of fatal breast cancer. *American Journal of Epidemiology, 138*(9), 675-681.

Cappelli, M., Verma, S., Korneluk, Y., Hunter, A., Tomiak, E., Allanson, J., . . . Humphreys, L. (2005). Psychological and genetic counseling implications for adolescent daughters of mothers with breast cancer. *Clinical genetics, 67*(6), 481-491.

Chart, P. L., & Franssen, E. (1997). Management of women at increased risk for breast cancer: preliminary results from a new program. *Canadian Medical Association Journal, 157*(9), 1235-1242.

Easton, D. F. (2002). Familial risks of breast cancer. *Breast Cancer Research, 4*(5), 179-181.

Hay, J. L., McCaul, K. D., & Magnan, R. E. (2006). Does worry about breast cancer predict screening behaviors? A meta-analysis of the prospective evidence. *Preventive medicine, 42*(6), 401-408.

Kash, K. M., Holland, J. C., Osborne, M. P., & Miller, D. G. (1995). Psychological counseling strategies for women at risk of breast cancer. *Journal of the National Cancer Institute. Monographs*(17), 73-79.

Katapodi, M. C., Lee, K. A., Facione, N. C., & Dodd, M. J. (2004). Predictors of perceived breast cancer risk and the relation between perceived risk and breast cancer screening: A meta-analytic review. *Preventive Medicine, 38*(4), 388-402.

Kuhl, C., Weigel, S., Schrading, S., Arand, B., Bieling, H., König, R., . . . Nordhoff, D. (2010). Prospective multicenter cohort study to refine management recommendations for women at elevated familial risk of breast cancer: The EVA trial. *Journal of Clinical Oncology, 28*(9), 1450-1457.

Kuschel, B., Lux, M., Goecke, T., & Beckmann, M. (2000). Prevention and therapy for BRCA1/2 mutation carriers and women at high risk for breast and ovarian cancer. *European Journal of Cancer Prevention, 9*(3), 139-150.

Larsson, L.-G., Nyström, L., Wall, S., Rutqvist, L., Andersson, I., Bjurstam, N., . . . Tabár, L. (1996). The Swedish randomised mammography screening trials: analysis of their effect on the breast cancer related excess mortality. *Journal of Medical Screening, 3*(3), 129.

Lindberg, N. M., & Wellisch, D. (2001). Anxiety and compliance among women at high risk for breast cancer. *Annals of Behavioral Medicine, 23*(4), 298-303.

Sattin, R. W., Rubin, G. L., Webster, L. A., Huezo, C. M., Wingo, P. A., Ory, H. W., & Layde, P. M. (1985). Family history and the risk of breast cancer. *Journal of the American Medical Association, 253*(13), 1908-1913.

Sellers, T. A., Walsh, A. J., Grabrick, D. M., Anderson, K. E., Cerhan, J. R., & Folsom, A. R. (1999). Family history, ethnicity, and relative risk of breast cancer in a prospective cohort study of older women. *Cancer Epidemiology Biomarkers & Prevention, 8*(5), 421-425.

Siegel, R., Naishadham, D., & Jemal, A. (2013). Cancer statistics, 2013. *CA: A Cancer Journal for Clinicians, 63*(1), 11-30.

Slattery, M. L., & Kerber, R. A. (1993). A comprehensive evaluation of family history and breast cancer risk. *Journal of the American Medical Association, 270*(13), 1563-1568.

Tabar, L., Fagerberg, G., Gad, A., Baldetorp, L., Holmberg, L., & Grφntoft, O. (1985). Reduction in breast cancer mortality by mass screening with mammography: First results of a randomised trial in two Swedish counties. *Lancet, 1,* 829-832.

Wellisch, D. K., Hoffman, A., Goldman, S., Hammerstein, J., Klein, K., & Bell, M. (1999). Depression and anxiety symptoms in women at high risk for breast cancer: pilot study of a group intervention. *The American journal of psychiatry, 156*(10), 1644-1645.