DEVELOPMENT AND TESTING OF THE

COLONOSCOPY EMBARRASSMENT SCALE

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Submitted to the faculty of the University Graduate School
in partial fulfillment of the requirements
for the degree
Doctor of Philosophy
in the School of Nursing,
Indiana University

April 2009

Accepted by the Faculty of Indiana University, in partial
fulfillment of the requirements for the degree of Doctor of Philosophy.

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ACKNOWLEDGEMENTS

I would like to thank Indiana University and the School of Nursing for giving me the opportunity to pursue doctoral studies at such a highly revered nursing school. I would like to acknowledge Dr. Roberta A. Smith, who supported my admission efforts and submitted a letter of recommendation on my behalf. I am grateful to those at the School of Nursing who admitted me and had confidence that I would successfully complete the program.

I want to thank Dr. Joanne Warner for bringing her vision of an online doctoral program at Indiana University School of Nursing to fruition. I would also like to extend appreciation to Dr. Daniel Pesut and Dr. Marion Broome for continued support of the program and for the necessary leadership to see plans through. I am grateful for the superior quality of the education I have received, and I want to thank each of the professors who have taught courses in the program. I have been impressed by your expertise and imprinted by your dedication to education and research.

I want to thank my Research Committee, Dr. Victoria Champion, Dr. Pamela Jeffries, and Dr. Janet Welch for their dedication to me and my dissertation research. I am grateful for their guidance, support, and for their research expertise. I am incredibly indebted to Dr. Susan Rawl for mentoring and advising me from the day she accepted me as her first doctoral student. It was from her that I first heard the saying, “Standing on the shoulders of giants”. She is indeed a giant. She has the knowledge, expertise, patience, and ability to be supportive in quantities that only a giant could have. I admire her accomplishments, her research knowledge, and the role model of professionalism that she

has been for me. I cannot imagine this journey without her, but it is difficult to thank someone when even the superlatives are inadequate.

I want to acknowledge the content experts who took time out of their busy schedules to offer their expertise when the Colonoscopy Embarrassment Scale was being developed. The content experts were Dr. Usha Menon, Dr. Rowland Miller, and Dr. Celette Skinner.

Thanks are in order for the typing that my sister-in-law, Laura Brewer did for me. Laura typed the cognitive interviews, which took many hours of her time.

I want to thank the librarians and library assistants at Saint Francis Medical Center College of Nursing, Peoria, IL who located articles and books that I was unable to obtain through online sources. Leslie Menz, Karl Gibson, and Justin Markle's dedication to procuring what I needed in such a timely fashion is greatly appreciated. I want to extend a special thanks to Leslie who seemed to receive the late night e-mails of desperation and responded so diligently and who continues to spontaneously send me information on colorectal cancer. I also want to thank Leslie for sharing her extensive knowledge of APA format with me. Karl is to be commended for superb management of this library.

In addition, I want to thank the administration of Saint Francis Medical Center College of Nursing, especially Dr. Lois Hamilton, for support in this endeavor. I am grateful for the significant financial support as well as smaller acts of support such as the use of copying services. I am also appreciative of the sabbatical that I was granted in order to finish data collection and begin writing. Thanks are also in order for Dr. Patricia Stockert's emotional support as well as for her time and patience while sharing her

knowledge of statistics. In addition, I want to thank to Dr. Janice Boundy for her support of research at the College of Nursing.

I am grateful to my colleagues who adjusted their workloads in order for me to take a sabbatical. Thanks to Rebecca Vaughn, Nancy Bailey, Peggy Jacques, Keli Briggs, and Lois Bentler-Lampe for making the sabbatical possible.

I want to acknowledge Sue Brown and Theresa Hoadley who set out on the doctoral degree journey within the same time frame as me. Both have been supportive and encouraging. Although we were not at the same university, we were kindred spirits as we negotiated each curve and bump in the road to a doctoral degree.

I would like to acknowledge my cohort who has been a rich source of emotional support. Thank you for the timely phone call, e-mails, and hugs. A special thanks to Wanda Robinson who is a world class paper "critiquer" and to Pat Mullen for words of wisdom and support. Thanks also to Cynthia Maskey, Cindy Reese, Beth Johnson, and Mary Spath for listening and for your support. I am also grateful to Julie Elam for keeping the distance students informed and for forwarding information. Thanks are also in order for the first cohort of distance students, the pioneers who made the path smoother for each cohort to follow.

I am forever grateful to OSF Health Plans for allowing me to survey their patient population. I am especially grateful to Kathy Stolz, RN for her quick response to numerous e-mails resulting in my ability to continue making progress. I also want to thank Kanika Brown for placing address labels on over 1000 mailings in a very prompt fashion.

I am grateful to the Nursing 2000 Scholarship Fund for the scholarship I was awarded. I am also thankful for the Education Enhancement Grant that provided financial resources for postage costs.

Lastly, but certainly, not least, I want to acknowledge my immediate family who has been supportive beyond words. I have a debt of gratitude to my husband, Steve, who made incalculable technical rescues, provided numerous shoulder tension massages, and patience, especially when I was not being patient. He was also ready with tissues and hugs through each crisis along the way. I want to thank him for reading draft after draft of technical, complex material. I am grateful for his feedback and deftness with the "green hornet". I want to thank my children, Tom and Sarah, for their undying support and cheerleading. I also want to thank them for waiting "just a little bit longer" until I could finish one "last" task and for their computer savvy.

In truth, I could not have earned this degree with out each and every person mentioned. I am grateful to all for their help.

ABSTRACT

Kimberly Ann Mitchell

DEVELOPMENT AND TESTING OF THE COLONOSCOPY EMBARRASSMENT SCALE

Colorectal cancer (CRC), the third leading cause of cancer-related death in the U.S., could largely be prevented if more people had polyps removed via colonoscopies. Embarrassment has been identified as one important barrier to colonoscopy, but little is known about embarrassment in this context. Further, there is no instrument available to measure this construct. Therefore, the purpose of this study was to develop a reliable and valid instrument to measure colonoscopy-related embarrassment. The study aims were to: 1) estimate reliability and validity of a new instrument, the Colonoscopy Embarrassment Scale (CES); 2) examine relationships among demographic/personal characteristics, health beliefs, and CES scores; 3) examine relationships among demographic/personal characteristics, physician recommendation, health beliefs, and colonoscopy compliance; and 4) evaluate participants' perceptions of aspects of having a colonoscopy that are most embarrassing and their suggestions for reducing embarrassment.

The Health Belief Model and Transtheoretical Model of Change provided theoretical support for this study. Participants were HMO members aged 50-65 years (n=234). Using a cross-sectional, descriptive research design, data were collected using a mailed survey. The response rate was 56%. Data were analyzed using independent samples t-tests, correlations, Chi Square, and regression. Results showed that the six-item CES had internal consistency (Cronbach's alpha of .89) and construct validity. Lower

income, higher BMI, lower CRC knowledge, higher barriers, and lower self-efficacy were related to higher CES scores (or more embarrassment). Higher CRC knowledge, lower barriers, higher self-efficacy, and a physician recommendation for the test were related to higher compliance with colonoscopy. Lower barriers, higher self-efficacy, and a physician recommendation were predictive of compliance with colonoscopy. In conclusion, embarrassment is a significant barrier to colonoscopy, yet there are steps that can be taken to reduce embarrassment such as increasing privacy and limiting bodily exposure. The CES is a tool that can be used to measure colonoscopy-related embarrassment and the results could be used in developing further interventions to reduce embarrassment, leading to increased colonoscopies and lower mortality.

Susan M. Rawl, PhD, RN, Chair

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CHAPTER ONE

THE NATURE OF THE STUDY

Problem

Colorectal cancer (CRC) is the third leading cause of death related to cancer in both men and women. Colorectal cancer is projected to kill 49,960 people in 2008 (Jemal et al., 2008). In addition, 108,070 cases of colon cancer and 40,740 cases of rectal cancer are expected to be diagnosed in 2008.

The presence of adenomatous polyps in the colon is thought to be a precursor to cancerous lesions (Morson, 1984; Winawer et al., 1993; American Cancer Society [ACS], 2007). Therefore, experts recommend removal of adenomatous polyps before they become a problem since early diagnosis and removal improves survival. Statistics gathered from 1995-2001 show that the 5-year survival rate for CRC diagnosed when the lesion was localized was 90% (Surveillance, Epidemiology and End Results [SEER] Program, 2003).

There are seven different methods of screening for CRC available for average risk individuals, but a colonoscopy is considered the "gold standard" (Levin et al., 2008; ACS, 2005). Individuals 50 years old or older who have no other risk factors are considered to be at *average risk* for CRC, whereas those with a personal history of CRC or adenomatous polyps, inflammatory bowel disease, a family history of CRC, or one of two inherited genetic mutations are considered higher risk (Smith, Cokkinides, & Brawley, 2008).

While sensitive CRC screening tests are available, many individuals are not getting needed screening even if they are at increased risk for the disease. Experts recommend that average risk individuals begin screening at age 50 (Smith, Cokkinides, &

Eyre, 2005; Winawer et al., 2003; ACS, 2005). Data from the 2006 Behavioral Risk Factor Surveillance System indicate that less than 25% of people 50 years or older reported having an FOBT in the past two years and less than 60% reported ever having had a sigmoidoscopy or colonoscopy (Centers for Disease Control [CDC], 2006). It is estimated that 76-90% of CRC could be prevented with the identification and removal of adenomatous polyps via colonoscopies (Winawer et al., 1993).

Research showed that higher barriers were associated with lower compliance with CRC screening in general (Gorin, 2005; Janz et al., 2003; Frank, Swedmark, & Grubbs, 2004; Manne et al., 2002) including endoscopic screening methods specifically (Janz et al.; Brenes & Paskett, 2000; James et al. 2002). Although there are many barriers to compliance with colonoscopy, one important barrier is embarrassment (Harewood et al., 2002; Kelly & Shank, 1992; Nelson & Schwartz, 2004; Lewis and Jensen, 1996; Denberg et al., 2005; Janz et al., 2003; Stockwell et al., 2003; Gipsh et al., 2004; Walsh et al., 2004; Codori et al., 2001; Rawl et al., 2004; Wardle et al., 2003 Nicholson & Korman, 2005; Busch, 2003). In fact, this was the barrier most often mentioned by first-degree relatives of CRC survivors (Rawl, Menon, Champion, Foster, & Skinner, 2000). In other studies (Janz et al.; Gipsh et al., 2004), participants identified embarrassment as the second most common reason for not getting a colonoscopy *(no need* 40%, *embarrassing* 35%, *anxiety* 32%, *pain* 28%, and *fear of injury* 11%). Green and Kelly (2004) found that 73.8% of African Americans identified embarrassment as a barrier. Additionally, Codori et al. found that embarrassment was the only barrier that differentiated individuals who had had an endoscopic exam from those who had not ($p<.0001$).

Some of the other barriers to endoscopic screening include discomfort, distaste, worry (Gipsh, Sullivan, & Dietz, 2004), fear of cancer (Gorin, 2005), and objection to the bowel preparation (Harewood et al., 2002; Gipsh, et al., 2004; Greisinger, Hawley, Bettencourt, Perz, & Vernon, 2006). Moreover, lack of physician recommendation for colonoscopy is the most common reason many individuals are not compliant with colonoscopy (Harewood, Wiersema, & Melton, 2002; Klabunde, Schenck, & Davis, 2006; Rawl et al., 2004; Tessaro, Mangone, Parkar, & Pawar, 2006; Brenes & Paskett, 2000; Codori, Peterson, Miglioretti, & Boyd, 2001; Gilbert & Kanarek, 2005; Honda, 2004; James, Campbell, & Hudson, 2002; Janz, Wren, Schottenfield, & Guire, 2003; Menon et al., 2003; Teng, Freidman, & Green, 2006; Rios, Reimann, Talavera, Esparza, & Talavera, 2006).

Strides have been made to reduce the impact of some barriers such as pain and aversion to the bowel preparation. For example, sedation is often given to address concerns about pain, and the newer bowel preparations are more palatable. However, embarrassment as a barrier to a colonoscopy has not been studied in-depth and therefore little is known. Anticipated embarrassment is a barrier that is conceivably modifiable. Aside from acknowledging that embarrassment in some individuals may be reduced by having an endoscopist of the same gender, little has been done to address embarrassment as a barrier to colonoscopy (Menees, Inadomi, Korsnes, Grace, & Elta, 2005).

By determining aspects of having a colonoscopy that contribute to embarrassment, interventions could be developed to reduce or eliminate embarrassment related to this lifesaving test so that more individuals would get screened resulting in decreased morbidity and mortality from CRC. However, there was no instrument

available to measure this construct. Thus, the purpose of this study was to develop a reliable and valid instrument to measure colonoscopy-related embarrassment. Therefore, the aims of this study were to 1) estimate reliability of new instrument, the Colonoscopy Embarrassment Scale (CES), among men and women aged 50-64 years old; 2) estimate validity of the CES among men and women aged 50-64 years old; 3) examine relationships among demographic/personal characteristics, health beliefs, and colonoscopy embarrassment scores; 4) examine relationships among demographic/personal characteristics, health beliefs, physician recommendation, and colonoscopy compliance; and 5) evaluate participants' perceptions of aspects of having a colonoscopy that are most embarrassing and participants' suggestions for reducing embarrassment.

Background and Significance

In this section, the background and significance of the problem of low rates of screening resulting in inadequate detection of CRC and factors that may partially explain this phenomenon will be discussed. Identifying these factors is important because death may result if adenomatous polyps are not identified and removed.

Colorectal Cancer

Colorectal cancer is preceded only by lung and breast cancer in women, and lung and prostate cancer in men, as the greatest cancer-related cause of death (ACS, 2008). Men are more likely to be diagnosed with and die from CRC than women. The incidence of CRC per 100,000 is 61.7 for men and 45.3 for women and the mortality rate is 24.0 and 16.8 respectively. Additionally, 1 of 18 men and women will be diagnosed with CRC in their lifetimes (SEER, 2003).

Adenomatous polyps of the colon are thought to transform into cancerous lesions over time (Morson, 1984; Winawer et al., 1993; ACS, 2008). A polyp is a protruding growth from a mucous membrane; an adenomatous polyp is a polyp with epithelial dysplasia. The adenomatous polyp can metastasize only after it crosses into the muscularis mucosae even though it has the characteristics of an adenocarcinoma (Morson). Therefore, a polypectomy before an adenomatous polyp has advanced into the muscularis mucosae has prevented a potentially lethal cellular transformation. However, if CRC has spread to the lymph nodes in the region, the five-year survival rate is 68% and if the cancer has metastasized to a distant area, the five-year survival rate is 10% (SEER, 2003). About 39% of CRC cases are diagnosed while the cancer is still confined to the primary site (localized), 37% are diagnosed after the cancer has spread to the region directly beyond the primary site, 19% are diagnosed after the cancer has already metastasized to distant areas of the body, and for the remaining 5%, the staging information was unknown (SEER).

CRC Screening Tests and Guidelines

Seven different methods of screening for CRC are available and recommended for individuals with average risk for CRC, but the time interval at which each test should be done varies. The test and the recommended intervals between testing are as follows: 1) annual guiac-based fecal occult blood test (FOBT), 2) annual fecal immunochemical test, 3) stool DNA (uncertain frequency), 4) flexible sigmoidoscopy every five years, 5) double-contrast barium enema every five years, 6) computed tomographic colonography every five years or, 7) colonoscopy every 10 years (Smith, Cokkinides, & Brawley, 2008; Levin et al., 2008). Until the 2008 guidelines were released, there were five CRC

screening tests recommended; computed tomographic colonography tests and stool DNA are the two new tests (U.S. Preventive Services Task Force, 2006). The colonoscopy is considered the superior CRC screening test because the rectum and entire colon are examined and suspicious tissue can be removed in one procedure. Also, the sensitivity is greater for this test (ACS, 2008).

Inadequate use of the Effective CRC Screening Tests

Effective CRC screening tests are available, but individuals are not getting screened. Experts recommend that average risk individuals begin screening at age 50 (Ahluwalia, Mack, Murphy, Mokdad, & Bales, 2003; Smith et al., 2005; Winawer et al., 2003; ACS, 2008) since statistics show that 91% of the new diagnoses and 94% of the mortality related to CRC occurs in individuals older than 50 years (ACS, 2005). Data from the 2006 Behavioral Risk Factor Surveillance System showed that only 24.2% of people 50 years or older have had FOBT in the last two years and 57.1% reported ever having had a sigmoidoscopy or colonoscopy (CDC, 2006).

Factors related to CRC Screening

A considerable body of literature exists that has explained factors related to participation in CRC screening in general, particularly FOBT. Less is known about factors related to obtaining a colonoscopy since colonoscopy has only recently been considered a screening, rather than a diagnostic, test.

Demographic Characteristics

Several demographic characteristics have been related to compliance to CRC screening. Older age has been associated with higher CRC screening participation (Denberg et al., 2006; Seeff et al., 2004; Liang, Phillips, Nagamine, Ladabaum, & Haas,

2006; Tessaro et al., 2006; Weinberg et al., 2004; Codori et al., 2001; Denberg et al., 2005; James et al., 2002; Gorin & Heck, 2005; Honda, 2004; Walsh et al., 2004).

Women were more likely to get FOBT (McQueen, Vernon, Meissner, & Klabunde, 2006), whereas men were more likely to get endoscopic CRC testing (Seeff et al., 2004; Tessaro et al., 2006; Lemon, Zapka, Puleo, Luckmann, Chasa-Tabor, 2001; Codori et al., 2001; Slattery, Kinney, & Levin, 2004; McCarthy & Moskowitz, 1993; Denberg et al., 2005; Gilbert & Kanarek, 2005; Segnan et al., 2005; Gorin & Heck, 2005; Green & Kelly, 2004). In general, higher incomes were associated with higher levels of CRC screening (Hsia et al., 2000; Seeff et al., 2004; Gilbert & Kanarek, 2005; Bostick, Sprafka, Virnig, & Potter, 1994; Kelly & Shank, 1992). Most studies showed that being married was not associated with higher rates of CRC compliance (Hay et al., 2003; Bostick et al.; Kelly & Shank, 1992; Lewis & Jensen, 1996; Slattery et al., 2004; Brenes & Paskett, 2000; Denberg et al., 2005; Menon et al., 2003).

CRC Knowledge

Greater CRC knowledge has been found to be positively related to CRC screening (Menon et al., 2003; Seeff et al., 2004; Tessaro et al., 2006; Klabunde et al., 2006; Green & Kelly, 2004).).CRC knowledge is considered cognitive information about CRC risk factors, screening, and prevention (Rawl et al., 2006),

Physician Recommendation

Several factors prompt individuals to make behavior changes. Having a physician recommend a colonoscopy is the most common reason many individuals are compliant with colonoscopy (Harewood, Wiersema, & Melton, 2002; Klabunde, Schenck, & Davis, 2006; Rawl et al., 2004; Tessaro, Mangone, Parkar, & Pawar, 2006; Brenes & Paskett,

2000; Codori, Peterson, Miglioretti, & Boyd, 2001; Gilbert & Kanarek, 2005; Honda, 2004; James, Campbell, & Hudson, 2002; Janz, Wren, Schottenfield, & Guire, 2003; Menon et al., 2003; Teng, Freidman, & Green, 2006; Rios, Reimann, Talavera, Esparza, & Talavera, 2006.

Beliefs

Self-efficacy.

Most studies showed that higher self-efficacy was predictive of greater CRC screening (Friedman, Everett, Peterson, Ogbonnaya, & Mendizabal, 2001; Menon, Belue, Skinner, Rothwell, & Champion, 2007; Hay et al., 2003). Self-efficacy is defined as "the conviction that one can successfully execute the behavior required to produce the outcome" (Bandura, 1977, p. 193)

General barriers to colonoscopic examination.

Although colonoscopies are an effective means of preventing CRC, individuals report many barriers to the test. Studies found that higher barriers were associated with lower compliance with CRC screening (Gorin, 2005; Janz et al., 2003; Frank et al., 2004; Manne et al., 2002) including endoscopic screening methods (Janz et al.; Brenes & Paskett, 2000).

Barriers included embarrassment (Honda & Gorin, 2005; Janz et al., 2003; Green & Kelly, 2004; Bastani, Gallardo, & Maxwell, 2001; Frank et al., 2004; Rawl et al., 2000, 2004; Tessaro et al., 2006; Beeker, Kraft, Southwell, & Jorgensen, 2000; Greisinger et al., 2006; Nelson & Schwartz, 2004; Lewis and Jensen, 1996; Denberg et al., 2005; Harewood et al., 2002; Kelly & Shank, 1992; Stockwell et al., 2003; Busch, 2003; Gipsh et al., 2004; Walsh et al., 2004; Codori et al., 2001; Nicholson & Korman, 2005; Wardle

et al., 2003) as well as discomfort, distaste, inconvenience, and worry (Gipsh et al., 2004). Additionally, anxiety about the procedure (Janz et al., 2003), fear of endoscopic testing (Farrye et al., 2004), fear of cancer (Gorin, 2005) difficulty scheduling appointments, and lack of knowledge (Green & Kelly, 2004; Harewood et al., 2002; Klabunde et al., 2006; Tessaro et al., 2006) were identified as barriers. The cost of the test (Greisinger et al., 2006; Harewood et al., 2002), concern about pain (Green & Kelly, 2004; Harewood et al., 2002; Janz et al., 2003; Rawl et al. 2004), and objection to the bowel preparation (Harewood et al., 2002; Gipsh, et al., 2004, Greisinger et al.) were also stated as reasons for not getting a colonoscopy. In addition, no perceived need (Janz et al.; Rawl et al., 2004; Tessaro et al.), messiness (Dolan et al., 2004), and for females, the lack of female endoscopists (Menees et al., 2005) were reported barriers.

Embarrassment as an important barrier to colonoscopy.

The barrier that was of primary interest in this study is embarrassment. Embarrassment was conceptually defined as an emotion associated with "a sudden and intense but temporary uneasy, awkward, self-conscious, exposed feeling that could be strong or weak, ranging from mild awkwardness or uneasiness and uncertainty to strong sensations of incapacitation, blushing and a desire to escape" (Miller, 1992, p. 192). Embarrassment has been found to be negatively related to completion of CRC screening tests (FOBT, sigmoidoscopy, or colonoscopy) (Honda & Gorin, 2005; Janz et al., 2003; Green & Kelly, 2004; Bastani et al., 2001; Frank et al., 2004; Rawl et al., 2000; Tessaro et al., 2006; Beeker et al., 2000; Greisinger et al., 2006) and also to endoscopic screening tests specifically (Nelson & Schwartz, 2004; Lewis and Jensen, 1996; Denberg et al., 2005; Harewood et al., 2002; Kelly & Shank, 1992; Janz et al., 2003; Stockwell et al.,

2003; Busch, 2003; Gipsh et al., 2004; Walsh et al., 2004; Codori et al., 2001; Rawl et al., 2004; Nicholson & Korman, 2005; Wardle et al., 2003). The percentage of participants who identified embarrassment related to colonoscopy ranged from 7% in a sample of Australians (Nicholson & Korman, 2005; Kelly & Shank, 1992) to 75% among African Americans (Green & Kelly, 2004).

Modigliani (1968) was the first to examine, in depth, a concept related to embarrassment, which he called embarrassability or "general susceptibility to embarrassment" (p. 316). He studied individual responses to embarrassing situations including *pratfalls* (humiliating blunders), an *inadequate response to an unanticipated occurrence, being the center of attention, observing someone else in an embarrassing situation,* and an *incident involving the opposite gender that is out of the norm*, such as a woman walking into the men's restroom. Modigliani found embarrassability was highly correlated with feelings of inadequacy. In addition, Edelman's work (1985) showed that embarrassment was associated with public self-consciousness and a desire to conform to others.

Miller (1996) described several different "categories" (p. 52) of embarrassment including *awkward interactions*, *failure of privacy regulation* (private thoughts, actions, or anatomy made public), *undue sensitivity* (overreacting to ordinary situations that typically produce only mild awkwardness), *loss of control over body* (inadvertent inability to restrain a bodily function), and *departure from personal goals* (behavior or appearance that is incongruous with one's own standards or expectations). It is possible that some of these categories are operating in the context of having a colonoscopy.

Studies have also shown that individuals try to avoid embarrassment (Foss & Crenshaw, 1978; Brown & Garland, 1971; Parrott & Smith, 1991). The psychology literature was helpful in understanding embarrassment, but more studies need to be conducted in the context of healthcare (cancer screenings in particular) and in populations other than undergraduate students.

Gaps in Knowledge

This study was designed to address specific gaps that were identified in the literature that will inform our understanding of factors related to embarrassment and compliance with colonoscopy. However, numerous gaps in knowledge were found in the literature related to the variables of interest in this study. For example, there are many studies that have identified embarrassment as a barrier to colonoscopy, but few that discussed the relationship of demographic variables and colonoscopy-related embarrassment. No studies were found that examined relationships between income levels and embarrassment. Only one study investigated the relationship between education level and embarrassment, and the sample for this study only included one ethnic group-Japanese Americans (Honda & Gorin, 2005).

In addition, just one study was found regarding embarrassment as related to marital status, and this study was limited to a sample of U.S. veterans living with an intestinal ostomy (Mitchell et al., 2007). Data relating educational levels and completion of endoscopic CRC screening were equivocal and without a clear relationship (Hsia et al., 2000; Seeff et al., 2004; Manne et al., 2002; Bostick et al., 1994; McCarthy & Moskowitz, 1993; Slattery et al., 2004; Gorin and Heck, 2005; Kelly & Shank, 1992; Lemon, et al., 2001; Menon et al., 2003; Hay et al., 2003; Lewis & Jensen, 1996; Brenes

& Paskett, 2000). Additionally, the studies examining personal characteristics, such as body mass index (BMI), and its relationship to embarrassment and compliance to endoscopic CRC screening guidelines showed no consistent findings (Ferrante, Strickland, Hudson, Hahn, Scott, & Crabtree, 2006; Rosen & Schneider, 2004; Menis et al., 2006; Ata et al., 2006; Slattery et al., 2004).

Inadequacy of Available Instruments to Measure Embarrassment

While no instrument was found in the literature that measured embarrassment related to colonoscopy, two instruments were found that measured embarrassability. One instrument, the Embarrassability Scale, measured embarrassability in the context of specific social situations such as a man inadvertently walking into the women's bathroom (Modigliani, 1968). The second instrument, the Susceptibility to Embarrassment Scale, measured embarrassability with personality trait-based statements such as *I feel unsure of myself* or *I don't like being in crowds* (Kelly & Jones, 1997).

Limitations of both the Embarrassability Scale and the Susceptibility to Embarrassment Scale were that 1) neither instrument assessed embarrassability in the context of a medical procedure, such as colonoscopy, and 2) the instruments were developed using undergraduate students as the subjects in the studies (Miller, 1987, 1992, 1995; Maltby & Day, 2000; Kelly & Jones, 1997). Therefore, this study was designed to develop and test an instrument that measured the construct of embarrassment related to colonoscopy in age appropriate individuals for whom the test is commonly ordered.

Theoretical Foundation

The theoretical foundation for this study consisted of two conceptual models; the Health Belief Model (Rosenstock, Stretcher, & Becker, 1988; Becker, 1978; Rosenstock,

1966) and the Transtheoretical Model of Behavior Change (Prochaska & Velicer, 1997). The Health Belief Model (HBM) is a theory frequently used to guide research seeking to gain an understanding about the likelihood that people would prevent, screen for, or control an illness. The model hypothesizes that health behaviors depend on the simultaneous occurrence of the following factors. One factor is that the individual's sense of vulnerability to an illness (perceived susceptibility) and a second is that the person recognizes the potential threat to their health (perceived seriousness). A third factor, self-efficacy, is the confidence an individual has that he/she could take the recommended action. A fourth factor is the belief that certain actions are advantageous (perceived benefit) and a fifth factor is that specific obstacles must be overcome in order to take action (perceived barriers). The model postulates that the individual must feel susceptible to an illness personally perceived as serious and the benefits of action must outweigh the barriers in order for a behavior change to take place. The sixth factor is called *cue to action,* which is a trigger that stimulates behavioral change, and an example of a cue to action would be a physician recommendation for a cancer screening test (Robinson & Kish, 2001).

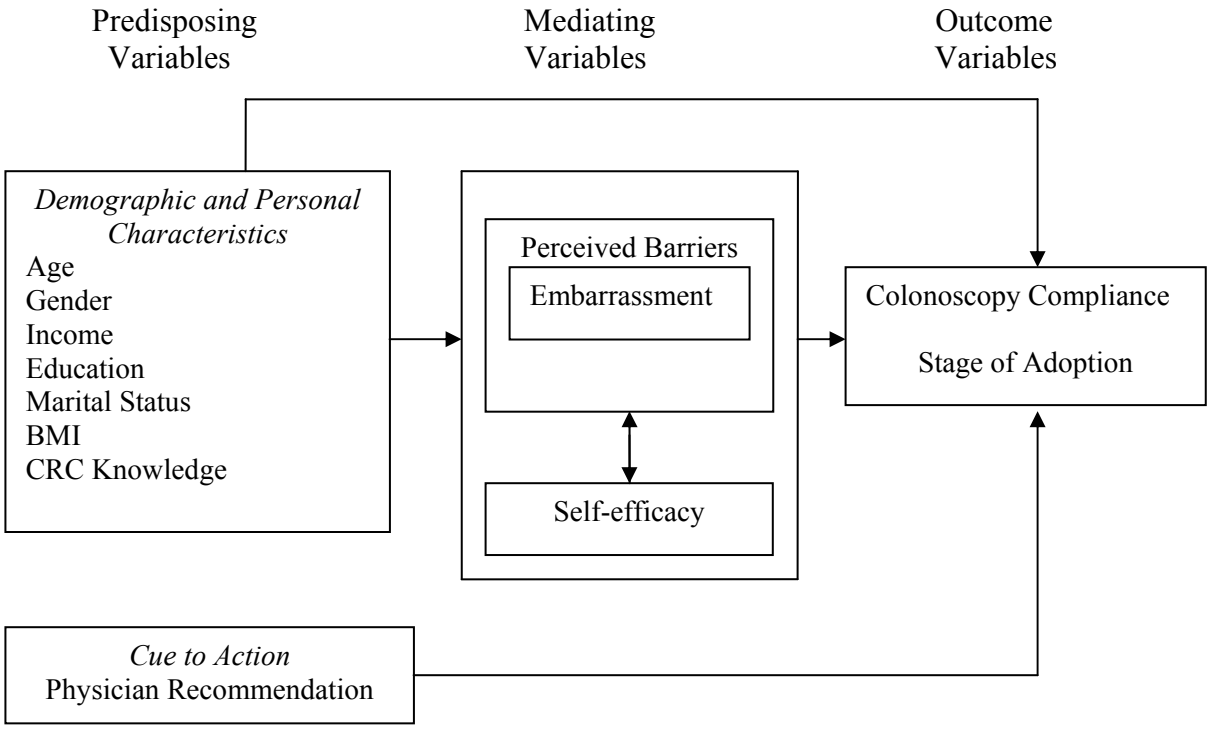
Not all constructs of the HBM were investigated in this study. Perceived seriousness and perceived benefits were not included because it is generally agreed that CRC is a serious disease and that CRC screening is beneficial. Since the focus of this study was embarrassment, a barrier to colonoscopy, perceived susceptibility was not incorporated in the model. However, perceived susceptibility many be important in predicting compliance with colonoscopy and could be assessed in future studies.

The Transtheoretical Model of Behavior Change (TTM) was also used in this study. The TTM posits four stages of change and a maintenance phase (Prochaska & Velicer, 1997). The four stages are: precontemplation (no intent to change), contemplation (thinking about changing but has no plans to get tested in the next six months), and preparation (intent to take action in the next six months), and action (behavior change occurs). The theory takes into account that the change in stages happens over time. In another aspect of the model, decisional balance, the individual weighs the pros and cons of making the behavior change. The balance of the pros to cons increases as the individual advances through the stages. For example, the individual in the precontemplation stage has far more cons than the individual in the action stage. The process of changing the balance of pros and cons is mediated by activities such as *consciousness-raising*, *self-evaluation*, *self-liberation*, and *helping relationships* (Prochaska & Velicer). As the process continues, individuals progress to a higher level of change.

Conceptual Framework

Based on important concepts from the HBM and TTM and a comprehensive review of the literature, a conceptual framework was specifically designed to guide this study (see Figure 1). The predisposing variables were comprised of demographic information including age, gender, income, education, and marital status as well as personal characteristics such as BMI and CRC knowledge. The other predisposing variable was a cue to action, physician recommendation. The mediating variables were perceived barriers, embarrassment, and self-efficacy. In addition to compliance with colonoscopy, the other outcome variable was stage of adoption.

Figure 1. Conceptual Framework.



Purpose

Little was known about embarrassment as a barrier to participating in invasive medical procedures such as colonoscopies. By determining the aspects of having a colonoscopy that contribute to embarrassment, interventions could be developed to reduce or eliminate embarrassment related to this lifesaving test so that more individuals would get screened and morbidity and mortality could be reduced. However, there was no instrument available to measure this construct. Therefore, the aims of this study were to 1) estimate reliability of a new instrument, the Colonoscopy Embarrassment Scale (CES), among men and women aged 50-64 years old; 2) estimate validity of the CES among men and women aged 50-64 years old; 3) examine relationships among demographic/personal characteristics, health beliefs, and CES scores; 4) examine relationships among demographic/personal characteristics, health beliefs, physician

recommendation, and compliance with colonoscopy; and 5) evaluate participants' perceptions of aspects of having a colonoscopy that are most embarrassing and participants' suggestions for reducing embarrassment.

Aims, Hypotheses, and Research Questions

Aim 1) Estimate reliability of the Colonoscopy Embarrassment Scale among men and women aged 50-64 years old.

H1: *The Colonoscopy Embarrassment Scale will demonstrate adequate internal consistency reliability with a Cronbach's alpha of at least .70 (Nunnally & Bernstein, 1994).*

Aim 2) Estimate validity of the Colonoscopy Embarrassment Scale among men and women aged 50-64 years old.

H2: *The Colonoscopy Embarrassment Scale will show evidence of construct validity as a unidimensional scale through principal components analysis.*

H3: *Construct validity of the CES will be demonstrated by lower CES scores in participants who are compliant with colonoscopy compared to participants who are not compliant.*

H4: *Construct validity of the CES will be supported by lower CES scores in participants at more advanced stages of adoption compared to participants at less advanced stages.*

Aim 3) Examine relationships among demographic/personal characteristics (BMI and CRC knowledge), health beliefs (perceived barriers and perceived self-efficacy), and Colonoscopy Embarrassment Scale scores.

Research Question 3.1: *Among men and women aged 50-64 years old, what are the relationships among demographic/personal characteristics (BMI and CRC knowledge) and CES scores?*

Research Question 3.2: *Among men and women aged 50-64 years old, what are the relationships among health beliefs (perceived barriers and perceived self-efficacy), and CES scores?*

Research Question 3.3: *Among men and women aged 50-64 years old, what variables are predictive of CES scores?*

Aim 4) Examine relationships among demographic/personal characteristics (BMI and CRC knowledge), health beliefs (perceived barriers and perceived self-efficacy), physician recommendation, and compliance with colonoscopy among men and women aged 50-64 years old.

Research Question 4.1: *What are the differences in demographic characteristics, BMI, and CRC knowledge scores in men and women 50-64 years old who are compliant with colonoscopy and those who are not?*

Research Question 4.2: *What are the differences in perceived barriers and self-efficacy in men and women 50-64 years old who are compliant with colonoscopy and those who are not?*

Research Question 4.3: *What are the differences in proportions of compliance with colonoscopy in men and women aged 50-64 years old who have received a physician's recommendation for colonoscopy and those who have not?*

Research Question 4.4: *Among men and women aged 50-64 years old, what variables are predictive of compliance with colonoscopy?*

Aim 5) Evaluate participants' perceptions of aspects of having a colonoscopy that are most embarrassing and participants' suggestions for reducing embarrassment.

Research Question 5: *What aspects of having a colonoscopy do men and women 50-64 years old report are the most embarrassing?*

Research Question 6: *What suggestions do men and women 50-64 years old offer for making the colonoscopy less embarrassing?*

Significance to Nursing

This descriptive study is important and necessary to nursing because embarrassment has been shown to be an important barrier to screening for CRC, the third most common type of cancer. Additionally, CRC is largely preventable if adenomatous polyps are removed. However, prior to this study, little was known about the degree of influence embarrassment had on compliance with colonoscopy, components of the test that were related to embarrassment, and which aspects of having a colonoscopy were most embarrassing. Research was needed to examine relationships among age, gender, income, education level, marital status, BMI, CRC knowledge, physician recommendation, barriers (specifically embarrassment), self-efficacy, and compliance with colonoscopy. By developing and testing an instrument to assess aspects of a having a colonoscopy that were associated with embarrassment, nurses could identify individuals

who are embarrassed by the prospect of a colonoscopy as well as their potential sources of embarrassment. Nurses could then test interventions, such as patient education and counseling, to alleviate or reduce embarrassment so that more individuals get screened, thereby resulting in reduced morbidity and mortality from CRC.

Variable Definitions

Dependent Variables

Colonoscopy Compliance

Conceptual definition. The participant had a screening colonoscopy within the last 10 years.

Operational definition. Colonoscopy compliance was confirmed by a self-reported dichotomous yes/no item, and a second item asking if the colonoscopy was within the last 10 years or more than 10 years ago (Rawl et al., 2006; Montano & Phillips, 1995; King, Rimer, Trock, Balshem, & Engstrom, 1990). The status of the colonoscopy as a screening colonoscopy was determined by current procedural terminology (CPT) billing codes.

Stages of Adoption

Conceptual definition. The four stages of adoption are *precontemplation, contemplation, preparation*, and *action. Precontemplation, contemplation,* and *preparation* apply to an individual who was not compliant with colonoscopy (had not had a colonoscopy within the last 10 years). In precontemplation, the first stage, the individual had no intent to change a behavior in the next six months (Prochaska & Velicer, 1997), and for this study, precontemplation was defined as individuals who were not compliant with colonoscopy and had no intent to obtain a colonoscopy in the next six

months. In the second stage, contemplation, the individual was aware that a change was needed and intended to get a colonoscopy in the next six months but had not committed to taking action. In this study, individuals in the contemplation stage were not compliant with colonoscopy but were planning to have one in the next six months. In the third stage, preparation, the individual planned to take action and had taken some steps toward the behavior change. In this study, individuals in the preparation stage were those who were not compliant with colonoscopy but had scheduled an appointment to have a colonoscopy. In the fourth stage, action, a specific behavior change had occurred and in this study, action was defined as someone who had a colonoscopy within the past 10 years (Rawl et al., 2006).

Operational definition. The stages of adoption were measured based on self report by asking respondents whether they had a colonoscopy within the past 10 years, planned to have a colonoscopy in the next six months, and had an appointment scheduled for a colonoscopy (Rawl et al., 2006).

Independent Variables

Demographic Variables

Conceptual definition. A social characteristic of a participant (age, marital status, educational level, income, and gender).

Operational definition. The information for these variables was gathered using an open response for the date of birth and categorical response items for marital status, level of education, and income. A dichotomous response option was used for gender (Rawl et al., 2006).

Body Mass Index (BMI)

Conceptual definition. The relative percentages of fat and muscle mass in humans (American Heritage Dictionary online, 2007).

Operational definition. BMI was measured using two open-ended items to obtain self-reported height and weight. Then the measures were converted from the English to the metric scale, and the weight in kilograms was divided by height in meters squared (American Heritage Dictionary online, 2007).

Colorectal Cancer Knowledge

Conceptual definition. Cognitive information about CRC risk factors, screening, and prevention (Rawl, et al., 2006).

Operational definition. CRC knowledge was measured with an 8-item multidimensional scale. The items were designed to assess knowledge about CRC risk, preventability of CRC, effective ways to reduce risk, and the purpose of a colonoscopy. Higher scores on the scale indicated higher CRC knowledge (Rawl, et al., 2006).

Physician Recommendation

Conceptual definition. A suggestion by a physician to a patient to obtain a colonoscopy.

Operational definition. Physician recommendation was measured by a single, self-reported item asking if a doctor had ever told the participant that he/she should have a colonoscopy (Rawl, et al., 2006).

Perceived Barriers

Conceptual definition. Specific obstacles that must be overcome in order to take action (Rosenstock et al., 1988; Becker, 1978; Rosenstock, 1966).

Operational definition. Perceived barriers were measured by a 14-item scale using a four point Likert-like rating. Higher scores on the scale indicated greater barriers. The reliability coefficient for the scale was .77 (Rawl et al., 2001; Rawl et al. 2006).

Embarrassment

Conceptual definition. Embarrassment is an emotion conceptually defined as "a sudden and intense but temporary uneasy, awkward, self-conscious, exposed feeling that can be strong or weak, ranging from mild awkwardness or, uneasiness, and uncertainty to strong sensations of incapacitations, blushing and a desire to escape" (Miller, 1992, p. 192).

Operational definition. This concept was measured with the Colonoscopy Embarrassment Scale, a new instrument developed to measure embarrassment associated with a colonoscopy. The 15-item instrument measured variables that had been identified in the literature or a clinical inquiry as related to embarrassment. The scale used a four point Likert-like rating including 1) *strongly disagree*, 2) *disagree*, 3) *agree*, and 4) *strongly agree.* The higher the score on the instrument, the higher the level of embarrassment associated with a colonoscopy. Content validity was established through cognitive interviewing techniques and calculation of the content validity index (CVI=.93) (Lynn, 1986; Wynd, Schmidt, & Schaefer, 2003).

Self-efficacy

Conceptual definition. "The conviction that one can successfully execute the behavior required to produce the outcome" (Bandura, 1977, p. 193), in this case screening for CRC with a colonoscopy, was the conceptual definition of self-efficacy.

Operational definition. Self-efficacy was measured with a 10-item scale using a 4-point Likert rating ranging from 1) *not sure at all,* 2) *not so sure,* 3) *somewhat sure*, to 4) *very sure.* Higher scores indicated higher self-efficacy. The Self-efficacy Scale for compliance with colonoscopy had an internal consistency of .92 (Menon, 2000; Rawl, 2006). Construct validity of the instrument was demonstrated by a significant relationship between high self-efficacy and colonoscopy compliance ($p<.001$) compared to low self-efficacy scores (Menon, 2000).

Summary

Currently, CRC is the third leading cause of cancer-related death in the United States (ACS, 2008). Adenomatous polyps that are allowed to grow are highly associated with CRC (Morson, 1984; Winawer et al., 1993; ACS, 2008). Timely removal of the polyps with a colonoscopy can prevent CRC. Individuals 50 years old and older are at higher risk for CRC, but less than two-thirds of individuals in this age group have ever had a colonoscopy or sigmoidoscopy (CDC, 2006). It has been established that physician recommendation is the factor most highly associated with completion of a colonoscopy, but there are other factors including the demographic/personal characteristics of the individual, perceived barriers, embarrassment as a specific barrier, and self-efficacy that are also related to compliance with colonoscopy. Although embarrassment had been found to be a barrier to the colonoscopy procedure prior to this study, there was little data regarding the sources of the embarrassment. Further, there was no instrument available to measure embarrassment associated with a colonoscopy, and as a result the CES was developed.

The aims of this study were to 1) develop and test the reliability and validity of a new instrument to measure colonoscopy-related embarrassment; 2) examine relationships among demographic/personal characteristics, health beliefs, and CES scores; 3) examine relationships among demographic/personal characteristics, health beliefs, physician recommendation, and compliance with colonoscopy; 4) to evaluate perceptions of aspects of having a colonoscopy that were most embarrassing, and 5) to assess participants' suggestions for reducing embarrassment in a group of men and women 50-64 years old.

The HBM and TTM were used as the theoretical foundations for this study. Based on the HBM, TTM, and what was known about the variables of interest, a conceptual model was developed, and the conceptual and operational definitions of the independent and dependent variables were provided. The significance of this study was based on the premise that if more was known about embarrassment as a barrier to colonoscopy, interventions could be developed to reduce or eliminate embarrassment resulting in an increased number of people using this life-saving test leading to reduced morbidity and mortality.

CHAPTER TWO

REVIEW OF LITERATURE

Introduction

In this chapter, the theoretical foundations and research related to variables presented in the conceptual framework are presented. Specifically, theories and research focused on the relationships among the predisposing variables (demographic/personal characteristics and cue to action) and compliance with colonoscopy are discussed first. Second, research on the relationships among colonoscopy compliance and the mediating variables (perceived barriers in general, embarrassment, and self-efficacy) are delineated. The mediating variable, embarrassment, is discussed last due to the depth of the discussion. Third, studies about the relationship between colonoscopy compliance and the stages of adoption are reviewed.

The next section discusses embarrassment as it relates to demographic/personal characteristics, the other mediating variables (barriers in general and self-efficacy), and stages of adoption. The literature on instruments currently available to measure embarrassability and embarrassment are also discussed.

The intent was to present the research related to the independent variables associated with obtaining a colonoscopy. If research was not available on these variables and completion of a colonoscopy, literature related to completion of sigmoidoscopy, barium enema, and/or FOBT was used. Some of the literature related to the variables was limited or inconclusive and in this situation, literature related to other cancer screening tests, such as mammography, was sometimes reviewed as background data.

Theoretical Foundation

No one theoretical framework was sufficient to serve as the foundation for this study. Therefore, two theoretical frameworks were used to inform this study, namely the HBM and TTM.

The HBM is one of the most widely used theoretical frameworks when investigating behavior related to prevention of disease (Robinson & Kish, 2001). The model hypothesizes that health behaviors depend on the simultaneous occurrence of the following factors. One factor is perceived susceptibility, or the vulnerability to an illness that an individual senses (Rosenstock et al., 1988; Becker, 1978; Rosenstock, 1974; Rosenstock, 1966). There is a spectrum of susceptibility from individuals who deny the possibility of contracting an illness to those who perceive a high likelihood of succumbing to a disease. This perception of susceptibility is not necessarily comparable to the individual's actual or objective risk for affliction with the disease.

A second factor is perceived seriousness or the recognition of the potential threat to the individual's health (Rosenstock et al., 1988; Becker, 1978; Rosenstock, 1974; Rosenstock, 1966). The individual may be concerned not only about the effects of the disease on the body, as far as morbidity and mortality, but also about the impact of the disease on aspects of one's life such as work, family, and social interactions. The individual's belief in the seriousness of a potential disease may have emotional as well as cognitive components.

A third factor, self-efficacy, is the confidence an individual has in his/her ability to take the recommended action. For some preventive actions such as accepting immunizations, little self-efficacy is required, but for more complex or threatening health

behaviors, such as smoking cessation and completing a colonoscopy, greater self-efficacy is required for achievement of the action (Rosenstock et al., 1988).

A fourth factor, in the HBM, is the perceived benefit or the belief that certain actions will result in positive outcomes (Rosenstock, 1974; Rosenstock et al., 1988; Becker, 1978; Rosenstock, 1966). Perceived benefits are affected by the perception of the availability and effectiveness of courses of action. Like all perceptions, the subjective benefits may not coincide with the objective benefits. Typically, benefits are perceived as something that will reduce the individual's susceptibility to a disease or the seriousness of the affliction.

The fifth factor is specific obstacles that must be overcome in order to take action (perceived barriers). Barriers are negative aspects of health behaviors and "may arouse conflicting motives of avoidance" (Rosenstock, 1974, p. 331). Some examples of barriers to taking action include expense, inconvenience, and embarrassment. The HBM posits that the individual must feel susceptible to an illness perceived as serious and the benefits of action must outweigh the barriers in order for a behavior change to take place (Rosenstock et al., 1988; Becker, 1978; Rosenstock, 1974; Rosenstock, 1966).

The sixth factor is *cue to action* or a trigger that stimulates behavioral change (Robinson & Kish, 2001). Some examples of cues to action in the context of colon cancer screening include a suggestion by a health care provider, mass media messages, and reminder postcards or phone calls from a physician's office. Additionally, a medical diagnosis of a friend or family member and promotional campaigns by celebrities are cues to action.

The other theoretical framework used was the Transtheoretical Model of Behavior Change (TTM). The TTM was included because the model allows researchers to operationalize behavior change as a series of cognitive changes rather than a single action and thus improves sensitivity of outcome measurement. There are three aspects to the TTM including stages, processes, and levels of change (Prochaska et al., 1994; Prochaska & Velicer, 1997). The TTM is based on the concept that a behavior change involves progression through five stages: precontemplation (no intent to change), contemplation (thinking about changing), preparation (intend to take action), action (behavior change occurs), and maintenance (sustaining the changed behavior). The model proposes that change happens over time (Prochaska & Velicer, 1997). In addition, as part of the process, the individual weighs the pros and cons of making the behavior change (decisional balance) with the pros outweighing the cons as the individual advances through the stages toward action. For example, an individual in the precontemplation stage perceives more cons to engaging in a specific behavior than an individual in the action stage. The process of changing the balance of pros and cons is mediated by activities such as *consciousness-raising*, *self-evaluation*, *self-liberation*, and *helping relationships* (Prochaska & Velicer). As the process continues, individuals progress to a more advanced stage of change.

The TTM is based on a number of assumptions (Prochaska & Velicer, 1997). These assumptions include: 1) one theory can not explain of all of the complexities of behavioral changes; 2) behavior change is temporal, meaning it is a process that takes time; 3) the stages are stable yet susceptible to change as risk factors change; 4) there is no inherent motivation to change without intervention; 5) individuals will be better

served if health care providers recognize stages of adoption rather than assume all individuals are ready for action; 6) interventions should be matched to the stage of adoption in order to make progress through the stages; and 7) chronic behaviors are influenced by biological, social, and self-control factors.

Theoretical Foundation and the Conceptual Framework for this Study

The HBM and TTM informed the conceptual framework for this study (see Figure 1). Based on aspects of the HBM, this study investigated several variables that may predispose one to change behavior (get a colonoscopy) such as age, gender, income, education level, marital status, BMI, and CRC knowledge as well as a cue to action (physician recommendation). Additionally, moderators related to compliance with colonoscopy including perceived barriers (in general), embarrassment, and self-efficacy were studied. This study investigated barriers as a whole and one particular barrier, embarrassment, related to compliance with screening guidelines for colonoscopy. The aspect of the TTM that informed this study is decisional balance where the individual weighs the pros and cons of making a behavior change. The balance of the pros to cons increases as the individual moves through the stages. This study examined the relationship between the degree of embarrassment and the stage of adoption.

Predisposing Variables related to Compliance with Colonoscopy

In this section, studies concerning the relationship of the predisposing variables, depicted in the conceptual framework, and colonoscopy compliance are reviewed (see Figure 1). The two categories of predisposing variables are demographic/personal characteristics and cue to action. The demographic variables include age, gender, income,

education level, marital status, and the personal characteristic variables are BMI and CRC knowledge. The cue to action variable is physician recommendation.

Demographic/Personal Characteristics

Age and CRC Screening

In most studies, age was positively related to CRC screening such that those who were older were more likely to obtain CRC screening (Denberg et al., 2006; Seeff et al., 2004; Liang et al., 2006; Codori et al., 2001; Denberg et al., 2005; Tessaro et al., 2006; Weinberg et al., 2004; Gorin & Heck, 2005; James et al., 2002; Honda, 2004; Walsh et al., 2004). In a randomized controlled trial, Denberg et al. (2006) examined the effect of a face-to-face meeting with the physician and a written referral to an endoscopist on colonoscopy completion levels. The intervention was more effective with older participants who were more likely to complete a colonoscopy than younger participants.

Two national surveys also found older age increased the likelihood of CRC screening (Seeff et al., 2004; Liang et al., 2006). Seeff et al. (2004) analyzed the data from the National Health Interview Survey (n=11,816) and found that older age was associated with greater likelihood of an endoscopic bowel examination until age 80 when the level of compliance decreased. Liang et al. (2006) found older age was associated with greater likelihood of ever being screened by FOBT, sigmoidoscopy, or colonoscopy in both 2000 (n=11,574) and 2003 (n=11,779) for individuals 50 years and older. These researchers used the 2000 and 2003 National Health Interview Surveys for their study.

Additionally, Codori et al. (2001) found that increased age was associated with increased endoscopic screening in a survey of first-degree relatives of CRC cancer patients recruited through the Johns Hopkins Tumor Registry (n=1160). Some limitations

of this study included having 5% of families contributing five or more participants to the sample, and the number of individuals in the sample that were compliant with colonoscopy was higher than usual. Denberg et al. (2005) found, in a retrospective study of 647 subjects, that the odds ratio for completion of a screening colonoscopy increased with age (ages 50-54 [reference]; 55-59, OR=1.61, 95% CI=1.04-2.51; 60-64, OR=1.86, 95% CI=1.16-2.97; 65-69, OR=2.65, 95% CI=1.39-5.09) until 70 years of age and older.

Tessaro et al. (2006) found that older age was associated with higher compliance to CRC screening guidelines (FOBT, sigmoidoscopy, colonoscopy, or barium enema). Using a cross-sectional, correlation study, individuals 50 years old and older, from 16 churches in the Appalachian region (n=824), were surveyed. Participants 65-74 years old were significantly more likely to be current in their CRC screening compared to those 50-64 years old ($p<.05$). Weinberg et al. (2004) conducted a cross-sectional, correlational study using a telephone survey and found increasing age was a predictor of completion of all types of CRC screening (adjusted OR=1.05, 95% CI=1.03-1.08). The sample surveyed was women aged 50-80 years old with average risk of CRC (n=406).

Higher age was associated with higher levels of endoscopic CRC screening in several racial/ethnic groups (Gorin & Heck, 2005; James et al., 2002; Honda, 2004; Walsh et al., 2004). Using the 2000 National Health Interview Survey, Gorin and Heck (2005) found that older age was related to greater use of endoscopic CRC testing in the Latino population (n=5,377). James et al. (2002) found that older age was associated with higher rates of completion of endoscopic CRC testing using telephone surveys of African Americans. The participants were at least 50 years old, eligible for endoscopic CRC screening, and from 12 randomly selected African American churches in rural North

Carolina (n=397). The limitations of this study included exclusion of individuals without a telephone and a predominance of females in the sample (72%). The results of the study by Honda (2004) showed older age was associated with having a sigmoidoscopy or colonoscopy in the past five years. This researcher conducted a study using random sampling of 305 Japanese subjects living in four cities across the U.S. who had never had CRC. Participants completed a bilingual questionnaire that was mailed to them (return rate 44%). Walsh et al. also found that increasing age was associated with greater levels of being up-to-date with colonoscopic examination in a population of Latino and Vietnamese Americans (n=775).

In contrast, Segnan et al. (2005) found that younger participants (55-59 years old) were more likely to complete a sigmoidoscopy than older ones. The researchers conducted a large, multicenter, randomized study in Italy that included 4466 participants aged 55-64 years old with average risk for CRC.

Other researchers found that age was not associated with whether or not participants obtained a flexible sigmoidoscopy (Kelly & Shank, 1992; Lewis & Jensen, 1996; Brenes & Paskett, 2000; McCarthy & Moskowitz, 1993; Hay et al., 2003). Kelly and Shank (1992) found no association between age and completion of a flexible sigmoidoscopy. The sample in this study (n=333) consisted of patients from a family practice residency clinic who were over 50 years old, and primarily Caucasian (97%). The researchers assessed the rate of sigmoidoscopy completion during a four month period without an intervention and then for four months with the intervention. The intervention consisted of a brochure about CRC screening for early detection of CRC and a reminder telephone call one week later. Lewis and Jensen (1996) also found that age

was not significantly associated with completion of a flexible sigmoidoscopy. The sample surveyed included patients 50-75 years old who were seen at a university-based general medicine clinic (n=236).

Additionally, Brenes and Paskett (2000) surveyed primarily low income African American women from North Carolina who were not compliant with CRC screening guidelines for flexible sigmoidoscopy (n=202) and also found no difference in the age of participants who had a screening sigmoidoscopy and those who did not. In addition, McCarthy and Moskowitz (1993) surveyed 105 patients aged 46-75 who were scheduled for a screening sigmoidoscopy in a hospital-based general medicine practice and found no relationship between age and having a sigmoidoscopy (p=.03). In addition, Hay et al. (2003) found that age was not related to CRC screening (FOBT, sigmoidoscopy, and colonoscopy combined) using a survey. These researchers conducted a cross-sectional, descriptive study using 2-stage equal size sampling of mainly Caucasian (76%) women (n=280).

In summary, five studies found no relationship between age and compliance with CRC screening, including colonoscopy. One research study found that being younger was related to higher compliance with endoscopic CRC screening, but eleven research studies showed that older age was related to greater compliance with CRC screening. Nine of these studies were specific to endoscopic CRC screening such that older age was related to greater compliance with endoscopic CRC screening.

Gender and CRC Screening

Most studies showed that male gender was associated with higher rates of obtaining CRC screening (Segnan et al., 2005; Seeff et al. 2004; Codori et al., 2001;

Slattery et al., 2004; Tessaro et al., 2006; Gorin & Heck, 2005; Green & Kelly, 2004; McCarthy & Moskowitz, 1993; Gilbert & Kanarek, 2005). Segnan et al. found that males were more likely than females to get a sigmoidoscopy in their study conducted in Italy (OR=1.22, 95% CI=1.14-1.32), but males were less likely than females to complete FOBT (OR=.82, 95% CI=.74-.90). The researchers conducted a large, multi-center, randomized controlled trial that included participants aged 55-64 years old with average risk for CRC (n=4466). The researchers compared participation and CRC cancer detection rates from five different methods of screening. The five methods included 1) mailed biennial FOBT, 2) biennial FOBT by practitioner, 3) participant's choice of FOBT or sigmoidoscopy, 4) sigmoidoscopy, 5) sigmoidoscopy followed by biennial FOBT.

Other researchers also found that males were more likely to complete endoscopic CRC screening (Seeff et al., 2004; Codori et al., 2001; Slattery et al., 2004; Tessaro et al., 2006; Gorin & Heck, 2005; Green & Kelly, 2004; McCarthy & Moskowitz, 1993; Gilbert & Kanarek, 2005; Lemon et al., 2001). Seeff et al. (2004) found that more males (37.4%) than females (31.1%) were current with endoscopic screening from their analysis of the data from the National Health Interview Survey (n=11,816). In addition, Codori et al. (2001) found being male was predictive of greater endoscopic screening rates (OR=1.4, 95% CI=1.1-1.9) in first degree relatives of individuals with CRC recruited through the Johns Hopkins Tumor Registry (n=1160). Some limitations of this study included having 5% of families contributing five or more participants to the sample, and the number of people who were compliant with colonoscopy was higher than usual. Other researchers (Slattery et al., 2004) also found that being male was associated with greater likelihood of

having a sigmoidoscopy (p<.01). Slattery et al. analyzed data from two case controls studies. One study was conducted from 1991-1994 (n=1346 cases and 1,544 controls) and another from 1997-2001 (n=952 cases and 1,205 controls). Tessaro et al. (2006) also found that males were significantly more likely to be compliant with CRC screening guidelines (sigmoidoscopy, barium enema, or colonoscopy) compared to females (p=.03). These researchers conducted a cross-sectional, correlational study in which 824 individuals 50 years old and older from one of 16 churches in the Appalachian region were surveyed.

Analyzing data from 2000 National Health Interview Survey (n=5377), Gorin and Heck (2005) found that Latino males were more likely to obtain endoscopic screening than females. In a cross-sectional, descriptive study, of a sample of 100 African Americans, Green and Kelly (2004) found more men (31%) than women (22%) had had a flexible sigmoidoscopy/colonoscopy in the last five years.

In addition, McCarthy and Moskowitz (1993) surveyed 105 patients aged 46-75 who were scheduled for a screening sigmoidoscopy in a hospital-based general medicine practice and found male gender was associated with greater likelihood of having a sigmoidoscopy (p=.03) and colonoscopy (p=.01). These results were from a retrospective study of all of patients 50 years old and older who were referred for endoscopic screening. The researchers cross referenced patient data with the electronic medical record for evidence of colonoscopy completion within six months after the referral (n=647). Gilbert and Kanarek (2005) conducted a secondary analysis of data collected in 2002 for the Maryland Cancer Survey (n=2994) and found that women were less likely to have had a screening colonoscopy than men (OR=.66; 95% CI=.51-.86; p<.002). This

sample consisted of Marylanders who were at least 40 years old, spoke English, owned a land line, and were not institutionalized. Limitations of this study included a low response rate (38%) and the exclusion of individuals without a land line or who did not speak English.

Lemon et al. (2001) also found males were significantly more likely to be compliant with CRC screening guidelines (five methods of testing combined) compared to females ($p<.001$). These researchers surveyed 954 individuals 50 years and older living in Massachusetts who were selected by random digit telephone dialing.

However, not all studies showed the aforementioned trend. Kelly and Shank (1992) found that gender was not significantly associated with completion of a flexible sigmoidoscopy. The sample in this study (n=333) consisted of patients from a family practice residency clinic, who were over 50 years old, and primarily Caucasian (97%). The researchers assessed the rate of sigmoidoscopy completion during a four month period without an intervention and then for four months with the intervention. The intervention consisted of a brochure about CRC screening for early detection and a reminder telephone call one week later. Lewis and Jensen (1996) also found that gender was not significantly associated with completion of a flexible sigmoidoscopy. The sample surveyed included patients 50-75 years old who were seen at a university-based general medicine clinic (n=236). Menon et al. (2003) conducted a survey of randomly selected workers at a worksite who were at least 40 years old (n=220) and found no relationship between gender and ever having had a colonoscopy.

In summation, nine studies showed that male gender was related to greater compliance with endoscopic CRC screening. Results of three studies found no

relationship between gender and compliance with endoscopic CRC screening. No researchers found that female gender was related to higher compliance with endoscopic CRC screening.

Income and CRC Screening

Higher income has typically been associated with higher participation rates in CRC screening (Hsia et al., 2000; Bostick et al., 1994; Seeff et al., 2004; Gilbert & Kanarek, 2005). Hsia et al. (2000) found that women in the Women's Health Initiative Observational Study (n=55,278) with higher incomes were more likely to have been screened with either FOBT or flexible sigmoidoscopy within the last five years ($p<.0001$). One criticism of this study is that *FOBT within the last five years* does not meet the screening recommendations for that test. Bostick et al. (1994) surveyed 4,915 Midwesterners from six communities aged 25-74 years and found higher income was associated with greater sigmoidoscopy screening levels. One limitation of this study was that the researchers included participants who were not in the age range that needed a screening colonoscopy. Seeff et al. analyzed data from the National Health Interview Survey (n=11,816) and found that there was a positive correlation with income level; as income level increased, the percentage of individuals screened endoscopically for CRC also increased. In addition, Gilbert and Kanarek found higher income was significantly related to colonoscopic screening for CRC in their sample of 50-64 year olds. Participants earning *$25,000-49,999* and *greater than $75,000* had higher odds of obtaining a colonoscopy than those earning *less than $25,000* (OR=1.66, 95% CI=1.01-2.73; p=0.05 and OR = 1.81; 95% CI=1.09-3.01; p=0.02 respectively).

Only one study found that participants with incomes less than $20,000 per year were more likely to be screened with a flexible sigmoidoscopy than those with annual incomes higher than $20,000 ($p<.001$) (Kelly & Shank, 1992). The sample in this study (n=333) consisted of patients in a family practice residency clinic, who were over 50 years old and primarily Caucasian (97%). The researchers assessed the rate of sigmoidoscopy completion during a four month period without an intervention and then for four months with the intervention. The intervention consisted of a brochure about CRC screening for early detection and a reminder telephone call one week later.

Since the data related to income and CRC screening were somewhat limited, literature related to mammography was reviewed with mixed results. Champion et al. (2007) found that income was not predictive of getting a mammogram in a group of lower income women who belonged to an HMO. This was a randomized control trial with four groups including 1) usual care, 2) tailored telephone counseling, 3) tailored print, and 4) tailored telephone and tailored print. The sample of women (n=1244) were from two sites-a clinic serving primarily low income patients and an HMO. On the other hand, Champion (1992) found that higher income was associated with greater compliance with mammography in a group of women 35 years and older that were randomly selected from a large Midwestern urban area (n=322). One limitation to this study is that the survey response rate was 43%. The data reported in this article were from the baseline survey of a longitudinal study.

In review, few studies were found that investigated the relationship between income and CRC screening compliance. Results of four studies showed that higher

income was related to compliance with endoscopic CRC screening. One study found that individuals with lower income had higher endoscopic screening rates.

Educational Level and CRC Screening

Results of studies examining relationships between education and CRC screening were mixed. Several studies showed that higher education was related to higher levels of CRC screening (Seeff et al., 2004; Bostick et al., 1994; McCarthy & Moskowitz, 1993; Slattery et al., 2004; Gorin & Heck, 2005 Hsia et al., 2000; Manne et al., 2002). Several studies also showed that higher education was associated with higher levels of endoscopic screening specifically (Seeff et al., 2004; Bostick et al., 1994; McCarthy & Moskowitz, 1993; Slattery et al., 2004; Gorin & Heck, 2005). According to the data from the National Health Interview Survey (n=11,816), the percentage of up-to-date endoscopic exams of the bowel increased as the level of education increased (Seeff et al., 2004).

Bostick et al. (1994) found that higher education was predictive of getting a sigmoidoscopy in their survey of 4,915 individuals aged 25-74 living in six communities in the Midwest. One limitation of this study was that over 50% of the sample was less than 50 years old. McCarthy and Moskowitz (1993) surveyed 105 patients aged 46-75 who were scheduled for a screening sigmoidoscopy in a hospital-based general medicine practice and also found higher education was predictive of getting a sigmoidoscopy. Slattery et al. (2004) analyzed data from two case-control studies. One study was conducted from 1991-1994 (n=1346 cases and 1,544 controls) and another from 1997-2001 (n=952 cases and 1,205 controls) and reported an increase in the rate of current endoscopic exams of the bowel as the level of education increased. Analyzing data from

2000 National Health Interview Survey (n=5377), Gorin and Heck (2005) found higher education positively influenced the use of endoscopic CRC testing in the Latino population.

From the Women's Health Initiative Observational Study (n=55,278), Hsia et al. (2000) found higher education (college degree or more) was associated with higher levels of screening with FOBT or flexible sigmoidoscopy within the last five years ($p<.0001$). Using a survey, Manne et al. (2002) reported that siblings (n=504) of CRC patients who were compliant with CRC guidelines (any test) were significantly better educated than those who were not compliant ($p<.0001$).

Three studies showed that lower levels of education were associated with completing CRC screening (Kelly & Shank, 1992; Lemon, et al., 2001; Menon et al., 2003). Kelly and Shank (1992) found that lower education (*no college education* compared to *at least some college education*) was significantly associated with completing a screening with a flexible sigmoidoscopy (OR=1.4; $p=.05$). The sample in this study (n=333) consisted of patients in a family practice residency clinic, who were over 50 years old, and primarily Caucasian (97%). The researchers assessed the rate of sigmoidoscopy completion during a four month period without an intervention and then for four months with the intervention. The intervention consisted of a brochure about CRC screening for early detection and a reminder telephone call one week later. Lemon et al. found that lower education (less than a high school education) was associated with higher levels of CRC screening rates (five methods of testing combined) ($p=.01$). The sample surveyed was 954 individuals 50 years and older living in Massachusetts who were selected by random digit telephone dialing. Additionally, Menon et al. (2003) also

found *less than a high school education* was significantly associated with ever having had a colonoscopy but so was having *some college* and *graduate or professional degree* levels of education ($p<.001$). However, having a *bachelor's degree* was not associated with ever having had a colonoscopy. The researchers surveyed randomly selected workers at a worksite who were at least 40 years old (n=220).

Other findings showed that educational levels were not significantly related to CRC screening (Lewis & Jensen, 1996; Brenes & Paskett, 2000; Hay et al., 2003). For example, Lewis & Jensen found no relationship in the educational level of participants and completion of a sigmoidoscopy when they surveyed 236 individuals 50-75 years old who received care at a university-based general medicine clinic in Wisconsin. In addition, Brenes and Paskett (2000) surveyed primarily low income African American women from North Carolina who were not compliant with CRC screening guidelines for flexible sigmoidoscopy (n=202) and also found no difference in the educational level of participants who had a screening sigmoidoscopy and those who did not. Hay et al. found that education level did not make a difference in CRC screening compliance (FOBT, sigmoidoscopy, and colonoscopy combined) in a cross-sectional, descriptive study using two-stage equal size sampling of mainly Caucasian (76%) women (n=280).

To summarize, the relationship between level of education and compliance with endoscopic CRC screening was not consistent. Five studies showed a positive relationship between level of education and endoscopic CRC screening compliance, two studies showed an inverse relationship, and two studies showed no relationship.

Marital Status and CRC Screening

Overall, most studies found that being married was not associated with higher rates of CRC screening completion (Kelly & Shank, 1992; Bostick et al., 1994; Lewis & Jensen, 1996; Slattery et al., 2004; Brenes & Paskett, 2000; Denberg et al., 2005; Menon et al., 2003; Hay et al., 2003). Kelly and Shank found that marital status was not associated with completion of a flexible sigmoidoscopy. The sample in this study (n=333) consisted of patients in a family practice residency clinic, who were over 50 years old, and primarily Caucasian (97%). The researchers assessed the rate of sigmoidoscopy completion during a four month period without an intervention and then for four months with the intervention. The intervention consisted of a brochure about CRC screening and a reminder telephone call one week later. Bostick et al. surveyed 4,915 individuals aged 25-74 living in six communities in the Midwest and also found that marital status was not predictive of getting a sigmoidoscopy.

In addition, Lewis and Jensen (1996) found marital status was not associated with completion of a flexible sigmoidoscopy based on their survey of 236 individuals 50-75 years old who received care at a university-based general medicine clinic in Wisconsin. Slattery et al., (2004) analyzed data from two case-control studies. One study was conducted from 1991-1994 (n=1346 cases and 1,544 controls) and another from 1997-2001 (n=952 cases and 1,205 controls) and results showed there was no relationship between marital status and completion of a sigmoidoscopy. Data from the Brenes and Paskett (2000) study showed that marital status was not associated with completion of a flexible sigmoidoscopy. These researchers surveyed primarily low income African

American women from North Carolina who were not compliant with CRC screening guidelines for flexible sigmoidoscopy (n=202).

Denberg et al. (2005) conducted a retrospective medical record review of all patients 50 years old and older who were referred for endoscopic screening and found that marital status was not associated with completion of a colonoscopy. The researchers cross-referenced patient information with the electronic medical record for documentation of completion of a colonoscopy within 6 months after the referral (n=647). Menon et al. (2003) also found no relationship between marital status and completion of a colonoscopy in their survey of randomly selected workers at a worksite who were at least 40 years old (n=220). Hay et al. (2003), found that marital status was not correlated with compliance to CRC screening (FOBT, sigmoidoscopy, and colonoscopy combined) in a cross-sectional, descriptive study using 2-stage equal size sampling of mainly Caucasian (76%) women (n=280).

In three studies, investigators found being married was associated with higher rates of endoscopic CRC screening completion (Hsia et al., 2000; Seeff et al., 2004; Juon, Han, Shin, Kim, & Kim, 2003). Hsia et al. found that participants in the Women's Health Initiative Observational Study (n=55,278) who were married or in a marriage-like relationship were more likely to have had flexible sigmoidoscopy in the last five years than those who were not ($p<.0001$). Seeff et al. found a higher proportion of married individuals (37.1%) reported having undergone an endoscopic examination of the bowel within the past 10 years compared to unmarried (29.1%) individuals according to the results of the analysis of the data from the 2000 National Health Interview Survey (n=11,816). Additionally, Juon et al. found that married individuals were more likely to

have had a sigmoidoscopy than participants who were not married (OR=4.90, 95% CI=1.09-21.9). The researchers used face-to-face interviews conducted by bilingual graduate students with a group of Korean-Americans at least 60 years of age (n=205).

To summarize, in eight studies marital status was not found to be related to completion of endoscopic screening for CRC. Only three studies found that marital status was positively related to completion of endoscopic screening.

Body Mass Index and CRC Screening

Findings of studies that examined the relationship between BMI and compliance to CRC screening guidelines were equivocal. Rosen and Schneider (2004) found that morbidly obese women had significantly fewer CRC screening tests (FOBT $p<.05$; endoscopic screening $p<.01$) than normal weight women. However, no differences were observed in screening rates when comparing overweight and obese women to women with a normal BMI. There also were no differences in screening rates among men of any weight category. These researchers analyzed data from the 1999 Behavioral Risk Factor Surveillance System using a sample of 52,886 individuals aged 51-64 years old. Ferrante et al. (2006) found that obese patients (male and female) were less likely to be screened for CRC (FOBT, sigmoidoscopy, and colonoscopy combined) than patients who were not obese (OR 0.75, 95% CI=0.62-0.91). These researchers conducted a retrospective review of patient records of individuals 50 years and older living in New Jersey and Pennsylvania (n=1297) to examine factors related to completion of CRC screening tests.

In contrast, Ata et al. (2006) found that compared to being underweight (OR=.77, 95% CI=.54-1.10), individuals who were overweight or obese were more likely to be current with FOBT or endoscopic tests (OR=1.09, 95% CI=0.97-1.22; OR=1.15, CI

95%=1.01-1.30 respectively). These results were obtained from the 2000 National Health Interviews Survey (n=9575). However, Menis et al. (2006) studied Marylanders aged 50 and older (n=3436) and found no significant difference in CRC screening rates (FOBT, sigmoidoscopy, and colonoscopy combined) based on BMI. The findings were obtained by analyzing data from the 2002 Maryland Cancer Survey.

A further example of the ambiguity of the finding concerning the association between BMI and CRC screening is the results of a secondary analysis conducted by Slattery et al. (2004). These researchers found that higher BMI in women, but not men, was associated with higher rates of screening with sigmoidoscopy from 1997-2001 but not from 1991-1994. The study involved comparing data from the controls from two case-control studies-one conducted in California and one in Utah (n=2749).

Since the findings related to the association of BMI and CRC screening behaviors were inconsistent, studies of BMI and other types of cancer screening tests were reviewed. Zhu, Wu, Jalai, Potter, and Shiver (2006) found that underweight (OR=1.8, 95% CI=1.2-2.6) women and women with a BMI of 40 or greater (extremely obese) (OR=1.3, 95% CI=1.0-1.8) were less likely to have had a mammogram in the last two years. These researchers studied over 20,000 women 40-80 years old and the calculated BMI was based on the participant's self-reported height and weight. Similarly, Fontaine, Heo, and Allison (2005) found that compared to women with a normal BMI, underweight women (OR=1.3, 95% CI=1.13-1.54), women with a BMI of 30-34.9 (OR=1.12, 95% CI=1.02-1.23), and women with a BMI of 40 or greater (OR=1.32, 95% CI=1.10-1.54) were less likely to have had a mammogram within the past two years. The results of this

study were based on the 1998 Behavioral Risk Factor Surveillance Survey of over 80,000 women.

Likewise, Reidpath, Crawford, Tilgner, and Gibbons (2002) studied 17,174 Australian women 20 years old and older and found that, compared to normal weight women, underweight (OR=.67, 95% CI=.48-.94), overweight women with a BMI of 25-30 (OR=.87, 95% CI=.70-1.08), and women with a BMI of 30 or greater (OR=.87, 95% CI=.67-1.15) were less likely to have had a mammogram in the past two years. One limitation of this study is that although the mammography data for women 50 or older were used, the article did not mention the sample size for this subgroup.

In sum, studies that examined the relationship between BMI and endoscopic CRC screening tests have not demonstrated a consistent relationship. Two studies showed that higher BMI in women, but not men, was inversely related to completion of endoscopic CRC screening tests. One study found overweight individuals, compared to normal weight individuals, were more likely to be compliant with endoscopic CRC screening. The relationship between BMI and endoscopic CRC screening compliance is not clear, therefore this variable was included in this study to determine its influence.

CRC Knowledge about CRC Screening

CRC knowledge is cognitive information about CRC risk factors, screening, and prevention (Rawl et al., 2006). Research findings suggested that greater knowledge of CRC screening was positively related to CRC screening (Menon et al., 2003; Seeff et al., 2004; Tessaro et al., 2006; Klabunde et al., 2006; Green & Kelly, 2004). Menon et al. found that higher CRC knowledge was associated with ever having had a colonoscopy (χ^2=10.48, p<.001). These researchers surveyed randomly selected workers at a worksite

who were at least 40 years old (n=220). Seeff et al. analyzed the data from the National Health Interview Survey (n=11,816) and found that the most common reason reported for not having endoscopic examination or FOBT was *not knowing the test was needed*. Additionally, Tessaro et al. reported 43% of the participants over 50 years old who had not been screened for CRC reported *not knowing that the test was needed.* These researchers used a cross-sectional, correlation design in their study of a sample individuals from the Appalachian region (n=824).

In addition, Klabunde et al. (2006) used a telephone survey and found that over 50% of the participants (n= 1901) who had never been tested for CRC said they had never heard of FOBT, a sigmoidoscopy, or a colonoscopy. The participants had Medicare, lived in North or South Carolina, did not have history of CRC, and were at least 50-80 years old. In a descriptive, correlational study by Green & Kelly (2004) of 100 African American men and women 50-90 years old, results showed that the most common barrier to CRC screening was *not knowing how to schedule a screening* and *knowledge about screening guidelines* was positively associated with being current on CRC screening ($p<.001$).

In contrast, Brenes and Paskett (2000) surveyed primarily low income African American women from North Carolina who were not compliant with CRC screening guidelines for flexible sigmoidoscopy (n=202) and found no relationship between CRC knowledge and higher rates of sigmoidoscopy completion. Menon et al. (2007) showed CRC knowledge was not significantly higher for those who had completed a sigmoidoscopy or FOBT compared to those who had not. In an ongoing cancer screening program, Burack and Liang (1987), found that cancer knowledge was not associated with

completion of FOBT in a sample of 76 primarily female, older, lower income African American participants who were interviewed by phone. In this study, physicians recommended CRC testing and confirmed completion through billing records. Gorin (2005) also reported that that there was no difference in the CRC knowledge of participants who completed FOBT during the study period compared to those who did not. This study was an ongoing cancer screening program for Hispanic women (n=950) who were participating in the National Breast and Cervical Cancer Screening Program in New York City.

Overall, greater CRC knowledge has been shown to be related to compliance with endoscopic CRC screening with three studies supporting this relationship. In contrast, in two studies, CRC knowledge was not related to compliance with endoscopic screening.

Physician Recommendation as Cue to Action and CRC Screening

In general, having a physician recommendation for CRC screening was positively related to higher CRC screening rates (Harewood et al., 2002; Janz et al., 2003; Menon et al., 2003; Rawl et al., 2004; Codori et al., 2001; Tessaro et al., 2006; James et al., 2002; Brenes & Paskett, 2000; Teng et al., 2006; Rios et al., 2006; Honda, 2004; Gilbert & Kanarek, 2005; Klabunde et al., 2006). In the prospective, controlled study by Harewood et al. the participants who had never been screened with a colonoscopy cited lack of physician recommendation as one of the top barriers to obtaining a colonoscopy (66% bowel prep, 43% fear of discomfort, 35% doctor did not recommend, and 30% embarrassment). Subjects were patients at the Mayo Clinic Outpatient Division of Gastroenterology (n=258) who were being seen for reasons other than lower GI concerns. One critique of this study was that although the participants were not having lower

gastrointestinal problems, they may have been more sensitive to gastrointestinal issues than the general population.

Likewise, Janz et al. (2003) found that of the participants who were compliant with screening guidelines for colonoscopy, 75% had the test recommended by their physician. These researchers conducted 355 phone interviews of people 50-79 years old with average risk for CRC. One limitation to this study was that individuals without phones were excluded. Menon et al., (2003) conducted a survey of randomly selected workers at a worksite who were at least 40 years old (n=220) and found that physician recommendation was predictive of ever having had a colonoscopy using logistic regression (OR=5.26, CI 2.23-12.45).

Physician recommendation was also positively associated with endoscopic CRC compliance in first-degree relatives of individuals with CRC. A study by Rawl et al. (2004) showed that participants without a physician recommendation were less likely to be in the action stage of adoption regarding colonoscopy compliance compared to those in the precontemplation stage ($p<.001$). The participants were first-degree relatives of individuals with CRC and they were surveyed by phone. In a second study of first degree relatives of individuals with CRC, Codori et al., (2001) found 91% of the participants reported they would have an endoscopic CRC screening test if their physician recommended the test. The sample was recruited through the Johns Hopkins Tumor Registry (n=1160). Some limitations of this study included having 5% of families contributing five or more participants to the sample, and the author acknowledged a higher than usual colonoscopy compliance rate in this population. Tessaro et al. (2006) found that the most common reason mentioned for not being screened for CRC with a

sigmoidoscopy, barium enema, or colonoscopy was lack of physician recommendation (68%). These researchers used a cross-sectional, correlational study to survey individuals 50 years old and older from 16 churches in the Appalachian region (n=824).

Studies on primarily African Americans found physician recommendation to be positively associated with endoscopic CRC screening. Using telephone surveys, James et al. (2002) found that physician recommendation was significantly associated with having a colonoscopy in the past five years ($p=.01$). Participants over 50 and eligible for CRC screening were recruited from 12 randomly selected African American churches in rural North Carolina (n=397). The limitations of this study include exclusion of individuals without a telephone and a predominance of females in the sample (72%). Brenes & Paskett, (2000) found that women in the action/maintenance phase (82%) were significantly more likely ($p<.0001$) to have received a physician recommendation for the flexible sigmoidoscopy compared to women in the precontemplation (13%) and contemplation stages (32%). The researchers surveyed primarily low income African American women from North Carolina who were not compliant with CRC screening guidelines for flexible sigmoidoscopy (n=202).

Physician recommendation for CRC screening was found to be influential in screening behavior among several other ethnic groups as well. Results of regression analyses showed that physician recommendation was significantly associated with Chinese Americans obtaining a colonoscopy ($p<.001$) (Teng et al., 2006). These researchers used a self-administered survey to investigate CRC screening behaviors and beliefs in 206 Chinese Americans living in San Francisco and Houston. Compliance to colonoscopy was found to be significantly influenced by physician recommendation

($p<.0001$) in Mexican Americans also (Rios et al., 2006). These participants (n= 287), surveyed by trained bilingual research assistants, were aged 50-89 years old and obtained health care at community health centers near the U.S. and Mexican border. In addition, Honda (2004) conducted a study using random sampling of 305 Japanese American subjects living in four cities across the U.S. who had never had CRC and found physician recommendation was predictive of having a sigmoidoscopy or colonoscopy in the past five years (OR=16.8, CI=8.8-32.1). Participants completed a bilingual questionnaire that was mailed to them (return rate 44%).

Gilbert and Kanarek (2005) found that for both age groups, 50-64 years old and 65 and older, physician recommendation was the strongest predictor of compliance with endoscopic or FOBT CRC screening testing and improved the odds of compliance by at least eight times for any CRC screening test. These researchers conducted a secondary analysis of data collected in 2002 for the Maryland Cancer Survey (n=2994). The sample consisted of Marylanders who were at least 40 years old, spoke English, owned a land line, and were not institutionalized. In addition, Klabunde et al. (2006) conducted a telephone study and found that of the participants that had never been tested for CRC (FOBT, sigmoidoscopy, or colonoscopy), 28% reported the reason they had not been tested was because a physician had not recommended the test. The participants consisted of a random sample of Medicare recipients aged 50-80 years old living in North and South Carolina (n=1901).

In summary, thirteen studies showed a positive relationship between physician's recommendation and compliance with endoscopic CRC screening tests. Studies also

showed a positive relationship between having a physician's recommendation and compliance with other types of CRC screening tests such as FOBT.

Mediating Variables

The literature reviewed in this section concerns the mediating variables of perceived barriers in general, self efficacy, and embarrassment as they relate to compliance with colonoscopy (see Figure 1). First, studies regarding the relationship between perceived barriers and compliance with colonoscopy are discussed. Second, findings concerning the relationship of self-efficacy to colonoscopy compliance are reported. Third an in-depth review of the research studies related to embarrassment is reviewed.

Barriers and Compliance with Colonoscopy

In this section, research studies on barriers to obtaining a colonoscopy are discussed. Barriers included anxiety about the procedure (Janz et al., 2003), fear of endoscopic testing (Farraye et al., 2004), fear of cancer (Gorin, 2005), difficulty scheduling appointments, and lack of knowledge (Green & Kelly, 2004; Harewood et al., 2002; Klabunde et al., 2006; Tessaro et al., 2006). The cost of the test (Greisinger et al., 2006; Harewood et al.), concern about pain (Green & Kelly, 2004; Harewood et al.; Janz et al., 2003; Rawl et al. 2004), and objection to the bowel preparation (Harewood et al.; Gipsh, et al., 2004, Greisinger et al.) were also stated as reasons for not getting a colonoscopy. In addition, no perceived need (Janz et al.; Rawl et al.; Tessaro et al.), messiness (Dolan et al., 2004), and for females, not having access to a female endoscopist (Menees et al., 2005) were reported barriers.

Barriers were consistently associated with lower screening rates when the relationship between barriers and CRC screening methods was assessed (Janz et al., 2003; Brenes & Paskett, 2000; James et al., 2002). Janz et al. found that a higher level of barriers was associated with lower rates of flexible sigmoidoscopy completion within the previous five years and (OR=.42, CI=.23-.77) and lower compliance to colonoscopy in the past 10 years (OR=.44, CI=.20-.96). The researchers conducted 355 phone interviews of people 50-79 years old with average risk for CRC. Similarly, Brenes and Paskett found that perceiving fewer barriers (OR=12.57, CI=1.67-94.63) was significantly associated with higher rates of screening with flexible sigmoidoscopy. These researchers surveyed primarily low income African American women, 50 years and older, from North Carolina who were not compliant with CRC screening guidelines for flexible sigmoidoscopy (n=202).

James et al. (2002) found that higher perceived barriers were associated with lower rates of completion of sigmoidoscopies within the past five years (OR=.92, 95% CI=.87-.97) but that higher perceived barriers were not associated with colonoscopy completion. Using telephone surveys, these researchers studied African Americans over 50 years old and who were eligible for CRC screening. The participants were recruited from 12 randomly selected African American churches in rural North Carolina (n=397). The limitations of this study included exclusion of individuals without a telephone and a predominance of females in the sample (72%).

Findings from the study by Frank et al., (2004) showed that higher perceived barriers to CRC screening (FOBT, sigmoidoscopy, colonoscopy, rectal exam, barium enema combined) were significantly associated with low CRC screening compliance

(r=.34, p<.015). These researchers studied 49 African American females over the age of 50 from four churches in four quadrants of Florida. Results were from a survey based on the Champion Health Belief Model Scale. One limitation of this study was a survey return rate of 35% and the sample size was relatively small. Using a survey, Manne et al. (2002) found that siblings (n=504) of CRC patients who reported more barriers to the tests were significantly less compliant with CRC guidelines (any test) than those who were compliant (p<.0001).

Studies showed that higher barriers were associated with lower compliance with FOBT guidelines (Gorin, 2005; Janz et al., 2003). Gorin reported that participants who were noncompliant were more likely to report greater barriers to completing the FOBT (p<.006) than those who were compliant with FOBT. This study was an ongoing cancer screening program for Hispanic women (n=950) who were participating in the National Breast and Cervical Cancer Screening Program in New York City. Janz et al., also found that a higher level of barriers was associated with lower rates of FOBT (OR=.91, CI=.86-.97). The researchers conducted 355 phone interviews of people 50-79 years old with average risk for CRC.

In contrast, Hay et al. (2003) used a multiple regression analyses and found that barriers were not predictive of completion of a FOBT, flexible sigmoidoscopy, or colonoscopy. This was a cross-sectional, descriptive study on women who were at least 50 years old and who did not have CRC (n=280). A limitation of this study was that the women were recruited at a mammography facility and may have been more aware of the need for cancer screening tests.

Since the data related to barriers and completion of various CRC screening tests were somewhat limited, the research related to barriers and compliance with mammography guidelines was reviewed. Most studies found that more barriers were associated with lower mammography compliance (Champion & Skinner, 2003; Rakowski, Fulton, & Feldman, 1993). Using a telephone survey, Champion and Skinner (2003) found that individuals who obtained a mammogram had significantly lower perceived barriers than individuals in other stages of behavior adoption ($p<.0001$). The sample was randomly selected to complete a telephone survey and consisted of 694 women recruited from a health maintenance organization and a general medicine clinic with an average age of 61 years. Additionally, Rakowski et al., found that in their sample of 676 women between the ages of 40 and 70 years old, participants who were not compliant with mammography had more barriers than those who were compliant ($p<.001$).

However, in another study (Champion, 1992), results showed that barriers were not significantly associated with completion of a mammogram. In this study, a survey was used to investigate a probability sample of 322 women, 35 years old or older, from a large metropolitan area in the Midwest.

In summary, similar to the findings in the studies of compliance with mammography, three studies showed that higher barriers were inversely related to compliance with endoscopic CRC screening, but one study showed no relationship. In addition, barriers were associated with decreased compliance with FOBT in two studies and showed no relationship in one study.

Self-efficacy and Compliance with Colonoscopy

Self-efficacy is a concept from the Social Cognitive Theory defined as "the conviction that one can successfully execute the behavior required to produce the outcome" (Bandura, 1977, p. 193). Three studies show that higher self-efficacy is predictive of greater CRC screening (Menon et al., 2007; Hay et al., 2003; Menon et al., 2003). Menon et al. (2007) conducted an intervention study but noted that the purpose of this article was to report results of the post intervention survey not the results of the intervention. Results showed that participants who had higher self-efficacy were more likely to complete a sigmoidoscopy than those with lower perceived self-efficacy ($p<.005$). The sample consisted of 169 individuals over the age of 50 from two sites, one in the Midwest and one in the West. One limitation to this study was the low response rate (25%).

Menon et al. (2003) also conducted a survey at a worksite (n=220) of individuals who were at least 40 years old and found that participants who reported higher self-efficacy were more likely to have ever had a colonoscopy in the past ($p<.001$). However, higher self-efficacy was not significantly associated with ever having an FOBT or having an FOBT in the past year. In a cross-sectional, descriptive study on women who were at least 50 years old and who did not have CRC (n=280), higher self-efficacy scores were significantly associated with completion of colonoscopy, flexible sigmoidoscopy, or FOBT ($p<0.001$) (Hay et al., 2003). A limitation of this study is that the women were recruited at a mammography facility and may be more aware of the need for cancer screening tests.

Other researchers have also found that self-efficacy was not predictive of having a sigmoidoscopy in the previous five years or FOBT in the past year, based on the baseline data collected for a randomized controlled trial. The intervention was an educational video. The 193 participants were at least 50 years old and were recruited from a community health clinic in Texas (Freidman, Webb, & Everett, 2004). In another study by Freidman et al. (2001), a randomized control study was conducted with 160 participants 50 years or older and found that higher self-efficacy was not associated with a higher FOBT completion. In addition, the results of a survey conducted by Dassow (2005) showed self-efficacy was not predictive of compliance with screening recommendations (FOBT, sigmoidoscopy, and colonoscopy combined) in a sample of 125 mostly Caucasian women living in Kentucky who were at least 52 years old. One limitation of this study is the low response rate (30%).

Since the research regarding self-efficacy and CRC screening was somewhat limited, other health promotion literature was reviewed. In a cross-sectional, descriptive study conducted in Cyprus, self-efficacy was shown to be the most predictive factor related to the intent to be screened with mammography (Tolma, Reininger, Evans, & Ureda, 2006). These researchers studied 293 women aged 40-65 who had never been screened with mammography. In addition, the results of the study by Dassow (2005) showed higher self-efficacy was positively related to completion of mammography (OR=4.29., 95% CI=1.31-14.07). The researchers surveyed 125 mostly Caucasian women living in Kentucky who were at least 52 years old. One limitation of this study is the low response rate (30%). On the other hand, self-efficacy was not found to be predictive of adhering to ACS guidelines for annual screening mammography in a

descriptive, retrospective, cross-sectional study of 111 African American women and 64 Caucasian women who were 40 and older (Russell, Perkins, Zollinger, Champion, 2006).

In review, studies on the relationship between self-efficacy and endoscopic screening were inconclusive. Three studies found that self-efficacy was positively related to compliance with endoscopic CRC screening, whereas two studies showed self-efficacy was not predictive of compliance with endoscopic CRC screening. Two out of three studies showed self-efficacy was positively related to compliance with mammography.

Embarrassment

Prior to this study, embarrassment was an understudied barrier and, as a result, few interventions have been developed to reduce or eliminate this barrier. Therefore, embarrassment was differentiated from the other barriers since it was a variable of particular interest in this study. The concept of embarrassment will be the focus of this section beginning, first, with a definition of embarrassment. Second, studies related to the development of categories of embarrassment and the tendency to try to avoid embarrassment will be reviewed in order to provide background information from the psychology literature. Third, the research concerning the relationship between embarrassment and CRC screening compliance will be reported in two sections: 1) the research studies related solely to endoscopic CRC screening and, 2) the studies where the researchers have not separated the types of CRC screening tests but rather have grouped several tests under the umbrella of CRC screening.

Definition and Background Psychological Studies

Embarrassment was conceptually defined as an emotion associated with "a sudden and intense but temporary uneasy, awkward, self-conscious, exposed feeling that

can be strong or weak, ranging from mild awkwardness or uneasiness, and uncertainty to strong sensations of incapacitation, blushing and a desire to escape" (Miller, 1992, p. 192). Modigliani (1968) was the first to examine, in depth, the concept which he called embarrassability or "general susceptibility to embarrassment" (p. 316). He studied individual responses to embarrassing situations including *pratfalls* (humiliating blunder), an *inadequate response to an unanticipated occurrence, being the center of attention, observing someone else in an embarrassing situation,* and an *incident involving the opposite gender that was out of the norm* (i.e. a woman walking into the men's restroom) and found embarrassability was highly correlated with feelings of inadequacy. Modigliani also used tools to assess empathy, self-esteem/instability of self-esteem, test anxiety, feelings of inadequacy, and need for social desirability. Embarrassability was shown to be highly correlated with feelings of inadequacy. A criticism of this study is that only one gender (males) was tested.

In one study, Miller's (1992) research aim was to "create a comprehensive list of embarrassing predicaments" (p. 190). Participants were high school and college students (n=80) who were asked to complete Modigliani's Embarrassability Scale (Modigliani, 1968), write a description of their last embarrassing situation, and rate the intensity of the situation on a scale of 1-4. The embarrassing situations were analyzed and grouped. Miller (1996) later made modifications to the categories outlined in the article and the list included *awkward interactions*, *failure of privacy regulation* (private thoughts, actions, or anatomy were made public), *undue sensitivity* (overreacting to ordinary situations that typically produced only mild awkwardness), *loss of control over body* (inadvertent

inability to restrain a bodily function), *departure from personal goals* (behavior or appearance that was incongruous with one's own standards or expectations).

Edelman (1985) wanted to test his hypothesis that embarrassment was associated with public self-consciousness and a desire to conform to others. Using the Self-Consciousness Scale, Self-Monitoring Scale, and the Embarrassability Scale, 100 part-time "mature" (p. 224) psychology students were surveyed. Edelman's hypothesis was supported by the significant positive correlation between the Embarrassability Scale and the Public Self-Consciousness Scale ($r=.39$, $p<.001$).

Studies have also shown that individuals try to avoid embarrassment. Foss and Crenshaw (1978) found that 72% of the sample picked up a box someone else had dropped when the box contained envelopes. However, only 47% of the subjects picked up the box when it was apparent that the contents were tampons ($p<0.05$). These researchers used a 2 x 2 factorial design and a sample consisting of 32 males and 32 females. Brown and Garland (1971) studied 72 undergraduate psychology students and found that those who were randomly told they were incompetent singers sang for shorter periods of time than those who were told they were competent singers ($p<.01$) although the participants were paid for singing by the minute. Also, the shortened singing time was associated with higher self-reported embarrassment ($p<.01$). Additionally, the most frequent way college students aged 17-27 ($n=242$) reported they would end an embarrassing situation was to "leave or hide" (p. 481) (Parrott & Smith, 1991). The psychology literature was helpful in understanding embarrassment but more studies need to be conducted on populations other than undergraduate students and studies are needed in the context of health care.

To summarize, studies by researchers in the discipline of psychology have identified various situations that are perceived as embarrassing. Additional studies showed that individuals tried to avoid embarrassment. However, little research has been done with individuals 50 and older with regard to embarrassment in the context of tests for cancer screening, specifically colonoscopy.

Embarrassment Associated with CRC Screening

Some researchers investigated only endoscopic methods of screening, whereas other researchers studied several methods of screening. Some of the researchers in the later group examined multiple methods of screening, but isolated the findings related to endoscopic methods. The relationship between embarrassment and endoscopic screening is discussed in the first section. In the second section, the researchers have grouped several screening methods in into an outcome variable called *CRC screening*. This section reports the relationship between *CRC screening* and embarrassment.

Embarrassment associated with endoscopic CRC screening tests.

In this section, studies that examine the relationship of embarrassment and endoscopic CRC screening will be reported. The percentage of participants who identified embarrassment related to endoscopic CRC testing ranged from 7% in Australians (Nicholson & Korman, 2005) to 57% in a group of participants that were contemplating a colonoscopy in the next 6 months (Rawl et al., 2004). This section includes both quantitative and qualitative findings. The surveys provided quantitative data related to the level of embarrassment and the qualitative data elucidated sources of embarrassment.

Embarrassment has been cited as one of the barriers to getting a colonoscopy (Harewood et al., 2002; Kelly & Shank, 1992; Nelson & Schwartz, 2004; Lewis and Jensen, 1996; Denberg et al., 2005; Janz et al., 2003; Stockwell et al., 2003; Gipsh et al., 2004; Walsh et al., 2004; Codori et al., 2001; Rawl et al., 2004; Wardle et al., 2003 Nicholson & Korman, 2005; Busch, 2003). In the prospective, controlled study by Harewood et al., 30% of the participants who had never been screened with a colonoscopy cited embarrassment as one of the top reasons why they did not want a colonoscopy (66% bowel prep, 43% fear of discomfort, 35% doctor did not recommend, and 30% embarrassment). Subjects were patients at the Mayo Clinic Outpatient Division of Gastroenterology (n=258) who were being seen for reasons other than lower GI concerns. Many respondents (n=126) reported never being screened and of those, 21% (29% women and 18% men) stated being able to choose the gender of the endoscopist would improve the colonoscopy experience. One critique of this study was that although the participants were not having lower gastrointestinal problems, they may have been more sensitive to gastrointestinal issues than the general population.

Additionally, in an interventional study, Kelly and Shank (1992) found that individuals who stated that it *would be embarrassing to have a flexible sigmoidoscopy* were significantly less likely to get a sigmoidoscopy compared to participants who did not agree that the test would be embarrassing ($p<.001$). The intervention consisted of a brochure about CRC screening for early detection and a reminder telephone call in one week. The sample in this study (n=333) consisted of patients in a family practice residency clinic who were over 50 years old and primarily Caucasian (97%).

The results of the study by Nelson and Schwartz (2004) showed that the level of embarrassment related to a colonoscopy was second only to that of a barium enema. Using a survey with a Likert-like scale of 1-4 with 4 being the highest level of embarrassment, the mean score for embarrassment related to a barium enema was 3.15, colonoscopy was 3.07, sigmoidoscopy 2.38, and FOBT 1.40. The study was conducted with 80 subjects including 54 participants who had never had any type of CRC screening. The convenience sample was obtained from parents and grandparents in a pediatrician's office and people at a nearby church (M=38.3 years and range of 18-54 years). One limitation of this study is the relatively young population tested.

Lewis and Jensen (1996) also found that embarrassment was significantly negatively associated with participants who had not had a screening sigmoidoscopy compared to those who had (p=.001). The researchers surveyed 236 individuals 50-75 years old who received care at a university-based general medicine clinic in Wisconsin. About half (48%) had never been screened before. Likewise, Denberg et al. (2005) conducted a qualitative study and interviewed 52 participants 50 years and older who did not complete colonoscopic screening and found *concerns about modesty* to be a significant barrier to the test (p=.01).

Similarly, Janz et al. (2003) found that for FOBT, sigmoidoscopy, and colonoscopy, the most common barrier to CRC screening was *no perceived need/no problem* and the second was *embarrassment*. For sigmoidoscopy and colonoscopy, 35% or more listed embarrassment as a barrier compared to 25% for FOBT. The researchers conducted 355 phone interviews of people 50-79 years old with average risk for CRC. One limitation to this study was that individuals without phones were excluded.

Stockwell et al. (2003) also investigated barriers and found that the most common reason women had not had endoscopic screening for CRC was because the physician had not recommended it (36%). Other commonly reported reasons included "fear of pain/discomfort (25%), embarrassment (14%), inconvenience (11%), expense (3%), and fear of the results (2%)" (p. 1877). The sample surveyed was comprised of women who were undergoing a screening mammogram (n=438). Additionally, women were less likely to have been screened if they preferred a female endoscopist. Similarly, in a study by Gipsh et al., (2004), barriers to colonoscopic screening identified, in descending order based on means scores, were discomfort (M=3.00, SD=1.21), embarrassment (M=2.90, SD=1.19), inconvenience (M=2.86, SD=1.00), distaste (M=2.81, 1.04), worry (2.60, SD 1.08), and objection to special diet (2.00, SD=1.13). A convenience sample (n=42) of subjects (47-83 years old) located in a waiting room in a general practitioner's office in California was surveyed. One of the limitations of the study was that there may have been a language barrier with the multicultural sample.

Embarrassment was also shown to be a barrier to endoscopic CRC screening in other diverse populations (Walsh et al., 2004). These researchers studied a diverse sample (n=775) that included Caucasian (44%), Latino (29%), and Vietnamese (30%) individuals. Seventeen percent of Caucasians, 25% of Latinos, and 11% of Vietnamese reported that having a colonoscopy or sigmoidoscopy would be embarrassing. Some (39%) reported having a sigmoidoscopy in the past and 29% had had a colonoscopy. This was a cross-sectional, correlational study and the telephone survey was read in the preferred language (English, Vietnamese, or Spanish).

In addition, embarrassment was found to be a barrier for first-degree relatives of CRC patients. In a study by Codori et al. (2001), embarrassment was the only barrier that differentiated individuals who had an endoscopic exam from those who had not. The sample was recruited through the Johns Hopkins Tumor Registry (n=1160). Some limitations of this study included having 5% of families contributing five or more participants to the sample, and the higher than usual rate of compliance with colonoscopy in this group. Rawl et al. (2004) also found embarrassment to be a significant barrier to colonoscopy in their sample of 257 first-degree relatives of CRC patients ($p<.006$). A cross-sectional study design was used in the study conducted in two Midwestern communities using phone interviews.

Embarrassment as a barrier to endoscopic CRC screening was not limited to Americans populations. Wardle et al. (2003) found embarrassment was an issue, but the intervention used was effective in reducing negative attitudes (i.e. concern about embarrassment or pain) and encouraging greater completion of screening flexible sigmoidoscopies ($p<.05$). These researchers conducted a randomized controlled trial in the United Kingdom with individuals who said, in a survey, that they would *probably* get a sigmoidoscopy (n=2966). The intervention group received an educational booklet including coping strategies for overcoming barriers, and the control group did not.

In addition, Nicholson and Korman (2005) studied an Australian sample (n=447) and found 8% who had a colonoscopy and 7% who had a sigmoidoscopy reported that they found the test embarrassing. The aim of the study was to determine the participant's experience with a colonoscopy using sedation or a sigmoidoscopy without sedation. The questionnaire for both the colonoscopy and the sigmoidoscopy asked if the experience

was embarrassing. There were numerous criticisms of this study, including the fact that only the questionnaire for the sigmoidoscopy included *embarrassment* as one of the options for the question about *the part of the test that concerned you the most*. In addition, only the colonoscopy questionnaire asked the reason the participant was having the test, so comparison was not possible.

Busch (2003), using a focus group of elderly African-American women (n=13), found that over half of the women had never had any type of CRC screening. One of the reasons cited for not getting CRC screening was embarrassment (15.4%). Participants in this convenience sample ranged in age from 45-69 years old. A criticism of the study is that the title says that the article discusses knowledge and beliefs of *elderly* African-American women when in fact, 38.5% of the group was 49 years old or less and only one participant was at least 65 years old.

Although some focus group participants mentioned embarrassment as an issue related to colonoscopic examination, embarrassment was not a problem for all. McCaffery et al. (2001) interviewed 30 men and 30 women who did not respond to a written invitation or responded but declined participation related to a study offering flexible sigmoidoscopies. The aim of the study was to learn more about the reasons potential subjects did not participate. Low perceived susceptibility was the most common reason for not participating and the authors note that other factors such as embarrassment, pain, or unpleasantness of the test were not mentioned by subjects very often.

In summary, research showed that embarrassment was a significant barrier to compliance with endoscopic CRC screening. This relationship was found in both qualitative and quantitative studies and in various diverse populations.

Embarrassment and CRC screening.

Some researchers grouped several screening methods in into an outcome variable called *CRC screening*. This section reports the relationship between *CRC screening* and embarrassment (Janz et al., 2003; Tessaro et al., 2006; Weinberg, Turner, Wang, Myers, & Miller, 2004; Green & Kelly, 2004; Bastani et al., 2001; Rawl et al., 2000; Beeker et al., 2000; Greisinger et al., 2006). The screening methods that are grouped into *CRC screening* are not consistent among these studies. For example, Janz et al. defined CRC screening as having had any one of the following tests-FOBT, sigmoidoscopy, or colonoscopy. Alternately, Tessaro et al., defined having CRC screening as having had a sigmoidoscopy, barium enema, or colonoscopy. If the methods of testing were reported, the types of tests are included in the discussion of the study. In the studies examined in this section, the percentage of participants that identified embarrassment related to CRC screening ranged from 0% (Weinberg et al.) to 75% (Green & Kelly).

In a cross-sectional, descriptive study of 100 African Americans in a low income urban housing unit, Green and Kelly (2004) found nearly three quarters of the women identified *embarrassment* as a barrier to CRC screening (FOBT, sigmoidoscopy, colonoscopy, and double contrast barium enema combined). However, 60% of the sample had had a flexible sigmoidoscopy or colonoscopy in the past two years.

From seven focus groups of Hispanic, African Americans, and Chinese individuals conducted by Bastani et al. (2001), it was found that "once the screening tests were described to them, men from all groups expressed a general sense of embarrassment or discomfort at getting screened for colon cancer" (p. 76). Some comments from the men included, "As males, there is a bashful thing and embarrassment, I feel embarrassed

when I bend over just to look at my behind (African American male) and a Chinese man said, “It is embarrassing to ask questions” (p. 76). The researchers also commented that most women also reported embarrassment because of the types of tests used for screening. One African American female commented that she felt the sigmoidoscopy she had was “more embarrassing than painful” (p. 77). Additionally, both Chinese and Hispanic women expressed a sense of taboo about discussing body parts such as the anus. Each focus group consisted of people of the same race/ethnicity and gender except for one mixed gender African American group (n=57). This same article reported results of a telephone survey that about one third of the first-degree relatives of individuals diagnosed with CRC (n=67) expressed embarrassment about CRC testing (FOBT, sigmoidoscopy/colonoscopy combined).

Rawl et al., (2000) found first degree relatives of CRC patients frequently cited embarrassment as a barrier to CRC screening tests (FOBT, sigmoidoscopy, and colonoscopy) in focus studies. Discussing “private matters” (p. 35) and having “her bottom up in the air” (p. 36) were two factors related to embarrassment. These researchers conducted focus groups with people at increased risk for CRC in order to identify perceived barriers and benefits of CRC screening.

Of those that had not had screening, less that 10% cited embarrassment as the barrier to screening in a study by Tessaro et al. (2006). These results were obtained from focus groups (n=205) of individuals from the Appalachian area who were asked if they had ever had CRC screening (FOBT, sigmoidoscopy, barium enema, or colonoscopy).

Beeker et al. (2000) conducted 14 focus groups, with 10-11 participants each, in Atlanta, Philadelphia, and Overland Park, Kansas. The groups were stratified by age (50-

64, 65 and older) and gender. Although CRC was described as embarrassing and a "private disease" (p. 270), participants were open in their discussions during the focus groups. One of the themes identified as embarrassing was *interactions with kin, friends, and partners*. Subjects made comments such as, "I can talk to my son, a physician, about anything but this", "rectal exams are not table talk" and that the disease seemed more "private" since it was not publicized in the mass media as much as other diseases such as breast or prostate cancer (p. 270). The researcher reported that the participants seemed relieved to be able to talk about CRC and CRC screening tests.

Greisinger et al. (2006) queried two focus groups of people 50 years or older, one in 2001 and another in 2003, about their knowledge of colorectal screening tests (FOBT, sigmoidoscopy, and colonoscopy combined). The 2001 sample consisted of 19 participants (89% female) and the 2003 sample was comprised of 23 subjects (56% female). Six questions were asked including one question specifically about barriers, "Is there anything that keeps you from getting screened for colorectal cancer?" "Embarrassment about CRC test procedures" (p. 69) was one of the major themes identified. The authors report that the participants had an "overall sense of embarrassment" (p. 70) and a few "expressed strong negative feelings" (p. 70) about CRC screening and said it was "too embarrassing to undergo a test" (p. 70). Some weaknesses of the study include not providing quantitative data about the numbers of people who voiced embarrassment as a barrier to CRC screening, and the first sample had an imbalance of females. Interestingly, the study did not find differences in the concerns of the participants after two years.

In summary, some researchers did not differentiate which CRC screening tests were studied; rather they used a general outcome of *CRC screening*. The various researchers were not consistent in the CRC screening tests included under this umbrella term. Between 10% and 75% of the individuals in the studies identified CRC screening tests as embarrassing. Comments from participants in focus groups also identified as CRC screening tests as embarrassing.

Embarrassment related to Predisposing Variables, Barriers, Self-efficacy, and Stage of Adoption

In this section, the relationships among embarrassment, demographic/personal characteristics, cue to action, barriers, self-efficacy, and stages of adoption will be discussed. First, the relationship among demographic/personal characteristics, cue to action, and embarrassment will be described. Second, the relationships among barriers in general, self-efficacy, and embarrassment will be reported. Third, the research findings about the relationship between stages of adoption and embarrassment will be described.

Demographic/Personal Characteristics, and Embarrassment

Embarrassment and Demographic Variables

Research on relationships among embarrassment and demographic variables (age, gender, income, education level, and marital status) is limited; most of the research on embarrassment has been conducted with undergraduate students and outside of the context of healthcare. The results of the available studies are reported in the following section.

Embarrassment and age.

There is a paucity of research about the association between embarrassment and age in the nursing and medical research. However, Honda and Gorin (2005) found that in Japanese Americans, older age was associated with less embarrassment with CRC screening ($p<.01$).

Literature on embarrassment and its relationship with age is limited in the psychology literature also. However, Carstensen, Pasupathi, Mayr, and Nesselroade (2000) found that there was a steady decrease in negative emotions, which included embarrassment, from 18 to 60 years of age. At 60 years, the amount of negative emotions leveled off. These researchers conducted a study of 184 individuals aged 18-94 years ($M=55$, $SD=20.4$) over a one week period. During this time, the participants, 54% women and 46% men, were instructed to record the degree to which they experienced 19 emotions during their daily lives on a seven-point response scale ranging from 1) *not at all* to 7) *extremely* each time they were paged by the investigators. The participants were paged five times each day at various times of the day from 9 a.m. to 9 p.m. One of the limitations of this study is that the time frame for the study was only one week.

Embarrassment and gender.

Research findings in the healthcare literature showed women were significantly more embarrassed about having a flexible sigmoidoscopy than men ($p<.01$) (Farraye et al., 2004). In this study, 14% of the women and 2.5% of the men reported that they were *very embarrassed* about having a sigmoidoscopy. Individuals ($n=554$) who were free of symptoms of CRC and who were at least 50 years of age were recruited to complete a survey one week after their routine health-care appointment (56% response rate).

Willingness to get a flexible sigmoidoscopy was more dependent on having an endoscopist of the same gender for females than for males ($p<.01$).

In a study by Menees et al. (2005), 43% of the women surveyed (n=202) preferred a female endoscopist (96% response rate) and embarrassment was cited 75% of the time as the most common reason for the gender preference. The preference for a same gender endoscopist was intense as 87% were willing to wait more than 30 days for the preferred gender, 14% were willing to pay more, and 5% stated they would not have a colonoscopy done if they could not have a female endoscopist. The sample consisted of women aged 40-70 years old (M=53) from four outpatient primary care offices.

The studies reported in the psychological literature typically show that females are more embarrassable than men (Miller, 1992, 1995; Sabini, Siepmann, Stein, & Meyerowitz, 2000). Miller (1992) found that females reported their embarrassing situations as more intense than males ($p<.06$), and women scored significantly higher in embarrassability than men ($p<.001$). Participants were high school and college students (n=80) who were asked to complete Modigliani's Embarrassability Scale (Modigliani, 1968), write a description of their last embarrassing situation, and rate the intensity of the situation on a scale of 1-4. Similarly, Sabini et al. found that women reported more embarrassment related to *committing faux pas* when using a sample that was primarily college students (n=78). On the other hand, there was no difference in the genders related to being the *center of attention* or in *sticky situations*. In 1995, Miller again found that women had significantly more embarrassability than men and also more *fear of negative evaluation.* Miller recruited 310 undergraduate psychology students to complete 10

questionnaires designed to measure embarrassability, self-consciousness, social skill, fear of negative evaluation, and positive and negative affect.

In contrast, Sabini, Garvey, and Hall (2001) found there was no difference in the level of embarrassment expected when comparing the responses of male and female undergraduate college students (n=46). The participants were asked to rate the embarrassment they thought they would feel if the specific scenarios presented did or did not involve them.

To summarize, most of the psychology research showed that women were more embarrassable than men. In addition, women were found to be more embarrassed about having endoscopic CRC screening than men, and having an endoscopist of the same gender was more important for women than for men.

Embarrassment, income, education level, and marital status.

Data related to the relationships among embarrassment, income, education level, and marital status were very limited. No studies were found that examined the relationship between income and level of embarrassment. One study found a relationship between level of education and embarrassment. Honda and Gorin (2005) found that lower education ($p < .05$) was associated with increased embarrassment in Japanese Americans. One study showed that individuals living with an intestinal ostomy who did not have a partner reported higher levels of embarrassment about their ostomy than individuals who did not have a spouse/partner ($p<.001$) (Mitchell et al., 2007).

Embarrassment and Personal Characteristics

Embarrassment, BMI, and CRC knowledge.

There was no information concerning embarrassment and CRC knowledge, and the literature did not provide support for a relationship between embarrassment and BMI. However, there were data concerning a related topic, the relationship between BMI and body image. Using surveys, Sarwer, Waddem, & Foster (1998) studied the source of obese women's dissatisfaction with their bodies. Ten percent of the obese women and none of the non-obese women were dissatisfied with their entire bodies. Eight percent of the obese women were dissatisfied with their lower bodies, but none of the non-obese were. In both the obese and non-obese, 5% of the women were dissatisfied with their buttocks. There were 79 obese participants and 43 controls in this clinical trial and the average age of participants was 45.14 (SD$\pm$ 9.57) years.

Fredrickson, Roberts, Noll, Quinn, and Twenge (1998), conducted two experiments and found that higher BMI predicted greater body shame. In the first experiment, 72 undergraduate women were told they were testing products and given either a sweater or swim suit in the size of their choosing to try on and then asked to taste test cookies. The participants were also weighed and completed a survey on body shame and self objectification (thinking and valuing their own body from a third person perspective rather than a first person perspective). The researchers found that BMI was positively correlated with body shame such that as the BMI increased, body shame increased. Additionally, higher self-objectification was associated with increased body shame, and body shame predicted restraint in the amount of cookies eaten. The greatest body shame was found in the women who tried on the swim suits and had the highest

self-objectification scores. Experiment 2 was similar to Experiment 1 but involved undergraduate men (40) and women (42). The researchers found that compared to men, only women restrained eating and had body shame, when trying on the swimsuit.

Embarrassment and Stages of Adoption

Embarrassment has been related to stages of adoption in some studies and the findings were mixed. First-degree relatives of patients with CRC (n=257) were studied by Rawl et al. (2004) and findings showed precontemplators and contemplators were significantly more likely to perceive a *colonoscopy as embarrassing* than actors (p=.006). Forty nine percent of the precontemplators, 57% of the contemplators, and 33% of those in action reported embarrassment as a barrier to colonoscopy. A cross-sectional study design was used in the study conducted in two Midwestern communities using phone interviews.

On the other hand, Brenes and Paskett (2000) found that stage of adoption was not related to embarrassment. All individuals, despite their stage of adoption, reported relatively high levels of embarrassment such that 45% of precontemplators, 42%, contemplators, and 58% of actors reported that *a rectal exam was embarrassing*. The researchers surveyed primarily low income African American women from North Carolina who were not compliant with CRC screening guidelines for flexible sigmoidoscopy (n=202).

Since the data related to embarrassment and stage of adoption for CRC screening were limited, data concerning other cancer screening tests were sought. Like Rawl et al. (2004), Champion and Skinner (2003) found that actors reported significantly less embarrassment than precontemplators in regard to getting a mammogram (p<.001). The

randomly selected sample of 694 women, with an average age of 61 years, completed a telephone survey. They were recruited from a health maintenance organization and a general medicine clinic.

Instruments to Measure Embarrassability and Embarrassment

Two instruments to measure embarrassability/embarrassment have been tested. One instrument measures embarrassability (Modigliani, 1968) in certain situations, and another instrument measures embarrassment by using personality trait-based statements (Kelly & Jones, 1997). The next section will discuss these two instruments.

Embarrassability Scale

The most well known instruments to measure embarrassability are the Embarrassability Scale designed by Modigliani (1968) and the modified Embarrassability Scale by Miller (1987) as cited by Robinson, Shaver, & Wrightsman, 1991. The original Embarrassability Scale is a 26 item instrument that uses a 9-point scale to determine how much embarrassment people think they would experience in certain situations. For the original Embarrassability Scale, the Cronbach's alpha was established at .88. Examination of convergent validity revealed that the scale was moderately (r=.33) correlated with embarrassment in real situations (Modigliani) but discriminant validity has not been published (Robinson et al.). The modified Embarrassability Scale also has 26 items but uses a 5-point response scale and more gender neutral wording. The Cronbach's alpha for the modified scale was also .88. Higher scores on both scales suggest more embarrassability (Robinson et al.).

Susceptibility to Embarrassment Scale

Another tool used to measure embarrassment is the Susceptibility to Embarrassment Scale (Kelly & Jones, 1997) which uses personality trait-based statements, rather than situations, to measure a person's vulnerability to embarrassment. Similar in length to Modigliani's Embarrassability Scale (Modigliani, 1968), this instrument consists of 25 items to measure "unpleasant aspects of interpersonal exposure which lead to a perceived loss in public esteem" (p. 328). Kelly and Jones also use a 7-point response scale. The authors sum the responses for a total score ranging from 25-175 such that higher scores indicate more embarrassment. The coefficient alpha was .92 and the correlation of the scale with the criterion item "I am easily embarrassed" (p. 322) was .75. Additionally, the Susceptibility to Embarrassment Scale correlated with the Embarrassability Scale (r=.60). Kelly and Jones also found that higher scores on their scale were consistent with higher scores on Modigliani's Embarrassment Scale. This tool has been used less often than Modigliani's instrument and needs further testing (Maltby & Day, 2000). Criticisms of both Embarrassability Scales and the Susceptibility to Embarrassment Scale are that none of them assess embarrassability in the context of healthcare and the instruments were developed using only undergraduate college students (Miller, 1987, 1992, 1995; Maltby & Day; Kelly & Jones).

Gaps in Knowledge

Although there are some data available, there are gaps in the scientific body of knowledge related to colonoscopies and embarrassment. A review of the literature showed that the data related to the relationship between educational levels, an individual's BMI, self-efficacy and compliance to endoscopic CRC screening guidelines

were limited and equivocal. Additionally, there is a dearth of data about relationships between embarrassment and age, income, education, marital status, BMI, and CRC knowledge. Although some psychological research was helpful, most of the research on embarrassment has been conducted with undergraduate college students and outside of the context of healthcare. Little data exist related to the sources or types of embarrassment related to anticipation of a colonoscopy, which is complicated by the lack of a reliable and valid instrument for measurement. This study aims to add to the body of knowledge in regard to the aforementioned deficits by development of an instrument for measuring this concept.

Summary

Colorectal cancer is the third leading cause of cancer-related deaths in the United States. Effective screening tests are available, yet individuals are not getting screened. The most effective test is the colonoscopy because identification of the adenomatous polyps and subsequent removal can be done in one procedure. Although the test is considered the "gold standard", it is invasive. There are numerous barriers to obtaining a colonoscopy and one of the ones commonly mentioned is embarrassment. Embarrassment is a barrier for between 7 and 75% of the population. The two models used for the theoretical framework for this study are the HBM and TTM. The theoretical and empirical data related to these two models were reviewed.

The data related to demographic variables (age, gender, income, education level, and marital status), personal characteristics (BMI and CRC knowledge), cue to action (physician recommendation), and the association with the completion of a colonoscopy or change in stage of adoption were reviewed. The results of the studies related to

embarrassment, other perceived barriers, self-efficacy, and colonoscopy compliance were also discussed.

Additionally, the concept of embarrassment, according to Miller (1992, 1996), and the psychological studies related to embarrassment were presented. The research findings concerning the demographic/personal characteristics, and the relationship to embarrassment were also reported. Finally, the two existing instruments to measure embarrassment and embarrassability were described.

In conclusion, studies have provided a considerable amount of information about barriers to colonoscopy and, to a lesser degree, embarrassment as a barrier. However, little is known about the sources of embarrassment related to a colonoscopy. The purpose of this study was to address this gap in the scientific body of knowledge by testing the psychometrics of a new instrument created for this reason. Improving the understanding of the role embarrassment plays in compliance with colonoscopy, and identifying the sources of embarrassment will enable interventions to be developed to reduce or eliminate embarrassment as a barrier. As a result, more individuals will obtain screening through a colonoscopy and more lives will be saved from this devastating, yet preventable, cancer.

CHAPTER THREE

METHODOLOGY

This chapter describes the methods that were used in this study. Included are a discussion of the study design, plan for protection of human subjects, data collection procedures, and data analyses plans. The methods used to establish content validity and the results of cognitive interviewing related to a new instrument, CES, are also described.

Study Design

A cross-sectional, descriptive research design was used for this study. Data were collected using a self-administered mailed survey. The survey yielded both quantitative and qualitative data to address the research questions.

Setting

Participants were recruited from the Order of Saint Francis Health Plan (OSF-HP), a Health Maintenance Organization (HMO) in Illinois. OSF-HP was part of the Order of Saint Francis Healthcare System, which has its corporate offices in Peoria, Illinois. Order of Saint Francis Healthcare System has six hospitals in Illinois and one in Michigan. The largest hospital, OSF Saint Francis, is a 616 bed tertiary care teaching facility.

OSF-HP has over 75,000 members from 32 counties in central and northern Illinois. Over 10,000 members are 50-64 years of age. At OSF-HP, no single method of CRC screening was encouraged more than another. Providers were reminded to encourage patients to have CRC screening through a provider newsletter, a blast fax, and preventive guidelines, which were each mailed to the providers annually. Additionally, preventive health guidelines were on the HMO website, including recommendations for

CRC screening. The rate of members who had a screening colonoscopy in the time period from 2000-2007 was 42.7%. Additionally, there was no "out-of-pocket" cost to members for a screening colonoscopy (personal communication, K. Stolz, December 30, 2007).

Sample and Eligibility Criteria

The sample consisted of people with current membership in OSF-HP. The goal was to have equal numbers of people who had a screening colonoscopy within the past 10 years (compliant with colonoscopy) and individuals who had no previous experience with colonoscopy (not compliant and colonoscopy naïve). The individuals who had not had a colonoscopy would also not be adherent to another CRC screening test. OSF-HP members were eligible to participate if they were aged 50-64 years old. Exclusion criteria included: 1) a personal history of CRC, inflammatory bowel disease, or total colectomy; 2) having had a colonoscopy for a reason other than screening; 3) ever having a sigmoidoscopy or barium enema; 4) or having completed an FOBT using a take home kit within the last 12 months.

Individuals over 64 years old were excluded due to the more stringent governmental regulations that must be met in order to study of the Medicare population. Individuals who had a personal history of CRC, inflammatory bowel disease, total colectomy, or who had a colonoscopy for diagnostic purposes were excluded because it could be argued that these individuals had a greater incentive for completing a colonoscopy than individuals of average risk. Individuals who had a sigmoidoscopy or barium enema in the past were excluded because these tests are invasive and are done without sedation/pain medications. These two aspects of the tests might bias the participants' opinions about another invasive procedure, screening colonoscopy.

Participants who had an FOBT in the past 12 months were up-to-date with CRC screening guidelines, and therefore there was no reason for their doctor to recommend or order a colonoscopy. The purpose of the exclusion criteria was to select participants with average risk for CRC who had never had a colonoscopy and who were not biased by other invasive tests for CRC.

A desired sample size of at least 200 was calculated based on numbers required to address the specific aims. In order to conduct the principal components analyses to determine construct validity of the CES, guidelines recommended 5-10 participants per item (Devellis, 2003; Tinsley & Tinsley, 1987). This analysis would require 75-150 subjects for this 15-item scale. Furthermore, it was determined, based on a power analysis, that a sample of 194 subjects was needed to detect a .20 correlation between embarrassment scores and colonoscopy compliance. At least 200 completed, usable surveys were needed to conduct these analyses (J. Wu, personal communication, January 15, 2008).

Recruitment

Four hundred potentially eligible participants were identified by OSF-HP personnel based on reviewing the database. The International Statistical Classifications of Diseases and Related Health Problems (ICD) codes and current procedural terminology (CPT) codes were used to exclude individuals meeting the exclusion criteria. The number of participants (n=400) who would be mailed surveys was chosen based on an estimated 50% return rate. Participants were randomly selected by Excel random sorting. The sample was stratified based on gender and compliance with colonoscopy and matched according to age.

Based on the number of surveys returned after the initial mailing, it became apparent that more participants needed to be recruited in order to obtain at least 200 usable surveys. Only 166 usable surveys had been collected, but the number of males and females responding was nearly equal (67 and 69 respectively). However, only 40% of the usable surveys were completed by participants who were not compliant with colonoscopy, whereas 60% were completed by individuals who were compliant. Based on a 50% return rate, with about two thirds of the returned surveys being usable, surveys were mailed to an additional 180 potential participants. Of the 180 surveys mailed, 60% of the surveys were sent to participants who were not compliant with colonoscopy (n=110) and 40% were sent to participants who were compliant with colonoscopy (n=70).

Protection of Human Subjects

Precautions were taken to protect human subjects. Recruitment procedures were developed to be consistent with Health Insurance Portability and Accountability Act (HIPPA) guidelines. The information that would identify an OSF-HP member was known only to OSF-HP personnel. OSF-HP developed a database that contained pertinent information and assigned an identifying code to the member. The materials mailed to each member had this unique identifying code. The researchers knew the individuals only by identifying code. The study was approved by the Institutional Review Board of Indiana University Purdue University at Indianapolis and the Peoria Institutional Review Board, Peoria, IL prior to commencement of the study and prior to mailing surveys to the second group of participants. The introductory letter included a statement that participation was completely voluntary. OSF-HP members were provided a phone number to call if they had questions.

The risks to participants were minimal and limited to mild anxiety, fear, or embarrassment. Answering survey questions may have caused participants to explore personal feelings about having a colonoscopy and potential sources of embarrassment. No participants expressed distress as a result of the survey, but if distress was experienced, a plan was in place. If a participant called the phone number for the designated HMO representative, the HMO representative would refer the participant to the researcher who would discuss the concerns with the participant. The researcher had experience as a family nurse practitioner and was competent in recognizing emotional distress. Emotional support would be provided and a referral would be made for additional counseling if necessary. Additionally, the researcher was available by phone Monday through Friday from 8 am to 5 pm for participant questions or concerns conveyed to the researcher through the HMO representative.

All possible measures were taken to protect confidentiality. The researcher had the survey results but not the identifying information of the participants. OSF-HP personnel possessed the personal identifying information of the members but not the individual survey results. The researchers and OSF-HP personnel did not share information. However, aggregate data were shared with OSF-HP personnel following completion of the study. OSF-HP personnel kept the database password-protected as did the researcher.

Data Collection

OSF-HP personnel created a database of the individuals who were selected for the study and they were grouped by gender and whether or not the participant was compliant (had a colonoscopy in the past 10 years). The participants were matched according to age.

The database also included the individual's name and address. An identifying code was then assigned to each individual by OSF-HP personnel. This database, *excluding* the names and addresses was then submitted to the researcher.

Packets containing an introductory letter (see Appendix A); the self-administered survey; a postage stamped and addressed return envelope; certificate of appreciation for participation (see Appendix B); and a two dollar bill, as a participation incentive, were prepared by the researcher. The researcher recorded each individual's identifying code on the survey and the outside of the packet of information. The postage paid packet was then labeled by OSF-HP personnel who matched the identifying code to the participant and mailed the packets.

A postage stamped reminder/thank you postcard (see Appendix C) labeled with each identifying code and arranged in numeric order was submitted to OSF-HP personnel. OSF-HP personnel applied the name and address labels by matching the identifying code to the participant's name. The postcards were mailed to all individuals, except anyone requesting exclusion, one week after the survey was sent (Dillman, 2000).

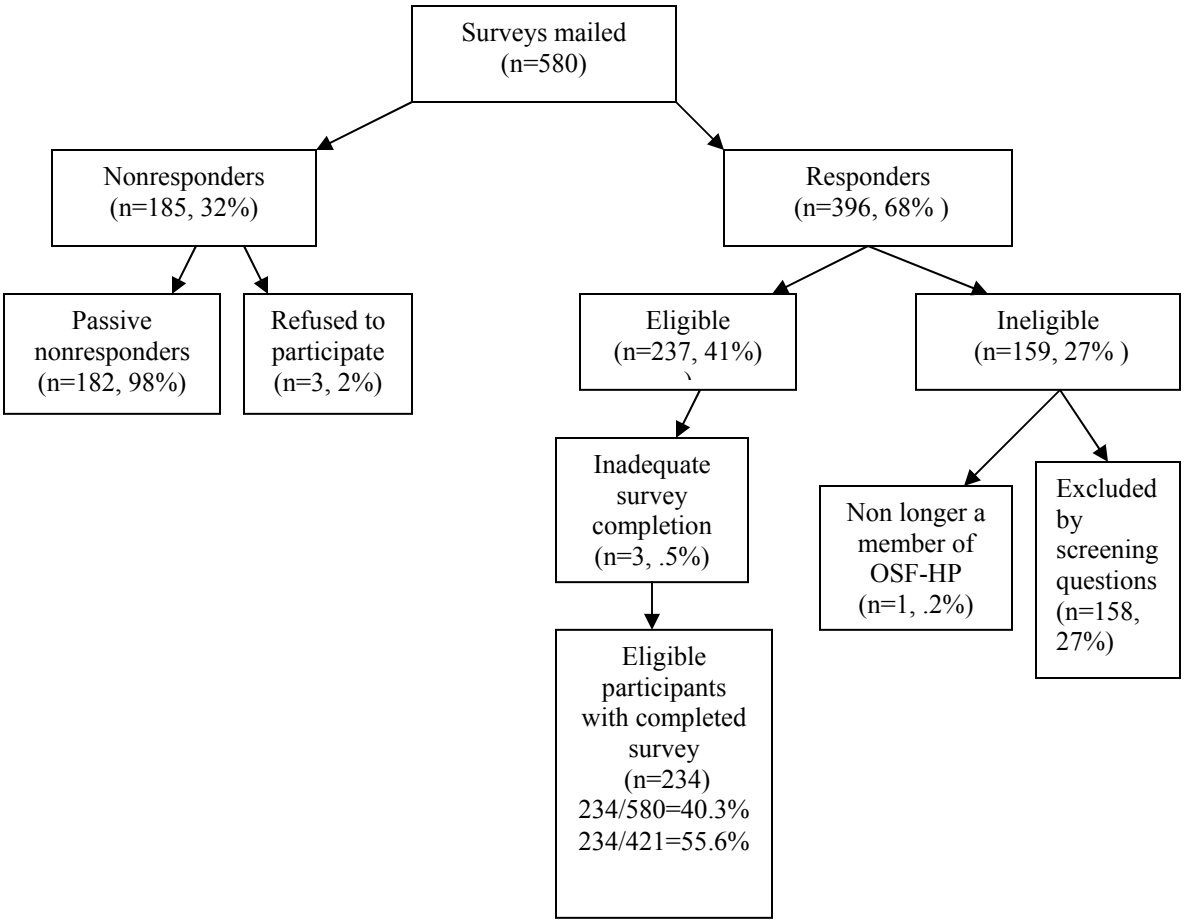
Two weeks after the postcards were sent, a third contact with potential participants who had not responded was mailed. The third mailing contained a letter to encourage the participant to complete the survey (see Appendix D), a replacement survey, and a postage stamped, pre-addressed return envelope (Dillman, 2000). The researcher recorded the identifying code on the survey and the outside of the postage stamped packet. OSF-HP personnel applied the name and address labels by matching the identifying code to the participant's name and mailed the packet.

Five hundred and eighty surveys were mailed to OSF-HP members (see Figure 2). There were 185 nonresponders and three of those were OSF-HP members who communicated that they did not want to participate. The other nonresponders simply did not return the survey.

On the other hand, 396 people did respond (68.3%). Of the 396 responders, 159 participants did not meet the inclusion criteria, based on the results of six screening questions. Thirty four of these (14.4%) were ineligible due to having had an FOBT in the past 12 months, while 88 (37.4%) were ineligible for ever having a sigmoidoscopy or flexible sigmoidoscopy. Ninety-one participants (38.7%) had had a barium enema sometime in their lifetime and were ineligible. Other participants were ineligible for a having a history of a colectomy (n=14, 6.0%), ulcerative colitis (n=4, 1.7 %), or cancer of the colon or rectum (n=4, 1.7%). Some participants met more than one exclusion criteria. Additionally, one person was ineligible because he was no longer a member of OSF-HP.

However, 237 did meet the inclusion criteria. Of those who met the inclusion criteria, three surveys were not usable due to inadequate completion of the survey resulting in 234 usable surveys. The response rate can be calculated in two ways. The first way is to calculate the response rate based on a denominator of 580 (number of surveys mailed), which results in a response rate of 40.3% (234/580). A second way to calculate the response rate is to subtract the number of ineligible participants from the total number of surveys mailed and use this number as the denominator. The response rate calculated in this manner (234/421) is 55.6%.

Figure 2.
Flow Diagram of Survey Responders and Nonresponders



Measures

Dependent Variables

Colonoscopy Compliance

Colonoscopy compliance was confirmed by a self-reported dichotomous yes/no item and a second item asking if the colonoscopy was within the last 10 years or more than 10 years ago (Rawl et al., 2006; Montano & Phillips, 1995; King et al., 1990). The status of the colonoscopy as a screening colonoscopy was determined by current procedural terminology (CPT) billing codes.

Stages of Adoption

The stages of adoption were measured based on self report by asking respondents whether they had a colonoscopy in the past 10 years, planned to have a colonoscopy in the next six months, and had an appointment scheduled for a colonoscopy (Rawl et al., 2006).

Independent Variables

Demographic Variables

The information for these variables was gathered using an open response for the date of birth and categorical response items for marital status, level of education, and income. A dichotomous response option was used for gender (Rawl et al., 2006).

Body Mass Index (BMI)

BMI was measured using two open-ended items to obtain self-reported height and weight. Then the measures were converted from the English to the metric scale, and the weight in kilograms were divided by height in meters squared (American Heritage Dictionary online, 2007).

Colorectal Cancer Knowledge

CRC knowledge was measured with an 8-item multidimensional scale. The items were designed to assess knowledge about CRC risk, preventability of CRC, effective ways to reduce risk, and the purpose of a colonoscopy. Higher scores on the scale indicated higher CRC knowledge (Rawl et al., 2006).

Physician Recommendation

Physician recommendation was measured by a single, self-reported item asking if a doctor had ever told the participant that he/she should have a colonoscopy (Rawl et al., 2006).

Perceived Barriers

Perceived barriers were measured by a 14-item scale using a four point Likert-like rating. The reliability coefficient for the scale was .77 (Rawl et al., 2001; Rawl et al., 2006).

Embarrassment

This concept was measured with the Colonoscopy Embarrassment Scale, a new instrument developed to measure embarrassment associated with a colonoscopy. The 15-item instrument measured variables that had been identified in the literature or a clinical inquiry as related to embarrassment. The scale used a four point Likert-like rating including 1) *strongly disagree*, 2) *disagree*, 3) *agree*, and 4) *strongly agree.* The higher the score on the instrument, the higher the level of embarrassment associated with a colonoscopy. Content validity was established through cognitive interviewing techniques and calculation of the content validity index (CVI=.93) (Lynn, 1986; Wynd et al., 2003).

Self-efficacy

Self-efficacy was measured with a 10-item scale using a 4-point Likert rating ranging from 1) *not sure at all,* 2) *not so sure,* 3) *somewhat sure*, to 4) *very sure.* Higher scores indicated higher self-efficacy. The Self-efficacy Scale for compliance with colonoscopy had an internal consistency of .92 (Menon, 2000; Rawl, 2006). Construct validity of the instrument was demonstrated by a significant relationship between high

self-efficacy and colonoscopy compliance ($p<.001$) compared to low self-efficacy scores (Menon, 2000).

Colonoscopy Embarrassment Scale

The 15-item instrument that was used for the data collection on embarrassment was the Colonoscopy Embarrassment Scale (CES). The CES was developed by the investigator specifically for this study. Development and pre-testing of this tool are described in the following section.

Development and Pre-testing Procedure

Item development process.

First, a review of the literature was conducted to identify as many factors as possible that related to embarrassment associated with a colonoscopy (Lynn, 1986). Second, a clinical inquiry with five people who had never had a colonoscopy was conducted. The participants in the clinical inquiry were asked, "When you think about getting a colonoscopy, what types of thoughts or anticipations make it difficult for you to get one?" Results from both the literature review and analysis of the clinical inquiry study were used to generate items to measure embarrassment. Third, the format and design of the instrument were based on recommendations that enhanced the visual appearance and reduced respondent burden (Dillman, 2000). A four-point response scale was used with response options ranging from 1) *strongly disagree*, 2) *disagree*, 3) *agree*, and 4) *strongly agree.* To avoid confusing participants, strongly disagree was always closest to the item. The Flesch-Kinkaid grade reading level was 6.1 (Microsoft Word, 2003). The scale was designed so that when summing the responses, higher scores indicated more embarrassment.

Content validity procedures: Interrater reliability.

The next step in the development of the instrument was to determine interrater reliability of the items with regard to the construct of embarrassment (DeVellis, 2003; Grant & Davis, 1997). This process involves an assessment of the items by a minimum of three experts (Lynn, 1986), chosen based on their knowledge of the construct, who independently evaluate the items.

Four doctorally-prepared experts were invited to evaluate the content validity of the instrument and three agreed. One declined because she was not going to be working at the time the evaluation needed to be completed. Two of the evaluators were selected because of their established expertise in the area of CRC (Grant & Davis, 1997). One of these was a nurse scientist whose research focus was interventions to increase cancer-screening behaviors and the other was a public health specialist with a similar research focus. Both of these authors were widely published and had acknowledged embarrassment in their publications related to CRC screening. The third expert, the Coordinator of Graduate Studies in Psychology at a large university, was selected based on his expertise in the area of embarrassment. He had numerous publications on embarrassment and his writings were used to inform the development of the instrument.

The aforementioned scholars were contacted by e-mail inviting them to serve as content experts. The researcher's desire to study the aspects of having a colonoscopy associated with embarrassment and the need to create an instrument to measure these aspects were explained. Once the experts agreed to evaluate the instrument for content validity, they were sent a cover letter, the CES, the method for scoring the results of the CES, and a tool for evaluating the instrument as suggested by Grant & Davis (1997). The

information sent to the content experts can be seen in Appendix E. The cover letter included an introduction, a conceptual definition for embarrassment, and instructions for completing the evaluation. The evaluation form listed each of the items as they were written on the survey. To the right of the each item, was a four-point scale for the experts to use in rating the *representativeness* of the item (Grant & Davis).

Representativeness was the degree to which the item was perceived as a factor related to embarrassment associated with a colonoscopy (Grant & Davis, 1997). The choices offered were 1) *not representative,* 2) *needing major revisions to be representative,* 3) *needing minor revisions to be representative*, and 4) *representative*. Each item also had a comment section for evaluator's remarks on the item wording, clarity, construction, or representativeness.

Results of the evaluations were compiled and were used for decisions on whether to keep, delete, modify, or add items (Grant & Davis, 1997). There were items that the experts unanimously agreed were not representative of the factors that related to embarrassment associated with a colonoscopy. For example, all three of the experts agreed that *I knew what was going to happen during the test* was not representative because the item was related to knowledge rather than embarrassment and the item was removed. On the other hand, some decisions were more difficult such as those that the evaluators inconsistently rated as representative such as *I had a prior bad experience related to someone touching my buttocks.* Additionally, there were some items that were similar and a decision needed to be made about which wording to select. For example, *the doctor was my primary (regular) doctor*, and *I knew the doctor doing my test* were considered redundant. Some items needed modification such as *I knew the doctor or*

nurse doing the test needed to be changed because the nurse would not be doing the test and with both the doctor and the nurse in the same item, the researcher could not discern if the participant meant that it was knowing the doctor *or* the nurse that was the source of embarrassment. This item was, therefore, separated into two items. In addition, one item was added based on the advice of the experts (*I might smell).*

The final decision about retention, deletion, modification, or addition was made by the two researchers conducting the study. Independently, the two researchers reviewed the content experts' ratings and decided the outcome of each item. Next, they compared decisions, which agreed 90% of the time. For any item that was equivocal, the item was discussed and a consensus decision was made or decisions were delayed pending the results of cognitive interviewing. As a result of the evaluation of the items by content experts, the number of items was reduced from 36 items and three open-ended questions to 26 items and three open-ended questions.

Additionally, the content validity index (CVI), a mathematical calculation of the content validity, was determined based on the ratings of the items by the content experts. The CVI for the items in an instrument is the proportion of items that were rated 3 or 4 by the experts. Davis as cited in Grant and Davis (1997) recommended a CVI of .80 as evidence of adequate content validity. The CVI for the 26 items in this instrument was .93 and considered acceptable.

Content validity procedures: Cognitive interviewing.

A pilot study, using cognitive interviewing techniques, was conducted to further examine validity of the instrument. Cognitive interviewing was created to help researchers understand how items in an instrument were interpreted and perceived by the

participants and to gain insight that otherwise would not be attainable (Lake et al., 2007; Carbone, Campbell, & Morreale, 2002; Springer, Olsson, O'Brien, & Stewart, 2006). In this study, cognitive interviews were conducted with 10 American men and women 50-54 years old.

The cognitive interviewing techniques used in the pilot study included thinking aloud, concurrent and retrospective probing questions, and paraphrasing (Springer et al., 2006; Lake et al., 2007; Carbone et al., 2002). Thinking aloud involved having the participant verbalize thoughts about survey items. Concurrent and retrospective probing questions were used for clarification when the survey question was read to the participant (concurrent) or later in the interview by returning to a particular item (retrospective). An example of a concurrent question used was, "Do you think 'bottom/buttocks' is common enough terminology to use in a survey?" and an example of a retrospective question was, "Let's go back to the item *joking with you about the exam since* that question seemed to be more difficult for you to understand. Do you have any suggestions on ways to make the question clearer?" With paraphrasing, participants were asked to repeat the question (item) in their own words. An example of a request for paraphrasing was, "Could you tell me in your own words what 'invades your privacy' means to you?"

To conduct the interviews, participants were recruited from a Baptist church in Peoria, IL. A connection to this church was made through communication with an African American housekeeper employed at a college of nursing in the same city. The housekeeper arranged a time and date for the researcher to talk to the members of the church choir. At this meeting, several topics were discussed including the higher risk of CRC in African Americans, the colonoscopy procedure, the benefits of a colonoscopy as

a screening method, and embarrassment as a barrier to completing colonoscopies. It was explained that the new instrument was developed to identify embarrassing aspects of having a colonoscopy and that the purpose of cognitive interviewing was to refine and validate the new tool.

Ten volunteers, 51-64 years old, who had never had a colonoscopy or had not had one for 10 years were sought. Five women, but no men, agreed to participate. Names and phone numbers were obtained. Each of the five women was asked if they knew any men who might be willing to be interviewed and they reported not knowing any. Pastors from two other predominantly African American churches were telephoned in order to request volunteers and no participants were found. Another contact successfully recruited five African American men who were personal friends and coworkers who agreed to be interviewed.

The age of the participants ranged from 50-54 years old. Subjects were all employed and the jobs of the female participants included light laborer, postal worker, housekeeper, Certified Nursing Assistant, and a receptionist at a social agency. The males were employed as a machinist, Human Resources trainer, Human Resources representative, health and safety trainer, and factory worker. Two of the women were married and three of the men were married. One of the women had a colonoscopy 10 years ago and one of the men had had one “some time in the past”. One man had a history of “3-4 colonoscopies” in the past.

Participants who were willing to be interviewed were called and an appointment was scheduled at a time and place that was convenient for them. Participants were reminded of the purpose of the interview and permission was sought for audio-recording.

Anonymity was maintained during the interviews and participants were assured that the tapes would be erased following transcription of the interviews. Also, identifying information such as name and phone number was erased as soon as the interview was completed. The colonoscopy procedure was explained to those who had not had a colonoscopy and the process of cognitive interviewing was discussed. The questions were read to the participants since the original methodology for the larger study involved telephone interviews.

Once participants were interviewed, the tapes were transcribed. The transcriptions were read once for an overview and then in more detail. Statements were highlighted and notes were made in the margins. The transcripts were read a third time to ensure that all pertinent comments had been analyzed. Two researchers independently read the transcripts and compared findings.

Results of cognitive interviewing.

Overall, participants expressed understanding of the items and one participant commented that the survey was simple enough "that a teenager could do it". However, the comments from other participants suggested the need for some changes (see Appendix G).

Items that caused particular misunderstanding were the two related to the gender of the physician. *Same sex* and *opposite sex* were confused by four participants. The researcher tried reversing the order and asking the question about the *opposite sex* after the *same sex* question but participants were still confused. One interview was interrupted by an emergency telephone call to the researcher. The participant was heard on the tape softly saying a "person of the opposite sex, a person of the opposite sex, a person of the

opposite sex" and tapping her pen as if she were trying to comprehend the concept. When she was asked the question, after the phone call, she did express correct understanding of the phrase. In general, participants thought both the provider of the same sex and opposite sex items should be retained, but to reduce respondent fatigue, it was decided to include only one. Four out of the five participants that commented on this item preferred not to have an endoscopist of the opposite gender. Therefore, the item concerning a physician of the opposite sex was maintained since it seemed to generate the strongest feelings.
A male and a female version of the CES were developed to ensure clarity on the *opposite sex* item.

The item about having *anyone in the room other than the doctor and a nurse* was redundant with having a medical or nursing student in the room. If additional people were to be in the room, they would most likely be students. Although participants said they would be embarrassed with others present, most of them commented that they understood students needed to learn. Therefore, removing *anyone other than the doctor and a nurse* allowed future participants to avoid imagining a crowd of onlookers and instead, to consider a "real" situation when deciding how embarrassing it would be to have people other than the doctor and a nurse in the room.

The item related to exposure of the penis/vagina, was maintained since one participant thought the test was still done while she was on her knees, buttocks in the air, and genitalia exposed. One other participant said exposure of her genitalia during a colonoscopy was a concern because of the close proximity of the vagina and rectum. However, the wording was changed from *if my penis/vagina was exposed during the test* to *because of concern that my penis/vagina would not be covered during the exam*. The

new item format was designed to determine if this was a concern without alarming participants that their genitalia would be exposed during the test. Additionally, the male and female versions of the instrument were genitalia-specific.

Many participants stated they would want *to know the doctor doing the test* whether that was to have their primary doctor do the exam or to know of the doctor through his/her reputation. Participants voiced more concerns about having someone they did not know or a "stranger" doing their test. This question was redundant with *I did not know the doctor doing the test*. Since the objective of the survey was to identify aspects of a colonoscopy related to embarrassment, this item was retained over *I knew the doctor doing the test*.

Item number eight, about *feeling like I had to have a bowel movement* was related to item 19, *my bowel might not be clean after the bowel prep*. Since it is more likely that the participant might know that their bowel was not completely clean prior to the test and less likely that they would feel the need to have a bowel movement during the test, item eight was deleted. In response to the item *if my bowel was not clean*, one participant asked if that meant *after the bowel prep* so the item was changed to read *if my bowel was not clean after the bowel prep*. This change seemed to clarify the item for participants.

I knew the nurse assisting with the test did not seem to be a factor related to embarrassment for the participants and one participant thought knowing the nurse would be beneficial. Since the objective of the instrument was to identify aspects of having a colonoscopy related to embarrassment, this item was removed.

One item that perplexed two participants was *the doctor or nurse joked with me about the test*. When the item was explained further, participants understood the item, but

none were able to offer a suggestion for improved clarity. However, all participants thought this item should be retained. This item on joking evoked some of the most intense feelings and many participants strongly opposed joking about "this serious matter". One participant stated "If it [joke] goes bad, it is going to go real bad". To make the item simpler, *or nurse* was removed so the item read *the doctor joked with me about the test.*

One participant suggested that if the item *if I had to talk to my doctor or nurse about my bottom/buttocks* was worded as *if I had to talk to my doctor or nurse about* ***problems with*** *my bottom/buttocks/rectum,* the item would be understood better. Once the new terminology was used, no further confusion arose.

There were two similar items related to consciousness during the test. It would be repetitive to have both. Participants commonly thought that *asleep or sedated* meant a having a general anesthetic. To avoid giving the impression that the participants would have a general anesthetic, the item *if I had to be awake during the test was used.*

Several males did not see the significance of the question about *how my buttocks look* and the item about *the size of my buttocks*. However, the females thought both items should be retained. Additionally, all of the experts who evaluated the items thought both items were representative of embarrassment. To reduce respondent fatigue, these two items related to the appearance of the buttocks were combined.

The word *when* in the item *when the tube is being put into my rectum* was changed to *because* so that the item would fit better with one of the precursor statements. One individual commented that the fact that the test was rectal caused the most embarrassment, and another stated that insertion of the tube was the most embarrassing

aspect of the test. A third participant commented that the test was "very, very invasive". However, the item about *invading my privacy* was not well understood. Since the "invasion" with the tube was addressed in the item above and concern about intimate parts was addressed with the genitalia item, this item was deleted.

The item *because I embarrass easily* was deleted because it was related to a personality trait. Interventions are unlikely to change embarrassability, but interventions could be developed to decrease the embarrassment associated with a colonoscopy.

Participants did not seem to understand the first open-ended question about why a colonoscopy would be more embarrassing for themselves than others. The other open-ended questions elicited the desired information. Therefore, the first open-ended question was deleted.

After final analysis and interpretation of the cognitive interviewing data, the clarity of the items was improved and the number of items was reduced from 26 items and three open-ended questions to 16 items and two open-ended questions. When the methodology changed from telephone interview to a self-administered test, the stem was placed in front of each question and the pronoun was changed from *you* to *I* (see Appendix H).

In addition to the CES, the final survey included CRC Knowledge Scale, Barriers to Colonoscopy Scale, and the Self-efficacy Scale. The Barriers to Colonoscopy Scale had a question related to degree of embarrassment associated with having a colonoscopy so the first question in the CES, as seen in the version in Appendix H, was deleted from the CES to avoid redundancy (see Appendix I for the final version of the CES and the two open-ended questions). For the final version of the survey, see Appendix J. Appendix

J is the male version of the survey. For the female version, question 50 read, "I would be embarrassed to have a colonoscopy if a *male* did the test", and question 63 read, "I would be embarrassed to have a colonoscopy because of concern that my *vagina* would not be covered during the test. Otherwise the male and female versions were identical.

Data Analyses

Data were entered into SPSS 13.0 and cleaned by conducting frequencies to identify outliers or inappropriate entries. If any data did not fall within the appropriate range or were not logical, the data were assessed for errors such as miscoding. Errors were corrected before progressing with further analyses.

Next, data distribution was assessed with an analysis of skewness and kurtosis of the CRC Knowledge Scale, Self-efficacy Scale, Barriers Scale, and CES-6 (CES reduced 6 items, which is discussed fully later) as well as the continuous variables age and BMI (see Table 1). Skewness and kurtosis scores of zero indicate a perfectly normal distribution (Field, 2005). The skewness values for the CRC Knowledge Scale, Barriers Scale, CES-6, BMI, and age data were relatively close to zero. However, the skewness score of the Self-efficacy Scale was -2.21 and 1.04 for BMI. The kurtosis values for the CRC Knowledge Scale, Barriers Scale, CES-6, and BMI were nearly zero. In contrast, the Self-efficacy Scale (4.9) and age (-1.28) veered away from zero.

Table 1.
Mean, Standard Deviation, Range, Skewness, and Kurtosis of Scales and Continuous Variables

Scale or Variable	M	(SD)	Range	Skewness	Kurtosis
Knowledge	3.22	(1.67)	0-7	.09	-.33
Barriers	26.82	(6.90)	14-49	.26	-.07
Self-efficacy	37.27	(4.47)	18-40	-2.21	4.90
CES-6	12.47	(4.03)	6-23	.02	-.51
Age	56.61	(4.21)	50-65	.03	-1.28
BMI	29.48	(6.80)	19-55	1.04	.94

For samples over 200, a visual inspection of a histogram of the distribution is valuable in determining the normality of distribution (Field, 2005; Tabachnick & Fidell, 2001). Histograms of the CRC Knowledge Scale, Barriers Scale, and CES-6 data were all relatively normally distributed. The histogram of the distribution of age values showed a platykurtoic curve as the ages were fairly evenly distributed, and the histogram of BMI was peaked and positively skewed. The histogram of the Self-efficacy Scale demonstrated an obvious severe negative skewness and a leptokurtic peak.

The overall evaluation of the skewness, kurtosis, and shape of the histograms showed that the data from the CRC Knowledge Scale, Barriers Scale, and CES-6, as well the age and BMI data were relatively normal. Data distributions that are relatively normal "allow the use of parametric statistics such as means and correlations" (Warner, 2008, p. 146) [without further adjustment such as transformation of the data]. However, transformation of the data was considered for the severely skewed Self-efficacy Scale data, but transformed data can be difficult to interpret (Field, 2005). Therefore, a statistician was consulted for guidance, and it was recommended to first run the statistical analyses with the Self-efficacy Scale as continuous data. Next, convert the Self-efficacy

Scale data into categories and run the appropriate statistical tests for categorical data. Finally, compare the findings for consistency. For example, if the results of an independent samples t-test using the Self-efficacy Scale data were statistically significant, and the results of the Chi Square analysis using of the Self-efficacy Scale categories were also statistically significant, the results would be considered consistent (T. Stump, personal communication, June 24, 2008) and reliable.

Outliers and Missing Data

Outliers were first assessed using boxplots (Field, 2005) and some cases were identified by SPSS that could be outliers. Raw data values for the outliers were confirmed to be accurate and thus reflected true scores. Upon consultation with a statistician, the outliers did not need to be considered true outliers because they were valid scores (T. Stump, personal communication, June 24, 2008).

Missing data were not a concern related to this data set. None of the scales or individual items had more that 5% missing data (Tabachnick & Fidell, 2001) and no scale had data missing from more than one participant. The variable with the most missing data was income with 10 participants (4.3%) not providing this information.

All analyses were carried out in SPSS and were conducted using p=.05 as the significance level. Due to the limited sample size and exploratory nature of these analyses, we believed that a fixed p-value was beneficial. Specific procedures used to address aims, hypotheses, and research questions are briefly discussed in the next section and described in detail in Chapter Four.

Data Analyses of Specific Aims

To address Aim 1, the reliability was determined by computing and evaluating inter-item correlation, inter-item covariance, and item-total statistics on the items in the scale, and the Cronbach's alpha for the scale.

To address Aim 2, principal components analysis with varimax rotation was used to test unidimensionality of the CES. Construct validity was also assessed by examining the relationship between colonoscopy compliance and CES scores. Specifically, CES scores of participants who were colonoscopy compliant and those who were not compliant were compared using independent samples t-tests. Relationships between CES scores and stages of adoption were examined using analyses of variance (ANOVA).

To address Aim 3, Pearson's product moment correlations were used to examine relationships among CES scores and all continuous variables. ANOVA was used to examine relationships between CES scores and categorical variables (marital status, education level, income, and gender). Multiple regression analyses were conducted in order to examine significant predictors of CES scores.

To address Aim 4, independent samples t-tests were used to examine differences between individuals who were compliant with colonoscopy and those who were not in terms of the continuous variables such as age and BMI. Chi Square was used to determine significant differences in proportions of participants who were compliant and those who were not based on categorical variables such as race and marital status. Logistic regression was used to examine predictors of compliance with colonoscopy.

To address Aim 5, the responses to the first open ended question asking about aspects of a colonoscopy participants found most embarrassing were analyzed by

recording all of the responses. Next, the responses were tallied and then similar responses were grouped together. The researchers independently identified common themes and then compared themes. The researchers discussed the comments and themes until consensus was reached. The responses to the second open-ended question, asking participants for suggestions for making the colonoscopy less embarrassing, were analyzed in the same way as the first open-ended question described above.

CHAPTER FOUR

RESULTS

In this chapter, the results of data analyses are presented in three sections. The first section describes the sample and descriptive statistics for all dependent and independent variables. In the second section, reliability and validity of the Barriers, Self-efficacy, and CRC Knowledge Scales are presented. The third section consists of results of hypotheses testing and findings related to the research questions.

Sample

Demographic Characteristics

Demographic characteristics of the study sample can be seen in Table 2. The sample consisted of nearly equal numbers of males (n=114, 48.7%) and females (n=120, 51.3%). The age range for the study sample was 50-65 years old (M=56.6, SD=4.2). There were 88 participants (37.6%) in the 50-54 year old age group, 75 (32.1%) in the 55-59 year old group, and 71(30.3%) in the 60-65 year old age group (one person turned 65 between the time the surveys were sent and the final data collection date). The primary self-described race was non-Hispanic white (n=221, 95.3%). Sixty-one participants (26.3%) had a high school diploma or less education, 74 (31.9%) had some college or vocational schooling, 53 (22.8%) had a college degree, and 44 (19%) had a graduate degree. Three quarters of the participants were married or living with a partner (n=175, 75.8%). Approximately one third of the population earned $50,000 or less (n=63, 28.1%) while another third (n=70, 31.3%) earned $50,001-75,000. Twenty percent (n=44) of participants earned $75,001-100,000 and 21.0% (n=47) earned $100,000 or more.

Table 2.
Demographic, Personal, and Other Characteristics of the Sample (n=234)

Variable	Noncompliant n (%)	Compliant n (%)	Total n (%)
Demographic characteristics			
Gender			
Male	43 (18.4)	71 (30.3)	114 (48.7)
Female	47 (20.1)	73 (31.2)	120 (51.3)
Age (M=56.6, SD=4.21)			
50-54 years old	39 (16.7)	49 (20.9)	88 (37.6)
55-59 years old	23 (9.8)	52 (22.2)	75 (32.1)
60-65 years old	28 (12.0)	43 (18.4)	71 (30.3)
Self-described race			
White (non Hispanic)	84 (36.2)	137 (59.1)	221 (95.3)
Other	5 (2.2)	6 (2.6)	11 (4.7)
Education			
High school graduate or less	21 (9.1)	40 (17.2)	61 (26.3)
Some college/vocational school	32 (13.8)	42 (18.1)	74 (31.9)
College graduate	23 (9.9)	30 (12.9)	53 (22.8)
Graduate degree	13 (5.6)	31 (13.4)	44 (19.0)
Marital status			
Married/partnered	70 (30.3)	105 (45.5)	175 (75.8)
Not married/not partnered	18 (7.8)	38 (16.5)	56 (24.2)
Household income			
$50,000 or less	30 (13.4)	33 (14.7)	63 (28.1)
$50,001-75,000	27 (12.1)	43 (19.2)	70 (31.3)
$75,001-100,000	16 (7.1)	28 (12.5)	44 (19.6)
$100,00 or higher	14 (6.3)	33 (14.7)	47 (21.0)
Personal Characteristics			
BMI (M=29.47, SD=6.80)			
Normal (18.5-24.9)	22 (9.6)	37 (16.2)	59 (25.9)
Overweight (25.0-29.9)	34 (14.9)	51 (22.4)	85 (37.3)
Obese (30.0-39.9)	22 (9.6)	38 (16.7)	60 (26.3)
Extremely obese (40.0 and >)	7 (3.1)	17 (7.5)	24 (10.5)
CRC knowledge scores (M=3.21, SD=1.67)			
Other Characteristics			
Physician recommendation			
Physician recommended	31 (13.5)	126 (54.8)	157 (68.3)
No recommendation	58 (25.2)	15 (6.5)	73 (31.7)
Stage of change			
Precontemplation	70 (30.0)	0 (0)	70 (30.0)
Contemplation/preparation	19 (8.2)	3 (1.3)	22 (9.4)
Action	0 (0)	141 (60.5)	141 (60.5)

Personal Characteristics

The data related to personal characteristics (BMI and CRC knowledge) of the study sample are also located in Table 2. BMIs ranged from 18.64-54.99 with a mean of 29.47 (SD=6.80). The BMIs were also examined after separation into the standardized categories (WebMD, 2007). None of the participants were underweight (BMI<18.5). About 26% of the sample was in the normal BMI range (n=59, 25.9%), and nearly 40% of participants were in the overweight group (n=85, 37.3%). Sixty participants (26.3%) were in the obese group, while 10.5% were in the extremely obese group (n=24). Total CRC Knowledge Scale Scores for the sample ranged from 0-7 correct answers with an average score of 3.21 (SD=1.67).

Physician Recommendation, Stage of Adoption, and Colonoscopy Testing

Data regarding receipt of a physician recommendation for a colonoscopy, stage of adoption, and colonoscopy testing within the past 10 years are found in Table 2. In this sample, 157 (68.3%) participants reported that they had received a physician recommendation for a colonoscopy compared to 73 (31.7%) who had never received a physician recommendation for this test. Of the 234 participants, 144 (61.5%) were compliant with CRC screening guidelines for colonoscopy, and 90 (38.5%) had never had a colonoscopy or any other type of CRC testing.

As mentioned above, not all of the participants have had a colonoscopy. The TTM posits four stages of transition toward a change in behavior over time, in this case getting a colonoscopy (Prochaska & Velicer, 1997). The four stages are: precontemplation (no intent to change), contemplation (thinking about changing but has no plans to get tested in the next six months), and preparation (intent to take action in the next six months), and

action (behavior change occurs). In this sample, 60.5% (n=144) of the participants were in action, 30.0% (n=70) were in precontemplation, and 9.4 % (n=22) were in contemplation/preparation (contemplation and preparation were combined due to low responses in both groups).

Description and Reliability of the Barriers, Self-efficacy, and CRC Knowledge Scales

The Barriers Scale consisted of 14 items that participants were asked to respond to by using a 4-point response scale with 1) *strongly disagree*, 2) *disagree*, 3) *agree*, or 4) *strongly agree*. The mean of the Barriers Scale scores was 26.82 (SD=6.91) with a range of 14 to 49. The Barriers Scale had good internal consistency demonstrated by a Cronbach's alpha of .89 (Nunnally & Bernstein, 1994).

The Self-efficacy Scale had 10 items, each with a 4-point response option ranging from 1) *not sure at all,* 2) *not so sure,* 3) *somewhat sure*, to 4) *very sure.* The possible range of scores was from 10 to 40, but the scores actually ranged from 18 to 40. The mean score was 37.27 (SD=4.47) with a median of 39. The Cronbach's alpha for the Self-efficacy Scale was .89 indicating the scale had good internal consistency (Nunnally & Bernstein, 1994).

The CRC Knowledge Scale had 8-items with between three and five response options for each item, however only one option was correct for each item. The number of correct answers was summed with each correct answer worth one point (Rawl, et al, 2006). The possible range of scores was from 0 to 8, but the actual scores ranged from 0 to 7 (M=3.22, SD=1.67). The CRC Knowledge Scale was evaluated using Kuder-Richardson (K-R) and the result was .53 (DeVellis, 2003). The lower K-R result was

expected since the CRC Knowledge Scale taps multiple knowledge domains and therefore is not unidimensional.

Aims, Hypotheses, and Research Questions

Aim 1) Estimate reliability of the Colonoscopy Embarrassment Scale among men and women aged 50-64 years old.

H1: *The Colonoscopy Embarrassment Scale will demonstrate adequate internal consistency reliability with a Cronbach's alpha of at least .70 (Nunnally & Bernstein, 1994).*

Internal consistency was estimated using Cronbach's alpha. The criterion for acceptable internal consistency was established at .70 (Nunnally & Bernstein, 1994). The Cronbach's alpha for all 15 items of the CES was .95. The CES was reduced to six items through a data reduction process and the Cronbach's alpha for the six items retained was .89. See the next section regarding data reduction.

Aim 2) Estimate validity of the Colonoscopy Embarrassment Scale among men and women aged 50-64 years old.

H2: *The Colonoscopy Embarrassment Scale will show evidence of construct validity as a unidimensional scale through principal components analysis.*

Data reduction was conducted using principal components analysis. Principal components analysis was chosen because it "is concerned only with establishing which linear components exist within the data and how a particular variable might contribute to that component" (Field, 2005, p. 631). The scree plot showed two components. Using the Kaiser rule, eigenvalues over 1.0 (Kaiser as cited in Field, 2005) were extracted as the components. In this case, two components were extracted. Component 1 had an

eigenvalue of 9.02, and component 2 had an eigenvalue of 1.01. Following Varimax rotation, 12 of the 15 items loaded onto the first component at a level of .65 or higher indicating substantial loading (DeVellis, 2003). The three items that did not load at .65 or higher were *did not know the doctor doing the test (*.62), *embarrassed if the doctor joked with me* (.34) and *had to be awake during the test* (.08) (see Table 3). The two items that loaded onto the second component at or above .65 were *embarrassed if the doctor joked with me* (.88) and *had to be awake during the test* (.65).

Table 3.
Component Loadings for 15 Colonoscopy Embarrassment Scale Items following Varimax Rotation

Item	Loading	
	Component 1	Component 2
Endoscopist of opposite gender	.73	.24
Did not know the doctor doing the test	.62	.35
Had medical or nursing student	.73	.31
Passed gas during the test	.70	.33
Embarrassed if awake during test	.34	.65
Embarrassed if Dr. joked about test	.08	.88
Talk to Dr./nurse about bowel movements	.71	.39
Talk to Dr./nurse about buttocks	.75	.34
Bowel may not be clean after bowel prep	.71	.37
Size or appearance of my buttocks	.77	.10
Someone will be touching my buttocks	.88	.20
Tube is being put into rectum	.86	.23
I might smell	.82	.26
Vagina/penis may not be covered	.80	.19
Dr./nurse will see my buttocks	.88	.13

In order to further examine the 15 items as unidimensional or multidimensional, additional analysis of the 15 items was warranted. An analysis was conducted to determine if all 15 items were significantly related to compliance with colonoscopy. To determine the relationships between the 15 individual items on the CES and compliance

with colonoscopy, all items were dichotomized into disagree (strongly disagree and disagree) and agree (strongly agree and agree). The relationships between the 15 items and compliance with colonoscopy were then analyzed using Chi Square since the data were categorical (see Table 4). Thirteen of the 15 items were significantly related to compliance with colonoscopy. However, *embarrassed if the doctor joked with me* (p=.49) and *had to be awake during the test* (p=.07) were not significantly related to compliance with colonoscopy. Therefore, the items *embarrassed if the doctor joked with me* and *had to be awake during the test* were deleted.

Table 4.
Agreement or Disagreement with 15 Embarrassment Items based on Compliance or Noncompliance with Colonoscopy (n=234)

	Noncompliant		Compliant		p
	n (%) Disagree	n (%) Agree	n (%) Disagree	n (%) Agree	
Endoscopist of opposite gender	50 (29.1)	39 (63.9)	122 (70.9)	22 (36.1)	.001
Did not know the doctor doing the test	67 (34.5)	22 (57.9)	127 (65.5)	16 (42.1)	.007
Had medical or nursing student	41 (26.6)	48 (60.8)	113 (73.4)	31 (39.2)	.001
Passed gas during the test	28 (22.6)	61 (56.0)	96 (77.4)	48 (44.0)	.001
Embarrassed if awake during test	33 (31.7)	56 (43.4)	71 (68.3)	73 (56.6)	.07
Embarrassed if Dr. joked about test	56 (36.6)	33 (41.3)	97 (63.4)	47 (58.8)	.49
Talk to Dr./nurse about bowel movements	68 (34.3)	21(60.0)	130 (65.7)	14 (40.0)	.004
Talk to Dr./nurse about buttocks	50 (29.1)	39 (63.9)	122 (70.9)	22 (36.1)	.001
Bowel may not be clean after bowel prep	45 (29.2)	44 (55.7)	109 (70.8)	35 (44.3)	.001
Size or appearance of my buttocks	68 (34.0)	21 (63.6)	132 (66.0)	12 (36.4)	.001
Someone will be touching my buttocks	58 (30.9)	31 (68.9)	130 (69.1)	14 (31.1)	.001
Tube is being put into rectum	44 (25.6)	45 (73.8)	128 (74.4)	16 (26.2)	.001
I might smell	54 (30.2)	34 (64.2)	125 (69.8)	19 (35.8)	.001
Vagina/penis may not be covered	58 (32.0)	30 (63.8)	123 (68.0)	17 (36.2)	.001
Dr./nurse will see my buttocks	59 (31.4)	28 (65.1)	129 (68.6)	15 (34.9)	.001

The remaining 13 embarrassment items were tested for unidimensionality using a scree plot and principal component analysis. The new scree plot showed one component. There was one eigenvalue over 1.0 (8.58), which accounted for 65.98% of the variance. The data were not rotated since there was only one component extracted. All of the items loaded above .65 (.71-.89) as shown in Table 5.

Since the 13 items loaded so highly, the determinant of the R-matrix was analyzed for multicollinearity among the items. An R-matrix less than the target of .00001 would indicate multicollinearity (Field, 2005), as did the R-matrix of 6.71E-006 for the 13 items. To reduce mulitcollinearity among the items, Field (2005) suggested removing all items with loadings greater than .80. Following this procedure, six items remained. The determinant for the R-matrix of the six items was .046, which was greater than the target of .00001, and indicated no multicollinearity among the items.

Table 5.
Component Loadings for 13 Colonoscopy Embarrassment Scale Items

Item	Loading
Endoscopist of opposite gender	.77
Did not know the doctor doing the test	.71
Had medical or nursing student	.79
Passed gas during the test	.77
Talk to Dr./nurse about bowel movements	.80
Talk to Dr./nurse about buttocks	.82
Bowel may not be clean after bowel prep	.79
Size or appearance of my buttocks	.76
Someone will be touching my buttocks	.89
Tube is being put into rectum	.89
I might smell	.86
Vagina/penis may not be covered	.81
Dr./nurse will see my buttocks	.87

The principal components analysis was run again and the six items loaded at .75-.86 (see Table 6). The Kaiser-Meyer-Olkin measure of sampling adequacy was .88 indicating that the factor analysis "should yield distinct and reliable factors" (Field, 2005, p. 640). Kaiser-Meyer-Olkin values between .8 and .9 are "great" (Hutcheson & Sofroniou, 1999 as cited in Field, 2005, p. 640).

Table 6.
Component Loadings for Six Colonoscopy Embarrassment Scale Items

Item	Loading
Endoscopist of opposite gender	.81
Did not know the doctor doing the test	.75
Had medical or nursing student	.86
Passed gas during the test	.82
Bowel may not be clean after bowel prep	.81
Size or appearance of my buttocks	.75

H3: *Construct validity of the CES will be demonstrated by lower CES scores in participants who are compliant with colonoscopy compared to participants who are not compliant.*

The independent samples t-test was used to test the hypothesis that participants who were compliant with colonoscopy would have lower CES-6 scores than those who were not compliant. Results showed that noncompliant participants had significantly higher mean CES-6 scores than the participants who were compliant with colonoscopy screening ($p<.001$) as shown in Table 7.

Table 7.
Comparison of CES-6 Scores between Participants who were Compliant with Colonoscopy and Not Compliant with Colonoscopy (n=233)

Variable	n	CES-6 Scores M (SD)	t	p
Compliance Status				
Compliant	144	11.15 (3.67)	7.03	.001
Not compliant	89	14.61 (3.64)		

H4: *Construct validity of the CES will be supported by lower CES scores in participants at more advanced stages of adoption compared to participants at less advanced stages.*

One-way ANOVA was used to test this hypothesis. Since there were only three participants in the preparation group, the contemplation and preparation stages of adoption were combined. The overall F for the ANOVA was statistically significant, $F(2, 229)=22.35$, $p<.001$. The means and standard deviations for the three groups are displayed in Table 8, the results of the Bonferroni post hoc tests showed that the action group scored significantly lower on the CES-6 than the precontemplation group ($p<.001$) and the contemplation/preparation group ($p<.001$). There was no significant difference in the means of the CES-6 scores between the precontemplation group compared to the contemplation/preparation group ($p=1.00$).

Table 8.
Relationship between Stages of Adoption and CES-6 Scores

	CES-6 Scores		
Variables	M(SD)	n	F
Precontemplation	14.51 (3.74)	69	22.35
Contemplation/planning	14.18 (3.39)	22	
Action	11.14 (3.66)***	141	

***p<.001

Aim 3) Examine relationships among demographic/personal characteristics (BMI and CRC knowledge), health beliefs (perceived barriers and perceived self-efficacy), and Colonoscopy Embarrassment Scale scores.

Research Question 3.1: *Among men and women aged 50-64 years old, what are the relationships among demographic/personal characteristics (BMI and CRC knowledge) and CES scores?*

CES-6 scores were compared for the demographic characteristics of gender, marital status, and age (see Table 9). Since the dependent variable was continuous data and the independent variables were dichotomous, independent samples t-tests were used for this analysis. Results showed no significant difference in the mean CES-6 scores by gender (p=.75), marital status (p=.36), or race (p=.31).

Table 9.
Comparison of Mean CES-6 Scores by Gender, Marital Status, and Race

Variable	n	CES-6 Scores M (SD)	t	p
Gender				
Female	119	12.55 (4.27)	.32	.75
Male	114	12.39 (3.77)		
Marital				
Not married/not partnered	55	12.89 (4.20)	.92	.36
Married/Partnered	175	12.33 (3.91)		
Race				
White	220	12.37 (3.96)	-1.02	.31
All other races	11	13.64 (4.70)		

One-way ANOVA tests were used for comparison of CES-6 scores (continuous data) and the variables with multiple categories such as income and education. The overall F for the one-way ANOVA for income was statistically significant, F(3, 24)=3.68, p=.01. The corresponding effect size was .05 indicating that none of the 5% of the variance in income was predicted by the level of income. Findings, depicted in Table 10, showed the means and standard deviations for each level of income. Bonferroni post hoc tests showed the mean CES-6 scores were significantly higher in the lowest income level ($50,000 or less) compared to the highest income level ($100,001 or higher) (p=.01). There were no significant differences observed when comparing the other income levels. There were also no significant differences among CES-6 scores and level of education F(3, 227), p=.24.

Table 10.
Comparison of Mean CES-6 Scores for Income and Education Levels

Variables	CES-6 Scores M(SD)	n	F
Income			3.68
$50,000 or less	13.44(4.37)	62	
$50,001-75,000	12.71(3.60)	70	
$75,001-100,000	11.89(3.72)	44	
$100,001 or higher	11.04(4.04)**	47	
Education			
High school diploma or less	13.21 (3.59)	61	
Some college or vocational	12.44 (4.04)	73	
College graduate	12.17 (3.83)	53	
Graduate degree	11.66 (4.55)	44	

**p=.01

In order to examine relationships among dependent and independent variables, both with continuous data, correlation coefficients were determined. Specifically, Pearson's correlation coefficients were used to analyze the relationships among the normally distributed data of age, BMI, CRC knowledge, and CES-6 scores (see Table 11). Since no hypothesis concerning these relationships was stated, a two-tailed test was conducted. CES-6 scores were significantly positively correlated with BMI ($r= .15$, $p=.02$). CES-6 scores were inversely correlated with CRC knowledge ($r= -.19$, $p<.01$). There was no significant correlation between age and CES-6 scores ($r= -.10$, $p=.15$).

Table 11.
Pearson's Correlation Coefficients among Age, BMI, CRC Knowledge, and CES-6 Scores (n=232)

Variables	CES-6	Age	BMI	CRC Knowledge
1. CES-6	--			
2. Age	-.10	--		
3. BMI	.15*	-.10	--	
4. CRC Knowledge	-.19**	.07	-.07	--

*p<.05, **p<.01

Research Question 3.2: *Among men and women aged 50-64 years old, what are the relationships among health beliefs (perceived barriers and perceived self-efficacy), and CES scores?*

Pearson's correlation coefficients would be an appropriate test to use for independent and dependent variables with normally distributed continuous data. However, prior to conducting the analysis, the Barriers Scale needed to be adjusted. *Having a colonoscopy is embarrassing* was an item on the Barriers Scale. The assumption of mutual exclusivity would be violated if the Barriers Scale and the CES-6 were tested for correlation. Therefore, the item related to embarrassment was removed from the Barriers Scale, leaving 13 items (Bar-13). CES-6 scores and Bar-13 scores were significantly positively correlated ($r=.68$, $p<.01$) as shown in Table 12. The variance shared between the CES-6 and the Bar-13 Scale scores was 46% ($r^2=.46$). The scatter plot showed that participants with higher scores on the Bar-13 Scale also had higher scores on the CES-6.

Table 12.
Correlations among Bar-13, Self-efficacy, and CES-6 Scores (n=233)

Variables	CES-6	Bar-13	Self-efficacy
1. CES-6	--		
2. Bar-13 Scale	.68**	--	
3. Self-efficacy Scale	-.42**	-.55**	--

**p<.01

Since the assumption of normal distribution could not be met by the severely skewed Self-efficacy Scale scores, the Spearman's rho test was used to assess the association among the scores on the Self-efficacy Scale, Bar-13 Scale, and CES-6 (Munro, 2001). Self-efficacy Scale scores were inversely related to CES-6 scores ($r= -.42$, $p<.01$). The correlation accounted for 18% of the variance (Munro). The scatter plot showed that higher Self-efficacy Scale scores were associated with lower CES-6 scores, but this was not a linear relationship.

Since Self-efficacy Scale scores were severely skewed, the relationship between Self-efficacy Scale scores and the CES-6 scores was further analyzed by recoding the Self-efficacy Scale scores as categorical data (T. Stump, personal communication, June 24, 2008). The median for the Self-efficacy Scale scores was 39.0 (SD=4.47) on a 40 point scale. A score of 40 was recoded as *very high* self-efficacy and a score of 39 or below was recoded as *high* self-efficacy based on the median. Results of the independent samples t-test seen in Table 13 showed that participants with *high* mean Self-efficacy Scale scores were significantly more likely to have higher mean CES-6 scores compared to individuals with *very high* Self-efficacy Scale scores ($p<.001$).

Table 13.
Comparison of Means of CES-6 Scores for High and Very High Self-efficacy Scale Scores

		CES-6 Scores			
Variable	n	M (SD)	Range	t	p
Self Efficacy Scores					
High	117	13.85 (3.96)	18-39	5.56	.001
Very High	116	11.09 (3.61)	40		

Research Question 3.3: *Among men and women aged 50-64 years old what variables are predictive of CES scores?*

Multiple regression was used to determine which variables predicted CES-6 scores. All of the variables that were significant at an alpha of .25 or lower in univariate analyses were included in the model (age, income and education levels, BMI, Self-efficacy Scale scores, Bar-13 Scale scores, and CRC Knowledge Scale scores). All variables were loaded at once (forced entry) in order to examine relationships without bias from the researcher (Field, 2005). Results showed that the Bar-13 Scale scores ($p<.001$) and BMI ($p=.04$) predicted CES-6 scores (see Table 14). These two variables accounted for 49% of the variance ($R^2 =.49$) for predictors of CES-6 scores.

The statistics provided evidence that this model was a good fit. For example, the R^2 of .49 and the adjusted R^2 of .48 were approximately the same and the difference of .01 meant that, if the model were derived from the population rather than a sample, it would account for approximately 1% less variance in the outcome (Field, 2005).

Table 14.
Predictors of CES-6 Scores using Forced Entry

	B	SE B	β	p	R^2
Model 1					.49
(Constant)	4.24	3.92		.28	
Bar-13 Scale	.44	.04	.67	.001	
Self-efficacy Scale	-.04	.06	-.05	.45	
Income	.14	.20	.04	.48	
Education	.08	.17	.02	.65	
Age	-.07	.05	-.07	.16	
BMI	.06	.03	.10	.04	
CRC Knowledge Scale	.06	.13	.02	.64	

In addition, diagnostic statistics showed that there were no serious breaches of the assumption of mulitcollinearity. The largest variance inflation factor (VIF) of 1.68 was well below 10, whereas a VIF greater than 10 would be "cause for concern" (Myers, 1990; Bowerman & O'Connell as cited in Field, 2005, p. 196). Additionally, the lowest tolerance was .60, and since none of the tolerance values were below .1, there was "no serious problem" (Field, p.196). Additionally, there were no tolerance values less than .2, which would have suggested that "a potential problem existed" (Menard, 1995 as cited in Field, p. 196).

Different methods of multiple regression include forced entry, forward stepwise, and backward stepwise. If all three methods showed the same results, confidence in the results would be strengthened (J. Wu, personal communication, September 9, 2008). In the forward stepwise analysis, all of the same independent variables were entered (age, income and education levels, BMI, Self-efficacy Scale scores, Bar-13 Scale scores, and CRC Knowledge Scale scores). In forward stepwise multiple regression, single independent variables were added into the model in order based on Rao's efficient score

statistic (score statistic) by the statistical program. The independent variable with the most significant score statistic was added into the model first, followed by the next highest score statistic until no independent variables had a score statistic at the .05 level or below. The results of the forward stepwise analysis were the same as the results of the forced entry analysis. Bar-13 Scale scores ($p<.001$) and BMI ($p=.04$) were again found to be predictive of higher CES-6 scores.

A multiple regression analysis using a backward stepwise approach was also conducted using the same independent variables as above. With the backward stepwise analysis, all predictors were placed in the model initially and the computer program deleted predictors based on the predictor's statistical contribution to the model and the predictor's redundancy related to the other predictors. The results of the backward stepwise analysis were identical to the results of the forced entry and forward stepwise analysis. Once more, the Bar-13 Scale scores ($p<.001$) and BMI ($p=.04$) were found to be predictive of higher CES-6 scores.

For the final multiple regression analysis, only the significant predictors from the previous forced entry, forward stepwise, and backward stepwise analyses (Bar-13 Scale scores and BMI) were analyzed using forced entry (J. Wu, personal communication, September 19, 2008). In this model, Bar Scale-13 scores ($p<.001$) and BMI ($p=.04$) were found to be predictive of higher CES-6 scores such that for each additional unit increase on the Bar-13 Scale, there was a .43 point increase in the score on the CES-6 and for each additional unit of BMI, there was a .06 point increase in the CES-6 score.

The statistics provided evidence that this final model was a good fit. The R^2 and the adjusted R^2 were both .48 and .47 respectively, signifying an excellent fit and

indicating that there would be very little change in the predictability of the Bar-13 Scale scores and BMI from this sample to the population at large (Field, 2005).

In addition, the statistics show that there were no serious breaches of the assumption of no mulitcollinearity. The VIF for both predictors was 1.01 well below 10, and therefore, not a concern (Myers, 1990; Bowerman & O'Connell as cited in Field, 2005, p. 196). The tolerance for both predictors was .99 (greater than the cutoff value of .2) indicating there were no potential problems (Menard, 1995 as cited in Field, p. 196).

Aim 4) Examine relationships among demographic/personal characteristics (BMI and CRC knowledge), health beliefs (perceived barriers and perceived self-efficacy), physician recommendation, and colonoscopy compliance among men and women aged 50-64 years old.

Research Question 4.1: *What are the differences in demographic characteristics, BMI, and CRC knowledge scores in men and women 50-64 years old who are compliant with colonoscopy and those who are not?*

For demographic characteristics that were categorical, Chi Square tests were run since the dependent variable was also categorical. As depicted in Table 15, Chi square tests showed no significant differences in proportions of participants who were compliant with colonoscopy and those who were not based on education levels (p=.37), marital status (p=.29), race (p=.62), income (p=.29), or gender (p=.78).

Table 15.
Comparison of Demographic Characteristics and Colonoscopy Compliant and Noncompliant Participants (n=234)

Variable Category	Noncompliant n (%)	Compliant n (%)	p
Education			
High school graduation or less	21 (23.6)	40 (28.0)	.37
Some college or vocational	32 (36.0)	42 (29.4)	
College graduate	23 (25.8)	30 (21.0)	
Graduate degree	13 (14.6)	31 (21.7)	
Marital			
Not married/not partnered	18 (20.5)	38 (26.6)	.29
Married or partnered	70 (79.5)	105 (73.4)	
Race			
White	84 (94.4)	137 (95.8)	.62
All other races	5 (5.6)	6 (4.2)*	
Income			
$50,000 or less	30 (34.5)	33 (24.1)	.29
$50,001-75,000	27 (31.0)	43 (31.4)	
$75,001-100,000	16 (18.4)	28 (20.4)	
$100,001 or more	14 (16.1)	33 (24.1)	
Gender			
Female	47 (52.2)	73 (50.3)	.78
Male	43 (47.8)	72 (49.7)	

*One cell with less than the expected count of 5.

Independent samples t-tests were used for demographic and personal characteristics that were continuous variables. As shown in Table 16, participants who were compliant with colonoscopy had significantly higher mean CRC Knowledge Scale scores (p=.04) compared to those who were noncompliant. Compliant and noncompliant participants did not differ in terms of mean age (p=.32) or mean BMI (p=.72).

Table 16.
Comparison of Colonoscopy Compliance based on Demographic and Personal Characteristics (n=234)

	Noncompliant		Compliant			
Variable	n	M (SD)	n	M (SD)	t	p
Age	90	56.27 (4.46)	144	56.83 (4.06)	-.99	.32
BMI	89	29.27 (6.73)	143	29.60 (6.86)	-.36	.72
CRC knowledge	90	2.92 (1.60)	145	3.38 (1.71)	-2.04	.04

Research Question 4.2: *What are the differences in perceived barriers and self-efficacy in men and women 50-64 years old who are compliant with colonoscopy and those who are not?*

Independent samples t-tests were used for continuous independent variables and a categorical dependent variable. As shown in Table 17, individuals who were compliant with colonoscopy had higher mean Self-efficacy Scale scores (p=.001) and lower mean Barrier Scale Scores (p=.001) as compared to those that were noncompliant.

Table 17.
Differences in Barriers Scale Scores and Self-efficacy Scale Scores by Colonoscopy Compliance Status

	Noncompliant		Compliant			
Variable	n	M (SD)	n	M (SD)	t	p
Barriers	90	30.98 (6.53)	144	24.23 (5.80)	8.25	.001
Self-efficacy	90	34.59 (5.75)	144	38.95 (2.15)	-8.23	.001

Normally distributed data are required for conducting independent samples t-tests. Since the Self-efficacy Scale scores were severely negatively skewed, dichotomizing self-efficacy into categories and conducting nonparametric statistical testing was recommended (T. Stump, personal communication, June 24, 2008). Chi square testing of

the categorical variables also showed a significant difference (χ^2=55.08, p=.001) between the groups (see Table 18). Again, a greater proportion of participants who were compliant with colonoscopy had *very high* Self-efficacy Scale scores compared to the proportion of participants who were noncompliant with colonoscopy.

Table 18.
Proportions of Self-efficacy related to Colonoscopy Compliance or Noncompliance

Variable	Category	Noncompliant Count (%)	Compliant Count (%)	p
Self-efficacy				
	High	73 (81.1)	45 (31.3)	.001
	Very high	17 (18.9)	99 (68.8)	

Research Question 4.3: *What are the differences in proportions of compliance with colonoscopy in men and women aged 50-64 years old who have received a physician's recommendation for colonoscopy and those who have not?*

Chi Square tests were used to examine categorical dependent and independent variables. Results shown in Table 19 indicate that a higher proportion of participants who were compliant with colonoscopy had received a physician's recommendation for a colonoscopy than the proportion of participants who were noncompliant (χ^2=74.88, p=.001).

Table 19.
Colonoscopy Compliance by Receipt of Physician's Recommendation for Colonoscopy

Variable Category	No M.D. Recommendation Received n (%)	M. D. Recommendation Received n (%)	p
Compliance Status			
Noncompliant	58 (65.2)	31 (34.8)	.001
Compliant	15 (10.6)	126 (89.4)	

Research Question 4.4: *Among men and women aged 50-64 years old, what variables are predictive of compliance with colonoscopy?*

Logistic regression analyses were used to determine the independent variables that were predictive of compliance with colonoscopy. The variables that were found to be significantly related to compliance with colonoscopy in univariate analyses with a p value of .25 or less were CRC Knowledge Scale scores, Bar-13 Scale scores, Self-efficacy Scale scores, CES-6 scores, and physician recommendation and these were the variables included in the logistic regression. Logistic regression requires that the independent variables be categorical (Warner, 2008; J. Wu, personal communication, September 19, 2008). Therefore, CRC Knowledge Scale scores, Bar-13 Scale scores, and CES-6 scores variables were dichotomized into high and low based on the mean and median values for continuous data. Self-efficacy was dichotomized into *very high*, for scores of 40, and *high* for all other scores. The two categories for physician recommendation were having a physician recommend a colonoscopy or not.

Three different methods of logistic regression including forced entry, forward stepwise, and backward stepwise were used. If all three methods showed the same results,

confidence in the results would be strengthened (J. Wu, personal communication, September 9, 2008).

The forced entry method placed all of the independent variables into the model at once (Field, 2005) and this analysis showed three variables significant at the .05 level or below including Bar-13 Scale scores ($p<.05$), Self-efficacy Scale scores ($p<.001$), and physician recommendation ($p<.001$) as shown in Table 20. The CES-6 scores were not significant predictors of colonoscopy compliance in the multivariate analyses.

Table 20.
Logistic Regression using Forced Entry to Test for Predictors of Compliance with Colonoscopy

			95% CI for exp b	
Variable	B (SE)	exp b	Lower	Upper
Constant	-1.34 (.54)	.26		
Knowledge	-.16 (.39)	.90	.40	1.84
Bar-13 Scale	-.86 (.44)	.42*	.18	.99
Self-efficacy Scale	2 .00 (.42)	7.41***	3.27	16.77
CES-6	-.50 (.43)	.61	.26	1.40
MD Recommendation	2.71(.42)	15.00***	6.54	34.39

Note Model R2=.42 (Cox and Snell), .57 (Nagelkerke), Model χ^2=125.34
*p<.05, **p<.01, ***p<.001

Next, forward stepwise logistic regression was conducted (see Table 21). In this analysis, single independent variables were added into the model in order based on Rao's efficient score statistic (score statistic). The variable with the most significant score statistic was added into the model first, followed by the next highest score statistic until no independent variables had a score statistic at the .05 level or below. The first variable added was physician recommendation ($p<.001$), followed in descending order by Self-efficacy Scale scores ($p<.001$), and Bar-13 Scale scores ($p=.01$).

Table 21.
Logistic Regression using Forward Stepwise to Test for Predictors of Compliance with Colonoscopy

Variable	B (SE)	exp b	95% CI for exp b Lower	Upper
Step 1				
MD Recommendation	2.74 (.35)	15.45***	7.74	30.83
Constant	-1.34 (.29)	.26		
Step 2				
MD Recommendation	2.79 (.41)	16.22***	7.16	36.50
Self-efficacy Scale	2.22 (.40)	10.03***	4.58	21.96
Constant	-2.36 (.40)	.09		
Step 3				
MD Recommendation	2.72 (.42)	15.20***	6.64	34.83
Self-efficacy Scale	2.06 (.41)	7.85***	3.52	17.56
Bar-13 Scale	-1.04 (.40)	.35**	.17	.76
Constant	-1.62 (.48)	.00		

Note Model R^2=.42 (Cox and Snell), .57 (Nagelkerke), Model =$\chi^2$123.82
R2=**p<.01, ***p<.001

Backward stepwise analysis was conducted as a third confirmation of the variables that predicted compliance with colonoscopy. In the backwards stepwise model, all predictors were placed in the model initially. Predictors were deleted based on statistical contribution to the model and redundancy. This analysis resulted in the same findings as the forward stepwise analysis.

A final forced entry analysis was conducted using only the three predictors that were consistently significant in the previous three multiple regression analyses. These included physician recommendation, Self-efficacy Scale scores, and Bar-13 Scale scores (see Table 22). In this final analysis, physician recommendation (p<.001), Self-efficacy Scale scores (p<.001), and Bar-13 Scale scores (p=.001) were significant predictors of compliance with colonoscopy. Physician recommendation was the strongest predictor

with an odds ratio of 15.35 (95% CI=6.71-35.13) indicating that individuals who had received a physician recommendation for colonoscopy were 15 times more likely to be compliant with colonoscopy than individuals without a physician recommendation. The odds ratio for Self-efficacy Scale scores was 7.90 (95% CI=3.54-17.66) meaning participants who scored a 40 on the Self-efficacy Scale were almost eight times more likely to get a colonoscopy than individuals with scores lower than 40. The exponential beta for the Bar-13 Scale scores was .35, which was converted into an odds ratio (1/.35) of 2.86 (95% CI=.17-.76) (J. Wu, personal communication, September 19, 2008). These findings indicated that individuals with higher Bar-13 Scale scores, were 2.86 times less likely to be compliant than individuals with low Bar-13 Scale scores.

Table 22.
Logistic Regression using Forced Entry to Determine Final Predictors of Colonoscopy Compliance

			95% CI for exp b	
Variable	B (SE)	exp b	Lower	Upper
MD Recommendation	2.73 (.42)	15.35***	6.71	35.13
Self-efficacy Scale	2.07 (.41)	7.90***	3.54	17.66
Bar-13 Scale	-1.04 (.39)	.35**	.17	.76
Constant	-1.63 (.48)	.20		

Note Model R^2=.42 (Cox and Snell), .57 (Nagelkerke), Model χ^2=125.59
**p<.01, ***p<.001

The Nagelkerke R^2 of .57 indicated that the final model accounted for 57% of the variance for predictors of compliance (Warner, 2008). The residuals were examined to determine the goodness of fit. The Cook's distance statistic was assessed to identify the influence of individual cases on the model. A Cook's distance greater than one is "cause for concern" (Field, 2005, p. 727). However, none of the Cook's distance statistics were

greater than one in this model. The leverage statistics (hat values) also reflected the degree of influence a particular case had on the model (Field). A leverage statistic of zero would indicate no influence and one would indicate complete influence. The average leverage is calculated by adding one to the number of variables in the model and dividing this sum by the number in the sample size. In this case, 1 plus 3 divided by 234 equals .02, thus .02 is considered the average leverage. Stevens (as cited in Field, 2005) stated that the leverage statistic needed to be greater than three times the average (.06) in order to be considered influential. Since none of the values were greater than .06, there were no values considered influential.

Aim 5) Evaluate participants' perceptions of aspects of having a colonoscopy that are most embarrassing and participants' suggestions for reducing embarrassment.

Research Question 5: *What aspects of having a colonoscopy do men and women 50-64 years old report are the most embarrassing?*

In this sample, 37% of the participants *agreed* or *strongly agreed* that a colonoscopy was embarrassing. Analysis of the findings from research question 5 helped elucidate some of the sources of colonoscopy-related embarrassment. Research question 5 was addressed in two ways. First, responses to the 15 items on the CES were examined. For each item, the four response categories were dichotomized by recoding into 1) *strongly agree/agree* and 2) *strongly disagree/disagree* in order to analyze the aspects of colonoscopy that were most embarrassing. As shown in Table 23, items were ranked based on the number of participants who strongly agreed/agreed that the items were embarrassing.

According to the results of the 15 item CES, *if I had to be awake for the test* was the most embarrassing aspect of having a colonoscopy with 129 (55.4%) participants *agreeing* or *strongly agreeing* that this would be the most embarrassing aspect of the test. The second most embarrassing aspect was *if I passed gas during the test* (109, 46.8%).

Table 23.
Rank Order of Most Embarrassing Aspects of Having a Colonoscopy Based on Items on CES-15 (n=234)

Items on the CES-15	Strongly Agree/ Agree n (%)	Strongly Disagree/ Disagree n (%)
If I had to be awake during test	129 (55.4)	104 (44.6)
If I passed gas during the test	109 (46.8)	124 (53.2)
If the doctor joked with me about test	80 (34.3)	153 (65.7)
If a medical/nursing student was in the room to watch	79 (33.9)	154 (66.1)
My bowel may not be clean after the bowel prep	79 (33.9)	154 (66.1)
Doctor of the opposite gender did the test	61 (26.2)	172 (73.8)
I had to talk about problems with my bottom/buttocks	61 (26.2)	172 (73.8)
Because the tube is being put into my rectum	61 (26.2)	172 (73.8)
Because I might smell	53 (22.8)	179 (77.2)
Because of concern my penis/vagina might not be covered	47 (20.6)	181 (79.4)
Because someone will be touching my bottom/buttocks	45 (19.3)	188 (80.7)
Because the Dr./nurse will see my bottom/buttocks	43 (18.6)	188 (81.4)
If I did not know the doctor doing the test	38 (16.4)	194 (83.6)
If I had to talk to the doctor or nurse about my bowel movements	35 (15.0)	198 (85.0)
Because of the size or appearance of my bottom/buttocks	33 (14.2)	200 (85.8)

Second, as part of the self-administered survey, participants were asked the following open-ended question, "For me, the most embarrassing part of having a colonoscopy would be:" All of the responses were recorded verbatim. Next, the responses were analyzed independently by two researchers. Each researcher read the responses, organized them into groups based on their commonalities, and identified the themes. The researchers then shared findings, discussed comments or themes where there were discrepancies, and came to mutually agreed upon categories and themes (see Appendix K).

Responses to First Open-Ended Question

The first open-ended question was, "For me, the most embarrassing part of having a colonoscopy would be:" Most participants (n=209, 89%) provided a written response with the most common response being that the test was not embarrassing (n=91, 43%). However, 118 (56%) participants offered reasons why a colonoscopy was embarrassing (see Appendix K). Seven themes that emerged were: 1) *exposure/lack of privacy*, 2) *loss of control, 3) invasion/body part involved,* 4) *bowel preparation,* 5) *being conscious*, 6) *familiarity,* and 7) *concerns about physical appearance.*

The largest number of comments mentioned as the most embarrassing part of having a colonoscopy were classified as *exposure/lack of privacy* (n=23, 20%). Comments categorized under *exposure/lack of privacy* included, "Getting naked in front of strangers" and "Laying on a table with my butt exposed". The second largest number of comments was categorized as *loss of control* (n=22, 18%). Responses related to *loss of control* included, "The passing of air after in recovery" and "Waking up and not knowing what happened".

The comments that were grouped into the themes *invasion/body part involved* and *bowel preparation* were the next most frequently reported with thirteen comments each (11%). Some examples of the embarrassing aspects of *invasion/body part involved* were, "Having something put up my rectum" and "Having someone do a procedure on that part of my body". Two examples of comments grouped into the *bowel preparation* theme were, "Getting an enema" and "Having to take the prep and spend hours running to the bathroom".

Comments related to *being conscious* were mentioned by nine participants (8%) as the most embarrassing aspect of a colonoscopy. Two examples of comments in this category included, "If I was awake" and "Being alert while the procedure was done". Seven participants (6%) responded with comments related to *familiarity* or knowing people, especially from work. Some of these comments included, "Having it at the hospital where I work and know the people", and "If you know people in the room". Comments centered around the theme *concerns about physical appearance* were mentioned by six participants (5%). "My weight makes all medical care embarrassing" is an example of the comments that were categorized into the theme *concerns about physical appearance.*

Research Question 6: *What suggestions do men and women 50-64 years old offer for making the colonoscopy less embarrassing?*

The second open-ended question was, "I would be less embarrassed to have a colonoscopy if:" The responses to research question 6 were analyzed using the same methods as the aforementioned open-ended question. One hundred sixty nine participants (72%) provided a written response to this question. Seventy-nine of those participants

(47%) responded to this question with comments such as “n/a”, “nothing”, “don’t know”, or “I wasn’t embarrassed”. However, 90 participants (53%) offered suggestions for making the colonoscopy less embarrassing and seven themes emerged (see Appendix K). The themes included: 1) *using a different procedure*, 2) *anonymity/familiarity,* 3) *gender matching,* 4) *unconsciousness,* 5) *using a different bowel preparation,* 6) *privacy,* and 7) *increased knowledge.*

Comments related to *using a different procedure* and *anonymity/familiarity* were mentioned by 18 participants each (20%). Some examples of the comments classified as *using a different procedure* included, “If it was not invasive”, “If it was like an x-ray”, and one participant wrote “if I could do it myself”. Some comments that were categorized as *anonymity/familiarity* expressed a desire for more anonymity such as “If I could do it anonymously”, and “If I didn’t work for the hospital where the test is done”, but others preferred familiarity for decreasing embarrassment. For example, one participant wrote that “If I didn’t have to be exposed to strangers” and another reported that they would be less embarrassed “If it was with a doctor I was familiar with”.

Thirteen participants (14%) made suggestions related to *gender matching* of the people present during the colonoscopy as a way to make a colonoscopy less embarrassing. Some of the comments participants wrote included “If I had a woman doctor”, “If female nurses were not present (old fashioned)”, and “If I had a male doctor”. Participants preferred people of their own gender to be present during the test.

Unconsciousness would make the procedure less embarrassing according to nine participants (10%). One commented, “If I didn’t know what was happening” and another stated, “If they put you out”. Eight participants (9%) wrote comments that were classified

as *using a different preparation.* Some comments representative of this theme were "If the preparation was more pleasant" and "If I didn't have to drink the laxative". Seven (8%) stated that more *privacy* was the key to decreasing embarrassment. "Recovery was in a private area" and "Only the doctors and nurses were present" were suggestions for reducing embarrassment that were grouped into the *privacy* theme. Five participants (6%) mentioned *increased knowledge* as a means of lowering embarrassment and one specifically stated she would be less embarrassed "If I was more informed" and another wrote, "If I knew more about it".

Summary of Data Analyses

The CES-6 was found to be a reliable and valid instrument for measuring colonoscopy-related embarrassment. The instrument had a Cronbach's alpha of .89. Validity was confirmed based on the unidimensionality of the scale, and that lower CES-6 scores were related to the action stage of adoption and compliance with colonoscopy.

Statistical analyses showed that participants with lower income, higher BMI, and lower CRC Knowledge scores were likely to have higher CES-6 scores. Participants with higher Bar-13 Scale scores and high (compared to very high) Self-efficacy Scale scores were more likely to have higher CES-6 scores. Higher Bar-13 Scale scores and higher BMIs were predictive of higher CES-6 scores.

Further testing showed that individuals with higher CRC Knowledge Scale scores, very high Self-efficacy Scale scores, lower Barrier Scale scores, and a recommendation from a physician for a colonoscopy were more likely to be compliant with colonoscopy. Having a physician recommendation, very high Self-efficacy Scale scores, and lower

Bar-13 Scale scores were predictive of compliance with colonoscopy explaining 50% of the variance in compliance.

According to the results of the 15 item CES, *if I had to be awake for the test* and *if I passed gas during the test* were the most embarrassing aspects of having a colonoscopy based on the number of participants that agreed or strongly agreed with the 15 items of the CES. Categorizing the responses to the question, "For me, the most embarrassing part of having a colonoscopy would be:" resulted in the identification of seven themes. The themes, reported in order of decreasing frequency of responses, were: 1) *exposure/lack of privacy*, 2) *loss of control, 3) invasion/body part involved,* 4) *bowel preparation,* 5) *being conscious*, 6) *familiarity,* and 7) *concerns about physical appearance.*

The second open-ended question was, "I would be less embarrassed to have a colonoscopy if:" The themes with the greatest frequency of responses were 1) *using a different procedure*, 2) *anonymity/familiarity,* 3) *gender matching,* 4) *unconsciousness,* 5) *using a different bowel preparation,* 6) *privacy,* and 7) *increased knowledge.*

CHAPTER FIVE

DISCUSSION

This chapter includes a summary of the study followed by a discussion of the major findings. Limitations of the study will be reported, recommendations for future research will be discussed, and conclusions will be stated.

Summary of the Study

A colonoscopy can prevent colon cancer, the third leading cause of cancer-related death (ACS, 2008). However, a considerable number of individuals are not being screened with colonoscopies and one barrier is embarrassment. Although it is recognized in the literature that embarrassment is a barrier, other barriers such as the bowel preparation and pain, have been studied in greater depth resulting in interventions that reduced these barriers to compliance with colonoscopy. However, embarrassment has not been fully studied; consequently little is known, in part, because there was no available instrument for measuring this barrier. Therefore, the purpose of this study was to develop and test an instrument to measure embarrassment related to colonoscopy.

This study was a cross-sectional survey of 234 members of an HMO in Illinois who were 50-64 years old. Data were collected using a mailed survey, followed by a postcard one week later, and a replacement survey three weeks after the initial survey was sent. The response rate was 56%.

The theoretical frameworks that guided the study were the HBM and TTM. Both models were used as no single conceptual framework was sufficient to function as the foundation for this study. The HBM is a theory frequently used to guide research seeking to gain an understanding about the likelihood that people will prevent, screen for, or

control an illness. This study investigated several variables that may predispose one to change behavior such as age, gender, income, education level, marital status, BMI, and CRC knowledge as well as a cue to action (physician recommendation). Additionally, moderators including perceived barriers (in general), embarrassment, and self-efficacy were studied. Perceived barriers have been shown to be the aspect of the HBM that was most predictive of completion of various preventive health behaviors (Pender, Murdaugh, Parsons, 2006). This study investigated barriers as a whole and one particular barrier, embarrassment, related to compliance with screening guidelines for colonoscopy, and found that higher barriers and high self-efficacy (compared to very high) were related to higher CES-6 scores.

The TTM theory takes into account that the transition in stages of adoption happens over time. One aspect of the model is decisional balance where the individual weighs the pros and cons of making a behavior change. The balance of the pros to cons increases as the individual moves through the stages. For example, the individual in the precontemplation stage has far more cons than the individual in the action stage (Prochaska, & Velicer). As the process continues, individuals progress to a more advanced stage of change. This study examined the relationship between the degree of embarrassment and the stage of adoption and supported this theory. Precontemplators had higher embarrassment (greater "con") than the actors (lower "con").

The sample consisted of primarily white (94%), high income, well-educated participants. The number of men and women was nearly equal and three quarters of the sample was married or living with a partner. The average age of participants was 57 years old with ages of participants fairly equally distributed across the 50-65 year age range.

The sample was considerably more homogenous racially than the population of Illinois or the United States, which were 79% and 80% white, respectively, in 2006 (U.S. Census Bureau, 2008). Seventy two percent of the sample earned more than the median household income for Illinois ($47,771) and the U.S. ($44,334) in 2004. Additionally, in 2000, more participants in the sample had a bachelor's degree or higher (42%) compared to the residents of Illinois (26%) or the U.S. as a whole (24%).

Nearly two thirds of the sample were compliant with CRC screening guidelines for colonoscopy. This percentage is about double the percentage of individuals who reported a colonoscopy in the past 10 years in the National Health Interview Surveys (32.2% of men and 29.8% of women) (Meissner, Breen, Klabunde, & Vernon, 2006).

The new instrument being tested, the CES, was found to be reliable, though redundant, with an initial Cronbach's alpha of .95. Following further analysis and data reduction, using principal components analysis, the CES was reduced to six items with a Cronbach's alpha of .89. The CES-6 also showed evidence of construct validity by demonstrating unidimensionality. In addition, respondents who had lower CES-6 scores were significantly less likely to be in more advanced stages of adoption and more likely to be compliant with colonoscopy.

Statistical analyses showed that participants with lower income, higher BMI, and lower CRC knowledge were likely to have higher CES-6 scores. Participants with higher Bar-13 Scale scores and high (compared to very high) Self-efficacy Scale scores were more likely to have higher CES-6 scores. Higher Bar-13 Scale scores and higher BMIs were predictive of higher CES-6 scores in multivariate analyses.

Univariate testing showed that individuals with higher CRC Knowledge Scale scores, very high Self-efficacy Scale scores, lower Bar-13 Scale score, and who had received a physician recommendation for a colonoscopy were more likely to be compliant with colonoscopy. Physician recommendation, very high Self-efficacy Scale scores, and lower Bar-13 Scale scores were predictive of compliance with colonoscopy. These findings supported the HBM.

Many participants (89%) responded to an open-ended question regarding sources of embarrassment related to having a colonoscopy. Identification and analysis of comments resulted in the following themes listed in descending order of frequency with which the comment was mentioned: 1) *exposure/lack of privacy*, 2) *loss of control,* 3) *invasion/body part involved,* 4) *bowel preparation,* 5) *being conscious*, 6) *familiarity*, and 7) *concerns about physical appearance.*

Participants were also asked for suggestions on ways to reduce embarrassment related to having a colonoscopy. Seventy two percent of the participants responded, and the themes that were identified are listed in descending order with regard to the frequency that the comments were stated: 1) *using a different procedure*, 2) *anonymity/familiarity,* 3) *gender matching,* 4) *unconsciousness,* 5) *using a different bowel preparation,* 6) *privacy,* and 7) *increased knowledge*.

Discussion

The current study is timely as CRC screening is becoming a health priority and colonoscopy is increasingly viewed as the "gold standard" of CRC screening tests (ACS, 2005). For example, in 2001, Medicare began covering the cost of screening colonoscopies for individuals at average risk for CRC (Phillips et al., 2007).

New Instrument to Measure Colonoscopy-related Embarrassment

The CES-6 is an important addition to the body of knowledge since previous researchers knew that embarrassment was a barrier to compliance with colonoscopy (Nelson & Schwartz, 2004; Lewis and Jensen, 1996; Denberg et al., 2005; Harewood et al., 2002; Kelly & Shank, 1992; Janz et al., 2003; Stockwell et al., 2003; Busch, 2003; Gipsh et al., 2004; Walsh et al., 2004; Codori et al., 2001; Rawl et al., 2004; Nicholson & Korman, 2005; Wardle et al., 2003), but they had no way to objectively measure embarrassment in this situation. The results of the current study provide initial evidence for internal consistency, construct validity, and factor structure of the CES-6 in the context of white, well-educated, relatively wealthy individuals with health insurance. Having a valid and reliable measure of embarrassment related to having a colonoscopy is important for determining patients who are more likely to be embarrassed by the procedure leading to test delay or noncompliance with recommendations for this life saving test.

The CES-6 is more informative than a single item asking the participant if having a colonoscopy is embarrassing, because the single item does not provide any information as to the source of embarrassment, where as the CES-6 does. Knowing the sources of embarrassment gives the physician or nurse an opportunity to address the specific concerns of the patient. Counseling based on specific issues could help alleviate the embarrassment so that the patient would comply with the recommended colonoscopy.

Additionally, the six-item, multiple choice scale with four responses is relatively short and quick to administer. The length of the instrument and number of possible responses make it an instrument that could reasonably be used in a busy healthcare

facility. Moreover, the six items on the CES-6 (gender of the endoscopist, knowing the endoscopist, having a nurse or medical student present in the room, concern about the bowel not being clean, and the size or appearance of the buttocks) will be important in future research to assist in identifying interventions for reducing or eliminating embarrassment and improving colonoscopy screening rates.

Factors Associated with Embarrassment

In this study, lower income was the only demographic variable significantly related to higher embarrassment as measured by the CES-6. This is new knowledge since no other studies were found that examined relationships between income level and embarrassment.

While other studies have shown significant relationships between embarrassment and the demographic variables of age, education, and marital status, this one did not. In a study of Japanese Americans, embarrassment related to CRC screening decreased as participants aged (Honda & Gorin, 2005). These researchers also found that lower education was associated with higher embarrassment in Japanese Americans. Perhaps the ethnic-cultural differences accounted for the divergence in findings related to age and education. In addition, others have shown that having a partner was associated with lower levels of embarrassment related to living with an intestinal ostomy (Mitchell et al., 2007).

Some researchers have shown that females were more embarrassable than males (Miller, 1992, 1995; Sabini, Siepmann, Stein, & Meyerowitz, 2000; Farraye et al., 2004). However, this study and a psychological study by Sabini, Garvey, and Hall (2001) did not find any differences in levels of embarrassment by gender. This is a topic that requires further investigation.

The current study showed a significant relationship between BMI and embarrassment, but no other studies were found that examined this specific relationship. However, other studies showed that BMI was related to body image (Sarwer, Wadden, & Foster, 1998; Fredrickson et al., 1998) such that higher BMI was associated with poorer body image. In future studies, an instrument that measures body image could be used, in addition to calculating BMI, so that the relationships among body image, BMI, and embarrassment could be examined.

This study showed that lower CRC knowledge was related to higher embarrassment. Additionally, 6% of the participants who offered suggestions for making a colonoscopy less embarrassing, mentioned greater knowledge as a possible solution. This is one of the novel findings of this study since no other studies were found that examined the relationship between CRC knowledge and embarrassment.

Higher perceived barriers to colonoscopy were related to higher embarrassment in this study, and very high self-efficacy was related to lower embarrassment. In previous research studies, embarrassment was considered a barrier, but embarrassment had not been examined in isolation in relation to the other barriers. In the same way, the relationship between self-efficacy and embarrassment had not been studied. These are new findings generated by this study.

This study found that individuals in the precontemplation stage of adoption had significantly higher colonoscopy-related embarrassment, according to the CES-6 scores, than individuals in the action stage. Rawl et al. (2004) reported the same findings in relation to colonoscopy testing, and Champion and Skinner (2003) found the same with

regard to mammography. In contrast, Brenes and Paskett (2000) found that stage of adoption was not related to embarrassment regarding a rectal exam.

Factors related to Compliance with Colonoscopy

In this study, none of the demographic variables were related to compliance with colonoscopy. Age was not associated with endoscopic screening of the colon in this study, and other researchers report this same finding (Kelly & Shank, 1992; Lewis & Jensen, 1996; Brenes & Paskett, 2000; McCarthy & Moskowitz, 1993). However, in one study, Segnan et al. (2005), lower age was found to be related to completion of endoscopic colon screening. In contrast, the results of most studies showed that age was positively related to screening such that those who were older were more likely to obtain endoscopic colon testing (Denberg et al., 2006; Weinberg et al., 2004; Codori et al., 2001; Denberg et al., 2005; James et al., 2002; Gorin & Heck, 2005; Honda, 2004; Walsh et al., 2004). This relationship needs further study.

The current study found no difference in the number of males and females that were compliant with colonoscopy and these findings were similar to two other studies (Kelly & Shank, 1992; Lewis & Jensen, 1996) that found that gender was not significantly associated with completion of a flexible sigmoidoscopy. However, most studies showed that male gender was associated with higher rates of endoscopic colon screening (Seeff et al. 2004; Codori et al., 2001; Slattery et al., 2004; McCarthy & Moskowitz, 1993; Gilbert & Kanarek, 2005; Segnan et al., 2005; Gorin & Heck, 2005; Green & Kelly, 2004). Maybe a relatively high education level negated the impact of gender in the decision to obtain a colonoscopy in the current study.

This study found no difference in compliance with colonoscopy based on income. However, higher income has typically been associated with higher participation rates in endoscopic testing for CRC (Seeff et al., 2004; Gilbert & Kanarek, 2005; Bostick et al., 1994; Kelly & Shank, 1992). It may be that income is not an issue for the study sample because all of the participants had insurance coverage for colonoscopy through the HMO.

Educational levels were not significantly related to compliance with colonoscopy in this study, and education was not related to sigmoidoscopy compliance in two other studies (Lewis & Jensen, 1996; Brenes & Paskett, 2000). While most studies showed that higher education levels were related to endoscopic CRC screening compliance (Seeff et al., 2004; Bostick et al., 1994; McCarthy & Moskowitz, 1993; Slattery et al., 2004; Gorin and Heck, 2005), two studies showed lower levels of education were related to completing endoscopic CRC screening (Kelly & Shank, 1992; Menon et al., 2003). The relatively high education levels of participants in this study may be the reason no relationship was detected between the educational levels and compliance with colonoscopy.

Consistent with the results of this study, most studies found that being married was not associated with higher rates of endoscopic CRC screening (Bostick et al., 1994; Kelly & Shank, 1992; Lewis & Jensen, 1996; Slattery et al., 2004; Brenes & Paskett, 2000; Denberg et al., 2005; Menon et al., 2003). However, in three studies, investigators found being married was associated with higher rates of endoscopic CRC screening completion (Hsia et al., 2000; Juon, Han, Shin, Kim, & Kim, 2003; Seeff et al., 2004).

The current study showed no relationship between BMI and compliance with colonoscopy, which is not surprising since the results from previous studies that

examined the relationship between BMI and compliance to endoscopic CRC screening guidelines were equivocal. For example, Slattery et al. (2004) found that higher BMI in women, but not men, was associated with higher rates of screening with sigmoidoscopy from 1997-2001 but not from 1991-1994. Rosen and Schneider (2004) found that morbidly obese women had significantly fewer endoscopic CRC screening tests than normal weight women, whereas Ata et al. (2006) found that overweight or obese individuals were more likely to be compliant with endoscopic tests than underweight women. The discrepancy in findings may be related to the use of self-reported height and weight in this study.

Higher CRC knowledge scores were related to compliance with colonoscopy in this study. Menon et al. (2003) also found that higher knowledge was associated with ever having had a colonoscopy, but Brenes and Paskett (2000) found no relationship between CRC knowledge and higher rates of sigmoidoscopy completion. Previous research found that greater knowledge of CRC screening was positively related to CRC screening (Freidman et al., 2001; Seeff et al., 2004; Tessaro et al., 2006; Green & Kelly, 2004; Klabunde et al., 2006; Menon et al., 2003; Menon, 2007), although findings were not specific to colonoscopy. Clearly, greater patient education on the part of physicians and nurses, as well as public education through mass media, improves knowledge, awareness, and CRC screening rates. These findings suggest more funding for education would be effective in increasing compliance with colonoscopy and other methods of CRC screening.

A cornerstone of the HBM is that individuals who perceive more barriers are less likely to be screened. This statement has been supported empirically in the past, in

relation to colonoscopy (Janz et al., 2003; Brenes & Paskett, 2000; James et al., 2002), and was supported with the findings from this study. Lower barrier scores were found to be predictive of compliance with colonoscopy suggesting that health care providers should strive to help patients reduce perceived barriers in order to increase the number of individuals screened and to reduce morbidity and mortality related to CRC.

Consistent with two other studies, this study showed that very high self-efficacy was related to higher rates of endoscopic CRC screening (Menon et al., 2007; Menon et al., 2003). However, one study found that self-efficacy was not predictive of having a sigmoidoscopy (Freidman, Webb, & Everett, 2004). One problem in interpreting this data may be the ceiling effect observed in this study. More research is needed concerning this relationship, but in this study, very high self-efficacy was predictive of compliance with colonoscopy. These findings suggest that health care providers need to assist patients to develop very high levels of self confidence in order to increase the likelihood that they will become compliant with colonoscopy.

In the current study, having a physician recommendation for colonoscopy was positively related to higher colonoscopy screening rates. Many other studies support this finding (Harewood et al., 2002; Gilbert & Kanarek, 2005; Janz et al., 2003; Menon et al., 2003; Tessaro et al., 2006; Brenes & Paskett, 2000; Teng et al., 2006; Rios et al., 2006; Rawl et al., 2004; Codori et al., 2001). This study showed that participants were 15 times more likely to be compliant with colonoscopy if a physician had recommended the test. Clearly, it is important that physicians recommend colonoscopy testing for CRC if the morbidity and mortality related to CRC is to be reduced.

This study found that having an endoscopist of the same gender was one way to make the procedure less embarrassing. Other researchers have found that the gender of the endoscopist is related to compliance with colonoscopy (Menees et al., 2005; Stockwell et al., 2003; Harewood et al., 2002). These findings support the need for adequate numbers of gastroenterologists of both genders and more balance in the numbers of nurses of both genders working in the gastroenterology labs. However, only 4% of American Society of Gastrointestinal Endoscopy are women (Varadarajulu, Petruff, & Ramsey, 2002) and the number of women entering the specialty is not increasing (Streett, 2007).

In both subjective and objective aspects of this study, participants stated that having to be conscious for a colonoscopy would increase embarrassment. Sedation during the colonoscopy is an advantage over the sigmoidoscopies done without sedation. However, it is possible that the general public does not recognize the difference in a colonoscopy and sigmoidoscopy. Therefore, the public may not be aware that sigmoidoscopies are done less frequently now and that sedation is used with the more common colonoscopy (ACS, 2005). The public needs to be informed about the type of testing being done and reassured that sedation is used, which may increase compliance with colonoscopy.

Similar to consciousness during a colonoscopy, concerns about gas were found to increase embarrassment in both the subjective and objective aspects of the study. Finding that the loss of control of gas expulsion or the lack of privacy when it occurs seems intuitive, but this relationship has not been reported in the literature as an embarrassing aspect of a colonoscopy in the past. The subjective comments also suggest that the item

concerning gas should read *passed gas after the test* rather than *during the test* since five of the comments associated with gas were related to expelling gas after the procedure.

In addition to the gas that the inflation of the bowel causes, two other aspects of the procedure were mentioned as the most embarrassing parts of having a colonoscopy in the open-ended questions. One was the invasiveness of the test and the other was the bowel preparation. The finding that there are aspects to the colonoscopy that individuals find embarrassing and suggestions for a different procedure as a way to make the test less embarrassing, are implications that researchers need to continue to search for methods of screening for CRC that are not as embarrassing with regard to the bowel preparation, inflation of the bowel, and invasiveness of the test. There are some new tests that may meet this need. For example, "computed tomographic colonography, simplified colonoscopy, DNA-based testing, and miniaturized imaging" were estimated to enter gastrointestinal practices by 2011 (Regueiro, 2006, p. 1288). Computed tomographic colonography and stool DNA testing are already being used. In fact, these two tests were added to the most current list of list of recommended tests for CRC screening (Smith, Cokkinides, & Brawley, 2008; Levin et al., 2008). Additionally, some of these tests may be able to be done by the patient themselves, such as the DNA testing, which would meet the requests for being able to do the test themselves.

Until new procedures are fully developed, it would behoove health professionals to be aware that a sense of exposure/lack of privacy are two issues related to colonoscopies that have been identified as sources of embarrassment related to a colonoscopy. One way participants suggested for reducing embarrassment was to

increase privacy. Perhaps some of the concerns individuals have with their physical appearance would be allayed with greater respect for privacy.

Eight percent of participants commented that greater privacy would help reduce embarrassment and two of the responses were specific to privacy in the recovery room. As colonoscopies are currently done, dilating the colon with air is necessary for visualization of the colon and identification of polyps. Perhaps new ways will be developed in the future that do not require air for visualization, but one possible way to reduce embarrassment related to expulsion of gas using the current colonoscopy technique, would be to provide more privacy in the recovery area.

Instruments to Measure Embarrassment Specific to Colonoscopy

Prior to this study, there were two scales to measure embarrassment including Modigliani's Embarrassability Scale (Modigliani, 1968) for measuring embarrassment in situations and the Susceptibility to Embarrassment Scale for measuring personality traits (Kelly & Jones, 1997). However, neither instrument assessed embarrassment in the context of a medical procedure, and the subjects in the studies were overwhelmingly undergraduate college students (Miller, 1987, 1992, 1995; Maltby & Day, 2000; Kelly & Jones, 1997). The advantage of the CES-6, over the aforementioned instruments was that it was specifically designed to measure colonoscopy-related embarrassment in people of the age group that are eligible for screening colonoscopies.

Limitations

There are several limitations of this study that should be noted. First, generalizability of the study results may be limited since the sample lacked racial and ethnic diversity and was wealthier and better educated than the general population.

Additionally, since all of the participants were members of an HMO, all had insurance coverage for colonoscopy, a relatively expensive screening test. Another limitation of the study is that, for the participants who had not had a colonoscopy, items on the CES were hypothetical (Dillman, 2000).

Although efforts were made to recruit noncompliant participants by sending more surveys to noncompliant HMO members when the second group of surveys was mailed, fewer surveys were returned from noncompliant individuals. The lower response rate from noncompliant individuals may have resulted in nonresponse bias (Polit & Beck, 2004). Therefore, this study may have identified less embarrassment than is present in the population at large, and may not have accurately determined the factors related to embarrassment associated with colonoscopy.

In addition, a new instrument was used in this study, and although the instrument performed well with this sample, it is not known how well it would perform with other populations. Also, results from this study suggest modifications should be made to the instrument. For example, based on the comments to the open-ended questions, the item that reads *I would be embarrassed to have a colonoscopy during the test* should be changed to *I would be embarrassed to have a colonoscopy after the test.*

Future Directions

The findings of this study need to be disseminated to physicians, nurses, department managers, and administrators in clinic and hospital settings to increase awareness that embarrassment is an issue for many people. Physicians and nurses could use the CES-6 to identify the patients who are more likely to have colonoscopy-related embarrassment and provide counseling to hopefully dispel embarrassment. For example,

informing patients that sedation is used and offering endocopists of both genders when making referrals may be helpful interventions. Department managers and administrators could use the results of the study findings when planning the layout of a gastrointestinal lab and the patient flow. For instance, recovery in private rooms, rather than bays separated by curtains, would provide more privacy when patients are expelling gas. In addition, knowing that some individuals were embarrassed to have a colonoscopy in a setting where they know the physicians, nurses, and other healthcare workers, administrators of the HMO could negotiate to have other settings available where members could be tested more anonymously.

The findings of the CES-6 could also be used when creating patient education materials. Informing patients that sedation is given prior to the procedure and that they can request not to have nursing or medical students present are possible education topics that may reduce embarrassment. Assuring patients that expelling gas after the procedure is normal and informing them about privacy protection during this time may also decrease embarrassment.

Ideas for future research include testing the reliability and validity of the CES-6 with different racial/ethnic groups, individuals with lower incomes, and less education than the sample used in this study. Additionally, the CES-6 needs to be tested on participants that do not have insurance coverage for screening colonoscopies. Comparison of embarrassment based on gender and age is another possible area of research.

The CES-6 could be used to measure the effectiveness of interventions created to reduce embarrassment. For example, pajama pants could be developed with a flap that

could be lowered for the procedure and replaced after the procedure to insure more privacy and to specifically address two identified sources of embarrassment-personal concerns about the size or appearance of the buttocks and having the buttocks exposed.

Additionally, the findings from this study bring into question the possibility that embarrassment may be a significant barrier to compliance with mammography, pap smears, and digital prostate exam screening tests. Further research to address embarrassment with these cancer screening tests could be conducted.

Conclusion

There are some people who will never be willing to have a screening colonoscopy but who would consider other options for testing that are less invasive, but still effective in detecting CRC, such as FOBT or stool DNA tests (Smith, Cokkinides, & Brawley, 2008; Levin et al., 2008). Additionally, the computed tomographic colonography, commonly called the virtual colonoscopy (Regueiro, 2006; Van Gelder et al. 2004), is available and some individuals may find this test more palatable than a colonoscopy. Even though the colonoscopy is the "gold standard" (ACS, 2005) for CRC testing, it is important for health care providers to help patients find a test that they will do if the incidence of CRC is to be reduced.

However, since colonoscopy is currently considered the best CRC screening test (ACS, 2005), it is important to continue to try to encourage individuals to have a colonoscopy, and this study suggests that increasing self-efficacy would help. However, findings from this study also showed that embarrassment is a significant barrier to compliance with colonoscopy. Prior to this study, little was known about the degree of influence embarrassment had on compliance with colonoscopy, components of the test

that contributed to embarrassment, and which aspects of having a colonoscopy were most embarrassing. Additionally, there was no valid and reliable way to measure colonoscopy-related embarrassment.

This study established the reliability and validity of the CES-6, a new instrument for measuring embarrassment related to colonoscopy. Although the CES-6 has shown reliability and validity when used with white, relatively wealthy, educated, and insured individuals, it is not known how the instrument would perform when used with minority, low income individuals.

This study showed that health care providers need to develop and test interventions to reduce barriers, including embarrassment, strive to increase self-efficacy, and that providers also need to continue to encourage patients to get colonoscopies. In addition, findings shed some light on some of the sources of embarrassment such as concerns about exposure and lack of privacy, loss of control of gas expulsion, invasion of an intimate area such as the rectum, knowing people in the procedure room, being conscious during the test, and having a physician of the opposite gender. There are some simple measures that can be taken to reduce colonoscopy-related embarrassment such as providing as much privacy as possible, reassuring patients that confidentiality will be maintained, informing patients that they will be unconscious for the test, and offering patients gastroenterologists of both genders when making a referral. Additionally, individuals need greater knowledge about CRC, the colonoscopy procedure, and the ability to prevent colon cancer in order to increase the number of individuals that are tested.

In the future, the CES-6 can be used to further test aspects of having a colonoscopy that contribute to embarrassment. Additional interventions can be developed to reduce or eliminate embarrassment related to this lifesaving test so that more individuals will get screened and lives can be saved.

Appendix A

Ralph Velazquez, M. D.
Vice President and Chief Medical Officer
OSF HealthPlans
Peoria, Illinois 61615

Dear HealthPlans Member,

You have been selected to participate in an important research study about your thoughts and opinions on colorectal cancer screenings. We are working with another member of our OSF family, Ms. Kim Mitchell, on this study. Ms. Mitchell is an Assistant Professor at Saint Francis College of Nursing and working on her PhD at Indiana University. This research study is part of her graduation requirements.

You are part of a select group of 400 HealthPlans members chosen to complete the enclosed survey. Your participation is **completely voluntary**. If you choose not to complete the survey, your medical care will not be affected in any way. If you have any questions or concerns about the study, please call Kathy at HealthPlans.

We want to assure you that your privacy has been protected and your name has not been released to anyone. The researcher will only know you by a randomly selected number. Your answers on the survey will be confidential and not shared with anyone other than the researcher.

If you are interested in participating in this study, please complete the survey within one week and return it in the enclosed stamped, self-addressed envelope. Included with the survey is a small token of appreciation for your time and effort.

We want to thank you in advance for completing this survey about colorectal cancer screening. Your thoughts and opinions will make a valuable contribution to science. In addition, your participation will assist Ms. Mitchell to complete her PhD in Nursing.

With appreciation,

Ralph R.Velazquez, M. D.
Vice President/Chief Medical Officer

Kimberly A. Mitchell RN, PhD(c)
Researcher

Appendix B

Certificate of Appreciation

THIS CERTIFICATE OF APPRECIATION IS AWARDED TO

_____

FOR PARTICIPATION IN THE COLON HEALTH RESEARCH STUDY
AND
CONTRIBUTING TO THE GENERATION OF NEW SCIENTIFIC KNOWLEDGE

SIGNED _____

DATED _____

Appendix C

Post Card

Dear HealthPlans Member,

Last week you received an important survey in an OSF HealthPlans envelope. This survey is part of a significant research study on colon health.

If you have already filled out and mailed the survey, **thank you**. If you have not completed the survey, **please finish it and send it today.** If you did not receive a survey, or if it was misplaced, please call Kathy at OSF HealthPlans. Another survey will be mailed to you promptly.

Ralph R. Velazquez, M. D.
Vice President
Chief Medical Officer

Kimberly A. Mitchell RN, PhD(c)
Researcher

Appendix D

Dear HealthPlans Member,

Several weeks ago you received a survey with questions about colon health. According to our records, it has not been returned yet.

We are writing again because of the importance of *your* survey answers to the research study. It is only by hearing from *everyone* chosen for the study that the results are most accurate and useful. Enclosed is another copy of the survey in case you misplaced the first one.

We want to remind you of the confidentiality of your survey answers. The researcher will only "know" you by an identifying code. Your answers on the survey will be confidential and not shared with anyone other than the researcher. Your participation is completely **voluntary.**

We hope you will complete the survey as soon as possible and return it in the stamped envelope.

With appreciation,

Ralph R. Velazquez, M. D.
Vice President/Chief Medical Officer

Kimberly A. Mitchell RN, PhD(c)
Researcher

P. S. If you have any questions, please feel free to call Kathy from HealthPlans.

Appendix E

Content Validity Analysis

Embarrassment Instrument Evaluation Form

Conceptual Definition: Embarrassment is a sudden and intense but temporary uneasy, awkward, self-conscious, exposed feeling that can be strong or weak, ranging from mild awkwardness or, uneasiness, and uncertainty to strong sensations of incapacitations, blushing and a desire to escape (Miller, 1992)

Note about how the embarrassment instrument will be scored: The instrument is scored such that the higher numbers indicate that the individual strongly agrees that the item is embarrassing. The items are worded such that the higher overall score indicates that the individual finds more factors related to a colonoscopy more embarrassing than someone with a lower score.

Instructions:
Please evaluate each item in the instrument for its construction, wording and clarity. Additionally, please use the rating scale provided to determine the representativeness of each item. You may use the comment section below each item for comments about the item wording, clarity, construction, or representativeness.

1=The item is **not** representative of factors that relate to embarrassment associated with anticipation of a colonoscopy.

2=The item needs **major** revisions to be representative of factors that relate to embarrassment associated with anticipation of a colonoscopy.

3=The item needs **minor** revisions to be representative of factors that relate to embarrassment associated with anticipation of a colonoscopy.

4=The item **is** representative of factors that relate to embarrassment associated with anticipation of a colonoscopy.

Embarrassment and Colon Cancer Prevention Survey

The goal of this survey is to find out what, if any, things people find embarrassing when they think about getting a colonoscopy. The fear of embarrassment prevents some people from getting colonoscopies. If we can find out what causes embarrassment, we can reduce these things, more people will get colonoscopies, and more lives will be saved. Thank you for your willingness to participate in this research study.
Evaluator comments:

Please circle the number that best describes your agreement or disagreement with the statements.

	Strongly Disagree	Disagree	Neutral	Agree	Strongly Agree
1. When thinking about getting a colonoscopy, I think I would be embarrassed having one.	1	2	3	4	5

Evaluator comments:

I think I would be embarrassed when having a colonoscopy if:

	Not rep	Major	Minor	Is rep
2. I did not know what was going to happen during the test.	1 X	2	3 X	4 X
Evaluator comments: Not clear. Would the embarrassed be because I felt stupid abut not knowing or felt afraid about no knowing and maybe assuming the worst? This is a tad awkward because you just told them about the test.				
3. A person of the opposite sex did the test.	1	2	3	4 XXX
Evaluator comments:				
4. Anyone but the doctor was in the room.	1 X	2	3	4 XX
Evaluator comments: More than 1-2 medical people were in the room. No procedure is ever done with only 1 person in the room, so irrelevant. Now I see item 5. Scrap this one.				
5. Anyone but the doctor and a nurse	1	2	3	4

were in the room.				XXX
Evaluator comments:				
6. Other people saw my buttocks.	1	2	3 X	4 XX
Evaluator comments: Change to the Dr. or the ns. Who else would be here?				
7. My vagina/penis was exposed during the test.	1	2	3 XX	4 X
Evaluator comments: May bother some. Might want one version for men and one for women Suggest using "or" instead of "/"				
8. I did not know the doctor doing the test.	1	2	3 X	4 XX
Evaluator comments: What about I did know the Dr.?				
9. I passed gas during the test.	1	2	3	4 XXX
Evaluator comments:				
10. I felt like I had to have a bowel movement during the test.	1 X	2	3	4 XX
Evaluator comments: This item is too subtle. The bowel will be empty and they'll be sedated, so a BM is not a realistic concern, Are you thinking sigmo here? If so, should the scale make the distinctions?				
11. A medical student was in the room.	1	2	3	4 XX
Evaluator comments:				
12. A nursing student was in the room.	1	2	3	4 XXX
Evaluator comments:				
13. I knew the doctor doing the test.	1	2	3	4 XXX
Evaluator comments:				
14. The doctor joked with me about the test.	1	2	3 X	4 XX

Evaluator comments: When?				
15. I had to talk to my doctor about my bowel movements.	1	2	3 X	4 XX
Evaluator comments:				
16. The doctor was nice looking (attractive)	1 X	2	3	4 XX
Evaluator comments: Unlike to other items in the scale, this is not a potential cause of distress that can be ameliorated by a change in education or procedure-and it is therefore of less interest. It is irrelevant to the things you can do with the results of your research.				
17. I had to talk to my doctor about my rectum/buttocks.	1	2 X	3	4 XX
Evaluator comments: When?				
18. The doctor doing the test was my primary (regular) doctor.	1	2	3	4 XXX
Evaluator comments: Same issue as 13?				
19. I had a prior bad experience related to someone touching my buttocks.	1 X	2 X	3	4 X
Evaluator comments: Does not work because it is hypothetical for some respondents. This one is similar to #24. See comment on 24. A history of such an event may be influential, but this is a different item from the rest in that is asks one to imagine a past event that (in most cases) did not occur instead of a future event that might. I fear it is a nonsensical question for most folks.				
20. I was awake and aware of what was happening during the test.	1	2 X	3	4 X
Evaluator comments: Change "was" to "might be". I am not sure about this one. If you're awake during the test, embarrassment is not going to be your main issue, pain will be. I think for those who have not had the test or don't know much about it,				

this would be tricky question-e.g. "Will I be awake? I heard they put you to sleep."				
21. My doctor was the same gender as me.	1 X	2	3 X	4 X
Evaluator comments: Rephrase as "a person of the same sex performed the test"				
22. Anyone else heard what the doctor found on my test.	1 XX	2	3	4 X
Evaluator comments: "Someone might hear". Not sure this would be unique for colonoscopy. Would be for any test. Not sure how this relates to actual embarrassment about the test.				
23. My bowel was not clean.	1	2	3 X	4 X
Evaluator comments: Change "was not" to "may not"				
24. I have had a prior bad experience with someone touching my buttocks/rectum	1 X	2 X	3	4
Evaluator comments: See comments on #19. This item is similar to 19; also I think this could lead to uneasiness to fear but not exactly embarrassment. This is another hypothetical past item that makes no sense for the most part				
25. I knew what was going to happen during the test.	1 XXX	2	3	4
Evaluator comments: Not sure this is embarrassment. Foreknowledge is important, but I think his item is irrelevant because one must be told what is happening mustn' one?				
26. I felt helpless during the test	1 XX	2	3	4
Evaluator comments: Different feeling, not embarrassment Helpless				

I think I would be embarrassed when having a colonoscopy:

	Not rep	Major	Minor	Is rep
27. Because of the way my buttocks look.	1	2	3	4 XXX
Evaluator comments:				
28. When the doctor tells me how the test will be done.	1 XX	2	3 X	4
Evaluator comments: There's nothing to be embarrassed about until I understand what the procedure is, so don't I have to be told before I can answer this question?				
29. Because of the invasion of my body with the tube.	1	2 X	3 X	4 X
Evaluator comments: What about people who don't know anything about the test and how it is performed? "invasive" is pejorative				
30. When the doctor tells me the test results.	1 X	2	3 X	4
Evaluator comments: The "when" is interfering with sentence flow from stem to #30."				
31. Because of the size of my buttocks.	1	2	3	4 XXX
Evaluator comments:				
32. Because someone would be touching my buttocks	1	2	3	4 XXX
Evaluator comments:				
33. When the tube is being put into my rectum.	1	2	3 X	4 X
Evaluator comments: Change to "because of the". Same issue re "when"; also what about those who don't know about the test?				
	Not rep	Major	Minor	Is rep
34. Because it invades my privacy.	1	2	3	4 XXX
Evaluator comments:				
35. Because I would feel vulnerable.	1 XX	2	3	4 X
Evaluator comments: Doesn't seem to be part of embarrassment. Vulnerable does not				

seem to fit with in the definition of embarrassment.				
36. Because I embarrass easily.	1	2	3	4 XX
Evaluator comments:				

Suggestions:
Because I might smell
Because I might not be clean

Please fill in the blank for the next three questions. I like these open ends.

37. This is test is more embarrassing for me than other people because _____
_____
Evaluator comments:

38. For me, the most embarrassing part of having a colonoscopy would be
_____
Evaluator comments:

39. I would be less embarrassed if _____
_____
Evaluator comments:

Thank you for taking the time to fill out this survey. The information you gave is very much appreciated and will be used to help prevent colon cancer in the future. If there is anything else you would like to tell us, please write it in the space below. Please return the completed survey in the envelope we gave you. **Thank you!**

Appendix F

Scale Revisions Based on Content Expert's Evaluation

Embarrassment and Colon Cancer Prevention Research Study

The goal of this survey is to find out what, if any, things people find embarrassing when they think about getting a colonoscopy**.** The fear of embarrassment prevents some people from getting colonoscopies. If we can find out what causes embarrassment, we can reduce these things, more people will get colonoscopies, and more lives will be saved. Thank you for your willingness to participate in this research study.

Please circle the number that best describes your agreement or disagreement with the statements.

	Strongly Disagree	Disagree	Agree	Strongly Agree
1. In general, how embarrassed do you think you would be to have a colonoscopy?	1	2	3	4

I think I would be embarrassed when having a colonoscopy if:

	Strongly Disagree	Disagree	Agree	Strongly Agree
2. A person of the opposite sex did the test.	1	2	3	4
3. Anyone but the doctor and a nurse were in the room.	1	2	3	4
4. Other people saw my bottom/buttocks.	1	2	3	4
5. My vagina/penis was exposed during the test.	1	2	3	4
6. I did not know the doctor doing the test.	1	2	3	4
7. I passed gas during the test.	1	2	3	4
8. I felt like I had to have a bowel movement during the test.	1	2	3	4
9. A medical student was in the room.	1	2	3	4
10. A nursing student was in the room	1	2	3	4
11. I knew the doctor doing the test.	1	2	3	4

I think I would be embarrassed when having a colonoscopy if:

	Strongly Disagree	Disagree	Agree	Strongly Agree
12. I knew the nurse assisting with the test.	1	2	3	4
13. The doctor or nurse joked with me about the test	1	2	3	4
14. I had to talk the doctor or nurse about my bowel movements.	1	2	3	4
15. I had to talk to my doctor or nurse about my bottom/buttocks.	1	2	3	4
16. If I was not asleep (sedated) for the test.	1	2	3	4
17. If I had to be awake for the test.	1	2	3	4
18. A person of the same sex performed the test.	1	2	3	4
19. My bowel was not clean.	1	2	3	4
20. Because of the way my bottom/buttocks look.	1	2	3	4
21. Because of the size of my bottom/buttocks	1	2	3	4
22. Because someone would be touching my bottom/buttocks.	1	2	3	4
23. When the tube is being put into my rectum	1	2	3	4
24. Because the test invades my privacy.	1	2	3	4
25. Because I embarrass easily	1	2	3	4
26. Because I might smell.	1	2	3	4

Please fill in the blank for the next three questions.

27. A colonoscopy would be more embarrassing for me than other people because _____
_____

28. For me, the most embarrassing part of having a colonoscopy would be
_____

29. I would be less embarrassed if _____
_____

Thank you for taking the time to fill out this survey. The information you gave is very much appreciated and will be used to help prevent colon cancer in the future. If there is anything else you would like to tell us, please write it in the space below. Please return the completed survey in the envelope we gave you. **Thank you!**

Appendix G

Results of Cognitive Interviewing

Colonoscopy Embarrassment Scale

The goal of this survey is to find out what, if any, things people find embarrassing when they think about getting a colonoscopy**.** The fear of embarrassment prevents some people from getting colonoscopies. If we can find out what causes embarrassment, we can reduce these things, more people will get colonoscopies, and more lives will be saved. Thank you for your willingness to participate in this research study.

Please state the number that best describes your agreement or disagreement with the statements.

In general, how embarrassed do you think you would be to have a colonoscopy?	W2- Would I be embarrassed, um, I, I am sure my rectum would need to be exposed. [Later] Okay. I would say, um, I would not be embarrassed. I agree. Not because I've never had one so I can't. (W5)- There's a neutral one strongly or no opinion. I don't like that one. (M3)-K-So what does that question mean to you? M3-Well, the first thing people think about, what the first I thought about, most guys think about, is the very, very, invasive embarrassing kind of procedure M4-Okay, ah, I would say, ah, it may be somewhat agree.	This specific item will be addressed separately in the parent study so will not be asked again here.

I think I would be embarrassed when having a colonoscopy if:

2. A person of the opposite sex did the test.	W1-Male Dr. for female. W2-*Interrupted by my phone ringing for an emergency call. Meanwhile, interviewee is recorded saying (very softly talking to herself, maybe reading the survey?) a person of the opposite, opposite sex, a person of the opposite sex did the test, a person of the opposite sex (tapping heard) did the test. [Answer when actually asked the question] female: male. I know I'm not. W3-Yes! [Would be embarrassed]. Opposite sex male: female. (W4)-K-I think I would be embarrassed when having a colonoscopy if a person of the opposite sex did the test. So you're female, what sex would your doctor be? W4-It doesn't matter. K-[Trying again] If a person of the opposite sex did it would it be a man or woman? W4-D-It really doesn't matter. K-What I want to know is if you understand this question. W4-Yes, I understand clearly. K-So a person of the opposite sex would be. W4-Male W5- I'm not real comfortable about having a man to examine me. (M1)- K-… I'm a female so if I had a person of the opposite sex what gender would my person doing the test? M1-It could be female or male. K-Okay, so if it's the opposite sex what would it be? M1-It could be either. K-Okay, but I'm female, so what would it be for me? M-It could be a male or it could be a female. (M2)- K-Alright. So you're a male. So what would the gender be of the person examining you if it was the opposite	Four participants confused same sex with opposite sex, but participants also expressed a definite gender preferences for the endoscopist. The question was revised to state clearly which gender the participant is considering in the item. An example of the revised question is: (for a male) I think I would be embarrassed when having a colonoscopy if a female did the test.

	sex? M2-Female. (M3)- K-You're a male. If you had someone of the opposite sex doing your test, what gender would they be? M3-Okay, yes, I understand the question and I would prefer I think a man. K-Okay, so you, okay, but a person of the opposite sex would be what gender, what sex? M3-A man, oh gosh, it would be a woman. (M4)-K-Okay, so if I'm female a person of the opposite sex would be what gender? M4-Ah, female. (Instead of the opposite sex, I asked the same sex questions first and this is his response)…(M5)-So, I am a female, so the person doing the test would be what gender? M5-A man.	
3. Anyone but the doctor and a nurse was in the room.	W3- Yes! [Would be embarrassed]. W4- No, I wouldn't be embarrassed. M3--I thought they [doctor] would be alone. M4-Ah, yes I would…Well, I didn't think that there would be anybody else in the room. Just more or less like a prostate exam, I don't think that I would be comfortable with anybody else in the room, but the doctor or maybe nurse.	Participants stated they did not expect anyone but the doctor to be in the room and once said she would be embarrassed with others in the room. The item is rather vague and may leave the participant wondering about who would be there and how many. In actuality, "extra people" would likely be students so the issue then becomes would having students in the room increase embarrassment. See items 9 and 10.
4. Other people saw my bottom/buttocks.	W1-An adult would know what that is. W2- I understand that question completely and that would be part of the	The comments by participants indicate that some people would see exposure of their

	test. W5- Yeah, uh, I know at times I have to examine things because things occur. I'm even embarrassed for example examining my own butt. W5-If someone else gets to look, I'd say oh my Lord what are they seeing. M1- M-Would you repeat that question? K-(repeated question). M1-That's a good question and it would be okay to ask someone that if they had a problem with that.	buttocks as a potential source of embarrassment. This item was retained.
5. My vagina/penis was exposed during the test.	W1-Very clear. Yes. W2-I understand the question. K-Okay, but you took a deep sigh. W2-Because I do that even with my pap smears. K-Did that thought even occur to you that that might be, when you're thinking about this test? W2-Yes. It would be proximity of vagina and rectum that is a concern. However, I understand your question. Um, I'm uncomfortable, but I understand the question…. Leave that question in. Yes, yes. W3- I would think they would have you up on your knees. [Later] Umm, (pause) about the knee thing. You said they have the technology now? A lot of people think you put, that's what I was thinking because that was what I had heard and that is when you would expose everything. And I wouldn't want to go because. W5- F-I would not like that. M1-That's a good question. M4-Ah, no.	Participants voiced concern about exposure of genitalia and stated this would be embarrassing. Wording of item was change to ***because of concern that my penis/vagina (specific to the gender) would not be covered.*** This form is designed to determine if this is a concern without alarming participants that their genitalia would be exposed during the test. Also, this item was moved to later in the survey.

6. I did not know the doctor doing the test.	W1-That it wasn't your own regular doctor. It was somebody different. W2-I understand the question and I would not feel uncomfortable, no. W3- I would know my doctor. I wouldn't want nobody no stranger. W4-Yeah, I understand that clearly. There might be some question about that. W5- Um, I would like to know that he has a good reputation. That he wouldn't do anything that he shouldn't do… So, I think I would like to have someone that I know about… No, I think I'd be embarrassed even if I did know the doctor. Really M1-That's an excellent question. K-Okay. M1-Chuckles. K-So when it says I did not know the doctor doing the test, what thoughts are going through your head. M1-Ahh, I don't have no experience with this guy. (M2)- K-Okay. So now would you be expecting your family doctor to do it or were you thinking you would be sent to someone else? M2-I would have assumed it would be my family doctor, but I would be more embarrassed if it was an outside source. M3-You know, it would be someone else [not family doctor]. M4-Um, its asking do I know the, am I familiar with the physician that's giving the exam... Um, no I don't think that I would be embarrassed, ah, but it there has to be a certain amount of trust factor involved in even getting to that point.	Many participants stated they would want to know the doctor whether that was to have their primary doctor do the exam or to know of the doctor through his/her reputation. Participants voiced more concerns about having someone they did not know or a "stranger" doing their test. This question is redundant with I knew the doctor doing the test. Since the objective of the survey is to identify aspects of a colonoscopy related to embarrassment, this item was retained over I knew the doctor doing the test.

	M5-Like a gastro doctor. K- So do you think I need both questions [about knowing your doctor and not knowing?] M5-No. K-So, which one do you think is better? M5-This one.	
7. I passed gas during the test.	W1-Sure. (Short laugh). I mean you know that's natural. W2- I've been reading up on that, we're supposed to do that. That's the natural release. I've been reading on that. W5- Oh, Lord. That can happen, and sometimes it has happened when I've had other tests and I would be embarrassed. But when you're messing back there anyway, it starts things to happen. M1- Well, most the time you're not going to know anyway… I've had 3 or 4 (colonoscopies). M4-No, I think that's just a normal part of the procedure, that it could happen at some time.	Participants tended to know this might happened and voiced that it was "natural" but one person was still embarrassed by it. This item was retained.
8. I felt like I had to have a bowel movement during the test.	W2- I understand the question and I would. However, I am sure that is probably a natural. -Ah, I, I'm sure that is a natural reaction to the test and I would be embarrassed. Yes. W5-Of course I would hate to let out something, but I imagine that it has happened. I hope I can control myself, but if I can't, well	Participants realized their bowel may not completely clean. This item is similar to *my bowel might not be clean after the bowel prep*. Since it is more likely that they might know that their bowel was not completely clean prior to the test and less likely that they would feel the need to have a bowel movement during the test, this item was deleted.
9. A medical	W1- Like a training person and so forth.	Participants understood

student was in the room.	W2-That would be someone who is studying. W3-It's a umm somebody being taught. W5-I would try to think that he's there to learn. I wouldn't be all comfortable having more eyes than just the doctor's on me. I would be embarrassed enough with just the doctor by himself, but I understand some people do have to learn. [Related to a pap smear]. And a it was a bit embarrassing to have anyone down there looking around for anything. Ah, but it isn't always just the doctor that is checking out things. Other people do have to learn things too. M1- It's someone studying to either be a doctor or a nurse. M2-A medical student would be someone who is taking um, that would be an intern for a doctor. They would basically taking instruction while the doctor was doing the exam. M3-A kid that is not a medical professional yet. An observer, I think I understand that question. M4-Ah, to my terminology a medical student is somebody that somebody is learning the process, but I don't know maybe I would be a bit concerned, um, just on a personal level because if there's, if you don't necessarily know the specialist doing your, that may be um, that may add a little bit more uncomfortability in that you don't know the specialist, nor do you know the student, so that may be a little bit of a gray area in there. (M5)- K-So tell me in your own words what a medical student is. M5-Someone	the medical student was learning but could not clearly articulate what their educational endpoint would be. Participants expressed that they did not want others in the room but recognized students had to learn. See comment below.

	learning to be a doctor.	
10. A nursing student was in the room	W1-Same thing. [Like a training person and so forth]. W2-She, or he, is also studying. W5- Just a little bit. K-So would you be less embarrassed with a nursing student than the medical student? Or would it matter. W5-I don't think it would really make much difference. It's just another person in there. W1- That's a great question. K-Okay and so a nursing student is studying to be? M1-a nurse. (M2)- K So, a nursing student similar? M2-Going to be a nurse or a nurses assistant maybe M3- That person would also be an observer, just a student, someone studying, someone that's about to practice nursing. M4-Um, I guess he or she would be studying the procedures, but then again, um, I think that these things should ah, I don't know maybe they should discussed prior to the exam so that maybe you would be given a choice because it may be okay with some people, but then it may not be okay with others.	Participants understood the nursing student was learning and seemed to understand that the student would become a nurse. There was less discussion about apprehension about having the nursing student observe. One participant stated it would not matter if the student was a medical student or nursing student. One participant stated they should have a choice as to whether students were present. Nursing student and medical student were combined into the same item.
11. I knew the doctor doing the test.	W1- Okay. So maybe it was your own doctor doing the test. W2-I would not have to know them because my own doctor may have recommended, or referred, this person. W3-Umm. If it was a young doctor I would be embarrassed. K-Is it because lack of experience or because they are better looking? You are nodding your	See item 6 above.

	head. W3-Both. M2- I think that would be implied that it was your family doctor. M3-That would be my family doctor. M4-No, I wouldn't be nervous if I knew the doctor… I guess there would be a bit of a safe haven knowing that you know the doctor. K-Now here's another question for you. As you recall, I asked you if I did not know the doctor and now I just asked you if I knew the doctor. Do you think I need both questions? M4-Yes, I think so. I think so, it sort of clarifies whatever answer, let's just say it clarifies the question a little bit better, it more or less gives the, I'm going to use the word applicant, a bit of a choice. M5-[That would be] my primary doctor.	
12. I knew the nurse assisting with the test.	W2-It is likely that I would not. W5- That would be helpful. M1- That's a good question. M3- Outside of the doctor, so a friend or friend of a friend. M4-I don't think that that's a big concern because I think that the trust factor relies within the doctor.	This item did not seem to be a an aspect of the a colonoscopy related to embarrassment and one participant thought knowing the nurse would be beneficial, this item was removed.
13.The doctor or nurse joked with me about the test	W1- Do you want to know if I would be upset if they did that or do I understand what you are saying?... Thought, you know, it was kind of funny. W2- I understand the question and I wouldn't consider that an option. W3-I don't quite understand the question. [Did not have suggestions for improving the question]. [Later] I wouldn't be embarrassed if he joked.	Although three participants thought joking about the test was acceptable, others expressed strong feelings against it. Two participants did not understand the question. *Or nurse* was removed to make the sentence simpler.

	W5-I don't think its funny myself. Yeah, I wouldn't really be so amused about it because its also embarrassing and so personal and all that that I wouldn't be really in a laughing mood right then. M1- The wording is fine because most of the time the doctors are trying to get you to be at ease and be relaxed as you get ready to go do the test. M-I like that [when they joke with me]. M2- N-I understand the question…Trying to make them loosen up. M3- Well, to me it means, and this has happened, so I can say this. That the doctor has a sense of humor that may not necessarily agree with mine. (Chuckle). O-I would prefer they did not joke with me, yes…O-Yeah, you know, it's a very awkward situation. I think it would really depend on the joke and these are good questions, Kim, (off the record) because I've had that experience. O-It wasn't a colonoscopy, but it was with my wife when she was pregnant. K-Okay. So you would rather they just kept it very professional, very medical, don't try the funny stuff then. M3-Yes, I would. I would because if it goes bad, it's going to go real bad. M4-I don't think that that's a good idea. K-Joking? M4-Right, ah, well, then again if there's a specialist there and you're not necessarily, you don't necessarily know the specialist, I think it should be conducted sort of in a business format, where you haven't reached that comfort level yet with a specialist or somebody that you don't know, but then there's still a trust factor that that physician knows his trade.	

14. I had to talk the doctor or nurse about my bowel movements.	W2-I understand your question. I would think they would need to know that to be able to perform an accurate test. W5- I am not one that always wants to talk about it myself, but I do get concerned when it's days and days and days and I haven't gone. M1- Pause. That's a good question. M3-I don't understand that question. M4-Yes, that sounds pretty clear because well any pre-exam that you have you have to be forthright and honest.	Participants realized they may have to talk about their bowel movements and one participant state she did not like to talk about it. This item was retained.
15. I had to talk to my doctor or nurse about my bottom/buttocks.	W2-That's also information that they will need to perform an accurate test. W5-I'd be embarrassed about telling about it? If this is the information that they need I'll try to share it with them. Ah, its good to always know what's happening with me, I guess, so. (M3)-K-Okay, so um, what I'm trying to say is that you know you're not having to talk about your bowel movement, but you're having to talk about your bottom and that bothers you. M3-Like hemorrhoids or something? K-Yeah, that's a great example. M3-O-Oh, oh, I understand that question then. K-Okay, but something is not coming across because you didn't understand it, so? M3-I think you almost have to get a little more specific, like a problem, like you had to talk to the doctor about a problem with your buttocks or rectum or rear. M4-No, you shouldn't be embarrassed. It's still more different than, for men, a prostate exam, there's some things that you have to, talk, trust the physician or specialist and you have divulge that	Participant comment that the question needed to be more specific was used in revising the question to read I had to talk to my doctor or nurse *about a problem with* my bottom/buttocks.

	information.	
16. If I was not asleep (sedated) for the test.	W1-That's medicated-that means whether or not they had to put you under anesthesia. W2-Sedated or asleep. Is it painful? W3-I'd be sedated. I won't be alert. W5-I'm supposed to be unconscious during these tests? (M1)-K Now sedated what does that mean to you? That means that they're going to use some kind of gas to put me out. (W2)- K-Okay. So, in your own words, if you were not asleep or sedated, what does that mean to you? M2-That would mean I would be conscious. M3-You're out, you're under anesthesia and you have no idea what's going on and they could do anything to you, you never know. M4-Okay, sedated, that means, um to me it means a little bit , um pain free so to speak, or discomfort free. Not necessarily unconscious, but discomfort free. K-Okay, so if the question said if I was not in a deeply relaxed state, would that convey that you are pretty much out, or is does that convey that you're still a little bit awake. M4-I think that does stay that you're a little bit awake. That you're conscious of basically what's going on around you, ah, you may not necessarily have any feeling in the area that's being questioned, but it does let you know that you'll still be conscious of what's going on. M5- MD-I was unconscious. They gave	Participants frequently thought that being asleep or sedated meant having a general anesthetic. The item that was similar if I had to be awake during the test was used instead. Also, some participants stated they wanted to be awake or somewhat awake.

	me something. K-So were you thinking this was a general anesthetic? M5-Yes. K-Well, typically they just give you something in an IV like Demerol. I'm not sure how to say this to convey what I mean. Can you think of a way to say it better? M5-No	
17. If I had to be awake for the test.	W1-No anesthesia. W5-I don't think I'd be too embarrassed. I would like to know what's happening. (M1) K-Okay. Now let me ask you another question. Do you think I need both of those questions? If I was not asleep or sedated for the test and the next one is if I had to be awake for the test. M-I think that if you asked that first one, I think you would be fine. M3-You're not sedated, you're not under any anesthesia, you're not under general, so you know what's going on, you're aware of everything around you. M4-Okay. Um, I don't know, that's a little bit difficult because each person has different ways that they would be more comfortable in the exam. I would think that somebody that has never had the exam before would want to be conscious awake to a certain degree. I don't think that a strange procedure should be done while the patient is totally unconscious. I don't think that anybody would want that. M5-Conscious.	See analysis above.
18. A person of the same sex performed the test.	W1- Female: female. W3-Female: male (W5)-I think I would be more comfortable if it was a female. [Later] I	Three participants incorrectly identified the same sex gender when asked directly. See item 2. This question will be

	was thinking as I said that, ah, well usually I feel more comfortable with female doctors, but even some of them can be. M1-That's a good question and I think you kind of touched on that back early. K-Uh huh. So do you think I need both of them? M1-I don't think you need both of them because, I think you kind of asked that in a couple of different ways. K-Uh huh. So which one do you think is the best? M1-I think the one that you asked up front. (M)-K- Okay, so the gender of that examiner for you would be? M2-Male. (M4)-K-So, I'm a female, so what gender would that person be doing my test. M4-That would be a male for you. Oh, no, wait you said of the same. So that would be female for you. K-I'm wondering if I asked the same sex question ahead of the opposite question if that might help people understand. M4-Yes, I think that possibly would. It possibly, well sometimes if you ask about the opposite sex it kind of throws up a red flag so to speak, it kind of puts you on guard, whereas you think if I'm a man, he's going to have, I don't know, having somebody with the opposite sex, let me, for example when I had my first prostate exam, it was a female, I felt more comfortable with a female doing it than I possible would with a man. I don't know, for me it was something a little bit more relaxing about females doing it than a male. Asked opposite sex question at this point in the interview… K-…if a person of the opposite sex performed the test. So, if I am a female, what gender would this person be? M5-	reduced to one question specific to the person taking the survey. It was decided to used opposite sex since more participants seemed to want a person of the same gender and the purpose of the survey is to identify aspects of a colonoscopy associated with embarrassment.

	Female.	
19. My bowel was not clean.	W1- (Long pause). What does that mean? Like you had to have an enema? Or you didn't have an enema? W2- My bowel was not clean, I'm trying to understand that question. My bowel was not clean. By clean, meaning? K-Completely emptied out. Would it be clear to say *my bowel was not cleaned after the preparations*? W2-Yes, yes. W3- would be embarrassed. Giggles. W5- Be embarrassed if I was cleaned out first? Yeah, because I don't like to make messes. M1-Pause. I don't know that you need that one because there not going to know anyway if you do it and you think you got everything out M2-f it was not clean? K-Right. So in your own words, what does that question mean to you? M2-Well, I would think that if my bowel wasn't clean it would mean that I still had to go to the bathroom. K-Okay. Now were you aware prior to the test that you do what they call prep where you drink this stuff and it pretty much empties out your bowel? M2-Yeah, flush. M4-I'm pretty big on cleanliness, so I think that should be a prerequisite from the physician. Although things do happen in route, but I still think that should be a prerequisite for both sides. K-Now how about the words *bowel prep*? What does that mean to you? M4-To me that means to clean the bowel area.	Participants did not seem to understand this question until *after the bowel prep* was added. Once this addition was made, participants answered more appropriately.
20. Because of the way my	W3-Nodding. (Eyes opened wider). [Largest of the women interviewed].	The males tended not to understand the question

bottom/buttocks look.	W5 It's not beautiful, so I'm not sure I'd be too pleased about people looking at it. M1-Pause. I don't think that's a good question… K-Okay. Leave it out or change it, or what do you think? M1-What would you say because of the way my buttocks looks? Ah, I just have a problem with the question. K- Can you think out loud for me? M1-Number one, I'm already going to a doctor, he's done seen my butt. M1-So, I know I'm not afraid of it because he's done seen it already, so ahh, if he's examining me, then that question would be irrelevant. (M2)- K-Okay, so in your own words, what does that say? M2-I would be embarrassed if my behind was looked at because I have a large or misshaped behind. M3-Um, I don't understand. K-So should I say because of the appearance of my bottom or buttocks do you think that would make it clearer, or what do you think?...M3-You know, I think that's a question, I believe, this is just my opinion, I believe that that's a question that if you asked a female that same question the same way you ask it, they would've took it in the context that it was meant. And I think men look at it a little bit different because I guess we don't think about like anybody caring what our butts look like, you know? M4-Well, I think that, I don't know, to me that would be some psychological disorder. I mean everybody has to accept whatever abnormalities that they may personally think that they have, but still you are what you are. The main objective is to go through the procedure…	or think it was unnecessary or even pathologic to worry about the appearance of the buttocks. However, females understood the question and some expressed that appearance of their buttocks was a potential source of embarrassment.

	hey you're not here for a fashion show, but you're here for a medical reason.	
21.Because of the size of my bottom/buttocks	W2-You don't want to ask that question and discourage them from the test. (W3)-K-Is the question above and this question the same? W3-No. W5- Ahh, no. K-Are the question above and this questions two different questions or are they the same? W5-It sounds pretty similar. M1- M-I guess I would answer that the same question (see answer for question above). M4-I don't think that, the question is, what you're saying is that that I would have a problem with the colonoscopy because of, then again what I look like, more or less. But that's not why you're there again. You're there to get a procedure done.	Two stated thinking this item was similar to the one above. Since both items were related to appearance, the items were combined and *looked* was changed to *appearance* to more clearly articulate the essence of the question.
22. Because someone would be touching my bottom/buttocks.	W1- How could they do the test if they don't? W2-That's clear. K-You took a deep breath, though. W2--I, I, I understand the question. There would be some embarrassment there. W3-(Nodding. Eyes opened wider). I would be embarrassed. W5- Yeah, a little bit, but if that's the way it has to be done, I'd try to live with it, you have to go through it. M1-That's along the same line of those other ones you've been saying (see M1's response to question 20).	Although some participants stated that touching would just be part of the testing procedure, others voiced embarrassment and this item was retained.
23. When the	W1- Well, you know, they have to see.	Participants understood

tube is being put into my rectum	W5- It just seems like it would be awfully uncomfortable. M1- M-Pause. Ahhh, I don't think that's a good question either. K-Okay, go ahead. M1-The doctor is going to explain what he is going to do prior to and he's going to tell them that they're going to be sedated and they're not going to feel pain. M4-That goes back to the question that you asked me about um, let's just say a localization, when you're unconscious, that that may be a choice that the doctor will have to explain if you feel, if you think you would be a little bit uncomfortable, I could give you something to make you relax, you know I think that that choice should be given prior to the exam.	that this had to be done but in their comments after all of the items had been asked indicated this was still a concern. See additional comments. This item was retained.
24. Because the test invades my privacy.	W1- Any time they put something *foreign* into you then that's an invasion of your privacy. (W2) K- So what does the word *invade* mean to you? W2-That what I would consider private or personal. That I would be sharing that with someone that I don't know. W3-Ummm. Long pause. I know what it is. Slight laugh. Pause. [Unable to articulate meaning] W5- I don't know if I would feel comfortable even the doctors knowing what's all in there. K-What does invade mean to you? W5-Well, that makes it, it sounds like to me like a you're going in there uninvited. I don't think I'd really like that. K-Do you think most people understand invades? Or do you think that I need to find a different word.	This item was not well understood. Since the "invasion" with the tube was addressed in the item above and concern about intimate parts was addressed with the genitalia item and the

	Especially the term invades my privacy. W5-It does not sound really good. K-Can you help me with what you mean by good? Is it too difficult of a word or do you think it's an uncomfortable phrase, invades my privacy, what do you mean by its not very good.W5-Well it seems, it makes me think of a rape. And I've had that experience and I don't even like thinking about it. So invasion seems like. K-So are you saying invasion seems too strong.W5-It seems like it is, yes. M1-M-Pause. I don't like that question. K-Can you think out loud for me? M1-Ah, I go to the doctor, I have complications and the HIPPA law talks about whatever the doctor finds is going to be confidential. (M2)- K-Okay, so invades my privacy, what does that mean to you? M2-That would be someone else sharing my, sharing my intimate side. (M3)-K-So tell me in your own words what does invade my privacy mean? M3-Well, um, my understanding of invading my privacy means, um because it's invasive and this is like the most embarrassing part of the procedure is because it's like um, I'm trying to be clean here, for lack of a better terminology, it's like this intrusive demeaning procedure M4-Well, I think that always a concern. What that means is that you're touching areas that are a little bit more private to me. It's not exactly exposed everyday to people that you don't know or the public so to speak, um, so that's probably a concern, but that's when the trust factor has to come into play. You have to understand that these are specialists and they have a job to do.	

25. Because I embarrass easily	W3-(Nodding head). K-Do you think some people embarrass more than others? W3-(Nodding quickly). Yes. W5-Sigh. Um, I'm learning to not be so embarrassed these days as much as I used to be. K-Do you think some people are more embarrassable than others? W5-Well, sure. M1-That's a good question. (M2)- K-Okay, does it make sense to you? Or have you thought that maybe some people would be more embarrassable than others? M2-Oh Yeah, M4-Well if that's the case, it's a pretty straight forward question, but if that's the case why do people go to doctors for let's just say any type of exam when you have to disclose. Now whether you're willing to put some of those concerns away and get to the root of the reason of why you have to have these exams done. I think that that's something you have to do work over within yourself.	Content experts thought this item was representative of embarrassment but since embarrassability is more of a trait and unable to be changed with common interventions, this item was deleted.
26. Because I might smell.	W1-Any time you are talking about bowel, you know, there's the smell. W5-Well, sure. I think it would be a smelly process. M1- Great question. K-Can you think out loud for me? M1-I think that some folks that have real bad body odor. They may think that they don't know it, you know they know and if they do they don't want to be around nobody with it… I don't know what the national average is, but I think that people do have some concerns. M4-That goes back, well I don't know. I	A content expert thought this item should be added. Participants thought smell could be a problem. This item was retained.

	think that any time that you expose your body to different procedures there hygiene. Hygiene is something that should be automatic on a day to day basis and because you're going to see a specialist for a specific exam that that should mean even more. Some things you might be able to get away with, you know just certain functions doing the things, but when you're going to see somebody that is about to explore a certain part of your body, I think that a little extra attention should be given.	

Please fill in the blank for the next three questions.

27. A colonoscopy would be more embarrassing for me than other people because_____	W2-You'd never have one. Can I continue? K-Mmm hmm. W2-The wait and the fear of the results and also it could be genetic. Maybe they would have found _____colon issues, that it could be cancer, or W5- Because they're trying to check out what my problem is. M3-A colonoscopy would be more embarrassing for me than other people because I would probably scream. (Laugh) M4-Yes, I would say for me because, well because it's never been done.	Participants did not seem to understand this question. The following questions elicited desired information better. Therefore, this item was deleted.
28. For me, the most embarrassing part of having a colonoscopy would be_____	W2-For me, the results. K-Okay. Now, you said fear, what about embarrassment? W2-No. The fear of the results. W5- Just having my bottom exposed for the whole world to see. M2- N-Yes, I would say showing my behind….Can I take that back? Actually the worst part would be having the tube inserted. M3-Someone knowing I had one. M4- Not knowing what they would find, or not knowing the results.	This item was helpful in understanding aspects of a colonoscopy associated with embarrassment and was retained.
29. I would be less embarrassed if_____	W1- In that case that might be if… it were a lady doctor or	This item was helpful in understanding ways to

	stuff like that. W2-Hmmm. I would be less embarrassed, no, because you have to go through what is necessary to perform the procedure. If you're going through the procedure, you obviously have gotten over a fear of embarrassment W5- F-Sigh, if um, you didn't have to have all these embarrassing tests. Umm, I was trying to think of answer or what to put there. So, I would say I'm getting better at not being quite as embarrassed as I was a few years ago about a whole lot of things. I guess I'm growing in a way. I try not to be quite as embarrassed anymore and having to just blurt out everything. M2-I would be less embarrassed if they put a cover or something over. M3-I would be less embarrassed if there was another type of procedure that I could use. M4-I would be less embarrassed if I knew the results. Okay, let me look at it this way, I would be less embarrassed if I knew the physician	reduce embarrassment and it was retained.

Additional comments:

W1-I personally wouldn't be embarrassed because I know how important they are but some people might be embarrassed to think that you had to, you know, go through those steps and have somebody touch you and put a tube upside your butt, you know.

(W2) K-What, was there any embarrassment when you were thinking about having to do this test? W2-The fact that it's rectal in all honesty. K-See that's part of the problem, you feel embarrassed even talking about it, right? see that's part of the problem, you feel embarrassed even talking about it, right? W2-Absolutely. And I go through the same thing when I have my annual pap smear. It's just the, it's not something that's discussed and even from the pap smear to the rectum, is oh my goodness…It's not something that I would want to share when on my way to work, well I just had my colonoscopy yesterday, and um…K-You were concerned about the results, but how about as far as any embarrassment issues, were there any? W2-No. K-Okay. That was not like a barrier for you? W2-No it isn't. My barrier would be to be able to get time off of work. In all honesty… Because that is my concern, but as far as embarrassment as far as the procedure, I've spoken with my mother… I would want a person of the same sex doing the test, myself. [She marked all of the questions she thought should be left in and only deleted the one on *the way my bottom looks, the size of my buttocks, invades my privacy,* and questioned *I embarrass easily*.]

W5-I might be embarrassed because I don't want to have a whole lot of folks to really know that I'm going through the examination but I am going, if I need to go I would like to know what's happening with me.

M1-(Talked to a friend who needed a colonoscopy). K-Now, it's been awhile I'm sure, but do you remember what was bugging him the most or what was causing the most anxiety for him?
M1-The fact that the doctor was going to be sticking a tube up his butt.

(M2) K-Okay. Is there anything else that you wanted to tell me about like colonoscopies and African American men that you think I should be aware of? M2-Nothing else that I can think of. I think a colonoscopy is going to be a laser because a lot of guys don't want to address that.
K-Okay. Are you saying they just don't want to deal with it? M2-Well, it's a source of embarrassment because, guys stay away from doctors because they don't want to be examined.
K-Okay. M2-And it's mainly not because of, um, they would rather not be examined, but they don't want to wait until they end up being ill and they have to go…I think it's kind of a, um, it goes back to childhood kind of thing. You don't want anybody messing with you down there unless you really are sick, you know? K-Okay. N-That's why a lot of guys would rather not go and get the examine because they would rather assume that they're well. K-Okay, so are you also saying that if you don't get the test then you don't find out you're ill and that's better, is that what you're saying? M2-Yeah, I've had a couple uncles that had exactly that happen. That they refuse to go get an examination and they could've had a chance to actually catch the disease at an early stage. K-Okay. N-And I know for a fact that they didn't want to go because they had a stigma with that.

M3-I think part of it, and this is probably not your study, I'm thinking that I know part of my fear is that they're going to find something, not just embarrassment, it's just you know. I don't know if that fits into your study, but I think that's a lot of people's fear…,

but it's still, Kim, like a private. A lot of times when you talk about it, for some reason you talk about it with someone who was brave enough to get it done and they're not afraid to talk about it…It's really fear, it's fear of like the unknown because you don't know what's going to happen, what they're going to say, you know it's going to mean that you've got to change something. I'm speaking for myself, but I can think I can speak for other people who thought about it, you think you're going to make some drastic lifestyle change and you don't want to, you don't want to think about anything being different, so you just avoid it, you avoid the whole thing. You avoid the conversations, you avoid the check-ups, you avoid, you know what I mean.

M4-Well, for me I'm pretty much an open minded person, so a lot of those things would not concern me as much as they probably would concern other people, but I can see questions that maybe should be asked prior to the exam, especially the one where, I think that for men the primary question is whether it's going to be a male or a female giving the exam. Even though you may not know either gender, they may send you to a specialist, she may be a female, you may be used to male doctors or vice verse, so I think that those would give the patient a little bit more comfortability because you can ask males, I mean the men that maybe they're used to male doctors, they may be old school. You know they may be, want a certain race to do it, these little things like that, but I would think that some of those questions should be asked or you should have the knowledge prior to going to see the specialist or doctor giving the exam…I think it would be, but like for me, I'm a little bit more open, I trust the fact that you are a specialist that you know your trade…But I'll tell you this though. I mean that me personally I would be more comfortable with a female than a male, that being the only discretion there.

Appendix H

Revisions Resulting from Cognitive Interviewing
Colonoscopy Embarrassment Scale

The goal of this survey is to find out what, if any, things people find embarrassing when they think about getting a colonoscopy**.** Embarrassment prevents some people from getting colonoscopies. If we can find out what causes embarrassment, we can reduce these things, more people will get colonoscopies, and more lives will be saved. Thank you for your willingness to participate in this research study.

Directions: Please circle the number that best describes your agreement or disagreement with the statements.

1. When thinking about getting a colonoscopy, I think I would be embarrassed having one.	Strongly Disagree	Disagree	Agree	Strongly Agree

I would be embarrassed when having a colonoscopy if:

	Strongly Disagree	Disagree	Agree	Strongly Agree
2. A male/female did the test. (Use female for male participant/ male for female participant)	1	2	3	4
3. I did not know the doctor doing the test.	1	2	3	4
4. A medical or nursing student was in the room.	1	2	3	4
5. I passed gas during the test.	1	2	3	4
6. I had to be awake for the test.	1	2	3	4
7. The doctor joked with me about the test	1	2	3	4
8. I had to talk the doctor or nurse about my bowel movements.	1	2	3	4
9. I had to talk to my doctor or nurse about problems with my bottom/buttocks.	1	2	3	4

I think I would be embarrassed when having a colonoscopy because:

	Strongly Disagree	Disagree	Agree	Strongly Agree
10. My bowel may not be clean after the bowel prep.	1	2	3	4
11. Of the size or appearance of my bottom/buttocks.	1	2	3	4
12. Someone will be touching my bottom/buttocks.	1	2	3	4
13. The tube is being put into my rectum.	1	2	3	4
14. I might smell.	1	2	3	4
15. Of concern that my vagina or penis would not be covered during the test. (Use vagina for females/penis for males)	1	2	3	4
16. The doctor or nurse will see my bottom/buttocks.	1	2	3	4

Please fill in the blank for the next three questions.

17. For me, the most embarrassing part of having a colonoscopy would be _____

18. I would be less embarrassed if _____
_____

Thank you for taking the time to fill out this survey. The information you gave is very much appreciated and will be used to help prevent colon cancer in the future. If there is anything else you would like to tell us, please write it in the space below. Please return the completed survey in the envelope we gave you. **Thank you!**

Appendix I

Final Version of Colonoscopy Embarrassment Scale

Questions 1-15 are statements about having a colonoscopy. Please indicate how much you AGREE or DISAGREE with each statement by marking a small X in one box per question.

1. I would be embarrassed to have a colonoscopy if a female did the test.

Strongly disagree ..... □
Disagree ..... □
Agree..... □
Strongly agree ..... □

2. I would be embarrassed to have a colonoscopy if I did not know the doctor doing the test.

Strongly disagree ..... □
Disagree ..... □
Agree..... □
Strongly agree ..... □

3. I would be embarrassed to have a colonoscopy if a medical student or nursing student was in the room to watch.

Strongly disagree ..... □
Disagree ..... □
Agree..... □
Strongly agree ..... □

4. I would be embarrassed to have a colonoscopy if I passed gas during the test.

Strongly disagree ..... □
Disagree ..... □
Agree..... □
Strongly agree ..... □

5. I would be embarrassed to have a colonoscopy if I had to be awake for the test.

Strongly disagree ..... □
Disagree ..... □
Agree..... □
Strongly agree ..... □

6. I would be embarrassed to have a colonoscopy if the doctor joked with me about the test.

Strongly disagree ..... □
Disagree ..... □
Agree..... □
Strongly agree ..... □

7. I would be embarrassed to have a colonoscopy if I had to talk to the doctor or nurse about my bowel movements.

Strongly disagree ..... □
Disagree ..... □
Agree..... □
Strongly agree ..... □

8. I would be embarrassed to have a colonoscopy if I had to talk to my doctor or nurse about problems with my bottom/buttocks.

Strongly disagree ..... □
Disagree ..... □
Agree..... □
Strongly agree ..... □

9. I would be embarrassed to have a colonoscopy because my bowel may not be clean after the bowel prep.

Strongly disagree ..... □
Disagree ..... □
Agree..... □
Strongly agree ..... □

10. I would be embarrassed to have a colonoscopy because of the size or appearance of my bottom/buttocks.

Strongly disagree ..... □
Disagree ..... □
Agree..... □
Strongly agree ..... □

11. I would be embarrassed to have a colonoscopy because someone will be touching my bottom/buttocks.

Strongly disagree ..... □
Disagree ..... □
Agree..... □
Strongly agree ..... □

12. I would be embarrassed to have a colonoscopy because the tube is being put into my rectum.

Strongly disagree ..... □
Disagree ..... □
Agree..... □
Strongly agree ..... □

13. I would be embarrassed to have a colonoscopy because I might smell.

Strongly disagree ..... □
Disagree ..... □
Agree..... □
Strongly agree ..... □

14. I would be embarrassed to have a colonoscopy because of concern that my penis would not be covered during the test.

Strongly disagree ..... □
Disagree ..... □
Agree..... □
Strongly agree ..... □

15. I would be embarrassed to have a colonoscopy because the doctor or nurse will see my bottom/buttocks.

Strongly disagree ..... □
Disagree ..... □
Agree..... □
Strongly agree ..... □

Please complete the statement by writing in the space provided:

16. For me, the most embarrassing part of having a colonoscopy would be:
_____

17. I would be less embarrassed if:_____
_____

Appendix J

Colon Health Survey (Male)

The survey takes 10-15 minutes to complete.

DIRECTIONS: Some participants will need to answer only the 6 questions on this page. Other participants will complete these 6 questions and the rest of the survey. To find out if you need to complete the entire survey, please answer the following 6 questions. Although some questions are personal in nature, please answer all of them to the best of your ability.

1. A stool blood test, also called a Hemoccult, is a test you do at home. For this test, you smear a small amount of your bowel movement on 3 cards that come in a kit and mail or bring the cards to your doctor. **Have you done a stool blood test at home in the last 12 months?**

Yes □ No □

2. A sigmoidoscopy is a test where a thin, flexible tube is inserted into the rectum to examine the lower part of your large intestine or bowel. You rarely need medicine to help you relax for this test. The test usually takes about 15 minutes. **Have you ever had a sigmoidoscopy or flexible sigmoidoscopy?**

Yes □ No □

3. A barium enema is a test where barium is inserted through the rectum into the large intestine (or bowel) and x-rays are taken. This test is also called a lower GI (gastrointestinal) exam. **Have you ever had a barium enema?**

Yes □ No □

4. A colectomy is a surgery done to take out the colon or part of the colon. **Have you ever had a colectomy?** Yes □ No □

5. Have you ever been told you have ulcerative colitis or Crohn's disease?

Yes □ No □

6. Have you ever had cancer of the colon or rectum? Yes □ No □

☆ If you answered **YES** to **ANY** of the above questions, **YOU** are **FINISHED!** Please **SEND** this page and the blank survey back in the stamped, addressed envelope provided. THANK YOU for participating in this study!

☆ If you answered **NO** to **ALL** of the questions above, **PLEASE TURN THE PAGE AND COMPLETE THE REMAINDER OF THE SURVEY!**

Start here: 

The first questions are about you. Please mark a small X in one box per question.

7. What is your highest level of education?

Eighth grade graduate .....☐
Some high school.....☐
High school graduate .....☐
Some college or vocational school .....☐
College graduate .....☐
Graduate degree .....☐

8. What is your marital status?

Single (never married) .....☐
Living with a partner.....☐
Married.....☐
Separated.....☐
Divorced.....☐
Widowed .....☐

9. What do you consider your race to be?

White (non Hispanic).....☐
African-American or Black.....☐
Native American .....☐
Hispanic or Latino.....☐
Pacific Islander.....☐
Bi-racial.....☐
Other .....☐
(If other, please specify)_____

10. What is your total yearly combined household income?

Up to $25,000..... ☐
25,001-50,000 ..... ☐
50,001-75,000 ..... ☐
75,001-100,000 ..... ☐
100,001 or higher ..... ☐

11. A colonoscopy is a test where a tube is inserted into the rectum to examine the rectum and entire colon (large intestine). You are given a medicine to help you relax. **Have you ever had a colonoscopy?**

Yes .....☐
No .....☐

12. When was your last colonoscopy?

Less than 10 years ago.....☐
More than 10 years ago.....☐
I have not had a colonoscopy....☐

13. Are you planning to have a colonoscopy in the next 6 months?

Yes .....☐
No .....☐

14. Do you have an appointment scheduled for a colonoscopy?

Yes .....☐
No .....☐

15. Has a doctor ever recommended that you get a colonoscopy?

Yes .....☐
No .....☐

<u>For questions 16-23, please DO NOT guess. Choose "don't know" if you do not know the answer.</u>

16. Can colon cancer ever be prevented?

Yes .....☐
No.....☐
Don't know .....☐

17. Who is most likely to get colon cancer?

A person younger than 50 years old..... □
A person older than 50 years old..... □
There is no difference..... □
Don't know..... □

18. Which group is more likely to get colon cancer?

Whites ..... □
Blacks..... □
Hispanics..... □
There is no difference..... □
Don't know..... □

19. Who is more likely to get colon cancer?

Someone whose spouse had colon cancer... □

Someone with one close blood relative (parent, brother, or sister) who had colon cancer ..... □

Someone with two close blood relatives (parent, brother, or sister) who had colon cancer ..... □

There is no difference..... □

Don't know..... □

20. Compared to a man, what is a woman's chance of getting colon cancer?

Much higher than a man's..... □
About the same as a man's..... □
Much lower than a man's..... □
Don't know ..... □

21. What is the most effective way for people to lower their chances of dying from colon cancer?

Exercising regularly ..... □
Limiting alcohol ..... □
Finding and removing polyps..... □
There is nothing that can be done ... □
Don't know..... □

22. What is a doctor able to see during a colonoscopy?

Inside only the lower part of the colon ..... □
Hidden blood in the stool..... □
Inside the entire length of the colon..... □
Don't know ..... □

23. If you choose to have a colonoscopy and everything is normal, when will you probably need to have your next one?

6 months..... □
1 year..... □
2 years ..... □
5 years ..... □
10 years ..... □
Don't know ..... □

<u>Questions 24-33 are about the steps required to complete a colonoscopy. Please indicate HOW SURE you are that you can complete each step by marking a small X in one box per question</u>.

24. I am able to get an appointment to have a colonoscopy.

Not at all sure..... □
Not so sure ..... □
Somewhat sure..... □
Very sure..... □

25. I am able to find time to have a colonoscopy.

Not at all sure..... □
Not so sure ..... □
Somewhat sure..... □
Very sure..... □

26. I am able to drink the special medicine (laxative) to clean out my bowel before a colonoscopy.

Not at all sure..... □
Not so sure ..... □
Somewhat sure..... □
Very sure..... □

27. I am able to go without solid food for a day before the colonoscopy.

Not at all sure..... □
Not so sure ..... □
Somewhat sure..... □
Very sure..... □

28. I am able to find transportation to get to and from the clinic to have a colonoscopy.

Not at all sure..... □
Not so sure ..... □
Somewhat sure..... □
Very sure..... □

29. I am able to get my questions answered about having a colonoscopy.

Not at all sure..... □
Not so sure ..... □
Somewhat sure..... □
Very sure..... □

30. I am able to follow instructions to clean out my bowel before a colonoscopy.

Not at all sure ..... □
Not so sure ..... □
Somewhat sure ..... □
Very sure ..... □

31. I am able to get a colonoscopy even if I am worried about the results.

Not at all sure ..... □
Not so sure ..... □
Somewhat sure ..... □
Very sure ..... □

32. I am able to have a colonoscopy even if I don't know what to expect.

Not at all sure ..... □
Not so sure ..... □
Somewhat sure ..... □
Very sure ..... □

33. I am able to have a colonoscopy even if I am anxious.

Not at all sure ..... □
Not so sure ..... □
Somewhat sure ..... □
Very sure ..... □

Questions 34-47 are statements about having a colonoscopy. Please indicate how much you AGREE or DISAGREE with each statement by marking a small X in one box per question.

34. I worry about finding something wrong during a colonoscopy.

Strongly disagree ..... □
Disagree ..... □
Agree ..... □
Strongly agree ..... □

35. Having a colonoscopy is embarrassing.

Strongly disagree ..... □
Disagree ..... □
Agree..... □
Strongly agree ..... □

36. I don't have the time to have a colonoscopy.

Strongly disagree ..... □
Disagree ..... □
Agree..... □
Strongly agree ..... □

37. I don't understand what will be done during a colonoscopy.

Strongly disagree ..... □
Disagree ..... □
Agree..... □
Strongly agree ..... □

38. A colonoscopy could be painful.

Strongly disagree ..... □
Disagree ..... □
Agree..... □
Strongly agree ..... □

39. I would need to have a colonoscopy only if I have bowel problems or symptoms.

Strongly disagree ..... □
Disagree ..... □
Agree..... □
Strongly agree ..... □

40. Having to find someone to drive me home would be hard.

Strongly disagree ..... □
Disagree ..... □
Agree..... □
Strongly agree ..... □

41. Having to take the special medicine (laxative) to clean out my bowel before the colonoscopy would be hard.

Strongly disagree ..... □
Disagree ..... □
Agree..... □
Strongly agree ..... □

42. Having to limit what I eat before the colonoscopy would be hard.

Strongly disagree ..... □
Disagree ..... □
Agree..... □
Strongly agree ..... □

43. I am afraid that my colon could be injured during a colonoscopy.

Strongly disagree ..... □
Disagree ..... □
Agree..... □
Strongly agree ..... □

44. Having a colonoscopy is not that important right now.

Strongly disagree ..... □
Disagree ..... □
Agree..... □
Strongly agree ..... □

45. Thinking about having a colonoscopy makes me feel nervous or jittery.

Strongly disagree ..... □
Disagree ..... □
Agree..... □
Strongly agree ..... □

46. Having to see a doctor I don't know would make it hard to have a colonoscopy.

Strongly disagree ..... □
Disagree ..... □
Agree..... □
Strongly agree ..... □

47. I don't need a colonoscopy at my age.

Strongly disagree ..... □
Disagree ..... □
Agree..... □
Strongly agree ..... □

For questions 48 and 49, please complete the statement by writing in the space provided:

48. For me, the most embarrassing part of having a colonoscopy would be:

_____
_____

49. I would be less embarrassed to have a colonoscopy if:

_____
_____

Questions 50-64 are statements about having a colonoscopy. Please indicate how much you AGREE or DISAGREE with each statement by marking a small X in one box per question.

50. I would be embarrassed to have a colonoscopy if a female did the test.

Strongly disagree ..... □
Disagree ..... □
Agree..... □
Strongly agree ..... □

51. I would be embarrassed to have a colonoscopy if I did not know the doctor doing the test.

Strongly disagree ..... □
Disagree ..... □
Agree..... □
Strongly agree ..... □

52. I would be embarrassed to have a colonoscopy if a medical student or nursing student was in the room to watch.

Strongly disagree ..... □
Disagree ..... □
Agree..... □
Strongly agree ..... □

53. I would be embarrassed to have a colonoscopy if I passed gas during the test.

Strongly disagree ..... □
Disagree ..... □
Agree..... □
Strongly agree ..... □

54. I would be embarrassed to have a colonoscopy if I had to be awake for the test.

Strongly disagree ..... □
Disagree ..... □
Agree..... □
Strongly agree ..... □

55. I would be embarrassed to have a colonoscopy if the doctor joked with me about the test.

Strongly disagree ..... □
Disagree ..... □
Agree..... □
Strongly agree ..... □

56. I would be embarrassed to have a colonoscopy if I had to talk to the doctor or nurse about my bowel movements.

Strongly disagree ..... □
Disagree ..... □
Agree..... □
Strongly agree ..... □

57. I would be embarrassed to have a colonoscopy if I had to talk to my doctor or nurse about problems with my bottom/buttocks.

Strongly disagree ..... □
Disagree ..... □
Agree..... □
Strongly agree ..... □

58. I would be embarrassed to have a colonoscopy because my bowel may not be clean after the bowel prep.

Strongly disagree ..... □
Disagree ..... □
Agree..... □
Strongly agree ..... □

59. I would be embarrassed to have a colonoscopy because of the size or appearance of my bottom/buttocks.

Strongly disagree ..... □
Disagree ..... □
Agree..... □
Strongly agree ..... □

60. I would be embarrassed to have a colonoscopy because someone will be touching my bottom/buttocks.

Strongly disagree ..... □
Disagree ..... □
Agree..... □
Strongly agree ..... □

61. I would be embarrassed to have a colonoscopy because the tube is being put into my rectum.

Strongly disagree ..... □
Disagree ..... □
Agree..... □
Strongly agree ..... □

62. I would be embarrassed to have a colonoscopy because I might smell.

Strongly disagree ..... □
Disagree ..... □
Agree..... □
Strongly agree ..... □

63. I would be embarrassed to have a colonoscopy because of concern that my penis would not be covered during the test.

Strongly disagree ..... □
Disagree ..... □
Agree..... □
Strongly agree ..... □

64. I would be embarrassed to have a colonoscopy because the doctor or nurse will see my bottom/buttocks.

Strongly disagree ..... □
Disagree ..... □
Agree..... □
Strongly agree ..... □

65. What is your date of birth?

Month_____ Day_____ Year____

66. What is your height?

_____Feet_____ Inches

67. What is your weight? _____pounds

Thank you for taking the time to fill out this survey. The information you gave is very much appreciated. If there is anything else you would like to tell me, please write it in the space below.

Please return the completed survey in the preaddressed, stamped envelope. **Thank you!**

Kimberly A. Mitchell

Appendix K

Comments to Open-Ended Questions Grouped according to Common Theme

Question 48. For me, the most embarrassing part of having a colonoscopy would be:

Theme: Exposure/lack of privacy-23 Exposing my rear end to strangers Exposed unnecessarily. Wearing a backless hospital gown. Being exposed to strangers. Laying in bed with just gown on. The obvious-bare exposure. No privacy. Getting naked in front of strangers. Exposure Laying on table with butt exposed to the world. Getting Nake[d] Getting naked. Showing my butt to the doc. Position you have to be in. Revealing my weight and buttocks! Showing my bottom. Telling some people I am having one. Lots of people around. In room WARD! Discussing with neighbors. Having interns present. Medical students. Having a strange Dr. get so personal with me. The prep **and having others involved with the procedure**.
Theme: Loss of control-22 The passing of air after in recovery. Passing gas post procedure. All the air they put in you. Discharge-passing gas Possible letting gas during the procedure Having gas after the procedure. Gassiness afterwards. The gas passing after the procedure while a friend is in the room. A gas attack! (Not really!) Gas Passing gas. The type of test **and the gas afterwards**. What I would say under sedation. Crossed out ‘would be’ and wrote in ‘was’ “Waking up and not knowing what

happened".
Having a discharge of BM during the procedure.
Having diarrhea on the examining table.
Waiting in the "prep" room a long time and feeling like I have to poop… (which happened at [hospital]-I waited over 1 hr).
Having stools still in my colon that I didn't remove completely
Taking the prep med and **being able to get to the bathroom every time with no mishap**
Not making it to the bathroom on time when cleaning out my bowels.
Passing gas and fear. Having to admit my fears.

Theme: Invasion/Body part involved-13
Having something put up my rectum.
Invasion of my body.
Invasiveness of that portion of my body! ☺
Having a scope in my rectum.
Inserting the tube.
Having something inserted in rectum
Where the scope goes
Having a tube placed in my rectum.
Having a camera inserted in my colon
Insertion
Having someone doing a procedure on that part of my body.
Somebody examine my private parts.
So personal

Theme: Bowel preparation-13
Lying on the bathroom floor with cramps and diarrhea all night before the test
Having to take the prep and spend hours running to the bathroom
Drinking the stuff to clean out my bowel.
Cleaning out the bowels.
Clean out time
Doing prep
The preparation
Getting an enema.
Having to go through the enema part.
The enema I had to have right before
The enema before the procedure
Prep
The prep and having others involved with the procedure

Theme: Being conscious-9
If I was awake.
It is not embarrassing to me since you are sedated before the procedure.
Being awake.
Awakening pre-maturely before procedure is complete

Being alert while procedure is being done. As long as I am out, I would not be embarrassed Being fully awake. Having to be awake. After having children, **this didn't embarrass me, especially since I was out during the procedure**
Theme: Familiarity-7 If you know people in the room. Having it at the hospital where I work and know the people. I know the doctor performing the test. Awakening pre-maturely before procedure is complete and meeting someone I knew during and after procedure To have employees I have worked with in the room Knowing Drs from work Knowing the doctor
Theme: Concerns about physical appearance-6 My weight makes all medical care embarrassing. My weight. I was having a period. My weight! If no excessive hair in the colon region. Revealing my weight and buttocks!

49. I would be less embarrassed to have a colonoscopy if:

Theme: Using a different procedure-18 It was done more effectively a different way. There was another way of doing it. There was another alternative. It was a 'virtual' colonoscopy. It could be done by swallowing a camera. It was like an x-ray. I could do it myself. ☺ I didn't have it. I didn't have to do it. I didn't pass gas I didn't have gas Procedure didn't involve my butt! ☺ It didn't entail the rectum! ☺ It could be done without going in. If it wasn't located where it is. They did not have to insert the tube. It was noninvasive. It were not invasive.
Theme: Anonymity/Familiarity-18 I did not know anyone whom had something to do with it. I could do it anonymously. ☺ I didn't know staff. I did not know anybody. I did not know the people doing it. If I never had to see the Dr. again I did not know the doctor. It wasn't with people I know I did not know the staff/Dr. The doctor was a stranger. I didn't know the nurses in the room I didn't work for the hospital where the test is done. I did not know anyone there. I didn't know the people, I worked at [hospital] for 28 years I knew the doctor It was a doctor I was familiar with. I didn't have to be exposed to strangers I knew the people at the clinic.
Theme: Gender matching-13 A male Dr Male doctor I had a woman Dr.

A woman was doing it. The doctor is a male. The doctor was a woman It were a female GI doctor Only Dr. doing scope in room-no females. Female nurses were not present (old fashioned) The doctor was a male. Female Dr. I had a female doctor. A woman did it.
Theme: Unconsciousness-9 They put you out. I was unconscious during all hospital aspects I was completely put to sleep I didn't know what was happening during the test. I am not awake during the procedure I was asleep Asleep. Sedated I was out for the procedure.
Theme: Using a different bowel preparation-8 Didn't have to purge my body. The prep med were more predictable in its results I did not have to drink the laxative. I didn't have an enema or a period!! The preparation was more pleasant. I was sure I was completely cleaned out at home before getting to the Dr's outpatient clinic. He changed the wording to say *I would be <u>more</u> embarrassed to have a colonoscopy if* "I did not prepare correctly for the procedure.
Theme: Privacy-7 Reassured that it (unnecessary exposure) won't happen. I could be more modest It could be done without my having to disrobe. Only the doctors and nurses were present. Lack of privacy before or after procedure. I noticed movement of strangers through recovery area More private. Recovery was in a private area.
Theme: Increased knowledge-5 Knew I needed one. If I was more informed.

I knew it was gonna help me stay alive. Knew more about it My doctor and his staff were very informative and helpful (and they were!).

Appendix L

Permissions and Institutional Review Board Approvals

OSF
HEALTH PLANS
AN AFFILIATE OF OSF HEALTHCARE

February 8, 2008

Kimberly A. Mitchell, RN, PhD(c)
Saint Francis Medical Center College of Nursing
511 N.E. Greenleaf
Peoria, Il 61603

Dear Ms. Mitchell:

You have requested the participation of OSF HealthPlans in a research study investigating the barriers related to obtaining colorectal cancer screening. You propose to survey individuals who are members of OSF HealthPlans to obtain your data. Participation by OSF HealthPlans members in the survey will be voluntary and the identity of the individuals participating will not be disclosed to you.

OSF HealthPlans will participate in this study after approval has been obtained from an Institutional Review Board as required by the HIPAA Privacy Regulation 42 CFR 164.512 (i). Please provide documentation of IRB approval to Kathy Stolz, Quality Management Specialist.

Sincerely,

Mary Anne Nieukirk
Compliance Manager
OSF HealthPlans
(309) 677-8279
maryanne.nieukirk@osfhealthcare.org

7915 N. Hale Avenue, Suite D Peoria, IL 61615 Phone (309) 677-8200

OSF
SAINT FRANCIS MEDICAL CENTER
A commitment to life.

February 26, 2008

Kimberly Mitchell, RN, PhD (c)
511 N.E. Greenleaf
Peoria, Illinois 61603

Subject: Research Study: Development and Testing of the Colonoscopy Embarrassment Scale

Dear Kim,

The Professional Nursing Congress Research Committee has approved your research proposal "Development and Testing of the Colonoscopy Embarrassment Scale." You may begin your study at your convenience.

Please send us a copy of your IRB approval letter. You are required to submit your findings to the IRB and to the PNC Research Committee within one year. Upon completion of your study, please send us a completed copy of the study.

Sincerely

Joan Ruppman, R.N., M.S.
Patient Care Administration
Director of Medical/Oncology

JR:mlb

530 N.E. Glen Oak Ave., Peoria, Illinois 61637 Phone (309) 655-2000
The Sisters of the Third Order of St. Francis

INTERDEPARTMENTAL COMMUNICATION

Research Compliance Administration
Indiana University-Purdue University Indianapolis

DATE: February 24, 2008

TO: Dr. Susan Rawl
Nursing
NU 340
IUPUI

FROM: Regina Wininger
Research Compliance Administration
UN 618
IUPUI

SUBJECT: IUPUI/Clarian Institutional Review Committee - Exempt Review of Human Study

Study No.: EX0802-54B
Study Title: "Development and Testing of the Colonoscopy Embarrassment Scale"

Your application for approval of the study named above has been accepted as meeting the criteria of exempt research as described by Federal Regulations [45 CFR 46.101(b), paragraph 2]. A copy of the acceptance is enclosed for your file. If the research is conducted at or funded by the VA, research may not be initiated until approval is received from the VA Research and Development Committee.

Please contact the Indiana University School of Medicine Office of Compliance Services for information regarding a Data Use Agreement, if applicable.

Although a continuing review is not required for an exempt study, prior approval must be obtained before change(s) to the originally approved study can be initiated. When you have completed your study, please inform our office in writing.

When corresponding with our office regarding this study, please refer to the exact study number and title.

If you should have any questions, please contact our office at 317-274-8289.

Enclosures: ☒ Copy of acceptance

If, after having completed the Exempt Research Checklist, the investigator still believes the study qualifies as exempt research, complete the rest of this page and submit the original to:

RESEARCH AND SPONSORED PROGRAMS
Union Building
Room 618
IUPUI

OR

METHODIST IRB OFFICE (for Clarian [at Methodist] IRB)
Academic Affairs - Research
B Building, Room 349
Methodist Hospital

Note that the study cannot be initiated until written acceptance for the IRB is given.

PLEASE ALLOW 5-10 WORKING DAYS FOR EXEMPT REVIEW PROCESSING.

SECTION I: INVESTIGATOR INFORMATION

Principal Investigator: **Rawl, Susan M.** Department: **School of Nursing**
(Last, First, Middle Initial-----must have faculty/staff status or faculty sponsor must sign)
Building/Room No.: **NH340H** Phone: **317-278-2217** E-Mail: **srawl@iupui.edu**
Contact Person: **Darlene Gettle** Phone: **317-278-2036** E-Mail: **dgettle@iupui.edu**

If this is a Student Protocol, List Name of the Student: **Kimberly A. Mitchell** Phone: **309-243-5080**
E-Mail: **kiamitch@iupui.edu**

Project Title: *Development and Testing of the Colonoscopy Embarrassment Scale*

Sponsor/Funding Agency: **N/A** PI on Grant: **N/A**
Sponsor Protocol #/Grant #: **N/A** Period: From: to
Sponsor Type: ☐ Federal; ☐ State; ☐ Industry ☐ Not-for-Profit ☒ Unfunded; ☐ Internally Funded
Grant Title (if different from project title): NA

SECTION II: PERFORMANCE SITE

- ☐ Bell Flower Clinic
- ☐ General Clinical Research Center (GCRC)*
- ☐ IU School of Dentistry
- ☐ IU Cancer Center*
- ☐ IU Medical Group Primary Care Clinic (IUMG-PC), including Wishard primary care clinics
- ☐ IU Medical Group Specialty Clinic (IUMG-SC)
- ☐ IUPUI Campus, Location: _____
- ☐ Krannert Institute of Cardiology
- ☐ Larue Carter Hospital
- ☐ Lilly Clinic
- ☐ Methodist Beltway Centers
- ☐ Methodist Hospital
- ☐ Methodist-Affiliated Centers/Private Practices
- ☐ Midtown Mental Health*
- ☐ Regenstrief Institute
- ☐ Rehabilitation Hospital of Indiana
- ☐ Riley Hospital
- ☐ University Hospital
- ☐ Veterans Affairs Medical Center*
- ☐ Wishard Memorial Hospital*
  - ☐ Hospital/ER
  - ☐ Non-primary care
    - ☐ Regenstrief Health Center
    - ☐ Wishard Specialty Clinics
    - ☐ OB/GYN Clinics

☒ Other: **Participants are members of an HMO in the Midwest called Order of Saint Francis HealthPlans. The HMO headquarters are in Peoria, IL.**

* Additional information or submission may be required prior to initiating the study. Please check with the specific performance site for additional information.

SECTION III: RESEARCH DESCRIPTION

1. Provide a brief description, in lay terms, of the purpose of the proposed project and the procedures to be used.

Purpose: Little is known about embarrassment as a barrier to participating in invasive medical procedures such as colonoscopies. By determining the factors associated with embarrassment as a barrier to colonoscopies, interventions can be developed to reduce or eliminate embarrassment related to this lifesaving test so that more individuals will get screened and lives can be saved. However, there is no instrument available to measure this construct. Therefore, the aims of this study are to:

1) **Estimate reliability of a new instrument, the Colonoscopy Embarrassment Scale (CES), among men and women aged 51-64 years old.**
2) **Estimate validity of the CES among men and women aged 51-64 years old.**
3) **Examine relationships between demographic characteristics, body mass index (BMI), colorectal cancer knowledge, physician recommendation, perceived barriers, self-efficacy, and colonoscopy embarrassment scores.**
4) **Examine relationships between demographic characteristics, BMI, colorectal cancer knowledge, physician recommendation, perceived barriers, self-efficacy, and colonoscopy adherence.**
5) **Evaluate participants' perceptions of aspects of having a colonoscopy that are most embarrassing and participants' suggestions for reducing embarrassment.**

Procedure

Recruitment:

OSF-HP personnel will create a database of the individuals who were selected for the study grouped by gender and whether or not the participant has had a colonoscopy. The potential participants will be matched by age. The database will also include the individual's name and address. An identifying code will then be assigned to each individual by OSF-HP personnel. This database, *excluding* the name and addresses will then be submitted to the researcher.

Data Collection:

A packet containing an introductory letter (See Appendix A), certificate of appreciation for participation (See Appendix B), the survey, two dollars as a participation incentive, and a postage stamped/preaddressed return envelop will be prepared by the researcher. The researcher will record each individual's identifying code on the survey and the outside of the packet of information. The postage paid packet will then be labeled by OSF-HP personnel matching the identifying code to the participant and then mailed. A copy of the survey is enclosed (See Appendix E).

A postage stamped reminder/thank you postcard (See appendix C) labeled with each identifying code and arranged in numeric order will be submitted to OSF-HP personnel. OSF-HP personnel will apply the name and address labels by matching the identifying code to the participant name. The postcards will be mailed to all individuals, except anyone requesting exclusion, one week after the survey was sent.

Two weeks after the postcard was sent, a third contact with potential participants who have not responded will be made. The researcher will have prepared packets containing a letter to encourage the participant to complete the survey (See Appendix D), a replacement survey, and a postage stamped, pre-addressed return envelop. The researcher will record the identifying code on the survey and the outside of the postage stamped packet. OSF-HP personnel will apply the name and address labels by matching the identifying code to the participant name.

Data Analysis

Data will be entered into SPSS 13.0 and cleaning of data will be done by conducting frequencies to identify outliers or inappropriate entries. Additionally, descriptive statistics will be used to assess distributions and normality in preparation for analysis. The reliability will be determined by computing and evaluating inter-item correlation, inter-item covariance, and item-total statistics on the items in the scale, and the Cronbach's alpha for the scale.

Unidimensionality of the CES will be determined using exploratory factor analysis with varimax rotation. Construct validity will also be supported by examining the relationship between colonoscopy adherence and CES scores. Specifically, CES scores of participants who are adherent and those who are not adherent to colonoscopy will be compared using independent samples t-tests. For Hypothesis 4, relationships between CES scores and stages of adoption will be examined using analyses of variance (ANOVA).

Pearson's product moment correlations will be used to examine relationships between CES scores and all continuous variables. One way analyses of variance (ANOVA) will be used to examine relationships between CES scores and categorical variables (marital status, education level, income, and gender). Multiple regression analyses will be conducted to examine significant predictors of CES scores.

Independent t tests will be used to examine relationships between colonoscopy adherence and continuous variables such as age and BMI. Chi Square will be used to examine relationships between colonoscopy adherence and categorical variables such as race and marital status. Logistic regression will be used to examine predictors of colonoscopy adherence.

Research question 5 will be analyzed by recording all of the responses, tallying the responses that are the same, and grouping similar responses together. The researchers will independently identify common themes and then compare themes and make compromise decisions, if necessary, to determine final themes. Research question 6, will be analyzed in the same way as for research question 5. All analyses will be carried out in SPSS and will be conducted using p=0.05 as the significant level. Due to the limited sample size and exploratory nature of these analyses, we believe that a fixed p-value will be beneficial for exploratory purposes.

ONLY COMPLETE 2-4 BELOW IF YOU SELECTED CATEGORY 1, 2, 3, 5, OR 6 ON THE EXEMPT RESEARCH CHECKLIST.

2. Provide the process by which individuals will be recruited.

Eligible participants are individuals who are 51-64 years old and are members of the Order of Saint Francis Health Plans, a Midwestern HMO. People are not eligible to participate if they have: 1) a personal history of CRC, inflammatory bowel disease, or total colectomy; 3) had a colonoscopy for a reason other than screening; 4) ever had a sigmoidoscopy, or barium enema; or 5) had a fecal occult blood test using a take-home kit in the last 12 months. The HMO personnel will search the database for all of the people who are eligible to participate. Then, 400 eligible participants will be randomly selected from the database of the HMO members using Excel random sorting. Participants will be randomly selected to include equal numbers of men and women with 200 men and women having had a colonoscopy in the past 10 years and 200 never having had a colonoscopy.

a. Explain how it will be ensured that recruitment or selection will not unfairly target a particular population or will target the population that will benefit from the project/research.

Excel random sorting will be used to randomly select participants from the individuals that are eligible. Additionally, the database being used does not include information on race or income levels.

3. Explain how it will be ensured that individuals will be treated with respect during interactions/observations with them. For those individuals with diminished autonomy (e.g. children, people with limited ability to make decisions), explain how they will be protected.

Respect for participants will be demonstrated in several ways. First, the purpose of the study will be clearly explained in the cover letter. Second, subjects will be informed that their participation is completely voluntary and if they choose not to complete the survey that their medial care will not be affected in any way. Third, confidentiality of all data collected will be maintained. Participants will receive a certificate of appreciation and a two dollar bill as a token of appreciation for completing the survey. Participants will receive no more than three mailings (the initial mailing, a reminder postcard, and second mailing of the survey). Finally, a phone number will be provided in case participants have questions or concerns about the study.

a. Explain how individual privacy will be protected. For example, if interviewing, where will that be conducted?

Privacy will be protected because participants will self-administer the survey in the privacy of their own home and return the completed survey directly to the researcher.

b. Explain how individual confidentiality will be protected. For example, what kind of information will be recorded and how will that be protected?

Confidentiality will be protected by using identifying codes so that names of participants will not be known to the researcher. Additionally, the completed surveys will be returned directly to the researcher. No individual survey responses will be shared with the HMO; only aggregate data will be provided to the HMO. Completed surveys will be kept in a locked file cabinet and computerized data will be password protected. Additionally, participants are given an HMO contact person's phone number to call if they do not want to participate. Therefore, the researcher will not know the names of those who choose not to participate.

4. How will you help to minimize potential risks that individuals may be exposed to while participating in the research? Potentials risks may include psychological, social, legal, physical, etc.

There are no physical risks to participation in this study. Subjects are at risk for a possible loss of confidentiality if they call the HMO employee with questions or to decline participation. Otherwise, precautions are imbedded in the procedures to minimize loss of confidentiality. Answering survey questions may cause participants to explore personal feelings about having a colonoscopy and potential sources of embarrassment. Should participants experience distress as a result of the survey, they will be encouraged to contact the designated HMO representative. The HMO representative will offer to refer the participant to the student researcher to discuss their concerns. The student researcher is a family nurse practitioner who is experienced in recognizing emotional distress and is able to provide emotional support or referral should this situation arise. Additionally, the student researcher will be available by phone Monday through Friday from 8 am to 5 pm at 309-243-5080 for participant questions or concerns conveyed to the researcher through the HMO representative.

Statement of Investigator (or Faculty Sponsor in the case of a student project). I have personally evaluated this project and am aware of my responsibility to provide supervision and guidance during its execution.

Signature: **Kimberly A. Mitchell RN, PhD(c)**_____ Date: **2-19-2008**

E-MAILED FEB 19 2008

SECTION III: EXEMPT REVIEW DETERMINATION

☒ Accepted, Exempt Category(ies): 2

☐ Denied, Reason:_____

Authorized IRB Signature_____ Date: FEB 24 2008

Recorded in the Minutes of: MAR 07 2008

UNIVERSITY OF ILLINOIS
COLLEGE OF MEDICINE AT PEORIA

Institutional Review Board
One Illini Drive
Box 1649
Peoria, Illinois 61656-1649

FWA 00005172
IRB #00000689
IRB #00003461
IRB #00000688

Tuesday, March 11, 2008

Kimberly Mitchell, RN
OSF Saint Francis
College of Nursing
511 NE Greenleaf
Peoria, IL. 61603

RE: IRB Study # 08-040

Dear Ms. Mitchell:

Meeting Date: 4/10/2008 **At:** IRB I

Protocol Title:
Developing and Testing the Colonoscopy Embarassment Scale

This is to advise you that the above referenced Study has been presented to the Institutional Review Board, and the following action taken subject to the conditions and explanation provided below.

Internal #:	New Appl
Expiration Date:	3/10/2009
On Agenda For:	Expedited
Reason 1:	
Description	Date Received- 3/11/2008; Date Expedited- 3/11/2008; Reason Expedited- 45 CFR 46.110 (F) (7) -
IRB ACTION:	**Expedited**
Action Explanation:	Approval has been granted for one year pursuant to 45CFR46.110(a)(F)(5) "Research involving materials (data, documents, records, or specimens) that have been collected, or will be collected solely for nonresearch purposes (such as medical treatment or diagnosis)" and (7) "Research on individual or group characteristics or behavior (including, but not limited to, research on perception, cognition, motivation, identity, language, communication, cultural beliefs or practices, and social behavior) or research employing survey, interview, oral history, focus group, program evaluation, human factors evaluation, or quality assurance methodologies." The date of this letter reflects the date of final approval for this study. The "Meeting Date" heading and its corresponding date indicate the time at which the board will be presented with the expedited item as an informational item ONLY. This research meets the regulatory requirements for approval as specified in 45 CFR 46.111 and 21 CFR 56.111. Specifically, the risks to subjects are minimized and reasonable in relation to anticipated benefits to subjects and the importance of the knowledge that may reasonably be expected to result. Your request for a partial waiver of authorization for screening/recruitment purposes has been granted by the Peoria Institutional Review Board. Additionally, the IRB is

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waiving the requirement for the investigator to obtain a signed consent form for all subjects pursuant to 45CFR46.117(c)(2) "That the research presents no more than minimal risk of harm to subjects and involves no procedures for which written consent is normally required outside of the research context."

A Continuing Review will be requested prior to the end of one year of study.

This study will expire: 3/10/09.

This study will be reviewed at the 2/12/09 meeting of the IRB.

A completed Continuing Review Form is expected by: 1/29/09.

Enclosed you will find the current IRB approved subject letter and survey stamped with the approval and expiration dates.

Please use these versions of the documents in the research process.

The University of Illinois College of Medicine at Peoria's (UICOMP) Office of Human Research Oversight (OHRP) will no longer accept local or non-local adverse events or safety reports for IRB review that do not meet the definition of an unanticipated problem involving risks to subjects or others (UPIRSO).

UPIRSOs are any incident, experience, or outcome that meets all of the following criteria: a. are not expected (in terms of nature, severity or frequency) given (a) the research procedures that are described in the protocol-related documents (such as the research protocol and informed consent document); and (b) the characteristics of the subject population being studied; b. are related or possibly related to participation in the research; and c. suggest that the research places subjects or others at greater risk of harm (including physical, psychological, economic, or social harm) than was previously known or recognized.

1. To qualify as an UPIRSO, an adverse event must either be : 1). serious, unexpected (in terms of either the nature, severity or frequency of its occurrence), and related or possibly related to participation in the research or 2). not serious, but unexpected, related or possibly related to the research and suggest that the research places subjects or others at a greater risk of physical or psychological harm than was previously known or recognized.

In accordance with the monitoring plan described in the IRB-approved protocol, adverse events occurring in a multicenter study (NON-LOCAL EVENTS) should be reviewed and analyzed by a monitoring entity that assesses whether the adverse event represents an unanticipated problem by applying the criteria for a UPIRSO as described above. The monitoring entity should report such a determination to the investigator for prompt reporting to the IRB.

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PLEASE NOTE: The UICOMP IRB will ONLY accept for review multicenter (non-local events) that have been determined to meet the definition of an UPIRSO by the monitoring entity. This policy may dramatically decrease the volume of non-local events accepted by the UICOMP IRB.

In the absence of a letter from the sponsor or monitoring entity identifying the event as a UPIRSO, or by identifying that the event has met the above referenced three criteria, it is the responsibility of the local PI to determine the meaningfulness of the reported event. If the investigator determines that the report is not useful or meaningful in the form presented, the IRB recommends contacting the sponsor and communicating this to them for further instruction. If the local PI does not contact the sponsor, it will be his/her responsibility to judge the meaningfulness of the report by relying on the sponsor's assessment and his/her own judgment as to whether the event meets the definition of a UPIRSO.

Local adverse events meeting the definition of a UPIRSO, per the PI, should be reported to the UICOMP IRB using the Unanticipated Problems Involving Risks to Others Form at:
http://www.uicomp.uic.edu/Dept/IRB/Unanticipated%20Problems%20Reporting%20Form.doc

Local adverse events not meeting the definition of an UPIRSO will be returned without IRB review.

Non-local adverse events lacking a UPIRSO determination from the monitoring entity will be returned without IRB review.

For additional information please refer to UICOMP UPIRSO policy at:
http://www.uicomp.uic.edu/Dept/IRB/S2_10.

Sincerely,

John Hafner, MD
Chairman
Institutional Review Board

JH/mar

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Wednesday, March 19, 2008

Kimberly Mitchell, RN
OSF Saint Francis
College of Nursing
511 NE Greenleaf
Peoria, IL. 61603

RE: IRB Study # 08-040

Dear Ms. Mitchell:

Meeting Date 4/10/2008 **At:** IRB I

Protocol Title
Developing and Testing the Colonoscopy Embarassment Scale

This is to advise you that the above referenced Study has been presented to the Institutional Review Board, and the following action taken subject to the conditions and explanation provided below.

Internal #:	13356
Expiration Date:	3/10/2009
On Agenda For:	Expedited
Reason 1	Procedure **Reason 2** Other
Description	Revised survey instrument; minor changes
IRB ACTION	**Approved**
Action Explanation:	This change in research has been approved or acknowledged under expedited procedures for the review of minor changes to previously approved research (45 CFR 46.110(b)(2) and if applicable, 21 CFR 56.110(b)(2). Please note that date of meeting indicates the date expedited material is presented to the Board for informational purposes only.

Sincerely,

John Hafner, MD
Chairman
Institutional Review Board

JH/mar

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CURRICULUM VITAE

Kimberly Ann Mitchell

EDUCATION

2009	Indiana University, Doctor of Philosophy	Indianapolis, IN
1990	University of Illinois at Chicago Master of Science	Chicago, IL
1980	University of Iowa Bachelor of Science in Nursing	Iowa City, IA

PROFESSIONAL EXPERIENCE

2000-Present	Saint Francis Medical Center College of Nursing Assistant Professor	Peoria, IL
2001-2004	Saint Francis Medical Center, Peoria, Illinois Private home care staff nurse.	Peoria, IL
1995-2000	Saint Francis Medical Center, Peoria, IL Nurse Practitioner for Women's Health Screening Center under Illinois Breast and Cervical Cancer Screening Grant	Peoria, IL
1995-2000	University of Illinois At Chicago, Peoria Regional Program Clinical Instructor for Family Nurse Practitioner program	Chicago, IL Peoria, IL
1992-1996	Springfield Clinic, Springfield, Illinois Women's Health Nurse Practitioner	Springfield, IL
1991	Lake of the Woods Medical Center, Dunlap, Illinois Family Nurse Practitioner	Dunlap, IL
1987-1992	Saint Francis Medical Center, Peoria, Illinois Staff Development Coordinator	Peoria, IL

1986-1987	Saint Francis Medical Center, Peoria, Illinois ENT Office Nurse	Peoria, IL
1985-1986	Saint Francis Medical Center, Peoria, Illinois Pediatric Staff- Level IV (out of IV) on clinical ladder	Peoria, IL
1982-1985	Saint Francis Medical Center, Peoria, Illinois Pediatric Clinical Nurse Educator	Peoria, IL
1980-1982	Saint Francis Medical Center, Peoria, Illinois Pediatric Staff Nurse	Peoria, IL

HONORS

1976	Phi Eta Sigma
	Sigma Theta Tau International
1980	

CERTIFICATIONS

1991-2001	ANCC Certified Family Nurse Practitioner
	ACLS Certification
1999-2001	

PROFESSIONAL MEMBERSHIPS

2004-present	Midwest Nursing Research Society
2004-present	Oncology Nursing Society
1991-Present	American Nurses Association
1991-Present	Illinois Nurses Association
1991-2000	Interdivisional Council of Nurse Practitioners, Central Region
1992-1995	American Heart Association, Illinois Affiliate
1980-Present	Sigma Theta Tau International: Vice President for Tau Omicron 2006-Present Research Day Committee 2003-Present Steering Committee for Tau Omicron 2003-2006

RESEARCH ENDEAVORS

1990	Traits Perceived by Adolescents as Important for a Career in Nursing (Unpublished)

SCHOLARLY ACTIVITIES AND PUBLICATIONS

2008	Saint Francis Medical Center College of Nursing and Tau Omicron Chapter of Sigma Theta Tau, Sixth Annual Research Day, Peoria, IL, Dec. 1, 2008. Keynote: Too Embarrassed to Test: Sources of Colonoscopy-Related Embarrassment.

2007	Mitchell, K. A., Rawl, S. M., Schmidt, C. M., Grant, M., Ko, C. Y., Baldwin, C. M., Wendel, C., Krouse, R. S. (2007). Demographic, clinical, and quality of life variables related to embarrassment in veterans living with an intestinal stoma. Journal of Wound, Ostomy and Continence Nursing, 34, 524-532.
2006	Midwest Nursing Research Society 30th Annual research Conference, Milwaukee, WI, Mar. 31-Apr. 3, 2006. Podium: Embarrassment Linked to Quality of Life Outcomes for Veterans with Intestinal Ostomies.
2006	Mitchell, K. A. (2006). Teacher. Nursing Education Perspectives, Jan.-Feb., p. 58.
2005	Saint Francis Medical Center College of Nursing and Saint Francis Medical Center College of Nursing Honor Society: Fourth Annual Research Day, Peoria, IL. Nov. 21, 2005. Podium: Effect of Embarrassment on Veteran with Intestinal Ostomies.
1996	Illinois Department of Public Health 1996 Conference on Women, Children, and Families. Hyatt Regency, Chicago, IL. Panel on Women's Health: An Integrated Program Approach.
1996	American College of Physicians Illinois Chapter Scientific Meeting. Renaissance Springfield Hotel, Springfield, IL. Cancer Screening and Health Assessment for Women: A Community Collaborative Experience.
1991	Nursing Research: Kaleidoscope for Future Practice. Bradley University, Peoria, IL. Personality Traits of Nurses as Viewed by Adolescents.

COMMUNITY SERVICE AND ACTIVITIES

1996-present	Westminster Infant Care Center: Vice President 2008 Board of Directors 1997, 2006, 2007, 2008 Volunteer Nurse 1996-2003
1980-Present	Westminster Church: Usher 2001-Present Vacation Bible School 2002, 2003, 2006 Stewardship Committee 1991, 2001-2006 Church School Teacher 1992-1993 Elder 1989-1991 Deacon 1985-1988, secretary 1986
1999-2006	YWCA Leader Luncheon Committee: Scholarship Committee Chair Legend Reception Committee Chair Awards/Judging Committee Chair Leader Luncheon Event Chair
1992-2005	South Side Mission: Volunteer
1999-2003	Illinois Valley Central High School Band Boosters: President 2000-2003 Camp Nurse 1999-2000 Vice-President 1998-2000
2002	Habitat for Humanity: Builder
1998-2000	Susan G. Komen Memorial Chapter: Educational Workshop Committee
1992-2000	Mossville School PTA: President 1994, 1999 Vice President 1997, 1998 School Activity Chair 1994, 1995 Art & Science Committee 1992, 1993
1997-1999	Heart of Illinois Harvest: Volunteer
1984-1999	Delta Gamma Alumnae Association: Treasurer 1991-1999 President 1987-1991 House Corporation President 1984-1988

1995-1996	Health Fair-Physicals for Underprivileged: FNP
1995	Heartland Community Clinic: FNP
1982-1983	Peoria Association for Retarded Citizens: Prevention Committee