The Meaning of a Family History of Colorectal Cancer in Black Families in the United States

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The Meaning of a Family History of Colorectal Cancer in Black Families in the United States

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A Dissertation Submitted to The Graduate School at the University of Missouri-St. Louis in partial fulfillment of the requirements for the degree
Doctor of Philosophy in Nursing

December
2018

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Abstract

The purpose of this study is to understand the meaning of a family history of colorectal cancer (CRC) for first-degree relatives of Blacks diagnosed with CRC. Even though CRC is more preventable than other cancers because of effective screening tests for prevention and early detection, Blacks experience a disproportionate burden of CRC compared to other groups. Interventions to increase CRC screening among Blacks have not produced a significant reduction in CRC disparity. Underutilization of CRC screening and low perceived risk of CRC are major factors contributing to CRC disparity. The informing methodological approach employed in this study was hermeneutic phenomenology, an interpretative paradigm based on the philosophy of Martin Heidegger and Hans Gadamer. In hermeneutic phenomenology, preunderstandings of the researcher, such as behavioral theories, are accounted for as research data but do not guide the research approach as in traditional empirical studies. After employing a hermeneutic phenomenological design and collecting in-depth narratives from family members (n=8), a hermeneutic team analyzed, transcribed, and de-identified interviews to construct patterns across texts. The results of the study revealed that a family history of CRC shows itself as a shortened illness trajectory involving several overlapping sub-patterns: facing a dreaded diagnosis, caregiving with gusto, preparing for the untimely death of a parent, coping with a burden too great, and dealing with emotional turmoil. A second showing was mobilizing the family against CRC, including the sub-patterns: asking questions about heredity, realizing one’s own mortality, and increasing awareness about CRC. Nurses encounter family members of CRC cases across the cancer continuum and are well-situated to
promote the translation of evidence into practice by intervening with families to promote awareness of risk and early detection activities.

*Keywords:* Blacks, colorectal cancer, family history, first-degree relatives, perception of colorectal cancer risk, screening, philosophical hermeneutics
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The Meaning of a Family History of Colorectal Cancer in Black Families in the United States

Chapter 1: Introduction to Study

Colorectal cancer (CRC) is the third most commonly diagnosed cancer in the world (Douaiher et al. 2017; Stigliano, Sanchez-Mete, Martayan, & Anti, 2014). At the same time, CRC is the most preventable of all types of cancer (ACS, 2017). However, the translation of science into practice, in terms of screening and early detection, has not benefited all equally, especially racial/ethnic minorities. The overall incidence of CRC is slowly decreasing around the world in developed countries. Currently, there is a trend of increasing incidence in the development of early-age, familial CRC before the age of 50 in the United States (U.S.) and the European Union (Ahnen et al., 2014; Bailey et al., 2015; Stigliano et al., 2014). A substantial proportion of CRC cases are familial. Familial cases account for approximately 20% - 30% of CRC cases in individuals under the age of 50, while hereditary colon cancer syndromes account for only 5% of cases (Ahnen et al., 2014; Maga, Balat, & Jung, 2017). Familial CRC cases occur more often than could be explained by chance, which may indicate the presence of a gene mutation that increases the risk of cancer (NCI, 2014).

Background and Significance of Problem

This widespread phenomenon of early-age CRC has significant implications for Blacks in America due to the already disproportional incidence and mortality rates among Blacks over the age of 50. Few studies have focused on Blacks under the age of 50, because CRC is considered a disease of the elderly. Young-adult relatives of Blacks diagnosed with CRC are the U.S. sub-population with the highest risk of developing
early-age CRC at more advanced stages (Chan et al., 2017; Ho et al., 2013; May et al., 2017). This group also experiences disparities in treatment and survival (Dorsey, Zhou, Masaoud, and Nimiri, 2013; Douaiher et al., 2017; Lai et al., 2016). Just as Black adults suffer a disproportionate burden of CRC across the cancer care continuum, Black young adults experience the same issue due to a trifecta effect from the interaction of race, age and family history of CRC (Ashtorab, Kupfer, Brim & Carethers, 2017).

After decades of disparity research and interventions to increase CRC screenings, Blacks continue to experience a persistent lack of reduction in the CRC disparity (AHRQ, 2013; Aizer et al., 2014). According to the Institute of Medicine (IOM, 2013), the American healthcare system is in a crisis, and needs to chart a new course to address the failures that contribute to persistent cancer disparities. CRC disparity among Blacks will persist if there remains a failure to recognize the need to improve the quality of cancer care at the initial stages of the cancer care continuum, beginning with risk assessment, primary prevention, screening, and detection. An example of the current failure in quality cancer care is the lack of awareness of the risk of developing early-age CRC among Black Americans under the age of 50. The present study is significant because of its potential impact on how age-related CRC trends will interact with U. S. population growth and longevity predictions in the future.

Based on U.S. Census Bureau predictions, almost one in five people will be 65 or older in 2050, and the working age (18-64) population is projected to fall to 57% from the current 63% (U.S. Census Bureau, 2017). The likelihood of developing CRC naturally increases with age, but when combined with the increased risk of young-age onset of CRC, the prevalence of CRC will limit the number of healthy, working-age
individuals expected to care for older family members. A failure to avert the current trend of early-age onset of CRC will impact the ability of Black families to cope with overwhelming financial and caregiving burdens.

Age and family history of CRC are considered the two most important risk factors for developing CRC. CRC affects 1 in 20 men and women and the risk increases with age. The likelihood of individuals younger than 40 developing CRC is 1:1200, as compared to 1:25 for individuals older than 70 (Bailey et al., 2015). The estimation of young adults’ risk for CRC suggests that age continues to be a protective factor. Nevertheless, the bulk of preventive health strategies ignores the question of preventing CRC in adults (age ≥ 50 years) and young adults (age ≤ 50) (Inra & Syngal, 2014; You, Xing, Feig, Chang & Cormier, 2012). The objective evidence shows that cancer is the second leading cause of death for Americans aged 35-44 years, and the fourth leading cause of death for those aged 24-35 years (CDC, 2016). CRC is the third leading cause of cancer-related deaths among individuals 20-39 years (Heron, 2013). CRC incidence and mortality rates among young adults (age ≤ 50 years) have been increasing significantly over the last decade, while the rates have been decreasing in adults over the age of 50 (Ahnen et al., 2014; Bailey et al., 2015).

**Family Context of Problem**

Family history contributes to the development of CRC because of shared genetic and environmental factors (Henrikson et al., 2015). From a social epidemiological perspective, the objective data also suggest that Blacks are more likely to share the CRC illness experience of a family member across the cancer care continuum. Familial factors may also contribute to early-age CRC due to shared family history, beliefs, attitudes,
behavioral health habits, patterns, attunements, and care structures. Illness beliefs are socially-constructed within a historical, cultural, and cancer-related context in the family situation (Castillo, Godoy-Izquierdo, Vazquez, & Goody, 2011). Families also share cultural and experiential perceptions of illness and develop responses to illness in the family that are transmitted generationally. It is evident that there are racial and ethnic differences in perceptions of CRC and CRC screening. For example, Blacks tend not to perceive themselves as being at risk for CRC (Orom, Kiviniemi, Underwood III, Ross, & Shavers, 2010; Orom, O’Quinn, Reilly, & Kiviniemi, 2015; Ward et al., 2008). Even Blacks with high levels of healthcare access report low levels of awareness, low-risk perception, and low CRC screening behaviors (Gwede et al., 2010). Low perception of CRC risk is a barrier to screening and the adoption of other preventive behaviors, which contributes to racial disparities across the CRC cancer continuum.

**Statement of Problem**

Black American adults under the age of 50 are more likely to develop early-age colorectal cancer than any other racial/ethnic population in the United States (Ashktorab et al., 2014; Bailey et al., 2015). However, despite often having experienced multiple relatives suffering with CRC, Blacks tend not to adopt risk-management behaviors such as CRC screening. Low-perceived risk of CRC and lack of awareness of increased risk due to family history are the most consistently reported barriers to CRC screening among Blacks (Orom, et al., 2015; & Rubin et al., 2009;). Why Blacks with a family history of CRC misperceive their risk of CRC and fail to utilize preventive screening has not been fully understood by studies that employ survey research alone. There are few studies on the perceptions of CRC risk and screening among young adult Blacks with a family
history of CRC. Therefore, it is critical to understand how the meaning of family history and perceptions of CRC severity, susceptibility, and preventability relate to family interactions.

Statement of Purpose

The purpose of this study is to understand the meaning of family history of colorectal cancer (CRC) for adult relatives, aged 18–49 years, of first-degree Black family members diagnosed with CRC at any stage of the cancer care continuum. The investigation of the meaning of phenomena is possible based on the hermeneutic philosophical assumption that human experiences are already meaningful, and are self-interpreting based on an individual’s unique socialization into a shared cultural and historical context as within a family. Therefore, the meaning of family history of CRC functions as an interpretation of human existence in the world.

Statement of the Research Question and Specific Aims

The present study’s research question is: What is the meaning of the family history of colorectal cancer for adult relatives, aged 18-49 years, of first-degree Black family members diagnosed with CRC? The specific aims of this study are:

- To generate an interpretation of the meaning of family history of colorectal cancer for adult relatives, aged 18-49 years, of first-degree Black family members diagnosed with colorectal cancer.
- To understand how relatives’ experience of family history of CRC influences their future disposition about CRC, cues to action, patterns of responses, and ideas about personal health behaviors.
**Research Approach**

The research question calls for an ontological investigation of the meaning of being. Therefore, a qualitative phenomenological method in the tradition of Heidegger’s philosophical hermeneutics is best suited for conducting this study. Hermeneutic phenomenology enables a deeper understanding of the previously-hidden concept of CRC family history. The investigation of a phenomenon such as family history is based on an individual’s experience of being-in-the-world in terms of sharing the illness journey across the cancer care continuum with relatives diagnosed with CRC. An existential analysis of the experiences, and meanings of those experiences, of young adult Blacks with a first-degree relative (mother, father, brother, sister, daughter, or son) diagnosed with CRC may provide a better understanding of family health history matters, concerns, and cues to preventive health actions and risk-management behaviors. The phenomenon of family history of colorectal cancer is the central concern of this phenomenological study, which “*shows itself in itself*” (Heidegger, 1962, p. 51). This phenomenon comprises what relatives reveal about experiencing and sharing the illness experience of a close relative diagnosed with CRC across the cancer care continuum.

**Rationale for Study**

Colorectal cancer is one of the most highly preventable cancers because of the advances in research and innovations to develop screening tests that are effective in the early detection and removal of precancerous polyps (Gupta Shah, & Balasubramanian, 2012; & Stock, Knudsen, Lansdorp-Vogelaar, Haug, & Breener, 2011). Colonoscopy screening has been the primary screening test to detect CRC in average and high-risk individuals (Skinner, et al. 2017). The effective use of colonoscopy screening has
prevented more than 7,000 colorectal cancer-related deaths among adults aged 50 years and over in the United States (Stock et al. 2011). Underutilization of CRC screening accounts for the greatest disparities in incidence, mortality, and survival rates. Differences in CRC screening account for a 42% disparity in CRC incidence and 19% disparity in mortality; 36% disparity of CRC mortality can be attributed to stage-specific differences relative to CRC survival (Lansdorp-Vogelaar et al., 2012). Screening and survival disparities explain more than 50% of the disparity in CRC mortality between African American/Blacks and Whites.

The rationale for this study emanates from a desire to promote the primary prevention of colorectal cancer, which is one of the most preventable of all types of cancers. The translation of advances in CRC prevention from science to practice has not fully benefited all patients. While some population groups have enjoyed a steady decline in CRC incidence and mortality rates, this has not occurred among the Black population, for reasons that are not yet fully understood. In order to understand this phenomenon, it is important to address the context of cancer in Black families who have experienced CRC. Little extant research has addressed significant aspects of CRC and screening for early detection and prevention among Black families. Until we understand the perception of risk of CRC in relation to race, and in the context of the closest social construct—the family—the disparity issue of CRC screening among Blacks will persist.

**Significance of Study to Nursing**

Nurses can contribute to ending African American/Black CRC disparity through research, education, and practice. According to the American Nurses Association (ANA), the Nursing’s Social Policy Statement (2010, p. 10), the duties of nurses are clear and
concise to provide “protection, promotion, and optimization of health and abilities, prevention of illness and injury, alleviation of suffering through the diagnosis and treatment of human response, and advocacy in the care of individuals, families, communities, and populations”. Additionally, the ANA (2010) defines nurses’ responsibility to research the domain of human responses to illness and develop the new nursing knowledge necessary to deliver patient and family-centered quality of care. Furthermore, nursing actions and interventions aim to alleviate suffering, including the persistent and disproportional burden of CRC among the Black population; nurses are responsible for advocating for individuals, families, communities, and populations, especially those which are vulnerable. In clinical practice, nurses are responsible for providing individualized care reflective of patients’ particular values, beliefs, and preferences, and for basing their practice on evidence and research findings (American Nurses Association [ANA], 2010). The results of this study will improve understanding within the nursing field of the informational needs of their patients with family risk of CRC. By understanding the phenomenon of CRC family history from the personal narratives of Black high-risk relatives, nurses will have the ability to respond to personal preferences, values, needs, and beliefs in a culturally congruent manner.

Advance practice registered nurses (APRN) are well-situated in the American healthcare system, particularly in primary care, to make a significant contribution to improving the quality of care of Blacks. With more than 3 million practitioners, the nursing profession is the largest segment of the healthcare workforce in America. Nurses have direct involvement in family risk assessment, identification of CRC risk factors, and in recommending and promoting the use of clinical preventive services (Berry, 2009). For
example, oncology nurses have a unique opportunity to facilitate CRC screening because they interact with CRC patients, family members, and friends across the cancer care continuum. Nurses working in primary and acute care settings, across a range of practice settings, can also facilitate CRC screening awareness. Nurses meet CRC patients, family members, and friends in settings including primary care, public health, gynecology, gerontology, intensive care, medical-surgical, home care, hospice, and palliative care.

**Delimitation of Study**

Perceptions of risk, at times, are influenced by a multitude of internal and external factors. These factors might include individual, family, community, and healthcare system domains. The focus of this study is to explore experiential risk perceptions of CRC as situated within a family context. In order to answer the research question, the specific aim of this study is to obtain thick, rich description of the everyday, lived experiences of relatives of individuals with CRC. First-degree relatives include mothers, fathers, sisters, brothers, sons, and daughters, who are considered co-survivors of CRC. While there is a recognition of the influence of friends, community, and media on perceptions of risk, the concern of this study is exploring the power of close family relations, in particular, a non-affected individual with a first-degree relationship to a CRC patient, on the perceptions of CRC risk among Blacks aged 18-49.

**Definitions of Key Terminology**

In qualitative research, it is essential to define the central ideas or concepts used in the study. Definitions of the terminology used in this study are as follows:

*Black or African American:* A person who has origins in any of the various Black racial groups of African descent (US Census Bureau, 2013). Hereafter the term Black in
this dissertation has the same meaning as African American, African-American/Black, and Non-Hispanic Black.

Cancer Care Continuum: A framework used to describe the delivery of health care over a certain time-period. For example, for a patient with CRC, the period covers all phases of the illness from diagnosis to end-of-life (National Cancer Institute [NCI], 2016).

Colonoscopy: A CRC screening test used to examine the inside of the colon of patients using a colonoscopy inserted through the rectum (ACS, 2016). Colonoscopy is used to detect CRC and prevent the disease via the removal of precancerous polyps that would be malignant in the long-term (ACS, 2016).

Colorectal Cancer (CRC): A type of cancer that develops in the rectum or colon, usually affecting persons at the age of 50 years (NCI, 2016).

Early-Age Colorectal Cancer: The development of CRC before the age of 50 years (Stigliano et al., 2014).

Familial Cancer - Cancer that occurs in families more often than is expected. These cancers usually occur at an early age and may indicate the presence of a gene mutation that increases the risk of cancer, or may be a sign of shared environmental and lifestyle factors (NCI, 2014).

Family History of Colorectal Cancer: Having at least one first-degree relative with CRC (Zlot, Silvery, Newell, Coats & Leman, 2012).

First-Degree Relative: A parent, brother, sister, or child of an individual. In the case of colorectal cancer, it is the relative diagnosed with cancer of the individuals listed (NCI, 2016).
Hermeneutic: Derived from the Greek word ἑρμηνεύω (hermeneuō, “translated, interpret), the technical term ‘hermeneia’ means interpretation or explanation (Strong, 1890). In this dissertation, hermeneutics concerns the interpretation of the text, as well as the methodology of interpretation in phenomenological research (Laverty, 2003).

Hermeneutic Circle (HC): Describes the present and future-oriented understanding of a phenomenon in an all-inclusive circular process that portrays human beings as self-interpretive beings (Diekelmann & Ironside, 2006). The principles of HC are used to inform the interpretation of data.

Medical History: A record of information about a person’s health. This history often is obtained by healthcare providers during a medical interview. It may include information about allergies, illnesses, medications, immunizations, surgeries, results of medical procedures, health habits, diet, exercise, and tests. It also includes questions about the medical history of close family members (parents, grandparents, children, and siblings). A medical history is comprised of the relatives’ past and current illnesses and is used to assess the existence of any heredity patterns of certain diseases (NCI, 2014).

Perceived Risk: The result of an individual’s perceived susceptibility to a threat (Ferrer & Klein, 2015).

Chapter Summary

This chapter presents the rationale for a hermeneutic phenomenological study of first-degree relatives’ experiential perceptions of the family history of colorectal cancer. It argues that it is exigent to understand the meaning of family history of CRC, and to discover what does and does not matter to individuals experiencing the phenomenon. It introduces the research problem, misperception of the risk associated with a family
history of CRC, starting with the background and context of the CRC disparity paradigm, then narrowing its scope to an individual/family level of analysis. Furthermore, the chapter explains the rationale and significance of understanding how experiencing cancer in the family context contributes to the utilization or underutilization of screenings to detect and prevent early-age onset of CRC among relatives of Black patients. This chapter also provides an overview of the study’s methodological approach and assumptions, congruent with its research question and specific aims. The next chapter presents a comprehensive review of the literature to understand the current state of the science related to the research question and methodology.
Chapter Two: Literature Review

The purpose of this study is to understand the meaning of a family history of colorectal cancer (CRC) for adult relatives, aged 18-49 years, of first-degree Black family members diagnosed with CRC across any stage of the cancer care continuum. The purpose of the literature review is to examine the state of the science relevant to the present study’s purpose, question, and specific aims. Smythe and Spence (2012) posit that the purpose of the literature review in hermeneutic research is to contextualize the phenomenon and provoke interest in understanding the meaning of a family history of CRC.

Colorectal cancer (CRC) affects more Black Americans than American citizens of other races. Blacks have a high risk for CRC and low levels of adherence to screening procedures (Williams et al., 2016a). Family histories of CRC and colon polyps are primary risk factors for developing CRC among individuals over the age of 50 (Kelley, 2011). This section of the dissertation provides a review of studies related to CRC risk among young adult relatives of Blacks affected by the disease. The topics addressed in this chapter are: search strategy, the background of CRC disparity in Blacks, prevention of CRC, screening guidelines for a family history of adenomas, CRC, objective risk of CRC in Blacks, barriers to CRC screening in Blacks, methodological issues in researching risk perceptions with Blacks, the potential for family-based intervention to increase screening, and a summary of the extant literature.

Search Strategy

The search strategy for this literature review initially started with inclusion criteria entailing: research located in the U.S., articles published in the English language,
peer-reviewed, scholarly journal articles, articles published between 2010 and 2017, and articles available in full text. The search terms used were: colorectal cancer, colorectal cancer risk, African Americans, Black Americans, perception of risk, family history, colorectal cancer risk, meaning of colorectal cancer risk, colorectal cancer screening, perceptions of colorectal cancer screening, barriers to CRC screening, facilitators to CRC screening, interventions, colon neoplasms, and polyps. The databases searched were Google Scholar, Cumulative Index to Nursing and Allied Health Literature (CINAHL), Ovid Embase, Ovid PsycInfo, PubMed/Medline, and Scopus. The search terms, in a variety of combinations, were used to collect articles meeting the criteria. The entire collection of articles was organized in terms of relevance to the study question and the reference lists of all articles were searched for further supporting articles.

The articles that address perceived risk of developing CRC due to a family history are included in this review. After an extensive search of the literature, the search strategy was modified to include articles published at any time in the US. The necessity of modifying the search strategy is probably due to low historical participation in health research among Blacks (Tanner, Kim, Friedman, Foster, & Bergeron, 2014).

**Blacks and Colorectal Cancer Disparity**

The following is a brief overview of the historical context of the Black American experience of unequal care and treatment in the American healthcare system. The research question in this study is rooted in the historical perspective of social epidemiology and aimed at understanding fundamental causes of colorectal cancer disparity. Entrenched social injustices in healthcare have been present in the country since the beginning of slavery of Black citizens. However, the public acknowledgment of
social injustices in healthcare by the United States Congress initiated a disparity of care paradigm that has reverberated throughout the healthcare system with mixed results over the last 14-plus years. At the request of Congress, the Institute of Medicine (IOM) reported on the condition of healthcare for racial and ethnic populations in a report titled: *Unequal Treatment: Confronting Racial and Ethnic Disparities in Healthcare* (Nelson, Stith, & Smedley, 2002). The report represents a significant landmark in American history because, for the first time, social inequities in healthcare were acknowledged. The key findings of the report documented the existing racial and ethnic disparities across a broad range of conditions and treatments in patient care. The report identified the complexity of racial and ethnic disparities that have occurred in the broader historical and contemporary social context.

Health disparity is often defined as the differences or gaps in care experienced by one population, as compared with another. The conceptualization of healthcare disparity is exhibited on three causal levels, including the patient, provider, and system. For example, healthcare delivery disparities may be due to differences in access to care, provider biases, poor provider-patient communication, poor health literacy, and other social determinants of health (Nelson et al., 2002).

After acknowledging the existence of racial and ethnic disparities in healthcare, Congress charged the United States Department of Health and Human Services (USDHHS) with fixing the problem of sub-optimum quality of care for racial and ethnic minorities. The Agency for Healthcare Research and Quality (AHRQ) within the USDHHS is charged with the mission of shaping healthcare policies, producing evidence, and promoting the dissemination of evidence-based healthcare for all citizens (AHRQ,
While the AHRQ works to improve the overall health of Americans, they intentionally target vulnerable populations that persistently lag behind White Americans in terms of healthcare quality. Vulnerable populations include the poor, underinsured, and racial and ethnic minorities which are often poor and uninsured or underinsured. Each year, the AHRQ prepares a report for Congress on their progress to ensure equitable care for all.

Year after year, the reports have shown slow progress in America’s efforts to reduce and eliminate healthcare disparities since 2002. For example, the 2013 minority health report showed that Blacks continue to experience a disproportionate burden of disease and disability due to healthcare disparities across a broad range of conditions, including the two leading causes of death in America: heart disease and cancer (ACS, 2017). In 2010, Black deaths from heart disease (24.1%) and cancer (23.0%) accounted for 47% of the top five leading causes of death (Heron, 2013). In the most recent National Healthcare Quality and Disparities Reports of 2016, the key findings again show only small decreases in disparities between 2002 and 2015 for the poor and underinsured. Among Blacks and Hispanics, small gaps were observed in only 20% of the measures, while 40% of measures show larger gaps among all poor and low-income racial and ethnic minorities (AHRQ, 2017). The conclusion is evident that major heart disease and cancer disparities remain persistent, 14 years after the landmark IOM report (Nelson et al., 2002).

**Blacks and a Family History of Colorectal Cancer**

Blacks have a high risk for cancer, especially CRC. The American Cancer Society (2017) has reported that for all cancer cases combined, Blacks men have a higher
mortality rate than White men. Having a family history of CRC elevates a person’s risk of the disease. Thus, informed decision-making to undertake cancer screening tests is likely to reduce or prevent the disease (Mitchell, Hawkins, & Watkins, 2013). Kelley (2011) pointed out that persons with a family history of CRC are prone to the disease and should be screened early. Currently, some medical societies in the US have recommended CRC screening for Blacks at the age of 45 years. According to Williams et al. (2016b), a 2016 report estimated 7,030 deaths and 17,240 new cases linked to CRC. CRC is ranked the third leading cause of cancer-related death among male and female Blacks.

Family members of CRC patients are an at-risk group and require an increased focus on ensuring that CRC screening is initiated earlier as compared to people without any family history of CRC. Approximately 25% of patients diagnosed with CRC are reported to have a family history, with at least one family member having been affected by the disease (Jackson, Oman, Patel & Vega, 2016). For instance, having one or two FDRs with CRC is linked with a 1.72 and 2.75-fold increased risk for CRC development. Thus, patients with a positive family history of CRC should be screened at a young age, then placed under frequent surveillance to determine the existence of potential cancers.

In general, patients who have a family history of CRC, as compared to those without CRC history, are more likely to undergo CRC screening (Jackson et al., 2016). Nonetheless, the trend is not uniform among all ethnicities and races. For example, Blacks with a CRC family history have the highest risk and incidence rates because of their low likelihood of participating in screening. Additionally, Blacks are less likely than Whites and Hispanics to be knowledgeable about their paternal history of cancer. Screened Black family members, compared to other racial and ethnic groups, are less
likely to inform their relatives and family members of their colonoscopy results. Therefore, lack of knowledge and information, transmittal of medical information, and understanding of facts related to CRC can potentially place a patient at increased risk for development of the disease (Jackson et al., 2016).

Cancer health disparities include differences in the prevalence, incidence, and mortality of cancer and linked adverse health conditions experienced by particular population groups. Disparities in CRC remain a major concern among Blacks, compared to other racial and ethnic groups in the US who have higher CRC incidence rates, which has led different health organizations to recommend screening (LoConte et al., 2011). As reported, Blacks have the shortest survival time and highest death rate from CRC, compared to other ethnic and racial groups in the U.S. Although cancer death rates among the Blacks population have decreased since the 1990s as a result of early screening, the racial disparities for CRC in men and breast cancer in women remain considerably high (LoConte et al., 2011). The CRC disparities may be associated with inequalities in access to healthcare, especially during screening and treatment. Williams et al. (2016b) pointed out that 49,190 deaths and 134,490 new cases associated with CRC occurred in 2016. African-American women and men have continued to have the highest rate of CRC mortality.

Historically, Blacks have been susceptible to chronic disease and have higher mortality and morbidity rates than all other ethnic and racial groups in the United States. According to the ACS (2016) the African-American population, compared to the White population, has 20% higher incidence and 45% higher mortality rates for CRC. Additionally, the Black population has less access to healthcare and CRC screening than
the White population. When compared to Whites, Blacks’ perception of CRC screening is low because they experience more barriers. Most CRC patients over the age of 50 have failed to undergo screening, and disparities have continued to persist, with African-American men having lower levels of CRC screening than Whites (Hall, Ruth, & Giri, 2012). This high incidence, accompanied by younger age in developing CRC among Blacks, means that increased education and awareness are necessary to change the perceptions and attitudes of Blacks regarding CRC screening, because a perception of increased risk for CRC is linked with higher CRC screening rates (Brittain, Taylor, Loveland-Cherry, Northouse, & Caldwell, 2012).

**CRC Incidence and Mortality**

The incidence of CRC between 2006 and 2010 was 25% higher among the Black population, while mortality rates were 50% higher among Blacks in comparison to Whites (Williams et al., 2016a). Furthermore, Blacks men in the US had an incidence rate of CRC between 20-25% higher than that of White men. For the same period, the incidence rate for Black women was 30% higher than that of White women (LoConte et al., 2011). Data derived from the Surveillance, Epidemiology, and End Results Program (SEER) showed that between 1975 and 2010, the incidence rates in the US for White men and women significantly declined by 40-45% (Williams et al., 2016a). However, the incidence of African-American men with CRC in the US increased during the same period. Thus, disparities in mortality and incidence of CRC have continued to persist among Blacks in spite of improved CRC treatment and widespread screening (Jackson & Vega, 2016). The findings on mortality rates are presented in Figure 1.
Colorectal Cancer Risk and a Family History

The primary risk factor for CRC is a family history of the disease. Having family members who have been diagnosed with colon cancer puts a person at higher risk of being vulnerable to CRC. Although most colon cancers occur individually, 5-10% are directly linked to heredity (Williams et al., 2016a). Currently, the use of patient family history knowledge is a primary factor in the guidelines for CRC screening, and screening initiation is recommended at the age of 40. Initiating screening at earlier ages for those with a family history is required to ensure early treatment of CRC. In comparison, Carethers (2016) estimates the link to be as high as 30% of all patients with CRC have a family history of this type of cancer, which puts such persons at higher risk for developing the disease. Healthcare providers use a family history information to inform patients for to the most suitable screening approach. Compared with Whites with
a family history of CRC, Blacks have the lowest probability of participating in screening (Carethers, 2016). Thus, Black patients are less likely to know their family history of cancer, while family members who were screened for CRC are less likely to inform their relatives of colon polyp findings.

The age at diagnosis of family members affected with CRC is important to the estimation of risk for relatives. Individuals with relatives diagnosed before the age of 50 are at a higher risk than those with relatives diagnosed later in life (Taylor, Burt, Williams, Haug, & Cannon-Albert, 2010). Williams et al. (2016a) established that there had been a shift in the age-related incidence of CRC, whereby most patients under the age of 50 are at risk of the disease. Research studies have consistently demonstrated that individuals with a family history of CRC have a likelihood of developing CRC in a range between 2.3 and 4.3 times greater than the average individual without a family history. These results depend on number of relatives affected and the age of CRC onset for those relatives (Touhy, et al., 2014; & Taylor et al., 2010).

Carethers (2015) established that multiple studies including SEER Program data had shown an earlier age onset for CRC among Blacks. For instance, CRC could start as early as five years before the mean age of 50 years for CRC. The early onset of CRC among Blacks has reduced the period required for screening and intervention. Additionally, younger CRC patients could possess a genetic cancer syndrome that would change the patient’s needs from screening to close surveillance. Given that most CRC starts with adenoma precursors, early onset means that adenomas could occur earlier in Blacks than Whites. For Whites, 5.5% of those with CRC occur before the age of 50
years while for Blacks, 10.6% of CRC cases occur before the age of 50 years (Carethers, 2015).

Age is not necessarily related to family history for CRC occurrence. Myers et al. (2013) undertook a retrospective analysis with the aim of investigating epidemiological characteristics of CRC among patients under 50 years of age. The variables considered in the research were age, tumor location, family history, presenting symptoms, post-operative complications, and stage of the disease. The results indicated that 180 of the patients under the age of 50 had CRC, while young patients accounted for 11.2% of colon cancer cases (Myers et al., 2013). The findings further indicated that advanced CRC (stage 3 or 4) affected 53% of patients. Eight percent of the patients in the retrospective data had a first-degree relative with CRC, while 12% had a second-degree relative with CRC history. Lastly, the study findings indicated that three patients (aged 49, 42, and 42 years) developed metachronous primary colon cancers within three years of their first resection (Myers et al., 2013). Myers et al. (2013) concluded that CRC was also prevalent among young patients who have no family history. Therefore, even young patients with colon cancer symptoms qualify for timely evaluation and screening to avoid late-stage CRC.

The degree of family relationship and the number of affected relatives can compound the effect of risk. For example, relatives of a first-degree CRC case have a greater risk of CRC than those with second-degree (SD) and third-degree (TDR) relatives. In a Utah population-based study of 126,936 individuals undergoing a colonoscopy, researchers found that relatives of patients with adenomas and advanced adenomas had an increased risk of colorectal cancer. The study compared patients with
adenomas with relatives of unaffected controls, and found that an elevated risk of colorectal neoplasia could be detected to the distance of third-degree relatives (Touhy et al., 2014). These findings are consistent with those of other studies showing that increased numbers of first-degree relatives (FDRs) with CRC influences risk more than second-degree relatives (SDRs) and third-degree relatives (TDRs). However, when combined with multiple first, second, and third-degree relatives there is a significant increase in the risk for CRC (Taylor et al., 2010).

Risk estimation factors of CRC are often found in a family history, particularly with regard to close relatives. Taylor et al. (2010) conducted a study on family history-specific risks associated with CRC and established that family history is often directly associated with the risk of CRC. Thus, a family history linked to an increased risk factor makes FDR a clinically significant predictor that can be used to determine who will develop CRC. Taylor et al. (2011) conducted a study using retrospective cohort to study the effectiveness of a family history in predicting who is prone to CRC during a 20-year period. The outcome of the research was that familial relative risk predictors were more significant (C=0.67) compared to Harrell's (C = 0.53) prediction. Thus, although family history is not a strong predictor of susceptibility of CRC within a 20-year period, FDR is useful in helping patients with a family history to focus on screening. However, alongside age, family history could be used to determine who exactly is at risk of CRC.

Experiencing a close family member undergoing colon cancer treatment increases the risk of developing CRC. At-risk family members must therefore make significant decisions to undergo subsequent screening and testing, prophylactic surgery, and disclose test results to family members (Tilburt et al., 2011). Having a family history of CRC is a
Major factor one must consider in terms of initiating early screening, testing, and treatment. Several studies have suggested that persons with a family history of CRC and who are knowledgeable about the disease are more likely to undergo screening compared to the average-risk population (Drake, Shelton, Gilligan, & Allen, 2010; Stock et al., 2011; Williams et al., 2016a). However, accessing family history for CRC is associated with some barriers, including fear, anxiety, and lack of trust in healthcare providers (Jones, Devers, Kuzel, & Woolf, 2010). Further, Black family members with a history of CRC are less likely to share such information with relatives. Patients with a family history of CRC are three to four times more likely to develop CRC compared to those without it (Zlot, et al., 2012). Therefore, it is a misconception that people without a family history should not undergo CRC screening and treatment.

**A Family History of Adenomatous Polyps**

A polyp is a type of growth found in the colon that might later turn into cancer. People with a family history of adenomatous polyps are encouraged to start screening for CRC at age 40 or earlier. Although family history intensifies the risks for colon cancer development, the majority of CRC cases appear among people without a prior family history. However, people at risk of CRC must start screening at age 50. Taylor et al. (2010) established that knowing the family history of adenomatous polyps is necessary because studies have shown that persons with a first-degree family member with polyps have a higher risk of developing the disease. Further, those with a family history of polyps are encouraged to begin the screening process earlier, at the age of 40. Alternatively, they may start screening ten years earlier than the age of the already affected family member. Similarly, Yim, Butterly, Goodrich, Weiss, and Onega (2012)
established that patients with a personal history of polyps, compared to those with no prior polypectomy, were more likely to accept that colonoscopy minimized their chances of dying early. Family history and personal history of polyps and CRC are significant predictors of patients’ positive attitudes regarding colonoscopy.

There is a close link between adenomatous polyps and family history. Lee, Liles, Bent, Levin and Corley (2014) assessed the relationship between family history and risk of colorectal adenoma among people aged 40-49. The subjects underwent colonoscopy, and their family histories were collected via self-administered questionnaires. Using multivariate analysis, Lee et al. (2014) found that persons with a family history were at a higher risk of adenoma development. Thus, a family history of CRC emerged as a major risk factor for developing multiple and advanced adenomas. Lee et al.’s (2014) findings thus support other studies indicating that a family history of CRC is one of the risk factors for multiple colorectal adenomas among persons in their 40s. Further, their findings support Yim et al.’s (2012) recommendations for early screening for colorectal neoplasms in persons with a family history of CRC.

Familial adenomatous polyposis (FAP) is a genetically inherited condition; most people with this condition are more likely to develop colorectal cancer before they reach the age of 50. FAP results in the development of multiple polyps along the colon as early as adolescence. Carethers (2015) pointed out that knowledge of patient history related to polyps is a primary determinant in the screening of CRC. Given that persons with FAP are more likely to develop polyps, it is recommended that they begin screening at the earlier age of 40. In cases where a family history shows possible familial cancer syndrome, it is recommended that patients undergo screening before the age of 50.
Polyps found in the colon raise pertinent questions for family members and patients in terms of predicting the development of CRC. Polyps are common in more than 30% of adult patients, two-thirds of whom are affected by adenomas polyps. Adenomas and a family history provide important information to assess increased risk of CRC in unaffected individuals. In support of these findings, Gupta, et al. (2012) compared Blacks age 40 – 49-year old Blacks first-degree relatives to a control group of the same age for the prevalence of adenomas discovered while undergoing screening colonoscopy. The finding reveals that Blacks in this study had a greater prevalence of adenomas. This is an area that needs further research to understand the role that the presence of polyps plays in prevention of CRC and when to initiate early screening among Blacks.

**Screening Guidelines for a Family History of Colorectal Cancer**

Guidelines of the American Cancer Society (ACS), the US Multi-Society Task Force on Colorectal Cancer, and the American College of Radiology (ACR) have recommended that first-degree relatives of individuals diagnosed with an adenoma before age 60 be screened every five years beginning 10 years before the age at diagnosis of the youngest affected relative or at age 40, whichever is earlier. (Levin et al., 2008). On the other hand, the American Society for Gastrointestinal Endoscopy (ASGE) guidelines recommend early screening for persons at average risk of CRC, because the disease often starts before 50 years of age among the Black population. In a recent retrospective study using the medical records of adults (n = 362) with a family history of CRC, the American Gastroenterological Association (AGA) found that 58.9% of patients with a family history suffer from late initiation of screening (Lin, Gluck, Nguyen, Koch & Kozarek, 2013).
Table 1

Guidelines for CRC Screening for Increased Risk Based on Family History

<table>
<thead>
<tr>
<th>Family History Criteria</th>
<th>Initial Screening</th>
<th>Surveillance Screening</th>
</tr>
</thead>
<tbody>
<tr>
<td>One first-degree relative with CRC aged &lt; 50 years or 2 first-degree relatives with CRC at any age</td>
<td>Colonoscopy beginning at age 40 years or 10 years before the affected relative’s diagnosis</td>
<td>Repeat colonoscopy every 3-5 years depending on individual family history</td>
</tr>
<tr>
<td>First-degree relative with CRC aged 50 ≥ years</td>
<td>Colonoscopy beginning at age 50 years or 10 years before the affected relative’s diagnosis</td>
<td>Repeat colonoscopy every five years</td>
</tr>
<tr>
<td>1 second-degree relative with CRC aged &lt; 50 years</td>
<td>Colonoscopy beginning at age 50 years</td>
<td>Repeat per colonoscopy findings</td>
</tr>
<tr>
<td>First-degree relative with advanced adenoma (s)</td>
<td>Colonoscopy beginning at age 50 years or at the age of onset of affected relative whichever is first</td>
<td>Repeat per colonoscopy findings</td>
</tr>
</tbody>
</table>

Table 1 provides the screening guidelines for CRC as developed by the ACR, ACS, and the US Multi-Society Task Force on CRC (Levin et al., 2008). The consensus guidelines for CRC offer a greater possibility for prevention of the disease via polypectomy. The updated guidelines also address the initial screening and surveillance screening required to detect CRC, especially for first-degree relatives with CRC. Levin et al. (2008) pointed out that clinicians must make patients aware of the available screening options. At a minimum, clinicians must be prepared to provide patients with the choice of screening test because of its effectiveness in both early CRC detection and prevention via the detection and removal of polyps. A screening test for CRC is recommended at 40 years of age for patients with a family history, because it could help in early cancer detection. The consensus guidelines provided by the three organizations suggest that colon cancer prevention must be the primary objective of screening.
In 2008, the American College of Gastroenterology (ACG) modified its CRC screening guidelines, emphasizing the significance of acquiring detailed family history of colorectal polyps including type, size, and number of adenomas present for the relative of a patient (Rex, Johnson, Anderson, Schoenfeld, Burke, & Inadomi, 2009). The information gathered in the family history could thus be used by clinicians to provide necessary guidelines for screening recommendations for CRC among patients. Elias, Romagnuolo, and Hoffman (2012) conducted a retrospective, single-center cohort pilot study with the aim of assessing the percentage of patients being screened for a family history of polyps to determine their knowledge levels. The findings of the study indicated that patients’ knowledge relating to family histories and details of polyp data was incomplete and a great deal of the information was unknown (Elias et al., 2012). Thus, it might not be feasible to integrate such information into CRC screening guidelines.

**Methods of CRC Screening**

The American Cancer Society (ACS), in collaboration with a consortium of five medical and surgical gastrointestinal societies introduced screening guidelines for CRC in the late 1990s (ACS, 2017). FDA-approved CRC screening tests available for the average-risk population, are: (a) tests used to perform a structural examination of the colon, and (b) stool-based studies. Structural inspection of the colon is an effective method for CRC prevention via the identification of pre-cancerous adenomatous polyps and CRC detection (He & Efron, 2011). Within a period, adenomas in patients over the age of 50 could become malignant and transform into adenocarcinomas or CRC. Structural screening tests can prevent CRC incidence when pre-cancerous adenomas are identified, and early CRC can be detected via identification of malignant
adenocarcinomas. Structural screening tests include two endoscopic studies and two radiographic studies: flexible sigmoidoscopy, computed tomography colonography, double contrast barium enema, and colonoscopy. The double-contrast barium enema and computed tomography colonography require a follow-up diagnostic colonoscopy to acquire a positive result, while colonoscopy and flexible sigmoidoscopy are more effective as they function as both screening and diagnostic tools.

Stool-based tests are more effective when used to detect malignant adenocarcinomas. The stool-based tests include Fecal Occult Blood Testing (FOBT), the newly FDA-approved stool DNA test (sDNA), and fecal immunochemistry testing (FIT). Stool-based tests require the patient to place a small portion of fecal material onto a reactive surface that can detect blood (FIT or FOBT). When the outcome of the test is positive, a colonoscopy is needed to establish the source of cancer cells. The FOBT, sDNA, and FIT are up to 98% effective regarding sensitivity for CRC; they are most effective at 20-50% sensitivity for adenomas and advanced adenomas (Lee, et al., 2014). The primary purpose of stool-based screening methods is to ensure early detection rather than primary prevention of CRC among patients.

**Screening Strategies to Prevent CRC**

Colonoscopy screening has been the primary screening test to detect CRC in both average and high-risk individuals. The effective use of colonoscopy screening has prevented more than 7,000 colorectal cancer-related deaths among adults aged 50 years and above in the United States (Stock et al. 2011). The differences in Black/White screening uptake account for 42% of the disparity in CRC incidence and 19% of the disparity in CRC mortality screening; it is possible that 36% of CRC mortality can be
attributed to differences in CRC survival (Lansdorp-Vogelaar et al., 2012). Figure 2 compares the proportion of adults that received a CRC screening during 2008-2010 based on the recent guidelines. All racial and ethnic minorities fall behind in screening compared to Whites in the U.S.

**Figure 2**

*Healthy People 2020 objective C-16*

![Bar chart showing the proportion of adults receiving CRC screening based on recent guidelines (2008 & 2010) for different racial and ethnic groups.]

*Note:* Healthy People 2020 objective C-16: increase the proportion of adults receiving CRC screening based on most recent guidelines (2008-2010). (USDHSS, Healthy People 2020, 2010)

**Adherence to Screening Recommendations among the Black Population**

Patient decisions depend on the manner in which CRC screening is presented. In a cross-sectional study of more than 13,000 patients, Jones, Vernon, and Woolf (2010) established that when two or more screening alternatives were presented adherence to
CRC screening decreases among both Blacks patients and Whites. In a randomized trial conducted to investigate adherence to CRC screening recommendations, Inadomi et al. (2012) found that the highest CRC screening rates among Blacks were realized when patients were advised to undergo FOBT (56%). Adherence also increases when CRC patients have a choice between colonoscopy and FOBT (54%). Similarly, a study by Jones et al. (2010), found that providing only the colonoscopy option to patients improved adherence rates. Poor adherence to guidelines provided is a result of inadequate provider knowledge, patient refusal of recommendations, ineffective communication between healthcare providers and patients, and failure on the part of healthcare providers to recommend suitable screening methods to Black patients.

While several factors can explain the health disparity between the Black and White population with regard to CRC, low participation in screening is the primary reason. Palmer, Chhabra, and McKinney (2011) conducted a study with the aim of identifying factors that influenced adherence to CRC screening among Blacks. Although 77% of participants were adherent to CRC screening guidelines, nearly 50% of those not adherent reported not having received a physician suggestion to be screened (Palmer et al., 2011). Additionally, CRC screening adherence was found to be related to health insurance; access to health insurance coverage and care appear to be an essential factor for CRC screening among Blacks. Disparity reduction measures should endeavor to ensure that Blacks with no adequate healthcare coverage are involved in CRC screening, and not excluded because of the costs of healthcare. However, participants with higher perceived CRC risk, especially those with a family history, were found to be more likely
to adhere to screening. Also, the participants who were caregivers reported less adherence to screening recommendations, because they were busy providing care to others.

Based on a 2010 report of the American Cancer Society, only 55% of patients aged 50-64 completed CRC screening, while 64% completed screening after reaching the age of 65 (Waghray, Jain, & Waghray, 2016). Waghray et al. (2016) assessed the percentage of Blacks who had finished a screening test for CRC before the age of 50. Of 480 patients aged 45 to 49 years, only 31 patients (17.4%) of Blacks eligible for screening received one screening for CRC. However, most of the patients (66.7%) received a colonoscopy. Further, Black females, as compared to Black males, had a higher likelihood of completing a screening test (17.8% compared to 16.7%; P < 0.01). Thus, screening and adherence to screening guidelines among Blacks remains low, which causes CRC disparities.

**Screening Disparities among High-Risk Relatives**

Extant research has suggested that individuals with a family history are more likely to undergo CRC screening than those with no family history (Martinez-Ochoa, 2012; Rees, Martin, & Macrae, 2008; Taylor et al., 2011; Townsend et al., 2013). However, there are racial and ethnic differences in the effect of a family history on CRC screening. Thus, the adoption of preventive health behaviors among Black patient with a family history of CRC is less likely to entail screening for CRC than among White patients with a family history (Griffith, McGuire, Royak-Schaler, Plowden, & Steinberger, 2008; Murff et al., 2008). Murff et al. (2007) examined whether disparities existed in the early initiation of CRC screenings at age 40 among FRDs (N= 5,564, aged 40-49 years) using self-report of sigmoidoscopy, colonoscopy, or fecal occult blood test.
The results revealed that Whites are more likely to have received a colonoscopy according to healthcare recommendations than Blacks, and the presence of an FDR with CRC has a stronger impact on CRC screening among Whites as compared to Blacks. Blacks with a family history have lower timely CRC screening rates compared to Whites, 38.8 to 65.5 respectively (Griffin et al., 2008 & Murff et al. 2008).

**Barriers to Colorectal Cancer Screening**

High participation rates play an integral role in ensuring the success of any form of cancer screening and testing. Researchers have identified numerous barriers to CRC screening (Williams et al., 2016b) Quantitative studies have found social determinants of health factors such as race and ethnicity, social class, language problems, level of acculturation, embarrassment, culture-specific beliefs, and lack of knowledge about CRC screening to be the primary barriers to screening (Mitchell, Watkins & Modlin, 2013 & Lasser, Ayanian, Fletcher, & Good, 2008). Other barriers to CRC screening include health disparities among African-American patients, fear of discovering cancer, feeling of violation, the shame of being viewed as weak and sick, mistrust, and fatalism. Additionally, patients may not be aware of where to acquire screening, which can hamper their ability to be screened for CRC. Lasser et al. (2008) found that lack of trust in physicians, the absence of symptoms, and fatalistic views about cancer were the primary barriers to CRC screening among Blacks. Conversely, physicians identified psychosocial stressors accompanied by comorbid medical illness as key barriers to screening for CRC. The issue of culture also emerged as a hindrance to CRC screening in high-risk relatives. James, Daley, and Greiner (2011) identified personal barriers and system-level barriers as hurdles to CRC screening. Personal barriers included dislike of preparation,
cost incurred, and discomfort with the tests. Fear of the tests and cancer were also reported to hinder screening for some people, while others feared cancer treatments: particularly those who believed that surgery for cancer caused CRC to spread to other parts of the body and accelerate a painful death. Further, lack of trust in the system created barriers. These system-level barriers between patients and the system/providers impeded care-seeking and CRC screening (James et al., 2011). For example, the Medicaid paperwork hinders access to screening and caused frustration. Other participants pointed out that waiting a long time for screening appointments has also created a barrier to screening.

Bass et al. (2011) conducted qualitative research to identify barriers to CRC screening among the Black population. The findings indicated that both men and women with no prior screening experience lacked knowledge about CRC, where to be screened, and screening modalities. The women interviewed pointed out that their perception of a sexual connotation prevented them from getting a colonoscopy. Lack of trust in the healthcare system and doctors were identified as barriers to CRC screening among men. Patients also reported that they feared going to the doctor for CRC testing and screening. There is a consensus that failure of physicians to provide recommendations for screening, cost, scheduling difficulties, lack of insurance coverage, fear, gaps in knowledge, embarrassment, and lack of symptoms and pain are factors that hinder patients from seeking CRC screening (Jones et al., 2010a). James et al. (2011) identified provider and system-level factors as the major barriers to CRC screening among Black patients. Therefore, both patient and system-level factors hinder colonoscopy screening among
Blacks, which contributes to the high levels of disparity in CRC incidence in the US (Bass et al., 2011; Phatak et al., 2013; Taggarshe et al., 2013).

Additional system-level barriers to CRC screening among Blacks include access to colonoscopy procedures, few specialist referrals, inadequate insurance coverage for the procedure, and absence of clinical guidelines for CRC (Benarroch-Gampel et al., 2012; James et al., 2011; Lukin et al., 2012; Palmer, Midgett & Dankwa, 2008). Healthcare access-related issues like lack of insurance and financial issues are barriers to CRC screening. The financial costs of colonoscopy are barriers to CRC screening; procedural costs, for instance, are prohibitive for uninsured Blacks, and even those with insurance that does not include provisions for covering the procedure (Palmer et al., 2008). The Affordable Care Act does not cover CRC screening, and the costs incurred during the procedure can be high, even for those who are insured (Benarroch-Gampel et al., 2012).

Infrequent interaction between patients and a primary care provider (PCP) could also be a barrier to CRC screening. Lukin et al. (2012) demonstrated that patients with close interactions with a PCP participated in CRC screening more regularly because they were provided with necessary information on the disease and possible treatment (Lukin et al., 2012). Media campaigns have been shown to be effective in increasing awareness of and promoting preventive health behaviors. For instance, media campaigns create awareness among patients with a CRC family history (Schroy, Glick, Robinson, Lydotes, Evans, & Emmons, 2008).

Provider-level barriers to CRC screening among patients with a family history include the absence of colonoscopy screening and the failure of PCPs to provide adequate patient counseling on screening. This can cause a profound lack of knowledge in
understanding available CRC screening. Lack of genetic counseling is also a barrier to screening among the Black population. Therefore, it is significant for Black patients with CRC risk factors to overcome provider-level barriers successfully (Bass et al., 2011; James et al., 2011; Palmer et al., 2008; Winterich et al., 2011). Moreover, Black physicians are more likely than non-Black PCPs to recommend 45 years as the CRC screening threshold (Williams et al., 2016b). Resident trainees have limited knowledge which affects their understanding on the importance of CRC screening for Black patients, which affects their recommendations for screening (Wilkins et al., 2012). Previous research has shown that doctor endorsement is a key factor in promoting screening participation (Blumenthal, Smith, Majett, & Alema-Mensah, 2010; Koskan et al., 2014; Williams et al., 2016a); therefore, provider recommendation must be considered (Bass et al., 2011; James et al., 2011; Winterich et al., 2011). Moreover, lack of physician recommendation could predict the absence of screening uptake by Blacks with a family history of CRC (James et al., 2011). Thus, there is a positive link between colonoscopy completion and physician recommendation, whereby those with a physician endorsement are more likely to undergo the procedure (Wilkins et al., 2012). Insufficient patient-provider communication in terms of when to undergo a colonoscopy contributes to higher levels of CRC disparity between Blacks and Whites (Coleman, Baltrus, Wallace, Blumenthal & Rust, 2013).

Medical mistrust among Black men is associated with delays in utilization of preventive health services (Hammond, Matthews, Mohottige, Agyemang, & Corbie-Smith, 2010; & Bynum, Davis, Green & Katz, 2012). Adams, et al, (2017) in a recent systematic review found that higher mistrust scores are linked to lower rates of CRC
screening among Black Americans. The majority of the quantitative studies in this review examined mistrust at the physician level with few examining the system-level. The qualitative studies highlighted themes of fear and intrusiveness of screening methods as unique to Black males. Bynum, et al., (2012) earlier identified fear, embarrassment trust as barriers to CRC screening among Blacks. These findings support the need to address issues of race, trust in physicians and health systems among Blacks with a family history of the disease.

Individual-level factors are those that relate to the patients and family attitudes, beliefs, knowledge, literacy, and emotions about CRC and screening. Even with education and awareness, beliefs involving cancer fatalism, racism and discrimination, and trust in the healthcare system remain. Hester et al. (2015) established that relatives with a family history of CRC reported more fatalistic cancer beliefs as the reason why they screen. However, such beliefs could conversely reduce adherence to CRC screening among at-risk relatives. According to Griffith, Passmore, Smith, and Wenzel (2012), Blacks report the following barriers to CRC screening: mistrust of the medical system, fear of serious illness, lack of information about CRC risk factors and benefits of screening, lack of access to care, absence of symptoms, community reticence about cancer, and disease myths. Griffith et al. also report that the facilitators for CRC screening among Blacks include receiving a healthcare provider recommendation, belief in one’s risk of developing CRC, and understanding that age is a risk factor.

The Black population’s perception of CRC screening is more negative than that of the White population because they experience more barriers. Most patients over the age of 50 years have failed to undergo screening, and disparities have continued to persist,
with African-American men having lower levels of CRC screening than Whites (Hall, et al., 2012). Changes to perceptions and attitudes are necessary, as having a perception of increased risk for CRC is linked with higher CRC screening rates (Brittain, et al., 2012).

Attitudes toward CRC screening vary from one individual to another and are influenced by family history. Shaw, Vivianm Orzech, Torres and Armin (2012) found that absence of prior cancer screening appears to be linked with more unfavorable attitudes to various types of screenings. Increasing awareness through social media networks could shape attitudes toward cancer screenings. Negative attitudes regarding cancer prevention information and its relationship to family history impedes the decision to be screened (Liu, Fleck, Goldfarb, Green & Porter, 2011). The degree of negativity is not necessarily related to the intention to be screened among non-adherent people with a family history. The use of culturally designed intervention programs can positively increase CRC knowledge and decrease cancer fatalism attitudes significantly (Morgan, Fogel, Tyler, & Jones, 2010). Understanding the impacts of CRC on health and the risk associated with a family history improves adherence to screening.

It is apparent that knowledge related to CRC, family history risks, and the need for screening increase adherence to testing. Nonetheless, lack of information, illiteracy, and inadequate information continue to affect incidence of screening. Sly, Edwards, Shelton, and Jandorf (2013) established that lack of knowledge is a major barrier to CRC screening, followed by inadequate provider communication, anxiety, pain, and fear. Communication from healthcare providers and family members could help allay these fears. Health concerns compel family members with a history of colon cancer to seek CRC screening. Thus, perceived CRC risk, health concerns, past colonoscopy history,
fear and support from friends and family could increase the intention to undergo colonoscopy (Boonyasiriwat et al., 2013).

**Perceived Risk of a Family History**

Individuals who are appropriately screened for CRC have higher mean scores for perceived cancer risk, subjective norms, and perceived benefits and lower scores for perceived barriers. Multivariate findings indicate that having high perceptions of risk for colorectal cancer was a significant correlate of being appropriately screened among individuals with a strong family history (Palmer et al., 2007). Several qualitative studies investigating the perception of a family history and risk for CRC have concluded that both lack of knowledge and information of screening affects individuals’ willingness to undergo CRC screening. Relatives willing to undergo CRC screening impacts the whole of the study (Griffith et al., 2012; Haden et al., 2011; James et al. 2011; Palmer et al., 2011; Winterich et al., 2011). Thus, when there are no recommendations by clinicians for patients with a family history of CRC to undergo screening, patients tend to have negative perceptions of CRC screening. Thus, lack of knowledge of CRC is a barrier to CRC screening. Further, Black men with little knowledge of sigmoidoscopy and limited knowledge of CRC and colonoscopy are less likely to be screened (Winterich et al., 2011).

Researchers have identified lack of knowledge and understanding of CRC and fear of pain and discomfort as barriers to screening (Ghevariya, Duddempudi, Ghevariya, Reddy, & Anand, 2013; McKinney & Palmer, 2014). Further, lack of information related to the importance of screening was the greatest barrier for the non-colonoscopy group (Wong, Bloomfield, Crookes, & Jandorf, 2013). Nonetheless, improved knowledge about
colonoscopies is the greatest facilitator to adherence among relatives with a family history of CRC. According to Wang et al. (2013), patients with a family history of cancer could seek CRC screening independently, but a provider recommendation for colonoscopy and family and friend encouragement would more effectively compel family members to undergo screening.

**Interventions to Increase CRC Screening Rates in African-American Relatives**

Intervention approaches can be used to reduce health disparities between the Black and White population, and to increase CRC screening rates. One intervention is education to increase the level of knowledge and information, which can be used to inform Black CRC patients’ relatives of the importance of CRC screening in relation to age. Lowery et al. (2014) assessed whether a tailored telephone counseling intervention could increase adherence to colonoscopy among members of high-risk families in a random-controlled trial (RCT). Colonoscopy adherence increased among persons in the tailored telephone intervention group, in comparison to the mailed group (Fenton et al., 2011). For example, the telephone intervention approach resulted in a 32% increase in screening adherence in comparison to those receiving the information by mail (Lowery et al., 2014). Thus, a tailored telephone intervention is an approach that may significantly increase colonoscopy adherence among high-risk persons, especially family relatives. The intervention is effective because it ensures broad dissemination of information and knowledge on the importance of CRC screening in high-risk populations. According to this study, the intervention can lead to improved adherence to colonoscopy screening among persons identified as high-risk and correspond to decrease incidence and mortality.
rates. However, the intervention has a limitation due to the inability to reach Black that are outside the healthcare system due to not having access to care.

Awareness of a family history related CRC risk could also reduce incidence and increase screening rates. Rubin et al. (2009) assessed whether patients with CRC were aware of the risk to family members. The parameters used in the survey were family history, familial risk of CRC, and knowledge on screening guidelines for relatives. Out of the 253 CRC patients involved in the study, only 47.4% were knowledgeable that their FDRs were at increased risk for developing CRC. Also, an educational intervention was mailed to the participants, and a survey conducted six months later. The findings indicated that the intervention approach did not increase understanding of family risk and CRC screening by relatives. Lowery et al. (2014) also established that mailed interventions were not effective in increasing knowledge and understanding for CRC screening among Black relatives.

Winterich et al. (2011) found education to be linked with knowledge about CRC and colonoscopy. Additionally, Winterich et al. (2011) found that while education improved FOBT knowledge, it did not increase knowledge of sigmoidoscopy. Thus, to increase CRC screening among Black relatives, intervention programs must tailor education about CRC and screening based on educational attainment levels rather than race (Winterich et al., 2011). Matsuyama et al. (2011) confirmed that education level must be considered when designing intervention tools, as it influences the extent to which knowledge on CRC is acquired.

Interventions to promote CRC screening among Black relatives could play an integral role in minimizing the percentage of the affected population. Christy et al. (2013)
compared the impacts of two clinic-based interventions on patient-provider discussions related to CRC screening; patients either received computer-delivered tailored intervention or a nontailored informational brochure for CRC screening. The findings showed that the computer-delivered tailored intervention group, in comparison to the brochure group, reported having discussed CRC screening (63% vs. 48%) with their provider (Christy et al., 2013). Compared to a nontailored brochure, the computer-delivered tailored intervention was found to be more effective in stimulating client-provider discussions on CRC screening. Moreover, patients who received the computer-delivered intervention were more likely to be screened for CRC.

Similarly, Christy, Mosher, and Rawl (2014) found that computer-delivered tailored interventions were effective interventions as they improved health beliefs and knowledge about CRC screening, changed patient behavior, and increased chances of CRC screening. Misra et al. (2011) found that tailored intervention for colorectal cancer screening promotion was less cost-effective than web-based intervention but should be encouraged to increase CRC screening adherence among Black relatives. Tailored print interventions for populations at risk of CRC can facilitate health-promoting behaviors. For example, tailored health communications have effectively influenced health behavior change and increased smoking cessation, cancer screening, and dietary change in comparison to nontailored communications. Further, Blacks who receive counseling reported a higher level of undertaking CRC screening. Halbert et al. (2010) established that integrated risk counseling in a community-based intervention benefited Black adults regarding improvements to knowledge. In addition to counseling, culturally based interventions could be used to enhance screening for CRC among the Black population.
**Spiritually-based Interventions to Increase CRC Screening**

Spiritually-based interventions can be used to inform patients and increase CRC awareness among Black relatives. Holt et al. (2012) assessed a spiritually-based approach in a Community Health Advisor-led intervention carried out in sixteen Black churches. Some participants received spiritually-based interventions, while others were exposed to non-spiritual interventions related to CRC. Both interventions resulted in positive pre- and post-increases in perceived benefits of screening, knowledge, and decreased perceived barriers to CRC screening (Holt et al., 2012). The spiritually-based intervention was more effective in women than men and led to a significantly higher increase in perceived benefits of CRC screening among Black relatives when compared to the non-spiritual intervention. In Black populations, spiritually-based interventions could be as effective as secular communication.

Morgan, Fogel Tyler and Jones, (2010) used a culturally-targeted faith/community-based educational intervention to provide education on CRC health risks. The outcomes were that educational programs on colorectal health increased CRC knowledge, decreased cancer fatalism, and promoted CRC screening via colonoscopy among Blacks. Thus, the intervention group had a positive effect regarding likelihood of having a colonoscopy within three months after the intervention initiated. The intervention program, therefore, could be used to increase CRC knowledge significantly, change attitudes, and raise incidence of CRC screening among Blacks (Morgan et al., 2010). Drake, Shelton, Gilligan and Allen, (2010) tested the use of a church-based intervention referred to as the roadmap and found outcomes of increased knowledge about prostate cancer screening and promotion of self-efficacy to be part of an informed
decision-making process. They concluded that a church-based intervention was a promising strategy that could be used to promote informed decision making for CRC screening among Black men.

**Family-Based Intervention to Increase Screening among Relatives**

While identifying people with a family history related to CRC is a challenge, the diagnosis of persons with CRC can increase intervention efficacy. Rawl et al. (2008) established that family-based interventions carried out during active treatment may have positive outcomes for at-risk family members. Rawl et al. (2008) also found that tailored print interventions were more effective to specific subgroups of the population. However, nontailored print interventions were also cost-effective approaches that motivated first-degree relatives (FDRs) of CRC survivors to seek medical help and be screened.

Nested interventions (mail + telephone) can be used to increase regular screening and significantly decrease mortality and incidence rates of CRC among FDRs. Bastani et al. (2015) used a print intervention among an ethnically-diverse sample of FDRs of CRC cases and found that it produced a statistically significant increase in CRC screening rates (OR = 1.6). Similarly, Lowery et al. (2014) established an OR of 1.32 when tailored telephone education was used in comparison to a mailing when intervening with a family history of CRC. The findings further indicated that a tailored telephone intervention successfully increased colonoscopy adherence among high-risk persons. For instance, telephone intervention was linked with a 32% increase in screening adherence in comparison to the mailed intervention. Additionally, the intervention has the potential to be disseminated broadly among high-risk populations. Lowery et al. (2014) found that colonoscopy adherence resulted in an 11% increase in the intervention group in
comparison to no significant change among the mailed group. A limitation of the study was that only White participants, who have a low risk of CRC when compared to Black participants, were included.

Carey et al. (2016) conducted RCT among people with CRC and their FDRs to establish the effectiveness of print-based interventions and found that after 12 months, 61% in the print-based intervention group and 58% of FDRs in the control group adhered to screening guidelines. Thus, the provision of personalized risk information has a significant impact on adherence to CRC screening among FDRs of individuals diagnosed with CRC (Carey et al., 2016).

**Methodological Issues in Researching Risk Perceptions**

Risk perception surveys have been used to study and design behavioral interventions because the knowledge gained can be used to motivate individuals to make decisions about healthy lifestyle behaviors including CRC screening. However, Waters, Hay, Orom, Kiviniemi, and Drake (2013) questioned how data from three commonly used surveys to assess perceived risk of CRC accounted for participants’ “don’t know” (DK) (p. 1) responses. The predominant methodological or statistical solution to “don’t know” responses has been to treat the responses as missing data; this solution essentially results in the exclusion of individuals who respond in this manner and a loss of important information about this sub-group.

Waters et al. (2013) examined the prevalence and correlation of DK responses to assess the perceived risk of CRC using two population-based, cross-sectional surveys, the 2005 National Health Interview Survey (NHIS), the 2005 Health Information National Trends Survey (HINTS), and another clinic-based survey comprised of participants from
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a low-income primary care setting. The low-income participants’ survey results are significant because the DK response was 49% for the chance and 69.3% for likely and DK responses were round to be associated with disparity and low education. The pattern of results varied among samples, questions, response scales, and formats. The implication of this study is critical because it suggests limited understanding of the perceived risk of CRC among low-income groups with large disparity gaps.

Gaps in Literature

The proposed study is not the first hermeneutic phenomenological study of the meaning of a family history of cancer among the Black population. Researchers have predominately studied breast and prostate risk perceptions among Blacks, with a limited number of studies focusing on the perception of pre-screening age groups with known familiar and genetic risk factors. For example, Fillippi et al. (2013) used focus groups with American Indian men and women aged 30-49 to understand the perceptions of adults under the age of 50. Miller (2014) examined the screening knowledge and risk perceptions of prostate cancer among Black males between the ages of 30 and 45 using an 86-item survey approach. In both studies, the researchers’ rationale was related to the limited knowledge available about the perceptions of the next generation of unaffected racial and ethnic minority populations with a high-risk of developing colorectal and prostate cancer.

This literature review addressed the perceptual environment of CRC patients’ relatives. The evidence shows that family members diagnosed with CRC are suffering from disparate health outcomes across the cancer care continuum. Additionally, perceptions of the risk of CRC are major barriers to the uptake of CRC screening among
older Blacks (Tammana & Laiyemo, 2014). Currently, the primary prevention strategies to reduce the incidence and mortality rates among Blacks have been hindered because of the poor uptake of CRC screening (Oliver et al., 2012; Stanley, King, Thomas, & Richardson, 2013). Interventions to increase CRC screenings among Blacks have not resulted in the uptake and full participation based on guidelines for reasons including system-related and patient-doctor interaction factors. Intervention and screening programs have consistently focused on the primary prevention strategies targeting older adults (Naylor, Ward, and Polite, 2012). Most of the available studies have focused on intervention methods tested on the White American population, and only a few limited studies have focused on the Black population. Further, few randomized studies of interventions exist, particularly those focusing on the promotion of colonoscopy adherence among persons at increased risk for CRC as a result of a family history (Rawl, Menon, Burness & Breslau, 2012). No known studies have included families of people with Hereditary Non-Polyposis Colorectal Cancer (HNPCC).

The current study proposes a new perspective based on a common-sense approach for identifying and targeting a sub-group of the African-American population with the highest risk for CRC located in a shared space: the family. It provides an intentional focus on the primary prevention of CRC among the relatives of Blacks because of a significant number of shared environmental, genetic, social, and cultural factors. Impressions about CRC and screenings develop over time as individuals encounter important informational sources such as family, friends, and healthcare providers (Wang et al., 2013). A family-based intervention with a focus on improving cancer-related informational needs of Blacks has the potential for success. However, it is critical to
understand the family-situated context in relation to forming beliefs, attitudes, feelings, emotions, and perceptions about CRC and screening.

Palmer (2014) has argued that future research is warranted to examine how best to design interventions that include multi-level interventions to influence the decision-making and acceptance of colonoscopy screening among FDRs of individuals with CRC. In a recent systematic review of factors that influence risk perceptions in high-risk populations, researchers characterized the science as evolving but relatively undeveloped because of a lack of focus on most other cancer types, excepting breast cancer (Tilburt et al., 2011). The major gaps in cancer risk perception research include a limited focus on males, with 70% of the studies focused exclusively on female populations; a limited number of studies including non-White populations; and 65% of studies addressed breast cancer risk perceptions while only 30% addressed colorectal cancer.

In an earlier review, Ward et al., (2008) concluded that to improve the effectiveness of interventions to increase CRC screening among the Black population, the research gaps warranting greater attention are risk perception, educational awareness, and culturally-specific barriers to CRC screening. The evidence identifying the problem and significance of misperceptions of CRC risk among the Black population has been supported by research findings consistently since Lipkus, Lyna, and Rimer, (2000). Research has demonstrated that the lack of information, awareness, knowledge about CRC, and perceptions of the risk of CRC are major barriers to the uptake of CRC screening among older Blacks (Tammana & Laiyemo, 2014). It is likely that the same lack of information, awareness, knowledge, and inadequate perceptions of CRC screening will become major barriers for high-risk young adults. Therefore, the present
study provides an intentional focus on the primary prevention of CRC among young adults, particularly Black young adults, because of the significant number of relatives with colorectal cancer. This exploration of the lived experiences of young adult relatives may facilitate the development of culturally-specific primary prevention strategies to increase the uptake of CRC screening among relatives.

**Chapter Summary**

This chapter reviewed the relevant literature related to the overall problem of healthcare disparity for Blacks in the U.S. The problem of Black CRC disparity was discussed as it relates to the social determinants of health particular to Blacks was discussed. How Blacks with a family history of CRC differ from Whites was highlighted because of the differences in CRC screening rates and corresponding outcomes such as late-stage diagnosis, and poorer survival rates. The current interventions to increase CRC screenings among Blacks was showed to be inadequate to reach Blacks at-risk of early age CRC. The gaps in the literature were identified as focusing more on the White population and those above the age of 50. Additionally, few of the previous studies considers the family as an important context for understanding how Blacks experience and interpret the meaning of CRC. The identification of age and race gaps supports the need to study Blacks with a family context.

The next chapter focuses on the methodology used in conducting the research. Areas to be covered include research approach, data collection methods, sample and sampling technique, data analysis, reliability and validity of research methods, and ethical considerations.
Chapter Three: Methodology and Methods

This chapter presents the research design and procedures for conducting a rigorous qualitative study to understand the meaning of a family history of colorectal cancer (CRC) within the socially, and historically situated context of Black Americans’ experience of having CRC in the family. Chapter three is organized into two major sections: methodology and methods. The methodology section explains the philosophical, hermeneutic assumptions that underpin the study and justifies the research method and procedures used to conduct the study (Carter & Little, 2007). The methods section describes the specific details for conducting the research study congruent with the methodology.

Methodology

This section of the chapter explains the methodological and philosophical foundations of the study and explains the researches’ grasp of hermeneutic phenomenology and its’ application to the research design. The design of this dissertation considered issues of trustworthiness and rigor. Annells (1999) provided the following set of questions to guide the development of research design to ensure rigor in an interpretive project:

- Does the question seek understanding and meaning or description and explanation?
- Is the approach an appropriate inquiry approach?
- Is the approach congruent with the stated methodology?
- Is there an understandable process of inquiry?
- Is the product understandable and an appreciable product?
The following discussion of methodology is organized using the questions proposed by Annells (1999), beginning with the study question and purpose.

**Investigation of Human Being and Understanding**

This study is ontological in that its primary concern is investigating how humans come to know the world from their experience of being-in-the-world and being-with-others in the world. The phenomenon—a family history of CRC—is a specific, unforeseen life situation experienced by unaffected relatives of CRC patients. First-degree relatives (parent, brother, sister, son or daughter) are more likely to share the experiences of a family member’s journey across the entire cancer care continuum including diagnosis, treatment, survival, and end-of-life. The analytic of being a relative of a close family member diagnosed with CRC is best investigated from the context of individuals experiences in their cultural and family (Dreyfus, 2004).

The research question and purpose are based on a pre-understanding of behavioral theories, such as the Health Belief Model (Janz & Becker, 1984), and empirical research demonstrating a positive association between perception of risk and preventive health behaviors such as CRC screening (Atkinson, Salz, Touzab, Li, & Hay, 2015). Empirical studies have consistently documented evidence of the persistence of underutilization of CRC screening and low perceived risk among Blacks since the Lipkus et al. (2000) study. Rather than another empirical study, the present study provides a hermeneutic phenomenological investigation to overcome the inherent limitation of these empirical studies: that they disengage human beings from the world in which they exist. Its research problem is low perceived risk of CRC and lack of awareness of the risk of a
family history of CRC among Black CRC patients and their relatives. Therefore, the purpose of this study is to understand the meaning of a family history of CRC in the situated context of cancer in the Black family. The research question is: What is the meaning of a family history of colorectal cancer of adult relatives, aged 18-49 years, of first-degree Black family members diagnosed with CRC? Additionally, the research aims are:

- To generate an interpretation of the meaning of a family history of colorectal cancer for adult relatives, aged 18-49 years, of first-degree Black family members diagnosed with colorectal cancer.
- To understand how relatives’ experience of a family history of CRC influences their future disposition about CRC, cues to action, patterns of responses, and ideas about personal health behaviors.

**Interpretive/Hermeneutic Approach**

The aim of the interpretative method is to uncover the background meanings derived from the shard experiences within the context of everyday practices. The aim of hermeneutic phenomenology goes beyond just describing the phenomenon. Hermeneutic phenomenology also focuses on the subjective experiences of persons and groups, and aims to understand the contextual meaning of experiences and their interpretation.

Benner, Tanner, and Chesla (1996) described the aim of the interpretive process as: “to make a clearing and offer one grasp of the meanings evident in this everyday language” (p. 357). The conceptualization of the clearing changed over time from a general clearing generalizable to all human beings to a local clearing specific to individuals and families (Heidegger, 1962). Further, Heidegger explained that the local clearing of an individual
or group has a specific clearing produced by a shared background of understanding. This distinction is important to this study because understanding the local clearing—Black families with CRC—is at the heart of this investigation.

Phenomenology is a school of philosophy that is influenced by the way people think with regard to a phenomenon. Phenomenology is the study of the structures of experiences, or “phenomena”: the study of the appearances of things, or things as they appear to the individual, or the ways individuals experience things and the meaning constructed from the experiences (Parson, 2010). Phenomenology emerged when approaches used to study the natural sciences, controlled experiments and quantitative measurements, were thought inappropriate for studying the human sciences (van Manen, 1990). According to Munhall (2011), phenomenological research is the quest for what it means to be human, in order to more deeply understand human experiences; it is the study of the individual’s life-world, as experienced rather than as theorized by others. Hermeneutic phenomenology started as a philosophy of the science of human undertraining, and later emerged as an interpretative method of research. Hermeneutical phenomenology is concerned with how individuals understand and engage things around them in the real world, including the self and others. Realistic phenomenology studies the structures of consciousness and intentionality. Phenomenology provides a richer understanding in the context of conscious experiences from the subjective or first-person point of view (Mackey, 2005; Smythe, Ironside, Sims, Swenson, & Spence, 2008). For the purposes of the present study, it is important to examine a wide range of experiences of racial/ethnic minority patients and advance practice nurses, ranging from their personal
perceptions, thoughts, memories, emotions, desires, embodied actions, social-cultural actions, and linguistic expressions (Mackey, 2005).

**Hermeneutic Phenomenology in Nursing**

The family is not widely recognized as a significant place for understanding phenomena such as meaning, attunements, moods, and the significance of experiential perceptions of health and illness. However, Chesla (1995) recognized the value of hermeneutic phenomenology as an appropriate approach to investigate the family and its shared experiences and was influential in articulating the need to examine shared patterns and understandings about health-related issues from a family level of analysis. Using a hermeneutic phenomenology method, this study expects to contribute to the understanding of family-based interventions to increase CRC screening among high-risk relatives.

Heidegger (1962) articulated the significance of understanding human existence both historically and in a social and cultural context. Black Americans are more likely to experience a diagnosis of CRC at both older and younger ages than any other racial/ethnic population in the U.S. An existential investigation from a social epidemiological perspective is essential to achieve the aims of this study. The central question of this inquiry values understanding the phenomenon—a family history of CRC—in its cultural context. Relatives of Black CRC patients are in a unique situation from which to make sense of the world, particularly with regard to the family environment. It assumed that relatives formulate their perspectives of CRC and preventive behavioral lifestyles from their experiential perceptions of living with and sharing the illness of close family members with CRC.
To my knowledge, this is the first hermeneutic phenomenological study to examine the meaning of a family history of CRC and screening among relatives, aged 18-49 years, from a social epidemiological perspective. The study of human responses to phenomena falls within the domain of nursing research (ANA, 2010b). Therefore, researching the understanding of experiential perceptions of a family history of CRC risk will inform future nursing actions to help promote, protect, and optimize the health of this high-risk Black population.

Assumptions

It is critical to articulate assumptions early in the research process to ensure transparency. The assumptions considered to be important for the applications of Heidegger’s philosophical hermeneutics vary among scholars. Dreyfus (1984) has maintained that there are three critical assumptions to hermeneutic phenomenology methodology:

1. Being (human being) is a self-interpreting activity.
2. Being involves understanding of what being means.
3. Understanding opens a clearing for human beings’ encounters. The everyday practices and awareness take place in the clearing and embody specific cultural ways of understanding what counts as real for individuals.

Dreyfus (1984) also argued that Heidegger’s idea of the clearing is essential to all three assumptions. The study is grounded in a synthesis of assumptions from multiple congruent paradigms including interpretivism, constructionism, and hermeneutic philosophy. The specific assumptions of Heideggerian phenomenology are:
A philosophical analysis is performed in the world’s naturalistic settings: “Dasein always understands itself regarding its existence” (Heidegger, 1962, p. 33). Human beings are always already interpreting the world (Benner, 1994, p. 71). “An understanding of Being is already in conceiving anything which one apprehends in entities” (Heidegger, 1962, p. 22). Both the situated context of meaning and interpretation of experiences are significant in the Heideggerian phenomenological method. According to Heidegger (1962), to understand the experiences of participants and derive meaning, a researcher must engage in seeing and hearing that person by processing the information gathered via the lens of those participants’ situated context. The term hermeneutics implies the interpretation of experiences, and Heidegger pointed out that lived experiences are interrelated to create creating meaning and realize a sense of understanding (Vandermause & Fleming, 2011). To explore lived experience, Heidegger focused on the concept of Dasein.

Human beings are social and dialogical beings (Benner, 1994, p. 71). A Heideggerian assumption of hermeneutic phenomenology was that understanding is based on shared interpretations and co-creation of knowledge between the researcher and the participants (Benner, 1994). Hermeneutic phenomenology entails the co-creation of knowledge, whereby production of meaning takes place via a circle of readings and interpretations. Thus, through the use of hermeneutic inquiry, it is possible to identify the participant’s meaning from participant-generated information and a mix of the researcher’s understanding of a phenomenon being studied (Heidegger, 1962; Koch, 1995). Heideggerian
hermeneutic phenomenology assumes that interpretation entails a shared
dialogical relationship between the interpreter and the interpreted, and both
researcher and participants share interpretations and co-create knowledge. Smith,
Flowers, and Larkin (2009) have noted that fore-structure can act as an obstacle to
interpretation. In addition, the priority in interpretation of a text and dialogue must
be given to the new object, instead of one’s preconceptions. Nonetheless, the
researcher’s understanding of the phenomenon under investigation is predicated
on certain fore-conceptions (Finlay, 2008). The fore-structure is always present,
although Heidegger argued that to understand one’s own fore-structures, a
researcher must be part of the experience (Heidegger, 1962). Thus, a researcher
has no knowledge of fore-structures beforehand, and the fore-structures can only
be uncovered through analysis of the phenomena.

- The fundamental aim of existential analysis is to allow the phenomenon to show
its existential meaning of what matters in everyday being-in-the-world. All human
beings are already in a hermeneutic circle of understanding and come to an
investigation with preunderstanding, biases, and prejudices (Benner, 1994). “This
vague average, understanding of Being can be infiltrated with traditional theories
and opinions about Being that these remain hidden as sources of the way in which
it is prevalently understood” (Heidegger, 1962, p. 25). The hermeneutic circle is
primary to the Heideggerian phenomenological method, and focuses on
interpretation. Heidegger suggested that knowledge was not only based on
immediate intuition, but also on its interpretation (Heidegger, 1962). The
hermeneutic circle of interpretation is a process employed to produce a greater
understanding of a phenomenon being studied. The hermeneutic circle is important to interpretive work; as a process of interpretation, it is iterative, reflective, and reflexive (Vandermause, 2008).

Research Design and Method

Sample and Sampling

Purposive sampling was used because of the need to select study participants who can inform an understanding of a family history of CRC in the Black family (Creswell, 2007). The participants of this study were comprised of first-degree relatives (FDRs) of Blacks diagnosed with CRC at any stage of care across the cancer continuum: diagnosis, treatment, survival, palliative care, and end-of-life. The target group is delimited to first-degree relatives because when a sibling, mother, or father is diagnosed before the age of 45, an individual’s risk of developing CRC is higher.

The rationale for this delimitation is to locate individuals with experience of a close relative’s illness. FDRs are more likely to have had more intimate experiences of CRC than second-degree relatives (SDRs). Therefore, FDRs provided a rich and thick descriptions based on an insider’s perception and experience of a family history of CRC.

Sample Size

The sample size is the number of participants needed to be recruited to answer the research question adequately. The initial goal is to recruit five Black families with at least two first-degree relatives (FDR) and one family member with CRC. From the five families, the goal is to recruit at least two FDRs from each family. The rationale for recruiting two relatives from each family is to establish rigor by having more than one relative’s perspective of experiencing a family history of CRC. FDRs include siblings, a
child, or a parent, and were targeted because they have an increased risk of CRC. The sample was composed of female and male participants aged 18 and above.

**Sampling Criteria**

The sampling criteria was a list of essential characteristics that determine whether recruited individuals were included or excluded from participation in the study.

**Inclusion criteria.** The inclusion criteria were the sampling characteristics that cause a person to be included in the target population. The inclusion criteria for participating in this study were:

- Self-identified as African American or Black
- Men and women between the ages of 18 and 49
- Ability to read and speak English
- At least one FDR diagnosed with CRC
- From a family with two or more FDR willing to participate in the study
- Resides in the southeastern region of Missouri
- Willing to consent to share their personal story of having an FDR diagnosed with CRC
- Willing to consent to a digital recording of an interview lasting for at least an hour to an hour and a half

**Exclusion criteria.** The exclusion criteria are the sampling characteristics that cause a person to be excluded from the target population. The exclusion criteria for this study are:

- Do not self-identify as African American/Black
- Aged below 18 or above 50
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- Individuals with CRC
- Individuals without FDRs diagnosed with CRC
- Non-biological relative of an FDR diagnosed with CRC
- Inability to read and speak English
- Limited cognitive abilities

**Recruitment**

Recruitment commenced immediately after the Institutional Review Board at the University of Missouri-St. Louis approves this study. Participants were recruited from Missouri through the use of several strategies, including flyers, word of mouth, and posters. Interested individuals were given a phone number to contact the primary researcher. To inform the participants of the study, recruitment posters, including “CDC Screen for Life – Terrance Howard” (see Appendix D), were posted in prominent locations on the Southeast Missouri State University campus, local Black churches, and local health departments. Interested individuals were given a phone number (312-852-5721) and email address (logginsc@umls.edu) to contact the primary researcher, Cassandra Loggins. The participants were informed that participation is voluntary and informed of their rights as human subjects. The Terrance Howard poster was selected as a means for Black potential participants to identify with a popular young Black actor whose mother died from early-age CRC. The poster provided interested individuals with information about the purpose of the study and the researcher’s contact information.

The researcher engaged in a conversation with potential study participants. For instance, potential callers were furnished with information related to the study, including the study purpose and inclusion criteria. If the criteria are met, an appointment was
scheduled for an interview (location on campus to be determined). Potential participants were willing to be interviewed face-to-face for about one hour and to consent to audio recording of the interview. Participants who do not meet inclusion criteria were excluded from participating in this research study.

**Ethical Considerations**

Approval for conducting this research study was provided by the Institutional Review Board (IRB) at the University of Missouri-St. Louis. Participant involvement and time requirements were explained to the participants after they have been approached for recruitment and selected to participate in this study. Verbal and written explanations detailing the study purpose and aims, anonymity and confidentiality rights, and the right of participants to withdraw from the study at any time without penalty was shared with each selected subject. Informed consent was sought from the participants and stored in a safe place to ensure anonymity. The data was collected via semi-structured interviews in the form of transcripts, audio recordings, field notes, and reflexive journals kept in a locked file cabinet in the home office of the researcher. Any other data was stored on the home computer of the researcher, which is password-protected.

*Potential benefits and harms.* The potential benefit of participating in this study is to gain knowledge, awareness, and information about CRC and screening tests. Considering the likelihood of recruiting families with little or no knowledge of CRC, there is a risk that the interviews could produce stress among participants. It might be especially sensitive to discuss issues related to the need for earlier than normal CRC screening and the potential consequences of delayed diagnosis and treatment. Therefore,
participants were advised of their right to stop the interview and withdraw from the study at any time.

This study also includes the potential to produce unintended consequences among Black participants based on how the researcher discusses and presents disparity messages. For example, Nicholson et al. (2008) reported that when Black adults are exposed to either a progressive message about improvements in reducing the disparity of CRC or a negative message, such as Blacks are doing worse than Whites, those exposed to the negative message were less likely to want to be screened for CRC. Of particular concern is the possibility of creating an emotional barrier to colorectal cancer screening. Therefore, caution was taken with the messaging used during data collection procedures because of the potential impact of negative messaging on Black participants.

Data Collection

The types of information collected in this hermeneutic phenomenological study includes two general sources: data from researcher and data from the participant. Both sources of data were brought together during the data analysis to achieve a holistic portrait of the lived experiences of relatives of Black participants with a family history of CRC.

Interview Protocol. The interview protocols were detailed sequential procedures to use while conducting hermeneutic interviews with study participants. The protocols were not meant to be an automatic way to implement the interview, but rather a guide for ensuring consistency across individual interviews (see Appendix A). No participant data was collected prior to receipt of participants’ informed consent (see Appendix B).
Data collected from researcher. The following data was collected from the researcher: pre-understanding of a family history of CRC and reflective journal notes.

Fore-structure. Fore-structures are the understanding about a particular phenomenon that researchers bring to the research inquiry. In qualitative research, the researcher is the instrument of inquiry; therefore, it is important to know what the researcher brings to the investigation and how this influences the interpretation of data. Interpretation has a three-fold structure: (a) “fore-structure” or “fore-having”: the premise that all interpretations are based on familiarity with the phenomena, (b) “fore-sight”: the interpretive lens that forms our perspective in understanding, and (c) “fore-conception”: the anticipated sense of expected interpretations (Ironside & Diekelmann, 1998, p. 243).

Reflective journaling. Reflection was an interpretive and systematic approach applied in the data collection process to enable a researcher to construct translucent and authentic accounts of experiences in the field (O’Connor, 2007). The concept of journaling was important to this dissertation because it gave the researcher a chance to clarify thoughts and experiences (Ortlipp, 2008). Maintaining a journal provided the researcher with a platform to reflect on field experiences and consider issues of bias. Immediately following the interviews, the researcher recorded feelings, thoughts, and responses in a reflexive journal. The rationale for choosing reflexive journaling was to understand the phenomenon of the prospective study and the research process. The researcher drew on the journal passages to make connections between existing literature reviewed, decisions made in the course of this study, and the reflexivity process. Accordingly, the journal was expected to reveal both professional and personal matters in
the course of the research process, whereas the field notes documented the data collection and analysis process (Cole & Knowles, 2001).

Reflective journaling was used to engage the researcher in the ongoing personal discovery of fore-structure to account for potential influences on data analysis and interpretation over the course of the entire study.

**Data collected from participants.** The data collected from participants included a demographic survey, a hermeneutic interview, and observations.

*Demographic survey.* Demographic data about the participants were collected using a short survey to describe the sample. The demographic survey (Appendix C) collected information about participants’ age, race, education, income, type of healthcare providers, family history of CRC, and history with CRC screenings.

*Hermeneutic interview.* Data collection was based upon a hermeneutic, semi-structured interview. A philosophical hermeneutic interview is a major source used to collect data required for qualitative research. Diekelmann and Ironside (2006) pointed out that a philosophical hermeneutic interview is applied when an interviewer seeks to unravel a story based on participants’ experiences. The rationale for adopting a philosophical hermeneutic interview was that this approach allowed the researcher to draw conclusions from experience. Interviews provided the researcher with rich and detailed qualitative data required to understand the experiences of the participants and the meaning derived from those experiences (Rubin & Rubin, 2012). The researcher shifted from positivist thinking and remained open-minded to unanticipated responses from the participants.
Semi-structured interviews were comprised of numerous key questions that assisted in defining research areas to be explored and allowed the interviewer to probe a response in order to obtain an in-depth insight. Semi-structured interviews are suitable for the nursing field because they provide researchers with guidance on areas to explore. Data collected through semi-structured interviews were used with the informed consent of the participants. A consent form informing the participants of their rights and their role in this study and the purpose of the study were given to the participants (see Appendix B). The semi-structured interview was used to elicit data about the meaning and interpretation of participants’ lived experiences (Denzin & Lincoln, 2005).

*Interview guide.* The interview guide (see Appendix D) was based on the following primary research question for this hermeneutic study: What is the meaning of having a family history of colorectal cancer in Black families? Munhall (2012) has suggested that researchers should keep the overarching question at the forefront, while not asking too many questions. For example, Munhall (2012) proposed that researchers start with a simple question (such as “What is it like?”), which allowed for description of an experience and its meaning in participants’ own words.

The interview guide was used to give the conversation a structure without being overly structured and controlled. Interview questions started with the following statement: *As you think about what it’s like to be a close relative of someone diagnosed with colorectal cancer (alive or deceased), is there anything that stands out for you? Is there a situation or a story that comes to mind?* The researcher had the opportunity to probe for rich, thick descriptions of experiences, thoughts, feelings, and meanings.
Field notes. Field note-taking was a key data collection method in other qualitative approaches such as ethnography. However, taking field notes had also emerged as an integral part of procedural documentation to facilitate critical reflections, maintain an audit trail, and document the researcher’s role in the research process (Munhall, 2003; & Munhall, 2012). For the purposes of this study, field notes are part of the data collection process and were recorded by the researcher immediately after the semi-structured interviews. Both descriptive and reflective information were recorded in the field notes. Descriptive information included field notes about the setting, participant behaviors, and attitudes expressed, both verbal and non-verbal, that related directly to the study’s purpose. Reflective information included the researcher’s thoughts, ideas, concerns, and questions experienced while collecting data from the participants (Munhall, 2003). The procedures for collecting, storing, and maintaining the security of the field notes are outlined.

Data Analysis and Synthesis

The primary purpose of this study is to understand the meaning of a family history of colorectal cancer among first-degree relatives of Black CRC patients. Information collected from both participants and the researcher, that was relevant to the existential analysis of the meaning of a family history of CRC, was considered as data in this study. In this way, the researcher and participants were involved in the co-creation of knowledge. However, the unit of analysis was the experience of CRC for a first-degree relative, rather than the researcher’s thoughts and understanding of the phenomenon. The researcher-created data gave the study rigor and credibility because it provided transparency and enabled others to judge how biases were accounted for throughout the
entire study process, including the reflective journal and post-interview reflections about the interview experience. The participant-created data included demographics, transcribed hermeneutic interviews, and post-interview observations and field notes. The specific aims of collecting this data were to generate an interpretation of the meaning of a family history of colorectal cancer for adult relatives and to understand how relatives’ experience of a family history of CRC influences their future disposition about CRC, cues to action, patterns of responses, and ideas about personal health behaviors.

**Team-based data analysis strategy.** The team-based analysis strategy involved assembling methodological or content experts as well as professional, lay, or student readers (See Appendix E for credentials and identification of the analysis team members) who studied the interview transcripts and the multi-layered text, then provided written and verbal analytical or interpretive input (Vandermause, 2011). The process of data analysis began immediately after the collection of the first hermeneutic interview with a team consisting of Dr. Vandermause’ doctoral students.

Vandermause (2011) developed a philosophical approach procedure of the analysis of transcribed interviews in a study of the methamphetamine addiction and recovery experience. This method is useful as a procedural approach to the data analysis and management process. Each line of the interview transcript was numbered for consistency and ease of reference to the text; transcripts were de-identified and assigned pseudonyms for each participant, then distributed to the analysis team. Data collection and analysis occurred simultaneously until completed. The research team began with the first interview immediately after the transcript was prepared and continued using the
same procedures until the team members analyzed all interviews. The following steps were used in analyzing text from interviews, as outlined by Vandermause (2011):

1) Read the transcript carefully, start to finish
2) Re-read the text line by line
3) Make notes about concepts or situations that stand out
4) Review notes and observe the general categories, noting frequency of related ideas, position in text, response to interview questions, style of response (halting, stuttering, slang, affect conveyed)
5) Re-read line-by-line with repeating ideas in mind
6) Devise rudimentary list of emerging categories
7) Review transcript with these categories in mind
8) Revise categories or make comments, ideas for naming themes
9) Write a summary of the transcript and notes with as much detail or support as time allows, including a basic summary of events, and a summary of emerging categories or themes, and interpretations, any or all with as much textual support (line references, exemplars) as time allows

After the members analyzed the first interview, the team met. The researcher compared data with team members, looked for differences in experiences and opinions presented by participants, applied the reflexive journals, and collated and refined themes in an iterative manner. Further, the hermeneutic team looked for plausibility, comprehensiveness, and coherence throughout the analysis process to ensure consistency (Diekelmann & Ironside, 2006). The team worked together to identify patterns and themes that overlapped and reflected any overlapping ideas (Vandermause, 2008). The procedures included:
1. Reviewing the written interpretations

2. Discussing the initial themes that emerged from the data of each interpretation

3. Deconstructing the text according to working themes, noting areas of overlap

4. Choosing verbatim, line-coded pieces of the transcript for their representation of the ideas/emerging categories identified in the interpretations

After the results of the study were developed, the presentation of interpretations also involved a team-based strategy using the following procedures:

1. Organizing excerpts (labeled by pseudonym and line locations) into folders that exemplify or represent ideas signified by the working themes; excerpts placed in more than one folder

2. Collecting and filing together all written interpretations as part of the multi-layered data that is “text”

3. Creating storage units using working themes (named pattern of ideas) using preferred software, or paper files after several transcripts are analyzed

4. Reviewing the storage units in their entirety and considering them against interpretations

5. Determining patterns and themes which are always subject to revision, and final writing begins

6. Written results include a summary and interpretation of each theme (typically two or three major themes that may subsume several subthemes; one or two overarching patterns may emerge from discussion or analysis) (Adapted from Vandermause, 2011 (p. 7) with verbal/written permission from R. Vandermause).
Data protection and security. Data was collected from the participants using encrypted digital audio devices and later downloaded to a secure password-protected and encrypted server at the University of Missouri. Files were transferred to a HIPPA-compliant transcription service, with a confidentiality agreement in place. The transfer was carried out through a secure password-protected file. The HIPAA-compliant professional transcription service transcribed data from recordings. The data collected via semi-structured interviews, in the form of transcripts, audio recordings, field notes, and reflexive journals, were kept in a locked file cabinet in the researcher’s home office. Any other form of data was stored on the password-protected home computer of the researcher. The transcriptions were stored on a secure server for five years, then destroyed.

Trustworthiness

The idea of rigor for a systematic scientific investigation includes reliability and validity as means to ensure confidence in quantitative research findings using statistical analysis. However, Lincoln and Guba (1985) have argued that it is inappropriate to apply criteria established for the evaluation of quantitative inquiry to qualitative inquiry because the two traditions are based on different paradigms. Additionally, qualitative research methods are too diverse to codify one set of criteria to ensure rigor. However, scholars agree on the fact that all researchers should concern themselves with issues of scientific rigor to ensure confidence in study results regardless of qualitative or quantitative tradition.

Guba and Lincoln (1982) proposed the concept of “trustworthiness” as an alternate criterion for qualitative research that provides a better fit with the assumptions
underlying naturalistic studies with diverse paradigms. The concept captures the need to demonstrate a high level of credibility in the procedures used to generate knowledge from qualitative research using a systematic approach. Guba and Lincoln (1982) proposed that trustworthiness was established using four elements: credibility as internal validity; transferability as external validity or generalizability; dependability as reliability; and confirmability as objectivity. When checking for trustworthiness and credibility, researchers test whether the information gathered in the study is accurate (Creswell, 2007).

**Chapter Summary**

This chapter discussed the research methodology and method for investigating the meaning of a family history of colorectal cancer of first-degree relatives of CRC patients in the context of the Black family. Relatives were interviewed and data analyzed to generate an interpretation of the meaning of a family history of CRC and to enable an understanding of how relatives’ experience of a family history influences their future disposition about CRC prevention. Chapter 4 addresses the results of the analysis presented.
Chapter Four: Findings and Interpretation

“...let people know that they don't have to die from colon cancer.” Jill

The purpose of this study is to gain an understanding of the meaning of a family history of colorectal cancer (CRC) situated in the Black American family and to answer the question: What is the meaning of family history of colorectal cancer for adult relatives, aged 18-49 years, of first-degree Black family members diagnosed with CRC? The following specific aims guided the study: 1) To generate an interpretation of the meaning of family history of colorectal cancer for adult relatives, aged 18-49 years, of first-degree Black family members diagnosed with colorectal cancer, and 2) To understand how relatives’ experience of family history of CRC influences their future disposition about CRC, cues to action, patterns of responses, and ideas about personal health behaviors.

Participants

The participants (see Table 2) are eight young adult men and women who volunteered because they had parents diagnosed with CRC. The group represents five families: three families having two siblings and two families having a single daughter. The participants were recruited from African-American churches through word of mouth and the influence of pastoral support for study in the community. The sampling was purposive and snowball.

Table 2

<table>
<thead>
<tr>
<th>Participant #</th>
<th>Gender</th>
<th>Age</th>
<th>Marital Status</th>
<th>Education</th>
<th>Employment Status</th>
<th>Income</th>
<th>Religious Beliefs</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Female</td>
<td>46</td>
<td>Married</td>
<td>Graduate Degree</td>
<td>Employed</td>
<td>60,000 or above</td>
<td>Christian</td>
</tr>
</tbody>
</table>
The participants’ ages ranged from 34 to 49 and the ages at the time of their parents’ diagnosis of CRC ranged from 27 to 40. All participants are employed and educated from some college to graduate degree. The time lapse since the death of the participants’ parents ranges from 5 to 11 years. Five participants lost a mother and three participants lost a father to advanced stage CRC. All participants are children or first-degree relatives. The rate of reported completion of CRC screening is 87.5%. Seven of the participants report the completion of serial CRC screenings since their parent’s death while one participant reports an intention to be screened soon. They are all CRC free and survivors of a preventable tragedy. Table 3 presents a summary of the participants’ experiences with CRC in the family.

**Table 3**

*Overview of participants’ experiences with CRC in the family*

<table>
<thead>
<tr>
<th>Participant’s age at diagnosis</th>
<th>Family #1</th>
<th>Family #2</th>
<th>Family #3</th>
<th>Family #4</th>
<th>Family #5</th>
<th>Averages Ranges</th>
</tr>
</thead>
<tbody>
<tr>
<td>Jill &amp; Lenny</td>
<td>36/37</td>
<td>30/36</td>
<td>38</td>
<td>40</td>
<td>27/29</td>
<td>34.125 years (27-40)</td>
</tr>
<tr>
<td>Family #1</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Family #2</td>
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<tr>
<td>Family #3</td>
<td></td>
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</tr>
<tr>
<td>Family #4</td>
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<td></td>
<td></td>
</tr>
<tr>
<td>Family #5</td>
<td></td>
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</tr>
</tbody>
</table>
Study Findings

The findings of the study are derived from the understanding and interpretation of the experience of having a parent diagnosed with CRC as narrated by eight young adult men and women of Blacks diagnosed with CRC. The summary of the data analysis is presented in Appendix H. The meaning of a family history of CRC shows itself as two overarching patterns shared across participants’ experiences of having a parent diagnosed with Stage IV colorectal cancer followed by a short illness trajectory. Blacks are more likely to get late stage diagnoses (Holowatyj, Ruterbusch, Rozek, Cote, & Stoffel, 2016).

Two patterns with related sub-patterns emerged from the hermeneutic data analysis of the eight individual interviews. The first pattern experiencing a shortened illness trajectory, includes five related patterns: 1) facing a dreaded diagnosis, 2) caregiving with gusto, 3) preparing for parent’s untimely death, 4) coping with a burden too great, and 5) dealing with emotional turmoil, including anger, depression, grief, guilt,
helplessness and regret. The second pattern, *mobilizing the family against CRC*, includes three related sub-patterns: 1) asking questions about heredity, 2) realizing one’s own mortality, and 3) increasing self, family and community awareness about CRC.

Results are presented as patterns and related sub-patterns. Verbatim excerpts of the participants’ stories are cited to validate the interpretations. The findings are the narrated stories of how young adult sons and daughters experienced their parents’ journey after receiving a diagnosis of Stage IV CRC. Although this is the story of eight participants, the pattern and sub-patterns that emerged are similar (see Table 4). Verbatim statements cited from the transcripts represent exemplars of the group story and are used to support the interpretation and findings.

**Table 4**

*Patterns and Sub-patterns*

<table>
<thead>
<tr>
<th>Patterns</th>
<th>Sub-patterns</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Experiencing a shortened illness trajectory</strong></td>
<td>1. Facing a dreaded diagnosis</td>
</tr>
<tr>
<td></td>
<td>2. Caregiving with gusto</td>
</tr>
<tr>
<td></td>
<td>3. Preparing for a parent’s untimely death</td>
</tr>
<tr>
<td></td>
<td>4. Coping with a burden too great</td>
</tr>
<tr>
<td></td>
<td>5. Dealing with emotional turmoil</td>
</tr>
<tr>
<td></td>
<td>Anger</td>
</tr>
<tr>
<td></td>
<td>Depression</td>
</tr>
<tr>
<td></td>
<td>Helplessness</td>
</tr>
<tr>
<td></td>
<td>Grief</td>
</tr>
<tr>
<td></td>
<td>Guilt</td>
</tr>
<tr>
<td></td>
<td>Regret</td>
</tr>
<tr>
<td><strong>Mobilizing the family against CRC</strong></td>
<td>1. Asking questions about heredity</td>
</tr>
<tr>
<td></td>
<td>2. Realizing own mortality</td>
</tr>
<tr>
<td></td>
<td>3. Increasing awareness about CRC</td>
</tr>
<tr>
<td></td>
<td>Self-awareness</td>
</tr>
<tr>
<td></td>
<td>Family awareness</td>
</tr>
<tr>
<td></td>
<td>Community awareness</td>
</tr>
</tbody>
</table>
Experiencing a Shortened Illness Trajectory

“…my mom was young. It was like she had a lot of living left to do.” Katherine

This investigation of a family history of CRC is based on each of the participants’ lived everyday experiences. These experiences are the result of being-in-the-world with a parent diagnosed with CRC and the shared illness journey across the cancer care continuum. The participants all experienced a sudden realization of being thrown into this particular life circumstance of cancer in the family. This pattern relates to Heideggerian concepts of ‘thrownness’ and ‘circumspection’ (Heidegger, 1962).

Thrownness refers to the idea that all of us do not choose our parents, rather we find that we are “thrown” into the family, the place and the culture all of which is beyond our control (Heidegger, 1962, p. 136). Circumspection, according to Heidegger, refers to the manner in which humans see and experience the world in relationship to the persons and things in the world that influence our perspective (Heidegger, 1962, p.123).

This pattern is consistent across all participant experiences because fatal conditions like Stage IV colorectal cancer follow an illness trajectory common to late stage cancers. The sub-patterns related to experiencing a shortened illness trajectory include what has shown itself across these eight participant interviews. They are 1) facing a dreaded diagnosis, 2) caregiving with gusto, 3) preparing for a parent’s untimely death, 4) coping with a burden too great, and 5) dealing with the emotional turmoil of being.

Facing a dreaded diagnosis. Diagnosis is the process of identifying a disease from its signs and symptoms. All eight participants contributed references to the issue of getting a diagnosis. The process involved becoming aware of parents’ sudden and
Family history of colorectal cancer appears in the lives of the participants in the pre-diagnosis stage of becoming aware of a sudden diminished health status. Lenny and Jill, the son and daughter of a 62-year-old father, noticed the decline in health which precipitated the entry into care. Up to this point, the participants’ parents have existed as autonomous consumers of healthcare and have been in control of their own healthcare decisions. However, the children of parents diagnosed with CRC must eventually deal with the consequences of those decisions.

Jill reported,

And when I pulled up, I looked at him, and I’m like, wow, my dad has lost a ton of weight. And it almost seemed as though it was like overnight, you know? Ah, ‘cause I guess maybe it had been about two weeks since I had seen him, but he had dropped a lot of weight very rapid. And, um – and I asked him, you know? And my dad was a very jovial man, and I – and I asked him had he had his prostate screened and, you know, had he had his colonoscopy. And he was very jovial and, you know, said that he had his prostate checked and he had his colonoscopy. You know? And we just kind of laughed it off. (F1J .51 -59).

Here we see Jill trying to make sense of her dad’s decisions to withhold information.

Getting to a diagnosis often involves groping for answers. Is this withholding an unintended consequence of the culture of patient autonomy and Health Insurance Patient Accountability Act (HIPAA) regulations? Jill described her attempts to exact information from her father.

I guess maybe it had been about two weeks since I had seen him, but he had dropped a lot of weight very rapid. And I asked him, you know? And my dad was a very jovial man, and I – and I asked him had he had his prostate screened and, you know, had he had his colonoscopy. And he was very jovial and, you know, said that he had his prostate checked and he had his colonoscopy. You know? And we just kind of laughed it off. And I said, “Oh, okay, and I asked him what was – what
was the results, you know, of his screenings that he said that he had. And, ah, he said everything was fine. Everything was good. (F1J. 51-61).

Because, you know, my dad wasn’t as forthcoming with his health as I would have liked for him to be. But given his age and era in which he grew up, that was – you know, that’s just something that’s kind of common where – ah, especially with men that they don’t like to share their, ah, medical illness. (F1J. 42-46).

Jill and Lenny’s family considered the usual suspects of sudden decline in health, like lung cancer. Because their father was a smoker, Jill said, “Dad was a smoker, and I was thinking maybe lung cancer, you know, because he did have COPD. But, um, not colon cancer” (F1J. 63-67). Jill still remembers her reaction to her father’s diagnosis of Stage IV CRC.

Well, I remember a lot about it. I remember, I remember, ah, when I got back home from my honeymoon – because I had to cut that short – um, I remember I rushed, you know, back to his house. And, um, when I got to his house and I went inside, he was sitting at the table. He was trying to eat. And I – and I was just so overcome with emotion – the first time that I saw him after he got his, um, diagnosis. And, um – and he stood up, and I was just sobbing. I was sobbing. And he held me in his arms, and he held me really tight, and he – um, I just could not stop sobbing. (F1J: 427-440).

At the time of diagnosis, Lenny tried to be hopeful and realistic at the same time.

And then he was Stage IV at his diagnosis, so, you know, he started going to treatment and he started feeling like, oh, I’m gonna beat this thing. You know, because, you know, the doctor said a year ago that he was going to be – (F1L. 127-130).

For Connie, the daughter of a 48-year-old mother, family history of CRC means having a loved one leave the world in an awful manner and much too fast. Connie lamented about losing her still young mother too fast.

…it’s awfully sad to see a loved one going through a process like that because you start thinking about all the times like when we were kids and, you know, we were playing. You know? We still loved our mom, but we still – um, we still did bad things that we shouldn’t have done. But when the time comes, you know, when she left this world, it was just – it – it—it just wasn’t good at all. You start thinking about all the good times and the bad times. And, you know – and what if and what
could have happened and what should have happened. Um, it’s just a big puzzle that you could put together, you know, on why she left and why did she have to get that diagnosis of this cancer. I mean, she left this world too fast. (F5C. 9-19). Um, that’s the thing about it is, you know, cancer in and of itself can be so cruel, um, when you’re trying to live with the diagnosis. What really stands out to me is initially when my mother was diagnosed, how the perception, I think, in the community was. Oh, it’s colon cancer. You’re gonna survive. That’s not one of the bad cancers so you’ll be okay. Um, and so she was a little – she knew it was serious. She knew it could be life threatening, but because so many people said it’s colon cancer and it’s, you know, slow moving and you really – you know, you you’ll fine. After your surgery, you’ll do a recovery and, you know, you’ll be back to normal in no time. So we expected that outcome going into it because we had been reassured, not just by others in the community who knew people who had it, but also medical staff would say, you know, colon cancer, um, the survival rate is much higher than with other cancers. So, we felt a sort of confidence that we would, you know, survive and overcome. That just wasn’t the case pretty much. So that’s what stands out to me is the community’s perception of colon cancer. (F3S. 11-27).

Caregiving with gusto. A caregiver is the person who gives care to the loved one who needs help. It can be anyone, however, among this group of participants, it is the children of adults diagnosed with CRC. The primary caregiver becomes the driver of how the parents will be cared for upon diagnosis. There is this sense of caring with gusto because the mother or father deserves it. The primary caregiver becomes whatever the parents need them to be. Susie shared her interpretation of caring for her mother as being organic and taking that priority in her life. Organic to her means that is comes naturally without thinking about what to do. She reported,

It was just very organic. Ah, not a lot of thought. Not a lot of questioning why or why me. You know, it’s my mama and she had the need, and I had to make sure her need was met. (F3S. 284-287). It was a pretty natural transition as you would see her getting weaker and her health failing where her needs just superseded or became the priority of the day making sure that she was comfortable, and she felt supported and taken care of, um, simply because he had always done it for us without complaint. Um, and it was kind of like reversing positions in life and me taking more of the parental role to make sure that her needs were met and that she felt loved and not so much of a burden as it was, ah, what I wanted to do. And for me, I never gave it a thought as to why I should or shouldn’t do it. It just needed to be done, and so I did it. So, I don’t know. (F3S. 271-280).
Three participants, Katherine, Lenny, and Jill are healthcare professionals. It was important to consider their professions in order to understand how their responses differ from the other siblings. The role of primary caregiver is taken up as an honor to the parents. For example, Katherine had to assume the role of provider, which was tough. She described the difference between her and her siblings and the family dynamic.

…with me being the provider in the family—the (vocational) in the family—you know, all of my sisters and brothers, and my mom, depended on my knowledge so everybody could have a clear understanding of what was going on. And so, I think it was more of a bigger burden on me because I was the one going to all the appointments, staying over at the hospital. Um, you know, it was—it was tough. But I always had to be, you know, the tough one and not show emotion. So, I didn’t really, um, get to show any emotions, especially in front of my mom, until like the very end. (F2K. 55-63).

Jill, a healthcare professional, described how she responded to being the primary caregiver.

Um, I think the point that was, ah, really, really tough for me—because, um, I became his primary caregiver. Um, in fact, I took an indefinite leave of absence from work and, um, I moved him in with me. Um, after all of the chemo and the surgeries and everything and the doctors said basically there was nothing else that they could do for him, that’s when I decided that it was up to me, and not considering anybody else at that point. I just felt like it was something that—something that I needed to do for my dad. And being a (occupational reference), I just felt like there was nobody else that could—that would take care of him better than I was going to take care. (F1J. 124-133).

Furthermore, Jill viewed herself as the needed translator and navigator during the frequent visits for healthcare. She described the importance of her role.

…I just tried to be very supportive with him. I tried; I was the sounding board for him. I was a translator for him. And I say translator because he would tell me that, you know, whenever he was going to the doctor, you know, “I don’t understand what they’re saying. They might as well be talking in Chinese to me ‘cause that’s about my level of understanding of what they’re telling me.” So, um—so at that point, I started going to every doctor’s appointment with him. I went to every chemo treatment with him. I was in the waiting room when he came out of surgery. I was always the first face that he saw. And, um—because I wanted to make sure that he knew that I was there and that if he had any questions that he needed answered or anything that he wasn’t clear about, I wanted to make sure that he understood everything so that he could make his own decisions—informe
decisions about his care as far as colorectal cancer. (F1J. 449-466).

Not all members of the family were able to assume the caregiving role. For example, Susie tried to engage her older brothers but found that, “some days it worked where they would step up and provide, but it was, you know, me kind of driving it and making sure that she was – that her needs were met” (F3S. 280 -284). In another family, Robert, the younger brother was not ready for direct caregiving. He said, “I kinda stood back for a while. You know, a lot of stuff was going on with the family. And I’m like, no, I don’t want to be a part of that” (F5R. 500-525). In this family, age and gender defined who the primary caregiver would be. Robert, the male in the family, was not raised to be a caregiver and found himself just standing by at times.

Preparing for a parent’s untimely death. Four of the five parents were diagnosed with Stage IV CRC and one parent was diagnosed with Stage II CRC with a brief period of remission and restaged with Stage IV CRC. Discovering the sudden decline of a parent diagnosed with CRC means quickly moving into treatment for a brief period, then end-of-life care. There is a great deal of uncertainty dealing with the short CRC illness trajectory from diagnosis to death. How many young adults are ready to face the untimely death of a parent? Jill never put much thought to the idea.

It was very surreal in the beginning because whenever I was – you know, you – you never think about death and dying with your parents. You know, we think – at least I thought that they were going to live forever (F1J. 211-214). Susie remembers what the doctors said, you know, each time they told us that this is it, she lived beyond whatever that time period was. So, the year before – in March 2010, they told us there was nothing else they could do. Um, they didn’t give her a very long-life expectancy, so we turned up in the doctor’s office a year later and they were shocked to see her because they had assumed that she had passed already. So, they gave us any time from imminent to no more than three to six months. (F3S. 664-672).

Lenny described the downturn that eventually came.
And he came – he went through a whole year and he felt like, you know, he’s gonna be okay. He’s gonna beat it. And then like after that first year went by, he was into that second year. You know, that’s when things really just took a downturn as far as his health, his mind. (F1L. 20-25).

Coping with a burden too great. The life of a daughter whose mother is dying of CRC represents a unique type of experience especially for an only daughter. The mother of Connie and Robert was 51 years old at diagnosis. Connie describes the gender differences in the family that placed a greater responsibility on her for the caregiving. She was 29 years old, the only daughter, and the oldest. The emotional trauma experienced by this daughter is almost too much to bear.

I really couldn’t handle it. Actually, I was – I had a nervous breakdown because I didn’t know what to do. (F5C. 155-156). Because I’m the only daughter and I didn’t know how to, you know, cope with the whole thing. I had to be strong. I couldn’t show anything – you know, what was going on. (F5C.158-160).

During this experience of having a parent diagnosed with CRC, the participants experienced their own life challenges. The stories of one’s own life challenges were told as background noises because the dominant story to tell was their parents’ story. The participants experienced pre-term labor, crisis pregnancy, marriage and honeymoon, two divorces, grieving grandchildren, busy jobs, raising children and making a living.

I was – I was pregnant. The baby was born – my daughter was born two months early and did nineteen days in the NICU. The stress of all that, um, caused me to have to go on bedrest for seven months. And I think a week-and-a-half on bedrest and like your blood pressure is just through the roof. What’s going on? I couldn’t wear shoes. I was swollen. But just couldn’t – I had to support my mom, so it just wasn’t a question of whether or not you got up and did what needed to be done. (F3S. 218-225).

I was having issues with my marriage, but we couldn’t focus on that because, you know, my mom had needs that superseded that. You know, this is life or death. You know, in my mind, I’m thinking let me make her the priority because we were always her priority, and once I get her settled I can deal with whatever else, um, we have to do. (F3S. 252-257).
Jill’s story of her honeymoon and getting the diagnosis day is profound.

I got married on (date reference), and he was very sick that day. On our wedding day, he was very sick. And, um, so after the wedding and everything, my dad, he hung around for a little while, but then he went home. So, um, the next day, ah, I left and I went on my honeymoon. Then I got a call from my sister maybe like two days later – two or three days later – and, she said, um, “Well, we got the results of the biopsy. Um, are you sitting down?” And I’m like, “Well, you know, just tell me. You know, just tell me.” You know? Cause I had already braced myself for the worst. And she said, “Well, Dad has Stage IV metastatic colorectal cancer.” And – and then the tears started because I felt at that point that, um, he had received a death sentence because it was so far gone. So – and, um, she said that the doctors had given him to the end of the year–maybe to the end of the year to live. (F1J. 84-96).

The strategies for coping with the stress of it all included prayer for all participants.

Lenny called on the faith of his father.

The faith aspect just helped me through some of those dark days and some of those dark nights when my dad was at my sister’s house and he was in that hospice bed. You know, just–I knew he was in God’s hands. I knew that his faith was carrying through where he was. (F1L. 257-260).

God had to speak to Katherine to get her attention.

But another thing that helped me, to get through all of that time is, you know, one day when I left the (facility reference) and I was a nervous wreck by myself–you know, driving home and crying–and, you know, I think I told you last time when God spoke to me. And it was like, you know, I’ve been here from day one. You don’t think I’m in control of this? You know? And so, I started looking at it in a different way, ah, from that moment forward. I stopped the crying and I just kind of put my big girl pants on and – and, you know, was there to help her–and help my other family members. (F2K. 103-115).

Susie talked with friends over a glass of wine. However, the struggle was real and ongoing.

I would go days and weeks and not really having any kind of emotional response to anything, and then something would happen, and I would want to pick up the phone and say, “Oh, Mama, guess what?” And it would just hit me like a ton of bricks. So, in those moments, I truly had to deal with it in a way that I hadn’t before. The pain was just very raw to me. And I’ve had to pull over on the highway. I’ve been, you know, preparing to leave home and I’ve had to go back and allow my emotions to have their way. You know, I got in control and felt better once I
released it and I would continue on with whatever I was doing. I think more than anything just talk with myself and a glass of wine with friends (laughter) is what’s really helped me to, I guess, make my way through the emotions and help, you know, try to have a process to handle it. (F3S. 497-509).

Connie had an interesting strategy that may or may not have helped, but she repeated an emotional routine often at the grave site. When asked if she ever thought about why, she said,

I never really thought about why. I mean, I just, I don’t even know if it’s even comforting for me. You know, I don’t know the actual location. But I just stand there. And I, I do that so I can get all of that over in my head on how we had the chairs and how we just sat there. How hot it was. How many people were in cars. I just replay it all over in my head. When I go stand there. And I can just visualize all of it. It’s just, I just can’t stop. (F5C. 670-681).

Susie tried journaling for a while.

I tried to journal through this process, um, but that didn’t work because it became too emotional and I couldn’t control really, um, reactions sometimes. You know, you want to be strong because I did have three children who were having some difficulty with the transition of the divorce, and now the transition of their grandmother. Um, and so I think I was just trying to be so there for everybody else that sometimes it really—being the caretaker, being the daughter and friend through the process as well—I never really—I mean, journaling just wasn’t it. I did some therapy, but that became frustrating for me because there were so many issues that we were trying to work through that it just became very difficult some days. (F3S.477-487).

**Dealing with emotional turmoil.** Emotional reactions to the fact that your parent has been diagnosed with Stage IV CRC is expected of any person. Dealing with one’s emotions was challenging for all eight participants. The five sub-patterns related to dealing with emotional turmoil patterns are 1) anger, 2) depression, 3) hopelessness 4) grief, 5) guilt, and 6) regret. Emotions are a normal part of experiencing a threat to family well-being but nonetheless difficult to control. Katherine admitted that for her “it was tough. But I always had to be, you know, the tough one and not show emotion. So, I didn’t really, um, get to show any emotions, especially in front of my mom, until
like the very end”. (F2K. 400-410). Susie had to bulk up and stay in a survival mode every day. She admitted to feeling like she could not show her emotions and remain authentic in the moment.

I wake up and it’s what do I have to do to make it through the day? What do we have on the agenda for the day? And making sure that everybody is where they need to be when they need to be there. And where do I need to be in that process? So, I didn’t spend – I was tired all the time, um, both mentally and physically, um, and trying hard not to let that show. Because she was really watching me because she didn’t want to feel like she was a burden to me. So, I had to appear that, you know, my days were fine and not complain about whatever it was that was going on. (F3S. 240-260.)

Anger. Anger is a transitive verb which means it is characterized by having a direct object. Living with anger is a common theme across the stories of children of parents with CRC. There is an anger with God and the relative. All eight participants expressed anger, however the direct object of their anger was different, including anger at the parent’s healthcare decisions, anger at losing potential opportunities with parents in the future, and anger with God. Across all of these stories of parents being diagnosed with CRC and dying too soon is the overwhelming sense of regret. It is the looking back and wondering what could have been done differently.

The anger felt about the parent’s failure to adopt preventive health screenings was the most challenging because the parents are now living with a fatal condition. For Lenny, there is the authentic expression of anger, then the retraction back into inauthenticity. Lenny said,

Just angry that, you know, we tried our best to get him into healthcare and get him to go get treatments, and he just didn’t go until he got too sick for it to even matter. And I really wasn’t mad at him. (F11 271-219).

Like Lenny, Robert expressed the same struggle dealing with his emotions. After his mother was first diagnosed, he attempted to make sense of it all.
The first thing that comes to my mind is – is early detection. If she would’ve went in earlier, this—she could’ve beat it. (F1L 13-14). Well, um, I think her diet should’ve been better and things like that. And, ah, the warning signs. You know, like blood in the stool. I talked to her about that. And, you know, when it – when she went in – she got sick and then they found the cancer. And that’s when it really got bad. I think she went in for a lower GI, and that’s when they found it. (F5R. 18-23).

Robert didn’t have a place for anger; he attempted to explain it away. Robert said, “First I was, you know, mad at my mom. Like, wow, why didn’t you go get checked? You know, you had all this time to.” (F5R. 124-127). Then Robert directed his anger at God. He admitted, “I had a little anger at the Lord at the time. You know, why do you want to take someone who’s so faithful? You know, at that time of anger, I didn’t, I didn’t think of Scripture” (F5R. 209-212).

Unlike Robert, Deborah didn’t want to just outright express anger at God.

Sometimes, I know we ain’t supposed to question God, but I’m quite sure people do it. And, you know, sometimes it would just be asking Him why. You know, my mom was, she was young. You know, why? (F2D. 404-406).

Jill was angry at the lost opportunities in the future for spending time with her father.

I was missing him already. I was missing him because I just feel like there was just so much that we hadn’t got a chance to do or say. Because I felt like, you know, all my life I had been cheated out of that opportunity to really get to know the person that my dad was and really get to know him. And in his last days is when I really got to know him. So, you know, it kind of made me angry. And it really sucked because I wanted. (F1J. 529-541).

Out of all the participants, Sabrina alone expressed her anger in front of her father. She later regretted it but remembered the time. “I remember probably, um, when my dad was in the hospital, I got really mad at him. Just some of that came out, you put this on yourself.” (F4S.209212). She went on to regret the anger.

Probably not one of my best moments. And I pretty much told him, like you did this to yourself. Um, and it kind of upset my husband ‘cause he couldn’t believe I
was being so disrespectful of my dad. I couldn’t believe I did that. Husband He was just very disappointed in me. (F4S. 214-218).

**Depression.** Depression is a mood disorder that is marked by sadness, dejection and hopelessness. Susie and Kathrine Two interpret their reactions to CRC in the family as having depression. Kathrine describes her depression and treatment.

But it’s, you know, I guess I went through the – severe depression. I had to actually start taking a medication to kind of help me cope, it started probably – I don’t know. I think I maybe got on something maybe two or three weeks after she was diagnosed because I couldn’t stop crying. Like it’s kind of even hard to put into words the – the – the feeling. And, you know, just like anybody else. You naturally try to go get information and – and try to find people that have survived and how long they survived and -- you know? So, I was just so bogged down. And then, um, so I think probably two or three weeks later, you know, after the diagnosis, I went ahead and started taking something because again I couldn’t stop crying. And I was up all night. And, like I said, I – I would leave the (facility reference) and cry the whole way there. Cry the whole way back driving from (geographical location reference) to (geographical location reference). And I think I started taking Zoloft – maybe Zoloft 50 milligrams a day – and that – it helped me. (F2K.53-103).

**Helplessness.** Helplessness is a feeling of distress due to a perceived lack of control over a situation. Lenny became overwhelmed, “Just to see (crying) – just to see him go through that and there ain’t nothin’ you can do” (F1L. 207-208). His sister Jill similarly expressed, “I can just remember thinking that even though I’m doing all that I can for my dad, he’s still leaving me. He’s still – he’s still going to be gone”. (F1J: 526-259). Katherine was willing to do anything to overcome the feeling of helplessness.

Cause I’m telling you if they’d have said if you walk from (geographical location reference) to (geographical location reference) and that would cure her – I would’ve done it. But anything that money can fix and all this stuff –you know, you can fix this stuff. But when it’s something like that that you’re just helpless. And I don’t like being helpless. (F2K. 550-558).

**Grief.** Grief is an overwhelming emotional response brought on by the loss of someone or something. The loss of a parent to CRC is especially distressful. One type of
grief experienced by caregivers is that of delayed pain. Katherine, the strong one in the family, felt a need to delay grieving because she had to concentrate on caring for her mother.

I guess, ah, since my experience with my mom, um, being diagnosed, ah, with Stage IV colon cancer and, um, going through it, what comes to mind now when I look at it is – is pain. You know? Pain and still just, you know, I guess delayed grief. Um, so even just the word cancer, um, you know, makes me cringe. Um, it’s one of the reasons why, you know, I’m a (vocational reference) now and a big advocate for, um, colon screening. Um, but I would have to say, you know, it’s pain when I look back at the – the entire situation. (F2K.11-18).

Katherine tried to make sense of the world around her while living in grief.

So, I think that’s probably one of the reasons why I have delayed grief now. Yeah, I think I am because again I don’t think I got a chance to grieve properly because, um, I was so, you know, there for everybody else. And then I took care of her in my home, and so I couldn’t let her see me cry. I always had to be in a good mood to keep her in good spirits. And, um, you know, like right at the end, I just – I just told her, you know, I’m sorry. I can’t just – I can’t just act like I’m not sad. You know, so I would cry in front of her in the end (F2K.166-177).

The grief that lingered prevented Katherine from placing the final headstone on her mother’s grave.

I want a real nice one. Like when I do it, I want to get exactly what I want. But what I want is gonna be thousands of dollars. And so, until everything is settled and I’m able to do that with no problem at all – I don’t know. I think I’m just waiting for this burden to be released. It’s not that I haven’t been able to go and buy it. I could’ve bought it years ago, but I don’t want to buy it and not feel a release of some of the grief. (F2K. 473-481).

All eight participants suffered with the effects of grief returning with the holidays and other special days of remembrance. Lenny was interviewed on Father’s Day and found it to be especially hard. He said,

The biggest thing I think and the largest impact this has had on me, you know, like I say, not only just holidays, you know, just birthdays and days like Father’s Day. You know, I still go through the city cause he was my mechanic—and like you said, it’s been like ten years, and I still miss the things he did for me in life and just think how much could I have gained, you know, could I, how much more time we could’ve had. (F1L. 502-521).
Deborah and Susie struggled with grief when Mother’s Day came around again.

It’s hard. I don’t want to be bothered with nobody. And we used to all get together for Mother’s Day and be by the house and stuff. And I don’t think we’ve did it in a while now. And I don’t even think we’ve done held up to what she asked of us before she left here. (F2D. 458-461).

Susie:

I mean, seven years later, I can still tell you my heart hurts some days when I look at things and I see my children – you know, I see milestones where I see other people with their mother. Some days are very hard. Some years Mother’s Day it’s just all I can do to get out of bed. (F3S.705-709).

Sabrina found the first thanksgiving to be particularly tough.

I cried over Thanksgiving cause I felt his presence. Um, well, we were just having a family dinner with me, mom – with me, mom, And I just felt his presence. I can’t remember if we started talking about Dad – funny stories. I can’t remember. I just missed him. (F4S. 451-465).

Connie re-interpreted a popular belief about time healing all wounds.

I’ve come to the conclusion that that’s just a saying when they say time heals all wounds. Because I have to disagree with that. I have to disagree. Cause it’s been five years now I’m – I think I’m a little bit better. But if I had to say on a scale of zero to ten, with ten being really good and completely over it and zero just, you know ah, I would probably say maybe a three. Two or three. But, um, it’s like a – one of the reasons why I say it’s – it’s – that’s not true when they say time heals all wounds because I feel like it took so much out of me. It’s like it took – it just took something out of me that I don’t think I’ll ever get back. I mean, I just haven’t been the same at all. (F5C. 236-392).

Katherine’s experience with holiday grief was so extreme that her son was not allowed to celebrate his birthday because it was also her mother’s birthday.

And then April comes along. Um, it’s her birthday. Um, that’s my son’s birthday. They have – they share the same day. He’s five, and I still haven’t been able to – And I still haven’t been able to have him a proper celebration. Um, I think by next year I maybe will be able to. This year, you know – the first couple years, I mean, I would just be in the bed, couldn’t get up. And this last year or so, it’s almost like I want to block it out and just act like it is no special day. You know? But I can’t keep doin’ him like this. Cause now he’s to a point where he – you know, I would have something at school or something, but it wasn’t no just big celebration. No big party. So hopefully that will change. (F2K. 208-292).
Her grief continued.

And the thing about it is I would say out of ten months, um – like I said, March, April her birthday, then you have Mother’s Day that comes up – um, so Mother’s Day. So, it’s like February, March, April, May. That’s four months that you’re not feeling good. Okay? And then May – or and then you get a little break. You know, June, July, August – you get a little break. And then by August and September, I already start dreading the holidays. And so, you know, out of a whole year, you’re probably talking about maybe a four-month period where I can just kinda go on and be okay. But then you dread the holidays. And when the holidays come, I mean, it’s like a cycle. I mean, you know, you get, um, Thanksgiving, Christmas, New Year’s. All that stuff back to back. And so, you know, by January, you have a month break. February. And they just – the process starts over. And so, like I said, I, I do, I just stay busy, and that’s kinda my outlet. (F2K.294-311).

Guilt. Guilt is a feeling of deserving blame for an offense. Guilt was especially difficult for the participants who are healthcare professionals. Jill felt it deeply.

Just being a (occupational reference) and knowing, I just felt like I—there was something that I could’ve done or should’ve done and I didn’t. I kind of felt like in some respects that I neglected or, ignored the, like ignored, ah, all the signs that something was going on with my dad. And, ah, by the signs, I mean the rapid weight loss. Um, he did complain at times about, ah, not being able to keep food down. Not being able to have bowel movements. So, the signs were there. Um, as a (occupational reference), I just felt like I didn’t dig deeper other than to ask him, you know, had he had his screenings done, prostate and colorectal cancer screening. (F1J. 18-33).

Regret. Regret has to do with mourning over the loss of something. The healthcare professionals express a particular type of regret because they are the healthcare providers in the family. Both Jill and Lenny are healthcare workers who possessed knowledge about CRC prevention, but could not make a difference in their own family. Jill lamented the preventability of CRC.

The one thing that jumps in my mind right away is the fact that, um, my dad had a treatable and a beatable condition that if he would have accepted the screenings early on in life that he could have prevented his death through colonoscopies. And the thing that I learned the most about losing him and that stood out the most was that, um, how preventable and treatable and beatable colon cancer is. So, um,
which makes it very tough to, um, swallow the fact that I did lose my dad to colon cancer. (F1J.12-16).

**Mobilizing the Family Against Colorectal Cancer.** The second pattern to emerge from the interviews is a mobilization not only in caring for the parent with this dreaded disease, but also against CRC in the next generation. This pattern, *mobilizing the family against CRC*, involves three related patterns: 1) *asking questions about heredity*, 2) *realizing own mortality*, and 3) *increasing self, family and community awareness*. This pattern also suggests that experience with parents’ CRC illness is a strong motivational factor for preventing CRC in the next generation. Seven of eight participants show a strong preference for getting screened for the early detection and prevention of CRC.

**Asking questions about heredity.** Preventing CRC from happening again in the family requires gaining and sharing information about the family health condition. When asked about the history of CRC in the family, five participants responded with varying degrees of understanding. Overall, knowledge about family history is, at best, murky for these study participants.

Lenny expressed the clearest knowledge of family history and heredity.

But then his uncle, which is my great-uncle, lived right across the street from us. And Unc used to say, “You need to go to the doctor, man, ‘cause you got the same thing I got. You complain about the same thing.” And my uncle died from colon cancer also; his uncle, which is my great-uncle, died, too (F1L. 56-59).

You know, ‘cause my grandmother, my great-uncle – ah, a couple cousins. You know, his side, a lot of that cancer. My grandmother had colon cancer. (F1L. 385-387).

Katherine:

Because, you know, statistically, genetically I know out of her children, someone is bound to, you know, have cancer. And so, to think that everybody now is getting a little bit older. I have a sister – I have three siblings now that have reached forty and above, and my mom was diagnosed at forty-eight. So, you know, now all I can do is urge them to, you know, get screened. So, it’s just a fear of – of cancer in
itself, you know, with my siblings. (F2K. 29-35).

Jill was convinced that the solution is to ask questions regarding family history. She thinks that her father’s early death from CRC should not be in vain.

Well, I think the most important thing is that I would say to everybody is when there are people, loved ones, that are sick in your family, that are ill, when people die in your family—especially close relatives—first-degree, second-degree, third-degree relatives ask why. Because what I—this whole experience that came full circle for me was that my dad would sacrifice to save his family. And that it can happen to anybody. But you need to know why people in your family died. Because it could be something as preventable, as treatable, as beatable as colorectal cancer. (F1J. 622-643).

**Realizing own mortality.** Katherine: “I guess about maybe six or seven months ago, eight months ago, because I need to get to a point where I can feel okay, realize that we’re all here to die. (F2K. 460-462). Jill reported that when she lost her father, “it made me realize my own mortality”. (F1J. 214-215). Lenny was able to make the connection between longevity and getting screened for CRC, which his father failed to do.

But if he would’ve taken his, um, treatments or went and got that colonoscopy twenty years prior to his diagnosis with colon cancer – because they say it takes twenty years for it to metastasize. He had colon cancer almost twenty years to the date that he was turning down. He was forty-something when his doctor was urging him, “Get your colon checked. Get your colon checked.” And at sixty, that’s when he got diagnosed. And, you know, that was the thing that stands out to me the most is the fact that he had something that he didn’t go get checked, and eventually he succumbed to it. (F1L.26-34).

According to Lenny, the logical response to this awareness was to change his own preventive health behaviors.

Well, the one thing is I try to take a little bit better care of myself. I try to listen to my son like, “Dad, you know, you should do this. You shouldn’t do that. You should be careful where you go. You shouldn’t go and do that security.” You know, just, I think about it because I try to, I think about longevity, but I also, with my dad’s passing, you know, it’s got me on the program to make sure I get my colon checked. I’m probably a little more eager than most to go and get my colon checked. (F1L. 26-34).
Lenny was concerned about how the attitudes of males toward CRC screening creates barriers to prevention.

My dad was like most men, like a man’s man. Didn’t want nobody fiddlin’ around with his backside nowhere. And the thought of somebody inserting something in his backside was his downfall in getting diagnosed and getting treated to the point that he didn’t—he didn’t seek treatment until it was too late—until he had a blockage in his colon. (F11. 19-26).

Lenny recognized the benefits of CRC screening. His family mobilized as a fighting force against CRC. They even made a family pact to have CRC screening and to reach out to other Blacks in the community.

Ah, as far as my family, after my dad passed away, of course we all, we all got together, you know? And, um, you know, basically we made a pact with each other that we were going to eradicate colorectal cancer from our family. And so, every year, I mean not every year, but every three years, three to five years, we have colon cancer screenings. (F1J. 329-333).

The Family Pact against CRC is striking.

As a matter of fact, three of my brothers, um, shortly after my dad passed away, we all had colorectal screenings, and three of my brothers did have, um, polyps. Um, one of ’em had diverticulitis. And so, I, I miss my dad so much beyond words, but, um, I feel like my dad saved, saved lives. He saved my brothers’ lives. You know? You know, I kind of feel like he was the sacrifice of our family. (F1J. 329-339).

Fear of screening. Fear is the unpleasant, often strong emotion caused by anticipation or awareness of danger. The type of fear that Deborah described is an emotional state that paralyzed and prevented her from making any definitive decision or actions, such as completing a CRC screening. Her mother died from CRC five years ago and she has not been screened because of fear. Her reasonings,

I was scared. I didn’t want to get checked. I didn’t want to know. But I know that’s not the best route to go, not knowin.’ I need to know. I need to go get, you know, checked out because it could be, you know, early prevention is the best. You know? Like I told you, just scared. Not really wanting to know. And I know that’s not the right way to go. If you heard the words cancer. To me, those words alone was scary to me. Because when people hear cancer, they automatically think I’m gonna die. You know? So just — I just didn’t want to go ‘cause I didn’t want to
hear no kind of bad news at all. But with them goin’ ahead and doin’ what they had to do, it just made me realize I might as well get checked because it could be, you know, preventative if it’s in the early stage or they get to take it out or remove whatever needs to be removed. And I was also afraid of surgery. (F2D. 29-59).

**Increasing self, family and community awareness about CRC.** Four of the participants recognized the importance of education about CRC for one’s self, family and the Black community. Jill started with her own self-awareness,

> It made me, um, it made me dive into researching colon cancer. Um, and when I started researching it and found out how curable and treatable it is – um, how much of a disparity that there is, um, for people – um, it really touched me in a way, um, that was very – I just knew that I didn’t want anybody else to die from colon cancer. And I didn’t want anybody else to feel what I was feeling. (F1J. 229-237).

**Self-awareness about CRC.** The self-awareness about CRC in the family cause Lenny to think about his own health and lifestyle behaviors. Lenny said, it’s just made me want to take care of myself more and do more for, not just for myself, but for the people that love and care about me.” (F1L. 32-36).

**Family Awareness.** All participants were asked about the types of health-related conversations that have occurred over the years. Although no direct conversations occurred between the participants and their parents about CRC, all of them report having conversations with their siblings and own children. Susie described this.

> My brothers and I had a very candid conversation about it. Ah, we’ve all talked about, um, how we want to do more things around awareness. Colon cancer awareness. But we’ve not really done anything actually around the issue. (F3S. 778-792).

The benefits of CRC screening are real for Jill. She was convinced that CRC would not take away her siblings. She said,

> When my brothers had polyps removed, and like I say, my youngest, the youngest brother was, um, thirty-eight, that really blew me away. And the one thing that I can remember saying is, “Lord, I thank you.” Although you took my dad, I thank
you.” Because he would’ve been going down that road again. (F1J.370-378).

Lenny was determined to break down a male-specific barrier to CRC screening in his life and the life of his 13-year-old-son.

Ah, my dad was like most men, like a man’s man. Didn’t want nobody fiddlin’ around with his backside nowhere. And the thought of somebody inserting something in his backside was his downfall in getting diagnosed and getting treated So, you know, I, I understood what the doctor was gettin’ at when he was saying, “(Name reference), you need to get your colon checked,” and all of that. But, you know, I just, you know, I just really thought about what a tragedy that, you know, you have to, that either you’re not educated enough to the point to know that this is something that’s gonna save your life and that you’re just too manly to allow medical things to transpire. Or just not educated enough to the point that you only go to the doctor when something is really, really bothering you. And that’s a problem, I think, that our black men have when it comes to, um, when it comes to getting ourselves checked out, either because the healthcare is not available or we’ve got superstitions about certain things or we feel like in order to be gravely ill, you have to be hurting. Because most things that’s gonna kill you—what I found out—don’t even hurt and you don’t know it until the last minute, but then it’s too late. (F1L. 19-97).

Lenny also said:

Yeah, it was, it was just a tragedy, you know, just because, you know, we all tried to encourage him to go get his prostate checked. You know, get your colonoscopy. You know? And it’s just a tragedy because, you know, I’ve seen polyps getting taken out. And some people from year to year, you know, they have a ton of those polyps in that little thing. And it’s like, wow, they’re growing that fast? You know? The tragedy of it all was that we all tried to make him go and get treated and all of that. And, you know, he opted not to until he got sick, which we all had to sit by and wait on the inevitable. (F1L. 103-111).

Communicating with the next generation to increase family awareness was a major concern for all. Jill declared, “I wanted my legacy to be for my children. And that this disease that claimed my dad, that it would never claim another life in this family.” (F1J. 221-222). When Robert’s children are older, he wants them to be able to recognize the signs of CRC and feel free and open enough to say, “Hey, I’ve got blood in my poop.” (F5R.479-480). Deborah and Connie have children in their twenties and they have
discussed with them the need to get checked and know the signs and symptoms of CRC.

*Community Awareness.* Jill, Lenny and their entire family ‘took the fight’ to CRC and mobilized an outreach to the entire Black community. Jill talked about how having a father who died from CRC ignited her and her family.

So, because of that, it put a fire inside of me and I started researching on how to start, um, a nonprofit organization for colon cancer. And I wanted to teach and let people know that they don’t have to die from colon cancer. And then once I got my 501(c)(3), then I began to go out into the community, go to churches. I would have the event within the community, ah, that was teaching awareness, prevention, what to do if you get a diagnosis of colon cancer. And my main goal was to be able to raise enough money, um, that I would have a fund that when people who needed colorectal screenings, that they could come to my foundation and we would, um, give them a grant. And I worked with different organizations – American Cancer Society, the Colon Cancer Coalition. I worked with the Relay for Life, which is the American Cancer Society. We did, also I did radio, um, advertisements and interviews. And all this was kind of a collective effort with my family. (F1J. 239-255).

This family made a concerted effort to target the ‘manly-man’ attitude in the Black community. Jill described how effective her brothers were in communicating to other Black men about CRC screening.

And, actually, my one brother was very instrumental. Because, you know, for some reason men, as a whole, they don’t like to talk about, um – they don’t like to talk about their bottoms. They are very, very, you know, they don’t want it touched. (Laughter.) They don’t want to talk about it. But, um, my one brother was very instrumental. He is a very good speaker. And he got a lot of feedback when he would go out to the different seminars. And he would speak, you know, he would get guys that were lining up to come to ask him questions whereas, you know, they wouldn’t come to me and ask me questions. But they would ask him, which was fine. It didn’t matter how they got the education. The point was that they were getting the education (F1J. 391-405).

And, and I was, you know, we were getting the word out. You know? So, I was, I was very pleased with, um, the fact that, you know, that they were responding, you know, to my siblings the way that they were. Especially the men. (F1J. 413-416).
Unlike the hypervigilance displayed by Jill, Lenny and their entire family, Susie contemplated her actions toward defeating CRC.

I have a lot of thoughts; I just don’t have a lot of time. And I have to make time to do something because this, you know, really changed our family. And it changed me in such a profound way. And I feel like I’ve gotta do something, you know, to help somebody else. I don’t know the process. I want to avoid it altogether, um, especially in light of the fact that we were thinking about how come. (F3S. 794-804).

**Chapter Summary**

Two patterns emerged from eight in-depth hermeneutic interviews from the young adult sons and daughters of five Blacks diagnosed with Stage IV CRC. The patterns are *experiencing a shortened illness trajectory* and *mobilizing the family against CRC*. The overarching pattern, *experiencing a shortened illness trajectory*, and *mobilizing the family against CRC*, along with five related sub-patterns, has been described using the words of the participants.

In Chapter 5 a discussion of the study’s findings and a synthesis of knowledge gained from this study, alongside the current literature, is provided. Chapter 5 also includes a discussion of the limitations of this research, recommendations for future research, and implications for policy, education, and clinical practice.
Chapter Five: Discussion of Findings

This study was conducted to advance the understanding of how Black Americans suffer a disproportional burden of CRC in comparison to other racial and ethnic groups in the U.S. The purpose of this study was to understand the meaning of a family history of colorectal cancer (CRC) for adult relatives, aged 18–49 years, of first-degree Black family members diagnosed with CRC at any stage of the cancer care continuum. In addition to furthering the understanding of the disproportional burden of colorectal cancer in this population, the specific aims were to: 1) generate an interpretation of the meaning of a family history of CRC for adult first-degree relatives and 2) to understand how the experience of family history of CRC influences future disposition about CRC, cues to action, patterns of responses, and ideas about personal health behaviors.

Summary of Findings

Cancer health disparities include differences in not just the prevalence, incidence, mortality, and survival rates but also a disproportional suffering in families with early onset and late-stage diagnosis. The findings of this study give new meanings to the characterization of Black race CRC disparity as a disproportional burden of suffering for Blacks in the U.S. The meaning of a family history of CRC shows itself as a shortened illness trajectory and mobilization of the family against CRC in the next generation for the young adult sons and daughters of Blacks diagnosed with the disease.

**Experiencing a Shortened Illness Trajectory.** Experiencing a shortened illness trajectory includes the overlapping sub-patterns: facing a dreaded diagnosis, caregiving with gusto, preparing for the untimely death of a parent, and coping with a burden too great. Late-stage presentation contributes to 60% of the survival differences in outcomes
between White and Black patients (Robbins, Siegel & Jemal, 2012). The average years of survival for the parents of the participants was 3.8 years with a range of 1-7 years. The survival rate of Whites in the U.S. is increasing as the quality of cancer care improves. A study of the 5-year survival rates by race/ethnicity and age in the United States shows increased survival for all groups except Blacks and Hispanics (Sineshaw, Robbins & Jemal, 2014). Considering the report on survival rates for Blacks, it is not surprising that a family history of CRC shows itself as a *shortened illness trajectory*. Lower survival rates for any population are a function of low uptake of CRC screening and early detection. Likewise, lower screening rates are a function of lack of information, awareness and timely risk assessments.

The barriers to CRC screening are multifactorial and a complex mixture of system, provider, and patient-level factors. The most common barriers to CRC screening reported by Blacks include no provider recommendation and lack of awareness and knowledge about CRC disease and screening tests (Gwede, et al., 2010; Agho, et al., 2012; Berkowitz, Hawkins, Peipins, White, & Nadel, 2008; & Goldsmith & Chiaro, 2008). Over the years, Blacks have repeatedly reported lack of knowledge as a major barrier to screening (Wong, et al., 2013a; Sly, et al., 2013; Griffith, et al. 2012 & Robison, et al., 2011). Knowledge deficiencies relate to a lack of understanding regarding the benefits of CRC screening (Wong, et al., 2013b; Griffith, et al., 2012) and a lack of knowledge about CRC (Harden, et al., 2011; James, et al., 2011).

*Mobilizing the Family Against Colorectal Cancer.* The second finding showed itself as a *mobilization of the family against CRC*. The participants of this study reported a strong tendency toward intentions to prevent CRC in their families. All had
conversations with other siblings and children about the symptoms of CRC and the benefits of screening. However, intentions alone will not reduce CRC racial disparity among Blacks.

Completion of an appropriate CRC screening test prevents the development of the disease. The adherence to CRC screening is only 87% in this group of participants. One of the participants had intentions to be screened for CRC but failed to do so five years after the death of her mother. The other seven participants have completed CRC screening and adopted preventive behaviors and a hypervigilance about preventing CRC from occurring in the family again. Participants’ actions toward fighting CRC range from inaction to direct actions within the family and within the Black community.

Niemela, et al., (2016) introduced the concept “cosurvivors” (p. 1381) which views the family unit as the targeting of health-promotion interventions for cancer prevention. The family members in this study, as cancer cosurvivors, must manage the stress of caregiving and their own lives simultaneously. The need to target cosurvivors is a positive call to action because this study has revealed the everydayness of the struggles to care for a loved one who has been diagnosed with Stage IV CRC as a burden too great.

**Findings Related to Extant Literature**

In the literature, quality cancer care is conceptualized as the ‘cancer care continuum’ which includes: risk assessment, primary prevention, early detection, diagnosis, treatment, survival-ship and end-of-life (see Figure 3). In 2013, the Institute of Medicine (IOM) revisited the 1999 report to reassess the quality of national cancer care. The IOM published the report, *Delivering High-Quality Cancer Care: Charting a New Course for a System in Crisis* (2013), to explain the continuing failures of the healthcare
system and make new recommendations. The committee reported on the failures that contribute to persistent disparities across the continuum of care which include the need to improve primary care for vulnerable and underserved populations. The IOM also published *Ensuring Quality Cancer Care* (1999), a report on the failures in steps and transitions in cancer care. This report stressed the importance of providing quality cancer care along the entire cancer care continuum. The IOM presented the “Model to Improve Quality: The Cancer Care Continuum” (MIQ: CCC, 1999) as a framework for understanding how the nation’s delivery of cancer care could be improved.

**Figure 3**

*Cancer Care Continuum*

The MIQ: CCC categorized the failures in cancer care into two categories: breakdowns in specific types of care and breakdowns during the transitions between types of care. These areas of concern have been corroborated in the current study and signal the needs to be targeted for intervention.

**Limitations**

The findings of this study are limited to a small group of family members and may not represent all experiences of Black relatives. However, understanding the experiences of the cohort in this study will lead to better understanding and the production of culturally-specific knowledge that can be translated rapidly into clinical
practice and the development of family-based interventions to increase screening among high-risk relatives of Blacks with CRC.

**Implications of Findings**

The implications for use of the findings from this hermeneutic phenomenological study include the areas of education, research, policy, and clinical practice. This section will discuss how the findings can inform nursing research, education, practice, and policy.

Recently, the National Colorectal Cancer Roundtable (NCCR), a national collaboration of public, private and voluntary organizations, announced a national initiative to increase CRC screening rates in the U.S. to 80% by 2018. Achieving the goal of increasing CRC screening uptake to 80% could potentially avert 288,000 new CRC cases and 200,000 deaths over the next 20 years. To achieve the NCCR goal to increase CRC screening uptake to 80%, approximately 24.4 million additional individuals need to have screenings (Fedewa et al., 2015). Achieving this goal means improving the awareness of CRC in the Black community and among medical providers including doctors and nurses.

**Recommendations for Future Research.** The question of meaning of a family history of CRC must be further explored among larger families with members younger than 30 years. The importance of understanding how to intervene and promote primary prevention across the age span is clear. Nurses encounter family members across the cancer care continuum. Study participants reported that they, as primary caregivers, were present for each of their parent’s medical appointments. We need to think ‘out of the
Box,’ think literally about how to reach family members of cancer patients who live ‘outside’ the healthcare system for reasons related to lack of access or lack of trust. There is a need to consider all potential avenues, just as Gonthier, et al. (2018) explored the implications of palliative care professionals who helped increase awareness regarding cancer screenings among the families they served. Other recommendations include investigating the following questions:

- What is the appropriate age to start promoting CRC screening in Black families?
- How useful is a family-based intervention to increase CRC screening?
- Can cosurvivors be targeted for interventions to prevent CRC?
- How accurate is patient-reported family history?
- For patients diagnosed with CRC, what, if anything, do they understand about their relative’s risk of CRC?
- Do patient information privacy policies facilitate or hinder the sharing of family health information?

**Education.** Today’s nurses’ practice in an era of evidence-based practice, quality of care paradigms, and post-genetic code breaking. The Institute of Medicine (IOM) has been a driving force in promoting higher standards in nursing education and practice. In 2003, the IOM published the report, *Health Professionals Education: A Bridge to Quality*, calling for core competency requirements for all health professionals’ education to enhance the quality of care in the U.S. Nursing educational standards were reformed to include these competencies such as the “Quality, and Safety Education for Nurses (QSEN) to meet the challenge to improve the quality and safety of the healthcare system
(Cronenwett et al. 2007). The goal of the QSEN project is to prepare nurses with the knowledge, skills, and attitudes (KSAs) needed to improve the quality and safety of patient care within their practice settings. There are six core QSEN competencies for nursing: patient-centered care, teamwork and collaboration, evidence-based practice, quality improvement, safety, and informatics.

Opportunities abound for nurses to improve in the delivery of quality care as well as improve their competencies in other important areas related to this study, especially cultural and genomics competency. Montgomery (2017) outlines the knowledge nurses need to acquire in the 21st century in order to better deliver quality care in terms of genomics. Nurses need to know how:

- To gather family history
- To identify heredity risk
- To make appropriate referrals for genetic testing and consultations
- The relationship of genetics and genomics helps in the prevention and screening of diseases like CRC
- To help individuals and families understand genetic test results
- To provide support for individual/family decision-making
- To encourage completion of recommendations for screening and treatment

**Practice.** In addition, nurses need to have cultural competency in order to best care for ethnic/racial minorities across the cancer care continuum. The “Expert Panel on Cultural Competence of the American Academy of Nursing” developed a position paper to ignite substantive action on the part of nurses to promote outcomes that reduce and eliminate health disparities among vulnerable populations across the U. S. (Giger &
Davidhizar, 2007). All nurses can contribute to ending Black CRC disparity. For example, oncology nurses have a unique opportunity to facilitate CRC screening because they interact with CRC patients, family members, and friends across the cancer care continuum. Nurses working in primary and acute care settings, across a range of practice areas, can facilitate CRC screening awareness. Nurses in other settings meet CRC patients, family members, and friends in primary care, public health, gynecology, gerontology, intensive care, medical-surgical, home care and hospice. For example, Gonthier, et al., (2018) investigated how palliative care providers responded to the concerns of end-of-life patients and relatives about their family history of cancer. These findings revealed a knowledge gap and low confidence level among doctors and nurses in responding to concerns about family history.

**Policy.** Collecting family health history is an important consideration for healthcare providers to deliver high-quality patient-centered care. The American Society of Clinical Oncology (ASCO) published an expert statement recommending the collection and use of family history for oncology providers (Lu, et al., 2014). If the quality of cancer care is to improve for ethnic/racial minority patients, healthcare providers must make the collection of family health history a priority. Preventing CRC begins with family health history and risk assessment.

**Chapter Summary**

This hermeneutic phenomenological study examined the meaning of a family history of CRC for young adult sons and daughters of parents who have been diagnosed with CRC. The participants reported on their perspective and experiences regarding their parents’ short illness trajectory following a late-stage diagnosis of CRC. Because of
these in-depth hermeneutic interviews, the voices of eight sons/daughters have been heard. They shouted that no one should experience this kind of loss to a preventable disease like CRC. They identify CRC as a thief that sneaks into a family with the intent of taking the lives of their parents long before it is time. The meaning of a family history of colorectal cancer for Blacks in the U.S. shows itself as a shortened CRC illness trajectory because of the disparity in cancer care from risk assessment to screening. CRC enters the family as a dreaded disease at diagnosis as family members, in this case the sons and daughters of parents diagnosed with Stage IV CRC, struggle with the untimely death of a loved one.

Will this disproportionate burden continue in the Black community? The findings of this study show that the trend may be changing because most of the participants know that CRC is preventable, beatable and treatable if detected. The mobilization of the family against CRC through increasing self, family and community awareness shows itself as a promising tool for potential change among the next generation.
Epilogue

This research journey began some years ago because of my belief that no one should die from colorectal cancer, no matter their race or ethnicity. As stated in Chapter 1, “The rationale for this study emanates from a desire to promote the primary prevention of colorectal cancer which is one of the most preventable of all types of cancers. The translation of advances in CRC prevention from science to practice has not fully benefited all patients. While some population groups have enjoyed a steady decline in CRC incidence and mortality rates, this has not occurred among the Black population, for reasons that are not yet fully understood.”

Upon conclusion of this study, a simple truth stands—no one should die from colorectal cancer. The blessings of scientific advances can improve the lives of all citizens equally if they are made available and the public recognizes their benefits for well-being. The participants of this study have affirmed my belief and commitment to this endeavor. As their voices so clearly documented their journey through a parent’s arduous battle with CRC, my brief journey with them can now also be given a voice. The following account is presented as evidence of the effect of this study upon me as a researcher—another voice.

During the long immersion into the data, I felt like I was tangled up in a knot and could not see my way through. Then one day, while I was out walking and listening for the voices of the participants, I had a life-changing encounter that helped me examine my own personal values about the stories people shared with us about themselves. When I finished my walk, I stepped in the doorway and realized that all those transcripts were ‘sacred’ texts and should be handled with extreme care and honor. The participants in
this study were ready to talk to someone who was willing to take the time to simply ask, “How are you doing?” How is that for the description of a methodology? Had I not been willing to set out on this Ph.D. journey because of the belief that no one should die from CRC, I would not have discovered how important it is to slow down and listen to others.
References


skills to explain an often-overlooked participants’ response. *Medical Decision Making*, 35(4), 436-45.


MEANING OF A FAMILY HISTORY OF COLORECTAL CANCER


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Martinez


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Appendices
Appendix A
Interview Protocol

Phase One: Time of Introductions, Explanation of Purpose and Procedures

Procedures before the In-depth Interview

- Describe the research project and how the semi-structured interview will be used.
- Explain the use of the audio recorder and selection of a pseudonym.
- Explain issues related to confidentiality and ethical issues.
- Ask for permission to audio-record the conversation.
- Discuss, read, and sign the informed consent.
- If the participant refuses to sign the consent, thank them for their time and end the discussion. Offer each participant a packet of information about family history of CRC after the interview and/or conversation.
- Have the participant complete and sign the Consent for Participation in the Study of the Meaning of Family History of Colorectal Cancer in Appendix B.
- Have the participant complete the Demographic Survey located in Appendix C.

Phase Two: The Interview

Procedures during the Interview

- Create an atmosphere in which the participant can give spontaneous, rich, non-judgmental narratives.
- Use interview guide for a semi-structured interview; see Appendix D.
• Respond to the participant’s narrative by using prompts in the interview guide.

• Offer the participant an opportunity to share relevant information not addressed in the interview.

**Phase Three: Ending the Interview**

Procedures after the Interview

• Thank the participant for their time and allow them time to reflect on the experience.

• Ask the participant to refer others who meet the inclusion criteria.

• Highlight the fact that the issues raised during the interview are important and there might be a need to discuss them with others such as family, friends, or a doctor.

• Give the participant an informational packet on family history of CRC.

• Have participant sign necessary paperwork for receiving a gift card.

• Give participant a $25.00 gift card as compensation for their time once paperwork has been signed.

• Thank the participant again, shake hands, assure the confidentiality of their responses, and request permission to call should questions arise.

**Phase Four: Post-Interview**

Procedure after the Interview

• Make field notes about interview in journal.

• Secure the digital recorder and field notes.

• Return all data and notes to the secure location on campus.
• Send the audio recording to transcriptionist by uploading to a secure Google Drive.
Appendix B

Informed Consent for Participation in the Study of the Meaning of a Family History of Colorectal Cancer

Participants _____________________________ HSC Approval Number ______________________

Principal Investigator: Cassandra Loggins PI’s Phone Number: 314-853-5721

Please listen carefully as I read this information to you. When we begin the recorded telephone interview I will ask you if you were provided with an informed consent reading and I will confirm that you understand your rights to participate or to stop at any time, and that you are fully willing to proceed.

1. You are invited to participate in a research study conducted by Cassandra Loggins and Roxanne Vandermause. The purpose of this research is to understand your experiences of being a close relative of someone living with colorectal cancer or now deceased as a result of the disease. By you sharing your personal experience, we can think about ways to help Black American families cope with and prevent the disease in other family members.

2. Your participation will involve:

   ➢ Participating in a recorded face-to-face interview. Approximately 10 close relatives from Black families with colorectal cancer will participate in the research. The study has been reviewed by the University of Missouri-St. Louis.

   ➢ The interview is an open conversational exchange that is expected to take approximately 60 minutes, depending upon how much or little you want to share. You will be asked to describe a situation or experience because of what it means to work with nurses of different generational groups. I will ask some questions about these descriptions but you will direct the conversation as you wish. Together we will explore how work situations relate to your desire to stay or leave your work setting and how working across age groups affects these issues.
➢ The entire interview will be audio-recorded and transcribed verbatim by an experienced transcriptionist living in another state. She will take all names and identifying features out of the transcripts so that the data is completely anonymous. The audio-recordings will be destroyed once the de-identified transcripts have been checked for accuracy. In the meantime, audio-recordings and de-identified transcripts are exchanged via a password-protected secure system. The de-identified transcripts will be kept indefinitely for research and educational purposes only.

➢ You will be given a $25.00 gift card as a token of appreciation for your time. I will give you a link to claim your gift and you will not need to give me your name or contact information.

3. There are no anticipated risks associated with this research. It is possible that you will experience some discomfort if you have troubling experiences to relate. Talking about family health experiences related to cancer may be stressful. As an experienced interviewer, I will do my best to conduct a comfortable interview.

4. There are no direct benefits for your participation in this study. However, your participation will contribute to knowledge about colorectal cancer in Black American families and may contribute to prevention of disease in these communities.

5. Your participation is voluntary and you may choose not to participate in this research study or to withdraw your consent at any time. You may choose not to answer any questions that you do not want to answer. You will NOT be penalized in any way should you choose not to participate or to withdraw.

6. By agreeing to participate, you understand and agree that your data may be shared with other researchers and educators in the form of presentations and/or publications. In rare instances, a researcher’s study must undergo an audit or program evaluation by an oversight agency (such as the Office for Human Research Protection). That agency would be required to maintain the confidentiality of your data. In addition, all data will be stored on a password-protected computer and/or in a locked office.

7. If you have any questions or concerns regarding this study, or if any problems arise, you may call me, Cassandra Loggins, at 314-853-8521. You may also ask questions or state concerns regarding your rights as a research participant to the UMSL Office of Research Administration at 314-516-5897.

Participant's Signature __________ Date __________

Signature of Investigator or Designee __________ Date __________
Appendix C
Demographic Survey

Date of Interview __________  Participant Research ID# __________

1. What is your gender? _________

2. What is your age? _______years

3. What best describes your marital status?
   1=Unmarried
   2=Married
   3=Divorced
   4=Separated
   5=Widowed
   6=Living with partner
   7=Prefer not to answer

4. What is the highest level of education you have completed?
   1=Grade school education
   2=High school graduate or equivalent
   3=Trade or vocational degree
   4=Some college
   5=Bachelor’s degree
   6=Graduate or professional degree
   7=Prefer not to answer

5. What best describes your employment status?
   1=Employed
   2=Unemployed
3=Disabled

4=Prefer not to answer

6. What range of income best describes your annual household last year?
   1=Less than $10,000
   2=$10,000 – 19,000
   3=$20,000 – 39,000
   4=$40,000 – 59,000
   5=60,000 and above
   6=Prefer not to answer

6. Religious beliefs
   1=Christian
   2=Islam
   3=Catholic
   4=Other
   5=Prefer not to answer

   **Family Colorectal Cancer Health History**

1. What first-degree relative in your family has been diagnosed with colorectal cancer?

   1=Father
   2=Mother
   3=Brother
   4=Sister
   5=Son
6 = Daughter

2. What best describes the stage of your relative's cancer journey?
   1 = Diagnosis
   2 = Treatment
   3 = Relapse
   4 = Survival
   5 = Terminal
   6 = Deceased

3. At what age was your relative diagnosed?
   1 = 20 - 29 years
   2 = 30 - 39 years
   3 = 40 - 40 years
   4 = 50 years and above

4. How many years of survival does your relative celebrate?
   1 = 1 - 4 years
   2 = 5 - 10 years
   3 = 10 plus years

5. Have you ever had any type of colorectal cancer screening?
   1 = No
   2 = Yes
   1 = 20 - 29 years
   2 = 30 - 39 years
   3 = 40 - 40 years
   4 = 50 years and above
Appendix D
Interview Guide for Phenomenological Study of the Meaning of a Family History of Colorectal Cancer

Opening Interrogative:

As you know, I’m interested in understanding how to assist in the prevention of colorectal cancer in Black American families who have a member diagnosed with colorectal cancer. I would like to know as much as I can about your experience of being a close relative of someone living with colorectal cancer or now deceased as a result of the disease. By you sharing your personal experience, we can think about ways to help Black American families cope with and prevent the disease in other family members.

I’ll be audio-recording the interview, and I’ll tell you when I start the recorder.

I will start the interview by asking you to complete a short survey about some basic information about your family, age, race, income, education, where you live, and about your history with having a colorectal cancer screening test. After this survey, I will start the recording and begin our conversation about your experiences.

I’ll ask an opening question, and then we’ll talk about your experiences as you tell me about them. Feel free to think for a while, take as much time to think as you like, and get comfortable. When you’ve said all you want to say, we will stop. The recording will be typed word for word, and any possible identifiers (your name, the names of others, places, anything unique that could identify you) will be taken out of the transcript used for the analysis.

Do you have any questions at all about the process? OK, let’s begin …

Hi, NAME…We’ve already talked about this study, and I’ve started recording our conversation. As you know, I am interested in your experiences of being a close relative of someone living with colorectal cancer or now deceased as a result of the disease. I’d like to begin by asking you…. 
As you think about what it’s like to be a close relative of someone diagnosed with colorectal cancer (alive or deceased), is there anything that stands out for you? Is there a situation or a story that comes to mind?

**Possible subsequent inquiries:**

Tell me more about the inquiries.

What was that like for you?

Does anything else come up around that?

What else was happening that day?

Anything more you remember?

Was there anything else going on?

Can you think of a “for instance”?

What did others say to me about the inquiries? Is that anything like your experience?

That’s interesting, isn’t it?
Appendix E
Research Team Members for Data Analysis

Cassandra Loggins, PhD. Student
Roxanne Vandermause PhD, RN
Shawn Manies PhD. Student
Lisa Cummings, PhD. Student
## Appendix F

### Data Codes

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Appendix G

Summary of Analysis Results

The following tables indicate the patterns/sub-patterns that emerged during data analysis and the categories that contributed to them. The categories included in each pattern/sub-pattern emerged during the implementation of Steps 6 and 7 of the analysis procedures developed by Vandermause (2011). The categories were grouped into patterns/sub-patterns in Step 8.

Pattern I

*Experiencing a shortened illness trajectory*. Eight out of eight participants contributed data to this pattern and 352 data units/codes were grouped into it during analysis. Table G1 indicates the patterns and sub-patterns that were grouped into the first theme, the number of participants who contributed data to each pattern, and the number of statements across all interviews that were included in the pattern.

Table G1

*Patterns and sub-patterns of Shortened Illness Trajectory Data Codes*

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<td>reduced mental state</td>
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<td>sudden remission and return of cancer</td>
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<td><strong>tragedy of ignorance</strong></td>
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<td><strong>moving to care for family</strong></td>
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<td><strong>letter of love-letting go</strong></td>
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<tr>
<td><strong>meeting last wishes</strong></td>
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<tr>
<td><strong>savoring a shake</strong></td>
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<tr>
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<td>4</td>
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<tr>
<td><strong>time with grandkids</strong></td>
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<tr>
<td><strong>reassured by supportive spouse</strong></td>
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<td><strong>remembering the good times</strong></td>
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<td><strong>seeking closure-release</strong></td>
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<tr>
<td><strong>son looks like grandma</strong></td>
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<td><strong>what would mama do</strong></td>
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<tr>
<td><strong>quality time</strong></td>
<td>8*</td>
<td>43*</td>
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<tr>
<td><strong>caregiving and bonding</strong></td>
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<td><strong>family gatherings and travel</strong></td>
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<td><strong>giving a break to caregiver</strong></td>
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<td><strong>letter of love-letting go</strong></td>
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<td><strong>meeting last wishes</strong></td>
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<tr>
<td><strong>savoring a shake</strong></td>
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<tr>
<td><strong>saying goodbyes</strong></td>
<td>3</td>
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<td><strong>continued pain and grief</strong></td>
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<td><strong>gratitude at catching siblings early</strong></td>
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<td><strong>holidays hurt-grief returns</strong></td>
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<td><strong>no regrets - at peace</strong></td>
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**MEANING OF A FAMILY HISTORY OF COLORECTAL CANCER**

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<th>Event</th>
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<td>anger at pending loss</td>
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<td>disrespectful to show anger</td>
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<td>burden of being the strong one</td>
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<td>cheated of time-let down</td>
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<tr>
<td>grief delayed-multiple life changes</td>
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<td>depression</td>
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<td><strong>Distress at diminishment</strong></td>
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<td>fear-being at risk</td>
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<td>guilt at negative thoughts</td>
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<td>guilt at not doing more</td>
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<td>helplessness</td>
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<td>avoidance of grief-survival mode</td>
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<td>denial</td>
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<td><strong>Overcome with grief</strong></td>
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<td>shock-disbelief</td>
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<td>struggling to adjust</td>
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<td><strong>Patient's emotions</strong></td>
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<td>feeling diminished</td>
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<td>optimistic beginning treatment</td>
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<td>softening in relationships</td>
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<td><strong>Tired of fighting</strong></td>
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<td>8</td>
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<tr>
<td><strong>Impact on other family members</strong></td>
<td>8*</td>
<td>41*</td>
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<tr>
<td><strong>Influence of faith</strong></td>
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<td>25*</td>
</tr>
</tbody>
</table>
MEANING OF A FAMILY HISTORY OF COLORECTAL CANCER

helped in processing-making sense of grief
inaction falling back on faith-in God’s hands
time with grandkids

Note. Values marked with an asterisk are aggregates of the values for the sub-patterns.

Pattern II

Mobilizing the family against CRC. Eight out of eight participants contributed data to this pattern and 116 data unit/codes were grouped into it during analysis. Table G2 indicates the codes that were grouped into the patterns and sub-patterns.

Table G2

Patterns and sub-patterns of Family Mobilization Data Codes

<table>
<thead>
<tr>
<th>Patterns and sub-patterns</th>
<th>Number of sources contributing</th>
<th>Number of data units included</th>
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</thead>
<tbody>
<tr>
<td>family history of CRC and cancer</td>
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<tr>
<td>perception as treatable and beatable</td>
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<td>7</td>
</tr>
<tr>
<td>personal impact</td>
<td>8*</td>
<td>75*</td>
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<tr>
<td>actions-reaching out</td>
<td>7*</td>
<td>25*</td>
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<tr>
<td>fulfilling a promise</td>
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<tr>
<td>information seeking on cancer</td>
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<tr>
<td>plans to honor the dead</td>
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<td>2</td>
</tr>
<tr>
<td>raising awareness</td>
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<td>4</td>
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<tr>
<td>responsible for own household</td>
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<tr>
<td>starting a non-profit</td>
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<td>6</td>
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<tr>
<td>health practices</td>
<td>7*</td>
<td>25*</td>
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<td>Value 1</td>
<td>Value 2</td>
</tr>
<tr>
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<td>---------</td>
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<tr>
<td>focus on self-care</td>
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<tr>
<td>getting screened</td>
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<td>19</td>
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<tr>
<td>perceptions</td>
<td>8*</td>
<td>25*</td>
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<tr>
<td>ask why</td>
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<td>3</td>
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<tr>
<td>limited conversations about CRC</td>
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<td>more aware of health as a family</td>
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<td>10</td>
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<tr>
<td>Importance of education in responding to CRC</td>
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</table>

*Note.* Values marked with an asterisk are aggregates of the values for the sub-patterns.
**Appendix H**

**Table of Participants’ Pseudonyms and Research Number**

<table>
<thead>
<tr>
<th>Pseudonyms</th>
<th>Research ID</th>
<th>First-Degree Relative</th>
<th>Diagnosed with Colorectal Cancer</th>
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</thead>
<tbody>
<tr>
<td>1</td>
<td>Jill</td>
<td>F1J</td>
<td>Father</td>
</tr>
<tr>
<td>2</td>
<td>Lenny</td>
<td>F1L</td>
<td>Father</td>
</tr>
<tr>
<td>3</td>
<td>Deborah</td>
<td>F2D</td>
<td>Mother</td>
</tr>
<tr>
<td>4</td>
<td>Katherine</td>
<td>F2D</td>
<td>Mother</td>
</tr>
<tr>
<td>5</td>
<td>Susie</td>
<td>F3S</td>
<td>Mother</td>
</tr>
<tr>
<td>6</td>
<td>Sabrina</td>
<td>F4S</td>
<td>Father</td>
</tr>
<tr>
<td>7</td>
<td>Robert</td>
<td>F5R</td>
<td>Mother</td>
</tr>
<tr>
<td>8</td>
<td>Connie</td>
<td>F5C</td>
<td>Mother</td>
</tr>
</tbody>
</table>
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