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The Role of Family Organization in Family Health History Communication about Cancer

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THE ROLE OF FAMILY ORGANIZATION IN
FAMILY HEALTH HISTORY COMMUNICATION ABOUT CANCER

A dissertation submitted in partial fulfillment of the requirements required for the degree of
Doctor of Philosophy at Virginia Commonwealth University

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Abstract

THE ROLE OF FAMILY ORGANIZATION IN FAMILY HEALTH HISTORY COMMUNICATION ABOUT CANCER

By Vivian M. Rodríguez, M.A., M.S.

A dissertation submitted in partial fulfillment of the requirements required for the degree of Doctor of Philosophy at Virginia Commonwealth University

Virginia Commonwealth University, 2013

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Family health history (FHH) has been recognized as an important tool in cancer prevention and health promotion. To date, literature on FHH discussions about cancer have largely focused on patient-physician communication or the dissemination of cancer-specific genetic tests results within the family. Fewer studies have sought to identify family factors that may promote FHH discussions, yet this type of information could be used to identify families needing support in having these conversations. Thus, the present study examined relations between family organization (cohesion and flexibility), communication openness, and FHH communication about cancer within a diverse group of women recruited from an urban, safety-net women's health clinic. Participants were enrolled in a randomized control trial examining the effects of an educational intervention on family communication about hereditary breast and colon cancers (Kin Fact Study). For the present study, baseline survey data for 472 women were analyzed. Participants completed measures on demographics, family organization, communication openness, and FHH communication. Average age was 34 years and 59%
reported being Black. Thirty-one percent had graduated high school and 28% reported having commercial health insurance. Seventy-five percent of women reported a family history of cancer in a first or second degree relative. Descriptive statistics, correlations, and multiple linear regression and hierarchical logistic regressions, adjusting for key factors, were performed. Nineteen percent of women actively collected FHH information about cancer and 11% reported actively sharing cancer risk information with relatives. Being older, having a greater educational attainment, and having a family history of cancer was associated with having collected FHH; while being older and reporting higher levels of cohesion/flexibility was associated with sharing cancer risk information. Adjusting for demographic variables, cohesion, flexibility, and openness were not significant predictors of collecting or sharing FHH. Family history of cancer did not moderate the relationship between family organization and FHH. Cohesion and flexibility levels did significantly predict communication openness. This study contributes to a small but emergent literature in the field of FHH communication about cancer as it explores family context factors that may aid in the development of prevention interventions. Clinical implications and directions for future research are discussed.
The Role of Family Organization in Family Health History Communication about Cancer

Cancer is the second leading cause of death in the United States (American Cancer Society (ACS), 2013a). According to the National Cancer Institute there were approximately 13.7 million individuals living with some form of cancer (either active or in remission) in January 1, 2012 (ACS, 2013a). In addition, it is estimated that close to 1.7 million individuals will be diagnosed with cancer in 2013 alone (ACS, 2013a). To help curb the rising incidence of cancer, the Department of Health and Human Services strongly encouraged scientific collaboration on health promotion and disease prevention by launching the Healthy People 2020 initiative (HealthyPeople.gov, 2011). With prevention as its core mission, this initiative, in part, addresses an urgent need for public health interventions to increase utilization of family health history in cancer prevention, potentially serving as a guide for determining risk and early screening for hereditary forms of cancer.

Approximately 5% to 10% of cancers are hereditary (ACS, 2013b), but an even larger proportion of cancers are "familial" and include both genetic and environmental factors that cluster in families. This generational pattern may be related to families often sharing the same environment and engaging in similar behaviors, such as smoking or consuming an unhealthy diet. In some cases, however, families may share a genetic mutation responsible for the etiology of certain types of cancers. To date, research has identified several genes whose mutations or changes have been associated with an increased risk of developing cancer; these include breast and ovarian cancers, colorectal cancers, and melanoma cancer (Schneider, 2002). Moreover, leading organizations in the area of cancer prevention and control (e.g., U.S. Preventive Services Task Force; American Cancer Society; National Comprehensive Cancer Network) strongly recommend that cancer screening schedules be tailored according to family health history,
highlighting its importance in prevention efforts. Thus, the presence of hereditary cancers and the significance of tailored cancer screenings suggest that family communication about the history of cancer within the family is important as it may have implications for early detection and potential reduction of cancer mortality.

Family health history communication broadly encompasses family discussions about the health of its members. With respect to cancer, family health history communication involves gathering specific information from family members about risk and screening behaviors, and actively sharing this information with other family members. The result of this communication among family members may consequently increase awareness of cancer risk in the family and lead to earlier screening and diagnosis of cancer. For instance, studies have suggested that knowledge of one's family health history is crucial to identifying genetic risk and is associated with cancer risk-reducing behaviors such as increased physical activity (McCusker, Yoon, Gwinn, Malarcher, Neff, & Khoury, 2004) and higher consumption of fruits and vegetables (Lemon, Zapka, & Clemow, 2004). Moreover, family health history knowledge is associated with early detection screening behaviors, such as breast self-exams (Jones, Denham, & Springerston, 2006) and mammography screening (Ersig, Williams, Hadley, & Koehly, 2009).

Despite recognition of family health history as an important cancer prevention tool, many Americans remain unaware that they may be at increased risk for cancer based on their family history alone because they fail to communicate this information with family members. To illustrate, a large, national survey study conducted with over 4,000 people by the Centers for Disease Control and Prevention showed that the majority of respondents (96%) believed that their family history was important and relevant for their own health (Yoon et al., 2004). Yet, only 30% had actively collected family health information for the purposes of creating a family
health history. This discrepancy coupled with evidence that demonstrates an association between family health history and cancer prevention practices highlights a need to better understand factors that facilitate or impede health history communication within families.

Research has identified important psychosocial and cultural factors that play a role in family communication about health history and familial cancer risk. Researchers have posited, for example, that communication about family health history depends on the type of family member involved. For instance, spouses or significant others have been identified as the initial “go-to” family member when it comes to disseminating information about genetic test results (Fosters, Eeles, Ardern-Jones, Moynihan, & Watson, 2004; Julian-Reynier et al., 2000).

Moreover, women are overwhelmingly seen as family health historians and the responsible ones for communicating health information within the family (Koehly et al., 2009; Nycum, Avard, & Knoppers, 2009; Wiseman, Dancyger, & Michie, 2010). Racial and ethnic differences have also been found in communication about family health history, with Latinos and Blacks holding cultural beliefs (i.e., stigma, shame, fatalistic beliefs) that may affect the likelihood of family health history communication (Haggstrom & Shapiro, 2006; Kinney, Gammon, Coworth, Simonsen, & Arce-Laretta, 2010). Furthermore, a generational pattern is seen in communication about family health history, with parents often waiting for the appropriate time (often when children have reached maturity) to inform children about family genetic predispositions (Aktan-Collan et al., 2011; Metcalfe, Coad, Plumridge, Gill, & Farndon, 2008). Lastly, emotional proximity or closeness with other family members has been identified as an important consideration in communication about family health history. For example, family members are more likely to share information about family health history with relatives who are emotionally close to them or have fewer degrees of relatedness separation (Claes et al., 2003; Nycum, Avard,
& Knoppers, 2009; Hay, Shuk, Zapolska et al., 2009). Although the aforementioned findings have provided insight into the conditions that are likely to improve or deter family health communication, there is much to learn regarding the contextual variables that influence family discussions about the history of cancer within the family (Wiseman, Dancyger, & Michie, 2010).

Much of the literature highlighting the importance of family health history discussions has focused on exploring best practices within a medical setting. For instance, family health history communication has been studied in the context of physicians disseminating cancer risk information to patients based on their family history (Arkin, 1999; Bortoff, Ratner, Johnson, Lovato, & Joab, 1998). Prior research also allocates great attention to dissemination of genetic test results within the family (Chivers Seymour, Addington-Hall, Lucassen, & Foster, 2010; Stoffel et al., 2008), with less exploration on how families talk about familial cancer risk and whether these discussions spark positive behavior change. Furthermore, largely missing from the literature are studies focusing on family context (i.e., organization, communication style) and its impact on family communication about family health history. The present study investigated this latter gap in the cancer prevention field in an effort to extend the literature in family health history communication about cancer.

The role of family organization in family health history communication has been relatively understudied (Harris et al., 2010). Family systems theory proposes that families are better understood as a unit, where communication serves as the medium through which shared beliefs, feelings, and emotions are transmitted and family functioning is maintained (Peterson, 2005). Furthermore, the family systems framework recognizes the importance of family organization in family functioning. According to David Olson's Circumplex Model of Marital and Family Systems (Olson, 2000; Olson & Gorrall, 2006) family organization consists of three
domains: cohesion, flexibility, and communication. When faced with stressful situations, such as knowledge of cancer in the family, the systems' functioning maps onto the balanced or unbalanced dimensions of cohesion and flexibility which in turn has implications for the family's well-being and healthy functioning. In this model, communication is seen as a facilitating dimension that helps families alter their levels of cohesion and flexibility.

Olson and colleagues (2006) propose two ways to examine a family's level of cohesion and flexibility. First, the model proposes a dimensional approach. Each dimension is composed of three levels: the cohesion levels are disengaged, balanced cohesion, and enmeshed, while the flexibility levels encompass rigid, balanced flexibility, and chaotic levels of functioning. The two balanced levels measure healthier or optimal functioning within the system while the four unbalanced levels measure more problematic functioning. Although families tend to move along the continuums of cohesion and flexibility when adjusting to stressors and challenges, it is the prolonged stay in the extremes that can lead to poor functioning. From these scales, a ratio of balanced to unbalanced functioning can be derived for cohesion and flexibility. In addition, the six scales can be examined separately by utilizing their raw scores. Second, the model allows researchers and clinicians to conceptualize families in terms of functional profiles along the cohesion and flexibility dimensions. The combination of cohesion and flexibility scores are used to represent the level of functionality within the family system, rather than just looking at each dimension separately (i.e., ratio scores). Thus, the family profiles provide a comprehensive way to examine family organization and functioning. Regardless of these two formats for understanding family organization, the main hypothesis of the model remains the same: balanced levels of cohesion and flexibility are most conducive to healthy functioning within the system while unbalanced levels tend to represent poor family functioning.
To date, little research has examined the role of family organization on family health history communication. One study found evidence that higher levels of cohesion and flexibility within the family was associated with perceiving more open platforms for sharing health information with relatives and increased support for melanoma discussions within families (Harris et al., 2010). Thus, gaining additional knowledge about the impact family cohesion and flexibility have on the likelihood of collecting or sharing family health history information as related to cancer is the primary goal of the present study.

Whether families have an open or blocked communication style is another area of research that may shed light on the impact of family context on communication about family health history of cancer (Kenen, Ardern-Jones, & Eeles, 2004). For example, Harris et al. (2010) found that out of 313 participants with melanoma in the family, less than half (42%) reported that their families had an open style of communication. In that sample, 28% of participants reported that sharing information about melanoma with first degree relatives was a difficult process, and they perceived significant barriers to the process of communication (i.e., direct refusal or lack of responsiveness to discuss health history). These findings suggest a potential connection between a family's organization and the style in which family members communicate with one another. Although the literature in this area is not extensive, families who are open to communicate about cancer may transmit valuable information through the family system, aiding cancer prevention and control efforts. Thus, in addition to examining family cohesion and flexibility, the present study examined communication openness as it relates to family health history communication.

In sum, scientific research and mass media alike have provided a clear message: awareness of family health history, particularly for hereditary types of cancer, has important
implications for prevention and health promotion (Niededeppe, Frosch, & Hornik, 2008). In an effort to add to the growing field of cancer prevention research, the present study explored associations between family context (i.e., family organization and communication openness) and family health history communication (i.e., collecting family health history and sharing cancer risk information) about cancer in a diverse sample of women attending a large, urban Women's Health Clinic. The primary aims of the study were to (1) examine relations between family organization (i.e., cohesion and flexibility) and family health history communication about cancer, (2) examine relations between family organization (i.e., cohesion and flexibility) and openness to discuss health problems within the family, (3) examine relations between openness to discuss health problems and family health history communication, (4) examine differences between women who collected/shared cancer risk information and women that did not collect/share such information on the six levels of family organization according to the Circumplex Model (Olson & Gorall, 2006), and (5) explore whether family health history communication differs between the two family groups (i.e., balanced and unbalanced) created by plotting each women's cohesion and flexibility dimension scores onto the Circumplex Model.

**Review of the Literature**

Family health history has been established as a strong predictor of cancer risk (Weitzel, Blazer, MacDonald, Culver, & Offit, 2011). As a publicly accessible screen for genetic cancer risk, collecting family health history is an efficient and cost-effective cancer prevention and control tool (Yoon, Scheuner, Peterson-Oehlke, Gwinn, Faucett, & Khoury, 2002; Wood, Stockdale, & Flynn, 2008). Previous research has suggested that the collection of family health history is helpful in the assessment of cancer risk and the development of tailored interventions to elicit behavior change (Valdez, Yoon, Qureshi, Green, & Khoury, 2010). Studies have also
indicated that having a positive family history of cancer may improve early detection of cancer and promote screening behaviors, and may be the basis for offering patients targeted preventive interventions (Cohen, 2006; McCaul et al., 1996; Rich et al., 2004; Tracy et al., 2008). With the added contributions of genetic testing for certain hereditary cancers and the repercussions this information may have for the family, understanding health communication within the family becomes highly relevant for cancer prevention and control.

**Family Health History Communication**

With recent advances in genetics and its contribution to the etiology of disease, the past two decades have seen a collective effort from health organizations and providers to recognize and highlight the importance of family health history. Several initiatives, such as the CDC’s Family History Public Health Initiative and Healthy People 2020, advocate for increased awareness of family health history in clinical practice as an effective tool for stratifying disease risk (CDC, 2011; Healthy People, 2011). With the introduction of electronic medical records, the hope is that collecting and archiving this information results in a hub of knowledge that can positively influence prevention and treatment practices, reduce health care costs, and decrease morbidity and mortality rates.

The main purpose of collecting family health history in a medical setting is that of risk assessment (Harris & McMullen, 2006). When presented with a positive family health history for certain diseases, physicians must follow set guidelines that prompt early screening interventions based on risk level. Families go through a similar interchange when faced with such information. Upon awareness of a positive history of cancer in a close relative, individual members of a family develop a perception of risk that guides communication with other relatives and may prompt them to engage in preventive behaviors (Audrain-McGovern, Hughes, &
Patterson, 2003; Tracy et al., 2008). However, problems arise when family health information is incomplete or unknown for certain family members (Kohut et al., 2011). Thus, encouraging and educating individuals about the importance of family health history communication is a promising intervention to get an accurate depiction of cancer risk within that family.

The collection of cancer family history is not only important to identify individuals at high risk for cancer but it also facilitates identification of individuals who may be more susceptible to the disease given a genetic or hereditary mutation. Over the past decade, genetic counseling and testing has received much attention given its relevance for counseling families at increased risk for gene mutations linked to certain types of cancer (Clark et al., 2000). Knowing that family members carry changes or mutations in those genes can lead to proactive behaviors that may greatly reduce one's risk for developing cancer. For instance, individuals who have a BRCA1/2 mutation, a gene commonly associated with breast and ovarian cancer, may elect to make healthier lifestyle choices, get more frequent and earlier screening tests, or undergo prophylactic preventive surgery (i.e., mastectomy or oophorectomy) to decrease their chances of developing breast and/or ovarian cancer (Schneider, 2002). Thus, in the age of genetics it is important to be aware and informed of your family's health history as a way to reduce mortality and promote healthy living.

A positive family history can give families an advantage in recognizing when they are at an increased risk for certain hereditary conditions (Forrest, Curnow, Delatycki, Skene, & Aitken, 2008). To further understand the implications of family history in cancer risk Glanz, Grove, Le Marchand, and Gotay (1999) conducted a study to examine the extent family members underreport a history of colon cancer and identify the predictors and correlates of such pattern. Participants in this study included either a sibling or adult child of a known case of colorectal
cancer, with the majority of participants being of Japanese descent (78.9%), followed by Hawaiian/Pacific Islanders (11.7%), and Whites (9.4%). A final sample of 426 participants completed a mailed survey that asked about family history awareness, knowledge about colorectal cancer, personal risk perception, family communication, and social support. Survey data revealed that those participants with a higher knowledge of cancer, greater family communication, elevated cancer worry, and a higher perceived risk of developing colon cancer were more likely to report a family history of colorectal cancer. Moreover, approximately 25% of participants were unaware that they had a positive history of colorectal cancer in a first degree relative. In this study, males and older participants were more likely to be uninformed. The authors posited that underreporting of family history may be due to lack of communication within the family. Thus, underreporting of family history can have significant negative consequences for surveillance and screening behaviors.

Personal cancer stories in the public eye, such as that of comedian Gilda Radner who died of metastatic ovarian cancer, highlight a culture of limited or inadequate family communication about cancer history (Piver, 2002). In this well-known case, Radner's relatives failed to communicate about the strong family history of ovarian cancer that existed within their family; potentially life-saving information that was missed and led to the late-recognition of her symptoms. Although the rationale for gathering and sharing family health history within the family system is convincing and may be regarded by some as common sense, it appears that the practice of communicating family health history is not as common as expected. A large, national survey study (HealthStyles Survey) conducted in 2004 by the Centers for Disease Control and Prevention showed that the majority of responders (96%) believed that their family history was important and relevant for their own health (Yoon et al., 2004). However, the authors found that
only 30% of responders had actively collected health information for the purposes of creating a family health history. This discrepancy highlights the need to learn more about the factors that facilitate and impede health communication within families.

Key barriers that make the process of collecting/giving family health history difficult to implement have been identified (Orlando et al., 2011; Williams, Collingridge, & Williams, 2011; Wood, Stockdale, & Flynn, 2008). Barriers include (1) patients' insufficient or incomplete knowledge about their family health histories, (2) strained family relationships, (3) concern that the message will be rejected given its serious nature, and (4) a limited understanding of the role of genetics and heredity in causing cancer (Claes et al., 2003; Hughes et al., 2002; Mellon et al., 2006). Despite these barriers, educating individuals on the advantages of collecting family health history information and sharing information about hereditary cancer risk with other relatives is critical in the proper treatment of certain cancers.

The literature describes several ways of assessing family cancer history, with different methodologies being used in clinical practice and research. Research typically relies on self-report questionnaires or checklists (Kohut et al., 2011; Mellon et al., 2009), while others in clinical practice have opted for electronic resources that collect family health history information through the use of a computer or internet-based platform, such as the 'Family Healthware' tool or 'My Family Portrait' website from the U.S. Surgeon's General (Acheson et al., 2010; Classen et al., 2010; O'Neill et al., 2009), or utilize family pedigrees or charts that are usually administered by genetic counselors or a health care providers (Koehly et al., 2009; Tracy et al., 2008; Schneider, 2002). Although no universal tool has been accepted, it has been well established that collecting family health history is important for clinical practice and treatment outcomes. The information gathered from these tools helps classify risk based on kinship, number of affected
family members, ages of diagnosis and/or death, and type(s) of cancer present. Less is known, however, about the communication methods that families use to collect and share family health history information. Raising awareness of the importance of family health history in clinical practice may be one way to foster intra-family communication about health history. It is also important to examine both the act of collecting (or gathering) information on family health history and sharing (or giving) information on hereditary cancer risk with other relatives (Yoon et al., 2004). These two family communication avenues have the potential to bridge gaps between knowledge and prevention. Therefore, the present study wishes to examine factors that may affect these two types of family communication about cancer, and label this communication process 'family health history communication'.

**When Diversity Becomes a Problem: Defining Family**

Whether individual members of families collect and share health history information with other relatives may be a function of the composition and structure of the family. In order to explore family communication about cancer risk, an important consideration that must be addressed is what constitutes a family. This is, by no means, a straightforward task. Several definitions have been proposed yet no universal definition has been adopted. Families have been viewed according to several different dimensions including individuals that are connected by genetic ties, through marriage and legal kinship, or even networks of individuals living together over a determined period of time (Galvin, Bylund, & Brommel, 2004). The variability in definitions among family members and researchers alike prolong an ongoing dilemma for understanding the complex dynamics that make up families but poses an interesting sociological debate.
Anthropological research demonstrates great diversity in the way cultures define and conceptualize family (McGrath & Edwards, 2009). For instance, Western families have evolved to have looser kinship ties that can be classified as fluid and heterogeneous. These diverse families value choice rather than genetics and place greater emphasis on social relationships rather than blood ties (Finkler, 2001). Furthermore, in certain cultural groups, it is not uncommon to have individuals who are formally or informally adopted into one's family. Informal adoptions are typically observed in the Black community, where family is often defined in terms of extended relatives (Baker, Schuette, & Urlmann, 1998). Members of the Black family tend to live close to one another and often share the responsibility of raising children. Formal adoptions, on the other hand, account for 4% of children added to U.S. families and typically result from families who have difficulty conceiving due to fertility problems (Le Poire, 2006). In other cultures, however, adoption is typically discouraged. For instance, Greek families value clear and definite boundaries between blood relatives and community members, and thus are less inclined to seek adoption as a method of adding children to the family (Baker, Schuette, & Urlmann, 1998). On the opposite side of the spectrum, members of the Native American community are known to have no distinctions between biological and non-biological kin. According to Garret (2004), in the Native American community "family is a matter of blood and of spirit" (p. 152) and, as such, they welcome relatives and non-relatives as family.

Traditionally, families in the United States have been defined from a nuclear standpoint – that is, two heterosexual individuals bonded by marriage that have biological offspring (Segrin & Flora, 2005). Presently, the U.S. Census estimates that only 21% of households are headed by a married couple making the overwhelming majority of households non-traditional (U.S. Census, 2010a). Therefore, modern families have evolved to transcend the traditional definition of
family to include a broader definition – that is, whether individuals identify themselves as part of
the group, share experiences, affection, and resources with one another, and, whether its
members refer to this group of individuals as their 'family' to others outside the group (Minow,
1998; Galvin, Bylund, & Brommel, 2004). Although changing times support a more
comprehensive definition of family, genetics research has been traditionally limited to examining
blood ties among relatives with much less efforts put forth to study the social meanings
attributed to relationships (Hallowell et al., 2005; McGrath & Edwards, 2009).

It is evident that when studying genetic contributions of disease, one must rely on blood
relatives to investigate the generational transmission of genetic markers, however, there is a gap
in the way research participants classify families and the way researchers' categorize families.
Taking into account genetic and environmental contributions, family structure can be divided
into the following categories: (1) *close or nuclear family*, which includes biological parents,
children, and siblings; (2) *kin*, this category relates to extended family members such as
grandparents, aunts/uncles, and cousins; and (3) *household*, which recognizes spouses and other
relationships through marriage or legal terms (Richards, 1996). Including these three dimensions
when studying family dynamics is important because they account for the majority of
configurations of the modern family, from biological ties to socialized relationships.

Knowing that a close blood relative has had cancer may raise awareness about the
importance of genetic risk as well as the value in sharing such information with other relatives
who may be at risk. Therefore, communication among biological family members either through
vertical (i.e., parents to children) or horizontal (i.e., brothers to sisters) channels helps
disseminate valuable information among the family system, and has the potential to impact
family prevention tactics. Nevertheless, it is important to recognize the potential of non-
biological kin in the process of cancer risk communication and the support they provide in terms of encouraging screening practices and preventive behaviors. Given that the focus of this study is on family communication about the family history of cancer, the present study adopted a narrower view on family to only include close blood relatives. Per Richards’ (1996) classification of family, the present study will focus on close or nuclear family members and kin given the relevance of heredity and genetics in discussions about cancer risk; however, future research should consider communication about cancer risk more generally (e.g., prevention of risk) with non-biological kin.

**Psychosocial Factors Influencing Communication**

The practice of family health history communication has been highlighted and encouraged by health departments and clinicians across the United States and abroad as a way to become more proactive and involved in one's health care (Koehly et al., 2009; Valdez, Yoon, Qureshi, Green, & Khoury, 2010). Although it may appear to be a relatively simple process, gathering health information from family members and disseminating this information to other members is not as easy as it sounds. Family communication is a complex process that is guided by principles of function, patterns, and rules (Peterson, 2005; Koerner & Fitzpatrick, 2006; Petronio & Caughlin, 2006). Furthermore, communication about cancer risk among family members is an intricate and dynamic process. When presented with the task of collecting and sharing health risk information to other family members, individuals may encounter several barriers that make this transactional process difficult and often challenging. Although the process can be daunting and multifaceted, researchers have also established facilitators that aid in the dissemination of this information. The following section explores psychosocial factors that may influence family communication patterns regarding cancer risk.
Communication with specific family members. Throughout this literature review, evidence has been presented to support the great diversity in family composition across families. It is no surprise that communication patterns and styles about family health history may also vary according to the composition of the family.

Significant others. The literature has documented the importance of nuclear families in the family health history communication process. Research has found that communication is often more common among spouses and legal partners than with biological family members, at least initially after diagnosis or genetic test results disclosure (Wilson et al. 2004). For instance, researchers in France conducted a study with 398 women with a positive family history of breast or ovarian cancer which examined women's attitudes toward dissemination of positive genetic tests results and identify factors related to communication (Julian-Reynier et al., 2000). Participants completed questionnaires before their genetic counseling visit and within a month of the visit. Forty-seven percent of women in the sample also had a personal history of cancer. Women were asked whether they would discuss a positive genetic test result with their first degree relatives, their spouses, or with their general practitioners. Results indicated that the overwhelming majority of women would report the results to their spouses (95%), followed by siblings (86% sisters, 79% brothers), mothers (71%), children (70%), and lastly, fathers (64%). To further illustrate, Foster et al. (2004) conducted in-depth interviews with 15 women before they received BRCA1/2 genetic testing results and six months after the result was provided. The authors found that prior to knowing their genetic test results women relied on their significant others rather than their relatives for emotional support in coping with their family history of breast cancer. Thus, communicating with spouses is often an important step in processing cancer risk information.
Women. The cancer risk communication literature has extensively documented that women tend to be considered the "kin keepers" of family health history and as such, are seen as the responsible ones for disseminating health information within the family (Foster, Eeles, Arden-Jones, Moynihan, & Watson, 2004; Koehly et al., 2009; Nycum, Avard, & Knoppers, 2009; Wiseman, Dancyger, & Michie, 2010). Qualitative accounts have also found that women create an atmosphere of "health talk", especially among sisters and other female relatives, which supports open discussion about health within the family (Forrest et al., 2003; Lindenmeyer, Griffiths, & Hodson, 2010). Claes and colleagues (2003) further support this finding. The authors assessed the extent to which 63 Belgian participants (only one male participant) informed close and distant relatives about genetic test results by means of semi-structured interviews and questionnaires. Utilizing non-parametric statistical methods, findings revealed a significant gender preference, in that participants informed genetic test results to sisters followed by female cousins over male relatives. Moreover, another study examined family communication among women who sought genetic counseling for breast or ovarian cancers in the U.K., but had no personal history of the disease (Green, Richards, Murton, Statham, & Hallowell, 1997). Participants (all White) were interviewed one week before their counseling session, approximately eight weeks later, and again one year later. A total of 46 participants were interviewed pre-visit, and 40 participants completed follow-up interviews thereafter. Findings revealed that when participants had a living mother they would communicate with her first, followed by sisters, cousins, and aunts. Thus, female relatives were much more likely to be approached to discuss family health history than were male relatives.

Socio-demographic factors. Cancer risk communication has been linked to several socio-demographic variables. The following is a brief discussion on the current findings
regarding the associations between family communication about cancer health history and race/ethnicity, generational status, and emotional closeness.

Race/ethnicity. The overwhelming majority of research in cancer risk communication has been conducted with White samples. Less is known about communication concerning cancer risk in different ethnic/racial populations (Royak-Schaler et al., 2004). For example, few empirical studies have highlighted cancer risk communication about cancer in the Latino community. First, a comparative study was conducted to examine the communication beliefs among Latinas and White women with a personal or family history of breast/ovarian cancers (MacDonald et al., 2008). A total of 183 Latinas and 292 White women completed questionnaires at a genetic cancer risk assessment appointment. Most women (92%) believed that their relatives needed to know if they had a positive genetic test result. Although the majority of women also believed that family members were responsible for sharing this information, Latinas who primarily spoke Spanish were more likely to believe that health care providers should be part of the process. There was also a greater preference for Latina women, compared to White women, to use face-to-face communication when discussing genetic risk information over other mediums of dissemination. On the surface, the cultural need for a personal connection with other family members and providers alike within the Latino community seems like a facilitator for family health history communication, however, it can serve as a barrier when considering access to health care disparities and difficulties reaching close family members outside the country.

Furthermore, a qualitative study examined factors that may influence Latino men and women's attitudes, beliefs, and awareness about hereditary breast and ovarian cancers (Kinney, Gammon, Coworth, Simonsen, & Arce-Laretta, 2010). Findings revealed that Latinos held
certain cultural taboos that surround secrecy and shame about cancer. In particular, there was considerable discussion about not wanting family members to know they had cancer in the family. The issue of shame and cancer stigma is a significant barrier to communication of family health history in this group and, in turn, a barrier for appropriate screening behaviors. Thus, communication about hereditary cancer risk in Latinos may be compromised by cultural barriers.

The literature on family health history communication within Black individuals is also scarce. There is some evidence to suggest that Black women are more pessimistic than White women about breast cancer screening benefits and breast cancer survival, and in turn may be less prone to communicate risk to family members because of fatalistic beliefs, that is the conviction that life events are pre-determined and individuals have no control or power to change their course (Haggstrom & Schapira, 2006). To illustrate, Phillips and colleagues (1999) conducted focus groups with 26 Black women, between the ages of 40-65 years, to explore their attitudes about breast cancer screening. Fear of finding breast cancer was one of the primary reasons why Black women in this sample reported not having regular mammograms. In addition, they held fatalistic views regarding breast cancer outcomes that added to their reluctance to engage in breast screening behaviors. It is interesting to note that compared to Whites, Blacks tend to have a lower risk for developing cancer yet they have higher mortality (Siegel, Ward, Brawley, & Jemal, 2011).

Furthermore, a large national study \((N = 5,581)\) utilizing data from the Health Information National Trends Survey (HINTS) survey investigated differences in perceived cancer risk amongst four racial/ethnic groups (i.e., Blacks, Asians, Whites, and Hispanics; Orom, Kiviniemi, Underwood III, Ross, & Shavers, 2010). Overall, participants in the minority groups had lower perceived cancer risk than Whites. Orom and colleagues also found that the
relationship between race/ethnicity and perceived cancer risk was mediated by family history of cancer. The authors posited that approximately 15% of the Black-White difference in perceived cancer risk was attributed to less frequent reporting of family history of cancer by Blacks. In addition, perceived cancer risk was positively correlated with reporting of family history of cancer among Black participants. With the increased cancer incidence and mortality for Blacks, having a low perceived risk of cancer has the potential to extend cancer screening disparities. Thus, communicating about the family health history of cancer may increase reporting of such information and enhance the likelihood of proper cancer screening and early detection practices in minority populations.

Upon awareness of a positive history of cancer in a close relative, individual members of a family develop a perception of risk that guides communication with other relatives and may prompt them to engage in preventive behaviors (Audrain-McGovern, Hughes, & Patterson, 2003). A study utilizing data from a diverse sample of women ($N = 899$), with a large proportion of Black women (45%), found that women with a first degree relative with breast cancer were 2.1 times more likely to have had a mammogram within the past year compared to women without this history (Tracy et al., 2008). The relationship between family health history and prevention behaviors in minority populations has also been noted in other chronic illnesses such as diabetes. For example, Baptise-Roberts et al. (2007) investigated the relation of family history of diabetes, risk factors, and health behaviors in a large sample of Black participants ($N = 1,585$) and found that participants reporting a positive family history of diabetes had increased awareness of diabetes risk factors than those without a family history of diabetes. In addition, those with diabetes in the family were more likely than those without this history to eat more fruits and vegetables and be screened for diabetes.
Taken together, these findings illustrate the great need to understand this transactional process in racial/ethnic minority groups and the importance of considering cultural barriers that interrupt or halt family communication about cancer risk. The present study will focus on a diverse sample of women and therefore will greatly contribute to expanding our knowledge of communication patterns in minority families.

**Generational Status.** The relationship between age and dissemination of cancer risk information within families has also been under studied. There has been, however, some work pertaining to the communication between parents and children regarding genetic test results. Results from a review of this research area reveal that parents are likely to communicate with their children about genetic predispositions, however, parents often struggle with the decision of when to tell their children about familial cancer risk (Metcalfe, Coad, Plumridge, Gill, & Farndon, 2008). As such, families often defer telling children until they have reached maturity or there is an imminent threat or problem that needs to be addressed (Aktan-Collan et al., 2011).

Family health history communication may also be dependent on generational patterns within the family or deferred to those members who are higher up in the hierarchy. For example, one study found that women who were over 45 years of age were 2.1 times more likely to inform children about their genetic risk than younger women (Julian-Reynier et al., 2000). Therefore, older generations play an important part in keeping family health history and disseminating this information to younger relatives (Koehly et al., 2009). Many families look up to their elders or second-degree relatives (grandmothers, aunts) to gather family health information, however, more research is needed to determine the effect age has on providing and receiving cancer risk information.
**Emotional Closeness.** Several reasons have been proposed for non-disclosure among family members, including having limited contact with relatives (McCann et al., 2009), geographical distance (Loescher, Crist, & Siaki, 2009), and emotional rifts (Hay, Shuk, Zapolska et al., 2009). Family members that are geographically and emotionally close to each other are more likely to maintain a relationship and communicate more frequently than distant relatives (Claes et al., 2003; Nycum, Avard, & Knoppers, 2009; Hay, Shuk, Zapolska et al., 2009). Furthermore, Hallowell and colleagues (2005) found that genetic test results were more likely to be shared with first and second degree relatives or emotionally close relatives than with members of the extended family. In addition, one study found that 68% of carriers of a genetic mutation assumed that others in the family close to the distant relatives would inform them of the risk (Claes et al., 2003). For some individuals, it may seem burdensome to approach distant relatives whom they have limited contact or have been estranged from the family for some time. Being the bearer of bad news makes this process even harder. In addition, a review examining communication about genetic risk within families found that the perception of both emotional and physical closeness facilitated discussions of genetic risk among family members (Wiseman, Dancyger, & Michie, 2010). On the other hand, they found that individuals felt little obligation toward disclosing or sharing genetic risk information with relatives whom they had lost contact with or did not know. Thus, emotional closeness among family members becomes an important factor when considering the collection and sharing of family health history information.

**Cancer Communication and Prevention: A Closer Look at Breast Cancer**

As previously mentioned, awareness of a positive family cancer history can give families an advantage in recognizing when they are at an increased risk for certain hereditary conditions (Forrest, Curnow, Delatycki, Skene, & Aitken, 2008). Some have posited that a cancer diagnosis
in the family may also serve as a teachable moment where other family members are made aware of their own possibilities of developing cancer, motivating them to change their behaviors and safeguard their health (Hay, Shuk, Zapolska et al., 2009). Thus, communication and dissemination of family health history information within relatives is of utmost importance because it has the potential to save lives.

One type of cancer that has received significant attention in the literature given its prevalence and ties to family health history is breast cancer. In the United States, breast cancer is the second most frequently diagnosed cancer in women (ACS, 2011). An estimated 232,620 new cases of breast cancer are expected to be diagnosed in 2011 alone (ACS, 2011). Furthermore, current statistics from the American Cancer Society rank breast cancer as the second cause of cancer death in women (second to lung cancer). Over the past two decades, mortality rates for breast cancer in women have steadily declined, with larger decreases seen in women younger than 50 (ACS, 2011). The decrease in breast cancer mortality is greatly attributed to better detection tools and more aggressive recommendations for treatment (NCI, 2010). This movement represents progress in earlier screening and detection of cancer, and improved and more effective treatment. Despite the decline observed in mortality, many women do not engage in proper screening for breast cancer or lack knowledge about risk factors and ways to prevent breast cancer (Bowen, Alfano, McGregor, & Andersen, 2004). Currently, the ACS estimates that approximately 30% of women over the age of 40 do not engage in adequate screening for breast cancer. Thus, there is a continued need for public health interventions to increase awareness of breast cancer risk and promote risk-reducing and preventive behaviors.

Several factors place women at a higher risk for developing breast cancer. Known risks for breast cancer include increasing age, early menarche, late menopause, use of hormonal
therapy, obesity, alcohol use, physical inactivity, and a family history of breast cancer (ACS, 2011). Women with a family history of breast cancer, especially in a first-degree relative (i.e., mother, sister, daughter, father, or brother), have a higher likelihood of developing breast cancer compared to women without this history. This risk increases if more than one first-degree relative developed breast cancer. For instance, women with one first-degree female relative affected with breast cancer are 1.8 times more likely to develop the disease than women with a negative family history of breast cancer, however, breast cancer risk is nearly 3 times higher for women with two affected relatives (ACS, 2011). Risk for breast cancer also increases the younger the relative was at the time of diagnosis (< 50 years) (Schwartz et al., 2008).

Knowledge and awareness of a positive family history of breast cancer may facilitate identification of women who may be more susceptible to the disease.

It is estimated that 5-10% of breast cancer cases result from inherited mutations, in particular those in the breast cancer susceptibility genes BRCA1 and BRCA2 (Mellon et al., 2009). While a family history of breast cancer suggests an inherited influence on cancer risk, BRCA1 or BRCA2 mutations account for only about 15 to 20% of familial breast cancers (Turnbull & Rahman, 2008). These mutations are present in less than 1% of the general population, but are seen more frequently in certain ethnic groups such as women of Ashkenazi Jewish descent (Schwartz et al., 2008). Although inherited breast cancer gene mutations are not the norm in the general population, women with BRCA1/BRCA2 mutations are estimated to have a 50-85% risk for developing breast cancer by age 70 (Schneider, 2002). Despite the relatively low incidence rates of hereditary forms of breast cancer, lack of awareness and collection of positive family cancer histories in the general public has the potential to limit our ability to identify hereditary cancer risk and act rapidly to decrease morbidity. Thus, the
possibility of hereditary forms of cancer support the need of increased communication among relatives about the family health history, especially considering the impact awareness of such history can have on early detection and preventive behaviors for cancer.

It has been widely established that having a family history of breast cancer increases one's risk for disease and accounts for approximately 20 to 30% of all breast cancers (ACS, 2011). Fortunately, women with a history of breast cancer have various options available to reduce their risk. Interventions to reduce one's risk for breast cancer include: (1) preventive behaviors (i.e., eating a low-fat diet plentiful in fruits and vegetables, increasing physical activity, reducing alcohol consumption, and abstaining from smoking), (2) cancer risk reducing interventions (i.e., chemoprevention and prophylactic surgery), and (3) early detection of breast cancer (i.e., self and clinical breast examinations, and screening mammography) (Lemon, Zapka, & Clemow, 2004; Madlensky, et al., 2005). Some evidence suggest that although the number of women who report changing their lifestyle or opt for early screening as a result of increased awareness of family health history is small, those with a family history of breast cancer are more likely to engage in these behaviors than women without a positive breast cancer family history (Sinicrope et al., 2009). Despite these options being readily available for most women there is much to be learned about the decision-making process that drive some women who have a positive history of breast cancer in the family to actually engage in these behaviors.

Given that patient-physician communication has been thoroughly studied and this relationship only account for a portion of the variance in breast cancer prevention outcomes, it is important to shift focus to examine other important sources of breast cancer risk information and screening guidelines: family networks (Clark et al., 2000; Green, Richards, Murton, Statham, & Hallowell, 1997; Richards et al., 1995). Although the literature has recognized the role family
history of breast cancer plays in early detection and prevention, the pathways through which this relationship operates are not well understood. One potential avenue of research that can help elucidate the association between family history knowledge and health-promoting/risk-reducing behaviors is family communication about breast cancer. Family communication not only has the potential to bridge the gap between history awareness and behaviors, but it may actually be an important point of intervention as a health education tool.

In an effort to begin understanding the connection between family communication and cancer prevention, one study investigated the extent to which mothers provided advice about breast cancer prevention and behaviors to their daughters, the content of such advice, and any factors that may influence advice-giving (Sinicrope et al., 2008). Participants were asked to complete a psychosocial questionnaire and answer open-ended questions about the nature of the advice given. A total of 2,459 participants (the majority of northern European descent) completed the study, with 55% of the women reporting providing advice to their daughters about breast cancer prevention. Advice was further categorized into three domains: (1) detection (self and clinical breast exams, mammograms), (2) lifestyle (family history of breast cancer, living a healthy lifestyle, avoiding hormone replacement therapy), or (3) both types of advice were given. Overall, 66% of women provided detection advice to their daughters, 13% provided lifestyle advice, and 15% reported providing both types of advice. Communication about breast cancer prevention was also more likely to take place if the participant was older, had a personal history of breast cancer, had a higher degree of cancer worry, and had ever performed a breast self-exam. Only 5% of women reported giving advice about the importance of being aware of family history of breast cancer and communicating this with their doctors, with the majority of advice
given surrounding having mammograms, performing breast self-exams or having a clinical breast exam, and maintaining a healthy lifestyle.

In a follow-up study, Sinicrope et al. (2009) examined the extent to which daughters reported following their mother's advice about cancer risk reduction and early detection of breast cancer. Their results showed that 56% of female relatives reported that their mother's advice influenced their behavior "significantly". Daughters who had received advice were more likely to report ever performing self-breast examinations and gotten a mammogram. An important limitation of this study, however, is the authors’ inability to cross reference the participants' self-reported intention with actual behavior change. In addition, the cross-sectional nature of the studies also inhibits causation. Thus, longitudinal studies that seek to address the cause-effect relationship between communication and breast cancer screening and prevention are necessary. Despite these limitations, the results of these studies show that family communication about breast cancer risk and prevention may encourage lifestyle changes and spark early and more frequent screening behaviors in relatives of breast cancer survivors.

Furthermore, a study conducted with 284 young college-aged women examined whether breast cancer screening behaviors differed by interpersonal sources of information (Jones, Denham, & Springston, 2006). The authors were particularly interested in the role of families and peer relationships as they relate to breast cancer screening behaviors. With respect to family communication, findings revealed that discussing breast cancer with a family member significantly predicted the frequency with which they reported performing breast self-examinations, in that those who reported greater communication with a relative engaged in breast self-exams more frequently and regularly. Overall, this study provides support for the
importance of examining communication patterns within close family members as they may play a role in screening practices and behaviors.

Interpersonal communication and exchanges of breast cancer information can also motivate relatives to engage in prevention practices. For instance, one study conducted in France with 42 women who attended genetic counseling for breast cancer risk assessment found that all women reported sharing the information received at the session with an immediate family member (60%) or their husbands (33%) (Christophe, Venin, Corbeil, Adenis, & Reich, 2009). Women were also quickly to share this information on the same day of the visit (70%) and many did so repeatedly (36%). The authors also gathered data on the women's motivations to share medical news and found that the majority of women did so essentially for preventive purposes (i.e., inform family members about what might happen to me and what may happen to them, suggest that they also go through genetic counseling). Women in this sample wanted family members to be aware of factors that may increase their risk of developing breast cancer with the goal of increasing prevention strategies. Furthermore, a qualitative study with 19 women who had just received news of a BRCA1/2 mutation in the family found that participants reported that their mothers "ingrained a sense of risk and need for vigilance" (p. 369) in order to find cancer early (Crotser & Dickerson, 2010). In addition, participants in this study reported being encouraged by their mothers to perform risk-reducing behaviors such as eating healthy foods and avoiding chemicals or carcinogens. Overall, these findings highlight a favorable trend showing that communication about breast cancer with relatives is likely to also have a positive impact on screening behaviors.

Furthermore, research studies examining other types of cancers have also contributed to the relationship between family health history communication and behaviors. For example,
Ersig, Williams, Hadley, and Koehly (2009) found that participants who communicated with a greater proportion of family members about hereditary non-polyposis colon cancer (HNPCC) were more likely to have more recent colonoscopies. In addition, the authors found that the act of having family members encourage colorectal screening was associated with more recent colonoscopies in study participants. Taken together, the aforementioned findings suggest a significant relationship between family communication about cancer and prevention outcomes. Thus, communication with relatives about cancer risk can have a powerful effect in getting individuals mobilized into preventive action improving early detection.

Despite increased attention on the connection between family health history communication and screening/preventive behaviors, it is necessary, however, to thoroughly examine factors that influence communication, and the psychosocial aspects that may affect such communication.

**Family Systems Theory: A Blueprint for Family Communication about Cancer Risk**

One theory that has received significant attention in the communication literature and serves as a framework for understanding facilitators and barriers for family communication about health history and cancer risk is *family systems theory*. Derived from the notion that families are better understood as a unit, family systems theory highlights the unique interactions between family members, the environment, and social context that set the stage for those dynamics to occur (Peterson, 2005). One important aspect of the family systems framework is communication. It is through the transmission of shared beliefs, feelings, and emotions that family functioning and trust is maintained, and the capacity to communicate openly and without hesitation is established (Galvin, Bylund, & Brommel, 2004). On the contrary, many families experience conflict and emotional barriers that interrupt this open communication and result in a
communicative shield that protects them from vulnerable and often painful feelings and/or experiences (Peterson, 2005). Given the barriers and conflicts faced, families adjust and adapt to learn from those experiences and work cohesively to resolve them. There is a give-and-take within families that determines the potential to achieve balance and a collective sense of unity. These different patterns within families offer a map of shared experiences that can elucidate the way individual members respond to challenges and demanding times.

The way families respond to stressors, such as cancer in the family, is determined by multiple dimensions of family functioning. From a family systems perspective, family functioning will depend on (1) the family structure and organization, (2) communication patterns, and (3) the shared health-beliefs held by the family (Peterson, 2005). According to Peterson, family organization is determined by having set boundaries that define the role each family member holds within the system. Its structure, in turn, relates to the hierarchical nature of families and the vertical or horizontal patterns of communication that vary in influence and power. As families face certain challenges (e.g., making informed decisions about cancer risk reduction strategies) having set boundaries and clear roles according to the structure of the family is likely to facilitate adjustment and communication about the disease. Families may also experience shifts in roles depending on who is affected and who is seen as the responsible member for disclosing and sharing information within the system. Thus, the organizational structure of families with their unique patterns and defined roles may influence communication, and in turn, has the potential to facilitate communication about cancer risk and early detection/prevention recommendations.

From a clinical standpoint, communication within the family system is going to be critical for the dissemination of disease risk and health promotion strategies among its members.
(Harris et al., 2010). Communication serves as an important tool families have to process life experiences and learn from past behaviors. When successful and effective communication is achieved, healthy family functioning is possible. Using a family systems perspective, communication acts as the medium individual members of the family have to preserve their ability to operate smoothly and safeguard their unique story that defines them through generations. This unique story ties into the health-related cognitions and beliefs that family members share. These cognitions are branded into the traditions and behaviors families have when responding to life events. Furthermore, these beliefs have the potential to influence family norms, roles, and meanings individual members make of shared experiences including having had cancer in the family. Communication about health risk is then influenced by the specific beliefs each system holds about the disease and the importance they give to its impact on the family as a whole.

In the context of cancer risk communication, family systems theory stands out given its ability to examine the family as a unit or system. It also does not require a rigid definition of family, which enhances its utility with future research on non-biological kin. Illustrated by Peterson (2005), systems theory views the cancer experience as affecting the entire family's functioning and does not limit its impact to the nuclear family. Thus, a cancer diagnosis in one member of the family will likely cause a ripple effect that casts influence on many different members of the family, potentially leading to increased communication and specific coping strategies to keep the system functioning properly. As a result, the use of this framework is important when developing interventions to improve breast cancer risk awareness and promote risk-reducing practices.
Important Players in Family Health History and Cancer Risk Communication

**Family organization.** Using family systems theory as a framework, several cancer risk communication researchers have recognized the importance of the family's organizational characteristics in regards to communication about cancer risk (Peterson, 2005; Harris et al., 2010; Yi, 2009). A succinct description of the predominant model for studying family organization, the Circumplex Model of Marital and Family Systems, and a discussion on the available research on family organization and family health history communication follows.

**Circumplex Model of Marital and Family Systems.** Family systems are said to have structure and organization, however, the degree of these characteristics is unique to each system and varies depending on the context. From this standpoint, one model has been proposed to understand the organizational structure of families and has received prominent attention in the communication literature. Olson's (2000) Circumplex Model of Marital and Family Systems takes into account the family's organizational structure in the study of family dynamics. According to Olson, family organization consists of three important domains that interact with one another to produce a certain type of functioning. These domains include cohesion, flexibility, and communication.

Family cohesion has been defined as "the emotional bond that family members have toward one another" (Olson, 2000). The concept of cohesion therefore represents how much weight family systems give to their family's degree of separateness and togetherness. According to the model, there are four levels of cohesion which fall on a continuum. At the low end of the cohesion dimension are families who are *disengaged* (very low cohesion) from one another, followed by families who are considered *separated* (low to moderate cohesion). At the higher end of the spectrum are *connected* families (moderate to high cohesion) and *enmeshed* families
(very high cohesion). The model proposes that either extreme of the continuum is problematic. Thus, families who are disengaged or enmeshed with one another will have the most challenging time functioning cohesively as a system. On the contrary, families who fall on the lesser extremes, separated and connected, are considered balanced and represent optimal family functioning. Separated relationships tend to have a healthy degree of emotional closeness but are still quite independent of one another when it comes to decision making. Connected relationships emphasize togetherness and loyalty but can still operate independently. According to Olson, families strive to achieve a balanced level of cohesion in order to minimize conflict and enhance smooth functioning.

The second domain of the Circumplex Model is flexibility (originally called adaptability, and often used interchangeably). Family flexibility is defined as "the amount of change in its leadership, role relationships and relationship rules" (Olson, 2000, p. 147). Flexibility is also conceptualized as having four levels and refers to the way family systems balance stability and change. For instance, families with very low levels of flexibility are considered rigid in their ability to respond to change. Moving along the continuum, the model proposes families who are structured (low to moderate flexibility), flexible (moderate to high flexibility) and chaotic (very high flexibility). Similarly to cohesion, families achieve balance in this dimension when they are structured or flexible. These balanced levels of flexibility are hypothesized to lead to optimal family functioning. Thus, families seek structured environments were democratic negotiations are plentiful and roles are, for the most part, stable. Flexible relationships stress egalitarian leadership in decision making and also share roles and responsibilities that are subject to change as necessary. Although families tend to move along the continuums of cohesion and flexibility
when adjusting to stressors and challenges, it is the prolonged stay in the extremes that can lead to poor functioning.

The third and last domain of the Circumplex Model is communication. Family communication has been deemed a facilitating dimension because it represents the medium through which families attempt to balance cohesion and flexibility (Yi, 2009). When families are faced with stressors and challenges, structural shifts are performed in order to maintain balance. Communication patterns among family members during times of crisis serve as a litmus test to determine how families will adjust and adapt to the new circumstances. For instance, families with positive communication skills such as clear messages, effective problem solving skills, supportive statements, and demonstration of empathy are hypothesized to be better able to alter their flexibility and cohesion in response to stressors (Segrin & Flora, 2005). Alternatively, families that do not listen well to each other, who use indirect messages, and who are excessively critical of each other are expected to be locked into one particular level of flexibility and cohesion, usually at one of the extremes, unable to change when they encounter a negative event or situation. As families progress through the life cycle and respond to different stresses and strains that are imposed by these development challenges, they make moderate adjustments in their flexibility and cohesion. According to this model, families who are balanced in cohesion and flexibility will most likely adapt well to changes in the family. Communication patterns in these families may initially shift as a reaction to the challenges ahead but are likely to bounce back after the family system adjust and adapts to the news.

In 2006, David Olson revised the Circumplex Model to include a new definition of flexibility and also modified the dimensions of the model (Olson & Gorrall, 2006). Flexibility is now defined as "the quality and expression of leadership and organization, role relationships, and
relationships rules and negotiations" (p. 3). The model itself remains very similar to its previous version, however, cohesion and flexibility now represent the two global dimensions of family functioning (see Figure 1 for model diagram on page 52). Within each dimension, levels of functionality reside. For instance, the cohesion dimension captures three levels: disengaged, balanced cohesion, and enmeshed. The flexibility dimension entails the following levels: rigid, balanced flexibility, and chaotic. The two balanced levels measure healthier functioning within the system while the four unbalanced levels measure more problematic functioning. In addition, the new revised model provides a way to conceptualize families in terms of profiles based on their level of functionality along the cohesion and flexibility dimensions. An important function of these family profiles stems from their composition, as they are generated by utilizing both cohesion and flexibility dimension scores to plot families in a particular point within the Circumplex Model. That is, the combination of cohesion and flexibility scores are used to represent the level of functionality within the family system, rather than just looking at each dimension separately (i.e., ratio scores). In essence, the family profiles provide a comprehensive way to examine family organization and functioning. Regardless of these changes, the main hypothesis of the model remains the same: balanced levels of cohesion and flexibility are most conducive to healthy functioning within the system. Given the novel interpretation of the organization dimensions by utilizing combined family profiles, the present study also explored family profiles according to cohesion and flexibility dimension scores and its relationship to family health history communication.

The Circumplex Model, as tested by the FACES-IV instrument, can be useful in both research and clinical settings. For instance, as it is proposed in this study, hypotheses can be tested that Balanced families are more health and functional than Unbalanced family systems and
hence more likely to communicate. On the other hand, clinicians will be able to explore the strengths and weaknesses of family systems in terms of six functional and organization scales to help plan, track, and evaluate the therapy they do with families.

**The role of family organization in cancer communication.** Research has investigated the role of family organization in families affected by a chronic illness. For instance, it has been proposed that family flexibility plays a role in adherence to treatment regimens like in the case of diabetes, while family cohesion typically promotes positive coping behaviors in the management of chronic illnesses such as cancer (Kouneski, 2000). Families that have successfully mastered the difficult regimen of diabetes by achieving metabolic control and good compliance to treatment, especially when the affected family member is a child, have been found to be characterized by a balanced degree of cohesion and flexibility (Sieffge-Krenke, 2002). In contrast, studies examining how families respond to a childhood cancer diagnosis have found a somewhat unexpected finding. That is, given the time-sensitive nature of cancer treatment it is imperative that families mobilize quickly to start treatments promptly and achieve the best prognosis. As this shift occurs, families are likely to undergo periods of extreme levels of functioning as they learn to cope with the new diagnosis. This has been found to happen even among well balanced families. To illustrate, Horwitz and Kazak (1990) found that 56% of families with a child undergoing cancer treatment fell in the 'rigid' and 'chaotic' range (extremes levels of flexibility), compared to only 20% of families with a healthy child. According to Olson (2000), when faced with a stressful situation families are likely to function at either extreme of the Circumplex Model without major problems. These extreme reactions are often necessary to activate the family's social support networks that will facilitate coping through the hard times. As previously mentioned, this extreme form of family functioning is adaptive for a limited
period of time, but if prolonged it may interfere with the family's overall functioning and ability to cope. This finding suggests that family organization may be a state (rather than trait) construct.

To date, very little research has examined the role of cohesion and flexibility in family health history communication. There is some evidence suggesting that higher levels of cohesion are instrumental in the successful adjustment and coping of breast cancer patients, with no significant relationships found between flexibility and adjustment (Friedman et al., 1988). A more recent study sought to identify structural and organizational characteristics that influenced communication in high-risk families for developing melanoma (Harris et al., 2010). Findings revealed that cohesion and flexibility were positively related to having an open communication style (i.e., a perception that information could be freely shared within the family and support for melanoma discussions was readily available). Their results showed that families who were more flexible were 3.22 times more likely to express that their families openly communicated with one another; that is, they perceived that melanoma information could be freely shared within the family and that family members supported each other in discussing this information. Moreover, this study demonstrated that having an active family coping style and a greater level of cohesion and flexibility within the family was related to a higher frequency of communication about melanoma risk among family members. Compared to families with low cohesion and flexibility, families who were more connected were 1.84 times more likely to report more frequent communication and those with greater flexibility were 1.87 times more likely to speak with family members about their unique risks for melanoma. Although focusing on melanoma risk, the results of this study conclude that family organizational variables such as cohesion, flexibility, and coping are important in determining whether families will have an open
communication style and whether they communicate with one another about familial cancer risk. Therefore, the present study wishes to add to the scarce literature on family organization and family health history communication.

**Communication openness.** The style in which families communicate may also have an effect on the kind of discussions had among family members that are conducive to proactive cancer preventive behaviors. A key study demonstrating the importance of assessing communicative styles within families in cancer communication research was conducted in the United Kingdom with a sample of 21 women attending a breast and ovarian cancer genetic clinic (Kenen, Ardern-Jones, & Eeles, 2004). This qualitative study sought to explore how family scripts influence family communication about hereditary breast and ovarian cancers. They conducted open-ended interviews with participants to capture the complexities of the communication process within families. They identified two main communication styles that families employed when communicating genetic risk information. The first style comprised open and supportive communication. Most of the women in the sample reported that they could identify at least one family member whom they could go to for support and openly discuss cancer risk. These family members were typically sisters or female cousins. The majority of the women preferred this style of communication, however, recognized that not everyone in the family would react positively to open discussions and therefore would limit communication with certain relatives to avoid causing harm or distress.

The second style of communication derived from Kenen et al.’s (2004) work can be divided into two sub-styles: blocked-direct and blocked-indirect. Although not prevalent, some women reported being confronted by direct refusal or rejection (blocked-direct style) from family members when discussions about cancer risk were initiated. In other families, there was
an implicit understanding that these conversations were out of limits. Families with a blocked-
indirect style tend to be passive in their avoidance and usually provide signals to the messenger
that they do not welcome cancer risk discussions. These family members tend to be
unresponsive and feel uncomfortable when confronted. The authors found that, in many cases,
male family members sent blocking signals. As a result of this indirect communication patterns,
women in the study often self-censored and aborted conversations when blocking signals were
given. In addition, some women resorted to using third parties or intermediaries to provide
cancer risk information as they thought others in the family needed to know the information.
Taken together, the results of this study suggest that families have communication scripts that
may inhibit or facilitate communication about cancer risk, and research studies that investigate
these styles and patterns will take us one step closer in developing targeted prevention
interventions for families according to their communication style.

Communication style and frequency of communication have also been examined in the
context of other forms of cancer. For example, Harris et al. (2010) examined the frequency and
style of communication in families affected by melanoma (N = 313 participants). They
measured communication style by creating a novel 8-item measure based on the qualitative work
by Kenen and colleagues (2004) on communication patterns in families with a family history of
breast/ovarian cancers. Items tapped into open and supportive communication styles, direct or
indirect blocked style, and self-censored communicative styles. Using principle component
analysis, two communication styles were extracted: open (i.e., perception that information about
melanoma could be freely shared) and blocked (i.e., direct refusal or lack of responsiveness to
discussing melanoma). Frequency of communication with relatives was also assessed. Results
showed that 42% of participants reported that their families had an open style of communication.
With regards to the participants' first degree relatives, approximately 28% reported perceiving barriers to information sharing. In regards to communication frequency, an estimated 49% of first degree relatives communicated frequently with other family members about melanoma, with the most common relative spoken to being mothers and sisters. Participants who reported engaging in active coping were also 2.75 times more likely to have an open communication style. Overall, the results of this study point to the importance of considering communication style and patterns in the context of familial cancer risk discussions, as these factors may influence coping mechanisms that can lead to preventive behaviors.

Another study investigated the quality of parent-adolescent communication when the parent has a cancer diagnosis (Huizinga, Visser, van der Graaf, Hoekstra, & Hoekstra-Weebers 2005). Two-hundred and twelve adolescent children, ages 11 to 18, with a parent with cancer completed questionnaires. The authors found that adolescents whose mothers had a cancer diagnosis reported less open communication with their mothers than adolescents with healthy mothers. Nevertheless, findings revealed that daughters, not sons, reported more open communication with ill parents than daughters of healthy parents. When mothers were undergoing non-invasive treatments for their cancer, daughters also expressed more open communication with them than when they were going invasive treatments. These results highlight the culture surrounding more open communication among females, and also portray how varying stages of cancer diagnosis and treatment can elicit different communication styles.

More recently, communication openness has been related to less psychological distress and in turn more proactive preventive behaviors in women at high risk for hereditary breast cancer. A group of researchers in the Netherlands investigated the personal and social resources of 222 women considered at high risk for breast cancer (den Heijer et al., 2012). They
investigated the role of communication openness within the family about breast cancer, as measured by Mester's (1997) Openness to Discuss Cancer in the Family Scale, as a social resource for enhancing psychological well being. The authors found a significant relationship between communication openness about cancer with the nuclear family and less stigmatization about this increased risk for cancer. It appeared that women who talked more openly about hereditary breast cancer with their partners and children were less likely to feel stigmatized or isolated, which, in turn, was associated with less psychological distress. Furthermore, the authors found that open communication regarding hereditary cancer within both the nuclear family and the family of origin was associated with a reduced sense of vulnerability. This particular finding has important implications for clinical practice as an elevated sense of vulnerability may affect preventive behaviors, such as the uptake of breast cancer screening.

Communication openness has been examined in other areas of family health communication research. For example, it has been established that openness to communicate in the family about sexual issues, particularly in parent-child dynamics, is associated with increased communication about sexual behaviors (DiIorio, Pluhar, & Belcher, 2003; Hadley et al., 2009). Although the literature on communication openness and cancer is less extensive, there is some evidence showing that having an open communication style within the family is related to positive health outcomes and serves as way to reduce distress and worry (Harris et al., 2010; den Heijer et al., 2012). Therefore, the present study proposes that families who openly and freely discuss cancer risk with family members may feel empowered to take prevention into their own hands and eventually engage in cancer-reducing activities.

Present Study
Previous research has established that the collection of family health history is helpful in the assessment of cancer risk and the development of tailored interventions to elicit behavior change (Valdez, Yoon, Qureshi, Green, & Khoury, 2010). With the added complexity of genetic testing for certain hereditary cancers and the repercussions this information may have for the family, understanding health communication within the family is highly relevant for cancer prevention and control. Although researchers have highlighted the significance of communication about hereditary cancer risk within families, less attention has been paid to family context factors, such as family organization and communication style, which may affect communication about familial cancer history. The present study examined the relation between family organization (i.e., cohesion and flexibility), openness to the discussion of health problems, and family health history communication in a diverse sample of women attending a women's health clinic. Associations between socio-demographic variables, family history of cancer and both predictors and outcome variables were also examined. Where appropriate, these variables were entered as covariates. The specific aims of the study with their corresponding hypotheses are presented below.

**Specific aim 1.** Examine relations between family organization (i.e., cohesion and flexibility) and family health history communication.

**Hypothesis 1.** Cohesion and flexibility will be associated with the collection of cancer history information, such that higher levels of each of these measures will predict increased collection of cancer history information from relatives.

**Hypothesis 2.** Similarly, cohesion and flexibility will be associated with actively giving information about hereditary cancer risk to family members, such that higher levels of each of
these measures will predict increased sharing of hereditary cancer risk information from relatives.

Specific aim 2. Examine relations between family organization (i.e., cohesion and flexibility) and openness to discuss health problems within the family.

Hypothesis 3. Cohesion and flexibility will be associated with openness to discuss health problems, such that higher levels of each of these measures will be predictive of increased openness to discuss health problems within the family.

Specific aim 3. Examine relations between openness to discuss health problems and family health history communication (i.e., collecting family health history and sharing cancer risk information).

Hypothesis 4. Openness to discuss health problems will be associated with the collection of cancer history information, such that higher levels of openness will predict increased collection of cancer history information from relatives.

Hypothesis 5. Similarly, openness to discuss health problems will be associated with actively giving information about hereditary cancer risk to family members, such that higher levels of openness will predict increased sharing of hereditary cancer risk information from relatives.

Specific aim 4. Explore whether family health history communication about cancer differs by levels of family organization.

Hypothesis 6. Women who reported having collected cancer history information will score higher on balanced cohesion and balanced flexibility and score lower on the enmeshed, disengaged, chaotic, and rigid scales (unbalanced scales) compared to women who did not report collecting information.
**Hypothesis 7.** Women who reported actively giving hereditary cancer risk information to relatives will score higher on balanced cohesion and balanced flexibility and score lower on the disengaged, enmeshed, rigid, and chaotic scales (unbalanced scales) compared to women who did not report actively giving this information.

**Specific Aim 5.** Examine relations between family organization and family health history communication (i.e., collecting family health history and sharing cancer risk information) by plotting each family onto the Circumplex Model (Olson & Gorral, 2006).

**Hypothesis 8.** Women whose families fall under the balanced area of the model are expected to be more likely to report collecting family health history about cancer than women whose families fall within the unbalanced areas of the model.

**Hypothesis 9.** Women whose families fall under the balanced area of the Circumplex model are expected to be more likely to report actively giving or sharing cancer risk information with other family members than women whose families fall within the unbalanced areas of the model.

**Method**

**Research Design**

The present study utilized data from the Kin Fact Study (R01-CA140959), an ongoing longitudinal randomized control trial (RCT) seeking to examine the effect of a brief intervention on family communication about hereditary breast and colon cancer. Participants enrolled in Kin Fact were asked to complete measures at baseline, and at one month, six months, and 14 months following enrollment in the study. The current study focused solely on data from the baseline questionnaire, therefore, it is a cross-sectional study. Baseline data collection occurred from July 2010 through January 2012.
Participants

A total of 490 women were recruited for participation from the Women’s Health Clinic at Virginia Commonwealth University (VCU) Medical Center. According to clinic records, approximately 27,000 patients attend the clinic for gynecological and obstetric care each year. Within this clinic, patients are served by two practices—a faculty practice and a resident practice. Participants were recruited from both practices. Almost half of patients seen by the resident clinic and 10% of patients seen by the faculty practice do not have traditional health insurance (i.e., are self-pay or receive financial assistance through the hospital; Bodurtha et al., 2007). Furthermore, approximately 19% of patient visits are paid through indigent care funds provided by the hospital with state support. Patients in this clinic are typically residents of the Richmond Metropolitan area, which has over 1.5 million people and includes a wide range of settings from rural to inner city. Approximately 51% of Richmond residents are Black with a median age of 32 years (U.S. Census, 2010b). Thus, the Women’s Health Clinic offered a large and diverse pool of women from which to recruit research participants.

Participants were eligible for the Kin Fact study if they were: (a) over 18 years of age; (b) a patient of the Clinic; and, (c) able to understand spoken English. Patients under the age of 18 years are not considered consenting adults, therefore they were not allowed to participate in the study. Women who reported a personal diagnosis of cancer were included in the Kin Fact study. Women who were adopted were also eligible to participate in the Kin Fact study, since they could still benefit from increased genetics knowledge and health messages about cancer prevention, especially as they relate to their descendants. However, for the purpose of the current study, women who were adopted were excluded since the main objective of the study is to examine family health history communication based on the biological family’s health
information. The final sample for the study was 472 women. A total of 17 women were excluded from analyses because they reported being adopted and 1 participant was excluded due to missing data. See Table 1 on page 47 for detailed socio-demographic data for the sample.
Table 1

*Socio-demographic Characteristics*

<table>
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<th>N</th>
<th>%</th>
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<td>Mean (SD)</td>
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</table>

*Note.* Based on 472 participants. Aside from the 17 participants who were adopted, one participant was excluded from analysis due to missing data in a predictor variable (see Missing Data section under Results). *Two participants did not provide information on their race. *One participant failed to indicate her living arrangements. *Seventy-nine participants were not asked about their education level.
Procedure

Potential participants were approached by research assistants following registration at the VCU Women's Health Clinic. Research assistants included two Latino females: a board certified genetic counselor and a clinical psychology doctoral student. One research assistant approached women individually in the waiting room as they waited to be called for their appointment. At that time, the research assistant introduced herself, explained study procedures, and assessed interest in participating in the research study. Following verbal consent, participants read and signed a consent form that explained the procedures of the study and their rights as a participant. The research assistant then collected contact information, administered a brief genetic literacy measure, and drew a family tree or pedigree, identifying biological kin and documenting information about 1st and 2nd degree relatives who have had cancer. Participants who reported being adopted were asked to provide any information available on their birth family. If no information on their birth relatives was known, they were then asked to provide information on their adopted family. Recruiters entered each participant's family history on a computer program called Cancer Gene (CaGene) to obtain a detailed genetic risk assessment for breast and colon cancer specifically. For participants whose birth family history was unknown, this part of the study was omitted. Participants then completed the baseline questionnaire, which took approximately 20 to 25 minutes to complete.

After completion of the baseline questionnaire and their physician's appointment, randomization into the treatment or control group followed. Participants randomized into the intervention group were led to a private room within the Clinic for a brief meeting (12 to 15 minutes) with the research assistant. During this meeting, the research assistant covered various topics using a Powerpoint slide-show presentation. Topics included: a) review of their family
history of cancer, b) information about the possible genetic component of cancer in their family, c) tailored screening recommendations based on risk and genetic assessment for breast cancer, d) important skills for collecting and communicating family cancer information, and e) importance of practicing cancer prevention behaviors. At the end of the intervention, participants were given a copy of the slides covered during the meeting which contained tailored risk information for breast cancer. Participants randomized to the control group received a one-page sheet with information on how to stay healthy and lower their risks for cancer along with information about standard screening recommendations for breast cancer. Following completion of randomization procedures, participants received a $20 gift card for their participation. One month, six months, and 14 months after enrollment, participants completed follow-up questionnaires via phone or mail.

Measures

Demographics. Participants reported their age, race/ethnicity, marital status, living arrangements, and highest level of education completed. Pregnancy status and health insurance level were recorded from medical records and entered in the Kin Fact baseline database. Health insurance was coded using three categories: commercial insurance, managed care insurance, or no insurance. In addition, a measure was created to categorize participants according to population density in their place of residence (i.e., rural or urban areas). This measure was generated by entering each participant's street address and zip code into the American FactFinder tool from the U.S. Census Bureau allowing classification of each address into an urban or rural geographical designation (U.S. Census Bureau, 2012). Four categories were created: urban (50,000 people or more), urban cluster (at least 2,500 and less than 50,000 people), rural (less than 2,500 people), and unknown (participants who did not provide a physical street address).
**Family history of cancer.** Family history of cancer in a first or second degree relative was identified through cancer pedigrees taken by research assistants at baseline. Participants were asked whether any of their first or second degree relatives had a cancer diagnosis to the best of their knowledge. If they had cancer, research assistants recorded the type of cancer, age of diagnosis, and age of death (as appropriate).

**Family organization.** The Family Adaptability and Cohesion Evaluation Scale, 4th edition (FACES-IV: Olson, Gorall, & Tiesel, 2007) was used to assess family cohesion and flexibility levels. The 42-item measure was developed using the Circumplex Model of Marital and Family Systems as a framework (Olson, 2000). Olson's Circumplex Model takes into account the family's organizational structure in the study of family dynamics. For Olson, family organization consists of three important domains that interact with one another to produce a certain type of functioning (i.e., cohesion, flexibility, and communication). FACES-IV focuses on the cohesion and flexibility domains. Each domain is composed of balanced and unbalanced organizations. According to the model, families strive to achieve a balanced level of cohesion/flexibility in order to minimize conflict and enhance smooth functioning; either extreme of the continuum is problematic. Based on this framework, the measure yields six scales: three capturing the cohesion dimension: (1) enmeshed, (2) balanced cohesion, (3) disengaged; and, three representing the flexibility continuum: (4) chaotic, (5) balanced flexibility, and (6) rigid. Each item was rated on a 5-point Likert scale from 1 (strongly disagree) to 5 (strongly agree). Sample items included: “We spend too much time together” (enmeshed), "Family members feel very close to each other" (balanced cohesion), “Family members are on their own when there is a problem to be solved” (disengaged), “It is unclear who is responsible for things (chores, activities) in our family” (chaotic), “Our family tries new ways
of dealing with problems” (balanced flexibility), and “Our family becomes frustrated when there is a change in our plans or routines” (rigid). Olson (2011) reports that FACES-IV has been well-validated and has shown strong internal consistency for each scale (Cronbach's alpha for the scales ranging from .77 to .89). For this study, the internal consistency (Cronbach's alpha) for the six scales ranged from .68 (rigid) to .87 (balanced cohesion).

There are several ways to score the FACES-IV measure: percentiles, ratios, and dimensions. The measure yields a total raw score for each scale, which can be converted into percentile scores. The FACES-IV system also creates ratio scores to indicate the perceived level of functional versus dysfunctional behavior in the family system. The ratio score is obtained by dividing the balanced score by the average of the unbalanced scores for each scale (i.e., Cohesion Ratio = Balanced Cohesion / [Disengaged + Enmeshment]/2; Flexibility Ratio = Balanced Flexibility / [Rigid + Chaotic]/2). One of the advantages of the balanced/unbalanced ratio score is that it provides a methodological approach for assessing curvilinearity of cohesion and flexibility. The higher the ratio score of balanced to unbalanced, the healthier the family system. Numerically, the lower the ratio score is below one, the more unbalanced the system. Conversely, the higher the ratio score is above one, the greater balance within the system. In addition, this ratio score also allows for the summarizing of a families relative strength and problem areas into a single score, thus avoiding some of the complexities of the six scale scores.

With FACES-IV, family profiles can also be calculated (Olson & Gorral, 2006). For the purposes of this study, each family was plotted onto the Circumplex Model (see Figure 1, page 52) using the cohesion and flexibility dimension scores. Families whose scores fell under the "Balanced" area of the model (i.e., 9 central cells of the model) were classified as such. Families whose scores fell outside the balanced area were then classified as "Unbalanced".
Openness to discuss health problems. In order to examine openness about family health communication participants completed a modified version of the Openness of Discussion in the Family Scale (Mesters et al., 1997). The original measure consisted of nine items, however, for this study the first question was omitted due to the relatively healthy participant pool typically seen at the Clinic (at least with respect to cancer). The omitted item read "I talk as little as possible about my illness because I don't want to make my family uneasy". Given our interest in communication among all blood relatives, not just the nuclear family, items that included "partner" or "children" were reworded to read "relatives". For example, the following items "My partner doesn't like me to talk about my problems" and "My children don't like me to
talk about my problems" were condensed to "My relatives don't like me to talk about health problems". The final scale completed by participants included six items which were rated on a 4-point Likert scale ranging from 1 (strongly agree) to 4 (strongly disagree). Higher scores reflect a more favorable and open environment for family health communication. Based on Mesters et al. (1997) work on the psychometric properties of the scale, the nine-item measure demonstrated good internal consistency and validity (Cronbach's alpha = .86). For this study sample, the measure demonstrated excellent reliability, α = .82.

**Family health history communication.** Family communication about hereditary cancer risk was assessed using two outcomes: (1) collection of information and, (2) information sharing. Two items were utilized to assess whether participants collected and/or shared cancer history information with other family members. These items were adapted from the 2004 Center for Disease Control and Prevention's HealthStyles Survey (Yoon, Scheuner, Gwinn, & Khoury, 2004). The questions asked: "Have you ever actively collected cancer information from your relatives for the purpose of creating a family health history?" (collecting information) and "Have you ever actively given your relatives information about hereditary cancer risk? (Hereditary cancer risk is cancer that tends to run in the family.)" (information sharing). If participants responded affirmatively they were asked to report what type of information was collected or shared, respectively (i.e., type of cancer, age of diagnosis, result of genetic test, and other). Responses were dichotomized (i.e., yes or no) based on whether or not participants collected or shared information about cancer with their relatives.
Results

Overview

The results section begins with a review of the data preparation and data cleaning procedures that were conducted prior to analysis. This includes an evaluation of any violations of statistical assumptions and discussion of treatment of missing data utilizing Bayesian multiple imputation. The descriptive statistics of all study variables are then presented followed by bivariate associations (intercorrelations) among study variables. This step was used to identify potential covariates that will be important to control for in analyses. Lastly, the specific analysis for each study aim is presented and discussed. A criterion level of p < .05 was used for all analyses. All analyses were conducted using IBM SPSS 20 statistical software.

Data Preparation

The first step taken to prepare the data for analyses was a thorough examination of any potential violation to the statistical assumptions of missing data, univariate outliers, multicollinearity, and normality.

Missing data. It has been suggested that the pattern of missing data is more important than the amount of missing data (Tabachnick & Fidell, 2007). Determining whether data is missing completely at random (MCAR), missing at random (MAR), or missing not at random (MNAR) will dictate the appropriate treatment of missing data. Data were carefully screened for the "missingness" mechanism (Schafer & Graham, 2002). Missing values for demographic data ranged from 0.2% to 17%. Two participants did not provide their race. These women, however, self-identified as Hispanic. One participant did not provide information on her living arrangements. Seventy-nine participants were not asked the question about educational attainment given that the education level item was added to the survey after initial recruitment.
had begun. Two participants did not complete the genetic literacy test due to visual impairments. Lastly, 14 participants did not provide a street address, rather provided a postal office box address, therefore, population density in their area of residence could not be obtained. Data was complete with respect to age, relationship status, pregnancy status, family history of cancer, and health insurance. Amongst the six items that compose the Openness to Discuss Health Problems scale there were 10 instances of missing values from six participants. Similarly, amongst the 42 items that make up the FACES-IV, there were 90 missing values from 62 participants. No missing values were observed in the two outcome variables.

In other to examine the pattern of missing data, a missing data analysis was performed for both the openness scale and FACES-IV utilizing the SPSS Missing Value Analysis function. To differentiate between MAR and MCAR, a few different strategies were used. First, as recommended by Schlomer, Bauman, and Card’s (2010), the Little’s (1988) MCAR test (an omnibus test to assess whether data are missing completely at random) was computed using all observed variables to be used for analyses. Tabachnick and Fidell (2007) suggest that "a statistically nonsignificant result is desired; it indicates that the probability that the pattern of missing diverges from randomness is greater than .05, so that MCAR may be inferred" (p. 63). For the Openness to Discuss Health Problems scale items, the Little's MCAR test was not significant \(p = .99\) indicating that the data for this scale is missing completely at random. The missing data for the openness scale is as follows: three participants failed to provide data on one of the six items of the scale (16.7% missing), two participants did not provide a response for two items (33.3% missing), and one participant missed three items (50% missing).

The Missing Values Analyses was then performed for the 42 items of the FACES-IV instrument. The analysis revealed that 48 participants missed one item (2.4% missing), 10
participants missed two items (4.8% missing), six participants missed three items (7.1% missing), and one participant missed four items (9.5% missing). The Little’s MCAR test was significant (p = .000) indicating that the pattern of missing data in this measure is not missing completely at random. Schlomer et al. (2010) recommend empirically evaluating the relationships between observed values and missing values to see if the missing data better fit a MAR assumption (e.g., whether the missing values on observed variables are dependent upon other variables in the data set). To evaluate potential patterns of "missingness" on FACES-IV that might provide support for the data being MAR, dummy codes were created for the analyzed observed variables within FACES-IV (1=missing and 0=not missing; Schlomer et al., 2010). Then, the relationship between these dummy-coded variables was compared with other variables in the data set. Analyses revealed significant correlations between the dummy coded variable for FACES-IV and other variables in the data set (i.e., education level, age, openness). According to Schlomer et al. (2010), when the dummy variables are associated with other variables, then the data are likely MAR or MNAR. In addition, the dummy-coded variables were used in two chi-square tests of independence to assess whether there were significant differences in amounts of missing data in FACES-IV and our dependent variables (i.e., collecting and sharing family health history information). The relationship between "missingness" in FACES-IV and sharing information was nonsignificant, however, the relationship between missingness and collecting information was slightly below .05. Taking all data into account, a decision was made to assume FACES-IV data is MAR, particularly since the probability for an individual to skip an item was related to other measurable variables in the data set. Furthermore, Collins, Schafer, and Kam (2001) demonstrated that in many cases, an erroneous assumption of MAR (e.g., failing to take
into account a correlate of missingness) may often have only a minor impact on estimates and standard errors.

Given the evidence for MCAR and MAR within the missing data in the openness and FACES-IV measures respectively, it was decided that case or listwise deletion should not be used (Schafer & Graham, 2002). Doing so would mean a significant loss in power for analyses testing the relationship between the predictors and outcomes. A decision was made, however, to exclude the participant with three missing items in the Openness to Discuss Health Problems scale due to a high percentage of missing data within the measure for this one participant (50% missing values). Therefore, our final sample after the missing values analysis is 472 participants. All analyses were performed using this final sample.

For this study, a Bayesian multiple imputation (MI) method was utilized (Schafer & Graham, 2002). MI is deemed appropriate for MAR or MCAR data; therefore, it was utilized for both the openness scale and the FACES-IV measure. In MI, the missing values for each participant are predicted from his or her own observed values, with “random noise added to preserve a correct amount of variability in the imputed data” (Schafer & Graham, 2002, p. 167). The predicted values are substituted for the missing values, resulting in an imputed full data set. This process is performed multiple times, producing multiple imputed datasets. Standard statistical analysis is carried out on each imputed dataset, producing multiple analysis results. These results are then combined to produce one overall analysis. Values for predictor variables were imputed at the item level (Gottschall, West, & Enders, 2012). Then the scales' total score was calculated on the imputed values.

Univariate outliers. The dataset was examined for univariate outliers by calculating z-scores for all continuous predictor variables (i.e., cohesion, flexibility, openness to discuss health
problems). Tabachnick and Fidell (2007, p. 73) suggest that cases with z-scores in excess of 3.29 are potential outliers; however they warn that in large samples it is expected to have few standardized scores above the cutoff. Analyses revealed five participants with z-scores slightly greater than the cut-off of 3.29 in the measure of cohesion (z-score = 3.59) and flexibility (z-scores = 3.41, 3.41, 3.70, and 3.99). Based on Tabachnick and Fidell's counsel, a decision was made to retain these participants in analyses.

**Multicollinearity.** Collinearity statistics were conducted. For predictor variables (i.e., openness, cohesion, and flexibility) the tolerance values were greater than .10 and variance inflation factors (VIF) values were less than 10, indicating a lack of multicollinearity (Field, 2005). Inter-correlations among predictor variables were also performed to gather additional evidence of the lack of multicollinearity. Among the variables of interest, no correlation coefficient was above .80, therefore, no variables were deemed "multicollinear" (see Table 4 on page 61).

**Normality.** Lastly, to determine whether the variables were normally distributed, descriptive statistics, including skewness and kurtosis, were calculated for all continuous variables. All variables of interest, including openness, cohesion, flexibility, age and level of education were within the normal range, with skewness and kurtosis scores below or slightly above the absolute value of 1. Therefore, no transformations were needed.

**Descriptive Statistics**

After ensuring that all statistical assumptions were met, descriptive statistics were performed. Frequencies for socio-demographic data are summarized in Table 1 (see page 47). Seventy-five percent ($N = 355$) of the sample reported having a family history of cancer in a first or second degree relative. Means and standard deviations were calculated for the study predictor
variables (presented in Table 2) and were further evaluated by race and pregnancy status (presented in Table 3). Of the 159 women in the sample who were pregnant at study enrollment, 88 (55.3%) reported being Black and 56 (35.2%) were White.

On average, the women in the sample reported a relatively open communication style with their families. The mean score for the Openness to Discuss Health Problems scale was 17.6 out of a possible 24 point score. With regards to family organization, the mean and standard deviations for the ratio scores of the cohesion and flexibility dimensions were calculated. The higher the ratio score is above one the higher the cohesion and flexibility amongst the family system. On average, women reported a relatively cohesive and flexible family environment given that the mean ratio scores for both measures was greater than one. Women reported that their families were slightly more cohesive than flexible.

Table 2

Means and Standard Deviations for All Predictor Variables

<table>
<thead>
<tr>
<th>Scale</th>
<th>Mean (SD)</th>
<th>Min</th>
<th>Max</th>
<th>N</th>
</tr>
</thead>
<tbody>
<tr>
<td>Openness to Discuss Health Problems</td>
<td>17.64(3.88)</td>
<td>6</td>
<td>24</td>
<td>472</td>
</tr>
<tr>
<td>Cohesion Ratio</td>
<td>1.88(0.84)</td>
<td>0.30</td>
<td>4.86</td>
<td>472</td>
</tr>
<tr>
<td>Flexibility Ratio</td>
<td>1.56(0.56)</td>
<td>0.30</td>
<td>3.76</td>
<td>472</td>
</tr>
</tbody>
</table>

Table 3

Means and Standard Deviations for Selected Variables by Race and Pregnancy Status

<table>
<thead>
<tr>
<th>Variable</th>
<th>Race</th>
<th></th>
<th>Pregnancy Status</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Black</td>
<td>White</td>
<td>Pregnant</td>
</tr>
<tr>
<td>Age</td>
<td>32.4(11.5)</td>
<td>36.5(12.6)*</td>
<td>31.5(11.3)</td>
</tr>
<tr>
<td>Openness to Discuss Health Problems</td>
<td>17.70(3.99)</td>
<td>17.64(3.48)</td>
<td>17.48(4.10)</td>
</tr>
<tr>
<td>Cohesion Ratio</td>
<td>1.81(0.83)</td>
<td>1.96(0.82)†</td>
<td>1.92(0.89)</td>
</tr>
<tr>
<td>Flexibility Ratio</td>
<td>1.58(0.60)</td>
<td>1.52(0.45)</td>
<td>1.58(0.57)</td>
</tr>
</tbody>
</table>

Note: †p<.10, *p < .01
Independent t-tests revealed significant differences in age among Black and White participants, with White participants ($M = 36.5$ yrs) being significantly older than Black participants ($M = 32.4$ yrs). Age also played a role in pregnancy status. Results showed that pregnant women ($M = 31.5$ yrs) were significantly younger than non-pregnant women ($M = 34.8$). Lastly, White women scored marginally significantly higher on family cohesion than Black women (see Table 3).

Descriptive statistics were also calculated for the unbalanced and balanced classification of families based on their cohesion and flexibility dimension scores. The data revealed that only 13 participants (2.8%) fell outside the "Balanced" quadrant of the Circumplex Model using the guidelines stipulated by Olson and Gorall (2006). The majority of women in the sample provided cohesion and flexibility scores that categorized them in the "Balanced" quadrant ($N = 459$, 97.2%).

Lastly, frequencies for the two outcome variables (i.e., collecting and sharing family health history of cancer) are provided (see Table 4, page 61). Overall, communication between family members about the family health history of cancer was relatively low. Nineteen percent of women reported actively collecting cancer information for the purposes of creating a family health history, while 11% of women reported actively sharing information about hereditary cancer risk with family members. Of those participants who reported collecting/gathering cancer information, the majority reported collecting information on the type of cancer (91%) followed by the age of diagnosis for the particular family member (49%). For those women who shared or gave information about hereditary cancer risk to other relatives, 65% reported sharing specific information about the risk for cancer in the family and 55% gave recommendations for cancer prevention to other family members.
Table 4

Frequencies for Outcome Variables (N = 472)

<table>
<thead>
<tr>
<th>Collecting/Gathering Information</th>
<th>N</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>No</td>
<td>384</td>
<td>81.4</td>
</tr>
<tr>
<td>Yes</td>
<td>88</td>
<td>18.6</td>
</tr>
<tr>
<td>- Type of cancer</td>
<td>80</td>
<td>91</td>
</tr>
<tr>
<td>- Age of diagnosis</td>
<td>43</td>
<td>49</td>
</tr>
<tr>
<td>- Results of genetic testing</td>
<td>8</td>
<td>9.1</td>
</tr>
<tr>
<td>- Other</td>
<td>9</td>
<td>10.2</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Sharing/Giving Information</th>
<th>N</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>No</td>
<td>421</td>
<td>89.2</td>
</tr>
<tr>
<td>Yes</td>
<td>51</td>
<td>10.8</td>
</tr>
<tr>
<td>- Medical information about cancer</td>
<td>25</td>
<td>49</td>
</tr>
<tr>
<td>- Risk for cancer in the family</td>
<td>33</td>
<td>65</td>
</tr>
<tr>
<td>- Recommendations for cancer prevention</td>
<td>28</td>
<td>55</td>
</tr>
<tr>
<td>- Results of genetic testing</td>
<td>3</td>
<td>5.8</td>
</tr>
<tr>
<td>- Other</td>
<td>1</td>
<td>1.9</td>
</tr>
</tbody>
</table>

Intercorrelations among Study Variables and Identification of Covariates

Bivariate Pearson correlations among all predictor and outcome variables, as well as socio-demographic variables (e.g., age, race, education level, insurance level, pregnancy status, population density) were performed. Race was dichotomized to include Black and White participants given that the sample was predominately comprised of women who self-identified either as Black or White. Population density was also dichotomized into urban and rural classifications. Table 5 (see page 64) presents the correlation matrix for all variables of interest. Demographic variables that were significantly related to the variables of interest were controlled for in subsequent analyses.

Correlational analyses revealed significant associations among demographic factors. For instance, as participant's age increased education level also increased ($r = .19, p < .01$). Age was negatively correlated with pregnancy status, in that younger women were more likely to be pregnant than older women ($r = -.13, p < .01$). In addition, older participants were more likely to
self-identify as White rather than Black \( (r = .17, p < .01) \). Education level was significantly correlated with insurance level \( (r = -.43, p < .01) \). Participants with a higher education attainment were more likely to have health insurance. Race was also found to be associated with education level \( (r = .40, p < .01) \) and insurance level \( (r = -.14, p < .01) \). White women were more likely to report a higher education background and health insurance level. Furthermore, having a family history of cancer was significantly associated with being older \( (r = .22, p < .01) \), more educated \( (r = .15, p < .01) \), and identifying as White \( (r = .24, p < .01) \).

Several demographic variables were also significantly related to the predictors and outcomes of interest. An open communication style in discussing health problems was negatively correlated with age \( (r = -.20, p < .01) \), and positively correlated with education level \( (r = .19, p < .01) \). That is, younger women were more likely to report having an open communication style than older women. In addition, women with a higher education attainment were more likely to report a more open communication style. A higher cohesion level within the family was significantly correlated with a higher education level \( (r = .31, p < .01) \) and having health insurance \( (r = -.15, p < .01) \), while being more flexible as a family system was only correlated with a greater education level \( (r = .18, p < .01) \).

With respect to the main outcomes for this study, collecting/gathering cancer information from relatives was significantly related with being older \( (r = .12, p < .05) \), having a higher education level \( (r = .10, p < .05) \), and having a family history of cancer \( (r = .20, p < .01) \). For sharing/giving cancer risk information to relatives, age was the only significant demographic correlate \( (r = .21, p < .01) \). That is, as women's age increased so did their sharing of cancer risk information among family members. In addition, a significant relationship was found between collection of family health history information and dissemination of cancer risk information with
relatives ($r = .31, p < .01$). That is, women who reported collecting family health history information about cancer were significantly more likely to also report sharing cancer risk information with other relatives.
Table 5

*Correlation Matrix for All Study Variables*

<table>
<thead>
<tr>
<th></th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
<th>6</th>
<th>7</th>
<th>8</th>
<th>9</th>
<th>10</th>
<th>11</th>
<th>12</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Age</td>
<td></td>
<td></td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>2. Education Level</td>
<td>.19**</td>
<td></td>
<td></td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>3. Insurance Level</td>
<td>-.04</td>
<td>-.43**</td>
<td></td>
<td></td>
<td></td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>4. Race</td>
<td>.17**</td>
<td>.40**</td>
<td>-1.44**</td>
<td></td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>5. Population Density</td>
<td>-.07</td>
<td>.00</td>
<td>-.06</td>
<td>-.09</td>
<td></td>
<td></td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>6. Pregnancy Status</td>
<td>-.13**</td>
<td>-.06</td>
<td>-.08</td>
<td>.04</td>
<td>.02</td>
<td></td>
<td></td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>7. Openness to Discuss Health Problems</td>
<td>-.20**</td>
<td>.19**</td>
<td>-.06</td>
<td>-.10</td>
<td>.05</td>
<td>-.03</td>
<td></td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>8. Cohesion Ratio</td>
<td>.06</td>
<td>.31**</td>
<td>-.15**</td>
<td>.09</td>
<td>.04</td>
<td>.04</td>
<td>.49**</td>
<td></td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>9. Flexibility Ratio</td>
<td>.05</td>
<td>.18**</td>
<td>-.07</td>
<td>-.06</td>
<td>.01</td>
<td>.03</td>
<td>.46**</td>
<td>.76**</td>
<td></td>
<td>-</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>10. Collecting/Gathering FHH</td>
<td>.12*</td>
<td>.10*</td>
<td>-.03</td>
<td>.09</td>
<td>-.08</td>
<td>-.03</td>
<td>-.03</td>
<td>.05</td>
<td>.02</td>
<td></td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>11. Sharing/Giving FHH</td>
<td>.21**</td>
<td>.07</td>
<td>-.05</td>
<td>.00</td>
<td>.03</td>
<td>-.02</td>
<td>-.02</td>
<td>.10*</td>
<td>.10*</td>
<td>.31**</td>
<td></td>
<td>-</td>
</tr>
<tr>
<td>12. Family History of Cancer</td>
<td>.22**</td>
<td>.15**</td>
<td>-.03</td>
<td>.24**</td>
<td>-.09</td>
<td>.07</td>
<td>-.07</td>
<td>.02</td>
<td>.02</td>
<td>.20**</td>
<td>.09</td>
<td></td>
</tr>
</tbody>
</table>

*Note: *p < .05, **p < .01*
Statistical Analyses for Specific Aims

Specific Aim 1: Family organization and FHH communication. The first aim of this study was to examine relations between family organization (i.e., cohesion and flexibility) and family health history communication outcomes. Two hierarchical logistic regressions were conducted. Age, education level, insurance level, and family history of cancer status were entered in the first step of the regressions in order to adjust for their variance in the dependent variable. Cohesion ratios and flexibility ratio scores were then entered independently as the predictor variables in each regression equation as the second step, while collecting health history information from relatives or actively giving cancer risk information was entered as the dependent variable. Each predictor was evaluated based on whether it accounted for a significant amount of variance in the outcome variable. Table 6 presents the model statistics for both analyses (see page 67).

The first logistic regression examined the effect of family organization on collecting family health history information about cancer controlling for age, education, insurance level, and family history of cancer. When control variables and family organization domains were entered into a logistic regression, the omnibus model for collecting cancer information from relatives was not significant, $\chi^2(2, N = 393) = .25, p = .88$. The Hosmer and Lemeshow test provided evidence that the model had adequate fit, $\chi^2(8, N = 393) = 5.45, p = .71$. Findings failed to support the hypothesis that cohesion and flexibility levels within the family would significantly predict the collection of family health history among relatives controlling for age, education level, insurance level and family history of cancer. However, a main effect was found for family history of cancer in that having a positive family history was significantly associated with collecting or gathering cancer information from relatives for the purposes of creating a
family health history. Women with a family history of cancer were almost 5 times more likely to report having collected such information compared to women without such history (OR = 4.86, 95% CI [1.88 - 12.56]).

The second analyses explored associations between family organization and the act of sharing or giving cancer risk information to other family members. Age, education, insurance level and family history of cancer were entered in the model as control variables. The omnibus test for sharing cancer information was not significant, $\chi^2(2, N = 393) = 4.49, p = .11$. The Hosmer and Lemeshow test provided support for an adequate model fit, $\chi^2(8, N = 393) = 4.71, p = .79$. The sole significant predictor of sharing/giving cancer risk information was age (OR = 1.04; 95%CI = 1.02-1.07). Older participants were 1.04 more likely to share or give cancer risk information with family members.
Table 6

Hierarchical Logistic Regression Analyses: Family Organization Predicting Family Health History Discussions

<table>
<thead>
<tr>
<th></th>
<th>B</th>
<th>SE</th>
<th>Wald χ² (1)</th>
<th>OR</th>
<th>95% CI</th>
<th>p</th>
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<tr>
<td>Age</td>
<td>.012</td>
<td>.011</td>
<td>1.286</td>
<td>1.01</td>
<td>[.99, 1.03]</td>
<td>.257</td>
</tr>
<tr>
<td>Education Level</td>
<td>.101</td>
<td>.086</td>
<td>1.358</td>
<td>1.11</td>
<td>[.93, 1.31]</td>
<td>.244</td>
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<tr>
<td>Insurance Level</td>
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<td>.186</td>
<td>.003</td>
<td>1.01</td>
<td>[.70, 1.45]</td>
<td>.959</td>
</tr>
<tr>
<td>Family History of Cancer</td>
<td>1.581</td>
<td>.485</td>
<td>10.615</td>
<td>4.86</td>
<td>[1.88, 12.56]</td>
<td>.001**</td>
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<td>[.92, 1.31]</td>
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<td>[.68, 1.82]</td>
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<tr>
<td>Flexibility Ratio</td>
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<td>.385</td>
<td>.030</td>
<td>.936</td>
<td>[.44, 1.99]</td>
<td>.863</td>
</tr>
</tbody>
</table>

| **Sharing Information**        |       |      |             |      |              |       |
| Step 1                         |       |      |             |      |              |       |
| Age                            | .041  | .013 | 10.755      | 1.04 | [1.02, 1.07] | .001**|
| Education Level                | .052  | .106 | .242        | 1.05 | [.86, 1.29]  | .623  |
| Insurance Level                | -.047 | .229 | .042        | .954 | [.61, 1.50]  | .838  |
| Family History of Cancer       | .268  | .446 | .359        | 1.31 | [.55, 3.13]  | .549  |
| Step 2                         |       |      |             |      |              |       |
| Age                            | .040  | .013 | 10.194      | 1.04 | [1.02, 1.07] | .001**|
| Education Level                | .021  | .109 | .035        | 1.02 | [.82, 1.27]  | .851  |
| Insurance Level                | -.038 | .229 | .027        | .963 | [.61, 1.51]  | .870  |
| Family History of Cancer       | .316  | .450 | .491        | 1.37 | [.56, 3.31]  | .483  |
| Cohesion Ratio                 | .105  | .287 | .133        | 1.11 | [.63, 1.95]  | .715  |
| Flexibility Ratio              | .511  | .434 | 1.386       | 1.67 | [.71, 3.91]  | .239  |

*Note.* **p < .01.

Women who endorse collecting (N = 88) or sharing (N = 51) cancer risk information with relatives were also asked what type of information they collected or shared. Options for type of information collected included (1) type of cancer, (2) age of diagnosis, (3) results of genetic testing, and (4) other. Options for type of cancer risk information shared included (1) medical information about cancer, (2) risk for cancer in the family, (3) recommendations for cancer prevention, (4) results of genetic testing, and (5) other. In order to examine if the type of
information collected or shared is related to family organization, a series of linear regressions were performed with family organization (i.e., cohesion and flexibility ratio scores) as the predictors and each piece of information collected or shared as the outcome. Only significant predictions are highlighted in the following narrative. Results revealed that cohesion was a significant predictor of collecting genetic test results, $\beta = -0.346, p = 0.016$, in that women who reported their families being less cohesive were more likely to report having had collected information on genetic test results. With regards to sharing information, a more flexible family environment was predictive of sharing medical information about cancer with other relatives, $\beta = 0.523, p = 0.006$. Lastly, a less cohesive family organization was predictive of sharing information about risk for cancer in the family, $\beta = -0.407, p = 0.036$. Given the relatively small number of women who endorsed collecting and sharing cancer information with relatives, these findings should be interpreted with caution and replicated in a larger sample.

A positive family history of cancer was significantly correlated with collecting cancer information, therefore a moderation analysis was performed to examine whether the relationship between family organization and the collection of family health history was different for women with a family history of cancer and for women without such history. It was hypothesized that the degree of cohesion and flexibility levels within the family reported by participants would be related to the collection of family health history of cancer for women with a family history of cancer but not for women without a family history of cancer. Interaction terms between cohesion/flexibility and family history, respectively, were computed by creating a dummy code for family history (coded 0 and 1) and multiplying these codes with the mean centered cohesion and flexibility ratio coefficients (i.e., COHxFH and FLEXxFH). These interaction terms were then entered on the second step of each hierarchical logistic regression equation. Table 7
presents the results of the two hierarchical logistic regressions performed for each predictor variable predicting the collection of FHH (see page 70).

First, moderation was examined for cohesion levels predicting the collection of cancer information from relatives. The omnibus test of the equation with the interaction term COHxFH was significant $\chi^2(3, N = 472) = 24.38, p = .000$. The Hosmer and Lemeshow test provided support for an adequate model fit, $\chi^2(8, N = 472) = 6.61, p = .58$. Results showed that family history did not moderate the relationship between family organization and collection of cancer information from relatives. Yet, a main effect was found for family history significantly predicting collecting family health history information. Second, moderation was examined for flexibility levels predicting the collection of family health history about cancer (FLEXxFH). Despite a significant omnibus model, $\chi^2(3, N = 472) = 23.33, p = .000$, no evidence of moderation was found. Having a family history of cancer was the sole predictor of collecting family health history information.
Table 7

Hierarchical Logistic Regressions Examining Moderation of Family History of Cancer

<table>
<thead>
<tr>
<th></th>
<th>B</th>
<th>SE</th>
<th>Wald χ² (1)</th>
<th>OR</th>
<th>95% CI</th>
<th>p</th>
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<tr>
<td><strong>Cohesion x Family History</strong></td>
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<td></td>
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<td></td>
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<tr>
<td>Step 1</td>
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<td></td>
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<tr>
<td>Cohesion Ratio</td>
<td>.156</td>
<td>.141</td>
<td>1.216</td>
<td>1.17</td>
<td>[.89, 1.54]</td>
<td>.270</td>
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<tr>
<td>Family History</td>
<td>1.72</td>
<td>.438</td>
<td>15.286</td>
<td>5.54</td>
<td>[2.35, 13.07]</td>
<td>.000**</td>
</tr>
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<td>Step 2</td>
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<td></td>
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<tr>
<td>Cohesion Ratio</td>
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<td>.432</td>
<td>.572</td>
<td>1.39</td>
<td>[.59, 3.24]</td>
<td>.449</td>
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<tr>
<td>Family History</td>
<td>1.74</td>
<td>.448</td>
<td>15.04</td>
<td>5.68</td>
<td>[2.36, 13.67]</td>
<td>.000**</td>
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<tr>
<td>COHxFH</td>
<td>-.190</td>
<td>.457</td>
<td>.173</td>
<td>.827</td>
<td>[.34, 2.03]</td>
<td>.677</td>
</tr>
</tbody>
</table>

| **Flexibility x Family History** |     |     |             |      |             |      |
| Step 1                   |     |     |             |      |             |      |
| Flexibility Ratio        | .101| .218| .216        | 1.11 | [.72, 1.70] | .642 |
| Family History           | 1.72| .438| 15.41       | 5.58 | [2.37, 13.16] | .000** |
| Step 2                   |     |     |             |      |             |      |
| Flexibility Ratio        | .296| .656| .203        | 1.34 | [.37, 4.87] | .652 |
| Family History           | 1.74| .445| 15.21       | 5.67 | [2.37, 13.58] | .000** |
| FLEXxFH                 | -.218| .696| .098        | .805 | [.21, 3.15] | .755 |

Note. **p < .01. DV = Collection of FHH.

Exploratory analyses were also performed to examine moderating effects of family history of cancer on collecting FHH information using the six different levels of family organization. First, each of the six levels of family organization (i.e., balanced cohesion, balanced flexibility, enmeshed, disengaged, rigid, and chaotic) were mean-centered. Interaction terms were then computed for each mean-centered level and family history of cancer. The outcome of interest was whether or not participants collected family health history information from their relatives. A separate hierarchical logistic regression was performed for each family organization level—that is, six separate analyses were conducted. The mean centered organization level variable and family history of cancer variable were entered on the first step, while the interaction term was entered on the second step. Analyses revealed non-significant interactions for all family organization subscales with the exception of rigid (see Table 8 for a summary of the interaction coefficients). Contrary to what theory would predict, women who
have a family history of cancer and who report higher levels of rigidity are 1.25 times more likely to collect FHH information from relatives than women who have lower levels of rigidity. It is likely that this significant finding is a mere product of multiple comparisons and may have resulted significant by chance.

Table 8

*Summary of Moderation Analyses of Family History of Cancer between Family Organization Levels and Collecting Family Health History*

<table>
<thead>
<tr>
<th>Interaction</th>
<th>B</th>
<th>SE</th>
<th>Wald $\chi^2$ (1)</th>
<th>OR</th>
<th>95% CI</th>
<th>p</th>
</tr>
</thead>
<tbody>
<tr>
<td>Balanced Cohesion x FH</td>
<td>.004</td>
<td>.080</td>
<td>.003</td>
<td>1.00</td>
<td>[0.86, 1.18]</td>
<td>.956</td>
</tr>
<tr>
<td>Balanced Flexibility x FH</td>
<td>.069</td>
<td>.077</td>
<td>.811</td>
<td>1.07</td>
<td>[0.92, 1.25]</td>
<td>.368</td>
</tr>
<tr>
<td>Enmeshed x FH</td>
<td>.096</td>
<td>.087</td>
<td>1.22</td>
<td>1.10</td>
<td>[0.93, 1.31]</td>
<td>.270</td>
</tr>
<tr>
<td>Disengaged x FH</td>
<td>.016</td>
<td>.079</td>
<td>.043</td>
<td>1.02</td>
<td>[0.87, 1.19]</td>
<td>.836</td>
</tr>
<tr>
<td>Rigid x FH</td>
<td>.219</td>
<td>.094</td>
<td>5.48</td>
<td>1.25</td>
<td>[1.04, 1.50]</td>
<td>.019*</td>
</tr>
<tr>
<td>Chaotic x FH</td>
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<td>.074</td>
<td>.111</td>
<td>0.98</td>
<td>[0.84, 1.13]</td>
<td>.739</td>
</tr>
</tbody>
</table>

*Note.* *p* < .05.

The sample for this study consisted of a large proportion of Black women (59.4%). In order to investigate whether the relationship between family organization and family health history communication differed by race, exploratory moderation analyses were performed. Interaction terms between cohesion/flexibility and race, respectively, were computed by creating a dummy code for race (coded 0 for White and 1 for Black) and multiplying these codes with the cohesion and flexibility ratio coefficients (i.e., COHxRACE and FLEXxRACE). These interaction terms were then entered on the second step of each hierarchical logistic regression equation.

First, moderation was examined for cohesion levels predicting the collection of cancer information from relatives. The omnibus test of the equation with the interaction term COHxRACE was not significant $\chi^2(3, N = 436) = 5.47, p = .14$. The Hosmer and Lemeshow test provided support for an adequate model fit, $\chi^2(8, N = 436) = 8.57, p = .38$. Results showed that
race did not moderate the relationship between family organization and collection of cancer information from relatives. Second, moderation by race was examined for flexibility levels predicting the collection of family health history about cancer (FLEXxRACE). A non-significant omnibus model, $\chi^2(3, N = 436) = .095, p = .76$, showed no evidence of moderation by race. Moderation was also examined by race between family organization and sharing family health history information. Once again moderation by race was not found for either cohesion, $\chi^2(3, N = 436) = .2.82, p = .42$, or flexibility, $\chi^2(3, N = 436) = 3.94, p = .27$, predicting the sharing of family healthy history information with other relatives. Thus, results revealed that the relationship between family organization and family health history communication is similar for both Black and White women.

**Specific aim 2: Family organization and communication openness.** Next, associations between family organization (i.e., cohesion and flexibility) and openness to discuss health problems within the family were examined. A hierarchical multiple linear regression was performed to examine whether cohesion and flexibility (i.e., ratio scores) significantly predicted openness to discuss health problems controlling for age, education, and insurance level. When control variables were entered in the first step, the model significantly predicted communication openness, $F(3, 389) = 11.89, p = .000$, adjusted $R^2 = .08$. When cohesion and flexibility levels were added, they significantly improved the prediction, $R^2$ change = .22, $F(2, 387), 62.35, p = .000$. The entire group of variables significantly predicted communication openness, $F(5, 387) = 34.32, p < .001$, adjusted $R^2 = .31$. Table 9 displays the beta weights for each variable suggesting that cohesion and flexibility levels contribute the most to predicting communication openness, with age and education level also significantly contributing to the model.
In terms of individual relationships between the independent variables and communication openness, age ($t = -5.34, p < .001$), education ($t = 2.45, p < .001$), cohesion ($t = 4.89, p < .001$), and flexibility ($t = 2.92, p < .01$) each significantly predicted openness. Over and above the variance accounted for by age and education in communication openness, cohesion and flexibility levels still significantly predicted openness levels. As hypothesized, as cohesion levels within the family increased communication openness also increased ($\beta = .33, p < .01$). Similarly, the more flexible the family system the more open they were to communicate and discuss health problems ($\beta = .19, p < .01$).

**Specific aim 3: Openness and FHH communication.** The third aim of the study was to examine relations between openness to discuss health problems and family health history communication (i.e., collecting family health history and sharing cancer risk information). Two hierarchical logistic regressions were conducted to examine these relationships. Covariates (i.e., age, education level, insurance level, and family history of cancer) were added on the first step. Communication openness was added as a predictor variable in the regression equation in the second step, while collecting health history information from relatives or actively giving cancer
risk information was entered as the dependent variable. Openness was evaluated based on whether it accounted for a significant amount of variance in each outcome variable over and above the control variables. Table 10 summarizes the model statistics for the two logistic regressions (see page 75).

The effect of communication openness on collecting family health history information about cancer controlling for age, education, insurance level and family history was examined first. Controlling for socio-demographic factors and family history, the omnibus model for collecting cancer information from relatives was not significant, $\chi^2(1, N = 393) = 0.09, p = .764$. The Hosmer and Lemeshow test provided evidence that the model had adequate fit, $\chi^2(8, N = 393) = 5.59, p = .69$. Findings revealed that an open communication style was not a significant predictor of the collection of family health history information about cancer, however, having a family history of cancer significantly predicted collecting cancer information for the purpose of creating a family health history (OR = 4.88, 95% CI [1.89 – 12.64]).

Next, the relation between communication openness and the act of sharing or giving cancer risk information to other family members controlling for socio-demographic factors was examined. The omnibus test for sharing cancer information was not significant, $\chi^2(1, N = 393) = .747, p = .388$. The Hosmer and Lemeshow test provided support for an adequate model fit, $\chi^2(8, N = 393) = 3.74, p = .88$. As seen previously in the model examining family organization and giving cancer information, age was the only significant predictor of this communication act (OR = 1.04, 95% CI [1.02 – 1.07]). Findings further revealed that openness to discuss health problems was not a significant predictor of sharing or giving family members information about hereditary cancer risk.
### Table 10

**Hierarchical Logistic Regression Analyses: Communication Openness Predicting Family Health History Discussions**

<table>
<thead>
<tr>
<th></th>
<th>B</th>
<th>SE</th>
<th>Wald $\chi^2$ (1)</th>
<th>OR</th>
<th>95% CI</th>
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<td><strong>Step 1</strong></td>
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<tr>
<td>Age</td>
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<td>.011</td>
<td>1.286</td>
<td>1.01</td>
<td>[.99, 1.03]</td>
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<td>Insurance Level</td>
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<td>.186</td>
<td>.003</td>
<td>1.01</td>
<td>[.70, 1.45]</td>
<td>.959</td>
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<tr>
<td>Family History of Cancer</td>
<td>1.581</td>
<td>.485</td>
<td>10.615</td>
<td>4.86</td>
<td>[1.88, 12.56]</td>
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<td>Family History of Cancer</td>
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<td>1.31</td>
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<td>.549</td>
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<td>.447</td>
<td>.402</td>
<td>1.33</td>
<td>[.55, 3.19]</td>
<td>.526</td>
</tr>
<tr>
<td>Openness</td>
<td>.040</td>
<td>.047</td>
<td>.730</td>
<td>1.04</td>
<td>[.95, 1.14]</td>
<td>.393</td>
</tr>
</tbody>
</table>

*Note.* **p < .01.

**Specific aim 4: Levels of family organization and FHH communication.** The fourth aim of the study sought to explore whether family health history communication about cancer differed by the different levels of family organization. Independent samples t-tests were performed to compare the groups (collected vs. did not collect information; shared vs. did not share information) on the raw scores for each of the six scales of FACES-IV (enmeshed, balanced cohesion, disengaged, chaotic, balanced flexibility, rigid). This analysis provides a way to capture whether women who collect/share cancer information have higher or lower scores.
on each of the scales that compose the FACES-IV instrument than those women who reported not collecting/sharing cancer information with their relatives. Stemming from a family systems perspective, this particular analysis is useful because it examines relationships between collecting/sharing family health history information and levels of functionality within the family by providing detailed information (rather than a global assessment of functioning) that takes into account all levels of each domain. This assessment of family functioning and organization may also have clinical relevance.

The first set of analyses examined differences on the six scales that compose the FACES-IV measure (i.e., disengaged, balanced cohesion, enmeshed, rigid, balanced flexibility, and chaotic) between women who collected cancer information and those who did not. Independent t-tests revealed no significant differences between these two groups of women on the different levels of functionality and organization. However, a marginal significant difference was found for balanced flexibility, in that women who reported collecting family health history information about cancer were marginally more likely to have higher scores on the balanced flexibility scale than women who did not collect such information from relatives, \( t(470) = -1.94, p = .053 \). Table 11 (see page 77) presents the means and standard deviations for each scale by group as well as the \( t \) statistics.

Next, differences between women who shared or did not share cancer risk information with family members were calculated. Analyses showed significant differences in scores on the balanced flexibility, \( t(470) = -2.32, p = .021 \), and disengaged, \( t(470) = 2.06, p = .040 \), scales of FACES-IV. That is, women who shared or gave cancer risk information were more likely to score higher on the balanced flexibility scale and lower on the disengaged scale than women who did not share or gave information to relatives. In addition, two marginally significant differences
were found for the balanced cohesion, $t(470) = -1.78, p = .075$, and chaotic scales, $t(470) = -1.94, p = .090$. These differences were in the expected direction; that is, women who shared cancer risk information scored higher on the balanced cohesion scale but lower on chaotic scale. The opposite pattern was seen for women who did not share such information. That is, women who reported not sharing cancer risk information scored marginally significantly lower on balanced cohesion and scored higher on the chaotic scale.

Table 11

<table>
<thead>
<tr>
<th>Collected Information</th>
<th>Yes (N = 88)</th>
<th>No (N = 384)</th>
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<tr>
<td>Balanced Cohesion</td>
<td>28.17</td>
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<td>25.34</td>
</tr>
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<td>16.93</td>
<td>17.88</td>
</tr>
<tr>
<td>Enmeshed</td>
<td>15.07</td>
<td>14.96</td>
</tr>
<tr>
<td>Rigid</td>
<td>19.60</td>
<td>18.89</td>
</tr>
<tr>
<td>Chaotic</td>
<td>15.70</td>
<td>15.89</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Sharing Information</th>
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<th>No (N = 421)</th>
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<tr>
<td>Balanced Cohesion</td>
<td>28.83</td>
<td>27.26</td>
</tr>
<tr>
<td>Balanced Flexibility</td>
<td>27.26</td>
<td>25.37</td>
</tr>
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<td>Disengaged</td>
<td>16.07</td>
<td>17.90</td>
</tr>
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<td>Enmeshed</td>
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<td>15.09</td>
</tr>
<tr>
<td>Rigid</td>
<td>18.77</td>
<td>19.05</td>
</tr>
<tr>
<td>Chaotic</td>
<td>14.52</td>
<td>16.02</td>
</tr>
</tbody>
</table>

Note: *$p < .05$, †$p < .10$.

Specific aim 5: Family organization dimensions and FHH communication. The final aim for this study was to examine relations between family organization and family health history communication (i.e., collecting family health history and sharing cancer risk information) by plotting each family onto the Circumplex Model. The cohesion and flexibility dimension scores for each participant provided the coordinates to be plotted onto the Circumplex Model in order to determine whether each participant's family fell within the "Balanced" or "Unbalanced" area of the model according to Olson & Gorral (2006). Figure 2 provides a modified visual
representation of the model. Scores falling within the inner solid lines represent the "Balanced" area of the model (i.e., scores between 0 and 100 on each axis). Data showed that the majority of women's family organization environment ($N = 459, 97.2\%$) was classified onto the balanced area of the quadrant.

Two chi-square tests of independence were performed to examine whether women in the "Balanced" area tend to collect and share more family health history information about cancer than women whose family organization scores fall in the "Unbalanced" area. A requirement of the chi-square test is that the expected frequencies in each cell must be greater than 5. When these expected frequencies are greater than 5 it can be safely assumed that the sampling distribution approximates a perfect chi-square distribution. The data failed to support this requirement as one of the cells in both of the chi-square tests performed (one for each communication outcome) had expected frequencies below 5. One method that has been proposed to deal with this issue is Fisher's Exact Test. This method computes the exact probability of the chi-square statistic and has been shown to be useful in small samples (Field, 2013). The Fisher's exact test method was then used as a correction for the small expected frequencies observed. Results revealed no significant associations between a balanced or unbalanced environment and the collection of family health history ($p = .478$). Similarly, no relationship was found between balanced/unbalanced family organization membership and sharing cancer risk information with other relatives ($p = .378$).
Figure 2. Cohesion and flexibility dimension scores plotted according to Olson's Circumplex Model

Discussion

Family health history has been recognized as an important tool in cancer prevention and health promotion given that its assessments allows determination of an individual's inherited cancer risk (Valdez et al., 2010; Yoon et al., 2004). To date, much of the literature on family health history discussions about cancer have focused on patient-physician communication (Arkin, 1999; Bortoff, Ratner, Johnson, Lovato, & Joab, 1998; Smith et al., 2011; Dickerson et al., 2012), communication in families with a history of cancer (Harris et al., 2010; Hay et al., 2009; Lawsin et al., 2009), and discussions surrounding dissemination of genetic test results (Aktan-Collan et al., 2011; McCann, et al., 2009; Seymour, Addington-Hall, Lucassen, & Foster, 2010; Stoffel et al., 2008; Vos et al., 2011). Fewer studies have sought to identify family factors that may promote family health history discussions, yet this type of information could be used to identify families who may need support in having these conversations.
The present study examined whether the family context (i.e., cohesion, flexibility, communication openness) was associated with family health history communication about cancer within a diverse group of women recruited from an urban, safety-net women's health clinic. To the best of my knowledge, this study proposes a novel and original research focus by investigating the role of the family's functioning and organization as it relates to cancer risk communication. In addition, this study examined family organization using different conceptualizations provided within the family systems framework. Family organization was measured by a global assessment of functioning which utilized the ratio of balanced to unbalanced levels of cohesion and flexibility but also by utilizing a targeted view of functionality which encompass each level of the cohesion and flexibility domain. By taking into account all levels of each domain, I was able to gather detailed information about the organizational structure of the family as reported by each participant and make predictions for important points of intervention. Thus, the present study aimed to expand the small but emergent literature on the role of family context in family health history discussions about cancer.

**Does Family Organization Affect Family Health History Discussions?**

Although correlational analyses revealed positive associations between family organization (i.e., cohesion and flexibility) and sharing cancer risk information these associations disappeared in multivariate analyses that adjusted for age, education level, insurance level, and family history of cancer. Cohesion and flexibility levels within the family, as reported by each participant, did not play a role in the act of collecting or gathering family health history about cancer from other relatives. These findings were unexpected as a small literature in the field suggests a connection between family organization and communication about cancer. For instance, Harris et al. (2010) found that, controlling for age, gender, education, and marital
status, both cohesion and flexibility levels in the family system were associated with the amount of communication that transpired between family members about melanoma risk.

Some thoughts regarding why these results were different from other studies include differences in the samples being studied. For example, participants in the Harris et al. (2010) study ranged in age from 19 to 91, with an average age of 51 years. In general, the present study recruited younger women, with an average age of 34 years (range 19-79 years). It may be that as individuals get older family organization may be more relevant to having family health history discussions because higher degrees of cohesion and flexibility have the potential to enable important social resources. For instance, Ashida and colleagues (2011) found that younger respondents (≤59 years) were more likely to declare older members in their family system as providers of social resources than younger members. In other work, Ashida et al. (2013) found that older adults tend to share family health information with those family members whom they feel closest to and have formed an emotional bond. Taken together, these prior findings in the literature indicate that family cohesion may be an important factor for older generations when it comes to communication but less so for younger individuals. This sample also differed from others in terms of racial/ethnic diversity and education level (Harris et al. 2010; Marsac & Alderfer, 2011) where the majority of the samples tend to be White and participants tend to come from higher income level families. Lastly, the Harris et al. study in particular focused on families affected by a specific type of cancer (i.e., melanoma) in a first degree relative. It may be that asking participants to think specifically about melanoma-related conversations that have transpired within the family and the frequency of such discussions come to mind more readily than asking generally about family health history about cancer discussions.
An argument can also be made that family level factors, such as general communication within the family and family satisfaction, may be more important to examine in regards to family health history discussions than family organization. For instance, a recent study examining the connection between family relationships and post-traumatic growth in a sample of breast cancer patients found no associations between cohesion and flexibility (as measured by FACES-IV) and post-traumatic growth (Svetina & Nastran, 2012). However, their findings revealed a significant association between family communication, family satisfaction and post-traumatic growth. Family communication and family satisfaction are two dimensions that can be measured using FACES-IV instrument, however, were not included in the present study. It may be that looking at general family communication and satisfaction with family relationships may better predict family health history communication about cancer. Knowing what the general communication patterns in the family are coupled with how satisfied individuals are with their family relationships may provide a better picture of the family environment and how it relates to cancer communication.

Each family members' readiness to collect or shared health history information with others in the system may be affected by the family environment, in particular, the degree of closeness between family members. A recent study by Butty et al. (2012) found an important link between stages of change and family health history communication. They conducted a community-based and culturally adapted workshop with African American participants to change genetics and health-related knowledge, intentions, and behavior. They asked participants to make three health behavior pledges they wished to pursue after the workshop. Results found that 43% of participants pledged to collect family health history information with members of their family. Of those who pledged to collect family health history, 50% where in the preparation
stage (stage 3) at the beginning of the workshop and 53% reported being in the maintenance stage (stage 5) at the 2 month follow-up. These findings suggest the need to explore the individual's readiness to change in order to enact the behavior of collecting or sharing family health history. Moreover, Ashida et al. (2013) found that participants reported they had shared family health information with those whom they feel close, provide emotional support, and engage in contact more frequently. It may be that a combination of factors such as the degree of readiness to collect/share information and the emotional closeness exhibited within the family system will affect family health history discussions.

One approach that has received great attention in the area of behavior change and may be useful in family health history communication research is motivational interviewing (MI). Stemming from theoretically driven models of behavior change including the Health Belief Model (HBM; Rosenstock, 1974) and the Transtheoretical Stages of Change model (Prochaska & DiClemente, 1982), MI is a patient-centered, collaborative approach that emphasizes the exploration of an individual's ambivalence for behavior change through the identification of the pros and cons of changing that behavior (Wahab, Menon, & Szalacha, 2008). The technique calls for enhancing self-efficacy to enact a behavior while attempting to minimize resistance (i.e., rolling with resistance). In the context of cancer screening, MI can be helpful in exploring the importance an individual attaches to screening, their confidence in their ability to get screened, and concerns about the actual screening process.

Recent intervention studies have examined the use of MI in the adoption of screening behaviors for colorectal cancer screening and mammography screening (Costanza et al., 2009; Lowery et al., 2012; Menon et al., 2011; Wahab, Menon, & Szalcha, 2008). Collectively, these studies suggest that MI is an effective intervention to help individuals think about their cancer
risk, explore the reasons for and against screening, and establish a specific plan to get screened. For instance, Costanza et al. 2009 found that almost 60% of participants who received a telephone-based MI counseling session got a mammogram within 12 months of the intervention. Out of the women who were counseled, 72% moved one stage closer to adhering to screening recommendations. In regards to communication, MI may be an effective technique used to foster family communication about cancer risk, and serve as a precursor to screening. That is, MI interventions may help families openly explore, in a non-judgmental manner, concerns about familial cancer risk and their ambivalence over following screening recommendations. Educational interventions that also include an MI component may be useful in increasing family health history communication and ultimately lead individual family members (or the collective) to comply with cancer screening recommendations.

Do Family Health History Discussions Vary According to Levels of Family Organization?

Although family cohesion and flexibility were not significant predictors of FHH communication in multivariate analyses, the FACES measure provides a different way of conceptualizing family cohesion and flexibility. For instance, when examining each scale of the FACES-IV instrument separately, a trend was found in the hypothesized direction that women who reported collecting and sharing cancer information from relatives scored higher on balanced flexibility than women who reported not collecting or sharing such information. Balanced flexibility is conceptualized as the quality and expression of leadership and organization, relationship rules and negotiations within the system (Olson & Gorall, 2006). It may be that women who reported collecting family health history information come from an environment where leadership, organization, and set relationship roles are common and therefore conducive of a greater desire to know about factors (i.e., cancer history) that may affect this balanced
organization. When examining cohesion, a trend was found indicating that cohesion levels are associated with sharing/giving cancer risk information (but not for the collecting information) as women who shared cancer risk information also scored higher on balanced cohesion. It appears that the degree of connectedness or emotional bond felt within the system is an important factor when deciding whether or not to share family health history information with other relatives but is a less important factor when considering the collection of family health history. Correlational analysis showed no association between cohesion/flexibility and collection of family health history but did confirm a relationship between organizational domains and sharing/giving cancer risk information to relatives. These trends demonstrate a need for additional research that investigates the underlying mechanisms of action that drive the relationship between family health history communication and family organization.

Is Family Organization Related to Communication Openness?

In addition to identifying factors associated with family health history discussions about cancer, I also explored whether family organization was related to openness to discuss health problems. Adjusting for age, education, and insurance level, findings revealed that cohesion and flexibility significantly predicted openness to discuss health problems. Said differently, feelings of connectedness and functional flexibility within the family system were associated with having a more open communication style with other family members regarding health issues. This finding is consistent with previous literature that has shown that individuals whose families were highly cohesive and flexible were more likely to communicate openly about melanoma cancer (Harris et al., 2010). It is important to note that the present study differs from the Harris et al. study as it highlights a significant link between cohesion/flexibility and communication openness about health problems in families who may or may not have a family history of cancer.
Therefore, even for women whose families have been unaffected by cancer, having a cohesive and flexible family environment predicts an open communication style within the family. This finding contributes to the small but emergent literature on the role of family organization on health communication more generally.

**Is Communication Openness Associated with Family Health History Discussions?**

Despite a significant association between levels of cohesion and flexibility within the family and communication openness, results showed that openness to discuss health problems was not associated with family health history discussions about cancer. It may be that openness to discuss health problems in general, as measured in the present study, does not fully capture the complexity and challenges that may arise when communicating with family members about cancer risk. For example, Kenen, Ardern-Jones, & Eeles (2004) found that women with a positive BRCA genetic test result could identify at least one family member whom they could go to for support and openly discuss their genetic cancer risk, however, they recognized times when openly communicating about the family cancer risk may bring about negative consequences, and therefore, reported limiting communication with certain relatives to minimize harm or distress.

Measuring openness to discuss the family health history of cancer with specific family members can potentially provide a better picture of the supportive and unsupportive ties within the family system. Identifying family members that are open and supportive to discussing cancer risk information with other relatives will help discern strategies for dissemination of important cancer risk information through the system. This information can be important when considering interventions that aim to increase family health history discussions.
What Role Does Having a Family History of Cancer Play on Family Discussions about Cancer?

Bivariate analyses showed that having a family history of cancer was positively correlated with having collected cancer information from other relatives. Furthermore, multivariate analyses indicated that women who reported being aware of a positive family history of cancer were almost five times more likely to report actively collecting (not sharing) cancer history information from relatives than women without a family history of cancer. An argument can be made that awareness of a family history of cancer involves a communicative process among family members potentially regarding the collection of specific cancer history information. This may include information on which relatives have had cancer, the age of diagnosis, the type of cancer among other topics (i.e., treatment, age of death). This process of gathering information is important as the literature has posited that upon awareness of a positive history of cancer in a close relative, individual members of a family develop risk perceptions that guide communication with other relatives and may prompt preventive behaviors (Audrain-McGovern, Hughes, & Patterson, 2003; Tracy et al., 2008). Yet, it is difficult to know, based on current results, which process precedes the other. That is, does family history awareness produce a more proactive approach to collecting family health history or does this active approach result in increased knowledge about the family history of cancer? Perhaps, a better research question may be whether family history awareness increases the frequency of communication with family members about cancer-related risk and early screening practices.

It is interesting to note that a positive family history of cancer was only associated with the process of collecting cancer information from other family members but not with sharing such information with other individuals. Interpreting this finding is somewhat puzzling as
intuitively one would think that the same motivators found in the collection of such cancer history are involved in the desire to share this knowledge with others in the family. However, it may be that the process of collecting information differs from the process of sharing cancer risk information to other relatives. It is possible that sharing information about cancer risk is linked to a sense of responsibility for initiating a conversation about the family health history in order to pass along this information through the family system. This sense of responsibility may result from older generations having an increased familiarity with the family health history and being in the best position to pass down this information to other relatives (Ashida et al. 2013).

Collecting information, on the other hand, may require hearing the information from other sources and then asking follow-up questions to obtain the most accurate and up-to-date family history information. For instance, Dickerson, Smith, Sosa, McKyer & Ory (2012) found that when given cues from friends and acquaintances, college-aged women were more likely to believe that they (not their physicians) were responsible for initiating family health history discussions. It may be that hearing about the family health history of others in their social network sparks interest in one's family resulting in the active collection of such information. Thus, there may be different factors associated with collecting and sharing cancer risk information depending on the perceived responsibility for initiating conversations about the family health history. More research is needed to tease apart the mechanisms involved in these two types of communication processes.

**What Socio-demographic Factors are related to Family Health History Discussions?**

Analyses revealed significant associations between several key socio-demographic variables and family communication about the family health history of cancer. Concordant with prior literature, age was positively correlated with both collecting and sharing cancer information
in this study. That is, older participants were more likely to report actively collecting and sharing family health history information specific to cancer. The generational aspect of family health history communication has been well established in the literature (Julian-Reynier et al., 2000; Foster, Watson, Moynihan, Ardern-Jones, & Eeles, 2002; Koehly et al., 2009). Recent work by Ashida and colleagues (2012; 2013) suggest that older individuals tend to be more familiar with the family health history than younger individuals and are therefore in a better position to disseminate the family's health history to younger relatives. This familiarity implies that older individuals have collected important family health information enabling them to disseminate or pass forward such information to younger generations. Familiarity with the family health history also makes older individuals ideal targets for family-based interventions to increase family communication about the family cancer history. It may also be that older individuals are more aware of their own health and how their family history contributes to their health than younger individuals who tend to show an optimistic bias when it comes to health behaviors (Ashida et al., 2011; Chock, 2011). Therefore, older individuals may be more encouraged of hearing family members discuss these issues. Using this generational pattern may be an important way to ensure a health history database is created within the family which will ultimately serve as an aid for future generations' decision-making surrounding health.

Educational attainment was also positively correlated with collecting or gathering cancer information from relatives. In this study, women who reported attending at least some college also reported increased family communication about the family health history of cancer. In prior literature, educational attainment has been shown to affect an individual’s ability to understand a cancer diagnosis and treatment options, their confidence and communication with healthcare professionals, and the way they share this information with their social networks (Gage, 2010).
Following this thinking, one interpretation is that women with a higher education level may be inclined to communicate with other family members about different topics surrounding the family health history of cancer given a higher sense of self-efficacy. It may also be that more educated women are more aware of the increased risk a positive family history of cancer poses for individual family members and are therefore more likely to communicate with relatives about this potential risk.

**Do the Cohesion and Flexibility Dimensions Help Us Further Examine Associations between Family Organization and Family Health History Communication?**

Lastly, no significant associations were found between the balanced and unbalanced dimensions of the Circumplex Model (Olson & Gorall, 2006) and family health history about cancer. A current search of the literature yielded null results in the examination of the balanced and unbalanced dimensions of the Circumplex Model. Several explanations are offered as to why the data may have yielded unremarkable results. It may be that in order to examine these dimensions as intended by the authors of FACES-IV, a larger sample is needed to fully capture the variability in functioning. Another possibility is that as the model stands, the classification of what constitutes a "balanced" or "unbalanced" family system is too broad. That is, it is unclear what differentiates a low or high score within the model. Performing qualitative analyses on the circumstances of women with the most extreme scores may yield a better understanding of what their family organization is like and how it affects their functioning including their communication patterns. Validity studies focusing on these dimensions of the FACES-IV measure will also be important as no research has been published examining the contribution of these two dimensions.
Clinical Implications and Future Directions

The literature has identified family health history communication as an important tool for cancer prevention, yet significantly missing are interventions that aim to improve communication about cancer history in the family, and that are practical for clinical settings. From empirical work on family communication and disclosure of genetic test results for hereditary cancers, we have learned a great deal about the barriers faced by individuals when communicating with their families (Cohen, 2006; Hay, Shuk, Zapolska et al., 2009; Wiseman, Dancyger, & Michie, 2010). Given the importance of family health history in prompting early (and more frequent) cancer screening for families at increased risk, it is important that future research translate what has been learned into pragmatic interventions that will bring awareness of risk factors and encourage life-saving conversations within family members. Thus, interventions that target the whole family as a system, where family communication and support is encouraged, objective risk information is disseminated, skills are provided to address communication challenges, and an action plan is established to reduce risk will likely contribute to the adoption of preventive behaviors (O'Leary et al., 2011; Williams, Mullan, & Todem, 2009).

The present study served as an initial examination of the contribution of three family context factors (i.e., cohesion, flexibility, and openness) to family health history communication about cancer. Results indicated a significant link between cohesion and flexibility and sharing of cancer risk information to relatives, however, failed to find a relationship between openness and family health history communication. Despite these findings, it appears that cohesion and flexibility play a small but significant role in cancer risk communication particular in the act of disseminating cancer risk information. The literature, therefore, may benefit from further investigation of this relationship. Future research could use a family systems framework to
identify properties within a family, for instance, that may increase the negative impact of communicating about the family health history of cancer (Hay, Shuk, Zapolska et al., 2009; Peterson, 2005). It may be that in a less cohesive family, encouraging an individual family member to discuss the family cancer history with other relatives may be more difficult to achieve or perhaps even negatively impact familial relationships. Interventions could use information about the family organization to provide tailored communication strategies or skills that may minimize adverse reactions when discussing family health history information (Harris et al., 2010). Alternatively, interventions can focus on the family by providing psycho-education on ways to improve emotional bonds among individual family members as well as increase structure and consistency in an effort to improve family functioning. This, in turn, may minimize the barriers toward communication and encourage a sense of social support and connectedness that may improve communication about the family health history. Thus, using the family systems framework may help in identifying families in need of alternative methods for disseminating health information.

It is important to consider that family organization may not operate in a vacuum—that is, it is likely that other important inter-personal and intra-personal constructs significantly contribute to the overall functioning of the family and therefore may play a role in both family organization and communication about the family health history (Black et al., 2012; Gaff, et al., 2007; Hay, Shuk, Zapolska et al., 2009). Constructs such as coping, health beliefs, risk perceptions, cancer worry, social support, family satisfaction, and general family communication would be important constructs to consider for future research and will likely contribute immensely to the emergent literature in this area. One potential avenue of research involves designing a longitudinal study were mediation may be assessed. It would be interesting to learn
whether constructs such as openness, cancer worry, or risk perception mediate the relationship between family organization and family health history communication about cancer. If such mediation is achieved, evidence suggesting points of intervention will start mounting.

Furthermore, linking communication to actual behavior becomes an important goal for prevention. Studies that examine the translational effect of talking about the family health history to actual practice of preventive behaviors including changing diet, increasing physical activity, and following recommended screening guidelines for personal risk level will be of utmost value to the existing literature (Ersig et al., 2009; Lemon, Zapka, & Clemow, 2004). I envision future work starting with a qualitative assessment of what entails family health history communication about cancer. That is, it would be important to assess the who, the what, the where, and the how of communication patterns about familial cancer risk in families with and without a family history of cancer. This formative work will likely inform appropriate cultural adaptations to interventions and provide a better sense of which family environment is more conducive to discussing the family health history about cancer. Careful considerations about cultural norms are also important to keep in mind as communication patterns and styles within families can vary and change considerably from culture to culture. Yet, viewing personal health from a family systems perspective promises to offer an effective and culturally relevant framework for enabling family networks into health (McGrath & Edwards, 2009). After initial examination of the communication content, prospective studies can then assess the impact of family health history communication about cancer on the family's collective health promoting behaviors and risk reducing practices.

The cancer risk communication literature has also recognized "kin keepers" as important players in the dissemination of health information within families (Koehly, et al., 2009; Loescher
et al., 2009; Williams, Mullan, & Todem, 2009). According to the literature, these family members naturally assume this role and take on the responsibility of collecting and maintaining health history across generations with the intent of keeping relatives informed of potential health threats to their family. Given this idea of family kin keepers, another potential avenue of research is the development of interventions that aim to empower individual family members (typically women) to own this role (Williams, Mullan, & Todem, 2009). One direction interventions could take is to identify that one person in the family that has naturally assumed the role of kin keeper and train them to serve as the health keeper of the family. Perhaps, this member within the family system is one who others rate highly on individual measures of cohesion, flexibility, and openness. This person could be in charge of disseminating cancer risk information to others in the system as well as help relatives' follow-through with screening appointments and encourage the adoption of health promoting behaviors. The idea being, that once you give this family "insider" the mission of collecting and imparting cancer risk knowledge, the information will travel quickly through the family system.

Another important issue to address in future work is the pronounced disparities in health care access and health-related information in underprivileged groups in society (Ashida et al., 2012; Butty et al., 2012). For some time, researchers have been determined to eliminate such disparities, yet much more work is still needed to understand the unique issues and barriers certain groups (and families) experience when it comes to health care. There is a dearth of studies focusing on race/ethnic differences in family health history communication and most of the literature on family health history discussions have been conducted with primarily White samples. Given that family communication is a dynamic and inherently cultural process, we need to better understand what is promoting or hindering communication about cancer risk in
racial/ethnic minorities (Corona et al., 2012). It is important to assess whether similar patterns of gathering and disseminating health risk information are observed within families of varied cultural and socioeconomic backgrounds. Little attention has also been given to exploring the impact of socio-economic status and health access on family communication about hereditary cancer risk. For many, the possibility of genetic counseling and/or testing is not an option due to high costs as well as the perception of discrimination by insurance companies or employers (Whitfield, Wiggins, & Brandon, 2003). The present study provides evidence showing that a higher educational attainment is related to the collection of family health history which highlights a disparity when it comes to discussing the family health history. Health disparities continue to be a significant problem, and it is important that future research develop interventions to reduce the gap between access and care. Understanding the family processes that contribute to the dissemination of health information across family members of minority and disadvantaged groups will help bridge this gap.

Lastly, the existing literature surrounding health history communication within families posits that discussions within families about health history are likely to result in improved health for families (Harris et al., 2010). However, few studies have shown that communication about genetic test results regarding cancer risk within the family, for example, can negatively impact families by increasing cancer-related distress (van Oostrom et al. 2007a; van Oostrom et al., 2007b). The results from this study provide insights on the value of identifying familial organization patterns, in particular cohesion and flexibility levels, as they may affect how and whether risk information is disseminated. Therefore, future studies should also consider the negative impact family health history discussions may have on the system and the potential protective nature of building a cohesive and flexible environment.
Methodological Limitations

A number of methodological limitations to the current study should be considered. These are related to the study design, procedures, and measurements used in the study. The following section will discuss their impact on the overall study findings.

Cross-sectional design. First, the current study design was cross-sectional in nature and, by definition, assessed participants at a given point in time (Kazdin, 2003, p. 144). A cross-sectional design does not allow the researcher to draw conclusions about causation rather they suggest patterns that should be tested longitudinally and in temporal-sequence in order to determine mechanisms of action. For the current study, all conclusions are relational and therefore I am only able to say that a relationship or association exists between variables. For instance, findings revealed a significant association between cohesion and flexibility levels and openness to discuss health problems. To this end, I am unable to determine whether having a more cohesive and flexible family environment promotes an open communication style where discussion about health problems is most suitable or whether openness to communicate with other family members contributes to a more cohesive and flexible environment. Given that findings are correlational, I can only determine relationships between variables and examine the strength of these associations without commenting on their causal implications. As described above, future research may benefit from examining these relationships longitudinally in order to translate findings into actual mechanisms of actions and behaviors.

Self-report. The present study relied on self-report data from participants and, as such, may have been influenced by aspects of measurement wording as well as bias by way of social desirability (Kazdin, 2003, p. 373). Wording issues will be discussed further in the following section. The aspect of social desirability, however, may have impacted the results in a
significant way. Social desirability refers to the tendency of research participants to provide answers that portrays them in the best possible light. When it comes to family organization measures as well as communication openness, it may be that women in the study felt the need to endorse a more balanced and open family environment in order to portray their family system as stable. The observed high mean scores on both of these measures correspond to answers that place women in the high openness communication range as well as the functional or balanced level of cohesion and flexibility. Perhaps different item wording which minimizes face validity is warranted in future studies to control for this type of bias. Lastly, future research should consider using multiple reporters as a way to gather collateral information on family functioning. One way to do this is by asking other members of the family (i.e., parents, siblings, children) to assess their family’s level of functioning and communication patterns. Additionally, the use of direct observation of family interactions can be more comprehensive way to capture the dynamics of the system. Taken together, these methodologies along with the information gathered through self-report measures is likely to yield a richer picture of how the family is organized and how messages are transmitted among family members.

**Measurement.** Several issues are worth noting regarding measurement limitations. Such limitations will be addressed by instrument for ease of discussion. First, the communication openness measure utilized for this study was modified from its original version by changing cancer-specific wording to wording that addressed discussion of health problems in general (Openness of Discussion in the Family Scale; Mesters et al., 1997). Given that a primary aim of the study was to examine relations between communication openness about cancer and family health history communication about cancer including a measure that was specific to cancer discussions within the family would have been a wiser choice. In retrospect, including an
additional measure of communication openness about cancer, such as the one developed from the formative work of Kenen and colleagues (2004) used by Harris et al. 2010, would have also strengthened the study.

Second, FACES has been the gold-standard instrument used when wanting to assess cohesion and flexibility levels within a family system. However, most published research uses previous versions of FACES which consider the constructs of cohesion and flexibility as linear. In the most recent version of the measure, FACES-IV, the authors revised the Circumplex Model and determined that the best way to examine and study cohesion and flexibility within the family system is by way of a curvilinear approach that includes both balanced and unbalanced aspects of each domain. The present study contributes novel insights into the relationship between cohesion/flexibility and a health-related topic (i.e., cancer risk communication), however, questions remain about its validity. The FACES-IV instrument was validated using a college student sample and may not generalize to other populations. FACES remains a popular measure to assess family organization in the research literature, yet more research is needed using its latest version.

Lastly, it is unclear whether participants followed instructions regarding who to consider part of their "family" when answering the items. At the beginning of the survey, participants were asked to think of their close blood relatives and answer questions accordingly. Given the variability in family definitions, answers may be confounded by participants answering questions regarding non-biological kin (e.g., spouses, in-laws, family friends who live in the home). Unfortunately, there is no good way of determining if this was the case. Thus, results are based on the assumption that participants responded to the items based on their close blood relatives.
Third, the main outcome of the study was measured using two dichotomous items adapted from the 2004 Center for Disease Control and Prevention's HealthStyles Survey (Yoon, Scheuner, Gwinn, & Khoury, 2004). To the best of my knowledge, the use of these items in research has not been replicated. The questions asked: "Have you ever actively collected cancer information from your relatives for the purpose of creating a family health history?" (collecting information) and "Have you ever actively given your relatives information about hereditary cancer risk? (Hereditary cancer risk is cancer that tends to run in the family.)" (sharing information). The wording of these items may be problematic to some participants, especially those with a lower education level, given the length of the question, the novelty of concepts (i.e., family health history or hereditary cancer risk), and the complexity of the behavior it intends to address (i.e., actively collecting and actively giving information). It may be that participants have had informal conversations about the family history of cancer, however, the way the main outcome of the study was phrased does not fully capture these important discussions. Future research may want to consider simplifying the wording of the measure. In addition, the use of an open-ended question format or a scale that better captures different domains of family communication (i.e., content, frequency, discussants) may be important for future research.

**Sample size.** The present study collected data on 472 participants, however, for analyses which included the education level variable as a covariate, the sample size was reduced to 393 participants due to missing data. I chose not to impute these data as education was a fixed factor with no other observable values that could be used for imputation. This reduction in sample size may have reduced statistical power. In addition, it appeared that the sample size obtained for the present study was not sufficient to test specific aim 5, as there was little variability in the number
of participants that were categorized in the unbalanced dimension of the Circumplex Model. Future research should consider gathering information on a larger number of participants.

Conclusions

The study of family health history communication about cancer is an important area of research given that an increased awareness of familial cancer risk gained by family communication may encourage early cancer screening practices and promote preventive behaviors in individuals at high risk. In general, findings revealed that an active involvement of women in collecting and sharing family health history as it pertains to cancer is low. Women with a higher education level, who are older, and who had a family history of cancer were more likely to report having collected family health history information about cancer; while being older and experiencing higher levels of cohesion and flexibility within the family was associated with sharing cancer risk information with relatives. Furthermore, little evidence was found to suggest that family organization and openness to discuss health problems are associated with family health history communication about cancer, however, support was found for an association between family organization and openness to discuss health problems. In sum, the present study contributes to a small but emergent literature in the field of family health history communication about cancer and proposes important avenues for future research.
List of References


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Vita

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