A QUALITATIVE EXAMINATION OF COLORECTAL CANCER SCREENING UTILIZATION IN AN URBAN POPULATION

by

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(Under the Direction of JESSICA L. MUILENBURG)

ABSTRACT

Colorectal cancer continues to rank as one the leading causes of cancer death in the United States on an annual basis. The majority of deaths are preventable through routine screening, beginning at the age of 50, as outlined and recommended in widely published clinical practice guidelines. The purpose of this research endeavor was to qualitatively examine how individuals over the age 50 perceive colorectal cancer and its causes, the individual, social, systemic, and environmental level obstacles faced when considering and attempting colorectal cancer screening as well as the communication strategies they employed or deemed appropriate toward utilizing screening options. Using in-depth one-on-one interviews, data was collected from 20 individuals 50 years or older living in the greater metropolitan Atlanta, GA area. Participants, a number of whom have medical background, reported knowledge of some known and widely reported risk factors for colorectal cancer. Family history and dietary habits were the most reported risk factors, followed by some mention of alcohol and tobacco consumption. Participants also communicated an awareness and knowledge of colonoscopy and fecal occult blood test (FOBTs) as colorectal cancer screening options. Regarding communication with healthcare providers, participants emphasized patient accountability in preparing for their

encounter with their personal healthcare providers, particularly about colorectal cancer screening. Participants engaging in screening were driven to do so by a perceived positive physician-patient interaction where the patient feels respected, feels the physician acts as an advocate, and where the physician engages the patient in informed and shared decision making about screening options. Finally, participants' intention to act as defined by adherence to screening recommendation is further driven by the desire to avoid the experiences of family and friends who were diagnosed at a late stage with colorectal cancer. The findings from this study have implications for healthcare providers and researchers developing and implementing health interventions targeting men and women eligible for colorectal cancer screening.

INDEX WORDS: Colorectal cancer, cancer screening, urban population, patient-physician communication

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DEDICATION

This dissertation is dedicated to people currently fighting colorectal cancer, and to those who fought the good fight but lost. I look forward to the day that this work helps to benefit the fight against cancer.

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Background

Colorectal cancer (CRC) ranks as the third leading cause of cancer death in the United States (R. Siegel, Naishadham, & Jemal, 2013). Survival from colorectal cancer is inversely related to stage of cancer and up to 90% of colorectal cancer deaths are preventable with early detection (CDC, 2016; R. Siegel, DeSantis, & Jemal, 2014). This makes colorectal cancer ideally suited for early screening strategies which reduce colorectal cancer mortality through early detection (Wang et al., 2015; Yong, Law, & Wang, 2013). With this understanding, national medical organizations recommend routine colorectal cancer screening beginning at age 50 years by utilizing one of the following: (1) fecal occult blood testing annually, (2) flexible sigmoidoscopy every 5 years, (3) combination of fecal occult blood testing annually and flexible sigmoidoscopy every 5 years, (4) colonoscopy every 10 years, or (5) barium enema every 5–10 years (Doubeni et al., 2013; Imperiale et al., 2014; Qaseem et al., 2012; Weinberg et al., 2014) These recommendations were most recently reviewed in 2008 and, as of the end of 2015, are in the process of being endorsed again by the US Preventive Services Task Force. (Force, 2015)

Healthy People 2020 goals for colorectal cancer are that 70.5 percent of the population report having CRC screening, up from the 2008 figure of 52.1% (Services., 2014). According to the 2001 Behavioral Risk Factor Surveillance System (BRESS) for the general population are 23.5% for FOBT within 12 months and 43.4% for lower endoscopy within 10 years. Given these low rates, increasing adherence is of critical importance. Although the colorectal cancer

screening tests identified by the guidelines are generally effective in identifying polyps and cancerous lesions, their usefulness depends on how compliant individuals are with the recommended long-term screening schedules. The importance of patient adherence has also been highlighted in several cost effectiveness analyses (Coldman et al., 2015; Ouakrim, Boussioutas, Lockett, Hopper, & Jenkins, 2014).

Epidemiology

Although there are screening options available, CRC is common, as well as lethal. There are different influences for CRC development, such as environmental and genetic factors. The incidence of CRC, as well as mortality rates, vary globally. For males, it is the third most common cancer diagnosis and for females, it is the second most common cancer diagnosis (Macrae, 2016). Since 2012, there have been an estimated 694,000 deaths and 1.4 million diagnoses of CRC (Torre et al., 2015). However, these rates are higher for males than females.

Despite the higher incidences of CRC, there have been decreases in the mortality rate of CRC. Out of the diagnoses, large bowel cancer accounts for 134,490 cases, with 95,270 affecting the colon and the remainder being rectal cancers (Macrae, 2016; R. L. Siegel, Miller, & Jemal, 2016). Research shows that 49,190 deaths (8 percent of all cancer deaths) occur annually within the United States from CRC (Macrae, 2016).

Global incidences of CRC varies. The highest can be found in Australia, New Zealand, Europe, and North America. In contrast, the lowest can be found in Africa and South-Central Asia (Torre et al., 2015). It is theorized that incidence differences occurs to dietary and environmental exposure differences, further influenced by genetics. In the United States during 2016, it has been found that 95,270 new incidences of colon cancer and 39,220 new incidences

of rectal cancer are expected (Society., 2016c). However, men have a 4.7% risk of being diagnosed with colorectal cancer, whereas women have 4.4% risk of being diagnosed with CRC (Society., 2016c). The mortality rate for CRC in 2016 is expected to be 49,190, nearly 10% of cancer death in the US. Both the late diagnosis rate and mortality rate are decreasing steadily (Society., 2016c). Both rates have decreased primarily due to early screening. At the same time, treatments have improved as medical technology has increased (Society., 2016c). This has resulted in over a million survivors of CRC within the United States today. However, this survival rate is based on patients with the same type and stage of cancer (Society, 2016e). The symptoms and definitions of CRC varies, as evidenced in the following table (Society, 2016e; Society., 2016d):

CRC develops in different stages (see Table 1) and has different treatments based on the stage and specific type of cancer. The top four methods are: (1) surgery; (2) radiation therapy; (3) chemotherapy; and/or (4) target therapy (American Cancer Society, 2016g). The following table shows common treatments based on the stage and type of cancer (American Cancer Society, 2016d; 2016e):

Table 1: Definition of CRC by Stage *(Society, 2016e; Society., 2016d)*

Stage	**Definition[1]**	**Treatment[2]**
Stage 0 Colon Cancer	Contained within inner lining of colon	Surgery
Stage 0 Rectal Cancer	Contained within inner lining of rectum	Surgery
Stage I Colon Cancer	Contained within colon walls	Surgery

1 Not all definitions are conclusive. Some patients may have other symptoms. These are generalized over the medical community as most common occurrences.

2 Not all treatments are definitive. Doctors may elect to utilize different options. The ones presented in Table 1 are the most common possible treatments for the various stages of both colon and rectal cancer.

Stage I Rectal Cancer	Contain within rectum walls	Surgery Chemotherapy Radiation therapy
Stage II Colon Cancer	Surpassed colon walls to nearby tissues, yet not within lymph nodes	Surgery Chemotherapy Radiation therapy
Stage II Rectal Cancer	Surpassed rectum walls to nearby tissues, yet not within lymph nodes	Surgery Chemotherapy Radiation therapy
Stage III Colon Cancer	Spread to lymph nodes	Surgery Chemotherapy Radiation therapy
Stage III Rectal Cancer	Spread to lymph nodes	Surgery Chemotherapy Radiation therapy
Stage IV Colon Cancer	Spread throughout body	Surgery Chemotherapy Ablation Embolization Targeted therapies Radiation therapy
Stage IV Rectal Cancer	Spread throughout body	Surgery Chemotherapy Radiation therapy Targeted therapies Ablation Embolization

The time period for survival rates are usually based on a 5 year time period. The 5 year time period does not mean that mortality occurs within 5 years. In fact, many patients live much longer than 5 years (Society, 2016e). The following table shows the survival rates by stages (Society, 2016e):

Table 2: Survival Rates of CRC by Stage *(Society., 2016f)*

Stage	**Percent (Approximation)**
Stage I Colon Cancer	92%

Stage I Rectal Cancer	87%
Stage IIA Colon Cancer	87%
Stage IIA Rectal Cancer	80%
Stage IIB Colon Cancer	63%
Stage IIB Rectal Cancer	49%
Stage IIIA Colon Cancer	89%
Stage IIIA Rectal Cancer	84%
Stage IIIB Colon Cancer	69%
Stage IIIB Rectal Cancer	71%
Stage IIIC Colon Cancer	53%
Stage IIIC Rectal Cancer	59%
Stage IV Colon Cancer	11%
Stage IV Rectal Cancer	12%

The incidence and mortality rates respectively are significantly lower than 2012 statistics, showing that there were 1.4 million diagnoses and 694,000 deaths (Ferlay et al., 2015). This cancer represents one of the top six incidences of cancer within the world as a whole and one of the top four incidences of cancer within developed nations. It is noted that during 2012, 55% of CRC diagnoses occurred within more developed regions (Ferlay et al., 2015). Importantly, these statistics show that mortalities were much lower within developed nations (8.3%) as compared to less developed nations (52%) (Ferlay et al., 2015).

Risk Factors

The risk factors for CRC vary and while some risk factors such as dietary intake can be changed, others such as genetic predisposition, cannot (Society, 2016b). At the same time, having a specific risk factor is not a definitive factor in having the disease. On the other hand, some with no risk factors are diagnosed with diseases. However, some research suggests that the strongest link between risk factors and incidences of CRC is between diet, weight, and exercise. It is also

shown that the link between weight and incidences of CRC is higher in men than in women (Society, 2016b). Lack of frequent exercise or other physical activity can increase risks of CRC. Dietary concerns can influence incidences of CRC. For example, research shows that although cooking meat at high temperatures can create chemicals known to increase cancer risks, it is unclear as to the effect this has on CRC specifically (Society, 2016b). Furthermore, fiber supplements have not been shown to decrease risks for CRC. On the other hand, low risks for CRC have been found for those that follow diets with high levels of vegetables, fruits, and whole grains. Behavioral risks, such as long-time smoking, can increase the risk of CRC and smokers are more likely to have CRC-related deaths (Society, 2016b). Alcohol use is controversial because excessive alcohol use is detrimental to health while limiting alcohol use, to 1 or 2 drinks a day for a man or 1 drink a day for a woman, can reduce the risk of CRC (Society, 2016b).

Some research suggests that the major differences in mortalities are caused by risk factors. However, according to two researchers, Tomasetti and Vogelstein (2015), stem cell divisions may be a dominant factor in the likelihood of the development of cancer. The study by Tomasetti and Vogelstein (2015) suggests that cancer risks are increased due to random errors during DNA replication (Tomasetti & Vogelstein, 2015). However, other researchers, such as Nan et al. (2015), suggest that incidences of CRC are decreased due to NSAID and aspirin use. In fact, according to the study by Nan, et al. (2015), CRC incidences were only 28% with participants that utilized NSAIDs and aspirin. On the other hand, those that did not use either had a CRC incidence rate of 38% (Nan et al., 2015). Yet, it is unclear as to the protection levels of early screening, such as through colonoscopy, endoscopy, or sigmoidoscopy (Nishihara et al., 2013). The study did suggest, however, that mortality was reduced through screening. For instance, a negative colonoscopy commonly meant reduced incidences of proximal colon cancer.

However, there were not reduced incidences of proximal colon cancer after sigmoidoscopy. CRC also experienced reduced mortality following screening (Nishihara et al., 2013). Importantly, it was shown through the study by Nishihara, et al. (2013) that CRC detected within 5 years of colonoscopy was most likely to have CpG island methylator phenotype (CIMP) and macrosatelitte instability. On the other hand, some researchers, such as Arnold, et al. (2015), suggested that in 2012, high incidences of CRC may be attributed to high body index mass. The study found that approximately 3 to 6% of the CRC cases diagnosed in 2012 can be attributed to high body mass indexes, commonly found within developed nations, causing the researchers to suggest that increasing body mass indices will cause the rate of CRC to become more prevalent (Arnold et al., 2015). Therefore, evidence is shown that CRC has potential to increase due to health factors.

Although younger adults do experience incidences of CRC, it is most likely to manifest in adults over 50 years of age. Polyps of the colon and rectum are usually benign and become common with age. The common polyp types include: adenomatous polyps, accounting for two-thirds of all polyps and which may develop into colon cancer over time; hyperplastic polyps, which usually do not develop into colon cancer; and serrated polyps, the least common type but may also develop into colon cancer over time. There is also a link between incidences of adenomatous polyps, particularly with large adenomatous polyps or many adenomatous polyps, and the development of CRC (Society, 2016b). Furthermore, if treatment has occurred for CRC, causing all of the cancer to be removed, the individual is at higher risk for other types of colon and/or rectal cancers. This is higher if the first incidence of CRC occurred when the individual was younger (Society, 2016b). At the same time, those with inflammatory bowel disease or Crohn's disease are more likely to develop CRC. A family history of CRC or adenomatous

polyps increases the risk of developing CRC (Society, 2016b). When more than one relative is involved or the relative(s) were diagnosed younger than 45 years of age, incidences of CRC increase. However, research shows that most with CRC have no family history, so this is not a final determinant. Those with inherited syndromes, such as familial adenomatous polyposis (FAP) and Lynch syndrome (hereditary non-polyposis colorectal cancer, or HNPCC) are more likely to develop CRC (Society, 2016b). It is believed that FAP contributes to approximately 1% of CRC incidences. Overall, approximately 5 to 10% of CRC incidences can be traced to inherited syndromes. It is noted that Lynch syndrome contributes to approximately 2 to 4% of CRC incidences (Society, 2016b). There are other syndromes that contribute to increased CRC risk, but they are very rare occurrences. Research shows that within the United States, CRC rates (both diagnosis and mortality) are highest for African Americans. However, in consideration of global ethnic groups, Ashkenazi Jews have one of the highest rates of CRC (Society, 2016b). Those with Type 2 diabetes have a higher risk of CRC, as well as a higher mortality rate (Society, 2016b).

There are other possible factors that contribute to CRC development, yet are controversial. To begin with, it is suggested that women working night shift have higher risks of CRC. This is suggested to influence CRC development due to melatonin differences (Society, 2016b). In other cases, other cancer treatments, such as those for testicular cancer, may increase the risk of CRC. However, it is also noted that cancer treatments that suggested increased CRC risks were occurring prior to modern treatment availabilities (Society, 2016b).

Importance of Colorectal Screening

Due to the benefits that may be achieved by screening and its current documented underutilization, it is vital to establish a clear understanding of what factors predict screening

adherence and what methods can be used to overcome barriers to, or facilitate completion of screening. Factors previously associated with screening adherence include age (Burt et al., 2013), gender (von Karsa et al., 2013), education level (Inadomi et al., 2012), race/ethnicity (Atkin et al., 2012; Green et al., 2013; Kuipers, Rösch, & Bretthauer, 2013), income (Joseph, King, Miller, & Richardson, 2012), marital status (Christy et al., 2013), fatalistic beliefs about cancer (Christy et al., 2013; Qaseem et al., 2012), and knowledge (Christy et al., 2013; Gupta et al., 2014), and fear of screening tests(Christy et al., 2013; Grubbs et al., 2013; Liss & Baker, 2014). Other factors such as physician involvement (Burt et al., 2013; Inadomi et al., 2012; von Karsa et al., 2013), access to health care(Green et al., 2013; Liss & Baker, 2014), geographic location (Kuipers et al., 2013; Liss & Baker, 2014; Qaseem et al., 2012), and test-specific barriers (Hawley et al., 2012; Myers et al., 2013; Schreuders et al., 2015) have been found to profoundly influence screening adherence.

Studies have been done on a number of demographic, social, and environmental determinants of colorectal cancer screening (e.g. insurance coverage, discussion with a medical professional (Burt et al., 2013; Liss & Baker, 2014). To address root causes of the disparities in colorectal screening utilization, interventions need to address multiple layers of factors that determine access to and utilization of care. This consideration fits well with the social determinants of health (SDH) perspective (Stewart & Wild, 2015). SDH focuses on structural, contextual, social, economic, and environmental conditions that impact health such as the social gradient, power, education, poverty, unemployment, work, lack of health insurance, social support, stress, social exclusion, food, addition, and transportation (Liss & Baker, 2014; Stewart & Wild, 2015; Suzuki, Wallace, & Small, 2015). Given that screening ultimately requires behavioral action on the part of the individual person (e.g. going to a colonoscopy appointment;

completing and mailing an FOBT card), understanding factors involved in individual decision making regarding screening is necessary to improve upon suboptimal screening compliance (Solmi et al., 2015). Considering that SDH provides a unique multi prism perspective to conceptualize colorectal cancer screening, this study will focus on an examination of the intrapersonal level of the social ecological model and how it can aid in the understanding of the continued underutilization of colorectal cancer screening.

The purpose of this qualitative study is to learn from participants who receive care through an urban health center about issues revolving around colorectal cancer and screening. There will be an attempt to focus on how participants perceive colorectal cancer and its causes, the individual, social, systemic, and environmental level obstacles faced when considering and attempting colorectal cancer screening as well as the strategies they employed or deemed appropriate toward utilizing screening options.

Strengths and Limitations

As with all methods of research, the constant comparative analytic process or grounded theory has its own strengths and weaknesses. Researchers using grounded theory find among its strengths is that it allows for the exploration of a broad range of management issues about behavior, relationships and communication of people and the suitability for emerging concepts through comparison (Wolfswinkel, Furtmueller, & Wilderom, 2013). On the other hand, a marked weakness of grounded theory is the idea that the researcher is assumed to be both objective and subjective when using grounded theory. This dichotomy can be seen when researchers using grounded theory are expected to maintain a degree of detached closeness. Researchers are expected to be objective in collecting data; however, in order to obtain rich data, they need to get close to participants and gain acceptance. Additionally, grounded theory

generated a large documentary overhead that can be difficult to manage. Finally, this type of research requires a high level of social skills from the investigator in addition to skill in the method of grounded theory (S. Lewis, 2015; Millberg, Berg, Brämberg, Nordström, & Öhlén, 2014; Timmermans & Tavory, 2012).

The particular strengths of grounded theory in the area of cancer research include: (1) the flexibility of methods which can be used; (2) novel methods of data collection can be conducted by the researcher as informed the research process itself; (3) the potential therapeutic nature of the interviews can allow participants a level of comfort lending to revealing their fears and concerns; (4) sensitive issues like the fear surrounding the topic of colorectal cancer can be handled very carefully in grounded theory methodology once a relationship is established between the researcher and the participants; and (5) any potential intervention can developed and modified from the data as it is being collected.

However, there are also a number of weaknesses associated with grounded theory methodology in cancer research. Those include: (1) availability of participants willing to engage in in-depth interviews over an extended period of time; (2) difficulty in reaching a point of data saturation; (3) maintaining participant confidentiality; (4) maintaining the distance of the researcher.

Research Questions

The purpose of this qualitative study is to learn from participants who receive care through an urban health center about their discussions with their health care providers about colorectal cancer, and how these discussions frame their subsequent actions including their "action plan" post visit. This formative research will attempt to identify misconceptions and barriers to the

understanding of colorectal cancer and its screening and determine how these existing misconceptions or barriers affect intention to follow through with screening utilization. There will be an attempt to focus on how participants perceive colorectal cancer and its causes, the individual, social, systemic, and environmental level obstacles faced when considering and attempting colorectal cancer screening as well as the strategies they employed or deemed appropriate toward utilizing screening options.

Three research-questions will guide the main research purpose:

1. What misconceptions do participants have or have heard from others about colorectal cancer and its screening?
2. What strategies for participants use to communicate with healthcare providers about colorectal cancer?
3. What action intentions do participants have for utilizing colorectal cancer screening? How is this intention influenced by communication with healthcare providers?

Chapter 2: Literature Review

Introduction

Current Screening Guidelines

Population-based recommendations or guidelines for CRC screening of four leading national health groups or organizations (National Cancer Institute, American Cancer Society Recommendations, U.S. Preventive Services Task Force, Canadian Task Force on the Periodic Health Examination) are presented in Table 3 (van Roon et al., 2013). Most are in agreement that screening with FOBT and sigmoidoscopy should be initiated at age 50 years in asymptomatic persons with no personal or family history of colorectal cancer or related conditions, although consensus is lacking about the frequency for high risk individuals. Recently, the use of colonoscopy as a primary screening tool has gained momentum due to several studies on its superior effectiveness in detecting polyps/reducing colorectal cancer mortality (Kaminski et al., 2012; Moreira et al., 2013). In fact, the American College of Gastroenterology has also endorsed colonoscopy as the preferred colorectal cancer screening strategy (Doubeni et al., 2013).

The most recent American College of Gastroenterology recommendation update occurred in 2008. The CRC screening tests are now grouped into cancer prevention tests and cancer detection tests with cancer prevention tests being preferred over detection tests. Other changes include recommending that African Americans begin screening at 45 years old, The other major change is to provide differing guidelines for average risk individuals than for higher risk individuals. Below are the tabulated recommendations for average risk and higher risk

individuals (Levin et al., 2008).

According to the American College of Gastroenterology (2016), the preferred CRC prevention test is through a colonoscopy every 10 years. The preferred CRC detection test is through annual guaiac fecal occult blood test (GFOBT) or fecal immunochemical testing (FIT). This testing uses antibodies directed against human hemoglobin to detect blood in the stool; a hallmark indicator of colorectal cancer. At the same time, it is recommended that African Americans commence testing at age 45 due to increased risks. It is recommended to utilize split dosing in order to improve the effectiveness and tolerability of bowel preparation (Gasteroenterology., 2016). Screening is important because early detection increases survival rates, polyps removal has decreased the development of CRC, and evidence from randomized trials show that CRC mortality is reduced from endoscopic evaluation and fecal occult blood tests (Elfant, 2015).

Significantly, in 2013, screening rates for adults between 50 and 75 years old was 58%, showing that barriers still exist. The most common barriers were: (1) unspecified fears; (2) concerns about bowel preparation; (3) lack of knowledge; (4) pain; and (5) lack of health care provider recommendation (Elfant, 2015). The offered tests are invasive or non-invasive. Common invasive tests include: (1) colonoscopy; (2) flexible sigmoidoscopy; and (3) computerized tomographic colonography. Common non-invasive tests include: (1) guaiac-based fecal occult blood test; (2) fecal immunochemical test; and (3) multi-target stool DNA test (Elfant, 2015). Although CRC is slow-growing, without early detection and prevention, it is less likely to be curable. Therefore, health care physicians need to emphasize the benefits of CRC screening and counsel patients to undergo these tests.

The following table suggests early detection screening for CRC for average, increased, and high risk individuals (Society., 2016a):

Table 3: CRC Prevention and Early Detection *(Society., 2016a)*

Risk Category	**When to Test**	**Test Frequency**	**Recommended Test(s)**
Average	Age 50	Every 5 years	Flexible sigmoidoscopy Double-contrast barium enema Virtual colonoscopy
		Every 10 years	Colonoscopy
		Annually	GFOBT FIT
		Every 3 Years	Stool DNA test
Increased Risk – small rectal hyperplastic polyps	Age 50	Every 5 years	Flexible sigmoidoscopy Double-contrast barium enema Virtual colonoscopy
		Every 10 years	Colonoscopy
		Annually	GFOBT FIT
		Every 3 Years	Stool DNA test
Increased Risk – 1 or 2 or small tubular adenomas with low-grade dysplasia	5 to 10 years following polyps removal		Colonoscopy
Increased Risk – 3 or 4 or large tubular adenomas with low-grade dysplasia	3 years after polyps removal		Colonoscopy
Increased Risk – More than 10 adenomas on a single exam	Within 3 years after polyps removal		Colonoscopy
Increased Risk – Sessile adenomas that are removed in pieces	2 to 6 months after polyps		Colonoscopy

	removal		
Increased Risk – Diagnosis of CRC	At time of surgery		Colonoscopy
	3 to 6 months following surgery		
Increased Risk – Removal of CRC	Within 1 year		Colonoscopy
Increased Risk – Family history of CRC	Age 40 or 10 years prior to youngest case of CRC	Every 5 years	Colonoscopy
Increased Risk – 1st degree family member with CRC	Age 40	Every 5 years	Flexible sigmoidoscopy Double-contrast barium enema Virtual Colonoscopy
		Every 10 years	Colonoscopy
		Annually	GFOBT FIT
		Every 3 Years	Stool DNA test
High Risk – FAP diagnosis by genetic testing	Age 10 to 12	Annually	Flexible sigmoidoscopy
High Risk – Lynch syndrome or increased risk of Lynch syndrome found through genetic testing	Age 20 to 25 or 10 years before youngest onset	1 to 2 years	Colonoscopy
High Risk – Inflammatory bowel syndrome	8 years after onset of IBS	1 to 2 years	Colonoscopy Biopsies

Screening Behavior of Patients and Physicians

The aim of this section is to discuss in depth screening practices of physicians and the impact that has on patient adherence. Currently, there has not been much in depth examination of the key factors impacting physician recommendation of colorectal cancer screening tests or the

impact of the interactions of physicians and patients on screening recommendation. Currently, reported rates of physician recommendation published in the literature range from 14% to 83% (Altobelli, Lattanzi, Paduano, Varassi, & Di Orio, 2014; Hoffman et al., 2014; Wallace, Baltrus, Wallace, Blumenthal, & Rust, 2013). This is a critical issue to examine given the low recommendation rates reported among some physicians. This review will attempt to address: (1) average adherence rates stratified by colorectal cancer test and patient characteristics, (2) predictors of patient adherence, (3) predictors of physician recommendation of screening tests, and (4) patterns in the type of colorectal cancer test recommended by physicians.

Average Adherence Rates

Numerous articles have been published that discuss utilization and adherence rates with colorectal cancer screening. These articles utilized a variety of methods including community surveys, randomized studies, prospective non randomized studies, and mass screening initiatives. Community surveys are retrospective and measure utilization based on all recommended tests. Other studies, including mass screening initiatives, are prospective interventions, which measure adherence. Prospective clinical studies, on average, report rates higher than mass screenings and community surveys. For adherence with specific tests in prospective studies, the average was about 60% for FOBT, around 50% for flexible sigmoidoscopy, and 75% for colonoscopy (Schoen, 2002; Schoen, Weissfeld, Trauth, Ling, & Hayran, 2002; Sinicrope et al., 2012; Thrasher et al., 2002; Wolf et al., 2001).

Factors Contributing to Patient Adherence

Generally, adherence rates are reported to be higher among those 65–74 years compared to those 50–64 years regardless of the type of test studied, no systematic differences emerge between males and females, and non-whites in general have lower adherence than whites.

Additionally, no differences among private payer, Medicaid, and Medicare enrollees emerge when examining insurance status with the exception of higher rates for members of Medicare HMOs. As expected, high-risk individuals are more compliant than individuals at average-risk (Cyhaniuk & Coombes, 2016; Subramanian, Klosterman, Amonkar, & Hunt, 2004). The studies presented in table 4 include a community survey and a randomized trial. Although the data yielded is very informative, it is imperative to realize that there are limitations to both of these designs. With regards to Erban, et al. (2001) community survey, there is no way to disregard the bias of the self-report data provided by respondents (Erban, Zapka, Puleo, & Vickers-Lahti, 2001). On the other hand, randomized control trials, such as Myers, et al. (2013) are limited by the type and location of the randomization further limiting generalizability (Myers et al., 2013).

Table 4. Utilization and adherence to screening by patient characteristics

Study	**Sample Size**	**Category Rate**		**Adherence Definition**	**Study Type**
Age		50-64 yo	64-74 yo		
(Erban et al., 2001)	1119	48%	55%	FOBT; FS	Community Survey
(Myers et al., 1991)	1600	37%	45%	FOBT	Randomized Control Trial
(McCarthy &	105	74%	79%	FS	

Moskowitz, 1993)					Prospective Study
Sex (Erban et al., 2001) (Myers et al., 1991)	1119 1600	Male 49% 36%	Female 52% 40%	FOBT; FS FOBT	Community Survey Randomized Control Trial
Race (Erban et al., 2001) (McCarthy & Moskowitz, 1993)	1119 105	White 51% 77%	Non-White 54% 71%	FOBT; FS FS	Community Survey Prospective Study
Insurance Status (Erban et al., 2001)	1119 Private Medicare	HMO 48% 63%	Non-HMO 48% 51%	FOBT; FS; COL	Community Survey

	Medicaid	47%			
Risk Status (Erban et al., 2001)	1119	Low Risk 49%	High Risk 62%	FOBT; FS; COL	Community Survey

FOBT= Fecal Occult Blood Test; FS = Flexible Sigmoidoscopy; COL=Colonoscopy

With this general understanding of what the adherence rates are as reported in current literature, it is important to next examine factors impacting patient adherence. Published literature points out that higher education is correlated with undergoing recommended screening tests (O'malley, Forrest, & Mandelblatt, 2002). Having medical insurance coverage and, surprisingly HMO membership, is related to higher levels of adherence with recommended tests (Myers et al., 2013; Zapka, Puleo, Vickers-Lahti, & Luckmann, 2002). Finally, income does not appear to have a consistently significant impact on adherence(Myers et al., 1991). However, acknowledging that cancer is preventable/curable and having a positive perception of testing was related to better adherence. Fear of cancer and pessimism on the other hand were reported to be barriers to screening, with rates as high as 70% of patients reporting that fear of finding cancer is the reason for not obtaining screening tests (Altobelli et al., 2014; Atkin et al., 2012; Burt et al., 2013). Other studies in the literature report that fatalism, the belief that death is inevitable when cancer is present, was the most important determinant of non-adherence in elderly African-Americans (Christy et al., 2013; Grubbs et al., 2013). On the other hand, evidence suggests that younger individuals are likely to have a less fatalistic attitude toward cancer than older

individuals (Burt et al., 2013). One caveat to be considered with these studies is their tendency to report data for one particular ethnic group, for example African Americans, making their findings challenging to generalize to the rest of the population.

Other factors examined in the literature include commitment to screening, defined as positive attitude toward screening and the belief that screening is beneficial was found to be positively related to adherence (Hsia et al., 2000). Additionally, there is evidence that family history of screening and screening for other cancers increases adherence with colorectal cancer screening. Lemon, et al. (2001; 2003) report that individuals with cancer in their family were twice as likely to be compliant than those without a family history (S. Lemon, Zapka, Puleo, Luckmann, & Chasan-Taber, 2001; S. C. Lemon, Zapka, Estabrook, Erban, & Luckmann, 2003).

Factors Contributing to Physician Recommendation

Reported factors that impact physician recommendation of screening tests have been found to include age, training, awareness/agreement with current screening guidelines, perceived effectiveness of the test, and perceived acceptance/adherence of test by patients. With respect to professional aspects, it is important to note that only training impacted screening recommendation but specialty as well. There is also a growing body of literature that highlights the importance of taking patient preference into account when recommending a colorectal cancer-screening test (Chokshi, Hovis, Colditz, Early, & Wang, 2013; Walsh et al., 2010).

With regard to physician recommendation, current literature includes several studies that have reported the importance of physician recommendation and relationship in fostering screening adherence (Chokshi et al., 2013; Christy et al., 2013; Green et al., 2013; Grubbs et al., 2013; Inadomi et al., 2012; Joseph et al., 2012; Patel, Nahar, Murray, & Salner, 2013; Zapka et al., 2002). For instance, when clinicians recommended flexible sigmoidoscopy, individuals were

12 times more likely to comply with screening guidelines (Zapka et al., 2002).

Age of physicians emerges from the literature as a factor affecting recommendation of screening. Studies show that younger physicians are more likely to perform sigmoidoscopy (J. Lewis & Asch, 1999; J. D. Lewis et al., 1999; Ling, Moskowitz, Wachs, Pearson, & Schroy, 2001; Schroy, Barrison, Ling, Wilson, & Geller, 2002; Schroy et al., 2001). Bergner, et al. (1990), in a random sample of physicians, found that physicians who graduated within the last 10 years were more likely to perform FOBT screening than those who graduated earlier (Bergner, Allison, Diehr, Ford, & Feigl, 1990). In addition to age, physician specialty and training in performing flexible sigmoidoscopy are essentials factors. Overall, there is a trend that more family practitioners and internist favor more invasive screening methods compared with other specialties. With regards to training, physicians who are trained to perform flexible sigmoidoscopy are more likely to perform/recommend testing with sigmoidoscopy (Hawley et al., 2012; Hawley et al., 2008; Schroy et al., 2001). With regard to flexible sigmoidoscopy, it seems that perceived effectives of the test is a significant factor in physician recommendation of screening (J. D. Lewis et al., 1999; Schroy et al., 2001).

Awareness of, and agreement with guidelines also emerge as significant factors influencing physician recommendation of screening tests. However, since studies discussing awareness and agreement with guidelines utilized various standard agencies issuing standard recommendations, specific conclusions about the impact of those guidelines on physician screening recommendation decision making cannot be made(Hawley et al., 2012; Hawley et al., 2008; Schroy et al., 2001). Finally, perceived poor patient willingness to accept was the most common barrier to screening sigmoidoscopy as reported by primary care physicians. Cooper et al. (1997) conducted a survey of 884 physicians from 10 states who stated that the most common

reason for failure to screen was poor patient willingness to accept (Cooper, Fortinsky, Hapke, & Landefeld, 1997). A unique finding about obstacles to colorectal cancer screening reported by physicians is that they did not include lack of time to discuss with patient, lack of efficacy data, cost, or lack of patient insurance.

Overall, most studies reported thus far relied on patient or physician responses to questions asked of them prompting a consideration of recall bias. Next, very few studies conducted medical chart reviews to verify the accuracy of the reported screening rates. As such patients and physicians responses may not be an accurate reflection of the tests performed and this should be taken into account in interpreting and using the results. In addition, many of the surveys, especially those aimed at physicians, tended to have low response rates and therefore could be biased if the pool of respondents were characteristically different from the non-respondents.

Communications and Interactions between Physicians and Patients

The physician and patient interaction is crucial to patient aligned care. Research shows that communication between the physician and patient is of central importance within primary care consultations (Rocque & Leanza, 2015). Through adequate communication between the physician and patient, a satisfactory relationship develops. This is crucial in that it allows for proper information exchange between the physician and patient, decide on treatment, and ensure adherence. Furthermore, effective communication has been linked through studies to result in positive outcomes, including patient satisfaction, higher quality of care, and improved physician-patient relationship (Rocque & Leanza, 2015). Despite these documented benefits, difficulties persist. For example, it has been noted that inadequate communication can result in patient dissatisfaction, not understanding treatment plan, non-adherence, lower quality of care, and

medical errors (Ritholz, Beverly, Brooks, Abrahamson, & Weinger, 2014; Rocque & Leanza, 2015; Silver, 2015), which could endanger the lives of patients. These difficulties happen most commonly with ethnic minority patients. In fact, more misunderstandings occur within this population (Rocque & Leanza, 2015). Therefore, it is necessary to consider culture and how experiences are interpreted by patients.

Many studies explore communication and consider culture to be the equivalent of ethnicity. This equivalency is considered by some inaccurate because it does not consider the understanding of socio-cultural aspects that are increasingly complex (Rocque & Leanza, 2015). Some researchers, therefore, suggest that individuals can belong to more than one cultural group. These may be known as micro-cultures (Rocque & Leanza, 2015). Ultimately, it is agreed that culture plays a central role in "helping individuals make sense of their universe and experiences, as well as helping individuals establish norms that will in turn guide their daily behaviors" (Rocque & Leanza, 2015). On the other hand, ethnicity "refers to the process in which individuals engage in when manipulating symbols and meanings in order to put forth a certain aspect of their identity in a given context, thus allowing them to cross cultural or micro-cultural boundaries and play with their different identities" (Rocque & Leanza, 2015). As a result, both factors are crucial to successful communication.

Within medical offices, it is suggested that "all medical encounters are intercultural from the outset, since being a physician involves having been socialized in a specific micro-culture; bio medicine"(Rocque & Leanza, 2015). It is also suggested that medical socialization is crucial to neutralization of societal differences. Ignoring these differences is not advised, as discrimination can occur, causing further issues between physicians and patients (Rocque & Leanza, 2015). According to the study by Rocque and Leanza (2015), "although patients reported

more negative experiences, they also recalled positive experiences relating to the opportunity to preserve one's sense of integrity by being treated with respect by an empathic and competent physician who is capable of individualizing care" (Rocque & Leanza, 2015). Communication outcomes were determined on the evaluation of the patient regarding interaction quality. It is noted that "vulnerability will likely persist to be part of patients' experiences due to the asymmetric physician-patient relationship. However, physicians should strive to treat patients with dignity and respect in order to alleviate the harmful effects of negative experiences" (Rocque & Leanza, 2015).

Shared and Informed Decision Making

As discussed earlier, several studies have indicated the importance of the recommendation of a physician in influencing a patient's colorectal cancer screening decision (Christy et al., 2013; O'malley et al., 2002; Schreuders et al., 2015; Zapka et al., 2002). While the importance of a physician recommendation has been widely reported, it has been suggested that merely mentioning colorectal cancer screening is not enough to motivate all patients to be screened. To date, an optimal approach for making colorectal screening recommendations has not emerged. Additionally, current approaches to making colorectal cancer screening recommendations have not been widely examined in depth and documented. Wackerbarth, et al. (2007) building on the framework of informed decision making conducted a qualitative study of the content of recommendations in order to describe how physicians present this information to patients (Wackerbarth, Tarasenko, Joyce, & Haist, 2007).

Informed decision making as discussed by Wackerbarth, et al. (2007) is comprised of seven criterions. The first criterion of informed decision making involves discussing the patient's role in decision making. Another aspect is the discussion of the clinical issue or nature of the

decision. This element involves coverage of the basic information – when, what, who, where, why, and how aspects – of the decision at hand. An example from the Wackerbarth, et al. (2007) study would involve a physician discussing colorectal cancer screening in the context with other preventive health issues in order to inform the patient about the procedure generally, and in relation to other potential more familiar procedures (Wackerbarth et al., 2007). Additional elements of informed decision making include: discussion of reasonable alternatives, discussion of the pros and cons of the alternatives, discussion of the uncertainties associated with the decision, assessment of patient's understanding, and exploration of patient preference (Wackerbarth et al., 2007).

Wackerbarth, et al. (2007) found that almost all the physicians in the study addressed the nature of decision element, and a majority discussed uncertainties, very few discussed the other elements of informed decision making. Most disappointing is that only about 6% of the physicians in the study indicated that they customarily inquire whether the patient had questions, as a means of assessing patient understating (Wackerbarth et al., 2007). Considering that colorectal cancer screening provides a wide variety of testing options, this lack of inquiring about patient understanding is almost as detrimental as not presenting the patient with the screening options at all. It is also a missed opportunity for the physicians to explore the patients' health beliefs and cultural perspectives which in turn influence their health decisions about utilizing colorectal cancer screening. Shared decision making requires a commitment from the physician and the patient in order to be successful. Attempts to improve shared decision making need to take into account the fact that patients need to have adequate access to health information outside the consultation with the physician and enough encouragement within the consultation in order to voice opinions, beliefs, question, and concerns.

The literature as summarized in this discussion leaves a gap in the picture presented about factors affecting patient and physician behavior with regards to screening of colorectal cancer. Although there is a thorough body of literature outlining what factors impact either patient adherence or physician recommendation, very little is available about the nature of the interaction and communication between patients and physicians during clinical visits in which colorectal cancer screening is discussed. An in depth examination of patient-physician relationships and patient preferences would yield valuable information about creating communication guidelines for patients and physicians that enhance encounters in which colorectal cancer screening is discussed.

Theoretical Framework

Socio-ecological Approach

In the socio-ecological approach, hierarchical levels of associated factors are considered to define the risk factors for irregular cancer screening among minorities. Sociologist C. Wright Mills argues that issues in society may be viewed as both troubles and issues (Stokols, 1996). This framework can be then extended to the socio-ecological framework in a way that supports the stance that a diagnosis with CRC may be termed a personal trouble if the diagnosis impacts only one person, but when there are competing events that influence barriers or gateways to CRC screening, such becomes social issue. There are a number of risk factors that increase the risk of cancer and are associated with inadequate screening including individual factors (age, income/socio-economic status), contextual factors (access to healthcare, insurance status, delayed screening and treatment, healthcare utilization) and cultural factors (nativity, language,

family structure, cultural perceptions/beliefs, social networks and social support).

The individual factors of age and income impact the cancer risk and health-seeking behavior for many older minorities. As stated in the previous section, there is a direct relationship between age and risk for colorectal cancer. In addition, minorities often have lower incidence of these cancers but markedly have greater morbidity and mortality upon diagnosis (Christy et al., 2013). Healthcare utilization and access, particularly cancer screening, may be further impeded by financial limitations. Older minorities often have lower incomes and limited financial resources that affect their ability to purchase insurance, pay co-payments for costly health services and participate in preventive health methods such as cancer screening (Liss & Baker, 2014). However, it is of interest to note that in 1998, the Centers for Medicare (providing insurance to those 65 and older) and Medicaid (providing insurance to those with a demonstrated financial need) began reimbursing the costs of commonly used CRC screening tests, covering 100% charges for flexible sigmoidoscopy and colonoscopy for high risk individuals (Patel et al., 2013). In July 2001, coverage was extended to include colonoscopy screening for average risk individuals. Whether a patient has health insurance represents an interesting factor in determining whether that patient will undergo recommended CRC screening. Data shows that despite the availability of published guidelines on who should be screened and at which intervals, patient follow-through with recommended CRC testing remains low (Society., 2016a). This is again especially true for racial and ethnic minorities and those in lower socioeconomic brackets. This trend further perpetuates within these populations despite assurance of full and complete Medicare or Medicaid reimbursement for the tests (Patel et al., 2013). Analyses have shown that having insurance coverage for these tests does not eliminate the disparities in CRC screening utilization. Due to changes in insurance coverage in relation to the ACA, these

screenings are possible as regular preventative activities, commonly covered in full under the act (Patel et al., 2013). Trends indicate that other mitigating factors may exist that prevent poor racial and ethnic minorities from undergoing CRC screening. These other factors could include: the embarrassing nature of the tests, inconvenience and awkwardness of collecting and storing stool samples at home, or discussing bowel-related issues with a healthcare provider (Patel et al., 2013).

Contextual factors represent community and individual level factors that reflect the access to care available to older minorities in their own communities. Time, transportation, finances, facility hours and provider availability may serve as barriers to care for many. Additionally, access to care, having a usual source of care, and recommendations for mammography by health care providers are greatly involved in influencing cancer screening utilizations among older minorities. There is an established positive relation between physician or health care provider recommendation for screening utilization for older minorities (Calvocoressi et al., 2004), therefore periodic healthcare is critical for improved physician communication and recommendations for preventive healthcare measures. Access to care is often cited as a barrier and having a usual source of health care is positively related to attaining a colonoscopy (Patel et al., 2013). Further, older minorities are more likely to be uninsured or underinsured and frequently have lower screening rates than younger minority women (Christy et al., 2013). Older minorities are also more likely to delay screening and treatment when symptoms arise.

Cultural factors are critical components in the health attitudes, beliefs and ultimately behaviors of minorities. Language can serve as a barrier to appropriate healthcare access and to physician-patient communication, particularly for immigrants. The incomplete articulation

and/or comprehension of illness symptoms and physician recommendations may lead to unnecessary delays in screening and treatment. Individual perceptions and cultural mores also play a part in healthcare utilization. Across all minority groups examined, distrust of the healthcare system and providers is prevalent. Some older minorities may question the motives, knowledge and background of healthcare providers. Cultural norms of limited shared-decision making with providers and the conception of illness will impact their perception of necessary healthcare services including cancer screening (Patel et al., 2013).

Family structure, social networks and the support they provide are also key elements to cancer screening for older minorities. Most perceive themselves as the “caregiver” in their own family units and have difficulty prioritizing their own healthcare, particularly for regular cancer screening without the presence of symptoms. However, social support and social networks have been shown to have positive effects on cancer screening. Authors across disciplines have noted the impact of social support on choosing to participate in screening, coping with diagnosis, treatment, and ultimately cancer mortality. For example, Farmer, et al. (2007) reported that older minority women having “functional and emotional social support” at “higher levels” were more likely to have cancer screening (Farmer, Reddick, & Jackson, 2007). This cross-sectional study evaluated the association of several psychosocial attributes and current screening behavior among older African American women. Those who had a screening in the last year were more likely to report higher social support than women who had not had a mammogram in the last year. This phenomenon has also been shown to be effective in promoting preventive health behaviors in Asian-American and Hispanic communities.

Personal relationships, socio-demographic, and health system factors also impact cancer screening utilization by older minority women. For instance, older African-Americans who had

"personal exposure" to cancer, for example friend or family member, were more likely to utilize cancer screening (Christy et al., 2013; Farmer et al., 2007). However, personal exposure can also impact beliefs, and attitudes (such as fatalism) which need to addressed in order to improve healthcare utilization. One must be cognizant of the nuances of the socio-ecological approach to understanding health care promotion as it informs the target population selection. The model is shown below:

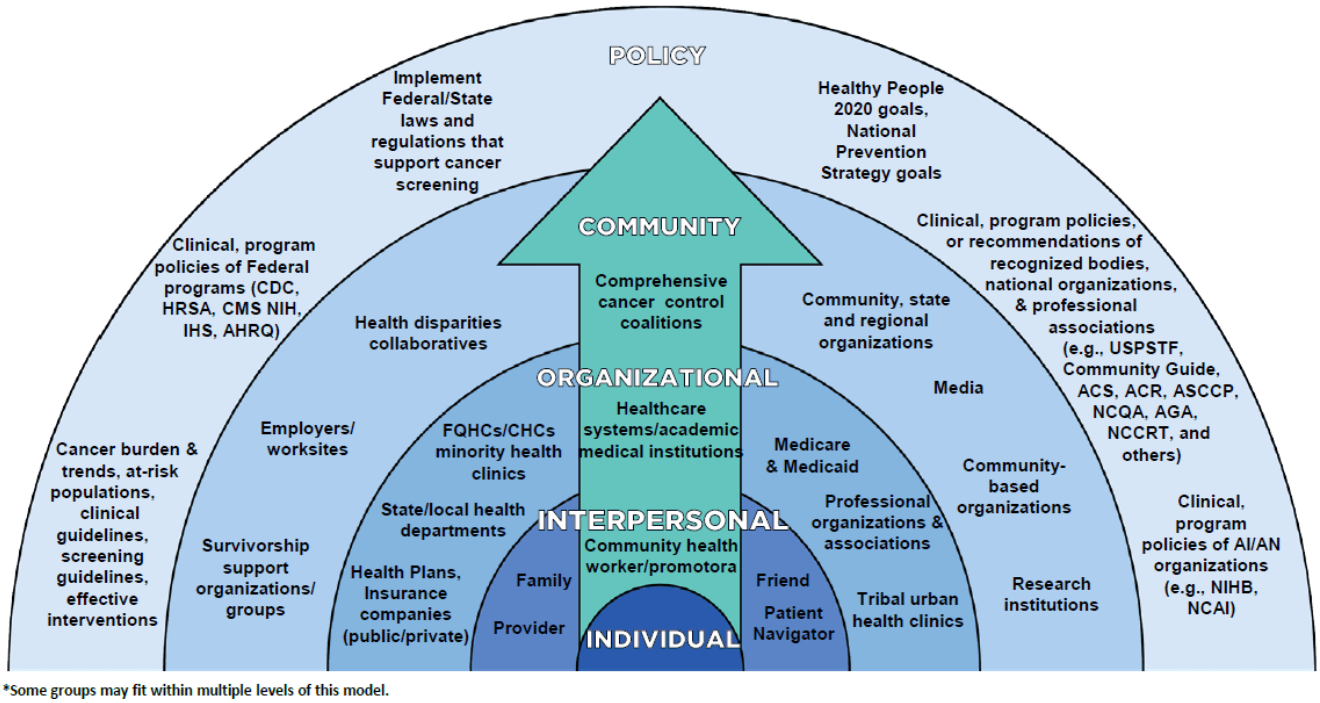

Figure 1: CDC Socio-ecological Model for CRC *(CDC, 2015)*

The CDC has adopted the socio-ecological model in order to provide a multi-level approach to CRC prevention. The levels are: (1) individual; (2) interpersonal; (3) organizational; (4) community; and (5) policy (CDC, 2015). It is noted that "at the core of the model is the individual, surrounded by four bands of influence representing the interpersonal, organizational, community, and policy levels" (CDC, 2015). At the individual level, the CDC focuses on

increasing “the individual’s knowledge and influence his or her attitudes toward, and beliefs regarding” the need for CRC screening, screening intentions, risks/benefits of screening, and access to screening (CDC, 2015). This is done through highlighting “the importance of providing individuals with high-quality, appropriate colorectal cancer screening and surveillance and ensuring timely initiation of treatment for people who are diagnosed with cancer” (CDC, 2015). At the interpersonal level, prevention activities are emphasized. In fact, “these activities are intended to facilitate individual behavior change by affecting social and cultural norms and overcoming individual-level barriers” (CDC, 2015). Appropriate interventions in this level are physician recommendations, receipt of reminders regarding screening, and barrier to screening removal (CDC, 2015). At the organizational level, prevention activities are provided that are intended to “facilitate individual behavior change by influencing organizational systems and policies. Health care systems, employers or worksites, health care plans, local health departments, tribal urban health clinics, and professional organizations represent potential sources of organizational messages and support” (CDC, 2015). These activities include promoting and using reminder systems, assessing providers and providing feedback, promoting benefit expansion to cover screening, and adopting preventative care sites (CDC, 2015).

At the community level, “activities are intended to facilitate individual behavior change by leveraging resources and participation of community-level institutions such as comprehensive cancer control coalitions, tribal health departments, media, and community advocacy groups, which represent potential sources of community communication and support” (CDC, 2015). Activities within this area include resource expansion and increasing awareness. The final level is the policy level, which “involve interpreting and implementing existing policy. Federal, state, local, and tribal government agencies may support policies that promote healthy behavior,

including screening" (CDC, 2015).This is done through activities that communicate policy decisions to the public and translate policy decisions (CDC, 2015).

Theories Informing Patient and Physician Decision Making

The Willingness to Communicate (WTC) concept was originally developed by McCroskey and Richmond (1990) to describe the intention to communicate when given the opportunity to do so (J. C. McCroskey & Richmond, 1990). McCroskey and Richmond (1990) found that people possess regularity and stability in their level of WTC across a variety of situations, thereby defining WTC as a personality trait. Additional research with WTC elucidated situational variations that further demonstrated the possibility that WTC is also a state characteristic (MacIntyre, Baker, Clément, & Conrod, 2001). This situational variation demonstrates the potential advantage of applying the WTC construct to other intergroup communication contexts, such as those in the health care setting since the health context involves groups of differing roles, status, and language trying to negotiate communication while at the same time maintaining their group identity (Baker & Watson, 2015).

Communication accommodation theory (CAT) was developed by Giles and colleagues (Giles, 1973; Giles & Gasiorek, 2013) in an effort to explain language patterns that can emerge in intergroup encounters. CAT emerged as an attempt to describe how people use language to signify and negotiate personal and group identities in communicative contexts. The theory describes how people's cognitions and emotions influence their communicative behavior to accommodate to their conversational partners, and the consequences of that behavior (Baker & Watson, 2015). Examples of accommodating behaviors that facilitate communications include explaining, listening and perspective taking. When individuals recognize that their communication partner have specific communication needs, this awareness leads to a friendly

communication environment. However, in the case of non-accommodation the interactant, for example a patient in a healthcare setting, can perceive the communication partner, the physician, as a member of a higher power group rather than an individual. Understandably, patients will perceive accommodative strategies more positively. In the case of healthcare, physician have been found to be used medical language during their interactions with patients that are daunting and overwhelming to the patients (Deuster, Christopher, Donovan, & Farrell, 2008; Thomas, Hariharan, Rana, Swain, & Andrew, 2014).

Preventive Health Model (PHM) was developed in the late 1980s drawing on earlier models, mainly the Health Belief Model and the Theory of Reasoned Action, to identify internal and external factors that influence health-related actions and behaviors that reflect a person's self-system (Myers, 2005). The PHM proposes that when an individual is faced with a health decision (e.g risk of colorectal cancer) the person forms an intention to act (e.g obtain screening) based on the relationships among facets of the self-system. According to PHM, the self-system includes socio-cultural background (e.g expectancies related to demographic and socioeconomic characteristics, personal and family medical history, and past preventive health behavior); cognitive and affective representations about disease, risk, and available behavioral alternatives; and the social support and influence of significant others, including family members and health care providers (Myers, 2005; Myers et al., 2005).

Chapter 3: Methodology

Research Design

Grounded theory will inform the analysis methodology employed in this study. It was developed by two sociologists, Barney Glaser and Anselm Strauss. Their collaboration in research on dying hospital patients led them to write the book Awareness of Dying. In this research they developed the constant comparative method later known as Grounded Theory (B. Glaser & Strauss, 1967; B. G. Glaser, 1978, 1994; B. G. Glaser & Strauss, 2009). Glaser and Strauss (B. Glaser & Strauss, 1967; B. G. Glaser, 1978, 1993, 1994; B. G. Glaser & Strauss, 2009)described the constant comparison method as following four distinct stages:

1. Comparing incidents applicable to each category
2. Integrating categories and their properties
3. Delimiting the theory
4. Writing the theory

Grounded theories are generated by discovering inductively which concepts and hypotheses are relevant to the area being studied. Glaser and Strauss introduced the idea that an assumption of grounded theory is that the researcher can be a passive recorder of information but rather simply by conducting research on a relevant topic, the researcher is actively hypothesizing and formulating ideas that can generate theory. Strauss further discussed a key assumption of grounded theory which is that social phenomena are a complex thing (B. G. Glaser, 1978).

Pilot Study

Data Collection

The project was undertaken between January 15th and May 7th, 2009. Data were collected from participants residing in the state of Georgia. Eligible adults were those who had no personal history of CRC. Since it is the aim of this study to identify a wide array of restraining and facilitating influences on screening behavior, participants were recruited with varying levels of CRC screening experience, ranging from no reported screening history to participation in any sort of screening, fully or partially. The interviews explored issues associated with colon cancer, CRC screening (barriers and motivators), nutrition, and physical activity. The interview guide used was phrased similarly to the following:

1. When I say the word cancer, what's the first thing that comes to mind?
2. So what words or feelings or ideas come to mind when you think about colon cancer in specific?
3. Do people you know talk about colon cancer much as compared with other cancers?
4. Are some people or groups of people more likely to get colon cancer?

Prompts

(a) What sorts of things do you think cause colon cancer?

(b) When it comes to preventing colon cancer, are there any ways that people can keep from getting colon cancer?

(c) What are your thoughts about finding colon cancer earlier versus finding it later? Does timing make a difference?

(d) Please share your initial reaction to the fecal occult blood testing, the sigmoidoscopy, and the colonoscopy test.

(e) What kind of things might make a person more likely to get screened for colon cancer?

(f) What kind of things might make a person less likely to get screened for colon cancer?

(g) How does cost figure in to the decision of whether or not to get screened?

(h) How does the doctor/heath care provider figure in?

(i) What kinds of conversations about colon cancer have you had with your doctor?

(j) What about conversations about screening?

(k) How do you feel about having a conversation with your doctor about colon cancer?

(l) Finally, if you could create an ideal situation where everyone would get screened for colon cancer, and no one would die from it, how would you do that?

In this study, a history of CRC screening was defined as the self-report of undergoing a fecal occult blood test (FOBT), flexible sigmoidoscopy, or colonoscopy within the recommended time period. Participants were asked if they had any of the CRC screening tests, and when they had their last test.

Interviews

There were a total of three interviews conducted. The interviews were conducted on two simultaneous days. On the first day, the first interview was conducted via the phone with participant 1. On the following day, one on one interviews with participant 2 and 3 were conducted. The interviews lasted about 30-60 minutes. All interviews were recorded and transcribed, and the findings were summarized.

Description of Participants

The population assessed in this project consisted of three voluntary participants who did not have a history of colorectal cancer. The participants were all females and in order of interviewing were 58, 47, and 45 years old respectively. Two participants were Caucasian and one participant was African American. With regards to professional status, the first participant is a doctoral student, the second is a research nurse, and the third is an administrative program coordinator.

Table 5: Pilot Study Participants

	Age	**Race**	**Occupation**
Participant 1 (LA)	58	Caucasian	Doctoral student
Participant 2 (AW)	47	African American	Research nurse
Participant 3 (MJP)	45	Caucasian	Administrative program coordinator

Results

The first interview was conducted with LA and I noted that she had quite a good working knowledge of colon cancer and the expectations surrounding screening. She pointed to the role of the media, in particular the Katie Couric campaign in garnering attention for colon cancer. This then led to a discussion about the visibility of colon cancer in comparisons to the more widely known and discussed cancers such as breast cancer. The next point of interest that noted in LA's responses was that she discussed her knowledge of a number of nurses who have ignored or postponed their own screenings. In thinking about that comment after the completion of the interview, the decision was made not to limit the eligible population only to those lacking knowledge about the medical field; in fact, I included them because they play a vital role in the delivery of the message of screening. I simply had one phrase repeat in my mind: "Healer, Heal Thy Self."

The second interview was conducted with AW, and immediately the area of the role of the media was touched on as she mentioned the Katie Couric campaign before I had a chance to introduce it by stating that "she made that such a visible disease". The next point of discussion that arose was about her utilization of preventive services and she stated that "if I had to pay to do those screenings, I think I would do it less rigorously". I noted that this is another point that I

did not incorporate in my original set of questions but was incorporated in the points of discussion addressed in the last interview. An important point that was made during this interview was AW's concreted awareness of the importance of screening which was contrasted with the fact that she did not place much importance on the reasoning driving it reflected in her statement "I do not think you particularly have to tell people why because you do not want them alarmed." Another significant point made during this interview related to the role that nurse practitioners and physician assistants can play reflected in AW's comment that "I think they spend more time and they explain everything they are doing where the doctors do not". This important point was incorporated in future the third interview as it addresses an area of need currently present in the patient-care provider relationship.

The third interview was conducted with MJP, and in this case the role of the media was not of significant importance to the participant. Interestingly, while she was not someone with a particularly scientific background, she primarily associated risk factors for colon cancer with genetic factors by stating that "think when I think of colon cancer I think of it more as almost … kind of a random thing rather… a mutant gene pool." Finally, an important observation that this participant brought to the conversation was about the difference in the mentality between urban and rural areas. The participant seems to be an insider to the culture of small towns as she stated that her family was originally from Lawrenceville and continued to see the family physician.

Lessons Learned

The most important lesson garnered from this qualitative pilot study was the fact that discussion about CRC can be very easily steered in many different directions. This exercise served as an excellent lesson on how to control future interviews and refocus the discussion on the specific topic of understanding the impact of a patient's communication with their physician

about colorectal cancer screening. This pilot study was crucial in allowing me to develop a better framework for conducting this dissertation study in terms of addressing the pilot study's limitations. The limitation included: small number of participants, homogenous gender of participants (all were females), and not all were over the CRC screening recommendation age of 50.

Selection of Recruitment Sites

For this study, Atlanta Metro Area served as the recruiting site as a local church, St. Mary's Orthodox Church of Atlanta. These were selected as the sites because of my affiliation with the locations. The Atlanta Metro is large city with an urban population of over 4.5 million inhabitants with a diverse ethnic profile.

Participant Eligibility Criteria

Fifteen eligible participants (men and women) were recruited based on the following inclusion criteria: 1) are 50 years or older; 2) residence within the larger Atlanta Metro Area. Prior to the interview, participants were presented with a low literacy consent form, and study description. For the convenience of participants, interviews were conducted over the phone and participants received a copy of the consent form as well as their $25 gift card of choice (Kroger or Target) via mail.

Study Flow Overview

Participants answered baseline questions to determine their eligibility and gather basic demographic information. After completing the baseline information intake, all participants were interviewed over the phone.

Interview Questions Development

The following table provides a visual linking the above interview questions to specific research questions:

Table 6: Interview Question Development

Research Question	**Interview Question**
1. What misconceptions do participants have or have heard from others about colorectal cancer and its screening?	
	1a. What does the term “cancer” mean to you? 1b. What words, feelings or ideas come to mind when you think about CRC specifically? 1c. Do you think you are more likely to get CRC cancer than other groups? If yes, what makes you believe that you are more likely to get CRC? If no, what makes you believe that you are less likely to get CRC? 1d. What can a person do to prevent getting CRC 1e. What are some of the things you do to prevent getting CRC?
2. What strategies do participants use to communicate with healthcare providers about colorectal cancer?	
	What do you do to prepare to talk with your healthcare provider about CRC? Have you heard about tests that people can take to find out whether they have CRC? If yes, which types of screening tests have you heard about Have you talked with a healthcare provider about the screening test?
What action intentions do participants have for utilizing colorectal cancer screening? a. How is this intention influenced by communication with healthcare providers?	
	Think back to the last time you meet with your health care provider. Were you referred to get a CRC screening exam? Did you get the exam When do you plan to get the exam? What are reasons that make may or may not get the recommended exam?

Subjectivity Statement

I believe that when I began delving into the arena of qualitative research I was mostly attracted to the constructionist epistemological stance. Constructivism is the epistemological view that all knowledge, and therefore all meaningful reality as such, is contingent upon human practices, being constructed in and out of interaction between human beings and their world, and developed and transmitted within an essentially social context.' Constructivism sees a reciprocal and interdependent relationship between objects in the world and consciousness – 'no object can be adequately described in isolation from the conscious being experiencing it, nor can any experience be adequately described in isolation from its object' (Crotty, 1998). So there is no essential meaning to be found within objects or the world that is independent of consciousness. All things depend upon human beings for their meanings. In particular, social constructivism stems from epistemological position - not an explanatory theory. It is an approach to knowledge which focuses on meaning and power. It focuses on meaning and power because its epistemological position dictates that meaning and power are all that we really can claim to know about. It is called 'social constructivism' because it aims to account for the ways in which phenomena are socially constructed. For example, consider the various constructions of 'cancer screening recommendations' which are currently not standardized across the board. We can see that there are multiple ways of constructing what a 'screening recommendation' is and what it would mean, that these are often mutually-exclusive, and that they are developed from various ideological perspectives (i.e. power) (Burr, 1998).

According to Crotty (1998), a theoretical framework is "the philosophical stance informing the methodology and thus providing a context for the process and grounding its logic and criteria." (Crotty, 1998) A theoretical framework can be then described as a system of ideas,

aims, goals, theories, and assumptions about knowledge; about how research should be carried out; and about how research should be reported that influences what kind of experiments can be carried out and the type of data that result from these experiments.

As I began to investigate more about qualitative methods of research, I found that my stance is no longer purely constructionist. I believe that entails that no one perspective or one true reality, but rather multiple perspectives, have value that are revealed through dialectical interaction. Although I think that I tend to approach my research from a social constructivism/postmodern perspective, I feel that there will be times that I lean towards the logical positivist side simply because I do believe that there are instances where individuals rather than society can determine power and status. As someone who is choosing to immerse herself in the field of healthcare for the underserved, I have to believe that change can rest in the hands of a few who are determined. I believe that it is naïve to expect society to rise up to change individuals' behaviors and to make a financial commitment to do so as well. Basically in my research, I like to show that there are many perspectives that may have common underlying themes.

I was originally drawn to this research topic because of the passing away of my mentor at the age of 52 of colon cancer. I chose to work with minorities and the medically underserved because as I reviewed the literature, I found a lack of studies providing solid recommendations as how to increase utilization of cancer screening services among minorities and medically underserved populations. I found this to be frustrating because I had spent years working as a basic science research working at the molecular level and feeling that this research was not translating into viable treatment options. In fact, I found people did not even utilize the screening available to them to get to the treatment options. As a researcher, I hope to contribute to the body

of research that explores the fundamental underlying issues that prevent individuals from utilizing available preventive care measures.

I feel that I have to keep myself in check as I conduct my research since I foresee allowing my attitudes to interfere. The attitudes I am referring to are about the neglect I perceive on the part of providers in furnishing patients with information at their level affect my research. This attitude is perhaps influence by my being the daughter of older parents who are immigrants. I always found it appalling that doctors did not seek to converse with patients at levels appropriate to the patient and the lack of patience displayed on the part of doctors at patients who demand more explanations or more time with the doctor. This lead me down the thought process of if my parents who are educated and well insured face such obstacles that make them dread their office visits then how are the underinsured, under-educated made to feel when they are visiting their doctor.

Data Analyses

Interviews were tape-recorded, and notes were taken. An open-ended interview script was used to guide the discussions. A grounded theory approach was used to collect, organize and analyze the interview data. Interviews were analyzed using ATLAS.ti to help uncover and systematically analyze complex phenomena hidden in interview transcripts. The program provides tools that will help to locate, code, and annotate findings in the transcripts to weigh and evaluate their importance, and to visualize complex relations between them. ATLAS.ti was also used to aid in consolidating large volumes of documents and keeps track of all notes, annotations, codes and memos in all fields that required close study and analysis.

The analysis started with open coding and progressed to axial coding (including merging and re-categorizing codes into broader categories). The first phase of analysis included a review of each transcript in detail to begin initial coding and analysis of the narratives. To get a sense of the interviews' flow and format, all transcripts were reviewed in their entirety. Next, individual findings were mapped to obtain consensus on categories. In the next phase of analysis, initial categories were reduced and collapsed by comparing and contrasting the narratives of the interviews. This allowed themes to emerge from the established categories. Consensus on the themes can only be reached by reviewing the concordance, elaboration and intensity of the responses provided.

CHAPTER 4

RESULTS

The purpose of this dissertation was to qualitatively examine how individuals over the age 50 perceive colorectal cancer and its causes, the individual, social, systemic, and environmental level obstacles faced when considering and attempting colorectal cancer screening as well as the communication strategies they employed or deemed appropriate toward utilizing screening options. The interviews explored issues associated with colon cancer, CRC screening (barriers and motivators), nutrition, and physical activity. Discussions strived to focus on how participants perceive colorectal cancer and its causes, the individual, social, systemic, and environmental level obstacles faced when considering and attempting colorectal cancer screening as well as the strategies they employed or deemed appropriate toward utilizing screening options

Target Setting

For this study, Atlanta Metro Area served as the recruiting site. Eligible adults were those who had no personal history of CRC. Since it was the aim of this study to identify a wide array of restraining and facilitating influences on screening behavior, eligibility was open to participants with varying levels of CRC screening experience, ranging from no reported screening history to participation in any sort of screening, fully or partially.

Description of the Participants

Fifteen participants participated in the study. The age range of the participants was 50 to 74, with the majority of participants (53.3%) being 50-55. The average participant age was 59.

Nine out of fifteen participants (60%) were female, while eight (53%) were Caucasian. Most participants reported having had a colonoscopy (86.6%) for their initial screening, while the remaining two participants reported a fecal occult blood test for the initial CRC screening. Among types for follow-up screenings, 7 out of 15 (47%) reported having a colonoscopy within the last 5 years, while one participant reported a colonoscopy within the last two years. Eight out of fifteen participants (53%) received a CRC screening because they were age appropriate. Table 7 displays aggregate demographics for study participants while table 8 presents CRC screening utilization of study participants

Table 7. Aggregate Participant Demographics (N = 15)

Age Range	N (%)
50-55	8 (53.3%)
56-60	1 (6.7%)
61-65	2 (13.3%)
66-70	3 (20%)
71 and over	1 (6.7%)
Gender	**N (%)**
Female	9 (60%)
Male	6 (40%)
Race	**N (%)**
African American	7 (47%)
Caucasian	8 (53%)
Screening type utilized for initial screening	**N (%)**
Colonoscopy	13 (86.6%)
Fecal Occult blood test	2 (13.4%)
Screening type utilized for follow-up screening	**N (%)**
Colonoscopy (2 years)	1 (6.7%)
Colonoscopy (5 years)	7 (46.7%)
Colonoscopy (10 years)	3 (20%)
Fecal Occult blood test	2 (13.3%)
Other	2 (13.3%)

Table 8. Participants CRC Screening Utilization (N = 15)

Participant #	Age at 1st screening	Type of Screening	Indication	Additional screening
#1, Maura	56	Colonoscopy	Age appropriate	Annual Fecal Occult blood test (FOBT),
#2, Vincent	43	Colonoscopy	Gastric bypass	Colonoscopy every 5 yrs
#3, Veronica	48	Colonoscopy	Family history Father = Colorectal Cancer	Colonoscopy every 2 years
#4, Ivan	51	Colonoscopy	Presenting with symptoms CRC stage IIA	Oncology follow up
#5, Monica	50	Colonoscopy	Age appropriate Family history Father = polyps	Colonoscopy every 5 yrs
#6, Daniel	32	Fecal Occult blood test (FOBT)	Part of job required physical exam	No longer follows up
#7, Laura	50	Colonoscopy	Age appropriate	Colonoscopy every 5 yrs
#8, Kourtney	53	Colonoscopy	Age appropriate	Colonoscopy every 5 yrs
#9, Robert	51	Colonoscopy	Age appropriate	Colonoscopy every 5 yrs
#10, Smith	48	Colonoscopy	Family History Brother = Prostate Cancer	Colonoscopy every 10 yrs
#11, Ally	50	Colonoscopy	Age appropriate	Colonoscopy every 5 yrs
#12, Sue	52	Colonoscopy	Family history Father = colorectal cancer	Colonoscopy every 5 yrs
#13, Jane	50	Colonoscopy	Age appropriate Family history = paternal uncle	Colonoscopy every 10 yrs
#14, Jerry	54	Colonoscopy	Age appropriate	Colonoscopy every 10 yrs
#15, Matty	62	Fecal Occult blood test (FOBT)	Age appropriate	Annual Fecal Occult blood test (FOBT),

Research Findings

Research question 1: What misconceptions do participants have or have heard from others about colorectal cancer and its screening?

Colorectal cancer impact on personal well-being.

Most participants discussed the impact colorectal cancer on their personal well-being. While many participants indicated the presence of an impact on their personal well-being, a few indicated a lack of impact as well. In addition, the association of colorectal cancer with death, the assessment of personal risk, and the assessment of prevention options also emerged as sub-themes. Table 9 displays descriptive statistics for the overall theme and sub-themes.

Table 9: Colorectal cancer impact on personal well-being theme and sub-themes

	Theme Frequency	Percent
100 CRC impact on personal well being	2	13%
101 Presence of impact	16	67%
102 Absence of impact	6	33%
103 Association with death	7	40%
104 Assessment of personal risk	**40**	**93%**
105 Assessment of prevention options	**21**	**93%**

Many participants (14 out of 15 participants, 93%) discussed their perspectives on cancer and its effect on them personally, as well as on their close friends and family. Generally, cancer, including colorectal cancer, was seen as impeding on personal well-being. A few participants

recalled their personal experience with being diagnosed and treated for colorectal cancer. One participant described their experience as being a “whirlwind,” going “blindly” to various treatments and doctors. **Ivan** shared the following:

> It just seems like any traumatic experience. Looking back on it now, it seems so much that it's just, I don’t know, I wouldn’t say blocked out. My wife will say something and I'll be like, "Oh yeah! I forgot about that." It's like sort of like being in a whirlwind. Maybe that's a good thing. Not very much is stuck. I guess you just blindly go where they tell you. That was always my thing. People would be like, "Oh, you're fighting cancer. You're battling this ogre like you're in some sort of Grimms' Fairy Tale or medieval joust," and I'm like, "Well, no, not really. I'm just going where they tell me to go when they tell me to be there."

Many participants recalled and discussed instances of colorectal cancer in friends and family members and how it impacted their lives. Some recall experiences with loved ones who died due to colorectal cancer. As **Jane** indicated:

> Because there was a reason for that. We had had a really good friend who actually was a nurse down at Midtown and just out of the blue, I hadn’t heard from her in a while and out of the blue I got an email from her saying that she was going to have to have a permanent colostomy done and so it turns out, that I don’t know if she…because she’s about 10 years older than I am. So she was probably maybe not quite 60 yet, but, you know, 58, 59 and I don’t know if she had never had a colonoscopy or if it had been a long time between times, but so because of her not acting on it and doing, you know, keeping up with just regular check-ups, she wound up having rectal cancer and it had gotten into the muscle wall so that there was nothing they could do about it.

Assessment of personal risk.

Among colorectal cancer impact on personal well-being, the most cited sub-theme was assessment of personal risk. Several participants talked about being susceptible to colorectal cancer because of age and/or race. Participants cited African-Americans as being of increased risk for colorectal cancer. Additional risk factors highlighted were family history of colorectal cancer, existing chronic gastrointestinal (GI) issues, diet, smoking, weight, and lack of exercise. In addition, a few participants also included the presence of pre-cancerous polyps as a risk factor.

Most participants feared being more likely to get colorectal cancer because of having a family history of colon cancer. Participants discussed in detail friends and/or family that have been diagnosed, treated, or passed away from colorectal cancer. As shared by **Laura**:

> So if there's a family history, it means that you are at a higher risk for it. If you have chronic GI issues like Crohn's [ulcerative colitis], they might be more prone to developing it because their protective mechanism has [gotten worse].

Jane indicated a similar understanding:

> I would say I could see myself as being more likely to get it and only because we have, well, first off, we have a family history of colon cancer, my uncle had colon cancer and actually I think that's…I'm not sure if that's what he died from because he had a couple different instances. But anyway, that…that was one of them that he had and…and we also have a history of polyps in our family, you know, colon and rectal polyps so…

A few participants saw cancer as something that affects everyone regardless of age or family history. **Veronica** indicated:

> There aren't no certain groups because anybody can have cancer now. You have babies that come in here with cancer, so it's no certain groups. What used to be when folks got old, they develop cancer, but now, shoot, it's hitting everybody.

Assessment of prevention options.

Many participants discussed their current colorectal cancer preventative strategies in detail. Many participants reported that they are being "checked" regularly or screened due to a family history of cancer. A few participants reported that the task of getting a regular check-up was facilitated by the requirement of a job or occupation to get regular or annual check-ups. In addition, living a healthy lifestyle, including eating a diet rich in fruits, vegetables, as well as foods that are high in fiber, were seen as preventative. **Ivan** stated:

> I had a diet high in vegetables and ate a fair amount of raw or very slightly cooked vegetables, a lot of fruit, and a little meat, but it was just a little meat. I wasn't chowing down on the steaks every night or anything. Things would be grilled or just lightly sautéed in olive oil.

Several participants also highlighted the importance of early detection, in addition to receiving screening at the occurrence of symptoms, such as blood in stool. In addition, if diagnosed with colorectal cancer, having accurate information about severity and treatment options, were mentioned as important in colorectal cancer prevention. **Vincent** shared:

> I believe getting early detection and treatment is better than trying to fight or fix something when it's already established in the system.

Most participants discussed family or friends who did not undergo preventative treatment and experienced adverse outcomes and, are now increasingly dedicated to their own colorectal cancer prevention and screening to avoid an adverse outcome. **Veronica's** comment illustrates her dedication to colorectal cancer prevention as a result of family member's adverse outcome:

> Because I don't want to be like my uncle, all these times, he knew he had cancer, but first of last year May or was it March, they told him that and my uncle did not tell if he was sick until I found it out when I was in the hospital with him and the doctors told me. I said, "What?" We didn't know my father had it until he started bleeding from his rectum. They didn't check my daddy for it. So I'm saying to myself, I don't want to go out like that. I want to know what's wrong with me. So if I can stop it, I will, but if it's God's will for me to go on, I'm going on.

Awareness of screening recommendations.

A majority of participants demonstrated an awareness of screening recommendations for colorectal cancer, with several participants citing accurate screening recommendations or guideline. Table 10 displays descriptive statistics for the overall theme and sub-themes.

Table 10. Awareness of screening recommendations theme and sub-themes

	Theme Frequency	Percent
200 Awareness of screening recommendations	**39**	**100%**
201 Presence of accurate awareness	15	60%
202 Absence of accurate awareness	2	13%

The majority of participants talked about their awareness of screening recommendations, including the benefits of early detection and treatment, and routine screenings. Many participants demonstrated awareness discussing screening recommendations, specifically at the recommended age of 50 or if a family history of colorectal cancer is present. **Laura** provided the comment below:

> The recommended age is 50, but you should do that if you got it in your family, a history of it in your family – should do it earlier, and with your routine physicals, if you have any blood in your stool or that kind of thing, then you need further work-up.

Participants talked about the benefits of routine primary care, citing that routine care is beneficial to all groups of people, not just high risk groups. Some participants discussed recollections of colorectal cancer screenings, specifically colonoscopies, as a part of their annual routine primary care visits. Also participants discussed seeking care in response to experiencing possible symptoms such as bleeding during bowel movement. For example, **Vincent** gave the following comment:

> Well my view of it is prevention and unfortunately a lot of people are still in denial. I think we need to have more education along these things where we have preventative maintenance where people of all walks of life should see their doctors on a regular basis and be screened, so that if there's any early detection, early treatment will be even better for all people across all socioeconomic backgrounds, and better access to healthcare would be one of the things that we can do the screenings and have it available to everybody, then we should be able to get a better result, a better outcome.

In addition, participants discussed observing screening recommendations on flyers or posters while in the doctor's office. The comment provided below by **Ally** describes an instance of this:

> I think it's pretty much in any Kaiser office I've been in, and I was just in one last two weeks ago with my daughter. It's like a poster and it's saying all different types of screenings and it gets into, you know, at this physical exam you will have and so it starts out with just basic things like blood pressure, weight--you know, basic screening. Then it says and at this age or at that age or if you have these factors or that factors, and it really just details pretty much all of the annual or every five-year test …mammogram, Pap smears … Colonoscopy is on there, why would you need to have an EKG, why would they need to do more of that, when do we need to do a urine test. It explains all that. So, it's kind of nice to see.

Summary.

In the overall theme of Colorectal Cancer Impact on Personal Well-being, colorectal cancer, and cancer in general, were seen as having a negative impact on personal well-being, as well as the well-being of family and friends. Experiences with cancer diagnosis were associated with feelings of being out of control and "blindly" following the recommendations of health care providers with little discretion.

Participants assessed their personal risk for colorectal cancer in regards to accurate risk factors, including family history and high-risk lifestyle choices. Many participants acknowledged prevention options including primary routine health care, healthy diet, and early detection. Some participants were able to garner further motivation towards cancer prevention through observing

family or friends who failed to assess their personal risk for colorectal cancer. Witnessing these adverse health outcomes was cited as a major motivating factor towards colorectal cancer prevention strategies.

Study participants demonstrated as awareness of colorectal cancer screening recommendations. This awareness was demonstrated through discussion of screening guidelines, benefits of early detection and treatment, and routine primary healthcare. In addition, participants discussed observations of screening guidelines in health care settings and mentioned screening methods, such as colonoscopies and fecal occult blood test.

Research Question 2- What strategies do participants use to communicate with healthcare providers about colorectal cancer?

Patient's personal accountability.

Many participants discussed patient's personal accountability with an emphasis on patient's engaging in fact finding or research prior to the patient-provider interaction. A few participants revealed incidents of presenting to the patient-provider interaction with no pre-developed knowledge. Table 11 displays descriptive statistics for the overall theme and sub-themes.

Table 11. Patient's personal accountability theme and sub-themes

	Theme Frequency	Percent
300 Patient's personal accountability	**44**	**93%**
301 Patient engages in fact finding or research before MD/pt interaction	15	60%
302 Patient presents to MD/pt interaction with no pre-developed knowledge	2	13%

Participants frequently discussed willingness to accept personal responsibility for one's own health and the need to participate in colorectal cancer screenings and preventative measures. Feelings of personal responsibility for one's health were discussed frequently. Many participants felt that if they could be proactive about attempting to detect cancer early, they could stay healthy longer and stay alive longer. Also being proactive about asking for colorectal cancer screening as opposed to waiting for a provider's recommendation, was frequently mentioned. This theme is highlighted in the comments below:

Monica stated:

> I've always encouraged them that we want to make sure we get proper care and take care of ourselves. We do all we can to take care of ourselves and make sure…and we can't do that without proper…when we grew up, what… our parents to go through about those and get proper care and everything…get you go and they needed to go.

Veronica indicated a similar understanding:

> Just tell them I want to be checked based on that because it's in my family and I want to make sure that I'm alright. They can't do nothing but comply with it. Most doctors will comply to your thing. If they see it in your family, most of the time they will have you checked for it, one way or another.

The comment below by **Ally** further illustrates the theme:

> It's up to you to remember to go to a visit. They're not calling you about that, but they will call about mammogram. They track you for that … for sure. If I don't go for an annual physical, nobody is going to contact me, but if I don't ... I don't even have to call to schedule mammogram. They will get in touch with me before it's even due. Very proactive about that.

Engaging in fact finding or research.

A sub-theme of the overall theme of personal accountability is the strategy of how participants attempted to take responsibility for their individual health. The strategy that emerged from the study was fact finding or research prior to interaction with their doctor. This includes writing down issues or symptoms to discuss with the doctor prior to the visit to help facilitate a positive provider interaction. **Kourtney** stated:

> I would suggest doing some research and then writing down some questions that you have, even though if you're not satisfied with what you researched on. But not everybody is a researcher. Then I would suggest that you write down some questions if you don't know about the procedure, what's the procedure like, what happens if they find cancer, that type of thing.

Participants talked about doing research on issues you may not understand in order to educate yourself. Also figuring out the right questions to ask their doctor and preparing them ahead of time was frequently cited by participants. There also was acknowledgement by participants that doctors are often busy with hectic schedules and many patients, and given these considerations, prepare questions in advance helps to ensure proper patient-provider communication during the health visit. Most participants also highlighted that even among busy providers, most will take the time to address prepared questions despite busy schedules. **Maura** shared:

> When doctors come in, they have a limited time, but if you have it on paper, they will take time to let you go down that list.

Veronica shared a similar understanding:

> The kind of questions you want to ask write them down because sometimes people may say things that's a dumb question, but there's no such thing as a dumb question. Write it down and then ask them. Sit down and tell your doctor you have some concerns, and you'd be surprised, your doctor will listen. Tell them you got concerns and see what you can sit down and do together. That's what they're there for. They'll tell you. They'll say, "Well, is there's anything that I can help you with today?" And you just tell them, I have some concerns with such and such and such and such, and I'm quite sure, as a physician, they're required by law to listen to you and help you. I know doctors have a lot of patients, but they will sit and listen to you, but you just got to know the right kind of questions to ask.

Negative patient-provider interaction.

Another theme that emerged from the study that acts as a deterrent to patient-provider communication is negative patient provider interactions. This theme includes discussions about lack of advocacy, lack of respect for the patient, and lack of informed decision making. Table 12 displays descriptive statistics for the overarching theme and the sub-themes.

Table 12. Negative provider-patient interaction theme and sub-themes

	Frequency	Percent
400 Negative MD/Pt Interaction	**18**	**40%**
401 Lack of advocacy for patient	3	13%
402 Lack of respect for patient	13	20%
403 Lack of informed and shared decision making	10	20%

Lack of respect.

The most frequently mentioned negative patient-provide interaction was lack of respect. Within the overall theme of negative interactions between providers and patients, participants talked about experiences with providers in which they felt a lack of respect from their healthcare provider. The lack of respect was perceived due to unclear communication from the provider to the patient regarding treatment options or issues. It may have also included not enough attention spent due to too many patients or being “spread quite thin”; and general lack of concern, “couldn’t care less” attitude.

As shared by **Ivan**:

> Actually, when I saw him, he kept taking phone calls from his wife. So, it was basically, "Okay. What we're going to do is cut out your liver, a part of your liver. Excuse me, let me get this phone call, come back in. Okay. So, we're going to do this," and then took another phone call. Other than the fact that he said he was going to operate on me, there wasn't much information that came from him.

Lack of shared decision-making.

Participants discussed instances where there was a lack of shared decision-making, including a lack of informed and shared decisions making, two-way communication, and equal participants both talking and listening. Participants expressed a desire of wanting to seek more a partnership with a provider, someone to "embark on the journey" together. As **Ivan** shared:

> It's very much, "Okay. Well, we're going to do this now," other than right at the beginning where they said, "Okay. We're going to do the radiation. You're going to take the Xeloda, and then we're going to do surgery." Actually, later on, it began to get rather annoying because it seems like we were never dealing beyond tomorrow. It was like, "Okay. Well, this has happened. We're going to do this now."

Daniel shared a similar understanding:

> I did go and see the woman who was designated as my primary care doctor. I guess I was looking for some sort of information or solace. I felt that I should go see her if we were embarking on this journey to see what she had to say, and I guess my expectations were a little high.

Lack of advocacy.

A few participants mentioned the lack of advocacy, or public support by the provider in favor of the best treatment for the good of the patient. This includes insensitivities surrounding financial issues as well as providers not making the best medical choices resulting in additional procedures or treatments. **Maura** described his experience in the comment below:

> He would have taken time and told me more. And we would have talked back and forth because I want, you know, not just for you to tell me. I want you to feel that my advocate with my patients is, you know, you are part of the team. You're supposed to be part of the team in your healthcare and not just do what the doctor said.

Positive patient-provider interaction.

A majority of participants talked about or recalled positive interactions and experiences with healthcare providers. The Positive Patient-Provider theme includes the sub-themes: Advocacy for patient, Respect for patient, and Informed and shared decision making. Table 13 displays descriptive statistics for the overall theme and sub-themes.

Table 13. Positive patient-provider interaction theme and sub-themes

	Frequency	Percent
500 Positive patient-provider interaction	**42**	**87%**
501 Advocacy for patient	6	20%
502 Respect for patient	12	40%
503 Informed and shared decision making	**30**	**80%**

Positive interactions were seen as those that result in successful treatment and/or screening where the patient sees value in the preventative treatment. Positive interactions also included satisfaction with service. Participants talked about providers keeping track of and reminding patients about screenings at the recommended time intervals. The comments below illustrate how participants perceive positive interactions with providers. As **Ally** shared:

> Just brought up the fact that I had already done the testing two years ago and that I didn't need to do it at this time. It was more of just, "Have you ever had?" and I said yes and they said when and looked up my records, so it's more confirming that I had already done what I'm supposed to do.

Vincent indicated a similar understanding:

> He feels like it should be repeated in five years. I think that was due also because they found the polyps, even though they were benign that we should do this again in five years, so the combination of both.

Vincent stated:

> The primary care physician I have here, they were pretty aggressive with standard of care. They call you and they follow-up and they send you reminders that you need to take this, this is coming up

Ally stated:

> Well, because you're sitting there waiting for them, it makes it so that you already can take a look and get an idea of what they're going to talk with you about. So then it kind of you already can bring up, "Hey! When was it that I had this or when did I have that?"

> Because I think when you're in the middle of screening and the middle of, you know, let's say I don't have to have one for five years, they really aren't bringing that up every year. They are more looking at what did you have, when … I don't think there is going to be a discussion at all until it's the year that I need to have it again. You know, there's not going to be a talk about it. It's going to be more like, "I see you had this. I see you had that. Therefore, this is what we need to do this visit." So, it makes you kind of educated about it. But if you don't need what's up on that poster, they're not really talking to you about it.

Vincent also shared:

> In New York what they had was like a team of doctors, and you would go in and you get a head to toe assessment of all the systems from the different specialists. It was one of the standards of care that we normally see really, just go check your blood pressure and you do this and do that. There were doctors that examined you. You spent like a day and you end from one office to the next to next in their facility, and they did a complete physical.

Informed and shared decision making.

The most frequently mentioned type of positive patient-provide interaction was informed and shared decision making. Participants discussed instance of two-way communication and decision making with their healthcare provider. Patients described experiences where they asked directly for screening and the provider was in agreement. For example, **Maura** shared::

> But both my primary care that I had in Florida, and my primary care here do send reminders or they do that I go in the office for other things because I do go for

> hypertension. We have our schedule that I make if … And I'm very upfront with them. Like sometimes when they don't ask me, I tell them I feel the need for my colonoscopy.

Informed and shared decision making also includes the freedom to ask question of your provider without hesitancy and the provider having patience in answering those questions. The following comments were made by study participants:

Monica indicated:

> Just keep as gentle as possible, giving the patient the chance to ask question and not just giving them a bunch of information and, "this is what we found" blah, blah, blah and then you leave. Give the patient the chance to ask about what you found, maybe ask them, did you fully understand what I said? Is there anything that is not clear to you? Is there anything I need to explain further to you? Any questions you may have?

Veronica also shared:

> Don't wait until you get a certain age. Some people…well I'm young. I don't worry about getting that. I asked them how they looked at obituary a year later. You got a bunch of young folks dying, not old folks. I think everybody, if you know your family history, and I think everybody needs to be more abreast of their family history, because once you become familiar with your family history, then you know. The doctors they ask you all these questions now. When they do your history thing, they ask you to give them a thing of your family history, and they ask you all this stuff, so you need to tell them. Yeah, this is in my family. This is in my family. Okay. Then the doctor says, "Well, you need to be checked for that because that's in your family because you don't know

> when that's going to hit you." I think everybody should take a step up and get checked out, that is if you know your history in the family.

Participants also talked about providers being easily accessible as well as being responsive to patients, including providing timely responses such as scheduling appointments and conducting laboratory tests. As indicated by **Vincent**:

> They're easily accessible also. I can pick up the phone and leave them a message. They'll call me back. I can send them an e-mail. They have one of those like MyChart. Then you have the EMR. I can send them messages and they respond. It's not a case where I want to see the doctor and I got to wait 6 months where they can't see me now. I send them a message and they respond immediately. If they need to see me, they'll tell me come in. If I need to come in for whatever reason or they'll order labs and tell me go get some labs and let's see what's happening. Then they get back to me and say, "Okay, this is what's happening. I think we should do this or I think we should do that."

Respect for patient.

The next most cited sub-theme within the positive patient-provider interaction theme was respect for the patient. According to study participants, provider respects for patients included clear and direct communication, trust, and good rapport. Participants also described providers who took the time to explain, in detail, to patients issues relevant to cancer growth and treatment. **Veronica** stated:

> She's really thorough. She's saying, "Well I'm not going to fool with you here. This can happen, this can happen or this can happen." She lets you know what options you have. You know basically what you're looking at and what you have to deal with.

Monica shared:

> I think there's got to be a good rapport between the patient and the doctor. There's got to be kind of like meeting in the middle and the patient has to bring certain…to the doctor's desk, so they have to kind of meet and the patient's got to feel like I can ask my doctor, I can go to my doctor, and he listens or she listens to what I say, and she is there if I need to ask to questions, I know I can where it's opposed to thinking, "Oh, I can't ask my doctor any questions.

Maura echoed similar sentiments:

> And like I said, even upon examination, the second doctor said to me, "From what I can feel in there, it doesn't have any form to it." He explained to me what a cancer feels like in his 35 years of that profession, what he usually feels when he feels it's cancer growth. And that this just felt like tissue that had built up from the prolapse. So, I mean it was just a totally different experience, conversation wise and information wise.

Advocacy for patient.

A third salient sub-theme was advocacy for the patient. Participants talked about experiences where their healthcare provider acted in their best interest. This included providing treatment in line with what the patient perceived as appropriate. For example, recommending screening if there was a family history of cancer and recommending reoccurring screenings over time, not just at one point in time. Participants talked about the importance of providers projecting into the future, specifically discussing developing a plan for long-term care including making appointments, referrals, and scheduling follow-up care on the patients' behalf.

As shared by **Vincent**:

> So after the discussion, they make appointments. They make referrals, and then they do follow-up to make sure that you do that. You go and you sit down and you have the discussion. They say, okay, well this is the plan. This is what we need to do. And then they make the referral for me to go, and I make the appointment and I go.

Veronica shared similar thoughts:

> Don't wait until you get a certain age. Some people…well I'm young. I don't worry about getting that. I asked them how they looked at obituary a year later. You got a bunch of young folks dying, not old folks. I think everybody, if you know your family history, and I think everybody needs to be more abreast of their family history, because once you become familiar with your family history, then you know. The doctors they ask you all these questions now. When they do your history thing, they ask you to give them a thing of your family history, and they ask you all this stuff, so you need to tell them. Yeah, this is in my family. This is in my family. Okay. Then the doctor says, "Well, you need to be checked for that because that's in your family because you don't know when that's going to hit you." I think everybody should take a step up and get checked out, that is if you know your history in the family.

Summary.

Three major themes are highlighted under the research question regarding strategies participants use communicate with healthcare providers about colorectal cancer. One of the most frequently cited themes, Patient's Personal Accountability, highlighted the importance of personal responsibility as a motivating factor in fact finding or research prior to patient-provider

interactions. Patients discussed preparing in advance for interactions with providers in order to avoid any potential barriers to communication due to the provider's hectic schedule. This preparation coupled with proactivity in addressing potential colorectal cancer screening needs are major contributors to effective communication between patients and healthcare providers.

Positive Patient-Provider Interaction and Negative Patient-Provider Interaction were discussed by participants in relation to seeking care and adhering to screening recommendations. Participants highlighted major factors that directly affected the patient-provider interaction. Respect, including fair treatment and consideration was cited as a factor. In addition, shared decision making and advocacy were also cited as significant characteristics critical to positive or negative patient-provider interactions.

Research Question 3 - What action intentions do participants have for utilizing colorectal cancer screening?

Adherence to screening recommendations.

Adherence to screening recommendation was discussed by the majority of participants. This theme included reasons or motivation for adherence, as well as reasons for non-adherence. Table 14 displays descriptive statistics for the overall theme and sub-themes.

Table 14. Adherence to screening recommendation theme and sub-themes

	Frequency	Percent
600 Adherence to screening recommendation	**48**	**87%**
601 Reasons/ motivation for adherence	**25**	**73%**

602 Reasons/ motivation for non-adherence	16	46%

Majority of participants talked about undergoing screening or treatment for colorectal cancer and following provider recommendations for routine screenings including colonoscopies and fecal occult blood test (FOBTs). Participants discussed following through with appointments and referrals. In addition, participants acknowledged screening recommendations, frequently citing time intervals, for example having screenings every "five" or "ten" years.

Most participants identified family history of cancer, age, and existing health issues as major motivating factors for adherence to screening recommendations. As shared by **Laura**:

> My mom has pre-cancerous polyps and my provider was very in favor of trying to get a colonoscopy done early even though we were concerned the insurance wouldn't pay for it.

One participant highlighted the important issue of providers making an effort to decrease the stigma or embarrassment of the subject area. This included encouraging the patient to think of colorectal cancer screenings as a "normal function" or just another health topic/area. As **Jerry** indicated below:

> I think obviously some people get uncomfortable talking about some types of body functions and parts of their body and stuff like that. And, you know, to me in my mind and because of my training and so forth, it's just a body part. You know, sometimes it works right. Sometimes it doesn't. You do what you need to do. So it doesn't bother me to talk about it, but I think if doctors would make an emphasis of making patients feel more comfortable and, you know, taking away any sort of embarrassment or discomfort

> that they may have about bringing up the subject and making them realize this is just a normal function. We want to keep an eye on it. You know, here's the reasons we do this, and it's a good thing to do periodically. So I think it's more of a sociological than a psychological thing. It's just, you know, there's certain barriers where people are just embarrassed about some stuff.

Among reasons cited for non-adherence, some participants discussed avoiding screenings due to fear or hesitancy regarding to the nature of colorectal cancer screenings. When discussing colorectal cancer screening, participants described the pre-screening preparations as "nasty", "uncomfortable', and "nauseating". Participants also discussed financial and socioeconomic access to care barriers, including healthcare providers who limit or refuse to take Medicare patients. This would lead to non-adherence given Medicare recipients represent the target age group for colorectal cancer screenings. A few participants also discussed the perception that healthcare providers want to diagnose an illness for financial reasons. The perception is that healthcare providers want to keep the costs of screenings and laboratory tests high to benefit economically. **Matty** indicated below:

> Cost is a big issue. You know, I'm on a…not a fixed income, but I just…it's so much money. You know, healthcare now days, I don't know where it's going. You know, you pay a fortune just to have health insurance, and then when you have anything that you need to have done, it costs more money. And so I don't know if the world is going to price people out of being able to have tests because, you know, they want your money before they'll do the test.

Robert shared thoughts:

> Lack of information, lack of funding, but probably the average, more affluent person than now, so I think it's probably more based on their ability to see a healthcare provider that recommended that and then can they afford it.

A few participants also discussed a fear of diagnosis, Daniel stated, “I’m not going to start a problem where there is none. And if it’s not broken, don’t fix it”. A related point made by a participant is the reluctance to see a healthcare provider if one feels relatively “normal”.

Mixed feelings were reported regarding in-home testing kits. One participant talked about the impersonal nature of submitting a stool sample using an in-home kit to the lab using a mail-in process as being a major deterrent to screening adherence. While another participant cited it as a motivating factor. As **Daniel** shared:

> And then he wanted me to send all the stuff in. I mean, they have gotten so impersonal. I guess that’s why they have so many patients and people. I would have thought that he would have taken a sample somehow the last time I saw him, but he just kind of handed it to me. He handed me this little bag full of stuff, and I was supposed to get a stool sample and send it in the mail in this thing to somebody to tell me what, I don’t know. Then I just didn’t do it.

Information retention by patient.

Another theme that was revealed by this study was the presence and type of colorectal cancer information retained by the patient. Table 15 displays descriptive statistics for the overall theme and sub-themes.

Table 15. Information retention by patient theme and sub-themes

	Frequency	Percent
700 Information retention by patient	**24**	**73%**
701 Present	12	53%
701.1 Type of information retained	2	13%
702 Absent	9	33%

Many participants talked about retaining information in relation to a presence of a family history of cancer. Participants talked about their desire to keep up with colorectal cancer information in order to benefit family, including parents and children. As **Veronica** shared:

> Cancer is in my family as well as heart disease. I try to keep up with all of that, and my mother does too. I'd be at my children making better choices in life.

Participants demonstrated colorectal cancer knowledge, including citing colorectal cancer is highly preventable if detected early as well as discussing general knowledge of screening recommendations. Participants also discussed knowledge of preparations for a colposcopy, what to expect, for example, **Ally** stated:

> The preparation. That's always. It worked because people generally need a day and a half plus you need to go home and start this. You're going to have to be off that day. People talk about it quite a bit. They don't talk about the disease; they just talk about, "Oh, I've got to go get a colonoscopy." You hear that frequently.

Few participants didn't talk about or acknowledge benefits of screening. These participants demonstrated a lack of knowledge, retention of risk factors, and screening

recommendations. One participant mentioned that while they have seen pamphlets in the doctor's office, they still were unsure about recommendations. As **Robert** indicated:

> Lisa [wife] and I were talking about it yesterday. I was thinking they said it was every 10 years after the initial one. She says she thinks I'm wrong. So I'm sure I will find out next time I go to have a physical, which I should probably do some time soon, in a while.

Screening recommendation to friends and family members.

Many participants also discussed screening recommendations to friends and family members regarding colorectal cancer. This theme not only includes whether or not the participants made recommendations, it also includes the types of recommendations given to friends and family. Table 16 contains descriptive statistics of the theme and sub-themes.

Table 16. Screening recommendations to friends and family members theme and sub-themes.

	Frequency	Percent
800 Screening recommendation to friends and family members	**26**	**67%**
801 Present	**20**	**53%**
801.1 Type of recommendation provided to family and friends	9	33%
802 Absent	2	13%

Most participants talked about discussing screening and preventive measures with friends and families. These discussions include recommendations for routine screenings, as well as lifestyle, and dietary changes. For example, **Veronica** shared:

> I told my sister I made better choice. I don't drink. I don't smoke. I don't do nothing. I eat right. I don't eat a lot of greasy food. I choose the food that I eat. I eat carefully. I don't eat out a lot. I may treat myself once a while, but not a whole lot, and I don't eat a lot of fat, greasy lean meat. I don't eat pork either. Nope. I try to make good choices.

Similarly, **Monica** shared:

> I encouraged my brothers and my sisters because they're all over that age and I've encouraged all of them to get theirs.

Participants also discuss giving suggestions or strategies for facilitating a positive interaction with healthcare providers. Participants specifically discussed researching and preparing questions in advance for healthcare providers. In addition, a few participants talked about self-discipline and having patience when following-up with health needs. For example, **Veronica** indicated:

> I think sometimes people don't have patience and wait to get things done, but I tell them, even my children, I try to tell my kids and my…is one of them. You don't want to be patient and wait. I told her, "So you're telling me you don't want to be patient to wait and see about your health." Okay. I told her I got a black dress for and I hate to say like that but I mean it. I sure did because that's the truth. You're telling me you don't have the patience to see about your health, oh Lord.

A few participants demonstrated an absence of recommendations for friends and family, in some cases as evident by a lack of action taken in their personal health in regards to colorectal cancer.

Matty stated:

> Colonoscopy talk comes up occasionally with people I know because I've got some friends who have to have it, you know, quite regularly because, you know, they've had polyps and they've had them removed and whatever. So, you know, they're always shocked that I say, "Oh, I've never had one."

Summary.

Three overarching themes fell under research question three regarding action intentions participants have for utilizing colorectal cancer screening. One theme, Adherence to Screening Recommendations highlighted major motivating factors for screening adherence. These factors included family history and existing health issues. Reasons or motivators for non-adherence included fear of diagnosis and/or poor health outcome, stigma of colorectal cancer, and financial barriers to healthcare. In regards to Information Retention by Patients, most participants demonstrated retention of information regarding screening types, benefits, and recommendations. When asked about family and friends, many participants cited the importance of sharing information with them, including the benefits of a healthy lifestyle and strategies for improved communication with providers.

Summary of Research Findings

The goal of this chapter was to report on the findings obtained from one-on-one interviews with participants who receive care through an urban health center about their discussions with their health care providers about colorectal cancer, and how these discussions frame their subsequent actions. Participants reported accurate knowledge of colorectal cancer, its screening guidelines, and prevention strategies. Communication strategies used to communicate

with healthcare providers also emerged from the study. Action intentions were discussed in correlation with personal accountability, patient-provider interaction, and personal motivating factors, such as family history and existing health issues. Table 17 below reflects themes and sub-themes that emerged as related to the study research questions.

Table 17. Themes and Sub-Themes as related to Study Research Questions

Research Question	Interview Question	Theme/Sub-Theme
What misconceptions do participants have or have heard from others about colorectal cancer and its screening?	• What does the term "cancer" mean to you? • What words, feelings or ideas come to mind when you think about CRC specifically? • Do you think you are more likely to get CRC cancer than other groups? o If yes, what makes you believe that you are more likely to get CRC o If no, what makes you believe that you are less likely to get CRC? • What can a person do to prevent getting CRC? What are some of the things you do to prevent getting CRC?	**Colorectal cancer impact on personal well being** Presence of impact Absence of impact Association with death Assessment of personal risk Assessment of prevention options **Awareness of screening recommendations** Presence of accurate awareness Absence of accurate awareness
What strategies do participants use to communicate with healthcare providers about colorectal cancer?	• What do you do to prepare to talk with your healthcare provider about CRC?	**Patient's personal accountability**

	• Have you heard about tests that people can take to find out whether they have CRC? o If yes, which types of screening tests have you heard about? o Have you talked with a healthcare provider about the screening test?	Patient engages in fact finding or research before MD/pt interaction Patient presents to MD/pt interaction with no pre-developed knowledge **Negative MD/Pt Interaction** Lack of advocacy for patient Lack of respect for patient Lack of informed and shared decision making **Positive MD/Pt interaction** Advocacy for patient Respect for patient Informed and shared decision making
What action intentions do participants have for utilizing colorectal cancer screening? a. How is this intention influenced by communication with healthcare providers?	2. Think back to the last time you meet with your health care provider: a. Were you referred to get a CRC screening exam? b. Did you get the exam? c. When do you plan to get the exam? What are reasons that make may or may not get the recommended exam?	**Information retention by patient** Present Type of information retained Absent **Screening recommendation to friends and family members** Present Type of recommendation

		provided to family and friends Absent

The next chapter will focus on four areas: 1) how the emergent themes fit with the existing literature; 2) on theories related to how participants perceive colorectal cancer and its causes; 3) the individual, social, systemic, and environmental level obstacles faced when considering and attempting colorectal cancer screening; and 4) the strategies they employed or deemed appropriate toward utilizing screening options.

CHAPTER 5

DISCUSSION

Colorectal cancer continues to rank as one the leading causes of cancer death in the United States on an annual basis. The majority of deaths are preventable through routine screening, beginning at the age of 50, as outlined and recommended in widely published clinical practice guidelines. The purpose of this research endeavor was to qualitatively examine how individuals over the age 50 perceive colorectal cancer and its causes, the individual, social, systemic, and environmental level obstacles faced when considering and attempting colorectal cancer screening as well as the communication strategies they employed or deemed appropriate toward utilizing screening options. This dissertation study used in-depth one-on-one interviews to collect data from individuals 50 years or older living in the greater metropolitan Atlanta, GA area.

Discussion of research findings

What knowledge and/or misconceptions do participants have or have heard from others about colorectal cancer and its screening?

Participants in this dissertation study reported knowledge of some known and widely reported risk factors for colorectal cancer. Family history and dietary habits were the most reported risk factors, followed by some mention of alcohol and tobacco consumption. These findings are consistent with the literature on colorectal cancer risk factor and screening knowledge among screening adherent patients (Palmer et al., 2007; Palmer, Midgette, &

Dankwa, 2008; Shah, Zhu, Palmer, & Wu, 2007). Participants also communicated an awareness and knowledge of colonoscopy and fecal occult blood test (FOBTs) as colorectal cancer screening options.

Of interest is that the screening knowledge of the participants is overall well-informed. None of the participants reported what might be considered misconceptions about screening. What is of particularly interest is finding that a significant number of participants in this study have a medical background (n=6). While that may lead to the assumption that they would know more about the screening process, the data do not reflect an intense knowledge of colorectal cancer risk factors nor the variety of screening options available. The later could be due to the fact that the American College of Gastroenterology has endorsed colonoscopy as the preferred colorectal cancer screening strategy (Doubeni et al., 2013); as such that is the screening of choice for physicians to discuss which in turn influences other medical professionals. In fact there is virtually no existing literature examining colorectal cancer knowledge among healthcare professionals beyond one study examining the limited knowledge physicians in training have about colorectal cancer screening guidelines for both average and high risk patients (Gennarelli et al., 2005).

What strategies do participants use to communicate with healthcare providers about colorectal cancer?

The participants in this study emphasized patient accountability in preparing for their encounter with their personal healthcare providers, particularly about colorectal cancer screening. Participants often referred to the fact that they actively engaged in advanced preparation for their face to face communication with their provider. This included researching questions to discuss with their healthcare providers and writing them down along with other

issues of concern they may have to bring to the appointment. The pattern of researching and going to the appointment with questions/concerns in hand fits in well with the patient willingness to communicate theory (WTC). WTC was reflected by the participants in their willingness to ask questions and to engage in a dialogue despite the differences in roles, status, or language (Baker & Watson, 2015).

Of particular note in the context of the findings of this study, research has found that the most consistent predictors of WTC are communication anxiety and perceived communication competence (Cao & Philp, 2006; MacIntyre et al., 2001). Communication anxiety is explained by McCroskey to be the anxiety associated with communication, either real or anticipated, with another person or group of people, which means that individuals anxious about communicating are less likely to choose to engage in communication (J. McCroskey, 1984). As mentioned previously, participants in this study emphasized advanced preparation by themselves (as patients) when contemplating upcoming healthcare provider communication. In the context of WTC, this would explain a desire to avoid communication anxiety during the actual face to face conversation. On the other hand, perceived communication competence refers to an individual's judgement that they will be able to communicate effectively. This subjective perception of competence ultimately determines the choice to communicate (Clément, Baker, & MacIntyre, 2003). While WTC can be thought of as the intention to initiate communication in a particular setting, there can be situations where this choice can be viewed as diminished. In the healthcare context, physicians are deemed to be in a high-status group and do not always convey a willingness to accommodate their patients' communication needs. This in turn can inhibit a patient's willingness to communicate (Baker & Watson, 2015). Of interest to this study is the

fact that a majority of participants reported that their physicians were open to their patients' communication needs and addressed their questions.

Participants in this study who engaged in screening reported they were driven to do so by a perceived positive physician-patient interaction where the patient feels respected, feels the physician acts as an advocate, and where the physician engages the patient in informed and shared decision making about screening options. By its very nature, the patient/provider interaction *is* interpersonal communication. One interaction-centered theory that guides an understanding of the data from this study is the communication accommodation theory. Communication accommodation theory (CAT) was developed by Giles and colleagues (Giles, 1973; Giles & Gasiorek, 2013) in an effort to explain language patterns that can emerge in intergroup encounters. CAT emerged as an attempt to describe how people use language to signify and negotiate personal and group identities in communicative contexts.

CAT is useful in the context of interpreting the findings of this study because the theory recognizes that participants enter an intergroup interaction with a social history (beliefs, values, and their own background), which can predispose participants to view the encounter in intergroup terms. Additionally, CAT helps to provide an understanding of the positive outcomes (i.e colorectal cancer screening utilization) reported by participants in this study who report a positive interaction with their healthcare providers.

What action intentions do participants have for utilizing colorectal cancer screening?

As discussed within the findings of this study, engaging in screening is driven by a perceived positive physician-patient interaction where the patient feels respected, feels the physician acts as an advocate, and most importantly the physician engages the patient in

informed and shared decision making about screening options. Several studies have indicated the importance of the recommendation of a physician in influencing a patient's colorectal cancer screening decision (Christy et al., 2013; O'malley et al., 2002; Schreuders et al., 2015; Zapka et al., 2002) . While the importance of a physician recommendation has been widely reported, it has been suggested that merely mentioning colorectal cancer screening is not enough to motivate all patients to be screened. To date, an optimal approach for making colorectal screening recommendations has not emerged. Additionally, current approaches to making colorectal cancer screening recommendations have not been widely examined in depth and documented.

Informed decision making as discussed by Wackerbarth, et al. (2007) is comprised of seven criterions. The first criterion of informed decision making involves discussing the patient's role in decision making. Another aspect is the discussion of the clinical issue or nature of the decision. This element involves coverage of the basic information – when, what, who, where, why, and how aspects – of the decision at hand. An example from the Wackerbarth, et al. (2007) study would involve a physician discussing colorectal cancer screening in the context with other preventive health issues in order to inform the patient about the procedure generally, and in relation to other potential more familiar procedures. Additional elements of informed decision making include: discussion of reasonable alternatives, discussion of the pros and cons of the alternatives, discussion of the uncertainties associated with the decision, assessment of patient's understanding, and exploration of patient preference (Wackerbarth et al., 2007). Considering that colorectal cancer screening provides a wide variety of testing options, a lack of inquiring about patient understanding is almost as detrimental as not presenting the patient with the screening options at all. It is also a missed opportunity for the physicians to explore the patients' health beliefs and cultural perspectives which in turn influence their health decisions about utilizing

colorectal cancer screening. Shared decision making requires a commitment from the physician and the patient in order to be successful. This seems to be in line with the findings of this study where participants reported that they obtained colorectal cancer screening because they felt engaged by their physicians in a shared decision making process where they had a sense of trust towards their physicians because of a sense of trust.

Further, findings of this study indicate that adherence to screening recommendation is further driven by the desire to avoid the experiences of family and friends who were diagnosed at a late stage with colorectal cancer. This can be explained well by considering the Preventive Health Model (PHM). When applied to the case of colorectal cancer screening, the process of preference clarification put forth by PHM may be understood as beginning at the point at which an individual becomes aware that she or he is at risk for the disease. Through individual initiative (patient's own research and question formulation, see section above regarding willingness to communicate) or actions of an outside information source (e.g., health care provider, family members' friends), she or he obtains additional information about the disease, the pros and cons of available cancer-screening tests (e.g., detection of disease when cure is possible, inconvenience of testing procedures), and available options (e.g., to screen or not to screen) (Myers, 2005). Preference clarification, which is central to informed decision making, occurs in everyday life as a self-regulation process. An understanding of the notion that a "good" choice is likely to be made when an individual is well informed and is provided an opportunity to actively consider personal values related to the decision-making situation is immensely useful in perpetuating a positive interaction between patients and physicians leading to a shared and informed decision making process.

Summary

This dissertation contributes to the clarification of the interaction of multiple personal and interpersonal factors on the decision to pursue colorectal cancer screening. The findings of this study elucidate the need to focus further research on the actual communication between patients and physicians about options for colorectal cancer screening; particularly from the patient perspective. As elucidated by this study, patients' willingness to communicate with their physicians is driven by their perception of their physicians' ability to accommodate and adjust their communication to their patients' needs. This can only occur when both patient and physician are willing to accommodate one another and engage in an informed and shared decision making process.

Strengths of the Study

This study has number of strengths that should be noted. Most importantly, the use of in-depth interviewing as a data collection tool allowed for rich and detailed information to be gathered on participants' knowledge about colorectal cancer and their utilization of screening options. This information may be used in future research to expand the understanding of the nature of communication between patients and physicians about colorectal cancer, its risk factors, and its screening options. Secondly, the use of open ended questions captured unique data by not restricting the response options and giving respondents complete freedom to describe their knowledge of CRC, their interactions with their physicians, and their future action intentions without external cures. Thirdly, this study recruited a significant number of participants who have a medical background. This is an often overlooked population that is rarely engaged in research that examines their own personal experiences as recipients of medical

advice. Finally, the participants in this study were an evenly represented mix of genders and races (African American and Caucasian).

Limitations of the Study

This study has its limitations considering the methodology selected for implementation. The information collected from participants was self-reported and subjective. Data that are self-reported can be biased based on individual perception of personal experiences, social norms, or even understanding of interview questions. Also, this study relied on retrospective accounts of patients' feelings about communication with their physicians. Such retrospective accounts can be clouded by current emotions and cannot be verified from the physician perspective. Only paired interviews could achieve such a thing. Information provided by participants regarding their own personal colorectal cancer screening utilization is confidential and there was no way to verify its accuracy. Additionally, participant perceptions of how they prepared for and handled their interaction with their physicians may be skewed; another factor that likely be elucidated via paired interviews. Because of the small sample size, the findings of this study are not representative of all individuals over the age of 50 with health insurance living in Atlanta, GA and so are not statistically generalizable.

Another limitation to consider is the lack of physicians as participants; particularly physicians who engage in recommending CRC screening to their patients. This study would have been stronger if the physician perspective of the CRC screening communication was explored as well. This would lend strength and more generalizability to study findings and recommendations. As a young researcher conducting the interviews with individuals who are at least seventeen years older or more, I may have encountered biases such as participants' sharing less information than with an older interviewer, or providing less than completely honest and truthful information.

Implications

Implications for Future Research

Since the findings of this study elucidated that the occurrence of a discussion between a patient and a healthcare provider increases the likelihood of compliance with CRC screening, it is would be enlightening to conduct a study evaluating the motivating factors and rationale for decision-making of physicians with regard to CRC screening recommendation. Additionally, a provider's recommendation of a specific test, particularly a colonoscopy, to the patient appears to prompt CRC screening utilization. As such, it would be useful to examine the motivating factors for physicians recommending particular screening methods over others (e.g colonoscopy vs. FOBT).

Participants in this study identified a positive relationship with their physician, defined by trust in his knowledge and recommendations as well as a sense of shared and informed decision making, to be the biggest motivator is utilizing CRC screening. Additional research should build on this study by looking at patients who do not have an established long standing relationship with a particular healthcare provider to ascertain how this vulnerable population can be engaged and persuaded to undergo CRC screening. This research should also be expanded to include other minorities, like Hispanics and Asian Americans, who were not represented in this study. These minority populations are growing rapidly in the Atlanta area and in the US overall and disparities exist in their access to quality healthcare (Agency for Healthcare Research and Quality, 2012).

Implications for Future Practice

This research has practical implications for healthcare providers and public health practitioners interested in further developing CRC screening utilization interventions and

awareness campaigns. The goal of interventions cannot be to solely focus on the patient behavior but to have a dual campaign that engages patients and physicians concurrently. For example, healthcare providers should check for patient understanding when using written and verbal information about CRC screening. Additional strategies can include presenting information about each cancer screening option more than once to ensure comprehension and to increase CRC screening intention. This study is an example of the positive outcome of the healthcare provider's continued engagement beyond just a verbal CRC screening recommendation.

Adherence to the recommendation is more likely to happen when the healthcare provider's office engage the patient in scheduling the next step, i.e the actual consult with gastroenterology leading to screening. Also, patient knowledge cannot be examined and measured in isolation without consideration of family history and experiences of close friends. A continued focus on the interpersonal level activities previously discussed in the context of the social ecological model is vital in understanding the role of family, friends and healthcare providers as sources of knowledge and support. While there have been significant strides in reducing the burden of CRC in our society today, for the men and women who still fight against CRC there is much research and clinical practice improvement to be done.

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APPENDIX A

Consent Form

UNIVERSITY OF GEORGIA
CONSENT FORM
Social Determinants of Colorectal Cancer Screening in an Urban Population

Researcher's Statement
We are asking you to take part in a research study. Before you decide to participate in this study, it is important that you understand why the research is being done and what it will involve. This form is designed to give you the information about the study so you can decide whether to be in the study or not. Please take the time to read the following information carefully. Please ask the researcher if there is anything that is not clear or if you need more information. When all your questions have been answered, you can decide if you want to be in the study or not. This process is called "informed consent." A copy of this form will be given to you.

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Purpose of the Study
Colorectal cancer (CRC) ranks as the third leading cause of cancer death in the United States. Survival from colorectal cancer is inversely related to stage of cancer and up to 90% of colorectal cancer deaths are preventable with early detection. This makes colorectal cancer ideally suited for early screening strategies which reduce colorectal cancer mortality through early detection. Due to the benefits that may be achieved by screening and its current documented underutilization, it is vital to establish a clear underrating of what factors predict screening adherence and what methods can be used to overcome barriers to, or facilitate completion of screening.

The purpose of this qualitative study is to learn from participants about their discussions with their health care providers about colorectal cancer, and how these discussions frame their subsequent actions including what their "action plan" post visit is.

Study Procedures
If you agree to participate, you will be asked to …
- *Answer general demographic questions that verify your eligibility for inclusion in the study*

- *Participate in a verbal tape recorded interview that is expected to take 45 minutes up to 90 minutes or longer depending on your responses.*

Risks and discomforts

It is expected that there are likely to be minimal risks associated with participating in the study. Possible risks include psychological risks such as feelings of discomfort or anxiety discussing the topic of colorectal cancer and screening method utilization associated with it.

Benefits
Although you may not benefit immediately or directly from participation in this study, your participation will be of benefit as it will help the study team identify misconceptions and barriers to the understanding of colorectal cancer and its screening and determine how these existing misconceptions or barriers affect intention to follow through with screening utilization.

Incentives for participation
You will receive a $25 store card of your choice (Either Kroger or Target) for a completed study visit and you will receive the store care even if you wish to skip interview questions. Once you have completed the interview then your participation in the study is complete.

Audio/Video Recording
Audio recording devices will be used to record interviews in this study. Recordings are necessary for this study so that written transcriptions of the conversations can be made. Upon completion of the analysis of the audio recordings and subsequent transcriptions, written transcripts will be retained for additional future analysis indefinitely.

Privacy/Confidentiality
Data that will be collected from you will include information that identifies you directly including your name and a contact phone number and indirectly (you will be assigned a participation identification number).
Whenever possible, a study number, rather than your name, will be used on study records. Your name and other identifying information will not appear when we present or publish the study results.

The project's research records may be reviewed by departments at the University of Georgia responsible for regulatory and research oversight.

Researchers will not release identifiable results of the study to anyone other than individuals working on the project without your written consent unless required by law.

Taking part is voluntary
Your involvement in the study is voluntary, and you may choose not to participate or to stop at any time without penalty or loss of benefits to which you are otherwise entitled.

If you decide to stop or withdraw from the study, the information/data collected from or about you up to the point of your withdrawal will be kept as part of the study and may continue to be analyzed.

If you are injured by this research
The researchers will exercise all reasonable care to protect you from harm as a result of your participation. In the event that any research-related activities result in an injury, the sole responsibility of the researchers will be to arrange for your transportation to an appropriate health care facility.

If you have questions
The main researcher conducting this study are Dr. Su-I Hou (professor) and Margret Kamel, MSPH, CCRC (graduate student) at the University of Georgia. Please ask any questions you have now. If you have questions later, you may contact Margret Kamel at mkamel@uga.edu or at 901-517-0981. If you have any questions or concerns regarding your rights as a research participant in this study, you may contact the Institutional Review Board (IRB) Chairperson at 706.542.3199 or irb@uga.edu.

Research Subject's Consent to Participate in Research:
To voluntarily agree to take part in this study, you must sign on the line below. Your signature below indicates that you have read or had read to you this entire consent form, and have had all of your questions answered.

_____	_____	_____
Name of Researcher	Signature	Date
_____	_____	_____
Name of Participant	Signature	Date

Please sign both copies, keep one and return one to the researcher.

APPENDIX B

Interview Guide

1. What does the term “cancer” mean to you?
2. What words, feelings or ideas come to mind when you think about CRC specifically?
3. Do you think you are more likely to get CRC cancer than other groups?
    a. If yes, what makes you believe that you are more likely to get CRC
    b. If no, what makes you believe that you are less likely to get CRC?
4. What can a person do to prevent getting CRC?
    a. What are some of the things you do to prevent getting CRC?
5. What do you do to prepare to talk with your healthcare provider about CRC?
6. Have you heard about tests that people can take to find out whether they have CRC?
    a. If yes, which types of screening tests have you heard about?
    b. Have you talked with a healthcare provider about the screening test?
7. Think back to the last time you meet with your health care provider:
    a. Were you referred to get a CRC screening exam?
    b. Did you get the exam?
    c. When do you plan to get the exam?
    d. What are reasons that you may or may not get the recommended exam?

APPENDIX C

Recruitment Flyer

ADULTS OVER THE AGE OF 50

NEEDED FOR RESEARCH STUDY ABOUT COLORECTAL CANCER

The Department of Health Promotion and Behavior at the University of Georgia is looking for adults who are over the age of 50 to participate in a research study.

The purpose of this study is to learn from participants about their discussions with their health care providers about colorectal cancer, and how these discussions frame their follow up actions.

Eligible adults must have be over the age of 50 and have 45 to 90 minutes of free time.

Study participants will:

- Complete a short eligibility and demographic survey
- Spend 45-90 minutes speaking with study investigator
- Be willing to allow discussion to be audio recorded

Payment for participation is $25.

Payment will be in the form of a store card to either Kroger or Target stores and will be presented to participants at the end of the interview session.

If interested in participating, please call Margret Kamel in the *Department of Health Promotion and Behavior* at 901-517-0981.