

Psychosocial Influences on the Colorectal Cancer Screening
Beliefs and Practices of African-American Women:
A Qualitative Study

by

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Abstract

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The purpose of this study is to investigate the psychosocial factors that affect the colorectal cancer (CRC) screening beliefs and practices of African-American women aged 50 years and older. This line of research is exceedingly important given the disproportionately high CRC mortality rates among African-American women compared to white women which is believed to be due in part to under use of primary prevention/early detection services (i.e., CRC screening) within this population. Therefore, gaining insight into the psychosocial factors that serve to hinder and/or promote CRC screening among African-American women is imperative in order to both improve rates of CRC screening and decrease CRC mortality rates within this demographic. Three theoretical models, the Health Belief Model, the Transtheoretical Model and resilience theory informed the conceptualization of this study and will be used to understand the CRC screening beliefs and practices of African American women.

Thirty seven African American women were interviewed in five focus groups. Group interviews were analyzed using qualitative data analysis methods. Seven barriers to CRC screening (fear, lack of knowledge, lack of symptoms, lack of money/insurance, lack of time, homeopathic Remedies and embarrassment) and five facilitators (screening as part of comprehensive care, doctor's recommendation, peace of mind, open communication with family/friends, and presence of symptoms) were identified. Findings suggest that African

American women do not believe that traditional recruitment techniques for CRC screening are effective. The women in this study reported that psychosocial factors play an important role in health seeking behaviors and adherence to CRC screening. Additionally, some beliefs that are historically linked with the resilience of African Americans were associated with decreased likelihood of screening. Findings will be discussed in light of the three aforementioned theoretical models in addition to recommendations for future research.

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Chapter I

Introduction

CRC: Epidemiology and Etiology

Colorectal cancer (CRC) - the abnormal growth of cells in the large intestine or rectum - is the third most common cancer diagnosis and the third highest cause of cancer death in the United States (American Cancer Society [ACS], 2008). One out of nineteen or 5.4% percent of all Americans will develop colorectal cancer (ACS, 2008). Ninety-one percent of new cases and ninety-four percent of deaths from colorectal cancer occur in individuals older than 50 (ACS, 2008.) Although overall death rates from CRC have declined since 1990, the reduction in deaths have been smaller for African Americans than for whites (.9% per year versus 1.9%) which has contributed to the disparate death rates. African-Americans have the highest incidence of colorectal cancer among all racial groups and the death rates have grown more disparate. Incidence rates among African-Americans are more than 20% higher than in whites and mortality rates were about 45% higher in African-Americans of both sexes (ACS, 2008.) In 2007, the colorectal cancer mortality rates were 16.2 per 100,000 for white women and were 23.4 per 100,000 for black women. Higher death rates from CRC account for about one fourth the disparity in cancer deaths between African American women and white women (ACS, 2007). For African American women, these health disparities are not at all unusual. African American women are also affected with other cancers in disproportionate numbers. In the case of breast cancer African American women have a 36% higher mortality rate than white women even though they have a lower incidence rate (ACS, 2008).

The disparity is so great for African-Americans in comparison to their white counterparts that Freeman and Alshafie (2002) concluded that Harlem and other similar areas with largely black populations have mortality rates so high as “to justify special consideration analogous to that given to natural disaster areas” (p.2330). Despite these statistics, colorectal cancer has only recently become a focus of mass media attention, aided greatly by celebrity spokespeople in addition to the implementation of national screening campaigns and consumer advocacy groups such as the “Colon Cancer Alliance” (Beeker, Kraft, & Goldman, 2001).

The etiology of colorectal cancer is related to interactions of genetic and environmental factors. Inherited syndromes such as familial adenomatous polyposis (a group of rare inherited disorders of the gastrointestinal system that, if left untreated, affected individuals usually develop cancer of the colon and/or rectum) only account for about 5% of cases. There is even a larger pool of people - approximately 25% of CRC cases - who are at elevated risk because they have at least one first degree relative with the disease which increases the risk 4 to 8 times. Despite these facts, studies show that high-risk individuals are no more likely to be screened than average risk individuals (Bastani, Gallardo & Maxwell, 2001).

CRC Screening Guidelines

We have the preventive knowledge and screening technology to substantially reduce both colorectal cancer incidence and death rates (Winawer 1993, 1997, 2003). Research indicates that CRC risk can be reduced through primary prevention (i.e. diet and exercise) and screening/early detection.

At the onset of this study population guidelines for early detection of colorectal cancer include a choice of five screening modalities beginning at age 50, and with varying recommended intervals for screening: 1) Fecal Occult Blood Test (FOBT) annually, 2) flexible sigmoidoscopy every 5 years, 3) flexible sigmoidoscopy every 5 years with fecal occult blood tests annually, 4) barium enema every 5 years, or 5) colonoscopy every 10 years (Smith et al., 2001, Winawer 1997, 2003). FOBT involves the detection of blood lost from early cancers in fecal samples. Flexible sigmoidoscopy (FS) uses a lighted instrument to exam the walls of the rectum and lower colon to identify precancerous changes as well as early asymptomatic lesions (Wardle, et al., 2000). Barium enema is a procedure in which barium sulfate, a chalky substance, in accordance with an x-ray, is used to take pictures of the colon. Colonoscopy is a test which allows the doctor to look at the interior lining of the large intestine (rectum and colon) through a thin, flexible viewing instrument called a colonoscopy. During a colonoscopy, tissue samples can be collected for biopsy and abnormal growths or polyps can be removed. Therefore, colonoscopy can be used as a method of prevention, an early detection/screening device and as treatment, and it is therefore considered to be the gold standard. Since this study was conducted two additional screening tools, stool DNA and computerized tomographic colonography (virtual colonoscopy,) have been approved and included in the ACS population guidelines. The following table (ACS, 2007) details the screening guidelines:

Table 1: ACS Population Guidelines

Test	Interval (beginning at age 50)	Comment
Fecal Occult Blood Test (FOBT) & Flexible Sigmoidoscopy	FOBT annually and flexible sigmoidoscopy every 5 years	Flexible sigmoidoscopy together with FOBT is preferred compared with FOBT or flexible sigmoidoscopy alone. All positive tests should be followed up with colonoscopy.
Flexible Sigmoidoscopy	Every 5 years	All positive tests should be followed up with colonoscopy.
Fecal Occult Blood Test	Yearly	The recommended take-home multiple sample method should be used. All positive tests should be followed up with colonoscopy.
Colonoscopy	Every 10 years	Colonoscopy provides an opportunity to visualize, sample and/or remove significant lesions.
Double Contrast Barium Enema (DCBE)	Every 5 years	All positive tests should be followed up with colonoscopy
Stool DNA Test*	This is a newer test, and the best length of time to go between tests is not yet clear.	Instead of looking for blood in the stool, these tests look for certain abnormal sections of DNA (genetic material) from cancer or polyp cells. All positive tests should be followed up with colonoscopy
CT Colonography (Virtual Colonoscopy)*	Every 5 years	This test is an advanced type of computed tomography (CT or CAT) scan of the colon and rectum. CT colonography involves the use of special computer programs to create both two dimensional x-ray pictures and a three-dimensional "fly-through" view of the inside of the colon and rectum, which allows the doctor to look for polyps or cancer. All positive tests should be followed up with colonoscopy

*This test was not included in the ACS population guidelines at the time of this study.

Studies show that primary prevention (e.g. diet and exercise) and secondary prevention (e.g. screening/early detection) strategies are effective in reducing both the incidence and mortality rates of colorectal cancer (ACS, 2008). Cancer survival is inversely related to the stage of cancer at the time of detection, with greater lengths of

survival associated with earlier stages of cancer. Regular screening increases the likelihood of cancer being detected at an early stage, and the cost of screening is far less than the costs of treatment at a medical, psychological and financial level as screening is less financially expensive, physically invasive and potentially less psychologically distressing than cancer diagnosis and treatment. Early detection is crucial because there can be a delayed period in which the disease is detectable through screening but asymptomatic to the individual. (James, Campbell & Hudson, 2002). The anxiety surrounding the screening process and the fear around the results of screening make colorectal cancer screening a major physical and mental health issue.

The Role of Screening in Racial Disparities in CRC Morbidity and Mortality

Much of the above-noted racial difference in CRC survival rates is attributed to the fact that African-Americans are more likely to be diagnosed in the advanced stages of cancer, leaving them with limited treatment options. It is likely that access to colorectal cancer screening, or lack of knowledge of the benefit of screening, acts as a primary mediating factor in acceptance of screening.

Given the current statistics on CRC mortality rates and the understanding that lack of screening is largely responsible for the disparate mortality rates, it is also essential that we understand the psychosocial factors that act as mediating variables (as both barriers and facilitators) to CRC screening. This information has important implications for interventions at both the prevention and screening levels, in addition to treatment.

Most studies examining CRC screening focus on a quantitative designs that measure behavioral outcomes (e.g., Who was screened?, How many people?, What form of screening?). Additionally, There are few studies that focus on CRC patterns and

predictors among African American women. Outcome studies that measure behaviors are essential so that we know what people are doing and when they are doing it. However, it is also essential that we understand the psychological and social processes behind the behavior with the hope that this knowledge will eventually aid in the formulation of effective interventions for behavioral change.

In the present study, psychosocial factors are defined as all those psychological, cognitive and social variables that play a role in a person obtaining colorectal cancer screening. The literature has indicated that psychosocial factors such as fear, cost, and lack of CRC screening knowledge play a large role in the CRC screening decisions of African-American women. These and other psycho-social factors will be explored as similar themes are expected to emerge from the interviews utilized in this study.

In sum, those variables that influence CRC screening beliefs and practices of African-American women are an extremely important and relevant topic considering the current health disparities. In order to further understand the issue, the literature on psychosocial factors that affect CRC screening among African American women will be explored. Additionally, the theoretical models traditionally used to understand and intervene with CRC screening behavior will also be reviewed. Specifically, the Health Belief Model and the Transtheoretical Model, which informed the conceptualization of this study and have been used in the past to understand CRC screening behavior, will be examined, followed by resilience theory, which informed both the conceptualization and design of this study.

Chapter II

Literature Review

A number of studies have identified psychological, social, physiological and cognitive factors that play a role in colorectal cancer screening. Factors such as lack of knowledge, including inaccurate knowledge about CRC or CRC screening, cost of screening, lack of physician's referral, underestimation of risk, mistrust of the medical community, reliance on self care, competing health priorities, fear of cancer and cancer fatalism have been shown to play a role as barriers to colorectal cancer screening. Other factors such as physicians' referrals and social support have been associated with facilitating CRC screening. These psychosocial factors and the roles they play in CRC screening will be discussed in greater detail in the sections that follow.

Psychosocial Factors

Knowledge

Lack of Knowledge about Colorectal Cancer and Screening

Lack of knowledge about colorectal cancer and how to obtain screening have been shown to be important factors in the use of CRC screening. One study of older African-American and White subjects found that, overall, both were poorly informed about colorectal cancer and the benefits of screening (Beeker, Kraft, Southwell & Jorgensen, 2000). There were few participants who knew that colorectal cancer can be present without symptoms. Similarly, James and colleagues (2002) noted that many African Americans were unaware that colorectal cancer can exist with the absence of current health problems and without symptoms. Additionally, only a minority of men and women were aware that risk increases with age and that both sexes were at risk for the

disease. Likewise, there was little knowledge that treatment of the disease is more effective if caught early and that colostomy (“the bag”) is no longer common (Beeker et al, 2000).

Likewise, Mandelson et al. (2000) found in a multi-racial sample that among older women there was uncertainty about the efficacy of tests and they were for the most part unaware that the disease can run in families. Beliefs such as surgery causes cancer to spread faster also act as barriers to CRC screening (Beeker et al., 2000). Green and Kelly (2004) note that there still remains a gap in the literature with respect to understanding the level of knowledge regarding colorectal cancer among older African-Americans, as relatively little research has been done within that demographic group.

Lack of knowledge of the CRC screening procedure itself may play a role in poor adherence to screening among African-American females. In one focus group study, nonwhites were almost twice as likely as whites to be concerned about pain during CRC screening (Bastani, Gallardo and Maxwell, 2001) and unpleasant aspects of the tests (James, et al., 2002 and Vernon, 1997). Lipkus et al (1996) reported that inaccurate and maladaptive beliefs about colorectal cancer were more strongly held by female respondents who were older and less educated. Formal education level has also been shown to be negatively correlated with viewing CRC as threatening and perceiving barriers to CRC screening. Perceiving barriers and viewing CRC as a threat were positively correlated with grade school education and were negatively correlated with having attained a secondary education and/or post-secondary education (Green & Kelly, 2004). Bastani, Gallardo and Maxwell (2001) found that overall, African-Americans provided more incorrect responses than whites on colorectal cancer knowledge. In fact, a

substantial percentage did not know the symptoms of CRC (e.g., abdominal pain, blood in the stool, fatigue and unexplained weight loss) and wrongly believed that being in good health negated the need to be screened. Also, there may be a lack of practical knowledge about the availability of screening as they also found that non-whites were about twice as likely as whites to state that they did not know where to go to get a colorectal cancer screening, especially in the absence of a referral (which, as will be discussed later, has also been shown to be a barrier.)

The ability to follow screening recommendations may be affected by both the health literacy and numeracy of African Americans. Research shows that low health literacy skills interfere with CRC screening as patients may not be able to understand and apply physicians' recommendations because of complex vocabulary associated with CRC screening. This in turn is associated with patients' inability to understand the concept of screening and the benefits of early detection (Davis et al., 2001). George, Bolton and Bennet (2004) found that African Americans with low health literacy scores are more likely to misunderstand directions for healthcare, take medications incorrectly and fail to follow a prescribed diet or treatment plan. Research has also shown that numeracy was strongly related to perceived benefits of other forms of cancer screening, such as mammography. Numeracy is the concept that quantitative information about risks for disease and benefits of treatment is only meaningful to the extent that patients have some understanding of basic probability (Schwarz et al., 1997). However, there is little research in the area of numeracy and African Americans in relation to CRC screening. All of these factors point to lack of knowledge as a major barrier to CRC screening. Nevertheless, it seems that even when African American women have acquired sufficient

knowledge and elect to get CRC screening, factors such as cost may play a role in adherence.

Cost of Screening

In a study conducted by Tabarrah, Nowalk & Raymund (2005), among patients screened via colonoscopy or any other CRC screening procedure, more African-Americans than Caucasians reported not getting screened because of cost or having problems paying for medical treatment. Among those who reported being screened by any CRC screening measure, 94% of Caucasians had health insurance compared to 85% of African Americans. In this study it was also noted that, compared to whites with health insurance, African-Americans without health insurance were 6 times more likely to report an FOBT (the more cost effective, less invasive option but also less effective option) compared to colonoscopy. The notion that African Americans may be offered inferior screening methods highlights the issue of health insurance coverage and the larger issue of socioeconomic status and race.

We know that income is strongly positively correlated with cancer screening in general and colorectal cancer screening in particular (Hoeffman-Goetz, 1998). Therefore, it is useful to note that twenty six percent of African-Americans live below the poverty line compared to eight percent of whites (Intercultural Cancer Council, 2001). Low-income minorities often seek healthcare in emergency rooms, where preventive care is not a priority (Beeker et al., 2001). It is also noteworthy that the five year survival rate for CRC is 30% higher among patients who are privately insured compared to those without health insurance (ACS, 2007). These statistics illustrate the fact that economic realities often coincide with health disparities in the U.S. The cost of screening and lack of quality

health insurance may make recommendation of CRC screening from physicians less likely for African Americans.

Lack of recommendation by physician/Limited opportunities to screen

Lack of physicians' referral has also been shown to act as a barrier to screening. Hoeffman-Goetz, Breen and Meissner (1998) studied the impact of social class on the use of cancer screening and found that older African-Americans who were poor or less educated reported less screening than older white Americans of a similar social class, leading the investigators to conclude that the disparity in screening was attributable to barriers other than SES, such as physician referral rates, social networks, racial discrimination and insurance. The importance of the physician's role as a facilitator to screening can not be underestimated. Tabarrah et al. (2005) found that patients who believed that their doctor "thinks they should get checked" for colon cancer were 19 times more likely to report a colonoscopy compared to patients who did not hold this belief. They noted that physician's support was the strongest single predictor of CRC screening above having health insurance and family/friends thinking they should be screened. Similarly, patients who reported visiting their physicians more frequently were more likely to report CRC screening than those who visit less frequently.

In a study of barriers to colorectal cancer screening, Bastani, Gallardo and Maxwell (2001) found that whites were much more likely than African Americans to have had an endoscopic exam (e.g., colonoscopy) than African-Americans. Moreover, they also found that more whites said that a health professional recommended that they undergo an endoscopic exam while more non-whites said that they were recommended an FOBT. This finding is problematic for many reasons, including the knowledge that an

endoscopic exam such as a colonoscopy may provide an immediate and preventive treatment option (i.e. removal of polyps), unlike non-endoscopic procedures. Thus, even when CRC screening is offered to racial minorities, they are less likely to be offered more rigorous forms of detection. Additionally, this lack of physician's referral is exceptionally problematic for blacks because, as Beeker et al. (2001) noted, when physicians do not recommend screening, patients may assume that screening is not necessary, which may coincide with many African-Americans underestimating their risk for CRC screening and distrusting the medical community that provides unequal access to care.

Underestimation of risk

Underestimating one's susceptibility for getting the cancer has also been shown to be a major barrier in patient noncompliance to cancer screening guidelines. In a study of perceptions of risk for CRC among African-Americans, Lipkus et al. (1996) found that the majority of respondents either rated their risk as below average or indicated that they did not know their level of risk. Participants who were older (≥ 70 years) had twice the odds of not knowing their risk than younger participants. Bastani, Gallardo and Maxwell (2001) found that nonwhites were much more likely than Whites to underestimate their personal risk for CRC despite knowledge of family history. Moreover, underestimation of risk may be related to other socio-cultural factors (race, socio-economic status, fatalism) which play a role in lack of screening. Understanding one's risk for CRC is crucial, as it was found that those African Americans and White Americans who felt they were at above average risk for colorectal cancer were more likely to select an action plan

than those who perceive themselves at below or average risk (Lipkus, Lyna & Rimer, 2000).

Mistrust of the medical community

In a study of barriers to colon cancer screening among an ethnically diverse population, Bastani et al (2001) found that African-American men cited a general distrust of physicians and lack of physicians' sensitivity as barriers. They were also skeptical about why physicians were "testing" and a few cited the Tuskegee experiments - in which poor African American sharecroppers were denied treatment for syphilis - as reasons for the mistrust. This is not to underestimate the notion that the mistrust that many African Americans experience may in part be due to a "healthy cultural paranoia" (Terrell & Terrell, 1981) which is a normal and adaptive distrust of White Americans formed as a result of centuries of oppression. This distrust is useful as it makes an individual aware of the negative elements that may be at play such as racism and discrimination (Bell & Tracey, 2006). Although distrust of the medical community has been cited as a barrier for African American men in seeking cancer screening (Blocker et al, 2006, Allen et al., 2007) we know little about the role of mistrust in African American women's health seeking behavior. Studies suggest that trusting one's primary care doctor has been a facilitating influence in getting low income African American women to utilize preventive health services (O'Malley et al., 2004). Historically, distrust of the medical community combined with limited access to care, economic disparities and the finding that African Americans report fewer opportunities to participate in the decision making about their health when seeing non African-American physicians (Cooper-Patrick, Gallo

and Gonzalez, 1999) may have lead to many African-Americans to rely on homeopathic remedies to both prevent and treat many conditions.

Reliance on Self Care

Reliance on home remedies has been shown to be a barrier to CRC screening adherence (Loehrer et al. 1991; Robinson, Kimmel & Yasko, 1995; Beeker et al., 2001). However, reliance on self care or home remedies can also be thought of as deeply rooted in African-American cultural beliefs about health and illness, which may be associated with a distrust of the health promotional activities run by outsiders. This distrust of public health in general may lead African Americans to refrain from utilizing health promotion activities (Beeker, 2001).

Competing Health Priorities

Additionally, competing health priorities (i.e diabetes versus CRC screening) may interfere in obtaining CRC screening. African Americans in one study stated that “health problems that I can see, like arthritis” (Beeker, 2001, p. 268) are more important than CRC screening. In another study, African-American women, who, despite having first degree relatives with CRC and having received a recommendation from their physicians to be tested, had still not undergone any form of CRC screening (Bastani, Gallardo and Maxwell, 2001). Perhaps there may be other psychological and social factors preventing them from pursuing screening. Some researchers have proposed that fear and fatalism may be one psychological factor in non-adherence to screening.

Fear of Cancer and Cancer Fatalism

Fear of finding cancer is a barrier stated in a number of studies (Bastani, Gallardo and Maxwell, 2001; Beeker et al, 2001; Rawl et al, 2001). Fear and anxiety about cancer

diagnosis has been shown to have an inverse relationship to CRC screening (Subramania, Klosterman, Amonkar and Hunt, 2004). However, cancer fatalism is a relatively new and unexplored barrier to colorectal cancer screening. Specifically, cancer fatalism is the belief that death is inevitable when cancer is present (Powe, 1995). This concept has emerged as a partial explanation of several findings, such as why, even when education is provided and traditional barriers such as cost and transportation are controlled, elderly African-Americans are still less likely to participate in FOBT than elderly whites (Powe, 1995). Cancer fatalism reinforces the notion that screening is futile because once diagnosed with cancer death is inevitable. Cancer fatalism is believed to be the result of a complex psychological cycle that is characterized by perceptions of hopelessness, worthlessness, meaninglessness, powerlessness and social despair (Powe, 1995). Cancer fatalism may be impacted by the development of previously mentioned factors including poverty, lack of knowledge about the disease, fear of hospitals and distrust of healthcare providers. These fatalistic perceptions are reinforced and may become self fulfilling prophecies as individuals are caught in a muddle of poverty, late cancer diagnosis and cancer deaths in family and community (Powe, 1995).

Although there is not a great deal of empirical evidence on the influence of fatalism on cancer screening, there is preliminary data that cancer fatalism is more prevalent among the less educated, the poor, African-Americans, women and those with less knowledge of CRC. Powe (1995) found that elderly African-American women in the South were significantly more fatalistic (on a questionnaire that measured attributes of fatalism including fear, pessimism, the inevitability of death and predetermination) and were less likely to participate in FOBT than White Americans. It seems that factors such

as insensitivity of healthcare providers, discrimination in the healthcare setting, mistrust of healthcare providers, decreased access to care and limited finances can reinforce fatalistic perceptions and keep populations in the cycle of cancer diagnosis and death, as they all act as deterrents to early detection and increase the likelihood of cancer and decrease the probability of adequate treatment. These factors present a bleak outlook on increasing screening rates among African-Americans.

Freeman (1998) has noted that recruitment of minorities into screening will require sensitivity and assurances to minority members. In meeting that end, it is important to assess the risk factors and barriers unique to the African-American community. However, in order to work towards correcting the discrepancies in screening beliefs and practices, it is also important to have an understanding of not just of the barriers but also of which factors facilitate screening in the African-American community.

Facilitators to Screening

Studies have also identified facilitators to cancer screening, including physician recommendations, social support and currently having symptoms.

Social Support

Although Powe (2001) notes that cultural and familial beliefs can influence individual fatalism, which may in turn negatively influence cancer screening behavior, other forms of social influence may actually facilitate adherence to cancer screening. The social support that an individual receives from their family, friends and community (church, coworkers, neighbors etc.) can play an important role in her decision to seek CRC screening. Indeed, social support has been shown to be a facilitator to CRC

screening (Robinson, Kimmel and Yasko, 1995). Beeker et al. (2000) found that social support that came in the form of talking about cancer with friends and family was viewed as a potential facilitator to CRC screening by subjects. Tabarrah et al. (2005) found that the viewpoints held by a patient's friends or family were significant factors associated with reporting CRC screening. Likewise, Lipkus et al. (1996) found that "a relative or friend told me to" was a major facilitating influence on CRC screening. For this reason a number of studies have made social entities such as the church the focal point of interventions to increase cancer screening, noting its powerful influence on its constituents (Mitchell Beren et al., 1989; James et al. 2002; Thrasher, Campbell & Oates, 2004). Churches also represent an important site for intervention given that, among religious African-Americans and in communities where the church plays a major social role, disease may be considered a private and shameful matter, thus creating an environment of silence and with little social support for screening.

Physicians Recommendation

In addition to the support of friends and family, doctor's referral has been shown to play an important role in CRC screening. Lipkus et al. (1996) found that "being told by a doctor to have one" was the most prominent reason for getting CRC screening by an African American Community Health Center Sample. This finding was replicated in a qualitative study by Beeker et al. (2000) where "will do if a doctor tells me to" was shown to be a facilitating influence on CRC screening in a sample of older African American and whites of both sexes. In a study by Bastani, Gallardo and Maxwell (2001) more whites than non whites reported having participated in endoscopic CRC screening, a finding that was mediated by the fact that more whites than non-whites reported that a

physician had recommended such an exam. Additionally, participants in this study who reported that they now appreciated the importance of CRC screening still said that they would wait for their physician to recommend the test rather than ask for it.

Symptoms

Currently having symptoms has been shown to be a motivating factor in seeking screening. “Having abdominal discomfort” was the second most stated reason for having any form of screening in a study by Lipkus et al.(1996). Conversely, not having symptoms was found to be a significant barrier to screening (James et al 2002). Dealing with observable symptoms from other disorders such as arthritis was perceived as more important than CRC screening (Beeker et al., 2000). The need for pain and discomfort to be present in order to seek medical attention is an understandable finding that has been reported in many studies. Additionally, relatively lower levels of cancer worry (Lipkus et al., 1996; James et al. 2002) and knowledge of good outcome (i.e. survival) if found early (Beeker et al., 2000) are reported facilitators to screening in which there is limited literature as it pertains to CRC screening behaviors among African Americans.

These psychological and social barriers and facilitators to CRC are some of the concepts used to understand the current screening rates among African Americans. Cancer researchers have also attempted to utilize a number of theoretical models to understand and intervene on CRC screening behaviors.

Interventions and Theoretical Models

In an attempt to address the underutilization of screening by African-Americans, cancer researchers have developed frameworks to understand and strategies to increase adherence. Paskett and colleagues (1999) showed that multi-faceted interventions that

included educational sessions, literature distributions, media use and church and community programs improved screening rates in low-income African American populations. Lannin and colleagues (2002) stressed the need for understanding the cultural beliefs that would greatly aid physicians in communicating with racial/ethnic minority patients and thereby assist in reducing the racial gap in cancer mortality. Freeman (1991) looked at the role of race and poverty in cancer screening and discussed cancer morbidity among African-American women being in part related to lack of employment, medical insurance, lack of education, inadequate housing and a fatalistic attitude. He also noted the importance of outreach and discussed the establishment of the Breast Examination Center of Harlem in that regard. Others have attempted to utilize the Health Belief Model (HBM) (Janz & Becker, 1984) and the Transtheoretical Model (Brenes & Paskett, 2000) to assess CRC knowledge and screening behaviors. These conceptual models informed the conceptualization of this study and therefore will be reviewed in greater detail.

The Health Belief Model

The Health Belief Model (HBM) (Janz & Beeker, 1984) suggests that there are several factors that are associated with the decision to engage in any kind of preventative health behavior. These include the person's perception that they are susceptible to the illness, the perceived seriousness of the illness, the perceived barriers to carrying out the preventive health behavior and lastly the perceived benefits to performing the behavior. The four factors previously stated informed the conceptualization of this study. However, the model also states that internal and external cues (such as body states and environmental factors) and self efficacy are also conceptual components that play a role

in the decision making process. The HBM has been used to understand motivation for CRC screening based on these criteria (Wardle et al., 2000). Central to the HBM is the value-expectancy framework that focuses on the function of perceived barriers to anticipated benefits from CRC screening. In other words, as perceived barriers begin to outweigh the anticipated benefits, the behavior becomes less likely (James et al 2002). This model has been important in studying psychosocial mechanisms to increase enactment of prevention behaviors to reduce risks and mortality rate of CRC in African-Americans compared to Whites. Despite its theoretical utility, this model has variable success in predicting patient behavior related to CRC screening. In one study, African-American's screening behavior was more influenced by perceived barriers for FOBT, in contrast to perceived benefits for colonoscopy (James, et al., 2002). Essentially, the person performs a "cost-benefit analysis" when deciding whether or not to seek CRC screening (Schroy, 2002). Family history, worry or perceived threat also contribute to participation in CRC screening. Demographic variables such as gender, education, and employment also account for some of the variance, with trends of those more deprived educationally and socioeconomically having less interest in participating in screening (Wardle, et al., 2000). The Health Belief Model is a useful tool in understanding cancer screening beliefs and practices. As the HBM does not fully predict screening behaviors, other models such as the Transtheoretical model (Brenes & Paskett, 2000) have been developed to understanding differences in beliefs and practices.

The Transtheoretical Model

The Transtheoretical Model has been employed to address low adherence of African-Americans to CRC screening (Brenes & Paskett, 2000). According to the

Transtheoretical model, people can be divided into stages based on where they are in their decision making process with respect to whether or not to engage in a preventative health behavior. “Pre-contemplators” are people who are not engaging in the behavior (e.g., they do not intend to be screened for CRC). “Contemplators” are also non-adherent but are thinking about engaging in the preventive health behavior (e.g., considering CRC screening). Those in the “Action and Maintenance” phase are currently engaged in the preventive health behavior (e.g., adherent to CRC screening guidelines). The final category, “Relapse”, includes those who were previously in the “Action and Maintenance” phase but are presently no longer engaged in the prevention health behavior/actions (e.g., non-adherent with CRC screening guidelines) (Brenes & Paskett, 2000). This theory has also been applied to mammography screening adherence (Champion, 1994) and smoking cessation (Pallonen et al., 1994). Brenes and Paskett (2000) reported that African-American precontemplators had considerably inaccurate information about CRC, negative views of the screening process experience, and were not likely to become adherent unless instructed by their physician. Although these theories each point to different aspects of the psychological, social and cognitive aspects involved in screening behavior, none have been reliably successful in predicting adherence or reducing the disparity of screening rates, which suggests that there are unaccounted for variables in screening behaviors that have not yet been explored.

The Transtheoretical model and the Health Belief Model both address the role of cognition and perception in behavior. More so than the Transtheoretical model, the HBM also addresses the specific barriers and benefits perceived by patients. However, neither

model considers the larger psychological and social constructs which may be at play for African-Americans.

Race and Class

The role of race and class in America are powerful social forces outside the individual but whose meaning may become internalized over the course of the lifetime. Of course, there are vast individual differences in one's ability to utilize both internal and external resources to navigate through psychological and social stressors. Lev (1997) notes that, at the individual level, lack of self-confidence or self-efficacy can intervene between verbal acceptance of screening and behavioral compliance. Although beyond the scope of the study, these individual traits may play a role in mediating social stresses and injustices. The level of social stressors experienced by African-Americans should not be underestimated.

African-Americans have only been legally entitled to equality in public facilities since the Civil Rights Act of 1964, when the Jim Crow segregation laws were repealed. However, it is well known that inequality in access to health, education and social services continued to a lesser degree in post-segregation America. Atrocities such as the Tuskegee Syphilis Study (1932-1972), in which hundreds of poor and illiterate African-American sharecroppers were denied access to penicillin after it was proven to treat the disease, added to medical distrust among African-Americans. These patients were not informed of their diagnosis and never consented to being part of a study.

For older African-Americans who grew up with substandard segregated services being the status quo, mistrust of the medical community, fatalism and reliance on self care makes both historical and practical sense. The HBM and the Transtheoretical Model

offer of a way to conceptualize preventative health behaviors that informs this study and play a role in the underlying conceptualization of this study.

Neither the HBM and the Transtheoretical Model can completely explain nor predict screening behavior. Therefore, it is necessary to investigate alternate domains which may also play a role in CRC screening behavior. There has been some evidence that people who generally take a more holistic approach to healthcare that incorporates a variety of positive health behaviors (e.g. taking vitamins, not smoking) are more likely to get CRC screening (Tabarrah et al., 2005). In one study of a faith and culturally based clinic which integrated the delivery of health services with spiritual components (such as prayer), the racial differences in self reported CRC screening were not observed (Tabarrah et al., 2005). Perhaps health behavior theorists have missed the importance of the broader physical and psychological needs of the person of which health behavior practices such as CRC screening is only a part.

With this goal of a more encompassing concept of health we will explore the concept of resilience. Resilience incorporates different aspects of the individual's psychological and social reality. While African-American health seeking behavior has been researched, rarely are internal models based on cultural, social, and familial norms/traditions employed across the lifespan included in these conceptualizations. Resilience theory provides a framework for understanding where illness prevention and health fits in the life schemas of persons at-risk because it considers multiple models for living that people employ to deal with a variety of life risks, including health. Resilience theory incorporates factors that determine the prioritization of other life domains (e.g. family, work, religion) in relation to health risk, including risk of CRC. This perhaps in

part explains the behavior of non-adherent African-Americans as this factor is deprioritized in favor of other life factors.

Resilience Theory

African-Americans are disproportionately faced with a number of psychological and sociological risk factors, including poverty, racial prejudice, lack of adequate health care, and substandard public education in many regions of the United States. Resilience theory offers another approach to examining these community-specific barriers. These risk factors make it necessary to prioritize obstacles in order to cope on a daily basis and be resilient. Resilience as defined by Masten, Best and Garmezy (1990) is the capacity for successful adaptation despite challenging or threatening circumstances. The concept of risk is essential for the understanding of resilience as it is the individual's accurate assessment of risk factors and their ability to utilize resources in order to counter those risks that allows for resilience. In order for African-Americans to be resilient they must successfully negotiate life's everyday hassles and crucial risk factors. These "culturally constructed modes of adaptation first learned in the family and at school, become the foundation for resilience across the years of childhood and adulthood" (Cohler, Scott & Musick, 1995, p. 785). In essence, African-Americans have created internal models of resilience based on cultural, environmental and familial norms and traditions. These norms and traditions (e.g. communal gatherings in which traditional foods are served and distrust of large institutions) may have been instrumental in getting individuals and communities through various adverse situations. These same behaviors may not be as adaptive when applied to health and screening behaviors. The role of resilience in the lifespan will now be examined.

A longitudinal study reported by Werner (1996) examined patterns of lifetime survival in the face of health risks (such as low birth weight), poverty, educational disadvantages, and other biopsychosocial indicators. Other resilience research focuses on those who “beat the odds” to survive and even thrive in spite of family psychopathology (such as depression or schizophrenia) (Rolf et al., 1990), and violence or trauma (such as sexual or physical abuse) (Spaccarelli & Kim, 1995). Research on resilience has also been conducted among persons who excel in academic and/or personal development in spite of poverty and inadequate urban school environments (Masten & Coatsworth, 1998, Wandersman & Nation, 1998, Wang & Gordon, 1994). Resilience is beginning to be examined among childhood cancer survivors (e.g., Lockhart et al., 2001). However, in the arena of cancer, resilience has only been studied in regard to coping with the disease as opposed to prevention (Wenzel et al., 2002; Rowland & Baker, 2005; Lechner et al 2003).

Resilience model addresses some of the gaps in current research by expanding the thinking about CRC screening practices utilizing a broader model of human behavior than the HBM or Transtheoretical models, which also examine psychosocial aspects of health behavior. Resilience research and theory, on the other hand, considers multiple models for living that people employ to deal with a variety of life risks, not just health alone. Following this orientation, I have incorporated factors that determine the interface and priority of other life domains (e.g., family, work, religion) that perhaps explain the unaccounted for variance in health practices, particularly for CRC screening non-adherents. As Beeker et al. (2001) note, competing health priorities may play a role that we need to address, and as Bastani, Gallardo and Maxwell (2001) note, the

underestimation of risk may serve as a protective mechanism to counter the fear and anxiety associated with a possible cancer diagnosis. Both these concepts can be understood through the lens of resilience as African Americans must prioritize daily challenges, especially those that create unwanted anxiety.

The conceptualization of resilience utilized in this study incorporates the larger social and community context when understanding how one successfully navigates through life. In other words, one's ability to negotiate larger individual, communal and societal obstacles (e.g. depression, poor family eating habits, racism) is instrumental in both the notion of resilience as well as whether or not one decides to engage in preventative health behavior. African-Americans have created internal models of resilience based on cultural, environmental and familial norms and traditions. However, many African-Americans may have learned ways to cope in ways that are counterproductive to their physical and mental well-being (e.g. eating heavily when bonding, socializing or to relieve stress.) These adaptive behaviors in one circumstance become maladaptive in another placing the individual at increased risk for a host of disorders, including colorectal cancer.

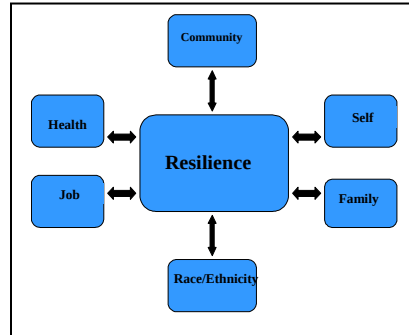
Another aspect of resilience theory that is applicable to CRC cancer screening is the concept of proximal and distal risk factors. Baldwin and colleagues (1990) discussed the distinction between proximal risk factors, which are those in the person's immediate social environment (such as arthritis or lack of childcare) and distal risk factors, which are larger psychological and social factors in the individual's world (such as poor medical care, racial prejudice). Of course, these distal risk factors, which may not be in a person's daily cognitive and social realm, can impinge on proximal factors (i.e. poor medical care

can exacerbate the pain of arthritis.) Nevertheless, in creating a hierarchy of daily living issues, African-Americans may often become preoccupied with negotiating the proximal factors because they seem immediate and pressing. When applied to health, proximal risk factors may be represented in the form of observable symptomatology. In terms of resilience theory, resistance to screenings may be viewed as an inability to negotiate or prioritize more distal issues that lack observable symptoms or seen as significantly related to proximal priorities. Response to distal factors therefore may be delayed in order to deal with proximal pressing needs. In addition, distal factors may be perceived as creating unwanted additional psychological stress and for that reason become deprioritized.

It is therefore important to understand in what manner the psychological determinants of health behaviors fit into the scope of other behavioral patterns used by people in order to be resilient. For example, research clearly shows that African-Americans would be more compliant if their physicians recommended CRC screening. When viewed from a resilience perspective we can interpret this behavioral pattern as also a product of African-Americans conventional view of the physician as counselor about life in general and not solely as a health practitioner. However, the physician as a help-seeking provider may still rank below minister and family as the person to go to first when in need of help in certain segments of the African-American community. The physician becomes more effective when he/she also encompasses other important roles. This community and personal orientation suggest that advice from providers, family, and respected community members is expected to address multiple psychosocial needs rather than just their area of specialization. It can be hypothesized that if you are able to meet

multiple interacting needs such as family, health and religious beliefs by an integration of interventions linked to an individual's approach to life, or choices in being resilient, then positive outcomes are more attainable (James, et al., 2002). Consequently, contributions of these and other life domains to an individual's decisions about health practices are important to consider in any equation of behavior or a behavioral intervention strategy. Resilience in effect becomes one's ability to determine the prioritization and interacting needs of all life domains (e.g. family, work, religion.) This prioritization effects life decisions, inclusive of health. The following diagram illustrates this multifaceted dynamic conceptualization of resilience. Resilience is both affected by and affects one's family, sense of self, community, health, etc (See Diagram 1.) In order to be resilient one has to negotiate the competing needs, expectations and demands of all these components.

Diagram 1: Conceptual Model of Resilience



This present study asks questions from African-American women in the Harlem community and purports to address some of the gaps in the literature regarding the beliefs of African-Americans regarding factors that both facilitate and hinder colorectal cancer screenings. Specifically, this study will explore both the barriers to screening and the protective mechanisms that African-American women have developed over the course of the lifespan that have helped them navigate through psychological and social hardships,

and to then understand the ways in which these protective mechanisms affect CRC screening beliefs and practices. An additional aim is to examine the role of the Transtheoretical Model and the Health Belief Model in CRC screening behavior. This study will utilize qualitative data methods and analysis, which is an underused tool in cancer research. Most studies seek to understand people's thoughts and behaviors through surveys and questionnaires. Qualitative group interviews will allow us to delve deeper into the intricacies of human behavior that can not be captured using quantitative tools.

The following research questions will be explored:

1. What are the psychosocial factors that act as barriers and facilitators to CRC screening for African-American women? Specifically:
 - a. What psychosocial factors lead to positive health outcomes (CRC screening?)
 - b. What psychosocial factors lead to negative health outcomes (non adherence to CRC screening?)
2. Will African-Americans feel that traditional techniques (i.e. pamphlets, PSAs) are effective for getting members of the African American community to adhere to CRC screening?
3. What role does resilience play in CRC screening behavior?
4. What resilient beliefs (i.e. prioritization of life issues) are associated with adherence to CRC screening guidelines?
5. What resilient beliefs are associated with non adherence to CRC screening guidelines?
6. What role does the HBM play in CRC screening?
7. What role does the Transtheoretical model play in CRC screening?

Chapter III

Methodology

Participants

This study consisted of 37 African-American women above age 50 who were part of a larger pilot study from Memorial Sloan Kettering Cancer Center (“Minority Recruitment to Colorectal Cancer Screening”) that also included male participants. The data derived from the male interviews will not be included in this study. The age limitation is based on the recommendation for colorectal cancer screening for those 50 years or older in the general population. The subjects ranged in age from 50-88 years old with a mean age of 69.25 years (SD=8.82). Due to the constraints of the larger research protocol, only a limited amount of demographic information was attained (gender, age and prior history of colorectal cancer). The breakdown of participants by age is as follows:

Table 2: Breakdown of Participants by Age

Age	Number of Participants
50-60 yrs.	5
61-70 yrs.	18
71-80 yrs.	9
81-90 yrs.	5

The participants all had no self-reported prior diagnosis of colorectal cancer. Participants were not excluded if they had a history of any other forms of cancer.

Recruitment

Subjects were recruited over a 2-year period from a Natural Occurring Retirement Center (NORC) in a middle-income cooperative housing complex and from a senior enrichment center offering computer classes, both in the Harlem community. At the

NORC, subjects were recruited through a flyer (see Appendix A) and by a social worker on staff. Subjects at the senior enrichment center were approached by one of three trained research assistants after an announcement of the study was made by the computer class instructor. Upon obtaining verbal consent, the subjects' contact information was taken and they were called to confirm interest, verify study eligibility (age 50 or above and no prior history of colorectal cancer) and were assigned to a same-sex focus group based on their scheduling availability. The study consisted of five focus groups which contained 14, 7, 4, 7 and 6 participants in each group.

Consenting Process

On the day of the focus group, the research assistants reviewed the consent form (see appendix B) with each participant. Participants were informed of the following:

- 1) the purpose of the study
- 2) the potential risk and the provisions for those risks
- 3) the lack of guarantee of benefit from participation
- 4) the voluntary nature of the study
- 5) the freedom to withdraw from the study or to refuse to answer specific questions or to participate in any aspect of the study at any time.

Subjects were asked to sign two copies of the consent form. Participants received one signed copy of the consent form (see appendix B).

Subjects were also required to sign two copies of the research authorization form (see appendix C), which is mandated by the Memorial Sloan Kettering Institutional Review Board in compliance with the Health Insurance Portability and Accountability Act (HIPAA.) The research authorization form informs subjects about confidentiality and

all those persons who may be able to access their medical records and research related study data. The Research Authorization requires a separate set of signatures from the subjects and the research staff. Each subject received a copy of the research authorization form. The consenting process took approximately 30 minutes.

Compensation

Based on a request from the director of the NORC, subjects were at first not paid but instead provided a catered lunch immediately following the focus group. At the senior enrichment center, subjects were paid \$20 and were provided with a small lunch (sandwich and beverage.)

The Semi-Structured Focus Group Interview

Subjects were interviewed in focus group format. A focus group interview was created by Dr. Anderson J. Franklin, Sweeney Oscar, Dr. Jennifer Hay and Dr. Ann Zauber (see Appendix D). The interview was guided by the theoretical frameworks of resilience theory, the Transtheoretical Model and the Health Belief Model, and by empirical knowledge of colon cancer screening behavior. The HBM has been used to understand motivation for CRC screening based on an individual's sense of susceptibility to CRC, perceived seriousness of CRC, and perceived barriers and benefits to engage in screening for CRC (e.g., Wardle, et al., 2000). The Transtheoretical model tries to understand how people change behavior at different psychological and cognitive stages. These two theories represent the underlying conceptualizations of various questions, including question 18b of the interview ("What do you think about the possibility of getting a colorectal cancer screening?"), which assesses the stage of contemplation and best represents the subject's current cognitive state based on the Transtheoretical Model.

A vignette (see Appendix D, question 16) assesses the perception of susceptibility, benefits and barriers to CRC screening, consistent with the HBM. Resilience as previously noted represents not only a means by which one overcomes adversity but also considers multiple models for living that people employ to deal with a variety of life risks, not health alone. Examples of questions inspired by resilience theory are seen throughout the interview, including questions on life prioritization, perception of risk and culturally specific barriers. Specific examples of questions based on the resilience theory include “Thinking about the period in one’s life between 50-55 years old, what would you list as the 3-5 most pressing life concerns at this time for you?”; “When do you think someone should start being concerned about colorectal cancer?”; and “Some people say that Black folks get too busy to go to the doctor. What do you think about that?” (See Appendix D, Questions 3, 13 and 6 respectively.) As part of the interview subjects were shown charts (see appendix E) of colorectal cancer statistics and asked to comment, which was done to ascertain knowledge of risks (see appendix D, question 15.)

The questionnaire was later revised to facilitate and streamline the discussion and remove redundant questioning through a series of team meetings until consensus was attained. A vignette similar to question 1 (see appendix D) was removed. Question 7 was changed from “what are you likely to do with information for reducing risk for preventing cancer?” to “Have you received brochure handouts? What do you do after reading these brochures?” Lastly, the questions were re-ordered to aid the flow of the conversation.

Procedure

Interviewer Protocol

1. Focus groups were led by a trained African-American female focus group interviewer who was above age 50, as it was hypothesized by the researchers that discussing sensitive health issues might be easier for seniors with a same sex individual in a similar age range.
2. The interviewer was trained in focus group interviewing techniques by two clinical psychologists and was audio-taped conducting mock focus groups over a 4 month period before the focus groups began.
3. Interviewers were also required to receive both Institutional Review Board and HIPAA certification before conducting focus groups

Subject Protocol

1. Upon arrival the subjects were first consented (see consenting process.)
2. Subjects were interviewed in groups that ranged in size from 5-14 individuals. Focus groups lasted between one-and-a half to two hours.
3. After the completion of the focus group, subjects were given a booklet that contained colorectal cancer and screening information (see appendix F). This booklet gave the names and phone numbers of facilities where CRC screening could be obtained.
4. The subjects were then paid and/or provided lunch.

All Focus groups were audiotaped. Immediately following the focus group, tapes were transcribed by one trained research assistant and then later verified by another research assistant for accuracy.

Qualitative Data Analysis

The data analysis was conducted in two phases. In phase I the focus group interviews were coded using grounded theory qualitative analysis methodology (Charmaz, 1995) to extract themes regarding psychosocial barriers and facilitators to screening. These themes are present throughout the data but are specifically related to questions such as, “When you think about the possibility of getting a screening, what would you say are the advantages of getting a screening? Which of these benefits stand out as being most important?” (See Appendix D, Questions, 9.)

Grounded theory qualitative data analysis allows us to label the raw data with codes that emerge and capture the meaning of the data (Strauss & Corbin, 1998.) In phase II the other qualitative analysis technique that was utilized is the examination of the data specifically for codes and themes regarding the theoretical frameworks that guided the study (Transtheoretical model, Health Belief Model and Resilience) to specifically examine the research questions and hypotheses in order to understand how they play a role in CRC screening. Thus, the data was analyzed and coded for these specific conceptual domains in addition to the initial step of allowing codes to emerge from the data.

As codes were generated from the statements of the group they will be compared and contrasted with existing codes and new codes will be generated as needed. This process is called the "constant comparative method of analysis" (Glaser & Strauss, 1967). Codes were applied to small units such as a word or sentence as well as larger units. Basic codes were grouped into larger theoretical codes in order to explore the aforementioned research questions. In addition, it is hypothesized that:

1. African-American women in Harlem will feel that psychosocial factors play an important role in health seeking behaviors and adherence to CRC screening.
2. Resilience plays a role in acquisition of CRC screening above and beyond what can be explained by the Transtheoretical model and the Health Belief Model.
3. Some Resilience Beliefs (i.e. relating to assessment of risk, life prioritization, cultural modes of adaptation, and overcoming obstacles) will be associated with decreased likelihood of screening.

These research questions correspond to the underlying conceptual domains and guides the analysis of the data. The coding strategy previously described was used to gather codes that have relevance to each of the aforementioned questions. There was continuous review of agreement between coders, refinement of decision rules to improve agreement by either expanding coding categories, or clarifying the coding. In phase I coding was conducted by two doctoral students and one master's level student until 80% inter-rater reliability is achieved on 40% of the transcripts, at which point the coding on the final 60% of the transcripts and Phase II coding was concluded by just one of the doctoral students, the principal investigator.

Chapter IV

Results

The data from two focus group transcripts representing the highest (76.1) and lowest (55.8) mean age of participants were analyzed by three raters to attain at least 80% inter-rater reliability. These two age groups were selected to achieve inter-rater reliability because it was thought that they represent the broadest range of participants' responses. The analysis of these two transcripts yielded 82.6% inter-rater reliability and 83.3% reliability, respectively. The remaining three focus group transcripts were then coded by the principal investigator.

The data were analyzed according to the methods outlined in Chapter III. In Phase I of the analysis of the data involved coding the data using the grounded theory method of analysis (Strauss & Corbin, 1998) which allows for codes and themes to emerge from the material. Grounded theories, because they "are drawn from the data are likely to offer insight, enhance understanding and provide meaningful guide to action" (Strauss & Corbin, 1998, p.12). The data were assigned codes by rater(s) to best represent the nature of the subjects' statements. In vivo codes or those that are taken from the words of the respondents (Glaser & Strauss, 1967) were used as much as possible because they best capture the essence of the respondents' sentiments. The codes that appear most frequently in the transcript will be presented. The most abundant codes were barriers and facilitators to CRC screening.

The data from phase I of the coding will be presented in the format of barriers and facilitators to screening followed by more general themes that emerged from the data that fall outside of the scope of barriers and facilitators to CRC screening.

In Phase II the research questions will be addressed specifically. Some of these questions may have been sufficiently reviewed in the first phase of coding while others will be further explored in this phase of the results.

Phase I

The African American women in this study reported a number of psychological and social factors that served as barriers and facilitators to CRC screening. Analysis of the data yielded fear, lack of knowledge, lack of money and/or insurance, lack of symptoms, lack of time/ other obligations, homeopathy and embarrassment as the most common barriers to screening. In addition to barriers, the women also reported factors that facilitate screening including screening as part of comprehensive healthcare, doctor's recommendations and open communication with family/ friends, especially when involving personal testimonials of CRC screening. Additionally, there were many recurring themes that emerged from the data about the screening behavior of African Americans and the relationship of African Americans to the medical community that do not fall within the domain of barriers and facilitators to CRC screening. These themes will also be presented as they are important to understanding the factors involved in CRC screening behavior.

Barriers to CRC screening

Fear

Consistent with the research, African American women reported that fear is a major barrier to screening (Bastani, Gallardo and Maxwell, 2001; Subramania, Klosterman, Amonkar and Hunt, 2004). However, fear is an emotion that was discussed in a number of different ways by focus group members in this study. Participants reported

fear that screening exams would involve pain or might result in unforeseen side effects.

Many were concerned about the safety of the exam itself. One participant reported:

the procedure that they use to detect it, is an invasive procedure and a lot of people don't want to have that type of operation performed on them, you know. Like going through all these miles and miles of um, what do you call that thing, in your stomach, colon and with a camera. And, um, you know some people feel that once you get in there you might open up to because that would be my fear of something going wrong. They could go in there and hit the wrong things. (6/28/04)

Fear of the unknown was an overarching theme present throughout all of the focus groups. One participant reported:

For me because I went through, because I was so scared, not scared, I just didn't want to know. (6/28/04)

Another participant noted that:

I think a lot of people are afraid of going to have the tests, because they are afraid of what they will find out and don't want to find out. (12/5/03)

Likewise, another respondent noted simply:

Some people just don't want to know certain things. They just don't want to know. (6/28/04)

More specifically, some participants reported that fear of cancer was also a considerable barrier. Many African women reported that fear of a cancer diagnosis was a major barrier to screening. In response to a vignette one group member noted that the main character does not seek CRC screening because:

I may have it (cancer). I just might have it and then what. (4/22/04)

Fear of death and cancer fatalism was repeated through all of the focus groups. Cancer fatalism is the belief that death is inevitable when cancer is present (Powe, 1995). Many

focus group members reported fear of imminent death once colorectal cancer was detected. This served as a deterrent to screening. One participant reported that

With the colon cancer I understand some people say it don't heal to good either...once you get that then you have it. (12/14/03)

Another participant reported that:

I have learned that it is an area of cancer that will take a life very quickly as suppose to other cancer in other areas of the body. (6/28/04)

Similarly, another participant discussed the seeming futility of screening and inevitable fatality of CRC, saying:

You know that's like pancreatic cancer. You don't know you got it until you're dead. (4/20/04)

These concerns were echoed in all the groups with another participant wondering:

I'm going to come out all right, Am I going to die? How long do I have to live? (12/5/03)

The role of fear and fatalism as a deterrent cannot be underestimated as they may paralyze many African American women into inaction. However, as evidenced by the previous statements, the fear experienced by African Americans may be related to mistruths about the screening exam or the treatability of CRC as a disease. Therefore, some fear may be related to lack of knowledge about CRC and screening. The lack of knowledge in the African American community is another barrier discussed pervasively throughout all focus groups.

Lack of knowledge/Information

Participants reported various degrees of understanding about the CRC screening procedures and the disease itself, with the majority being unfamiliar with flexible sigmoidoscopy. Some participants had a vague familiarity with fecal occult testing and

most were familiar with colonoscopy. Despite some familiarity with the latter two procedures many participants expressed confusion between the procedures. When discussing the different screening options another participant noted:

Now I think we are talking two different things I was listening to what this lady was saying about the fecal ah occal testing and with the sticks and stuff that was one type of a test for stool now down there at the other end they are talking something else. I'm getting a little confused. (12/14/03)

Some participants extolled the importance of getting first hand verbal descriptions about the procedure rather than reading about them in brochures.

You need to let them know more about the procedure, rather just the brochure. From the brochures, I probably would not have gone to have it done. (12/5/03)

In addition to a lack of understanding of the CRC screening exams, many participants expressed confusion about when one should begin CRC screening and how to go about getting screened. One participant asked:

Where do you get the information, unless you are looking at TV. I don't know. (12/5/03)

Others reported misinformation about CRC such as confusion about CRC screening as a test only for men:

A lot of people are thinking it's geared towards men... I don't know I'm going to ask because I never had it done to me (6/28/04)

The lack of knowledge which was pervasive in the focus groups and conceivably in the larger community poses a dangerous barrier as it invokes an array of emotions including confusion and anxiety. Another emotion discussed pervasively in all the groups was embarrassment. African American women reported that embarrassment about the nature of the exam as a key factor in deciding whether or not to get screened.

Embarrassment

Embarrassment was another common theme that permeated all transcripts.

Women across all groups reported that embarrassment related to the nature of the exam was a major deterrent from screening. A fairly common perception was expressed by one participant who said:

I'm a southerner so I can say this people who come out of the south ah certain things you ah just might not believe in going to the doctor for...you may not want the doctor to look up certain areas on your body and that kind of thing (12/14/03)

Another participant pointedly reported

It's embarrassing. I think it is very embarrassing. I dread the time come for me. I had to take the stuff to clean myself out. I did that. It's very embarrassing. That's why a lot of people ignore it too. It's embarrassing. (12/5/03)

In order to endure the anxiety and embarrassment involved in CRC screening some reported that they could not foresee getting such an exam without a reason such as the presentation of symptoms.

Lack of Symptoms

Many group members held the belief that such screenings are not needed without symptoms. As one participant reported:

I feel that as long as one is feeling good, feeling well and strong, they don't see the need to have an annual check-up or two years or whatever. (4/20/04)

Likewise many women reported that they go to the doctor only when they are experiencing pain or discomfort as one participant shared:

Most likely I will go when I'm like, um, when I get a pain and it doesn't go away and when you try to rub it down or whatever. And it constantly stays, you will say to yourself, I will say to myself I think I may need to get it checked, have him take a look at it. 6/28/04)

One participant discussed why CRC screening in particular gets regularly postponed saying:

That's the one thing that you will put off, because there is no symptom there is no feeling there is nothing that tells you that there is a polyp inside of your body and its needs to come out or its needs to be addressed if you have something on your hand or something on your you can see you'll run to the doctor this is something that is hidden so you keep putting it off and instead of having it taking care of ...and I'm speaking from experience with that. I know I need to go this year but I think I'll... I'll be able to do it. (12/14/03)

Many participants discussed others in their family and in the community who only go to the community when their medical conditions have greatly exacerbated saying:

Black people have a tendency of waiting until things get really, really bad before they go see a doctor.(6/28/04)

Also present in this theme was the idea that was coded "What you don't know won't hurt you." One participant captured the essence of this code when she said:

I've heard people say if it's not bothering me, I'm not going to bother it. They just don't want to know if there is anything wrong. (4/20/04)

One participant spoke about her prior lack of self care saying:

I had to take control of my health. I had to decide to take control. But I went through that fear or whatever. If I'm not in pain, I'm not going. (6/28/04)

Lack of Money/Insurance

Other factors such as lack of insurance and or money were reported to be barriers to screening. Many women discussed difficulties experienced in maneuvering the healthcare system, especially when attempting to get referrals even with insurance. They also discussed the difficulty for those in the community without insurance or resources saying:

Some people just don't have the money to get to the doctor. That could be an issue because now they give out those Metrocards in order for them to be able to get there and back. (6/28/04)

Another participant reported:

A lot of people sometimes don't have the coverage that they need that (is) used for some of these procedures. (12/5/03)

One participant spoke about the link between lack of insurance and homeopathy

Saying;

Well, you've got medical coverage if you don't have medical coverage you don't go looking for a doctor. You try to do it yourself but if you got hospitalization and all kinds of coverage that pays for your medicine and everything. You go to the doctor. (12/5/03)

Home Remedies

The use of home remedies was a barrier to screening that was widely discussed during the focus groups:

I would use home remedies, if something is wrong, I would try to doctor it myself, first. Then if I find what I'm doing is not working, then I would go to the doctor. It would not be my first thought to go to the doctor. (12/5/03)

Another participant commented on the cultural and historical roots of homeopathic remedies saying:

My mother told me that she, she was brought up in the country down south, we didn't run to the doctor for every little thing. Something was wrong, her mother knew how to go out and get the herbs and the roots. Doctors and going to doctors were not a priority. Too many other things you have to do. (4/22/04)

This participant also points to the relationship between the use of home remedies and the need to prioritize the many commitments of African Americans because of a lack of time.

Lack of Time

Lack of time, family and work commitments were also reported to be barriers to going to the doctor and/or seeking screening.

I think most people feel they don't have time. You know, to take care of themselves or to do anything for themselves. They are more concerned with family, their jobs, whatever. (4/20/04)

Many of the women in this study discussed the need to prioritize their life obligations and screening is often low on the list of priorities. Another participant reported:

By the time they finish working, going home, taking care of small kids, a husband and a this and that. They really don't have time. (4/22/04)

However, others noted that busyness may cover up other issues such as fear. One participant noted:

Well they say that they are busy but they may be afraid to go to the doctor. People always so oh no I'm not going to the doctor, whatever it is I don't want to be bothered, he may tell me something I don't want to hear. (6/28/04)

Whether participants believed that the lack of time was real or perceived, the notion that African American women needed to prioritize their commitments to survive and function optimally was present throughout the transcripts.

Facilitators to Screening

While barriers to screening presented a greater percentage of codes generated in all focus groups, African American women also reported a number of facilitators. Screening as part of comprehensive care, doctor's recommendation, peace of mind, open communication with family/friends, and presence of symptoms were all reported to be facilitating factors in seeking CRC screening.

Good general care/ screening as part of comprehensive care

Across all transcripts there was the proposal that CRC screening should be a part of good general health care. Some participants complained that they do not believe that the physical exams that they routinely receive are comprehensive enough. Women in this study reported that they believe CRC screening would be increased if it were incorporated into a comprehensive routine physical exam and expressed disdain for the lack of thoroughness of their current care such as:

I was saying that I do a health screening every year too but I mean it's just like limited if I don't you know say, 'don't you think I should have my chest examined' or 'I should have a pap smear' or whatever they don't, you're in and out of these places in two minutes...[discussion in group] they don't consider it all that stuff as part of the yearly exam (12/14/03)

Others reported that they would participate in screening if it were part of routine comprehensive exam recommended by the primary care physician.

It should be part of the regular exam, from your doctor, the doctor needs to push it a little bit more than they do. (12/14/03)

This last quote also encompasses the importance of doctor's recommendation, another widely discussed major facilitator to screening.

Doctor's Recommendation

Many women in this study reported only going to the doctor or getting additional screenings because of physicians' recommendations, as one participant succinctly commented:

I go to the doctor because my doctor tells me I have to go. (4/22/04)

Personal contact and follow up from doctors was also reported to increase screening compliance.

Now I have my own private doctor and if I go to him and he says go and take this exam or that exam. I go because he's going to follow up he says call me back tomorrow. (12/14/03)

This type of personal communication with doctors was believed to increase proactive health behavior. African American women discussed their desire for more personal contact with doctors. This is perhaps reflects a hope to replicate the beneficial aspects of speaking with family/friends that can also serve as a facilitator to screening.

Communication with Family and Friends

Support and open communication from family and friends about healthcare issues was reported to be a facilitating factor in CRC screening behavior. Although some participants discussed the difficulty with open communication with family members such as:

I can't discuss this with my niece because she's a lady. She says that's so personal please change the subject. I can't be bothered with that. That's a horrible thing to be describing to me. So I don't discuss it. (6/28/04)

However, when communication was present, the benefits were significant for group members. One participant described such communication saying:

I have five sisters so something is always breaking down on a girl. And what we do, we get together, if I gain weight or I feel like this or this is bothering me. So we do talk about health. I did the mammogram, did you go, etc. (6/28/04)

More specifically, participants went on to report that this open communication is even more likely to result in CRC screening participation when it involves shared first hand knowledge from someone who had CRC screening. One participant commented after hearing group members talk about their screening experiences:

And I think that once you have someone, especially that you know, who has gone through it, that's how things work in life. Someone tells you about it, you say it's okay but you hear it again from someone else that

kind of , it kind of calms you down, it sets your mind at ease. TY said she had it and it was wonderful. CW said it was good to her, it was a breeze.
(6/28/04)

The communal and supportive aspect of the group discussion seemed to be particularly encouraging to women in this study as it serves to both form or strengthen bonds and reduce anxiety.

Peace of mind

Fear and embarrassment were emotions that were found to be barriers to screening. Participants reported that gaining “peace of mind” was a major benefit to seeking screening. One respondent noted the benefit of screening saying that it:

Put your mind at ease that you’re not effected by whatever they are screening for. (4/20/04)

Another reported:

... it gives you a peace of mind, know that you are on the right track, you are doing the right thing. You don’t have to worry about it. (12/5/03)

As a result of the group’s discussion about peace of mind, one participant reported:

I have to go home and think about what I’m going to do if I get a bad report...so for that reason I am going to the doctor.....soon and I’m going to tell her along with everything else that I want to do please set me up for a screening for colon...cancer. I need it for my peace of mind. (12/14/03)

So it seems that despite great anxiety, the anticipation of peace of mind can be a motivating factor to screening that was evidenced in this particular group.

Presence of Symptoms

The presence of symptoms was also noted to be a facilitating force to seek medical care in general and CRC screening in particular. One participant commented that one goes to the doctor:

If you develop unusual symptoms, then you, um, then you go (4/22/04)

While another participant specified about the presence of pain saying:

One thing I can say is different is pain, as soon as I feel pain I go straight to my doctor (6/28/04)

In terms of seeking CRC screening in particular another participant reported:

I think that why a person might go, when they really go is when they see their stool and the darkness of it, I think that's the time they go. (12/5/03)

The following chart outlines the codes representing the most popular and widely discussed barriers and facilitators to CRC screening in this study:

Table 3: Barriers and Facilitators to CRC Screening

<u>Barriers</u>	<u>Facilitators</u>
Fear of: The unknown The Exam Death/Cancer Fatalism	CRC screening as part of comprehensive care
Lack of Knowledge	Doctor's Recommendation
Lack of Symptoms	Presence of Symptoms
Lack of Money/Insurance	Communication with family/friends
Homeopathic Remedies	Peace of Mind
Embarrassment	
Lack of time	

Themes

As previously mentioned, there were a number of themes that were prominent throughout the focus groups. These themes do not necessarily fall within the heading of barriers or facilitators but provide important information about screening behavior and the relationship between African Americans and the medical community.

Projection of Maladaptive Health Behavior

Although some participants readily discussed their poor health habits, others could only seem to recognize such behavior in others. Projection of maladaptive health behavior onto the larger community was a notable theme in the focus groups. In response

to a question that asked group members to rank areas of importance, participants ranked health as the top priority followed by family, work, money and social life. A common response was:

Health because in a sense that I want to stay well so that I can continue to work. But if you're not well, you can't continue to work. (4/22/04)

However, when asked how they believed others in the community would rank these same areas, participants believed money would be ranked first followed by family then health.

I think some would say money first. My friends that I have, they have to make a living. So they are going to say money first. (6/28/04)

The Importance of Race of Medical Professional

There was a range of opinions about the importance of the race of the doctor, with some participants reporting positive experiences with non-black medical professionals.

However, the importance of black doctors was noted in every focus group. A response from one participant was a common sentiment:

Well, I for one, I was brought up with the notion that you go to a black doctor because he is going to treat you better. And fortunately I have not had any adverse effects with doctors. As a child we always had a black doctor and whenever I need a doctor that is one of the prerequisites. I would prefer having a knowledgeable black doctor than any other group. In some cases, I would have to use a Caucasian or Oriental but my choice would be for the black doctor and I have been treated well. (4/20/04)

Some participants expressed even stronger beliefs such as:

I think that my black doctors treat me better than their white doctors treat them. Now within the last ten years or 15 years, there has been a little switch in it. I have some conversations, I've seen that white doctors are becoming more compassionate or whatever. But my experience is that my black doctors have always been there for me whereas white doctors, the few that I have been exposed to, they were impersonal... If, you know, my sister comes to sit next to me and tells me she has a problem, she is going to hear my problem better than someone from Europe. You know. (4/20/04)

In addition to the importance of same race doctors some noted the importance of good healthcare within the community and associated this with African American doctors.

Some people prefer Afro-American doctors rather than going to like downtown (6/28/04)

Distrust of medical community

A similar theme that was not explicitly stated to be a barrier to screening but plays a role in the relationship between the African-American and medical community is a general distrust of the medical community, as expressed by a participant who said:

We just feel that, more or less, years ago we had no black doctors, only white doctors. And I think we felt that we couldn't trust them. We feel we didn't get the care or they were not taking care of us the way should. We don't trust them. (12/5/03)

Some participants connected this distrust back to atrocities such as Tuskegee Syphilis Study and the fear and distrust of the medical community that African American's retained as a result.

With the Tuskegee thing, a lot of people don't trust doctors. They don't trust their corporation, this medicine because they are, its still within their mind and they won't be able to get it out of their mind. Especially the older ones. (12/5/03)

Another participant wondered:

Are they using us as guinea pigs? (12/5/03)

The Role of Prayer

Another important aspect of the African American community is the role of religion and prayer. Prayer served at times as both a barrier and facilitator to screening. Some participants spoke about using prayer in lieu of going to the doctor.

If you do have something... wrong with you you're supposed to meditate and pray on it and I believe that sometimes with your faith it gets better. (12/14/03)

However, for most, prayer would not replace visits to the doctor, as exemplified by one participant who stated:

Well I believe in prayer but if I really don't feel well I'm going to the doctor... (12/14/03)

And another who said:

If I'm hurting or have some kind of symptom, I will go to God in prayer. I ask for his guidance and healing. And then if it is, you know, I know that with prayer you still have to seek the physician. (4/20/04)

There were those for whom going to the doctor was also supplemented by prayer.

I believe in praying on it but then I believe that God has given the doctors the knowledge to help you. (12/14/03)

One participant described her view of religion and health saying:

Well in the respect that your body is suppose to be the temple and you have to take care of the temple. So that to me would be encouraging to, you know to take care of myself, you know. Go to the doctor be evaluated on a regular basis. (4/22/04)

For a small minority prayer played no role.

I hope and pray that everything is okay but the first instinct is to see the doctor. I don't pray over going to see the doctor. It's automatic. (4/20/04)

For most participants prayer was noted to be an important aspect of the daily lives of African American women in this study that served as a coping mechanism for life's challenges. Interestingly, more participants in the groups with lower mean age reported that prayer was not a factor or played a limited role in seeking treatment and going to the doctor while older participants were more likely to report that prayer was instrumental in the process of seeking healthcare and positive treatment outcome.

Phase II: Analysis of Research Questions

In this section, the research questions proposed in the previous chapter will be listed and addressed specifically. Some of the questions have been reviewed in Phase I of the analysis and therefore will not be presented in this question with similar detail.

1. What are the psychosocial factors that act as barriers and facilitators to CRC screening for African-American women?

As discussed in Phase I of the analysis, fear, lack of knowledge, lack of money and/or insurance, lack of symptoms, use of homeopathy, lack of time/ other obligations and embarrassment were the most common barriers to screening. Participants reported screening as part of comprehensive healthcare, doctor's recommendations and open communication with family/ friends, especially when involving personal testimonials of CRC screening were facilitators to screening.

2. Will African-Americans feel that traditional techniques (i.e. pamphlets, PSAs) are effective for getting members of the African American community to adhere to CRC screening?

The majority of African American women did not find traditional techniques to be effective for increasing screening participation personally or in the community as a whole. One participant described what she does with pamphlets:

I'm being honest. I will read it, you know, sort it and what not and throw it away. (6/28/04)

Another participant commented about the community in general saying:

People don't read the information, they don't want to read it. They don't read it in its entirety (12/14/03)

Women also reported reading health information only if:

"it is related to issues in my life" (6/28/04)

Therefore health information that is perceived to be irrelevant to oneself is not

considered. Moreover, as previously mentioned, the women in this study reported that first hand word of mouth strategies would be a more effective anxiety reducing means of improving CRC screening rates.

I just told all my friends like when I mentioned that I was going through it that I had to take the test. They told me yeah my doctor says that they want me to take it but I'm not doing it. So after I experienced it, I called them all, everyone who said they were scheduled to have it and I told them. It was a breeze. You have nothing to worry and it, cause it was. (6/28/04)

Other women discussed the counter effect of too much health information and the anxiety that it may create saying:

You know, sometimes, with certain illnesses, sometimes you're just bombarded with information that puts you, put me on the edge of my seat about it. (4/20/04)

Additionally, some women reported that the church should play a larger role in getting the word out about CRC screening.

the preacher has a very good and captive audience... I think he has a responsibility to talk about some of the things that affect his parishioners on a daily basis (4/22/04)

The women in this study believed that these strategies would be more effective in increasing CRC screening rates than brochures and PSAs.

3. What role does resilience play in CRC screening behavior?

As previously discussed, resilience as defined by Masten, Best and Garmezy (1990) is the capacity for successful adaptation despite challenging or threatening circumstances. The conceptualization of resilience utilized in this study incorporates the larger social and community context when understanding how one successfully navigates through life. In other words, one's ability to negotiate larger individual, communal and societal obstacles (e.g. depression, poor family eating habits, racism) is instrumental in both the notion of

resilience as well as whether or not one decides to engage in preventative health behavior. The African American women in this study reported that they needed to navigate many societal and psychological hurdles to successfully navigate through life. African American women reported prioritization as an important tool to achieve this goal. To that end, many reported that while family, work and community are important and necessary for individual happiness and resilience, can serve as a barrier to screening. Although some women readily admitted their difficulties with health and self prioritization, most did not report this struggle. However, it was most telling that many women, although saying that health was a priority for them, doubted that this was a community wide priority, stating instead that most others would report money and work as most important without necessarily discussing this as a personal struggle. This perhaps points to a conflict that exists for these women about prioritizing their needs which is easily recognizable in the behavior of others. Similarly, when speaking about whether or not others in the community get too busy to go to the doctor, the women in this study freely discussed how others put children, work and relationships above their health. This may again point to this conflict and speak to a need that African American women have to prioritize their families and jobs as the most proximal of needs for maintaining resilience. However, health needs when there are no observable symptoms are distal factors and therefore de-prioritized according to resilience theory.

4. What resilient beliefs (i.e. prioritization of life issues) are associated with adherence to CRC screening guidelines?

Self prioritization, prayer, understanding risks, and family/friends are all beliefs that fit into the scope of resilience theory that women in this study reported are important

for seeking CRC screening.

Prayer and Religion

Prayer and religion have been a cornerstone of African American culture and thereby a source of resilience. The participants in this study reported that when prayer was used in conjunction with the medical community it had the potential to facilitate adherence to screening.

I believe in praying on it but then I believe that God has given the doctors the knowledge to help you so I but I know some people won't go because they feel you know God will take care of if they'll leave it in God's hands (12/14/03)

One woman described the importance of self care as it embodies her religious beliefs by saying:

Well in the respect that your body is suppose to be the temple and you have to take care of the temple.(4/22/04)

Utilization of family/friends

The ability to seek out and utilize resources is an important aspect of resilience. Community and family have traditionally been important aspects of the African American culture. For African Americans the ability to seek out familial and community resources have been historically adaptive. Participants in this study reported that family and friends can serve as a support for seeking screening.

I think it's important to because they are your friends and they've told you about their experiences and this would make you go too (12/14/03.)

Understanding Risk

Understanding risk is another important aspect of resilience. Among the women in this study there were various levels of understanding risk for CRC screening. Those participants who had an adequate understanding of their risk and were not burdened by

overwhelming fear discussed seeking screening in a positive light.

I think that we are at greater risk because it shows it right there. And I would imagine it comes more so from our diet. (4/20/04)

One overweight participant in this group who had CRC screening noted:

I'm (have) one risk factor, obesity. (4/20/04)

Self Prioritization

Self prioritization served to increase adherence with screening. Those participants who reported that they put themselves first also spoke about it in the context of also prioritizing their individual health needs. For example, one participant who reported having been screened for CRC in the past said:

I love me, I'm always going to take care of me. Whatever I eat will be good for or anything to better my health or life, I'll do it (12/5/03)

Another participant discussed prioritizing health saying:

I think my health would come first because if I'm not healthy then I (can't) worry about my family's. So my health would be first then family (4/22/04)

5. What resilient beliefs are associated with non adherence to CRC screening guidelines?

Prioritization of work and family

While self prioritization was associated with adherence to screening, prioritization to work and family was not. Work and family are fundamental in most cultures, the African American women in this study reported that this can often come at the expense of self care and lead to non-adherence to screening, as evidenced by one participant who said:

You've got to cram so much in one day, until people just don't have enough time to take care of their health. (4/22/04)

Distrust of the medical community

Distrust of the medical community makes historical sense given the history of poor treatment African Americans have received from the medical institutions. This distrust may have once proved adaptive and may have been an aspect of healthy cultural paranoia (Terrell & Terrell, 1981) as it minimized exposure to racism and/or exploitation. This distrust is rooted in the belief that for generations African Americans have received subpar medical care as captured in the following statement:

They talk to you like you're a moron. They don't tell you things, sometimes you don't know the questions to ask. You understand and they don't volunteer information like they should. That's how I feel about some doctors. (6/28/04)

However, this distrust and by extension avoidance of the medical community can prove deadly when it comes to health as it decreases the likelihood that African American women benefit from potentially lifesaving benefits of early detection CRC screening.

6. What role does the HBM play in CRC screening?

The Health Belief Model (HBM) (Janz & Becker, 1984) suggests that there are factors that are associated with the decision to engage in any kind of preventative health behavior; perception of susceptibility to the illness, the perceived seriousness of the illness, the perceived barriers to carrying out the preventive health behavior and lastly the perceived benefits to performing the behavior. The following is a vignette which represented the various aspects of the HBM:

Tom/Mary has heard the radio ads (Public Service Announcements) about the risks of colorectal cancer. He/she believes he/she is at risk, believes that it's a serious illness, knows he/she can get to the doctor, insurance will take care of costs, plus his/her children have been encouraging him/her to go, but Tom/Mary continues to go back and forth about going

in for colorectal cancer screening. What do you think are all the things going on in Tom's/Mary's mind about this?

Group members reported that fear of the unknown, misinformation about possible outcomes from screening, fear of the exam and lack of time as reasons that Mary would not seek screening despite accounting for all aspects of the Health Belief Model being satisfied. According to the women in this study, these HBM factors may not be adequately compelling to seek screening when factors such as fear and other life obligations are still at play. The focus group members believed the perceived barriers still seemed to outweigh the perceived benefits for getting screened in this scenario. The following quotes are a sampling of the reactions to this vignette:

and also she's heard of people who have this and have to wear the colostomy bag and they don't want to wear that bag. (12/14/03)

I think she is probably afraid of what they're going to find out. And it's really, really serious. (12/5/03)

Just can't even find the time to go. You think that you have all these important things to do in your everyday life. And that's the most important thing. But um, you know you can't see it. Out of sight, out of mind, if you don't know, you don't know. (6/28/04)

7. What role does the Transtheoretical model play in CRC screening?

The Transtheoretical Model has been employed to address low adherence of African-Americans to CRC screening (Brenes & Paskett, 2000). According to the Transtheoretical Model, people can be divided into stages based on where they are in their decision making process with respect to whether or not to engage in a preventative health behavior. There were a number of group members who had CRC screening in the past. However, of those who had not yet been screened, many reported to be currently in the contemplative stage and shared their ambivalence with the group. Some group

members reported that the group was acting as a facilitator to screening. Quite a number of women expressed the intention to seek screening in the future. One participant noted:

Well, I think I would ask my doctor about it. I have a doctor's appointment on the 14th. (6/28/04)

Utilizing the Transtheoretical Model to determine stage of decision making in order to intervene during the contemplative stage may be a useful tool to increase CRC screening rates.

Chapter V

Discussion

A number of studies have looked at the CRC screening behavior of African Americans but few studies have specifically addressed the issues particular to African American women. Fewer still have used qualitative research methods to understand the unique perspective of African American women. The present study examined the psychological and social influences on CRC screening beliefs and practices of African American women. The women who participated in this study were candid about their views on CRC screening and provided valuable insights into their beliefs and practices as well as those of others in the community.

Discussion of Hypotheses and Research Questions

The first aim of this study was to identify the psycho-social barriers and facilitators that lead to compliance or non-adherence to CRC screening. The hypothesis that African-American women in Harlem will feel that psychosocial factors play an important role in health seeking and CRC screening behavior was confirmed.

Seven barriers and five facilitators were identified in this sample. Many of these factors have been well documented in the literature including fear, lack of knowledge, lack of symptoms and lack of money/insurance. Others including lack of time and embarrassment were less prominent in the literature.

Although less widely discussed in the literature, embarrassment was a persistent theme among these women. Perhaps the presence of an older African American woman as the focus group leader facilitated the discussion of this sensitive issue. The theme of embarrassment also shed light on what is perhaps a cultural resistance to CRC screening.

Some women discussed their southern heritage and the difficulty in shedding their modesty to engage in such as personal exam. Perhaps the latest CRC screening technology such as the virtual colonoscopy can be used to alleviate some of the anxiety, fear, anticipated discomfort and embarrassment related to CRC screening as it provides less invasive screening methods.

Although lack of time was a theme that was less represented in the literature, a similar concept, competing health priorities (Beeker, 2001) was noted to be a barrier among African American women. Both lack of time and competing health priorities are themes that contain the idea that African American women have to prioritize their life and health needs to function optimally which is a hallmark concept in resilience theory. The women in this study discussed the challenges of daily life that get in the way of screening. From the standpoint of resilience it is understandable that CRC screening would be deprioritized in favor of more tangible and proximal needs. However, the prioritization of these daily life challenges may have come at the expense of healthcare related issues such as CRC screening.

Many of the facilitators discussed in the study were also reported in the literature including doctor's recommendation, presence of symptoms and communication with family/friends. Unique to this study was the belief that screening should be part of comprehensive healthcare and the possibility of gaining peace of mind about one's health through screening.

Many of the women believed that there should be no additional steps involved in obtaining screening and it should be performed by one's primary care doctor. This belief may point to a number of different possibilities including a lack of knowledge that

primary care physicians may not be trained to perform CRC screening but it may also be indicative of a sense of comfort with a trusted doctor which makes him/her a preferred choice to perform an invasive exam. It may also be a commentary on the larger issue of the structure of medical insurance and the US healthcare system that often involves a tedious referral process that can be daunting and act as a deterrent. This is especially problematic as many women also reported a distrust of the medical community and a lack of personal attention from doctors. The combination of a labor intensive health care process with a lack of personal connection with one's doctor may decrease the likelihood of requesting CRC screening or following through with a referral. Perhaps the hope for same race doctors expressed by many women in the study reflects a desire for understanding and connection that would hopefully result in better treatment and more comprehensive healthcare.

The themes of distrust of the medical community and desire for same race doctors were not explicitly stated to be barriers or facilitators to CRC screening but emerged in the process of discussing the pros and cons of CRC screening. This distrust has historical roots and group members discussed their experiences of perceived racism with medical professionals and cited the Tuskegee Syphilis Study as the ultimate injustice by medical professionals against the African American community. The issue of trust should be addressed in order for community members to internalize the suggestions of the medical community. This distrust was perceived by the researchers in this study when attempting to recruit participants. Many community members, especially men (who were recruited as part of the larger study) were skeptical about participating in a study that involved a large medical research institution.

Another theme that emerged was one that reflected the process rather than the content discussed in the groups. Some women were forthcoming of their difficulties with adhering to medical advice. However, many only discussed maladaptive health behavior of others. This may perhaps reflect a sample that was more proactive about their healthcare and therefore could only participate by discussing the difficulties of others. However, it may also reflect the projection of maladaptive beliefs and behaviors onto the community that is rooted in individual anxiety about the state of one's health or health related behaviors. Understanding the roots of the resistance to CRC screening as well as the wishes and expectations can be useful in designing an intervention tool for African American women.

The second aim of this study was to understand the utility of traditional recruitment techniques for CRC screening. Whether they placed the blame within the healthcare system for not providing engaging materials or with members of the community for not engaging with the material, the women in this study agreed that traditional recruitment techniques were not effective. Similar to the wish for more a personalized approach to healthcare, African American women believed that attempts to engage community members in screening should also be more personalized and suggested "word of mouth" strategies to increase CRC screening rates as was illustrated by a participant who said:

I think that once you have someone, especially that you know, who has gone through it, that's how things work in life. Someone tells you about it, you say it's okay but you hear it again from someone else that kind of calms you down, it sets your mind at ease. (6/28/04)

Many women also discussed the role of the church in this regard believing that pastors can be an intermediary between the African American community and the medical community to spread the word about CRC screening. In general, there is a consistent theme of the need for a more personalized approach to how healthcare information is disseminated and medical care is provided.

The third aim of this study was to begin to understand the role of resilience in CRC screening behavior. It was proposed that some resilience beliefs would be conducive to seeking screening and adhering to screening recommendations while others may have a less facilitating effect. In this study self prioritization, utilization of friends/family as a resource, understanding risk was a facilitating influence while prioritization of others and distrust of the medical community were associated with decreased likelihood of adhering to screening recommendations. Prayer/Religion was shown to be an important aspect in helping African American women to cope with life's challenges and a facilitating influence for CRC screening when used in conjunction with as opposed to in lieu of medical care.

Resilience beliefs such as prioritization of friends and family and distrust of outsiders especially those representing large institutions and the medical community have been historically adaptive. However, those same protective factors that have historically lead to psychological resilience in the African American community may be detrimental when applied to seeking healthcare as they may lead to an opposite effect resulting in avoidance of healthcare and lower screening rates. In this way resilience theory provides a unique perspective for understanding the health behavior of African Americans that goes beyond what can be understood via the Transtheoretical and the Health Belief

Models. Resilience theory allows us to understand behavior within the individual, familial and cultural context and to determine where CRC screening fits into these dimensions.

The final aim of this study was to understand the role that the HBM and the Transtheoretical models play in CRC screening in the sample. The Transtheoretical Model was useful in determining that many women in the study who had not yet screened were in the contemplative stage. The Health belief Model was instrumental in assessing the perceived barriers and benefits of the women in the study. However, participants still reported that it is likely that even when perceived benefits seemingly outweigh perceived barriers action may still be unlikely. Resilience theory can be used to understand the variance by taking into account the individual, psychological cultural, familial and social needs of the individuals who are non-adherent to CRC screening.

Limitations

There were a number of limitations to this study. The collection of demographic information was limited by the restrictions of the Memorial Sloan Kettering IRB and the larger study “Minority Recruitment to Colorectal Cancer Screening.” Information such as level of education and income could not be ascertained. It is therefore impossible to determine whether or not the sample was skewed towards higher income and more educated women. Additionally, this study may be limited by self selection bias. Recruitment was done at a senior citizen center and at senior computer classes. Seniors who attended either group may have been more proactive by nature of their participation in these enrichment activities. Similarly, those seniors agreeing to participate in this study

may be more interested in preventative healthcare, cancer screening and be more adept at seeking healthcare or accessing community resources.

Additionally, although many participants reported that they enjoyed the camaraderie and information sharing in the group format, the group may have influenced some participants to censor their beliefs and/or conform to the tone and/or beliefs of the group. It is also possible that some participants may have had difficulty discussing their personal beliefs and practices within the group format. This may in part explain those group members who only discussed maladaptive health behaviors in the community as opposed to personal difficulties.

Future Research

At the end of each group, participants were given information on how to attain free or low cost CRC screening with or without insurance. Many women reported enjoying the focus group discussion and felt compelled to action by the testimonials of other women in the group. A number of women reported that they planned to use the information provided at the end of the focus group to seek CRC screening. Participation in the group and the information provided can be viewed as an intervention. However, due to limitations of this study, it was not possible to follow up on the effect of the focus group as an intervention to determine how many women received CRC screening post focus group. Future qualitative research can investigate the effects of similar information gathering group discussions on CRC screening behavior or the process of the research itself as an intervention.

Resilience theory has not been used to understand CRC screening behavior in the past. Perhaps future research can investigate dimensions of individual resilience such as

life prioritization, ability to utilize community resources and estimation of risk to determine their relationship to CRC screening behavior.

Additionally, resilience can be utilized in combination with other theoretical models. For example, the Transtheoretical Model can be used to determine stage of contemplation and when it would be best to intervene. Resilience beliefs such as the importance of self prioritization and the utilization of family/friends and other understandings gleaned from this study such as the desire for more comprehensive healthcare and personal attention from doctors can be useful tools in bridging the gap between non-adherent African American women and the medical community. Ultimately, it is my hope that resilience theory can be used in further research to understand individual behaviors within a familial, societal and cultural context that would increase the rates of CRC screening among African American women.

Appendix A**Flyer****THE ESPLANADE GARDENS GOLDEN HERITAGE
NORC PROGRAM****WOULD LIKE TO INVITE YOU TO ATTEND****A DISCUSSION ON OPINIONS
ABOUT CANCER SCREENING****IN NOVEMBER AND DECEMBER****THE DISCUSSION IS OPEN TO ALL SENIORS,
AGES 50+****COMMUNITY ROOM #3
BUILDING #3****HOT LUNCH WILL BE SERVED****PLEASE CALL 212-234-0978
FOR AVAILABLE TIMES
AND REGISTRATION**

Appendix B

Consent Form



Memorial Sloan-Kettering Cancer Center IRB Protocol

IRB#: 03-102 A (4)

PATIENT INFORMED CONSENT FOR CLINICAL RESEARCH

1.0 INTRODUCTION (INCLUDING TITLE OF THE STUDY)

You are being asked to participate in a clinical research study. We hope it will help us learn more about why people take part in cancer screening. To make an informed decision about whether or not you want to be part of this study, you should understand its risks and benefits. This process is known as informed consent.

This consent form gives you detailed information about the research study. Once you understand the study, its risks, benefits, and alternatives, you will be asked to sign this form if you wish to take part. You will be given a copy to keep.

The title of the study is **MINORITY RECRUITMENT FOR COLORECTAL CANCER SCREENING.**

2.0 PURPOSE OF THE RESEARCH

Colorectal cancer is the third most common cancer in the US. There are screening tests that can find this cancer early, when it is more likely to be cured. The tests might also find polyps. These can become cancer over time. If they are taken out, a cancer should not develop. The purpose of this study is to find out what stops some African-Americans from having screening tests for colon and rectal cancer.

3.0 DESCRIPTION OF THE RESEARCH PROCEDURES

For this study, we will be talking to people who live in NORC (Naturally Occurring Retirement Center) of Esplanade Gardens or who are found through Senior Tek and who signed up for a focus group or agreed to an individual interview. and who signed up for a focus group. Should you be willing to join the study, we will ask you to come to a focus group discussion. A focus group is a discussion about a topic. You will share your thoughts and feelings about colon and rectal cancer screening. The focus group will involve up to 14 other African-Americans and a trained focus group moderator who will lead the discussion group. We will audio tape the discussion. Only the research team will hear this tape. We will type up what was said during the conversation so other researchers can learn of your views. We will not attach your name in any way to this document. Your contact information will not be shared with anyone outside this project and you will not be contacted by anyone other than us.

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PB**

Amended: 5/11/04

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**Memorial Sloan-Kettering Cancer Center
IRB Protocol**

IRB#: 03-102 A (4)

During the focus group we will explore a number of topics. We will ask you about what you know about colon and rectal cancer screening. We will discuss reasons why you would get screened or reasons why you would not get screened. We will ask you how you think about colon and rectal cancer screening. We will use a question-answer format.

4.0 SIDE EFFECTS/RISKS/BENEFITS

Joining the study does not pose any physical harm or risk to you. There is a small chance that talking about cancer may upset you. If you wish to speak to someone after the focus group because you are upset, we will arrange for you to speak with Dr. A.J. Franklin or Dr. Jennifer Hay, who are in charge of this study.

BENEFITS

We hope this study will help you and others, but we cannot say that it will help you directly. We may learn how to improve health screening for others. We will also give you information about where you can learn more and get colorectal screening in your community.

You will receive a postal money order (a check to you that can be cashed at any U.S. post office) of \$20 for completing this study.

5.0 COMPENSATION IN CASE OF RESEARCH-RELATED INJURY

We do not anticipate any injury from your being a part of this study. If you are injured as a result of being in this research study, the hospital will provide the care you need. The hospital will not give you any money to cover this care. You or your insurance carrier will be billed for it.

6.0 ALTERNATIVES

You do not need to join this study to learn about colorectal cancer screening. We can refer you to a physician who can give you information or testing as part of preventive health care.

7.0 FINANCIAL COST

You will not be charged for any costs if you join the study. If you decide to have colorectal cancer screening, this study will not pay for this. We can refer you to a hospital with sliding fee scale programs. Information about colorectal screening programs will be provided to you at the focus group.

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8.0 CONFIDENTIALITY/PRIVACY

Your name and anything else that can identify you will not be used in any reports or articles that come from this study. Every effort will be made to keep your study records private. All focus group members will be asked to keep private what is shared during the discussions. We will keep all information that you share during the focus groups completely private. Your contact information (name, address and telephone number) will be kept separately. We will not use your name or any other information that could identify you in reports or articles about this study. Study materials will be kept in a locked file. Trained staff at Memorial Hospital, the Food and Drug Administration, or other sponsors such as the National Cancer Institute may review your records if necessary. Anything discussed during the focus group is also considered private health information and will be handled under the same standards.

By signing this consent form, you are giving the following people or institutions permission to use the interview data:

1. The researchers from MSKCC and the City College of New York. They include the study's principal investigator, Dr. Ann Zauber, and other research staff. Your data, combined with data from other research participants, will be used to prepare a final research report. The data will never include your name or any other information that could identify you or your family member.
2. Other State or Federal agencies, such as the Food and Drug Administration, may review the research records and practices. All of these reviewers will keep your information private.
3. The data may also be used for presentations in other professional settings. This may include other health care settings and conferences. The audience can include health care providers, researchers, advocates, health officials, patients, and people affected by cancer.

8.1 PRIVACY

It is the responsibility of the research staff at Memorial Hospital to ensure that your records are managed in such a way to protect your privacy. Access to your medical information will be limited to those listed in the Research Authorization Form which is a part of the informed consent process.

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**Memorial Sloan-Kettering Cancer Center
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9.0 RIGHT TO REFUSE OR WITHDRAW/NEW FINDINGS

The choice to take part in this study or not is yours. Make your choice based on what we have explained to you and what you have read about the study and other forms of care. We will answer your questions about the study at any time. While you are part of the study, we will inform you of any results that might affect your willingness to continue in it. You have a right to withdraw at any time.

10.0 TERMINATION

N/A

11.0 CONCLUSION

Any hospital that does research on people has an Institutional Review Board (IRB). This board reviews all new studies to make sure that patients' rights and welfare are protected. The IRB at Memorial Hospital has reviewed this study.

The principal investigator in charge of this study is Dr. Ann Zauber, telephone number (646) 735-8160. If you need to know more about this study before you decide to join, or at any other time, you may wish to contact her. In the event that you do decide to take part in the study, she should be called or contacted if you would like to have a referral for screening or if there are colorectal screening questions from the study. If you have a non-physical or psychological side effect, you may wish to contact the psychologists involved in this study, Dr. A.J. Franklin at (212) 650-8566, Dr. Jennifer Hay at (212) 583-3009. A non-physician you may call to find out more about the consent process, research patients' rights, or research-related injuries is Janice Levy, Patient Representative, telephone number (212) 639-5804.

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**Memorial Sloan-Kettering Cancer Center
IRB Protocol**

IRB#: 03-102 A (4)

MINORITY RECRUITMENT FOR COLORECTAL CANCER SCREENING

Purpose:

Statement of professional obtaining consent

I have fully explained this research study to the subject_____. In my judgment and the subject's, there was sufficient access to information, including risks and benefits to make an informed decision.

Date: _____ Investigator's Signature: _____

Investigator's Name: _____
(Print)

Subject's Statement

I have read the description of the clinical research study or have had it translated into a language I understand. I have also talked it over with the investigator to my satisfaction. I understand that my participation is voluntary. I know enough about the purpose, methods, risks, and benefits of the research study to judge that I want to take part in it.

Date: _____ Subject's Signature: _____

Subject's Name: _____
(Print)

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Appendix C**Research Authorization Form**

**Memorial Sloan-Kettering Cancer Center
IRB Protocol**

IRB#: 03-102 A (4)

RESEARCH AUTHORIZATION

MINORITY RECRUITMENT FOR COLORECTAL CANCER SCREENING

Information about you and your health is personal. It is "Protected Health Information." We cannot use any of your health information for research unless you tell us that we can. If you take part in this research, the people or organizations that can look at your information are listed below. You will have to sign this form to tell us we have your permission to share your protected health information.

The following persons and/or organizations may use or disclose your information for purposes related to this research:

- The people in charge of the study and their assistants and support staff.
 - Principal Investigator and Co-Principal Investigator(s): Dr. Ann Zauber, Dr. Jennifer Hay
 - Members of the Research Team including the participating investigators, research assistants, clinical nurses, fellows/residents and clerical support staff including: Dr. Bruce Rapkin, Dr. Anderson J. Franklin, Ms. Sweeney Oscar, Ms. Shameeka Faulkner, Ms. Monique Guishard, Mr. Joe Brown, and Ms. Betty Jenkins

The following persons and/or organizations may look at your information for purposes related to this research:

- Members and staff of the hospital's Office of Clinical Research, Data Safety Monitoring Board and the Quality Assurance Committee.
- Members and staff of the hospital's Institutional Review Board and Privacy Board.
- The National Cancer Institute, National Institutes of Health, U.S. Food and Drug Administration, and other agencies responsible for oversight.
- Others:
 - City College of New York (Dr. AJ Franklin and his research group)
 - Heritage NORC Program* and other focus group participants
 - Senior Tek

* NORC (Naturally Occurring Retirement Center) of Esplanade Gardens in Harlem and Senior Tek will help the researchers identify participants for the focus groups, but will have no other involvement in the study.

The following information will be used and/or disclosed for this research:

- Your entire research record: **This means your discussions shared as a part of this focus group or interview.**

**IRB
PB**

Approved by MSKCC's Privacy Officer on 5/11/04

Judy Hagerty-Paglia



**Memorial Sloan-Kettering Cancer Center
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- HIV-related information. This includes any information showing that you had an HIV-related test, have HIV infection, HIV-related illnesses or AIDS, or any information that could mean you might have been exposed to HIV. New York State requires us to obtain this consent. **We do not intend to ask you about HIV for this study, but you may discuss anything related to your health during the focus group or interview.**
- ☒ HIV-related information collected during this study if you choose to disclose it when talking to any of the staff. **All discussions shared as a part of this focus group or interview will be kept private.**
- ☒ The following information:
 - Comments or feedback that you may provide in the focus group or interview
 - Audiotapes

If you sign this form, it means you are giving us permission to share your protected health information. We can only share it with the people or organizations describe above. The purpose for the use and sharing of this information is to conduct this study. This signed form allows us to make sure that everyone who needs information related to this study can get it.

Your protected health information may also be used for your research treatment, to collect payment for care you receive while on the study, and to run the business operations of the hospital.

Some of the people or organizations listed above may not be subject to privacy laws. This means they could share your information again.

You do not have to sign this form. If you do not sign it, you will not be able to take part in the study. Your health care outside the study will not be affected. The payment for your health care or your health benefits will not be affected.

You have the right to withdraw from the study at any time. If you sign this authorization form, you also have the right to withdraw it at any time. If you withdraw it, we cannot use or share anymore of your research data. If the hospital has already used or shared your information, it cannot be taken back. This authorization allows us to use your information until you say we cannot use it anymore. If you want to withdraw your authorization, write to: Dr. Ann Zauber, Memorial Sloan-Kettering Cancer Center, Department of Epidemiology and Biostatistics, at 307 East 63rd Street, 3rd floor, New York, NY 10021.

**IRB
PB**

Approved by MSKCC's Privacy Officer on 5/11/04

JudyHagerty-Paglia

Appendix D



Memorial Sloan-Kettering Cancer Center IRB Protocol

IRB#: 03-102A (4)

Appendix 1: Focus group questions

A. Ground rules

The moderator will begin the focus group by covering the items below.

- State his or her name
- Thank the participants for attending
- State that researchers are conducting a study to understand the factors that may influence an individual in the community to undergo colorectal cancer screening
- State the participants will be asked to discuss their knowledge and attitudes about colorectal cancer and screening, their likelihood of seeking screening, and the primary benefits and barriers of going through the screening process
- Explain that researchers invited the participants because they are all African-American. As members of the African-American community, participants may be able to provide insight into the broader beliefs of that community towards colorectal screening
- Explain that researchers will summarize information provided and use the findings to help inform questions that will be written for a broader survey. Explain that all findings from the session will be aggregated across all participants and no names will be attached to comments
- Assure that all information provided will be kept in the strictest confidence
- Explain that there are no right or wrong answers but rather differing points of view. It is important that participants feel comfortable sharing their opinions when they differ from those of others
- Explain that participants do not need to answer questions that make them feel uncomfortable
- Encourage participants to speak loudly, but not interrupt others
- State that the session will be audio taped so as not to miss any comments. Encourage participants not to speak over each other as doing so garbles the recording
- Encourage participants to refer to the moderator and to each other by first name (name placards will be used)
- Explain that all information shared will be helpful and that it is important not to censor for fear that thoughts are boring
- Explain that the session will last an hour and a half

B. Introduction

- Before we begin our discussion, let's go around the room and state your name for the group
- Please be sure to speak up so that we do not miss your voice on the tape

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C. Present Behavior, Beliefs and Practices

1. Louise/Louis and friends as they are leaving church service talked about the health program promoted at the church that morning. Encouraged by the Pastor to take care of themselves the group talked about why it seems so hard to follow advice about taking care of one's health. What do you think were some of the things they said?
2. How do you think religion or prayer plays a part in your decision to go to the doctor? (Ex. If you're not feeling well, will you pray on it?)

D. Life Priorities and Resilience

3. Thinking about the period in one's life between 50-55 years old, what would you list as the 3-5 most pressing life concerns at this time for you?
 - a. during the ages 60-65?
 - b. at the present time?
4. We have identified 5 areas of daily life that people are concerned with: family, work, health, social life, and money. How do you think yourself or others would rank them in importance?

E. Community Specific Probes

5. How do you think Black folks have been treated by doctors over the years in Harlem?
6. Some people say that Black folks get too busy with other things to go to the doctor. What do you think about that? What are some of those things?

F. Present Behavior, Beliefs and Practices

Now we want to know about how you use health information.

7. Have you received brochure handouts on health information?
8. What do you do after reading these brochures?

G. Benefits and Barriers to Health Screening

9. When you think about the possibility of getting a health screening, what would you say are the advantages of getting a screening? Which of these benefits stand out as being most important?
10. When are you most likely to go to the doctor?

H. Knowledge About colorectal cancer screening

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11. When I say colorectal cancer, what are the first things that come to mind for you?
12. Do you know anyone who has had colorectal cancer? What do you know about their experience with their disease?

I. Risks

13. When do you think someone should start being concerned about cancer? What about colorectal cancer?
14. There are several ways that you could get tested for colorectal cancer. Let's talk about the different tests.
 - a. The first is fecal occult blood testing, has anyone heard about this?
[Explain procedure]
 - b. What about sigmoidoscopy, has anyone heard about this one?
[Explain procedure]
 - c. What about colonoscopy?
[Explain procedure]
15. The moderator will present graphs depicting colorectal cancer risks for African Americans. [See graphs attached] What do you think about this?
16. Tom/Mary has heard the radio ads (Public Service Announcements) about the risks of colorectal cancer. He/she believes he/she is at risk, believes that it's a serious illness, knows he/she can get to the doctor, insurance will take care of costs, plus his/her children have been encouraging him/her to go, but Tom/Mary continues to go back and forth about going in for colorectal cancer screening. What do you think are all the things going on in Tom's/Mary's mind about this?

I. Intentions/Health Beliefs Model

17. What other things in a person's life might come first before seeking colorectal cancer screening?
- 18(a). What do you think would really help someone make the decision to get colorectal cancer screening?
- 18(b). What do you think about the possibility of getting a colorectal cancer screening?

J. Social Supports

19. Given the things you routinely talk about with family and friends how often do you discuss health concerns?
Cancer concerns?
Colorectal cancer concerns?

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20. How important are family and friends in getting health screening or colorectal cancer screening?

K. Ending Question

In conclusion do you have any suggestions on how we can help increase the number of Black folks getting colorectal cancer screening?

Again, thank you all so much for your candor and your willingness to speak your mind. We've learned a lot today, and your view will help us tremendously as we move forward with this research. If you'd like, please feel free to stick around if you have any questions about our research, or have any comments you'd like to share.

Appendix E

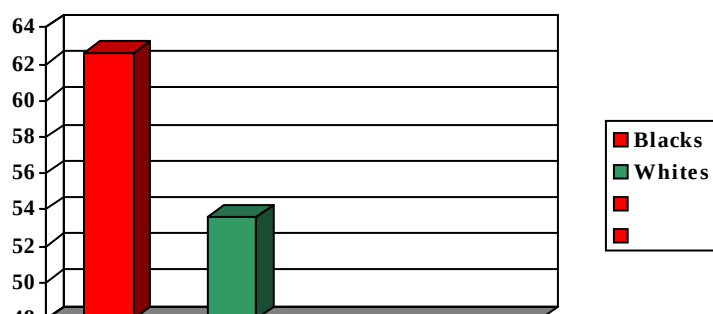
Graphs

Graph 1

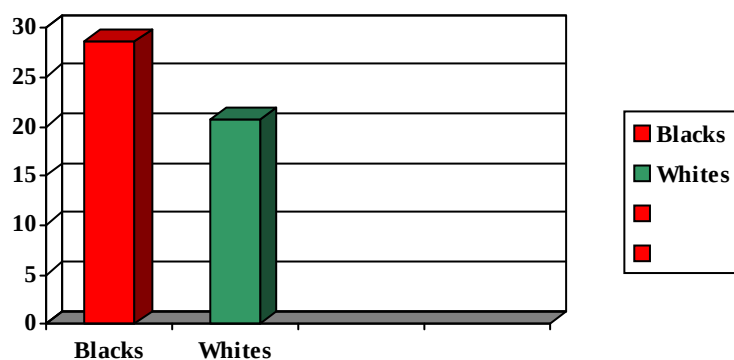
Risk Factors for Colorectal Cancer

- Obesity
- Lack of Physical Activity
- Unhealthy Diet
- Smoking

Graph 2

Risk of Having Colorectal Cancer

Graph 3

Risk of Dying From Colorectal Cancer

Appendix F

Subject Handout



Memorial Sloan-Kettering Cancer Center IRB Protocol

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Appendix 3. Colorectal Cancer Facts and Screening

Colon Cancer: The Facts

What is colon cancer?

Colon cancer is an abnormal growth of cells in the large intestine, or colon.

Who gets it?

Colon cancer is one of the most common cancers in the United States; anybody can get colon cancer.

Can it be treated?

When detected early, colon cancer has a very high cure rate – up to 90 percent of cases can be cured without radical surgery.

Where does it come from?

Colon cancers start out as small benign growths called polyps, in the lining of the colon.

Is it possible to keep polyps from developing into cancer?

Colon cancer can be prevented by removing polyps, usually without surgery, before they develop into cancer.

Might I be more at risk than other people might?

- Your risk of colon cancer is increased if you have a parent, brother or sister with a history of polyps, colon cancer or other cancers.
- If you have a history of polyps, Ulcerative Colitis, or Crohn's disease then you are also at increased risk of colon cancer.
- Currently, colon cancer is the second highest cause of cancer death in the United States. While the incidence and mortality rates have declined for whites since 1973, the rates for African-Americans have increased.
- In Harlem, the mortality rates are higher than the national average for African Americans

A regular program of prevention and early detection would be beneficial.

How do I know if I have colon cancer polyps?

With a variety of tests a doctor can determine whether you have colon cancer polyps.

For men and women, age 50 or older, periodic check ups with the following tests are recommended:

- ◆ Stool blood test – annually and
- ◆ Flexible Sigmoidoscopy – every 5 years or
- ◆ Colonoscopy – this examination is currently being evaluated as a general population screening test and is considered to be an additional option for screening instead of the above tests.

How else can I reduce my chances of getting colon cancer?

Studies suggest that your lifestyle may affect your chances of developing colon cancer. Experts suggest that you:

- ◆ Decrease the amount of fat in your diet.
- ◆ Increase your consumption of fruits and vegetables and salads
- ◆ Maintain the proper body weight for your size
- ◆ Engage in regular physical activity
- ◆ Don't smoke
- ◆ Don't drink excessive alcohol

Are there any symptoms of colon cancer?

Not always, but The American Cancer Society recommends that people with any of the following symptoms consult their doctor:

- ◆ A change in bowel habits such as diarrhea, constipation, or narrowing of the stool that lasts for more than a few days
- ◆ Rectal bleeding or blood in the stool
- ◆ Cramping or steady abdominal (stomach area) pain
- ◆ Unexplained weight loss
- ◆ Jaundice (yellow-green discoloration of the skin and white part of the eyes).

Please contact your Health Care Provider if you would like more information about colon cancer screening or to make an appointment for a screening test.

Appendix G**Colorectal Cancer Screening Referral Information**

Memorial Sloan-Kettering Cancer Center
IRB Protocol

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Appendix 5. Colorectal Cancer Screening Services in Harlem

Please refer to the Screening Services in Harlem Sheets for information on colorectal cancer screening and how you can be screened at Ralph Lauren Center, North General Hospital and the Harlem Hospital Center.

Please refer to the Cancer Information Services sheet to get information on colorectal cancer and screening across New York City and State.



Memorial Sloan-Kettering Cancer Center
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Appendix 6. Colorectal Cancer Screening Referral Information

Ralph Lauren Center for Cancer Care and Prevention

A Partnership between North General Hospital and Memorial Sloan-Kettering Cancer Center

Contact Information

Screening Help Line (212) 212-987-1777
 1919 Madison Avenue
 New York, New York 10035

Insurance

No Insurance/
 Under Insured \$350 (\$50 at pre-screening meeting, \$300 at screening)

Insurance Medicaid, Medicare and other are insurance accepted

Referral Mechanisms

Self Referral Colonoscopy screening is advised for those above age 50 or younger than age 50 with a personal or family history of colorectal cancer

Physician Referrals It is helpful to have a written physician referral but not required.

Please call to make an appointment. Demographic and insurance information will be asked when calling to set up the appointment. The first appointment includes a medical history review and a pre-procedure evaluation. The second appointment will be the actual screening which will be provided two blocks away at North General Hospital. The address for North General Hospital is 1879 Madison Avenue, between 121 & 122 Streets, New York, New York 10035. A referral to North General will be provided after the first appointment at the Ralph Lauren Center.



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Appendix 7. Colorectal Cancer Screening Referral Information

Harlem Hospital Center

Contact Information

Screening Help Line	(212) 939 - 8035
	Cancer Screening Unit Colonoscopy Ambulatory/Surgical Unit Ron Brown Building 4th Floor 506 Lennox Avenue New York New York 10037

Insurance

No Insurance/ Under Insured	\$20-200: A sliding fee scale based on income levels is used to cover the first medical visit. Processing of financial assistance is provided at the first appointment for further medical appointments and procedures.
Insurance	Medicaid, Medicare and other insurance are accepted

Referral Mechanisms

Walk-in Cancer	On Thursdays registration is from 12-1 PM for a same day pre-screening. The screening Unit appointment between 1 and 3:30 pm On Saturdays, registration is from 8:30 -9:30 AM for a same day pre-screening appointment between 10 AM and 1 PM
Physician Referrals	It is helpful to have a written provider referral from within the Healthy Hospital Network but not required.

Pre-admission clearance and financial assistance are evaluated during registration prior to the colonoscopy screening appointment.



**Memorial Sloan-Kettering Cancer Center
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Appendix 8. Colorectal Cancer Screening Referral Information

Cancer Information Service

Contact Information:

Toll Free: 1-800-4-CANCER (1-800-422-6237)

TTY (for deaf and hard of hearing callers): 1-800-332-8615

NCI Online: <http://cancer.gov> to reach the NCI's Web Site.

LiveHelp: Cancer Information Specialists offer online assistance through the *LiveHelp* link on the NCI's Web Site.

Insurance:

CIS provides information and referrals on colorectal cancer screening facilities for those with and without insurance.

Referral Mechanism:

CIS works with the caller to identify a medical provider who will discuss colorectal cancer screening and provide a referral for the screening.

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