WHEN FAMILY HISTORY IS A MYSTERY— HOW ADULT ADOPTEES COPE WITH AMBIGUOUS RISK FOR BREAST CANCER: A MIXED-METHODS STUDY

by

REBECCA GLOVER KUDON

(Under the Direction of David DeJoy)

ABSTRACT

Family history has taken on public health significance given its role in predicting a variety of chronic diseases common in adulthood, including breast cancer. Having a positive biological family history of breast cancer is generally associated with increased risk perception and mammography screening rates among first-degree relatives. Little is known, however, about the health beliefs and health practices of persons with unknown biological family history. In particular, middle-aged and older adults reared in adoptive families typically do not have access to current biological family history information without engagement in a birthparent search.

Utilizing a sequential explanatory mixed-methods design, this study examined a breast cancer risk construction and risk management process among adult adoptees from a stress and coping perspective. Female adult adoptees over 40 years of age (N = 452) completed an online questionnaire that assessed vicarious experience, family history ambiguity, breast cancer risk perception, cancer worry, perceived control, perceived value of family history information, birthparent information-seeking, mammography compliance, and future screening intention. Structural equation modeling allowed the interplay of these 9 factors to be tested, and qualitative inquiry (N = 12) augmented quantitative findings by exploring aspects of risk perception development in greater depth.

Quantitative results provide evidence that vicarious experience with breast cancer is a significant stressor that shapes perceived risk and motivates birthparent information-seeking, mammography compliance, and future screening intention. Qualitative results corroborate the importance of threat salience in risk estimation and suggest that adoptees further consider the impact of their lifestyle and screening behavior as either reducing or elevating their personal disease risk. Adoptees' ability to exercise cognitive control and/or emotional regulation over the threat posed by family history ambiguity, the valence placed on family history as a risk factor, and the degree to which potential familial risks are internalized also contribute to the risk construction process.

Reflections on health behavior theory are offered in light of integrated mixed-methods findings and study limitations. Implications for research and practice are provided. Emphasis is placed on adoptees as a special population worthy of further research and advocacy in the era of genomics-based medicine.

INDEX WORDS: Family history, Risk perception, Worry, Breast cancer, Mammography, Information-seeking, Stress and coping, Adult adoptees, Mixed-methods, Structural equation modeling, Qualitative methods, Web-based research

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DEDICATION

To my chosen family—Lou, Zohara, and Ginseng

&

my forever family—Mom, Dad, and Sandy

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CHAPTER 1: INTRODUCTION

Problem Background

Family history is a primary risk factor for several diseases affecting a large proportion of the population in the United States. Individuals who have close blood relatives with conditions such as heart disease, diabetes, and cancer of the breast, ovary, colon, or prostate are themselves more likely to develop the same disease. While inherited genetic susceptibility is often attributed to the increased risk of disease, 'family history' is also the product of common physical, cultural, and social environments as well as shared behavior (Yoon & Scheuner, 2003; Yoon, Scheuner, Peterson-Oehlke, Gwinn, Faucett, & Khoury, 2002).

That heredity contributes to health and disease risk is universally acknowledged by medical practitioners, as it has been for well over a century (Guttmacher & Collins, 2002). What differs today is the specificity of our understanding, brought about by the sequencing of the human genome, and the scope of applicability to the clinical practice setting. In the pregenomics era, geneticists studied single-gene mutations (e.g., cystic fibrosis) according to Mendelian principles (Guttmacher & Collins, 2002). Genome sequencing helped identify additional monogenic disorders and spawned development of genetic tests, which are now commonly available for a host of conditions (Rich et al., 2004). *BRCA1* and *BRCA2*, for example, are genetic alterations responsible for 5-10% of breast and ovarian cancer cases (Myers & Jorgensen, 2005). Because of the highly penetrant nature of genetic disorders, genetic testing revolutionizes healthcare for families with suspected hereditary forms of disease. Genetic test results along with genetic counseling help guide otherwise healthy patients and their physicians in making important decisions related to reproduction, frequency of screening, and even prophylactic treatment through surgery or chemo-prevention. From a public health perspective, however, the problem remains that genetic testing only benefits a small proportion of the population given low prevalence rates of monogenic disorders relative to overall disease burden.

Genomics researchers now work more broadly than traditional geneticists to understand not just how single-gene mutations occur, but how various genes interact in multiple environmental contexts (Centers for Disease Control and Prevention [CDC], 2005a; Guttmacher & Collins, 2002). According to CDC, genetic susceptibility plays a causal role in nine of the ten leading causes of death (Gebbie, Rosenstock, & Hernandez, 2003). For the majority of persons with chronic diseases such as heart disease and cancer, researchers assert that the etiology is multi-factorial, however, rather than monogenic. That is, personal risk stems from the confluence of genetic inheritance and both risk-reducing and risk-enhancing environments and behavior (Yoon et al., 2003b). Based on its almost universal applicability, family history, therefore, is an essential genomic tool (Yoon et al., 2002) in its ability to capture familial patterns of not only disease, but also shared environments and behavior. Family history's scope of applicability, therefore, has expanded beyond a few cases in the clinical setting to having population-based relevance.

The benefits of knowing biological family history are well-established. Family history information aids practitioners in assessing personalized disease risk, making diagnoses, informing screening and treatment regimens, and estimating pre-test probability and predictive value of genetic tests (Rich et al., 2004; Yoon et al., 2002). Still, despite widespread acceptance of family history's clinical and public health importance, a number of barriers exist to maximizing the utility of family information in practice. Only 30% of adults have actively

documented their family history (Centers for Disease Control and Prevention [CDC], 2004), and the accuracy of self-reported family history information varies by disease type and degree of blood related closeness (Murff, Spigel, & Syngal, 2004). Among small families, the information obtained by a family history interview may have limited value. For adopted persons without knowledge of biological relatives, current practice of recording family medical history offers no insight into inherited disease risk (Mayo Clinic, 2006, What Can't Your Family Medical History Tell You?). At present, therefore, adoptees with unknown biological family medical history are not in the position to benefit from scientific advances in genomics-based medicine.

Statement of the Problem

Breast cancer is the most prevalent cancer among women in the United States (excluding skin cancers) and is a leading cause of death, second only to lung cancer (American Cancer Society [ACS], 2005a). Along with simply being female and growing older, having a biological family history of breast cancer significantly increases a woman's risk for disease. Risk models suggest that having a family history of breast cancer in one first-degree relative (i.e., immediate blood relative sharing approximately half of one's genes) more than doubles a woman's risk of developing the disease. Having a history with two or more first-degree relatives elevates risk four-fold (ACS, 2005a) and can suggest the presence of an inherited genetic mutation (CDC, n.d.). While genetically inherited forms of breast cancer represent only 5-10% of cases, women from suspected genetically-at-risk families can have up to a 80-95% lifetime risk of developing the disease (Eyre, Lange, & Morris, 2002).

Women at average risk can reduce their chances of developing breast cancer by making certain lifestyle changes including avoiding alcohol, maintaining proper weight, exercising, and not undergoing post-menopausal hormone replacement therapy (American Cancer Society, 2005a; 2005b; 2007). Given the importance of non-modifiable risk factors like gender, age, and family history, early detection remains the best strategy for managing risk by controlling the potential severity of disease if diagnosed at a later stage. For women 40 and older at average risk, breast cancer screening guidelines include optional monthly breast self-examination (BSE), annual clinical breast examination (CBE), and, most importantly, annual mammography (ACS, 2005a). While mammography improves survival rates, adherence to recommended screening among women over 40 in the U.S. is estimated at 61.5% (ACS, 2005a). Even among women at high-risk, screening rates fall well below desired levels (Meiser et al., 2000; Schwartz, Taylor, & Willard, 2003).

Risk categorization, clearly, has implications for the importance of cancer vigilance. However, for roughly 5-10 million Americans, or roughly 2-4% of the U.S. population (Carp, 1998), risk categorization, which depends on knowing one's biological family history, may have little relevance. Adult adoptees, for example, may have scant information about biological family medical history. This is especially true for middle-aged and older adults who were adopted under closed systems, prevalent until the late 1970s (Carp, 1998; Carp, 2004), characterized by little, if any, contact and information sharing between birth and adoptive parents. Given potential ambiguity about family medical history, prudence suggests adult adoptees should be at a minimum adherent to screening guidelines for those at average risk. The current health research literature, however, is woefully inadequate and provides little insight into the screening practices of this special population for whom compliance should be a high priority.

The study was designed to fill an important gap in the breast cancer literature as well as the burgeoning literature on adult adoptees as a special population worthy of study in the new era of genetics-based medicine. The breast cancer literature suggests that a history of breast cancer in the family elevates risk perception and anxiety among healthy female relatives. Because research has almost exclusively included only those who are biologically related, researchers, heretofore, have missed an important opportunity to fully understand the complexity of family history as a contributing factor in risk perception development, cancer worry, and related behavior aimed at reducing health risks. Shared susceptibility among biologically-related family members is a well-known risk factor for breast cancer (Audrain-McGovern, Hughes, & Patterson, 2003) that serves to heighten perceived risk and cancer worry. Arguably, however, one's perceived risk and level of worry also result from the experiential aspects of witnessing a family member's disease process (Montgomery, Erblich, DiLorenzo, & Bovbjerg, 2003; Rees, Fry, & Cull, 2001).

Given adoptees' potential inability to anchor their perceived risk amidst known biological family history, they may be equally likely, logically speaking, to worry very little or, conversely, a great deal about genetic inheritance. For the adoptee without birth parent contact, family history of breast cancer is primarily experiential and tied to adoptive family members, although some risk may be attributed to shared lifestyle behavior (ACS, 2005a). Approximately 47% of adult adoptees search for birthparents, often fueled by a desire for information about biological family medical history (Finkler, 2000). For successful searchers, family history of cancer, therefore, becomes an amalgam of consanguinity and lived experience. The odyssey of information-seeking about biological family medical history, however, may create the sense of being a perpetual patient (Finkler, 2000). As such, information-seeking may be part of an overall process of coping with the stress of health threats amidst genetic uncertainty.

The Transactional Model of Stress and Coping (TMSC) describes the process by which individuals give meaning to stressors amidst their social and physical environment. According to Lazarus and Folkman (1984), individuals interpret and act upon stressors differently based on perceived relevance, personal disposition, emotional states, and coping resources. Working in tandem with the aforementioned conceptual framework, classic works by Tversky and Kahneman (1974) explain how individuals process risk information amidst uncertainty by utilizing an array of cognitive heuristics or "shortcuts" including availability, representativeness, and illusion of control. Behavioral research on cancer-specific risk perception, anxiety, and preventive health practices provides further contextual foundation for the proposed study. This literature typically describes health beliefs that motivate preventive health behavior (Janz, Champion, & Strecher, 2002) and problem-focused and emotion-focused reactions as means of coping with health threats or stressors (Wenzel, Glanz, & Lerman, 2002). Although the TMSC has served as the guiding framework for a number of studies examining health behavior among unaffected first-degree relatives of women with breast cancer (Absetz, Aro, & Sutton, 2002; Cohen, 2002; Decruyenaere, Evers-Kiebooms, Welkenhuysen, Denayer, & Claes, 2000), model constructs have never been validated among adult adoptees as a special target population.

Purpose of the Study

The proposed study has three aims, which can be described respectively as substantive, theoretical, and methodological (Wallace & Wray, 2006). First, the investigator sought to describe perceived susceptibility to breast cancer, cancer worry, information-seeking about biological family medical history, and screening practices of adult women reared in unrelated adoptive families. Second, the study explored whether the Transactional Model of Stress and Coping adequately explained adoptees' emotion- and problem-focused coping efforts aimed at reducing the abstract threat of breast cancer amidst genetic uncertainty. Third, by following-up on extreme cases qualitatively, the investigator sought deeper understanding about the TMSC in

its application to adult adoptees, which culminated in suggestions about model refinement. The overall study utilized a sequential explanatory mixed-methods design with a constructivist grounded theory approach.

Research Questions

The research was intended to answer specific questions corresponding to the three study aims. First, basic descriptive data provide answers to the following questions. What are the health beliefs of adopted women over 40 in regard to their perceived risk of developing breast cancer? What is their level of cancer worry? To what extent do adult adoptees know their consanguine family medical history? To what extent do adult adoptees feel breast cancer risk is controllable? To what extent do they adhere to mammography screening recommendations? To what extent are adult adoptees involved in information-seeking about their biological family medical history? The proposed study is unique in that it is the first known research effort designed to understand and quantify adoptees' perceived threat of disease, behavioral and emotional coping efforts aimed at reducing risk, health beliefs, and health practices. Admittedly, statistical estimates are not definitive given reliance on non-probability sampling techniques necessary for accessing this hard-to-reach population. Nonetheless, initial estimates of adoptees' perceived risk, level of cancer worry, and adherence to mammography significantly advance current understanding about this special population.

The second research aim encompasses the lion's share of the research effort. In general, the research is designed to test the fit of a proposed full structural model in explaining the relationships among several constructs according to the theoretical tenets of the Transactional Model of Stress and Coping. The overarching question, therefore, is how well does TMSC explain adult adoptees' emotion-based (e.g., worry) and problem-focused (e.g., mammography, information-seeking) coping efforts aimed at reducing the abstract threat of breast cancer? Based on careful review of the literature, specific hypotheses, discussed further in Chapter 2, were formulated about the existence and direction of relationships among the following constructs: ambiguity about biological family history, vicarious experience with breast cancer, breast cancer risk perception, perceived control, cancer worry, perceived value of biological family medical history, information-seeking about biological family history, mammography adherence, and future mammography intention. Testing the fit of the model helped answer the following sorts of questions. Is breast cancer risk perception influenced by the cognitive threat posed by ambiguity about biological family history as well as an emotional threat of having adoptive familial experience with cancer? Is an adoptee's level of breast cancer worry directly influenced by both perceived risk and family history ambiguity? How does an adoptee's sense of perceived control over developing breast cancer impact cancer worry and mammography screening behavior? Does perceived risk affect mammography adherence through perceived control? Does the value of having biological family medical history information mediate the relationship between perceived risk and information-seeking? And, finally, do various coping efforts (i.e., worry, mammography, and information-seeking) predict future screening intention?

The third aim was somewhat emergent and dependent on the outcomes of doing sequential explanatory mixed-methods research. Qualitative inquiry was planned at the outset to elucidate particular findings from the quantitative phase of research described above and to deepen understanding of TMSC in its application to adult adoptees. The exact purpose of qualitative inquiry was shaped by findings regarding the model fit. Broadly, the following research questions were pursued in the second phase of research: 1) How do adult adoptees construct personalized risk estimates for breast cancer? and 2) How do cognitive representations differ between adoptees with high versus low perceived risk?

Significance of the Study

This is the first known study to quantify the health beliefs and screening practices of adult adoptees as a special population worthy of consideration in the new era of genetics-based medicine. Given the importance placed on biological family history as a risk factor for a variety of diseases including breast cancer, this study will shed light on adult adoptees as a high-priority group for screening compliance. Moreover, this research may inform future dialogue on recommended screening guidelines for this unique population subgroup. Advocacy organizations for adoptees, adoptive parents, and birth parents will likely be especially interested in the research findings, as will individual triad members and organizations that promote breast cancer screening.

The study benefits physicians with adult adoptees in their clinical practices, particularly in regard to their interactions about family medical history. With greater understanding of the issues pertaining to adoptee-patients, more effective patient-physician relationships may be forged by improving healthcare delivery, tailoring health communications, and fostering more active consumerism surrounding health and wellness, which may include physician-assisted information-seeking about consanguine family medical history. Similarly, genetics counselors, social work researchers and practioners, and clinical psychologists may benefit from greater understanding of stress and coping processes utilized by adoptees to manage perceived disease risks.

From a content perspective, better understanding about the relative contribution of two components of family history, experience and biological connectedness, to risk perception

development will advance behavioral health research forward, not only for adoptees, but for all persons. In particular, the study highlights a population who may be resistant to health promotion messages involving family history. While the present study is focused on breast cancer, deconstructing family history into its two components has potential for innovative examination of psycho-social-behavioral aspects of a variety of other chronic diseases and conditions as well. Therefore, several other research disciplines stand to benefit from this study including not only health promotion, but health communication, genomics, and health psychology, among others.

Delimitations

Upon receiving a web-based research invitation, respondents self-selected for participation following certain eligibility criteria. The study was delimited to healthy female adult adoptees over 40 years of age who were reared in unrelated adoptive families in the United States. For purposes of this study, 'healthy' is defined as never having had a breast cancer diagnosis. The age range captured the minimum age at which women should start receiving mammography, according to screening guidelines published by the American Cancer Society (2005a). Given that adult adoptees can be characterized as a hard-to-reach population and that virtual communities exist to provide a mechanism for social support, the Internet was used for recruitment and the bulk of data collection. Participants were, therefore, also fluent in English and active on the World Wide Web.

CHAPTER 2: REVIEW OF RELATED LITERATURE

The following review of the related literature provides a rationale for the proposed study's importance, research design, hypothesized relationships, and implementation. This chapter presents an overview of the theoretical framework, synthesizes and critiques the current research literature, and situates the proposed study in its socio-cultural-historical context.

Adoption in the United States

Adoption establishes a legal parent-child relationship between biologically unrelated persons. Although adoption has been legally and socially accepted since the mid-to-late 1800s (Finkler, 2000; Reed, 1994), accurate figures on the number of adoptions in the United States do not exist. It is estimated, however, that approximately "2% to 4% of American families include an adopted child" (Stolley, 1993, p. 26).

The reasons for having inaccurate data on adoption are numerous. As Stolley (1993) described, national data were aggregated only *periodically* between 1944 and 1957 and *annually* between 1957 and 1975 by the National Center for Social Statistics (NCSS) using data from voluntary state reporting systems, often with anemic participation. After dissolution of the NCSS in 1975, other agencies conducting national surveys were charged with producing estimates on adoption. Because states maintain different case definitions and reporting requirements, true even today (Child Welfare Information Gateway [CWIG], 2003), the resulting data are regarded as incomplete and inconsistent (Chandra, Abma, Maza, & Bachrach, 1999). Adoption cases are further under-reported because many occur informally, perhaps more so

nowadays than in the past (Chandra et al.,1999; Child Welfare Information Gateway [CWIG], 2005). Despite these challenges, existing national statistics on adoption are summarized below.

According to Stolley (1993), approximately 50,000 children were relinquished for adoption in 1944. The number of adoptions increased in the following decades, peaking around 175,000 in 1970 before declining. In 1990, adoptions numbered around 119,000. These figures include formal adoptions between both unrelated and related persons (e.g., step-parent). Rather consistently since the mid-1950s, the total number of adoptions is roughly equally divided between related and unrelated persons. Since the mid-1970s, approximately 51,000 formal adoptions per year occur domestically between unrelated persons (Stolley, 1993). Pertman (2000) asserted that between five and six million adoptees currently live in the United States.

The vast majority (88%) of adoption cases continues to be children of unwed mothers, although most unmarried women who give birth parent their own child (Stolley, 1993). Prior to 1973, the year *Roe vs. Wade* legalized abortion, approximately 9% of never married women relinquished their children for adoption. Today, that figure is closer to 1% among never married women giving birth. Relinquishment among never married Black women remains low (never above 1.5% since 1973), while the same figure for White women has plummeted from almost 20% before 1973 to around 2% in 1995 (Chandra et al., 1999; CWIG, 2005). Interestingly, the decline in adoption does not appear associated with increased rates of abortion (Chandra et al., 1999), as some might speculate. Rather, researchers cite other causes including the aforementioned increase in informal adoption, greater social acceptance of single parenting, and a trend in giving birth at older ages with greater financial security (CWIG, 2005).

The process of adoption itself has changed dramatically for members of the "adoption triad" (birth parents, adoptee, and adoptive parents). Prior to the mid-1970s, adoptions occurred

under closed systems, characterized by little, if any, contact and information sharing between birth and adoptive parents (Carp, 1998; Carp, 2004). Today, however, a more open adoption process is the norm, stemming at least in part from the political action of angry adoptees denied information about their heritage (see www.bastards.org, www.almasociety.org, and www.americanadoptioncongress.org) as well as research results showing psychological benefit among adoptees who have greater information about and connection with birth parents (Brodzinsky & Schechter, 1990; Reed, 1994). The issue of birth parent searching will be among the topics discussed in the following section.

Adoptees as Health Care Consumers

Psychosocial Differences

To understand issues for adult adoptees in a healthcare context, it is important to examine what potentially makes an adoptee different than someone reared in a biologically-related family. Researchers have examined these differences for decades and generally acknowledge that being adopted is a lifelong process that poses some unique challenges. Feelings of loss, grief, rejection, separation, and abandonment are not uncommon for the adoptee, and can be accentuated at certain life milestones such as birthdays, graduations, marriage, birth, or death of an adoptive parent (Reed, 1994; National Adoption Information Clearinghouse [NAIC], n.d., Issues Facing Adult Adoptees). Questioning self-identity is, perhaps, the quintessential existential struggle for adoptees.

Issues with self-identity formation manifest differently across the lifespan, yet can peak during adolescence when teen adoptees grapple with the business of belonging. Questions about familial resemblance, adoption circumstances, and educational, cultural, or class differences commonly surface during adolescence (Child Welfare Information Gateway [CWIG], 2004; NAIC, n.d., Issues Facing Adult Adoptees). Sexual identity formation among females, in particular, may also be challenged by ambiguity over a closer perceived connection to a possibly infertile adoptive mother or an unknown, more fertile birth mother who, for whatever reason, was unable to care for her biological child (Reed, 1994). Studies have also found that adoptees score lower on self-esteem and self-confidence measures, possibly reflecting a general feeling of being "unwelcome," "rejected," or simply different than non-adopted peers who have the opportunity to develop more complete self-identities (CWIG, 2004).

Self-identity issues may continue into adulthood or simply resurface as adoptees mature and possibly have their own biologically-related children (CWIG, 2004). Childbearing for the adult adoptee may provoke anxiety over not knowing and being able to share biological family heritage with offspring. According to Krueger and Hanna (1997), the search for identity is universal for adult adoptees, whether or not it exists as a formal process (e.g., birth parent searching) or remains only at the psychological level.

Some may argue that adoptees and their non-adopted counterparts lead vastly similar lives, given the diversity found among adopted persons (CWIG, 2004). However, clearly, there are unique experiences to being adopted. Medical encounters, perhaps, provide the most poignant examples.

When Family History is a Mystery

A key difference between adoptees and persons reared in biologically-related families is having lack of access to information about biological family medical history (CWIG, 2004). Being asked to complete the ubiquitous "family history form" during physician visits is a constant reminder and requires decision making on the part of the adoptee. Because consanguinity with relatives is generally assumed, there is typically no opportunity to list one's adoption status on standard family medical history questionnaires. Therefore, adoptees negotiate for themselves whether and how to answer questions about family medical history, disclosing, if anything, sketchy biological information, more complete adoptive family history information, or some combination of the two. In her qualitative study on the value of health information to adult adoptees, Tam (2004) discovered overwhelming support to the potential addition of an "adoption status" question to the standard family medical history form. Participants in Tam's study provided de-stigmatization and the opportunity to initiate dialogue about family history with healthcare practitioners as rationale.

Over time, adult adoptees may become frustrated, angry, or resentful at the request for family medical history information (Finkler, 2000; Tam, 2004). The request itself emphasizes the importance of biological family history to health and creates expectations that the physician is willing to discuss the ramifications of family history ambiguity with the adoptee-patient. Rather typically, however, adoptees experience awkward interactions with physicians, who may be reluctant, even avoidant, to address the topic because of inexperience, discomfort, lack of training, or concern over potential sensitivity of the subject matter (Tam, 2004). As a result, some adoptees describe feeling like a lesser person or "alien" in regard to their medical encounters. Quoting an adoptee, "when you go to the doctor, you do not have a medical history, and you are not a person" (Finkler, 2000, p. 122).

Not having information about biological family medical history, coupled with potential dissatisfaction with their health care interactions, adoptees may question the quality of their care. As Tam (2004) reported, adoptees recognize the value of biological family medical history in a health context as useful in explaining, understanding, and treating symptoms and conditions and in making disease risk predictions. Because of this, adoptees perceive themselves as being

passive participants in healthcare decisions (Tam, 2004), which is detrimental in today's consumer-focused market. From qualitative studies (Finkler, 2000; Tam, 2004), adoptees report perceived substandard treatment, being denied treatment, and receiving delayed or, in stark contrast, overzealous treatment because physicians and/or insurance companies do not have access to their biological family history information.

Arguably, other health-related decisions, including prevention and early detection practices, may be impacted by ambiguous family history as well. Adoptees describe the inherent risk in being a "blank slate" (Tam, 2004, p. 22), citing numerous potential psychosocial sequelae such as forgoing childbearing, worrying about passing on unknown health risks to biological children, and regret over not knowing the best way to take care of oneself by engaging in behaviors that reduce inherited biological risk (Finkler, 2000; Tam, 2004). Arthritis, cancer, specifically of the breast, diabetes, and heart disease are of particular concern to adoptees, given their known linkage to biological family history (Finkler, 2000; Tam, 2004).

In the general population, knowledge of family history is instrumental in disease risk perception development. Among laypersons, beliefs about inherited risks are influenced by the number of family members with a certain condition (Hunt et al., 2000 as cited in Tam, 2004). Furthermore, individuals often remain unconvinced of inherited risks unless a diagnosis is made within the family (Ponder et al., 1996 as cited in Tam, 2004). Given ambiguity of biological family history, adoptees' level of disease worry remains unclear as they may be equally likely, logically speaking, to worry about nothing or, conversely, everything. Fear, worry, and anxiety are important psychological concerns for individuals and their healthcare providers as they have been shown to impact screening behavior (Hay, Buckley, & Ostroff, 2005; Katapodi, Lee, Facione, & Dodd, 2004; McCaul, Branstetter, Schroeder, & Glasgow, 1996; McCaul,

Branstetter, O'Donnell, Jacobson, & Quinlan, 1998). Interestingly, worry about "genetic mystery" may be transferred to adoptees by their adoptive parents, who have been shown to have exaggerated anxiety about their children's health (Lebner, 2000).

In summary, there is some evidence that not having biological family medical history is perceived as a liability by both adoptee-patients and possibly their physicians. As a result, many adoptees are prompted to search for information about their biological heritage, sometimes with encouragement and less often assistance, by their physician (Finkler, 2000; Tam, 2004). The search for information, in whatever form, is regarded as an adaptive coping response to anxiety, ambiguity, and uncertainty and promotes mental health and wellness for the adult adoptee (Krueger & Hanna, 1997). The next section describes three potential avenues for obtaining biological family medical history information.

Information Seeking about Biological Family Medical History

Genetic Testing

As the number and availability of genetic tests increase, interest among members of the adoption triad will likely result in heightened demand for genetic testing/counseling services (American Society for Human Genetics [ASHG], 2000). The desire for genetic testing services will likely be reinforced by companies with commercial interests that use direct marketing campaigns to create demand among adoptees (DNA Direct, 2006). Media accounts about advances in genetic testing also provide additional cues that generate interest (Jacobson, 2006; Kalb, 2006).

Anticipating such interest, the American Society for Human Genetics (ASHG) issued a joint statement with the American College of Medical Genetics (ACMG) to clarify their stance on the practical value of genetically testing newborns and children relinquished for adoption

(ASHG, 2000). In general, the benefits of testing vary by the specific nature of the test and must be weighed against the accompanying ethical quandaries facing members of the adoptive triad and social work professionals involved in adoption cases. In short, the ASHG and the ACMG recommend testing protocols that are consistent with those for children of a similar age for diagnostic or preventive purposes (e.g., phenylketonuria or PKU). This practice limits testing to those conditions that appear in childhood or for which preventive action is clearly indicated in childhood.

Interestingly, ASHG and ACMG explicitly advise against testing newborns and children for adult-onset disorders. In their view, possible benefits in prevention are overshadowed by potential negative consequences including labeling, discrimination, stigmatization, and sideeffects from long-term medical treatment (e.g., chemoprevention) (ASHG, 2000). Furthermore, the predictive value of certain types of genetic tests is compromised for adoptees without biological family history information (Myers & Jorgensen, 2005). To that end, ASHG and ACMG recommend the application of population-based prevention guidelines (exercise, reduced sun exposure, maintaining a low-fat diet, etc.) for otherwise healthy children involved in an adoption process.

Requesting Adoption Records

Although ASHG does not endorse genetic testing for adult-onset disorders, the organization does support adoptees' access to biological family history information. In an earlier policy statement, the ASHG advocates adoptees' access to their personal medical records, compilation of biological family medical history as standard practice in the adoption process, maintenance of adoption records to allow for voluntary periodic updating, and age-appropriate

sharing of biological family medical history when medically indicated, keeping due respect for privacy (American Society for Human Genetics, 1991).

Fifteen years after ASHG issued this policy statement, access to genetic and biological family medical history information remains limited and is governed by highly varied state laws (Child Welfare Information Gateway [CWIG], 2006). Nearly all states have instituted policies that allow adopted adults access to non-identifying information about birth parents through formal request procedures governed by the court system (CWIG, 2006), although "good cause" is typically required to open sealed records. Non-identifying information typically includes biological family medical history at the time of adoption (CWIG, 2006); however, the value of this information becomes increasingly lackluster given the passage of time. For many adoptees who ultimately search for information, decades pass before any attempts are made to access original records that document family medical history. Undoubtedly, the information has changed, likely dramatically, as affected persons grow older and inevitably experience health concerns. To address this potentiality, some states have developed systems that allow for submission of medical updates. However, these systems rely on voluntary contact by birth relatives, which is severely complicated by potential unwillingness to participate, lack of knowledge about the adoption's occurrence, and lack of awareness about the existence of such a database.

Because of the numerous challenges involved in obtaining an up-to-date biological family history, some adoptees desire involvement from their physicians in establishing "good cause" and facilitating the request procedures (Tam, 2004). In their view, physicians could be granted access to important medical information pertaining to family history, whether or not the information was made available to the adoptee-patient. Contrary opinion is also found among

adoptees who feel responsibility rests with the legal system that precludes information-sharing. In Tam's study (2004), adult adoptees recommended additional training for physicians on the spectrum of issues facing adoptee-patients. Chief among these training priorities are the logistical and psychosocial aspects of searching for birth relatives.

Birthparent Searching in Adulthood

Today, adults adopted under more closed systems of the past may choose to engage in birth parent search and reunion, as many as 47% by some estimates (Finkler, 2000). According to Finkler (2000), birth parent searching is rooted in the 1960s, coinciding with our "collective consciousness concerning genetic inheritance" (p. 121) and the biomedical emphasis on genetic etiology of disease. While an individual's impetus for searching may vary, a desire for information about biological family medical history is generally regarded as one of the strongest correlates and often coincides with major life events along an adult trajectory (CWIG, 2004; Finkler, 2000; Reed, 1994; Tam, 2004). Expert opinion vacillates as to whether the quest is driven by the expressed need for tangible information regarding biological family medical history or whether pursuit of that information simply grants oneself permission to search to satisfy more existential longings (Finkler, 2000; Krueger & Hanna, 1997; Sobol & Cardiff, 1983; Tam, 2004).

The literature characterizes searchers as having two common characteristics: being an adoptee in early to middle adulthood and female (Finkler, 2000; Krueger & Hanna, 1997; Pertman, 2000; Reed, 1994; Sobol & Cardiff, 1983; Tam, 2004). Other researchers describe differences between adoptees who engage in formal searches and those who do not. Sobol and Cardiff (1983) described searchers, relative to non-searchers, as having more traumatic adoption stories, strained relationships with adoptive families, poor self image, greater life stress, and

more acute feelings of being incomplete. Kowal and Schilling (1985, as cited in Tam, 2004) described searchers as being older upon learning about being adopted and reaching adult developmental milestones (e.g., marriage, pregnancy, childbirth, death of adoptive parent) that precipitate the desire to search. Krueger and Hanna (1997) suggested non-searchers' anxieties about searching hinder search readiness and ultimate engagement. For both searchers and non-searchers, however, guilt may be omnipresent, either from "transgression against self" from not searching or feelings of betrayal against adoptive parents if searching (Kruger & Hanna, 1997).

Tam's (2004) more contemporary study revealed that searching for biological family medical history may help promote more active health consumerism through fostering a greater internal locus of control. In turn, adoptees would, then, have greater information to make informed decisions about prevention, screening, and treatment. Referencing the reverse side of the same coin, Finkler (2000) cautioned that search and reunion resulting in discovery of biological family medical history may create "perpetual patients" who live anew, quite possibly, with a chronic disease trajectory.

Summary

As discussed in the preceding sections of this chapter, the medical literature related to biological family history and adoption centers around the practical value of collecting genetic information during the adoption process itself, when adoptees are infants and children. Genetic testing technology is not currently recommended for adult-onset disorders, although demand for genetic counseling may rise with continued media exposure about advances in genetic testing. Adoptees are typically dissatisfied with their medical encounters in regard to ambiguous family history, as physicians remain ill-equipped or prepared to discuss the psychosocial and clinical ramifications of adoption with their adoptee-patients. It is widely accepted that interest in biological family medical history information prompts some adult adoptees to search for information about birth relatives, either by petitioning the courts to open sealed records or through attempting birth parent search and reunion. Biological family health history information is perceived as valuable to adult adoptees and potentially their physicians. Adoptees envision practicing more effective prevention and early detection practices if armed with family medical history information. The current medical literature, however, is devoid of research around the actual health practices of adult adoptees. How do they perceive various health risks in the era of genetics-based medicine? What is their level of disease worry? Do adoptees, in fact, grow up to adhere to population-based prevention and early detection guidelines, as recommended by ASHG?

Breast Cancer Provides Perfect Research Context

To initiate development of a body of literature on the health practices of adult adoptees, breast cancer provides the perfect research context. Similar to the unique confluence of events that produced the historic meteorological event recounted in the popular book and movie, *The Perfect Storm* (Junger, 1997), a combination of factors beckons behavioral researchers to study genomics information-seeking (Johnson, Case, Andrews, & Allard, 2005) and breast health practices of those with ambiguous biological family history.

As Finkler and colleagues asserted (Finkler, 2000; Finkler, 2003; Finkler, 2005; Finkler, 2001; Finkler, Skrzynia, & Evans, 2003), the "hegemony of the gene" fosters the "medicalization of kinship." As such, adult adoptees stand in bold relief as a group worthy of consideration in the new era of genetics-based medicine, particularly for what they may lack and come to desire access to their biological family medical histories. Unarmed with this information, adoptees may experience unnecessary anxiety in the medical marketplace that is increasingly emphasizing the "medical and conceptual power of genetic connectedness" (Lebner, 2000, p. 371) as well as informed consumerism. This potentiality warrants further research on risk perception and health practices of this unique population subgroup. It is quite possible, as Lebner (2000) reminds, that continued "medicalization and intensifying geneticization of North American society may contribute to the persistence of a latent social bias against non-biologically related families" (p. 373), which may include the provision of health services.

Adoptees are of particular interest to genomics and behavioral researchers for their ability to highlight differences between environmental and genetic factors (Osler, Holst, Prescott, & Sorensen, 2001; Petersen, Nielsen, Andersen, & Sorensen, 2002; Petersen, Sorensen, & Andersen, 2003; Petersen, Andersen, & Sorensen, 2005). As a group, they also stimulate dialogue on ethical issues involving adoption in genetics counseling environments, such as health professionals' duty to warn (Venne, Botkin, & Buys, 2003). From a health communication standpoint, adoptees represent a special population who may be resistant to health promotion campaigns targeting knowledge of family history and preventive lifestyle behavior, which is now a national priority (see www.cdc.gov/genomics).

Breast cancer is the most common disease referenced in a searchable database (HuGE Pub Lit) of published literature on population-based epidemiological studies involving human genes (Lin et al., 2006). The proliferation of genetic testing and technology also poses additional context. While genetic testing is now available for breast cancer, interpretation occurs alongside examination of biological family history, rendering its applicability as severely limited for adoptees. Despite this, companies with genetic testing services are engaging in direct marketing campaigns aimed at adoptees with potential vulnerability to media influence on this sensitive topic. Historical research participation demonstrates interest in biological family medical history is strongest among female adult adoptees in early to middle adulthood. With this demographic profile, interest in breast cancer is almost certain. Breast cancer is one of the primary diseases affecting women, for which biological family history is a significant risk factor, and for which effective screening tools are available. In the general population, psychosocial issues pertaining to breast cancer are highly researched, facilitating some comparison. The current literature, for example, suggests that most women overestimate their breast cancer risk. Worry, an important correlate to risk perception and screening, is of particular interest when studying adoptees, who may be unable to anchor their perceptions and beliefs amidst a known biological family history.

A variety of assistance is now available through the World Wide Web to adoptees interested in searching for biological family medical history. The internet has facilitated creation of virtual communities for adopted persons, and it is used by organizations offering search and reunion support services. Therefore, internet-based data collection offered a promising vehicle for reaching out to this otherwise hard-to-reach population.

Given the dearth of research in this area, the study examined the health beliefs of female adult adoptees in accordance with theoretical assumptions applied to the general (i.e., biologically related to family members) population, unless otherwise indicated. The following sections will make these theoretical relationships explicit. Beforehand, however, it is helpful to review basic breast cancer epidemiology, as well as current early detection guidelines for the general population.
Breast Cancer Incidence, Morbidity and Mortality

Over the last 30 years, the 5-year relative survival rate for all cancers has increased from 50% to 65%. Still, cancer remains the second leading cause of death for persons in the United States. The American Cancer Society (ACS) estimated that 1,399,790 new cases of cancer would be diagnosed in 2006, while 564,830 persons with cancer would die of the disease. Approximately two-thirds of cancer deaths are considered preventable and attributed to lifestyle factors such as tobacco use, poor diet, physical inactivity, and excess weight (American Cancer Society [ACS], 2006b).

Breast cancer is the leading cancer among women, representing 31% of all new cancer cases. In 2006 ACS estimated there were 212,920 new breast cancer diagnoses among women in the United States and approximately 40,970 deaths from the disease. While breast cancer among males is relatively rare, ACS estimated 1,720 new cases of breast cancer and 460 deaths among males in 2006. Incidence rates for breast cancer have increased sharply since the 1980s. The surge, however, primarily reflects technological advances in early detection through mammography, which enables clinicians to detect the disease prior to the development of noticeable symptoms (ACS, 2006b).

Breast Cancer Screening Guidelines

The National Cancer Institute (NCI) defines screening as the process of detecting cancer early among asymptomatic persons. For a variety of cancers, early detection prevents premature death and lessens morbidity by reducing disease severity and the need for more aggressive treatment typically associated with more advanced stages of disease (National Cancer Institute [NCI], 2005b, Cancer Screening Overview Health Professional Version). In fact, the 5-year survival rate for cancers with recommended screening guidelines (i.e., breast, colon, rectum, cervix, prostate, testes, oral cavity, and skin) is around 82% (American Cancer Society, 2002), which is substantially higher than the rate for all cancers combined.

For screening to be considered useful, three conditions must be met. First, the screening test must detect cancer prior to the presence of clinical symptoms. Second, initiation of treatment at earlier stages of the disease process must result in improved health outcomes. Third, and most importantly, screening must produce lower disease-specific mortality rates (NCI, 2005b). Early detection procedures include visual inspection of lesions, palpation to detect abnormal lumps in affected areas, and internal tests including assessment of laboratory specimens, radiological, ultrasound, or magnetic resonance imaging (MRI) (NCI, 2005b). Scientists formulate screening recommendations for the general population by taking the specific test's predictive value and disease prevalence into account, aspiring to minimize the number of false positives and false negatives (NCI, 2005b).

Recommended screening guidelines for breast cancer have fluctuated over the years along with the current state of the science. In 1976 annual screening mammography was routinely recommended only for women over 50 years of age. From the mid-1980s until 1997, mammography was recommended annually for women over 50 and every 1-2 years for women between 40 and 49. In 1997, the American Cancer Society revised its screening guidelines and has since advocated annual screening mammography for all women beginning at age 40 (American Cancer Society [ACS], 2006c). Based on its capacity to detect 80-90% of breast cancer cases among asymptomatic women, mammography is currently regarded as the single best weapon in the breast cancer screening arsenal (ACS, 2005a). Numerous research efforts, including those with randomized clinical trial designs, have demonstrated its effectiveness in increasing the likelihood of successful treatment and decreasing mortality (ACS, 2005a; 2006b). Between 1983 and May 2003, ACS guidelines also included monthly breast-self examination (BSE) for women over 20 (ACS, 2006c). In the wake of a well-conducted randomized clinical trial involving BSE, which failed to demonstrate significant benefit beyond simple self-awareness (ACS, 2006c; National Cancer Institute [NCI], 2005a, Breast Cancer Screening Health Professional Version), ACS revised BSE guidelines as optional for women of all ages. Instead, along with optional BSE, ACS now advocates that women be familiar with the normal feel of their breasts and informed about the benefits and risks of BSE, which can include an increased number of breast biopsies and diagnoses of benign lesions (Thomas et al., 2002). Other studies provide mixed evidence on the relative benefits and risks of BSE, although it is generally acknowledged that typical BSE proficiency and/or self-efficacy is lacking (American Cancer Society, 2003; NCI, 2005a).

There are no definitive studies showing the efficacy of clinical breast examination (CBE) as a sole screening modality (NCI, 2005a). Rather, CBE is intended to be a complementary screening tool to mammography, deemed important for its potential in detecting a small proportion of breast cancer cases left undetected by mammography (ACS, 2005a). The positive value added by CBE over mammography alone was keenly demonstrated by Gui, Hogben, Walsh, Ahern, and Eeles (2001) in their study of women at heightened familial risk. CBE screening guidelines have remained consistent for women over 40, conducted preferably on an annual basis as part of a regular health exam. Younger women, aged 20-39, are encouraged to obtain a CBE at least every three years (ACS, 2005a; 2006c).

In summary, current state of the science regarding the effectiveness of various screening modalities for breast cancer has led ACS to recommend the following schedule. The best approach involves a combination of the three available screening tools—self-awareness through

BSE, clinical breast examination, and mammography. Asymptomatic women may choose to begin BSE around age 20 to gain self-awareness, after receiving some instruction by a qualified practitioner. Younger women (<40) should also obtain a CBE at least every 3 years as part of their routine checkup. After age 40, women can continue BSE and should begin annual CBE and screening mammography (ACS, 2005a; 2006a; 2006c). Asymptomatic women with a strong biological family history of breast cancer are encouraged to confer with their physician about the need for more frequent examination, additional testing, and possibly even genetic testing for an inherited mutation (i.e., *BRCA1* or *BRCA2*).

Breast Cancer Screening Adherence

The message that mammography is the most effective screening tool for breast cancer appears to have reached the majority of U.S. women. *First-time* mammography rates have practically doubled since 1987 from 36% to around 67% (Richards, Viadro, & Earp, 1998). Despite the gains in first-time screening, a substantial proportion of women over 40, approximately 39%, are non-compliant with screening recommendations at any point in time, having not had a screening mammogram in the past year (ACS, 2005). This figure may be even higher for specific population subgroups including women of color, for example (Richards et al., 1998; Sadler & Fullerton, 2001; Ho et al., 2005; Juon, Kim, Shankar, & Han, 2004; Yu & Wu, 2005). The challenge for health educators today quite clearly is increasing the rate of *consistent* screening as prescribed by adherence to guidelines broadly accepted by the scientific medical community.

Numerous studies highlight the problem of lackluster screening rates among women shown to have elevated clinical risk, including older women (Levy-Storms, Bastani, & Reuben, 2004), lesbians (Burnett, Steakley, Slack, Roth, & Lerman, 1999), women treated with radiation during adolescence for other cancers (Kash & Dabney, 2001), Ashkenazi Jewish women (Lehmann, Weeks, Klar, & Garber, 2002), and women with a strong biological family history (Lindberg & Wellisch, 2001; Meiser et al., 2000; Rothemund, Paepke, & Flor, 2001; Schwartz et al., 1999; Schwartz et al., 2003). Given their greater likelihood of developing breast cancer at some point in their lives, compliance with regular screening is especially critical. Reasons behind suboptimal screening rates are numerous yet center on individual or cultural differences in health beliefs and overcoming a variety of barriers including negative perceptions of the disease and/or screening procedure (e.g., fear, embarrassment, anxiety), not having access to screening services, and inability to pay (Richards et al., 1998). To further explain lack of adherence to screening guidelines, researchers have also explored differences between subjective and objective disease risk estimates (Davis, Stewart, & Bloom, 2004) as well as how affective processing (e.g., worry, anxiety, distress) influences risk perception and screening behavior or intent (Hay et al., 2005).

The Transactional Model of Stress and Coping served as the guiding framework for the study. As discussed in the following sections, the role family history plays in personal risk construction and screening decision making was emphasized. For better applicability to the adoptee-patient context, information-seeking about biological family history served as an additional outcome of interest.

Theoretical Explanation of Coping with Breast Cancer Risk amidst an Unknown Biological Family History

Overview

The Transactional Model of Stress and Coping provides a framework for understanding how individuals cope with specific stressors, such as the threat of illness. According to Lazarus and Folkman (1984), individuals perceive the meaning of stressful events differently, depending on a variety of factors including personal disposition, psychological states, coping resources, and environmental demands. The interpretation of the stressor, therefore, rather than the stressor itself, drives subsequent cognition, emotion, and behavior aimed at coping with the perceived threat. The coping process involves, first, a primary appraisal of the threat, which is followed by a secondary appraisal of one's ability to reduce or manage the magnitude of the stressor. This may include, for example, evaluating the potential effectiveness of available coping resources after pondering supporting evidence on which to base a personalized sense of disease risk. Next, coping efforts ensue, with the goals of emotional regulation and, more cognitively, problem management. Depending on the relative short and long-term success of the coping effort, the outcome of the coping process may be adaptive (e.g., emotional well-being) or maladaptive (e.g., distress). The coping process is regarded as cyclical as primary and secondary threat reappraisal lends itself to new coping attempts (Wenzel et al., 2002).

While the Health Belief Model (HBM) (Janz et al., 2002) is the more typical theoretical application in the psychological literature pertaining to risk perception and screening, support is growing for using the Transactional Model of Stress and Coping (TMSC) (Wenzel et al., 2002) to explain cancer-related behaviors amidst suspected genetic risk (Absetz et al., 2002; Decruyenaere et al., 2000; Cohen, 2002; Gooding, Organista, Burack, & Biesecker, 2006; van Dijk et al., 2004). As Gooding et al. (2006) described, the TMSC has two major strengths over the HBM. First, the HBM portrays a primarily cognitive reasoning process that involves weighing the costs and benefits of screening in the wake of perceived risk for disease. A large body of research (Lerman, Trock, & Rimer, 1991a; Redelmeier, Rozin, & Kahneman, 1993) has consistently challenged the notion that individuals make purely cognitive decisions without

regard to emotional experience. In contrast, the TMSC contains an inherent assumption that emotional responses help produce and are produced by perceived risk (Gooding et al., 2006). A second major strength of the TMSC over the HBM is that the stress and coping model represents a reflective, dynamic process of health decision making, rather than describing a one-time event. Breast cancer screening in the long run is influenced not only by appraisal of risk, emotional states, and perceived effectiveness of coping strategies, but also *reappraisal*, which then incorporates information gleaned from previous health behavior and coping efforts (Gooding et al., 2006) in making subsequent screening decisions.

The constructs selected for the proposed study operationalize components of the Transactional Model of Stress and Coping and are tailored to fit a given context, perceived risk for breast cancer amidst genetic uncertainty, among a specific and unique target population, female adult adoptees. How the constructs are defined and applied in the present study is presented in Appendix A. The specific hypothesized relationships, depicted in Figure 2.1 and described in the following sections, are grounded in existing scholarly literature on breast cancer risk perception, screening, and cognitive and emotional responses to perceived risk. A review of the literature precedes hypothesized relationships, which are represented by arrowed line segments in the proposed structural model.

Description of Structural Relationships

Deconstructing Family History

Psycho-social-behavioral research on adopted persons brings two elements of family medical history into bold relief—objective risk posed by genetic inheritance and the opportunity for having lived experience with affected family members (Montgomery et al., 2003). For persons reared in biologically-related families, the two components of family history are

inextricably intertwined and stem from one conjoined source. Moreover, a positive family history for disease elevates actual disease risk among otherwise healthy biologically-related family members. For adoptees reared in biologically-unrelated families, family medical history is decidedly more complex. For adoptees with access to documented biological family medical history, albeit outdated, some information regarding objective genetic risk may be available. For adoptees who have established contact with biological relatives, shared experience with disease is possible with both adoptive and biological families, and family history, therefore, becomes an amalgam of consanguinity and lived experience. For adoptees without information or contact with biological relatives, however, the origins of genetic inheritance are unknown and any family history with disease is solely experiential.



Figure 2.1. Hypothesized stress and coping model for healthy adult adoptees pondering their personalized risk for breast cancer.

Some researchers have isolated a direct connection between family history and screening behavior (Audrain-McGovern et al., 2003; McCaul et al., 1996; Murabito et al., 2001; Rutledge, Barsevick, Knobf, & Bookbinder, 2001). However, close examination of this research reveals either an assumption that family members are biologically related or inclusion criteria that specify knowing about blood relatives (e.g., Finney & Iannotti, 2001), thereby excluding many adoptees from participation. Therefore, family history serves as an indicator for actual disease risk, which is either categorized as 'average,' or 'population-based' for persons without a positive family history of disease or, in contrast, as 'elevated,' 'increased,' 'moderate,' or 'high' for persons with a positive family history. Clearly, adoptees inherited disease risk from biological parents; however, unarmed with biological family medical history information, their actual level of risk is exceedingly difficult, if not impossible, to quantify. Existing disease risk calculation tools (e.g., Gail Model, Claus Model, BRCA tool) simply do not apply to adoptees given their emphasis on knowing biological family history.¹ As a result, the relationship between family history as an objective risk indicator and screening is noticeably, yet appropriately, absent from the proposed model. Rather, the relationship between family history and screening is best described as operating through *perceived susceptibility* as distinct from actual, objective clinical risk.

The degree to which adoptees attribute disease risk to genetic factors, identify with adoptive and/or biological relatives, and have vicarious lived experience with illness shapes their personalized disease risk construction and affects the likelihood of seeking screening. Evidence from the breast cancer risk perception literature, described below, further supports this assertion.

¹ For information on the Gail Model, see Botttorff et al., 2004; McGregor et al., 2004; and Schapira et al., 2004. For information on the Claus Model, see Kash & Dabney, 2001; and Rothemund et al., 2001. For information on the BRCA tool, see Davis et al., 2004.

Ambiguity of Biological Family Medical History as a Stressor

The body of literature on decision making amidst uncertainty informs the present study, which asserts that ambiguity about biological family medical history serves as a significant stressor for adoptees pondering their inherited disease risk for adult-onset disorders. In general, individuals are averse to ambiguity which worsens when evidence about risk is unreliable or incomplete (Han, Moser, & Klein, 2006). Seminal research by Ellsberg (1961) demonstrated 'ambiguity aversion' and expanded upon earlier conceptualizations of uncertainty by adding a dimensional element about the quality of information available to assess risk (Han et al., 2006). Individuals' tendency to adjust perceived risk based on the quality of information at hand, a socalled pessimistic bias, has been shown in a variety of research contexts, including cancer, (Absetz, Aro, Rehnberg, & Sutton, 2000; Absetz et al., 2002; Han et al., 2006; McGregor et al., 2004). As Han et al. (2006) reveal in their study examining ambiguity of cancer prevention recommendations, ambiguity has both a positive direct effect on worry and a positive indirect effect through perceived risk. Given the similarity to the present research context, these relationships are hypothesized to exist in the proposed study as well. Researchers estimate that between two-thirds and three-fourths of women are aware that biological family history is a risk factor for breast cancer (Audrain-McGovern et al., 2003). Therefore, greater perceived ambiguity over biological family medical history will result in heightened perceived breast cancer risk as well as heightened worry about developing the disease.

Vicarious Experience with Cancer as a Stressor

For persons reared in biologically-related families, having a family history of breast cancer elevates perceived risk among first-degree relatives (Absetz et al., 2002; Facione, 2002; Katapodi et al., 2004; Montgomery et al., 2003). However, in examining relationships between family history and a host of other constructs including anxiety and screening uptake, most researchers, with a few exceptions (Drossaert, Boer, & Seydel, 1996; Montgomery et al., 2003), do not separate family history into its two components--being biologically related (and, therefore, at greater clinical risk) and having experience with a loved one facing a particular illness. To study adoptees in a health context, understanding how lived experience contributes to risk perception, disease-specific anxiety, and screening behavior is critical. The literature provides ample evidence that adoptive family history shapes perceived risk for breast cancer, despite the absence of a biological risk component. Even among biologically-related persons, objective risk only partially explains personalized risk constructions (Drossaert et al., 1996).

Research on the impact of cancer diagnoses among friends on the worried well is analogous to the adoptee's relationship to adoptive family members, given that it represents social closeness without consanguinity. Evidence of an apparent "friend effect" in elevating women's risk perception has been demonstrated for breast cancer, heart disease, diabetes, and colon cancer, although the same is not true for men who tend to be less affected by friend and family history of disease (Montgomery et al., 2003). Facione (2002) observed a tendency, albeit not statistically significant, for women who have a female friend with breast cancer to rate their own risk for breast cancer as higher than women who do not have a friend with that disease history.

Further support for the importance of subjective experience in shaping perceived breast cancer risk is found in the literature on the use of heuristics in decision making. Given complex tasks involving probabilities and prediction, individuals utilize shortcuts, or heuristics, to simplify cognitive processing. According to classic decision making theorists, Tversky and Kahneman (1974), heuristics create cognitive efficiency at the expense of the accuracy of logical reasoning. Personalized estimates of vulnerability, therefore, are formed by considering objective risks, such as genetic susceptibility, and making corrective subjective adjustments (Hopwood, 2000), either downward or upward, however accurate or inaccurate. These personalized corrections flow through cognitive filters that serve to bias otherwise logical judgment. Two heuristics that are commonly discussed in the breast cancer risk perception literature that specifically apply to family history are *availability* and *representativeness* (Facione, 2002; Katapodi, Facione, Humphreys, & Dodd, 2005; Rees et al., 2001). Each heuristic will be discussed in turn.

Individuals using the availability heuristic evaluate probability by the ease with which similar instances can be recalled (Tversky & Kahneman, 1973). Recent, dramatic, or emotionally-charged events, such as having a family member with cancer, alter one's own perception of personal risk. Researchers have shown elevated risk assessments among persons who have unpleasant, vivid memories of a loved one's illness or death, citing increased feelings of vulnerability based on the emotionality of the experience (Jacobsen et al., 2004; Kenen, Ardern-Jones & Eeles, 2003a; Sanders, Campbell, Sharp & Donovan, 2003). Preoccupation with personal risk (i.e., engaged risk information processing) as an attempt to cope with uncertainty further exacerbates feelings of susceptibility (McAllister, 2003).

Risk perception is also influenced by the extent to which a sample is deemed representative of a parent population (Kahneman & Tversky, 1972). Among biologically-related families, inherited risk of disease is a quintessential example of this concept, which can also be extended to adoptive families in its application, although, perhaps, to a lesser degree. The cognitive process underlying the representativeness heuristic is described in various qualitative studies of members of hereditary cancer families (Arar et al., 2000; Kenen et al., 2003a; McAllister, 2003; Sanders et al., 2003), as well as in Rees et al.'s (2001) theoretical discussion paper. Although the perceived connection between shared physical characteristics (e.g., body type, resemblance) and risk does not apply to adoptees, other perceived familial similarities do. According to this body of literature, an unaffected relative's risk perception for disease is shaped by perceived similarities or dissimilarities to the affected family member in terms of same-sex gender identification, personality, social or emotional closeness, age at diagnosis, and lifestyle behavior (Brain et al., 2000; Decruyenaere et al., 2000; Katapodi et al., 2005; Rees et al., 2001; Richards & Ponder, 1996).

The Relationship between Perceived Risk and Various Coping Efforts

It is important to reiterate that perceived risk is conceptually and empirically distinct from objective clinical risk (Bottorff et al., 2004; Davis et al., 2004; Lindberg & Wellisch, 2001; Meiser et al., 2001; Schapira, Davids, McAuliffe, & Nattinger, 2004), which is exceedingly difficult to determine for an adoptee without biological family history information. To date, no studies are known to exist that seek to measure disease risk perception or coping efforts aimed at controlling the particular stressors of adult adoptees faced with the abstract threat of illness. The following sections will outline the hypothesized relationship between perceived risk for breast cancer and emotion-based and problem-based coping efforts including cancer-specific worry, screening mammography, and information-seeking about biological family medical history. According to the TMSC, specific coping attempts are preceded by an evaluation, or secondary appraisal, of coping options including, for example, perceived controllability of the threat and perceived effectiveness of coping resources (i.e., outcome efficacy) (Folkman & Greer, 2000; Wenzel et al., 2002).

Relationship between Perceived Risk and Cancer Worry

There is consensus in the literature that perceived risk and cancer worry or distress are positively correlated (Katapodi et al., 2004; Meiser et al., 2000; Thewes, Meiser, Tucker, & Schnieden, 2003), albeit weakly (i.e., r = .30 on average) (Lipkus et al., 2000). Researchers have demonstrated that perceived threat, in fact, predicts cancer worry, whether or not perceived susceptibility is well-calibrated with actual objective risk levels. Evidence of this relationship has been found among women at high-risk for breast cancer (Hopwood et al., 2001) as well as population-based samples of women at average risk (McGregor et al., 2004). Interestingly, Lipkus et al. (2000) established that worry about breast cancer stems from a consideration of both perceived absolute risk as well as comparative risk (i.e., self versus other women of similar age/race).

The Role of Perceived Control over Disease Risk

Research indicates the general population has an inaccurate understanding of genetic, behavioral, and environmental risks for developing cancer (Eyre et al., 2002; Kinney et al., 2000). Individuals tend to overestimate causal linkages outside their control (e.g., genetic inheritance) and underestimate more controllable voluntary behaviors (e.g., smoking, diet, exercise) (Eyre et al., 2002). Perceived control over disease risk is another cognitive heuristic, termed *illusion of control*, which stems from mistaken notions about one's ability to control chance events despite at least some knowledge of chance and probability (Langer, 1975). As Katapodi et al. (2005) assert, this perception is based on hindsight, whereas individuals attribute some previous outcome (e.g., remaining healthy) as having been controlled by some personal action (e.g., exercise). Future chance events, like the risk of developing breast cancer, are therefore viewed as controllable as well. In a hereditary cancer context, this may involve

adoption of certain lifestyle behaviors (e.g., diet) or vigilant cancer screening in an attempt to control genetic risk or prevent the development of cancer (Kenen et al., 2003b). Conversely, individuals may overly ascribe disease etiology as being purely genetic, and, therefore, less controllable. Interestingly, as Finkler (2000) discovered in her interviews with adult adoptees engaged in birthparent searching, adoptees in particular may have a tendency toward overemphasizing inherited risk factors for disease when pondering personal susceptibility.

The exact relationship between perceived risk and perceived control is not entirely understood. According to Klein and Helweg-Larsen's (2002) meta-analytic review, having an optimistic bias (i.e., perceiving oneself to be at lower risk than someone else of similar age and gender) is moderately related to having greater perceived control (r = 0.31, on average). As Klein and Helweg-Larsen point out, however, the directionality of the relationship cannot be determined within cross-sectional studies. Findings from other studies, however, lend support to the notion that perceived control mediates the relationship between perceived breast cancer risk and positive behavioral change including physical activity and screening (Cohen, 2002; Katapodi et al., 2004; Lemon, Zapka, & Clemow, 2004). For the current study, therefore, heightened comparative perceived risk (i.e., low optimism) is hypothesized as having an inverse relationship to perceived control. This hypothesis is consistent with the current literature and the directionality of the relationship as prescribed by use of the TMSC.

Together, primary and secondary appraisals determine the nature of the coping effort. That is, individuals tend to match coping processes with the type and degree of threat as determined by the appraisal process. Controllable threats are met more often with problemfocused coping efforts (e.g., information-seeking, screening), while uncontrollable ones provoke more intense emotional reactions, such as worry or seeking social support (Folkman & Greer, 2002; Gooding et al., 2006). Some consider control attempts as generally protective active coping behaviors, positive illusions from a psychological standpoint (Taylor et al., 2000 cited from Kenen, Ardern-Jones, & Eeles, 2003a); however, depending on the nature of the attribution or behavior, control attempts may also be somewhat detrimental. It is not uncommon, for example, for women to confuse controllability with preventability in regard to mammography. As a result, they incorrectly assume that mammography helps prevent onset, rather than that it offers an opportunity for early detection (Facione, 2002). Researchers have also found that women may overly attribute having a positive relationship with their doctor as having preventive qualities over breast cancer (Katapodi et al., 2005). The same researchers also posit that a possibly erroneous, absolute sense of control may also result in less confidence in the health care system and over-reliance on arguably less effective self-care behavior (e.g., taking vitamins, prayer) to reduce disease risk.

Whether or not the specific coping effort may ultimately be judged as adaptive or maladaptive depends on how well the coping effort is calibrated with the actual controllability of the stressor (Gooding et al., 2006). For the present study, a heightened sense of control over breast cancer risk was hypothesized as having a positive relationship with mammography and an inverse relationship with cancer worry.

The Role of Perceived Effectiveness of Coping Resources

Perceived effectiveness of coping resources, also termed outcome efficacy (Folkman & Greer, 2000), is another type of secondary appraisal that individuals conduct prior to engagement in specific coping efforts. In theory, having strong beliefs regarding the effectiveness of mammography propels women to seek screening. While there is some support for this proposed predictive relationship (Champion 1999; Finney Rutten & Iannotti, 2003), findings from other

research lend doubt, as perceived benefits of mammography failed to predict screening behavior (Champion & Scott, 1997; Russell, Perkins, Zollinger, & Champion, 2006; Rutledge et al., 2001; Wu & Yu, 2003; Yu & Wu, 2005). Outcome efficacy for mammography is, therefore, excluded in the present study.

In contrast, outcome efficacy appears to be the predominant construct for examining secondary appraisal processes that predict information-seeking about biological family medical history. Although this is an entirely nascent area of behavioral health research, exploratory qualitative research has shown that a primary impetus for birth parent searching is the desire to have biological family medical history information (Finkler, 2000; Tam, 2004), presumably because of its perceived value. As both Tam (2004) and Finkler (2000) discovered in their interviews with adult adoptees, feeling at risk for illness is a common trigger for search initiation that often coincides with a personal medical diagnosis or, alternatively, one in a biologically-related child.

The proposed study is believed to be the first to utilize quantitative techniques to explain health-related behavior of adult-adoptees. It is hypothesized that the perceived value of biological family medical history will mediate the relationship between perceived risk and information-seeking. Although there is less empirical support in the literature to justify this hypothesis, the logic is consistent with cognitive coping processes as specified in the TMSC.

Relationship between Cancer Worry and Screening Mammography

The relationship between cancer worry or distress and mammography is decidedly less straightforward, however. Research exists that purports no significant relationship between worry and mammography (Isaacs et al., 2002), a positive linear relationship (Burnett et al., 1999), a negative linear relationship where anxiety deters screening (Kash & Dabney, 2001), and a curvilinear relationship with moderate worry serving to optimize early detection behavior (Andersen, Smith, Meischke, Bowen, & Urban, 2003; Decruyenaere et al., 2000; Lerman et al., 1991a; Schwartz et al., 2003). In reviewing this literature, careful attention is required to assess varying definitions of worry and distress, the variance in certain populations' level of worry, the overall study design (Hay et al., 2005), and the specific screening behavior being examined. These will be discussed in turn.

In the clinical literature, worry is considered primarily a cognitive process that enables individuals to prepare for a given threat. The process itself may produce an emotional response that includes fear and anxiety. One's level of worry falls on an adaptive-maladaptive continuum. On one end, non-pathological worry enables emotionally healthy individuals to take necessary precautions; on the other end, worry is consistent with somewhat disabling pathological distress (Hay et al., 2005). In the breast cancer prevention literature, cancer-specific worry emphasizes the emotional or affective dimension, as more cognitive processes, like perceived risk, have psychometrically distinct properties (Hay et al., 2005; Lipkus et al., 2000). From this vantage point, breast cancer-specific worry is regarded as an adaptive coping response that motivates screening behavior (McCaul et al., 1998), particularly when worry is bounded to concern about the abstract risk of developing the disease rather than specific events such as worry about a diagnostic test (Hay et al., 2005).

For most women at both average and high-risk for breast cancer, the level of cancer worry tends to be low and non-pathological (Hay et al., 2005; Hopwood et al., 2001). Establishing a curvilinear relationship with mammography, however, can require examination of screening adherence at three levels of worry. The skewed distribution of worry among research participants hampers advancement of the curvilinear argument given low power to detect differences among three distinct groups of worriers (Hay et al., 2005). Similarly, given a lack of variance, a negative or non-existent relationship is also possible. In a study where both breast cancer-specific worry and overall distress were examined, no differences in worry were found between mammography-compliant and non-compliant women at high-risk, although non-compliant women were more likely to report distress (Isaacs et al., 2002). Isaacs et al. (2002) themselves highlight that the most severely worried and/or distressed may be under-represented in clinical research settings that rely on self-referral.

Other aspects of research design are troubling when attempting to understand the relationship between worry and early detection practices. Most research in this area is cross-sectional (Hay et al., 2005; Tiro et al., 2005); therefore, temporality between worry and screening is difficult to determine without a prospective design, or at least inclusion of future screening intention as a construct (Hay et al., 2005). As Hay et al. (2005) remind, in cross-sectional work, competing explanations of a negative relationship are equally valid--that worrying deters screening or that screening reduces the level of worry. Inclusion criteria, too, are important to assess. Kash & Dabney (2001), for example, report a negative relationship between anxiety and screening, although their case-control groups arguably lack comparability.

Screening is sometimes painted with a broad brush in the corpus of literature on breast cancer, particularly in published written abstracts. Decruyenaere et al. (2000), for example, posit that risk reduction behaviors and emotional distress may have a positive linear relationship, while a curvilinear relationship exists for early detection behaviors. By reviewing the literature with closer scrutiny in regard to specific behaviors, supporting evidence exists for a positive linear relationship between worry and *mammography* and a curvilinear relationship for worry and *breast self-examination* (Lerman et al., 1991a), both of which are early detection behaviors.

In the present study, prior adherence to mammography was assessed, along with future mammography intention. It was hypothesized that heightened perceived risk prompts cancer worry, which, in turn, prompts screening intention. Moreover, the literature also suggests that past mammography behavior predicts future screening intention and uptake (Lechner, de Vries, & Offermans, 1997; Mayne & Earp, 2003). This configuration is consistent with testing the applicability of the Transactional Model of Stress and Coping, as the success of prior coping efforts is factored into subsequent screening decisions.

The Relationship between Information-seeking and Screening

To date, there are no known published studies that examine the relationship between family history information-seeking and screening intention among healthy persons, let alone adult adoptees. However, information-seeking is generally regarded as an active coping process that leads to adaptive outcomes, including psychological well-being and protective health action (Andrews, Johnson, Case, Allard, & Kelly, 2005; Wenzel et al., 2002). Population-based research on interest in genetic testing, albeit a different level of family medical history information-seeking, revealed that lack of interest in genetic testing predicted lower levels of protective health behavior (Andrykowski, Munn, & Studts, 1996). More recently, Shim, Kelly, and Hornick (2006) found that individuals who search for cancer information are more likely to seek certain types of cancer screening and have healthier lifestyles. Therefore, a somewhat exploratory hypothesis is posited—adult adoptees with greater information-seeking engagement about biological family medical history will have greater future screening intention.

Summary

With the Transactional Model of Stress and Coping as the guiding theoretical framework, the researcher endeavored to explain breast cancer risk perception, cancer worry, mammography adherence, and family medical history information-seeking among adult adoptees. It was hypothesized that two stressors, vicarious experience with breast cancer and biological family medical history ambiguity, serve to elevate risk perception. Further, the researcher postulated that efforts to cope with perceived susceptibility are motivated by perceived control over disease risk and the expected outcome efficacy of having biological health information. Ultimately, it was assumed that decisions about future screening are made after reappraising the effectiveness of previous coping efforts.

Six hypotheses undergirded the proposed study. 1) Greater ambiguity about biological family history heightens perceived risk and disease-specific worry. 2) Vicarious experience with disease elevates perceived risk through affective processes. 3) A heightened sense of risk influences disease-specific worry directly and indirectly through perceived control. 4) The relationship between perceived risk and mammography adherence is mediated by perceived control. 5) The relationship between risk perception and information-seeking is mediated by the perceived value of having biological family medical history as a risk management tool. 6) Screening intention is directly impacted by coping efforts. As such, greater breast cancer worry, past screening adherence, and information-seeking about biological family medical history serve to motivate future screening efforts.

CHAPTER 3: METHODOLOGY

Research Design

Overview

The study has a mixed-methods design, characterized by the use of both quantitative and qualitative methods in a single study (Creswell, 2003; Morse, 2003). While mixed-methods research has many similarities to traditional research approaches, it involves the additional steps of identifying a theoretical lens that influences methodological choices (e.g., advocacy, feminism) (Crotty, 1998), deciding whether the two types of data have equivalency or whether one type has dominance, specifying how data collection will occur (i.e., sequentially or concurrently), and deciding when and where data integration will occur (Hanson, Creswell, Plano Clark, Petska, & Creswell, 2005).

There are numerous ways to conduct mixed-methods research. A discussion of the major typologies is outside the scope of the present study; therefore, readers are encouraged to read the works of Creswell (2003; 2002), Johnson and Onwuegbuzie (2004), Tashakkori and Teddlie (2003; Teddlie & Tashakkori, 2003), and Morse (2003) to gain a broader perspective. The study utilized a sequential explanatory design, which is described more fully in the first section of this chapter. Consistent with the sequential explanatory design, the study was conducted in two separate and distinct phases. Quantitative data collection occurred during spring 2007, and qualitative data were collected during winter 2008. The first quantitative phase involved testing the fit of the TMSC to explain coping behaviors of adult adoptees contemplating their risk for

breast cancer. The second qualitative phase augmented the quantitative results by explaining unexpected findings.

Data collection included a self-administered online questionnaire and semi-structured interviews, which are the most common data collection strategies in mixed-methods research (Bryman, 2006). Interviews were conducted by telephone and e-mail dialogue via elicited text (Charmaz, 2006). In general, the primary strengths of combining quantitative and qualitative research are that researchers can overcome the weaknesses of one method with the strengths of the other, and that greater insight and fuller understanding is possible to inform theory and practice. Challenges to conducting mixed-method research include its time consuming nature, higher cost, and attention to two forms of methodological rigor, which may be difficult for a lone researcher (Johnson & Onwuegbuzie, 2004), and in particular a novice one.

This chapter is organized as follows. First, an overview of the sequential explanatory mixed-methods design is presented, along with specific rationale for mixing data in the proposed study. Next, details regarding sampling, recruitment, data collection, data handling, and data analysis are discussed for each phase of research in turn. Finally, the chapter concludes with a methodological discussion of data integration.

Sequential Explanatory Mixed-Methods Design

Using standard notation for mixed-methods research originally developed by Morse (1991), Figure 3.1 depicts the sequential explanatory design. Hallmarks of this notation reveal the relative weight placed on quantitative or qualitative data, the sequence of data collection, and approach to data integration (Creswell, 2002). As the model shows, the sequential explanatory mixed-methods design is characterized by two distinct phases of data collection and analysis. The first phase involves collection and analysis of quantitative data, which are given greater

priority in the research effort and written report. The dominance of the first phase is represented by uppercase letters (i.e., QUAN). In the sequential explanatory design, lesser emphasis is given to the subsequent qualitative data collection and analysis phase, represented by lowercase letters (i.e., qual), which serves to help explain quantitative findings in greater depth. The sequential nature of the two phases (represented by an arrow) is inherent to the explanatory approach and is distinct from concurrent data collection (represented by a plus sign), which is more commonly used in a triangulation mixed-methods design (Creswell, 2002). In the present study, the purpose of the qualitative phase is to inform future model refinement based on follow-up examination of unexpected findings. A more detailed discussion regarding the rationale for mixing quantitative and qualitative data in the proposed study is presented next.



Figure 3.1. Depiction of sequential explanatory mixed-methods design.

Rationale for Mixing Quantitative and Qualitative Data

There are multiple reasons for combining quantitative and qualitative approaches to inquiry. Utilizing Bryman's (2006) detailed schema, the following reasons are proffered: 1) to provide a more complete and well-rounded understanding of how adult adoptees cope with genetic uncertainty, 2) to understand the process adoptees use to develop personalized breast cancer risk constructions, 3) to describe extreme cases to better understand the proposed theoretical explanation of stress and coping, 4) to help explain unexpected findings (e.g., lack of fit), 5) to guide sampling decisions from one phase to the next, and 6) to provide rich illustration

of quantitative findings through quotes and descriptive accounts from adult adoptees, a population about whom we know very little.

The following two sections outline details of sampling, informed consent, data collection, data handling, and data analysis for each phase of the research process. The more dominant quantitative phase will be described first, followed by the second qualitative phase which was conducted to augment quantitative findings.

Phase One: Quantitative Data Collection and Analysis

Pilot-testing

Prior to the launch of online data collection, pilot-testing was conducted in five phases to improve instrument performance. First, a hardcopy version of the instrument was distributed to six adult adoptees, who completed the questionnaire and provided feedback via phone or e-mail on the appropriateness and clarity of instructions, item wording, and response options, as well as response burden and overall tone and flow. Pilot participants were identified through the researcher's social network and were all women over 30 years of age who varied in their interest to engage in birthparent searching. Second, four experts also reviewed the draft instrument relative to their respective areas of expertise including two website designers, one internet researcher, and one genetics counselor with experience conducting qualitative research on the perceived value of health information to adult adoptees. From the first two phases of piloting, a few items were revised based on pilot participant feedback. Revisions were made prior to submitting the instrument to the website developers hosting online data collection.

Once the data collection website was ready for beta-testing, the researcher reviewed the instrument's screen presence to monitor adherence to style guidelines given to web developers. A series of itemized revisions were furnished to the web developers who then made subsequent

corrections and stylistic changes. Next, the researcher entered 10 test records with known response patterns to verify website functionality and coding accuracy. A hand-entered dataset was compared against the online dataset downloaded by the web developers and provided to the researcher in SPSS format. These phases represent the third and fourth steps in the piloting process. In particular, the fourth phase proved invaluable in helping the researcher prepare for data analysis in advance of having the final dataset (e.g., recoding, developing syntax). Fifth, and finally, six health education professionals reviewed the data collection website before its official launch to identify any remaining problems, whether typographical or technical in nature, or issues pertaining to different computer platforms and user-settings. Several revisions and adjustments were made following beta-testing. Although minor, these changes likely improved the online experience for respondents.

Sampling

Adult adoptees can be characterized as a hard-to-reach population from several fronts. A clear sampling frame simply does not exist, the basis for which is legally entangled or inaccessible in different state vital records, social service, and reunion database systems. Excluding adoption reunion databases, which may be more current, other data that may exist are devoid of current contact information. Since no federal agency has had consistent authority to capture adoption statistics, national estimates of the number of adoptees that do exist are believed inaccurate (Pertman, 2000). Community-based adoption statistics are also suspect and believed underestimates because of the shroud of family secrecy that permeated adoptions prior to the adoption reform movement since the 1980s that created more open records. Finally, salience of being an adopted person varies widely and is influenced in part by age at adoption, age made aware of the adoption, satisfaction with adoptive family, etc. Therefore, many

otherwise eligible respondents would not necessarily consider 'adoptee' as a central component of their self-identity. Accordingly, these persons would be less likely to be part of any organized group or virtual community. Those who do participate in organized adoptee groups are more likely to be women (Carp, 2004), however.

Web-based data collection is especially well-suited for research among adult adoptees for whom being adopted is a salient aspect of self-identity. This is especially true for women involved in birth parent searching, including those who have participated in state-sponsored voluntary online registry services, and those who are active in virtual adoptee communities and support groups. According to Pertman (2000), the Internet has been vital to the overall adult adoptee advocacy movement. Given this context, non-probability purposeful sampling (Trochim, 2001) was used to select Internet-active female adult adoptees for research participation.

Recruitment

To recruit a variety of adopted women, diverse in ethnicity, adoption salience, and their interest in birth parent searching, a multi-prong strategy was implemented to invite participation and publicize the survey's web address. This strategy is similar to recruitment approaches that have been used by other researchers to locate hard-to-reach subpopulations (Burnett et al., 1999). Specific recruitment efforts are described below.

Recruitment and data collection occurred together during an 8-week period in spring 2007 and involved, for the researcher, reliance on both active and passive processes. During active recruitment, which lasted about five weeks, the researcher identified existing adoptionrelated organizations throughout the United States and e-mailed the designated contact person(s) an invitation for online research participation specifying the research purpose and general eligibility criteria. The invitation also featured a URL-hotlink to the survey website, which was fully operational when recruitment began, along with a request to further distribute the invitation broadly among the group's membership. A sample research invitation is presented in Appendix B.

Passive recruitment relied on snowball sampling, whereby primary contact persons, typically adoption triad members if not potential respondents themselves, forwarded the survey link to others in their personal network. For a three-week period, passive recruitment was the sole modality. As such, the data collection website was active, yet the researcher had stopped sending new requests for participation. From the researcher's perspective, recruitment occurred in the background (i.e., snowballing) as motivated respondents, interested triad members, and adoption professionals helped further expand the sampling frame. Passive recruitment was particularly effective in that 29% of respondents accessed the website during this final leg of recruitment and data collection.

To maximize diffusion, the researcher initially targeted national organizations to help distribute the research invitation. The Adoptees' Liberty Movement Association (ALMA), Bastard Nation, the American Adoption Congress (AAC), and Concerned United Birthparents (CUB), for example, were among the first to receive the research announcement. Next, the researcher conducted additional internet research to identify other national, state, and local organizations that provided registry services, post-adoption support, adult adoptee networking, birthparent search assistance, adult adoptee advocacy, or adoption-related resources and education. Examples of this type of association include Soul of Adoption, the Minnesota Coalition for Adoption Reform, and Adoptees in Search/Colorado Triad Connection. Groups that tailor their efforts around a specific community of adult adoptees were also located to enhance the diversity of the respondent pool. Among others, GLBTIQ & Adopted (serving gay, lesbian, bisexual, transgender, intersex and queer adult adoptees), the Korean American Adoptee Adoptive Family Network (KAAN), and Asian Adult Adoptees of Washington are examples of special interest associations that were invited to participate. In total, the researcher e-mailed the research invitation to 236 different agencies. A work log of recruitment communication listing the name, web address, agency description, mailing address, date of contact, and contact person along with his or her e-mail address facilitated record-keeping and tracking and curtailed inundating primary contacts with duplicate requests.

Throughout data collection, the researcher monitored response progress by state of residence. When encountering states with low participation, the researcher scanned and responded to personal ads placed on a specific registry website, Adoption Registry Connect. This online registry is populated by adoptees or their family members who are searching for birth family information, often for purposes of reunion. The ads each have an identification number and an anonymous e-mail address to which responses are sent. Because these ads typically include gender, date of birth, and triad position, the researcher contacted those candidates most likely to fit eligibility criteria, in total 214 individuals.

Consistent with other internet-based researchers' practice (Mustanski, 2001), no direct incentives were offered to bolster participation. As anticipated, adult adoptees who volunteered to participate in the online study had intrinsic motivation for completing the questionnaire. Moreover, as described more fully elsewhere, a large proportion of online respondents volunteered to participate during the second, qualitative phase of the study.

Sample Size

It is difficult to pinpoint the exact sample size needed when using structural equation modeling, although it is generally considered a "large-sample technique" (Kline, 2005, p. 14). The complexity of the model helps determine how large a sample should be, with simpler models (e.g., path models) requiring smaller samples. According to Kline (2005), 100 is an absolute minimum for all but the simplest models. Up to 200 is the medium level, while over 200 would be considered large. Given that a couple of scales were developed for the proposed study and that no other pre-existing scale has yet been validated with an adult adoptee population, a conservative sample size of 400 was set as a goal. One advantage of using a Web-based questionnaire is that sound design can increase the likelihood of retaining each record for analysis (Strickland et al., 2003). As discussed below, there was robust interest in the study. The sample size goal was surpassed, even after excluding records with missing data.

Online Data Collection

The Survey Research Center (www.src.uga.edu) at The University of Georgia (UGA) hosted online data collection under a work agreement with the researcher. Respondents accessed the data collection website through the advertised URL address provided in the research invitation and advanced through the questionnaire by answering 74 questions through radio-style buttons, pull-down menus, and short text boxes. Respondents also had the option of printing and mailing in the entire questionnaire; however, no completed surveys were received using this mechanism.

According to the data collection website's automated timestamp feature, the survey took about 15 minutes to complete on average, excluding anomalies. While taking the survey, a progress bar served to motivate respondents by estimating the proportion of completed and remaining questions. Screen shots depicting the actual data collection experience are presented in Appendix C. Depending on the answers to certain questions, eligible respondents viewed a maximum of 12 screens in total, each of which is described below.

The first screen served as a welcome page for potential respondents by explaining the purpose of the study, introducing the researcher as a doctoral candidate and adult adoptee, and legitimizing the research effort by inclusion of the researcher's university affiliation, logo, and contact information. After reviewing the welcome screen, potential respondents advanced to the next screen by clicking a "continue" button.

The second screen presented eligibility criteria to potential respondents who were asked to read and attest to the veracity of each of five statements. Eligible respondents included women over 40 years of age who were adopted as children by unrelated persons (i.e., excluding persons adopted by another biological family member or step-parent). Further, eligibility was restricted to women who have never been diagnosed with breast cancer. After designating their eligibility status, ineligible respondents were forwarded to a screen designed especially for them. A "thank you" screen not only acknowledged their willingness to participate, but also created interest in the final screen which, among other things, invited ineligible respondents to contact the researcher by e-mail to volunteer for future studies and forward the survey link to other adoptees in their social network who may be eligible and interested in participating. Eligible respondents advanced to the next screen, designed to foster and elicit informed consent.

Before reading additional details about their participation, respondents were encouraged to print and retain the informed consent page, which was visible on the screen and formatted as a downloadable .PDF file. In reading about the survey, respondents gained familiarity with the research title and purpose, eligibility criteria, anticipated risks and benefits, and estimated time

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for completion (15 minutes). In addition, the informed consent screen emphasized the voluntary and confidential nature of participation. Finally, a statement of institutional review board (IRB) approval and inclusion of contact information assured respondents of the legitimacy of the research effort and accessibility of the researcher. In order to view survey questions, respondents clicked on an "I agree" button to indicate their consent to participate in the research study under the conditions outlined.

The body of the survey was divided into six sections, one screen each, to enhance flow for online participants. The first set of questions asked about specific interactions at the doctor's office. Similar to what happens during a doctor's office visit, the second set of questions asked respondents about the extent of their familiarity with biological family medical history and about the value respondents place on biological family history in a medical context. The third section inquired about respondents' interest and involvement in searching for information about birthparents, which may involve requests for adoption records through steps toward reunion. The fourth section focused on personal and familial medical history, both adoptive and biological, as well as frequency of routine breast cancer screening. Following this, respondents were asked in the fifth section to describe their beliefs and concerns about breast cancer risk. The final section, aimed at describing participants, consisted primarily of questions pertaining to demographics.

To plan for the qualitative phase of data collection and to wind down the survey, respondents were asked about their interest in continued participation through telephone interview. Those who expressed interest were then asked to provide their contact information before concluding the survey. Those who were not interested in being considered for further participation were forwarded immediately to the final screen, described next.

Unless respondents aborted the survey midway, everyone arrived at the same multipurposed, printable screen to conclude their online research participation. First and foremost, the final screen was designed to convey appreciation for survey participation. Next, respondents received the toll-free phone number for the American Cancer Society's Information Resource Center and a hotlink to the breast cancer section of their consumer-oriented website should they desire additional information about disease risk factors, prevention, and early detection. Given a priori reliance on snowball sampling for recruitment purposes, respondents were next prompted to share the survey link with other adoptees in their social network. The researcher's contact information was supplied again in case respondents had questions, concerns, or technical difficulties, wanted to submit additional comments, volunteer for future research, or request an executive summary of research findings. Finally, after clicking on the "exit survey" button, respondents were led to the homepage of UGA's Survey Research Center to signify successful transmission of their survey responses. Respondents also received a reminder about closing their browser when complete to protect against unwanted viewing of their responses by a shared user of their computer.

Online Questionnaire Response

Over an 8-week period, the data collection website was accessed 890 times. Assuming individuals accessed the site only once, which was specifically requested in recruitment announcements, 209 persons simply browsed, answering none of the survey questions. Half of the browsers (102) indicated that they were eligible to take the survey, while the other half (107) did not respond to inclusion criteria presented on the eligibility screen. One hundred three persons expressed interest in participating but did not meet each of the five eligibility criteria. One hundred twenty-four individuals partially completed the survey, 25 of whom did not

indicate their eligibility to participate and 99 of whom were otherwise eligible respondents. For reasons explained in Chapter 4, these 124 records with missing data were excluded from the final dataset. Four hundred fifty-four individuals who indicated that they met eligibility criteria fully participated in the online survey by answering each question that served as a construct item. Further screening on personal breast cancer history, which was verified a second time inside the survey, resulted in discarding two records. Therefore, the final dataset contained 452 complete records. Figure 3.2 depicts how the final dataset (N = 452) was derived.



Figure 3.2. Derivation of final data set for quantitative analysis.

Description of the Sample

Table 3.1 summarizes data on geographic residence, age, education, race/ethnicity, marital status, and the decision to parent. All data but those of race/ethnicity were captured as closed-ended responses. Open-ended data for race/ethnicity were examined at the individual record level and then coded to allow for aggregation.

Adult adoptees from every U.S. state and the District of Columbia were invited to participate using the online recruitment strategies previously described. Consistent with this approach, respondents resided all over the United States, although slightly more than half (56.2%) lived in one of nine states including TX, NY, CA, PA, FL, WA, GA, NJ, and MI. Recruitment strategies failed in only four states (SD, ND, NH, and MT) by virtue of having zero resident-participants. Overall, approximately 37% lived in the southern U.S., and 18% resided in the Midwest. Northeastern residents comprised 23% of respondents, while westerners accounted for 22%. Regions follow state configurations as defined by the U.S. Census Bureau *(www.census.gov/geo/www/us_regdiv.pdf)*.

The majority of respondents (60.6%) were between 40 and 49 years of age. Thirty percent (29.8%) were between 50 and 59 years old. Less than 10% of respondents were 60 or older, and those over 70 comprised the smallest subgroup (1.3%). Given this distribution, the mean age was 49.0 (sd = 7.3). As a whole, respondents were well educated. The majority (54.3%) earned at least a college degree, half of whom graduated with an advanced graduate degree. Slightly over a third had some college or technical school, and about 12% completed or almost completed high school.

Race and Hispanic origin were categorized according to definitions in use during the 2000 U.S. Census (*www.census.gov/prod/2001pubs/c2kbr01-1.pdf*). Overwhelmingly,

respondents described themselves as non-Hispanic (96.4%). Hispanic origin was indicated by 1.8% of respondents, while an equal share was of "unknown" ethnicity. As anticipated given available statistics on adoption, the vast majority (87.8%) of respondents self-described as being White. A small number of respondents reported their race as Black or African American (1.1%), Asian (2.3%), American Indian or Alaskan Native (1.1%), Native Hawaiian or Other Pacific Islander (0.2%), or some other race (1.1%), while 4.7% categorized themselves as being of two or more different races. A small number of respondents (1.6%), in various ways, voiced that their race is unknown to them as an adoptee.

Almost three-fourths (74.1%) of respondents were married or in a committed partnership. Around 15% was divorced or separated, and only 1% was widowed, which is reflective, perhaps, of the age distribution favoring younger middle adulthood. Less than 10% of respondents (9.3%) described themselves as single. The vast majority (81.6%) of survey participants were parents. About 73% had biological children, while an almost equal share had either adoptive children exclusively (4.5%) or a combination of adoptive and biological children (4.1%). A substantial proportion of respondents (18.5%), either through circumstance or choice, had no children.

Measures

The online questionnaire that was used to measure the following constructs is presented in Appendix C. Each respondent completed the same version of the instrument. A matrix summarizing how the items correspond to the various constructs is presented in Table 3.2.
Demographic Characteristic	n	%
US Region $(n = 441)$		
Northeast	100	22.7
Midwest	79	17.9
South	165	37.4
West	97	22.0
Age $(n = 447)$		
40-49	271	60.6
50-59	133	29.8
60-69	37	8.3
70-79	6	1.3
Hispanic Origin ($n = 441$)		
Hispanic or Latino	8	1.8
Not Hispanic or Latino	425	96.4
Ethnicity "unknown"	8	1.8
Race $(n = 443)$		
One race		
White	389	87.8
Black or African American	5	1.1
American Indian/Alaska Native	5	1.1
Asian	10	2.3
Native Hawaiian/Other Pacific	1	0.2
Some other race	5	11
Two or more races	21	47
Race "unknown"	-1 7	1.6
Education $(n = 446)$,	1.0
High school or less	53	11.8
Some college or technical school	151	33.9
College graduate	118	26.5
Some graduate school	28	63
Graduate or other advanced degree	<u>-</u> ° 96	21.5
Marital Status $(n = 443)$	20	21.0
Single	41	93
Married	291	65.7
Partnered in committed relationship	37	84
Divorced or separated	67	15.1
Widowed	7	16
Parenthood $(n = 443)$,	1.0
No children	82	18.5
Adoptive child(ren)	20	4.5
Biological child(ren)	323	72.9
Both adoptive & biological children	18	4.1

Table 3.1: Demographic Characteristics of Respondents

Ambiguity about biological family medical history

Four items were combined into one scale measuring ambiguity about biological family medical history. The items were developed specifically for the proposed study, although three of the four items were tested previously by the author in an unpublished pilot study about family history awareness among undergraduates biologically related to their parents. Using a 5-point Likert scale, adult adoptees assessed their relative agreement or disagreement with statements about having access to biological family history information, having written documentation about biological family history, being given information through oral history, and being familiar with biological family medical history. The scale ranged, therefore, between 4 and 20. Items were coded such that higher scores indicated greater ambiguity.

Vicarious experience with breast cancer

Respondents were asked about their own personal cancer history to examine the effectiveness of having stated inclusion criteria as a condition of participation. Adult adoptees who elected to participate in the study should have never received a personal breast cancer diagnosis. Following questions about personal cancer history, adult adoptees were asked whether anyone in their adoptive family or biological family (if known) had ever been diagnosed with breast cancer, or any close friend or acquaintance. Vicarious experience with breast cancer was measured by summing scores on three dichotomous (e.g., yes/no) items (range 0-3). Given the likelihood of adoptees' not having biological family medical history information, *don't know* was included as a response option. *No* or *don't know* responses were combined for analytic purposes. Research indicates that self-reported family medical history among first-degree relatives is reasonably accurate compared to medical records (e.g., r = .85), particularly for breast

cancer (Finney Ruttan & Iannotti, 2003; Murff et al., 2004), although no such research is known to exist among adoptive families.

Perceived risk

Perceived susceptibility to breast cancer, or the belief regarding one's chances of developing breast cancer, was measured using a 5-item, 5-point Likert scale. Items included Champion's (1999) 3-item breast cancer susceptibility scale (alpha = .87) plus two additional items of particular relevance when studying adult adoptees. Using Champion's scale, adult adoptees were asked the likelihood of developing breast cancer in general, during the next few years, and within their lifetime. To capture comparative optimism directly (Klein & Helweg-Larsen, 2002), adoptees were asked to assess their breast cancer risk relative to average women their same age and race. Given the topical focus on genetic inheritance, adoptees were asked their perceived likelihood of inheriting a breast cancer gene (i.e., BRCA1 or BRCA2) (Hailey, Carter, & Burnett, 2000). A total score for perceived risk (range = 5-25) was calculated by summing the score for each item.

Breast cancer worry

A four-item adaptation of Lerman's (1991a) widely used cancer worry scale was utilized to measure the extent to which concern about breast cancer impairs daily functioning. Respondents were asked to respond to a 4-point scale about frequency of worrying about developing breast cancer, how frequently this worry impacts mood and the ability to function normally, and the level of anxiety regarding future mammogram results. Wording of the present scale and its scale points follows that used by Davis and colleagues (2004) with the addition of Lerman's original item assessing current concern about future mammogram results. The number of scale points of one of Lerman's original items was reduced from 5 to 4, which mirrors the approach taken by other researchers (Burnett et al., 1999; Hopwood et al., 2001; Davis et al., 2004; McGregor et al., 2004). Responses to each item were summed to form a total scale score, ranging from 4-16. Prior research using similar scales slightly modified from the original demonstrate acceptable reliability, with alphas ranging from .73-.86 (Burnett et al., 1999; Davis et al., 2004; Hay et al., 2005; Hopwood et al., 2001; McGregor et al., 2004).

Perceived control

Perceived control over disease risk was assessed by the sum of two items presented along a 4-point Likert scale. For most women and, again, for themselves, adult adoptees were asked to describe their beliefs regarding the likelihood of being able to reduce one's risk for developing breast cancer (1 = not at all possible to 4 = very possible). The scale range for perceived controllability, therefore, is 2-8. Item wording is consistent with that used by other researchers (Fletcher et al., 2006; Lemon et al., 2004).

Perceived value of health information

A 12-item, 5-point Likert scale was developed for the proposed study based on findings from Tam's (2004) qualitative interviews with adult adoptees regarding whether and how they value having biological family medical history information (range = 12-60). The items support understanding of the practical use of information gleaned from taking biological family medical histories in primary care settings as well as the role biological family history plays in shaping personal health behavior. For example, physicians routinely take a family history, ideally a three-generation pedigree, to help assess a patient's disease risk, recommend screening based on its predictive value, and prescribe treatment (Rich et al., 2004). Individuals also use information

about biological family history to make decisions about lifestyle behavior (e.g., diet, exercise) (Lemon et al., 2004). Sample items included the extent of agreement that having biological family medical history would *"help me develop good health habits, help me take a more active role in my healthcare, and provide information about me that's important to share with others."*

Information-seeking about biological family medical history

A scale measuring degree of engagement in seeking information about biological family medical history was developed for the proposed study. Items were crafted from review of the literature describing various ways in which adult adoptees may go about searching for information (CWIG, 2006; Fischer, 2002; Pertman, 2000; Tam, 2004), which may be determined by desired degree of involvement with birth parents as well as state laws governing search procedures. Given that some adoptees unintentionally discover information surrounding their birth circumstance, only deliberate information-seeking behavior and cognition were included among the scale items. The total scale score (range 0-12) was derived by summing a series of dichotomous items (yes = 1).

Mammography adherence

Compliance with annual mammography screening guidelines was measured with a single item, which is a consistent practice among researchers (Andersen et al., 2003; Burnett et al., 1999; Schwartz et al., 1999; Schwartz et al., 2003), given acceptable reliability of self-reported mammography behavior (King, Rimer, Trock, Balshem, & Engstrom, 1990). Adult adoptees were asked "*when did you have your last mammogram?*" Item wording and scale points (1 = never to 5 = within past year) closely matched those used by Burnett and colleagues (1999). A higher score indicated a history of being adherent to recommended screening guidelines.

Screening intention

Future screening intention was measured using a 3-item scale (alpha = .88), adapted from research by Godin and colleagues (2001). Adult adoptees assessed their relative agreement or disagreement (5-point Likert scale) with two statements pertaining to their future intentions to seek annual mammography screening. A third item asked respondents about the chances (ranging from 1 = very low to 5 = very high) of their having an annual mammogram. Scale items were summed to produce a total scale score ranging from 3 to 15.

Sociodemographic variables

Several sociodemographic variables were collected for descriptive purposes including age, race/ethnicity, education, marital status, and geographic area of residence. Several other independent variables important to the adoptive context were assessed including physician awareness of patient's having been adopted and method of completing family history forms during visits to the doctor. Items pertaining to patient-physician interaction were not analyzed as part of the present study.

Construct/ Variable	Description	Psychometric Properties of Original/Modified Scale	Scale in Present Study	Questionnaire Location	Scoring in Present Study
Biological family medical history ambiguity	Familiarity with biological family medical history information	Investigator developed & piloted similar 4-item scale for the present study (N=131 persons with biological parents); Alpha = .62	4 items	Q8-11	1-5 Likert scale (strongly disagree to strongly agree) with total scores ranging from 4-20. Reverse coded such that higher scores indicate greater ambiguity.
Vicarious breast cancer experience	Having breast cancer diagnoses among friends/co-workers, adoptive family members, and/or biological family members	Scale adapted from Finney Ruttan & Iannotti, 2003 r = .85 for biologically- related persons, comparing recall of family history of breast cancer to medical record review	3 items	Q39, 40, 42	Total scale sums dichotomous items (yes = 1, no or don't know = 0). Total scale range is 0-3. Higher values indicate greater vicarious experience.
Perceived risk	One's belief regarding the chance of getting breast cancer	3 items (Q59, Q61, Q62) are from Champion (1999). Alpha=.87; Q60 (Klein & Helweg- Larsen, 2002); Q63 (Hailey et al., 2000)	5 items	Q59-63	1-5 Likert scale (strongly disagree to strongly agree) with scores ranging from 5- 25. Higher scores indicate greater perceived risk.
Breast cancer worry	Cancer-specific psychological distress	Lerman et al., 1991a Adaptations: Burnett et al., 1999; Davis et al., 2004; Hopwood et al., 2001; McGregor et al., 2004. Alpha = .7386	4 items	Q55-58	1-4 Likert scale (none to a lot) ranging from 4-16. Higher values indicate greater levels of worry.

 Table 3.2: Psychometric Properties of Scales and Scoring Procedures

Construct/ Variable	Description	Psychometric Properties of Original/Modified Scale	Scale in Present Study	Questionnaire Location	Scoring in Present Study
Perceived control	Perceived ability to control risk for developing breast cancer	2 items, r=.67 (Lemon et al., 2004)	2 items	Q53, Q54	1-4 Likert scale (not at all possible to very possible) with total scale scores ranging 2-8. Higher values indicate higher levels of perceived control.
Perceived value of biological family medical history information	Perceived benefit of having information about biological family medical history	12-items, investigator developed & piloted for the present study based on Tam (2004) (N=131 persons with biological parents); Alpha = .90	12 items	Q12-23	1-5 Likert scale (strongly disagree to strongly agree) with total scores ranging from 12-60. Higher values indicate greater perceived value.
Information- seeking about biological family medical history	Degree of an adopted person's involvement in seeking information about his/her biological family medical history	Investigator developed	12 items	Q25-36	Total scale sums dichotomous items (yes = 1; no = 0). Total scale ranges from 0-12. Higher values indicate greater information-seeking involvement.
Mammography screening adherence	Adherence to age- specific early detection guidelines for mammography	Burnett et al., 1999; Self- reported mammography behavior is deemed reliable (King et al., 1990).	1 item	Q46	Single-item 1-5 Likert scale (never to within past year). Higher score indicates greater compliance.
Screening intention	Future plans for obtaining an annual screening mammogram	Adapted from Godin et al., 2001; Alpha=.88	3 items	Q48-50	1-5 Likert scale (very low to very high; strongly disagree to strongly agree) with total scores ranging from 3-15. Higher scores indicate greater screening intention.

 Table 3.2: Psychometric Properties of Scales and Scoring Procedures (continued)

SEM Data Analysis Procedures

Data analysis utilizing structural equation modeling (SEM) is somewhat iterative, yet proceeds through six fundamental steps. As Kline (2005) described, analysis and interpretation through SEM requires 1) model specification, 2) model identification, 3) data collection, preparation, and screening, 4) model estimation, 5) fit assessment, and 6) model respecification. These steps will be discussed in turn.

Model specification involves graphical depiction of hypothesized relationships. Standard symbols are used to reflect various conceptual elements (e.g., circles for latent constructs; squares for observed variables). Careful review of the literature is a pre-requisite to sound model specification, which is best undergirded by theory, or, alternatively, explicit logic. Attention to theory ensures important constructs are not omitted, bolsters resulting evidence about hypothesized relationships in the model, and lends greater credibility to its interpretation. The proposed model for the current study, presented in Chapter 2, follows conventional practice for depicting proposed structural relationships. A full structural model was utilized in the current project.

Model identification refers to the theoretical likelihood of deriving a unique solution for each parameter estimate in the proposed model (Keith, 1999; Kline, 2005). An identified model has at least as many known pieces of information (i.e., covariances) as unknown (e.g., parameter estimates). In general, an overidentified model is preferable even though multiple solutions are possible. As Keith (1999) asserted, having multiple solutions allows examination of various parameter estimates which can then help identify problems with model specification. When planning SEM, data collection occurs only after the researcher ascertains that the proposed model will result in an identifiable solution. Absent this, the researcher may not collect sufficient information to run the desired analyses. For the current study, the proposed structural model was determined to be overidentified.

After data are in hand, the researcher must then begin a deliberate data screening and preparation process prior to model testing through SEM analyses. This screening process involves, first of all, deleting cases with missing data in listwise fashion, as SEM analyses must be conducted with the same intact group of respondents, which pairwise deletion does not allow (Kline, 2005). Missing data were not imputed in the present study for reasons explained more fully elsewhere.

Second, continuous data must be screened for the presence of outliers as well as univariate and multivariate normality. Univariate normality, which can be affected by outliers, is easily determined by examining a variable's descriptive statistics including skewness and kurtosis, both of which should be no greater than the absolute value of two. Univariate normality does not necessarily indicate multivariate normality, however. Therefore, multivariate screening was also required. To screen for outliers and multivariate normality simultaneously, researchers may choose to use a macro developed by DeCarlo (1997) that automatically generates statistics for the leading outlier candidates based on multivariate Mahalanobi's distances. This macro is especially useful for large datasets, as the number of outliers generated can be set *a priori*. Based on the results of these screening procedures, as well as the nature of the problem being investigated, researchers decide for themselves whether to retain or remove outlying cases. Variable transformations are also possible to satisfy the multivariate normality assumption of SEM (Kline, 2005).

Finally, the third data screening step involves checking for multicollinearity. This is accomplished by examination of bivariate correlations, which should be no greater than .90

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(Kline, 2005). Multicollinearity is problematic in SEM because, if severe, non-sensical mathematical operations can occur (Kline, 2005). Problems stemming from multicollinearity can be handled by combining like constructs or dropping a redundant construct (Kline, 2005).

Model estimation is the process by which parameter values are estimated. Utilizing a fit function and the least squares criterion, estimates are iteratively calculated by providing the smallest difference between the reproduced covariance matrix offered by the proposed model and the actual or observed sample covariance matrix. Different weighting procedures (e.g., maximum likelihood, asymptotic distribution free) enable this process and were chosen based on data characteristics such as normality and sample size.

The next step in SEM is measuring how well the proposed model fits the actual data by explaining the observed covariance. Rarely, if ever, do models fit perfectly. Rather, fit is ascertained *by degree* with evidence mounting from a variety of sources, including fit indices. Currently, dozens of fit indices exist, the relative strengths of which remain an active and expanding area of research (Kline, 2005). Kline (2005) recommended building the fit case by assessing the following indices: model chi-square, RMSEA, CFI, and SRMR. In addition, evidence regarding fit is accumulated through examination of path coefficients (i.e., significance, magnitude, and direction), standardized residuals, R-square values, and improper solutions. The current study adhered to current practice recommendations regarding fit indices, following Hu and Bentler's (1998; 1999) cut-off criteria presented in Table 3.3 below.

Fit Index	Cut-Off
Chi-square	Non-significance is desired.
RMSEA	.06 (maximum)
NNFI	.95 (minimum)
CFI	.95 (minimum)
RFI	.95 (minimum)
SRMR	.08 (maximum)

Table 3.3: Hu & Bentler's (1998) Cutoff Criteria for Various Fit Indices

The final step in SEM is model modification, also termed respecification. If the model is deemed ill-fitting by its failure to produce a theoretically-sound and parsimonious explanation of the data, the model may require adjustment or respecification. This process can be guided by modification indices provided by statistical software. Likely causes of misfitting models are omission of necessary paths and inclusion of unnecessary ones (Kline, 2005). Modification decisions, however, should ideally be made on theoretical grounds, not statistical ones.

In practice, model identification, model estimation, model testing, model fit evaluation, and model respecification occur iteratively. Evaluation of the full structural model and its related hypotheses, presented in Chapter 2, followed a two-step modeling process that takes the measurement and structural aspects of the model into account separately. The rationale for the two-step process is that it allows the researcher to identify and possibly repair sources of specification error in the model prior to assessing hypothesized structural relationships. Having a valid measurement model is essential in that it provides protection against drawing incorrect conclusions about hypothesized relationships (Kline, 2005).

Phase Two: Qualitative Data Collection and Analysis

Theoretical Framework

Having an interpretive theoretical perspective, the researcher's epistemological stance is constructionism, which claims that individuals construct meaning as they engage in and interpret the physical and social world around them (Crotty, 1998). As such, the researcher believes that individuals construct personal interpretations of disease risk based on a variety of influences, which includes, as discussed in Chapter 2, knowledge about disease etiology, but also vicarious experience, emotional states, and heuristic reasoning. While actual risk may be "objectively" quantifiable by medical science, perceived or "subjective" risk becomes individuals' realities on which health decisions are made. For adoptees without their biological family medical history, this seems particularly true given the absence of genetic risk information.

This study is further rooted in constructivist grounded theory (Charmaz, 2000) as a methodology. The business of grounded theory is theory generation, not testing, based on systematic analytical methods that are described elsewhere. As grounded theory evolved, the methodology also allows elaboration and modification of existing theoretical explanation based on how newly acquired data fit earlier conceptualizations (Strauss & Corbin, 1994). Consistent with the tenets of constructivism, the existence of "multiple realities" are acknowledged, and it is assumed that the researcher's interpretation of the data will be shaped by his or her own analytic interests, subjectivities (see Appendix D), socio-historical-cultural context, etc. (Charmaz, 2000; Patton, 2002). Grounded theory research is designed to explore relationships among concepts, without suggestion of causality or intention to generalize. The resulting theory, or refinement, is regarded as a "working theory," grounded in the data, yet somewhat ephemeral given its vulnerability to change based on incorporation of newly acquired evidence. Constructivist

grounded theory, in particular, is regarded as representing "*a* reality, rather than *the* reality—that is, objective, true, and external" (Charmaz, 2000, p. 523).

This theoretical approach to the qualitative phase of research is not inconsistent with structural equation modeling, contrary perhaps to typical assumptions about a method also called 'causal modeling' (Kline, 2005). Model fit as demonstrated by structural equation modeling represents *one* explanation of observed covariance, while competing models potentially produce an equivalent fit. Absent an experimental design, actual covariance, and longitudinal measures, researchers using structural equation modeling cannot claim to offer causal explanations (Bullock, Harlow, & Mulaik, 1994).

The scope of the present study allowed the researcher to take the first steps toward generating grounded theory. While the study utilized a constructivist grounded theory approach to analysis, the results offered herein are considered an initial interpretive rendering.

Sampling and Recruitment

Respondents who completed the online questionnaire had the option of volunteering for participation during the second, qualitative phase of the study. In doing so, participants shared their contact information with the researcher. The majority of respondents, 71.2%, expressed their willingness to participate in a more in-depth interview if needed.

Based on quantitative findings, the researcher decided to explore further the relationship between biological family medical history ambiguity and perceived risk. To understand how healthy adult adoptees with a similar lack of information about biological family medical history construct personal estimations of their disease risk, the researcher employed theoretical sampling (Auberbach & Silverstein, 2003; Patton, 2002) to select potential participants. In particular, extreme cases were selected for potential information richness in their ability to illuminate various manifestations of theoretical constructs.

Using quantitative results on the verbal risk perception scale, 24 respondents were selected for potential participation in the qualitative phase to represent the distal ends of the risk perception continuum (i.e., the lowest and highest 10%). All 24 also indicated having a high degree of ambiguity in regard to their biological family medical history, which was the other selection criterion. E-mail invitations were sent to 21 adult adoptees along with an attached informational letter written to explain aspects of research participation and elicit informed consent. Recruitment continued until 12 respondents, half with low perceived risk and half with high perceived risk, agreed to participate and either completed a telephone interview or engaged in e-mail dialogue with the researcher.

The overall response rate, 57%, was consistent among risk perception groups and data collection method. Among ten adult adoptees with high perceived risk who were sent research invitations, six participated, half by e-mail and half by phone. Each data collection method, therefore, garnered a 60% response rate. Among those with low perceived risk, eleven were invited to participate, seven by phone and four by e-mail. Six participated, four by phone and two by e-mail, yielding 57% and 50% response rates, respectively. The quality of the data collected, however, varied considerably as will be described more fully below.

Qualitative Data Collection

As previously mentioned, the University of Georgia's Institutional Review Board approved plans for conducting both phases of the proposed research prior to data collection. During the qualitative phase, individuals' identities were protected through the use of pseudonyms, regardless of whether respondents were willing to share their actual names. The principal investigator kept participants' actual names separate from transcripts which were electronically saved by pseudonym as the filename.

After receiving the adult adoptee's e-mailed response expressing willingness to participate, the researcher either scheduled an appointment for a telephone interview or forwarded questions to which respondents provided written answers. Logistical considerations (e.g., mutual availability for an interview), respondent preference, and the richness of openended responses provided during the online phase guided the decision about which interview modality to use for data collection. A semi-structured interview guide (Punch, 1998) was used for telephone interviews, which allowed the researcher to achieve a certain degree of standardization across interviews while allowing flexibility to vary the exact wording and order of the questions and freedom to expand content in response to contextual cues provided by the participant. Interview guides are particularly well-suited for establishing a free-flowing conversation while maintaining a pre-determined focus, both of which contribute to maximizing data quality with limited interview time (Patton, 2002). A sample interview guide is included in Appendix E.

The researcher began each interview by reiterating key elements of informed consent including the purpose of the study, confidentiality procedures, expected time commitment (30-60 minutes), and assurance about respondents' rights to discontinue participation. Using a set of core questions, albeit with slight variations, the researcher asked respondents to describe: 1) their interest in searching for information about birthparents; 2) the primary motivation for searching (or not searching); 3) perceived health-related similarities and differences between themselves and adoptive/biological family members; 4) how ambiguity about biological family medical history impacts their self-care; 5) their reaction to breast cancer risk statistics for persons

with a biological family history of the disease; 6) their personal risk and protective factors for breast cancer; 7) physical and mental health conditions of greatest concern to them; and 8) how being an adoptee shapes personal health practices and an overall sense of health and well-being. Small revisions were made to the interview guide, mostly in terms of probes, following initial cursory analysis of the first two transcripts. Overall, the interview guide was developed to elicit better understanding about how adult adoptees develop personalized risk estimates for breast cancer and how the process might vary according to perceived level of risk.

Telephone interviews were digitally audio-recorded with the respondent's permission and transcribed verbatim by the researcher. Transcription occurred as soon as possible following the interview to maximize the researcher's retention of data. During transcription, the researcher made at least three attempts at capturing inaudible passages by varying the speed and volume of playback. Telephone interviews lasted 60 minutes on average (range 30-90 min.), and written transcripts averaged 18.5 pages per interview.

E-mail dialogue proceeded similarly in the utilization of the core set of questions. The quality of the data, however, was much poorer (i.e., less rich with fewer contextual examples). With e-mail dialogue, elicited text transcriptions (i.e., written responses pasted together with questions in sequence) averaged only 5 pages. In four instances, the researcher sent follow-up questions to participants to clarify answers and/or gain additional context. Unfortunately, only one of four persons provided a second set of responses, despite receiving one or two e-mail reminders.

Transcripts from telephone interviews and e-mail dialogue, 154 pages in all, were loaded into Atlas.ti (version 5.2.19) (Muhr, 2004), a type of qualitative data analysis (QDA) software. Analytic steps will be described in the following section. Beforehand, however, it is important to dispel a common misconception about QDA software (Auerbach & Silverstein, 2003). While QDA packages can assist the researcher with data storage, coding, retrieval, and linking, only the researcher can perform the analytic interpretation of the data. Software is a mere tool that assists with the mechanical aspects of the process. Atlas.ti, in particular, was designed "not to automatize the process of text analysis, but rather to…effectively [support] the human interpreter, especially in the handling of complex informational structures" (Muhr, 1991, p. 350).

Qualitative Data Analysis

Overview

The present study utilized analytic techniques consistent with a constructivist grounded theory approach (Charmaz, 2006). *Grounded theory*, as the term implies, requires that working theories emerge from the data, which serve to ground the conceptual rendering. Originally described by Glaser and Strauss (1967) and later advanced by Strauss and Corbin (1990; 1994), grounded theory "moves qualitative inquiry from descriptive studies into the realm of explanatory theoretical frameworks" (Charmaz, 2006, p. 6) by virtue of its explicit, systematic analytic procedures. In the sequential explanatory mixed-methods design of the present study, the goal was potential theory refinement or elaboration (Strauss & Corbin, 1994; Vaughan, 1992) rather than nascent theory generation.

As a departure from Glaser and Strauss' positivistic assumptions about the researcher as a neutral objective observer, Charmaz (2006) asserted grounded theories are not discovered but constructed. As such, grounded theory represents not a singular reality but one analytic interpretation informed by the researcher's own perspective, past and current experiences, relationship with participants, and research practices. To create transparency in the present

study, the researcher's subjectivity statement is presented in Appendix D, and specific, detailed analytic procedures are described in the following section.

By way of overview, grounded theory involves a primarily inductive analytic technique that contains complementary deductive processes. Termed the constant comparative method (Glaser & Strauss, 1967; Strauss & Corbin, 1994), analysis proceeds iteratively, yet systematically, through a process whereby emergent themes identified inductively are then verified deductively by confirming or disconfirming them through subsequent data comparisons, which, then, spawn other inductive cycles (Huberman & Miles, 1994). Analysis, therefore, is both "intellectual and mechanical" (Patton, 2002, p. 462) as the researcher engages with the text by: assigning codes to reflect meaning in the raw data; finding patterns through the identification and grouping of recurrent ideas; labeling categories or themes; evaluating themes or categories for their ability to work together (internal homogeneity) and distinguish themselves from each other (external homogeneity); and developing an integrated classification system that describes how categories relate to each other, thereby offering an analytic interpretation of the data's core meaning (Patton, 2002). According to Charmaz (2006), comparison forms the basis of analytic development as higher levels of abstraction are attained by comparing data to data, data to categories, categories to categories, and categories to higher order concepts. Movement between levels of abstraction is facilitated by memo-writing, a hallmark feature of grounded theory technique, which is a useful strategy for prompting early analysis of data and the coding schema used for accounting and categorization (Charmaz, 2006).

Analytic Procedures

Far from lockstep, analysis in grounded theory is flexible, but follows the general progression described above. Constructivist grounded theory (Charmaz, 2006) espouses the

utilization of the principles and practices of grounded theory as guidelines, not prescriptive rules to which researchers must adhere. In keeping with that approach, the specific analytic process employed in the present study was informed by the work of several—Strauss and Corbin (1990) for the overall strategy, Charmaz (2006) for coding specificity, Huberman and Miles (1994) for the use of data displays to move analysis forward, and Auerbach and Silverstein (2003) for the mechanical aspects of data reduction and abstraction that culminate in a theoretical narrative. While the analytic procedure was actually iterative in nature, it will be presented here in four steps, each of which will be discussed in turn.

Pre-analysis

Initial, cursory analysis began with transcription. The act of transcribing allowed the researcher to remain close to the data and begin to generate insights and questions to ask of the data (Patton, 2002). As ideas occurred, notes about questions or potential codes were placed in the margin of the transcript. These notes later created fodder for analytic memos.

For interviews completed by telephone, field notes were added to the end of transcripts as a way of capturing initial thoughts about the interviewee and the interview itself. In the field notes, the researcher documented anything unusual about the interview (e.g., interruptions) and made methodological (e.g., rapport), analytical (e.g., possible cross-cutting themes), and personal (e.g., subjectivities) reflections. The field notes were also used to create a portrait of the interviewee, sometimes through metaphor, and to record ethical dilemmas encountered, or areas requiring further follow-up. A similar process of recording case reflections was used with e-mail dialogue, although at a later step. As Patton (2002) advised, field notes proved to be an invaluable source of information during cross-case analysis. Before discussion of formal analytic steps, it is important to set the stage. With a grounded theory approach, data are not forced into fitting pre-existing categories. Rather, data patterns emerge through inductive processes. That explained, it is important to note that analysis is, however, informed by sensitizing concepts. As Patton (2002) explained, qualitative inquiry requires open-mindedness; however, "some way of organizing the complexity of experience is virtually a prerequisite for perception itself" (p. 279). In the qualitative phase of the study, the resulting analytic interpretation was undoubtedly shaped by the quantitative findings, the theoretical sampling strategy that emphasized comparison, and the specific questions and probes developed to explore research concerns. In particular, data patterns involving ambiguity of biological family medical history, familial affinity, cognitive heuristics, and risk attribution were anticipated.

Initial coding

For each transcript, initial coding began by assigning meaning to data fragments through open codes. 'Open' references the researcher's being open to possibilities existing in the data. Close examination of data in small chunks encourages the researcher to see the data mindfully in its present form, less tainted by preconceived notions. With this first pass, 106 different codes were used to describe action in the data. Relevant text was highlighted, then "tagged" with a descriptive handle or code. Software allows the researcher to sort and export data by codes or code combinations, functions that can also be performed manually, albeit more laboriously.

After open-coding, the researcher wrote within case memos about each interview or elicited text (i.e., e-mail dialogue), incorporating ideas from field notes and the initial coding experience. The purpose of memo-writing at this stage was to interact with the data, summarize action, and generate questions. This activity stimulated thought before advancing to more theoretical coding of the data, which Charmaz (2006) calls focused-coding. Memo-writing also served as the "parking lot" for ideas about future research, which, once documented, brought focus back to the research questions.

Concurrently, as a way of lending structure to the analytic process, sensitizing concepts were used to explore data for initial meaning. The process involved viewing the data from three different angles (ambiguity, familial affinity, and risk attribution) and making within group and across group comparisons. Figure 3.3 depicts this conceptualization and is an example of how data displays can advance one's thinking or analytic progression.

Perceived		Cognitive	Representations of Pe Cancer Risk	presentations of Personal Breast Cancer Risk			
Risk for Breast	Respondents	Sensitizing Concepts					
Cancer		Ambiguity	Familial Affinity	Risk Attribution			
Low	Linda, Kate, Michelle, Alicia, Celeste, Barbara						
High	Nancy, Susan, Janice, Jacquelyn, Debbie, Abigail						

Figure 3.3. Initial analysis plan for qualitative data.

In addition to open codes, data were also tagged as responses to core questions on the interview guide. Using a combination of core question tags and typical open codes associated with those same data as filters, data (i.e., quotes) were sorted and exported by risk perception group. In all, 41 codes were used to sample the data, 8 for ambiguity, 13 for familial affinity, and 20 for risk attribution. This sampling of quotes was then reviewed again both within and across risk perception groups for repeating ideas and possible themes or categories that tie ideas together, comparing data to data. Again, analytic memos were used to capture initial ideas about patterns. Essentially, initial analysis proceeded in three waves before advancing to the next stage

of coding. This technique of utilizing sensitizing concepts as analytic catalysts proved useful for making the volume of data seem manageable and, somewhat unexpectedly, sparked ideas that ultimately resulted in better thematic integration.

Focused coding

Armed with greater data intimacy, the second stage of coding began, focused coding (Charmaz, 2006). In this stage, larger blocks of text were analyzed against a refined set of codes made stronger with greater focus on emerging categories that spoke to the research questions. In this stage, transcripts were reanalyzed, comparing data to improved codes, with a better eye toward selecting the most relevant text, expanding the net in some places and collapsing it elsewhere. Some open codes were kept as focused codes, and others were lumped together or split apart. New codes were also established. In all, there were 12 focused codes that corresponded to data on the broad topic of ambiguity, 19 for familial affinity, and 27 for risk attribution.

The process of sorting and exporting quotes tagged with focused codes and displaying them by risk perception group was repeated. Similarly, memo-writing ensued to help compare data to data, data to codes, and codes to codes both within and across risk perception groups. Codes were revised as deemed appropriate, in accordance with the burgeoning analytic schema.

Comparing and abstracting

As previously mentioned, grounded theory coding takes the researcher from raw data to higher levels of abstraction, ultimately reducing the data to its core essence. Auerbach and Silverstein (2003) explicated the process effectively through their use of an inductively derived outline that demonstrates hierarchical relationships residing in the data. Their procedures for comparing and abstracting were adopted for the present study and undergird the entire analytic process.

After first selecting relevant text from raw data, the researcher looked for repeating ideas across transcripts, often with different wording, that addressed research interests. Next, repeating ideas with some perceived commonality were grouped together into themes or categories. This step is analogous to axial or theoretical coding as described by other researchers (Punch, 1998). Following considerable sorting and re-arranging of repeating ideas, along with additional comparison both within and across perceived risk groups, themes or categories were then grouped at a higher level of abstraction, termed theoretical constructs. Considered collectively, the constructs and their component parts provide the basis for a theoretical narrative that summarizes the data interpretation. Presented in Chapter 4, the narrative interweaves the research questions with the lived experiences of the adult adoptees (Auerbach & Silverstein, 2003).

The resulting inductively-derived outline is presented in Appendix F. For brevity, only the repeating ideas, themes, and theoretical constructs are shown. It is interesting to note that although sensitizing concepts (ambiguity, familial affinity, and risk attribution) served as analytic starting points, they do not dominate the data classification system. Using Auerbach and Silverstein's (2003) steps in comparing and abstracting data, the researcher approached analysis initially with the idea of creating the inductive outline by working each data third individually (per sensitizing concept). However, as analysis progressed, themes spanning analytic thirds began to dovetail to create a coherent structure. As foreshadowed, this integration enhanced the overall interpretive rendering.

Integrating Quantitative and Qualitative Data

As depicted in Appendix G, data integration occurred at two main connection points, consistent with the sequential explanatory mixed-methods design (Ivankova, Creswell, & Stick, 2006). First, research question formulation and sampling for inclusion in the second qualitative phase followed data collection and analysis in the first quantitative phase. As such, results from the quantitative phase informed how the qualitative phase was conducted. Second, findings from both phases were then integrated (in Chapter 5) at the point of interpreting the data's meaning, which is typical of studies with sequential explanatory designs (Creswell, 2003; Creswell & Plano Clark, 2007; Erzberger & Kelle, 2003; Hanson et al., 2005; Ivankova et al., 2006; Onwuegbuzie & Teddlie, 2003; Punch, 1998). The goal of interpretation, as Tashakkori and Teddlie (2003) described, is to weave inferences together to create a more coherent, holistic understanding of the research problem. Interpreted findings may be presented as one integrated whole or two separate ones, quantitative and qualitative (Onwuegbuzie & Teddlie, 2003), as was the case for this research study.

Given the juxtaposition of the quantitative and qualitative phases in the present study, results are viewed as primarily complementary to each other. Figure 3.4 depicts the researcher's process of integration as adapted from Erzberger and Kelle (2003), who provided a useful strategy for arriving at the whole of the data through triangulation.

The complementarity model of triangulation assumes that different methods showcase different aspects of the phenomenon of interest (Erzberger & Kelle, 2003). The present study began with testing the theoretical proposition that a stress and coping process (fueled by biological family medical history ambiguity and vicarious experience) explained adult adoptees' mammography screening intention (step 1). As described in Chapter 4, data revealed partial support for this proposition through deductive reasoning (step 2). An unexpected finding regarding biological family history ambiguity and perceived risk focused qualitative inquiry around the commonsense notion that, perhaps, the risk construction process differed for adoptees who arrived at polarized risk estimates (step 3). The resulting interpretive rendering of qualitative data offers factors that exert upward and downward pressure on perceived risk (step 4). The factors that surfaced were derived mostly inductively with some deductive framing provided by sensitizing concepts (represented by double-arrowed line segment between steps 3 and 4). Finally, integration occurred by considering the value that qualitative inquiry added to understanding the research problem as presented in Chapter 1 (step 5). In this fifth step, a newly integrated understanding is offered and implications for future research are identified.



Figure 3.4. Complementarity model of triangulation used to integrate quantitative and qualitative findings.

CHAPTER 4: RESULTS

Given the sequential explanatory mixed-methods research design, this chapter is organized into two parts representing the quantitative and qualitative phases of the study. The first part summarizes the results of quantitative analysis conducted to address the research questions outlined in Chapter 1. The quantitative results are organized into several sections. First, data preparation and screening are discussed as important precursors to SEM. Next, SEM results are presented according to the two-step procedure used for confirming whether the observed data contain the proposed stress and coping model factor structure. Results from testing the measurement model are, therefore, described first, followed by results from testing the structural aspects of the model. The final section in the quantitative portion of the chapter presents the results from using the same two-step procedure to examine the structure of a modified stress and coping model involving fewer factors against observed data.

As mentioned in Chapter 3, qualitative inquiry served to follow-up on an unexpected finding encountered during the quantitative phase. Results from the qualitative follow-up phase of the study are presented in the second part of the chapter. The research questions, formulated after analysis of quantitative data, are presented first. The next two sections portray adoptees who contributed their stories to better understand the complex relationship between ambiguous biological family medical history and perceived risk for breast cancer. A collective demographic portrait is painted first. Then, a more detailed biographical narrative for each respondent is shared for contextual foundation for viewing the qualitative data. The chapter concludes by presenting the researcher's theoretical rendering of the core meaning underlying adoptees' stories that emerged during qualitative analysis.

Quantitative Results

Data Preparation and Screening

Data preparation and screening are important precursors to conducting structural equation modeling (SEM), a correlational research method. Reliance on the correlation among variables to produce parameter estimates requires attention to several factors that could impact the variance-covariance among the variables. These include missing data, outliers, non-normality, and multicollinearity (Kline, 2005; Schumacker & Lomax, 2004). The preparation and screening process is critical to ensuring the computational success of parameter estimation, defined by the production of a logical solution, which can be hampered by data-related problems. Steps undertaken to prepare and screen the data are described below.

Missing Data

There are numerous ways to handle the problem of missing data. Pairwise deletion is an unacceptable practice with SEM given its tendency to produce non-positive definite matrices that result, at least in part, from producing estimates based on potentially different persons, depending on their response pattern (Kline, 2005). Listwise deletion is an improvement given complete data from the same respondent group throughout the estimation process (Kline, 2005) but is regarded as inferior to maximum likelihood techniques for producing estimates with incomplete data sets (Enders & Bandalos, 2001).

In the present study, the researcher's intention was to utilize maximum likelihood techniques on the dataset containing records with 90% completeness or better. However, results

from the normality assessment, described below, and feasibility considerations for imputation in regard to access and familiarity to statistical software thwarted that initial plan. Therefore, only records with complete data on manifest variables of interest were retained for analysis. As described and depicted in Chapter 3, SEM included 452 complete records from 655 eligible respondents.

Outliers

DeCarlo's macro (1997) was used to test for outlying cases. The macro was modified slightly to produce the top 50 observations with the largest Mahalanobi's distances, rather than the top 10 which is the default setting. Based on a critical F-value of 68.63 for a single multivariate outlier (.05 level), there was evidence of 18 outlying cases. These records were examined individually for any obvious explanations (e.g., data entry errors, illogical response patterns), and none were found. Means for these records were examined alongside those of the remaining records to locate aberrant patterns. On 33 items, the means of 16 were virtually identical. Only one mean was higher for the outlier group relative to the other respondents, whereas another 16 were lower. By and large, given the nascent nature of the research topic, further removal of outlying cases seemed unwarranted. Therefore, further analyses were performed with the inclusion of outlying cases.

Multivariate Normality

Most estimation procedures in SEM assume multivariate normality, that is, the joint distribution of all combinations of variables is normal (Kline, 2005). A necessary but not sufficient condition for multivariate normality is univariate normality, which is assessed first. For each variable, evidence of normality exists when both skewness and kurtosis do not exceed

the absolute value of two. As demonstrated in Table 4.1, ten of 33 variables are not normally distributed. According to guidelines described by Enders (2001a) and Kline (2005), the extent of non-normality can be described as mild for two variables, moderate for six variables, and extreme for two variables. In addition to univariate non-normality, Mardia's tests of multivariate skewness (z-score = 63.44, p = 0.0) and kurtosis (z-score = 22.21, p = 0.0) provided ample evidence of a violation of the normality assumption.

Researchers recommend either rescaled statistics (Kline, 2005), such as the Satorra-Bentler (SB) correction, or modified Bollen-Stine (B-S) bootstrapping (Enders, 2005) to correct for multivariate non-normality. AMOS has Bollen-Stine bootstrapping capability with complete data, and Enders (2005) published a SAS macro for bootstrapping with complete or missing data. For the present study, however, the researcher employed the Satorra-Bentler (1994) correction given greater familiarity and access to SPSS and Lisrel.

Multicollinearity

The full correlation matrix of 33 manifest variables containing 528 bi-variate correlations is available by contacting the researcher. Examination of the correlation matrix revealed eight bi-variate correlations of at least .800. One correlation in particular, that between two items (Q8, Q9) on the *ambiguity of biological family medical history* scale (r = .927), indicated multicollinearity to the extent that one item required immediate removal. Q8 was discarded, with better contextual fit serving as the criterion for retention. A second bi-variate correlation (r = .861) exceeded the .85 multicollinearity cut-off suggested by Kline (2005), that between two items of the *perceived value of biological family medical history information* scale (Q19, Q20). Given its borderline nature relative to the more obvious problematic correlation, no further action was taken at this point in analysis. However, both of these items were later

removed in the course of estimating, testing, and modifying the measurement model, as

described below.

Variable	M	SD	Skewness	Kurtosis
Perceived Value of BFam Medical Hx Info				
Q12	4.80	0.55	-4.23***	23.40^{***}
Q13	4.44	0.89	-1.91	3.80**
Q14	4.24	0.99	-1.29	1.16
Q15	3.98	1.08	-0.76	-0.24
Q16	4.34	0.95	-1.64	2.53^{*}
Q17	4.11	1.09	-1.14	0.57
Q18	4.29	0.92	-1.38	1.72
Q19	4.53	0.76	-1.88	4.28^{**}
Q20	4.42	0.85	-1.76	3.42*
Q21	4.64	0.78	-2.68**	7.69**
Q22	4.58	0.78	-2.44**	6.98^{**}
Q23	4.62	0.70	-2.46**	7.81**
Mammography Screening Adherence				
Q46	3.72	1.50	-0.85	-0.81
Mammography Screening Intention				
048	3 48	1 47	-0.35	-1 33
049	3 78	1 34	-0.78	-0.63
050	4 00	1.23	-1 19	0.24
Perceived Control		1.20		0.2
053	2 77	0.84	-0.14	-0.65
054	2.77	0.87	-0.27	-0.50
Dreast Cancon Warms	2.01	0.02	0.27	0.50
Official Cancer worry	2.11	0.02	0.42	0.72
Q33	2.11	0.95	0.42	-0.73
Q30	1.0/	0.75	1.05	0.90
Q57	1.29	0.58	2.32	6.03
	1.10	0.39	4.38	21.47
Perceived Risk	2 50	0.04	0.42	0.04
Q59	2.58	0.84	-0.43	-0.24
Q60	2.55	0.89	-0.11	-0.29
Q61	2.43	0.86	-0.18	-0.34
Q62	2.57	0.91	-0.24	-0.50
Q63	2.62	0.87	-0.33	0.29
Ambiguity of Biological Family Medical History			0.45	1.10
Q8	3.56	1.54	-0.45	-1.43
Q9	3.70	1.47	-0.59	-1.23
Q10	3.32	1.53	-0.07	-1.67
Q11	4.17	1.20	-1.31	0.48
Vicarious Experience with Breast Cancer				
BCExp	1.10	0.83	0.25	-0.64
Information Seeking about BFam Medical Hx				
Infoseek	6.21	2.22	-0.06	0.05

Table 4.1: Univariate Summary Statistics for Continuous Variables (n = 452)

* = mildly non-normal; ** = moderately non-normal; *** = extremely non-normal

Data Description

Scale Distribution and Performance

In keeping with the first study aim, basic descriptive data provide new information about female adult adoptees as healthcare consumers. On average, adoptees agreed that their biological family medical history information was a source of some ambiguity in their lives. Over one-third (36.1%) reported the highest degree of ambiguity for all four items which inquired about access to and familiarity with biological family medical history information, as well as whether information had ever been shared verbally or in written form. Overall, adoptees placed a high value on the importance of having biological family history information in a medical context. To name a few, the majority strongly believed that family history is valuable for creating awareness about various health risks (84.1%), giving peace of mind (76.8%), reducing uncertainty about disease risks (70.4%), providing important information to share with others (e.g., children) (69.5%), and helping physicians diagnose medical problems (65.3%). Almost all (99.1%) had some degree of engagement with searching for information about biological family members and/or biological family medical history. Beyond giving serious consideration to searching, the most common forms of engagement were conducting research online (88.1%), asking adoptive parents for information about birth family (70.6%), participating in a government-sponsored reunion registry (70.1%), and enlisting the help of a third-party (66.8%) to locate birthparents. Only 14% had ever requested help from their physician in an attempt to obtain medical records.

In regard to breast cancer, adoptees expressed a slight degree of optimism in regard to their personal disease risk. For each item in the risk perception scale, the average response was close to the neutral scale point, albeit in a direction favoring lower risk. As a whole, adoptees believed it was somewhat possible to reduce the likelihood of developing breast cancer, somewhere between "a little" and "moderately possible." As a group, adoptees had low breast cancer worry scores and, on average, had little vicarious experience with the disease. The majority (65.3%) had at least one friend with breast cancer, and 33.0% had vicarious experience through their adoptive families. Only 12% reported a breast cancer history among biological family members, but, of course, this figure is highly dependent on information access. One fourth (25.2%) reported no vicarious experience with breast cancer.

Less than half expressed strong intention for seeking annual mammography screening in the future. For three items, only 39.8 - 48.7% of adoptees selected the highest scale point on screening intention. Indeed, results showed that most adoptees (55.5%) were out of compliance with age-appropriate mammography screening guidelines at the time of completing the online questionnaire, including 16.8% who had never had a mammogram. On average, most had their last mammogram 2-3 years ago, translating the mean score to scale points. Only 44.5% were classified as compliant, having had their last mammogram within the past 12 months.

Table 4.2 shows the means and standard deviations of total scales, along with statistics for skewness, kurtosis, and internal reliability. As foreshadowed by the multivariate non-normality, two scales are somewhat problematic. Both leptokurtic as the primary concern, breast cancer worry is a bit positively skewed, while perceived value of biological family medical history information is somewhat negatively skewed. As measured by Cronbach's alpha (1951), the reliability of five scales is high, ranging from .88 to .95. The internal reliability for breast cancer worry is lower, yet acceptable, at .72. Alpha values for two scales warrant comment. Vicarious experience with breast cancer should be regarded as an additive scale. While each type of experience (friend, adoptive family member, or biological family member) potentially

contributes to the overall total, inter-item correlation is not assumed. Similar logic is applied to the information seeking scale, which contains distinct behavioral items related to searching for biological family medical history information. Together, the items represent overall engagement, but individual items would not necessarily correlate with each other as specific information-seeking steps are dependent on outside factors such as state laws and existing social service systems.

Table 4.2: Descriptive Statisics and Internal Reliability for Total Scale Scores (N = 452)

Scale (# items)	М	SD	Skewness	Kurtosis	α
Ambiguity of Biological Family Medical	14.74	5.11	-0.47	-1.05	.91
History (4)					
Vicarious Experience with Breast Cancer (3)	1.10	0.83	0.25	-0.64	.28 ^a
Perceived Risk (5)	12.75	3.89	-0.43	-0.10	.93
Breast Cancer Worry (4)	6.17	2.04	1.29	2.16 ^b	.72
Perceived Control (2)	5.61	1.59	-0.26	-0.38	.91
Perceived Value of Biological Family Medical History Information (12)	52.99	8.29	-1.96	6.09 ^b	.95
Information Seeking about Biological Family Medical History (12)	6.21	2.22	-0.06	0.05	.64 ^a
Mammography Screening Adherence (1)	3.72	1.50	-0.85	-0.81	n/a
Mammography Screening Intention (3)	11.26	3.67	-0.61	-0.80	.88

a Would not expect high internal consistency. b Non-normally distributed.

Correlation

With SEM, the goal is to reproduce the observed correlation matrix by specifying the relationship between variables. Specifically, reproduced correlations equal the sum of direct and indirect paths between variables. Estimation through SEM involves minimizing the difference between the reproduced and observed correlations. For simplicity and ease of discussion, the correlations among scale scores are presented in Table 4.3. These were examined for expected

magnitude and direction, along with their bi-variate underpinnings. Discussion here is limited to correlations between variables in hypothesized relationships.

As shown in Table 4.3, having ambiguity about biological family medical history does not appear related to either perceived risk for breast cancer or breast cancer worry, as both bivariate correlations are not statistically significant or different from zero. As hypothesized, vicarious experience with breast cancer is positively correlated with perceived risk, although the relationship appears weak (r = .14, p < .01). One of the strongest correlations in the matrix is between perceived risk and breast cancer worry (r = .48, p < .01). As hypothesized, the relationship is in the expected direction, as is that between perceived risk and perceived control over breast cancer risk (r = -.17, p < .01). In contrast, perceived control and breast cancer worry appear to have no significant relationship, creating doubt about finding an indirect effect between perceived risk and breast cancer worry. Based on correlations, the hypothesized relationship between perceived risk and mammography screening adherence through perceived control appears in jeopardy. As previously mentioned, perceived risk and perceived control have an expected inverse relationship, but no relationship was found between perceived control and mammography screening. The perceived value of having biological family medical history is significantly related to information-seeking (r = .21, p < .01), but the correlation between perceived risk and perceived value of biological family medical history works in the opposite direction than expected, although with a low magnitude (r = -.10, p < .05). Finally, two out of three relationships between coping efforts and mammography screening intention appear to hold. Breast cancer worry and past mammography screening adherence are both positively correlated with future screening intention (r = .16 and r = .58, respectively, p < .01). The relationship

between biological family medical history information seeking and screening intention, however, is not significantly different than zero.

Latent Construct	1	2	3	4	5	6	7	8	9
1. Ambiguity of Biological Family Medical History	_								
2. Vicarious Experience with Breast Cancer	18**	_							
3. Perceived Risk	.06	.14**	_						
4. Breast Cancer Worry	.06	.06	.48**	_					
5. Perceived Control	13**	02	17**	.01	_				
6. Perceived Value of Biological Family Medical History Information	08	.00	10*	.20**	.04	_			
7. Information Seeking about Biological Family Medical History	12**	.17**	.08	.23**	.00	.21**	_		
8. Mammography Screening Adherence	02	.15**	.06	01	.06	06	08	_	
9. Mammography Screening Intention	07	.15**	.24**	.16**	.09	.09	.03	.58**	_
$p^* < .05$. $p^* < .01$.									

Table 4.3: Correlations among Latent Constructs

Estimation Procedures

Hypotheses were tested using structural equation modeling (SEM) as it applies to a full structural or hybrid model. SEM allows hypothesis testing while simultaneously taking measurement error into account (Bollen, 1989 as cited in Gowan, Riordan, & Gatewood, 1999). Analysis followed the two-step process described by Anderson and Gerbing (1988) that
prescribes, first, estimation and modification of the measurement model using confirmatory factor analysis (CFA) followed by subsequent estimation of the theoretical model, which specifies the imposed structural relations among the factors. Estimation of the structural model typically proceeds only after a well-fitting, parsimonious measurement model is identified. Models were analyzed with Lisrel Version 8.8 (Jöreskog & Sörbom, 2006), using covariance and asymptotic covariance matrices generated by PRELIS Version 2.80 (Jöreskog & Sörbom, 1999). The covariance matrices, too large for a print-based medium, are available by contacting the researcher.

Testing the Measurement Model

The covariance and asymptotic covariance matrices were used as input to examine the measurement model comprised of nine factors (ambiguity of biological family medical history, vicarious experience with breast cancer, perceived risk, perceived control, perceived value of biological family medical history information, breast cancer worry, information-seeking about biological family medical history, mammography screening adherence, and mammography screening intention). Latent variables represented by one observed variable (mammography screening adherence) or total score² (vicarious experience with breast cancer, information-seeking about biological family medical history) required fixing the lambda and theta coefficients. Lamda coefficients, or factor loadings, were set to 1. Theta coefficients, or random error variance, were determined by multiplying the observed variance times 1 minus the reliability of the measure (Kline, 2005). Given that the measures related to behavior rather than perceptual constructs, reliability was conservatively estimated at .8.

² Dichotomously scored items were summed to produce a total scale score.

Estimation of the original model through CFA (with all factors set to correlate) prior to any modification produced a non-positive definite error stemming from extreme collinearity (r =.927) between two observed variables for the ambiguity of biological family medical history construct, as already described. The decision about which item to remove (Q8) was predicated on better contextual fit,³ and removal indeed facilitated a converged solution. Parameter estimates for the proposed measurement model with that single modification are presented in Table 4.4 and labeled as Model 1 in Table 4.7.

Variables were coded to expect factor loadings with positive signs. As Table 4.4 reveals, all items loaded onto their respective factor with statistical significance. Examination of R^2 values, item variance explained by its related factor, provided further evidence about item performance. One manifest variable for breast cancer worry (Q55) stood out immediately as a poorly performing item that required discarding (R^2 = .28). Four other items were lackluster in their ability to uniquely represent their respective factor with R^2 values falling below .50. Standardized residuals pointed toward the measurement model's poor fit with over 10% of values exceeding the absolute value of two. Various indices, summarized in Table 4.7 for Model 1, provided concurrent evidence of an ill-fitting model (SB Chi-square = 1885.0, p = 0.0; RMSEA = 0.086; NNFI = 0.91, CFI = 0.92; RFI = 0.88) based on Hu and Bentler's (1998, 1999) recommended cut-off values.

Modification indices (MIs) were then assessed for potential clues about how to improve the fit of the measurement model. Four pairs of items measuring the *perceived value of biological family medical history information* appeared especially problematic in that their error terms seemed to co-vary. Two items, Q20 and Q19, which focused on the perceived value of

³ Specifically, the choice was between "I am familiar with" or "I have access to" biological family medical history information.

biological family medical history information to physicians, versus the individual, were removed outright during subsequent estimation. These two items added considerably (236.1) to the measurement model's high Chi-square value. One item from each of three pairs with high potential for reducing the Chi-square value were also removed (Q14, Q21, and Q16). Given the indication of error term covariance, items were either redundant, shared the same source of problematic measurement, or represented a third missing factor. These pairs each contributed between 108.2 and 120.1 to the Chi-square value.

Subsequent estimation attempts proceeded similarly and involved dropping items, then scrutinizing R^2 values, standardized residuals, and fit indices. Each time the estimated measurement model was ill-fitting, modification indices were taken into account for potential areas of refinement. Five additional models were estimated in an attempt to sufficiently reproduce the observed covariance matrix. Three items were dropped because of having correlated error terms with other items in their shared scale (Q17, Q22, and Q23). Two items were removed at one point and later returned to the model as estimation produced an illogical solution containing negative variances (Q48, Q56). The final version of the proposed measurement model (labeled Model 2 in Table 4.7) was evaluated as having only plausible fit at best, with the rescaled Chi-square statistic still indicating overall lack of fit (SB Chi-square = 443.40, p = 0.0, df = 197; RMSEA = 0.053; NNFI = 0.95; CFI = 0.96; RFI = 0.92; SRMR = 0.044). With some semblance of fit in the measurement model, the structural model was then tested and evaluated for its ability to add information.

Latent and manifest variables	Unstandardized factor loading	t	SE	R^2
Perceived Value of Biological Family				
Medical History Information				
Q12	0.39	5.59	0.07	.50
Õ13	0 71	12 71	0.06	64
014	0.83	18 25	0.05	70
015	0.84	21.31	0.03	60
016	0.77	14 60	0.04	.00
017	0.77	14.09	0.03	.05
Q17 Q18	0.04	19.51	0.04	.00
Q18	0.73	14.84	0.05	.03
QI9	0.61	11.39	0.05	.64
Q20	0.69	13.33	0.05	.66
Q21	0.58	8.66	0.07	.56
Q22	0.55	8.50	0.07	.49
Q23	0.52	8.61	0.06	.55
Mammography Screening Adherence				
Q46	1.00			.80
Mammography Screening Intention				
048	1 10	16 74	0.07	56
049	1 32	30.40	0.04	97
050	1.02	19 69	0.01	71
Paraeived Control	1.07	17.07	0.00	./1
	0.92	14.07	0.06	06
Q33	0.82	14.97	0.00	.90
Q54	0.70	14.11	0.05	./3
Breast Cancer worry	0.50	10.65	0.05	•
Q55*	0.50	10.65	0.05	.28
Q56	0.47	12.10	0.04	.40
Q57	0.50	10.48	0.05	.74
Q58	0.27	5.80	0.05	.48
Perceived Risk				
Q59	0.76	25.37	0.03	.81
Q60	0.77	23.74	0.03	.75
Õ61	0.75	24.54	0.03	.76
062	0.81	26.82	0.03	.79
063	0.66	16.56	0.04	57
Ambiguity of Biological Family Medical	0.00	10.50	0.01	
History**				
	1 24	27 18	0.05	82
Q ⁹ 010	1.34	21.40	0.05	.03
	1.30	31./3	0.04	./9
	0.//	15.10	0.06	.41
vicarious Experience with Breast Cancer	1 0 0			0.0
BCExp	1.00			.80
Information Seeking about Biological				
Family Medical History				
Infoseek	1.00			80

 Table 4.4: Parameter Values for Proposed Measurement Model

Testing the Structural Model

Fit of the structural model is tested similarly to that of the measurement model, although with the inclusion of paths connecting those factors with hypothesized direct and indirect relationships. Path coefficient estimation produces structural equations analogous to those used in multiple linear regression. Results of parameter estimation appear in Tables 4.5 and 4.6 below.

As shown in Table 4.5, all items loaded onto their respective factor with statistical significance. The magnitude of factor loadings is mixed for perceived value of biological family medical history information, breast cancer worry, and biological family history ambiguity. The R^2 values for at least one item in each of these scales speak to the aforementioned ongoing measurement challenges.

Table 4.6 presents coefficients for direct and indirect paths in the proposed model that correspond to study hypotheses. Direct path coefficients are also depicted in Figure 4.1. Each path was examined for statistical significance as evidence to support or refute study hypotheses. Each will be discussed in turn.

Hypothesis 1 stated that greater ambiguity about biological family medical history elevates breast cancer risk perception and worry. Both direct paths were not statistically different than zero, indicating lack of a relationship between ambiguity and the two other factors. This finding was foreshadowed by non-significant correlation values described earlier.

Hypothesis 2 posited that vicarious experience with breast cancer heightens one's perceived risk. This hypothesis is supported as evidenced by a significant direct path coefficient (0.25). Hypothesis 3, that perceived risk influenced cancer-specific worry both directly and indirectly through perceived control, was partially supported. The direct path between perceived

risk and breast cancer worry was significant (0.43), but the indirect pathway was not. Notice in Table 4.6 and Figure 4.1 that one component of the indirect path, that between perceived control and worry, was significant but in the opposite direction than expected.

Hypothesis 4 claimed that the relationship between perceived risk and mammography screening adherence is mediated by perceived control over disease risk. This hypothesis was not supported as shown by the indirect path coefficient. Interestingly, one component of the indirect path was not statistically significant from zero, the direct path to mammography screening adherence from perceived control.

Hypothesis 5 predicted that perceived risk for breast cancer influences informationseeking about biological family medical history through the perceived value of having birth family information. The evidence does not support this hypothesis as the indirect path coefficient is non-significant. In this case, both component direct paths were significant, but one was quite weak in magnitude.

The sixth and final hypothesis posited that each coping effort (worry, mammography adherence, and information-seeking) serves to motivate future mammography screening intention. Results provide partial support for Hypothesis 6. Worry and past mammography behavior appear to influence future intention, but information-seeking for biological family medical history does not.

Taken together, various fit indices suggest that the structural model (Model 3 in Table 4.7) is an exceedingly borderline representation of observed data (SB Chi-square statistic = 548.0, p = 0.0, df = 220; CFI = .95; NNFI = .95; RFI = .91; RMSEA = .057; and SRMR = .072). The proportion of standardized residuals exceeding the absolute value of 2 (24%) further supports this assertion. While the proportion is not extreme, typically thought of as 30% or

higher, it exceeds the maximum threshold of good fit, generally regarded as 10%. Moreover, when comparing the structural and measurement models against each other, the Chi-square change statistic (104.6, df = 23) reveals with significance that there is a difference in fit between the two models, indicating that the structural model does not offer informational value. Table 4.7 presents this analysis in greater detail.

 Table 4.5: Measurement Equations in Structural Model

Construct and item	lamda	t	SE	R^2
Perceived Value of Biological Family Medical				
History Information				
Q12	0.36	n/a	n/a	0.43
Q13	0.77	6.97	0.11	0.74
Q15	0.83	5.89	0.14	0.58
Õ18	0.67	7.52	0.09	0.52
Mammography Screening Adherence				
O46	1.00	n/a	n/a	0.80
Mammography Screening Intention				
O48	1.09	n/a	n/a	0.55
Õ49	1.33	13.42	0.10	0.99
O50	1.07	12.28	0.09	0.70
Perceived Control				
053	0.79	n/a	n/a	0.89
054	0.73	6.95	0.11	0.79
Breast Cancer Worry		• • • •		
056	0.43	n/a	n/a	0 33
057	0.53	9.18	0.06	0.84
058	0.27	6 26	0.04	0.50
Perceived Risk				
059	0 76	n/a	n/a	0.81
Q60	0.77	28.09	0.03	0.75
O61	0.76	28.44	0.03	0.76
062	0.81	32.63	0.03	0.78
Q63	0.66	18.01	0.04	0.57
Ambiguity of Biological Family Medical History	0.00	10.01	0.01	0.07
O9	1 34	26.98	0.05	0.83
$\hat{\mathbf{O}}_{10}$	1.34	31.08	0.02	0.05
011	0.77	13.12	0.06	0.75
Vicarious Experience with Breast Cancer	0.11	10.12	0.00	0.11
BCEvn	1.00	n/a	n/a	0.80
Information Seeking about Biological Family	1.00	11/ a	11/ a	0.00
Medical History				
Infoseek	1.00	n/a	n/a	0.80

Path to Path from $PC t PC t$	R^2
Perceived Risk	0.04
Vicarious Experience with BC 0.25 3.31	
Ambiguity of BFam Medical Hx 0.09 1.71 ^{ns}	
Info	
Perceived Control	0.03
Vicarious Experience with BC -0.05 -2.62	
Ambiguity of BFam Medical Hx -0.02 -1.44"	
Inio Demoived Diele 0.19 2.56	
Perceived Kisk -0.18 -5.50 Derceived Value of	0.01
BEam Medical Hy	0.01
Information	
Vications Experience with BC 0.03 1.91 ⁿ	
Ambiguity of BFam Medical Hx 0.01 ± 1.01	
Information	
Perceived Risk 0.10 2.20	
Breast Cancer Worry	0.18
Vicarious Experience with BC 0.10 2.74	
Ambiguity of BFam Medical Hx -0.01 os -0.14 ns 0.04 1.64 n	
Info	
Perceived Risk 0.43 5.80 -0.02 -1.81 ⁿ	
Perceived control $0.11^{\circ s}$ 2.08	
Information-seeking	0.05
about BFam medical hx	
Vicarious Experience with BC 0.01 1.43	
Ambiguity of BFam Medical Hx 0.00 1.1/"	
INIO Demonstrad Distriction 0.05 1.52 h	
Perceived KISK 0.05 1.52 Derceived Value of PEam Medical 0.45 2.37	
Hy Information	
Mammography	0.01
adherence	0.01
Vicarious Experience with BC $0.00 -1.22^{n}$	
Ambiguity of BFam Medical Hx 0.00 -1.02 ⁿ	
Info	
Perceived Risk $-0.02 -1.32^{n}$	
Perceived control $0.10 1.35^{ns}$	
Screening intention	0.34
Vicarious Experience with BC 0.01 2.15	
Ambiguity of BFam Medical Hx 0.00 0.44 ⁿ	
Info	
Perceived Risk 0.05 2.85	
Perceived control 0.06 1.71"	
Breast Cancer Worry 0.13 3.79 Derevived Value of PEar Medical 0.01 1.06 ⁿ	
FUCEIVEU VALUE OF DEFAILI MEDICAL 0.01 1.00 Hy Information	
Information-seeking about RFam 0.03 1.30 ns	
medical hx	
Mammography adherence 0.42 8.07	

Table 4.6: Path Coefficients, t-values, and R^2 Values for Proposed Structural Model

ns= t-value not statistically significant at .05 level; os= sign in opposite direction than expected.

Model	df	$SB X^2$	CFI	NNFI	RFI	RMSEA	SRMR	X^2_{diff}
1. Proposed 9- factor measurement model	431	1885.00*	0.92	0.91	0.88	0.086	0.054	un
 Modified 9- factor measurement model 	197	443.40*	0.96	0.95	0.92	0.053	0.044	
3. 9-factor structural model	220	548.00*	0.95	0.95	0.91	0.057	0.072	
Difference between Model 2 & Model 3	23							104.60*
 Modified 9- factor structural model 	216	488.06*	0.96	0.95	0.92	0.053	0.055	
Difference between Model 2 & Model 4	19							44.66*

 Table 4.7: Fit Indices for Proposed Measurement and Structural Models

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Figure 4.1. Graphical depiction of 9-factor structural model.

Modification of the Proposed Structural Model

Given that the current structural model poses no better fit than the measurement model, examination of the modification indices created potential for *post hoc* improvement. At this step, priority was placed on better understanding the structural relationships as they pertain to observed data. The modification indices highlighted four new paths that would improve the overall fit of the model: one between breast cancer worry and information-seeking, two stemming from vicarious experience with breast cancer to information-seeking and mammography screening adherence, and another between perceived risk and future screening intention. This model, labeled Model 4 in Table 4.7, containing the originally proposed relationships with the additional four paths, still did not improve overall fit relative to the measurement model (Model 2). Fit indices, again, showed only plausible fit (SB Chi-Square = 488.06, p = 0.0, df = 216; CFI = .96; NNFI = 0.95; RFI = .92; RMSEA = 0.053; and SRMR = 0.055), and standardized residuals exceeded the threshold of acceptability. The Chi-square change statistic was significant (44.66, df = 19), indicating the structural model's inability to provide meaningful information.

Analytic Summary of Proposed Model

The proposed model is plagued by measurement challenges. As R^2 values show (Table 4.6), the structural model explained a moderate proportion of variance in only screening intention (.34) and breast cancer worry (.18). For the remaining factors, explained variance was negligible (.01-.05). Further evidence of measurement model misspecification emanates from the high proportion of standardized residuals, inconsistent and/or low values for explained item variance by certain factors, possible correlated error terms, and exceedingly marginal fit indices, even after modification. Likely sources of inferior measurement stem from four factors in particular: perceived control, the perceived value of health information, breast cancer worry, and ambiguity of biological family medical history. Not surprisingly in retrospect, perceived value of biological family medical history information and breast cancer worry have substantial issues with univariate non-normality. While non-normality isn't necessarily problematic in that analytic corrections are available through the use of re-scaled statistics, restriction of range and measurement insensitivity are also distinct possibilities that, if present, can be deleterious to the model in its ability to demonstrate existing relationships.

While fit indices arguably indicated marginal fit, the structural model contained several paths that were not statistically significant from zero. Moreover, two paths had parameter estimates with the opposite than hypothesized sign, one of which was statistically significant. Further support for the model's measurement issues was revealed by the results of the Chi-square difference test. Ideally, an equally-fitting structural model is desired and accepted as offering informational value on the basis of achieving greater parsimony.

While disappointing, measurement hurdles are not uncommon to structural equation modeling. Given the complexity of a nine-factor model, the likelihood of having measurement problems is amplified. This model, however, may be particularly vulnerable to measurement problems in its somewhat experimental use of nascent measures and its use of existing measures with unknown performance on an adult adoptee population. To further exacerbate the overall measurement challenge, *stress and coping* is a relatively novel theoretical approach to this topic, not without its own measurement challenges. As previously mentioned in Chapter 2, breast cancer worry is an especially vexing construct to define and measure.

In an effort to benefit health promotion practice, a more parsimonious model was examined in its ability or partial ability to shed light on the average adult adoptee's complex process of coping with the abstract risk for breast cancer. A simpler *post hoc* model will be presented and discussed next. The model maintains key constructs of interest while eliminating the more problematic constructs from a measurement perspective, specifically the perceived value of biological family medical history information and perceived control, both secondary appraisals of risk and options at one's disposal to control risk, and breast cancer worry. Despite suspected measurement problems, ambiguity of biological family medical history information was retained in the simplified model due to the contextual importance for adult adoptees.

Testing a More Parsimonious Model of Stress and Coping

The two-step process was again followed to test how well the full structural model fits the observed data. The simpler model contains six of the original nine constructs. This time only two coping mechanisms, being compliant with mammography screening guidelines and information-seeking about biological family medical history, were included, and both operationalized examples of secondary appraisal were dropped. Both stressors for adult adoptees, vicarious experience with breast cancer and ambiguity of biological family medical history information, were hypothesized as having direct paths to perceived risk and each coping strategy. In addition, the exogenous factors were posited as having indirect paths to both coping efforts through perceived risk. Primary appraisal of risk, one's risk perception or belief about personal susceptibility, was hypothesized as having a direct path to each coping effort and the coping outcome, future screening intention. Additionally, an indirect relationship between perceived risk and screening intention was posited as working through both coping efforts. Figure 4.2 below depicts the hypothesized relationships. Parameter estimation will be explained next.

The initial estimation of the parsimonious measurement model reached a converged solution. Parameter estimates are presented in Table 4.8 below. As shown, factor loadings were all statistically significant and in the desired direction. Three items were suspiciously poor performers based on their R² values (Q48, Q63, and Q11). Standardized residuals were not inconsistent with model fit, as slightly less than 10% were beyond the absolute value of 2. Fit indices (Model 5 in Table 4.11), however, belie this assertion (SB Chi-square = 250.05, df = 65, p = 0.0; RMSEA = 0.08; NNFI = 0.94; CFI = 0.96; RFI = 0.92; SRMR = 0.05). Modification indices show correlated error terms among several bi-variate pairs from the latent construct

perceived risk. As a result, the decision was made to drop Q60 due to its fit improvement potential but also because of its contextual difference. This item asked respondents to rate their breast cancer risk in comparison to others of their same age and race, while sister items were centered only on the individual.



Figure 4.2. Graphical depiction of final 6-factor structural model.

The subsequent iteration (Model 6 in Table 4.11) produced fit indices suggestive of an ill-fitting, possibly borderline, model (SB Chi-square = 208.21, p = 0.0; RMSEA = 0.08; NNFI = 0.93; CFI = 0.95; RFI = 0.91; SRMR = 0.05) as also forecasted by the proportion of standardized residuals considered unacceptable, roughly 10%. Modification indices pointed strongly toward

Latent and manifest variables	Factor loading	t	SE	R^2
Mammography Screening Adherence				
Q46	1.00	n/a	n/a	0.80
Mammography Screening Intention				
Q48	1.09	16.68	0.07	0.55
Q49	1.33	30.49	0.04	0.98
Q50	1.07	19.49	0.05	0.70
Perceived Risk				
Q59	0.76	25.25	0.03	0.81
Q60	0.77	23.73	0.03	0.75
Q61	0.75	24.55	0.03	0.76
Q62	0.81	26.85	0.03	0.79
Q63	0.66	16.55	0.04	0.57
Ambiguity of Biological Family Medical History				
Q9	1.34	27.54	0.05	0.84
Q10	1.36	31.35	0.04	0.79
Q11	0.77	13.10	0.06	0.40
Vicarious Experience with Breast Cancer				
BCExp	1.00	n/a	n/a	0.80
Information Seeking about Biological Family				
Medical History				
Infoseek	1.00	n/a	n/a	0.80

Table 4.8: Estimated Parameters for Parsimonious Measurement Model Prior to Modification

the presence of correlated error terms between Q48 and Q46; however, removal of Q48 produced negative error variance upon estimation. Given that Q46 is the single-item indicator of mammography screening adherence, both of these items were retained. Another correlated error term was suggested between Q63 and Q49; therefore, the next iteration was conducted without Q63. The selection of Q63 was informed by the total number of items serving as indicators as well as contextual considerations, also reflected in this item's low R² value. Again, this particular item differs from its companions in that its focus is on one's belief about genetic risk for breast cancer, not simply generalized risk. Again, the measurement model (Model 7 in Table 4.11) was deemed ill-fitting, taking the fit indices under collective consideration (SB Chi-square = 170.46, p = 0.0, df = 42; RMSEA = 0.08; NNFI = 0.93; CFI = 0.95; RFI = 0.91; SRMR = 0.04). This time, however, the standardized residuals tell a different story with less than 10%

exceeding the absolute value of 2. Modification indices highlight a possible error covariance between two indicators of screening intention, one of which was removed (Q50) before the final measurement model estimation.

Parameter estimates for the final version of the parsimonious measurement model (Model 8 in Table 4.11) are presented in Table 4.9. All factor loadings are statistically significant and in the desired direction with expected magnitude. Standardized residuals are well within the acceptable proportion to indicate fit, and, indeed, fit indices are consistently aligned for the first time in their support of having a well-fitting measurement model (SB Chi-square = 36.63, df = 32, p = 0.26; RMSEA = 0.02; NNFI = 1.0; CFI = 1.0; RFI = 0.97; SRMR = 0.03). Results from the full structural model (Model 9 in Table 4.11) are depicted in Figure 4.2, and finer details about direct and indirect effects are shown in Table 4.10.

As detailed in Table 4.10, six paths in the structural model were not significantly different than zero, indicating an absent hypothesized relationship. Three of these emanated from biological family history ambiguity, and two stemmed from perceived risk as they relate to the two problem-focused coping efforts, mammography and biological family history information-seeking. The sixth non-significant path failed to connect information-seeking to screening intention, a similar finding to that of the 9-factor model.

In the 6-factor model, evidence supports only some of the *post hoc* hypotheses. Namely, vicarious experience with breast cancer elevates risk perception directly and appears to motivate mammography and information-seeking. In related fashion, vicarious experience also increases future screening intention significantly through its indirect impact on perceived risk and past adherence to mammography screening guidelines.

Latent constructs and	Factor	t	SE	R^2
manifest variables	loading			
Mammography Screening				
Adherence				
Q46	1.00	n/a	n/a	0.80
Mammography Screening				
Intention				
Q48	1.44	34.13	0.04	0.96
Q49	1.01	19.61	0.05	0.57
Perceived Risk				
Q59	0.77	24.52	0.03	0.84
Q61	0.72	21.43	0.03	0.70
Q62	0.82	26.37	0.03	0.82
Ambiguity of Biological				
Family Medical History				
Q9	1.34	27.45	0.05	0.84
Q10	1.36	31.35	0.04	0.79
Q11	0.77	13.10	0.06	0.41
Vicarious Experience with				
Breast Cancer				
BCExp	1.00	n/a	n/a	0.80
Information Seeking about				
Biological Family Medical				
History				
Infoseek	1.00	n/a	n/a	0.80

Table 4.9: Final Parsimonious Measurement Model

Fit indices strongly suggest that the structural model represented the observed data well (SB Chi-square = 47.52, df = 35, p = 0.08; RMSEA = 0.03; NNFI = 0.99; CFI = 0.99; RFI = 0.97; and SRMR = 0.03). However, results of the Chi-square change test (10.89, df = 3) reveal pervasive underlying measurement issues as the six-factor structural model, again, did not add significant information value over the measurement model. R^2 values strongly suggest model misspecification in all factors, with the possible exception of screening intention.

		Dire	ect	Ind	irect	
Path to	Path from	PC	t	PC	t	R^2
Perceived risk						0.03
	Vicarious experience with BC	0.25	3.17			
	Ambiguity of BFam Medical	0.05	0.98 ^{ns}			
	History					
Information-seeking						0.06
about biological family						
medical history			a a a 195			
	Perceived risk	0.09	0.82 115			
	Vicarious experience with BC	0.48	3.00	0.02	0.81 ^{ms}	
	Ambiguity of BFam Medical	$-0.20^{\circ s}$	-1.72 ^{ms}	0.00	0.60^{ms}	
	History					
Mammography						0.04
screening adherence	D · 1 · 1	0.05	o cans			
	Perceived risk	0.05	0.67 "	0.04	0 6 6 10	
	Vicarious experience with BC	0.33	2.88	0.01	0.66^{113}	
	Ambiguity of BFam Medical	-0.01^{03}	-0.12 ^{ns}	0.00	0.55	
a	History					0.60
Screening intention	D 111	0.16	1.26	0.02	0 (7 lls	0.62
	Perceived risk	0.16	4.36	0.03	0.6/***	
	Information-seeking about	0.00	0.19			
	biological family medical history	0.56	16.00			
	Mammography Screening	0.56	16.80			
	Adherence			0.24	2.00	
	A mbiguity of DEam Madigal			0.24	3.00	
	Amonguity of Bram Medical			0.00	0.09	
	HISTOLA					

Table 4.10: Path Coefficients, t-values, and R^2 Values for Final Parsimonious Model

ns = t-value not statistically significant at .05 level. os = Sign in opposite direction than expected.

Table 4.11: Fit Indices for Parsimonious Measurement and Structural Models

	Model	df	SBX^2	CFI	NNFI	RFI	RMSEA	SRMR	X^2_{diff}
5.	6-factor	65	250.05*	0.96	0.94	0.92	0.079	0.045	
	measurement model								
6.	Modified 6-factor measurement model	53	208.21*	0.95	0.93	0.91	0.081	0.047	
7	Further modified 6-	42	170 46*	0.95	0.93	0.91	0.082	0.042	
7.	factor measurement model	12	170.10	0.90	0.90	0.91	0.002	0.012	
8.	Final modified 6-	32	36.63	1.00	1.00	0.97	0.018	0.027	
	factor measurement model								
9.	6-factor structural	35	47.52	0.99	0.99	0.97	0.028	0.034	
	model								
Dif	ference between	3							10.89*
Mc	del 8 and Model 9								
*	< 05								

* p < .05

Qualitative Results

Research Questions

The qualitative phase of the study served to follow-up on a particular path in the full structural model that remained non-significant throughout estimation, that between ambiguity of biological family medical history and perceived risk. Qualitative examination of this relationship was undertaken to better understand how respondents take their lack of biological family medical history into account when developing personal disease risk estimates, which can vary considerably. By better understanding cognitive processes, and, most importantly, comparing processes typified by persons who believe themselves to be at both low and high risk, future model refinement is tenable.

Two main research questions guided qualitative inquiry: 1) How do adult adoptees construct personalized risk estimates for breast cancer? and 2) How do cognitive representations differ between persons with high vs. low perceived risk? A semi-structured interview guide was created to elicit from respondents the role that biological family medical history ambiguity, familial affinity, and risk attribution play in exerting upward or downward pressure on perceived risk for breast cancer. Moreover, questions were designed to reveal evidence of heuristic thinking when constructing risk estimates, specifically the deployment of anchoring and adjustment, availability, representativeness, and illusion of control. A sample interview guide is found in Appendix E.

Biographical Description of Respondents

Table 4.12 presents a biographical summary of the twelve respondents who are identified by pseudonyms. All are married or partnered, and, with the exception of Michelle, each has biological children of her own. Each has at least some college education, with four having earned either college or graduate degrees. Seven adoptees self-described as being White, and two others indicated being bi- or multi-racial. Two identify as Asian and are of Korean descent, although one describes herself as being reared "White" by her adoptive parents. One shared that her race/ethnicity is unknown to her as an adoptee. Although not part of the sampling strategy, respondents from both low and high risk perception groups were evenly split on their compliance to age-specific mammography guidelines.

Mammography compliance designations for three respondents warrant further explanation (see Table 4.12). When completing the online questionnaire, Michelle confirmed that she satisfied all inclusion criteria which included being at least 40 years of age. In addition, she selected '1967' as her birth year from a pull-down menu, the most recent date listed. However, during her phone interview, Michelle revealed that she was 38 years of age, two years shy of the recommended age for initiating regular screening mammography. Her transcript was retained for analysis with this caveat given its richness in demonstrating key concepts of relevance to the research questions. Abigail underwent screening mammography in between the time period of completing the online questionnaire and participating in the telephone interview. Because a pattern of compliance could not be established, Abigail was categorized as noncompliant for purposes of qualitative analysis. Nancy is considered compliant with mammography screening guidelines, although due to benign breast symptoms, she undergoes screening on a more frequent basis than standard guidelines recommend.

Stories about Adoption and Searching for Birthparent Information

To establish rapport, the researcher, herself an adult adoptee, began each interview and/or e-mail dialogue by asking respondents to tell their adoption stories and describe their current

Pseudonym	Age	Race/ ethnicity	Education	Perceived Risk	Mammography Compliance	Last Exam
Linda	55	White	Some college	Low	Yes	Within past year
Kate	49	Asian	Some college	Low	Yes	Within past year
Michelle	38 ^a	Asian, reared "White"	Some college	Low	Yes ^b	Never
Barbara	47	Multi-racial	Some college	Low	No	1-2 yrs. ago
Alicia	42	Unknown	Some college	Low	No	Never
Celeste	54	White	Some college	Low	No	1-2 yrs. ago
Janice	42	White	Some college	High	Yes	Within past year
Nancy	42	White	Graduate degree	High	Yes	Within past year (every 6 months)
Susan	45	White	College graduate	High	Yes	Within past year
Debbie	46	White	Graduate degree	High	No	1-2 yrs. ago
Jacquelyn	52	White	College graduate	High	No	1-2 yrs. ago
Abigail	44	White/ Puerto Rican	Some college	High	No ^c	Within past year

Table 4.12: Description of Respondents Who Participated in the Qualitative Phase

^a = on phone interview; ^b = <40 yrs. of age; ^c = recently compliant as determined during phone interview (previous interval established online was 3-4 yrs. ago).

interest in and motivation for searching for their birthparents, which can range from no interest/action to receiving only non-identifying information to establishing personal contact for purposes of reunion. Analysis of these stories falls outside the scope of the present study; however, brief, biographical chronicles (Coffey & Atkinson, 1996) are presented below to introduce respondents to the reader and to provide context for the analytical interpretation that follows.

Linda

Linda, 55, describes feeling like a "fish out of water" in relation to her adoptive family. Even today, she describes not feeling bonded or close to them. Her initial interest in searching for her birthparent(s) developed during adolescence, a time during which she felt "not very pretty." She has searched off and on over the years, most intensely during the last decade. Her search experience has led her to understand that her birthmother "truly did not have a choice" in placing her for adoption and that "she truly did what she thought was in my best interest at the time." She suspects that her birthmother has not searched for her out of shame. Because of that, coupled with having a common surname at birth, Linda believes it's unlikely that she'll locate her birthmother, likening her search to "looking for a needle in a haystack."

Kate

Kate, 49, was born in Korea and for the first 10 years of her life lived in an orphanage where malnourishment, neglect, and even abuse occurred. She was adopted by a young couple from America who already had two biological sons, so Kate joined the family as the older sister. She described herself as a child who never smiled and had no joy. "I was the most downcast little child, the worst a poster child could be." She credits her adoptive family as saving her life in a way, and she's eternally grateful to them. Kate remains close to her adoptive parents and siblings, who are all still living and reside in the same state. She describes having a "bad start but a wonderful ending." Kate is the only adoptee interviewed for this study who has taken no formal steps toward birthparent searching, explaining that she has "very small hope of finding anything out." Kate is an active member of a local Korean adoptee association that provides cultural enrichment, emotional support, and friendship.

Michelle

Michelle, 38, also came to the United States from a Korean orphanage at the age of six. Michelle never knew her birth mother, who died when Michelle was a baby. The exact details are unknown to her, but Michelle grew up thinking her mother died in childbirth. She remembers being dropped off at the orphanage by her grandmother with a promise to return, but she never saw her again. In addition to her grandmother, she remembers her biological father, an abusive alcoholic who used to beat her, as well as an older brother and sister. Michelle was adopted into a "White family" with three biological children, two boys and a girl. Michelle's age placed her in the middle of this sibling group, but she appeared physically like the youngest due to being malnourished and severely underweight at the time of her adoption. She never bonded with her adoptive family members who Michelle described as abusive. Michelle left home at 17, having never returned to the "unhealthy environment" of her youth, and does not maintain contact with anyone in her adoptive family. Michelle traveled to Korea about four years ago to search for information about her birth family. Because records were not kept by the orphanage at that time, Michelle's search was unsuccessful. She has serious doubts about ever successfully completing her search. "There's so little information, you just hit too many dead ends, and it's so emotionally draining." Michelle, now married, finds a sense of family, belonging, and kinship among other Korean adoptees in her local area who meet and socialize together on a regular basis.

Barbara

Barbara, 47, was adopted by older parents in their 50s. Barbara always wanted to search for her birth parents but believed this would be hurtful to her adoptive parents. In her early 20s, Barbara wrote to the adoption agency for non-identifying information, which she then kept without taking further action. Around that same time, the state in which she was born created a reunion registry which required registration by each triad member—the adoptee, the adoptive parents, and the birth parents. Given that Barbara did not want to offend her adoptive parents, particularly her mother, she planned to "[wait] until they passed away" before making subsequent search attempts. When Barbara turned 40, she was experiencing health problems that renewed her search interests. At this point, her mother had developed Alzheimer's disease and her father was quite elderly, relieving her guilt burden about searching. Barbara hired a master of the court to conduct the search, who was eventually successful in locating the maternal side of her birth family. Unfortunately, however, Barbara learned that her birth mother had died in 1969, when Barbara was 10 years of age. Barbara was able to contact her birth mother's brother, who learned of her existence for the first time. Two weeks prior to her phone interview, Barbara's birth uncle sent her a packet of information detailing, to the best of his knowledge, the family tree and the medical history of its family members.

Alicia

Alicia, 42, longs for information about her birth parents and desires reunion. Her search interests are supported by her adoptive mother. Alicia refers to the "dark side of adoption" and distrusts the adoption agency that handled her case. She suspects being the product of incest, which she believes is something that gets passed down in families. She is interested in reunion for the sake of her own children, to get a better understanding of them as individuals.

Celeste

Celeste, 54, grew up feeling "unwanted" and "thrown away." She did not mention much about her adoptive family members, other than the fact that she has similarity to them in physical appearance, which is reflective of the placement practices during the time period in which she was adopted. Celeste has always been interested in searching, especially for her birth mother. She has received non-identifying information but has not located either birth parent. She expressed doubt in ever being successful in her search due to limited information, time, and financial resources.

Janice

Janice, 42, describes her adoptive parents as "wonderful." They explained to Janice that she was adopted at a very young age and made her feel "special and chosen." Janice is a longterm searcher, going back over 25 years. Her interest in finding information about her biological roots piqued initially in early childhood and accelerated in adolescence when she became pregnant at 15 with her first child. When Janice approached her mother for information about her adoption so that she could obtain medical history for her baby, her mother gave it to her willingly. Being an adoptee who is actively searching is a major aspect of Janice's identity. Janice has written to the courts, the hospital in which she was born, the social services agency that handled her adoption, as well as members of the state legislature as part of her quest and advocacy efforts. So far, her search efforts have yielded little information. The cost associated with searching in her birth state is a major impediment, as is its distance from her current state of residence.

Nancy

Nancy, 42, explained that her primary interest in searching for her birthmother used to be based on "health reasons." Upon reflection "both on [her] own and with therapist professionals," she now describes "a deep sense of sadness" and "a deep need to connect with the woman who gave [her] life," citing an ever present "hole in [her] heart and in [her] soul" that began "moments after [she] was born." At this point in her life, Nancy desires reunion, but not a mother/daughter relationship per se. Nancy has begun to accept the fact that reunion is increasingly less likely given "state laws, time, and my own age." Nancy made no mention of her adoptive family members.

Susan

Susan, 45, describes an "overall lack of identity" as an adoptee, at times feeling "detached from herself." She has been searching for her birth mother "off and on for 20 years," having located her very recently through a private investigator. Susan sent her birth mother a letter to initiate contact but has not, as of yet, received a response. Susan is motivated primarily by the desire to fill the void in her identity and is open to possible reunion. She's "most definitely" interested in medical and family tree information as well.

Debbie

Debbie, 46, has some oral history passed down to her from her adoptive mother both directly and indirectly through a "nosy neighbor" who lived next door to her family as a baby. She questions the complete veracity of the information, sensing, perhaps, that she was not getting the full story from her mom who told her that the records at the hospital where she was born "burned up." Debbie knew from a very early age, around 3, that she was adopted, and her parents made that a point of pride. As a teen struggling with identity issues, Debbie became interested in her biological roots and began asking her mother for information. It was clear that her mother "[felt] really bad" when she raised this topic, so Debbie was reluctant to delve much further. In her mid-20s, Debbie joined an adoptee group that, among other things, advocated for changes in adoption law. As her parents aged and, in the case of her mother, died, Debbie felt free to search for information. Now, Debbie is interested in medical history information for her sons and herself as she gets older. Several years ago, Debbie engaged in a search process with the support of others who are knowledgeable about search tactics. Through fabrication of situational circumstances and a slip-up by a hospital staff member, Debbie was successful in obtaining the first letter of her birth mother's name, her own last name at birth, and some vital

statistics documented in her hospital birth record. However, Debbie received "no real [biological family] medical history to speak of."

Jacquelyn

Jacquelyn, 52, related feeling a void and that she "always felt like [she] didn't quite fit in." Jacquelyn describes herself as "constantly hoping and searching." She has hit many dead ends during her quest for information about her birth circumstances, which leaves her "depressed." She was born and adopted in two different states, both with sealed records, and believes that she does not have the financial resources to fight the courts and/or pay for searchers. Her primary motivation for searching is to obtain "medical history and ethnic background," although Jacquelyn is also open to reunion at least in part because it would shed additional light on her "missing information." She describes lack of biological family medical history as a significant source of stress for herself and her children, on whom it is "tough not knowing their background." On several occasions, interactions with friends and her children's schools, churches, sports and recreational organizations, and, of course, doctors, have reminded Jacquelyn about the importance placed on family medical history information by others, experiences which have often left her uncomfortable and stressed.

Abigail

Abigail, 44, was adopted at 6 weeks of age by older parents "who missed the pitter patter of little feet." Abigail describes her adoptive family as "very loving, supporting, and caring," who never kept her adoption a secret. Abigail has an older adoptive sister, biological offspring from her adoptive parents, and mentioned having a brother who is also an adoptee. As a teenager, Abigail struggled with feelings of abandonment. Even though she felt close to her adoptive family, she knew she would search one day. Quite simply, Abigail felt too guilty to initiate a search while her parents were still living. In particular, Abigail felt she lacked connection to anyone who resembled her. As Abigail grew older and started her own family, her curiosity about her biological family background heightened. As an adult, having family medical history was Abigail's primary impetus for searching for information. Abigail spoke of recent reunion with her birth mother and other birth relatives, which she found overwhelmingly disappointing and not at all similar to the situation Abigail had hoped for, and even fantasized about. She looks back on her search effort and its results as "[opening] a can of worms." Even before meeting in person, Abigail was steadfast in that she was not looking for a motherdaughter, nurturing relationship at 45 years of age. After meeting in person, Abigail is now not certain that she will maintain contact with her birth relatives, "unless something was to come up," and even then, Abigail envisions only calling by phone. According to Abigail, the socioeconomic, educational, and lifestyle differences are simply too vast to forge a comfortable relationship.

How Adult Adoptees Construct Estimates of Breast Cancer Risk

The remainder of the chapter presents a theoretical narrative that summarizes the researcher's interpretation of the core meaning found in the qualitative data. The following interpretation was rendered through the analytic process described in Chapter 3. The results are presented thematically to advance understanding of the varied processes used to construct personal estimates of breast cancer risk. Adoptees' lived experiences with not having access to biological family medical history information are shared to illustrate how interrelated thematic elements shape a lay understanding of disease risk. In particular, adoptees engage in a multifaceted cognitive process that takes several factors into account to create an overall sense of risk.

As described below, adoptees weigh the following factors for their relative influence on risk: salience of breast cancer as a disease threat, cognitive focus on risk controllability, behavioral control of breast cancer risk, and internalization of familial risks. As detailed in the following narrative, each theoretical construct is presented using polarized examples emanating from adoptees' stories explaining personal estimations of breast cancer risk, both low and high. Table 4.13 is offered as an advanced organizer for reviewing themes contained in the narrative.

	Influence on P	erceived Risk
Theoretical Constructs	Decreases	Increases
Salience of Breast Cancer as a Disease Threat	 Lack of personal relevance 	 Personal relevance
Cognitive Focus on Risk Controllability	• Within sphere of control	 Outside sphere of control
Behavioral Control of Breast Cancer Risk	 Preventive lifestyle behavior 	 Risk enhancing behavior
	 Screening as early detection 	 Screening as prevention (i.e., illusion of control)
Internalization of Familial Risks	 Avoidance 	 Acceptance

Table 4.13: Thematic Elements Contained in Theoretical Narrative

Threat Salience

Lacking personal relevance. One theme found only among those with low perceived risk is that breast cancer is not a topic with much personal salience. For Alicia and Kate, a knowledge gap about risk factors may be present. Alicia, for example, downplayed her need for mammography screening because of being "small busted." Kate seemed relatively unaware of the link between family history and breast cancer risk elevation. Moreover, throughout her interview, Kate presented a fatalistic attitude toward disease risks in general and undervalues preventive behavior for breast cancer as beneficial, stating, "Either you either get it or you don't get it." Here, Kate questions the value of having information about biological family medical history.

As for myself, it doesn't seem like it matters whether my mother had breast cancer or my aunt or uncle, or relative, because the fact is, I myself, feel like whatever comes to me health-wise, doctors only can handle the current situation. So, I don't know if anything in my family history can help me. (Kate)

Lack of numeracy skills may also be a problem for Kate, who mentioned struggling in school and having problems with English as a second language. When asked to react to statistical information about the *risk* of developing breast cancer one day, Kate replied, "Well, there's nothing I can do I guess. Really, I feel once I've been diagnosed, I can't do nothing [sic] about it. I already have it."

Michelle described her lack of knowledge about breast cancer risk factors when asked to react to risk statistics. She attributed her knowledge gap to never having had a reason to seek out information about breast cancer.

I don't know too much about breast cancer. Maybe I should, but most people if you don't have it or if you don't know your family history, you don't learn about it because you're not thinking about that you're going to get it. If I knew that my mother or my aunt or whatever had breast cancer, then I'd be more interested in learning about it to make sure that I'm not prone to it. But, without that, I just don't know, I shouldn't use the word 'disinterested' but I'm not interested because it's something I don't think about... I mean, I don't have any friends with breast cancer either. Sometimes if you have a friend, you want to find out what is this thing they have? But I don't have any friends with breast

cancer either, so I don't really know about it. When you're not around something that you or anyone you love has it, you don't tend to find information. (Michelle)

Linda, too, has no vicarious experience with breast cancer and explained that her mammograms have thus far come out "clear and fine." However, she does have experience with heart disease through her adoptive father's bypass operation. Admittedly, Linda fears heart disease more than breast cancer and even recalled specific cues she received in the media (i.e., on the Oprah Winfrey Show) about heart disease and current diagnostic technology. Both of these examples offered by Michelle and Linda demonstrate the cognitive heuristic called *availability*. A tenet of availability is that individuals will overestimate risk given the presence of environmental and other cues. For Linda, heart disease represents a more salient concern. For Michelle, not having breast cancer in her social environment allows the disease to fall "off radar."

Personal relevance. In contrast, the threat of breast cancer resonates with Barbara, Nancy, Debbie, Susan and Janice, and, with the exception of Barbara, each believes her personal risk is high. In her elicited text, Nancy described having "concern" about her risk for breast cancer, which, at least in part, is fueled by having some breast symptoms. In her words, "I have had a small lump for several years that has been closely monitored and as of this writing has not 'turned into' anything of concern for my doctor." Debbie mentioned "different kinds of cancer" as being one of her chief health concerns for the future, adding, "You don't know sometimes until the last minute." Although the impetus for which was not shared, Debbie reported attending a training in breast self-examination. Despite efforts at skill development, Debbie's self-efficacy for BSE remains low. You're supposed to check yourself. But that's frustrating because, I've even gone to a little class on it, and I still don't get it. It still seems like there might be little things there, and they say it's nothing... I just don't think it's very accurate. (Debbie)

Barbara, who considers herself at low risk for breast cancer, has fibrocystic breasts and a history of bilateral breast biopsies. In light of not having biological family medical history information, she views personal breast symptoms almost as an advantage. Upon probing, Barbara clarified feeling rather fortunate that she has not had to depend solely on absent biological family medical history as a motivator for seeking healthcare. Moreover, she acknowledges her preference for less ambiguous circumstances when making healthcare decisions, a luxury she has not commonly experienced. Here, she shows appreciation for the simplicity of a clear-cut decision to undergo mammography.

Barbara: I've had bilateral breast biopsies, although this is something that I knew I had fibrocystic breasts, but as soon as I felt a lump, I went on to the doctor. You know, so you have to keep track of this sort of thing. I don't think not having a family medical history would make me more prone to do it, it's just the fact that not having a family medical history has made it more easy. Because your doctors are always urging you to have mammograms...

Interviewer: So, I want to clarify something you just said. You said not having your medical history made it easy to avoid going to the doctor or just made the process easier? *Barbara*: No, no. What I'm saying is that by not having it, a lot of the decisions I've made health wise in terms of staying on top of things was done routinely, not because I didn't have a family medical history...Because of the simple fact that I knew I had fibrocystic breasts..., if I felt something that seemed suspicious I would get it checked, as

opposed to, because I didn't know my family medical history. I did know that I had lumps in my breast.

Breast cancer carries additional salience for Barbara through the vicarious experience of friends, yet her own perceived risk remains low. Barbara's quote here foreshadows another theme that surfaced more prominently among the high perceived risk group, worry as part of risk internalization. Barbara illustrates this concept well, although she tends to remain somewhat of an enigma when one contemplates her low verbal risk perception score relative to personal and vicarious experience.

And, I have friends where the mothers and the daughters have both breast cancer and ovarian cancer. One friend had a prophylactic hysterectomy because the sister had breast cancer and because of whatever that gene is that makes it more likely that she was at greater risk for ovarian cancer, so she had a prophylactic hysterectomy...It caused some concern about breast cancer when two friends get diagnosed. You start realizing, yeah, it can happen. It did cause some concern, but it's something in the back of your mind, as opposed to something in the front that I was worrying about a lot. (Barbara)

Susan and Janice also have vicarious experience with cancer through their adoptive parents. In her elicited text, Susan briefly discussed that her mother is a breast cancer survivor and that she hopes to spare herself and her children that experience. Further, Susan has participated in at least one community breast cancer awareness event in symbolic support of her mother. Janice provides another example of threat salience in that "both of [her] parents died of cancer." Although questionably informed about genomics, the topic resonates for Janice who considers herself at higher risk for breast cancer. Because both of my parents died of cancer, I kind of keep up on the cancer thing. And, when I hear anything about cancer, I really tune into it. And, I've heard that there is a cancer gene that is passed on in everybody. They just don't know what triggers that cancer gene to re-populate as a threat. So, it's not "Will you get it or will you not get it?" It's "What's going to trigger that gene to start spreading through your body?" (Janice)

Cognitive Focus on Risk Controllability

Risks within sphere of control. A second theme that predominates among the adult adoptees with low perceived risk for breast cancer is placing cognitive emphasis on risk factors within their control. Linda and Michelle have made a conscious choice to save their intellectual energies for tangible realities, not abstractions posed by an unknown biological family medical history. Michelle, in particular, doesn't mince words.

I would like to age gracefully, so I think that's what motivates me, not that I think I don't know my medical history, so, therefore, I need to take care of myself. It's just that I want to age gracefully. I don't want to be fat and all this other stuff...I don't think I ever really think about medical history...I just don't think about it. I don't worry about. I don't know anything, and I don't have [a known] family history of breast cancer so I just don't worry about it. I mean, it'd be the same as if I walk out the door, I can't be worrying about if I'm going to get mugged or not. (Michelle)

Linda describes personal growth that comes with aging and reflection. While acknowledging that having biological family medical history might provide valuable information, she's made a conscious effort to not use emotion-based coping in the area of genetics, which would include worry. "You know what? I can't worry about what I can't control. This is something that I can't control, and so I just have faith that everything's going to be OK." Linda remarked that this is a relatively recent revelation, adding, "It's taken me a long time to get that."

Linda wondered whether her proactive approach to healthcare, described more fully in the section on behavioral control, would be the same if she weren't an adoptee, citing nonadoptees who also take proactive stances. For her, it's hard to separate being an adoptee from her conscious decision not to worry about what she doesn't know in terms of biological family medical history.

I think it just makes me try to be very, very proactive. I don't know if I knew [birthparents], whether I'd still be the same. You know, I know lots of people who do know their medical [history] and are very proactive too, so I don't know. Uhm, part of me thinks that's part of it, and then part of me thinks that I've made a choice that I just can't worry about what I don't know too, so, uhm, I don't know if that would make any difference or not. (Linda)

Linda makes a concerted effort to surround herself with positive energy as a means of controlling stress which she feels can be deleterious to health. Linda's approach is about staying centered which allows her to feel in control. Michelle, on the other hand, chooses not to think about not having biological family medical history to avoid feeling out of control. As she puts it, "I can't really think about anything of that nature because then I'd have to think about every disease and sickness out there and be paranoid about it."

Risks outside sphere of control. In contrast to Linda and Michelle, other adoptees concentrate on risk factors outside their control when constructing their personalized disease estimates. Kate, Celeste, Debbie, Alicia, Susan and Nancy attributed the lion's share of their breast cancer risk, whether perceived as high or low, to relatively uncontrollable factors, namely genetic inheritance and environmental exposures, both general and specific. While this theme may not stand alone in tipping the figurative risk perception scales, it should be considered in light of other complementary processes that are described herein.

Alicia and Susan have low and high perceived risk, respectively. When asked to describe their personal risk factors for developing breast cancer, each mentioned "genetics" or "heredity" as primary. Celeste, Debbie, and Janice each mentioned family history's largesse with breast cancer risk, but also expressed belief that environment plays a prominent role, a link which has not been firmly established scientifically (ACS, 2007, What Causes Breast Cancer?). Following are quotes related to the aforementioned query.

Celeste: Family history, toxins in our food supply, the food and water containers we use, toxins that are in our environment that we inhale or otherwise ingest.

Debbie: I think that genetics would be the most prominent one, and then a second area could be environmental.

Janice: Well, obviously, I don't know if it runs in the family. I think a lot of cancers are environmental, as well as genetic. And, in [my city], there's a lot of pollution, a lot of smog, and a lot of contributing factors that can cause cancer in general.

Kate places all her risk attribution "eggs" in the same basket, environmental exposure to electric fields, in particular. This was a dominant thread woven throughout Kate's interview. As presented elsewhere, Kate doesn't have a lot of belief in the idea that individuals can control their disease risks, other than removing oneself from environments deemed harmful. When asked to describe her personal risk factors, Kate compared life in the U.S. to her life as a young girl in Korea.
[Another] risk factor might be radiation through electronic equipment, electronic appliances, all the electrical things we encounter. If I was out in the country without all these electric equipment and appliances, I would say I wouldn't have the percentage that I mentioned likely to have breast cancer. (Kate)

She went on to describe her risks as a first-generation American. Kate described cumulative exposure to electricity as risk enhancing, dismissing aging and other potentially missing "third variables" as carrying any etiological weight.

All these things, you go through the airport, you get checked with equipment. You go to the grocery store and the scanning—they're all electronic. You have all these electrical waves every day—the stores, the workplace, everywhere we go, we're bombarded ... Maybe you don't get it if you're from a remote area, your whole family line. Like I said, the more you're in an environment that has a high electrical environment, every generation that's in that environment the greater each generation is susceptible of developing. For myself, I'm a first generation. I've been here [in the U.S.] 40 years in a high-tech world, so my chances are getting greater and greater of getting any type of cancer. You know, I don't think breast cancer is any higher risk than any other cancer. (Kate)

Behavioral Control of Breast Cancer Risk

Lifestyle. Respondents were asked to describe their risk and protective factors for breast cancer. Strikingly, everyone except Kate in the low perceived risk group mentioned the roles that diet, exercise, and weight management play in reducing breast cancer risk. Kate assumes that her American diet places her at slightly higher risk than if she had maintained a traditional

Korean diet. For Michelle, eating a healthy diet and exercising are examples of functioning within her sphere of control and not focusing on uncontrollable risk factors like family history.

The only thing I can do is try to eat right and exercise and be as healthy a person I can be and not worry about if I'm susceptible to certain types of cancer or conditions. I just can't because there's nothing I can do about it. I don't have any [knowledge of my] history, but other things that I can think about within my control, I can do things like that... just eat right, exercise, that's the only thing I can use for any kind of prevention without knowing anything, just kind of stay healthy. Live a balanced life, and hopefully that will do it. (Michelle)

Celeste, Linda, and Alicia approach diet and exercise in a generalized fashion, although their practices are perceived as contributing to lowering breast cancer risk. Celeste, who is environmentally conscious, mentioned "cleaning up [her] diet radically and changing the types of food storage [her family members] use" as personal strategies in cancer control. Linda supposes that "[trying] to live a healthy lifestyle, [exercising], and that sort of thing" along with "[keeping] an even keel" have provided some protective benefit in regard to breast cancer. However, she recognizes that her "roller coaster" weight gain and loss cycles, present since adolescence, put her at some risk. Alicia, too, tries to "eat right" and takes vitamins and other nutritional supplements including "ginseng, gingko, a multi-vitamin, vitamin E, vitamin C, flaxseed oil, calcium, garlic, and a couple of others." Alicia's smoking, however, belies her low risk perception score, leaving an impression of behavioral inconsistency, if not cognitive dissonance.

Barbara's dietary behavior is specifically tailored to manage or not exacerbate problems with fibroid tumors. In particular, she "made a definite effort to stay away from soy products" to limit exposure to phytoestrogens. In doing so, Barbara recognizes potential spillover benefit in reducing breast cancer risk. Obesity is another modifiable risk factor for both conditions which concerns Barbara. Having recently lost a significant amount of weight, Barbara admonishes herself for not doing more to further lower her risk for breast cancer, especially now that she's menopausal.

I feel like I could make a lot more changes in terms of diet, fat, continuing to lose weight, finding time to exercise and things like that. I feel like the risk factors are probably high in some areas; for some other things, there's nothing I can do about it at this point... I'm no longer having periods any more. So, I would say that probably I'm either in menopause or I'm post-menopausal. I don't know, I believe that's also a risk factor [for breast cancer]. (Barbara)

Debbie and Janice, who perceive their risk of developing breast cancer as high, also mentioned using diet and/or exercise as preventive strategies. With Debbie, exercise behavior carried less intentionality, and she expressed uncertainty about whether exercise was associated with reducing breast cancer risk. In response to the question "So, are there other things that you do to protect yourself against breast cancer?" Debbie replied, "Give me some ideas of what else I could do…I really don't know what else I could do… I do exercise, not as much as I should, but I'll be doing better in January. If that has anything to do with breast cancer, I do that." Janice was proud of her family's seasonal vegetable consumption and, in particular, her husband's role in cultivating the garden. Still, this preventive behavior was mentioned in juxtaposition to less healthy behavior.

Yeah, we try to eat healthy, fresh vegetables when we can. The climate, you know, goes cold to warm. We try to eat, my husband plants a vegetable garden every spring, so we

eat from that. So, we try to maintain a healthy lifestyle. Granted, you're going to go to Burger King once in a while. And, for the most part, we rarely drink. We both cut back our smoking. And, we're working on quitting that, and, you know, exercising and getting our checkups. Is there more that can be done? (Janice)

Susan, Jacquelyn, Nancy, and Abigail, all of whom scored high in perceived risk, curiously did not mention diet and exercise in their preventive repertoires. Susan, in fact, admitted needing improvement in this area, adding, "I don't smoke any longer, but am still slightly overweight and drink on occasion." Nancy, too, mentioned being overweight but not obese. Abigail, also a smoker, rejected the idea that she should think about preventive measures for breast cancer. In her words, "I don't wake up everyday thinking what can I do, what can I take, so that I don't get hit with cancer? I'm not paranoid. That to me just sounds like paranoia. So, no, it's not in the forefront of my everyday thinking." Moreover, she questioned whether diet had any effect on breast cancer risk, yielding perhaps to a sense of fatalism or an external locus of control.

They say anything and everything that you do nowadays, cancer, cancer, cancer. You know, don't microwave this, don't leave your water bottles in the car. Everything's linked to cancer, so I don't know really. I haven't really done a whole lot of research on it, but, you know, if it's genetic and I'm going to get it, I'm going to get it. Uhm, can I avoid it? I don't think so. I mean, diet and nutrition's going to play a role with me avoiding it? I don't think so. You know, so I really don't know what else I can do aside from just going for a mammogram every year. If I'm going to get it, I'm going to get it. (Abigail)

Jacquelyn, a smoker, also indicated screening as her primary preventive strategy, as did Nancy, a non-smoker and non-drinker. This repeating idea within the behavioral control theme warrants additional discussion below.

Screening. As previously mentioned elsewhere, screening modalities for breast cancer which include mammography, self-breast exam, and clinical breast exam are all tools for early detection of breast cancer. Each does nothing, however, to prevent the development of the disease. Rather, screening offers the opportunity to arrest further development of the disease, which is more treatable if detected early. In this way, screening is thought to prevent a worse case scenario. However, if using the cognitive heuristic *illusion of control*, women seeking screening mistakenly think that they're engaging in preventive behavior that lowers their actual risk. Interestingly, the data among adult adoptees who consider themselves at high risk for breast cancer reveal this type of heuristic thinking. When asked to describe their protective factors or behaviors to prevent breast cancer development, Nancy, Debbie, Janice, and Jacquelyn each cited at least one screening modality.

Nancy, who monitors benign breast symptoms, has "a mammogram every 6 months and [sees] a 'breast specialist,' not a regular doctor." She further describes "health practices steeped in vigilance," "not [missing her] yearly check-ups," and "[keeping] careful notes on changes in [her] health and a file of all check-ups." Nancy has noticed that her approach to healthcare consumerism is "much different than many of [her] non-adopted friends who put off appointments or who do not follow up with tests."

In addition to receiving an annual clinical breast exam by her physician, Debbie began mammography at an earlier age than standard guidelines recommend because of not having her biological family medical history. She recalls being the first to suggest early screening, not her doctor, who was content to follow standard guidelines for patients with average risk.

I asked my doctor to pretty early on, um, start the mammograms. And, so, I get those done annually. Um, you know, she said, "well, you usually don't…." I don't know when I started, but I know it was a couple of years earlier than what they ask you to, and I told her, "well, I'm adopted and don't know my history, I'd like to know." So, she started them then. (Debbie)

Similarly motivated by not having biological family medical history information, Jacquelyn described performing "self exams regularly and [having] mammograms regularly." Janice wonders if her screening practices, which include breast self-exam and mammography, are sufficient to stave off disease.

Well, I do my breast exams every month and my mammograms once a year, but is that enough? You know, because I don't know history. That might be a question for any woman. I do my breast exams. I get my mammograms. Is that enough to circumvent getting cancer? You know, anything to stop it. The only thing you can really do is have early detection. (Janice)

In contrast, Linda, who believes herself to be at low risk for breast cancer, makes a clear distinction between prevention and early detection.

You can be walking around with a time bomb and not even know it. But, what I have done is I just try to be really proactive with my health screenings, and I try to do everything possible I can to ensure, you know, if anything does occur, you know, you're on top of it. Like my mammograms, I make sure to keep up with them. Other than that, I've chosen to make good decisions. (Linda)

Internalization of Familial Risks

Avoidance. A prominent theme observed most keenly in the low risk perception group involves avoiding the internalization of risk information. Cognitively, this occurs in several ways labeled here as normalizing, deflecting, and discounting. Each will be presented in turn with relevant examples from adoptees' lived experience.

Each in their own way, Barbara, Kate and Michelle make efforts to normalize their circumstances as an adoptee. They are able to remind themselves (and consumers of this research) that while they have actual risk, they are no different than anyone else in that regard. The difference is that they have fewer "pieces of the puzzle," to quote Barbara.

Given an example of a famous person with breast cancer, Kate responded, "Well, it's nice that the celebrity speaks up and says it can happen to anybody." In a sense, Kate is repositioning herself back into the mainstream population. Michelle acknowledges that risk is uncertain by its very nature. She offers a flip-side explanation analogous to "stuff happens." In her words, "I don't want to sit here and say that just because I see the gynecologist once a year and exercise and eat healthy doesn't mean [I'm] not going to get breast cancer." In another example of normalization, Barbara thinks about her risk from a population average perspective.

Well, the thing is, it's a scary thought, because I still don't have all the information. You know, I don't know if it means I'm at increased risk, but it means I'm at risk obviously. But, I have no way of assessing how much that risk is other than knowing I have this generalized risk for breast cancer... I know how it runs in families, and I know there's a possibility of increased risk, but I don't know what that would be. So, it's just one of those things where you just have to treat it as if you're at increased risk anyway. (Barbara)

Barbara also demonstrates the use of deflection as a strategy for avoiding internalization of risk, even though she's well aware that she's doing it. Deflection is viewed as pretending that biological family history-related risks, while decidedly abstract for adoptees without information, don't apply or don't exist. In other words, the approach to constructing a personalized disease risk estimate may be characterized as "ignorance is bliss."

It's almost as if you know you have these risk factors, but they're just so vague because everybody has these risk factors. You read an article which [talks about the importance of family history], but it's almost like it doesn't ever apply to me. Unfortunately, I can't use that information because I don't know. (Barbara)

Michelle echoes this idea of blissful ignorance in regard to not having biological family medical history information, saying, "In a way I suppose ignorance keeps me worry free." She explained further, "I think not having it makes you not think about it. If I knew my background or my family had a certain health issue, I might be more conscientious of it. Because I don't, I just don't think about any kind of health issue because I don't know what kind of health issues I have."

In thinking about her health risks, Janice appears to have a degree of cognitive dissonance. She is a smoker, yet doesn't feel at higher risk for "any sort of cancer." She admits to having a "mentality of it happens to other people, not to me." This cognitive approach carries over to how she processes her potential risk for breast cancer. Janice described her typical reaction to hearing about someone in the media spotlight being diagnosed with breast cancer with a similar sense of denial.

Interviewer: So, is that, sort of how you think about it, that if you don't have the information, then, that risk...

Janice: didn't happen. Yeah. A lot of times yes. Just like when you watch the news on TV, and people go, "it happens in every neighborhood, but it doesn't happen in ours." It's that kind of mentality for me. Well, I don't know anything about it. I don't have any, I don't know, the history about it, so it's not going to happen.

The third form of risk internalization avoidance is termed discounting and was used by two adoptees, one with low perceived risk (Celeste) and one with high (Abigail). Celeste acknowledges family history's importance to disease risk, but seems to minimize it by placing greater emphasis on the environment when making attributions more globally about cancer risk. Following is an excerpt from her elicited text.

As I have little or no medical history (truly it exists, I just have no knowledge of it) it is very much a concern of mine. I do believe that family history is important; however, environmentally we are exposed to many toxins in the air we breathe and in our food supply that can definitely affect our chances of any type of cancer, not just breast cancer. (Celeste)

Abigail's "before and after" story provides an emboldened example of the *representativeness* heuristic at work within the discounting framework. Individuals using this type of heuristic thinking will assume themselves to be at higher risk if they perceive themselves as similar (i.e., a subset) to affected persons with certain risk, or at least known heightened risk. Recall from her biographical chronicle that Abigail located members of her maternal biological family. From Abigail's point of view, the reunion was disastrous, especially in contrast to expectations. In retrospect, Abigail now believes that she "dodged a bullet" by not being raised in the environment offered by her biological family, speculating that she would have likely ended up addicted to drugs and/or in jail. Prior to meeting biological relatives, Abigail, by her

own admission, attributed any health problem to genetic inheritance. Now, after placing herself at considerable social distance from her birth relatives, Abigail has cleaved even closer to her adoptive family and is certain that environment plays the larger role.

Even when faced with actual information about biological family medical history related to breast cancer, Abigail downplays its significance in its potential relevance to her own risk. That is, she uses personal affinity to help construct her disease risk estimate, aligning herself more closely with adoptive family, of whom she feels like a representative member. Here, perceived differences with her birth mother allow her to redirect attention away from her maternal lineage.

Interviewer: You said you found breast cancer in a biological aunt, but it's not pervasive in the family, it sounds like. So, do you feel at less risk than you did before for breast cancer, about the same, or..?

Abigail: Well, pretty much the same. Because, even though I got a clean bill of health, like two months ago, I mean, who knows what's going to happen down the road? You know what I mean? I guess I just have to keep going for my yearly one and keep my fingers crossed. I mean, [the birth mother] does not have it, and her sister is from a different father, so, it could be just on that side of the family and not from my birth mother's side of the family.

Acceptance. In stark contrast to normalizing, deflecting and discounting, a reverse approach to risk construction was observed solely among adoptees with a heightened sense of breast cancer risk. As interpreted from their quotes, it's possible that Jacquelyn and Nancy believe to a certain degree that being an adoptee increases their *actual* disease risk relative to someone who has access to information about biological family history. In describing personal

risk factors for breast cancer, Nancy said, "The only two areas that worry me as a risk factor are family history, or lack thereof, and my weight..." Subsequently, when asked to describe illnesses or conditions that concern her the most, including physical and mental health, Nancy responded that she worries that "not knowing health history can be dangerous for [herself] and for [her] family." She then stated that "cancer or other potentially fatal health issues" are among her chief concerns. Along with smoking and long-term exposure to second-hand smoke, Jacquelyn cited "having no medical history" as increasing her breast cancer risk.

Further evidence that some adoptees may perceive themselves to be chronically at risk surfaced in transcripts from adoptees with, not surprisingly, a heightened sense of breast cancerspecific risk. Nancy, Debbie, Janice, and Abigail each related how being an adoptee and not having information about one's familial medical background creates internal torment. Nancy believes that having family history information would "give me less stress or worry in my own life's situation." Moreover, her self-described vigilant approach to self-care, described elsewhere, stems from worry. According to Nancy, she "[worries] because [she has] no basis NOT to be concerned," adding, "It is the best practice for me and for my life."

Debbie describes increased awareness about a multitude of risks because of not knowing her biological family history. She expressed that adoptees must not solely depend on physicians' advice about risk. In her words, "You know, there are so many risks that we don't know about. So, it makes you worry more about different things. You can't just look to your doctor for what issues they had." Janice, too, indicated heightened risk awareness as an adoptee, which is a major aspect of her identity. When prompted, she replied, "Oh, it's always on my mind... I couldn't even begin to describe what concerns me the most. If I look at the whole picture as to anything and everything that could possibly go wrong with myself or with my children medically, I get overwhelmed."

Despite her disappointing reunion with biological relatives, Abigail recalls a sense of relief once she obtained her family medical background. Before reunion, when hearing about others with breast cancer, Abigail described herself as a "nervous wreck," thinking, "Oh, my god, that could be me, and I don't know [about family history]." Abigail is now worried about getting her cholesterol checked, which is "directly from the birth mom, the high cholesterol." Curiously, a maternal aunt's breast cancer diagnosis did not elevate her concern. Therefore, it seems Abigail is selective about what risks she discounts and accepts for personal application.

Two different cognitive heuristics have relevance to this discussion on chronic worry and risk elevation. As previously mentioned, *availability* evokes individuals' increased risk estimates based on recent or repetitive exposure to the threat, emotionality of experiences related to the threat, and/or rumination. The second, *anchoring and adjustment*, refers to individuals' tendency to make differing risk estimates as dependent on the available starting point and incremental range. In this way, family history serves as an anchor for estimation that both creates and limits perceptions about disease risk, possibly shaping health-related behavior.

Here, Michelle demonstrates how *anchoring and adjustment* influences her thinking. Her example, albeit in the context of alcohol use, also brings *representativeness* back into the forefront as Michelle grapples with the meaning of her biological connection to her father, whom she still remembers. *Availability*, too, might play a role given Michelle's vivid memories of abuse at her father's hand.

The only thing that I used to do growing up, which was very rare, when I was really conscious of my actions, is because my biological father was an alcoholic. So, I read as

an adolescent that alcoholism is passed down, so I was very nervous about becoming an alcoholic. Because if my biological dad was an alcoholic, would I be an alcoholic too? So, because of that awareness, I'm not an alcoholic and it made me as a teenager more responsible. It doesn't mean I never drank, but I was very responsible. (Michelle)

Michelle's story demonstrates how perceived similarity to her biological father affects her risk estimation in regard to alcoholism. While not fully elucidated here, Michelle is somewhat of an extreme case given her chosen estrangement from adoptive relatives, with whom she feels little in common in terms of health. Abigail, on the other hand, portrays in her "before and after" story how lack of affinity to biological relatives (and, conversely, closer affinity to adoptive family) can also impact risk perception, in her case by adjusting it downward in the face of confirmed risk information. Barbara, who feels some connection to both adoptive and biological relatives, albeit in different ways, provides a "middle of the road" example. When describing the illnesses and conditions that concern her the most, those that she feels most likely to develop, Barbara mentioned, along with diabetes, Alzheimer's disease, which affected her birth grandmother, adoptive mother, and adoptive aunt.

Taken together, these adoptees' stories provide examples that illustrate how affinity to one's adoptive or biological family can shape disease risk perception. How perceived sameness and difference are viewed appears dependent on personal circumstances and familial context. Using the representativeness cognitive heuristic framework, perceived similarity or difference in both familial contexts, regardless of consanguinity, has bearing on personal constructions of risk.

Summary

Figure 4.3 depicts the researcher's interpretation of the data as it emerged through qualitative analysis. As presented in the narrative, theoretical constructs appear at the fulcrum.

For each construct (i.e., threat salience, cognitive focus on risk controllability, behavioral control of risk, and familial risk internalization), there are thematic elements that exert either upward or downward pressure on perceived risk during the cognitive process of personalized risk construction. Factors that appear to lower perceived risk will be summarized first, followed by those that tend to elevate one's estimation of risk.

As revealed in adoptees' stories, personal constructions of breast cancer risk appeared lower in the presence of several themes. First, for some, breast cancer simply carries less salience as a threat. Lack of knowledge about the disease and its risk factors contributes to this phenomenon, as does not having experience with breast cancer that emanates from personal health scares or, vicariously, through one's family and other social networks. At times, personal or vicarious experience with other health conditions can also divert cognitive attention elsewhere. Second, adoptees with lower perceived risk seemed to make a conscious effort to focus on risk factors within their control, like diet and exercise, and not ruminate on less controllable risk factors like biological family history which is largely unknown to them. Third, when confronted with biological family history information, either actual or hypothetical, adoptees tend to utilize one of three techniques to arrive at a lower estimation of risk by avoiding the internalization of the threat. Specifically, they may normalize their sense of risk by aligning themselves with others who have access to biological family history information and also face similar risks. Unanchored by tangible evidence, other adoptees deflect the idea that biological family history risks apply to them. Similarly, when attributing risk to various factors, they may discount the role of biological family history as being less important.

Converse thematic elements dominate the stories of adoptees whose personalized risk constructions result in higher estimations of threat. In the wake of prior breast symptoms

determined to be benign, breast cancer carries salience as a disease threat. The disease also carries personal relevance to those with friends and/or adoptive family members with cancer diagnoses and to those who are otherwise attentive to environmental cues. In contrast to adoptees who choose not to worry about an unknown biological family history, others exhibit catastrophic thinking in regard to their lack of information, feeling chronically concerned and disadvantaged from a risk perspective. In its starkest form, some adoptees may internalize the threat posed by not having biological family history as increasing their actual risk for disease. More so than adoptees with low perceived risk, adoptees with higher estimations emphasize uncontrollable factors, like biological family history, when making risk attributions, and, in tandem, may discount the importance of their own behavioral risks.



Figure 4.3. Depiction of thematic elements' influence on personalized risk construction.

CHAPTER 5: DISCUSSION

This chapter serves several distinct purposes and is organized accordingly. First, a brief summary of quantitative and qualitative findings is presented. Second, these findings are discussed as an integrated whole in the context of the research literature on breast cancer risk perception, stress and coping, and screening behavior. Third, reflections on health behavior theory are offered in light of integrated mixed-methods findings. Fourth, limitations of the current study are addressed to guide the research consumer in making appropriate inferences about the data based on the strengths and weaknesses of the research design, data collection procedures, and analytic processes. Fifth, implications for future research and health promotion practice are provided with emphasis on adult adoptees as a special population worthy of further consideration in the era of genomics-based medicine. Finally, discussion culminates in general conclusions.

Summary of Findings

This study utilized a sequential explanatory mixed-methods design to examine how adult adoptees cope with the perceived threat of breast cancer. Structural equation modeling was employed to assess global fit of the proposed stress and coping model in its ability to represent observed covariance and to investigate the interplay of the various factors simultaneously. As planned, qualitative inquiry served to augment quantitative results through more in-depth exploration of selected findings. Model development was informed by the Transactional Model of Stress and Coping (Wenzel et al., 2002), the extant literature on breast cancer risk perception, worry, and screening, and the contextual literature on adoptees and birthparent information-seeking. More specifically, the proposed model depicted the researcher's hypotheses about how female adult adoptees construct personalized risk estimates for breast cancer, engage in problem-focused and emotionfocused coping efforts as a way of managing perceived risk, and arrive at future mammography screening intention. The iterative process of model specification, estimation, testing, and modification ultimately yielded a six-factor solution that provided partial support for the hypothesized relationships. In particular, vicarious experience with breast cancer emerged as a significant stressor that shapes perceived risk and motivates birthparent information-seeking, mammography compliance, and future screening intention, while ambiguity about biological family medical history did not.

Given the epidemiological importance of biological family medical history to breast cancer, qualitative inquiry served to shed additional light on the relationship between ambiguous biological family history and disease risk perception. Specifically, the researcher sought to understand how adult adoptees with a high degree of biological family history ambiguity constructed personalized estimates of their breast cancer risk and how this process differed depending on whether risk perception was high or low. A qualitative contrasting case analysis (Onwuegbuzie & Teddlie, 2003) and constructivist grounded theory techniques (Charmaz, 2006) allowed the researcher to render an overall interpretation of the data. Four theoretical constructs surfaced as exerting positive or negative pressure on perceived risk. As elicited through adoptees' stories, breast cancer risk perception appears to be a personal amalgam of several elements including disease salience, risk factor internalization, cognitive control, and behavioral risk attribution.

Integration of Quantitative and Qualitative Findings

Although qualitative inquiry served to examine the relationship between biological family medical history ambiguity and perceived risk, other factors beyond these constructs naturally surfaced for adoptees as they pondered the meaning of disease risk amidst ambiguous inheritance. Using the data integration process described in Chapter 3, qualitative findings were examined alongside quantitative findings for their complementary, divergent, or corroborative properties. Integrated findings will be discussed next as they pertain to the proposed stress and coping model and related extant literature.

Vicarious Experience as a Stressor

The current study and the extant literature speak to adoptees' particular stressors in healthcare contexts. As demonstrated by structural equation modeling, vicarious experience with breast cancer serves as a stressor that influences risk perception and motivates coping responses both directly and indirectly. Ample support for this phenomenon appeared amongst qualitative data as well, providing further corroborative evidence of its existence. As shown among the sample of extreme cases, breast cancer salience appeared thematically among adoptees with heightened risk perception, and lack of salience was typified by adoptees with low perceived risk. While salience can be garnered in multiple ways (e.g., knowledge acquisition, personal experience with benign conditions, environmental cues), vicarious experience is a clear-cut mechanism with evidentiary support from the literature. Researchers (Katapodi et al., 2005; Kenan et al., 2003a) described elevated risk perception in light of vicarious experience as occurring through cognitive heuristics, specifically availability or representativeness depending on personal circumstances. Among the general population, vicarious experience with first-degree relatives is implicated in elevating perceived risk and screening behavior (Katapodi et al., 2004; Murabito et al., 2001), but research also conflates consanguinity with family history, rendering it difficult to separate out the socioemotional impact versus the knowledge of biological connectedness.

That vicarious experience elevates perceived risk makes female adoptees similar to their non-adopted counterparts, at least in regard to breast cancer for which a "friend effect" has been identified (Montgomery et al., 2003). A key difference for adoptees, however, is that vicarious experience stems from an additional source, the adoptive family. How adoptive family experience compares to friend or biological family experience in terms of risk construction is not addressed here, but that may be of interest to researchers who seek to tease out the more emotional aspect of social closeness versus the more cognitive contribution of consanguinity to perceived risk.

A second potential key difference for adoptees relative to non-adopted counterparts is that vicarious disease experience appears to prompt biological family history information-seeking as demonstrated by the significant direct effect in SEM results. Little research has been conducted on the predictors of family history information-seeking in the general population, so it is difficult to make comparisons to the adoptee population. However, researchers estimate that approximately 30% of American adults have actively engaged in family medical history data collection and that being female, ever married, educated beyond high school, and diagnosed with certain medical conditions (i.e., type II diabetes) make the behavior more likely (CDC, 2004).

Qualitative data and the extant adoption literature on birthparent searching, however, provide additional context for interpreting the link between vicarious disease experience and information-seeking. As discussed in Chapter 2, it is widely regarded that major life events are catalysts for adoptee search engagement (CWIG, 2004; Finkler, 2000; Reed, 1994; Tam, 2004). Indeed, in the present study, adoptees described the timing of search initiation as coinciding with pregnancy, having biological children, personal health problems, and experiencing the death of adoptive parents. It is possible, therefore, that vicarious disease experience serves as yet another developmental milestone in the trajectory of adulthood for the adoptee. In this way, adoptees are confronted with their own aging, particularly if perceived representativeness is also present, and reminded that time is also passing for yet unknown biological relatives as well. Alternatively, one could also hypothesize that birthparent information-seeking stems from the urging of friends, adoptive relatives, or significant others affected with cancer.

Biological Family History Ambiguity as a Stressor

The role that biological family history ambiguity plays in risk construction and risk management is less clear, taking quantitative and qualitative results and the extant literature into joint consideration. In the present study, SEM yielded no significant direct or indirect effects stemming from ambiguity to other constructs in the stress and coping model. Surprisingly and in contrast to the findings of Han and colleagues (2006), quantitative analysis also produced nonsignificant correlations between ambiguity and both perceived risk and disease-specific worry. Key differences with prior research are noted, however, as the present study measured a different type of ambiguity and cancer site-specific perceived risk and worry, whereas Han et al. (2006) employed generalized cancer measures. Other evidence provided through SEM suggests, however, that the family history ambiguity construct was not well measured, tempering conclusions about the lesser importance of this construct to adoptees' threat appraisal and coping responses. In particular, multicollinearity and low R^2 values were observed among some items in this scale. As mentioned earlier, the biological family history ambiguity scale was developed for the present study without prior psychometric validation among an adult adoptee population. While internally reliable (alpha = .91), validity of the scale is suspect. In retrospect, lack of demarcation between maternal and paternal lineage may have yielded overly amorphous data.

Despite quantitative results, there is ample support in the extant literature that biological family history ambiguity plays a role in adoptees' risk perception and information-seeking. Quite fundamentally, having absent biological family history information is a defining feature of being an adoptee (CWIG, 2004; Finkler, 2000), particularly for those in this age group who were typically adopted under closed systems that restricted information sharing. In this way, adoptees' self-identities are formed in the negative space around genetic hegemony which pervades Western culture (Finkler 2000; 2005). As Finkler (2000) asserted, the medicalization of kinship is a primary impetus for birthparent searching, a notion also supported by other researchers as working in tandem with perceived risk (Tam, 2004). Indeed, the right to medical history information is a primary argument among advocates striving for adoption reform toward greater transparency and open records (Baer, 2004).

In the present study, adoptees mentioned or strongly alluded to their ambiguous family histories when describing their personal disease estimation and, with the exception of one interviewee (Kate), acknowledged genetic factors as contributing to disease risk. Despite similar lay understandings about genetics and a similar level of family history ambiguity, adoptees

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constructed breast cancer risk estimates in the present study quite differently. What seems clear is that the varied interpretations of ambiguity's meaning to disease risk differed according to the presence of other factors. As highlighted in the qualitative analysis, adoptees' breast cancer risk perceptions are shaped by the meaning ascribed to lifestyle behavior (i.e., risk-enhancing or risk-reducing), the valence placed on family history as a risk factor (i.e., compared to environmental exposures), the ability to exercise cognitive control over the abstract threat posed by unknown biological family history (i.e., choose not to worry or worry about everything), and the degree to which potential family history risks are internalized (e.g., deflected or accepted).

Together with the extant literature, these results suggest that risk perception may be influenced by a number of moderating factors missing from the current theoretical model. These include coping style (Consedine, Magai, Krivoshekova, Ryzewicz, & Neugut, 2004; Pieterse et al., 2007), tolerance for uncertainty (Buhr & Dugas, 2006; Grenier, Barrette, & Ladouceur, 2005), and knowledge about disease-specific risk factors (Absetz et al., 2002; Audrain-McGovern et al., 2003). It may be prudent, therefore, to include these factors in future model specifications involving family history ambiguity and risk perception.

Reflections on Theory and Directions for Future Research

This section reflects on the use of the stress and coping model and its ability to advance current understanding about adult adoptees' cognitive and emotional responses to the potential threat of breast cancer amidst unknown biological family medical history. Here, three questions will be addressed. First, what contributions did the present study make toward better understanding stress and coping as a model? Second, in retrospect, was stress and coping a useful application for examining screening behavior among adult adoptees? Third, what other theoretical approaches are worth considering for future research efforts?

In general, the exact nature of the relationships among stress and coping model constructs tends to be elusive and highly context dependent (Wenzel et al., 2002). From a methodological perspective, a major strength of the present study is its mixed-methods design. In particular, structural equation modeling allowed simultaneous examination of the interplay among several factors across each component of the stress and coping model. According to Buhi, Goodson, and Neilands (2007), this benefit, along with the ability to correct estimates for measurement error, should thrust SEM into methodological prominence among health behavior researchers who have traditionally relied on statistical techniques of lesser quality including ANOVA and regression. SEM offers, therefore, a more robust way to examine stress and coping model structures. In addition, SEM allows comparisons of nested models, model invariance across groups, and latent growth models. Qualitative contrasting analysis (Collins, Onwuegbuzie, & Sutton, 2006; Onwuegbuzie & Teddlie, 2003) generated theoretical constructs grounded in the data that shed light on alternate or complementary risk construction and risk management processes. These constructs can be incorporated in future specifications of the stress and coping model.

In regard to the present model, results underscore the importance of including emotional aspects of risk perception development along with more cognitive factors. As Gooding et al. (2006) discussed, this feature improves upon purely cognitive theories (e.g., Health Belief Model) that assume a logical application of beliefs predicts behavior. Here, the emotional threat posed by vicarious experience, predominantly through friends and adoptive family members, drove adult adoptees to greater levels of perceived risk, mammography screening, and birthparent information-seeking.

Within the proposed stress and coping model, mammography and information-seeking were regarded as problem-focused strategies to reduce the perceived threat of breast cancer. This operationalization is most consistent with the extant literature (Wenzel et al., 2002). However, given the role that vicarious experience played in the model, findings lend credence to the idea that these coping efforts are, rather, attempts at emotional regulation. Gooding et al. (2006) speculated similarly in their review of health behavior theories as they apply to genetic testing.

Further support for emotion-based processing resides in the small body of literature on adoptees as healthcare consumers. The extant literature on health-related decision making of adoptees (Tam, 2004; Finkler, 2000) posits that feelings about disease risk, stemming from a personal diagnosis or a child's diagnosis, triggers birthparent searching. The present study refutes this assertion through its demonstration of direct and indirect effects. In contrast, evidence points to vicarious experience, not risk perception, as directly driving birthparent information-seeking. What is more, medical information-seeking may be the tangible reason proffered for searching, which is, in fact, rooted in more existential desires. Other researchers (Finkler, 2000; Krueger & Hanna, 1997; Sobol & Cardiff, 1983; Tam, 2004) have speculated as much.

As described in Chapter 2, the more typical application of stress and coping in the breast cancer literature is in the contexts of psychological adjustment to personal medical diagnoses and/or decision making about whether to undergo genetic counseling and testing. In each context, scholarly attention is placed on the reaction (e.g., distress) to newly discovered, strongly suspected, or confirmed information about personal risk. Use of stress and coping to describe the impact of *missing* information about biological family medical history, in this case as it

applies to adult adoptees, is entirely novel. Again, the proposed model was partially supported, and the proportion of explained variance among total scales remained low with the exception of screening intention, indicating significant opportunity for improvement.

In retrospect, the operationalization of perceived control in the 9-factor model was illchosen given the inclusion of screening behavior and not lifestyle behavior. As presently worded, items better reflect preventability than controllability; therefore, the lack of correlation between perceived control and mammography is not that surprising and is even encouraging if we assume that women clearly understand the benefits of mammography. Amusingly, it also points to the researcher's own use of the illusion of control heuristic when conceptualizing the model despite giving scholarly attention to this cognitive shortcut.

Measurement challenges notwithstanding, stress and coping appears to have at least some relevance to understanding the health behavior of persons with ambiguous family medical history circumstances. Given the nascency of this topic, however, examination of other theoretical explanations is warranted. The complexity of the research problem brings several theoretical approaches to the forefront including the Common Sense Model of Self-Regulation (Leventhal, Brissette & Leventhal, 2003; Leventhal, Meyer & Nerenz, 1980), the Social Ecological Model (McLeroy, Bibeau, Steckler, & Glanz, 1988), and the Life Course Health Development Model (Halfon & Hochstein, 2002). Each will be discussed briefly below.

Given focus on cognitive and emotional processing, Leventhal's self-regulatory and common sense models may be useful strategies for examining adoptees' reactions to the stress of potentially having familial risk of disease. According to the self-regulatory model, health threats generate two parallel processes, one cognitive and the other emotional (Gooding et al., 2004). After identifying the health threat, the cognitive process of risk estimation involves evaluating common sense attributes of the disease including its causes, controllability, cure potential/consequences, and timeline for development (Gooding et al., 2004; Kelly et al., 2005). Efforts to cope with cognitive representations of the threat are termed 'danger control' attempts. 'Fear control' attempts, on the other hand, arise from a parallel process in which individuals subconsciously (e.g., avoidance, denial) or consciously (e.g., social support seeking) attempt to manage the more emotional aspect of feeling threatened (Gooding et al., 2004).

This family of models has been successfully applied in various contexts with the goals of understanding psychological adjustment (van Oostrom et al., 2007) and risk perception development (Kelly et al., 2005) following genetic testing and counseling, and development of chronic disease prevention and management interventions (McAndrew et al., 2008). The models could be operationalized for adoptee populations to include birthparent information-seeking and birthparent reunion-seeking to reflect cognitive and emotional coping efforts, respectively, in accordance with parallel processes of self-regulation. The Common Sense Model could help frame the study of personalized risk construction, particularly as it relates to family history risk attribution and perceived timeline for disease development. Further, the model could be extended to include perceived time left to conduct a birthparent(s) search.

A social ecological approach acknowledges the interaction between the individual and his/her physical, sociocultural, and political environment (Sallis & Owen, 2002). The hallmark of an ecological framework is the multi-level approach to population health. The present study focused primarily on interpersonal factors with some attention on the intrapersonal with the inclusion of vicarious disease experience and discussion of social relationships between adoptive and biological relatives that emerged from adoptees' stories. Future research efforts, however, may benefit from widening the lens. With the goal of better understanding screening compliance among adoptees, the breast cancer literature is rife with clues about potentially important predictors that fit within a multilevel ecological framework. To name a few, potential constructs of interest include: physician recommendation (Richards et al., 1998; Juon et al., 2004; Sadler & Fullerton, 2001), access to mammography services, and health insurance coverage (Juon et al., 2004; Richards et al., 1998). Adoption-related policies involving creation and maintenance of adoption records (e.g., inclusion of a third-generation pedigree) (ASHG, 1991; CWIG, 2003; CWIG, 2004), access to adoption records (CWIG, 2006), and use of mutual consent registries (CWIG, 2006; Fischer, 2002), for example, may further shape health practices of the adoptee and, if a minor, his/her parents. Scientific advances in genomics-based medicine (Knoppers & Scriver, 2004; Turnbull & Rahman, 2008) will undoubtedly change the healthcare landscape for adoptees and their healthcare providers who are increasingly incorporating family history tools and genetic testing in primary care (Carroll, Blaine, & Ashbury, 2004; Rich et al., 2004; Wattendorf & Hadley, 2005; Yoon et al., 2002).

A complementary framework to the social ecological model is the Life Course Health Development Model (LCHD) (Best et al., 2003) developed by Halfon and Hochstein (2002). Like the social ecological model, LCHD situates health amidst its "genetic, biological, behavioral, social, and economic contexts" (Halfon & Hochstein, 2002, p. 433) yet adds a temporal dimension that emphasizes change across the lifespan (Best et al., 2003). An individual's health trajectory, therefore, arises from cumulative risk and protective factors and embedded experiences that become programmed into bio-behavioral systems during key developmental periods. As it pertains to health promotion, LCHD is important for understanding determinants of health and strategies for prevention and intervention across developmental stages (Best et al., 2003). This lifespan approach illuminates the need to understand the importance of early experiences and developmental milestones for adoptees which are arguably different from their non-adopted counterparts and may result in varied physical and mental health outcomes in adulthood. Examples abound and include, naming a few: breast-feeding and early nutrition, parental bonding, self-identity development, self-esteem development, sexual-identity development, depression, and substance use.

Limitations

Consumers of this research effort are advised to consider several limitations to the study. These limitations, which span every stage in the research process, affect the quality of inference and applicability of findings to other contexts. In this section, limitations are identified that stem from the researcher's choices in study design, sampling, data collection, and data analysis.

In regard to design, the study provides a cross-sectional representation of a stress and coping process that culminates in adoptees' future mammography screening intention. When measurement is concurrent, the directionality of pathways, which implies temporal sequence in the structural model, is assigned somewhat arbitrarily (MacCallum & Austin, 2000). That is, with cross-sectional data a path drawn in the opposite direction than proposed has statistical equivalence. In addition to temporal priority and sequence, another caveat is that while the interplay of factors is depicted in SEM as an ordered process, causality cannot be inferred without also observing association among factors and ruling out confounding explanations for cause and effect (Buhi, Goodson, & Neilands, 2007; Bullock et al., 1994). Given that the research design omitted a non-adopted comparison group, findings cannot be considered necessarily unique to adoptees. Non-adopted persons, for example, also have ambiguous or unfamiliar biological family health histories.

While inclusive of female adult adoptees in the United States over 40 years of age, sampling and data collection procedures do not allow the findings to be generalized to the broader adoptee population as a whole. Males, for example, were excluded from participation although they do carry some risk for developing breast cancer. Moreover, in the absence of an existing sampling frame, a non-probability sampling technique was utilized that relied on convenience and snowball sampling among adoptees who use the Internet for some adoptionrelated purpose, typically social support or information-seeking about birth relatives. While purposeful and effective for achieving a sufficiently large sample size for structural equation modeling, recruitment decisions excluded non-Internet users and likely minimized participation by adoptees who are not active in adoption-related organizations. In this way, restriction of range is a distinct possibility. Rather than capturing the full range of adoptees' experiences, it is possible that the sample more aptly represents activist adoptees interested in adoption reform, birthparent searchers, and/or those for whom being adopted is a highly salient aspect of selfidentity.

Older adoptees also may be less represented depending on their computer usage but also by the social practices surrounding adoption in earlier decades that promoted secrecy and stigmatization. The vast majority of online respondents were White and likely middle to uppermiddle class, which is consistent with the known demographic distribution of adoptees in the targeted age range (Chandra et al., 1999; Finkler, 2000). Adoptees of color and those who identify as lesbian, gay, or transgender were specifically recruited, but without comparative national statistics it is difficult to comment on how well they are represented by the overall sample. The same is true for differently-abled persons. Fortunately, the qualitative data give voice to adoptees from varied racial and ethnic backgrounds. Other limitations emanate from data collection procedures. Common method variance is likely given sole reliance on web-based data collection and self-reporting during the quantitative phase, although the exact degree is unknown. Some researchers (Podsakoff, MacKenzie, Lee, & Podsakoff, 2003) attribute artifactual covariance to a common medium, while others (Spector, 2006) claim the problem is grossly overstated. Compared to other research platforms (e.g., face-to-face interviews), Internet-based data collection is fairly accurate with less social-desirability response bias (Podsakoff et al., 2003), but a few characteristic challenges remain.

Internet-based research is largely anonymous. As such, respondents' adherence to inclusion criteria is voluntary and somewhat dependent on their careful attention to written instructions about participation. As discovered during an interview in the qualitative phase, for example, at least one person (Michelle) completed the online survey who did not meet the stated minimum age criterion. The records of two others were discarded during data screening because of having a prior personal history of breast cancer. The likelihood of respondents' not satisfying inclusion criteria is tempered, however, by the fact that data collection required active agreement with eligibility statements. Moreover, adoptees had to specifically attest to meeting eligibility criteria to have their record retained for structural equation modeling. In addition, because mammography screening guidelines were those of the American Cancer Society, the researcher intended to include those adoptees who currently live in the United States. That point was not emphasized well enough during the online experience, however, so it is possible that non-U.S. residents, with possibly different views on appropriate mammography intervals, completed the online instrument. As shown in Chapter 3, however, only 11 of 452 persons did not provide a U.S. state of residence.

From a measurement standpoint, specific items and scales posed potential problems worthy of discussion. As already discussed, ambiguity about biological family medical history may have been measured, ironically, too ambiguously, which can lead to results confounded by individual interpretation (Podsakoff et al., 2003). Two scales, worry and perceived value of biological family history information, may be insufficiently sensitive as demonstrated by their non-normal distributions, which were found to be consistent with the literature (Hay at al., 2005; Khoury & Mensah, 2005). Perceived risk, too, is not without its challenges. In the present study, a verbal scale was used, rather than an absolute numerical scale. Depending on individuals' risk aversion, calibration to actual breast cancer risk statistics and numeracy, a "low" verbal score on perceived risk could have very different underlying absolute risk assessments. As previously alluded, restriction of range may impact measurement of birthparent information-seeking behavior given Web-based recruitment practices. Mammography compliance and screening intention are somewhat subject to biases inherent to having respondents as common raters. In this way, consistency motif and social desirability may be potential biasing factors (Podsakoff et al., 2003) in addition to recall error.

Data analysis decisions during both quantitative and qualitative phases bring other limitations to the forefront. As discussed in Chapter 4, no imputation procedures or maximum likelihood algorithm techniques were employed to make use of records containing missing data. If multivariate normality had not been an issue, imputation procedures would have allowed 68 more records into the final dataset that contained 10% or fewer missing data elements. Listwise deletion is widely regarded as inferior to maximum likelihood techniques in regard to parameter estimate bias, parameter estimate efficiency, and model fit (Enders, 2001b; Enders & Bandalos, 2001; Peters & Enders, 2002; Roth, 1994). As described more fully in Chapter 3, the researcher ascribes to the tenets of constructivism in conducting qualitative inquiry. The researcher acknowledges her role in serving as the data collection instrument and in possessing one of the many lenses through which data could be analyzed and interpreted. While qualitative data are plentiful, feasibility constraints, such as limiting single phone interviews to an hour, may have limited respondents' truth space (Patton, 2002). It is also worth noting that the range of biological family history ambiguity examined during the qualitative phase was restricted to the upper bounds. In the future, broadening the sampling criterion to include persons with less ambiguity may allow new patterns to emerge.

The notion of multiple realities can also be applied to quantitative approaches as well. In structural equation modeling, a model is tested for its ability to reproduce the reality of observed covariance. Even when discovering a well-fitting parsimonious structural model, another theory-informed model might fit just as well, if not better, and explain a larger proportion of variance among its various factors. Another possibility is that adoptees' "true" stress and coping process as it relates to breast cancer and absent family history information is non-recursive. That is, the model may not function in linear form, but, rather, may contain loops between factors. For example, it stands to reason that the results from prior mammography screening feed back into cognitive processes about future risk. While not attempted in the present study, SEM procedures allow model estimation with feedback loops.

A final limitation worth noting involves the use of both confirmatory and exploratory approaches in the same study. As Anderson and Gerbing (1988) discussed, having a dual approach is not uncommon in applied research, and, in particular, is considered an ordered progression when testing and developing theory using structural equation modeling given, for example, the possible use of measures with unknown composition and the typical practice of model respecification. Still, when both approaches are utilized together, it is possible that the results obtained capitalized on chance, yielding conclusions too closely bound to a potentially idiosyncratic, single sample (Raykov & Widaman, 1995). Without having an unused split-half sample, cross-validation on a new independent sample is necessary for determining consistency of the results (Anderson & Gerbing, 1988; Raykov & Widaman, 1995).

Implications

Research findings expand the knowledge base of several disciplines including, but not limited to, health promotion and education, health psychology, social work, public health genomics, and primary care. Given the scope and nascent nature of this research, there are numerous implications for both research and practice. This section highlights these implications in three domains— prevention and early detection, the primary care setting, and public health genomics. For each domain, implications for advocacy will also be presented in recognition of the potential significance of this work to members of the adoption triad and organizations that advocate on their behalf.

Several factors comprise the futuristic landscape that serves as a backdrop for the study's implications. First, as genomics-based medicine advances, primary care physicians are increasingly using family history tools for a variety of purposes including risk assessment, genetic testing referral, and targeted therapy (Rich et al., 2004), further reinforcing the importance of biological inheritance to healthcare decision making. Second, the fields of health promotion and health communication will be charged with developing and evaluating tailored strategies for social marketing, risk communication, and health education that center around the interaction of behavior and familial risk. Third, adoptees and other members of recombinant

families who may have incomplete biological familial health histories will likely emerge as a new underserved population. Fourth, advocacy organizations that serve adoption triad members will leverage scientific advances in genomics to bolster their positions on adoption-related legal, policy, and practice reform. Together, therefore, research, practice and advocacy are synergistic elements for creating an adoptee health movement.

Implications for Prevention and Early Detection

In documenting lower than average mammography screening compliance rates among this sample of adult adoptees (45%), this study sounds an alarm to behavioral health researchers interested in chronic disease prevention and early detection. While a single study is clearly not definitive, findings raise questions about compliance to screening guidelines for a host of conditions for which family history is a predominant risk factor (e.g., colon cancer, prostate cancer, and hypertension). A cavernous research gap also exists in understanding adherence to recommended lifestyle behavior important for chronic disease prevention (e.g., not smoking, maintaining healthy bodyweight, exercise, and eating low-fat diet).

Future research efforts could undoubtedly address shortcomings of the present study and expand beyond breast cancer to other chronic diseases with adult-onset. From a psychometric perspective, an obvious area to pursue relative to study findings and limitations is scale development and validation among adoptee populations. In particular, biological family history ambiguity, accessibility, and familiarity along with risk factor knowledge and risk attribution are likely important constructs to understand, not only for adoptees but also the general population, as they relate to perceived risk, prevention and early detection behavior, and medical decision making. Qualitative inquiry is especially well-suited to assist in scale development. Future

research, therefore, might employ a sequential exploratory mixed-methods design (i.e., qual \rightarrow QUAN) (Creswell & Plano Clark, 2007) toward that end.

In collaboration with researchers, the public health practice community, particularly at the federal level (e.g., U.S. Preventive Services Task Force, American Cancer Society, Centers for Disease Control and Prevention), plays a role in developing and disseminating populationbased guidelines for screening and other clinical preventive services based on a review of the scientific evidence. Resulting recommendations may differ depending on presence or absence of a known positive family history of disease. Without family history information, it may be unclear which specific guideline to follow or, in the case of physicians, which to recommend.

While a population-average stance is reasonable, some practitioners may take a more risk-averse approach and recommend early or more frequent screening for asymptomatic individuals without family history information. In either case, there are inherent risks (e.g., complications, cost) and benefits (e.g., peace of mind, earlier stage cancer detected) that should be carefully weighed. Ideally, as public health genomics advances, public health practice organizations will convene scientific dialogue around appropriate screening intervals for persons without familial risk information. Similarly, health promotion and health risk communication strategies should be developed and evaluated for persons potentially resistant to messages involving family history as a motivator for action.

With their lifetime focus on triad members, adoption-related organizations should be viewed as collaborators for advancing research and practice agendas in prevention and early detection for persons with unknown familial risk. As the present study demonstrated, there is already a willingness to circulate research announcements for recruitment purposes and a receptive audience for research results (Glover-Kudon, 2008). An untapped area for partnership
involves creating awareness about behavioral health recommendations across the lifespan. To advocate for themselves, adoptees should develop preventive behavior for a lifetime, place a high priority on screening and early detection, and become savvy and informed healthcare consumers with a high degree of health literacy. Adoption-related organizations can help advocate for adoptees' becoming active consumers in their healthcare by developing and providing communication tools to use with healthcare providers in various settings.

Implications for Primary Care

The role vicarious experience played in risk perception development, mammography compliance, and information-seeking was a key finding in the present study. It stands to reason that clinicians should be aware of this source of stress for adoptee-patients. Current practice, however, excludes adoptive family history and/or friend history from patient intake forms, limiting communication opportunities during medical encounters. Family history forms could easily be updated to capture adoptive family history along with biological family history. This small change offers several benefits including less marginalization of adoptee-patients, reduced confusion over which family history is reported, and enhanced rapport building between adoptee-patients and their healthcare providers.

While individual clinicians could alter family history forms, organizations providing technical assistance to the practice community (e.g., CDC, AMA) could spearhead development of improved family history tools that take ambiguous circumstances into account. Further, physician training on risk assessment and communication would vastly improve the quality of primary care encounters. Now more than ever, primary care physicians are expected to have fundamental knowledge about predictive genetic testing (Rich et al., 2004), which may or may not have clinical and analytic validity for persons without family history information.

For researchers interested in physician-patient communication, a fertile area of inquiry might involve examination of the dyad match on risk aversion and ambiguity tolerance. An adoptee with a high tolerance for risk and/or ambiguity, for example, might be satisfied with a physician's population-average approach of initiating mammography screening at the age of 40, whereas another adoptee with greater risk aversion and less ambiguity tolerance might prefer screening at an earlier age. Similarly, these factors may affect perceived medical benefit of birthparent information-seeking and physician willingness to lend support to the search effort.

Implications for Public Health Genomics

According to CDC researchers, despite almost universal (97%) acceptance of the idea that having family (i.e., biological) health history is important, only 30% of persons in the general population has actively sought to collect this information (Khoury & Mensah, 2005). Therefore, while logical, the assumption that adoptees have greater ambiguity about their biological familial medical heritage than non-adopted persons may be somewhat naïve. If estimates are accurate that 47% of adoptees search for birthparent information (Finkler, 2000), the assumed discrepancy in biological family health history familiarity rates between adoptees and non-adoptees may not be as vast as first postulated, depending on search outcomes. It stands to reason that fruitful birthparent searches would yield a high degree of family history information familiarity among this highly motivated group. Public health genomics researchers interested in studying motivating factors for family health history information-seeking may benefit from including adoptees in their investigations.

Given the decidedly complex nature of studying human behavior in its biological, cultural, social, political, and economic contexts, researchers are advised to work in multidisciplinary teams. A multi-disciplinary approach to inquiry is especially important for researching adoptee populations, which now more than ever are comprised of individuals with trans-national backgrounds. While traditionally included in research efforts to isolate so-called nature versus nurture effects in the mainstream population, adoptees are a special population worthy of respectful study in their own right. Accordingly, researchers should involve adoptees as stakeholders in setting research agendas, include adoptee-researchers whenever possible (Langrehr, Prebin, Kwon Dobbs, & Leventhal, 2008), and endeavor to give voice to adoptees as a marginalized group. As such, collaboration with state human resources departments and mutual consent registries is an important strategy for obtaining access to more probability-based sampling frames, but will also likely require developing research projects of mutual benefit.

As the genomics era advances, numerous ethical quandaries have surfaced that have been the subject of spirited dialogue among researchers and practitioners alike (Clayton, 2003; Hogarth, Javitt, & Melzer, 2008). As outlined by the University of Michigan's Center for Public Health and Community Genomics (n.d.), ethical issues in public health genetics include among others: discrimination, health disparities, distributive justice, and individual privacy versus group rights. The current ethics dialogue, however, should be extended to explicitly encompass the special concerns of adoptees and others who may be left underserved by advances in genomics.

Adoptees reared in non-biologically related families offer a stark example of individuals who have at best only partial access to information about biological family medical history. However, adoptees represent only one type of recombinant family (Finkler, 2005). As anthropological scholars (Finkler, 2005) remind, postmodern family units of today have redefined kinship as broader than its traditional biogenetic boundaries. In the United States more so than ever before, kin is determined largely by choice. Separation, divorce, single-parenthood, and lesbian/gay partnerships are but a few examples of recombinant families to which we can now add surrogacy and sperm/egg donation. With growing emphasis on genetics as providing authoritative knowledge about health and disease, it is imperative from both ethical and public health viewpoints that we not lose sight of various types of families who cannot provide the third-degree pedigree favored in genetics counseling environments when planning and delivering prevention and healthcare services.

Personalized medicine (Laberge, 2004), while decidedly beneficial for some, creates an inherent underserved population to which population genomics researchers must respond. In particular, this call for advocacy dovetails with the efforts of the Genomics and Public Health Toolkit Workgroup working under the auspices of the Association of State and Territorial Health Officials (ASTHO) charged with developing a framework for integrating genetics policies and practices with core public health functions and essential services (University of Washington, n.d.). Specifically, this workgroup has put forth goals to empower citizens to reduce their disease burden through the use of genetic information, to help citizens make informed decisions in regard to genetic risks, and to develop culturally appropriate genetic information and services, to name a few (Association of State and Territorial Health Officials [ASTHO], n.d.).

Conclusions

This study is among the first—if not the first—to explore aspects of health behavior among adult adoptees. The research effort, therefore, expanded the knowledge base about a largely unstudied population in the field of health promotion. By producing basic descriptive statistics about mammography screening behavior, let alone theoretical model testing, the study advances our thinking about a new potentially underserved population in the era of genomicsbased medicine. Qualitative data gave voice to adoptees as a marginalized population and generated ideas for future refinement of the stress and coping model. Directions for future research, practice, and advocacy were provided to stimulate broad-scale thinking about establishment of an adoptee health movement.

REFERENCES

- Absetz, P., Aro, A. R., & Sutton, S. R. (2002). Factors associated with breast cancer risk perception and psychological distress in a representative sample of middle-aged Finnish women. *Anxiety Stress and Coping*, *15*, 61-73.
- Absetz, P., Aro, A. R., Rehnberg, G., & Sutton, S. R. (2000). Comparative optimism in breast cancer risk perception: effects of experience and risk factor knowledge. *Psychology, Health & Medicine 5*(4), 367-376.
- American Cancer Society (2002). *Early Detection*. Retrieved March 6, 2006 from http://www.cancer.org/docroot/PED/content.
- American Cancer Society (2003). Role of breast self-examination changes in guidelines: Focus on awareness rather than detection. Retrieved January 1, 2006 from http://www.cancer.org/docroot/NWS/content.
- American Cancer Society. (2005a). *Breast Cancer Facts and Figures 2005-2006*. Atlanta, GA: American Cancer Society, Inc.
- American Cancer Society. (2005b). Detailed Guide: Breast Cancer. What are the risk factors for breast cancer? Retrieved January 1, 2006 from

http://www.cancer.org/docroot/CRI/content.

- American Cancer Society (2006a). ACS Cancer Detection Guidelines. Retrieved March 6, 2006 from http://www.cancer.org/docroot/PED/content.
- American Cancer Society. (2006b). *Cancer Facts and Figures 2006*. Atlanta, GA: American Cancer Society, Inc.

American Cancer Society (2006c). Chronological History of ACS Recommendations on Early Detection of Cancer. Retrieved March 6, 2006 from

http://www.cancer.org/docroot/PED/content.

American Cancer Society. (2007). *What causes breast cancer*? Retrieved December 31, 2007 from

http://www.cancer.org/docroot/CRI/content/CRI_2_2_2X_What_causes_breast_cancer_5 .asp.

- American Society of Human Genetics [ASHG]. (1991). Report on genetics and adoption: Points to consider. *American Journal of Human Genetics*, *48*, 1009-1010.
- American Society of Human Genetics [ASHG]. (2000). Genetic testing in adoption. *American Journal of Human Genetics*, 66(3), 761-767.
- Andersen, M. R., Smith, R., Meischke, H., Bowen D., & Urban, N. (2003). Breast cancer worry and mammography use by women with and without a family history in a populationbased sample. *Cancer Epidemiology, Biomarkers and Prevention*, 12, 314-320.
- Anderson, J. C., & Gerbing, D. W. (1988). Structural equation modeling in practice: A review and recommended two-step approach. *Psychological Bulletin*, *103*, 411-423.
- Andrews, J. E., Johnson, J. D., Case, D. O., Allard, S., & Kelly, K. (2005). Intention to seek information on cancer genetics. *Information Research*, 10(4) paper 238 [Available at http://InformationR.net/ir/10-4/paper238.html]
- Andrykowski, M. A., Munn, R. K., & Studts, J. L. (1996). Interest in learning of personal genetic risk for cancer: A general population survey. *Preventive Medicine*, *25*, 527-536.

- Arar, N., Thompson, I., Sarosdy, M., Harris, M., Shepherd, D., Troyer, D., & Plaetke, R. (2000).
 Risk perceptions among patients and their relatives regarding prostate cancer and its heredity. *Prostate Cancer and Prostatic Diseases, 3*, 176-185.
- Association of State and Territorial Health Officials (ASTHO), Genomics and Public Health Toolkit Workgroup. *Framework for public health genetics policies and practices in state and local public health agencies*. Retrieved September 8, 2008 from http://www.astho.org/templates/display_pub.php?pub_id=453.
- Audrain-McGovern, J., Hughes, C., & Patterson, F. (2003). Effecting behavior change: Awareness of family history. *American Journal of Preventive Medicine*, *24*, 183.
- Auerbach, C. F., & Silverstein, L. B. (2003). Qualitative data: An introduction to coding and analysis. NY: New York University Press.
- Baer, J. (2004). *Growing in the dark: Adoption secrecy and its consequences*. Philadelphia, PA: Xlibris Corporation.
- Best, A., Stokols, D., Green, L. W., Leischow, S., Holmes, B., & Buchholz, K. (2003). An integrative framework for community partnering to translate theory into effective health promotion strategy. *American Journal of Health Promotion*, 18(2), 168-176.
- Bottorff, J. L., Richardson, C., Balneaves, L. G., McCullum, M., Buxton, J. A., Ratner, P. A. et al. (2004). Unraveling women's perceptions of risk for breast cancer. *Health Education Research*, 19, 469-475.
- Brain, K., Gray, J., Norman, P., Parsons, E., Clarke, A., Rogers, C., et al. (2000). Why do women attend familial breast cancer clinics? *Journal of Medical Genetics*, *37*(13), 197-202.

- Brodzinsky, D. M., & Schechter, M. D. (Eds.). 1990. The psychology of adoption. New York, NY: Oxford University Press.
- Bryman, A. (2006). Integrating quantitative and qualitative research: How is it done? *Qualitative Research, 6*, 97-113.
- Buhi, E. R., Goodson, P., & Neilands, T. B. (2007). Structural equation modeling: A primer for health behavior researchers. *American Journal of Health Behavior*, 31(1), 74-85.
- Buhr, K., & Dugas, M. J. (2006). Investigating the construct validity of intolerance of uncertainty and its unique relationship with worry. *Anxiety Disorders*, 20, 222-236.
- Bullock, H. E., Harlow, L. L., & Mulaik, S. (1994). Causation issues in structural equation modeling research. *Structural Equation Modeling*, 1(3), 253-267.
- Burnett, C. B., Steakley, C. S., Slack, R., Roth, J., & Lerman, C. (1999). Patterns of breast cancer screening among lesbians at increased risk for breast cancer. *Women & Health, 29*, 35.
- Carp, E. W. (1998). *Family matters: Secrecy and disclosure in the history of adoption*. Cambridge, MA: Harvard University Press.
- Carp, E. W. (2004). Adoption politics: Bastard Nation and Ballot Initiative 58. Lawrence, Kansas: University Press of Kansas.
- Carroll, J. C., Blaine, S., & Ashbury, F. D. (2004). Family physicians and genetic medicine:
 Roles and challenges. In B. M. Knoppers & C. Scriver (Eds.), *Genomics, Health and Society: Emerging issues for public policy* (pp. 67-81). Canada: Policy Research
 Initiative.
- Centers for Disease Control and Prevention. (2004). Awareness of family health history as a risk factor for disease. *Morbidity and Mortality Weekly Report*, *53*(44), 1044-1047.

- Centers for Disease Control and Prevention, Office of Genomics and Disease Prevention. (2005a). *Family History Public Health Initiative*. Retrieved on November 10, 2005 from http://www.cdc.gov/genomics/info/factshts/famhist.htm.
- Centers for Disease Control and Prevention, Office of Genomics and Disease Prevention. (2005b). *Genomics and Population Health 2005*. Atlanta (GA). Also available from URL: www.cdc.gov/genomics/activities/ogdp/2005.htm.
- Centers for Disease Control and Prevention. (n.d.) *Family history is important for your health*. Retrieved November 30, 2008 from

http://www.cdc.gov/genomics/public/file/print/FamHistFactSheet.pdf.

- Champion, V. L. (1999). Revised susceptibility, benefits, and barriers scale for mammography screening. *Research in Nursing and Health, 22*, 341-348.
- Champion, V. L., & Scott, C. R. (1997). Reliability and validity of breast cancer screening belief scales in African American women. *Nursing Research*, 46(6), 331-337.
- Chandra, A., Abma, J., Maza, P., & Bachrach, C. (1999). Adoption, adoption seeking, and relinquishment for adoption in the United States. Advance Data (No. 306) from Vital and Health Statistics of the Centers for Disease Control and Prevention, National Center for Health Statistics, U.S. Department of Health and Human Services. Retrieved July 23, 2006 from http://www.cdc.gov/nchs/data/ad/ad306.pdf.
- Charmaz, K. (2000). Grounded theory: Objectivist and constructivist methods. In N. K. Denzin & Y. Lincoln (Eds.) *Handbook of qualitative research* (pp. 509-535). Thousand Oaks, CA: Sage.
- Charmaz, K. (2006). *Constructing grounded theory: A practical guide through qualitative analysis*. London: SAGE Publications.

Child Welfare Information Gateway. (2003). Collection of family information about adopted persons, birth parents, and adoptive parents: Summary of state laws. Retrieved June 29, 2006 from

http://www.childwelfare.gov/systemwide/laws policies/statutes/collection.pdf.

- Child Welfare Information Gateway. (2004). *Impact of adoption on adopted persons*. Retrieved June 29, 2006 from http://www.childwelfare.gov/pubs/f_adimpact.cfm.
- Child Welfare Information Gateway. (2005). *Voluntary relinquishment for adoption*. Retrieved July 23, 2006 from http://www.childwelfare.gov/pubs/s_place.cfm.
- Child Welfare Information Gateway. (2006). Access to adoption records: Summary of state laws. Retrieved June 29, 2006 from

http://www.childwelfare.gov/systemwide/laws_policies/statutes/infoaccessapall.pdf.

- Clayton, E. W. (2003). Ethical, legal and social implications of genomic medicine. *The New England Journal of Medicine, 349*(6), 562-569.
- Coffey, A. & Atkinson, P. (1996). *Making sense of qualitative data: Complementary research strategies*. Thousand Oaks, CA: SAGE Publications.
- Cohen, M. (2002). First-degree relatives of breast-cancer patients: Cognitive perceptions, coping, and adherence to breast self-examination. *Behavioral Medicine 28*(1), 15-22.
- Collins, K. M. T., Onwuegbuzie, A. J., & Sutton, I. L. (2006). A model incorporating the rationale and purpose for conducting mixed-methods research in special education and beyond. *Learning Disabilities: A Contemporary Journal*, *4*(1), 67-100.
- 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.

- Creswell, J. W. (2002). *Educational research: Planning, conducting, and evaluating quantitative and qualitative research*. Upper Saddle River, NJ: Merrill Prentice-Hall.
- Creswell, J. W. (2003). *Research design: Qualitative, quantitative and mixed approaches*. (2nd ed.) Thousand Oaks, CA: Sage Publications.
- Creswell, J. W., & Plano Clark, V. L. (2007). *Designing and conducting mixed methods research*. Thousand Oaks, CA: Sage.
- Cronbach, L. J. (1951). Coefficient Alpha and the Internal Structure of Tests. *Psychometrika*, *16*, 297-334.
- Crotty, M. (1998). *The foundations of social research: Meaning and perspective in the research process*. St. Leonards, Australia: Allen & Unwin.
- Davis, S., Stewart, S., & Bloom, J. (2004). Increasing the accuracy of perceived breast cancer risk: Results from a randomized trial with cancer information service callers. *Preventive Medicine*, 39, 64-73.

DeCarlo, L. T. (1997). On the meaning and use of kurtosis. Psychological Methods, 2, 292-307.

- Decruyenaere, M., Evers-Kiebooms, G., Welkenhuysen, M., Denayer, L., & Claes, E. (2000).
 Cognitive representations of breast cancer, emotional distress and preventive health
 behaviour: a theoretical perspective. *Psycho-Oncology 9*(6), 528-536.
- DNA Direct. *Genetic testing for adoptees* (heading). Retrieved June 30, 2006 from http://www.dnadirect.com/resource/adoptees/index.jsp.
- Drossaert, C. C. H., Boer, H., & Seydel, E. R. (1996). Perceived risk, anxiety, mammogram uptake, and breast self-examination of women with a family history of breast cancer: the role of knowing to be at risk. *Cancer Detection and Prevention*, *20*, 76-85.

- Ellsberg, D. (1961). Risk, ambiguity, and the savage axioms. *Quarterly Journal of Economics*, 75, 643-669.
- Enders, C. (2001a). The impact of nonnormality on full information maximum-likelihood estimation for structural equation models with missing data. *Psychological Methods*, *6*(4), 352-370.
- Enders, C. (2001b). A primer on maximum likelihood algorithms available for use with missing data. *Structural Equation Modeling*, *8*(1), 128-141.
- Enders, C. (2005). An SAS macro for implementing the modified Bollen-Stine Bootstrap for missing data: Implementing the bootstrap using existing structural equation modeling software. *Structural Equation Modeling*, 12(4), 620-641.
- Enders, C., & Bandalos, D. (2001). The relative performance of full information maximum likelihood estimation for missing data in structural equation models. *Structural Equation Modeling*, 8(3), 430-457.
- Erzberger, C., & Kelle, U. (2003). Making inferences in mixed methods: The rules of integration. In A. Tashakkori & C. Teddlie (Eds.), *Handbook of mixed methods in social* and behavioral research (pp. 457-488). Thousand Oaks, CA: Sage.
- Eyre, H.J., Lange, D.P., & Morris, L.B. (2002). Informed decisions: The complete book of cancer diagnosis, treatment, and recovery (2nd ed.). Atlanta, GA: American Cancer Society.
- Facione, N. C. (2002). Perceived risk of breast cancer: influence of heuristic thinking. *Cancer Practice*, *10*(5), 256-262.
- Finkler, K. (2000). *Experiencing the new genetics: Family and kinship on the medical frontier*.Philadelphia: University of Pennsylvania Press.

Finkler, K. (2001). The Kin in the Gene. Current Anthropology 42(2), 235-263.

- Finkler, K. (2003). Illusions of controlling the future: risk and genetic inheritance. *Anthropology* & *Medicine 10*(1), 51-71.
- Finkler, K. (2005). Family, kinship, memory and temporality in the age of the new genetics. *Social Science & Medicine, 61*, 1059-1071.
- Finkler, K., Skrzynia, C. & Evans, J. P. (2003). The new genetics and its consequences for family, kinship, medicine and medical genetics. *Social Science & Medicine* 57(3), 403-412.
- Finney Rutten, L. J. & Iannotti, R. J. (2003). Health beliefs, salience of breast cancer family history, and involvement with breast cancer issues: adherence to annual mammography screening recommendations. *Cancer Detection and Prevention*, 27, 353-359.
- Finney, L. J. & Iannotti, R. J. (2001). The impact of family history of breast cancer on women's health beliefs, salience of breast cancer family history, and degree of involvement in breast cancer issues. *Women & Health*, 33, 15-28.
- Fischer, R. L. (2002). The emerging role of adoption reunion registries: Adoptee and birthparent views. *Child Welfare*, *81*(3), 445-470.
- Fletcher, K. E., Clemow, L., Peterson, B. A., Lemon, S. C., & Estabrook, B. (2006). A path analysis of factors associated with distress among first-degree female relatives of women with breast cancer diagnosis. *Health Psychology*, 25(3), 413-424.
- Folkman, S., & Greer, S. (2000). Promoting psychological well-being in the face of serious illness: When theory, research and practice inform each other. *Psycho-Oncology*, *9*, 11-19.

- Gebbie, K., Rosenstock, L., & Hernandez, L. M. (Eds.). (2003). Who will keep the public healthy? Educating public health professionals for the 21st century. Washington, DC: The National Academies Press.
- Glaser, B., & Strauss, A. L. (1967). *The discovery of grounded theory: Strategies for qualitative research*. New York: Aldine de Gruyter.
- Glover-Kudon, R. (2008, July). When family history is a mystery: Helping adult adoptees cope with the lack of a medical history. Paper presented at the meeting of the Korean American Adoptee Adoptive Family Network, Chicago, IL.
- Godin, G., Gagne, C., Maziade, J., Moreault, L., Beaulieu, D., & Morel, S. (2001). Breast cancer: The intention to have a mammography and a clinical breast examination application of the theory of planned behavior. *Psychology and Health, 16*, 423-441.
- Gooding, H. C., Organista, K., Burack, J., & Bowles Biesecker, B. (2006). Genetic susceptibility testing from a stress and coping perspective. *Social Science and Medicine*, 62, 1880-1890.
- Gowan, M. A., Riordan, C. M., & Gatewood, R.D. (1999). Test of a model of coping with involuntary job loss following a company closing. *Journal of Applied Psychology*, 84(1), 75-86.
- Grenier, S., Barette, A-M., & Ladouceur, R. (2005). Intolerance of uncertainty and intolerance of ambiguity: Similarities and differences. *Personality and Individual Differences, 39*, 593-600.
- Guttmacher, A. E., & Collins, F. S. (2002). Genomic medicine—a primer. *The New England Journal of Medicine*, 347(19), 1512-1520.

- Gui, G. P., Hogben, R. K., Walsh, G., Ahern, R., & Eeles, R. (2001). The incidence of breast cancer from screening women according to family history risk: Does annual clinical examination add to mammography? *European Journal of Cancer*, 37(13), 1668-1673.
- 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*, 701-715.
- Halfon, N., & Hochstein, M. (2002). Life course health development: An integrated framework for developing health, policy, and research. *The Milbank Quarterly*, *80*(3), 433-479.
- Han, P. K. J., Moser, R. P., & Klein, W. M. P. (2006). Perceived ambiguity about cancer prevention recommendations: Relationship to perceptions of cancer preventability, risk, and worry. *Journal of Health Communications*, 11, 51-69.
- Hanson, W. E., Creswell, J. W., Plano Clark, V. L., Petska, K. S., & Creswell, J. D. (2005).
 Mixed methods research designs in counseling psychology. *Journal of Counseling Psychology*, 52(2), 224-235.
- Hay, J. L., Buckley, T. R., & Ostroff, J. S. (2005). The role of cancer worry in cancer screening:A theoretical and empirical review of the literature. *Psycho-Oncology*, *14*, 517-534.
- Ho, V., Yamal, J. M., Atkinson, E. N., Basen-Engquist, K., Tortolero-Luna, G., & Follen, M.
 (2005). Predictors of breast and cervical screening in Vietnamese women in Harris
 County, Houston, Texas. *Cancer Nursing*, 28, 119-129.
- Hogarth, S., Javitt, G., & Melzer, D. (2008). The current landscape for direct-to-consumer genetic testing: Legal, ethical, and policy issues. *Annual Review of Genomics and Human Genetics*, 9, 161-182.

- Hopwood, P., Shenton, A., Lalloo, F., Evans, D. G. R., & Howell, A. (2001). Risk perception and cancer worry: An exploratory study of the impact of genetic risk counseling in women with a family history of breast cancer. *Journal of Medical Genetics*, 38(2), 139.
- Hopwood, P. (2000). Breast cancer risk perception: what do we know and understand? *Breast Cancer Research, 2*, 387-391.
- Hu, L., & Bentler, P. M. (1999). Cutoff criteria for fit indexes in covariance structure analysis:Conventional criteria versus new alternatives. *Structural Equation Modeling*, 6(1), 1-55.
- Hu, L., & Bentler, P. M. (1998). Fit indices in covariance structure modeling: Sensitivity to underparameterized model misspecification. *Psychological Methods*, 3, 424-453.
- Huberman, A.M. & Miles, M.B. (1994). Data management and analysis methods. In N.K.Denzin & Y.S. Lincoln (Eds.), *Handbook of qualitative research* (pp. 428-444).Thousand Oaks, CA: SAGE Publications.
- 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, 103-112.
- Ivankova, N. V., Creswell, J. W., & Stick, S. L. (2006). Using mixed-methods sequential explanatory design: From theory to practice. *Field Methods*, *18*(1), 3-20.
- Jacobsen, P. B., Lamonde, L. A., Honour, M., Kash, K., Hudson, P. B., & Pow-Sang, J. (2004). Relation of family history of prostate cancer to perceived vulnerability and screening behavior. *Psycho-Oncology*, *13*, 80-85.

Jacobson, A. (2006, February 20). [Letter to the editor]. Newsweek, 147(8), p. 22.

- Janz, N. K., Champion, V. L., & Strecher, V. J. (2002). The health belief model. In K. Glanz, B. Rimer, & F. Lewis (Eds.), *Health behavior and health education* (pp. 45-66). San Francisco: Jossey-Bass.
- Johnson, J. D., Case, D. O., Andrews, J. E., & Allard, S. L. (2005). Genomics—The perfect information-seeking research problem. *Journal of Health Communication*, *10*, 323-329.
- Johnson, R. B., & Onwuegbuzie, A. J. (2004). Mixed methods research: A research paradigm whose time has come. *Educational Researcher*, *33*(7), 14-26.
- Jöreskog, K. G. & Sörbom, D. (1999). *PRELIS 2: User's Reference Guide*. Lincolnwood, Ill: Scientific Software International, Inc.
- Jöreskog K. G., & Sörbom, D.. (2006). LISREL 8.8. Lincolnwood, IL, Scientific Software Inc.
- Junger, S. (1997). *The perfect storm: A true story of men against the sea*. New York: W. W. Norton.
- Juon, H. S., Kim, M., Shankar, S., & Han, W. (2004). Predictors of adherence to screening mammography among Korean American women. *Preventive Medicine*, 39, 474-481.
- Kahneman, D. & Tversky, A. (1972). Subjective Probability Judgment of Representativeness. *Cognitive Psychology*, *3*, 430-454.
- Kalb, C. (2006, February 6). In our blood. Newsweek, 147(6), 46-55.
- Kash, K. M. & Dabney, M. R. (2001). Psychological aspects of cancer screening in high-risk populations. *Medical and Pediatric Oncology*, 36, 519-524.
- Katapodi, M. C., Facione, N. C., Humphreys, J. C., & Dodd, M. J. (2005). Perceived breast cancer risk: Heuristic reasoning and search for a dominance structure. *Social Science and Medicine*, 60, 421-432.

- 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, 388-402.
- Keith, T. Z. (1999). Structural equation modeling in school psychology. In C. R. Reynolds & T.B. Gutkin (Eds.), *Handbook of School Psychology* (3rd ed.), New York: Wiley.
- Kelly, K., Leventhal, H., Andrykowski, M., Toppmeyer, D., Much, J., Dermody, J., et al. (2005).Using the common sense model to understand perceived cancer risk in individuals testing for brca1/2 mutations. *Psycho-Oncology*, *14*(1), 34-48.
- Kenen, R., Ardern-Jones, A., & Eeles, R. (2003a). Family stories and the use of heuristics:
 Women from suspected hereditary breast and ovarian cancer (HBOC) families. *Sociology* of Health and Illness, 25(7), 838-865.
- Kenen, R., Ardern-Jones, A., & Eeles, R. (2003b). Living with chronic risk: healthy women with a family history of breast/ovarian cancer. *Health, Risk & Society 5*(3), 315-331.
- Khoury, M. J., & Mensah, G. A. (2005). Genomics and the prevention and control of common chronic diseases: Emerging priorities for public health action. *Preventing Chronic Disease, 2*(2) [serial online], Retrieved September 8, 2008 from http://www.cdc.gov/pcd/issues/2005/apr/05_0011.htm.
- Kinney, A. Y., Choi, Y. A., DeVellis, B., Millikan, R., Kobetz, E., & Sandler, R. S. (2000).
 Attitudes toward genetic testing in patients with colorectal cancer. *Cancer Practice*, *8*, 178-186.
- King, E., Rimer, B. K., Trock, B., Balshem, A., & Engstrom, P. (1990). How valid are mammography self-reports? *American Journal of Public Health*, 80, 1386-1388.

- Klein, C. T. F., & Helweg-Larsen, M. (2002). Perceived control and the optimistic bias: A metaanalytic review. *Psychology and Health*, *17*(4), 437-446.
- Kline, R. B. (2005). *Principles and practice of structural equation modeling*. (2nd ed.) New York: The Guilford Press.
- Knoppers, B. M., & Scriver, C. (Eds.). (2004). Genomics, health and society: Emerging issues for public policy. Canada: Policy Research Initiative.
- Krueger, M. J., & Hanna, F. J. (1997). Why adoptees search: An existential treatment perspective. *Journal of Consulting and Development*, *75*, 195-202.
- Laberge, C. (2004). Genomics, health and society. In B. M. Knoppers & C. Scriver (Eds.),*Genomics, Health and Society: Emerging issues for public policy* (pp. 11-21). Canada:Policy Research Initiative.
- Langer, E. J. (1975). The illusion of control. *The Journal of Personality and Social Psychology*, *32*, 311-328.
- Langrehr, K., Prebin, E., Kwon Dobbs, J., & Leventhal, D. (2008, July). Is there an adoptee voice in adoption research? Paper presented at the meeting of the Korean American Adoptee Adoptive Family Network, Chicago, IL.
- Lazarus, R. S., & Folkman, S. (1984). *Stress, appraisal, and coping*. New York: Springer Publishing.
- Lebner, A. (2000). Genetic "mysteries" and international adoption: The cultural impact of biomedical technologies on the adoptive family experience. *Family Relations, 49*, 371-377.

- Lechner, L., de Vries, H., & Offermans, N. (1997). Participation in a breast cancer screening program: Influence of past behavior and determinants on future screening participation. *Preventive Medicine*, 26, 473-482.
- Lehmann, L. S., Weeks, J. C., Klar, N., & Garber, J. E. (2002). A population-based study of Ashkenazi Jewish women's attitudes toward genetic discrimination and BRCA1/2 testing. *Genetics in Medicine*, *4*, 346-352.
- Lemon, S. C., Zapka, J. G., & Clemow, L. (2004). Health behavior change among women with recent familial diagnosis of breast cancer. *Preventive Medicine*, *39*, 253-262.
- Lerman, C., Trock, B, Rimer, B. K. (1991a). Psychological side effects of breast cancer screening. *Health Psychology*, 10, 259-267.
- Lerman, C., Trock, B., Rimer, B. K., Boyce, A., Jepson, C., & Engstrom, P.F. (1991b).
 Psychological and behavioral implications of abnormal mammograms. *Annals of Internal Medicine*, 114, 657-661.
- Leventhal, H., Brissette, I., & Leventhal, E. (2003). The common-sense model of self-regulation of health and illness. In L. D. Cameron & H. Leventhal (Eds.), *The self-regulation of health and illness behaviour* (pp. 42-65). New York: Routledge.
- Leventhal, H., Meyer, D., & Nerenz, D. R. (1980). The common sense representation of illness danger. In S. Rachman (Ed.), *Contributions to medical psychology* (Vol. 2, pp. 7-30). New York: Pergamon Press.
- Levy-Storms, L., Bastani, R., & Reuben, D. B. (2004). Predictors of Varying Levels of Nonadherence to Mammography Screening in Older Women. *Journal of the American Geriatrics Society*, 52, 768-773.

- Lin, B. K., Clyne, M., Walsh, M., Gomez, O., Yu, W., Gwinn, M., et al. (2006). Tracking the epidemiology of human genes in the literature: The HuGE Published Literature Database. *American Journal of Epidemiology (Advance Access), April 26, 2006*, 1-4.
- Lindberg, N. M. & Wellisch, D. (2001). Anxiety and compliance among women at high risk for breast cancer. *Annals of Behavioral Medicine*, *23*, 298-303.
- Lipkus, I. M., Kuchibhatla, M., McBride, C. M., Bosworth, H. B., Pollak, K. I., Siegler, I. C., & Rimer, B. (2000). Relationships among breast cancer perceived absolute risk, comparative risk, and worries. *Cancer Epidemiology, Biomarkers, & Prevention, 9*, 973-975.
- MacCallum, R. C., & Austin, J. T. (2000). Applications of structural equation modeling in psychological research. *Annual Review of Psychology*, 51, 201-226.
- Mayne, L., & Earp, J. (2003). Initial and repeat mammography screening: Different behaviors/different predictors. *Journal of Rural Health*, *19*, 63-71.
- Mayo Clinic (2006). *How to compile your family medical history*. Retrieved February 11, 2006, from http://www.mayoclinic.com/health/medical-history/HQ01707.
- McAllister, M. (2003). Personal theories of inheritance, coping strategies, risk perception and engagement in hereditary non-polyposis colon cancer families offered genetic testing. *Clinical Genetics*, 64, 179-189.
- McAndrew, L. M., Musumeci-Szabo, T. J., Mora, P. A., Vileikyte, L., Burns, E., Halm, E. A., et al. (2008). Using the common sense model to design interventions for the prevention and management of chronic illness threats: From description to process. British Journal of *Health Psychology*, 13(2), 195-204.

- 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*, 565-579.
- McCaul, K. D., Branstetter, A. D., Schroeder, D. M., & Glasgow, R. E. (1996). What Is the Relationship Between Breast Cancer Risk and Mammography Screening? A Meta-Analytic Review. *Health Psychology*, 15, 423-429.
- McGregor, B. A., Bowen, D. J., Ankerst, D. P., Andersen, M. R., Yasui, Y., & McTiernan, A. (2004). Optimism, Perceived Risk of Breast Cancer, and Cancer Worry Among a Community-Based Sample of Women. *Health Psychology*, 23, 339-344.
- McLeroy, K. R., Bibeau, D., Steckler, A., & Glanz, K. (1988). An ecological perspective on health promotion programs. *Health Education Quarterly*, 15, 351-377.
- Meiser, B., Butow, P., Barratt, A., Friedlander, M., Kirk, J., Gaff, C. et al. (2000). Breast cancer screening uptake in women at increased risk of developing hereditary breast cancer. *Breast Cancer Research and Treatment*, 59, 101-111.
- Meiser, B., Butow, P., Barratt, A., Gattas, M., Gaff, C., Haan, E. et al. (2001). Risk perceptions and knowledge of breast cancer genetics in women at increased risk of developing hereditary breast cancer. *Psychology & Health*, 16, 297-311.
- Montgomery, G. H., Erblich, J., DiLorenzo, T., & Bovbjerg, D. H. (2003). Family and friends with disease: their impact on perceived risk. *Preventive Medicine*, *37*, 242-249.
- Morse, J. (1991). Approaches to qualitative-quantitative methodological triangulation. *Nursing Research*, 40, 120-123.
- Morse, J. (2003). Principles of mixed-and multi-method research design. In A. Tashakkori C.
 Tedddlie (Eds.) *Handbook of mixed methods in social and behavioral research* (pp. 189-208). Thousand Oaks, CA: SAGE.

- Muhr, T. (2004). User's Manual for ATLAS.ti 5.0, Berlin: ATLAS.ti Scientific Software Development GmbH.
- Muhr, T. (1991). ATLAS/ti: A prototype for the support of text interpretation. *Qualitative Sociology*, *14*(4), 349-371.
- Murabito, J. M., Evans, J. C., Larson, M. G., Kreger, B. E., Splansky, G. L., Freund, K. M. et al. (2001). Family breast cancer history and mammography - Framingham Offspring Study. *American Journal of Epidemiology*, 154, 916-923.
- Murff, H. J., Spigel, D. R., & Syngal, S. (2004). Does this patient have a family history of cancer? An evidence-based analysis of the accuracy of family cancer history. *JAMA*, 292(12), 1480-1489.
- Mustanski, B. (2001). Getting wired: Exploiting the Internet for the collection of valid sexuality data. *The Journal of Sex Research*, *38*, 292-301.
- Myers, M. F., & Jorgensen, C. (2005). Direct-to-consumer marketing campaign: Genetic testing for susceptibility to breast and ovarian cancer. In *Genomics and Population Health 2005*, pp. 19-26. Atlanta, GA: Centers for Disease Control and Prevention.
- National Adoption Information Clearinghouse (n.d.). *Issues Facing Adult Adoptees*. Retrieved March 5, 2004, from http://naic.acf.hhs.gov.
- National Cancer Institute. (2005a). Breast Cancer (PDQ) Screening: Health Professional Version. Retrieved January 2, 2006 from

http://www.cancer.gov/cancertopics/pdq/screening/breast/HealthProfessional/page3/print.

National Cancer Institute (2005b). *Cancer Screening Overview (PDQ): Health Professional Version*. Retrieved March 6, 2006 from

www.cancer.gov/cancertopics/pdq/screening/overview/healthprofessional.

- Onwueghbuzie, A., & Teddlie, C. (2003). A framework for analyzing data in mixed methods research. In A. Tashakkori & C. Teddlie (Eds.) *Handbook of mixed methods in social and behavioral research* (pp. 351-383). Thousand Oaks, CA: Sage.
- Osler, M., Holst, C., Prescott, E., & Sorensen, T. I. A. (2001). Influence of genes and family environment on adult smoking behavior assessed in an adoption study. *Genetic Epidemiology*, 21, 193-200.
- Patton, M. Q. (2002). *Qualitative research and evaluation methods*. (3rd ed.) Thousand Oaks, CA: SAGE.
- Pertman, A. (2000). *Adoption nation: How the adoption revolution is transforming america*. New York: Basic Books.
- Peters, C. L. O., & Enders, C. (2002). A primer for the estimation of structural equation models in the presence of missing data: Maximum likelihood algorithms. *Journal of Targeting, Measurement and Analysis for Marketing, 11*(1), 81-95.
- Petersen, L., Andersen, P. K., & Sorensen, T. I. A. (2005). Premature death of adult adoptees: Analyses of a case-cohort sample. *Genetic Epidemiology*, *28*, 376-382.
- Petersen, L., Nielsen, G. G., Andersen, P. K., & Sorensen, T. I. A. (2002). Case-control study and environmental of genetic influences on premature death of adult adoptees. *Genetic Epidemiology*, 23, 123-132.
- Petersen, L., Sorensen, T. I. A., & Andersen, P. K. (2003). Comparison of case-cohort estimators based on data on premature death of adult adoptees. *Statistics in Medicine*, 22, 3795-3803.

- Pieterse, K., van Dooren, C., Seynaeve, C. C. M., Bartels, A. J., Rijnsburger, H. J., de Koning, J. G. M., et al. (2007). Passive coping and psychological distress in women adhering to regular breast cancer surveillance. *Psycho-Oncology*, *16*, 851-858.
- Podsakoff, P. M., MacKenzie, S. B., Lee, J. Y., & Podsakoff, N. P. (2003). Common method biases in behavioral research: A critical review of the literature and recommended remedies. *Journal of Applied Psychology*, 88, 879-903.
- Punch, K. F. (1998). Introduction to social research: Quantitative and qualitative approaches. London: Sage Publications.
- Raykov, T., & Widaman, K. F. (1995). Issues in applied structural equation modeling research. *Structural Equation Modeling*, *2*(4), 289-318.
- Redelmeier, D. A., Rozin, P., & Kahneman, D. (1993). Understanding Patients Decisions -Cognitive and Emotional Perspectives. *JAMA-Journal of the American Medical Association*, 270, 72-76.
- Reed, S. R. (1994). Adult adoptee perceptions of search readiness: Implications for adoptive parent education. Unpublished master's thesis, University of Texas at Arlington, Arlington.
- Rees, G., Fry, A., & Cull, A. (2001). A family history of breast cancer: women's experiences from a theoretical perspective. *Social Science & Medicine*, *52*, 1433-1440.
- Rich, E. C., Burke, W., Heaton, C. J., Haga, S., Pinsky, L., Short, P., et al. (2004).
 Reconsidering the family history in primary care. *Journal of General Internal Medicine*, *19*(3), 273-280.

- Richards, C. L., Viadro, C. I., & Earp, J. A. (1998). Bringing Down the Barriers to
 Mammography: A Review of Current Research and Interventions. *Breast Disease*, 10, 33.
- Richards, M., & Ponder, M. (1996). Lay understanding of genetics: A test of a hypothesis. *Hypothesis*, *33*, 1032-1036.
- Roth, P. L. (1994). Missing data: A conceptual review for applied psychologists. *Personnel Psychology*, *47*, 537-560.
- Rothemund, Y., Paepke, S., & Flor, H. (2001). Perception of risk, anxiety, and health behaviors in women at high risk for breast cancer. *International Journal of Behavioral Medicine*, 8, 230-239.
- Russell, K. M., Perkins, S. M., Zollinger, T. W., & Champion, V. L. (2006). Sociocultural context of mammography screening use. *Oncology Nursing Forum*, 33(1), 105-112.
- Rutledge, D. N., Barsevick, A., Knobf, M. T., & Bookbinder, M. (2001). Breast cancer detection: Knowledge, attitudes, and behaviors of women from Pennsylvania. *Oncology Nursing Forum, 28*, 1032.
- Sadler, G. & Fullerton, J. T. (2001). Effective strategies that enhance adherence to breast cancer screening guidelines. *Breast Disease*, *13*, 3.
- Sallis, J. F., & Owen, N. (2002). Ecological models of health behavior. In K. Glanz, B. Rimer,
 & F. Lewis (Eds.), *Health behavior and health education* (pp. 462-484). San Francisco: Jossey-Bass.
- Sanders, T., Campbell, R., Sharp, D., & Donovan, J. (2003). Risk constructions among people who have a first-degree relative with cancer. *Health, Risk, & Society, 5*(1), 53-68.

- Satorra, A., & Bentler, P. M. (1994). Corrections to test statistics and standard errors in covariance structure analysis. In A. von Eye & C. C. Clogg (Eds.), *Latent variable analysis: Applications for developmental research* (pp. 399-419). Thousand Oaks, CA: Sage.
- Schapira, M. M., Davids, S. L., McAuliffe, T. L., & Nattinger, A. B. (2004). Agreement Between Scales in the Measurement of Breast Cancer Risk Perceptions. *Psycho-Oncology 24*[3], 665-673. Blackwell Publishing Limited.
- Schwartz, M. D., Taylor, K. L., & Willard, K. S. (2003). Prospective association between distress and mammography utilization among women with a family history of breast cancer. *Journal of Behavioral Medicine*, 26, 105.
- Schwartz, M. D., Taylor, K. L., Willard, K. S., Siegel, J. E., Lamdan, R. M., & Moran, K. (1999). Distress, personality, and mammography utilization among women with a family history of breast cancer. *Health Psychology*, *18*, 327-332.
- Schumacker, R. E., & Lomax, R. G. (2004). *A beginner's guide to structural equation modeling* (2nd ed.). Mahwah, NJ: Lawrence Erlbaum Associates.
- Shim, M., Kelly, B., & Hornik, R. (2006). Cancer information scanning and seeking behavior is associated with knowledge, lifestyle choices, and screening. *Journal of Health Communication, 11*, 157-172.
- Sobol, M. P., & Cardiff, J. (1983). A sociopsychological investigation of adult adoptees' search for birth parents. *Family Relations*, 32, 477-483.
- Spector, P. E. (2006). Method variance in organizational research: Truth or urban legend? *Organizational Research Methods*, *9*, 221-232.

- Stolley, K. S. (1993). Statistics on adoption in the United States. *The Future of Children Adoption, 3*, 26-42.
- Strauss, A. & Corbin, J. (1990). *Basics of qualitative research: Grounded theory procedures and techniques*. Newbury Park, CA: SAGE.
- Strauss, A. & Corbin, J. (1994). Grounded theory methodology: An overview. In N.K. Denzin & Y.S. Lincoln (Eds.), *Handbook of qualitative research* (pp. 273-285). Thousand Oaks, CA: SAGE Publications.
- Strickland, O. L., Moloney, M. F., Dietrich, A. S., Myerberg, S., Cotsonis, G. A., & Johnson, R.
 V. (2003). Measurement issues related to data collection on the World Wide Web.
 Advances in Nursing Science, 26(4), 246-256.
- Strauss, A. & Corbin, J. (1994). Grounded theory methodology. In N. Denzin & Y. Lincoln (Eds.), *Handbook of qualitative research* (pp. 273-285). Thousand Oaks, CA: Sage.
- Tam, K. (2004). Exploring the value of health information to adult adoptees. Unpublished master's thesis, Johns Hopkins University, Baltimore, MD.
- Tashakkori, A., & Teddlie, C. (2003). The past and future of mixed methods research: From data triangulation to mixed model designs. In A. Tashakkori & C. Teddlie (Eds.), *Handbook of mixed methods in social and behavioral research* (pp. 671-701). Thousand Oaks, CA: Sage.
- Teddlie, C., & Tashakkori, A. (2003). Major issues and controversies in the use of mixed methods in the social and behavioral sciences. In A. Tashakkori & C. Teddlie (Eds.), *Handbook of mixed methods in social and behavioral research* (pp. 3-50). Thousand Oaks, CA: Sage.

- 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
- Thomas, D. B., Gao, D. L., Ray, R. M., Wang, W. W., Allison, C. J., Chen, F.L., et al. (2002). Randomized trial of breast self-examination in Shanghai: Final results. *Journal of the National Cancer Institute*, 94(19), 1445-1457.
- Tiro, J. A., Diamond, P. M., Perz, C. A., Fernandez, M., Rakowski, W., DiClemente, C. C. et al. (2005). Validation of Scales Measuring Attitudes and Norms Related to Mammography Screening in Women Veterans. *Health Psychology*, 24, 555-566.
- Trochim, W. M. K. (2001). *Research methods knowledge base* (2nd ed.). Cincinnati, OH: Atomic Dog Publishing.
- Turnbull, C., & Rahman, N. (2008). Genetic predisposition to breast cancer: Past, present, and future. Annual Review of Genomics and Human Genetics, 9, 321-345.
- Tversky, A. & Kahneman, D. (1973). Availability Heuristic for judging frequency and probability. *Cognitive Psychology*, *5*, 207-232.
- Tversky, A. & Kahneman, D. (1974). Judgment under uncertainty heuristics and biases. *Science*, 185, 1124-1131.
- University of Michigan Center for Public Health and Community Genomics. *Ethical, legal and social issues in public health genetics (PHELSI)*. Retrieved September 8, 2008 from http://www.sph.umich.edu/genomics/site042408/media/subpage_autogen/PHELSI.pdf.
- University of Washington, Center for Genomics and Public Health, Training and Resources, *Tools for Public Health Professionals*. Retrieved September 30, 2008 from http://depts.washington.edu/cgph/OnlineTools.htm.

- van Dijk, S., Otten, W., van Asperen, C. J., Timmermans, D. R. M., Tiben, A., Zoeteweij, M.
 W., et al. (2004). Feeling at risk: How women interpret their familial breast cancer risk. *American Journal of Medical Genetics*, *131A*, 42-49.
- van Oostrom, I., Meijers-Heijboer, H., Duivenvoorden, H. J., Brocker-Vriends, A. H. J. T., van Asperen, C. J., Sijmons, R. H., et al. (2007). The common sense model of self-regulation and psychological adjustment to predictive genetic testing: A prospective study. *Psycho-Oncology*, 16(12), 1121-1129.
- Vaughan, D. (1992). Theory elaboration: The heuristics of case analysis. In H. Becker & C.Ragin (Eds.), *What is a case*? (pp. 173-202). New York: Cambridge University Press.
- Venne, V. L., Botkin, J. R., & Buys, S. S. (2003). Professional opportunities and responsibilities in the provision of genetic information to children relinquished for adoption. *American Journal of Medical Genetics Part A*, 119A, 41-46.
- Wallace, M., & Wray, A. (2006). Critical reading and writing for postgraduates. Thousand Oaks, CA: Sage.
- Wattendorf, D. J., & Hadley, D. W. (2005). Family history: The three-generation pedigree. *American Family Physician*, 72, 441-448.
- Wenzel, L., Glanz, K., & Lerman, C. (2002). Stress, coping, and health behavior. In K. Glanz,
 B. Rimer, & F. Lewis (Eds.), *Health behavior and health education* (pp. 210-239). San Francisco: Jossey-Bass.
- Wu, T. Y., & Yu, M. Y. (2003). Reliability and validity of the mammography screening beliefs questionnaire among Chinese American women. *Cancer Nursing*, 26(2), 131-142.

Yoon, P., & Scheuner, M. (2003a). The family history public health initiative. In: *Genomics and Population Health: United States 2003*. Atlanta (GA): Centers for Disease Control and Prevention, Office of Genomics and Disease Prevention [online] 2003 pp. 39-45 [cited 2005 Mar 4]. Available from URL:

http://www.cdc.gov/genomics/activities/ogdp/2003/chap06.htm.

- Yoon, P. W., Scheuner, M. T., & Khoury, M. J. (2003b). Research priorities for evaluating family history in the prevention of common chronic diseases. *American Journal of Preventive Medicine*, 24(2), 128-135.
- Yoon, P. W., Schuener, M. T., Peterson-Oehlke, K. L., Gwinn, M., Faucett, A., & Khoury, M.
 (2002). Can family history be used as a tool for public health and preventive medicine? *Genetics in Medicine*, 4(4), 304-310.
- Yu, M. Y. & Wu, T. Y. (2005). Factors influencing mammography screening of Chinese American women. *Journal of Obstetric Gynecologic and Neonatal Nursing*, 34, 386-394.

APPENDICES

TMSC Term/Concept	Definition	Application
Primary Appraisal	Personal assessment of the relevance of existing risk factors for disease.	Perceived risk of developing breast cancer
Secondary Appraisal	Perceived effectiveness of available resources to cope with disease risk.	Perceived value of obtaining mammograms and information about biological family medical history.
		Perceived control over disease risk.
Coping Efforts	Strategies that mediate primary and secondary appraisals	Strategies can be adaptive or maladaptive.
Problem Management	Cognitive, emotional, or behavioral strategies used to ameliorate a stressful situation.	Seeking mammography to detect disease early and reduce its severity.
		Seeking information about biological family medical history as a way of reducing the uncertainty about disease risk factors and exerting control over health decision making.
Emotional Regulation	Situation-specific emotional response to change one's feelings or thoughts about a stressful situation.	Worry about breast cancer

Appendix A: Definition of Constructs for TMSC

Note: Table mirrors that in Wenzel, Glanz, & Lerman, 2002

Appendix B: Research Invitation

Please distribute this research invitation broadly.

Are you a female adoptee at least 40 years of age? If so, you're invited to participate in an important research study about how adopted persons take care of their health.

To participate online, visit the following site: <u>https://src.ibr.uga.edu/surveys/adopteehealth/intro.htm</u>

At most, the survey should take **only 15 minutes** to complete. Participation is completely voluntary and confidential.

This research is being conducted by an **adult adoptee** who is a doctoral candidate in the College of Public Health at The University of Georgia. If you have any questions, please contact the researcher, Rebecca Glover-Kudon, by e-mail at adoptee.health@yahoo.com. The researcher will make research findings available upon request.

If you receive multiple requests for participation, please complete the survey only one time.

Thank you!

Appendix C: Online Questionnaire


Adult Adoptee Health Survey

Thanks for your interest in participating in this important study about how adopted persons take care of their health. Your answers to this survey will help researchers understand how adoptees think about their disease risks, develop health promoting practices, and discuss family medical history with their doctors. Your participation is both voluntary and confidential.

This research is being conducted by a fellow adult adoptee who is currently a doctoral candidate in the College of Public Health at The University of Georgia in the Department of Health Promotion and Behavior. If you have any questions or experience technical difficulties, please contact the researcher by email at <u>adoptee.health@yahoo.com</u> or call 706-542-3313.

Please click the button below to continue to the next screen, which will assess your eligibility for the study.



Survey Eligibility

Please read the following statements to determine your eligibility for the study.
I am a woman at least 40 years of age.
I was adopted as an infant or child.
Neither of my adoptive parents is biologically-related to me.
Neither of my adoptive parents is my step-parent.
I have never been diagnosed with breast cancer.

If each statement is true, please select here.

If any statement is not true, please select here.

Continue

Thank you for your time and interest. However, you do not meet the eligibility criteria for this particular study.

Please exit the survey by clicking the button below. The final screen provides information about how to get involved in future health-related research efforts involving adoptees.

Continue

Please print a copy of this letter for your records.

Vour Progress

About the Survey

Dear Adult Adoptee:

I am a doctoral candidate under the direction of Dr. David DeJoy in the Department of Health Promotion and Behavior at The University of Georgia. Linvite you to participate in a research study entitled **"When Family History is a Mystery"** that I am conducting for my dissertation. The purpose of this study is to understand how adopted persons think about their risk for disease and how they take care of their health.

To be eligible to participate, you must be a female adoptee at least 40 years of age who has never been diagnosed with breast cancer and is fluent in English. In addition, you must have been raised by parents who are **not** biologically-related to you. (You may or may not have contact with birth parents at this point in your life.)

Your participation will involve **completing an online survey** and should only take about **15 minutes**. Your involvement in the study is **voluntary**, and you may choose not to participate or to stop at any time without penalty. Although research results may be published, your identity will not be associated with your responses in any way. No personally identifying information about you, like your name, email, or IP address, will be available to the researcher unless optionally disclosed by you. Your participation is, therefore, **anonymous**. However, there is a limit to the confidentiality that can be guaranteed due to the technology itself. There is a slight risk that data sent through the Internet can be intercepted by a third-party. A secure server and encryption technology are being used to guard against unauthorized receipt of data.

You will not benefit directly from participation in the study. However, you may indirectly benefit by reflecting on your own health practices. No physical discomfort is expected, but you may experience some psychological distress in reflecting on your adoption circumstances, potential risks for disease, and health practices.

The University of Georgia's Institutional Review Board has approved this research effort for adequately protecting the rights of research participants. Questions or concerns about your rights as a research participant should be directed to The Chairperson, University of Georgia Institutional Review Board, 612 Boyd GSRC, Athens, Georgia 30602-7411; telephone (706) 542-3199; email address inb@uga.edu.

If you have any questions about this research project, please feel free to contact me, **Rebecca Glover Kudon**, at **(706) 542-3313** or by email at <u>adoptee.health@yahoo.com</u>

Sincerely, Rebecca Glover Kudon, PhD Candidate

By completing the survey, you are agreeing to participate in the research study. If you agree, click the button below.

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Prefer Paper? Click <u>here</u> for a mail-in version of the survey.

Directions: Answer each question carefully by clicking on the button that best matches your response. To change an answer, select another response. To remove an answer, click on the reset button at the bottom of the page, and it will clear out all of the responses on that page. The progress bar, located in the upper-right-hand corner of your screen, indicates how much of the survey you've completed. There are 74 questions that should take about 15 minutes to answer.

The first set of questions refers to experiences you may have had at the doctor's office.

	Yes	No
1. Do you currently have a primary care physician?	\bullet	\bullet
2. Have you told your primary care physician that you are an adoptee?	0	0
3. When asked, do you complete family history forms at your primary care physician's office? [if no, skip to #5]	•	•

4. If "yes" to question 3 above, which medical history do you use when completing family history forms?

- Adoptive family medical history only
- Biological family medical history only
- O Blend of adoptive and biological family medical history
- O Other (please explain)

5. Does the family history form used by your doctor specifically ask whether or not you're an adoptee?

- 🔿 Yes
- 🔿 No
- 🔿 Don't recall

	Yes	No
6. Has your physician ever talked with you about hereditary disease risks?	•	\bullet
7. Has your physician ever suggested that you consider searching for information about your biological family medical history?	0	0

Comments (Optional): Please limit comments to 5 lines. Additional comments may be emailed to the researcher.



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The next set of questions refers to how much information you may or may not have about your biological family medical history.

	Strongly disagree	Disagree	Neither agree nor disagree	Agree	Strongly agree
8. I have access to information about my biological family medical history.	•	•	•	•	•
9. I am familiar with my biological family members' health histories.	0	0	0	0	0
10. I've been told information about my biological family medical history.	•	•	•	•	•
11. I have written documentation about my biological family medical history.	0	0	0	0	0

Having biological family medical history information would						
					1	
	Strongly disagree	Disagree	Neither agree nor disagree	Agree	Strongly agree	
12. Help me be more aware of risks for various medical conditions.	•	•	•	•	•	
13. Help me take a more active role in my healthcare.	0	0	0	0	0	
14. Help me take better care of myself.	•	•	•	•	•	
15. Help me develop good health habits.	0	0	0	0	0	
16. Prompt me to see a physician at the first sign of problems.	•	•	•	•	•	
17. Prompt me to get regular health screenings.	0	0	0	0	0	
18. Help me understand or explain physical symptoms to my healthcare provider.	•	•	•	•	•	
19. Help physicians diagnose my medical problems.	0	0	0	0	0	
20. Help physicians suggest treatment options.	•	•	•	•	•	
21. Give me peace of mind.	0	0	0	0	0	
22. Provide information about me that's important to share with others.	•	•	•	•	•	
23. Reduce uncertainty about my risks for disease.	0	0	0	0	0	

Comments (Optional): Please limit comments to 5 lines. Additional comments may be emailed to the researcher.

Continue Reset

The next set of questions asks about your level of interest in searching for information about your biological family medical history.

24. What is your current level of interest in searching for information about your birth parent(s)?

○ Not at all interested

Somewhat interested

○ Very interested

Extremely interested

Have you ever		
	Yes	N
25. Asked adoptive parents for information about your biological family medical history?	•	C
26. Seriously considered searching for your birth parent(s)?	0	0
27. Conducted research online about how to conduct a birth parent search?	•	C
28. Petitioned the court system for your adoption records?	0	
29. Given information to or requested information from a government-sponsored reunion registry or database?	•	
30. Contacted a third-party for help in locating birth parent(s)?	0	C
31. Participated in a support group for adopted persons searching for birth parents?	•	C
32. Contacted the adoption agency that handled your case about providing biological family medical history information?	0	0
33. Contacted the lawyer who handled your adoption for biological family medical history information?	•	
34. Placed a personal advertisement for help in locating biological family members?	0	0
35. Requested help from your doctor in obtaining your biological family medical history?	•	
36. Asked your doctor or other healthcare professional about getting tested for genetic disorders or abnormalities?	0	0

Comments (Optional): Please limit comments to 5 lines. Additional comments may be emailed to the researcher.

Continue Reset

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Vour Progress

The next set of questions refers to your personal and family medical history, including how often you seek routine cancer screening.

	Yes	No	Don't Know
37. Have you ever been diagnosed with breast cancer?	\bullet	\circ	•
38. Have you ever been diagnosed with any other type of cancer?	0	0	0
39. Have any of your close friends or acquaintances been diagnosed with breast cancer?	•	•	•
40. Has anyone in your adoptive family been diagnosed with breast cancer?	0	0	0
41. Has anyone in your adoptive family been diagnosed with any other type of cancer?	•	•	•
42. Has anyone in your biological family been diagnosed with breast cancer?	0	0	0
43. Has anyone in your biological family been diagnosed with any other type of cancer?	•	•	•

44. How often do you perform breast self-examination?

O Never

- 🔘 Less than once a year
- 🔿 1-6 times per year
- 🔿 7-12 times per year
- More often than monthly

45. How often do you have clinical breast examinations done by your physician or other health care professional?

🔿 Never

- Once every few years
- 🔿 Once a year
- O More than once per year

46. When did you have your LAST mammogram?

Never [skip to question #48]

- 🔘 More than 4 years ago
- 🔿 3-4 years ago
- 🔿 1-2 years ago
- 🔿 Within past year

47. A screening mammogram occurs when there are NO symptoms or concerns present. At what age did you have your first *screening* mammogram?

[2-digit age in years]

48. I estimate that the likelihood of my having a mammogram every year is:

- 🔿 Very low
- 🔿 Low
- 🔿 Good
- 🔿 High
- O Very High

	Strongly disagree	Disagree	Neither agree nor disagree	Agree	Strongly agree
49. I intend to have a mammogram every year.	•	•	•	•	•
50. If I have the opportunity, I will have a mammogram every year.	0	0	0	0	0

Comments (Optional): Please limit comments to 5 lines. Additional comments may be emailed to the researcher.

Continue Reset

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Scale range means 0 = "no chance" and 100 = "definitely will."

51. <u>On a scale from 0 to 100</u>, what's the probability that the *average woman* your age and race will develop breast cancer during her lifetime?

52. <u>On a scale from 0 to 100</u>, what's the probability that *you* will develop breast cancer during your lifetime?

	Not at all possible	A little possible	Moderately possible	Very possible
53. To what extent is it possible to reduce YOUR risk of developing breast cancer?	•	•	•	•
54. To what extent is it possible for MOST WOMEN to reduce their risk of developing breast cancer?	0	0	0	0

55. What is your current level of anxiety about the results of future mammograms?

- 🔿 None
- 🔿 A little
- 🔘 Somewhat
- 🔿 A lot

During the past month				
	Not at all or rarely	Sometimes	Often	A lot
56. How often have you thought about your own chances of getting breast cancer?	•	•	•	•
57. How often have thoughts about your chances of getting breast cancer affected your mood?	0	0	0	0
58. How often have thoughts about your chances of getting breast cancer affected your ability to perform your daily activities?	•	•	•	•

	Strongly disagree	Disagree	Neither agree nor disagree	Agree	Strongly agree
59. It is likely that I will get breast cancer.	•	•	•	•	•
60. Compared to most women my age and race, I am more likely to develop breast cancer.	0	0	0	0	0
61. My chances of getting breast cancer in the next few years are great.	•	•	•	•	•
62 I feel I will get breast cancer sometime during my life.	0	0	0	0	0
63. It is likely that I have the breast cancer gene.	•	•	•	•	•

Comments (Optional): Please limit comments to 5 lines. Additional comments may be emailed to the researcher.

Your Progress

The final set of questions will be used to describe study participants.

64. In what state do you currently live?

Select one 🛛 🔽

65. What is your 5-digit Zip Code?

[5-digits]

66. In what state were you adopted, if known?

Select one 🛛 🔽 💌

67. What year were you born?

Selectione 💌

68. How would you describe your race or ethnicity?

69. What is the highest level of education you have obtained?
Select one

70. What is your current relationship status?

71. Do you have adoptive children?

○ Yes

72. Do you have biological children?		
⊙ Yes ⊙ No		

73. Where did you first learn about this survey?		
Selectone		
	Continue Reset	

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Your Progress

Interest in Future Research

The researcher may wish to follow-up with you by telephone to seek more in- depth understanding about your health beliefs and health practices. Telephone interviews should last about 20-30 minutes.

74. Would you be interested in participating in the second phase of research, if needed?

🔿 Yes

🔿 No thanks

Continue Reset

Optional: Please provide your contact information.

Name:	
Email address:	

Phone number: (XXX) XXX-XXXX

The best day to reach me is generally:

🔿 A Weekday

🔿 A Weekend

The best time of day to reach me is generally:

- 🚫 8:00 a.m. Noon
- 🚫 Noon 3:00 p.m.
- 🚫 3:00 p.m. 6:00 p.m.
- 🔿 6:00 p.m. 9:00 p.m.

I am in the following time zone:

- 🔘 Eastern
- 🔘 Central
- 🔿 Mountain
- O Pacific

Continue Reset

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Your Progress

Thank you! Your time and thoughtful responses are greatly appreciated.

Print

For More Information		
For more information about breast cancer, including risk factors, prevention, and early detection, please call the American Cancer Society at 1-800-ACS-2345 (7 days/wk. & 24 hrs. /day) or visit their website at: http://www.cancer.org/docroot/CRI/CRI 3x.asp?dt=5		
\aleph		
Please Help Recruit		
Do you know other female adult adoptees who may be interested in completing this survey? If so, pleas copy the following link and forward it to them from your email account. <u>https://src.ibr.uga.edu/surveys/adopteehealth/intro.htm</u>	е	
Contact the Researcher		
Please contact the researcher with any comments, questions, or problems, or to request an executive summary of the research findings, which should be available around December 2007.		
Rebecca Glover Kudon, PhD Candidate		
Dept. of Health Promotion and Behavior		
College of Public Health		
The University of Georgia		
Athens GA 30602		
Phone: 706-542-3313		
Email: adoptee.health@yahoo.com		
Not Eligible? If you would like to be considered for participation in future health-related research involving adult adoptees, please email the researcher and provide the following information: name, email address, phone number, gender, and age.	I	

Thank you for taking the time to participate in this important survey. Don't forget to close your browser after exiting the survey.

<u>Exit survey</u>

Appendix D: Researcher Subjectivity Statement

I am a doctoral candidate in health promotion and behavior at a southeastern public university. I am a married, heterosexual, Caucasian woman in my late thirties. I have no children, am able-bodied, and consider myself socio-economically middle-class. Perhaps most influential in developing my research interests is the fact that I am an adoptee, since infancy, and also a cancer survivor, since adolescence. I have little desire to engage in a birth parent search, although genetic family history is among the etiologic risk factors for the type of cancer I experienced. I have scant information regarding my birth parents other than their approximate age at my birth and general geographic location of residence. My adoptive family, to whom I am very close, includes my parents, now in their 70s, and an older sister who is also an adoptee.

As a health education professional, I advocate preventive health practices and ageappropriate screening for early detection of cancer as risk reduction strategies for all persons. My personal and professional desire is to calibrate perceived risk as close as possible to "actual" risk in order to produce appropriate prevention and screening levels that will curb disease morbidity and mortality without unnecessarily elevating cancer anxiety, worry, and distress. I believe that genetic testing for persons with unknown risk must have clinical utility to be recommended and feel that the costs and benefits of genetic testing should be carefully considered at all risk levels, given the potential psychosocial ramifications on individuals and family members.

My personal background is shared to promote transparency of the research process, given that it served as the lens through which data were collected, analyzed, and interpreted. My background was arguably beneficial to the study in that some aspects of internal validity in the qualitative sense were somewhat "hard wired." Having an emic perspective on my topic (Patton,

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2002) likely facilitated rapport establishment with respondents and aided the overall analytic, interpretive rendering.

Appendix E: Semi-structured Interview Guide

Informational Letter for Telephone Participants

E-mailed prior to Interview

I previously participated in the research study entitled "When Family History is a Mystery: How Adult Adoptees Cope with Ambiguous Risk for Breast Cancer" by answering questions online. Now, I am extending my participation by agreeing to be interviewed by telephone for approximately 30 minutes. The purpose of this phase of the research study is to better understand the role that ambiguity of biological family medical history plays in breast cancer risk perception development.

I understand that my participation is voluntary and that I can stop taking part or refuse to answer any question without giving any reason, and without penalty. I can ask to have all of the information about me returned, removed from the research records, or destroyed up until the point of finalization of the written report.

The researcher will audiotape the interview with my permission to help with note taking and transcribing. Audio files will be destroyed after a written transcript is created. My interview will be treated as confidential. As such, no personally-identifiable information about me will be released without my written permission, unless required by law. The information that I share and any quotes used by the researcher in written or oral presentations will not be attributed to me personally. Rather, my identity will be disguised by use of a pseudonym, or fake name.

I will not benefit directly from my participation in the study. However, I may indirectly benefit by reflecting on my own health practices. No physical discomforts are expected, but I may experience some emotional discomfort in reflecting on my adoption circumstances, potential risks for cancer, and health practices.

The researcher for both phases of the research study is an adult adoptee named Rebecca Glover-Kudon, a doctoral candidate from the College of Public Health at the University of Georgia, who is working under the direction of Dr. David DeJoy in the Department of Health Promotion and Behavior (706-542-3313). Rebecca will answer any further questions about the research, now or during the course of the project. She can be reached by telephone at (706) 542-4900 or by email at <u>adoptee.health@yahoo.com</u>. The mailing address is: Rebecca Glover Kudon, Doctoral Candidate, Health Promotion and Behavior, University of Georgia, 316 Ramsey Center, Athens, GA 30602.

By completing the telephone interview, I am indicating that the researcher has answered any questions to my satisfaction and that I consent to volunteer for this study.

Additional questions or problems regarding my rights as a research participant should be addressed to: The IRB Chairperson, Institutional Review Board, University of Georgia, 612 Boyd Graduate Studies Research Center, Athens, Georgia 30602-7411; Telephone (706) 542-3199; E-Mail Address: IRB@uga.edu.

Interviewee Number: Name & Contact Information: (removed for field notes, transcripts) Biographic profile: Age, region of country, information-seeking score, current interest in birthparent searching (info taken from online survey responses)

Adult Adoptee Interview Guide---this page is for the researcher only

in ontriparent searching	
(info taken from online survey responses)	
Pseudonym:	
Date of Interview:	
Time of Interview (start-stop):	
Audio file name:	
Field notes file name: (if applicable)	

Background

This interview guide is designed to explore the relationship between ambiguity of biological family medical history information and perceived risk for breast cancer. Respondents were selected using two criteria, 1) having a high degree of ambiguity about their biological family medical history and 2) having either a very high or very low personalized estimate of breast cancer risk. Cognitive representations of risk will be explored along with potential differences between persons with varying personalized constructions of breast cancer risk.

Research Questions:

- What are adult adoptees' cognitive representations of their personal breast cancer risk?
 - What role does ambiguity of biological family medical history play in constructing personalized breast cancer risk estimates?
 - How do adult adoptees attribute risk and protective factors when constructing personalized disease risk estimates?
 - How does having greater affinity (i.e., perceived sameness) for either one's adoptive or biological parent impact personalized constructions of risk?
 - What cognitive heuristics do adult adoptees employ when constructing personalized disease risk estimates?
- How do these cognitive representations differ between persons with high vs. low perceived risk?

Semi-structured Interview Guide for Phone Participants: Verbal Script

Introduction

Hi, my name is Rebecca Glover-Kudon from the University of Georgia. Let me start by thanking you for taking the time to talk with me today. This interview will last about 30 minutes. Is that OK for you? *(If not, reschedule for another time.)*

Great. Did you have a chance to review the information letter about the study that I emailed you? Just as a reminder, this interview is confidential. You can refuse to answer any question or stop the interview entirely, without giving any reason and without penalty. In written reports or oral presentations, information you share or any quotes that I use will not be attributed to you personally. I'll be using a pseudonym or fake name to present ideas from any particular person.

I'm conducting this interview to better understand the relationship between biological family medical history ambiguity and disease risk perception. You were selected to participate in a telephone interview because you indicated having a great deal of ambiguity about your biological family medical history.

I'd like to audiotape the interview to capture our conversation and help with note taking. The audio file will be destroyed after transcription.

Do I have your permission to tape record this interview? Yes / No

[If **yes**, Ok. I'll start the recorder now.]

[If **no**, then provide this explanation before the closing statement.]

OK. I respect your decision and will make every effort to capture your responses accurately in my notes. Is it OK to use thematic elements in my report, but not direct quotes?

[If yes, then provide this explanation and continue with the interview.]

Before we begin, do you have any questions for me or need clarification about anything I have said?

OK. Let's get started.

[If **no**, "thank you for your time and for considering participation."]

Introduction: As you may know, I'm also an adoptee and am interested in how being an adoptee shapes health beliefs and health practices....I've chosen to focus on breast cancer because it's an important issue for women & it's a disease for which biological family history is a risk factor.

You may have noticed from the list of topics that I sent that we have a lot to cover in a short time. [Name], You've so graciously offered 30 minutes of your time, and I want to honor that. It's likely that we'll both be so interested in this topic that we could talk for hours, but I'm going to do my best to honor your 30 minute commitment. If we spend too much time in any one area or veer off on a tangent, I'm going to do my best to bring us back to the list of questions I have. If you have time afterwards and are still interested in talking further, I'm happy to do that.

Questions for Phone Participants

1) From the online survey, you indicated that you didn't know a lot about your biological family medical history and that you were extremely interested in searching for your birth parents. Can you tell me more about that?

Probes:

- € What's your primary reason/motivation for searching (or not searching)?
- € What prompted you to search (in beginning, and now?) –was there a specific event?
- € Is it important to you to know your biological family medical history? Why or why not?
- € Are you (were you) more interested in reunion or in having information? –what type of info?
- € Do you want identifying or non-identifying information?
- € What type of information do you have about either biological parent?
- € Does that information include medical history?
- \in How did you get the information that you have?
- € Have you been reunited with either birth parent or members of their extended family?

2) Thinking of both your adoptive and biological family members *(which may only be in abstract)*, who are you most like in terms of your health? How are you different? What makes you feel this way?

Probe: which is more important to your overall health, nature or nurture?

3) Given that you don't have a great deal of information about your biological family medical history, how do you handle that in terms of taking care of your health? the health of your own children?

Up until now, we've been talking about health in general. Now, I'm going to move into questions about breast cancer.

4) The American Cancer Society estimates that about 1 in 8 women will get breast cancer in their lifetime. The risk is higher among women whose close blood relatives have the disease. What does this information mean to you personally?

Probes:

- € How does being an adoptee (having greater uncertainty about your biological family medical history) affect how you think about your own breast cancer risk?
- € Do you think it's likely that you will develop breast cancer one day? What makes you think so [or not]?
- € Most women are at least a little concerned about developing breast cancer one day. Can you describe your level of concern about developing breast cancer?

5) There are certain factors that increase women's risk for developing breast cancer. When you think about your own risk for developing breast cancer, what risk factors come to mind?

Probes:

- € What factors do you think contribute to your breast cancer risk?
- \in On what do you base your risk estimate?

6) Are there factors in your life, or things that you do, to protect yourself against breast cancer?

Probe: Some people say prayer, diet, or exercise helps protect them against disease, while others place emphasis on other things. What do you think is the most likely reason for your staying *disease free*?

7) So far, I've been asking about breast cancer. But you may have concerns about other types of illness, including both physical and mental conditions. When you think about your personal risk for disease, what illnesses or conditions concern you the most?

Probes:

- \in Are there certain diseases that you worry about developing one day?
- € What makes you worry about these conditions specifically?
- 8) Is there anything else you'd like to share with me regarding how being an adoptee shapes your health practices and overall sense of health and well-being?

THANK YOU FOR YOUR TIME!!!! Would you like to receive a copy of the executive summary from the research report? (Confirm email address.)

Informational Letter for Online Participants Adult Adoptee Health Study

E-mailed prior to dialogue

I previously participated in the research study entitled "When Family History is a Mystery: How Adult Adoptees Cope with Ambiguous Risk for Breast Cancer" by answering questions online. Now, I am extending my participation by agreeing to answer additional questions posed to me by the researcher via email. My participation is expected to take no more than 1 hour. The purpose of this phase of the research study is to better understand the role that uncertainty about biological family medical history plays in breast cancer risk perception development.

I understand that my participation is voluntary and that I can stop taking part or refuse to answer any question without giving any reason, and without penalty. I can ask to have all of the information about me returned, removed from the research records, or destroyed up until the point of finalization of the written report.

My online interview will be treated as confidential. As such, no personally-identifiable information about me will be released without my written permission, unless required by law. The information that I share and any quotes used by the researcher in written or oral presentations will not be attributed to me personally. Rather, my identity will be disguised by use of a pseudonym, or fake name.

I will not benefit directly from my participation in the study. However, I may indirectly benefit by reflecting on my own health practices. No physical discomforts are expected, but I may experience some emotional discomfort in reflecting on my adoption circumstances, potential risks for cancer, and health practices.

The researcher for both phases of the research study is an adult adoptee named Rebecca Glover-Kudon, a doctoral candidate from the College of Public Health at the University of Georgia, who is working under the direction of Dr. David DeJoy in the Department of Health Promotion and Behavior (706-542-3313). Rebecca will answer any further questions about the research, now or during the course of the project. She can be reached by telephone at (706) 542-4900 or by email at <u>adoptee.health@yahoo.com</u>. The mailing address is: Rebecca Glover Kudon, Doctoral Candidate, Health Promotion and Behavior, University of Georgia, 316 Ramsey Center, Athens, GA 30602.

By completing the online interview, I am indicating that the researcher has answered any questions to my satisfaction and that I consent to volunteer for this study.

Additional questions or problems regarding my rights as a research participant should be addressed to: The IRB Chairperson, Institutional Review Board, University of Georgia, 612 Boyd Graduate Studies Research Center, Athens, Georgia 30602-7411; Telephone (706) 542-3199; E-Mail Address: IRB@uga.edu.

Questions for Online Participants (sample email dialogue)

Thanks for participating in this phase of the research. What I'd like to do is send you about 10 questions to respond to by email.

Before I send the questions, did you have a chance to read the informational letter that I sent you? Please print a copy of it for your records. Do you have any questions about the study or what I'm asking you to do?

As the letter states, please know that:

- your participation is voluntary
- your responses will be treated with confidentiality
- you can skip any question or refuse to answer, without penalty and without giving any reason
- your participation will result in no direct benefit to you
- you may experience some emotional discomfort as you reflect on health matters as an adult adoptee

And, please know that your time and participation is greatly appreciated, should you be willing and able to continue!!

Questions:

1. From the online survey, you indicated that you didn't know a lot about your biological family medical history and that you had **[little, some, a great deal of]** interest in searching for your birth parents. Please tell me more about that.

For example, what's your primary reason for wanting to search for information? Do you desire reunion, family tree information, or family medical history information?

2. Thinking of both your adoptive and biological family members (even if you've never met them), whom are you most like in terms of your health? How are you different?

In other words, which is more important to your health---nature or nurture? What makes you feel this way?

3. Given that you don't have a great deal of information about your biological family medical history, how do you handle that in terms of taking care of your health?

If you have children who are biologically related to you, how does not having your own family medical history impact how you care for them or teach them about their own health?

Now, moving on to breast cancer specifically.....

4. The American Cancer Society estimates that about 1 in 8 women will get breast cancer in their lifetime. The risk is higher among women whose close blood relatives have the disease. What does this information mean to you personally?

5. There are certain factors that increase women's risk for developing breast cancer. When you think about your own risk for developing breast cancer, what risk factors come to mind?

6) Are there factors in your life, or things that you do, to protect yourself against breast cancer?

7. So far, I've been asking about breast cancer, but you may have concerns about other types of illness, including both physical and mental conditions. When you think about your personal risk for disease, what illnesses or conditions concern you the most? Please explain why you selected these conditions.

8. Is there anything else you'd like to share with me regarding how being an adoptee shapes your health practices and overall sense of health and well-being?

Thank you:

Thank you so much for your thoughtful responses!

Would you like me to send you an executive summary of the research findings when they're available?

If you'd like more information about risk factors for breast cancer, please visit the American Cancer Society's website: <u>http://www.cancer.org/docroot/CRI/CRI_2_1x.asp?dt=5</u>

Appendix F: Inductive Outline

I. Adjust Risk Constructions Downward

A. Lacking Salience

- lack of knowledge about breast cancer risk factors
- focused on other issues than breast cancer
- lack of vicarious experience with breast cancer

B. Avoiding Internalization

- Normalizing
- Deflection
- Discounting

C. Exercising Cognitive Control

- Can't worry about what I can't control
- Focus on what I can control in managing disease risks
- Conscious choice not to think/worry about abstract unknown

D. Exercising Behavioral Control

- Limiting alcohol
- Exercise/diet
- Screening + illusion of control

II. Adjust Risk Constructions Upward

A. Identifying with Topic (i.e., having salience)

- Personal experience (e.g., breast symptoms)
- Vicarious experience
- Environmental cues

B. Internalizing Risk Information

- Having unknown biological family medical history perceived as increasing actual risk
- Chronic concern/stress/worry
- Sharing risk factors with representative adoptive/biological family members

C. Cognitively Focusing on Uncontrollable Risk Factors

- Environmental Exposures
- Family History/Genetics

D. Engaging in Behavioral Risk

- Not eating healthy diet
- Being overweight
- Smoking
- Alcohol Use

Phase	Procedure	Product
QUANTITATIVE Data Collection	 Cross-sectional, Web-based survey of healthy female adult adoptees over 40. 	 Numeric data
QUANTITATIVE Data Analysis	 Data screening (univariate, multivariate normality) Frequencies Structural equation modeling Deductive theory testing Scale refinement Parameter estimation SPSS Lisrel Prelis 	 Missing data Outliers Descriptive statistics Covariance matrix Cronbach's alphas Factor loadings Regression equation coefficients Residuals Fit indices Modification indices
Connecting QUAN & Qual Phases	 Develop qualitative interview questions based on quantitative findings Purposeful selection of extreme cases to participate in qualitative interview 	 Extreme cases (n = 12) at both ends of the risk continuum (6 with low perceived risk, 6 with high) Semi-structured qualitative data collection instrument
Qual Data Collection	 In-depth telephone interviews and/or e-mail dialogue with 12 participants 	 Text data (e-mail correspondence, interview transcripts)
Qual Data Analysis	 Coding and thematic analysis, according to conventions of constructivist grounded theory Inductive & deductive reasoning Atlas-ti 	 Codes Themes Rich & thick description Illustrative quotes Suggested refinements to theoretical model
Integration of QUAN & Qual Findings	Interpretation of quantitative and qualitative findings—"combining inferences into a coherent whole"	 Refined theoretical explanation of female adult adoptees' coping responses to the threat of breast cancer amidst ambiguous biological family medical history Implications Limitations Suggestions for future research

Appendix G: Sequential Explanatory Mixed-Methods Design

Note: Design of this figure borrows heavily from Ivankova, Creswell, & Stick (2006). Grey shading indicates where data are mixed.