

**UNDERSTANDING PATIENT COMMITMENT FOR COLORECTAL CANCER
SCREENING IN SOUTHERN ALBERTA**

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Dedication Page

To my Grandmother, Maxine McBean, who has always been a champion of education and encouraged her grandchildren to stay in school: Thank you for being excited about this experience and for your love throughout the years.

To my parents, Bryan and Dode McBean, who have been a rock of stability: thank you for providing me with love and support throughout this journey.

Finally, to my loving family, who have been incredibly supportive and have encouraged me every step of the way. I could not have done this without you all in my corner! Thank you Jim, Emma, and Matthew.

Abstract

The purpose of this naturalistic inquiry was to understand factors that influence patients' commitment to colorectal cancer screening, specifically colonoscopy. Fifteen person-centred interviews were conducted: 10 with individuals who had completed screening, and 5 with individuals who declined. Three subthemes (relationship, motivation, and human agency) were associated with the overarching theme of regard or disregard for vulnerability. Participants who perceived a disregard for their vulnerability by their health care provider (HCP) frequently chose to decline screening even though they showed a high level of commitment to health promotion. Participants who perceived a regard for vulnerability by their HCP frequently chose to accept screening. The nursing profession can show a regard for patient vulnerability by enhancing communication techniques and concentrating on being attentive to patient concerns which will build a trusting relationship with patients and enhance screening rates. Persistence in the relationship can change a patient's decision in time.

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Chapter One: Statement of the Problem

Rationale for Study

According to the Alberta Cancer Board (2008), colorectal cancer (CRC) is the second leading cause of cancer deaths in the province. CRC is a cancer of the colon or large bowel and includes growths in the colon, rectum, and appendix. Nationally, the Canadian Cancer Society (2012b) estimated that 23,300 new cases of CRC will be diagnosed and 9,200 Canadians will die from it in 2012. Despite these figures, the 5-year survival rate is high, 90% or more, if CRC is detected early and treated promptly (Alberta Cancer Board, 2007). Unfortunately, the survival rate drops significantly to 60% or less if the disease is not treated until the person is symptomatic (Alberta Cancer Board, 2007). Public awareness campaigns have been successful in educating Canadians to the importance of CRC screening; however, there remains a general lack of knowledge around screening. People continue to misunderstand the need to screen before they become symptomatic (Canadian Cancer Society). Many Canadians mistakenly believe (and report) that screening for CRC is required only after symptoms are present. The Canadian Cancer Society stated that screening rates for CRC remain low even though these rates have risen to an estimated 50% in 2012. The purpose of the current study was to better understand the factors that influence a patient's commitment to CRC screening.

Most CRC begins as one or more small, benign polyps on the inner wall of the rectum or colon. These benign polyps can take up to 10 years to become malignant (Kronborg & Fenger, 1999). The chance that a polyp (a small growth found in the colon) becomes malignant increases with its size, the degree of dysplasia (abnormal cellular development or growth), and its content. This disease does not provide any early signs of

its presence and patients can live asymptotically for many years. However, symptoms such as rectal bleeding, abdominal pain, or a change in bowel habits may indicate that the cancer has spread, and in these cases the 5-year survival rate drops significantly (Alberta Cancer Board, 2007). While anyone can develop CRC, more than 90% of affected people are 50 years of age or older, highlighting the need for screening among this group (Alberta Cancer Board, 2008; Laine, Goldmann, & Weinberg, 2008). CRC screening involves only those patients who are asymptomatic; for the purposes of this research, asymptomatic individuals comprised the participant group.

Since 1984, the United States Preventive Services Task Force (USPSTF, 2008) has been releasing evidence-based recommendations for physicians to support specific screening methods to detect CRC early in an effort to decrease morbidity and mortality. Many countries such as the United States, the United Kingdom, Australia, Israel, and Canada have conducted extensive studies of CRC, and great strides have been made to create cohesive and comprehensive screening plans. Canada, the United States, and the United Kingdom have enacted task forces that arrived at very similar recommendations for dealing with CRC. However, despite all the available knowledge surrounding CRC, including the task force recommendations of several countries, screening rates are just now reaching the 50th percentile (Canadian Cancer Society, 2012).

Screening has been determined to be effective at detecting CRC at its earliest stages, thereby reducing morbidity, mortality (Hardcastle et al., 1996; Kronborg, Fenger, Olsen, Jørgensen, & Søndergaard, 1996; Lasser, Ayanian, Fletcher, & DelVecchio Good, 2008, Mandel et al., 1993; Winawer et al., 1993), and cost to the healthcare system (Pignone, Rich, Teutsch, Berg, & Lohr, 2002). Screening for CRC has been endorsed by

many professional organizations (Canadian Task Force on Preventive Health Care, 2001; Leddin et al., 2004; Ontario Expert Panel on Colorectal Cancer Screening, 1999; USPSTF, 2002) and, unlike many other diseases, has four options: fecal occult blood test (FOBT), colonoscopy, sigmoidoscopy, and barium enema. Although all four screening modalities are recognized as effective for CRC screening, the primary approaches used in Southern Alberta are the FOBT and the colonoscopy.

Definitions of Screening Modalities

The *FOBT* is the least invasive, most common, and most cost-effective screening strategy. This test comprises three stool tests that are easy to administer and safe to use. The FOBT tests for the presence of blood in the stool. There is good evidence of reduction in CRC mortality with this type of screening (Alberta Cancer Board, 2008). However, some patients may find stool collection distasteful and, therefore, may not choose this form of screening. Because polyps bleed intermittently, the FOBT may not detect the presence of a polyp. This screening modality is recommended yearly or biennially beginning at age 50.

The *colonoscopy* test is considered the gold standard for CRC because it allows direct visualization of the entire colorectum and permits the removal of polyps during the procedure (polypectomy). Colonoscopy limitations include a two-day bowel preparation routine, risk of bowel perforation (1:1,000), and conscious sedation for some people, which means the patient must take a day off from work or from his or her regular daily activities as well as arrange a ride home from the procedure.

The *sigmoidoscopy* test involves a shorter flexible tube that allows visualization of only about half of the colon. Limitations include bowel preparation and risk of bowel

perforation (1:10,000) or bleeding, but the procedure does not require sedation and, therefore, patients are not required to take a day off work.

The *barium enema* test is a relatively safe screening modality, which is utilized less often than other CRC screening tests. Although this procedure permits visualization of the entire colorectum via X-ray, there are some limitations associated with it. Patients must undergo bowel preparation prior to the procedure and, given the frequent inability to cleanse the colon completely, shadows often show up in X-rays. These shadows must be investigated for polyps or cancers. The unnecessary stress for the patient, as well as the follow up colonoscopy, result in limited use of the barium enema.

Review of the Research Problem

The literature search strategy involved a review of five electronic databases: CINAHL, MEDLINE, EBSCO, Science Direct, and ProQuest starting, where possible, at 1990. Keywords included colorectal cancer, colorectal neoplasm, compliance, adherence and screening. Reviews were also included in this literature search and secondary resources included websites from the Canadian Cancer Society, American College of Physicians, Health Canada, the Canadian Task Force on Preventive Health Care, the Alberta Cancer Board, and Cancer Care Ontario. In total, 116 articles were reviewed and analyzed for a better understanding of CRC screening practices. The studies retrieved along with the secondary resources revealed consistent messages about CRC. All authors claimed that early detection of CRC through screening was the best opportunity for positive patient outcomes (Alberta Cancer Board, 2008; American College of Physicians, 2012; Baron et al., 2008; Bazensky, Shoobridge-Moran, & Yoder, 2007; Brouse et al., 2003; Bryant & McGregor, 2008; Canadian Cancer Society, 2012a; Canadian Task Force

on Preventive Health Care, 2012). Screening is an accepted means of improving patient results. Both primary and secondary prevention have been studied extensively to determine the best outcomes for individuals. Many countries have implemented task forces to develop specific preventive screening practices. Although best practices have been developed and are available in many countries, low screening rates for CRC persist.

Patient commitment to CRC screening is defined as an individual's decision to follow through with the CRC screening modality (FOBT or colonoscopy) recommended by a healthcare professional. In the case of individuals who have received a positive FOBT result, indicating the presence of occult blood in the stool, commitment includes follow up with a colonoscopy.

The literature search about CRC, screening modalities, and patient commitment to screening revealed that CRC screening and subsequent treatment saves lives (Alberta Cancer Board, 2008; American College of Physicians, 2012; Bryant & McGregor, 2008; Canadian Cancer Society, 2012a; Rees, Martin, & Macrae, 2008; Subramanian, Klosterman, Amonkar, & Hunt, 2004; Vernon, 1997). Authors have shown that individuals' commitment to health screening is influenced by factors that include physician recommendation, prevention intention, and demographics (Subramian et al., 2004); however, researchers have yet to determine why CRC screening rates are low. As a result, this project was undertaken to explore the decision-making process of individuals who choose or decline to screen for CRC.

Conceptual Framework

Pender's health promotion model (Pender, Murdaugh, & Parsons, 2002) was used to better understand the decisions individuals make when healthcare practitioners

recommend CRC screening. Pender's model was specifically chosen because of its emphasis on the multidimensional nature of individuals and how they interact within their own interpersonal and physical environments in pursuit of health (Pender et al., 2002). In this model, health is defined as a positive dynamic state (rather than an absence of disease) focused upon increasing wellbeing. Pender's health promotion model emphasizes three areas: individual characteristics and experiences; behaviour specific cognitions and affect; and behavioural outcomes.

Classified under individual characteristics and experiences are two factors: prior related behaviour and personal factors. Prior behaviour is considered a good predictor of future behaviour and personal factors consist of biological, psychological, and sociocultural variables.

Behaviour-specific cognitions and affect variables are considered to be highly modifiable through nursing action. These variables include perceived benefits of action, perceived barriers to action, perceived self-efficacy, activity related affect, interpersonal influences, and situational influences.

The behavioural outcome is the final piece of Pender's model and refers to the plan of action. The commitment to the plan of action can be influenced by immediate competing demands (of which the individual has low control) and preferences (of which the individual has high control) (Pender et al., 2002).

Pender's health promotion model (Pender et al., 2002) also includes interpersonal and situational factors that determine whether or not an individual has the support or ability to adopt new health behaviours. Examples of interpersonal influences are family, peers, healthcare providers, expectations of spouses, support received from others, and

the impact of watching others model specific behaviours. Examples of situational influences include perceived options for individuals and aesthetics. Environment and aesthetics influence individuals to perform better in settings in which they feel more comfortable (Pender et al., 2002). Pender's model was deemed most appropriate for use in CRC screening because it includes both interpersonal and situational factors that have been shown to be instrumental in an individual's decision of whether or not to undertake cancer screening (Gorin, 2004; Honda & Gorin, 2004; McCaffery, Wardle, Nadel, & Atkin, 2002; Subramanian et al., 2004).

Overview of Method

This study was a naturalistic inquiry that focused on the social constructs of research participants. One of the main purposes of naturalistic inquiry is to reach an understanding of essential meanings (Appleton & King, 1997) and to contribute to the pursuit of evidence-based health care by understanding client behaviours, experiences, and perspectives (Popey & Williams, 1998). A social construction is a concept that is developed by an individual or a group of individuals that gives meaning to their experience or interaction based upon reality, knowledge, and learning (Hammell, 2002; Lacey & Luff, 2007). Social constructions develop as a result of interactions with others, and the subsequent sense of meaning is the result of such interactions. Social construction, therefore, becomes critical, as it explains how individuals engage in the world and events that surround them. Person-centred interviewing (Hollan, 2005; Levy & Hollan, 1998; Polit & Hungler, 1991) served as the method for data collection in this study.

Levy and Hollan (1998) described person-centred interviews as a set of questions which the interviewee answers as either an informant or as a respondent. The advantage of this method of questioning, requesting informant or respondent answers, comes from the depth of understanding that results. For example, answers to CRC screening questions as an informant allowed me, as the interviewer, to gain a sociocultural perspective about CRC screening. Answers to CRC screening questions from the respondent allowed me to gain the individual's perspective about CRC screening, particularly the interviewee's own experience with screening, and views of the body, health, and healing. The objective of person-centred interviewing is to elicit a comprehensive understanding of how participants perceived the CRC screening process. The semistructured interview guide also provided the framework needed to examine/explore the inquiry questions, yet allowed the participant to address understandings that were important to him or her. The method is described in further detail in Chapter 3.

Research Questions

The following research questions framed this study:

1. What factors influenced the decision-making process for individuals who committed to CRC screening?
2. What factors influenced the decision-making process for individuals who declined CRC screening?

Significance

Understanding the complex interaction between individuals' characteristics, experiences, cognitions, affect, and behavioural outcomes provides healthcare professionals with a multidimensional look at the factors and processes that lead to

decisions on health screening. Individuals interact within their own environment to meet their goal of health and it is their personal characteristics and experiences that affect their decisions to accept or decline CRC screening. Understanding the factors that influence whether or not a patient commits to CRC screening may benefit nurses, healthcare teams, patients, and their families. The practical knowledge gained from this study informs healthcare professionals of both the barriers and the motivators that contribute to patients' decisions about screening. The findings may have an impact on primary care clinics regarding the potential for screening algorithms.

Chapter Two: Literature Review

CRC is the second leading cause of cancer deaths in the province (Alberta Cancer Board, 2008). The Canadian Cancer Society (2012b) estimated that 23,300 new cases of CRC will be diagnosed and 9,200 Canadians will die from CRC in 2012. However, there is good news, as the 5-year survival rate is 90% or higher if the disease is detected early (Alberta Cancer Board, 2007). The survival rate drops to less than 60% if the cancer is not treated before individuals become symptomatic (Alberta Cancer Board, 2007). This statistic alone should raise alarm bells in the health community. Further concern should be raised because there remains considerable confusion surrounding CRC screening. Although CRC screening rates have increased dramatically and are estimated to be at 50% for the average risk group for 2012, many individuals in this group mistakenly believe they need to be symptomatic to screen (Canadian Cancer Society).

This chapter begins with a brief background about CRC, followed by an overview of the epidemiology of the disease and the prospects for primary prevention. Next, secondary prevention consisting of current screening methods is covered in detail, focusing on the four screening modalities and the different levels of risk stratification. The many factors that impact patient commitment to screening such as physician recommendation, prevention intention, motivation, and demographics are also explored. Areas of controversy in the literature are discussed and knowledge gaps are identified.

Background

A journal search requesting information about CRC brought up thousands of articles. For this study, five electronic databases were searched (CINAHL, MEDLINE, EBSCO, Science Direct, and ProQuest) with a limit, where possible, to articles published

on or after 1990. The following key terms were used: colorectal cancer, colorectal neoplasm, compliance, adherence, and screening. Other resources were searched and included the following websites: the Canadian Cancer Society, American College of Physicians, Health Canada, the Canadian Task Force on Preventive Health Care, the Alberta Cancer Board, and Cancer Care Ontario (Rees, Martin & Macrae, 2007; Subramanian et al., 2004; Swaroop & Larson, 2002; Vernon, 1997).

From this extensive review, it is easy to understand why CRC has been referred to as the most preventable cancer, given the 5-year survival rate of 90% if treated early (Colorectal Cancer Association of Canada, 2010). Unfortunately, this survival rate drops to less than 60% if CRC is not detected early, and the rate drops even more if the disease becomes metastatic (Alberta Cancer Board, 2007). In 2007, less than 20% of Canada's average risk population underwent screening for CRC (McGregor, Hilsden, Li, Bryant, & Murray, 2007; McLeod, 2001). The Canadian Cancer Society (2012b) stated screening rates for CRC remain low, even though screening rates are expected to rise to 50% by 2012. Although screening rates have risen dramatically among Canadians, there remains a lack of general knowledge around screening.

For the past 24 years the United States Coalition Task Force for Health Promotion has released evidence-based recommendations for physicians and healthcare providers to support specific screening methods to detect CRC early in an effort to decrease morbidity and mortality (USPSTF, 2008). Many countries such as the United States, The United Kingdom, Australia, Israel, and Canada have been involved in extensive studies of CRC, and great strides have been made to create a cohesive and comprehensive screening plan. Task forces in Canada, the United States, and the United Kingdom all have arrived at

very similar recommendations in dealing with CRC (Rees, Martin & Macrae, 2007; Subramanian et al., 2004; Swaroop & Larson, 2002; Vernon, 1997). However, despite the available knowledge the percentage of those screened remains low.

Epidemiology of CRC

Most CRC begins as one or more small, benign polyps that live on the inner wall of the rectum or colon. These benign polyps can take up to 10 years to become malignant (Kronborg & Fenger, 1999). The chance that a polyp becomes malignant increases with its size, the degree of dysplasia (abnormal cellular development or growth), and its content. Since this disease does not provide any indication of its presence, people can live asymptotically for many years. When symptoms do appear, the cancer has usually spread and the 5-year survival rate is significantly reduced (Alberta Cancer Board, 2007). On a positive note, while anyone can develop CRC, more than 90% of people who develop it are aged 50 and older (Alberta Cancer Board, 2007). Identifying this group as the most at risk for developing CRC allows healthcare providers to target these individuals.

CRC also has a high rate of occurrence when there is a positive family history of CRC, Lynch syndrome or familial adenomatous polyposis (FAP), or if chronic inflammatory bowel diseases such as ulcerative colitis or Crohn's disease are present. The Alberta Cancer Board (2008) estimated that individuals with FAP have an 80–100% chance of developing CRC. Although the number of individuals with these diseases is low, the risk factors are significant enough to warrant close observation and screening.

CRC afflicts men and women almost equally, with men being only slightly higher in incidence than women (Alberta Cancer Board, 2008; McMahon & Gazelle, 2000).

Some investigators have focused on the prevalence of CRC within certain racial groups. African American, American Indian, Japanese, and Hispanic people all appear to be increasingly vulnerable to developing this disease (Beeker, Kraft, Goldman, & Jorgensen, 2001; Gorin, 2004; Honda & Kagawa-Singer, 2006). Many researchers have established correlations between lifestyle, such as diet and exercise, and the development of CRC (Beeker et al., 2001; Béliveau & Gingras, 2007; McLeod, 2001). Most authors agreed that age is the greatest risk factor to the development of CRC (Alberta Cancer Board, 2008; Beeker et al., 2001; Feldman, McCord, & Freiden, 2003; Gorin, 2004; Honda & Kagawa-Singer, 2006; McMahon & Gazelle, 2000). Age has been determined to be a significant, albeit uncontrollable factor for CRC development. More than 93% of diagnoses occur in patients aged 50 years and older (Laine et al., 2008), highlighting that individuals in this cohort require attention.

Prospects for Primary Prevention

Primary prevention is an action an individual takes to prevent a disease from developing and occurs prior to any signs or symptoms of a disease. Although the exact etiology of CRC is unknown, some factors have been identified that increase the likelihood of developing CRC, including age, high-fat diet, alcohol, obesity, smoking, and a sedentary lifestyle (Alberta Cancer Board, 2008; Laine et al., 2008).

Of the controllable factors, researchers most frequently cite diet to be an important link in the development of this disease (Agrawal et al., 2005; Bazensky et al., 2007; Laine et al., 2008). Linking diet and lifestyle to cancer is not a new idea. As far back as 1981, in a landmark study, researchers Doll and Peto showed that cancer could be

prevented in up to 80% of cases by lifestyle changes such as smoking cessation and a low-fat diet.

Béliveau and Gingras (2007) published a review in which they highlighted the role of nutrition in the prevention of cancer. Epidemiological, animal, and laboratory studies all showed that eating high amounts of plant origin food such as fruit, vegetables, legumes, and grains reduces the risk of many kinds of cancer. These foods have a chemopreventive effect because they contain phytochemicals, which block precancerous cells from developing into malignant ones.

Canadian authors Ryan-Harshman and Aldoori (2007) reviewed several studies, primarily case-control or meta-analyses that focused on individual foods, such as red meat, fibre, folic acid, calcium, and vitamin D to better understand the effects of certain foods on the development of CRC. The results of the review were disappointing because evidence linking red meat and fibre with the development of CRC was conflicting. In contrast, evidence linking vitamin D, calcium, and folate to a reduction of CRC was more promising, maintaining a moderate evidence link. Ryan-Harshman and Aldoori encouraged physicians to advise their patients to increase their vegetable and fruit intake.

Since primary prevention takes place in advance of disease and heavily relies upon lifestyle choices, it is important to continue to educate and support the public to embrace primary prevention strategies.

Secondary Prevention

Secondary prevention is an action an individual takes once early symptoms have been identified to prevent further complication from a disease. Screening has been determined to be effective at detecting CRC at its earliest stages, thereby reducing

morbidity, mortality, and cost to the healthcare system. Many countries have been involved in extensive studies of CRC and great strides have been made to create a cohesive and comprehensive screening plan. CRC, unlike many other diseases, has four different screening options: FOBT, colonoscopy, sigmoidoscopy, and barium enema. I describe each of these options in detail below and in Table 1.

Fecal occult blood test. The FOBT is frequently used as the front-line test because it is noninvasive and inexpensive, typically costing less than \$5 per individual (Greenwald, 2005). This test detects occult (or hidden) blood in the stool. Advantages of this test include its ease of administration, safety, and strong evidence of reduction in CRC mortality. However, patients may find stool collection distasteful and, since this test does not involve direct visualization of the colon, polyps may be missed. Additionally, polyps bleed intermittently and, this test can only identify a polyp if it is bleeding at the time of stool collection. Sensitivity is also a concern, as only 35–50% of the cases of bleeding polyps will be identified through FOBT, leaving 50-65% of cases undetected and therefore not subject to follow up with a colonoscopy. One other limitation of this test is that patients must follow the directions closely or the results will not be valid. However, American studies have shown that screening with FOBT followed closely by treatment of removing precancerous polyps has reduced CRC by approximately 20% (Agency for Healthcare Research and Quality, 2008).

Colonoscopy. Colonoscopy is often referred to as the gold standard of screening because it allows the clinician to visualize the entire colon. Polyps can be removed during this procedure, and average-risk patients (aged 50 years and older with no family/personal history of CRC) only require a colonoscopy every 10 years. Although

this appears to be the most efficient method of screening, most countries simply do not have the capacity to provide screening colonoscopies for their at-risk populations.

Colonoscopies are the most expensive procedure for CRC screening and require the expertise of an endoscopist (or at least a specially trained physician) and a team of nurses. Colonoscopy is in fact a diagnostic procedure that comes with some risk. Patients must undergo bowel preparation and perhaps sedation and be willing to accept the risk of bowel perforation. Complications such as perforation or bleeding occur in 1 of 1,000 procedures (Alberta Cancer Board, 2008). This test also requires the patient to take time off work or from their daily responsibilities if sedation is used.

Sigmoidoscopy. Flexible sigmoidoscopy is another commonly used test for CRC that is effective for visualizing the left colon and rectum. Advantages of sigmoidoscopy include acceptable tolerance by patients, moderate cost, and good evidence of decreased mortality from CRC with screening. Disadvantages include the requirement for bowel preparation, patient discomfort, visualization limited to the lower colon, and the risk of perforation or bleeding. A major disadvantage is that the length of the scope is 60 cm resulting in 40-60% of polyps or CRCs being left undetected because of their location (Alberta Cancer Board, 2008). Sigmoidoscopy complications such as bleeding or perforation occur in 1 of 10,000 procedures (Alberta Cancer Board, 2008). Due to the limitations of this screening tool, a combination of FOBT and a sigmoidoscopy is frequently used. A nonrandomized controlled trial of FOBT in patients having a sigmoidoscopy increased the sensitivity to 75% (Laine et al., 2008).

Barium enema. Although the double-contrast barium enema has been placed on the recommended screening protocol list, evidence of success for this method is limited.

This procedure consists of a bowel preparation enabling the entire colon and rectum to be viewed via an X-ray on screen. Although this is a relatively safe procedure and no sedation is required, the risk of radiation exposure is nevertheless present and bowel preparation is required, which causes discomfort to the patient. A major drawback is that this test often creates a false positive because of incomplete cleansing of the bowel. Shadowing caused by stool creates uncertainty in the test resulting in the need for further diagnostics, usually a colonoscopy, to rule out polyps or CRC. The Alberta Cancer Board (2008) continues to accept this as a screening modality for CRC but acknowledges that it is uncommonly used. Table 1 summarizes information of the four screening methods discussed in this section.

Risk Categories. Asymptomatic individuals are differentiated into one of four stratification groups: low risk; average risk; moderate risk; and high risk. Only asymptomatic participants were included in this study.

People at low risk are under 50 years of age with no family or personal history of CRC. There is no recommendation to screen this group. Individuals can lower their risk of future development of CRC by implementing primary prevention methods already discussed. Once these individuals reach 50 years of age, they are automatically placed in the average risk group.

The average risk category encompasses people aged 50 years and older with no family history of CRC. While the majority of people fall into this group, this is also the group that is most likely to have or develop CRC. According to the Alberta Cancer Board (2008), 70–80% of CRCs occur in this group. This means that people in this age group are highly susceptible to developing CRC, yet are likely the least prepared because of

Table 1. *Four Screening Methods for Colorectal Cancer*

Screening Method	Description of Test	Sensitivity	Advantages	Disadvantages
FOBT	Take home test requiring a collection of stool samples. Detects presence of blood.	35-50% for cancer	Inexpensive. Non-invasive. Strong evidence of CRC mortality with screening.	Patients must collect own stool samples. No direct colon visualization. Polyps can easily be missed. Dietary restrictions. Yearly exams.
Colonoscopy	Visualization of entire colon with polyp removal possible.	90% for polyps >90% for CRC	Only requires testing every 10 years.	Requires bowel preparation. Patients may require assistance home and time off work. Uncomfortable. Risk of bowel perforation (1:1,000).
Sigmoidoscopy	Visualization of left colon and rectum.	50-70% of advanced adenomas and CRC	Requires testing every 5 years. Well tolerated without sedation.	Requires bowel preparation. Uncomfortable. Screens only half of the colon. Risk of perforation (1:10,000).
Barium Enema*	Visualization of entire colon and rectum.	48% for large adenomas 55-85% for CRC.	Sedation not required. Relatively safe.	Requires bowel preparation. Exposure to radiation.

Note. *Uncommonly used for screening in southern Alberta. CRC = Colorectal Cancer; FOBT = Fecal Occult Blood Test. Modified from Alberta Cancer Board (2008).

their lack of awareness. In Canada, the recommendation for this group is to have an annual or biennial FOBT (Alberta Cancer Board; McLeod, 2001). If the FOBT is positive, then a colonoscopy is the next step for screening.

The moderate risk group includes individuals who have a personal history or family history of colorectal adenomatous polyps or CRC. Family history is defined by having one or more first-degree relatives with CRC. Screening for this group begins at age 40 years or 10 years younger than the youngest case in their family history. Screening recommendations for this group are subdivided into two groups depending upon the age of the family member diagnosed with CRC. The first group (relatives diagnosed with CRC after age 60) should follow the average risk group recommendation and begin annual FOBTs at age 40. The second group (relatives diagnosed with CRC before age 60) should have colonoscopies every five years (Alberta Cancer Board, 2007).

High-risk individuals have a family history of Lynch syndrome, FAP, or have many family members diagnosed with CRC. High-risk individuals also include those who have a personal history of inflammatory bowel disease. Due to their health history, these individuals are typically flagged early and are closely watched by their healthcare provider for frequent screening practice. A flexible sigmoidoscopy or genetic testing is recommended for people with FAP (Alberta Cancer Board, 2007). Colonoscopies are recommended for people with hereditary nonpolyposis and for individuals previously diagnosed with colon cancer (Alberta Cancer Board, 2007). Colonoscopies are also recommended for people with a family history of CRC (Alberta Cancer Board, 2007). Table 2 summarizes the screening modalities for each of the four stratification levels.

Table 2. *Recommendations by Risk Category*

Risk	Personal History	Family History	Age to Begin Screening
Low	Nil	Nil	50 years old
Average	Nil	Nil	50 years old
Moderate	Personal history of CRC	One first degree relative with CRC	40 years old or 10 years before youngest relative diagnosed with CRC
High	Personal history of inflammatory disease	Family history of Lynch syndrome, FAP, or having >1 family member with CRC	20 years old

Note. CRC = Colorectal Cancer; FAP = Familial Adenomatous Polyposis.

CRC Screening

The United States Coalition Task Force for Health Promotion (Coalition Force) began recommending CRC screening in 1982 (USPSTF, 2008). A decade later, the Coalition Force set a goal for the year 2000 whereby 50% of Americans aged 49 years and older would have had a FOBT within two years, and 40% of people in this age group would have had a sigmoidoscopy (Agency for Healthcare Research and Quality, 2008). While the goal itself was laudable, the results were less encouraging because screening rates did not increase significantly. The Coalition Force then extended the timeframe for meeting this goal to 2010. In other words, the screening rate appeared to be static or the more recent goal aimed too low. More recent statistics have shown, however, that Americans are almost at their screening goal with rates as high as 40–50% (Zarychanski & Dhaliwal, 2008). This outcome clearly shows that the goal can be achieved; however, a time span of 10 years to achieve the goal is too long considering the consequences of not screening.

In contrast, in 2008 Canada could not claim the same success as the Americans, as Canadian CRC screening rates are consistently less than 20% (Alberta Cancer Board, 2008; Bryant & McGregor, 2008; McGregor et al., 2007; McLeod, 2001). In Southwestern Alberta, CRC screening was low at 19.2%, with some clinics averaging only 10% (Chinook Primary Care Network, 2007). In an effort to address their poor adherence rates, all provinces across Canada have announced or have already begun to implement organized screening programs (Canadian Cancer Society, 2012b). Cancer Care Ontario implemented an overall provincial screening strategy to fund and implement a colorectal screening pilot program to meet its target of having 90% of Ontarians participate in an organized colorectal screening program (Provincial Cancer Prevention and Screening Council, 2006).

Alberta began the process of phasing in a 5-year CRC screening program in 2007 and targeted Albertans between the ages of 50 and 74 of average risk (Alberta Cancer Board, 2008). Before the Alberta CRC screening program began, the province lacked the consistency of clinical guidelines to direct healthcare providers in choosing the best screening modality and frequency of screening individuals needed. Since the rollout of CRC clinical guidelines (Toward Optimized Practice, 2008) screening requirements have been established province wide and a great deal of emphasis has been placed upon appropriately screening individuals for CRC. Both of these programs demonstrate the importance of screening and how the provincial government can become involved with disease prevention. The Canadian Cancer Society (2012b) estimated Canadians will reach the 50% screening rate for individuals aged 50 years and above for CRC in 2012.

Results of Other Cancer Screening Programs

The fact that Canadians are not fully embracing the CRC screening guidelines is not surprising. In fact, other cancer screening programs have taken years to become fully implemented in the Canadian healthcare system. Change takes time, and the perception of the importance for CRC screening is still relatively new. When the Papanicolaou (Pap) test was initially introduced in 1943 as a method of cervical cancer screening, it took many years before it was fully accepted as an important screening tool for the general public. By 1966 the United States reported only 26% of women were regularly completing a Pap test during their annual exams (Bryant & McGregor, 2008). Not unlike CRC screening, barriers for the Pap test included resource issues and the more insidious and practical issues of patient distaste for the test as well as the fear of cancer.

Patient Commitment to CRC Screening

In an attempt to increase screening participation, many researchers have focused upon factors that increase patient screening involvement. Words such as compliance and adherence are found frequently within the titles of CRC screening articles (Hay et al., 2003; Mant et al., 1992; Myers, Balshem, Wolf, Ross, & Millner, 1993; Neilson & Whynes, 1995; Richardson, Danley, Mondrus, Deapen, & Mack, 1995; Sewitch, Fournier, Ciampi, & Dyachenko, 2007; Weinberg, Turner, Wang, Myers, & Miller, 2004). Patients are considered adherent when they do what their physician recommends; nonadherence leads to increased morbidity and mortality and wastes resources (DiMatteo, 2004). In the *McGraw-Hill Concise Dictionary of Modern Medicine* patient compliance is defined as “the degree of adherence of a patient prescribed for treatment and whether the patient returns for re-exams, follow up or treatment” (“Compliance,”

2006, p. 37). The *American Heritage Medical Dictionary* defined adherence as “the extent to which the patient continues the agreed-upon mode of treatment under limited supervision when faced with conflicting demands, as distinguished from compliance or maintenance” (“Adherence,” para. 2). Clearly, these terms are constricting for individuals and imply that patients who do not conform to the treatment as prescribed by the physician are doing something wrong.

The term “patient commitment” was carefully chosen for this study in recognition of the fact that individuals’ decisions about health are influenced by a variety of factors. Patient commitment represents a relationship between the patient and the healthcare professional that extends beyond the simple office visit. Patient commitment encompasses the impact of professional advice, the professional relationship, individual attributes such as the patient’s education level, and contextual factors such as the influence of family and sociocultural context. Some of the factors that impact patient commitment include physician recommendation, prevention intention, and demographics such as age, education, gender, and marital status (Subramanian et al., 2004); these factors are discussed in the following section.

Physician Recommendations

Researchers exploring patient commitment to CRC screening consistently report the importance of physician recommendation (Shokar, Carlson, & Shokar, 2006; Subramanian et al., 2004). Vernon (1997) compared 18 studies that focused on experimental interventions to increase commitment to FOBT; only 10 were successful in achieving a 50% or greater commitment rate (Vernon, 1997). Greater commitment rates positively correlated with a letter or interview by a physician, educational booklets if

followed up by phone calls, nurse practitioner involvement, and a series of reminders including follow-up letters and phone calls that required staff involvement. The greatest commitment rates of 93% occurred when a physician spoke to the patient on the purpose and importance of FOBT and when a nurse practitioner gave instructions on how to prepare kits (Vernon, 1997). The importance of patient education by healthcare professionals seems to be an important factor. Subramanian et al. (2004) concluded, “Physician–patient relationship and trust are key factors to successfully implement colorectal cancer screening and more studies on this relationship are required” (p. 547).

Prevention Intention

Beliefs about prevention intention are linked strongly to commitment to screening. An example of prevention intention is engagement of other health-promoting behaviours such as regular dental or medical appointments. Individuals who believe cancer is preventable or screening is beneficial have higher rates of screening commitment (Subramian et al., 2004; Vernon, 1997). Vernon (1997) also found that patients were most receptive to screening when they also had high rates of prevention orientation, perceived benefits of screening, and high self-efficacy. Not surprisingly, individuals participating in other health promoting behaviours, such as regular medical or dental check ups, were the most consistent with commitment to screening (Vernon). While individuals with a strong prevention intention have a greater-than-average screening record, one must be careful not to over simplify this relationship by suggesting that intention equals action. Power et al. (2008) suggested that variables such as life difficulties play a large role in predicting action, even after controlling for intention to screen.

Demographics

Age, education, gender, marital status and ethnocultural influences are demographic variables that have been studied in relation to CRC screening. I explore each of these demographics in this section.

Age is commonly studied while examining patient commitment for CRC and it appears to be an important factor for individuals who follow through with screening. Subramian et al. (2004) reviewed 14 studies, 11 of which found that age had a positive impact on screening commitment, indicating older individuals responded to screening more favourably than their younger counterparts. Generally, peak commitment for CRC screening is age 75. Individuals younger than 65 years of age show the least commitment to screening. If these findings are indeed valid, then the 50- to 65-year-old individuals are the target group most likely to benefit from screening commitment.

Researchers also showed a positive correlation between higher education and follow through with screening protocols (Subramanian et al., 2004; Vernon, 1997). In Glasgow, Scotland, socioeconomic deprivation was indeed a factor associated with decreased participation in sigmoidoscopic screening for CRC (McCaffery, Wardle, Nadel, & Atkin, 2002). Interest in screening, completion of questionnaires, and attendance were all lower in the lower socioeconomic groups. McCaffery et al. (2002) concluded that while direct economic barriers alone do not explain the difference in participation, new ways to reduce inequalities are important if health practitioners wish “to avoid exacerbating social gradients in cancer mortality” (p. 104). Perhaps providing easier accessibility to FOBT kits and education about the test procedure would increase participation of CRC screening in the lower socioeconomic groups.

Gender and marital status have also been studied as potential factors for CRC screening. According to Vernon (1997) women slightly outperform men with compliance to the FOBT (27% to 25%), while men outperform woman when utilizing sigmoidoscopy or colonoscopy (12% to 7%). More recent study findings also showed women participated in colonoscopy screening less often than men (Wardle, Miles, & Atkin, 2005; Weinberg et al., 2004). Some authors have shown a higher rate of compliance among married persons (Morrow, Way, Hoagland, & Cooper, 1982; Richardson et al., 1995; Sandler, Devellis, Blalock, & Holland, 1989), but because the studies are dated and so few in number, this correlation warrants further confirmation.

Low rates of commitment have been observed in people of American Indian or African American backgrounds, Asian, Latino, or Hispanic ethnicity (Baron et al., 2008; Beeker et al., 2001; Gorin, 2004; Honda & Kagawa-Singer, 2006). Patients cited fatalism, fear of cancer, embarrassment, reliance on self-care, and limited opportunities for screening as reasons for not being screened (Beeker et al., 2001; Honda & Gorin, 2004; Powe, 1997). Suggestions to increase the involvement of these groups include taking a community-based approach to raise awareness and promote acceptance of screening, distribution of FOBT kits with instruction for their use, and reducing barriers by working with ethnocultural communities to provide the necessary social support (Beeker et al., 2001; Gorin, 2004; Honda & Gorin, 2005).

Areas of Controversy

If CRC screening is considered by the medical profession to be the panacea that decreases morbidity, mortality, and results in cost savings, then one might question why this simple method is not successful in its implementation. The reality is that controversy

surrounds CRC screening. Some of the controversies include differing opinions among physicians about which screening methods to use and the required frequency of the test methods. Some confusion also exists about FOBT testing and the guidelines for screening.

Zbidi, Hazazi, Niv, and Birkenfeld (2007) examined the results of a group of primary care physicians and gastroenterologists who completed a 10-question survey about the frequency and method of CRC screening. The questionnaire focused on patients who had polyps removed. The proportion of correct answers given within the primary care physician group ranged from 6.2% to 58.5% (Zbidi et al.). The gastroenterologists performed considerably better with correct results ranging from 18.7% to 93.75% (Zbidi et al.). Grassini et al. (2008) focused on the number of appropriate versus inappropriate diagnostic colonoscopies being performed. Physicians in Italy were given clear selection criteria that identified American Society for Gastrointestinal Endoscopy and Italian Society of Digestive Endoscopy guidelines for performing colonoscopies (Grassini et al.). Inappropriate screening in the study was identified as performing colonoscopies on individuals who did not meet the guidelines. Grassini et al. queried if educating physicians about correct screening programs could decrease the number of inappropriate colonoscopies performed. After providing an educational session to physicians, these authors found a dramatic decrease in the number of inappropriate colonoscopies performed, and the results showed reduced patient wait time accompanied by considerable cost savings (Grassini et al.). Both Zbidi et al. and Grassini et al.'s studies indicated that additional physician education might be required to decrease the confusion surrounding CRC screening.

Confusion about FOBT testing is another concern that was identified in the literature. Bryant and McGregor (2008) suggested that FOBT is not occurring as recommended by the Canadian Task Force and Cancer Board because of the lack of physician confidence in the test, as well as physicians' perceptions that the patient will not comply with the test. Bryant and McGregor reported that 88.2% of Alberta physicians had concerns about the false-negative and false-positive rates of this test, and 39.8% of physicians believed they would have low patient compliance with FOBT because of embarrassment or anxiety. Interestingly, Klablunde et al. (2005) examined the perception of patient embarrassment or anxiety about FOBT and found only 8.5% of patients had such concerns.

Finally, the CRC screening guidelines have created some confusion. In 2002, more than half of Alberta physicians surveyed agreed that the CRC recommendations were inconsistent and physicians found it difficult to determine which test to administer (McGregor, Hilsden, Murray, & Bryant, 2004). One example is that screening recommendations (approved by all of the task forces from a variety of countries) continue to place barium enema on its list when evidence suggests this test is uncertain at best. In 2008, a clinical guideline for Alberta healthcare professionals was created and distributed providing a clear reference tool for healthcare professionals to assist them in the implementation of CRC screening. The barium enema remains as a screening modality although it is used less frequently than the other modalities.

Gaps in the Literature

Across the CRC literature there remain gaps and limitations in knowledge and understanding. No researchers have examined the long-term commitment rate of FOBT.

This screening modality is recommended for yearly or biennial practice, and it is by far the easiest step to screening. Studies have not been conducted that measure patients' commitment to have this screening conducted according to the guideline.

Furthermore, few researchers have examined the reasons why individuals choose not to be screened. An individual's perception of CRC is perhaps critical to health practitioners' understanding of the phenomenon of not getting screened. The challenge associated with this type of study is that patients who decided not to be screened may not be willing to be interviewed about their decision.

Finally, the literature review revealed substantial information and statistics that could be examined to better understand patient commitment in relation to CRC screening. The primary methodology used to research patient commitment was telephone or mail surveys while other researchers used chart review (Rees et al., 2008; Subramanian et al., 2004; Vernon, 1997). All three methods have some limitations in that telephone and mail surveys are prone to poor return rates and response bias, and charts may not be complete, which creates difficulty in performing the reviews. For these reasons, a qualitative approach may better address the concerns or beliefs of individuals about CRC screening. There were many qualitative studies describing patients' perspectives on other screening programs for cancer but few were specific to CRC. Among those few, some similarities were noted. The study samples primarily consisted of visible minority groups in the United States and the methods included semistructured interviews, focus groups, telephone surveys, and observation and audiotape. Results of these studies showed poor rates of CRC screening related to lack of knowledge, lack of trust, fear, denial, and fatalism (Brouse et al., 2003; Lasser, Kelly et al., 2008; Weitzman, Zapka, Estabrook, &

Goins, 2001). Although the population base in southern Alberta is not primarily made up of visible minority groups, the results from these studies were used as a guide in this research project.

Applying Pender's Health Promotion Model

Pender's health promotion model (Pender et al., 2002) guided this qualitative study. The model was applied as a lens to CRC screening in an effort to better understand an individual's perception of screening methods. This model was chosen because of its multidimensional attention to individuals, their personal characteristics, and how they interact within their environment in pursuit of health. Pender's health promotion model is a competence-oriented model (Pender et al., 2002). Interestingly, although this model has not been used for CRC screening research to date, it can be found in other health promotion areas such as self-management and diabetes (Kwan Ho, Berggren, & Dahlborg-Lyckhage, 2010).

Pender's health promotion model (Pender et al., 2002) focuses on three areas: individual characteristics and experiences, behaviour specific cognitions and affect, and behavioural outcome. Health is defined as a positive dynamic state, rather than an absence of disease, and focuses upon increasing the wellbeing of individuals.

Individual characteristics and experiences provide a lens to examine previous health-related behaviour as an approach to understanding individuals' perceptions of benefit, barriers, self-efficacy, and activity. These variables constitute the critical core of interventions and are significant because they can be modified through nursing action (Pender et al., 2002). Measuring changes in these core variables is "essential to determine if such changes actually result from the intervention and, in turn, influence changes in

commitment or in the occurrence of health-promoting behaviors” (Pender et al., 2002, p. 69). Understanding individuals’ perceptions about these variables (i.e., benefit, barriers, self-efficacy, and activity) and possible influencing factors may assist healthcare professionals in communicating and supporting their patients, resulting in an increase in screening.

Pender’s health promotion model (Pender et al., 2002) also includes personal factors such as interpersonal and situational factors. Sources of interpersonal influence include family, peers, and healthcare providers. Examples of interpersonal influences are spouses’ expectations, the support individuals receive from others, and the influence that comes from watching others model specific behaviours. These interpersonal influences are subtle and can influence an individual’s behaviours, beliefs, or attitudes. Many authors (Honda & Gorin, 2005; Subramanian et al., 2005; Vernon, 1997) revealed that these interpersonal influences affect an individual’s decision about participation in health promoting behaviours (Pender et al., 2002). Perhaps this is not surprising, as researchers have established an increase in CRC screening when individuals are encouraged by a healthcare professional or when individuals have already adopted health promotion behaviours (Honda & Gorin, 2005; Sewich et al., 2007; Subramanian et al., 2004).

Examples of situational influences include perceived options for individuals and aesthetics. Pender’s health promotion model (Pender et al., 2002) suggests that individuals perform better in environments in which they feel more comfortable. This also means that individuals may or may not choose to participate in screening because of their own perceptions or understandings of their surroundings. If an individual feels included rather than excluded, safe rather than threatened, reassured rather than ignored,

he or she may be more likely to engage in health promotion activities. Therefore, if patients are provided opportunity to discuss their concerns and questions, perhaps screening rates for CRC may increase.

Summary of Chapter Two

CRC has a high rate of survival if diagnosed early. Early diagnosis relies on well-established screening methods that have been in existence for many years. Although CRC screening rates have increased because of public awareness initiatives over the past few years, rates remain relatively low. Public awareness campaigns have been successful in educating Canadians to the importance of CRC screening; however, there remains a general lack of knowledge around screening. People continue to misunderstand the need to screen before they become symptomatic. Even after being screened for CRC, many Canadians mistakenly believe (and report) the need for screening with symptoms. The Canadian Cancer Society (2012b) stated screening rates for CRC remain low even though screening rates have risen to an estimated 50% this year.

Information that should be known by the healthcare community and accepted by the population is slow to be realized. Like other screening tests (e.g., Pap smears) there is a lag time before prevention becomes a reality. However, the current political climate is focused on healthcare. Healthcare budgets are under scrutiny to accomplish more than before to deal with the aging baby boomer generation. What is required is a greater understanding of the discrepancies between increased potential of screening and low uptake. This understanding will result in healthcare professionals adopting more effective approaches for individuals who choose to decline screening.

Chapter Three: Methodology

A nonexperimental, naturalistic inquiry approach was chosen for this research. Naturalistic inquiry is a form of qualitative research that relies heavily on understanding and uncovering what is meaningful to the participant (Appleton, 1995; Appleton & King, 1997; Donalek & Soldwisch, 2004). Naturalistic inquiry is significant to practice and has gained popularity in the field of evaluative health research (Appleton & King, 1997), contributing to evidence based health care by asking questions of the medical system, evaluating policy initiatives, and understanding client behaviours, experiences and perspectives (Popay & Williams, 1998). The goal of naturalistic inquiry is to achieve full understanding and is an iterative process. It “cannot be given in advance; it must emerge, develop, unfold” (Lincoln & Guba, 1985, p. 225). Social constructions occur as a result of interactions with others, and the subsequent sense or meaning is the result of these interactions. Social construction, therefore, becomes critical because this personal reality or paradigm determines how individuals respond to the world and events that surround them. The qualitative method allows researchers to explore and to reach an understanding of the essential meaning of an individual’s construction (Lacey & Luff, 2007).

Individual person-centred interviews (Levy & Hollan, 1998), utilizing open-ended questions, served to generate the data for this study. Through these interviews, meanings attributed to screening and CRC were investigated. It was the meanings and ideas that a participant has about CRC screening that were of interest. The aim of this study was to develop a greater understanding of patient commitment to CRC as explained by participants who engaged in or refused CRC screening.

A search through the literature about CRC screening revealed an absence of qualitative studies that explored low screening rates within the context of people's lives. Many studies of other cancers have been conducted using both qualitative and quantitative approaches (Dubé, Fuller, Rosen, Fagan, & O'Donnell, 2004; Fisher, Dowding, Pickett, & Fylan, 2007; Oscarsson, Wijma, & Benezien, 2008). In contrast, CRC screening has been understood through mostly quantitative studies covering topics such as the types of screening methods most often used, physician recommendations, prevention intention, and demographics. According to Popay and Williams (1998), qualitative research can greatly contribute to evidence-based healthcare, particularly when examining client or provider behaviour and exploring client experiences. This study examined the meaning and context of patients' decisions regarding CRC screening. Qualitative methodology was most appropriate for understanding this phenomenon.

Semistructured Interview Guide

The semistructured interview guide (Appendix A) was designed to promote a rich understanding of patient commitment to CRC screening by using the information already identified in the literature such as physician recommendation, demographics, and prevention intention. Most of the 34 questions were open-ended to encourage individualized contextual responses. Questions covered a general understanding of CRC screening as well as information arising from the literature review. Interview questions 4, 9–10, 14–18, 24, and 29 address Pender's health promotion model (Pender et al., 2002), while questions 3, 8, 13, and 22 were based on the literature review. The remaining questions in the guide served to better understand individuals' perceptions of the screening process. To establish content validity of the interview tool, one male and one

female from the average risk group participated in a pilot interview before any letters of invitation were sent out.

Inclusion and Exclusion Criteria

Inclusion criteria included the following: belonging to average or moderate risk group, participated in or declined CRC screening, and English speaking. Exclusion criteria included the following: unable to speak English, and belonging to the low or high-risk group.

Recruitment of Participants

Participants for this study were recruited through a CRC screening clinic in Southern Alberta by way of a purposeful and convenience sampling strategy. Purposeful sampling is frequently used in qualitative research and is described as “selecting information-rich cases for study in depth” (Patton, 1990, p. 169). A total of 150 letters of invitation (Appendix B) were sent out to individuals in southern Alberta. Additionally, posters were placed in local senior centers for recruitment purposes. Fifteen adults between the ages of 50 and 74 years agreed to participate in this study. The age parameters were set to correspond with the average and moderate risk levels set by the Alberta Cancer Board (2008).

The total participant number of 15 was divided into groups consisting of individuals who agreed to be screened for CRC, and individuals who refused to be screened for CRC. The number of interviews, subdivided into +/- commitment to screening ($n = 15$) was accepted as this was the number of interviews I was able to conduct based on successful recruitment. This sample size was expected to generate a

robust qualitative data set with the likelihood of reaching saturation (Hesse-Biber & Leavy, 2006).

The intention of this study was to invite people who had either accepted (AC) or declined (DN) colorectal screening via colonoscopy to discuss with me their decisions about the screening in a 60–90 minute semistructured interview. Although the FOBT is also accepted as a screening modality for CRC, I have used the term screening in this research to refer only to one specific screening modality—the colonoscopy. Access to participants was obtained from a local CRC screening clinic. A written letter outlining the study was provided to the clinic manager requesting access to clients. The clinic sent out a letter of invitation to potential participants on my behalf for participation in the study.

The letter of invitation explained the process and included an assurance of anonymity and confidentiality, a description of anticipated use of data, instructions for accessing survey results, and my contact information. Interested participants were asked to contact me directly by email or telephone to obtain more information about the study and to discuss the possibility of participation.

Recruitment letters were sent out in two waves. The first wave of 60 recruitment letters were sent to individuals who tested positive with FOBT and either presented for a colonoscopy or did not book a follow-up colonoscopy. Based upon the response of this first wave I implemented a second wave of 60 letters to individuals who booked colonoscopies but did not present or who underwent a colonoscopy without having conducted a FOBT.

After the two separate mail-outs, 10 AC and 3 DN individuals responded. Given that fewer DN individuals responded to the initial invitations, I implemented a new

recruitment strategy in hopes of attracting more individuals from this group. I distributed posters (Appendix C) to two seniors' centres in the community and offered the option of a telephone interview. As well, the clinic staff sent out an additional 30 letters to the DN group. Two additional individuals were recruited and interviewed over the telephone. The same interview guide was used for both interviews (telephone and in-person) and no noticeable difference was noted between the quality of the interviews. In total, ten interviews with the AC group and five interviews with the DN group were completed. The interviews took place between September 2011 and April 2012 at an agreed upon location convenient to the participants.

Interview Process

All participants were asked to complete an informed consent (Appendix D) at the time of the interview. A verbal consent by the participant was given over the telephone as well as permission to tape the interview. At the beginning of the interview, each participant was advised that he or she could refuse to answer any of the questions. Participants were also advised that withdrawal from the study at any time was possible without any negative consequences, including the provision of healthcare. Reassurance was given to individuals that no one at the clinic would know who participated in the study. The demographic questionnaire (Appendix E) was completed prior to the interview. The semistructured interview tool was chosen to give basic structure and consistency to the interviews but also to allow flexibility for participants to discuss other aspects that were not covered in the questions. Through these conversations and careful listening an effort was made to better understand patient commitment to CRC.

Interviews lasted approximately 60 minutes and were digitally audiotaped with the permission of the participants and transcribed verbatim. To ensure accuracy I listened to the tape while reading the transcript. Recognition of participation was in the form of a \$15.00 gift certificate for a coffee shop or bookstore in the local area.

Data Generation

Person-centred interviews involve the participant in two different roles, that of the informant and that of the respondent. The informant is considered to be a knowledgeable participant in his or her culture and capable of answering features of the social systems. Examples of informant questions are: Do you know anybody affected by CRC, or can you tell me about their experiences? The role of the informant is to describe an experience generally as another member from the same group would describe it. Examples of respondent questions are: Can you describe to me the influence/impact of CRC on your life, or can you tell me about what influenced your decision whether to get screened or not? The role of the respondent is to describe an experience solely from his or her specific perspective (Levy & Hollan, 1998).

The semistructured interview was viewed as the means most likely to elicit detailed understanding of how a person perceives CRC screening. Semistructured interviews also contribute to a comprehensive and rich account of the phenomenon. The semistructured interview guide provided the structure needed to answer the study questions, and permitted a broad depth of understanding.

Data Analysis

In keeping with a naturalistic inquiry and a constructivist approach, data gathered during the interview were analyzed as they were collected. According to Marshall and

Rossmann (2006), there are seven phases of analysis, in which the researcher organizes the data, immerses in the data, codes the data, generates categories and themes, offers interpretations through analytic memos, searches for alternative understandings, and writes the report for presentation.

Organizing the data was an ongoing process. Notes were made before and after interviews were conducted and log sheets were created identifying dates, location of interview, participant, screening views, and general feelings about the interview.

Immersion in the data consisted of reading and rereading transcripts. Notes were made alongside transcripts to describe the tone of the conversation as well as the unspoken communication during the interview. Interviewing all of the participants was a lengthy process and took approximately eight months to complete. During this time I had the opportunity to spend more time rereading the transcripts and recalling participants' stories. This process gave me an in-depth understanding of the interview content and a familiarity with the data allowing for easier coding and generating categories.

Coding the data and generating categories and themes was perhaps the most difficult and uncertain phase of the research. All the transcripts were carefully read through and highlighted with different colours identifying patterns, subthemes and themes that showed linkages and indicated importance. After spending considerable time on this process, I knew my data well but the connections were difficult to see because of the enormous quantity of information. I then created a condensed version of key words to all the questions asked in the interview so that I could place all of these easily beside each other to identify trends. These results were looked at again and compared to my initial

research questions for comparison. This technique was successful in helping me to develop subthemes and themes.

Marshall and Rossman (2006) encouraged researchers to write throughout the research process to record notes, reflective memos, and thoughts to generate insight and to move the researcher from the mundane and obvious to the creative. Notes were taken throughout the research process and evolved over time to include discussions with participants before and after the interview, discussions on the telephone to follow up with participants, and personal thoughts and reflections about the interview and participants' subsequent stories and experiences. These notes helped me to understand meanings of participants' experiences and, along with the assistance of my supervisor, helped me to create a model to explain these research findings.

Once subthemes and themes are developed, Marshall and Rossman (2006) suggested the researcher evaluate the plausibility of this newly developed understanding by critically challenging the patterns that seem obvious to the researcher. Searching for alternate understandings to the themes and looking for negative instances of the patterns allows the researcher to build logical interrelationships among them.

Marshall and Rossman (2006) indicated that the final step of writing the report is an ongoing, analytic process that cannot be separated from all the previous writing and note taking because the choosing of words to reflect meaning for the participants is interpretive and lends shape and meaning to the voluminous amount of data gathered. As a researcher, I worked closely with my supervisor to interpret and give meaning to the various stories that I heard during the interviews.

Ethical Consideration

The University of Lethbridge Human Subjects Research Committee and the Chinook Health Region Research and Ethics Committee granted ethical approval for this study. Each participant was advised of his/her rights related to involvement in the study and was given a copy of the signed consent form.

Raw data from this study have been secured in a locked filing cabinet in my home accessible only to me. My supervisor had access to the raw but anonymized transcripts. Lists of names, participant consent forms, and personal information are stored securely and separate from other data in my locked office at my workplace. All participants were given an opportunity to choose their own pseudonym or were assigned one in order to maintain anonymity. Research policies for the University of Lethbridge and Alberta Health Services were followed and all data will remain locked in a cabinet for a period of 7 years, after which all materials will be disposed of as confidential waste.

Rigour

Guba and Lincoln (1981) suggested that truth-value (or credibility) could be evaluated only by taking the data back to its original source, the participant, and asking whether the results are believable and plausible. Sandelowski (1986) claimed a qualitative study is credible if it reveals an accurate description of an individual's experience and that individuals should be able to recognize their experience from the research. The truth-value was assessed through member checks with certain participants after the initial compilation of data and draft findings. Four member-check participants consisted of one male and one female who agreed to CRC screening, and one male and one female who chose not to be screened. Member checks took place as a discussion over

the telephone. Criteria for choosing individuals to participate in these member checks included gender; agreement to participate in a follow-up member check; and representation of decisions regarding either accepting or declining screening for CRC. Carrying out a member check gave me the opportunity to test the preliminary findings for factual and interpretative accuracy with the participants. All the member check participants were given a summary of the findings and the model was explained to them. These participants stated they felt their perspective was captured correctly and they believed the findings represented their stories.

Applicability (or transferability) can be thought of in terms such as its “fittingness” (Guba & Lincoln, 1981). Guba and Lincoln further explained when a qualitative study has findings that fit contexts that are beyond current research there is applicability. Sandelowski (1986) claimed that applicability occurs when readers or practitioners see study findings as meaningful and applicable from their own perspectives and experiences. Applicability for this study by providing thick and detailed descriptions of the participants’ experiences that provided a database for this group of individuals.

Consistency (or dependability) can be thought of in terms such as repeatability, replicability, or stability (Brink, 1989; Guba & Lincoln, 1981; Powers & Knapp, 1990). Given that qualitative research is based upon an emphasis on the uniqueness of human experience, the research cannot necessarily be repeated. Guba and Lincoln (1981) suggested that consistency could be judged as auditable, and thus reliable, if readers are able to follow a decision trail of the research process. Consistency was enacted in this study by detailing sufficient information throughout the research process so that the reader can follow and understand the researcher’s decision-making process.

Chapter Four: Findings

The purpose of this research was to develop an understanding of the influences affecting individuals' decision to either accept or decline CRC screening. The overarching theme was regard or disregard for vulnerability, vulnerability being the susceptibility for emotional or physical injury. Thematic findings labelled as subthemes comprised: relationships, motivation, and human agency. Important elements supporting the subthemes are: trust in physician, confidence in health care system, family history, media influence, safety, and intuition. Although the subthemes and elements were crucial factors for influencing individuals, independently none of them could adequately be selected as the overarching theme. Rather, when analyzing the subthemes and elements as a whole, vulnerability most accurately captured the essence of all of these factors combined. Individuals were strongly influenced to accept or decline screening based upon their perception of whether or not there was a regard or disregard shown toward them. Disregard for vulnerability represented those individuals who believed they were not listened to or understood by their healthcare practitioner (HCP). Furthermore, these individuals were uncomfortable putting themselves in a vulnerable position (such as CRC screening) when they perceived a lack of trust in this relationship. Regard for vulnerability represented those individuals who believed they had a healthy relationship with their HCP and felt respected as individuals. These individuals had a high level of trust and were comfortable allowing themselves to be vulnerable during CRC screening.

Another exciting finding from this research was the level of engagement in active health promotion from participants choosing to decline CRC screening. All five individuals who chose to decline screening actively participated in health promotion and

preventative behaviours. A common perception might be to assume the dissenters to shun or not be educated in health promotion. This was untrue for this group and the fact that this group was actively participating in health promotion behaviour was encouraging even though the desired outcome (accept screening) was not realized. More details of this finding will be included in this chapter.

Throughout this chapter direct quotations from participants have been used to support the study findings. These quotes are cited using pseudonyms that were either assigned to or chosen by the participant, along with the AC (i.e., accepted) or DN (i.e., declined) code (e.g., Mary-AC, Tom-DN).

Demographics

Participants were middle-aged and older adults; 13 of the 15 were married, Christian, and had at least a high school education. Of the 15, 10 were female and five were male. Three of the women (30%) and two of the men (40%) chose to not be screened; overall, 67% of participants chose to have the colonoscopy. Of the five DN individuals, one had a positive FOBT, one had a negative FOBT, and the rest of the DN individuals refused both the FOBT and the colonoscopy. Half of the participants had a personal or family history of cancer (see Table 3).

Four individuals had a total family income level of \$50,000 or less. Of these four, two chose not to have the colonoscopy. Of the 11 individuals who reported a total family income of greater than \$50,000, three chose not to screen (see Table 4).

Table 3. *Participants' Health Screening History*

	Pseudonym	FOBT Result	Personal History of CRC	Family History of CRC	Personal History of Cancer	Other Screening Tests	Last Screening Tests
Accepted CRC Screening	Mary	+ve			Uterine, Stomach	Mammo, Pap	2 years
	Carol	U		2 siblings	Basal cell	Mammo, Pap	1 year
	Sue	+ve	Y			Mammo, Pap	< year
	Evelyn	U		1 sibling		Mammo, Pap	< year
	Sherry	U			Cervical	Mammo, Pap	5 months
	Helen	R				Mammo, Pap	1-2 year
	Josie	U				Mammo, Pap	1 year
	Mike	+ve				Prostate	2 months
	John	U		Father	Basal cell	Prostate, skin	< year
	Frank	+ve				Prostate	< year
Declined CRC Screening	Liz	-ve				Pap, Bone density	2 months
	Teresa	R				Mammo, Pap	2 months
	Mira	R				Mammo, Pap Bone density	1 year
	Tom	+ve				Prostate	1 year
	Dave	R				Prostate	1 year

Note. U = Unknown; R = Refused fecal occult blood test; Y = yes; +ve = Positive; -ve = Negative; Mammo = Mammogram; Pap = Papanicolaou test.

Table 4. *Participants' General Demographics*

	Pseudonym	Gender	Age (Years)	Marital Status	Highest Education Achieved	Income (in \$1000s)	Religion
Accepted CRC Screening	Mary	F	73	MD	College	< 65	Roman Catholic
	Carol	F	61	MD	College	< 79	Roman Catholic
	Sue	F	63	MD	High School	< 35	Anglican
	Evelyn	F	67	MD	High School	< 79	Lutheran
	Sherry	F	52	MD	College	> 80	None
	Helen	F	63	MD	University	< 79	Anglican
	Josie	F	75	MD	High School	< 65	United
	Mike	M	69	MD	< High School	< 50	Roman Catholic
	John	M	49	CL	High School	> 80	None
	Frank	M	70	MD	High School	> 80	Roman Catholic
Declined CRC Screening	Liz	F	74	W	High School	< 35	United
	Teresa	F	52	MD	University	> 80	None
	Mira	F	75	MD	University	< 65	United
	Tom	M	64	MD	High School	< 20	Roman Catholic
	Dave	M	76	MD	High School	> 80	Lutheran

Note. F = Female; M = Male; MD = Married; CL = Common Law; W = Widowed; College = College Diploma; University = University Degree; High School = completed.

Overarching Theme of Vulnerability

Participants shared their perspectives and knowledge about CRC and CRC screening with candour. Their stories were multilayered and the decision to screen or not was the result of a combination of factors. These factors were grouped together and identified as subthemes and elements. They are as follows: (a) relationship, including levels of trust in physicians and confidence in the health care system; (b) motivation,

including family or personal history of CRC and media influence; and (c) human agency, including safety and intuition. Explaining the interrelationship of these factors took considerable time and thought. Each of the above factors was considered independently to be the sole influence or overarching theme but none of these factors stood out enough above the others. It was clear from the findings that it was a combination of factors from the subthemes and elements that influenced the decision to screen. By grouping and analyzing the subthemes and elements together, the perceptions of personal safety (either physically or emotionally) resonated strongly with all the participants. Building on the perceptions of safety, the overarching theme of (dis) regard for vulnerability, vulnerability being the susceptibility to physical or emotional injury, was developed.

When there was a high level of trust in a physician, for example, participants perceived the physician to have a high regard for their vulnerability allowing them to feel safe. Conversely, if participants had a low level of confidence in the health care system or a decreased level of trust in the physician, then they perceived a disregard for their vulnerability. Individuals viewed colonoscopy as a procedure that makes them susceptible to physical injury such as perforation or susceptible to emotional injury such as facing cancer or an invasive procedure. In all these cases, the participants feared either physical or emotional injury and did not feel safe.

During the interviews it became clear that individuals spoke of multiple factors that led to their decision to accept or decline screening. If a participant had a family history of CRC and understood positive messages from the media (the importance of screening), he/she perceived a regard for personal vulnerability. Alternatively, if a participant did not have a family history of CRC and focussed upon negative media

messages (such as large scale medical errors made), he/she perceived a disregard for his/her vulnerability. There was a good chance that participants who described a high level of trust in their physician, a high level of confidence in the healthcare system, and a positive family history of CRC would perceive a regard for their vulnerability by their HCP and choose to be screened. Alternatively, individuals who perceived a low level of safety for CRC screening, negative media influence, and who had little trust in their physicians would most likely perceive a disregard for their vulnerability and would therefore decline screening.

A vulnerability model (see Figures 1 and 2) shows the interrelationship of the subthemes and elements as they relate to the overarching theme. This model is dynamic, and these factors can be influenced and change over time and with experience. Individuals can move from being in the centre of the circle, in which there is a perceived regard for their vulnerability and a high chance of screening, to being on the outside of the circle with a perceived disregard for their vulnerability and a low chance of screening. An example of this was explained by one of the participants. She told me her first colonoscopy was performed without any sedation and she was so upset by this painful experience that she chose to ignore the advice to undergo a yearly colonoscopy. It was not until five years later and after having a lengthy discussion with her physician that she accepted screening. During this important discussion she was able to voice her concerns about her painful experience and was then assured by her physician that she would receive sedation for the colonoscopy. From this participant's experience, we can see the shift from a disregard to regard for her vulnerability.



Figure 1. Vulnerability model for CRC screening.

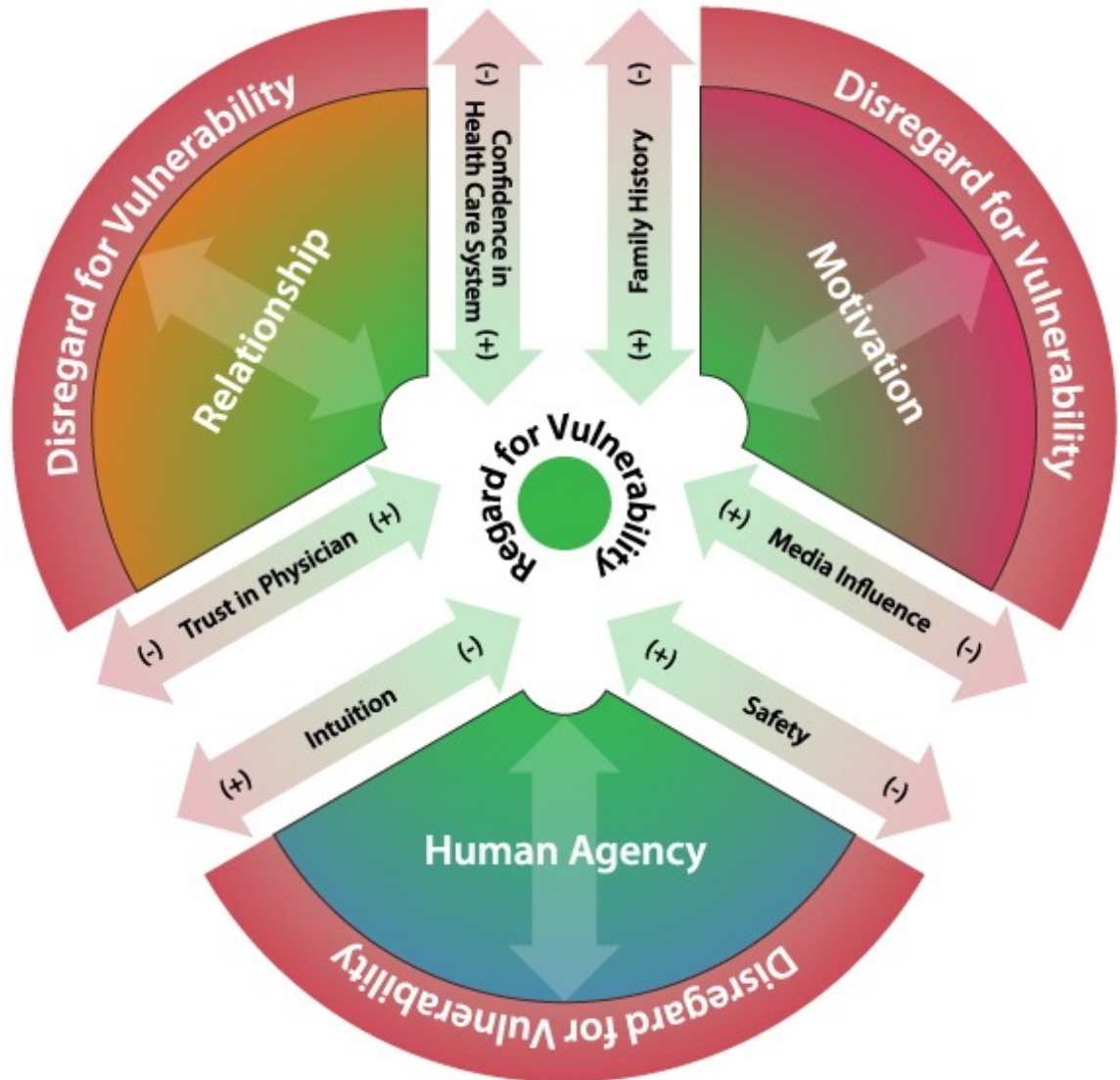


Figure 2. Expanded vulnerability model for CRC screening.

Relationships

Participants identified respectful and trusting relationships as important factors for whether or not they would undergo CRC screening. If an individual perceived regard by the HCP for his or her vulnerability as a person, he/she would often consider screening for CRC. If an individual perceived disregard for his or her vulnerability as a person he/she would frequently refuse to screen. The interaction between the individual and family physicians or other HCPs working in the healthcare system had a strong influence

on whether or not screening took place. Individuals identified that respectful interaction was important to them, which included being listened to, the ability to verbalize differences without jeopardizing the relationship, and being mindful of their time. Two factors that influenced participants were communication with and trust in the physician and confidence in the healthcare system.

Communication with and trust in physicians. Participants described a trusting relationship with their physician as one where they could openly communicate with the physician in which they felt the physician had their best interests at heart. When patients felt their physician understood them, they also felt safe to be vulnerable. Participants spoke about the necessity of being heard and of being able to spend time with the physician during the appointment so they could ensure they understood what was being communicated.

I feel very comfortable with [my physician] and I know that I'm getting looked after. He is open and frank, and I like him. Great deal of trust in him. I couldn't go to a doctor that I couldn't talk to. (Mary-AC)

I think [the relationship is] quite good. He explains things. . . . I need to have, you know, kind of a good relationship. (Helen-AC)

Well, trust is important. Also you have to feel that she's listening to you. That's important. Umm, I think you have to assume they know what they're talking about. You have to assume they have a good medical background. Their education is important so, you know, diplomas on the wall are important. But really having good listening skills is important. (Liz-DN)

I do feel you need to talk. I seem to have had a few doctors that I can really talk to and relate to, and I wouldn't leave her. I know she left her clinic and went on her own, and personally I think it made her a better doctor because she could relate with her patients, I honestly do. So when she moved, I moved with her because we can talk. We have a very good relationship. (Sue-AC)

Sherry explained that having a physician who listened was so important to her that she found another family physician when she felt her previous doctor was not

hearing her concerns. Sherry decided that perhaps a female physician would meet her needs. She is now very happy with her family physician and believes they have a good working relationship. Sherry followed through with CRC screening and regularly participates in other health screening.

Many years ago I had a doctor, he's retired, but I had lumpy breasts, and I would feel things and I had to go tell him that, and he would never pursue it. So I lost faith in what he saw me as. So I thought, I'm going to a female.

These participants felt it was important to be able to trust their physician and wanted a relationship in which they felt it was safe to be vulnerable. When participants perceived a lack of trust or faith they looked for another physician.

Lack of communication with and mistrust in physicians. Some participants spoke frankly about mistrust of their physicians, and others referred to the lack of communication or the physician's unwillingness to engage the participants during their appointments, resulting in a sense of mistrust. One participant who declined CRC screening talked openly about his mistrust of physicians. Dave was a retired farmer who led an active life and regularly saw his physician for yearly check ups. His family physician retired after many years and Dave reluctantly had been seeing a younger physician for the past three years. He agreed to participate in other health screening such as a prostate exam while he was having his annual examination because, he stated, "I didn't want to fight with my physician." When Dave was offered CRC screening he declined the procedure, stating he does not always follow the advice his physician gives him.

Oh, I don't have any great deal of trust in any physician. I mean, I don't think they're infallible. I think a lot of them kind of think they're God, and they come in there. I think they're just human beings. They put on their pants one leg at a time.

Another participant, Tom, chose to decline screening and spoke about the tenuous relationship he had with his physician. When asked if he felt if he had a good relationship with his physician, Tom answered that although he believed he did, it was only because he directed the care and knew his own body. Tom told his family to “be careful of doctors and taking medications” and that “most people put doctors on a throne.”

Duration of patient–physician relationship. Participants reported varying durations of the relationship with their physician. All 15 people reported having a regular family physician; however, the length of their relationship varied from three weeks to more than 25 years. Some participants also spoke about the difficulties of finding the right fit with a new physician once their former physician retired. The length of participants’ relationship with their physician did not necessarily reflect an increased sense of trust. Participants described a sense of trust with their physician when they spoke about good communication and understanding.

Teresa began seeing her physician three weeks before our interview and stated she was very happy with her and had a high level of trust in her care. The reasons she gave for this trust included approachability, “impeccable medicine,” specialty training, and being the same age and gender as the patient. Conversely, Liz had been seeing the same physician for 15 years, yet she did not feel she could communicate well with him. Liz indicated that she could talk to him but believed that their level of communication was poor. Liz shared that her physician was always too busy and too distracted to really listen to her concerns. This lack of connection had her questioning whether or not she should find another physician.

He’s very pleasant, but sometimes I feel like I’m on an assembly belt, like I’ll sit and wait for an hour or sometimes more because I think that he overbooked.

Tom had also been with his physician for many years and believed his doctor was too busy to talk with him. He described the relationship as hurried and rarely consulted him other than for his annual check ups.

I will go to see my doctor sometimes. You look at a clock, he comes in, goes through me, and he's out the door and I'm saying, hey, he didn't even check my pulse or whatever, do my blood pressure. The nurse says, "Oh, he's already on to his next patient." Doctors, there's not enough of them; they're pressured too much. It's not like the old days when they took a personal interest of you as a human body. You're a serial number and they have, what, a hundred people they go through every couple of minutes. I don't know quite how they get like that.

Individuals identified desirable physician traits as being respectful, trustworthy, possessing good communication skills, and being knowledgeable. When participants felt they were being heard they reported greater satisfaction with their relationship.

Confidence in the health care system. Participants were asked if their past healthcare experiences or those of their family contributed to their decisions about screening. Individuals shared that past experiences were indeed important influences for them to either accept screening or decline screening. Individuals who were satisfied with previous experiences also screened for CRC and talked about the importance of early diagnosis and intervention. Individuals who chose to decline screening acknowledged their dissatisfaction with the healthcare system as the reason. Four of the five participants who chose to decline screening spoke about their mistrust of the healthcare system in light of previous negative experiences. These participants also spoke of newspaper articles highlighting medical mistakes in Canada as a reason to be suspicious of the advice given by their physicians.

Previous history of other health screening. All 15 people in the study stated they participated in other health screening regularly and all of them claimed to have had other health screening in the past 2 years. The screening tests they regularly underwent

included Pap tests, mammograms, prostate examinations, and bone density tests (see Table 3).

Mary noted that she was diagnosed with cancer of the uterus after a routine Pap test when she was in her early 40s. She talked about the importance of screening and the responsibility of being there for her children.

Well, they weren't young, but they were children in their teens. And you know it's so important to stay alive. So important to stay alive until your family is raised . . . and I always have felt strongly about that. And I guess it's because my mother died at a very young age, I was 14, and I think that an abiding thing with me is to stay around for your children.

Years later, Mary was diagnosed with cancer of the stomach after she underwent routine CRC screening. She discussed the benefit of screening and how this simple test saved her life.

They would never have found that [stomach cancer]. I just think that would have been probably fatal eventually. They [a polyp at the ilium and stomach tumour] would have grown. I think if I hadn't had that test that started that, because I had no symptoms, I didn't have any blood, I had no symptoms that I had polyps.

Mary also spoke of the benefit of her immediate surgery and the fact that she caught the cancer at such an early stage.

I mean, and because I had no symptoms, I really think all of this is going to be under control you know? I might have to go in for both gastric and a scope every 6 months or a year or whatever, just to keep an eye on thing. But that's good.

Mary now clearly advocates for screening and talks with her family and friends about screening. She is aware of the necessity of screening in the absence of symptoms.

I am an advocate of screening all the way around. I read articles on it, I listen to articles. And I talk to people about it. People who've had this experience. You don't have to talk to everybody about it. I mean you don't have to be a chatty Cathy. Pick your people. But for heavens sakes do. Find out.

Helen has also participated in health screening for many years. She regularly has Pap and breast examinations. She had her first colonoscopy when she turned 50 years old

and described this experience as very positive because of the support of her family physician and “good staffing.” She believes the positive experiences that she had in her previous health screening affected her decision to accept CRC screening.

[My screening has been positive] because of the staff who do them. Amazing! Of course, my family physician helps me and everything. . . . Colorectal cancer, to me it means if you’re prudent [to screen] and you’re not afraid to do these things [screen], I think colorectal cancer can be dealt with. I don’t see it as a death sentence, I suppose is what I’m trying to say.

Dissatisfaction with the healthcare system. Of the individuals who declined screening, four shared personal or family stories about negative experiences with the healthcare system that led them to question physician recommendations. These participants described their frustration with the Canadian healthcare system during their emergency room visit, hospitalization stay, and even at discharge. Participants described incidents that happened 15 or more years ago and others that took place more recently. All of them spoke about their reluctance to trust the information that was given to them. These experiences have left these participants with a considerable lack of trust in the system, and they admit they choose not to screen because of these experiences.

Tom declined CRC screening because his uncle died from a bowel perforation during a colonoscopy. His mistrust of the healthcare system was further entrenched when his sister was mistakenly diagnosed with breast cancer. Later on when his sister was informed of the error, Tom was angry about the way the information was delivered to her. He believed the message was delivered flippantly and without care or thought toward his sister.

Mira shared her story of being dismissed by a triage nurse in a hospital Emergency Department and left waiting for hours while she bled internally from an injury. Hours later when a physician saw Mira, she was immediately admitted to the

hospital and sent for surgery. She spent one week at her local hospital before she was discharged home and then spent the following year regaining her health. This experience left her with a general mistrust of the healthcare system, and she is very cautious about any medical procedure.

Yeah and I'm not going to stick my neck out anywhere along the way. So I guess I've become very cautious and hesitant. There is a lack of trust, and I just thought, "Why should I [screen for CRC]?"

She continued,

I feel that healthcare has let me down. We just should not have to go through this type of healthcare, and I don't mean our own private doctor. Nobody seems to be able to figure out what it [the problem with the healthcare system] is.

Liz was another participant who had numerous negative experiences with the healthcare system. Her son was mistakenly diagnosed with diabetes when he was a child, leading her to restrict his diet and follow up with specialists unnecessarily. She herself experienced complications from two minor surgeries that she felt could have been prevented with more care. Liz also explained many of the difficulties she faced while her husband was dying in the hospital. She was distraught as she negotiated his care and felt little support from staff members at her hospital. Finally, she shared a story about a close family friend who kept going to the doctor with complaints of pain after surgery. The doctor diagnosed this friend with a mental illness and it was not until another doctor ordered an X-ray that they found the source of her pain. The surgeon had left a medical forcep in her during the surgery. All of these events have had a significant impact on Liz and the way she viewed medical advice or treatment. She now decides only after asking many questions whether she will follow her physician's advice.

Anyway so all this, like my life's experiences to this point in time, have made me question, and so I don't think, you know because, "Oh I do this because my doctor said I should." No, he's a human being and he makes errors.

Participants remembered their bad experiences and these memories have become the reason for choosing not to follow medical advice. Evelyn recalled having her first colonoscopy without any sedation. This painful experience left her mistrustful of the system. When she was asked to return for follow-up appointments because of polyp findings, she refused to go back for years. When she finally went back to see her physician five years later, she spoke to him about her experience. She was guaranteed sedation and has been regularly going for check ups and CRC screening ever since.

Motivation

Participants were asked about the motivating factors they believed influenced them to either accept or decline screening. They were also asked about their understanding of CRC and CRC screening. The most influential factors identified by participants that contributed to their decision included family or personal history of CRC, FOBT results, and media awareness.

Family or personal history of CRC. When asked if they thought their family history or friends encouraged or motivated them to go for screening, participants responded in the affirmative.

Oh absolutely. Well, I mean with my brother, really if it would have been detected earlier, I think he would not have had nearly as many complications in the end so absolutely it has influenced me. Oh yeah, all of my siblings, there's 9 of us, should be tested so that was it. (Evelyn-AC)

Micky explained that one of her brothers died from CRC and another brother chose not to screen and has now been diagnosed with CRC: "Once my brother was diagnosed, his wife called to tell the rest of the family to get screened." Sue was diagnosed with CRC and successfully underwent treatment. She spoke about how she has

influenced family and friends to get screened for CRC because having a screening colonoscopy is far better than surgery for cancer:

I've had some people tell me that they're going to get screened [because of me]. I've had some friends whose doctor wanted them to do the stool test . . . and they didn't want to do it because it's really yucky. And I'm going, "But it's really good." I have told them to go in for a colonoscopy and treat it before it's worse [and they need] . . . the [surgical] procedure. My sister now gets screened.

In this study, three of the ten individuals who participated in CRC screening had a family history of the disease, and two shared that a family member had died from CRC. Many participants, even those with the positive FOBT, indicated that they were not at high risk because they did not have a family history of CRC. Perceptions about the need for screening were frequently associated with having a family history or being symptomatic.

Unless there's a family history, or there are some symptoms, why be a burden on the medical system? (Evelyn-AC)

I would believe that your entire risk [for CRC] was family history. (Teresa-DN)

Guess I would if family history or if I suspected something. It is somewhat [important to screen] but not a great deal. I mean I believe that your length of life depends on your gene pool and your lifestyle. (Liz-DN)

If you went to your physician and you lost weight or you've had a drop in your hemoglobin . . . then they could prompt you in that direction [to screen], right? (Mira-DN)

These individuals spoke about family dynamics, belief systems, and how their families coped with these events. John lost his father to CRC in 1999 after being diagnosed only four months earlier. John knew his father was ill because he had visibly lost a great deal of weight and did not appear healthy. His father was 66 years old and rarely saw his physician. Even John's mother could not pinpoint what was happening and was unsuccessful in getting her husband to see his physician. When his father finally

went for help he was almost immediately diagnosed with cancer. John then realized how serious his father's condition was and "it all began to make sense to [me]." John explained that, at that stage, the cancer had already metastasized everywhere, and it was a "big impact losing my father." John believes strongly that the death of his father has motivated him to get screened for CRC.

Micky identified that even with a family history of CRC, not everyone chooses to get screened. Her eldest brother was diagnosed with CRC and subsequently died from it. His death affected her greatly, and she believes the biggest mistake her brother made was to neglect his health by ignoring the screening. She talked about her brother's fear of screening, and she felt there had to be a better way to approach screening rather than blocking it all out: "I think it was the way he viewed it and the fact that he put his head in the sand and didn't act on his symptoms. That's my perspective." Micky began screening for CRC after her brother was diagnosed; however, her youngest brother chose not to accept screening. He waited until he was symptomatic and only with the encouragement of Micky did he see his physician.

I told him . . . "You have to do something." And so that's when he had a colonoscopy. They saw this polyp in his bowel and the surgeon then decided he would do a CT [computed tomography] scan the next day and there was a mass sitting on top of his bowel. They did a couple of biopsies and they opened and closed him. And his surgeon was well aware of our family history of bowel cancer. So they opened and closed him and we were devastated. Stage IV cancer, colon cancer.

She has become a strong advocate of screening and encourages her family and friends to screen for CRC.

FOBT results. Having a positive FOBT also influenced individuals' decisions about screening. Nine of ten individuals who were screened had either a family history of CRC or a positive FOBT result. Four participants tested positive on the FOBT and

subsequently two were diagnosed with cancer, one with CRC and the other with cancer of the stomach. For the group of five participants who opted not to screen, one had a positive FOBT, one had a negative FOBT, and the remaining three refused both FOBT and colonoscopy.

Mary and Sue both participated in screening and became vocal advocates of early screening after they were diagnosed with cancer of the stomach and CRC respectively. These participants explained that they had developed symptoms before seeing their physician.

It started off with low iron, and then she recommended the stool test. She said I've never had low iron, so that's when we did the stool, and we found blood in every sample. (Sue-AC)

Then I started having a little bit of change in the bowel movement. There was blood in the stool in two of the three cultures, so he arranged for a colonoscopy to be done. (Mary-AC)

Even after the positive FOBT result, Mary explained that if the nurse at the colonoscopy clinic had not been so helpful with providing her information and support she may not have undergone the colonoscopy.

That took the burden off me. . . . I might not have followed through [with the colonoscopy]. I might not have known what to do if it was in my hands. But it was out of my hands. It just sort of, the ball just kept rolling. So I went out there and did everything that I was supposed to do on my instructions, and it was over in no time.

Media influence. Media and media reports have had influence on both groups of participants. The group that accepted screening spoke positively about seeing and hearing various CRC advertisements or infomercials, while the group that declined screening commented on the media reports highlighting medical errors that have occurred in Canada over the past few years.

Many of the participants who accepted screening spoke about seeing CRC screening advertisements on television and in magazines. They thought the information was instructive and believed by increasing their awareness of CRC, it also influenced them to screen. John liked the advertisements and remembered them because they were funny.

There were a few of the ads that were somewhat kind of humorous or, you know, something about your butt or something. I do recall those. There's lot of good information on a variety of cancers obviously. But I definitely remember those ads for sure.

Helen also believed that the media prompted her to screen for CRC:

I guess mostly just that whole idea of turning 50 and increased chances of, you know, having polyps or cancer, thing like that after age 50. That's sort of what the media seemed to push.

The media had an influence on the individuals who chose to decline CRC screening as well. Two individuals spoke about the numerous medical errors related to breast cancer in Canada in recent years. They spoke about large-scale errors and the fact that many women died because of mistakes made by physicians and the healthcare system. The errors reported on such a large scale made participants realize that errors can and do happen to everyone.

The news media issues about breast cancer and the errors, and the statistics that say, you know, how many, the percentage of deaths because of physician error. (Liz-DN)

So, you know, it makes me [think] that physicians and surgeons are not exempt from making errors in judgment. (Mira-DN)

Individuals were heavily influenced by internal and external factors when deciding to accept or decline screening. They came to the interview with thoughtful and reasonable explanations about their decision-making processes. Both groups were knowledgeable about CRC screening and they both made firm and opposite decisions

about screening. Individuals with a family history of CRC were frequently motivated to screen and commonly spoke about their family support and encouragement to follow through with screening. These individuals were highly motivated to accept screening and made every effort to screen even when it was inconvenient or uncomfortable. Other individuals were less motivated to screen and spoke about the barriers and dangers with CRC screening. They often had little trust in the healthcare system and looked for reasons why they did not need to screen. These individuals did not believe they were at risk for CRC and they believed the potential risk of screening, particularly with a system that makes mistakes, was higher than not being screened at all. This group also spoke about their belief of being low risk for developing CRC due to their active participation in health promotion behaviors.

Human Agency

The final subtheme emerging from this study was human agency. Human agency is the capacity for human beings to make choices and to act upon these choices in the world. All participants made clear decisions about CRC screening. Some influencing factors for this subtheme included safety and intuition. When individuals perceived CRC screening as safe, they also demonstrated an increased tolerance for the procedure and talked about their relationship with their physician and their willingness to follow recommendations. On the other hand, when individuals perceived CRC screening as unsafe, they felt vulnerable and chose to decline screening. These individuals frequently spoke about following their sense of intuition for health decisions.

Safety. Perceptions of safety included participants' assessments of the procedure itself as well their level of trust with the healthcare team. Individuals must have a great

deal of confidence in the safety of the procedure but they also must have confidence in their personal safety, because colonoscopies naturally render people vulnerable. This perception of safety significantly influenced the participant's decision on whether or not to screen. An individual who believed the procedure was a safe, accurate, life-saving screening tool wholeheartedly approved of the colonoscopy. Furthermore, these individuals did everything in their power to make it happen. Individuals who believed their physician should be directing their care also believed that colonoscopy was the right thing to do, and they followed through with the necessary screening. Individuals who had concerns about the colonoscopy frequently decided they did not require this type of screening. Two factors emerged as influences on decision-making: physician-directed care and increased tolerance for procedure.

Physician-directed care. Nine of 15 participants initially acknowledged that they were responsible for their own screening, yet later in the interview all stated their physician was responsible for their screening. Only a few individuals said they would request CRC screening if it was not offered to them. Many individuals expected their physicians to direct their care, and they would not have participated in CRC screening unless their physician had suggested it to them.

Mickey, an avid supporter of screening with a strong family history of CRC, thought that physicians should “prod” patients to get screened. She has been seeing her physician for about 15 years and described their relationship as “good” because he let her do “pretty much whatever I want to do.” She said she would not have requested CRC screening without her physician's encouragement.

Frank had been seeing his family physician for almost 20 years and had a great deal of trust in him. He followed his physician's suggestions without question: "Follow through with, yeah. That's what they get paid for, you know?". Frank also said that he would have not agreed to the screening if his physician had not mentioned it to him:

I probably wouldn't [request screening] because it's not something that's resting on your mind the whole time, you know what I mean? If you did that, Holy Christ. You'd go bonkers worrying about it then. (Frank-AC)

Education about CRC, I think it's gotta come from the top. . . . It's up to the doctors to talk about screening. (Mary-AC)

Oh, fear, it's always present, but it wouldn't, I mean it would not stop me. I have to pursue whatever. I mean, you have to believe your doctors. I think if your physician says get it, then get it done. And then afterwards, then you can make some decisions on your own. I want all the information. I think it's a partnership. (Sherry-AC)

We need to know about this. . . . I would say most people are unaware of it, totally unaware of it. Unless they'd had either a friend or family member who's affected by it, most of them would never think of it. Who wants a colonoscopy? Because we really don't know. And I guess, unless you're a healthcare professional there's no need for us to know all of this. We're depending on our doctor and our primary healthcare professional to keep on top of it and try and keep us healthy . . . that's what I'm looking for from my primary healthcare giver. (Evelyn-AC)

Increased tolerance for procedure – the “right thing to do.” A positive, “just get it done” attitude seemed to accompany many of the individuals who chose to screen. Individuals talked about doing the “right thing,” and they talked about a sense of relief when the screening was over. Participants openly discussed parts of the screening that they did not like, such as the diet preparation as well as the actual procedure, but these inconveniences did not prevent these individuals from being screened. If an individual decided that it was the right thing to do then nothing would prevent him or her from following through with the procedure.

Mike believed in screening and said that nothing discouraged him from having a colonoscopy; the procedure did not bother him at all. John claimed screening for him “just seems the right thing to do,” and many of his friends were lining up to get it done as well. This pragmatic approach to screening was shared by others in the study.

I can't imagine anything that would stop me from screening. No, I don't think anything would change my mind about that. (Mary-AC)

But no, I just chose to do it because I knew it was the right thing to do, and even though I didn't want to do it, yeah. (Carol-AC)

Just a matter of getting it done, and colonoscopy is something you should do. (Frank-AC)

Many participants shared their relief at getting the screening done.

It was positive because now you have more information yourself. They did not find any terrible thing in you. So that's all positive, a sense of relief. (Sherry-AC)

I don't look at it as an inconvenience. I look at it as they're helping me. You know, without the diagnosis how do they know what's going on inside of me? (Carol-AC)

Knowledge and I feel I'm healthy. Well, not healthier because you know, again you don't know what's in you. So now I know whatever it was is gone. (Mary-AC)

Peace of mind. (Mike-AC)

Peace of mind, definitely, peace of mind. (Evelyn-AC)

Individuals from both groups verbalized the need for preventive care and spoke about a mind-body connection. Participants who chose not to screen talked about prevention and attitude just as much as the group that screened.

Body is my temple. (Tom-DN)

Prevention is always a lot less money than the cure. Early intervention is always the best route to go. (Helen-AC)

Healthy mind, healthy body kind of go hand in hand. (John-AC)

Positive attitude can change the status of your health. Again this is from my observations, people who have a positive outlook on life, they just, they seem healthier. They're more active; they're just with it. (Evelyn-AC)

Self-reliance. Self-reliance refers to a sense of independence and independent decision making. All participants who chose to decline screening were knowledgeable about CRC and CRC screening. Many of them had read extensively about CRC and had decided screening was something they chose not to do at that time. The reasons given for declining screening were inconvenience, a sense that they were at low risk for CRC, and a reluctance to do the preparation for the test or undergo the procedure. Many of these participants gave a variety of reasons for declining screening, but all of them made this decision independently and chose to rely on their own judgment for their health choices.

Although three female participants initially reported that inconvenience was the reason they did not want to screen for CRC, two later suggested the reason for not screening was deeper than their original answer.

During an annual physical my GP [general practitioner] suggested a colonoscopy and every time that they phoned and said a spot was available, it wasn't conducive to my schedule so I never bothered with it. (Liz-DN)

I didn't want to stop my medication, and I wanted to go on vacation. I chose to go to California instead [of getting screened]. (Mira-DN)

I didn't feel like drinking all that yucky drink. (Teresa-DN)

Liz shared her story of many years ago when she underwent a sigmoidoscopy for unknown reasons. She explained that although the procedure itself was "not excruciating but really high on the uncomfortable list" it was the disrespectful interaction with staff that left her warning her friends to be careful if they had to go in for this procedure. She was angry that nobody had prepared her for what she should expect during or after the procedure. She felt ill-informed during the procedure and incapable of resuming the rest

of her day after the procedure. Between this experience and others that she had undergone, Liz developed her own sense of health. She sees her physician regularly but chooses what information and advice that she will accept.

Mira initially stated that she declined screening because she did not want to be inconvenienced. She explained she wanted to travel and not worry about missing an appointment. She also shared her story about being mistreated in the emergency room. Her unfortunate experience with the healthcare system left her deeply mistrustful and hesitant to simply follow medical instructions. She stated, “I need to be a participant in my healthcare.” She was not concerned with her physician’s reaction when she chose to decline screening. She was comfortable with her choice, and she felt that her physician respected her decision and did not try to convince her to screen. He has not mentioned screening to Mira again. She felt that she and her husband have a respectful relationship with her physician and she was comfortable with his care.

We give our two cents worth. I think he was a little annoyed when we first met him because we would go in and tell him what we thought we should have. But as time has gone by I think he appreciates us and we also appreciate him. He gets a little ticked off sometimes because he feels like he is treating our holiday and not us.

Almost as an afterthought, Mira talked about her year of recovery following her hospitalization and the amount of effort it took for her to begin feeling better. Her comment below suggested that screening would create even more discomfort for her.

I mean I’m just uncomfortable with getting into that [screening] when hopefully I won’t have any problem with it. No, I think it boils down to the fact that I thought I really don’t want to be feeling uncomfortable. I think that trauma [the bleed] just, you just think, “Why bother?”

Teresa also chose to decline screening because she did not want to do the preparation. She was certain that drinking the oral purgative would be distasteful and she

was not willing to go through this type of preparation for the procedure. She believed she is at low risk for developing CRC in light of her clear family history. She was comfortable with her decision and believed that it did not impact negatively on her relationship with her physician.

Tom had reservations about the procedure itself and did not believe a colonoscopy was particularly safe after his uncle died from a perforation. He believed that a colonoscopy posed an unacceptably high risk for perforation. He also shared his strong belief regarding the procedure: “I don’t have the wordings right but you understand. The anus is no place to be shoving things.”

Dave simply stated, “I wasn’t interested in doing it” when offered a colonoscopy. He talked about the negative influences such as perforation and discomfort with the procedure. When asked about other influences he might have, he shared his concern that the colonoscopy may uncover something and then he would have to deal with the findings: “I don’t know whether the stress of finding something would be as bad as the disease”. Dave agreed when he was asked if his preference was to simply not screen and to adopt the attitude “if something happens then it happens.” He added,

I think that’s probably the way I think a little bit. Because I would rather try and live healthy so that I try and keep away from these different diseases. I mean, I know I’m not completely immune to diseases but I think I live a pretty healthy lifestyle.

Intuition. A few individuals shared that they instinctively knew their bodies well and they would be able to sense if something were wrong with their health. These participants spoke about trusting their bodies and the importance of being in touch with themselves. Tom noted the importance of listening to his body and not believing everything the physician told him. He believed that he creates health by following a diet

of fresh garden vegetables and meat that comes directly from a farm. He consciously decreased his level of stress, got sufficient sleep, and enjoyed being physically active.

So, but all this you know is stored in the back of my mind, that even, you know you have to use your own instinct. The human body is the most amazing thing. It'll protect you and it'll protect itself. Give the body a chance to heal itself. Basically you have to know your own body. You have to have a lot of faith in your body to heal itself.

Liz also spoke about listening to her own body and her belief that people should use their own instincts to guide them with decisions about health matters. When she was diagnosed with osteoporosis she was quick to let her physician know that she was not going to take the prescription medication that he gave her. She stated that she uses her own judgment when she has a health concern: "So you have to use your own intuition and gut feeling and your sensibility about what you do."

Liz engaged in a very healthy lifestyle, tried to eat organic foods, and exercised daily. Both Liz and Tom spoke with great concern over the pesticides used in farming as well as the hormones fed to animals: "Anyway, I mean this is all part to do with my attitude with the medical profession."

These individuals took an active interest in their health and were involved in health promotion activities. They were not passive in their approach nor did they avoid screening because of a lack of commitment. They made personal choices in their daily lives to increase their health and they believed by living a healthy lifestyle they mitigated their risk of cancer.

Summary

Many different factors influenced an individual's decision to accept or decline screening. Both groups of individuals believed strongly that they had made the correct

decision for themselves, whether it was to accept or to decline screening. Both groups were comfortable and confident with their decisions.

A high level of trust in family physicians appeared to influence individuals to accept screening for CRC. A family history of CRC was also a strong influence to screen. When individuals had both influences, a high level of trust and a family history of CRC, screening rates were very high. Individuals who accepted screening shared many similar characteristics such as a healthy approach to life, a pragmatic approach to screening and a perception of a good relationship with their physician. Participants also shared similar opinions to one another and noted that although they wanted a respectful relationship with their physicians, they also wanted the physician to direct their care. These individuals generally indicated an increased tolerance for the discomfort of colonoscopies and have become advocates of CRC screening. When participants believed there was a high regard for their vulnerability they were very likely to screen.

Alternatively, negative previous experiences with the healthcare system heavily influenced participants to decline CRC screening. Most of the individuals initially reported reasons for not screening were related to inconvenience of the procedure, belief they were low risk for CRC or reluctance to undergo the preparation or the procedure. Almost all the participants revealed other reasons why they chose not to screen as the interview progressed. These reasons were based upon trust, or more accurately, mistrust of the healthcare system and fear. One participant's fear of finding cancer left him unwilling to pursue screening and another's fear of the unknown and mistrust in the system prevented him from screening. Through negative experiences these individuals have learned to become advocates of self-reliance. When participants believed there was

disregard for their vulnerability they were unlikely to screen. These individuals were not passive in their avoidance of screening. They were purposeful, both in their choice to decline screening, as well as their approach to healthy living. They chose to eat healthy, exercise daily, and decrease their level of stress to mitigate perceived risk of developing CRC. These individuals embraced primary prevention and believed they were low risk.

Perceptions of patient–physician relationships characterized participants’ need for an open and communicative interaction with physicians. Bad experiences with the healthcare system have led some individuals and their families to mistrust the healthcare system and in some cases their HCPs. In the final chapter, these findings will be discussed as they relate to participants’ decision-making process when considering CRC screening.

Chapter 5: Discussion

In this chapter, I provide an overview of how participants in this study presented their thoughts on CRC screening with the purpose of increasing knowledge about the decision-making matrix for people when considering the procedure. An overview of CRC showed this form of cancer is the second leading cause of cancer deaths in Canada, and despite high 5-year survival rates of 90% if CRC is detected and treated early, screening rates remain low (Canadian Cancer Society, 2012b).

In most cases, CRC begins as one or more small, benign polyps that live on the inner wall of the rectum or colon. These polyps can take up to ten years to become malignant and do not provide any early signs of their presence (Kronborg & Fenger, 1999). Individuals can live for years without any symptoms such as rectal bleeding, abdominal pain, or a change in bowel habits; however, once these symptoms appear, the 5-year survival rate drops significantly (Alberta Cancer Board, 2007). More than 90% of people who develop CRC are aged 50 and older, identifying the need for screening in this age group (Alberta Cancer Board, 2007). Although four screening modalities are recognized for CRC screening, the primary approaches used in Southern Alberta are the FOBT and the colonoscopy. Public awareness campaigns have been successful in educating Canadians as to the importance of CRC screening; however, there remains a general lack of knowledge around screening. People continue to misunderstand the need to screen before they become symptomatic (Canadian Cancer Society, 2012b).

In this chapter, an overview of the study findings and the related model are discussed and recommendations for current practice are presented as well as

recommendations for future research. Limitations of the study are also discussed, followed by reflection on the study and the overall conclusions.

Overview of Study

The study was conducted because of my perception that screening rates for CRC were low in Southern Alberta. This situation is concerning because CRC is the second leading cause of death from cancer in Canada (Canadian Cancer Society, 2012b) and screening is the best means to detect the disease. If detected early enough, treatment for CRC offers a very high success rate. This led me to wonder, if a simple screening procedure can offer such benefit, then why is the rate of screening so low? I engaged in this research because developing a better understanding of the factors that contribute to an individual's decision about participating in screening for CRC should inform measures to increase uptake of screening procedures, thereby increasing the frequency and effectiveness of treatment. Screening was defined as completing a colonoscopy following a physician's recommendation or a positive result on a FOBT.

Using Pender's health promotion model (Pender et al., 2002) as a guideline, a qualitative naturalistic inquiry was chosen to address the following research questions:

1. What factors influenced the decision making process for individuals who committed to CRC screening?
2. What factors influenced the decision making process for individuals who declined CRC screening?

Pender's model was applied as a lens to CRC screening in an effort to better understand the decisions individuals make about CRC screening. This model was specifically chosen because of its emphasis on the multidimensional nature of individuals and how they

interact within their own interpersonal and physical environments in pursuit of health (Pender et al., 2002).

Invitation letters were sent to potential participants by a CRC screening clinic in Southern Alberta after approval was granted by the relevant research ethics review boards. Purposeful sampling, as described by Patton (1990), was followed; individuals in the average to moderate risk categories, as described by the Alberta Cancer Board (2008), received letters. Further solicitation through notices posted in community centres was used to recruit individuals who chose to decline screening to enhance the richness of the data. In all, 15 individuals were interviewed between September of 2011 and April of 2012. The interviews were 60 to 90 minutes in duration and were recorded and transcribed verbatim. Analysis of the data occurred simultaneously with data collection and was guided by Marshall and Rossman's (2006) seven phases of research, in which the researcher organizes the data, immerses in the data, codes the data, generates categories and themes, offers interpretations through analytic memos, searches for alternative understandings, and writes the report for presentation. The findings led to the development of the overarching theme of regard or disregard for vulnerability and the three subthemes of relationship, motivation, and human agency. The overarching theme and associated factors are described in detail in the next sections.

Utility of Framework or Model

Pender's health promotion model (Pender et al., 2002) was useful for this study because of its focus on three areas: individual characteristics and experiences, behaviour-specific cognitions and affect, and behavioural outcomes. This model also includes interpersonal and situational factors to explore whether or not an individual has the

support or ability to adopt new health behaviours. This model was deemed most appropriate for use in CRC screening because it includes both interpersonal and situational factors that many authors have shown to be instrumental in whether or not an individual chooses to undertake cancer screening (Gorin, 2004; Honda & Gorin, 2005; McCaffery et al., 2002; Subramanian et al., 2004). Although this model was useful at the beginning of this study and assisted in developing a framework for the interview guide, it fell short while examining the findings. Pender's model is linear in structure and the predictive outcomes are based upon modifying behaviour. For example, Pender's model predicates that if health is a priority to an individual, then he/she will act in adopting health prevention. Similarly and appropriate to this study, if an individual believes colonoscopy prevents CRC, then he/she would accept the procedure. Pender's model clearly does not support the findings from this study whereby participants were active in health promotion but chose to decline screening. In other words, they believed but they did not accept the procedure. Additionally, Pender's model does not adequately capture the relationship of the influencing behaviours. Pender's model is absolute in that one behaviour can have a predictive outcome that is not in relation to other influencing factors. Personal stories recounted by the participants in this study were often related to other factors. Also, the participants in this study identified that screening habits could change over time. Pender's model was not useful to show how changes could be shown over time. Therefore, the Vulnerability Model (Figures 1 and 2) were developed to more accurately depict relational influences that can change over time.

Regard or Disregard for Vulnerability

The overarching theme was the regard or disregard for vulnerability.

Vulnerability is explored in various ways in the literature. For example, Clarke and Driever (1983) addressed vulnerability as being the subjective perspective of the individual. They believed a person was vulnerable when he/she believed himself/herself to be vulnerable. Vulnerability in this study was in terms of feeling safe in relation to another, the HCP most often. Sellman (2005) discussed vulnerability in nursing practice as well as in more general terms. He explored a broader perception that all people are vulnerable in various degrees. The broader definition of vulnerability as discussed by Sellman (2005) was not congruent with this study's findings. Vulnerability in this study referred to whether or not an individual believed the health care provider had regard or disregard for his/her vulnerability as a person and most accurately explained the relationship of the subthemes and elements. Also, this study explored how an individual can view colonoscopy as a procedure that makes them susceptible to physical injury such as perforation or susceptible to emotional injury such as facing cancer or an invasive procedure. Vulnerability in this study was more multifaceted. For example, screening for CRC most often occurred when participants had a family history, felt they could trust their HCP and there was a confidence in the healthcare system. Conversely, lower screening rates were associated with mistrust of the HCP and the healthcare system or both.

Vulnerability is not defined clearly in the nursing literature except in adult protection when describing adults requiring community care because of disability, age, or illness (Abley, Bond, & Robinson, 2011; Department of Health, 2001). Vulnerability has

been described as a condition of being susceptible to harmful agents, either actual or potential (Scanlon & Lee, 2006). Other authors described vulnerability in a variety of ways, including being human, an emotional response to being in a specific situation, susceptibility to harmful agents, and having certain characteristics such as physical, psychological, or social conditions (Abley et al., 2011; Malone, 2000; Scanlon & Lee, 2006; Stenbock-Hult & Sarvimäki, 2011). Vulnerability has also been described as having two distinct aspects: etic and emic vulnerability (Abley et al., 2011). Etic vulnerability refers to an externally evaluated risk that is determined by others, in this case by someone in the healthcare field. Emic vulnerability refers to an individual's perception of his or her risk level, which is usually based on the individual's past experiences (Abley et al., 2011). For this research study, vulnerability referred to whether or not the participant believed their HCP was respectful of them as human beings.

In a patient–physician relationship, vulnerability is both literal and metaphorical. Literally, a patient is physically vulnerable while exposed during examinations and procedures that include the possibility of physical discomfort or harm. Metaphorically, a patient is vulnerable while exposing anxieties and fears during an examination that allows the possibility of personal judgment or critical messages. People want to be validated and heard and not be minimised or dismissed. They could be facing a life threatening disease, which could be very difficult to cope with and they have to talk about embarrassing areas of their body. Many authors spoke about vulnerability being directly related to trust as in when one is most vulnerable, a high level of trust is required (Lupton, 1996; Shenoliker, Balkrishnan, & Hall, 2004; Sokolowski, 1991; Sulmasy, 2006). In fact, trust seems to be irrevocably linked to vulnerability.

According to Shenoliker et al. (2004), the experiences of critical medical situations such as hospitalizations and surgery are significant because they affect trust and because the role of vulnerability for patients is directly related to the psychology of trust. Shenoliker et al. identified the increased need for trust, particularly when people were most vulnerable. Several researchers found that when individuals felt an increase in their vulnerability their need for trust in others increased (Lupton, 1996; Shenoliker et al.; Sokolowski, 1991; Sulmasy, 2006). These authors also found a sense of vulnerability could lead to distrust when a patient's needs were not met. Strong associations were found between the patient's experiences with medical care and his or her level of trust in the medical profession and trust in the primary physician. Shenoliker et al. found positive correlations between patients' level of trust in physicians and being hospitalized as well as patients' level of trust in physicians and their belief of being assessed for a serious condition. These associations are congruent with the findings of this study. Participants in this study spoke about their experiences, both positive and negative, and how these experiences directly contributed to their level of comfort in accepting or declining CRC screening.

Sokolowski (1991) and Sulmasy (2006) equated vulnerability to risk. Anyone who presents themselves to a HCP leaves his or her person open to risk and, therefore, vulnerable. Sokolowski maintained that individuals who seek assistance from professionals such as physicians, lawyers, or teachers are subjected to judgment from the professional. This personal judgment of the individual creates a sense of vulnerability. Lupton (1996) indicated vulnerability from a patient's perspective is associated with the way information is exchanged. A common scenario is one in which an HCP shares

scientific or technical information with the patient. In this situation, the HCP becomes the expert, which defaults the patient to role of the novice, and hence the patient is placed in a position where he/she is vulnerable. In this current study, participants stated they were given CRC information by their HCP and were encouraged to screen. Many participants spoke about being given the information in a matter-of-fact way, and none of the participants spoke about feeling as if they were novices. A few participants spoke about their HCP as being the expert, and these participants shared their beliefs to simply follow the directions of the HCP. None of the participants spoke about feeling an increase in vulnerability when they were given medical information by their HCP.

The literature on vulnerability was congruent with my findings. Vulnerability referred to whether or not patients believed their HCP was aware of and took into consideration their sense of vulnerability. The candour and the emotion of the participants spoke volumes about the significance of their experiences with HCPs and the healthcare system, which ultimately influenced their decision to screen.

Relationship, Trust, and Communication

Given that participants' sense of vulnerability was tied to their decision-making process to accept or decline CRC screening, what factor most influences the regard for vulnerability? There is no simple answer because regard for vulnerability is complex and multilayered. Some of the influences include trust, communication, and depth of relationship. Many participants spoke of trust based upon communication. Participants wanted the opportunity to speak with their HCP and spend some time in the office to have their questions answered. Participants spoke about an increased level of trust with their HCP when they had the opportunity to have their questions answered. When

participants mentioned trust, they described it in the context of communication. When participants mentioned mistrust, they also described it in the context of communication. The decision to screen was based upon whether or not the participant felt there was regard for their sense of vulnerability.

Mistrust was associated with a disregard for vulnerability, and trust with a regard for vulnerability. Mistrust or a lack of trust in the healthcare system was expressed in several ways, including awareness of medical errors. Entwistle and Quick (2006) explored the level of patients' trust in HCPs given their increased awareness of iatrogenic harm. They identified the following four observations about trust (pp. 398-399):

1. Trust involves risk (those who trust run the risk of letting those they trust near things that they care about);
2. Those who trust give those whom they trust some discretion as to how their trust should be fulfilled, and are willing to forgo an immediate accounting of whether and how this is done;
3. Trust facilitates cooperation and allows people to inhabit a less threatening world in which they need not plan for every contingency; and
4. Trust and distrust are self-confirming (those who trust tend to interpret favourably the behaviours of those they trust and may also encourage trustworthy behaviour).

Entwistle and Quick (2006) also spoke about trust being neither infinite nor a sign of dependency. Trust should not be equated with dependency nor is it static. Trust moves along a continuum and can change over time and with experience, a finding that was reflected among the participants. One male participant had a high level of trust with his

physician. However, once this physician retired and the participant had a new family physician, he expressed unhappiness with the new relationship and a lack of trust.

Another participant decided that her previous physician did not listen to her concerns and she lost trust in him. She decided to find another physician. She now believes she has a good relationship with the new physician and consequently perceives a high level of trust.

Individuals most likely to refuse to screen were the ones who expressed mistrust in HCPs, the healthcare system, or both. The fact that trust can change over time is very encouraging because it implies the possibility that trust can be rebuilt and invitations to screen may at some time in the future be accepted. The challenge will be to recognize the individuals who do not trust their HCPs or the healthcare system and engage them for the purpose of fostering better relationships.

Osorio (2011) described how patients' interactions with physicians have changed over time from genuine relationships to simple encounters as a result of new approaches to medical practice and the roles of insurance and pharmaceutical companies. Osorio suggested that the ideal relationship between patient and physician is based upon trust and physician availability, and that a more transient society has contributed to a relative lack of trust and disconnectedness. In this study, some participants shared they were unhappy with their new family physician since their previous one retired. Other participants reported not trusting their HCP because they felt they were not given individualized care or their concerns were not fully addressed in their brief interactions with the physician. Participants expressed that duration of interaction or communication was important to gain trust. When personal interaction or communication was perceived to be absent, participants experienced diminished trust.

Fitzpatrick, Friend, and Costly (2005) studied trust among men and women with their HCP. This study found men and women differed in their perceptions and understanding of trust. Both groups identified honesty as an important contributor to trustworthiness. However, they found that women linked honesty with capability and their physician's ability to put the needs of the patient first. If a physician was unable to help them, women defined honesty as the physician's ability to refer them to someone else but remain as an agent of their care. Women identified immediate action and continued support as important factors for trust, and they appreciated that they were not left feeling helpless or abandoned.

Fitzpatrick et al. (2005) found that men, on the other hand, had a more general definition of trust. Men believed the physician was trustworthy if he or she demonstrated openness and was frank in discussions with them. Fitzpatrick et al. (p. 6) also noted that men identified a sense of genuineness from their practitioner, by being "decent guys" or "down to earth", as an important factor in their personal connection with the physician. Men also identified physicians who were unable to make this connection with them and described their sense of relational power imbalance, referring to these physicians as "God like". Two men in my study spoke about their physician in a similar manner and indicated that their relationship was not as good as it could have been, nor did they always do what their physician recommended. Neither of these men agreed to screen for CRC. Had the relationship with their physician been perceived more favourably, perhaps these participants would have accepted screening.

According to Saha and Beach (2011), patient-centred communication is a specific skill set and behaviour that physicians use to increase patient relationships. In that study,

patients rated videos of physicians recommending bypass surgery. These authors concluded that physicians who exhibited greater communication skills could enhance screening rates (Saha & Beach, p. 391).

Family History, Media Influences, and Motivation

Motivation propels individuals to do something. The participants in this study were influenced to choose screening by family history and media influence. Participants were strongly motivated to screen for CRC when there was a family history of CRC and they remained motivated to screen regularly if they had a personal history of CRC. Family history became an educational tool in which awareness of CRC was forced to the forefront.

Media is an even more powerful educational tool today than it was in the past given the rise of the Internet and social networking sites. The media has had a profound effect on educating the public on iatrogenic injuries, medical mistakes, and screening. Perhaps more thought should be given at the administrator level of health boards to further embrace and use the media for the purpose of promoting good practice and educating the public on the most recent practices to ensure a healthy population. What better way to combat negative media than to promote positive media? Those who screened did not recount negative health care experiences but those who refused to screen readily did.

Intuition, Safety, and Human Agency

Human agency is the capacity for human beings to make and execute personal choices. While it is clear that all participants made a choice to either screen or not screen, the degree of physician interaction or influence is not so clear. Without consultation with

a physician, patients may choose to try to navigate the healthcare system relying on their own ability to do what they think is best. Alternatively, patients may consult other physicians who they feel are more understanding. In either case, many questions arise: How well do we know our own bodies? How well do we know what is best without interaction with a physician? How can we decide whether or not a procedure is safe? Nine of 15 participants responded that they felt they were responsible for their screening, but later in the interview all of these participants acknowledged that the physician was responsible for their screening. Many of these participants wanted to make independent decisions regarding CRC screening, but realized they needed some assistance from their physician either for information or referrals. This further reinforces the need for a positive relationship.

Intuition is defined as “the ability to acquire knowledge without the use of reason” (“Intuition,” 2012b, para. 2) or “the act . . . of knowing or sensing without the use of rational processes” (“Intuition,” 2012a, para. 2). Some participants in this study spoke of intuition as awareness and understanding of their own body. These participants described their innate ability to know if they had health issues, such as CRC, occurring within their body. The individuals who identified intuition as an important part of their life and health were also the individuals who had negative health system experiences and, therefore, were mistrustful of medical advice. To address those who claimed to have intuitive knowledge of their body, HCPs must establish if there is a sense of mistrust or misunderstanding. If there is a sense of mistrust, then the cause of the mistrust must be addressed. Mistrust can easily occur as a result of a medical error or when the patient’s needs are not met. One participant recounted an unpleasant sigmoidoscopy but stressed it

was the disrespectful interaction with the staff that caused her to take health matters into her own hands. On the other hand, several participants spoke of the pleasant interaction with the staff during the screening process as a positive factor in their decision to screen.

The Canadian Nurses Association (2008) has a *Code of Ethics for Registered Nurses*, developed for the purpose of providing assistance for ethical practice of working through challenging situations with patients and families. Two Canadian scholars, Doane and Varcoe (2007), have authored a book on relational nursing and suggested using communication skills to establish a personal connection. Relational questions can also assist nurses to navigate the highly complex nature of communicating and working with patients and families. Some of the questions Doane and Varcoe suggested the nurse ask of him or herself included: “What circumstance have brought us together? What circumstances hinder collaboration? What are the circumstances of the other? What circumstances shape their experience? How is my context shaping my perceptions? What is possible in these circumstances? What is knowable?” (p. 266). Doane and Varcoe’s questions give nurses the opportunity to reflect on their own perceptions and how patients or their families understand their situations.

A radical shift has occurred in healthcare over the past half century, and medical practice has moved away from a paternalistic approach toward one that respects the patient’s capacity to make decisions about health (Chin, 2002; Pellegrino, 1994; Scherger, 2009). Self-reliance refers to one’s sense of independence and capacity for independent decision-making. All participants who chose to decline screening were knowledgeable about CRC and CRC screening. Many of them had read extensively about CRC and chose not to undergo screening because of inconvenience, a belief that

colonoscopy was unsafe, a sense they were at low risk for CRC, and a reluctance to do the preparation for the test or undergo the procedure. More striking, however, is that of the five participants who declined screening, two later recounted traumatic personal healthcare experiences that left them thinking, “Why bother?” Those participants who trusted their HCP and spoke highly of the healthcare system tolerated the inconvenience and discomfort of the colonoscopy, found the support required to take a day off work, and arranged a ride to the clinic. Those who expressed a lack of trust in their HCP or a lack of trust in the healthcare system expressed their belief the procedure was unsafe. I wonder if patients who declined screening would have changed their decision had they been approached by a nurse who asked relational questions to understand the patient’s perspective. One of the women in this study was informed she needed to have a yearly colonoscopy owing to polyps found during the initial colonoscopy. However, she refused further CRC screening after experiencing a painful procedure because she did not receive any sedation. Five years later when she was in for a physical exam, her physician asked her about her follow up with CRC screening. She admitted she had never gone and, after a lengthy conversation and being assured she would receive sedation, she agreed to screen and has continued ever since. In this case, a participant who had declined screening changed her mind and accepted screening because her concerns of pain and discomfort were addressed and she felt certain she would be comfortable during the procedure.

A concept related to healthcare is patient autonomy which confers on individuals the right to make informed decisions, even when their decision conflicts with their physician’s advice. Patient autonomy is counterintuitive to the paternalistic, biomedical

model that has been the primary focus of medicine and the way in which our healthcare system has operated for years. Although patient autonomy is a relatively new concept in healthcare, it has gained popularity over the past 25 to 30 years (Entwistle, Carter, Cribb, & McCaffery, 2010; Pellegrino, 1994; Quill & Brody, 1996; Williams & Quill, 2004). The debate continues regarding which system is better, paternalism or autonomy, and more importantly, whether or not autonomy is attainable (Chin, 2002; Pellegrino, 1994; Quill & Brody, 1996; Williams & Quill, 2004). Involving patients more in their healthcare decisions is plausible and possible, but complete autonomy or an approach based on intuition alone is impractical and minimizes medical education and medical science advances.

Safety was about participants feeling secure with the procedure and feeling they could trust the staff performing the procedure. Safety was interrelated with trust and confidence but it differed with each individual's experience. When participants felt there was little risk to the procedure and they were safe, they screened for CRC. Participants who felt there was a heightened risk of injury, as in the case of the individual whose uncle died from a bowel perforation, chose to decline screening. Other participants felt any procedure carried a risk of injury, and they alone would evaluate whether or not to accept the risk of complications. Misdiagnosis, medical instruments being left in people during surgery, and bowel perforations have all led participants to perceive their safety was not ensured.

Patient safety has been identified as a concern in the medical community. A landmark report titled *To Err is Human* was published by the Institute of Medicine (1999); this report identified the magnitude of safety concerns in healthcare. The Institute

of Medicine identified that as many as 98,000 people die annually from medical error in the United States. The media campaign created widespread public awareness and American policy makers began a quest for a comprehensive and nationwide improvement plan for patient safety (Leape & Berwick, 2005). Patient safety has since become a focal point for healthcare leaders, media, and patients. The Institute of Medicine suggested errors made in medicine were mostly due to system, rather than individual failures. Leape and Berwick (2005) claimed that the culture of medicine actually works against the development of safety practices. These authors argued that the training of a physician is based upon perfection; the inability to admit mistakes leads to cover ups. Physicians may learn from their own mistakes, but they do not share this learning, and Leape and Berwick argued that sharing these mistakes allows others to learn. Although this campaign and the resulting policy changes reflect good practice, I believe one of the most important aspects that came out of this study was the importance of transparency and speaking with patients if errors occur. Being able to partner with the patient for an increased level of safety and better care will likely lead to a better relationship and an increase in trust.

Growing awareness of medical errors prompted Keopke, Swift, Ferrer, and Miranda (2000) to examine the willingness of the public to take specific preventive actions to ensure their safety. Keopke et al. suggested individuals would be willing to keep their physician informed of new events and ensure they received proper information about their care, but they would not be comfortable challenging professional authority. For example, these individuals were uncomfortable asking healthcare workers who had direct contact with them whether or not they had washed their hands. This reluctance to

challenge professional authority was also apparent in the current study. One participant agreed to prostate screening because he did not feel he had the choice to say no. When this same individual was advised to screen for CRC he agreed while he was in the office, but once he left he decided against undergoing the screening procedure. This participant indicated a lack of trust in his physician, but his unwillingness to share his decision for screening may have also signified his discomfort in challenging authority, which may have been present because of a lack of connection with his physician.

In this study, the participants who chose to decline screening were the only ones who mentioned safety concerns. These participants spoke of worrying about the procedure and possible complications as well as medical errors or misunderstandings reported by the media. Peters, Slovic, Hibbard, and Tusler (2006) examined the role of worry and perceived risk in individuals within the healthcare system and found that personal experience with medical errors was not related to worry or the patient's perceived likelihood of another medical error occurring. For some patients, elevated concern did not occur unless it was for the same medical error as the one previously experienced (Peters et al.). These authors also suggested patients may not worry about errors because they believe mistakes are not preventable. Further exploration of the association between medical errors and patients' decisions regarding screening is warranted.

Recommendations for Practice

The study findings provided valuable insights that have the potential to inform and guide clinical nursing practice. Participants clearly identified the importance of good relationships between patients and HCPs. Communication with and trust in the physician

as well as confidence in the healthcare system had a profound effect on participants' decisions to accept screening. Even more profound were the cases in which individuals declined screening because the patient-physician relationship was perceived to be weak or superficial. The healthcare team's communication skills are, therefore, of vital importance to the patient. Improved interpersonal communication leads patients to believe their HCP has a high regard for their vulnerability.

To understand the impact of this relationship HCPs need to examine their practice and ask themselves difficult questions such as: How are our actions perceived? What do we communicate to our patients? Do we provide clarity and respectful direction to our patients, or do we add to the chaos of the diverse and confusing system of medical care? Do we respectfully engage patients in a collaborative process of information assessment and decision making?

The first step in improving CRC screening rates is to educate and promote awareness about the importance of communication, not only for the relationship with the patient, but also for his/her safety. Offering opportunities to increase their knowledge of relational practice and nursing obligations would allow nurses a safe venue to voice their concerns and their observations. An ongoing class or even a few workshops could provide some much needed support to nursing staff to learn ways to improve communication and service. Increased nursing demands, limited resources, and the multigenerational workforce have all provided challenges for HCPs. Understanding the way relational inquiry can support and assist nurses to practice in today's busy time would be beneficial to both the nurse and the patient (Doane & Varcoe, 2007).

An article in the *Boston Globe* in July 1995 described the relationship between a newly diagnosed lung cancer patient, Ken Schwartz, and his HCPs. Although the HCPs' daily workloads and time constraints made it difficult to address each patient, Schwartz described how compassion goes a long way in that even "the smallest acts of kindness made the unbearable bearable" (Abbasi, 2012, p. 93). Accepting CRC screening subjects the patient to the possibility of a cancer diagnosis. While the odds are that early screening allows a favourable outlook, cancer is cancer, and this can be terrifying for the patient. Ken Schwartz succumbed to cancer but not before founding the Kenneth B. Schwartz Centre at the Massachusetts General Hospital, dedicated to helping bring compassion to the process to aid in healing (Abbasi, 2012). I believe genuine compassion and empathy in caregivers will lead to improved interpersonal communication, which may promote greater confidence in patients, which will encourage them to accept CRC screening.

Recommendations for Future Research

Further research into the decision making process for individuals who choose to decline screening may provide more opportunity to understand this phenomenon in southern Alberta. Although this group of individuals had been difficult to recruit, perhaps researching their decision making process would be more successful in gaining participants.

This study lacked representation from any minority group in the local area. Southern Alberta has a diverse group setting of Hutterites, First Nation Aboriginals, and Low German-speaking Mennonites to name a few. Research on CRC screening identified low rates of commitment in American Indians, people of Asian, Latino, or Hispanic ethnicity, and African Americans (Baron et al., 2008; Beeker et al., 2001; Gorin, 2004;

Honda & Kagawa-Singer, 2006). The lack of minority participants in this research reflects current literature, and the influence of the participant group on commitment to screening remains unknown. Further research of CRC screening rates for minority groups in southern Alberta may provide some insight into ways to reach these groups.

Limitations of the Study

This study was designed to learn more about patients' decision-making process with regard to CRC screening. A limitation of this study was the small number of participants, particularly those who declined colonoscopy. In addition, participants were recruited from only one clinic in southern Alberta. Outreach and mobile services are not available, limiting the group of potential participants to those individuals who had access to the clinic.

Finally, my former role as the health educator in the clinic and my own biases and perspectives can be viewed to have both limiting and facilitating effects on the outcomes of the study. Limiting effects include being a nurse and perhaps viewed as part of the problem with healthcare. Facilitating effects include being able to take the time to listen to participants' stories, particularly the negative experiences, and provide a safe outlet for people to express themselves without being judged.

Reflection

When I conceived this study, I had recently been hired as the nurse educator for a new CRC screening program in southern Alberta. All the research surrounding CRC at the time showed dismal screening rates across Canada, in Alberta, and particularly in southern Alberta. I was motivated to find out how individuals perceived screening and to discover the reasons behind their decisions to accept or decline screening for CRC.

Although I left that nursing position prior to data collection, I remained committed to learning more about patient decision-making and the factors that influenced the process.

Having graduated from a nursing program more than 20 years ago, I was most familiar with the biomedical model in a hierarchical context: physicians directed care, nurses followed directions, and patients listened to all HCPs. I worked in acute care hospital units in which patients were supposed to follow directions given to them by the staff. When patients rejected the care plan or treatment they were receiving, they were commonly seen as problem patients. Critical information was not always shared with patients and their perspectives were frequently misunderstood. In short, I practiced nursing in an environment in which the HCPs believed themselves to be in charge and made decisions based upon algorithms, accepted practice, and orders.

Thankfully, attitudes in hospitals began to change, and the patient became the focus of care. Although many nurses now practice in a patient-centred system, I would be wrong to suggest this is always the case. In fact, patient-centred care is too often missing, even though this is what the nursing profession advocates as best for the patient. It is the nurse's job to respect patients, recognize the importance of listening, and be an advocate. Patients frequently come well prepared with information they have found on the Internet and they have an increased awareness of their own rights; however, HCPs continue to exert pressure for patients to conform and not to question or challenge HCPs' suggestions. In order to fully support patients, HCPs need to create an environment in which patients are comfortable communicating their needs to their HCPs. To provide patient-centred care, HCPs must question the predominant paradigm of influences and

question whether or not they are providing patients with care in the most respectful and helpful manner.

This study has certainly opened my eyes and provided me with a way to reflect and see things from the patient's perspective. I am very grateful for this experience and all the learning I can take away from it. I only hope I can apply this knowledge for improved health for all members of the community.

Conclusion

As individuals become increasingly knowledgeable about their own health, HCPs can respectfully work alongside them to improve their health status. Healthcare providers are educated and expected to be capable of developing therapeutic relationships with patients. These practitioners must demonstrate integrity and ongoing quality improvement to earn the confidence and respect of the community.

I have learned firsthand how negative medical experiences have remained with individuals, sometimes lasting many years after the event. I have learned how these negative experiences shape the perceptions and inform present day decisions of these individuals. These interviews have also uncovered some encouraging news, that many individuals are content with their HCPs and feel a sense of connection with good communication and a high level of trust.

People are now coming to medical appointments prepared with knowledge and interest. Many of them want and expect to participate in their healthcare choices. HCPs need to engage these individuals as a partner in their care and develop a respectful, transparent, and trusting relationship. HCPs need to take the time to answer patients' questions and speak to their concerns. When individuals do not agree with HCPs'

suggestions, the HCPs need to dig a little further to understand the reasons why patients choose to accept or decline treatment. This type of approach takes time and effort, but it is the right and humane thing to do for patients.

Misunderstandings with HCPs and the healthcare system will continue to occur but HCPs can learn from mistakes and be accountable to patients. Perhaps this persistent lack of trust will be an opportunity for HCPs to engage individuals in more thoughtful and respectful communication.

Trusting relationships and increased communication can save lives. HCPs need to listen to what patients are saying and communicate with them in a way that meets their needs. Many nurses entered the profession to be able to make a difference and to connect with patients. With improved communication and understanding of what patients' needs are, HCPs can do the job they so desperately want to do. Experiences with the healthcare system, both good and bad, resonate with patients and stay with them long after the incidents. Nurses have the opportunity to make a difference. One bad day for an HCP can alter patients' perceptions of the entire system. Nurses can positively or negatively impact patients' decisions to engage in health promotion activities through understanding and regarding people's sense of vulnerability. "As a human condition, vulnerability connects nurses and patients" (Stenbock-Hult & Sarvimaki, 2011, p. 32).

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Appendix A: Semi-Structured Interview Guide

1. **Did you participate in the colorectal cancer-screening program?**
YES What type of screening did you agreed to? _____
NO Can you tell me why you did not screen for CRC?

2. **Were you ever diagnosed with CRC?**

3. **Do you have any family members that were diagnosed with CRC?**

4. **Can you describe to me the influence/impact that CRC has had on your life?**

5. **How many screening options for CRC were you aware of?**
 - Were you aware of the colonoscopy? YES NO
 - Were you aware of the FOBT? YES NO
 - Were you aware of barium enema? YES NO
 - Were you aware of the sigmoidoscopy? YES NO

6. **How did you learn about these screening options?**
 - Physician? YES NO
 - Personal Study? YES NO
 - Media? YES NO
 - Family? YES NO
 - Friends? YES NO
 - Other? _____

7. **Do you know anybody affected by CRC?**
 - Can you tell me about their experiences?
 - Do you think their experience influenced you in any way? Could you tell me about this?

8. **Can you tell me about what may have influenced your decision whether to get screened or not?**
 - Did your physician influence you? YES NO
 - Did a family member? YES NO
 - Which family member?
 - Did a close friend? YES NO
 - Did the media have any influence on your decision? YES NO
 - Time? YES NO
 - Transportation?
 - FEAR?
 - Discomfort?
 - Other? Specify:

9. **Can you tell me if you have participated in any other Cancer health screening? (PAP, prostate, breast)?**

- What screening exams have been offered to you?
- Did you agree to go for screening? YES NO
- Would you describe your experience as being positive? YES NO
 - Why?

10. Can you tell me if your previous health screening affected your decision to screen for CRC? YES NO Why?

11. Can you tell me about your experience with the CRC screening program?

- Positive? YES NO
- Meet expectations? YES NO

12. What does colorectal cancer mean to you?

13. Can you tell me about the risk factors of CRC?

- Are you aware that family history will be an increased factor? YES NO
- Are you aware that age increases the risk? YES NO
- Are you aware that diet influences the risk factor? YES NO
 - About your diet, do you?
 - Eat fresh fruits and veggies daily (5-8 servings)? YES NO
 - Eat red meat? #servings/week 1 2 3 4 5 6 7 8
 - Eat fish? #servings/week 1 2 3 4 5 6 7 8
 - Fast food? #servings/week 1 2 3 4 5 6 7 8
- Do you participate in regular exercise (min 3x/week for 30 minutes)?
 - YES NO
 - # sessions/week? 1 2 3 4 5 6 7 8

14. How do you know when you are feeling healthy?

- What is your definition of health?
- Can you describe for me what “healthy” looks like

15. How do you know when you are not feeling healthy?

- Describe your definition of unhealthy
- Describe what ‘unhealthy’ looks like

16. Can you tell me about your health status?

- How would you describe your health?
- Do you smoke now or have you ever smoked in the past?
- How often do you see your physician?
- Regular checkups? Or only when something is of concern?

17. Do you believe that you have the ability to change the status of your health?

- Can you describe how for me?

18. Do you consider your family in general to be healthy?

- How does your family embrace health?
- Can you describe what 'healthy' looks like in your family?

19. Do your family members believe that they have the ability to change the status of their health?

- Can you describe how members of your family improve the status of their health?

20. Do you consider yourself a risk taker?

- Do you always wear a seat belt?
- Are your immunizations up to date?
- Prescriptions?

21. Do you consider your family to be risk takers?

- Seat belts?
- Immunizations?
- Prescriptions?

22. Did anything about CRC screening bother you?

- Preparation
- Diet
- Procedure
- Time off
- Time involved
- Apprehension?
- Fear of? Finding something?
- Not comfortable with medical procedure?
- General / physical discomfort?

23. Would anything change your decision?

24. Do you think CRC screening benefited you?

- Can you tell me how CRC screening was helpful to you?

25. Earlier, you mentioned that you had a FOBT.

- Did you find the FOBT difficult to do? Why or why not?
- Can you tell me if there is anything you like about this test?
- Can you tell me if there is anything you do not like about this test?

26. Earlier, you mentioned that you had a colonoscopy.

- Can you tell me if you found anything positive about having the colonoscopy?
- Can you tell me if you found anything negative about having the colonoscopy?
- Did you find having a colonoscopy uncomfortable? Why or why not?

27. Do you have a preferred method of CRC screening?

- If yes, what is it? Why?
- If no, can you tell me why?

28. Would you recommend CRC screening to your family or friends?

- If yes, why?
- If no, why not?

29. Who do you believe is responsible for CRC screening?

- Can you tell me who you believe is most responsible for their health?
- Can you tell me who has the ability to create health in their life?
- Does your family share this view?

31. Can you tell me about the relationship that you have with your health care provider?

- Do you have a regular family doctor?
- Have you been seeing this physician for a long period of time?
- How would you describe your relationship with him/her?
- Do you have a great deal of trust in your physician?
- Did this relationship have anything to do with your decision to screen?
- If your physician did not mention screening, would you have requested it on your own?

32. Can you describe some of the positive things about CRC screening that might motivate you to go for other health screening?

33. Can you describe some of the negative things about CRC screening that might discourage you from screening?

34. In your opinion, how can health professionals make CRC screening more patient-friendly?

Appendix B: Letter of Invitation

Gayle Knapik, RN, BN
[telephone number]
Email: [email address]

Dear Patient,

I am a master's student in the Faculty of Health Sciences at the University of Lethbridge. I am conducting a research study entitled, "Understanding Patient Commitment to Colorectal Screening in Southern Alberta." The purpose of this study is to understand the reasons why patients choose to get screened for colorectal cancer and the reasons why patients choose not to get screened. Patients who have agreed to screening as well as those who have not agreed to screening will be invited to participate in this study.

Your health care provider will not be aware whether you choose to participate in this study or whether you choose not to participate in this study. Your current health care will not be affected in any way, whether you choose to participate in this study or not.

Your participation in this study will include one interview with me to discuss your thoughts about colorectal cancer screening. The interview will take no more than 60 minutes. The interview would take place at a time and location, which are convenient for you. I would also like to record the interview with your permission. I will offer you a small gift \$15.00 in recognition of your participation in the study.

If you are interested in participating in this study, please contact me by telephone at [telephone number] or email at [email address] to obtain additional information about the study.

Thank you for your consideration of this invitation.

Sincerely,

Gayle Knapik

Appendix C: Informational Posters at Seniors' Centres

WANTED

60 minutes of your time

- ★ *seeking individuals who have been referred for a colonoscopy but have chosen not to have one*
- ★ *interviews (in person or by telephone) with Master's student will take no longer than 1 hour*



I want to learn from you!

Have you chosen another way to take care of your health?

Do you question conventional health treatment?

A study, in partial fulfillment of the Masters of Science program at the University of Lethbridge

Please contact Gayle at [telephone number] OR [email address]

For additional information, please contact my supervisor, Dr. Jean Harrowing at [phone number] or [email address]

Appendix D: Informed Consent Form

Understanding Patient Commitment to CRC Screening in Southern Alberta

Investigator: Gayle Knapik R.N., B.N.

Telephone: [telephone number]

Email: [email address]

Supervisor: Dr. Jean Harrowing, University of Lethbridge, Faculty of Health Sciences

Telephone: [telephone number]

Email: [email address]

On-site Committee Member: Raphael Lencucha, University of Lethbridge, Faculty of Health Sciences

Telephone: [telephone number]

Email: [email address]

Dear Participant,

I am a master's student in the Faculty of Health Sciences at the University of Lethbridge. I am completing my graduate degree (MSc) in Nursing. I am conducting a research study entitled, "Understanding Patient Commitment to Colorectal Cancer Screening in Southern Alberta". The purpose of this study is to increase our understanding about why people agree to colorectal cancer screening (CRC) and why others refuse such screening.

None of your health care providers will know whether you participated in this study or not.

Your participation in this study will include one face-to-face interview with the researcher to discuss why you chose to participate in screening or alternatively, why you chose not to participate in screening. The interview has been designed to take no longer than 60 minutes. Interviews will take place at a location and time agreed upon by you. With permission, the interviews will be audiotaped (recorded) and transcribed to allow for an accurate understanding of your perspectives.

The risk associated with your participation in the study is minimal. You may feel a little uncomfortable talking about colorectal screening or CRC. However, the information that you share may help with future nursing research and education. I will offer you a Tim Horton's or a Chapter's gift certificate in the amount of \$15.00 in recognition of your participation in the study.

Confidentiality and anonymity will be maintained at all times. Only my supervisor and I will have access to the data collected during this study however, your name will not be used; an identification number will be assigned to your interviews. Your identity will not ever be disclosed. Names and identifying information will be removed from any report or presentations. Information obtained for this study will remain in a locked cabinet in my

home for the required period of five to seven years in accordance with research principles. Information after this time will be placed in a confidential bin at the University of Lethbridge to be destroyed.

You have the right to refuse to answer any question during the interview without negative consequences. Your participation in this study is voluntary and you may choose to withdraw from the study at any time without consequences. Whether you choose to participate or not, your health care will not be affected. Furthermore, your care provider (physician or nurse) will not be aware of your participation in the study.

The study findings will be used in my Master's thesis. A summary of the study will be made available to you if this is of interest to you. In addition, a letter addressing my preliminary findings will be mailed to four participants. The four participants chosen will represent both genders and will represent those participants who have chosen to have CRC screening and those who have chosen to refuse CRC screening.

Please keep your copy of the consent form and if you have any questions about this study you can contact me at [telephone number] or my supervisor, Dr. Jean Harrowing at [telephone number]. If you have any questions related to your rights as a participant in this research, please contact the Office of Research Services, University of Lethbridge at [telephone number].

Thank you for your assistance with this study.

Sincerely,

Gayle Knapik

Your signature below indicates that you understand the above information and agree to participate in this study.

Participant's Signature

Printed Name

Date

Your signature below indicates that you agree to be audiotaped for this interview.

Participant's Signature

Please check box if you would like to receive a summary of the study findings.

Please send me a summary of the study findings.

_____ email address *or*

_____ mailing address

Appendix E: Demographic Questionnaire – CRC Screening

Please fill in all the white blank areas. Do not fill in the grayed areas.

Research Number:		Pseudonym:
Age:	_____ years old	
Gender:	Male _____ Female _____	
Religious Affiliation:	_____ <i>or</i> No identity with any religion ____	Regularly attend worship: Y or N (please circle one)
Marital Status:	Single _____ Married _____ Common Law _____ Divorced _____ Widowed _____	
Education:	Less than high school diploma _____ High school diploma &/or some post secondary _____ College diploma _____ University degree _____	
Income Level	Gross family income: Less than \$20,000 _____ 21,000 – 35,000 _____ 36,000 – 50,000 _____ 51,000 – 65,000 _____ 66,000 – 79,000 _____ More than \$80,000 _____	
Personal history of colorectal cancer?	Yes _____ No _____	Identified at what age?
Family history of colorectal cancer?	Yes _____ No _____	Who?
Previous history of cancer?	Yes _____ No _____	What kind of cancer?
Do you participate in other screening activities? (ie PAP, prostate etc)	Yes _____ No _____	Which ones? When was the last time you engaged in any screening activities?