2022

Is This Going to Be the End? Understanding Problematic Integration Among Appalachian Patients in Colorectal Cancer Screening Navigation

Audrey Smith Bachman
University of Kentucky, audreysmithbachman@gmail.com
Author ORCID Identifier:
https://orcid.org/0000-0002-0584-8997

Digital Object Identifier: https://doi.org/10.13023/etd.2022.90

Recommended Citation

Bachman, Audrey Smith, "Is This Going to Be the End? Understanding Problematic Integration Among Appalachian Patients in Colorectal Cancer Screening Navigation" (2022). *Theses and Dissertations--Communication*. 116.
https://uknowledge.uky.edu/comm_etds/116

STUDENT AGREEMENT:

I represent that my thesis or dissertation and abstract are my original work. Proper attribution has been given to all outside sources. I understand that I am solely responsible for obtaining any needed copyright permissions. I have obtained needed written permission statement(s) from the owner(s) of each third-party copyrighted matter to be included in my work, allowing electronic distribution (if such use is not permitted by the fair use doctrine) which will be submitted to UKnowledge as Additional File.

I hereby grant to The University of Kentucky and its agents the irrevocable, non-exclusive, and royalty-free license to archive and make accessible my work in whole or in part in all forms of media, now or hereafter known. I agree that the document mentioned above may be made available immediately for worldwide access unless an embargo applies.

I retain all other ownership rights to the copyright of my work. I also retain the right to use in future works (such as articles or books) all or part of my work. I understand that I am free to register the copyright to my work.

REVIEW, APPROVAL AND ACCEPTANCE

The document mentioned above has been reviewed and accepted by the student's advisor, on behalf of the advisory committee, and by the Director of Graduate Studies (DGS), on behalf of the program; we verify that this is the final, approved version of the student's thesis including all changes required by the advisory committee. The undersigned agree to abide by the statements above.

Audrey Smith Bachman, Student

Dr. Elisia Cohen, Major Professor

Dr. Anthony Limperos, Director of Graduate Studies

IS THIS GOING TO BE THE END? UNDERSTANDING PROBLEMATIC INTEGRATION AMONG APPALACHIAN PATIENTS IN COLORECTAL CANCER SCREENING NAVIGATION

DISSERTATION

A dissertation submitted in partial fulfillment of the
requirements for the degree of Doctor of Philosophy in the
College of Communication and Information Science
at the University of Kentucky

By

Audrey Smith Bachman

Lexington, Kentucky

Co- Directors: Dr. Elisia Cohen, Professor of Communication

and Dr. Anthony Limperos, Professor of Communication

Lexington, Kentucky

2022

https://orcid.org/0000-0002-0584-8997

ABSTRACT OF DISSERTATION

IS THIS GOING TO BE THE END? UNDERSTANDING PROBLEMATIC INTEGRATION AMONG APPALACHIAN PATIENTS IN COLORECTAL CANCER SCREENING NAVIGATION

Colorectal cancer (CRC) is preventable through regular screening; however, incidence and mortality rates in Appalachia are among the highest in the United States. Public health programs and interventions meant to mitigate the higher CRC burden and increase screening rates are ongoing in the U.S. and Appalachia. In continuing the efforts to reduce the burden of CRC in Appalachian communities, this dissertation uses a two-part study to investigate communication practices relative to problematic integration and health beliefs in CRC screening conversations from the perspective of both patients and patient navigators in the region. As part of efforts directed by the Rural Cancer Prevention Center (RCPC; 2009-2019), patients who received a positive fecal immunochemical test (FIT) and the patient navigators assigned to connect them with direct visualization follow-up testing were interviewed one-on-one to better understand the role of problematic integration in CRC screening communication. Study 1 investigates patient navigators' (n = 9) perspectives of their efforts to connect patients with appropriate CRC screening, while Study 2 analyzes the accounts of patients (n = 10) with positive FIT who refused follow-up colonoscopy testing (at the time of recruitment) after engaging in patient navigation services. With problematic integration theory and the health belief model as a guide, data from these two studies in the Appalachian Kentucky context support an overarching model for how patient navigators and patients address uncertainty in CRC screening. Analyzing these phenomena at the intersection of communication and health behavior theories highlights the utility of health communication research expertise in guiding interventions across the healthcare continuum. In addition, data from the studies may be used to understand the nature of participation in CRC screening conversations and how these dynamics contribute to patient-centered care and shared decision-making, which is especially important with the additional challenges for screening exacerbated by a global COVID-19 pandemic. The findings from these studies are discussed in terms of contributing to more effective clinical and patient navigation communication practices and providing public health practitioners with essential considerations for shaping interventions to support shared decision-making and improve CRC screening rates in similar populations.

KEYWORDS: [Health Communication, Colorectal Cancer Screening, Problematic Integration, Health Belief Model, Patient Navigation, Shared Decision-Making]

Audrey Smith Bachman
(Name of Student)

4/22/2022
Date

IS THIS GOING TO BE THE END? UNDERSTANDING PROBLEMATIC INTEGRATION AMONG APPALACHIAN PATIENTS IN COLORECTAL CANCER SCREENING NAVIGATION

By
Audrey Smith Bachman

Dr. Elisia Cohen
Co-Director of Dissertation

Dr. Anthony Limperos
Co-Director of Dissertation

Dr. Anthony Limperos
Director of Graduate Studies

4/22/2022
Date

DEDICATION

This dissertation is dedicated to my Appalachian ancestors and those whose hearts belong to the mountains.

ACKNOWLEDGMENTS

While an individual work, the following dissertation benefited from the insights and direction of several people. First, to my Dissertation Chair, Dr. Elisia Cohen, thank you for sticking with me through the dissertation process and helping me to (finally) finish this project. In addition, many thanks to my Co-Chair, Dr. Anthony Limperos, for joining my committee and helping to get me to the finish line. Next, I wish to thank the complete Dissertation Committee and outside reader, Dr. Don Helme, Dr. Robin Vanderpool, and Dr. Bin Huang. Thank you for providing insights that guided and challenged my thinking and helped to polish the finished product. I would also like to recognize the professors at Eastern Kentucky University who saw my academic potential as an undergraduate and persuaded me to pursue graduate degrees; a special thanks to Dr. Jayne Violette, Dr. Eric Meiners, Dr. Jennifer Fairchild, Krista Kimmel, and John Strada. Finally, tremendous gratitude to the amazing women who helped me analyze the data sets and conduct member checks, Dr. Sarah Sheff, Dr. Diane Loeffler, and Penny Dishman.

In addition to the technical and instrumental assistance above, I received equally important support from family, friends, colleagues, and neighbors. First, my deepest gratitude to my amazing husband and partner, Ryan Bachman, who provided ongoing encouragement and support throughout my experiences in graduate school and during the dissertation process. Thank you for believing in me and helping me build the courage and confidence I needed to succeed. In addition, to Ryan’s family – thank you for checking in, cheering me on, and reminding me to take the time to celebrate my accomplishments. Next, to my graduate school cohorts and colleagues – while I can't possibly name everyone who helped along the way, I'm eternally grateful and in awe of your brilliance.

One of the greatest gifts I’ve received is meeting people from all walks of life during my time in graduate school; thank you for exponentially expanding my worldview. Finally, I wish to thank my colleagues at the former Rural Cancer Prevention Center and the respondents of each study included in this dissertation. I will never forget your passion for supporting Appalachian communities.

TABLE OF CONTENTS

LIST OF FIGURES

CHAPTER 1. INTRODUCTION

1.1 Introduction

Across the United States, cancer incidence and mortality rates have steadily declined. Unfortunately, many rural communities have not experienced the same decline as research over the past decade has shown that rural populations are experiencing steady or rising rates compared with urban areas (e.g., Chow et al., 2015; Meilleur et al., 2013; MMWR Rural Health Series, 2017; Singh, Williams, Siahpush, & Mulhollen, 2011). Cancer is a leading cause of death in rural areas like the Appalachian region, where cancer rates have a higher association with modifiable risks like fewer choices or options of preventive screening modalities as compared to urban areas (Blackley, Behringer, & Zheng, 2012; Zahnd et al., 2018). While colorectal cancer (CRC) is preventable through regular screening, incidence and mortality rates in Appalachia are the highest in the U.S. (Siegel et al., 2020). The lower screening rates and higher CRC mortality burden in Appalachia are well-known among public health professionals serving patients in the region – programs and interventions meant to mitigate this burden have been ongoing.

In continuing the efforts to reduce the disease burden of CRC in Appalachian communities, the following dissertation uses a two-part study to investigate communication practices within CRC screening conversations from the perspective of both patients and patient navigators in the region. These studies will improve public understanding of the ways Appalachian patients participate in cancer screening conversations and how this contributes to patient-centered care and shared decision-making. Specifically, this dissertation uses elements of problematic integration (PI) theory (Babrow, 1992) and the health belief model (HBM; Hochbaum, Kegels, & Rosenstock,

1952) to explore how patients integrate their personal and practical understanding of the benefits and barriers of CRC screening to their probabilistic and evaluative orientations. Analyzing these phenomena at the intersection of communication and health behavior theories illustrates the utility of health communication research expertise in guiding interventions across the healthcare continuum. Moreover, exploring participation in this context may contribute to more effective clinical and patient navigation communication practices and provide public health practitioners with essential considerations for shaping interventions to support shared decision-making and improve CRC screening rates in similar populations.

1.2 Colorectal Cancer in Appalachia

Each year millions of Americans receive a CRC diagnosis. The National Cancer Institute (NCI; 2020) reports an estimated 1,324,922 people living with colon and rectum cancer in the United States. Approximately 4.2 percent of men and women will be diagnosed at some point during their lifetime. Excluding skin cancers, CRC is the third most common cancer diagnosed in men and women in the U.S. (American Cancer Society; ACS, 2020). CRC is common among men and women, with an increasing risk after 50 (U.S. National Library of Medicine, 2016). CRC occurs when tumors form in the lining of the large intestine. Typically, a medical history of colorectal polyps, a family history of CRC, ulcerative colitis, or Crohn's disease increases the likelihood of developing CRC. In addition, there are several behavioral risk factors; individuals are at greater risk for CRC if they are overweight or obese, physically inactive, eat a diet high in red or processed meats, use alcohol heavily, or smoke (ACS, 2018).

In rural Appalachia, cancer rates from 1969 to 2011 rose from 182.2 to 195.2 per 100,000, while cancer rates in urban populations fell from 203.8 to 170.2 per 100,000 (Yao, Alcala, Anderson, & Balkrishnan, 2016). Overall, communities in Appalachian Kentucky experience greater CRC incidence and mortality rates while screening rates remain lower than in other regions. According to ACS (2018) data compiled from 2012-2016, age-adjusted mortality rates for CRC are higher in Kentucky than national rates at 14.2 per 100,000. Moreover, according to 2014-2018 data from the Kentucky Cancer Registry (KCR; 2018), Appalachian Kentuckians experience colorectal cancer (CRC) age-adjusted mortality rates of 19.1 per 100,00 compared to non-Appalachia Kentuckians at 15.4 per 100,000. Appalachian Kentuckians bear a heavier burden of CRC than the rest of the state and the nation.

Vanderpool and colleagues (2020) discuss the elevated burden of cancer in Appalachia and how it is associated with various risk factors occurring across multiple levels of influence (e.g., individual, provider, community, policy). For example, communities in Appalachia experience higher rates of obesity and tobacco use, lower cancer screening rates, poor diet, physical inactivity, limited access to healthcare services, lower socioeconomic status (SES), geographic isolation, and limited smoke-free legislation at the state and community level (Donahoe, Titus, & Fleischer, 2018; Freeman et al., 2005; Katz et al., 2015; Michimi & Wimberly, 2010; PDA Inc., 2012, 2017; Reiter, Katz, & Paskett, 2012; Rodriguez, Vanderford, Huang, & Vanderpool, 2018; Schoenberg, Huang, Seshadri, & Tucker, 2015; Wewers, Katz, Paskett, & Fickle, 2006). Furthermore, there is often decreased access to cancer screening services in the area, which means patients must travel farther to see a doctor, presenting a substantial impediment for those without access to reliable transportation (see Anderson et al., 2014). Other determinants impacting cancer screening rates include health literacy, risk perception, lack of health insurance, or fatalistic beliefs (Atkinson et al., 2015; Crosby & Collins, 2017; Davis et al., 2002; Collazo et al., 2015).

Knowledge and beliefs about cancer may also influence how people engage in cancer information-seeking, healthy behaviors like a mindful diet, and/or adherence to recommended cancer screening (Vanderpool et al., 2020). There is ample research demonstrating how knowledge (e.g., cancer etiology, screening guidelines) and/or fatalistic beliefs (e.g., God's will) may negatively impact individuals' attitudes, intention, internal locus of control, and self-efficacy to participate in appropriate prevention-centered behaviors like screening (Emanuel et al., 2015; Han, Moser, & Klein, 2007; Johnson, 1997; Kobayashi & Smith, 2016; Niederdeppe & Levy, 2007; Powe & Finnie, 2003; Rutten et al., 2009; Viswanath et al., 2006). Negative and/or unhealthy beliefs and perceptions in Appalachia are driven by many factors, including the health and socioeconomic disparities in the region; the influence of inadequate patient-provider communication; deleterious community norms related to cancer; lack of community infrastructure, legislation, and resources supportive of health; and barriers to health care across the cancer continuum (Behringer & Friedell, 2006; Donahoe, Titus, & Fleischer, 2018; Huston, Dorgan, Phillips, & Behringer, 2007; Rice et al., 2018). In sum, there are many barriers with the potential to interfere with appropriate and timely cancer screening in Appalachian Kentucky communities.

Data from the National Comprehensive Cancer Control Program (2021) shows that CRC screening test use in Kentucky has increased from 63% to 69% from 2012 to 2018.

The improvement in screening rates may be attributed to public health efforts in the Appalachian region to decrease patients' barriers throughout the CRC screening process. For example, funding to various programs from the Centers for Disease Control and Prevention (CDC) has increased accessibility for patients to annual testing mechanisms like FIT (fecal immunochemical testing), which requires less time and effort and fewer resources than other screening services like a colonoscopy. Nevertheless, even with ongoing public health programs designed to increase access to necessary CRC screening services, many patients in the region remain unscreened and experience late-stage diagnosis, which means that some barriers persist and pose issues for screening adherence. Health communication is vital in creating, understanding, and managing health experiences across the cancer continuum.

Since well before its addition to the U.S. Department of Health and Human Services Healthy People objectives, health communication has been an integral aspect of virtually every dimension of our health and well-being (Parrot, 2004). In Healthy People 2030, the overarching goal to improve health communication has multiple objectives. Only one objective (currently classified as a research objective) focuses on cancer (C-R02): increasing the proportion of counseled persons or engaged in shared decision-making with their providers for clinical services to prevent cancer. The classification as a research objective means that it is a high-priority public health issue, and there are not sufficient evidence-based interventions developed to address it. This objective reflects the reality that CRC screening saves lives, yet less than two-thirds of Americans who should be screened are up to date with screening (Bibbins-Domingo et al., 2016). This gap between who should be screened and who is up to date with screening is also likely to have grown, as many individuals missed, canceled, or delayed routine screening visits during the height of the coronavirus pandemic between 2020-2022. To support shared decision-making related to colorectal cancer prevention, especially in rural areas like Appalachia, an exploration of communication in this context from multiple perspectives is needed. Specifically, if future interventions of screening communication are to be implemented at multiple levels (e.g., patients, patient navigators, clinical, community), insights from as many representative groups as possible can help inform critical strategies and best practices.

1.3 Communication Issues in Cancer Screening

Several critical communication tasks and outcomes vary across the cancer continuum. The cancer care continuum starts with the prevention phase and ends with the survivorship or end-of-life phases; this dissertation focuses on communication within the screening phase. A patient's screening experience may vary widely depending on the type of cancer detection being performed. There are several options of both diagnostic and direct visualization methods with CRC screening, and clinical recommendations are often made on a case-by-case basis. For example, clinicians may recommend different types of screening (e.g., FIT, colonoscopy, sigmoidoscopy) or a different screening schedule (i.e., age to begin regular screening, frequency of screening) based on family history of CRC or other risk factors. Communication serves multiple functions in the screening phase as patients and providers use it to share updates; manage the emotional impact of a potentially life-threatening illness; understand and remember complex information; communicate with multiple health professionals; identify statistics related to prognosis; deal with uncertainty while maintaining hope; build trust that will sustain long-term clinical relationships; make treatment decisions based on screening results, possibly including participation in clinical trials; and adopt health-promoting behaviors (Epstein & Street, 2007).

Existing research shows there are many barriers to screening that patients regularly report. These barriers include not knowing that screening is recommended, not being told by a clinician to get screened, financial concerns, misconceptions about the risks and benefits of screening, fear of finding cancer, and test-specific barriers such as not wanting to do a bowel preparation for colonoscopy (Jones et al., 2010). Several interventions have been designed to alleviate these barriers and increase screening rates. These interventions include one-on-one education, alerts and reminders for patients and clinicians, reduced out-of-pocket expenses, and reduced structural barriers (Sabatino et al., 2012). Although the screening barriers are well-documented and there are interventions to promote screening, less is known about the relative importance of communication factors associated with recommended screening, particularly for more underserved populations (Krist et al., 2020). Identifying relevant communication barriers may help inform intervention design, prioritization, and implementation in communities similar to those in Appalachian, Kentucky.

Considerable research has been conducted to explore communication barriers to cancer screening in Appalachian communities. One notable example explored barriers to human papillomavirus (HPV) vaccination as a tool for cancer prevention. Head and Cohen (2012) found that normative influences from important social networks could provide cues to action (or inaction) relative to HPV vaccination among young women in Appalachia. In addition, they found both environmental and contextual barriers to what they deemed “performing” behaviors for screening. Specifically, participants perceived significant barriers to concerns about cost, a lack of providers, and privacy threats when attending clinic appointments in a small community. This finding echoes the “concerns with privacy and anonymity in small close-knit communities” described by Hatcher and colleagues (2011) related to CRC screening specifically (p. 9). In sum, in small, rural communities, there is a greater likelihood that a person may worry about being “seen” at a health appointment or encountering a provider with whom they share social connections.

In the context of breast cancer, Cohen and colleagues (2016) described how pain and embarrassment, less personal and less professional mammography experiences, cancer fears, and poor provider communication posed barriers to timely and appropriate mammography schedule adherence and follow-up care among Appalachian Kentucky women. The poor provider communication described in the study centered primarily on difficulty communicating with mammography technicians during screening and a lack of primary care provider follow-up (i.e., “checking in” to see if patients had engaged in recommending screening). In addition, and consistent with prior research, Record et al. (2017) found that women in the Appalachian region placed a significant value on the information they obtained from the stories of their family members and friends to guide their breast cancer prevention behaviors.

Other studies have explicitly focused on CRC screening barriers. For example, a pilot study designed to use the FIT mechanism to increase CRC screening rates in Appalachia found that a lack of CRC-related knowledge and perceived CRC risk were the screening barriers most highly associated with patients not adhering to screening recommendations (Kluhsman et al., 2012). Another study exploring fatalistic beliefs about cancer screening in Appalachian Kentucky found some evidence to suggest that pessimistic or fatalistic thinking may contribute to attitudes that cancer screening is of little value; however, the authors recognized an alternative possibility that realism plays a more significant role (Royse & Dignan, 2011). For example, individuals may be more concerned about practical barriers (e.g., the cost of screening).

Other research confirms that potential barriers to CRC screening remain despite the presence of positive beliefs about screening and knowledge of the significance of timely detection for cancer treatment (Schoenberg, Hatcher, & Dignan, 2008). For example, in a study with primary care providers and patients, Hatcher, Dignan, and Schoenberg (2012) found distinct differences in the perceptions of each group relative to CRC screening. Specifically, providers discussed patient characteristics, financial issues, and healthcare delivery system factors as challenges to screening. At the same time, participants reported fear, embarrassment, economic issues, lack of perceived need, test qualities, lack of provider recommendation, and health care delivery barriers. An important area where perceptions diverged involved provider recommendation of CRC screening. Providers reported that they routinely recommended a colonoscopy, while patients mentioned a lack of provider recommendations for screening. The findings of this study are in line with other research showing that a lack of physician recommendation is a frequently noted barrier to CRC screening (Brenes & Paskett, 2000; Ellerbeck et al., 2001; Mandelson et al., 2000). Since receiving physician recommendations is generally viewed as a critical influence in screening uptake, the inconsistency in (or lack of) recommendation is problematic.

Bachman and colleagues (2018) detail how they asked screening-eligible residents of the Kentucky River Area Development District (KRADD) in southeastern Kentucky about how healthcare providers could communicate more effectively to be patient-centered in their approach to CRC screening conversations. Participants wanted more precise recommendations, more information or options about CRC screening, clearer and more direct language, and a high-sensitivity approach to screening conversations. Participants who were up to date on their CRC screening discussed specific information about their providers' communication, including the importance, timing, and appropriateness of screening. However, despite conversations with providers, other participants who remained unscreened reported providers' attempts to use persuasive communication strategies that did not necessarily result in CRC screening, particularly for colonoscopy.

There are various obstacles to improving screening rates in Appalachian communities that cut across several types of cancer. To address these obstacles, researchers have identified the utility of community health workers (CHWs) and patient navigation as a tool to improve cancer screening rates in hard-to-reach populations like Appalachia (e.g., Ali-Faisal, Colella, Medina-Jaudes, & Scott, 2017; Percac-Lima et al., 2009; Wells et al., 2011). CHWs are typically lay individuals trained to serve as a liaison between community members and healthcare services in low-income, medically underserved, and/or hard-to-reach populations (Swider, 2002; Witmer, Seifer, Finocchio, Leslie, & Neil, 1995). The patient navigator's role was developed in the early 1990s to improve health outcomes in vulnerable populations by eliminating barriers to timely diagnosis and treatment of cancer and other chronic diseases (Freeman & Rodriguez, 2011). Generally, patient navigation (1) provides individual patients cancer-related care, (2) ends when health services are complete, (3) targets a defined set of health services, (4) focuses on the identification of individual patient-level barriers to accessing cancer care, (5) aims to reduce delays of diagnosis and treatment, and (6) intends to decrease the number of patients lost to follow up (Wells et al., 2008, p. 4). A focus on barriers (e.g., transportation, income, health literacy) produces four general intervention strategies, including addressing and overcoming patient barriers to care, providing health education across the cancer continuum of care, and providing psychosocial support (Wells et al., 2008, p. 5).

Research shows that patient navigation interventions are more effective than standard care (Donaldson et al., 2012; Myers et al., 2008; Percac-Lima et al., 2009). For example, Ali-Faisal, Colella, Medina-Jaudes, and Scott (2017) found that compared to standard of care, patients who received navigation were significantly more likely to access health screening and attend a recommended care event (i.e., colonoscopy). In addition, patient navigation increased adherence to cancer care follow-up treatment. Several studies corroborate these findings and highlight how patient navigation interventions improve FIT adherence and increase follow-up to CRC screening services like a colonoscopy (Nuss et al., 2012; Percac-Lima et al., 2009; Shapiro et al., 2010; Wells et al., 2008; Wells et al., 2012). Research also supports that patient navigation is a critical tool for increasing CRC screening rates among minority and low socioeconomic status populations and underserved communities who experience significant procedure-related barriers (Jandorf et al., 2005; Lebwohl et al., 2011; Percac-Lima et al., 2009).

A few studies have documented the use of CHWs or patient navigation services in Appalachia. For example, Feltner and colleagues (2012) found that a CHW-delivered cancer education program increased participants' knowledge of cancer risk and awareness of the benefits of CRC screening from pretest to post-test in a sample of low income, medically underserved Appalachian residents. Another notable example used a social-ecological perspective to examine lay patient navigators' interpersonal level of support for cervical cancer prevention. Cohen, Scott, White, and Dignan (2013) found that patient navigators provided significant support to women in managing their uncertainties. In addition, the navigators were well-trained to problem-solve logistical barriers to receiving follow-up care. Even so, their analysis discovered that the navigators often engaged in conversations in which they did not have the resources or tools to contribute to communication strategies that adequately addressed patient uncertainties for appropriate follow-up care. For example, even though navigators supported patients in managing their uncertainty by assisting in information seeking or avoiding, providing instrumental support, giving acceptance or validation, encouraging perspective shifts, and normalizing disease-related experiences, they reported experiencing significant frustration when they were unsuccessful in helping a patient or emotional distress when they had to deliver bad news. Cohen and colleagues maintain that while many patient navigation programs have been developed with a focus on training lay people as CHWs who have cultural knowledge and expertise to identify and address logistical, procedural, and practical barriers to care, navigators also need the ability to manage more abstract obstacles to care, such as those associated with uncertainty.

The current study examines an overarching model for exploring CRC screening conversations and experience to address how patient navigators and patients address uncertainty in the screening context. Babrow (1992, 1995) created problematic integration (PI) theory as a way to understand communication in situations in which forming and integrating (or synthesizing) knowledge and values are troublesome. PI theory centers on the idea that people orient their lives based on expectations and evaluations, which Babrow identified as probabilistic and evaluative orientations to their world. Probabilistic orientations refer to how likely an event or issue may occur, while evaluative orientations refer to the assessment of the desirability (or undesirability) of a possible outcome. This dissertation examines how individual orientations to screening behaviors influence the probabilistic and evaluative ways people integrate information to address uncertainty related to CRC screening decision-making. More specifically, a person's orientation to CRC screening as a behavioral outcome can be understood based on their pre-existing health beliefs. Therefore, the HBM is applied to supplement PI theory to help explicate individual orientations to behavior change.

There is a shortage of research considering the perspectives of both patients and patient navigators relative to CRC screening. In addition, much more is known about how navigators address tangible barriers to care than obstacles driven by uncertainty and risk perception. The following dissertation investigates the perceptions of a group of experienced CHWs and navigators and the Appalachian patients they serve to address the following research questions:

RQ1: *How do patient navigators describe patients' probabilistic and evaluative orientations in their CRC screening conversations?*

RQ2: *How do patients communicate shared decision-making related to follow-up care following an abnormal FIT result?*

RQ3: *How do patients work with navigators to resolve their probabilistic and evaluative orientations to CRC screening?*

1.4 Project Overview

A two-part study is presented to investigate communication practices relative to problematic integration and health beliefs in CRC screening conversations from patients' and CHW/navigators' perspectives. With problematic integration theory and the health belief model as a guide, data from these two studies may be used to understand the nature of participation in CRC screening conversations and how these dynamics contribute to patient-centered care and shared decision-making. In addition, by taking patients' unique perspectives and navigators into account, the primary researcher may contribute to training strategies for more effective clinical and patient navigation communication practices and considerations for shaping interventions to support shared decision-making and improve CRC screening rates in similar populations.

Chapter two presents the theoretical grounding for the study. First, critical issues surrounding increasing CRC screening rates in Appalachia are discussed, focusing on how investigating issues related to screening from a health communication perspective is advantageous. Specifically, the nature of uncertainty in communication about cancer screening is explained from the perspective of problematic integration (PI) theory. Then, connections to problematic integration relevant to the health belief model (HBM) are explained. By using constructs from HBM to examine how they anchor probabilistic and evaluative beliefs from PI theory, this dissertation can provide an integrated perspective into CRC screening decision-making among patients and offer support for navigation programs designed to increase screening and transition to follow-up care in underserved areas.

Chapter three details Study 1 in this dissertation, which includes insights from individuals who served as patient navigators for the Rural Cancer Prevention Center (RCPC). A semi-structured, qualitative interview approach was utilized by RCPC staff to better understand the facilitators and barriers to successful patient navigation to colonoscopy after a positive FIT result. This chapter also details how patient navigators manage patient uncertainty and privacy concerns and describes participants' perceived relationships with clinical networks.

Chapter four describes participants' stories in Study 2, which includes patients who received a positive FIT result and enrolled in RCPC patient navigation services but did not follow up with colonoscopy screening. Members of the RCPC staff interviewed participants to better understand the process behind their decision not to receive follow-up care. Patients were asked to detail their experiences receiving a positive FIT result and speaking with a patient navigator about scheduling a colonoscopy. Specifically, patients were asked to enumerate and elaborate on any perceived barriers to scheduling and completing colonoscopy screening.

Chapter five includes a discussion of the overall findings from this research project, implications for future work, and an explanation of this project's limitations. Specifically, the model (see Figure 1.1) proposed in this dissertation (and that is supported by the data collected) illustrates how the primary elements of HBM (i.e., perceived severity, perceived susceptibility, perceived benefits, cues to action, self-efficacy) oscillate to inform patients' integration of recommended health behaviors.

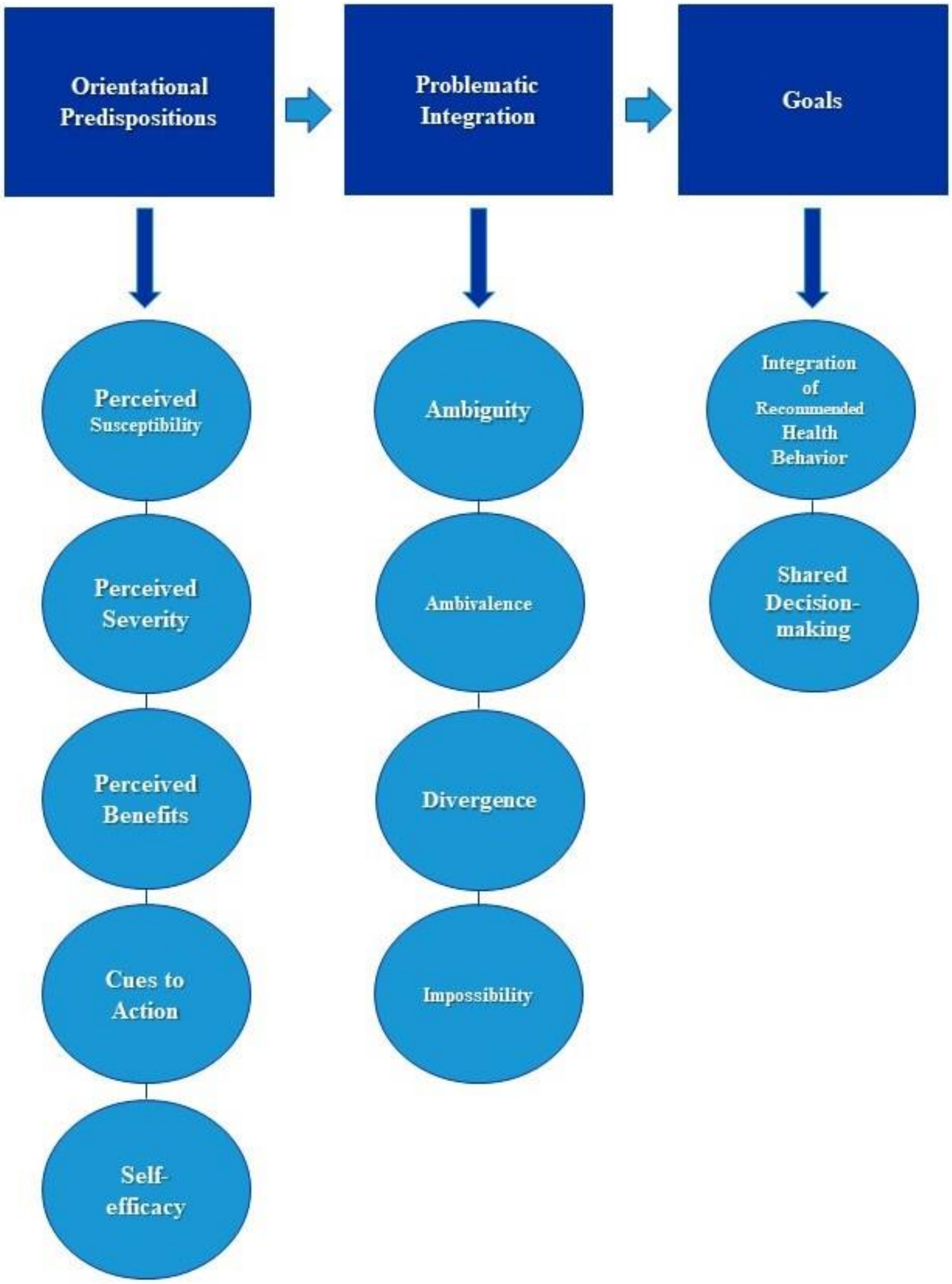

Figure 1.1 Problematic Integration of Health Behavior Framework

CHAPTER 2. LITERATURE REVIEW

2.1 Communication and Colorectal Cancer Screening

Effectively engaging patients across the cancer care continuum requires appropriate and effective communication, which is often challenging. Patient-centered communication is a medical provider's "effort to elicit, understand and validate a patient's perspective, to [involve] the patient in care and decision making to the extent he or she needs or wants to be, to [provide] clear understandable explanations, and to [foster] a relationship characterized by trust and commitment" (Politi & Street, 2011, p. 580). The number of "psychological and socioemotional issues surrounding different individuals' experiences with cancer" poses challenges for interpersonal communication and patient-centered communication practices (Kreps, 2003, p. 163). In other words, healthcare providers must work to ensure that messages align with the needs and preferences of the patient as it is much more likely that patients will adhere to a treatment plan when they actively participate in decision-making (e.g., asking questions, sharing goals; Politi & Street, 2011). In the screening phase of the cancer continuum, knowledge deficits, fear, uncertainty, poor access, and poor understanding of probabilistic estimates of risks and benefits can be addressed using effective communication, which includes (a) clarifying the reason for screening (b) gaining the patient's trust, (c) offering tangible help for navigating the healthcare system, (d) providing interpreters when necessary, (e) providing low-literacy, culturally informed educational materials (Epstein & Street, 2007).

Several studies show that increasing cancer screening rates in regions like Appalachia will require a greater focus on improving patient-provider communication.

For example, existing research demonstrates that providers' recommendation for cancer screening is a substantial factor in patients' screening knowledge and adherence to screening recommendations in Appalachian communities (Bachman et al., 2018; Krok-Schoen et al., 2015). Moreover, research shows that even after controlling for traditional socio-demographic factors such as age, race, and socioeconomic status, providers' communication with patients (i.e., efforts to build trust) remained the most significant driver of screening completion among low-income patients (Gupta et al., 2014).

While research shows that clinicians' recommendations are essential to patient adherence to cancer screening, suggestions for effective communication often focus solely on the content of screening conversations or offer ideal communication behaviors without identifying specific strategies for providers to implement (Peterson et al., 2016). In a systematic review of studies that focused on the role of patient-provider communication in screening behavior, Peterson and colleagues (2016) found a positive association between provider recommendation and patient screening adherence in virtually all studies regardless of population or types of cancer. They also found that the strongest indicators of screening adherence were patients' perceived amount of provider enthusiasm and encouragement, the removal of patients' cited barriers to care, and clear, thorough explanations of screening procedures. In addition, they found some evidence that the quality of communication in cancer screening conversations may be influenced by providers' own biases and expectations about a patient's likely adherence. Peterson and colleagues concluded that clinicians' recommendations are necessary but not sufficient for adherence, stating that "provider-patient communication is more nuanced than just a simple recommendation, and the quality and content of the discussion surrounding the recommendation may have an additional and important bearing on a patient's decision to get screened" (p. 101). They recommended that researchers interested in cancer prevention and control expand their focus on understanding how message quality and content converge to create optimal patient-provider communication about screening. More effective communication practices may support increased screening adherence; however, identifying best practices becomes difficult in light of how patients experience uncertainty related to cancer screening.

Uncertainty often arises during the decision-making process about CRC screening. There are two primary methods of CRC screening – stool-based tests and direct visualization tests. There are several options for each CRC screening method, including (1) fecal immunochemical testing (FIT) or high sensitivity (e.g., Hemmocult SENSA) guaiac-based fecal occult blood testing (FOBT) every year, (2) sDNA-FIT every one to three years, (3) flexible sigmoidoscopy every five years, (4) flexible sigmoidoscopy every ten years plus FIT annually, (5) colonoscopy every ten years, or (5) CT colonography every five years (U.S. Preventive Services Task Force, 2021). There are risks and benefits associated with both stool-based screening (e.g., FIT) and direct visualization tests (e.g., colonoscopy). To that end, providers often make screening recommendations on a case-by-case basis. For example, colonoscopy is recommended every ten years but requires relatively more outstanding obligations of both time and effort for bowel preparation, the procedure, and post-procedure recovery. Stool-based screening, such as FOBT and FIT, can be used to screen for referral to diagnostic colonoscopy. These tests require the individual to use a stick or brush to obtain a sample of their feces but are a relatively quick and non-invasive test performed in the comfort of the home and then mailed to the laboratory for results. Similar to FOBT, FIT is a stool-based screening tool. However, unlike FOBT, FIT specifically tests for human blood. Guaiac tests are not as sensitive and require individuals to alter their diet (e.g., no red meat) or lifestyle (e.g., no aspirin) before testing. FIT is moderately sensitive, highly specific, and has high overall diagnostic accuracy for detecting CRC (Lee, Liles, Bent, Levin, & Corley, 2014). There are clear advantages to the annual use of FIT as a supplement to direct visualization CRC screening such as colonoscopy.

From a public health perspective, innovative screening mechanisms like FIT have the potential to counter many commonly reported barriers, including (1) a lack of patient awareness of the importance of screening; (2) concerns about pain, discomfort, privacy, embarrassment, or unpleasantness associated with testing; (3) the requirements of screening test preparation (e.g., bowel cleansing, diet change); (3) fear of test results or the need for follow-up procedures; and (4) concerns about the efficacy of screening tests (Bachman et al., 2018; Bardach, Schoenberg, Fleming, & Hatcher, 2012; DiPalma, Barnes, & DiPalma, 1998; Klabunde et al., 2005; Weitzman, Zapka, Estabrook, & Goins, 2001). In addition, individuals often perceive a low level of risk and believe that testing is not required in the absence of symptoms (Bachman et al., 2017; Rawl, Menon, Champion, Foster, & Skinner, 2000). Clearly, patients across a variety of populations report many barriers that prevent them from following the recommended CRC screening schedule.

Appalachian communities face unique barriers to CRC screening adherence, such as geographic isolation and lack of screening services. A recent study by Bachman and colleagues (2018) showed that patients in Appalachian, Kentucky felt skepticism toward screening practices due to what was perceived to be frequent changes to screening guidelines and inconsistencies in providers' communication practices surrounding screening. Many patients in the study maintained that they would use the FIT option for screening if their doctor recommended it. However, research shows an absence of consensus on the influential factors of CRC screening decision-making between family practitioners, general internists, and patients and significant variability in the content (e.g., the patient's role in decision-making, risks, benefits, and screening alternatives) of CRC screening recommendations (Wackerbarth, Tarasenko, Joyce, & Haist, 2007; Tarasenko, Wackerbarth, Love, Joyce, & Haist, 2011).

FIT is an option for early detection of adenomas and cancerous polyps that addresses many barriers listed above; however, when a patient has a positive FIT (i.e., the presence of blood is detected), follow-up diagnostic screening is needed. While the dissemination of FIT kits by various health agencies in areas disproportionately affected by CRC counters many barriers affecting initial screening and annual adherence to FIT, patient navigation is critical for addressing patient concerns and ensuring adherence to the necessary follow-up testing with direct visualization procedures like colonoscopy. For those with a positive FIT, there may be various concerns about what the result means, reservations about the colonoscopy prep and procedure, and fear surrounding a potential cancer diagnosis. These issues, which vary by patient, need individual attention to reduce the burden of cancer in places like Appalachian, Kentucky.

2.2 Patient-Centered Uncertainty Management and Decision-Making

One of the reasons patient navigation services are so critical to cancer screening programs is the uncertainty experienced by patients on an individual level. Throughout the process of cancer screening, diagnosis, treatment, and survivorship, there are many points of uncertainty in health decision-making resulting from a variety of factors (Babrow, Kasch, & Ford, 1998; Mishel, 1988). According to Brashers (2001), uncertainty exists ‘‘when details of situations are ambiguous, complex, unpredictable, or probabilistic; when information is unavailable or inconsistent; and when people feel insecure in their own state of knowledge or the state of knowledge in general’’ (p. 478). Uncertainty management theory (UMT) holds that people use communication to manage uncertainty as they make health-related decisions (Brashers, 2001; Ford, Babrow, & Stohl, 1996). Uncertainty is particularly salient in cancer care, which means that managing uncertainty is a critical function in patient-centered communication in this context. The core of patient-centeredness is to understand the individual patient’s perspective and needs. There are six core functions of patient-centered communication, which are neither independent nor hierarchical (Epstein & Street, 2007). The functions include (1) fostering relationships, (2) exchanging information, (3) responding to emotions, (4) managing uncertainty, (5) shared decision-making, and (6) patient self-management. Research shows that when patients receive quality patient-centered communication, they can better manage uncertainty while making health-related decisions (Mishel et al., 2005; Politi & Street, 2011).

Responses during uncertain conversations are marked by appraisals and emotional reactions (Berger, 1995). Appraisals are often shaped by the relevance, likelihood, and evaluation of the event. At the same time, emotional responses can be negative, positive, neutral, or a combination of these. Appraisals and emotional responses are often complex and may shift over time. Generally, theories of uncertainty management focus on how people (a) seek and avoid information, (b) adapt to chronic uncertainty (e.g., the trajectory of chronic illness), (c) obtain assistance with uncertainty management through social support (e.g., family members, patient navigators), and (d) manage uncertainty management (e.g., managing and manipulating the uncertainty of others). Medical sources of uncertainty are well documented and include issues with insufficient information about a diagnosis, ambiguous symptom patterns, complex systems of treatment and care, and unpredictable disease progression (Brashers, Neidig, Reynolds, & Hass, 1998). In the patient navigation encounter, navigators may see one or more issues with managing patients' uncertainty about CRC screening, treatment, care, and survivorship. Effective communicative behavior from a patient-centered perspective supports uncertainty management and encourages patient participation in decision-making; however, what constitutes effective communication from both the patient and patient navigators' perspective is less clear, especially in practice (Politi & Street, 2011). Understanding how patients experience uncertainty through the lens of problematic integration and how patient navigators address this integration provides utility for informing future interventions to support communication practices surrounding appropriate and timely CRC screening.

2.3 Problematic Integration Theory

The theory of uncertainty management presented uncertainty as something managed by communication; Babrow (1992) argued that the act of communication served as a means to create and experience uncertainty. This perspective is particularly valuable to understanding how people talk about cancer, given the uncertainties around screening, prevention, and detection and how some uncertainties may not be resolvable or may be continuous as part of everyday living and health care. Babrow (1992, 1995) created problematic integration (PI) theory as a way to understand communication in situations in which forming and integrating (or synthesizing) knowledge and values are troublesome. Babrow (1992) argued that the theory offered significant implications for the field of communication, specifically as it relates to the human experience of integrating our understanding of the world around us. Babrow (2001) was initially curious about situations involving uncertainty, ambivalence, and clashing expectations and desires; however, he later broadened this conception. The theory was developed as a general perspective on communication and uncertainty and centers on the idea that people orient their lives in terms of expectations and evaluations; in other words, individuals form probabilistic and evaluative orientations to their world.

Seven central claims support PI theory. First, people need both probabilistic and evaluative orientations to their world, and these orientations are integrated into the individual experience. Second, integration is often problematic, and "illness" is essentially the ongoing experience of interwoven problematic integrations. Finally, the integrative dilemma experience entails processes in which given forms of PI are transformed in various ways, and communication is integral to how PI is formed and transformed.

People need probabilistic orientations to their world. Probabilistic orientations refer to how likely an event or issue may occur and "may take the form of conscious beliefs or expectations or of tacit and unconscious assumptions about the nature of the world" (Babrow et al. 2000, p. 67). These beliefs may pertain to the nature of the physical world and abstractions (Babrow, 1995). According to Babrow and colleagues (2000), probabilistic orientations “may be contemporaneous with experience, prospective, or retrospective (respectively)” and “may be held as tacit or unconscious assumptions about the nature of the world” (p. 67). Babrow promoted the term probabilistic orientation as an overarching label and recognized that “even though we may be certain of - and therefore take for granted - most of our understandings of the world, even the most basic articles of faith can be challenged and made uncertain by experiences such as illness” (p. 67).

People need evaluative orientations to their world. Evaluative orientations refer to the assessment of the desirability (or undesirability) of a possible outcome. Evaluative orientations are grounded in emotion, while probabilistic orientations are rooted in cognition; however, PI theory recognizes co-occurring orientations. In other words, while probabilistic and evaluative orientations should be distinguishable, they are mutually influential and must be integrated into a person’s existing network of beliefs, experiences, and emotions. Therefore, problematic integration occurs when individuals’ expectations and the evaluations they think will occur are uncertain. In other words, uncertainty occurs when there are incompatible judgments about the likelihood of an outcome.

PI theory claims that probabilistic and evaluative orientations are integrated into the human experience. Babrow et al. (2000) argue that there are two ways people integrate these propositions in experience: a) through their reciprocal influences and b) through their connectedness to the person’s probabilities and evaluations of other things. Probability and value orientations can destabilize each other due to reciprocal influence. For example, the evaluation of an outcome may change when one determines that the desired outcome is highly improbable. The assessment of the probability of an outcome may also change when its value becomes more positive or negative.

Regarding connectedness, integration is when new information is compared to existing cognitive, affective, and behavioral orientations. For example, Babrow (1995) maintains that “unstable subjective estimates” of chance and individual values may create difficulties for people to interpret messages and make decisions. In sum, problematic integration refers to the “difficulty we experience when probabilistic and evaluative orientations to a particular object (e.g., person, thing, event, idea) destabilize one another and unsettle such orientations to associated objects” (Babrow 1995, p. 284).

PI theory states that integration is inevitable and a core element of the human experience. However, the experience of integration may be either routine or problematic. In fact, Babrow (1995) argues that “integration processes can range from mundane and automatic to challenging and absorbing to profoundly difficult and debilitating” (p. 285). In this way of thinking, routine and problematic integration represents a continuum, where “as integration of probability and evaluation becomes more problematic, it becomes increasingly difficult to form and maintain associated cognitive, affective, and behavioral orientations” (Babrow, 1992, p. 98). In the context of health, there may be various forms of integrative dilemmas. Babrow (1992) reveals four ways in which integration is problematic, including a) divergence, b) ambiguity, c) ambivalence, and d) impossibility.

Integration may become problematic for a variety of reasons. First, divergence may occur. Divergence refers to when a discrepancy exists between our desires and assessments of the likelihood of said desires. The discrepancy may occur when an outcome a person believes is good, has a low chance of happening, or believes a lousy outcome has a high probability of occurring. Regardless, “the integration of belief and evaluation is difficult to the extent that the expectation and desire diverge" (Babrow, 1995, p. 284). When a person cannot create a clear probabilistic orientation, they may experience ambiguity.

According to Babrow (1992), "ambiguity exists when one is uncertain about which among a set of probabilities might describe the given situation" (pp. 111-112). He defines ambiguity as a "lack of clarity about some probability" and goes on to add that ambiguity "causes integrative problems to the extent that we desire or dread that which is ambiguous, and to the extent that the likelihood of what we desire or dread is unclear" (1995, pp. 284-285). Thus, ambiguity may interfere with probabilistic orientations due to the challenge of integrating desire with uncertainty.

Third, ambivalence may also create integration problems. Babrow (1995) states that "a single idea, object, person, or act can evoke contradictory evaluations" (p. 285). Thus, ambivalence exists in two forms: a) ambivalence due to mutually exclusive alternatives and b) ambivalence of contradictory responses. In other words, ambivalence may occur when two alternatives are equally valued, but one cannot be chosen without turning down the other or when an alternative has equally positive and negative characteristics.

Finally, impossibility may create problematic integration. Babrow (1995) described impossibility as an "impossible desire" or "certain unpleasantness" (p. 285). Impossibility is the only form of problematic integration that relies on some type of probabilistic certainty. Babrow (1995) states that "impossibility is characterized by the practical and epistemological problems of proof" (p. 285). Integrating an impossibility becomes more problematic as the evaluative proposition becomes more positive. Babrow

(1992) argues that one’s linguistic choices often determine what form of problematic integration exists (e.g., “likely” vs. “impossible”; “very good” vs. “adequate”).

Several forms of problematic integration correlate with an individual’s configuration of probability and evaluation; this configuration determines the degree of difficulty a person may experience in the integrative dilemma. Babrow (1995) argues that integration becomes more challenging when there is a) a lack of clarity surrounding probability, b) increased conflict associated with values, and c) an increased divergence between expectation and desire. In addition, Babrow (1995) states that “a second (necessary but not sufficient) determinant of the degree of integrative difficulty is the location of the particular expectancy or evaluation in one’s systems of beliefs and values” (p. 285). He argues that more central values and probability judgments present a greater likelihood of problematic integration.

Illness is essentially the ongoing experience of interwoven problematic integrations. The illness experience is one that Babrow (1995) described as phased (e.g., symptoms, diagnosis, prognosis, treatment, remission, and recurrence). He argues that in each phase, communication is essential to the experience. The cancer control continuum presented by the NIH (2020) is similar (i.e., etiology, prevention, detection, diagnosis, treatment, and survivorship) in that communication impacts every focus in the framework. More specifically, Babrow et al. (2000) argue that all health problems are “united by the theme of uncertainty” (p. 57). Thus, uncertainty is a central feature in illness experience, and communication is essential to the construction, management, and resolution of uncertainty (Babrow, Kasch, & Ford, 1998).

People experience dilemmas that are integrated, and this experience includes processes in which problematic integrations are transformed in various ways. PI claims that communication is central to the aforementioned experience of PI and its transformation. Communication is the vehicle or core source of the experience of problematic integration. Babrow (1995) argues that communication is essential to problematic dilemmas because it serves as a "source, medium, and resource" (p. 286). Communication is a source of knowledge, and "communicative acts are themselves objects of both probabilistic and evaluative orientations" (p. 286). In fact, Babrow (2001) asserted that "communication gives rise to, conveys, and shapes difficulties in integrating probabilistic and evaluative orientations with one another and with related beliefs, attitudes, and intentions" (p. 556). Communication is a medium by which problematic integration is disseminated as it may often be directly associated with probabilities and values. Babrow (1995) states that "problematic potentialities and evaluations are conveyed both by informal, spontaneous, playful interactions and by formal, planned, and purposeful communication" (p. 286). Over time, these problematic potentialities and values may become part of norms and culture. Communication is a resource during PI as we attempt to manage the experience. According to Babrow (1995), many speech acts may serve as a resource during PI, a variety that largely depends on who is experiencing PI. Moreover, interactions themselves may become a medium for the dissemination of PI.

To discern the role of communication as a source, medium, and resource, Babrow (1995) offered "extended chains of PI" characterized by interrelations among a) forms, b) foci, and c) layers of experiences. First, PI chains manifest interrelations among the various forms of problematic integration (i.e., divergence, ambiguity, ambivalence, and impossibility). A chain may be created when an “attempt to resolve one PI leads to another form of integrative dilemma” (p. 287). Second, chains of PI manifest when “the initial experience of some particular or focal problematic potentiality and evaluation can problematize orientations to related matters (p. 287). Third, the integration process supports the chaining from one primary dilemma to another. Finally, chains of PI manifest as a result of the interrelation among layers of experience. Specifically, PI is both an individual psychological process and a communicative act, wherein the abilities of others (e.g., sympathy, empathy) or the act of joining with others (e.g., social support groups) can “spread PI beyond the individual-psychological mode” (p. 287).

Babrow’s work demonstrates that probabilistic and evaluative orientations are formed, sustained, and transformed through communication. Thus, PI is an individual psychological process and simultaneously a communicative phenomenon. In the context of cancer communication, communication may foster a reappraisal of probability and value or perhaps a more holistic reframing of the situation.

PI has been used as a theoretical foundation for many researchers. For example, Matthias and Babrow (2007) examined PI in the context of pregnancy. They found that PI sheds light on what individuals “ought to believe and whether what they believe is good or bad” (p. 788). In addition, they found that communication serves as a coping mechanism for individuals experiencing PI and enables individuals “to reappraise the value she or he places on a particular event or object” (p. 789). In another example investigating problematic integration for the seriously ill elderly, Hines and colleagues (2001) used PI to analyze the communication flaws to provide clinicians with multiple explanations for different kinds of uncertainties experienced by elderly dialysis patients. They found that patients seek information to cope with debilitating dialysis treatments rather than the information nurses believe is necessary to make informed choices about undergoing such treatments. The tension between perceived information needs created challenges for effective communication about end-of-life issues. Participants in both of these examples identified complex beliefs and variance in what is considered effective communication associated with a particular health behavior.

Cancer communication researchers have found utility in PI theory as well. For example, Ford, Babrow, and Stohl (1996) found evidence that "supportive communication is that which facilitates adaptive uncertainty management" (p. 191). Specifically, they discovered that social support messages might be designed to sustain, increase, or decrease uncertainty. They also found that context certainty does not solely determine the aim of supportive messages related to uncertainty, which means that the context value contributes to message design in interesting ways. For example, in applying PI to the context of breast cancer, they found two necessary (but not sufficient) factors in the design of a supportive message: the a) message designer's perception of the patient's level of certainty or uncertainty about some potential reality and b) patient's evaluation of that reality. In another study, Dean (2014) explored PI theory in the context of previvors' management of uncertainty for hereditary cancer. They found that PI helps understand the relational context of uncertainty as previvors and clinicians work together to achieve a shared understanding of the problem and ultimately take appropriate actions to address the problem. Dean also emphasized the importance of communication as a resource for coping or managing uncertainty.

Another notable study supports the utility of exploring cancer communication through the lens of PI theory. Cohen (2009) conducted focus group conversations with African American women that revealed challenges for cancer communication. She found probabilistic and evaluative beliefs that included pervasive worry about cancer and its prevalence, ambivalence, and pervasive forms of uncertainty and that what is not uncertain about breast cancer is inevitable and awful. Several women believed that cancer was the devil's work and could be rebuked through prayer. Perhaps most striking was the belief that "naming" cancer (i.e., talking about it) could "enhance its power in the world" (p. 408). Participants described emotional reasons for fear and avoidance, particularly the need to avoid burdening their family members or loved ones. Despite this, a cancer diagnosis is identified by some women as an uncomfortable but productive moment for communication with loved ones about cancer, particularly as mothers, wives, sisters, and daughters. Cohen's work supports PI theory in that communication often creates the reality (and uncertainty) that exists in light of particular health behavior such as mammography screening.

As mentioned previously, PI theory maintains that illness is the ongoing experience of interwoven problematic integrations. Though the theory was developed in consideration of the illness experience, it has been applied in other health contexts, including screening. The illness experience involves the diagnosis and a continuing experience of the medical system, treatment, and care with various probabilistic and evaluative outcomes. However, it is also essential to consider how the uncertainty about illness and disease manifests in prevention and detection or "pre-illness" experiences and evaluations about decision-making. In considering appropriate and timely CRC screening, an individual’s orientation to the health behavior and illness (i.e., their susceptibility, concerns about the severity of potential illness, benefits of early detection, the cues that they have had in their environment supporting screening) may be important to how people integrate their probabilistic and evaluative orientations to screening and cancer detection, itself. Babrow (1995) described the illness experience as phased but does not explicitly explore or explicate the nature of communication and how it impacts probabilistic orientations relative to the screening phase. Thus, this dissertation examines how individual orientations to screening behaviors influence the probabilistic and evaluative ways people integrate information to address uncertainty related to CRC screening decision-making. More specifically, a person’s orientation to CRC screening as a behavioral outcome can be understood based on their pre-existing health beliefs. As a broad model of health behavior, the health belief model can assist in identifying these individual orientations to behavior change and provide a supplement for communication researchers using PI theory to support public health efforts.

2.4 Health Belief Model

One of the earliest models developed to explain health behavior was the health belief model (HBM). Specifically, HBM was developed to explain behavior related to tuberculosis screening (Hochbaum, Kegels, & Rosenstock, 1952; Hochbaum, 1958). Based on psychological theory, HBM includes several primary concepts that predict why people will take action to prevent, screen, or control illness conditions (Champion & Skinner, 2008). Salazar and colleagues (2013) maintain that this value-expectancy model “is predicated on the basis that behavior change will occur only when sufficient benefits remain after subtracting the costs incurred by performing the behavior” (p. 87). In other words, HBM suggests that a person's belief in a personal threat of an illness or disease coupled with a belief in the effectiveness of the recommended health behavior or action will predict the likelihood the person will adopt the behavior. HBM identifies two core components of health-related behavior: 1) the desire to avoid illness or get well if already ill and 2) the belief that a specific health action will prevent or cure illness. The theory suggests that a person's course of action depends on the person's perceptions of the benefits and barriers related to the recommended health behavior.

HBM attempts to predict health-related behavior in terms of specific belief patterns. A person's motivation to engage in healthy behavior can be divided into individual perceptions, modifying factors, and the likelihood of action. Individual perceptions affect the importance of health, perceived susceptibility, and perceived severity. Modifying factors include demographic variables, perceived threats, and cues to action. The likelihood of action is the perceived benefits minus the perceived barriers of taking the recommended health action. Combining these factors causes a response that often manifests into the likelihood of that behavior occurring (Janz & Becker, 1984; Rosenstock & Strecher, 1988). Salazar and colleagues (2013) argue that the HBM calls for health promotion programs to "find a way to inspire realistic perceptions of threat among the target population" (p. 89). Thus, the challenge for health communication researchers supporting public health professionals is dissecting the reasoning that leads to the perceived threat.

Critical concepts of HBM include perceived threat (i.e., susceptibility, severity), perceived benefits, perceived barriers, cues to action, and self-efficacy. Perceived susceptibility refers to a person's subjective perception of the risk of acquiring a particular illness or disease. Generally speaking, people’s actual and perceived vulnerability to an illness or disease varies widely. Perceived severity refers to a person's feelings concerning the seriousness of contracting an illness or disease (or even leaving the illness or disease untreated). Similar to perceived susceptibility, there is wide variation in a person's feelings of severity, and, when evaluating the severity, a person usually considers consequences at different levels. For example, a patient might consider both the medical (e.g., death, disability) and social (e.g., family life, social relationships) consequences of being diagnosed with CRC. Perceived benefits refer to a person's perception of the effectiveness of health behavior to reduce the threat of illness or disease (or to cure illness or disease). The course of action a person takes in preventing (or curing) illness or disease relies on how they consider and evaluate both the perceived susceptibility and perceived benefit, such that the person would accept a provider’s recommendation for screening if it were perceived as beneficial. Perceived barriers refer to a person's feelings on the obstacles to performing recommended health behaviors.

There can be wide variation in a person's feelings of barriers or obstacles that impact the cost/benefit analysis regarding the recommended behavior. For example, a person might grapple with the effectiveness of the behavior (e.g., cancer prevention) against the perceptions that it may be expensive, dangerous (e.g., side effects), unpleasant (e.g., painful), time-consuming, or inconvenient. In addition, a stimulus is needed to trigger the decision-making process to accept a recommended health behavior – stimuli of this nature are referred to as cues to action. These cues can be internal (e.g., pain, discomfort) or external (e.g., advice from others, illness of family members). Finally, self-efficacy refers to a person's confidence in performing a behavior successfully. Self-efficacy is a construct in many behavioral theories as it directly relates to whether a person performs the desired behavior.

HBM theorists maintain that perceptions of health behavior threat are influenced by several factors, including general health values (e.g., interest in and concern about health), specific health beliefs about vulnerability to a particular health threat, and beliefs about the consequences of the health issue (Hochbaum, Kegels, & Rosenstock, 1952). For example, if a person perceives a health threat, is consecutively cued to action, and their perceived benefits outweigh the perceived barriers, they are likely to adhere to the recommended preventive health behavior. Specifically, the HBM predicts that people are more likely to engage in preventive behaviors a) if they believe they are susceptible to a specific health risk (perceived susceptibility); b) if they believe the health condition will lead to potentially serious consequences (perceived severity); c) if they believe that a specific, accessible behavior will be beneficial in reducing either their susceptibility to or the severity of the condition (perceived benefits); and d) if they believe that the costs of taking action do not outweigh the benefits (perceived barriers).

Several studies have explored the utility of HBM relative to CRC screening. For example, a recent systematic review by Lau and colleagues (2020) of quantitative studies evaluating the association between constructs of HBM and CRC screening in screening-eligible general populations found that higher perceived susceptibility and benefits were the two constructs most commonly associated with screening intention or behavior. They also found that cues to action were consistently associated with CRC screening adherence, and the most common cue across studies was the presence of a physician’s recommendation to screen and advice from family or friends. In addition, they found that perceived barriers (e.g., structural, psychosocial) were inversely associated with screening intention or behavior within most of the studies. Perceived severity was inversely associated with screening intention and behavior in a few studies, which is interesting considering that, theoretically, high perceived severity should instead predict an increased likelihood of performing the behavior (Champion and Skinner, 2008).

In another example, Sohler, Jerant, and Franks (2015) used observational analyses of data from a randomized intervention trial to examine the independent associations of several HBM factors relative to CRC screening (i.e., knowledge, self-efficacy, stage of readiness, barriers, and discussion with a provider) with objectively measured CRC screening after one year. They found that self-efficacy, stage of readiness, and discussions with a provider were associated with screening, while barriers and knowledge were not independently associated with CRC screening. Thus, they concluded that measures of self-efficacy and readiness might help predict which patients are most likely to engage in CRC screening. They also argued that the importance of screening discussion with a provider is a valuable tool to increase CRC screening if supported by patient-focused, HBM-tailored interventions.

2.5 CRC Screening and Shared Decision-Making

CRC screening saves lives; yet less than two-thirds of Americans who should be screened are up to date with screening (Bibbins-Domingo et al., 2016). In addition, early-onset CRC has been on the rise over the past four decades and is expected to rise by greater than 140% by 2030 (Bailey et al., 2015; Mauri et al., 2019; Patel & Ahnen, 2018). The implications of shared decision-making (SDM) in cancer screening conversations will continue to be a hot-button issue as cancer screening decisions grow more complex and personalized. A key *Healthy People 2030* objective is to increase the proportion of persons who are counseled or engaged in SDM with their providers for clinical services to prevent cancer (Caverly, Kerr, & Saini, 2016; Jimbo et al., 2013). SDM has been used to describe a collaborative model in which a patient and their clinician(s) reach an agreement about a health decision (Charles, Gafni, & Whalen, 1999; Edwards & Elwyn, 2006; LeBlanc, Kenny, O'Connor, & Legare, 2009). SDM occurs when patients receive information and expertise from providers, and providers invite patients to share in the medical decision-making process guiding their treatment and care. Charles, Gafni, and Whelan (1997) maintain that key characteristics of SDM are that (a) at least two participants (e.g., physician, patient) be involved, (b) both parties share information, (c) both parties take steps to build a consensus about the preferred treatment, and (d) that an agreement is reached on the treatment to implement.

In practice, engaging in SDM means that clinicians are actively providing high-quality information and supporting deliberation by exploring patients' reactions to that information (Elwyn et al., 2012). SDM in the context of CRC screening is nuanced as conversations may include communication about the risks (e.g., cancer diagnosis) and benefits of screening (e.g., early detection), multiple options for screening (e.g., sigmoidoscopy, colonoscopy, FOBT, or FIT for CRC screening), and personalized risk factors (Caverly, Kerr, & Saini, 2016; Sepucha et al., 2014). Research suggests that in efforts to improve CRC cancer screening rates, adherence to screening alone may not be the best outcome measure because it does not necessarily consider the needs, values, and expressed preferences of the patient and maintains that examining different outcomes such as decisional conflict and the extent to which patients are informed and receive screening tests that fulfill their goals may be more supportive of future intervention efforts (O'Connor, 1993; Sepucha, Fowler, & Mulley, 2004; Sepucha et al., 2014).

The primary methods of CRC screening are stool-based tests and direct visualization tests. Effective stool-based CRC screening (e.g., FIT) is dependent on patients with an abnormal result completing timely diagnostic evaluation (Tiro et al., 2014). Providers must accurately identify patients with abnormal FIT results and refer patients for diagnostic colonoscopy; then, patients must navigate the healthcare system for testing and comply with surveillance recommendations (Zapka et al., 2010). Existing research suggests that a lack of provider referrals for testing and patient nonadherence contributes to patients with abnormal FIT failing to undergo follow-up direct visualization tests like a diagnostic colonoscopy (Carlson et al., 2011; Fisher, Jeffreys, Coffman, & Fasanella, 2006).

Martin and colleagues (2017) sought to characterize patient-, provider-, and system-level reasons for lack of follow-up colonoscopy within one year of abnormal FIT among a racially diverse and socioeconomically disadvantaged cohort of patients engaged in primary care at a large, population-based, integrated safety-net health system. Their retrospective electronic medical record review found that of 1267 patients with an abnormal FIT, 42.3% failed to undergo follow-up colonoscopy within one year. Failure was attributable to several factors, including patient-level (57%), provider-level (18%), and system-level factors (22%). The most commonly cited patient failure in the study was missing preoperative evaluation appointments or colonoscopy procedures. Provider factors included failure to inform the patient of the abnormal result, order a colonoscopy, or order any necessary preprocedural evaluation. System-level factors included failure to process colonoscopy referrals, failure to schedule appointments or colonoscopy procedures, and cancellation or delayed receipt (>12 months) of procedures due to lack of endoscopic capacity.

From a communication perspective, the essential message providers must convey to patients is that CRC screening effectively leads to the diagnosis of polyps and is a form of cancer prevention. Even so, that message is often challenging to communicate given the complexities of the preferences, knowledge, and experiences of both patients and providers. For example, Bardach, Schoenberg, Fleming, and Hatcher (2013) examined the relationship between CRC screening adherence and knowledge among vulnerable rural residents of Appalachian, Kentucky. They found that while 67% of CRC-screening eligible patients indicated receiving their screenings according to guidelines, respondents also demonstrated significant knowledge deficiencies about screening recommendations. Almost half of the participants in the study were unable to identify the recommended screening frequency for any of the CRC screening modalities. Although participants were more likely to report receiving colonoscopy than any other type of screening, only 12.3% accurately reported the recommended screening frequency. Only 15.9% of respondents were able to identify the correct screening frequency for two of the screening options, and nearly half of all respondents were unable to identify the recommended frequency for any test. They found that accuracy in identifying the recommended frequency of screening was positively associated with screening adherence. In addition, they found that respondents with fewer medical conditions, in better health, and with higher socioeconomic status were more likely to respond accurately about screening recommendations. After controlling for other notable factors (e.g., sex, age, number of conditions, education, financial status, subjective health), knowledge about the frequency of screening recommendations remained a significant predictor of screening adherence. The results of this study suggest a dose-response relationship between knowledge and screening, with a greater degree of knowledge associated with an increased likelihood of adherence to screening.

From a provider perspective, research by Kelly and colleagues (2007) conducted in primary care offices serving rural Appalachian patients examined physician and staff perceptions of barriers to CRC screening. In focus groups, physicians agreed that CRC tests were needed when symptoms were present, but some physicians acknowledged that this was diagnostic rather than screening. From their accounts, it appeared that screening was recommended selectively for those with symptoms (i.e., diagnostic) and those with family history. In addition, physicians in the focus groups also described ways in which they tried to overcome patient barriers to CRC screening by developing trust, easing preparation for screening, establishing follow-up procedures, and educating patients about screening. Participants reported mixed success when using these methods.

To date, the training and education of providers have served as a key intervention mechanism in increasing screening in Appalachia. For example, Dignan and colleagues (2014) conducted a randomized controlled trial of an intervention to increase CRC screening in primary care practices in Appalachian, Kentucky. They randomized 66 primary care practices to early or delayed intervention groups. The intervention was provided at practices using academic detailing, a method of education where providers receive information on a specific topic through personal contact. Data collected in cross-sectional surveys of medical records at baseline and six months post-intervention showed that rates of documented screening results (especially colonoscopy) were higher for all practices at the six-month follow-up. Data from this study is consistent with other research demonstrating that provider recommendation is one of the most critical factors in encouraging patients to get screened. The intervention detailed in this study included training that may have helped the providers deliver more straightforward messages recommending screening. In addition, this study highlighted that patients were more willing to obtain colonoscopy with a providers’ recommendation and inferred that providers’ recommendation of other types of screening (e.g., FOBT, FIT) might be helpful in vulnerable populations that experience substantial barriers to screening (e.g., cost, travel).

Existing research supports different intervention mechanisms for patients and providers. For example, while conducting focus groups, Hatcher, Dignan, and Schoenberg (2011) found marked differences in the perceptions of communication about CRC screening among rural healthcare providers and their patients. Patients mentioned a lack of provider recommendations and expressed confusion regarding screening recommendations, as it was often unclear to them that their providers even recommended screening. Meanwhile, providers reported that they routinely (and clearly) recommended a colonoscopy. In addition, patients reported that they received recommendations and reminders to obtain other screening tests such as mammograms, but they acknowledged receiving fewer CRC screening recommendations. Providers’ emphasis on other screenings may have led to patients’ assumptions that CRC screening is a lower priority. In fact, both groups agreed that CRC screening was a relatively low priority issue and acknowledged that other health concerns often take time away from communication about screening-related topics; however, there was variation in how each group described this prioritization. In line with research by Kelly and colleagues (2007), patients reported less communication about CRC screening unless they experienced symptoms or had a family history. Conversely, providers reported that they nearly always advised their patients to obtain CRC screening and that ultimately patients postponed or neglected screening due to other more pressing health concerns.

Many experts argue that interventions aimed at increasing CRC screening rates should be multilevel, meaning that the intervention components should address issues at the patient, provider, and system levels simultaneously or in some planned sequence. For example, Yu and colleagues (2018) designed, implemented, and evaluated the impact of an intervention on CRC screening uptake among unscreened patients in a large managed care population. Patient-level components included a mailed letter with education about screening options and pre-colonoscopy telephone counseling. Provider-level components included facilitated communication about the delivery of screening test results and workflow for abnormal results. Finally, system-level modifications included the connection to a patient navigator, expedited work-up for abnormal results, and streamlined colonoscopy scheduling. In measuring the rate of screening uptake overall, screening uptake by modality, change in the proportion of the population screened, and positive fecal immunochemical test (FIT) follow-up rates in the one-year study period, they found increases in screening participation and screening rates. Even so, approximately half of the patients with positive FITs did not undergo diagnostic colonoscopy within one year, which is consistent with existing research showing a 40-60% colonoscopy follow-up rate after receiving a positive FIT result (Chubak et al., 2016; Issaka et al., 2017; Jimbo et al., 2009; Martin et al., 2017; Oluloro et al., 2016; Partin et al., 2017).

Similarly, Zoellner et al. (2020) conducted a study with staff and patients to investigate multilevel challenges to CRC screening at federally qualified health centers (FQHCs) in Appalachia and found that perceptions surrounding CRC screening compatibility, relative priority, and available resources tended to vary. Their interviews found that patients rated CRC screening barriers relatively low; however, patients consistently discussed barriers with specific personal examples. Meanwhile, patients in the study rated the benefits of CRC screening as high yet offered far fewer insights on the potential benefits. Largely, patients' negative personal and family experiences with CRC screenings (i.e., colonoscopies) outweighed the positive accounts. In addition, Zoellner and colleagues found significant opportunities to improve patient navigation when colonoscopies were ordered and increase patient awareness of screening recommendations and their self-efficacy to prevent CRC. Finally, their findings suggested incorporating patient activation (a pivotal pathway to shared decision-making; see Poon, Shortell, & Rodriguez, 2020) with culturally appropriate and literacy-sensitive messaging that highlight positive narratives and outcomes from early detection efforts to future multilevel CRC screening interventions.

Research shows tremendous utility for increasing screening rates by implementing patient navigation programs. In a recent systematic review and meta-analysis of 73 randomized clinical trials, Dougherty and colleagues (2018) evaluated interventions intended to increase CRC screening rates in the U.S. They found that patient navigation and fecal test outreach had the most substantial evidence supporting a significant increase in completion of initial screening. In addition, their findings support combining interventions (e.g., navigation with test outreach) as this practice was associated with further increases in screening. Dougherty and colleagues surmised that the net benefit could be even more significant if these interventions were combined with clinician reminders or academic detailing or were implemented as part of multicomponent interventions in general.

Public health efforts to improve screening in Appalachia in light of the challenges and nuance described above are ongoing. For example, research by Crosby, Stradtman, Collins, and Vanderpool (2017) found that an outreach-based CRC screening program could yield high return rates of FIT kits in rural Kentucky. They found that when people can interface with staff members in the initial provision of a FIT kit, people with low income (< $15,000 annually), individuals with low educational attainment, or those who lack a regular health care provider may be more likely to return kits for processing. In addition, their findings showed that those who do have have the perception that they are overweight or obese may be particularly likely to return FIT kits. It is important to note that in evaluating FIT as a population-level screening model in Appalachia, cost-benefit analyses conducted by Crosby, Mamaril, and Collins (2021) show that screening programs begin to yield positive net benefits at the stage of screening in which following a positive FIT result, participants undergo colonoscopy. The life years gained in this process make navigating patients with a positive FIT a critical step in interventions and illustrate a growing need for intensified outreach.

Many interventions include using patient navigators to support positive health communication to increase screening rates. However, little research has examined how communication may impact patients' reticence to accept provider recommendations, especially in the context of choosing to undergo colonoscopy following a positive FIT result. While patient navigation is common to help individuals overcome the logistical, financial, and other structural barriers to receiving a colonoscopy, FIT-testing, and follow-up care, little research has examined the patient navigation communication practices and how they address patients' orientations toward screening.

2.6 Patient Navigation

Patient navigation for cancer care was initially developed in the early 1990s to improve health outcomes in vulnerable populations by eliminating barriers to timely diagnosis and treatment of cancer and other chronic diseases (Freeman & Rodriguez, 2011). Generally, patient navigation (1) provides individual patients cancer-related care, (2) ends when health services are complete, (3) targets a defined set of health services, (4) focuses on the identification of individual patient-level barriers to accessing cancer care, (5) aims to reduce delays of diagnosis and treatment, and (6) intends to decrease the number of patients lost to follow up (Wells et al., 2008, p. 4). Navigation programs are typically barrier-focused and include elements designed to address and overcome patient barriers to care, provide health education across the cancer continuum of care, and deliver psychosocial support (Wells et al., 2008, p. 5).

Research shows that patient navigation is a valuable tool to improve cancer screening rates even among populations that are hardest to reach (e.g., Ali-Faisal, Colella, Medina-Jaudes, & Scott, 2017; Percac-Lima et al., 2009). In addition, patient navigation increased adherence to cancer care follow-up treatment and care. For example, Paskett and colleagues (2012) conducted a group-randomized trial with 862 patients from 18 clinics and found that patients with abnormal cancer screening tests or symptoms resolved faster if assigned to a patient navigator than those not assigned to a navigator. Data show that navigation may help address cancer-related health disparities after an abnormal screening test. Several studies corroborate these findings and highlight how patient navigation interventions improve FIT adherence and increase follow-up to CRC screening services like a colonoscopy (Nuss et al., 2012; Percac-Lima et al., 2009; Shapiro et al., 2010; Wells et al., 2008; Wells et al., 2012). Patient navigation is also a critical tool for increasing CRC screening rates among minority and low socioeconomic status populations and underserved communities who experience significant procedure-related barriers (Jandorf et al., 2005; Lebwohl et al., 2011; Percac-Lima et al., 2009). However, even with the success of patient navigation programs, for patient navigators, effectively communicating with patients can be challenging.

Although many studies show the effectiveness of navigation programs, fewer studies describe the challenges that navigators face in communicating with patients and the nature of communicative uncertainty that exists within these interactions. One exception is Rohan and colleagues’ (2016) investigation that uncovered navigators’ difficulties while providing navigation services to patients. They analyzed a hospital-based navigator service delivery program where patients were navigated for colonoscopy screening after randomization into an intervention. They investigated several variables, including barriers to colonoscopy, activities navigators undertook to reduce barriers, time navigators spent on each activity and per contact, and patient satisfaction with navigation services. On average, navigators spent 44 minutes with each patient. Descriptive analysis showed that navigators spent the most time assessing patient barriers/needs; facilitating appointment scheduling; reminding patients of appointments; educating patients about colorectal cancer, the importance of screening, and the colonoscopy preparation and procedures; and arranging transportation. In addition, patients valued the navigators, especially for providing emotional support and clearly explaining screening procedures and bowel preparation. However, little is known about the nature of patients' experiences of problematic integration regarding CRC screening following a positive FIT and the navigators' role in that process.

Even fewer studies investigate navigators' realities when serving rural communities like Appalachian Kentucky. The scarcity of research is problematic because culturally centered interventions are often the crux of program success. Few studies currently investigate the facilitators and barriers to successful CRC screening navigation from the perspective of patient navigators in rural areas, especially those that use communication theory to anchor the research. One study, conducted by Cohen, Scott, White, and Dignan (2013), uncovered the views of navigators helping patients receive cervical cancer screening in Appalachia. They analyzed in-depth interview transcripts with four lay patient navigators in a randomized navigation trial to examine patient-reported barriers to follow-up cervical cancer care and learn what communication strategies navigators used to successfully (or unsuccessfully) help patients navigate around those barriers. They identified three primary themes in the navigators' accounts. First, they found that logistical barriers to care (i.e., barriers related to the procurement, fulfillment, and maintenance of appropriate health care) often masked patient uncertainties about care outcomes. Second, navigators strategically use certain (e.g., using brochures) and uncertain (e.g., referring patients back to nurse practitioners) information about cervical abnormalities to motivate patients to receive appropriate follow-up care. Finally, they found that relational (e.g., intimate partner concerns/questions) and personal value (e.g., healing through prayer) conflicts posed significant challenges to navigation. This work highlights important culturally relevant barriers to communicating about cervical cancer screening; however, navigating to CRC screening services is different from that of cervical cancer screening due to the nature and different types of preventive screening and treatment services and disease outcomes. These issues influence CRC decision-making and adherence to navigator recommendations.

Several studies show that face-to-face, interpersonal communication bolsters the effectiveness of patient navigation interventions. For example, Percac-Lima and colleagues (2009) investigated the efficacy of a culturally tailored nurse navigation intervention to increase CRC screening among low-income, non-English speaking patients. They found that patients contacted by navigators in person were more likely to complete CRC screening than those reached by other methods. Jean-Pierre and colleagues (2011) revealed that navigators with more highly rated interpersonal relationships with patients yield improved outcomes for patients in terms of their experience with cancer-related care. The effects of interpersonal relationships were significantly greater for men and African Americans. Studies like these highlight the importance of interpersonal communication skills among patient navigators, especially when countering barriers patients face in getting the care they need. Patient navigators often tackle logistical barriers like transportation and insurance coverage while simultaneously addressing patients’ uncertainty-related barriers.

2.7 Model for CRC Screening Shared Decision-Making

In sum, in the context of the screening phase of the cancer care continuum, using constructs from HBM to examine how they anchor probabilistic and evaluative beliefs from PI theory can provide an integrated perspective into CRC screening decision-making among patients and offer support for navigation programs designed to increase screening and transition to follow-up care in underserved areas (see Figure 1.1). This dissertation examines the ways patients and patient navigators communicate the ambiguity, ambivalence, divergence, and impossibilities they see related to their goals of CRC screening and shared decision-making. The study explores how these uncertainties (characterized by ambiguity, ambivalence, divergence, and impossible communication) are oriented by individuals' perceptions relevant to their goals [e.g., susceptibility to CRC, the severity of CRC or concerns related to colonoscopy/fit, benefits of colonoscopy/FIT/early detection, cues to action (past recommendations/experiences), and self-efficacy].

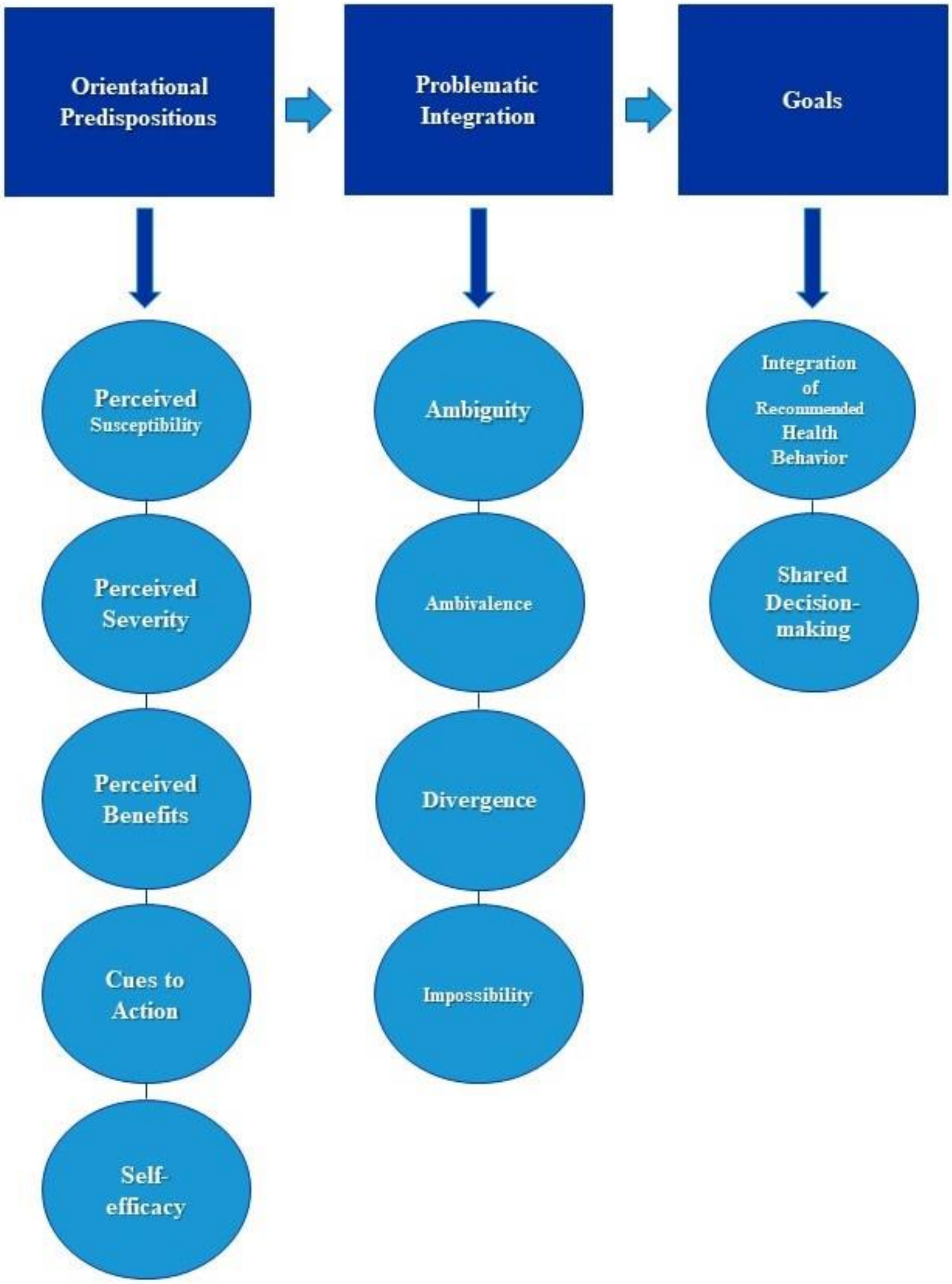

Figure 2.1 Problematic Integration of Health Behavior Framework

In addition, understanding the unique aspects of problematic integration, perceived threat, perceived benefits and barriers, cues to action, and feelings of self-efficacy among Appalachian patients can support intervention design that is culturally appropriate and patient centered. The following dissertation is a two-part qualitative study designed to dive deeper into the experiences of Appalachian patients and their navigators from a health communication-centered perspective to support ongoing public health efforts to increase screening in the area.

More information is needed about how Appalachian patients perceive CRC screening experiences and communication, specifically related to their probabilistic and evaluative orientations surrounding the act of being screened. In addition, more insight is necessary regarding how patient navigators describe patients' orientations to screening and how they respond to those orientations to support adherence to screening. Therefore, the following research questions are posed:

RQ1: *How do patient navigators describe patients' probabilistic and evaluative orientations in their CRC screening conversations?*

RQ2: *How do patients communicate shared decision-making related to follow-up care following an abnormal FIT result?*

RQ3: *How do patients work with navigators to resolve their probabilistic and evaluative orientations to CRC screening?*

The investigation of these research questions is detailed in chapters three and four of this dissertation. The knowledge gained from exploring these phenomena will help support ongoing, culturally informed efforts at increasing screening in rural communities like those in Appalachia.

CHAPTER 3. PATIENT NAVIGATORS (STUDY 1)

3.1 Introduction

The primary objective of Study 1 was to gain a better understanding of the facilitators and barriers to successful patient navigation to colonoscopy after a positive FIT result and the nature of participatory communication as perceived by navigators. To address this objective and the research questions posed, data from a semi-structured, qualitative interview approach used by RCPC staff were analyzed in-depth. Data consisted of the transcribed accounts of patient navigators who worked with patients that received a positive FIT result. In the following sections, the participants in Study 1 are described, and the procedures for collecting and analyzing the data are explained. Finally, a discussion of the findings and the limitations of this study is provided at the conclusion of this chapter.

3.2 Methods

The Rural Cancer Prevention Center (RCPC) was a CDC-funded Prevention Research Center from 2009-2019 that conducted a multi-pronged effort to reduce CRC among residents of the Kentucky River Area Health District (KRADD). Counties in the intervention area included Breathitt, Knott, Lee, Leslie, Letcher, Owsley, Perry, and Wolfe. As part of these efforts, local health departments and their affiliate health organization networks in each district provided FIT kits to people ages 50 to 75 that had not been previously screened for CRC. The result provided by this type of testing serves as a mechanism to identify whether a more invasive screening procedure like colonoscopy is needed. More specifically, if the test is negative, no action is usually needed outside of repeating the test in 11 months; however, additional screening is necessary if the test is positive. Thus, an essential element of RCPC's multilevel public health intervention was identifying patients receiving a positive FIT test and connecting them with patient navigation services for assistance with follow-up care.

3.2.1 Participants

With the support of RCPC staff, nine individuals (eight female, one male) who served as patient navigators were recruited to participate in one-on-one interviews. Participants identified as community health workers (n = 5; CHW), patient navigators (n = 2; PN), or nurse practitioners (n = 2; NP). A semi-structured, qualitative interview approach was utilized to better understand the facilitators and barriers to successful patient navigation to colonoscopy after a positive FIT result and the nature of participatory communication as recalled by navigators.

3.2.2 Recruitment

The RCPC team and staff of the UK Center for Excellence in Rural Health who had conducted patient navigation or case management to individuals receiving a positive FIT result were recruited to participate in one-on-one, in-depth interviews to evaluate screening intervention efforts in the Kentucky River community. The project manager connected with multiple RCPC navigation projects sent each participant a direct invitation to interview. Once the invitation was accepted, the participants' information was given to local research coordinators to set up the interviews.

3.2.3 Data Collection

From late-2017 to early-2018, two research coordinators trained by RCPC staff conducted one-on-one interviews either face-to-face or over the phone depending on participant availability. Each participant chose the day, time, and location for his or her interview. Upon enrollment, each participant was provided an informed consent document. Interviews were audio-recorded and lasted approximately 15-35 minutes. Participants did not receive an incentive for their time. Audio recordings of the interviews were transcribed verbatim for subsequent analysis. The transcripts were provided to the primary researcher de-identified; subsequently, pseudonyms were created for in-vivo quotations, data analysis, and clarity in reporting. Additionally, identifiers of the roles of each participant were included for clarity. Specifically, the primary researcher discerned those who played a role as a patient navigator (PN) in the intervention, as well as those who were serving in other roles and projects in the community, such as community health workers (CHW) and nurse practitioners (NP).

3.2.4 Protocol

The RCPC research team developed a semi-structured interview protocol designed to reveal participants' perceptions of dealing with barriers to screening and eliciting any logistical elements that supported or hindered effective patient navigation. First, the interviewer asked about the "easiest" and "most difficult" elements in assisting patients to follow-up care after an abnormal FIT result. Second, participants were directed to tell a story about patients with a positive FIT but still did not believe they were at high risk for colon cancer. Following this directive, the participants were asked probing questions, such as "how did you respond to this patient?" to uncover how they navigated patient uncertainty. Participants were also asked about the types of questions patients asked them and how they explained test results and diagnoses. Third, participants were asked about follow-up care using the same narrative question method. For example, participants were asked, “Can you tell me a story about a patient who was not willing to follow up after their diagnosis?” Participants were also asked about any barriers reported by their patients (e.g., cost, time, transportation) and how they communicated with patients to reduce those barriers. Fourth, participants were asked to tell a story about a patient who had privacy concerns. The interviewer asked follow-up questions to elicit how navigators responded to the patient, what they did when patients seemed unwilling to talk about their diagnosis, and what they said to patients concerned about privacy. Fifth, participants were questioned about their experiences working with other health care providers to identify how they coordinated patient care with consideration for the health care system in which their efforts took place. Participants were asked to identify the types of healthcare workers they often collaborated with and what made these encounters easy or difficult. Finally, the interviewer asked participants to identify any changes they might make concerning navigating patients and what advice they would provide to a patient navigator who was new to the profession. The interviewer closed the interview with a clearinghouse question to uncover any other topics the navigator may have wanted to share. Participants were thanked for their time at the close of each interview.

3.2.5 Data Analysis

Data collected were analyzed using a thematic framework analysis methodology. Generally, thematic analysis is a method for uncovering a collection of themes that at some level, reflect a patterned response or meaning (Braun & Clarke, 2006). Traditionally, thematic analysis goes beyond simply counting words or phrases to analyses aimed at “identifying and describing both implicit and explicit ideas” (Guest, MacQueen, & Namey, 2012). The use of thematic analysis spans academic disciplines wherein the topics addressed are diverse; the method is often used to understand experiences, perceptions, practices, and causal factors of varying phenomena (Braun & Clarke, 2013). Ritchie and Spencer (1994) developed the thematic framework analytic approach in conducting applied qualitative policy research. The primary researcher chose this method because it supported the primary objectives of Study 1, which are contextual, specifically identifying the form and nature of the experiences of patient navigators and their communication with the communities they serve. In addition, the method supports successive and inductive inquiry as the process may produce numerous yet distinct interconnected stages. Finally, the primary researcher used a robust constant-comparative methodology consistently in this dissertation as a means for refining and reviewing the conceptualizations of themes (or categories) against the empirical data (Lindlof & Taylor, 2011). The framework approach outlined by Ritchie and Spencer is “a systematic process of sifting, charting, and sorting material according to key issues and themes” (p. 310). In Study 1, the key issue is how patient navigators respond to various patient orientations, address problematic integration, and engage in shared decision-making to facilitate successful adherence to recommended CRC screening services.

To begin the analysis, several read-throughs of the transcripts were conducted to support familiarity with the data. In Study 1, the primary researcher only had access to the transcriptions, so multiple read-throughs were used to support immersion in the data. The next step was to identify and construct the framework (or index). The primary researcher drew upon a priori issues, emergent topics raised by patient navigators, and themes arising from the recurrence or patterning of navigators’ experiences. To that aim, follow-up read-throughs were conducted to support open coding. First, the primary researcher highlighted phrases and passages that pertained to patients' problematic integration as described by navigators and any language-related or relevant to practices associated with shared decision-making. Then, the primary researcher worked to identify categories to support indexing. According to Ritchie and Spencer, "indexing refers to the process whereby the thematic framework or index is systematically applied to the data in their textual form" (p. 316). They add that "applying an index is not a routine exercise as it involves making numerous judgments as to the meaning and significance of the data" (p. 316). In light of this, the primary researcher used inductive referencing to derive categories from the content to create the index. Lindlof and Taylor (2011) describe a category as "a covering term for an array of general phenomena: concepts, constructs, themes, and other types of "bins" in which to put items that are similar" (p. 246). The categorical approach is common in qualitative descriptive analysis and was conducted to offer a first-level description of the nature of participants' responses (Sandelowski, 2000; Sandelowski & Barroso, 2002). Initial categories included how participants navigated patients in the presence of various orientations and problematic integration and concepts related to shared decision-making; all the data were read and annotated according to these initial categories (or themes).

The final step in this method of data analysis is charting. Charting was used to create a picture of the data as a whole as the process supports the consideration of navigators' experiences for each theme. In this process, data were isolated from their original context and rearranged based on the appropriate thematic reference. These themes were established as primary headings in a codebook in which relevant participant quotes were placed. Specifically, the primary researcher placed quotations from the interviews into a master outline consisting of framework headings and subheadings (see Appendix 2) that identified primary and secondary themes (Ritchie & Spencer, 1994). The framework, which highlights major ideas and recurring themes present in participants' responses, is clarified in the findings section.

The primary researcher asked two trained coders to compile and compare findings, noting any differences in opinion or responses to questions. The requirements for coders included having graduate-level educational experience along with knowledge of basic qualitative methods. The primary researcher and coders reviewed and assessed the categories to reorganize major and minor themes within the data. Disagreements were negotiated, and the team established that the themes accurately reflected the experiences of navigators.

3.3 Findings

The purpose of Study 1 was to identify the form and nature of the experiences of patient navigators and their communication with the communities they serve. Specifically, this study sought to identify the nature of navigators' experiences addressing patients' probabilistic and evaluative orientations and engaging in shared decision-making in patient navigation practices. The three primary themes identified from the data include (1) navigating problematic integration, (2) supporting shared decision-making, and (3) improving perceived self-efficacy for future navigational communication. These themes and relevant sub-themes are described and supported by in-vivo quotations from participants in the following paragraphs.

The first primary theme was patient navigators' experiences in (1) navigating problematic integration among patients. Data show that the navigators experienced various types of problematic integration, including (1.1) ambiguity, (1.2) ambivalence, (1.3) impossibility, and (1.4) divergence. These types of PI are grounded in the research literature and constitute unique sub-themes for navigating problematic integration.

The first sub-theme identified is related to navigators' experiences attending to ambiguity. Recall that ambiguity exists when there is a lack of clarity about some probability. In some instances, a lack of clarity existed in the logistical elements of navigating the healthcare system. For example, Mary Jo (NP) said, "The most difficult thing [about working with providers] is that everyone requires something different for a referral. So it's just a matter of getting whatever somebody needs. And it's not really that big of a deal, ya know. It's just finding out what they want and getting it to them basically." Navigators knew that patients with a positive FIT result needed a diagnostic colonoscopy, but what was needed to successfully schedule varied by providers in the area. Informational ambiguity related to patient referral was described by several navigators.

In many of the navigators' experiences, ambiguity manifested among patients in their reactions to being informed of a positive FIT result. For example, Suzanne (CHW) stated, "They [patients] get apprehensive and worried and scared. They're like, 'Well, it says that it's positive [FIT], and that means I have cancer.' Panic sets in. And I'm like, 'let's wait a minute here. This doesn't necessarily mean you have cancer.' I try to be supportive, whatever the situation is." The task of managing panic about the meaning of results and the fear of a potential cancer diagnosis was evident.

Other navigators encountered similar occurrences with patients. Julia (NP) said, "…people who got a positive FIT result would automatically think, 'oh, I have colon cancer,' and I would say that it doesn't necessarily mean that, [it] just means that they need to follow up…. I usually tell them that as long as they follow up and do what they are supposed to do, then it's treatable, and there is a lot that can be done. And then, I would also tell them that early detection and early medicine are the biggest things that keep you from having a problem. I try to emphasize on the importance of them following up.” The presence of ambiguity around positive FIT was so strong that navigators made strategic decisions about the type of language they used with patients. For instance, Julia (NP) explained, “I tried not to use the C-word [cancer] with them terribly much; I just want them to go to their appointments and follow up. Ya know – I try to focus on more [the fact] that this doesn’t necessarily mean there is anything terrible, it just means that we need to be on it and take care of you.”

Other navigators detailed using a step-by-step formula for explaining FIT results and relied on framing follow-up diagnostic testing as an opportunity. Specifically, Anthony (PN) stated, “But when I talk with individuals about the positive FIT result and the importance of the colonoscopy, the first thing I have to do is actually explain what these FIT results actually mean. I have to tell them, this does not mean you have colon cancer. When I frame it that way and tell them that, this is an opportunity to find out if there is anything in there that may become colon cancer, and it is getting you a chance to get that removed before it does.” Reframing what was uncertain as an opportunity to get ahead of potential problems emerged as a strategy for several navigators.

The third sub-theme is related to navigators’ experiences addressing ambivalence. Recall that ambivalence exists when two alternatives are equally valued, but one cannot be chosen without turning down the other or when an alternative has equally positive and negative characteristics. For navigators, patients often presented alternatives related to family experiences or commitments. One navigator made a striking generalization related to her experiences navigating patients to diagnostic services following a positive FIT result. Julia (NP) said, "…patients who have a family history were even worse at following up than patients that didn't, and I think it was just out of fear." Patients were seemingly fearful of the consequences of follow-up testing.

Some patients described the origin of their apprehension. Suzanne (CHW) said, "They will say that 'mom was sick', and she went to the doctor and they did all these treatments. And they ran her up and down the road [gave her the run-around] and she just got sicker and sicker and sicker, so I'm not going to do that. I'm not gonna do these tests." Charlene (CHW) echoed this experience, saying, "What is most difficult [is] that there are several different factors I think with one being the people are afraid of getting the test done either for what they may find out or horror stories especially when it comes to colonoscopies and patients go by what their grandparents told them or what their parents told them."

In other cases, navigators detailed how patients were often faced with challenging decisions related to the ambivalence they experienced. For example, Anthony (PN) said, "I worked with one case where the lady that had the positive FIT result. When we originally approached her about a colonoscopy, she said yes, and she would…The health department I worked through to get her to a free colonoscopy called and said this lady didn't show up. So, when I was actually able to talk with her, I found out that she couldn't keep that appointment because she is taking care of a husband, who is ill…He was suffering from cancer himself, pancreatic cancer. Because of that, she has to be the caregiver for him and doesn't have the ability to go take care of herself." One might imagine the emotional labor associated with weighing the positive and negative characteristics of these alternatives. Some navigators witnessed the phenomenon of ambivalence related to "choosing" between personal health and that of a family member relatively frequently. For example, Anthony (PN) asserted, "Women are the primary caregiver in a household, and if the woman feels like there is a need for her family, she will put that first before her own health…we have so many people within the age range of colon cancer screening again, especially women, who are raising their grandchildren…and because of that, they're not able to dedicate as much time to their own needs."

In other instances, the alternatives were related to spirituality and faith. For instance, Charlene (CHW) said, "A lot of them [patients] will be like, one lady in particular who uses her faith…believes that if she requests prayer then that will be taken care of, which I believe in that too but still, I try to let her know that you know, the Lord has provided the doctors the education in order to help and the facilities in order to help take care of her now so that later on she won't have to go through cancer or things like that." Charlene's experience with this type of problematic integration, coupled with her individual spirituality, allowed her to develop a response that might help patients more successfully integrate their health decisions with their faith.

Other navigators seemed to follow suit in developing responses to patients experiencing this type of problematic integration. For example, Mary Jo (NP) said, "I draw out the 'you have children' card, and 'you want to be here to raise your children'." In this case, personal knowledge of the patients' family may have assisted in addressing ambivalence.

For patients who cited family commitments as a hindrance to follow-up diagnostic screening, other navigators used similar tactics. For example, Julia (NP) stated, “I would say ‘what’s a day out of your schedule that could save your life in the future?’.” Interestingly, navigators seemed to articulate providing responses like these more often to those patients who were seemingly experiencing ambivalence.

The final sub-theme identified is related to navigators’ experiences identifying impossibility among the patients they encounter. Recall that impossibility exists when there is an “impossible desire” or “certain unpleasantness.” Several navigators lamented about the impossible desires experienced in the patient population they served. Specifically, many patients expressed the desire for follow-up screening but could not justify the act in light of their current circumstances. For example, Julia (NP) said, “A lot of our patients don’t have cars; or we recruited some people from the homeless shelter, so, ya know. If you’re worried about where you’re going to stay at night and where you’re going to eat, you’re not really worried about whether or not you’re going to show up at your doctor’s appointment.” Julia’s account highlights that many patients may be struggling to have their basic needs met and the reality that potentially life-saving diagnostic follow-up healthcare simply may not be a priority.

Charlene (CHW) supported experiencing this reality, saying, “…if they come in uninsured and then they are over the income for any type of financial assistance and being able to get the colonoscopy completed once they have a reactive test because they can’t afford it. They can’t afford the hospital part or the procedure…one lady in particular she doesn’t have any insurance at all and over the income financials over at the hospital and when we called to get her colonoscopy, because she was reactive. The hospital informed us that they went over the price and how much it would cost if she just came in as preventative, you know? And then once, if there were any polyps found, then it goes into diagnostic and another 2-3,000 dollars is what it would cost for her to have that colonoscopy completed. So she opted out of it.” Experiences like this illustrate the need for policy-related interventions to support access to diagnostic follow-up care regardless of the ability to pay.

As many navigators detailed their experiences countering impossibility-related concerns such as the ability to pay for care, another issue emerged that may have other, deeper implications for serving male patients, specifically. Some navigators experienced increased frustration with navigating male patients to colonoscopy services. Carlene (PN) said, “A lot of times, I guess they just are not willing to do the colonoscopy…it's pretty easy to get them to take…the FIT test, but when it comes down to actually getting them to schedule a colonoscopy when they have a positive, especially with men in this area and they…are not willing to do that.” She elaborated on a specific patient, saying, “He said, ‘that's just something that's private, and I really just don't even want to discuss it.’ So, it was real…hard on trying to convince him, and to this day, I don't think he ever did the colonoscopy…I tried to encourage him and telling him it wasn't as bad as everybody [says]. He just said he didn't feel comfortable with somebody being in that area of his body, pretty much.” She surmised that his issue was related to privacy, but in the dialogue of her interview, one could tell that she suspected a deeper concern. She continued, “…then with the males, they just don't – they don't want anybody in that area of their body with a foreign object. So, I would just… [guessing about the root of the patient’s concern] a stigma? I guess, I don't know.”

Another male navigator was more certain about the issue at hand. Anthony (PN) stated, “Just because of the area of the body, where this screening is going to take place, and the way we have all been conditioned to believe that that area of our body is even maybe more private than our genitals, that you know, you don’t show that part of your body to people. Especially don’t let someone put a tube up in it, especially if you are a male in eastern Kentucky. A transfer of homophobia associated with this medical process can come into play especially with men.” As a male, he believed that he was more readily equipped to address the issue among male patients. He continued, “I can talk to other men about this because I am a man who’s had a colonoscopy and I can tell them, you’re not going to remember one thing about what happens to that part of your body, you’re not gonna be aware that anyone saw that part of your body, and that no one is going to tell you what that part of your body looked like or whatever. So, when you can actually tell them you experienced this firsthand, and there were no negative outcomes to you as a result to this; if you are successful at gaining some trust from them, then more than likely they will listen to that.” Patients’ perceived implications of the colonoscopy procedure for their gender identity or sexual orientation is an issue that navigators must be prepared to address; however, patients may not clearly articulate these concerns, and these attitudes may be difficult to uncover in conversation.

The final sub-theme identified is related to navigators’ experiences dealing with divergence. Divergence exists when there is a discrepancy between what is desired and the likelihood of those desires. Interestingly, themes of divergence appeared in navigators’ accounts of working with healthcare providers. For example, Anthony (PN) said, “…occasionally you will find healthcare workers…who are not that dedicated into what they are doing…I almost felt like I was trying to be a counselor and trying to re-instill these characteristics in them that I know they must have had at some point in order to be in health care in the first place, so it's like I'm working with two clients at the same time at that point. That is a very hard day." The added emotional labor of not only persuading patients to get screened but also attempting to influence providers to be patient-centered was evident. The navigator did not elaborate on what exactly constituted a lack of dedication to patient care.

Another navigator's account may shed light on these perceptions. In commenting on the most difficult element of patient navigation, Julia (NP) said, "I'd say the most difficult thing was, um, getting the patients to actually show up to their appointments and then, therefore, the healthcare providers to reschedule them – once somebody has missed 4 or 5 appointments, your provider gets a little iffy about continuing to reschedule them." There seems to be a possibility that patients being a "no-show" to appointments may impact healthcare workers perceptions and perhaps their willingness to extend care.

In both of these examples, divergence existed for the navigators and the providers they encountered as they attempted to assist patients in receiving timely follow-up screening. While this theme is unique, it is possible that navigators perceived divergence between themselves and other providers in values associated with patient-centered care (e.g., respect for patients' needs and preferences), while in reality, ambiguity and uncertainty surrounding appointment and rescheduling procedures was a stronger contributing factor. System-level variables, such as policies for missed appointments, may influence communication associated with patient navigation to the degree that navigators' perceptions of providers may shape their approach to certain navigational practices.

The second primary theme was navigators' descriptions of how they engaged in (2) supporting shared decision-making. Key sub-themes associated with this theme include navigators' accounts of providing information to patients about CRC screening and supporting deliberation on the decision to receive follow-up diagnostic testing following a reactive FIT. One of the primary ways navigators described their work was situated in (2.1) providing information to their patients. The act of providing information was detailed in several different ways. The first way was providing information in a way that respected patients' privacy preferences. For example, Suzanne (CHW) said, "Some people are very private about their medical issues. We always adhere here at the office to one-on-one [consultation], unless they bring their spouse because then they want them to know." Navigators seemed well-versed in managing the interaction in light of patients' preferences. Julia's (NP) accounts support this. She said, "I made sure that if I was going to talk to someone about their test results and navigation, that we were alone and in a place that was like a secure place. Or I would be like, 'we need to talk about some private stuff. Make sure that there's nobody around'…we always made sure to talk directly to the patient – not family members. Cause a lot of patients didn't want their family to know they had done a FIT test, let alone the results."

Many navigators' perceived credibility in the community hinged on their ability to respect patients' information preferences. For instance, Suzanne (CHW) said, "Don't share information outside of the office…and that goes with your reputation. You don't hear me out on the street talking about someone else's health issues. They know me better than that." Many navigators understood the reality of how quickly information can travel in small communities and maintained a reputation for supporting privacy.

The second way navigators discussed the experience of providing information was through their longing for partners in information-sharing responsibilities. For example, Charlene (CHW) said, "...here when a patient does into to see a doctor, they are going because they are sick or they need a shot because they don't feel well and I guess just the doctor actually talking to them about their preventative care, they just don't take the time to do it you know? They are so busy in their clinics because everyone almost has insurance now. When a patient comes in, they take care of that one need, and then they send them on their way when they should be spending more time talking to them about their preventative services that they need. If you're 40, then it's time for your mammogram. If you're 50, it's time for your colonoscopy. If you have family history, you need to be seen before then. So I think that's just not enough time with their provider I think." Charlene seemed to believe that incorporating information about appropriate screening into non-routine visits might supplement patients' understanding of and willingness to be screened for various types of cancers.

The third way navigators reported sharing information was by providing patients with data related to the potential consequences of avoiding follow-up diagnostic screening. For example, Mary Jo (NP) said, "I start talking about…statistics for Kentucky and sit down with them in front of the computer and say, 'this is why…you want to…go ahead and do this'. And then I will go, 'okay, let me tell you what can happen'. And, explaining some of the kinds of things that can happen – if you uh, get cancer, and, you know, if this is preventable now, why would you want to go that far? Why would you want to go there? Why would you want to get to the point when you have a bowel reconstruction? Or, uh, ya know, chemo and radiology/ radiation? So, ya know. I probably will try to put some fear in them." While this tactic may have worked anecdotally for this navigator, the utility of information sharing as a fear appeal to support adherence to follow-up direct visualization screening remains unclear.

Navigators in the study detailed many ways they help to disseminate important information about CRC screening to patients, and these efforts were often coupled with strategies for (2.2) supporting deliberation of the decision to be screened. One of the ways that navigators supported deliberation of recommended screening was through their efforts to build trust with patients. For example, Juila (NP) said, "…if you have a patient that doesn't trust you, then there's lots of ways that you can build trust…if they are uneasy about the providers that I would be sending them to for a colonoscopy…I give them providers that I think are really reliable or especially good at what they do, then I usually tell them, 'I would let them take care of me and take my family'. That usually helps." For Julia, the familiarity with providers in the community provided tremendous utility in helping patients feel a bit more confident in their choice to get follow-up screening.

Sometimes building trust meant acknowledging that another navigator or clinical partner might be better suited to support patients. For example, Suzanne (CHW) said, "You can't force them. If the patient is not willing to talk about it or willing to proceed, I can't force them of course into treatment. I can just be supportive, give them the education I have, and offer to get more and offer to get someone else if they would rather talk to someone other than me. And some people would open up more…maybe open [up] to a stranger [more] than someone they have known for a while. You have to feel out the patient and see what's going to work for them." Seemingly, attempts to "feel out the patient" often meant a greater investment of time and resources. Julia (NP) echoed this reality, saying, “You can’t force patients to talk to you about things they don't want to talk about. You can just let them know you’re there and available to talk. And obviously, ya know, reinforce the fact that denying it or ignoring it’s not going to change anything. And being available to them, because a lot of times they don't want to talk to you then, they will want to talk to you later.” In many cases, supporting deliberation meant providing patients with more time, even if it meant greater worry and anxiety for the navigator.

Often, navigators used their relationships with providers in the community to support timely and appropriate care. In some instances, this extended to issues unrelated to screening. For example, Suzanne (CHW) said, “He [a physician] called my office, and he explained that this is not good news [prognosis for a patient], and the family does not understand. And I am very close with every member of that family, so I became the liaison between the two. And I had to learn a lot of those big words, but it helped the family, it helped me to know what was going on, and that’s my job. That’s what I’m supposed to do. It’s awesome to be that liaison.” Suzanne’s account shows that for navigators, serving as a liaison involves many different tasks, including learning ways to make complex information make sense to patients and their families.

For many navigators, using tactics to involve patients’ friends and family became a large part of their role. For example, Carlene (PN) said, “He [a patient] didn’t want to take the test at first, and then we actually met up with him at a senior center, and he saw that there were more of his friends doing the test so he [...] was like, ‘I'll do this’.” In this case, the patient seeing his friends engage in the recommended health behavior was the cue to action needed to supplement the decision-making process to get screened.

Several navigators detailed their service to patients going beyond one interaction or consultation. For many navigators, convincing patients to get screened was an ongoing endeavor. For instance, Anthony (PN) reported, “After working with me quite a while, me twisting their arm and harassing them long enough and getting their family members to help me harass them, they finally got his done and they found out they had some polyps in there and the polyps were removed before they ever had a chance of becoming cancerous.” Anthony’s persistence paid off in this case with the news of a positive outcome.

In many navigators’ accounts, there was a sense of exasperation in the reports of persistence. For instance, Suzanne (CHW) said, “…you still just try to be supportive, you give them the best education you can, you work with their doctor IF they will go to a doctor. Talk to a family member; you kinda weasel your way in there and you talk to the wife.” Another navigator was willing to go to great lengths in her persistence. Bonnie Jean (CHW) said, “…begin with that patient and whatever their need is, you see to that need and you work with that provider and that nurse and their health care to make sure that that need is met. Whatever it takes.” The “whatever it takes” attitude was certainly present in other navigators’ accounts, to the extent that supporting deliberation meant providing patients with instrumental support.

At least two navigators in the study reported physically taking their clients to colonoscopy appointments. Suzanne (CHW) said, “…you just gotta step in, and I said ‘I’ll go. I’ll make the trip with you and I’ll go with you. You’re not alone in this. It’s very important.’ And that’s what I did. I went with her. I took her to have her colonoscopy.” Julia (NP) reported a similar situation. She said, “…we had one patient that kept canceling her appointments because I guess she was afraid. And come to find out she didn’t have anyone to go with her, and she wanted someone to go with her. So, I ended up going with her and with her, through her appointment with her, and she was fine. She did well with that. That was the only way we could actually get her there." The sense of caring for patients in the community was abundantly clear in so many of the navigator's stories. Navigators consistently expressed a willingness to go above and beyond to support deliberation among their patients, and hopefully, the ultimate integration of timely and appropriate CRC screening.

The third (and final) primary theme relates to the advice provided by navigators for (3) increasing self-efficacy among future patient navigators. Navigators' advice focused primarily on using social capital and interpersonal influence to more successfully navigate patients. The first sub-theme details navigators' advice for (3.1) building a network and a solid knowledge base to serve patients better. One provider mentioned that a working knowledge of screening practices was critical to her success, particularly in making referrals. Mary Jo (NP) said, "…familiarize yourself first of all with the test [FIT, colonoscopy] itself; know the ins and outs. Know what it actually does. How it's actually different…who you need to refer to and why."

Other navigators stressed the importance of networking with healthcare organizations and workers in the area. Anthony (PN) said, "Before you ever take on your first client, [...] you need to get yourself out there and know all the people that you can think of that you are gonna have to make referrals to. Any other health care workers you are gonna have to work with, any other community agencies that provides a service to the clients that you are gonna be working with might need, go out there and do some lunches with those people and pass out business cards and collect theirs so that you know that team you are fitting into and that you are gonna become a part of because you need to see yourself as a part of a team that is helping the management to this person’s health care.”

Along with social capital, navigators stressed the need for a few vital interpersonal characteristics. The second sub-theme details words of advice for future navigators about (3.2) being honest, empathetic, and (most of all) persistent when working with patients and providers. Being yourself and remaining honest with patients was important for navigators. For example, Carlene (PN) said, “…just be yourself and be honest and try to help them make them feel comfortable about what they’re doing and express the importance of this test and the follow-up test.”

In addition to honesty, navigators mentioned the importance of empathy skills. For instance, Bonnie Jean (CHW) said, “…if you can kinda put yourself in their shoes, you know, and figure out what is causing the unwillingness. If you can figure that cause out then most of the time you can fix whatever is causing that unwillingness.” For some, empathy seemed to complement other skills, such as problem-solving. For example, Mary Jo (NP) said, “Try to help them work through it and try to figure out a way around it, or over it, or under it, or something…it’s all about problem-solving.”

Finally, many navigators highlighted the importance of being persistent with patients. Suzanne (CHW) spoke about being a “little voice” for her patients. She said, “I make a lot of phone calls; ‘Did you go do that yet?’ You want to be that little voice that [says] ‘someone cares about me. She’s still calling. Maybe I ought to go.’ You just hope for that breakthrough that they will listen before it’s too late.”

3.4 Discussion

The research question posed in this study related to how patient navigators describe patients' probabilistic and evaluative orientations in their CRC screening conversations following an abnormal FIT result. Connections from these findings relate to how navigators' communication practices help patients overcome obstacles to follow-up care (by helping them address and transcend ambiguity) and utilize strong interpersonal skills to build a supportive social network of care providers for referrals. Findings indicate how patient navigators actively focused on the identification of individual patient-level barriers to access cancer care yet are struggling to reduce delays of diagnosis and treatment and lamenting the number of patients who are lost to follow-up due to system-related challenges. Patient navigators also demonstrate a willingness to identify and manage readiness for screening on a case-by-case basis and often respond to different types of problematic integration in interesting ways. Data show that navigators are pursuing a collaborative approach to navigating patients. Several navigators indicated that their community-specific knowledge was the key ingredient for developing rapport with their patients.

The data presents several strategies supporting shared decision-making among patients, including active work in broadening participation in medical decisions and advice for how future navigators might be even more successful. The six core functions of patient-clinician communication are demonstrated (or longed for) by patient navigators in several interesting ways. In terms of fostering relationships, building relationships with patients is an evident focus for the navigators that were interviewed for this study. This was apparent not only in navigators' stories of relief (or anguish) about patient outcomes but in the ways they defined and protected privacy for their patients. Navigators were clear with patients about the nature of the information that may be discussed in their encounters and also engaged in dialogue with patients about the additional “stakeholders” (e.g., family members) in the screening conversation. For navigators, the importance of relational dynamics did not end with patients - they also stressed how building relationships with clinicians was central to their practice. Many navigators reported benefitting from a familiarity with the system, wherein the “system” included important clinical gatekeepers. Navigators gained such a familiarity with the system that they reported noticing a lack of patient-centered care in the contexts in which they worked with patients. In other words, participants were not simply “navigating” the system - they seemed to report influencing it to at least some degree.

Exchanging information appeared as a critical job function (and frustration) for navigators. Many navigators reported benefitting from knowing precisely the type of information required by different clinics on referral documentation. In addition to navigating the nuances of clinicians’ information, navigators also reported translating various types of health information for their patients. There was also much lament about the need for primary care clinicians to discuss the importance of and options for screening with their patients.

Navigators reported working diligently to respond to patients’ emotions and managing uncertainty. For many navigators, helping patients to manage fear and panic was simply part of the job. Many patients reported being fearful or experiencing panic to their navigators, to which navigators reported responding by asking questions and listening. In this practice, navigators seemed to uncover a strong connection between reticence to be screened and stories of family members who’d had poor health experiences. Responding to a patient's certainty that they had cancer following a positive FIT result was a frequent occurrence in the navigators’ work to manage patients’ uncertainty.

Navigators reported inviting patients to participate, presenting screening options, and assisting patients in evaluating their options based on individual goals and concerns. However, while many navigators focused on the benefits of screening (e.g., preventing future, more severe issues), very little discussion of screening risks with patients was reported outside of the risk to remain unscreened. Several navigators discussed facilitating deliberation and decision-making by including friends or family members in their efforts.

In terms of patient self-management, navigators focused on advocacy to support their patients. Advocacy for patients did not come without challenges as some navigators reported experiencing frustrations with the healthcare system. One example wherein a navigator had finally convinced a patient to receive follow-up colonoscopy, but then the patient discovered the cost of care was not within a feasible range for her situation highlights the considerable setbacks navigators may encounter as they work to help patients seek appropriate care. Patient navigators are actively focusing on the identification of individual patient-level barriers to access cancer care, yet are struggling to reduce delays of diagnosis and treatment and lamenting the number of patients who are lost to follow-up due to system-related challenges.

Patient navigators demonstrate a willingness to identify and manage readiness for screening on a case-by-case basis and often respond to different types of problematic integration in interesting ways. Data show that navigators are pursuing a collaborative approach to navigating patients. Several navigators indicated that their community-specific knowledge was the key ingredient for developing rapport with their patients. The data presents several strategies supporting shared decision-making among patients, including active work in broadening participation in medical decisions and advice for how future navigators might be even more successful.

3.5 Limitations

As with any study, there are a few limitations to note. First, Study 1 featured a small sample of patient navigators serving a single intervention area, and little demographic information was provided to the primary researcher outside of the participants' sex and occupation. This limitation occludes effective consideration of responses by factors such as age. Second, the interview protocol was designed by RCPC staff as a means for programmatic evaluation, and the data was collected without guidance from the primary researcher. There are several passages from the transcriptions where the primary researcher longed for additional information that supplementary probing questions may have produced. Finally, data from Study 1 is self-reported and may contain several potential sources of bias. Participants in this study likely wished to represent their knowledge, skills, and abilities as navigators in the most positive terms. In other words, social desirability bias and other biases, such as selective memory, attribution, or exaggeration, are important factors to consider in the interpretation of the findings.

3.6 Conclusion

Patient navigators are experiencing barriers to navigating patients to follow-up care following an abnormal FIT result and offer unique insight into the nature of addressing problematic integration in patient navigation practices. The three primary themes identified include (1) navigating problematic integration, (2) supporting shared decision-making, and (3) increasing self-efficacy for future navigators. In addition, the data reveal important connections to core functions of patient-clinician communication used to respond to varying types of problematic integration and provide patient navigation strategies aimed at supporting shared decision-making and the integration of timely and appropriate CRC screening among patients.

CHAPTER 4. PATIENTS (STUDY 2)

4.1 Introduction

The primary objective of Study 2 was to better understand patients' perceptions of decision-making related to follow-up care following an abnormal (or positive) FIT result. Specifically, the primary researcher sought to identify how patients communicate shared decision-making, as well as how they work with navigators to resolve their probabilistic and evaluative orientations to CRC screening. An in-depth analysis of the data from a semi-structured, qualitative interview approach used by RCPC staff addressed this objective. Data consisted of the transcribed accounts of patients who received patient navigation services following a positive FIT result. Study 2 is described in the following sections, and procedures for collecting and analyzing the data are explained. A discussion of the findings and the limitations of this Study 2 is also provided in this chapter.

4.2 Methods

Access to the stories of patients who received a positive FIT result and subsequent navigation services to colonoscopy was made possible by the RCPC, a CDC-funded Prevention Research Center that facilitated a multi-pronged effort to reduce the burden of CRC in Appalachian communities. As mentioned in Chapter 3, a fundamental element in the multilevel public health intervention led by the RCPC was coordinating with local health departments and their affiliate health organization networks in several Appalachian communities to disseminate FIT kits to people ages 50 to 75 who had not been previously screened for CRC. In addition, to complement the diffusion of FIT kits, patients with a positive FIT result were identified and connected to patient navigators to support their screening decision-making related to receiving follow-up care, which most usually includes colonoscopy services.

4.2.1 Participants

With the support of RCPC staff, ten patients (three female, seven male) were recruited from the intervention area (i.e., Breathitt, Knott, Lee, Leslie, Letcher, Owsley, Perry, and Wolfe counties) to participate in one-on-one interviews. Patients who participated in the interviews had received a positive FIT result but had not completed recommended follow-up colonoscopy screening at the time of recruitment. Patients who participated had also engaged in patient navigation services aimed at connecting them with appropriate follow-up care. Therefore, a semi-structured, qualitative interview approach was designed to understand the decision not to pursue follow-up care. The transcribed accounts of the patients were made available to the primary researcher without any identifying information, including crucial demographic information about the sample.

4.2.2 Recruitment

Any individual who received a positive screening result on FIT kits provided by the RCPC service delivery project was offered patient navigation to colonoscopy and, if necessary, treatment. After patient navigation was provided at no cost to participants, they were asked if they would like to volunteer for a research project studying the effect of patient navigation on receiving further screening and accessing treatment, if needed. Individuals accepting patient navigation who indicated they wished to enroll were enrolled at their first patient navigation session. Individuals who declined patient navigation but indicated they would like to participate were asked to schedule a meeting with an RCPC team member at their convenience.

4.2.3 Data Collection

From 2017 to 2018, several research coordinators trained by RCPC staff conducted one-on-one interviews either face-to-face or over the phone, depending on individual availability. Each participant chose the day, time, and location for their interview. Upon enrollment, each participant was provided an informed consent document. Interviews were audio-recorded and lasted approximately 15-30 minutes. Participants received a $20 gift card at the end of the interview. Audio recordings of the interviews were transcribed verbatim and provided to the primary researcher de-identified. Pseudonyms were created for in-vivo quotations for data analysis and description.

4.2.4 Protocol

The RCPC research team used a semi-structured interview protocol to understand patients’ decision-making processes related to colonoscopy after receiving a positive FIT result. These efforts were part of larger implementation assessments of the efforts included in the larger intervention. First, participants were asked to recall their thoughts after being initially notified of a positive FIT result. Then, participants were asked to recount their experiences with the patient navigation services and whether their views about colonoscopy had changed since they received navigation. Third, participants were asked about their experience with a range of barriers to CRC screening identified by existing research (i.e., cost, transportation, childcare, family care, assistance with appointments, fear). Finally, participants were asked about the likelihood of receiving a colonoscopy within the following year. The protocol also included a clearinghouse question to allow participants to add any other vital insights they believed helpful for the interviewer to understand their experience.

4.2.5 Data Analysis

Data collected in Study 2 were analyzed using a thematic framework analysis methodology (Ritchie & Spencer, 1994). The primary researcher chose this method because it supports applied qualitative policy research and aligns with the primary (and contextual) objectives of Study 2. Specifically, the aim of Study 2 was to uncover the form and nature of the experiences of patients who refuse colonoscopy following a positive FIT result. The primary researcher aims to use a robust constant-comparative methodology consistently in this dissertation, and this method supports successive, inductive inquiry. As a reminder, this framework approach is a systematic process for analyzing material according to critical issues and themes. In Study 2, the critical issue is patients' perceptions of decision-making about refusing colonoscopy even after detecting an abnormal FIT result.

Similar to Study 1, the primary researcher conducted an analysis of the transcriptions, so several read-throughs of the transcripts were conducted to support familiarity with and immersion in the data. Next, the primary researcher drew upon a priori issues, emergent topics raised by patients, and themes arising from the recurrence or patterning of patients' experiences to identify and construct the framework (or index). Then, follow-up read-throughs were conducted in which the primary researcher highlighted phrases and passages that pertained to patients' decision-making and participatory communication practices. Next, similar to Study 1, categories were created using inductive referencing to support indexing. Initial categories included key concepts related to decision-making and participatory communication; all the data were read and annotated according to these initial categories (or themes).

Finally, the primary research used charting to create a picture of the data as a whole. To that aim, data were isolated from their original context and rearranged based on the appropriate thematic reference. These themes were established as primary headings in a codebook in which relevant participant quotes were placed. Specifically, the primary researcher put quotations from the interviews into a master outline consisting of framework headings and subheadings (see Appendix 4) that identified primary and secondary themes (Ritchie & Spencer, 1994). The framework, which focuses on the significant ideas and recurring themes present in patients' responses, is clarified in the findings section.

The primary researcher asked two trained coders to compile and compare findings, noting any differences in opinion or responses to questions. As with Study 1, the requirements for coders in Study 2 included having graduate-level educational experience along with a working knowledge of basic qualitative methods. The primary researcher and coders reviewed and assessed the categories to reorganize major and minor themes within the data. The team negotiated any disagreements and found a consensus that the themes accurately reflected the experiences of the patients included in the study.

4.3 Findings

The purpose of Study 2 was to better understand patients' probabilistic and evaluative orientations to CRC screening and their perceptions of shared decision-making related to follow-up care following an abnormal FIT result. The four primary themes identified include (1) lacking key assurances required for screening and understanding results, (2) engaging in the emotional labor of screening decisions, (3) reconciling screening and results with everyday life, and (4) conducting personal analyses of screening practices. Themes 1 and 2 relate to shared decision-making (RQ2), specifically patients' difficulties receiving patient-centered care and accepting navigational support. Themes 3 and 4 detail the ways in which patients work with navigators (and others) to resolve their probabilistic and evaluative orientations to CRC screening (RQ3). These themes and relevant sub-themes are described and supported by in-vivo quotations from participants in the following paragraphs.

The first primary theme was patients' (1) lacking key assurances required for screening and understanding results. Many patients reported a lack of confidence or certainty that CRC screening was beneficial for them. The sub-themes supporting this theme include (1.1) needing quality and affordable care, (1.2) overcoming challenges getting to the appointment, and (1.3) desiring more information about testing and the meaning of results.

First, patients' stories reflected a need for quality and affordable care to support their screening decision. Nick, who remained unscreened at the time of the interview, said, “I'm not trying to go through all the things that you have to go through.” While he did not elaborate about the “things” of particular concern, he went on to ask the interviewer additional questions about the cost of colonoscopy. He said, “So, there will be no cost to me or any of my family or anything like that? My insurance will pay it?” Other patients were more specific about the support they needed to get screened.

Gill, who had refused follow-up colonoscopy before the interview, inevitably decided to undergo the procedure. He said, “I already figured get in there and get it done and if this turns into cancer, let's get it straightened out before it does turn into cancer...it all [the screening process] went good. Good people that did the test and good people that told me about it and whatever not, and I think it all turned out wonderful.” He did not elaborate on “good people.” However, it is important to note that this particular participant reported receiving polyp removal following colonoscopy.

Second, patients reported overcoming challenges getting to the appointment. Getting to the appointment was an issue for several patients that impacted their decision to be screened. For some patients, receiving care closer to home was a crucial factor in getting screened. For example, Julianne said, “I can get to Hazard and stuff...I won’t go to Lexington and all that stuff.” Reliable transportation is a known challenge in the area, and there are several transportation services available to assist patients in getting to appointments. One patient detailed using a transportation program. Sara said, “I get the transit to take me to get a referral. If it's [medical appointment] not in Jackson, then you have to get a referral. You have to let them know within 72 hours.” Other patients reported relying on friends or family members for transportation to the appointment. For example, Gill said, “My truck ain't the best. But I went down with somebody else...both of us had appointments that same day.” Others did not report having the same type of instrumental social support. For instance, David said, “[Getting someone to go with me to an appointment] was kind of a problem too.”

Third, many patients seemed to desire more information about testing and the meaning of results. In terms of follow-up colonoscopy screening, patients reported having many questions about the screening logistics and the time commitment associated with the process. Namely, Gill said, “I was just thinking where I should have it done and who could do it and whatever like that. And how long it was going to take to get it set up to get it done.”

For some patients, the FIT screening mechanism was a novelty about which she wanted others to know. For example, Catherine said, “Well, I just think that this test probably saved me from ever having cancer in the colon and further trouble...because I never had heard of these [FIT kits] until you were telling me about them...and nobody knows about it. I never heard of it...I recommend this to everybody to do, you know.”

Other patients were more focused on the meaning of a positive FIT result. For example, Nick asked the interview, “Is there anything besides colon cancer that a positive test would mean?” The uncertainty about the meaning of results was a salient factor for other patients as well. For instance, in describing his first reaction to receiving a positive FIT result, Greg said, “I was kind of worried…[about] what the hell it meant.” Likewise, Raymond echoed feelings of anxiety and fear, saying, “I was uncomfortable, and I was kind of scared. I was afraid of my result.” Patients’ comments illustrate the importance of attending to informational and emotional needs during screening conversations.

The second primary theme uncovered in the data highlights how patients are (2) engaging in the emotional labor of screening decisions. Sub-themes related to this theme include (2.1) experiencing fear and worry about cancer being the ultimate result, (2.2) remembering loved ones' (often poor) health experiences, and (2.3) consulting with family about the decision to screen. Many patients reported experiencing fear and worry about cancer being the ultimate result following a positive FIT result. For some patients, the screening conversation prompted significant deliberation. For example, Nick said, "The thoughts that I'm having is that I go back to question one and it's 'do I have colon cancer?' It just ends in all kinds of crazy thoughts into my head. It's, 'do I have colon cancer? Am I dying? Is this going to be the end? Is in my 50s as far as I'm going to make it?' I want to live a good, long life, and it's just…my thoughts keep sending me right back to, you know, do I really want to know or do I just want to ignore it, and it wind up being colon cancer, and it just wipe me out." For some patients, the fear and worry stem from prior experience with cancer. Namely, Catherine said, "[I was] Kinda afraid of finding out what it might be going on with me and stuff because I done went through the process of cancer before and things run through your mind with it. So, kinda scary."

Patients reported their own prior experiences with cancer; however, remembering loved ones' (often poor) health experiences was a significant factor in screening-related decision-making. For some patients, stories of bad experiences were articulated in a more general way. For instance, Conrad said, "I was scared about the results I would get back and what my test would show. I always heard bad things about it."

Other patients recalled more specific stories about family members who had suffered. Namely, Nick said, "I didn't know what to do. I didn't know what to say. I thought back about when my grandfather had got his, and you know he had colon cancer back in the 80s, back when they had to go in and put colostomy bags on people. The death rate for it I assume would be pretty high and I thought how he struggled and how he fought with it. And you know he was late in age, and I just wondered would that be me? You know, if I went through and had it, I guess I thought that what would be the point in it." The experiences of loved ones and the emotions they provoke are certainly part of patients' deliberations of screening decisions.

Loved ones are such a significant factor that many patients reported consulting with family about the decision to get screened; however, this did not necessarily result in the patient receiving screening. For example, Catherine, who refused follow-up colonoscopy care at the time of the interview, stated, "I just haven't talked with my mom, having to visit with her a lot and help take care of her and everything. So that kinda did sway me from having it done at the time." However, she did not specify if she wanted her mother to be part of the decision to be screened or had not yet received screening because of obligations to her mother's care.

In the case of another patient, there was more specificity about consulting with family, yet even so, he remained steadfast in the decision to refuse follow-up screening after a positive FIT. Nick said, "I've had my youngins [children] talk to me about it. They're kind of worried. I wish that I wouldn't have even said anything about it. More than anything, I wish that I never went through with the test."

The third primary theme relates to how patients are (3) reconciling screening and results with their everyday life. Sub-themes associated with this theme include (3.1) ongoing comorbid health issues take priority and (3.2) navigating existing family commitments. For some patients, ongoing comorbid health issues take priority over follow-up care. For example, when asked about delaying the decision for follow-up colonoscopy screening, Greg said, “I didn't get around to it because I think I had an accident where they had to take my stomach out and put it back in, and I ruptured my spleen. After that, I kind of forgot about that [positive FIT result] and worried more about this….I've had other health problems, and it just kind of swept my mind until you talked to me about it today.” With evidence of Appalachian communities experiencing increased risk for myriad health issues, navigating multiple comorbidities may result in delayed screening.

For other patients, getting a follow-up colonoscopy following a positive FIT result meant navigating existing family commitments, particularly for those who would need care for their grandchildren while undergoing the procedure. For several participants, it was “hard to get away” from their responsibilities to receive screening. For example, David said, [Getting a colonoscopy is] “an issue because I have my grandkids, and it's hard to get away and do anything that I need to get done.” Conrad echoed this sentiment, saying, [childcare] “was a[n] issue because I have my grandkids and it’s hard to get away to get anything done...I haven't thought about it [follow-up colonoscopy] anymore. I’ve been so busy with other things.” Even so, participants still seemed to recognize the importance of screening, and some even appeared willing to try to work around their childcare responsibilities. For example, Julianne said, “I will have a colonoscopy, but it would have to be done on Wednesday because sometimes my granddaughter...I have a daughter that we adopted and she’s a junior in high school. She has another year, and I just want to make sure I’m around for her.” Julianne’s comment highlights an interesting phenomenon in which there is significant deliberation about taking time away from childcare responsibilities in the present, coupled with the realization that if follow-up screening is not completed, the risk of cancer may impede their ability to care for their children in the future.

Findings show that patients are deliberating receiving screening based on individual goals and concerns; patients also reported considering specific screening-related factors. Thus, the fourth and final primary theme details how patients are (4) conducting their own personal analyses of screening practices. Sub-themes related to this theme include (4.1) accepting the risk of “knowing” and (4.2) challenging the efficacy of screening. For many patients, engaging in screening meant accepting the risk of “knowing” undesirable information about their personal health. For example, Sara said, “I was afraid to go get one [colonoscopy]...I was afraid it would show up with something.” The fear of bad news following screening services was apparent.

Some patients responded to fear and worry with fatalism and a desire for unawareness. For example, Raymond said, “I was kind of reluctant [to receive follow-up screening]. You know it’s sometimes better to just not find out what’s going on in your body.” Greg elaborated on how not knowing was “better,” saying, “I'd kinda like to know...Then again, when you think about it, you don't really know if you want to know...If it is, it is, and if it ain't, it ain't.” The belief that the outcome is inevitable was apparent.

Another participant regretted having more knowledge about his health status through screening. Nick said, “I guess I regretted taking it [the FIT test]. I guess I thought now that I've done it, what now? Am I going to die? I just didn't know what to think. So my first thought was probably, is this the end? That's what really sent me over the edge. That really put me in the mind frame of I'm still not going to do it. I don't want to know. If it kills me, then it's just going to have to kill me. I really regretted messing with the whole thing and never changed my mind. I pretty much ignored the whole navigator thing. I just sat there and listened. I didn't want to know...I guess it's more of the psychological thing than anything." He seemed adamant that any choices or actions moving forward would not make a difference in his health. This particular participant's words reflected a probabilistic deliberation of receiving colonoscopy following a positive FIT result. Nick stated, "Because part of me wants to have it and part of me doesn't. And right now the part of me that doesn't want to have it is trumping the part that does. Like I said, my kids are really pushing me to have it and myself is telling me not to have it because I don't want to know. You know, it's 70/30, the 70 is saying don't have it and the 30 is saying have it. It all boils down to do I wanna go through with it, do I wanna go through being aggravated with doctors? Because I was never one to really want to go to a doctor. And to be quite honest, I'm really regretting the whole thing. I'm regretting all of it." This type of probabilistic deliberation about screening presents unique challenges for clinicians concerning shared decision-making and patient self-management.

Another type of patients' probabilistic deliberations related to challenging the efficacy of screening mechanisms used by clinicians, specifically FIT. For example, Jim said, "I was worried and wondered if the last test was accurate...I still don't know if they are the same or what's going on. I would like to do another test to see if the results are the same." In another instance, Greg said, "Two positive [FIT results] is better than one. Cause one could be a false." He did not elaborate, but one must assume he was referring to a false negative result. Other patients desired additional testing to “confirm” their FIT results before committing to follow-up care. For example, David said, “I'd like to have another test to confirm the test results and then I might get a colonoscopy.” Similarly, Conrad stated, “I’d really like to have another test to confirm my test results and then I might have a colonoscopy.” Additional assurances were needed for some patients to support the decision to undergo a follow-up colonoscopy after a positive FIT result.

4.4 Discussion

Findings from this study highlight core functions of patient-centered communication, specifically, the ways the functions may overlap and interact. While participants did not explicitly report behaviors meant to foster their relationships with clinicians, the needs they reported overlap in interesting ways. While some patients remarked about needing quality care from “good people,” others desired more information from clinicians about testing and the meaning of their results.

For some patients, receiving a positive FIT result was an event that generated fear and worry. Experiencing fear and worry about cancer being the ultimate result of their screening journey was reported by several patients. In many cases, this emotion seemed to be related to patients’ memories of their loved ones’ (often poor) health experiences. Findings show that the functions of fostering relationships, exchanging information, and responding to emotions overlap in this context and influence communication that can affect important health outcomes.

Several patients reported attempts to manage uncertainty in the context of screening. For some patients, ongoing comorbid health issues took priority over receiving timely screening. Accepting the risk of “knowing” something was wrong with their health generated emotions like worry and regret for other patients. These emotions seemed to be present in some patients’ deliberations about receiving follow-up colonoscopy care.

In terms of shared decision-making, two critical factors appeared in the findings. First, several patients reported the need to consult with family members about the decision to receive screening. Nevertheless, even in seeking this participation with their own family members, some patients remained unscreened. One participant even reported regretting sharing his positive FIT result with family members. Second, several participants challenged the efficacy of screening, specifically the FIT mechanism. There is no evidence that multiple tests increase the accuracy of the screening result, but some participants seemed adamant that two tests were better than one. A gap in health literacy exists in understanding and interpreting test results.

Patients reported several challenges to self-managing in the screening process. Self-management relates to important aspects of illness, including the ability to find information and seek appropriate care. While some patients reported concerns about the affordability of follow-up colonoscopy, many patients reported overcoming significant challenges getting to the appointment. For some, lack of reliable transportation meant reaching out to social connections to get to appointments. Others relied on local (often free) transportation services to receive follow-up care. For many, navigating existing family commitments, explicitly caring for grandchildren or aging parents, was an additional barrier to follow-up screening.

4.5 Limitations

As with any study, there are a few limitations the reader should consider. First, the sample size of patients was relatively small and only represented patients who accepted navigation services. Little is known about the perceptions of patients in this intervention who refused navigation. Additionally, the patients' demographic information was unavailable to include as part of the analysis. Pseudonyms assigned were chosen merely based on contextual clues and occasional participant identifiers included in the transcriptions. Participants were part of the RCPC's intervention group, which means all patients were of current screening age (i.e., 50-75) at the time of recruitment. Without specific data on participants' age, it is difficult to speak to how perceptions around screening navigation may vary by place in the lifespan.

Second, the interview protocol was designed by RCPC staff to evaluate a multilevel public health intervention, and the data was collected without guidance from the primary researcher. As a result, there are several passages from the transcriptions where supplementary probing questions may have produced more robust information from participants. Additionally, there were several instances where the primary researcher identified potential errors in transcription solely because of personal, cultural knowledge of Appalachian expressions and mannerisms. Unfortunately, the accuracy of these passages cannot be reviewed or verified as the primary researcher does not have access to the audio files of participant interviews.

4.6 Conclusion

Even with an active multilevel public health intervention that provided free CRC screening and patient navigation services, patients in Appalachian communities are experiencing barriers to follow-up screening. These barriers included (1) lacking key assurances required for screening and understanding results, (2) engaging in the emotional labor of screening decisions, (3) reconciling screening and results with everyday life, and (4) conducting personal analyses of screening practices. Patients' difficulties receiving patient-centered care and accepting navigational support may influence shared decision-making. Data show opportunities for patient navigators and other clinicians to tailor screening messages that are aligned with how patients work to resolve their probabilistic and evaluative orientations.

CHAPTER 5. DISCUSSION

5.1 Introduction

Even with ongoing public health programs designed to increase access to necessary CRC screening services, many patients in the Appalachian region remain unscreened and experience late-stage diagnoses. As with many public health issues, health communication is vital in creating, understanding, and managing health experiences across the cancer continuum, especially in those populations experiencing health inequities. The purpose of this two-part dissertation was to investigate the communication practices within CRC screening conversations from the perspective of patients and patient navigators. Specifically, this dissertation used elements of problematic integration theory and the health belief model to better understand how patients integrate their personal and practical understanding of the benefits and barriers of CRC screening to their probabilistic and evaluative orientations. The following chapter serves several purposes. First, this discussion chapter identifies some of the major implications of the findings from both studies. Second, the discussion elaborates on the limitations of both studies. Finally, the chapter concludes with ideas for future research and health interventions.

5.2 Implications

The efforts conducted by RCPC and other partners in Appalachian Kentucky contributed to an improvement in age-adjusted mortality rates, incidence rates, and screening rates in the region. Data from the Kentucky Cancer Registry (2018) showed a decline in age-adjusted mortality rates in the Appalachian region since 2015, moving from 19.8 per 100,000 to 19.1 per 100,000. While this is a substantial improvement, there remains a disparity between Appalachian and non-Appalachian Kentuckians (15.4 per 100,000). Similarly, KCR data show that CRC incidence rates have fallen in the same time period; however, incidence rates remain higher among Appalachians (54.3 per 100,000) as compared to non-Appalachian Kentuckians (45.2 per 100,000). The decrease in mortality rates and incidence rates partly reflect the uptake of CRC screening. Siegel and colleagues (2020) reported an increase in the prevalence of up-to-date screening with any recommended test among eligible individuals in the U.S. (from 38% in 2000 to 66% in 2018); however, the data show that screening rates vary with age as individuals ages 50-54 (48%) experience lower screening rates as compared to those 55-64 (68%). In sum, while CRC incidence and mortality continue to decline and screening rates increase, striking disparities still exist in younger age groups and certain geographical locations.

The disparities experienced by Appalachian communities are likely exacerbated by other characteristics shown to be associated with low screening prevalence, including being uninsured, having insurance through Medicaid, or receiving care at a federally qualified health center (Siegel et al., 2020). The reality for many Appalachian Kentucky communities is that even with ongoing public health funding and multi-level interventions designed to reduce the burden of CRC, many folks are continuing to experience health disparities as compared to their non-Appalachian neighbors. Finding solutions to this complex issue hinges on our ability as researchers to listen to the people who are experiencing disparities and share their stories with healthcare providers and community members serving the area.

The goal of this study was to answer three research questions that explored how patients communicate shared decision-making and work with navigators to resolve their probabilistic and evaluative orientations related to CRC follow-up care, as well as how patient navigators described these orientations among patients. Specifically, the primary researcher asked, how do patient navigators describe patients' probabilistic and evaluative orientations in their CRC screening conversations? How do patients communicate shared decision-making related to follow-up care following an abnormal FIT result? And finally, how do patients work with navigators to resolve their probabilistic and evaluative orientations to CRC screening? The data analyses presented in Chapters 3 and 4 provide evidentiary support to address these questions. To address these findings, the following sections examine in detail the appreciable implications of interest for health communication scholars, public health professionals, health educators, and patient navigators.

First, there are many implications for health communication scholars. Perhaps the most important implication of this dissertation is a proposed extension of problematic integration theory for application in contexts where problematic integration of a recommended health behavior is expected. Recall that integration within PI theory refers to the ways that people integrate probabilistic and evaluative orientations in experience through their reciprocal influences and through their connectedness to probabilities and evaluations of other things. The data from both studies in this dissertation provide evidence that the notion of reciprocal influence and connectedness may be influenced by a variety of factors; key concepts from HBM (i.e., perceived susceptibility, perceived severity, perceived benefits, cues to action, self-efficacy) help to explicate this phenomenon in a pragmatic way. The variables included in HBM seem to oscillate and inform problematic integration in this context. In other words, the experience of problematic integration through the orientations of ambiguity, ambivalence, divergence, and impossibility seems to be impacted by perceived susceptibility, perceived severity, benefits, cues to action, and self-efficacy. For the sake of this dissertation, the primary researcher identified the potential connections between variables associated with HBM and problematic integration as orientational pre-dispositions. The model below (see Figure 2) is a result of an additional round of axial coding that bridges findings from Study 1 and 2 to illustrate how the thematic framework uncovered connections between PI and HBM theories in consideration of the goals of the integration of recommended health behavior (i.e., CRC screening) and shared decision-making. The abbreviations of S1/N and S2/P denote studies one and two and the corresponding population, respectively. The thematic framework developed for each population includes an index (see Appendices 2 and 4), which is also referenced in Figure 2.

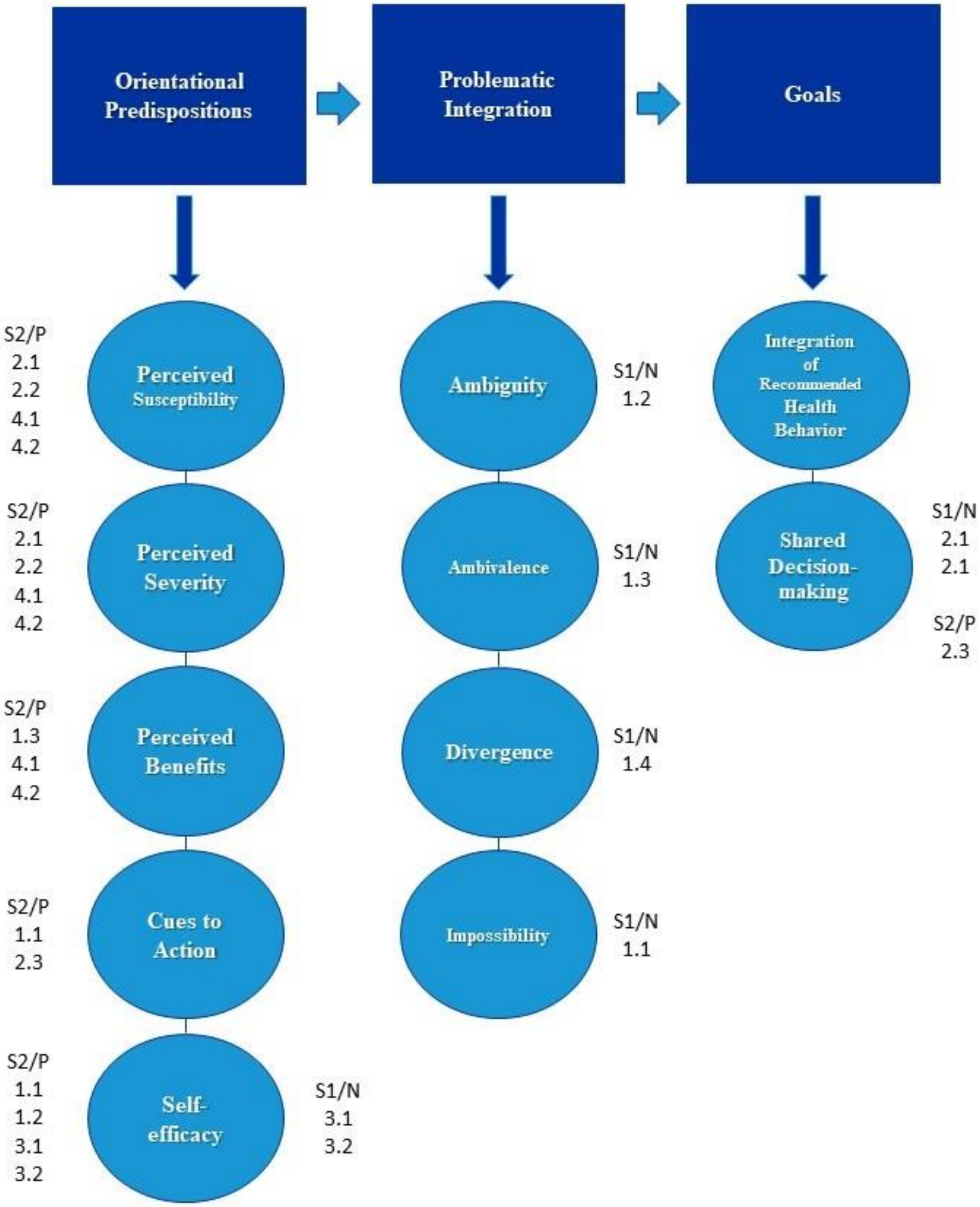

Figure 5.1 Problematic Integration of Health Behavior Framework with Data Index

The connection between PI and HBM theories forms a gestalt from which more meaningful considerations for informing interventions may be made. In conducting another round of mapping and charting as detailed by Ritchie and Spencer (1994), important associations between the variables associated with HBM (termed here as orientational predispositions) and that of the phenomenon of problematic integration were discovered. First, navigators' accounts reflect that in some form, they expressed an awareness of problematic integration, elaborating on the many ways in which they tried to address or counter patients' experiences. Second, from the patients' perspective, they actively cited factors driving problematic integration in the experience of receiving preliminary screening and needing follow-up diagnostic evaluation. Third, navigators also revealed ways in which future navigators may increase their own self-efficacy when conducting this type of work. Finally, both patients and navigators described the experience of shared decision-making in this context. For patients, this came in the form of consulting with family members about the decision to screen. For navigators, shared decision-making was described from the angle of providing patients with relevant and timely information as well as supporting patients' deliberation of the decision to be screened, and many times, this meant addressing unique psychosocial needs.

The thematic framework method utilized in this dissertation provided some unique theoretical insights that are ripe for exploration. According to Johnson (2003), "for interpretivists, a greater understanding of context is necessary for the rich description of specific cases, which can lead to theoretical insights" (p. 738). Key tenets of theory construction often include words such as validation and verification; however, in Weick's (1989) explication of theory construction as "disciplined imagination," he said, "the contribution of social science does not lie in validated knowledge, but rather in the suggestion of relationships and connections that had previously not been suspected, relationships that change actions and perspectives" (p. 524). While scholars interested in health behavior involving uncertainty may intuitively suspect that the orientations featured in PI theory are driven by specific attitudes and experiences, the framework presented in this dissertation names these drivers and illustrates the potential relationships of variables featured in two theories to form a model that provides utility in the design of future interventions in similar contexts.

In sum, the role of theory is critical to the interpretation of the data presented in this dissertation, and Lindlof and Taylor (2011) maintain that "two or more theories may even be put in creative tension with each other in order to explain issues that you are dealing with" (p. 267). The expanded and interdisciplinary model proposed in this dissertation highlights the importance of continued efforts to bridge disciplines and "stretch [the] imagination and create and validate claims" when planning to intervene in complex human decision-making regarding health behavior (Lindlof & Taylor, 2011). Additional research and theory-building efforts are needed to continue the exploration of these associations; suggestions for this work are further explained as future directions below.

An additional implication for health communication scholars is the way in which patients questioned the efficacy of screening in the current study. Patients had agreed to diagnostic screening; however, they wanted more than a single FIT to confirm the need to engage in follow-up colonoscopy. In this way, the act of communicating about FIT with those who receive an abnormal test via patient navigation may create additional problematic integration related to any necessary follow-up screening. Even so, patient navigators did not offer specific strategies to overcome patients' experiences with scientific uncertainty related to a positive FIT. A study by Kim, Kim, and Niederdeppe (2015) found that relative to cancer risk-reducing behaviors, different intervention approaches may be more or less effective depending on the level of scientific uncertainty associated with the behavior. They recommend that for behaviors that are scientifically uncertain, descriptive normative information may be an important criterion from which to decide whether to perform it. This may explain why several navigators found success in persuading patients to complete FIT using the social influence of patients' friends and family. More research is needed to uncover the ways scientific uncertainty may impact screening behaviors that potentially require multiple steps.

Second, there are several implications for public health practitioners. Recall that research conducted by Bachman and colleagues (2017) uncovered that a patient's decision to get screened was often affected by their own poor prior experiences with screening. The findings in this dissertation support that the experiences of others may also have an impact on the screening decision. Findings show that many patients used the horror stories told by loved ones as an objection to follow-up colonoscopy services. Designers of future programs may consider some of the tactics detailed by the navigators in Study 1. Specifically, getting supportive friends and family members involved to try to counter any objections related to past screening events or stories. If patients view loved ones' thoughts and opinions as critical to their decision to be screened, future programs may implement mechanisms to involve friends and family members as a complement to achieve shared decision-making in this context.

In addition to considering how to involve family members in shared decision-making efforts, public health practitioners designing interventions should be mindful that many patients in Appalachian communities may be simultaneously navigating family commitments while attempting to manage their health. Obligations to family members were identified by several patients as a barrier to screening. Patient navigators also reported that folks who cared for close kin were particularly difficult to navigate to follow-up screening. Many times, patients are caring for aging loved ones, but in Appalachia, the likelihood of children being removed from homes due to opioid-related issues and being raised by grandparents or other family members is higher. According to the National Association of Counties and the Appalachian Regional Commission (2017), Appalachian counties had an opioid overdose death rate that was 72% higher than in non-Appalachian counties throughout the country. There remains a dearth of research investigating ways to support preventive cancer screening services alongside an opioid epidemic that is reshaping family commitments in the region. Future research should address how the responsibilities associated with an aging population caring for elders while simultaneously raising young children may impact screening rates and adherence. Novel interventions will be required to address this barrier appropriately. One option might be offering FIT kits for adults and a pathway to CRC screening navigation at pediatric or school clinics. Alternatively, future efforts aimed at reducing health disparities in the region may consider a multi-pronged approach to addressing the domino effect of opioid use disorder in Appalachian communities including the potential impact on screening adherence and delays to follow-up healthcare.

An additional implication for public health practitioners is that a couple of navigators reported significant issues navigating men to follow-up colonoscopy. While it is important to note that communication strategies used to navigate patients may vary by gender, there is not enough evidence presented in these studies to support any type of specific intervention or approach. Theoretically, the male patients interviewed in Study 2 were already malleable to screening simply by agreeing to diagnostic FIT as part of RCPC's intervention, which makes patients' refusal of follow-up colonoscopy following positive FIT concerning. Public health practitioners should take a pause to consider how the adoption of FIT (or other diagnostic screening tools) is marketed to intervention populations. Specifically, was the adoption of FIT framed in terms of a way to avoid colonoscopy? If so, this could further problematize the communication surrounding follow-up screening.

Another implication of the studies presented in this dissertation is the need for the application of the proposed problematic integration of health behavior framework in designing interventions and campaigns. The application of the proposed framework in contexts where problematic integration is expected may provide additional utility for designing more robust public health efforts and support a more holistic approach considering the health behavior phenomena of concern. The findings in this dissertation and the proposed model may support more effective consideration of the variables from HBM and PI theory when intervening in similar populations.

Third, there are important implications for health educators and patient navigators. Navigators in the current study offered a wealth of advice that may be useful to future patient navigation programs. First, participants alluded to (and often explicitly stated) specific skills to increase self-efficacy, and ultimately, successful navigation. Namely, participants believed that navigators should be knowledgeable, patient, accommodating, supportive, and well-connected. Additional characteristics associated with patient navigators' self-efficacy were high emotional intelligence, persistence, and resiliency. In a recent review of patient navigation training, Ustjanauskas, Bredice, Nuhaily, Kath, and

Wells (2016) found relatively few studies that documented training practices specifically designed to help patient navigators address patients' psychosocial needs. Patient navigators in current Study 1 primarily focused on the skills necessary to address these needs; therefore, future research should address uncovering and explicating these skills, and future training programs should spend more time discussing these skills and documenting procedures for teaching navigators and health educators how to use them.

The potential for the problematic integration of health behavior framework to be used for supporting navigator training and education is fruitful. In the current study, patient navigators were well-trained to address structural barriers in the region such as transportation and cost; however, many navigators seemed to encounter issues addressing other, less tangible barriers. For example, navigators described patients' problematic integration regarding family commitments, comorbidities, and issues related to the opioid epidemic. Patients reported actively trying to reconcile the act of screening and the results with their everyday lives; an integration that is problematic and most likely due to ambivalence. In other words, patients are making hard choices and having trouble prioritizing multiple health behaviors. In future patient navigation training programs, the framework provides utility for understanding the population and goals in a more robust way, especially with the presence of lay navigators or community health workers who have tacit, working knowledge of the experiences unique to that population. In using this model for training, clearer goals for navigators and community health workers may be presented as the integration of the recommended health behavior associated with the intervention. Second, orientational predispositions may be informed by formative research among a population and key demographic data and presented in quick-reference guides. Finally, specific strategies for identifying the probabilistic and evaluative orientations driving problematic integration and addressing the ambiguity, ambivalence, divergence, and/or impossibility associated with it could be modeled and practiced. Education and training that taps into both the theoretical knowledge presented in this framework and the community knowledge navigators in interventions often possess may create more culturally appropriate and supportive motivational interviewing practices.

5.3 Limitations

There are several limitations associated with both studies presented in this dissertation that deserve attention and that readers should be aware of as they consider the results of this project. First, in both studies, interview protocols and data collection efforts were conducted without guidance from the primary researcher. RCPC staff designed the interview protocol and conducted data collection as a means for programmatic evaluation. While the primary researcher worked closely with RCPC staff in numerous efforts of the multilevel intervention, the opportunity to contribute to creating a more robust interview protocol was not present. There are several passages from the transcriptions where additional questions may have produced more robust information from participants. Additionally, interviews in both studies were conducted by lay interviewers. Although each interviewer received training before interviewing participants, they were not extensively trained in qualitative methods. There were several instances where the interviewers missed opportunities to ask additional probing questions to obtain richer descriptions from the participants.

Second, in both studies, the sample size is relatively low. Study 1 featured a small sample of patient navigators serving a single intervention area. Even so, the sample did represent the majority of navigators serving the RCPC’s programmatic efforts, and some themes became repetitive, suggesting theoretical saturation had been reached. In addition, Study 1 examined the perspectives of patient navigators who serve a rural, predominantly white community, which may present even greater limitations on the generalizability of the findings. Similarly, the sample size of patients in Study 2 was also relatively small and only represented patients who accepted navigation services. This dissertation provides little to no insight into the perceptions of patients in this intervention who refused navigation and follow-up screening. Data associated with patient navigators and patients’ demographic information was unavailable to include as part of the analysis. Regarding the patient navigators’ data, the primary researcher was able to identify each participants’ sex and occupation with the information included within the transcription. In the patient data set, the pseudonyms used were chosen merely based on contextual clues and occasional participant identifiers included in the transcriptions. The lack of demographic data in both studies occludes effective consideration of responses by factors such as age.

Third, data from both studies are self-reported and may contain several potential sources of bias. For example, patient navigators in Study 1 likely wished to represent their knowledge, skills, and abilities as navigators in the most positive terms. In other words, social desirability bias and other biases, such as selective memory, attribution, or exaggeration, are important factors to consider in the interpretation of the findings. Additionally, there were several instances where the primary researcher identified potential errors in transcription solely because of personal, cultural knowledge of Appalachian expressions and mannerisms. Unfortunately, the accuracy of these passages cannot be reviewed or verified as the primary researcher does not have access to the audio files of participant interviews.

Finally, attempts to generalize these findings to similar communities and interventions should be approached with a pause to contemplate the attributes of the population that is being studied and the desired health intervention. Many researchers across disciplines opine that qualitative research is of lesser importance because the findings may not be generalized like that of quantitative research. Interestingly, generalization is not the core purpose of qualitative research. Corbin and Strauss (2015) maintain that “the idea behind qualitative research is to gain understanding about some phenomenon, and a researcher can learn a lot about a phenomenon from the study of one…as researchers, we are analyzing data for their concepts and their relationships (p. 377). Nonetheless, the work in this dissertation was driven by tenants of validity, credibility, truthfulness, and rigor. Hammersley (1987) argued that a study may be considered valid if “it represents accurately those features of the phenomena that it is intended to describe, explain, or theorize (p. 67). Silverman (2005) proposed several strategies for increasing the validity of findings that the primary researcher followed throughout this work, including engaging in the refuting principle (i.e., refuting assumptions against data), using the constant comparative method (i.e., comparing one case against each other), doing comprehensive data treatment (e.g., incorporating all cases into the analysis), and searching for deviant cases. The primary researcher also followed several of Lincoln and Guba’s (1985) prescriptions for credibility and truthfulness, including prolonged engagement and persistent observation in the field, triangulation with a coding team, using peer review and debriefing, clarifying researcher bias, and rich, thick description of in-vivo quotation. In sum, over the course of completing this project, the primary researcher attempted to create the conditions that foster quality qualitative research, including methodological training, consistency, and awareness; clarity of purpose; and a sensitivity to the participants providing the data for this dissertation (Corbin & Strauss, 2015).

5.4 Future Directions

There are three noteworthy areas for future research with regard to this dissertation. The first area of future research exists in the continued exploration of the associations between variables in the health belief model and problematic integration theory. The author entertained a multitude of additional questions related to the connectedness of the variables in the process of analyzing, indexing, and charting the data as prescribed by Ritchie and Spencer (1994). For example, how does the grouping of variables in HBM (named "orientational predispositions" in this dissertation) specifically impact the process of problematic integration? How might the incorporation of additional benefits or cues to action affect the experience of problematic integration? Do certain variables reduce or increase the likelihood of problematic integration? What potential exists in changing a person's orientational predispositions to reduce the likelihood or ease the process of problematic integration? How do ambiguity, ambivalence, divergence, and impossibility potentially mediate the integration of recommended health behavior? These are just a few examples of potential questions that may be answered via a variety of research methods. Much of the work centered on PI theory has been qualitative, and the specific ways in which the probability-evaluation relationship is impacted by other variables and the potential for shifts and changes have not been modeled explicitly (Bradac, 2001). Clearly, the attributes of complexity, dynamism, and simultaneity that Babrow (1992, 1995) details as part of problematic integration present challenges for measurement, and Bradac (2001) argued that this presents “webs of possibilities, instead of logically compelled theorems” (p. 467). Future researchers might consider a survey design incorporating key questions about the variables presented here to potentially provide more predictive and correlational evidence to support PI theory, the proposed theoretical framework featured in this dissertation, and interventions wherein problematic integration is expected.

The second area of future research uncovered relates to connecting with a population of clinical providers as a complement to the representative populations included in this dissertation. While the studies included in this dissertation provide a thick description of the experiences of patients and the patient navigators and community health workers who support them, insights from additional clinical partners are crucial for appropriately painting a fuller, clearer picture of the reality of cancer communication in and out of clinical environments. Politi and Street (2011) maintain that shared decision-making is collaborative due to “mutual participation and cooperation among clinicians, patients, and family members” (p. 400). In practice, engaging in shared decision-making means that clinicians are actively providing high-quality information and supporting deliberation by exploring patients’ reactions to that information (Elwyn et al., 2012). Effective communicative behavior from a patient-centered perspective supports uncertainty management and encourages patient participation in decision-making (Politi

& Street, 2011). Future research should focus on clinical providers as the population as a means to better understand the phenomena at play, and perhaps, such research may provide additional triangulation for the model presented in this dissertation. Both patients and patient navigators in the current studies named clinical providers as key partners in the decision to be screened, and more insight is needed regarding the nature of information-sharing about CRC screening between patients and clinical partners.

In addition, with the wealth of decision aids designed to support shared decision-making, future research should further explore if and how these tools are being used. Existing research shows that in regard to shared decision-making, patients often perceive screening conversations differently than clinicians. For example, Wunderlich et al. (2010) coded audio recordings from 363 primary care visits (wherein patients were eligible for CRC screening) for elements of SDM and compared them to a post-visit patient survey assessing the patient-reported decision-making processes and relational communication (e.g., receptivity, trust) during the visit. They found that while 70% of patients preferred SDM for preventive health decisions, only 47% of patients reported use of an SDM process, with only one of the coded screening discussions including all the key elements of SDM. Patients' reports of SDM were significantly associated with female physician gender and patient-reported relational communication. Another example is a recent qualitative study conducted by Wiener and colleagues (2018), which sought to characterize patient and clinician impressions of communication and decision-making about lung cancer screening and perceived barriers to achieving shared decision-making. They found that the information clinicians shared varied, identified a lack of use of decision aids, and discovered that clinicians perceived that they adequately explained the rationale of screening and provided information about the risks and benefits of screening to their patients. Even so, patients in the study reported receiving little information about screening and its risks and benefits, and several patients did not realize what type of cancer the test was intended as a screening mechanism for. In addition, both clinicians and patients did not perceive adequate deliberation in the encounter, which is a key component of shared decision-making. Research focused on supportive decision aids may potentially support their utility in future interventions wherein shared decision-making is expanded to include not only a doctor or nurse, but also patient navigators, community health workers, and close kin or loved ones.

The third area for potential research and intervention efforts exists within exploring the potential for tailoring motivational interviewing based on variables included in the problematic integration of health behavior framework presented in this dissertation. Motivational interviewing is a common counseling approach to help people explore and resolve ambivalence about behavioral change (Elwyn et al., 2014). The philosophy of motivational interviewing is that people approach change with varying levels of readiness and that the role of helping professionals is to assist clients in becoming more aware of the implications of change and/or of not changing. Usually, this is accomplished using a nonjudgmental interview in which clients do most of the talking (see Appendix 3). The central tenet of motivational interviewing is its collaborative nature which is defined by a strong rapport between the professional and the client. Most studies on motivational interviewing have shown positive effects on lifestyle change and psychological outcomes; however, most research relates to one-time dichotomous decisions rather than ongoing decisions, such as the choice to engage in annual FIT testing (Elwyn et al., 2014). Future research should explore the utility of motivational interviewing patients at multiple checkpoints, such as initial FIT screening to navigation following positive FIT to follow-up direct visualization, if necessary. The “checkpoint” approach will require increased collaboration among clinical and community partners to be successful in future navigational interventions.

5.5 Conclusion

The purpose of this research project was to investigate communication practices relative to problematic integration and health beliefs in CRC screening conversations from patients’ and navigators’ perspectives. With problematic integration theory and the health belief model as a guide, data from these two studies may be used to understand the nature of participation in CRC screening conversations and how these dynamics contribute to patient-centered care and shared decision-making. By accounting for patients’ and navigators’ unique perspectives, this dissertation contributes to training strategies for more effective clinical and patient navigation communication practices and considerations for shaping interventions to support shared decision-making and improve CRC screening rates in similar populations.

In the process of writing this dissertation, the world was changed by the global COVID-19 pandemic. A recent cohort study by Chen, Haynes, and Du (2021) found sharp declines in several types of cancer screening in 2020 as a result of the suspension of non-essential healthcare services, with CRC screening down by 79.3% from March to May 2020 as compared to the same time frame in 2019. Their analysis showed that telehealth use was associated with higher rates of screening, and they recommended that clinicians focus on increased use of screening modalities that do not require a procedure. The

President’s Cancer Panel (2022) identified several action steps for closing gaps in cancer screening related to the disparities both created and exacerbated by the pandemic, including improving and aligning communication, facilitating equitable access, strengthening workforce collaborations, and creating effective health information technology (IT). The Panel recommended increasing the use of stool-based diagnostic testing (or self-sampling) and targeting healthcare providers with messaging, education, and training; specifically, ensuring that clinicians stay up to date on screening guidelines, are capable of effectively assessing cancer risk, and can appropriately promote screening for patients. Regarding equitable access, the Panel recommended continued use and widespread adoption of programs utilizing community health workers. Finally, the Panel suggested adopting health IT tools to monitor initiation, completion of multi-step screening processes, and the receipt of follow-up care. Data from the current study support several of these approaches, especially considering the reality that even with patients’ willingness to engage in self-sampling, they may be lost to follow-up after a positive FIT result due to a range of barriers that are often complex and interconnected. While self-sampling interventions supported by programs like RCPC experienced success through increased screening rates via FIT, this dissertation highlights the collaborative approaches that must be taken at multiple levels to support successful multistep cancer screening in populations like those in Appalachia.

5.6 Final Thoughts

Many of us have experienced significant challenges as we continue to survive a global pandemic. The process of finishing this dissertation was not exempt from those challenges. The initial prospectus presented for this dissertation was a study investigating clinical perceptions of communication in cancer screening conversations. Specifically, the prospectus detailed recruiting physicians, nurses, and other clinical partners serving the Appalachian region to better understand the barriers they experience in engaging in shared decision-making with their patients in regard to CRC and lung cancer screening. Many health and organizational communication scholars have detailed the challenges in recruiting within a clinical population, and the initial work in the process of this dissertation was no exception. The primary researcher successfully recruited and interviewed several clinicians that generated rich data; however, in the shift of clinical priorities due to the pandemic, recruitment came to a standstill. In retrospect, additional (and ample) funding for recruiting clinicians may have better-supported recruitment; however, the primary researcher now recognizes (more than ever) the importance of the expertise and connections that may be generated in working with a transdisciplinary research team. The closure of RCPC made it difficult to generate support for research efforts. In the future, it would be amazing to work with a transdisciplinary team to design, implement, and evaluate a multilevel intervention promoting self-sampling and timely follow-up tailored to clinicians, patients, and patient navigators in Appalachia. In an already overwhelmed system, clinicians face a substantial barrier of having much to do in the patient interaction with little time to make it happen. An intervention that implements some of the suggestions presented by the President’s Panel (2022) would be ideal; specifically, with tailored education and training for providers accompanied by advances in health IT to support alerts for appropriate screening and the ability to keep track of patients across the cancer screening phase and further into the care continuum, if necessary. In addition, patient education campaigns should be implemented in clinics, schools, and other types of community centers across Appalachia to continue to boost knowledge about screening and social acceptability for so doing. The Appalachian community is strong and resilient, so building ways for the community to care for each other’s health is critical for the sustainability of any future intervention or campaign.

APPENDICES

APPENDIX 1. PATIENT NAVIGATOR INTERVIEW PROTOCOL

1) Introduction
    a) We're interested in learning more about your experience as a patient navigator/nurse case manager. This first set of questions asks you about your experience in general.
    b) What has been the easiest part of being a patient navigator/nurse case manager assisting patients to follow up to receive appropriate care after an abnormal FIT test? What has made this easy?
    c) What has been the most difficult part of being a patient navigator/nurse case manager? What has made this difficult?
2) Patient Uncertainty
    a) After having a reactive FIT test, many patients might experience a lot of uncertainty, or have a lot of questions or concerns about their diagnosis. We're interested in learning more about how you help patients deal with their uncertainty.
    b) Can you tell me a story about a patient who had a positive FIT result but didn't believe she really had a high risk for colon cancer? How did you respond to this patient?
    c) What kinds of questions do patients ask you about their risk or diagnosis of colon cancer? How do you respond to these questions?
    d) When a patient receives a positive FIT test but doesn't understand what that means, what do you say to explain the diagnosis?
3) Follow-up Care

   a) There are a number of things that can prevent patients from getting follow-up care after a reactive FIT test. We’re interested in learning more about how you help patients seek follow-up care.
   b) Can you tell me a story about a patient who wasn’t willing to follow up after their diagnosis? How did you respond to this patient?
   c) What kinds of things keep people from seeking follow-up care after being having a positive FIT?
   d) What do you say or do when patients say that they’re not getting follow-up care because of (a) cost? (b) time? (c) transportation? (d) lack of knowledge? (e) insurance? (f) lack of doctors? (g) lack of trust in health care providers? (h) literacy? (i) fear of the procedure or what they might find?
   e) How do you respond when a patient says that it would help them seek follow-up care if they had (a) more support? (b) someone to go with them or set up their appointments? (c) several doctors to choose from? (d) more information? (e) concerns about prep?

4) Privacy
   a) Many patients have concerns about privacy when it comes to their health. We’re interested in learning more about how you deal with privacy issues when you talk with patients.
   b) Can you tell me a story about a patient who was concerned about privacy? How did you respond to this patient?
   c) When a patient seems unwilling to talk about her diagnosis with you, how do you respond?

    - d) When a patient says they are concerned about privacy issues, what do you say?

5) Health Care Providers
    - a) As a patient navigator/nurse case manager, you work with a variety of other health care providers. We're interested in learning more about your experience with these health care providers.
    - b) What has gone well in working with health care providers? What has made these things go well?
    - c) What has been difficult in working with other health care providers? What has made these things difficult?
    - d) What are some of the different types of other health care workers that you have worked with?
6) Conclusion
    - a) If you could change something about the way the patient navigator/nurse case managers work with patients, what would you change? Why would you make this change?
    - b) If a new patient navigator/nurse case manager were to come to you and ask for advice, what would you say?
    - c) Do you have anything else you'd like to talk about before we end the interview?

APPENDIX 2. PATIENT NAVIGATOR THEMATIC FRAMEWORK INDEX

1. Navigating problematic integration

    1.1. Identifying impossibility

        1.1.1. Julia (NP): “A lot of our patients don’t have cars; or we recruited some people from the homeless shelter, so, ya know. If you’re worried about where you’re going to stay at night and where you’re going to eat, you’re not really worried about whether or not you’re going to show up at your doctor’s appointment.”

        1.1.2. Carlene (PN): “A lot of times, I guess they just are not willing to do the colonoscopy…it's pretty easy to get them to take…the FIT test, but when it comes down to actually getting them to schedule a colonoscopy when they have a positive, especially with men in this area and they…are not willing to do that.”

        1.1.3. Charlene (CHW): “…if they come in uninsured and then they are over the income for any type of financial assistance and being able to get the colonoscopy completed once they have a reactive test because they can’t afford it. They can’t afford the hospital part or the procedure…one lady in particular she doesn’t have any insurance at all and over the income financials over at the hospital and when we called to get her colonoscopy, because she was reactive. The hospital informed us that they went over the price and how much it would cost if she just came in as preventative, you know? And then once, if there were any polyps found, then it goes into diagnostic and another 2-3,000 dollars is what it would cost for her to have that colonoscopy completed. So she opted out of it."

- 1.1.4. Mary Jo (NP): "I start talking about…statistics for Kentucky and sit down with them in front of the computer and say, 'this is why…you want to…go ahead and do this'. And then I will go, 'okay, let me tell you what can happen'. And, explaining some of the kinds of things that can happen – if you uh, get cancer, and, you know, if this is preventable now, why would you want to go that far? Why would you want to go there? Why would you want to get to the point when you have a bowel reconstruction? Or, uh, ya know, chemo and radiology/ radiation? So, ya know. I probably will try to put some fear in them."

1.2. Attending to ambiguity

- 1.2.1. Mary Jo (NP): "The most difficult thing [about working with providers] is that everyone requires something different for a referral. So it's just a matter of getting whatever somebody needs. And it's not really that big of a deal, ya know. It's just finding out what they want and getting it to them basically."
- 1.2.2. Suzanne (CHW): "They [patients] get apprehensive and worried and scared. They're like 'Well it says that it's positive [FIT] and that means I have cancer.' Panic sets in. And I'm like, 'let's wait a minute here. This doesn't necessarily mean you have cancer.' I try to be supportive, whatever the situation is."
- 1.2.3. Julia (NP): "…people who got a positive fit result would automatically think, 'oh I have colon cancer', and I would say that it doesn't necessarily

mean that, [it] just means that they need to follow up…. I usually tell them that as long as they follow up and do what they are supposed to do, then it's treatable and there is a lot that can be done. And then I would also tell them that early detection and early medicine are the biggest things that keep you from having a problem. I try to emphasize on the importance of them following up."

1.2.4. Julia (NP): "I tried not to use the C-word [cancer] with them terribly much; I just want them to go to their appointments and follow up. Ya know – I try to focus on more [the fact] that this doesn't necessarily mean there is anything terrible, it just means that we need to be on it and take care of you."

1.2.5. Anthony (PN): "But when I talk with individuals about the positive FIT result and the importance of the colonoscopy, the first thing I have to do is actually explain what these FIT results actually mean. I have to tell them, this does not mean you have colon cancer. When I frame it that way and tell them that, this is an opportunity to find out if there is anything in there that may become colon cancer and it is getting you a chance to get that removed before it does."

1.3. Addressing ambivalence

1.3.1. Julia (NP): "…patients who have a family history were even worse at following up than patients that didn't, and I think it was just out of fear."

1.3.2. Suzanne (CHW): "They will say that "mom was sick", and she went to the doctor and they did all these treatments. And they ran her up and down the road [gave her the run-around] and she just got sicker and sicker and sicker, so I’m not going to do that. I’m not gonna do these tests.”

1.3.3. Charlene (CHW): “What is most difficult [is] that there are several different factors I think with one being the people are afraid of getting the test done either for what they may find out or horror stories especially when it comes to colonoscopies and patients go by what their grandparents told them or what their parents told them.”

1.3.4. Anthony (PN): I worked with one case where the lady that had the positive FIT result. When we originally approached her about a colonoscopy, she said yes, and she would…The health department I worked through to get her to a free colonoscopy called and said this lady didn’t show up. So, when I was actually able to talk with her, I found out that she couldn’t keep that appointment because she is taking care of a husband, who is ill…He was suffering from cancer himself, pancreatic cancer. Because of that, she has to be the caregiver for him and doesn’t have the ability to go take care of herself.”

1.3.5. Anthony (PN): “Women are the primary caregiver in a household and if the woman feels like there is a need for her family, she will put that first before her own health…we have so many people within the age range of colon cancer screening again, especially women, who are raising their grandchildren…and because of that, they’re not able to dedicate as much time to their own needs.”

        1.3.6. Charlene (CHW): "A lot of them will be like, one lady in particular who uses her faith…believes that if she requests prayer then that will be taken care of, which I believe in that too but still, I try to let her know that you know, the Lord has provided the doctors the education in order to help and the facilities in order to help take care of her now so that later on she won't have to go through cancer or things like that."
        1.3.7. Mary Jo (NP): "I draw out the 'you have children' card, and 'you want to be here to raise your children'."
        1.3.8. Julia (NP): "I would say 'what's a day out of your schedule that could save your life in the future?'."
    1.4. Dealing with divergence
        1.4.1. Anthony (PN): "…occasionally you will find health care workers…who are not that dedicated into what they are doing…I almost felt like I was trying to be a counselor and trying to re-instill these characteristics in them that I know they must have had at some point, in order to be in health care in the first place, so its like I'm working with two clients at the same time at that point. That is a very hard day."
        1.4.2. Julia (NP): "I'd say the most difficult thing was, um, getting the patients to actually show up to their appointments and then therefore the health care providers to reschedule them – once somebody has missed 4 or 5 appointments, your provider gets a little iffy about continuing to reschedule them."

2. Supporting Shared Decision-Making

2.1. Providing information

  - 2.1.1. Charlene (CHW): “I guess just the doctor actually talking to them about their preventative care, they just don’t take the time to do it you know? They are so busy in their clinics because everyone almost has insurance now, when a patient comes in, they take care of that one need and then they send them on their way when they should be spending more time talking to them about their preventative services that they need.”
  - 2.1.2. Suzanne (CHW): “Some people are very private about their medical issues. We always adhere here at the office to one-on-one [consultation], unless they bring their spouse because then they want them to know.”
  - 2.1.3. Julia (NP): “I made sure that if I was going to talk to someone about their test results and navigation, that we were alone and in a place that was like a secure place. Or I would be like, ‘we need to talk about some private stuff. Make sure that there’s nobody around’…we always made sure to talk directly to the patient – not family members. Cause a lot of patients didn’t want their family to know they had done a FIT test, let alone the results.”
  - 2.1.4. Suzanne (CHW): “Don’t share information outside of the office…and that goes with your reputation. You don’t hear me out on the street talking about someone else’s health issues. They know me better than that.”

2.2. Supporting deliberation

  - 2.2.1. Suzanne (CHW): “He [a physician] called my office, and he explained that this is not good news [prognosis for a patient], and the family does not understand. And I am very close with every member of that family, so I became the liaison between the two. And I had to learn a lot of those big words, but it helped the family, it helped me to know what was going on, and that's my job. That's what I'm supposed to do. It's awesome to be that liaison."

2.2.2. Julia (NP): "…if you have a patient that doesn't trust you, then there's lots of ways that you can build trust…if they are uneasy about the providers that I would be sending them to for a colonoscopy…I give them providers that I think are really reliable or especially good at what they do, then I usually tell them, 'I would let them take care of me and take my family'. That usually helps."

2.2.3. Carlene (PN): "He [a patient] didn't want to take the test at first, and then we actually met up with him at a senior center, and he saw that there were more of his friends doing the test so he [...] was like, 'I'll do this'."

2.2.4. Anthony (PN): "After working with me quite a while, me twisting their arm and harassing them long enough and getting their family members to help me harass them, they finally got his done and they found out they had some polyps in there and the polyps were removed before they ever had a chance of becoming cancerous."

2.2.5. Suzanne (CHW): "…you still just try to be supportive, you give them the best education you can, you work with their doctor IF they will go to a doctor. Talk to a family member; you kinda weasel your way in there and you talk to the wife."

2.2.6. Bonnie Jean (CHW): “…begin with that patient and whatever their need is, you see to that need and you work with that provider and that nurse and their health care to make sure that that need is met. Whatever it takes.”

2.2.7. Suzanne (CHW): “…you just gotta step in, and I said ‘I’ll go. I’ll make the trip with you and I’ll go with you. You’re not alone in this. It’s very important.’ And that’s what I did. I went with her. I took her to have her colonoscopy.”

2.2.8. Julia (NP): “…we had one patient that kept canceling her appointments because, I guess she was afraid. And come to find out she didn’t have anyone to go with her, and she wanted someone to go with her. So, I ended up going with her and with her, through her appointment with her, and she was fine. She did well with that. That was the only way we could actually get her there.”

2.2.9. Suzanne (CHW): “You can’t force them. If the patient is not willing to talk about it or willing to proceed, I can’t force them of course into treatment. I can just be supportive, give them the education I have and offer to get more and offer to get someone else if they would rather talk to someone other than me. And some people would open up more…maybe open [up] to a stranger [more] than someone they have known for a while. You have to feel out the patient and see what’s going to work for them.”

2.2.10. Julia (NP): “You can’t force patients to talk to you about things they don't want to talk about. You can just let them know you’re there and available to talk. And obviously, ya know, reinforce the fact that denying it or ignoring it’s not going to change anything. And being available to them, because a lot of times they don't want to talk to you then, they will want to talk to you later.”

3. Increasing self-efficacy for future navigators
    3.1. Building a network and a solid knowledge base
        3.1.1. Anthony (PN): “Before you ever take on your first client, [...] you need to get yourself out there and know all the people that you can think of that you are gonna have to make referrals to. Any other health care workers you are gonna have to work with, any other community agencies that provides a service to the clients that you are gonna be working with might need, go out there and do some lunches with those people and pass out business cards and collect theirs so that you know that team you are fitting into and that you are gonna become a part of because you need to see yourself as a part of a team that is helping the management to this person’s health care.”
        3.1.2. Mary Jo (NP): “…familiarize yourself first of all with the test [FIT, colonoscopy] itself; know the ins and outs. Know what it actually does. How it’s actually different…who you need to refer to and why.”
        3.1.3. Suzanne (CHW): “And that [learning what works] comes from working for years with the community and knowing the people that I went to to do the FIT test. Ya know them, ya know their family, ya know their grandparents…Ya learn kinda how to talk to the people.”
        3.1.4. Suzanne (CHW): “It started slow – building relationships with local doctors. They know who I am because I’m from the community where [the]

office is. I'm a part of [this] community. I've helped with fundraisers, [patients] who are sick or need a wheelchair; whatever that need was, [I was] out in the public and they see first-hand what I do. Therefore, they don't even second-guess if they should help me with the paperwork or anything like that. They aren't worried about that."

3.1.5. Suzanne (CHW): "…you build up a reputation with people. The doctors believe in you after a while; [they will say] "I know what she does. If she calls, I'll talk to her. She's working with this particular patient to help me get something done." You build up trust with your community."

3.1.6. Mary Jo (NP): "…communication and respect…for their scheduling, their office protocols or whatever…when you get familiar with a couple of doctors that you work with, and um, that you refer to, it's kinda like anything else. You get a comfort level and a rapport buildup with their office, and that makes it go easier I think."

3.2. Being honest, empathetic, and (most of all) persistent

3.2.1. Bonnie Jean (CHW): "…if you can kinda put yourself in their shoes, you know, and figure out what is causing the unwillingness. If you can figure that cause out then most of the time you can fix whatever is causing that unwillingness."

3.2.2. Carlene (PN): "…just be yourself and be honest and try to help them make them feel comfortable about what they're doing and express the importance of this test and the follow up test."

3.2.3. Suzanne (CHW): “I make a lot of phone calls; ‘Did you go do that yet?’ You want to be that little voice that [says] ‘someone cares about me. She’s still calling. Maybe I ought to go.’ You just hope for that breakthrough that they will listen before it’s too late.”

3.2.4. Mary Jo (NP): “Try to help them work through it and try to figure out a way around it, or over it, or under it, or something…it’s all about problem solving.”

APPENDIX 3. PATIENT INTERVIEW PROTOCOL

1. We are interested in learning more about your decision-making process to not receive a colonoscopy.
2. I would like you to think back when you first received your positive FIT results. What were your thoughts?
3. Tell me about your thoughts when you and your navigator discussed you getting a colonoscopy.
4. Have your thoughts about getting a colonoscopy changed at any time since you were receiving navigation?
5. You decided not to have a colonoscopy. What things prevented you from getting a colonoscopy?
6. Did you have any financial reasons that prevented you from scheduling your colonoscopy?
7. What about transportation issues? Did you have any of those?
8. What about childcare or other family care issues?
9. Did you have trouble getting someone to go with you?
10. Were you afraid of the test or the possible results you would get once you did go have a colonoscopy?
11. What is the chance that you would change your mind and have a colonoscopy within the next year?
12. Please ask me any questions that you have or tell me about any other things you think we should know.

APPENDIX 4. PATIENT THEMATIC FRAMEWORK INDEX

1. Lacking key assurances required for screening and understanding results:
    - 1.1. Needing quality and affordable care
        - 1.1.1. Gill: “I already figured get in there and get it done and if this turns into cancer, let's get it straightened out before it does turn into cancer...it all [the screening process] went good. Good people that did the test and good people that told me about it and whatever not and I think it all turned out wonderful.”
        - 1.1.2. Nick: “I'm not trying to go through all the things that you have to go through.”
        - 1.1.3. Nick: “So, there will be no cost to me or any of my family or anything like that? My insurance will pay it?”
    - 1.2. Overcoming challenges getting to the appointment
        - 1.2.1. Gill: “My truck ain't the best. But I went down with somebody else...both of us had appointments that same day.”
        - 1.2.2. Sara: “I get the transit to take me to get a referral. If it's [medical appointment] not in Jackson, then you have to get a referral. You have to let them know within 72 hours.”
        - 1.2.3. David: [Getting someone to go with me to an appointment] “was kind of a problem too.”
        - 1.2.4. Julianne: “I can get to Hazard and stuff...I won’t go to Lexington and all that stuff.”
    - 1.3. Desiring more information about testing and meaning of results

        1.3.1. Catherine: “Well, I just think that this test probably saved me from ever having cancer in the colon and further trouble...I recommend this to everybody to do, you know.”
        1.3.2. Gill: “I was just thinking where I should have it done and who could do it and whatever like that. And how long it was going to take to get it set up to get it done.”
        1.3.3. Nick: “Is there anything besides colon cancer that a positive test would mean?”
        1.3.4. Greg: “I was kind of worried…[about] what the hell it meant.”
        1.3.5. Raymond: “I was uncomfortable and I was kind of scared. I was afraid of my result.”

2. Engaging in the emotional labor of screening decisions:
    2.1. Experiencing fear & worry about cancer being the ultimate result
        2.1.1. Nick: “The thoughts that I'm having is that I go back to question one and it's do I have colon cancer. It just ends in all kinds of crazy thoughts into my head. It's do I have colon cancer? Am I dying? Is this going to be the end? Is in my 50s as far as I'm going to make it? I want to live a good, long life and it's just…my thoughts keep sending me right back to, you know, do I really want to know or do I just want to ignore it and it wind up being colon cancer and it just wipe me out.”
        2.1.2. Catherine: “Kinda afraid of finding out what it might be going on with me and stuff because I done went through the process of cancer before and things run through your mind with it. So, kinda scary.”

    2.2. Remembering loved ones' (often poor) health experiences
        2.2.1. Nick: "I didn't know what to do. I didn't know what to say. I thought back about when my grandfather had got his and you know he had colon cancer back in the 80s, back when they had to go in and put colostomy bags on people. The death rate for it I assume would be pretty high and I thought how he struggled and how he fought with it. And you know he was late in age and I just wondered would that be me? You know, if I went through and had it, I guess I thought that what would be the point in it."
        2.2.2. Conrad: "I was scared about the results I would get back and what my test would show. I always heard bad things about it."
    2.3. Consulting with family about the decision to screen
        2.3.1. Catherine: "I just haven't talked with my mom, having to visit with her a lot and help take care of her and everything. So that kinda did sway me from having it done at the time."
        2.3.2. Nick: "I've had my youngins [children] talk to me about it. They're kind of worried. I wish that I wouldn't have even said anything about it. More than anything, I wish that I never went through with the test."
3. Reconciling screening and results with everyday life:
    3.1. Ongoing comorbid health issues take priority
        3.1.1. Greg: "I didn't get around to it because I think I had an accident where they had to take my stomach out and put it back in and I ruptured my spleen. After that, I kind of forgot about that [positive FIT result] and worried more

about this….I've had other health problems and it just kind of swept my mind until you talked to me about it today."

- 3.2. Navigating existing family commitments
  - 3.2.1. David: [Getting a colonoscopy is] "an issue because I have my grandkids and it's hard to get away and do anything that I need to get done."
  - 3.2.2. Julianne: "I will have a colonoscopy but it would have to be done on Wednesday because sometimes my granddaughter...I have a daughter that we adopted and she's a junior in high school. She has another year and I just want to make sure I'm around for her."
  - 3.2.3. Conrad: [Childcare] "was a[n] issue because I have my grandkids and it's hard to get away to get anything done...I haven't thought about it anymore. I've been so busy with other things."

4. Conducting personal analyses of screening practices:
   - 4.1. Accepting the risk of "knowing"
     - 4.1.1. Nick: "I guess I regretted taking it [the FIT test]. I guess I thought now that I've done it, what now? Am I going to die? I just didn't know what to think. So my first thought was probably, is this the end? That's what really sent me over the edge. That really put me in the mind frame of I'm still not going to do it. I don't want to know. If it kills me, then it's just going to have to kill me. I really regretted messing with the whole thing and never changed my mind. I pretty much ignored the whole navigator thing. I just sat there and listened. I didn't want to know...I guess it's more of the psychological thing than anything."

4.1.2. Greg: “I'd kinda like to know ... Then again when you think about it, you don't really know if you want to know...If it is, it is and if it ain't, it ain't.”

4.1.3. Sara: “I was afraid to go get one...I was afraid it would show up with something.”

4.1.4. Nick: “Because part of me wants to have it and part of me doesn't. And right now the part of me that doesn't want to have it is trumping the part that does. Like I said, my kids are really pushing me to have it and myself is telling me not to have it because I don't want to know. You know, it's 70/30, the 70 is saying don't have it and the 30 is saying have it. It all boils down to do I wanna go through with it, do I wanna go through being aggravated with doctors? Because I was never one to really want to go to a doctor. And to be quite honest, I'm really regretting the whole thing. I'm regretting all of it.”

4.1.5. Raymond: “I was kind of reluctant. You know it’s sometimes better to just not find out what’s going on in your body.”

4.2. Challenging the efficacy of screening

4.2.1. Greg: “Two positive [FIT results] is better than one. Cause one could be a false.”

4.2.2. David: “I'd like to have another test to confirm the test results and then I might get a colonoscopy.”

4.2.3. Conrad: “I’d really like to have another test to confirm my test results and then I might have a colonoscopy.”

4.2.4. Jim: “I was worried and wondered if the last test was accurate...I still don’t know if they are the same or what’s going on. I would like to do another test to see if the results are the same.”

REFERENCES

Ali-Faisal, S. F., Colella, T. J., Medina-Jaudes, N., & Scott, L. B. (2017). The effectiveness of patient navigation to improve healthcare utilization outcomes: A meta-analysis of randomized controlled trials. *Patient Education and Counseling*, *100,* 436-448.

Babrow, A. S. (1992). Communication and problematic integration: Understanding diverging probability and value, ambiguity, ambivalence, and impossibility. *Communication Theory*, *2,* 95-130.

Babrow, A. S. (1995). Communication and problematic integration: Milan Kundera's "lost letters" in the book of laughter and forgetting. *Communication Monographs*, *62,* 283-300.

Babrow, A. S., Kasch, C. R., & Ford, L. A. (1998). The many meanings of uncertainty in illness: Toward a systematic accounting. *Health Communication*, *10,* 1-23.

Babrow, A. S., Hines, S. C., & Kasch, C. R. (2000). Managing uncertainty in illness explanation: An application of problematic integration theory. In B. Whaley (Ed.), *Explaining illness: Research, theory, and strategies* (pp. 41-67). Erlbaum.

Babrow, A. S. (2001). Uncertainty, value, communication, and problematic integration. *Journal of Communication*, *51,* 553-573.

Bachman, A. S., Cohen, E. L., Collins, T., Hatcher, J., Crosby, R., & Vanderpool, R. C. (2018). Identifying communication barriers to colorectal cancer screening adherence among Appalachian Kentuckians. *Health Communication*, *33,* 1284-1292.

Bardach, S. H., Schoenberg, N. E., Fleming, S. T., & Hatcher, J. (2012). The relationship between colorectal cancer screening adherence and knowledge among vulnerable rural residents of Appalachian Kentucky. *Cancer Nursing*, *35,* 288.

Behringer, B., & Friedell, G. H. (2006). Appalachia: Where place matters in health. *Preventing Chronic Disease*, *3*(4).

Berger, C. R. (1995). Inscrutable goals, uncertain plans, and the production of communicative action. In C. R. Berger & H. M. Burgoon (Eds.), *Communication and social influence processes* (pp. 1-28). Michigan State University Press.

Bibbins-Domingo, K., Grossman, D. C., Curry, S. J., Davidson, K. W., Epling, J. W., García, F. A., ... & Siu, A. L. (2016). Screening for colorectal cancer: US Preventive Services Task Force recommendation statement. *JAMA*, *315,* 2564-2575.

Blackley, D., Behringer, B., & Zheng, S. (2012). Cancer mortality rates in Appalachia: Descriptive epidemiology and an approach to explaining differences in outcomes. *Journal of Community Health*, *37,* 804–813.

Bradac, J. J. (2001). Theory comparison: Uncertainty reduction, problematic integration, uncertainty management, and other curious constructs. *Journal of Communication*, *51,* 456-476.

Brashers, D. E., Neidig, J. L., Reynolds, N. R., & Haas, S. M. (1998). Uncertainty in illness across the HIV/AIDS trajectory. *Journal of the Association of Nurses in AIDS Care, 9,* 66-77.

Brashers, D. E. (2001). Communication and uncertainty management. *Journal of Communication, 51,* 477-497.

Braun, V., & Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative Research in Psychology, 3,* 77–101.

Braun, V., & Clarke, V. (2013). *Successful qualitative research: A practical guide for beginners*. Sage.

Brenes, G. A., & Paskett, E. D. (2000). Predictors of stage of adoption for colorectal cancer screening. *Preventive Medicine, 31,* 410-416.

Champion, V. L. & Skinner, C. S. (2008). The health belief model. In K. Glanz, B. K. Rimer, & K. Viswanath *Health behavior and health education: Theory, research, and practice* (pp. 45-65). John Wiley & Sons.

Charles, C., Gafni, A., & Whelan, T. (1997). Shared decision-making in the medical encounter: What does it mean? (or it takes at least two to tango). *Social Science & Medicine, 44,* 681-692.

Charles, C., Gafni, A., & Whelan, T. (1999). Decision-making in the physician–patient encounter: Revisiting the shared treatment decision-making model. *Social Science & Medicine, 49,* 651-661.

Chen, R. C., Haynes, K., Du, S., Barron, J., & Katz, A. J. (2021). Association of cancer screening deficit in the United States with the COVID-19 pandemic. *JAMA Oncology, 7,* 878-884.

Chow, C. J., Al-Refaie, W. B., Abraham, A., Markin, A., Zhong, W., Rothenberger, D. A., ... & Habermann, E. B. (2015). Does patient rurality predict quality colon cancer care? A population based study. *Diseases of the Colon and Rectum, 58,* 415

Chubak, J., Garcia, M. P., Burnett-Hartman, A. N., Zheng, Y., Corley, D. A., Halm, E. A., Singal, A. G., Klabunde, C. N., Doubeni, C. A., Kamineni, A., Levin, T. R., Schottinger, J. E., Green, B. B., Quinn, V. P., & Rutter, C. M. (2016). Time to colonoscopy after positive fecal blood test in four US health care systems. *Cancer Epidemiology and Prevention Biomarkers, 25,* 344-350.

Cohen, E. L. (2009). Naming and claiming cancer among African American women: An application of problematic integration theory. *Journal of Applied Communication Research, 37,* 397-417.

Cohen, E. L., Scott, A. M., White, C. R., & Dignan, M. B. (2013). Evaluation of patient needs and patient navigator communication about cervical cancer prevention in Appalachian Kentucky. *Journal of Communication, 63,* 72-94.

Cohen, E. L., Wilson, B. R., Vanderpool, R. C., & Collins, T. (2016). Identifying sociocultural barriers to mammography adherence among Appalachian Kentucky women. *Health Communication, 31,* 72–82.

Corbin, J., & Strauss, A. (2015). *Basics of qualitative research* (4th edition). Sage.

Crosby, R. A., & Collins, T. (2017). Correlates of community-based colorectal cancer screening in a rural population: The role of fatalism. *The Journal of Rural Health 33,* 402–405.

Crosby, R. A., Stradtman, L., Collins, T., & Vanderpool, R. (2017). Community-based colorectal cancer screening in a rural population: Who returns fecal immunochemical test (FIT) kits?. *The Journal of Rural Health, 33,* 371-374.

Crosby, R. A., Mamaril, C. B., & Collins, T. (2021). Cost of increasing years-of-life-gained (YLG) using fecal immunochemical testing as a population-level screening model in a rural Appalachian population. *The Journal of Rural Health, 37,* 576–584.

Dougherty, M. K., Brenner, A. T., Crockett, S. D., Gupta, S., Wheeler, S. B., Coker-Schwimmer, M., Cubillos, L., Malo, T., & Reuland, D. S. (2018). Evaluation of interventions intended to increase colorectal cancer screening rates in the United States: A systematic review and meta-analysis. *JAMA Internal Medicine, 178,* 1645-1658.

Dean, M. L. (2014). *"It's not if I get cancer, it's when I get cancer": Exploring previvors' management of uncertainty for hereditary cancer in clinical encounters* [Doctoral dissertation, Texas A&M University]. OAKTrust.

DiPalma, A. M., Barnes, S. E., & DiPalma, J. A. (1998). Patient participation in colon cancer screening programs. *Southern Medical Journal, 91,* 342-344.

Donahoe, J. T., Titus, A. R., & Fleischer, N. L. (2018). Key factors inhibiting legislative progress toward smoke-free coverage in Appalachia. *American Journal of Public Health, 108,* 372-378.

Donaldson, E. A., Holtgrave, D. R., Duffin, R. A., Feltner, F., Funderburk, W., & Freeman, H. P. (2012). Patient navigation for breast and colorectal cancer in 3 community hospital settings: An economic evaluation. *Cancer, 118,* 4851-4859.

Edwards, A., & Elwyn, G. (2006). Inside the black box of shared decision making: Distinguishing between the process of involvement and who makes the decision. *Health Expectations, 9,* 307-320.

Ellerbeck, E. F., Engelman, K. K., Gladden, J., Mosier, M. C., Raju, G. S., & Ahluwalia, J. S. (2001). Direct observation of counseling on colorectal cancer in rural primary care practices. *Journal of General Internal Medicine, 16,* 697-700.

Elwyn, G., Frosch, D., Thomson, R., Joseph-Williams, N., Lloyd, A., Kinnersley, P., Cording, E., Tomson, D., Dodd, C., Tollnick, S., Edwards, A., & Barry, M. (2012). Shared decision making: a model for clinical practice. *Journal of General Internal Medicine, 27,* 1361-1367.

Elwyn, G., Dehlendorf, C., Epstein, R. M., Marrin, K., White, J., & Frosch, D. L. (2014). Shared decision making and motivational interviewing: Achieving patient-centered care across the spectrum of health care problems. *The Annals of Family Medicine, 12,* 270-275.

Emanuel, A. S., Kiviniemi, M. T., Howell, J. L., Hay, J. L., Waters, E. A., Orom, H., & Shepperd, J. A. (2015). Avoiding cancer risk information. *Social Science & Medicine, 147,* 113-120.

Epstein, R. M., & Street R. L. (2007). Patient-centered communication in cancer care: Promoting healing and reducing suffering. National Cancer Institute, NIH Publication No. 07-6225. Bethesda, MD.

Feltner, F. J., Ely, G. E., Whitler, E. T., Gross, D., & Dignan, M. (2012). Effectiveness of community health workers in providing outreach and education for colorectal cancer screening in Appalachian Kentucky. *Social Work in Health Care, 51,* 430-440.

Ford, L. A., Babrow, A. S., & Stohl, C. (1996). Social support messages and the management of uncertainty in the experience of breast cancer: An application of problematic integration theory. *Communications Monographs, 63,* 189-207.

Freeman, H. P., Wingrove, B. K., & Center to Reduce Cancer Health Disparities, (2005). Excess cervical cancer mortality: A marker for low access to health care in poor communities: an analysis. Rockville, MD: National Cancer Institute, Center to Reduce Cancer Health Disparities.

Freeman, H. P., & Rodriguez, R. L. (2011). History and principles of patient navigation. *Cancer, 117*(S15), 3537-3540.

Guest, G., MacQueen, K. M., & Namey, E. E. (2012). *Applied thematic analysis.* Sage.

Hammersley, M. (1987). Some notes on the terms ‘validity and ‘reliability’. *British Educational Research Journal, 13,* 73-82.

Hatcher, J., Dignan, M. B., & Schoenberg, N. (2011). How do rural health care providers and patients view barriers to colorectal cancer screening? Insights from Appalachian Kentucky. *The Nursing Clinics of North America, 46*(2), 181–vi.

Han, P. K., Moser, R. P., & Klein, W. M. (2007). Perceived ambiguity about cancer prevention recommendations: associations with cancer-related perceptions and behaviours in a US population survey. *Health Expectations, 10,* 321-336.

Head, K. J., & Cohen, E. L. (2012). Young women’s perspectives on cervical cancer prevention in Appalachian Kentucky. *Qualitative Health Research, 22,* 476-487.

Hochbaum, G., Kegels, S. & Rosenstock, I. (1952). Health belief model. *U. S. Public Health Service: Washington, DC.*

Hochbaum, G. M. (1958). *Public participation in medical screening programs: A socio-psychological study* (No. 572). US Department of Health, Education, and Welfare, Public Health Service, Bureau of State Services, Division of Special Health Services, Tuberculosis Program.

Hines, S. C., Babrow, A. S., Badzek, L., & Moss, A. (2001). From coping with life to coping with death: Problematic integration for the seriously ill elderly. *Health Communication, 13,* 327-342.

Issaka, R. B., Singh, M. H., Oshima, S. M., Laleau, V. J., Rachocki, C. D., Chen, E. H., Day, L. W., Sarkar, U., & Somsouk, M. (2017). Inadequate utilization of diagnostic colonoscopy following abnormal FIT results in an integrated safety-net system. *The American Journal of Gastroenterology, 112,* 375.

Jandorf, L., Gutierrez, Y., Lopez, J., Christie, J., & Itzkowitz, S. H. (2005). Use of a patient navigator to increase colorectal cancer screening in an urban neighborhood health clinic. *Journal of Urban Health*, *82,* 216-224.

Janz, N. K., & Becker, M. H. (1984). The health belief model: A decade later. *Health Education Quarterly*, *11,* 1-47.

Jean-Pierre, P., Hendren, S., Fiscella, K., Loader, S., Rousseau, S., Schwartzbauer, B., ... & Epstein, R. (2011). Understanding the processes of patient navigation to reduce disparities in cancer care: perspectives of trained navigators from the field. *Journal of Cancer Education*, *26,* 111-120.

Jimbo, M., Myers, R. E., Meyer, B., Hyslop, T., Cocroft, J., Turner, B. J., & Weinberg, D. S. (2009). Reasons patients with a positive fecal occult blood test result do not undergo complete diagnostic evaluation. *The Annals of Family Medicine*, *7,* 11-16.

Johnson, J. D. (1997). *Cancer-related information seeking*. Hampton Press.

Johnson, J. D. (2003). On contexts of information seeking. *Information Processing & Management*, *39,* 735-760.

Jones, R. M., Woolf, S. H., Cunningham, T. D., Johnson, R. E., Krist, A. H., Rothemich, S. F., & Vernon, S. W. (2010). The relative importance of patient-reported barriers to colorectal cancer screening. *American Journal of Preventive Medicine*, *38,* 499-507.

Katz, M. L., Reiter, P. L., Young, G. S., Pennell, M. L., Tatum, C. M., & Paskett, E. D. (2015). Adherence to multiple cancer screening tests among women living in Appalachia Ohio. *Cancer Epidemiology and Prevention Biomarkers*, *24,* 1489-1494.

Kelly, K. M., Phillips, C. M., Jenkins, C., Norling, G., White, C., Jenkins, T., Armstrong, D., Petrik, J., Steinkuhl, A., Washington, R., & Dignan, M. (2007). Physician and staff perceptions of barriers to colorectal cancer screening in Appalachian Kentucky. *Cancer Control*, *14,* 167-175.

Kentucky Cancer Registry. (2018). Age-adjusted cancer mortality rates in Kentucky: Colon and rectum, 2014-2018. Retrieved from https://www.cancer-rates.info/ky/

Kentucky Cancer Registry. (2018). Invasive cancer incidence rates in Kentucky: Colon and rectum, 2014-2018. Retrieved from https://www.cancer-rates.info/ky/

Kim, H. K., Kim, S., & Niederdeppe, J. (2015). Scientific uncertainty as a moderator of the relationship between descriptive norm and intentions to engage in cancer risk–reducing behaviors. *Journal of Health Communication*, *20,* 387-395.

Klabunde, C. N., Vernon, S. W., Nadel, M. R., Breen, N., Seeff, L. C., & Brown, M. L. (2005). Barriers to colorectal cancer screening: A comparison of reports from primary care physicians and average-risk adults. *Medical Care*, 939-944.

Kluhsman, B. C., Lengerich, E. J., Fleisher, L., Paskett, E. D., Miller-Halegoua, S. M., Balshem, A., Bencivenga, M. M., Spleen, A. M., Schreiber, P., & Dignan, M. B. (2012). A pilot study for using fecal immunochemical testing to increase colorectal cancer screening in Appalachia, 2008-2009. *Preventing Chronic Disease*, *9*, E77.

Kobayashi, L. C., & Smith, S. G. (2016). Cancer fatalism, literacy, and cancer information seeking in the American public. *Health Education & Behavior*, *43,* 461-470.

Kreps, G. L. (2003). The impact of communication on cancer risk, incidence, morbidity, mortality, and quality of life. *Health Communication, 15*, 161-169.

Krist, A. H., Hochheimer, C. J., Sabo, R. T., Puro, J., Peele, E., Lail-Kashiri, P., & Vernon, S. W. (2020). Patient, clinician, and communication factors associated with colorectal cancer screening. *The Journal of the American Board of Family Medicine, 33,* 779-784.

Lau, J., Lim, T. Z., Jianlin Wong, G., & Tan, K. K. (2020). The health belief model and colorectal cancer screening in the general population: A systematic review. *Preventive Medicine Reports*, *20*, 101223.

LeBlanc, A., Kenny, D. A., O'Connor, A. M., & Légaré, F. (2009). Decisional conflict in patients and their physicians: A dyadic approach to shared decision making. *Medical Decision Making*, *29,* 61-68.

Lebwohl, B., Neugut, A. I., Stavsky, E., Villegas, S., Meli, C., Rodriguez, O., ... & Rosenberg, R. (2011). Effect of a patient navigator program on the volume and quality of colonoscopy. *Journal of Clinical Gastroenterology*, *45*(5), e47.

Lee, J. K., Liles, E. G., Bent, S., Levin, T. R., & Corley, D. A. (2014). Accuracy of fecal immunochemical tests for colorectal cancer: systematic review and meta-analysis. *Annals of Internal Medicine*, *160,* 171-181.

Lincoln, Y. S., & Guba, E. G. (1985). *Naturalistic inquiry.* Sage.

Mandelson, M. T., Curry, S. J., Anderson, L. A., Nadel, M. R., Lee, N. C., Rutter, C. M., & LaCroix, A. Z. (2000). Colorectal cancer screening participation by older women. *American Journal of Preventive Medicine*, *19,* 149-154.

Martin, J., Halm, E. A., Tiro, J. A., Merchant, Z., Balasubramanian, B. A., McCallister, K., ... & Singal, A. G. (2017). Reasons for lack of diagnostic colonoscopy after positive result on fecal immunochemical test in a safety-net health system. *The American Journal of Medicine*, *130*(1), 93-e1.

Matthias, M. S., & Babrow, A. S. (2007). Problematic integration of uncertainty and desire in pregnancy. *Qualitative Health Research, 17,* 786-798.

Meilleur, A., Subramanian, S. V., Plascak, J. J., Fisher, J. L., Paskett, E. D., & Lamont, E. B. (2013). Rural residence and cancer outcomes in the United States: Issues and challenges. *Cancer Epidemiology and Prevention Biomarkers*, *22,* 1657-1667.

Michimi, A., & Wimberly, M. C. (2010). Spatial patterns of obesity and associated risk factors in the conterminous US. *American Journal of Preventive Medicine, 39,* e1-e12.

Mishel, M. H. (1988). Uncertainty in illness. *Image: The Journal of Nursing Scholarship, 20,* 225-232.

Mishel, M. H., Germino, B. B., Gil, K. M., Belyea, M., LaNey, I. C., Stewart, J., ... & Clayton, M. (2005). Benefits from an uncertainty management intervention for African–American and

Caucasian older long-term breast cancer survivors. *Psycho-Oncology: Journal of the Psychological, Social and Behavioral Dimensions of Cancer*, *14,* 962-978.

Morbidity and Mortality Weekly Report. (2017). MMWR rural health series. Retrieved from https://www.cdc.gov/mmwr/rural_health_series.html

Myers, R. E., Hyslop, T., Sifri, R., Bittner-Fagan, H., Katurakes, N. C., Cocroft, J., . . . Wolf, T. (2008). Tailored navigation in colorectal cancer screening. *Medical Care, 46*(9), S123-S131.

National Association of Counties and the Appalachian Regional Commission. (2017). Opioids in Appalachia: The role of counties in reversing a regional epidemic. Retrieved from https://www.naco.org/sites/default/files/documents/Opioids-Full.pdf

National Comprehensive Cancer Control Program. (2021). Colorectal cancer screening test use in Kentucky. Retrieved from https://www.cdc.gov/cancer/ncccp/screening-test-use/index.htm?CDC_AA_refVal=https%3A%2F%2Fwww.cdc.gov%2Fcancer%2Fncccp%2Fscreening-rates%2Findex.htm

National Institutes of Health. (2020). *Cancer control continuum*. https://cancercontrol.cancer.gov/about-dccps/about-cc/cancer-control-continuum.

Niederdeppe, J., & Levy, A. G. (2007). Fatalistic beliefs about cancer prevention and three prevention behaviors. *Cancer Epidemiology and Prevention Biomarkers*, *16,* 998-1003.

Nuss, H. J., Williams, D. L., Hayden, J., & Huard, C. R. (2012). Applying the social ecological model to evaluate a demonstration colorectal cancer screening program in Louisiana. *Journal of Health Care for the Poor and Underserved, 23,* 1026-1035.

Oluloro, A., Petrik, A. F., Turner, A., Kapka, T., Rivelli, J., Carney, P. A., ... & Coronado, G. D. (2016). Timeliness of colonoscopy after abnormal fecal test results in a safety net practice. *Journal of Community Health, 41,* 864-870.

Parrott, R. (2004). Emphasizing "communication" in health communication. *Journal of Communication*, *54,* 751-787.

Partin, M. R., Gravely, A. A., Burgess Jr, J. F., Haggstrom, D. A., Lillie, S. E., Nelson, D. B., ... & Burgess, D. J. (2017). Contribution of patient, physician, and environmental factors to demographic and health variation in colonoscopy follow-up for abnormal colorectal cancer screening test results. *Cancer, 123,* 3502-3512.

Paskett, E. D., Katz, M. L., Post, D. M., Pennell, M. L., Young, G. S., Seiber, E. E., Harrop, J. P., DeGraffinreid, C. R., Tatum, C. M., Dean, J. A., & Murray, D. M. (2012). The Ohio Patient Navigation Research Program: Does the American Cancer Society patient navigation model improve time to resolution in patients with abnormal screening tests? *Cancer Epidemiology Biomarkers Prevention, 21,* 1620-1628.

Percac-Lima, S., Grant, R. W., Green, A. R., Ashburner, J. M., Gamba, G., Oo, S., ... & Atlas, S. J. (2009). A culturally tailored navigator program for colorectal cancer screening in a community health center: a randomized, controlled trial. *Journal of General Internal Medicine*, *24,* 211-217.

PDA Inc., Cecil B. Sheps Center for Health Services Research. Health Care Costs and Access Disparities in Appalachia. Raleigh, NC (PDA Inc.), Chapel Hill, NC (Sheps Center); 2012.

PDA Inc., Cecil G. Sheps Center for Health Services Research, and the Appalachian Regional Commission. Health Disparities in Appalachia. Raleigh, NC (PDA Inc.), Chapel Hill, NC (Sheps Center), Washington, DC (ARC); 2017.

Politi, M., & Street, R. L. (2011). Patient-centered communication during collaborative decision-making. In T. L. Thompson, R. Parrott, & J. F. Nussbaum (Eds.), *The Routledge handbook of health communication* (2nd ed., pp. 399-413). Routledge.

Poon, B. Y., Shortell, S. M., & Rodriguez, H. P. (2020). Patient activation as a pathway to shared decision-making for adults with diabetes or cardiovascular disease. *Journal of General Internal Medicine*, *35*(3), 732–742.

Powe, B. D., & Finnie, R. (2003). Cancer fatalism: The state of the science. *Cancer Nursing*, *26*, 454-467.

President's Cancer Panel. (2022). Closing gaps in cancer screening: Connecting people, communities, and systems to improve equity and access. Retrieved from https://prescancerpanel.cancer.gov/report/cancerscreening/index.html

Rawl, S. M., Menon, U., Champion, V. L., Foster, J. L., & Skinner, C. S. (2000). Colorectal cancer screening beliefs: Focus groups with first-degree relatives. *Cancer Practice*, *8,* 32-37.

Record, R. A., Scott, A. M., Shaunfield, S., Jones, M. G., Collins, T., & Cohen, E. L. (2017). Lay epistemology of breast cancer screening guidelines among Appalachian women. *Health Communication*, *32*, 1112-1120.

Reiter, P. L., Katz, M. L., & Paskett, E. D. (2012). HPV vaccination among adolescent females from Appalachia: implications for cervical cancer disparities. *Cancer Epidemiology and Prevention Biomarkers*, *21*, 2220-2230.

Rice, E. L., Patel, M., Serrano, K. J., Thai, C. L., Blake, K. D., & Vanderpool, R. C. (2018). Beliefs about behavioral determinants of obesity in Appalachia, 2011-2014. *Public Health Reports, 133,* 379-384.

Rodriguez, S., Vanderford, N. L., Huang, B., & Vanderpool, R. (2018). A social-ecological review of cancer disparities in Kentucky. *Southern Medical Journal, 111,* 213.

Rohan, E. A., Slotman, B., DeGroff, A., Morrissey, K. G., Murillo, J., & Schroy, P. (2016). Refining the patient navigation role in a colorectal cancer screening program: results from an intervention study. *Journal of the National Comprehensive Cancer Network*, *14,* 1371-1378.

Rosenstock, I. M., Strecher, V. J., & Becker, M. H. (1988). Social learning theory and the health belief model. *Health Education Quarterly*, *15,* 175-183.

Royse, D., & Dignan, M. (2011). Fatalism and cancer screening in Appalachian Kentucky. *Family & Community Health*, *34*, 126-133.

Rutten, L. F., Hesse, B. W., Moser, R. P., McCaul, K. D., & Rothman, A. J. (2009). Public perceptions of cancer prevention, screening, and survival: Comparison with state-of-science evidence for colon, skin, and lung cancer. *Journal of Cancer Education*, *24*, 40-48.

Sabatino, S. A., Lawrence, B., Elder, R., Mercer, S. L., Wilson, K. M., DeVinney, B., ... & Community Preventive Services Task Force. (2012). Effectiveness of interventions to increase screening for breast, cervical, and colorectal cancers: Nine updated systematic reviews for the guide to community preventive services. *American Journal of Preventive Medicine*, *43,* 97-118.

Salazar, L. F., Crosby, R. A., Noar, S. M., Walker, J. H., & DiClemente, R. J. (2013). Models based on perceived threat and fear appeals. In R. J. DiClemente, Salazar, L. F., & R. A. Crosby *Health behavior theory for public health: Principles, foundations, and applications* (pp. 83-104). Jones & Bartlett Learning.

Schoenberg, N. E., Hatcher, J., & Dignan, M. B. (2008). Appalachian women's perceptions of their community's health threats. *Journal of Rural Health*, *24*, 75-83.

Schoenberg, N. E., Huang, B., Seshadri, S., & Tucker, T. C. (2015). Trends in cigarette smoking and obesity in Appalachian Kentucky. *Southern Medical Journal*, *108,* 170-177.

Shapiro, E. A., Krauskopf, M. S., Wyatt, L., Stoudt, B. G., Weber, T. K., & Winawer, S. J. (2010). 128 increased colonoscopy volume and elimination of racial disparities are enhanced by a patient navigator program: Results from the New York City DOHMH/C5 Program. *Gastroenterology, 138*(5), S-24.

Siegel, R. L., Miller, K. D., Goding Sauer, A., Fedewa, S. A., Butterly, L. F., Anderson, J. C., ... & Jemal, A. (2020). Colorectal cancer statistics, 2020. *CA: A Cancer Journal for Clinicians*, *70,* 145-164.

Silverman, D. (2005). *Doing qualitative research* (2nd edition). Sage.

Singh, G. K., Williams, S. D., Siahpush, M., & Mulhollen, A. (2011). Socioeconomic, rural-urban, and racial inequalities in US cancer mortality: part I—all cancers and lung cancer and part II—colorectal, prostate, breast, and cervical cancers. *Journal of Cancer Epidemiology*, *2011*.

Sohler, N. L., Jerant, A., & Franks, P. (2015). Socio-psychological factors in the expanded health belief model and subsequent colorectal cancer screening. *Patient Education and Counseling*, *98,* 901-907.

Swider, S. M. (2002). Outcome effectiveness of community health workers: An integrative literature review. *Public Health Nursing*, *19,* 11-20.

Tarasenko, Y. N., Wackerbarth, S. B., Love, M. M., Joyce, J. M., & Haist, S. A. (2011). Colorectal cancer screening: Patients' and physicians' perspectives on decision-making factors. *Journal of Cancer Education*, *26,* 285-293.

U.S. Department of Health and Human Services. (2020). *Healthy People 2030*. https://health.gov/healthypeople.

U.S. Preventive Services Task Force. (2021). Colorectal cancer screening recommendation update. Retrieved September 11, 2021 from https://www.uspreventiveservicestaskforce.org/uspstf/recommendation/colorectal-cancer-screening

Viswanath, K., Breen, N., Meissner, H., Moser, R. P., Hesse, B., Steele, W. R., & Rakowski, W. (2006). Cancer knowledge and disparities in the information age. *Journal of Health Communication, 11*(S1), 1-17.

Wackerbarth, S. B., Tarasenko, Y. N., Joyce, J. M., & Haist, S. A. (2007). Physician colorectal cancer screening recommendations: An examination based on informed decision making. *Patient Education and Counseling, 66,* 43-50.

Weick, K. E. (1989). Theory construction as disciplined imagination. *Academy of Management Review, 14,* 516-531.

Wells, K. J., Battaglia, T. A., Dudley, D. J., Garcia, R., Greene, A., Calhoun, E., Mandelblatt, J. S., Pasket, E. D., Raich, P. C., & Patient Navigation Research Program. (2008). Patient navigation: State of the art or is it science? *Cancer*, *113,* 1999-2010.

Wells, K. J., Luque, J. S., Miladinovic, B., Vargas, N., Asvat, Y., Roetzheim and Kumar, A. (2011). Do community health workers interventions improve rates of screening mammography in the United States? A systematic review. *Cancer, Epidemiology & Biomarkers Prevention, 20,* 1580–1598.

Wells, K. J., Lee, J. H., Calcano, E. R., Meade, C. D., Rivera, M., Fulp, W. J., & Roetzheim, R. G. (2012). A cluster randomized trial evaluating the efficacy of patient navigation in improving quality of diagnostic care for patients with breast or colorectal cancer abnormalities. *Cancer Epidemiology, Biomarkers, & Prevention, 21,* 1664-1672.

Weitzman, E. R., Zapka, J., Estabrook, B., & Goins, K. V. (2001). Risk and reluctance: Understanding impediments to colorectal cancer screening. *Preventive Medicine, 32*, 502-513.

Wewers, M. E., Katz, M., Paskett, E. D., & Fickle, D. (2006). Risky behaviors among Ohio Appalachian adults. *Preventing Chronic Disease, 3*(4).

Witmer, A., Seifer, S. D., Finocchio, L., Leslie, J., & O'Neil, E. H. (1995). Community health workers: integral members of the health care work force. *American Journal of Public Health*, *85,* 1055-1058.

Yu, C., Skootsky, S., Grossman, M., Garner, O. B., Betlachin, A., Esrailian, E., Hommes, D. W., & May, F. P. (2018). A multi-level fit-based quality improvement initiative to improve colorectal cancer screening in a managed care population. *Clinical and Translational Gastroenterology*, *9,* 177.

Zahnd, W. E., James, A. S., Jenkins, W. D., Izadi, S. R., Fogleman, A. J., Steward, D. E., Colditz, G. A., & Brard, L. (2018). Rural–urban differences in cancer incidence and trends in the United States. *Cancer Epidemiology, Biomarkers, & Prevention, 27,* 1265-1274.

Zoellner, J., Porter, K., Thatcher, E., Kennedy, E., Werth Jr, J. L., Grossman, B., Roatsey, T., Hamilton, H., Anderson, R., & Cohn, W. (2020). A multilevel approach to understand the context and potential solutions for low colorectal cancer (CRC) screening rates in rural Appalachia clinics. *The Journal of Rural Health*, *37*, 585-601.

VITA

Audrey Smith Bachman, Ph.D., MPH

1. Hometown – Manchester, Kentucky
2. Education
    - University of Kentucky, MPH (2018)
    - University of Kentucky, MA (2015)
    - Eastern Kentucky University, BA (2012)
3. Professional Positions
    - Lead Learning Consultant, FICO, (present)
    - Senior Training Specialist, University of Kentucky (2019-2022)
    - Teaching & Research Assistant, University of Kentucky (2013-2018)
    - Retail Sales Consultant, Verizon Wireless, (2010-2012)
    - Retail Sales Consultant, AT&T, (2007-2010)
4. Scholastic and Professional Honors
    - Dissertation Year Fellowship, UK College of Communication & Information, 2018
    - Palmgreen Fellowship, UK College of Communication & Information, 2017
    - Leadership Legacy, UK Center for Interprofessional Health Education, 2017
    - Dorothy M. Carozza Memorial Fellowship, UK College of Communication & Information, 2016
5. Professional Publications
    - Bachman, A. S., Vanderpool, R. C., Cohen, E. L., Wilburn, A., & Johnson, S. (2018). Exploring the framing of human papillomavirus messages in television programming. *Kentucky Journal of Communication*.
    - Bachman, A. S., Cohen, E. L., Collins, T., Hatcher, J., Crosby, R., & Vanderpool, R. C. (2018). Identifying communication barriers to colorectal cancer screening adherence among Appalachian Kentuckians. *Health Communication, 33,* 1284-1292.
    - Cohen, E. L., Head, K. J., Westgate, P., Vanderpool, R. C., Parrish, A., Reno, J., Bachman, A. S., Vos, S., & Wombacher, K. (2018). An evaluation of the 'protect their future' video intervention on parents' intentions to immunize adolescents. *Journal of Communication in Healthcare, 11,* 288-296.
    - Bachman, A. S. (2016). Review of What doctors feel: How emotions affect the practice of medicine, by D. Ofri. *Health Communication, 31,* 1178–1179.
    - Frisby, B. N., Beck, A., Bachman, A. S., Byars, C., Lamberth, C., & Thompson, J. (2016). The influence of instructor-student rapport on

instructors' professional and organizational outcomes. *Communication Research Reports, 33*, 103-110.