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"YOU'RE NOT ALONE IN THIS": NAVIGATING PATIENTS TO COLORECTAL CANCER SCREENING IN APPALACHIAN KENTUCKY COMMUNITIES

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"YOU'RE NOT ALONE IN THIS": NAVIGATING PATIENTS TO COLORECTAL CANCER SCREENING IN APPALACHIAN KENTUCKY COMMUNITIES

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ABSTRACT

In eastern Kentucky, some communities experience colorectal cancer (CRC) mortality rates as high as 25.9 deaths per 100,000 people as compared to the national rate of 14.8 deaths per 100,000 people (NCI, 2018; Kentucky Cancer Registry, 2018). Innovative screening mechanisms, coupled with patient navigation services, may be the key to increasing screening rates and preventing unnecessary deaths in the region. The current study focuses on the accounts of patient navigators (n = 9) to identify the essential ingredients for addressing barriers to CRC screening cited by Appalachian Kentucky patients. Using the core tenants of effective patient navigation programs (Freeman & Rodriguez, 2011) and uncertainty and communication privacy management theories (Brashers, 2001; Petronio, 2002), data were analyzed using a qualitative framework analysis methodology (Ritchie & Spencer, 1994). Six primary themes were discovered including (a) common (and seemingly insurmountable) barriers to navigation; (b) facilitating navigation through the system using relational capital; (c) managing uncertainty using education, social support, and emotional appeals; (d) countering uncertainty and privacy concerns with stories and help from friends and family; (e) accommodating and supporting patients to manage privacy concerns; and (e) honest advice for future navigators. Findings from this study may be used to inform future patient navigation programs in regions similar to Appalachia and catalyze future research efforts.

Keywords: public health, colorectal cancer screening, patient navigation, Appalachia

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ACRONYMS AND ABBREVIATIONS

ACS – American Cancer Society
CHW – community health worker
CPM – communication privacy management theory
CRC – colorectal cancer
FIT – fecal immunochemical testing
FOBT – fecal occult blood testing
KRADD – Kentucky River Area Development District
NP – nurse practitioner
PN – patient navigator
RCPC – Rural Cancer Prevention Center

INTRODUCTION

The National Cancer Institute (NCI, 2018) reports an estimated 1.3 million people are living with colon and rectum cancer (CRC) in the United States (U.S.). The American Cancer Society (ACS; 2018) estimates 140,250 new cases of CRC will be diagnosed in 2018, with an estimated 50,630 deaths in the same period. The lifetime risk of developing CRC is similar for both men (4.49%) and women (4.15%), and the risk of developing CRC increases significantly after the age of 50 (ACS, 2018). The risk of CRC increases with age. CRC screening guidelines recommend initiating regular screenings at age 50 and continuing until age 75 (U.S. Preventative Services Task Force, 2016). In addition, The American Cancer Society (2018) recommends that people at average risk of colorectal cancer start regular screening at age 45. Average risk factors for developing CRC include a personal history of CRC, adenomatous polyps, or inflammatory bowel disease (ulcerative colitis or Crohn's disease), a confirmed or suspected hereditary colorectal cancer syndrome (e.g., familial adenomatous polyposis or Lynch syndrome), or a personal history of getting radiation to the abdomen (belly) or pelvic area to treat a prior cancer (ACS, 2018). Additionally, individuals are at greater risk for CRC if they are overweight or obese, physically inactive, eat a diet high in red meats, use alcohol heavily, smoke, or are exposed to environmental tobacco smoke (ACS, 2016). The differing guidelines (start date and mode) is a factor leading to variability in the screening recommendations made by physicians.

Age-adjusted five-year incidence rates for CRC remain higher among Kentuckians (50 per 100,000 persons) as compared to national rates (39.8 per 100,000); moreover, age-adjusted mortality rates are considerably higher in Kentucky (17.2) than in the U.S. as a whole (14.8; NCI, 2018). In eastern Kentucky, some counties in the Kentucky River

Area Development District (KRADD) like Breathitt county experience CRC five-year mortality rates of 25.9 deaths per 100,000 people, and five-year incidence rates for CRC are 62.5 per 100,000 people (Kentucky Cancer Registry, 2018). These figures do not meet the target goal of 14.5 deaths per 100,000 recommended by the Centers for Disease Control and Prevention (CDC) and Prevention and the National Institute of Health (NIH) in the *Healthy People 2020* objectives. Appalachian communities like those in the KRADD experience many factors that proliferate widespread health disparities. In fact, eastern Kentucky counties that are designated as "Appalachia" by the Appalachian Regional Commission are disproportionately affected by late-stage cancer diagnoses, significant socioeconomic disparities, and are underserved by the health care system (Wingo et al., 2008). These issues may contribute to suboptimal cancer screening rates in the region. For example, research from the Kentucky Department for Public Health (2017) shows that adults ages 50 and older living in counties (i.e., Breathitt, Knott, Lee, Leslie, Letcher, Owsley, Perry, and Wolfe) in the KRADD have considerably lower colonoscopy screening rates (64.7%)[1] as compared to state-wide rates (71.7%)[2]. Disparities in adherence to cancer screenings may contribute to CRC incidence and mortality in eastern Kentucky (Kentucky Health Facts, 2012). Uncovering ways to support adherence to recommended CRC screening is crucial for reducing preventable cancer deaths in Appalachian Kentucky.

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[1] As compared to 55.9% in 2015
[2] As compared to 69.6% in 2015

Screening Guidelines

There are several options for CRC screening including (1) fecal immunochemical testing (FIT) or high sensitivity (e.g. Hemmocult SENSA) guaiac-based fecal occult blood testing (FOBT) every year, (2) flexible sigmoidoscopy every five years, or (3) colonoscopy every ten years (U.S. Preventative Services Task Force, 2016). There are risks and benefits associated with both stool-based screening (e.g., FIT) and direct visualization tests (e.g., colonoscopy), and many considerations are made on a case-by-case basis. For example, colonoscopy is recommended every ten years but requires relatively greater obligations of both time and effort for bowel preparation, the procedure, and post-procedure recovery. New options are available for those with limited access to facilities that provide colonoscopy services. Stool-based screening, such as FOBT and FIT, requires the individual to use a stick or brush to obtain a sample of his or her feces but is a relatively quick and noninvasive 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 his or her 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 an alternative to more invasive types of CRC screening such as colonoscopy and less sensitive tests like FOBT. FIT has the potential to counter many commonly reported barriers to screening.

Common Barriers to Screening

The use of FIT can assist the effort to overcome many significant barriers to CRC screening. Common obstacles to CRC screening include (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 of the need for follow-up procedures; and (4) concerns about the efficacy of screening tests (Bachman et al., 2017; Bardach, Schoenberg, Fleming, & Hatcher, 2012; DiPalma, Barnes, & DiPalma, 1998; Klabunde et al., 2005; Weitzman, Zapka, Estabrook, & Goins, 2001). Also, 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). Appalachian communities' in particular face unique barriers to CRC screening adherence, such as geographic isolation and lack of screening services. A recent study by Bachman and colleagues (2017) showed that patients in Appalachian Kentucky felt skepticism toward screening practices as a result of 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 and benefits, and screening alternatives) of CRC screening recommendations (Wackerbarth, Tarasenko, Joyce, & Haist, 2007; Tarasenko, Wackerbarth, Love, Joyce, & Haist, 2011).

FIT is an innovative option for early detection of both 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 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 who have a positive FIT, there may be a variety of 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 if we are to reduce the burden of cancer in places like Appalachian Kentucky. The dissemination of FIT kits, coupled with patient navigation services, may be the key to increasing screening rates and preventing unnecessary deaths.

Patient Navigation to Cancer Screening Services

According to Freeman and Rodriguez (2011), the role of patient navigator was originally 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. The first patient navigation program, spearheaded by Dr. Harold Freeman, addressed breast cancer disparities experienced by African-American women in Harlem. This pilot project identified significant barriers to timely care (i.e., lack of health insurance; communication and information barriers; medical system barriers; fear, distrust, and emotional barriers). The intervention, which combined free and low-cost mammograms with patient navigation services, achieved tremendous success and became

the model for subsequent patient navigation programs. 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).

Freeman and Rodriguez (2011) identify nine primary principles that should guide any patient navigation program. Patient navigation programs should: (1) be patient-centric; (2) integrate a fragmented health care system for the individual patient; (3) eliminate barriers to timely care across all segments of the health care continuum; (4) be defined with a clear scope of practice that distinguishes the role and responsibilities of the navigator from that of all other providers; (5) be cost-effective and commensurate with the training and skills necessary to navigate an individual through a particular phase of the care continuum; (6) determine who should navigate by the level of skills required at a given phase of navigation; (7) define the point at which navigation begins, and the point at which navigation ends; (8) navigate patients across disconnected systems of care; and (9) be viewed as a system that requires coordination (p. 3541). A patient navigation program that follows these guidelines serves as an intervention with the potential to significantly increase access to diagnosis and treatment for vulnerable populations like the communities in eastern Kentucky. Research shows that patient navigation is a useful

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).

Effectiveness of Patient Navigation Interventions

Research shows that patient navigation interventions are more effective than standard care (Donaldson et al., 2012; Meyers et al., 2013; Percac-Lima et al., 2009). A recent study by 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). Patient navigation was found to increase adherence to cancer care follow-up treatment and obtain diagnoses. There are several studies that corroborate these findings and highlight how patient navigation interventions improve FIT adherence and increase follow-up to CRC screening services like 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 for underserved communities who experience significant procedure-related barriers (Jandorf et al., 2005; Lebwohl et al., 2011; Percac-Lima et al., 2009). Even with the success of patient navigation programs, for patient navigators, communicating with patients can be a time-consuming and arduous task.

Although many studies show the effectiveness of navigation programs, fewer studies describe the challenges that navigators face in communicating with patients. One exception is a recent study by Rohan and colleagues (2016) that uncovered difficulties that navigators at Boston Medical Center, which is the largest safety net hospital in New England, faced while providing navigation services to patients. They analyzed a

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. Patients valued the navigators, especially for providing emotional support and explaining screening procedures and bowel preparation clearly.

There are even fewer studies that investigate the challenges that navigators face when serving rural communities like Appalachian Kentucky. The scarcity of research is problematic because culturally centered interventions are often the crux of program success. At present, there are virtually no studies that investigate the facilitators and barriers to successful CRC screening navigation from the perspective of patient navigators in rural areas. One study, conducted by Cohen, Scott, White, and Dignan (2013), uncovered the perspectives 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 used 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 than that of cervical cancer screening due to the nature of the disease and the types of screening services used. In the face of varying barriers to screening and cultural differences among populations, what are the factors that facilitate the effectiveness of patient navigators' communication during patient interventions to increase CRC screening?

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 who were contacted by navigators in person were more likely to complete CRC screening than those contacted by other methods. Another study by Jean-Pierre and colleagues (2013) 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 are often tackling logistical barriers like transportation and insurance coverage, while simultaneously addressing emotional barriers related to uncertainty and privacy.

Uncertainty and Communication Privacy Management Theories

Uncertainty management theory has been studied and applied in many contexts where communication about health occurs (Vevea & Miller, 2010). 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). Managing uncertainty is crucial in interpersonal communication, as relationships experience uncertainty about their own and others' communication skills and abilities, goals, plans, affective states, and beliefs (Berger, 1995). Responses during uncertain conversations are marked by appraisals and emotional reactions. Appraisals are often shaped by the relevance, likelihood, and evaluation of the event, while 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 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 of these issues with managing patients' uncertainty about CRC screening, treatment, care, and survivorship.

In addition to managing uncertainty among patients, navigators may have to address concerns about privacy. Communication privacy management theory (CPM; Petronio, 2002) was developed to better understand how people make decisions about revealing or concealing private information in their social relationships. There are five primary principals of CPM theory. First, people believe that they own their private information and have the right to control others' access to this information. Second, people have developed rules to control the boundary surrounding their information. For example, a privacy rule in the context of CRC screening conversations may be that a patient has developed a rule about to whom, how much, and if and when others may know about issues related to irregular or abnormal bowel movements. These rules are often derived from cultural expectations, gender norms, personal motivations, assessments of risks or benefits, and situational needs. For example, discussing CRC screening procedures that refer to "private parts" may be taboo for certain patients (see Bachman et al., 2017). Rules may also be malleable due to the dynamics of relationships (e.g., closeness) and situations (e.g., illness trajectories). The third principle states that revealing private information to someone means that person becomes a co-owner of the disclosed information, where the co-owner then holds responsibility for protecting that information. The fourth principle is that post-disclosure, owners and co-owners of the information must coordinate rules for privacy. Specifically, the owners coordinate

linkage (i.e., who else can know), permeability (i.e., how much third parties can know), and ownership (i.e., how much control each party may exercise in their ownership) rules. In the health setting, co-ownership of information and rule coordination is often dictated by policies such as HIPPA. Successful coordination is expected but may fail. Therefore, the fifth principle is that boundary turbulence may occur when there is a failure to coordinate privacy rules between the owner and co-owners. Boundary turbulence may lead to violations, invasions, and privacy dilemmas.

Patient navigators should be skilled in managing uncertainty and privacy concerns among patients, but a recent meta-analysis conducted by Ustjanauskas, Bredice, Nuhaily, Kath, and Wells (2016) showed that most existing research does not thoroughly document patient navigation training practices. Additionally, their analysis showed that programs that did document training their found that training practices varied widely regarding the featured content. In light of training content variability and the need for culturally centered navigation practices, what are the active ingredients for effectively managing uncertainty and privacy concerns while navigating Appalachian Kentucky patients through a host of logistical barriers? The current study focuses on the accounts of patient navigators providing care to patients with a positive FIT result in the KRADD to answer the following research questions:

RQ1: What are the facilitators and barriers to navigating patients in Appalachian Kentucky to follow-up care following an abnormal FIT result?

RQ2: What is the nature of uncertainty management techniques in patient navigation?

RQ3: What is the nature of communication privacy management techniques in patient

navigation?

RQ4: What advice do experienced patient navigators have for those new to the profession?

METHODS

The Rural Cancer Prevention Center (RCPC) is a CDC-funded Prevention

Research Center, and the current study is part of a multi-pronged effort by RCPC to

reduce CRC among residents of the Kentucky River Health District and other rural

communities in Appalachia. Currently, the research team is conducting a community-

level FIT intervention that includes patient navigation services in KRADD. This

intervention will be compared to the standard use of FIT in another district with similar

cancer incidence and mortality rates and demographic data. Local health departments and

their affiliate health organization networks in each district are being provided with FIT

kits to distribute to people ages 50 to 75 that have not been previously screened for CRC.

Data from the present study may serve as a process evaluation to identify the active

ingredients for skillfully navigating patients with a positive FIT result to follow-up care

(i.e., colonoscopy). With the support of RCPC staff, nine individuals (8 female, 1 male;

no data for race/age currently) who served as patient navigators were recruited to

participate in in-depth interviews. Participants identified as community health workers (n

= 5; CHW), patient navigators (n = 2; PN), or nurse practitioners (n = 2; NP) at the

beginning of each interview. A semi-structured, qualitative interview approach was

utilized to gain a better understanding of the facilitators and barriers to successful patient

navigation to colonoscopy after a positive FIT result, the ways that participants managed

uncertainty and privacy concerns with patients, participants' relationships with networks

of providers, and experienced navigators' advice to those new to the profession.

Procedures

Recruitment. 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. The Principal Investigator sent each participant a direct invitation to participate in an interview. Once the invitation was accepted, the participants' information was given to local research coordinators to set up the interviews.

Data Collection. Each participant chose the day, time, and location for his or her interview. Two trained research coordinators conducted the one-on-one interviews either face-to-face or over the phone depending on participant availability. 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. Pseudonyms were used to facilitate in-vivo quotation and data de-identification so that participant quotations were not linked to identifiers in the manuscript. The University of Kentucky Institutional Review Board approved all study procedures.

Protocol. A semi-structured interview protocol (see Appendix A) facilitated discovering the "interpretations that people attribute to their motivations to act" (Lindlof & Taylor, 2011, p. 179). After reviewing the literature and best practices for uncertainty and communication privacy management (Brashers, 2001; Petronio, 2002), the research team developed a protocol designed to reveal participants' perceptions of dealing with issues related to these emotional barriers. In addition, the protocol was designed to elicit 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 a patient they may have dealt with that had a positive FIT but still didn't believe were at high risk for colon cancer. The participants were asked probing questions following this directive, 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 wasn't 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 concerns about privacy. 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 who were 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 health care workers they often worked with, what made these encounters go well, and what made these encounters 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.

Data Analysis

Data were analyzed using a framework analysis methodology, which is a qualitative method of successive, inductive inquiry (Ritchie & Spencer, 1994). After reading the transcripts, the first author used inductive referencing to derive categories from the content, following standard approaches to qualitative descriptive analysis (Sandelowski, 2000; Sandelowski & Barroso, 2002) to offer a first-level description of the nature of participants' responses. Initial categories of the barriers and facilitators to patient navigation, managing uncertainty and privacy concerns among patients, and advice for future patient navigators were established as primary headings in a codebook in which relevant participants' quotes were placed. Then, a second round of coding examined constructs of uncertainty and communication privacy management to confirm and identify relevant theoretical concerns to patient navigation. The transcripts were examined for participants' responses to patients' appraisals and emotional responses to uncertain information (e.g., a positive FIT result) and techniques for controlling access to, identifying rules for, and malleability of patients' private information. The transcripts were analyzed for the specific strategies that participants used in managing uncertainty and navigating privacy concerns. Finally, using qualitative descriptive analysis techniques, the primary researcher identified the recommendations that interviewees described for how future navigators should prepare for working in the profession.

The constant-comparative methodology utilized in this manuscript is a means for refining and reviewing the conceptualizations of categories against the empirical data

(Lindlof & Taylor, 2002). In the present draft, the first author placed quotations from the interviews into a master outline consisting of framework headings and subheadings (see Appendix B) 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. Prior to publication of this manuscript, the first author will ask members of the research team to convene to compile and compare findings, noting any differences in opinion or responses to questions. The current manuscript includes a proposal of an initial set of categories, of which the research team will be tasked with reviewing and assessing the categories to reorganize major and minor themes within the data, if necessary. Once a framework is finalized, the team should negotiate any disagreements and agree on the placement of in vivo quotations until a consensus is reached. This type of iterative approach will help to support the methodological rigor required for publication in a top-tier journal in public health or health communication.

RESULTS

Following extensive data analysis, six primary themes with corresponding secondary themes (see Appendix B) were discovered in the patient navigators' accounts. Themes include (a) common (and seemingly insurmountable) barriers to navigation; (b) facilitating navigation through the system using relational capital; (c) managing uncertainty using education, social support, and emotional appeals; (d) countering uncertainty and privacy concerns with stories, social norms, and help from friends and family; (e) accommodating and supporting patients to manage privacy concerns; and (e) honest advice for future navigators. The following sections detail each of the themes and provide participants' quotations as a means to support the primary researcher's claims, illustrate ideas, and illuminate navigators' experiences (Sandelowski, 1994). Recall that pseudonyms are used in place of participants' names to protect their identities.

Common (And Seemingly Insurmountable) Barriers to Navigation

Medical distrust as a result of family experiences. One common barrier reported by navigators was that poor prior experiences of friends and family members were often cited as patients' reasoning for foregoing even preliminary CRC screening tests like FIT. Navigators expressed that patients reported seeing family members suffer with cancer treatment and often refused screening services as a result of the experience. 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'." Poor experiences of friends and family members, coupled with the fear of receiving a cancer diagnosis, exacerbated the screening decision for some patients.

Charlene (CHW) stated, "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." One navigator even went as far to say that patients who had a family history of cancer were the "worst" to navigate. 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." Clearly, navigating patients with a family history of cancer or who had been told stories by close kin were a challenge to persuade to get screened.

Phone service and availability. Eastern Kentucky is known for its pristine beauty – the mountains are a great source of pride in the area, but they can also become a hindrance for good cellphone coverage. Navigators were often faced with the challenge of having patients' contact information but being unable to reach them due to issues with cellphone reception. Anthony (PN) stated:

> People have cell phones but if you don't have service, your cell phone is useless and that is a big thing in eastern Kentucky and is again, almost everyone has a cell phone in their pocket but they might not have any service where they are so keeping up with people in phone calls can sometimes be difficult just to make sure you verify that appointment with someone.

Other navigators had issues contacting patients because their contact information became invalid. Bernice (CHW) said, "I would have to say [a barrier is] probably the phone numbers and trying to get a hold of them. Cause they will give you a number by the time they get (the FIT test) it and when they do get the results, their phone may no longer be in

service or something like that." Issues with lines no longer being in service may be a result of several issues; however, one plausible reason is the use of prepaid cellular service. Once funds are depleted for a prepaid service, an automated message notifies callers that the number is no longer in service. Unfortunately, too, it is often more economically feasible to open a new account with a new number than to "put minutes" on an existing prepaid phone.

Tensions with referrals and no-shows. Most navigators reported dealing with patients who did not show up to their follow-up appointments. Unfortunately, patients' no-shows often caused relational tension with the providers offering screening services. 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 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." In addition to tensions with rescheduling patients, navigators faced challenges with knowing what information was needed for referrals. Specifically, navigators felt stress when different providers required different information than others. 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."

Obligations to faith and family. Many navigators experienced barriers related to patients' commitments to their religion and obligations to their family. One navigator served a patient who preferred the healing power of prayer as opposed to follow-up screening. Charlene (CHW) said:

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…

In this instance, the navigator used her own convictions to counter objections presented

by the patient. If another navigator who was not religious or did not share the same faith

served this particular patient, the outcome may have been quite different.

Navigators reported many instances where the needs of a patient's family

members outweighed their own need for screening or follow-up care. 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.

Anthony also had experience with patients who served as caregivers for younger family

members. He said:

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.

Women are known to serve as caregivers in greater numbers than men nationwide, but the increasing incidence of grandparents caring for grandchildren is a cultural consideration of which navigators in the area should be aware. The opioid epidemic has had a huge impact on the region, and as a result, many young adults are unable to care for their children due to addiction, incarceration, or overdose-related death.

Frustrations with the health care system. Several navigators identified their frustrations with the health care system. One navigator reported being frustrated by doctors in the area, who she perceived to be lacking in providing their patients with adequate information about preventive services. Charlene (CHW) stated:

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.

Other navigators reported having to deal with health care workers who they did not perceive to share a commitment to caring for patients. Anthony (PN) said:

…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 it's like I'm working with two clients at the same time at that point. That is a very hard day.

Systemic issues, specifically a perceived disconnect between their own efforts and commitment and that of local providers, were a source of exasperation for navigators.

Seemingly insurmountable barriers. Most navigators stressed a confidence in their ability to address commonly presented barriers, but there were some accounts where barriers were perceived as almost insurmountable, no matter what steps they took to try and overcome them. One navigator lamented about socioeconomic status as a barrier that superseded her efforts to serve patients. Julia (NP) said, "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."

Other navigators experienced frustration navigating male patients from FIT to colonoscopy. Carlene (PN) stated:

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.

Several navigators discussed the financial burden of screening services as a huge hindrance to their ability to care for patients. Charlene (CHW) said:

They can't afford the hospital part or the procedure…one lady in particular she doesn't have any insurance at all and [she was] 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 preventive, 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.

For some navigators, there are barriers that cannot be overcome even with a range of

resources available to patient navigation programs and local health organizations.

Facilitating Navigation through the System Using Relational Capital

    Familiarity with the system. Although navigators identified more barriers than

facilitators, there were factors that appeared to help them serve patients more efficiently

and effectively. One navigator in particular felt confident in helping patients schedule

follow-up care. Julia (NP) said, "I found that it was pretty easy to get them where they

needed to be, if they already had the FIT test done. So even if they were symptomatic or

asymptomatic, once they had their results, I didn't have any issues finding a place for

them to go or someone who would give them treatment." She also expressed comfort in

her ability to navigate across the KRADD. She stated, "I could pretty much pick up the

phone and get anyone in any of the surrounding counties I could find someone to do a

colonoscopy. So, I would be like 'ya know, we can find you somebody – just give me a

time and tell me when you can go, and we will find somebody'." Other navigators did not

express this level of confidence, which may be due to this particular navigator's

experience working in the local system as a nurse practitioner prior to navigating for the

RCPC program.

    Building relationships with patients and providers. One facilitator that was

mentioned by almost every navigator was the benefit of having established relationships

with their patients, patients' families, and the providers who served the region. One

navigator felt so confident in her knowledge of patients and their families that she was

confident going off script.

Suzanne (CHW) said:

> 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. If I was a total stranger, I would have stuck to the directions
>
> until I knew them a little better.

Building trust was perceived as a huge benefit for many navigators, especially when they

made conscious efforts to build trust by talking with people in the community face-to-

face. Bernice (CHW) stated:

> I've had better outturns [turn outs] on just being out in the community and face-
>
> to-face contact and talking face-to-face cause I've had a bigger outturn [turn out]
>
> on just doing that out there rather than working through other departments or
>
> anything like that. Because I get a personal relationship with people after talking
>
> to them and getting the kind of trust and it's a really good thing to go into.

Many navigators reported benefits that resulted from having familiarity with providers in

the area. One navigator even reported that she was able to address feelings of uncertainty

among patients through her personal knowledge of providers. Julia (NP) said, "I give

them [refer patients to] 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."

Other navigators felt a sense of comfort from knowing providers and training with a close-knit group of navigators. Carlene (PN) said:

> …we're a small county and – or counties. There are several counties we work in that we know all the health departments and we work across with the health departments. We talked to them, we did training together. So, we feel comfortable talking to each other and kind of like a team in a sense.

The perception that she was part of a team helped Carlene navigate patients; however, for some navigators, building relationships with a network of providers required some time and effort. Suzanne (CHW) stated:

> 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.

Even with a slow start, Suzanne reported the benefits of building her reputation as a navigator. She continued, "…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." Another navigator echoed the sentiment of benefitting from getting to know local providers and their procedures. Mary Jo (NP) said, "…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…you

get a comfort level and a rapport buildup with their office, and that makes it go easier I think." Clearly, navigators experienced advantages as a result of their efforts to get familiar with the health care system in the area and build relationships with local providers.

Managing Uncertainty Using Education, Social Support, and Emotional Appeals

      Mitigating panic after a positive FIT result. Several navigators reported patients' emotional distress after a positive FIT, which typically resulted from the fear of a cancer diagnosis. Suzanne (CHW) said:

> They [patients] get apprehensive and worried and scared. They're like 'Well it says that its 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.

In the face of panic, several navigators reported that they would offer support and education about the meaning of a positive FIT result and the benefits of follow-up care. 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 its 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.

Some navigators took a more specific approach to stressing follow-up care to patients, such as explaining the potential removal of polyps during the colonoscopy process as an opportunity to be proactive about their health and prevent cancer. 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.

Other navigators were not as specific with their patients, often leaving out specific key words that might increase patients' stress. One participant avoided mentioning the word "cancer" altogether. Julia (NP) said:

> 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.

Navigators used a variety of tactics to manage uncertainty among patients, but almost all the participants chose to frame a positive FIT result as an opportunity for the patient to be proactive about their health.

Translating medical jargon and complex diagnoses. When complex health information became unavoidable, one navigator reported using a combination of lay language and humor to respond to negative emotional responses. For example, Suzanne (CHW) said, "Sometimes it's the big words at the doctor that scare you. So, you bring it

down to a level where you kinda joke with them about it. And you make it like it's not a big deal…" Suzanne also reported having to step out of her comfort zone to learn medical jargon in order to serve her patients. She 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.

For Suzanne, addressing negative emotional responses using simpler language was a helpful tool for connecting with patients and feeling commitment to her job as a navigator.

Being willing to offer short-term and long-term support. Patient navigators reported that offering instrumental support to patients was an ideal way to reduce uncertainty among patients. Julia (NP) discussed a time when attending an appointment with a patient was the difference maker in her decision to get screened. 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.

Several navigators felt that it was their duty to offer social support – both short and long-term. 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." Similarly, Carlene (PN) said that she would often, "…express willingness and try to help them and let them know that I would help them through that and I have helped people through that, and just assure them that they won't be alone." Navigators in the current study certainly felt driven to support their patients in any way they could.

Use humor but know when to get serious. Several navigators reported being well-equipped to use emotion to counter patients' uncertainty. One navigator recalled a story where she used humor to persuade a patient to complete FIT, then switched to a more serious tone when she discovered a positive FIT result. Suzanne (CHW) recalled:

I pointed my finger at him [patient], and I'm like, 'I got something for you to do [FIT test], and I don't want to hear any lip. And I need this back in about 3 days.' When [his] report came back that it was reactive, I called him into the office, and I said that I need to talk serious with you. All jokes aside, I need to talk to you serious. And he was like 'oh no' and I said 'oh yea. This is serious, and you're going to follow up with this or I'll call your wife.' And he went home and told [his wife], and she got right on it. Called and made an appointment with [a doctor] and sure enough, he had colon cancer. And then [he] has been so grateful; he and his family...[he] had to have a bowel reconstruction, and they said that he was cancer free when he was finished with the surgery.

While Suzanne used both positive and negative emotional appeals, most navigators stuck to one or the other. Julia (NP) reported using a "good cop/bad cop" approach, saying:

I would just try to tell them that, 'you know as well as I do that you have this in your family history, and not wanting to do anything about it isn't going to change the outcome…we can be friends and we can ignore it, or we can go ahead and fix it and get the peace of mind that there's nothing, or have early detection and have a good outcome, rather than a negative outcome that you're afraid of.'

Other navigators used fear appeals as a means to persuade patients to follow-up; specifically, bringing up a litany of potential (and perhaps frightening) treatments for CRC. Mary Jo (NP) recalled some of the tactics she utilized with patients, saying:

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.

Other navigators persuaded patients with an appeal to their future or the future of close family members. Julia (NP) said, "I would say 'what's a day out of your schedule that could save your life in the future?'." Similarly, Mary Jo (NP) stated, "I draw out the 'you have children' card, and 'you want to be here to raise your children'." Navigators used a variety of emotional appeals as tactics to manipulate the uncertainty of their patients and persuade them to pursue follow-up care. The decision-making process associated with what type of emotional appeal to use and when to use it remains unclear.

Countering Uncertainty and Privacy Concerns with Stories and Help from Friends and Family

The majority of patient navigators reported using stories or help from friends and family members to persuade patients to get screened. One navigator experienced resistance from a patient to complete the FIT test, but the presence of social norms became enough to persuade him to finally get tested. Carlene (PN) recalled, "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 takes [it] and was like, 'I'll do this'." Clearly, there is persuasive power that results patients seeing screening as a normative behavior in their community.

There were many accounts from navigators where they recalled telling their patients stories in order to counter their uncertainty about procedures or mitigate their privacy-related concerns. One navigator recalled specific patient stories to counter uncertainty. Anthony (PN) stated:

> If I can counter that by telling them stories about someone I worked with and not revealing any information about who, you know, I have worked with other people who at some point in their time, they were just like you, when I first started working with them, they were just like you. They didn't want to deal with the fact that this could be happening to them and they didn't want to face the possibility that they could have cancer. 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 polys in there and the polys were removed before they ever had a chance of becoming cancerous.

The framing of other patients being "just like you" was seemingly enough to make patients feel more confident about follow-up treatment and care. Some navigators even went as far to disclose their own personal struggles. One navigator recalled bringing up the medical issues her own grandson had experienced. Bonnie Jean (CHW) said:

> …this patient was…probably in his early 70s or something like that, and he was in the mind frame that something was going to kill him. I hate to say that but sometimes people are in that mind frame. You know, actually, it took a while, but I was able to convince him into the follow up by saying, 'You know, colon cancer doesn't have to be that thing, they can go in and take a certain amount of your colon out if that's the case'. I do have a grandson that doesn't have any large intestine, and I use that as an example sometimes. So that kind of hits home with them when I can use that as an example because this guy was dead set on not following up whatsoever.

Navigators were also adamant about avoiding "pushing" patients to discuss topics they were not comfortable disclosing. For some navigators, patience was a means to gain the trust of their patients, which often prompted future disclosures. Charlene (CHW) said:

> We don't push them; we don't force them to talk about anything that they are uncomfortable with even though they are sitting here, they may not open up to me but I can give them real-life examples that I know of or that experiences that other patients have talked to me about and kind of just listen. Even though we are not going to force them to do anything we don't want them to do. But they become comfortable with us and you know, my patients will come in here and just visit.

Other navigators echoed the importance of patience and its utility in helping to understand and encourage patients. Allison (CHW) stated:

> [make sure to respond] with patience and understanding and encouraging and trying to be supportive. And you know, tell them a story about, you know, if you have a family member or a patient, of course not using the name, you know and what happened in another instance. And try to be supportive as much as possible.

Allowing patients to disclose information or discuss uncomfortable topics at their own pace was a theme present in several navigators' accounts.

Addressing privacy concerns or countering homophobia. As many navigators detailed their experiences countering uncertainty and privacy concerns, one privacy-related issue emerged that may have other, deeper implications for serving male patients, specifically. As detailed in the theme referencing barriers to patient navigation, some navigators experienced increased frustration with navigating male patients to colonoscopy services. Two navigators discussed this issue at length in their accounts. Carlene (PN) recalled a specific encounter with a 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 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 happen 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 first
> hand, 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.

Clearly, this is an issue that female navigators may be ill-equipped to address when
serving male patients who have concerns (that are often difficult to uncover in
conversation) about the implications of the colonoscopy procedure for their gender
identity or sexual orientation.

Accommodating and Supporting Patients to Manage Privacy Concerns

Being accommodating and building a reputation of protecting privacy.

Navigators cited many encounters with patients where privacy became an issue and noted that they often made environmental accommodations for their consultations with patients. 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." Outside a formal office setting, navigators often worked with their patients to ensure a private consultation. Julia (NP) stated:

> If they were concerned about privacy issues I would say… 'let's wait until we
>
> have a more private place to talk? Or, do we need to be alone?' Ya know, because
>
> if you call someone and they are standing in the middle of their kitchen, and
>
> the kids are running around, and all that stuff, it'd be like 'let's set up a time that
>
> works so that you can be by yourself, and we can just sit together and talk'.

Many times, Julia would also be mindful of mitigating any inadvertent co-owners of the information she discussed with her patients, noting that many patients preferred family members not being part of the conversation. She continued:

> 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.

Regardless, several navigators were clear in their commitment to patients' privacy and knew that one misstep may cost their relationship with the patient or their reputation as a

navigator. Suzanne (CHW) warned, "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."

Meeting the patient where they are. Several navigators echoed the fact that patients should not be forced to discuss anything they did not want to; however, in the instance where this was the case, there were navigators who chose offer support to patients in an effort to get them to open up. Some navigators were more direct than others. For example, Mary Jo (NP) said:

> …if I feel like someone has a concern about privacy, I would say…uh, 'what is it that's causing you to not want to talk about it? Uh, how can I help with it? What do you need me to do?'…that kind of thing. Just make myself available.

For her, asking questions served as a means to get to the heart of patients' barriers to discussing screening, treatment, and care and a way to offer informational support. Another navigator chose to mitigate patients attempts to avoid difficult discussions with an emotional support. Julia (NP) said:

> 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.

Other navigators offered the option to provide their patient with someone else to talk to, if that is what it took to get them to open up. 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.

She recognized the well-documented "stranger on the train" phenomenon of disclosure,

wherein sometimes people are willing to disclose more information to strangers because

there is less risk posed to their relationships. In this instance, being well-known in the

community may be more of a detriment than a benefit.

Honest Advice for Future Navigators

Have tacit knowledge with a dash of cynicism. When asked to provide advice to

future patient navigators, participants in the current study had no shortage of guidance.

However, there were some navigators who had trouble articulating the specific skills

needed to be a successful navigator. Suzanne (CHW) said, "You don't learn this from a

textbook. I didn't. I've always been a people person…I just kinda had to learn how I

went." She pointed to inherent characteristics (e.g., being friendly) as a means to

successful navigation. She continued:

It's hard to put it in words or in textbook what you do and this is the way it goes.

With every patient or client its different; the understanding level is different, their

level of trust for you. It's an awesome experience to be a part of their life. I love

it.

Perhaps she is pointing to being able to adapt to a variety of situations or having high emotional intelligence as needed characteristics for being a successful navigator; regardless, she clearly felt confidence about and joy for navigating patients. Another navigator was not as positive. When asked to provide advice, Julia (NP) said, "To be honest, I would say good luck, and I hope you have better luck getting patients to show up to appointments than I did." Her statement (while a bit cynical), points to resiliency being a crucial skill for navigators.

  Build a network and a solid knowledge base. The critical need for having a network of relationships to facilitate successful navigation is discussed in a prior theme, but navigators had solid advice for how those new to the profession could be efficacious in building their own relationships. Anthony (PN) advised:

    Before you ever take on your first client, before you crack open that first manila folder when reading the specifics of a patient/research subject/client, is that 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.

The team-based mindset seemed helpful for many navigators. In addition, having a good foundation in knowledge of CRC screening, treatment, and care was deemed a crucial

element for good navigation. 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." Clearly, having a strong knowledge base is an asset to future navigators.

Be honest, empathetic, and (most of all) persistent. While some navigators were unable to clearly articulate the traits needed for successful navigation, others pointed to specific characteristics. Being honest was a big deal for one navigator. Carlene (PN) said, "…just be yourself and be honest and try to help them make feel comfortable about what they're doing..." Another navigator believed empathy was a critical skill for overcoming barriers to navigation. 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." Finally, persistence (perhaps coupled with resiliency) was a key element for navigating patients. Suzanne (CHW) stated, "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."

Do whatever it takes. Participants' commitment to their patients was evident in their accounts. Many navigators stressed that their job was do whatever it took to serve their patients. 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." Another navigator echoed this sentiment. Charlene (CHW) said, "Every person that walks through your

door, you just got to take care of them and take care of their need no matter what it is."

One navigator offered homing in on problem-solving skills as a way to accomplish this

feat. Mary Jo (NP) said, "Try to help them work though it and try to figure out a way

around it, or over it, or under it, or something…it's all about problem solving."

But know that it takes a village. While many navigators stressed the "do

whatever it takes" mindset, they also advocated for reaching out for help when needed.

Suzanne (CHW) recommended seeking out others, saying, "If you're not

comfortable…seek out someone you can talk to. This is life or death. This is serious

stuff." She also emphasized the need for a team approach to ensure successful navigation.

She said:

> We hear…'I can't afford to go. I don't have the gas money to go. I don't have a
>
> vehicle that will make it. I don't have anybody to go with me.' And you just have
>
> to be encouraging and just [jump] on the band wagon with the family doctor that's
>
> trying to encourage these people to get screenings, that can be lifesaving.

She recommended working with both providers and family members to persuade patients

to follow-up, saying, "…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." Other

navigators supported Suzanne's sentiment. For example, Julia (NP) said, "I think the best

way to be a patient navigator…is to give them lots of resources and support…make sure

they know all the resources available to them and is translated to the patient." Clearly,

having a strong knowledge base, coupled with working as a team is highly-valued among

the participants in this sample.

Beware of the emotional toll of patient navigation. While not a specific piece of advice from patient navigators themselves, this theme emerged through emotional accounts of instances where navigators felt sadness, helplessness, and defeat. Suzanne (CHW) recalled a heartbreaking story of one of her patients, saying:

> He [a patient] went so long. And then he said he wished he had went on [longer without knowing] …he let it go, and then he got bladder and colon cancer and prostate cancer. And then this last month he passed away.

Bonnie Jean (CHW) had a similar account, saying:

> I actually have a client that it may be a little too late for him. They called me after he was diagnosed with colon cancer so that's pretty bad. So, I don't give up on it [navigating after positive FIT] because colon cancer is the most thing that you could fix over anything probably. Out of any of the cancers. And the earlier you find it, the better you are.

Some navigators internalized the sadness and felt defeated when they were unable to persuade patients to follow-up. Anthony (PN) said:

> So, if they have a positive or reactive FIT result, I feel like that it is really on me to try and get them to a colonoscopy and find out if there is anything that is wrong. And when I run into patients…have that [a negative] attitude about the colonoscopy, then that just crushes me because here I am feeling like it is my responsibility to get this person onto a colonoscopy and they are not seeing the benefit of that colonoscopy, they are just shutting it down.

Another navigator detailed the inevitability of not being able to "fix" the barriers that patients experience. Charlene (CHW) said:

>…it ultimately falls back on to the patient if there has to be funding, they have to meet us half way and if they are not able to do that then it's sad. Whatever their hurdle or obstacle is or what, we try to get around it and try to fix it. Sometimes we can't, sometimes we can.

Many navigators are undoubtedly experiencing a negative emotional impact from what they perceive to be unsuccessful efforts to patient navigation.

DISCUSSION and CONCLUSION

The findings suggest that patient navigators are facing many commonly identified barriers to CRC screening in Appalachia. Prior research (e.g., Bardach et al., 2012, Curry et al., 2011) corroborates the barriers reported in the current study, such as cost of treatment, knowledge of screening guidelines, and transportation. The present study extends these findings by highlighting other salient barriers such as problems with cell phone coverage due to the nature of the terrain in the region or lack of cell phone service as a result of the continuity of prepaid cellphones. Future programs should consider the limitations of cellphone coverage among their patient population. Prompting navigators to ask patients about the best times to call or having patients provide a secondary contact in the event that their phone is disconnected may be useful strategies for addressing contact-related barriers.

Research conducted by Bachman and colleagues (2017) uncovered that many times, patients' decisions to get screened were impeded by their own poor prior experiences with screening. The current study extends these findings by eliciting the fact that the experiences of others may also have an impact on the screening decision. Findings show that may participants used stories told to them by family members as an objection to follow-up colonoscopy services. Future programs may consider some of the tactics used by the navigators in the current study. Specifically, the use of stories from similar patients with comparable experiences may be used to try to counter any objections related to past screening events or stories.

Fatalism and commitments to faith as barriers to cancer prevention efforts have been widely studied in Appalachia. In fact, a recent study demonstrated that fatalism was a key correlate in the likelihood of not engaging in CRC screening (Crosby & Collins,

2017). One issue of note brought to light in this study is that in addition to commitments to faith, obligations to family often served as an impediment for women to be screened. Specifically, navigators reported that women who served as caregivers for close kin were particularly difficult to navigate to follow-up screening. A recent policy analysis of New Hampshire's opioid epidemic addressed the issue of the increasing number of children being removed from homes due to substance-related allegations and placed in out-of-home care with a relative like grandparents (Smith, 2018). While the author argued that placing children with caregivers with stable connections and emotional bonding enable them "to make social and emotional connections and build resilience that can buffer against the negative experience of living with a parent with a substance use disorder," the author did not present any implications for the health of the caregiver, such as neglecting their own health (p. 1). The policy implications for caregivers like grandparents were discussed by Daley, Smith, Balogh, and Toscolani (2018), who argued for "the concerns, problems, and needs of family members affected by SUDs [substance use disorders] to be heard, understood, and accepted by anyone involved in planning, providing, or funding services" (p. 109). While there have been several federal and state advances in helping grandfamilies (see Beltran, 2017), there remains a dearth of research investigating ways to support preventive cancer screening services in light of unexpected familial commitments. Future research should address how the responsibilities associated with an aging population raising young children may impact screening rates and adherence. Novel interventions, such as offering FIT kits for adults and a path to CRC screening navigation at pediatric clinics, may be required to address this barrier appropriately.

Findings show that patient navigators felt confident in addressing a litany of patients' obstacles to screening, but there were some barriers that they felt unequipped to address. Frustrations with the health care system, whether it be the cost of procedures or poor experiences with other providers, were common. Future programs should focus on the ways that navigators in the current study used their familiarity with the system and their relational capital to try and overcome even the seemingly insurmountable barriers to navigation. Choosing navigators that have well-established networks or providing new navigators opportunities to network in the community and with local providers may bolster the success of navigation programs.

Navigators in the current study managed uncertainty using a variety of tactics including providing information, explaining complex medical information, offering social support, and using emotional appeals. Many times, providing more details or breaking down complex medical language in everyday terms was the key to successful navigation. This means that programs should plan to provide a wealth of resources to their navigators that facilitate these processes. Providing ways to access critical information, such as a local information management system, may help to give the navigators critical resources on the go. Moreover, future research should investigate navigators' use of social support and emotional appeals. While participants indicated a variety of strategies that worked for them, many variables in this decision-making process remain unclear. Researchers should investigate the cues that navigators look for that prompt their offers of social support as well as the triggers for using certain types of emotional appeals to persuade their patients.

Stories were critical for countering patients' uncertainty and privacy concerns in the current study. The majority of navigators used this strategy to make screening seem

more common and less of a burden to patients. One salient obstacle that navigators cited as a tough barrier to break down (even with the use of stories) was navigating male patients to colonoscopy screening. The "transfer of homophobia" to the colonoscopy procedure mentioned by navigators in this study is not an issue exclusive to this region. A recent study conducted by Hennelly, Sly, Villagra, and Jandorf (2015) described this as a "unique" barrier to colonoscopy for Latino men; however, a systematic review conducted by Rogers and colleagues (2017) found the same phenomenon described in qualitative studies of male, African American populations. Clearly, this barrier is not exclusive to race, ethnicity, or region; however, there are virtually no studies that address ways to overcome the threat that colonoscopy may pose to male masculinity or sexuality. Results of the current study reveal that at least one female navigator felt unprepared to counter objections related to this concern among male patients; however, a male navigator in the study did feel confident in both identifying and addressing this barrier. Future programs may want to consider recruiting more male navigators as a means to counter masculinity-related barriers to screening, but this recommendation should be taken with caution. Future research is needed to investigate what mechanisms (e.g., education, counter-narratives) that navigators may use to effectively assuage concerns related to masculinity or sexuality among male patients.

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 they perceived to be the active ingredients for successful navigation. Namely, participants believed that navigators should be knowledgeable, patient, accommodating, supportive, and well-connected. Other desired characteristics

were high emotional intelligence, persistence, and resiliency. While there were navigators that reported frustration or seemed cynical, it was clear that all of the participants in the study were committed to serving patients, even if that service placed an emotional burden on themselves. In a recent review of patient navigation training content, Ustjanauskas, Bredice, Nuhaily, Kath, and Wells (2016) found few studies that documented training on addressing patients' psychosocial needs. Participants in the current study primarily focused on skills needed 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 how to use them. In addition, future research should investigate the ways that patient navigators engage in emotional labor and the potential impact of the emotional burden placed on navigators.

Limitations

As with any research, there are limitations to consider. First, the size of the sample in the current study was relatively small. 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. Second, the current study examines patient navigators who serve a rural, predominantly White community, which may present even greater limitations on the generalizability of the findings. Third, at present, the primary researcher has not sought outside review of the emergent themes of participants' accounts. Prior to publication, outside reviewers must compare the established framework to the interview transcriptions and negotiate any disagreements or discrepancies to support methodological rigor. Finally, the interviews were conducted by

lay interviewers. Although each interviewer received some training before interviewing participants, they are not extensively trained in qualitative methods. There were several instances where the interviewers missed opportunities to ask additional probing questions to obtain richer description from the participants, which may have been a result of an absence of nonverbal cues in phone interviews.

Conclusion

Conversations with patient navigators serving Appalachian communities presented both facilitators and barriers to persuading patients to engage in initial and follow-up CRC screening. Although navigators did face significant challenges in navigating patients, they offered multiple strategies that were effective for them in overcoming even the most problematic barriers. The current study has implications for several of the essential public health services. First, patient navigation is an essential tool for linking people to health services and assuring the provision of health care, especially in regions like eastern Kentucky that experience an increased burden of health disparities. Many of the navigators in the study were CHWs who lived in the communities they served. Given that most participants indicated that relationships were critical to their navigation abilities, health programs and organizations should consider employing CHWs to provide patient navigation services. Hiring navigators who are from the community takes advantage of existing relational capital because CHWs have key connections for getting patients the resources they need and know enough people in the community to involve friends and family members in their efforts to persuade patients to follow-up screening services like colonoscopy. In addition, organizations could take advantage of reimbursement from the Centers for Medicare and Medicaid Services (CMS) when

employing CHWs, which allows state Medicaid agencies to reimburse for preventive services provided by professionals that may fall outside of a state's clinical licensure system, to help manage costs of their programs.

Second, the current study provides evidence for policies to help assure a competent public and personal health care workforce. Given that CHWs are successfully navigating patients to critical cancer screening services despite a litany of barriers, it is clear that they play an essential role in reducing health disparities in the region. Participants' perspectives on what navigators need to be effective can lend to efforts to identify the skills and competencies needed for certification. For example, communication is already identified as a core competency by Kentucky's Statewide CHW Workgroup, and the current study identifies specific communication skills (e.g., persistence, empathy) and strategies (e.g., engaging family members, telling stories) that will be useful in training and certifying future CHWs.

Finally, this study identifies new insights and innovative solutions to health problems. Specifically, participants' accounts provided evidence for matching male navigators with male patients experiencing masculinity or sexuality-related privacy concerns. Findings also show that patients are foregoing health services for themselves to care for family members. Offering patient counseling or FIT screening options in a variety of locations (e.g., pediatric clinics) may help to eliminate these types of barriers to screening. Overall, this project helps to inform several aspects of the delivery of public health and offers several promising avenues for future research.

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APPENDIX A

Interview Protocol

Introduction

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.

1. 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?

2. What has been the most difficult part of being a Patient Navigator/Nurse Case Manager? What has made this difficult?

Patient Uncertainty

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.

1. Can you tell me a story about a patient who was 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?

2. What kinds of questions do patients ask you about their risk or diagnosis of colon cancer? How do you respond to these questions?

3. When a patient receives a positive FIT test, but doesn't understand what that means, what do you say to explain the diagnosis?

Follow-up Care

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.

1. 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?

2. What kinds of things keep people from seeking follow-up care after being having a positive FIT?

3. 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?

4. 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?

Privacy

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.

1. Can you tell me a story about a patient who was concerned about privacy? How did you respond to this patient?

2. When a patient seems unwilling to talk about her diagnosis with you, how do you respond?

3. When a patient says they are concerned about privacy issues, what do you say?

<u>Health Care Providers</u>

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.

1. What has gone well in working with health care providers? What has made these things go well?

2. What has been difficult in working with other health care providers? What has made these things difficult?

3. What are some of the different types of other health care workers that you have worked with?

<u>Conclusion</u>

We have just a few more questions before we end the interview.

1. 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?

2. If a new Patient Navigator/Nurse Case Manager were to come to you and ask for advice, what would you say?

Do you have anything else you'd like to talk about before we end the interview?

APPENDIX B

Pseudonym Guide and Coding Framework

Participant Pseudonym and Identification Guide:

Participant 1 (ID: Suzanne) – Community Health Worker (CHW)

Participant 2 (ID: Julia) – Nurse Practitioner (NP)

Participant 3 (ID: Carlene) – Patient Navigator (PN)

Participant 4 (ID: Mary Jo) – Nurse Practitioner (NP)

Participant 5 (ID: Anthony) – Patient Navigator (PN)

Participant 6 (ID: Charlene) – Community Health Worker (CHW)

Participant 7 (ID: Bonnie Jean) – Community Health Worker (CHW)

Participant 8 (ID: Bernice) – Community Health Worker (CHW)

Participant 9 (ID: Allison) – Community Health Worker (CHW)

Coding Framework:

Theme 1: Common (And Seemingly Insurmountable) Barriers to Navigation

Subtheme 1: Medical Distrust as a Result of Family Experiences

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."

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."

Charlene (CHW): "What is most difficult 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."

Subtheme 2: Phone Service and Availability

Bernice (CHW): "I would have to say probably the phone numbers and trying to get a hold of them. Cause they will give you a number by the time they get (the FIT test) it and when they do get the results, their phone may no longer be in service or something like that."

Anthony (PN): "People have cell phones but if you don't have service, your cell phone is useless and that is a big thing in Eastern Kentucky and is again, almost everyone has a cell phone in their pocket but they might not have any service where they are so keeping up with people in phone calls can sometimes be difficult just to make sure you verify that appointment with someone."

Subtheme 3: Dealing with No-Shows

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."

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."

Subtheme 4: Obligations to Faith and Family

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."

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."

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. But one in particular was faith."

Subtheme 5: Frustrations with the Health care System

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 it's like I'm working with two clients at the same time at that point. That is a very hard day."

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."

Subtheme 6: Seemingly Insurmountable Barriers

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."

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 me in this area and they…are not willing to do that."

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."

Theme 2: Facilitating Navigation through the System Using Relational Capital
Subtheme 1: Familiarity with the System
Julia (NP): "I found that it was pretty easy to get them where they needed to be, if they already had the FIT test done. So even if they were symptomatic or asymptomatic, once they had their results, I didn't have any issues finding a place for them to go or someone who would give them treatment."

Julia (NP): "I could pretty much pick up the phone and get anyone in any of the surrounding counties I could find someone to do a colonoscopy. So, I would be like 'ya know, we can find you somebody – just give me a time and tell me when you can go, and we will find somebody'."

Subtheme 2: Building Relationships with Patients and Providers

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. If I was a total stranger, I would have stuck to the directions until I knew them a little better."

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."

Bernice (CHW): "I've had better outturns on just being out in the community and face-to-face contact and talking face-to-face cause I've had a bigger outturn on just doing that out there rather than working through other departments or anything like that. Because I get a personal relationship with people after talking to them and getting the kind of trust and it's a really good thing to go into."

Carlene (PN): "…we're a small county and – or counties. There are several counties we work in that we know all the health departments and we work across with the health departments. We talked to them, we did training together. So, we feel comfortable talking to each other and kind of like a team in a sense."

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."

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."

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."

Theme 3: Managing Uncertainty Using Education, Social Support, and Emotional Appeals

Subtheme 1: Mitigating Panic After a Positive FIT Result

Suzanne (CHW): "They [patients] get apprehensive and worried and scared. They're like 'Well it says that its 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."

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 its 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."

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."

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."

Subtheme 2: Translating Medical Jargon and Complex Diagnoses

Suzanne (CHW): "Sometimes it's the big words at the doctor that scare you. So, you bring it down to a level where you kinda joke with them about it. And you make it like it's not a big deal…"

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."

Subtheme 3: Being Willing to Offer Short-Term and Long-Term Support

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."

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."

Carlene (PN): "I would express willingness and try to help them and let them know that I would help them through that and I have helped people through that, and just assure them that they won't be alone."

Subtheme 4: Use Humor, but Know When to Get Serious

Suzanne (CHW): "I pointed my finger at him [patient], and I'm like, 'I got something for you to do [FIT test], and I don't want to hear any lip. And I need this back in about 3 days.' When [his] report came back that it was reactive, I called him into the office, and I said that I need to talk serious with you. All jokes aside, I need to talk to you serious. And he was like 'oh no' and I said 'oh yea. This is serious, and you're going to follow up with this or I'll call your wife.' And he went home and told [his wife], and she got right on it. Called and made an appointment with [a doctor] and sure enough, he had colon cancer. And then [he] has been so grateful; he and his family...[he] had to have a bowel reconstruction, and they said that he was cancer free when he was finished with the surgery."

Julia (NP): "I would just try to tell them that, 'you know as well as I do that you have this in your family history, and not wanting to do anything about it isn't going to change the outcome…we can be friends and we can ignore it, or we can go ahead and fix it and get the peace of mind that there's nothing, or have early detection and have a good outcome, rather than a negative outcome that you're afraid of.'"

Julia (NP): "I would say 'what's a day out of your schedule that could save your life in the future?'."

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."

Mary Jo (NP): "I draw out the 'you have children' card, and 'you want to be here to raise your children'."

Theme 4: Countering Uncertainty and Privacy Concerns with Stories, Social Norms, and Help from Friends and Family

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 take and was like, 'I'll do this'."

Anthony (PN): "If I can counter that by telling them stories about someone I worked with and not revealing any information about who, you know, I have worked with other people who at some point in their time, they were just like you, when I first started working with them, they were just like you. They didn't want to deal with the fact that this could be happening to them and they didn't want to face the possibility that they could have cancer. 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 polys in there and the polys were removed before they ever had a chance of becoming cancerous."

Charlene (CHW): "We don't push them; we don't force them to talk about anything that they are uncomfortable with even though they are sitting here, they may not open up to me, but I can give them real-life examples that I know of or that experiences that other patients have talked to me about and kind of just listen. Even though we are not going to force them to do anything we don't want them to do. But they become comfortable with us and you know, my patients will come in here and just visit."

Bonnie Jean (CHW): "…this patient was…probably in his early 70s or something like that, and he was in the mind frame that something was going to kill him. I hate to say that

but sometimes people are in that mind frame. You know, actually, it took a while, but I was able to convince him into the follow up by saying, 'You know, colon cancer doesn't have to be that thing, they can go in and take a certain amount of your colon out if that's the case'. I do have a grandson that doesn't have any large intestine, and I use that as an example sometimes. So that kind of hits home with them when I can use that as an example because this guy was dead set on not following up what so ever."

Allison (CHW): "[make sure to respond] with patience and understanding and encouraging and trying to be supportive. And you know, maybe tell them a story about, you know, if you have a family member or a patient, of course not using the name, you know and what happened in another instance. And try to be supportive as much as possible."

Subtheme 1: Addressing Privacy Concerns or Countering Homophobia?

Carlene (PN): "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."

Carlene (PN): "…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."

Carlene (PN): "Just mostly with the males, they're not comfortable about how procedure and they're real – just their lack of willingness do procedures such as that. And I feel like that's an area of their body that not meant to be probed by another human being…women are very much more willing to do these procedures and don't worry about, I guess, because it's just a little different for them."

Anthony (PN): "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."

Anthony (PN): "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 happen 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 first hand, 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."

Theme 5: Accommodating and Supporting Patients to Manage Privacy Concerns

Subtheme 1: Being Accommodating and Building a Reputation of Protecting Privacy

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."

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."

Julia (NP): If they were concerned about privacy issues I would say… 'let's wait until we have a more private place to talk? Or, do we need to be alone?' Ya know, because if you call someone and they are standing in the middle of their kitchen, and the kids are running around, and all that stuff, it'd be like 'let's set up a time that works so that you can be by yourself, and we can just sit together and talk'."

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."

Subtheme 2: Meeting the Patient Where They Are

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."

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."

Mary Jo (NP): "…if I feel like someone has a concern about privacy, I would say… uh, 'what is it that's causing you to not want to talk about it? Uh, how can I help with it? What do you need me to do?'…that kind of thing. Just make myself available."

Theme 6: Honest Advice for Future Navigators

Subtheme 1: Have Tacit Knowledge with a Dash of Cynicism

Suzanne (CHW): "You don't learn this from a textbook. I didn't. I've always been a people person…I just kinda had to learn how I went."

Suzanne (CHW): "It's hard to put it in words or in textbook what you do, and this is the way it goes. With every patient or client its different; the understanding level is different, their level of trust for you. It's an awesome experience to be a part of their life. I love it."

Julia (NP): "To be honest, I would say good luck, and I hope you have better luck getting patients to show up to appointments than I did."

Subtheme 2: Build a Network and a Solid Knowledge Base

Anthony (PN): "Before you ever take on your first client, before you crack open that first manila folder when reading the specifics of a patient/research subject/client, is that 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."

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."

Subtheme 3: Be Honest, Empathetic, and (Most of All) Persistent

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."

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

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.

Subtheme 4: Do Whatever It Takes

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."

Charlene (CHW): "Every person that walks through your door, you just got to take care of them and take care of their need no matter what it is."

Mary Jo (NP): "Try to help them work though it and try to figure out a way around it, or over it, or under it, or something…it's all about problem solving."

Subtheme 5: But Know That It Takes a Village

Suzanne (CHW): "If you're not comfortable…seek out someone you can talk to. This is life or death. This is serious stuff."

Suzanne (CHW): "We hear all [logistical barriers] of the above. 'I can't afford to go. I don't have the gas money to go. I don't have a vehicle that will make it. I don't have anybody to go with me.' And you just have to be encouraging and just [jump] on the band wagon with the family doctor that's trying to encourage these people to get screenings, that can be lifesaving."

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."

Julia (NP): "I think the best way to be a patient navigator…is to give them lots of resources and support…make sure they know all the resources available to them and is translated to the patient."

Subtheme 6: Beware of the Emotional Toll of Patient Navigation

Suzanne (CHW): "He [a patient] went so long. And then he said he wished he had went on [longer without knowing] …he let it go, and then he got bladder and colon cancer and prostate cancer. And then this last month he passed away."

Anthony (PN): "So if they have a positive or reactive FIT result, I feel like that it is really on me to try and get them to a colonoscopy and find out if there is anything that is wrong. And when I run into patients…have that [a negative] attitude about the colonoscopy, then that just crushes me because here I am feeling like it is my responsibility to get this person onto a colonoscopy and they are not seeing the benefit of that colonoscopy, they are just shutting it down."

Charlene (CHW): "…it ultimately falls back on to the patient if there has to be funding, they have to meet us half way and if they are not able to do that then it's sad. Whatever their hurdle or obstacle is or what, we try to get around it and try to fix it. Sometimes we can't, sometimes we can."

Bonnie Jean (CHW): "I actually have a client that it may be a little too late for him. They called me after he was diagnosed with colon cancer so that's pretty bad. So, I don't give up on it [navigating after positive FIT] because colon cancer is the most thing that you could fix over anything probably. Out of any of the cancers. And the earlier you find it, the better you are."

BIOGRAPHICAL SKETCH

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