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## Identifying Communication Barriers to Colorectal Cancer Screening Adherence among Appalachian Kentuckians

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### Abstract

Utilizing data from 40 in-depth interviews, this article identifies both barriers and facilitators to colorectal screening guideline adherence among Appalachian Kentucky adults recruited through a community-based research network. Key findings identify (a) varying levels of knowledge about screening guidelines, (b) reticence to engage in screening processes, and (c) nuanced communication with healthcare providers and family members regarding screening adherence. What participants knew about the screening process was often derived from personal stories or recalled stories from family members about their screening experiences. Reticence to engage in screening processes reflected reports of cumbersome preparation, privacy issues, embarrassment, medical mistrust, fear of receiving a cancer diagnosis, and lack of symptoms. Participants cited many ways to enhance patient-centered communication, and the findings from this study have implications for health communication message design and communication strategies for healthcare practices in Appalachian Kentucky clinics.

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The National Cancer Institute (NCI, 2016) reports an estimated 1,177,556 people living with colon and rectum cancer (CRC) in the U.S. Excluding skin cancers, CRC is the third most common cancer diagnosed in both men and women in the U.S. (American Cancer Society (ACS), 2016a). The ACS (2016c) estimates that 134,490 new cases of CRC will be diagnosed in 2016, with an estimated 41,190 deaths in the same period. CRC is common among both men and women as approximately 4.4% of men and women will receive a CRC diagnosis at some point during their lifetime. The risk of developing CRC increases significantly after the age of 50 (National Cancer Institute, 2016; U.S. National Library of Medicine, 2016).

CRC screening guidelines are recommended to begin at age 50 and continue until age 75 (U.S. Preventative Services Task Force, 2016). Some risk factors for developing CRC

include a personal history of CRC, adenomatous polyps, or inflammatory bowel disease (ACS, 2016b). Additionally, individuals are at greater risk for CRC if they are overweight or obese, physically inactive, eat a diet high in red and processed meats, use alcohol heavily, smoke, or are exposed to environmental tobacco smoke (American Cancer Society, 2016b). Age-adjusted incidence rates remain higher in Kentucky (51.4 per 100,000 persons) than in the U.S. (41.9 per 100,000); moreover, age-adjusted mortality rates are considerably higher in Kentucky (18.1) than in the U.S. as a whole (15.5) (NCI, 2012). In eastern Kentucky communities specifically, mortality rates are nearly double the national average at 28 deaths per 100,000 people, and incidence rates for CRC are as high as 63.2 per 100,000 people (Kentucky Cancer Registry, 2012). Eastern Kentucky counties that are designated as “Appalachia” by the Appalachian Regional Commission (ARC) are disproportionately affected by late-staged cancer diagnoses, significant socioeconomic disparities, and are underserved by the healthcare system (ARC, 2016). Research from the Kentucky Department for Public Health (2015) shows that adults ages 50 and older living in counties in the Kentucky River Area Development District have considerably lower colonoscopy screening rates (55.9%) as compared to state-wide rates (69.6%). Disparities in adherence to cancer screenings may contribute to the disparate burden of CRC mortality experienced by these medically underserved Appalachian Kentucky communities (Kentucky Health Facts, 2012). Investigation is needed to uncover innovative communication strategies to reach underserved communities with practical approaches to CRC screening and adherence to address the challenges of reducing the disparate burden of CRC in medically underserved populations.

Efforts to improve CRC screening in Appalachian regions have had limited success. Dignan and colleagues’ (2014) review of 3,844 medical records indicates that primary care providers recommend colonoscopy (43.4%) much more frequently than the fecal occult blood test (FOBT; 18.0%), despite lower cost and ease of use. Lack of provider reimbursement for unreturned FOBT kits, low return rates, and perceptions that colonoscopy is the “gold standard” for prevention may contribute to providers’ recommendation (Dignan et al., 2014). Importantly, the U.S. Preventive Services Task Force (Bibbins-Domingo et al., 2016) now recommends a multipronged approach for CRC screening such that all adults ages 50 through 75 years old consider using (a) fecal immunochemical testing (FIT) or high sensitivity (e.g., Hemmocult Sensa) guaiac-based FOBT every year, (b) flexible sigmoidoscopy every five years, or (c) colonoscopy every 10 years.

## Diffusion of innovations

As a new preventive health innovation, the accuracy and specificity of FIT use as part of a CRC screening process in medically underserved communities may provide patients an option for annual screening that is lower cost and more accessible than colonoscopy. There are clear benefits and relative costs of each screening option, and clinical guidelines support an individualized recommendation from a medical provider (Bibbins-Domingo et al., 2016). 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 and transportation. Fortunately, FIT is available for rural communities experiencing limited access to colonoscopy services. FIT is a new generation of FOBT, which provides an

enhanced ability to detect smaller cancers and more adenomas, with far greater specificity than FOBT. The annual use of FIT is an alternative to more invasive types of CRC screening such as colonoscopy (and less sensitive tests like FOBT) given that Appalachian communities' geographic isolation and lack of screening services further exacerbate issues with CRC screening adherence.

There are substantial knowledge deficiencies regarding recommendations for the frequency of CRC screening among Appalachians (Bardach, Schoenberg, Fleming, & Hatcher, 2012). Additionally, Bardach et al. (2012) discovered that participants who most accurately reported the recommended frequency of CRC screening were more likely to adhere to screening recommendations and proposed enhanced screening counseling conducted by primary care providers as a strategy for increasing knowledge.

From a diffusion of innovations perspective, however, it is the case that often medically underserved populations are less likely to have early access to innovations. Theoretically, diffusion of innovations (DOI) relies on interacting communication processes and results from the interacting factors of an innovation, the communication channels (including health care providers) utilized for diffusion, the larger social system in which the innovation is being diffused, and the time frame of diffusion (Rogers, 2003). The success of the diffusion system often hinges on the efficacious use of change agents, whose role includes advocacy, the provision of innovation information, and support for innovation implementation (Dearing, 2008). In the context of CRC screening, health care providers may serve as change agents by influencing patients' innovation decision-making about FIT. Other change agents may include family members and loved ones who may influence medical decision-making (Krieger, 2014). Research is needed to identify communication strategies that adequately inform patients of CRC screening options and simultaneously address barriers primary care providers face in providing patient education.

### **Patient-provider communication**

Promoting timely and appropriate CRC screening requires improved patient-provider communication. Gupta, Brenner, Ratanawongsa, and Inadomi (2014) found that even after controlling for traditional socio-demographic factors (i.e., age, race, socioeconomic status), communication with providers that facilitated trust remained the only significant driver of CRC screening completion among low-income patients. This line of research also suggests that focusing on patient-centered communication interventions may improve CRC screening rates by helping patients navigate the healthcare system to follow-up on test results and addressing patients' worries and concerns (Epstein & Street, 2007; Gupta et al., 2014). Research shows that providers' recommendation for CRC screening is a significant predictor of Appalachian patients' screening adherence (Krok-Schoen et al., 2015). Primary care physicians serving rural areas identify the need for enhanced patient education to improve CRC screening; however, many believe that the lack of resources, personnel, and time hamper their abilities to provide sufficient screening education (Dignan et al., 2014; Rosenwasser et al., 2013).

From the patient's perspective, communications about CRC risk and screening are complex (Canary, Bullis, Cummings, & Kinney, 2015). Multiple sources of influential communication bear upon the patient-provider relationship, with many participants involving their family system in decisions concerning preventive health behaviors. More research is needed to uncover ways in which family and provider communication may converge to improve patients' adherence to CRC screening. Furthermore, even in cases where appropriate screening knowledge and supportive attitudes toward CRC screenings may be present, substantial gaps may exist between patients' individual knowledge, supportive attitudes toward CRC screening, and adherence to screening protocols. For example, Schoenberg, Hatcher, and Dignan (2008) found that potential barriers to CRC screening exist despite the presence of positive beliefs about screening and knowledge of the significance of timely detection for CRC treatment and survival outcomes.

Patient-centered communication is a multi-faceted construct that focuses on (a) determining and understanding the patient's perspective, (b) understanding the patient's psychosocial context, (c) reaching a shared understanding with the patient that aligns with the patient's values, and (d) helping patients to share power and responsibility in healthcare decisions (Epstein et al., 2005, p. 1517). There are six core functions of patient-clinician communication including fostering healing relationships, exchanging information, responding to emotions, managing uncertainty, making decisions, and enabling patient self-management (Epstein & Street, 2007). These core functions are utilized across the cancer continuum, but are particularly important to screening and cancer prevention activities where the use of effective communication strategies may address knowledge deficits, fear, uncertainty, limited access to care, and inadequate understanding of the risks and benefits of cancer screening options (Epstein & Street, 2007, p. 72). Understanding communication needs about CRC screening options from the patient's perspective is critical, particularly given recent innovations in CRC screening and the opportunity to improve patient-provider communication to enhance demand for FIT.

From a theoretical perspective, several questions remain regarding communication gaps and opportunities for patient-centered communication of CRC screening guidelines. This research study investigates communication about CRC screening knowledge, recent innovations in screening tests and their diffusion, and patient-reported conversations with providers and family members about adherence to CRC screening guidelines. Thus, the following theoretically informed research questions guide the current investigation:

RQ1: What are the gaps in Appalachians' CRC screening guideline knowledge and screening practices?

RQ2: What messages do Appalachian patients recall hearing about CRC screening guidelines from providers and family members about colonoscopy, FOBT, and/or FIT?

RQ3: In what ways do Appalachians think providers could communicate more effectively to be patient-centered in their approach to CRC screening conversations with patients?

These questions were designed to explore the range of challenges and opportunities present improving colorectal cancer screening adherence and related health outcomes in Appalachian Kentucky.

## Method

As part of a broader research project by the Rural Cancer Prevention Center's (RCPC) multi-year effort to improve cancer prevention communication among medically underserved Appalachians, the current study utilized in-depth, face-to-face interviews with Appalachian Kentuckians to gather patient stories about colorectal cancer screening practices. We recruited participants through local health care providers with support from three community-based staff members who regularly meet with a Community Advisory Board (CAB). CAB members contacted local healthcare providers (Dr., OD, PA, NP, RN, LPN, and CNAs) to develop eligible contacts interested in participating in research related to this project. Specifically, CAB members provided referrals for eligible individuals (aged 50 – 75) who were asked to participate in an in-depth interview lasting about 45 minutes. These interviews were designed to allow our team to collect patient perspectives about FIT screening. We recruited 12 men and 28 women ( $n = 40$ ), who were referred to our research coordinators by our CAB members, to participate in one-on-one, in-depth interviews. The three local research coordinators recruited participants with the assistance of the CAB members' referrals; in the process, CAB members worked with health care providers who have conducted patient navigation for colonoscopy, informed potentially eligible participants of the research study, and provided referrals of potentially eligible participants to the research coordinators. Recruitment began in May 2015 and continued through December 2015. Interested individuals granted permission for the CAB member to have the RCPC research coordinator call his or her home to describe the study further; all calls were expected, and no cold calls were made.

Participants' age ranged from 51–73 years old ( $M = 61.9$ ). All were non-Hispanic white, reflecting the dominant racial/ethnic composition of the population. Fourteen were in compliance with current screening guidelines; four additional participants had a history of colonoscopy but were past due/hadn't had an annual FOBT/FIT, and 22 never had a colonoscopy and did not have annual FOBT/FIT. A semi-structured, qualitative interview approach was utilized to understand participants' CRC screening knowledge and attitudes, communication practices centered on screening, and his or her screening experiences. Participants were given pseudonyms as identifiers and labeled based on what types of CRC screening they reported having before the interview. Identification included having a history of no screening (NS), colonoscopy screening (CS), FOBT, or FIT (FOBT or FIT). Some participants were unsure if they had screening in the past (US) or reported some screening (SS) but were unsure of the type.

## Participants and procedures

**Sample**—Individuals were eligible for study participation if they were residents of an eight-county area located in southeastern Kentucky. Other inclusion criteria were: English-speaking, between the ages of 50 and 75, and not screened for CRC by any method in the

last 12 months. Prospective participants were ineligible for participation if he or she had a prior diagnosis of CRC.

**Data collection**—Each participant chose the day, time, and location for his or her enrollment meeting and study interview. Three trained local research coordinators conducted the one-on-one interviews. Upon enrollment, each participant was provided an informed consent document, which the interviewer verbally reviewed for understanding; two copies of the document were signed, one for the researcher and one for personal records. Interviewers assured participants that there was no obligation to undergo CRC screening as part of the research study; however, if they were interested in FIT screening the research coordinators could make that available to them. Interviews were audio-recorded and lasted 20–45 minutes. Upon completing the interview, participants received a \$30 gift card for their time. Audio recordings of the interviews were transcribed for 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 Institutional Review Board approved all study procedures.

**Protocol**—A semi-structured interview protocol 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 communication around CRC screening (Epstein & Street, 2007; Tan et al., 2012), the research team developed an interview protocol designed to reveal participants’ perceptions of screening recommendations from providers and other influential members of their social network. Following Epstein and colleagues’ (2005) conceptualization of patient-centered communication, first the interviewers identified the patient’s perspective and knowledge of CRC screening. Second, the interviewers explored the patient’s psychosocial context and values; in so doing, the interviewer uncovered patient concerns about CRC screening. Finally, the interviewers defined patient-centered communication and invited participants to describe how providers could better help patients share power and responsibility in CRC screening decisions. In so doing, the interviewers identified patient’s knowledge, attitudes, and practices of CRC screening to understand the diffusion of information about CRC screening recommendations before being asked to discuss how, from their perspective as a patient, their health care providers could present screening recommendations in a patient-centered manner.

Participants were asked about current screening status, specifically, whether or not he or she completed FOBT/FIT or colonoscopy screening(s) in the past. Guided by principles of patient-centered communication, the interview protocol first assessed patients’ current screening status and their knowledge of CRC screening guidelines. In eliciting this knowledge, interviewers probed for stories and expressions of concern where participants’ knowledge (or lack) of appropriate screening guidelines was consistent (or inconsistent) with their beliefs about the screening process and their personal screening practices. The interviewer then identified the interviewee’s last screening, and whether or not they were compliant with recommended guidelines. If recommended screening protocols were unknown, the local research interviewer provided the participant with information about screening guidelines. After discussing both colonoscopy and FIT screening options,

participants were invited to share any worries or concerns he or she may have about these types of screening. Participants were asked to tell a story related to a prior discussion they had with a family member or healthcare provider about CRC screening. Participants also were asked about whether or not family members' (e.g., mother, father, grandmother) beliefs about cancer screening would affect his or her decision to receive CRC screening.

To better understand the communicative needs of this population, participants were engaged in a discussion about patient-centered communication in the context of CRC screenings. The interviewers explained the goals of patient-centered communication using Epstein and Street's (2007) definition and asked participants to identify ways providers might be more patient-centered in their recommendation of the FIT and colonoscopy.

**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' screening knowledge and screening practices. In so doing, the derived category (gaps of knowledge and experience) was also confirmed by the research literature and the sensitizing framework of diffusion of innovations. Then, a second round of coding examined constructs of patient-centered communication to confirm and identify relevant theoretical concerns to CRC screening adherence. The transcripts were examined for how providers broached the screening conversation, consistencies in patient-reported provider communication practices and their characteristics, and tensions between provider recommendations and the interviewees' (patients) reported thinking or experiences. Finally, using qualitative descriptive analysis techniques, the researchers identified the recommendations that interviewees described for improving their provider's provision of CRC screening recommendations and information.

Commensurate with the constant-comparative methodology, the transcripts were reviewed and annotated for major ideas and recurring themes. This method is a tool to refine and review the conceptualizations of categories against empirical data (Lindlof & Taylor, 2011). The first author placed quotations from the interviews into a master outline consisting of framework headings and subheadings (Ritchie & Spencer, 1994). The researchers then convened to compile and compare findings, noting differences in opinion or responses to questions that were sensitive to screening history. After the proposal of an initial set of categories, the research team met to review and assess the categories to organize major and minor themes within the data. Team members reexamined the annotated transcripts and clarified important constructs related to participants' CRC screening guideline knowledge, perceptions of screening barriers, previous communication with healthcare providers and family members, and their recommendations for improved patient-centered communication regarding CRC screening methods. Upon completing the established framework, the team negotiated disagreements and agreed on the placement of in vivo quotations until the research team reached consensus. This iterative work was performed to corroborate the trustworthiness of the researchers' data understanding to support methodological rigor.

## Findings

Participants reported a range of personal experiences and beliefs that related to their CRC screening perceptions, which inevitably shaped communication about screening with family members and healthcare providers. To address the research questions, qualitative descriptive analysis identified the findings of gaps in personal knowledge (experience), attitudes, and practices among both screened and unscreened participants. The analysis that follows describes the interviewees' personal knowledge and experiences with CRC screenings. Second, we explore the patients' provider and family communication context influencing their decision-making. Finally, we identify the recommendations patients provided offering insight into how providers may communicate better to reach a shared understanding of CRC screening needs that align with their values, and to help patients "share power and responsibility" for CRC decision-making (Epstein & Street, 2007, p. 1517).

**Gaps in personal knowledge and experience**—Knowledge about CRC screening guidelines varied among participants. Many communicated having very little knowledge of the guidelines even after having talked with their doctors and, in some cases, receiving screening. When asked about her awareness of CRC guidelines, Patty (NS) stated, "No, I don't know anything about them. It changes all the time." Her statement reflected uncertainty about the timing and accuracy of information provided about screening guidelines. Other participants expressed having no knowledge of the guidelines, yet seemed to be compliant with a doctor's orders for colonoscopy. Doug (CS) stated, "I don't know anything about them, I was just told by my doctor the last time I was there I was due for one." When asked if his healthcare provider discussed the timing and appropriateness of CRC screenings with him, Roger (US) stated, "They said I was past the time I needed to be looking into that, so I set it up and did it."

When participants had received prior CRC screening, they seemed to have some common knowledge about the guidelines and screening processes. In reference to the age requirements in CRC screening services, Sophia stated, "They begin at age 50 and then if it is clear, it's every five years after." Other participants knew more about the interval process recommended for the frequency of screening. Rhonda (CS) said, "I don't know except if you don't have anything wrong he says come back in three years, and if you have a really good sample I think it's five years." In reference to colonoscopy, Janet (CS) said, "I think like after 50 they want you to have one like ever [sic] ten years. I think. If you ever had any problems...anything show up...they want you to have them done more often, like ever [sic] three years or something." Some participants could identify guidelines even without having prior CRC screening. Linda (NS) recalled, "...over 50 years of age. I believe one should have one every five to ten years, depending on your history and your family history."

Alternatively, participants expressed confidence in knowing the guidelines but struggled to articulate accurate information about screening. For example, Stan (CS) stated, "It's maybe once every year or once every two year [sic] maybe, or something like that." Similarly, Theda (FOBT) stated, "I know they recommend it after you are older. I am not sure about the age, but I think they recommend it yearly after a certain age."



### **Screening uncertainty, fear of results, and confidence in a lack of symptoms—**

What participants knew about CRC screening procedures was often derived from personal stories about their experiences with screening or recalled stories from family members about their screening experiences. For example, Rhonda recalled a story about her mother's experience with colonoscopy screening. She said, "My mother went and had this done way before I did. I won't tell you what she called it...I just couldn't bring myself to do it." In line with prior research, one often-cited barrier to repeating CRC screening was the certain knowledge of the cumbersome preparation leading up to colonoscopy screening. Stan (CS) said, "But the worst part was probably drinking the prep, and you know all night long going to the restroom..." Moreover, participants reported uncomfortable side effects of the preparation of bowel evacuation. Janet (CS) stated, "I just don't like the prep. Last time it made me sick." Other participants did not mind the procedure itself but identified similar side effects of the preparation. Louise (CS) said, "Well the colonoscopy itself is not that bad, the prep before you just get so nauseous and sick, and I think that's the reason a lot of people don't want to have the colonoscopies done..." Participants also reported a general fear of CRC screening procedures, and the technology itself. Linda (NS) communicated concerns about colonoscopy saying she was, "...apprehensive about the scope itself. Just going to the OR [operating room]. The sedation. The scope. I've never had anything like that."

Related to the issue of a technology scoping their "private parts," participants also reported privacy or embarrassment as a barrier to receiving a regular colonoscopy. These feelings were present regardless of the person's age or gender. Theda (FOBT) reflected on personal concerns saying, "That is a private part of your body. It's embarrassing to me." Louise (CS) recalled her experiences having the colonoscopy procedure, saying, "Doing a colonoscopy is very invasive..." She referred to the procedure as occurring in a "very delicate place." Gary (NS) shared his fear and worry of "being violated." Participants who had not experienced any screening reported reticence to screen due to privacy concerns. Mary Jo (NS) said, "I think I am a shy person, so that would be my hold back on that."

Participants also reported how their medical mistrust and reticence to repeat screening originated from prior poor experience(s) with a provider/technician, which posed a barrier to timely colonoscopy. For example, Rhonda (CS) recalled her experiences having a colonoscopy, saying she was "humiliated in the doctor's office." In her case, supplementary tests were needed in addition to the colonoscopy, which led to her being sent to another office wearing the backless hospital gown. She said, "It just seemed so insensitive. It almost bordered on, not abuse, but you know, something weird – that I have to sit there like that. He could have given me a towel to sit on."

Another critical barrier to CRC screening was participants' self-admitted fear of receiving a cancer diagnosis, or the belief that after having received a negative screening result that they were better to "not know" if there was a change in the future. Participants communicated their fear of CRC screening results in relationship to their reticence to return for screening: Sandy (CS) said, "I'm sure nobody likes having them [colonoscopy] done, but I am always afraid when you have tests that something will come back wrong."

Finally, several participants expressed reluctance to have CRC screening due to the lack of symptoms. Charlene (NS) said, “I’ve never had one, so I don’t feel I need one. Nothing’s wrong.” Barbara (NS) reiterated this by saying, “If there was [sic] problems, and I thought maybe there needed to be one, I wouldn’t care to do one.” Linda (NS) recalled speaking with her father about colonoscopy. She said, “We’ve talked about it some. I guess I thought if you have a change in your bowel habit, and I try to watch my stools and do a lot of things like that, and never had any problems one way or the other. Thought it might be okay.”

**Inconsistent provider communication practices and personal obligations to family**—Participants reported that many of their providers engaged in encouraging talk about CRC screening with them to try to overcome their reluctance to screen. When asked how his doctor brought up colonoscopy screening, Stan (CS) stated, “...the doctor will say, you got ye [sic] flu shot? Have you done this? Have you done that? And they come around to that and ask ye [sic], you know.” Rhonda (CS) spoke of conversations with her doctor about past medical issues. She recalled her doctor saying, “...it was really important that I get a colonoscopy within a year because since I had this problem, it was highly likely that I would have another problem.” Rose (CS) also reported persuasive messages from her providers, stating, “After I turned 50 they started talking to me about it and stuff and I finally had it done.” Janet (CS) said that her doctor “...emphasized the importance of regular colonoscopies.” Louise (CS) remembered specific information about screening guidelines because of conversations with her physician. She said, “...he [doctor] said that after 50 that it’s a good idea to have a colonoscopy done, and then he made me the appointment, and I went and had it done.” Patients who were current on their screening reported providers’ communication about the importance, timing, and appropriateness of the CRC screening they recommended, often making an appointment or giving them a test to take home that day.

Despite conversations with providers, other participants reported provider encouragement that did not necessarily result in CRC screening, particularly for colonoscopy. Phil (NS) stated, “Well, she’s tried to get me to have it [colonoscopy] done, and this and that and the other, and I’m bull-headed.” Some participants reported having conversations with multiple doctors about screening. Dorothy (NS) said, “I only have had interactions with two doctors, but they have both encouraged me to have this [colonoscopy] done.” Other participants recalled messages from specific providers that outweighed the recommendations of others. Theda (FOBT) said, “I have only talked with a nurse at the health department. She informed me ten years ago that she thought the stool specimen was as good as a colonoscopy. I didn’t think it was worth having one [the colonoscopy] done.” This statement reflects how contradictory or unclear provider messages around a combined screening approach could further a lack of understanding of CRC screening guidelines in patients.

In both the presence and absence of conversations with providers, a related issue was how interpersonal communication with family members about screening might affect participants’ decision-making to adhere to CRC screening guidelines. Conversations with family members were rare. However, one promising fact is that among the participants that reported having these conversations ( $n = 14$ ), only a few remained unscreened ( $n = 4$ ) and participants described how this supportive talk, coupled with provider recommendations,

bolstered their loved ones' willingness to be screened. In some cases, participants reported encouragement from multiple family members. Stan (CS) said, "...My wife and everybody just wanted us to have one."

Participants who had been screened reported talk with family members in attempts to encourage them to get screened. Janet (CS) said, "My mother is like 75, and I have talked to her occasionally about having it [colonoscopy] done." Another participant conveyed a sense of accomplishment based on conversations about screening with her husband. Rhonda (CS) said, "I did convince my husband to have one [colonoscopy], which was a big deal because there was no way he was going to do it." Fear of CRC screening procedures could be overwhelming, and other participants seemed discouraged about conversations with family members. Rose (CS) explained, "I have talked to my siblings, and they still have not had it [colonoscopy] done." One participant reported using a fear appeal to convince her granddaughter to get screened. Rebecca (CS) stated, "I talked to my granddaughter because she was having some problems. I told her she needs to go and could end up with cancer." Fear of the colonoscopy procedure and the potential for a cancer diagnosis seemed to be pervasive. Julia (SS) and her sister shared this dual concern, "Me and my sister talked about it [colonoscopy], but we didn't go into a lot of it. She doesn't want anything to do with it because she is afraid of it too."

There were meaningful connections between participants' prior communication with providers and their subsequent communication with family members. In the case of one participant, the interview with a community health worker served as encouragement to have a conversation with a family member. Tina (NS) stated, "I haven't done it [talked with family], but I will now. I will talk with my older sister." Differences in interpersonal communication about screening may be a difference that makes a difference in adhering to CRC screening guidelines. Even so, another participant remained reticent even with having multiple conversations with both family members and healthcare providers. Blanche (NS) said, "Everybody in the family's got one...now you've gotta go get one. I said, but I don't have no problems." Of those participants who remained unscreened, the absence of symptoms, and fear of a diagnostic procedure seemed to override encouragement of screening from both providers and family members.

#### **Participants' recommendations for providers on patient-centeredness—**

Interviewers asked participants about how healthcare providers could communicate more effectively to be patient-centered in their approach to CRC screening conversations. Participants reflections noted (a) the absence of recommendation, (b) the need for more information or options about CRC screening, (c) the need for clearer and more direct language, (d) the preference of conversations with specified types or gender of providers, and (e) the need to approach the conversation with greater sensitivity.

Based on prior experience with their providers, several participants did not have particular recommendations for conversations about CRC screening. Many participants expressed satisfaction with their communication with their health care. Janet (CS) stated, "My doctor that I go to, he explains everything really well and is usually pretty patient about it." Satisfaction with providers' use of language was evident among some participants. Sandy

(CS) said, “Most of them seem to do well getting down on my level.” Despite not having CRC screening, Tina (NS) stated, “...my doctor is really helping me.” Conversely, other participants thought that communication with their provider did not matter in the context of CRC screening recommendations. Roger (US) said, “That [screening] is up to me. At my age, where things happen more often, I am 61, so that’s really my responsibility the way I look at it. They can suggest whatever, but again I do not talk to doctors much, so they do not get a lot of opportunity to share with me...”

However, participants also recommended that their provider offer more information about or more options for CRC screening. This recommendation was especially salient among participants who had not been screened. Gary (NS) reflected on the lack of information provided by his doctor saying, “Well since mine hasn’t said anything, then they need to be a little more proactive.” Linda (NS), who reported having conversations with family members about colonoscopy, described a lack of explanation from her doctor about screening options. She said, “I think just explaining, doing a little bit more explaining, even like the FIT test. I’d never heard of that. So, tell you what’s out there...” Furthermore, participants reported thoughts about how to provide information, specifically referring to elements of motivation and consequence to engage in screening. Suzanne (NS) said, “Yeah, just knowing the guidelines and what could happen. That should motivate you...”

Multiple participants recommended changes in providers’ use of language when communicating about CRC screening. Specifically, participants desired clear and direct language. As Anthony (NS) clarified, “Having a doctor that you can understand. Talk plain English. Be straight with you...just tell me what I need to do to get better.” Other participants requested providers use more lay language and offer deeper explanations of screening. Julia (SS) stated, “They can say it out plainer and explain it better...” Lay and direct language was recommended as well, specifically reporting their discomfort with uncertainty. Stan (CS) said, “I’m the type of guy I just ask ‘em. Hold it! Wait! We need to explain this, and you know let me know exactly what you’re talking about...cause if I don’t know, I wanna know.” Although most of the recommendations for improved patient-centered communication were supportive in nature, one participant reflected on perceived ulterior motives driving provider small talk. Patty (NS) referred to a specific provider who was, “after bucks. Let’s be honest. They are after money. Which I have good insurances [sic] and stuff. I don’t care, but I want good service. That’s all I want. I don’t want to sit and listen to someone talk about...stupid stuff like that, I don’t care.”

A salient element of participants’ recommendations included a preference for a specific type or gender of provider. When asked who he would like to receive information about CRC screening recommendations from, Stan (CS) said, “Probably the doctor because if you have any questions, maybe he would... be more apt to be able to answer your question versus the nurse.” Gary (NS) reiterated this sentiment by saying, “So if one of them [doctor] comes in there and says, hey you know you’re at that age we think we need to schedule you for that. I’m going to do it before I would [have] the nurse coming in and trying to talk to me.” While the preference for conversations with a doctor was evident with many male participants, female participants preferred to talk with nurses. Blanche (NS) stated, “Well when I go to the doctor, I’d much rather go to the nurse unless the doctor’s a woman.”

Multiple participants recommended sensitivity during conversations about screening and the procedure experience. One participant even took caution communicating with her interviewer about prior conversations with her provider. Louise (CS) said, "...doing a colonoscopy is very invasive, you know you have something that is going in one very delicate place. I'm trying to word this very carefully..." Another female participant recalled clear differences that occurred between the recommendation of colonoscopy and the actual procedure. Reflecting on her experiences, Rhonda (CS) stated, "I think with your initial appointments, when I've gone in to discuss things and everything, I think they're very polite, and I have felt comfortable. But actually the day that you get this test, I was humiliated in the doctor's office...it just seemed insensitive."

These recommendations provide clear opportunities to improve patient-provider communication about CRC screening guidelines and procedures in Appalachian community clinics. Providers should consider communication modeled to enhance patient engagement in conversations with family members about CRC screening guidelines and options, particularly if patients are reticent to receive screening services. Moreover, findings related to the persuasive potential of family communication present unique options for message design.

## Discussion

Our findings suggest that gaps in knowledge about CRC screening guidelines are common among residents of rural Appalachia, which corresponds with prior research (Bardach et al., 2012). Very few participants could articulate screening guidelines with accuracy and often recalled "bits and pieces" of the guidelines. What participants did know about CRC screening processes reflected negative attitudes, reticence to engage in colonoscopy screening, and fear of receiving a cancer diagnosis. However, participants reported having encouraging conversations with providers and family members about engaging in CRC screening and presented many patient-centered recommendations for providers to consider for future communication about screening. Thus, opportunities exist to improve the conversations about CRC screening guidelines between patients and providers thereby giving patients a more accurate understanding of screening procedures for colorectal cancer.

Prior research (e.g., Curry et al., 2011) identifies the most frequently mentioned barriers to CRC screening reported by participants including time constraints, embarrassment, cost, concern regarding the competence of their provider, and distance/transportation to screening services. The current study extends these findings by eliciting the perspective of Appalachian patients to gain their understanding of salient barriers to engaging in CRC screening. Some participants reported feelings of medical mistrust due to poor prior experiences with CRC screening. Moreover, fear of certain, awful diagnosis or reluctance to participate in cancer detection may significantly affect decision-making related to CRC screening practices.

Undoubtedly, many participants were frightened by the chance of being diagnosed with cancer and communicated some certainty that they would rather not know; even participants with a history of CRC screening did not articulate the benefits of early detection and timely,

routine screening with ease or regularity. This finding has important implications for health communication message design targeted toward this rural population where access to appropriate treatment and care may be a concern. Namely, focusing on communication strategies providers use to respond to fear and manage screening uncertainty is critical, particularly in the case of colonoscopy where the treatment (of removing polyps), itself, may be a cure. While recognizing and uncovering emotions during the patient encounter is often difficult, providers may effectively respond to emotional expression by using communication techniques such as legitimation and validation (Epstein & Street, 2007). These empathetic techniques reflect an understanding of the patient's psychosocial context and may aid in addressing patients' concerns, worries, and fears.

Even in the absence of guideline literacy, participants recalled many messages communicated to them by their family members and healthcare providers. The salience of encouraging talk from kin in close-knit Appalachian communities has powerful implications for those patients who have enduring uncertainty about engaging in screening. As mentioned above, targeted communication strategies based on the unique barriers (e.g., fear of results, modesty) that Appalachians identify regarding screening have the potential to improve CRC-related health outcomes. Based on the findings of the current study, interpersonal communication with family members about CRC screening in addition to healthcare providers present a unique, persuasive opportunity. Relatively few participants who reported previous conversations about CRC screening with family members remained unscreened. The family and social environment are shown to be an extrinsic moderator of the relationship between the patient's needs, communication, and health outcomes; our findings underscore the necessity for clinicians to envision screening decisions as a family issue, regardless of family presence during the patient encounter (Epstein & Street, 2007). Consistent with prior research (Canary et al., 2015; Krieger et al., 2016), incorporating family members into the conversation about screening has clear value in cancer prevention among Appalachians in this study.

Considering the recommendations that this population proposes for improved patient-centered communication is important for developing targeted communication strategies. Several implications for promoting FIT and ways to improve patient-centered communication materialized from interviews with Appalachian men and women. During conversations about CRC screening guidelines and procedures, providers must consider recommendations for offering more information and options to participants. Providing patients, particularly in rural, medically underserved communities, with additional options allow providers to share decisional power with the patient in conversations about CRC screening. There is evidence that FIT and FOBT screening are a more acceptable, less invasive alternative to colonoscopy and, if positive, would enhance patients understanding of the need for further testing. Findings from this study highlight the potential for providers in the Appalachian region to serve as change agents in diffusing the FIT innovation.

Clear and direct language during patient-provider interactions is a necessity for fostering effective screening decision-making. Using language that includes less medical jargon and clearly communicates the risks and benefits of CRC screening is critical because patients may not have considered screening options before their visit and are often unfamiliar with

providers' rationale for certain screening recommendations (Epstein & Street, 2007). Furthermore, because discussions about CRC screening are sensitive in nature, participants value language and a bedside manner that is "polite" and "delicate." This finding is in accord with research demonstrating that minor changes in providers' language can reduce patients' unmet concerns (Heritage, Robinson, Elliot, Beckett, & Wilkes, 2007). Subtle changes in the language used in pre-screening conversations and during screening procedures may help to establish trust, develop positive rapport, and reflect an understanding of the patient's psychosocial context, which are all crucial for fostering positive patient-provider relationships.

Finally, taking into consideration the preferences of patients in this population may be highly beneficial for aligning patient and clinician perspectives. Simply asking patients if they would prefer to discuss screening with a nurse rather than a doctor or a female provider rather than a male conveys that the patient's wishes are valued, which could lead to more positive perceptions of screening options. Soliciting these preferences to adapt to patients' needs provides another way to foster the patient-provider relationship.

### **Limitations and areas for future research**

As with any research, there are limitations to consider. First, community health workers who were trained as lay research coordinators conducted participant interviews. Although each worker received training before interviewing participants, they are not extensively trained in qualitative methods. There were instances where the interviewers missed opportunities to ask additional probing questions to obtain richer description from the participants. Nonetheless, the workers are an integral part of the community in which this study took place and could connect to participants in a way that outsiders could not. Second, participants were asked to reflect on past conversations with family members and providers about CRC screening. Recalling past events is challenging, to say the least; there are details that may have been omitted or that participants failed to remember due to the amount of time between their conversations with family members and providers and the interviews for our study.

There are also several important implications for future efforts to diffuse the FIT innovation in the Appalachian region. First, the need for further investigation of patients' perceptions of FIT as a CRC screening alternative is clear. Uncovering attitudes about the using and repeating FIT is necessary as patients' may have varying beliefs about the ease of use of the FIT kit, specifically related to collecting the specimen, mailing the completed kit, and attending any necessary follow-up visits to their provider. Moreover, research must examine patients' ability to engage in self-management by repeating FIT annually and following up with colonoscopy screening if needed.

Second, in addition to patients' perceptions, uncovering providers' attitudes about FIT is crucial. Because colonoscopy is shown to be the "gold standard" among providers, there may be a reluctance to recommend FIT to patients. The current study provides several recommendations for patient-centered communication about CRC screening; it is our hope that these suggestions may help shape conversations about FIT as an alternative to

colonoscopy. Future research should focus on providers' engagement in communication about FIT and how this may impact annual screening adherence.

Finally, future investigation is needed to explore family members' influence on patients' decisions to repeat FIT annually. Our research uncovered important implications for integrating family members in communications about screening. Interventions may be designed to include family members in the patient-provider interaction or to facilitate direct communication with patient-preferred family contacts via monthly reminders to get screened. This type of intervention may serve as a promising complement to the existing standard of care of 11-month screening reminders.

## Conclusion

Conversations with Appalachian residents in these in-depth interviews revealed challenges and opportunities for patient-provider communication about CRC screening. Although dissemination of more and better quality information about CRC screening options like FIT is needed, this study offers clear evidence that communication about screening with both healthcare providers and family members is important to improve CRC screening adherence. By offering culturally appropriate, patient-centered screening messages from providers and engaging family members in the screening conversation, practitioners may promote adherence to CRC screening in populations similar to rural, Appalachian Kentucky.

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