# Individualized Colorectal Cancer Screening Discussions Between Older Adults and Their Primary Care Providers: A Cross-Sectional Study



MDM Policy & Practice 1–12 © The Author(s) 2018 Reprints and permissions: sagepub.com/journalsPermissions.nav DOI: 10.1177/2381468318765172 journals.sagepub.com/home/mdm **SAGE** 

# Christine E. Kistler, Carol Golin, Anupama Sundaram, Carolyn Morris, Alexandra F. Dalton, Renee Ferrari, and Carmen L. Lewis

#### Abstract

Introduction. Discussions of colorectal cancer (CRC) screening with older adults should be individualized to maximize appropriate screening. Our aim was to describe CRC screening discussions and explore their associations with patient characteristics and screening intentions. Methods. Cross-sectional survey of 422 primary care patients aged  $\geq$ 70 years and eligible for CRC screening, including open-ended questions about CRC screening discussions. Primary outcomes were the frequency with which CRC screening discussions occurred, who had those discussions, and the domains that emerged from thematic analysis of participants' brief reports of their discussions. We also examined the associations between 1) patient characteristics and whether a screening discussion occurred and 2) the domains discussed and what screening decisions were made. Results. Of 422 participants, 209 reported having discussions and 201 responded to open-ended questions about CRC discussions. In a regression analysis, several factors were associated with increased odds of having a discussion: participants' preference to pursue screening (odds ratio [OR] 2.3, 95% confidence interval [CI] 1.3, 3.9), good health (OR 2.9, 95% CI 1.7, 4.8), and receipt of the decision aid (OR 2.1, 95% CI 1.4, 3.2). Our thematic analysis identified five domains related to discussion content and three related to discussion process. The CRC screening-related information domain was the most commonly discussed content domain, and the timing/frequency domain was associated with increased odds of intent to pursue screening. Decision-making role, the most commonly discussed process domain, was associated with increased odds of the intent to forgo CRC screening. Conclusions and Relevance. CRC screening discussions varied by type of participant and content. Future work is needed to determine if interventions focused on specific domains alters the appropriateness of participants' colorectal cancer screening intentions.

# Keywords

colorectal cancer screening, individualized decision making, older adults, patient preference, screening discussions

Date received: March 16, 2017; accepted: February 8, 2018

Guidelines recommend colorectal cancer (CRC) screening for all adults aged 50 to 75 years, but encourage individualized decision making for patients aged 76 to 85 years, with screening only recommended for those most likely to benefit.<sup>1</sup> Despite the recommendations, current evidence shows that some adults  $\geq$ 75 years continue to receive inappropriate screening: those likely to benefit from screening do not receive screening and those unlikely to benefit do.<sup>2</sup> In fact, evidence suggests that CRC screening is likely not helpful in those in their early

**Corresponding Author** 

Christine E. Kistler, Department of Family Medicine, University of North Carolina, 590 Manning Drive, CB #7595, Chapel Hill, NC 27599, USA; phone: (919) 843-5849, fax: (919) 966-6126. (Christine\_kistler@med.unc.edu)

This Creative Commons Non Commercial CC-BY-NC: This article is distributed under the terms of the Creative Commons Attribution-NonCommercial 4.0 License (http://www.creativecommons.org/licenses/by-nc/4.0/) which permits non-commercial use, reproduction and distribution of the work without further permission provided the original work is attributed as specified on the SAGE and Open Access pages (https://us.sagepub.com/en-us/nam/open-access-at-sage).

70s in very poor health.<sup>3</sup> Individualized decision making provides a mechanism to maximize the benefit and minimize the harms from CRC screening in this population. One important component of individualized decision making for CRC screening in adults 70 and older is patient–provider communication.<sup>4</sup> Hence, an important and little-explored target for increasing individualized CRC screening in this population may be improving the quality of patient–provider discussions about CRC screening. To date, however, little is known about the extent to which these discussions occur among older adults or the content of these discussions to identify clear targets for improvement.

On the patient side of a discussion, patients' personal values, worries, health status, cancer risk, and other factors may hinder or augment individualized CRC screening decisions.<sup>5-7</sup> Other issues like potential side effects of the screening tests, the logistics of screening (screening process and barriers), and test characteristics like false positives also appear to influence final screening decisions.<sup>7-10</sup> Additionally, one small study of older adults aged 63 to 91 showed that if older adults' primary care providers recommended that they forgo screening, this recommendation would jeopardize their trust in that provider.<sup>11</sup> Patients of all ages often lack basic knowledge about CRC screening,<sup>12</sup> which can lead to uninformed decisions about whether or not to participate in screening.<sup>13</sup> Non-evidence-based factors, such as personal exposure to a nonrelated individual who had colorectal cancer, increases patients' preference to pursue CRC screening.<sup>14</sup> In fact, a

study of 399 adults aged 65 and older visiting their primary care providers found that accessing evidence-based information about CRC screening prior to their visit had no impact on screening preference.<sup>15</sup> Therefore, while patient characteristics seem important to screening intentions, it is unclear exactly how they affect the CRC screening discussions with providers and whether discussions affect patients' screening intentions.

Medical providers also play a vital role in discussing and individualizing CRC screening decisions, but providers rarely have in-depth discussions about screening issues. In a mixed-methods study of 65 primary care providers, providers rarely explored the risks and benefits of CRC screening or patients' preferences about screening.<sup>16</sup> In fact, a study of 11,427 US patients aged 50 to 75 found that the most common reason for failing to pursue screening was that patients were unaware they needed it. Additionally, when patients chose screening, their physicians did not help them decide which form of CRC screening they wanted.<sup>17</sup> While a qualitative study of 103 primary care providers identified discussions with patients as a facilitator of screening,<sup>14</sup> these discussions rarely encouraged patient participation in the decision-making process.<sup>18</sup> It is well established that provider recommendations for CRC screening are strongly associated with receipt of screening,<sup>14</sup> and lack of a recommendation is associated with a lack of screening.<sup>19</sup> A downside of recommendations can occur when provider recommendations run counter to older patients' likelihood of benefit. Patients will often defer to providers and may yield to recommendations unlikely to benefit them.<sup>20</sup> The limited evidence available suggests that provider engagement in the discussion process may be important to the screening decision.

Unfortunately, most of the studies of CRC screening discussions included small numbers of adults aged 70 and older for whom individualized decision making is recommended.<sup>5–10,17</sup> While these studies help us understand CRC screening discussions for middle-aged adults, they do little to inform our understanding of whether or how discussions occur in older adults. It is unclear if findings in younger populations where screening is universally recommended will hold true in older populations. Furthermore, much of the research noted above was conducted before the US Preventive Services Task Force (USPSTF) guideline changes regarding older adults in 2008 recommended individualized decision making.<sup>6,7,14,19</sup> We sought to address these issues by including open-ended questions about CRC screening discussions among participants in a randomized controlled trial (RCT) of a CRC screening decision aid (DA). The main purpose of the study reported here was

Department of Family Medicine, University of North Carolina at Chapel Hill School of Medicine, Chapel Hill, NC, USA (CEK, CM); Department of Medicine, and Department of Health Behavior, Gillings School of Global Health, University of North Carolina at Chapel Hill, Chapel Hill, NC, USA (CG); School of Medicine, Northeast Ohio Medical University, Rootstown, OH, USA (AS); Division of General Internal Medicine, University of Colorado School of Medicine, Aurora, CO, USA (AFD, CLL); Cecil G. Sheps Center for Health Services Research, University of North Carolina at Chapel Hill, Chapel Hill, NC, USA (RF). Financial support for this study was provided entirely by grants from the following organizations: UNC-CH Summer Research in Aging for Medical Students (NIA 5-T35-AG038047-05); Lineberger Comprehensive Cancer Center (6-34080); Dr. Golin's salary for conducting this work was partly supported by the Eunice Kennedy Shriver National Institute of Child Health and Human Development (K24-HD06920, K24-DA03710); and Agency for Healthcare Research and Quality (AHRQ) Research Centers for Excellence in Clinical Preventive Services (Grant Number P01 HS021133). The funding agreements ensured the authors' independence in designing the study, interpreting the data, writing, and publishing the report.

These findings were also presented at the 2015 national meeting of the American Geriatrics Society. We would like to thank Dr. Christopher Wretman for his analytic assistance and guidance.

to describe how many older adult patients had CRC screening discussions and these adults' perceptions of these discussions. We also sought to explore whether patient characteristics were associated with CRC screening discussion occurrence, as well as associations between discussion domains and screening intentions. Last, given that available data suggest discussions may be important to screening intentions, we also sought to explore how often discussions may have led to shifts in participants' preferences for inappropriate screening toward appropriate screening intentions.

# Methods

#### Study Design

The parent RCT was conducted within a primary care research consortium among patients who were scheduled to see their primary care provider from December 2012 to May 2014 to assess the effects of a CRC screening DA for older adults. Participants were randomized to receive either a targeted CRC screening DA or an attention control pamphlet about driving safety. The RCT included a series of five surveys: an eligibility survey, a baseline survey, a postintervention survey, a postvisit survey, and a 6-month follow-up survey.<sup>21</sup> Pertinent to this study, participants received the baseline survey in the clinic on the day of that appointment. They were then randomized to receive the DA or attention control. Participants then saw their provider, after which they completed the postvisit survey, which included one of two possible openended questions about CRC discussions. Research assistants wrote down brief summaries of participants' verbal responses to open-ended questions. Participants received up to \$50 for participating in the RCT. The study was approved by the Duke University and University of North Carolina at Chapel Hill Institutional Review Boards.

# **Participants**

The RCT included primary care patients aged 70 to 85 years who were not up-to-date with CRC screening, defined as having no evidence of fecal occult blood test within 1 year or sigmoidoscopy within 5 years, previous negative colonoscopy  $\geq 10$  years ago, or a negative colonoscopy  $\geq 5$  years ago that showed hyperplastic polyps.<sup>22,23</sup> The rationale for including patients with polyps is that their risk of CRC is similar to those without polyps with the same potential risk of harms. Additionally, older adults were eligible if they were fluent English-speakers and able to use the printed

intervention. Participants were assigned to one of three health states (good, intermediate, or poor) based on their Charlson Comorbidity Index score and age.<sup>24</sup> The RCT closed recruitment to a health state once 150 individuals were enrolled in that health state. Exclusion criteria included possible dementia (assessed via a three-item recall and three-item orientation screener given prior to consent)<sup>25</sup> or a previous history of colorectal cancer or inflammatory bowel disease.

# Survey Measures

The baseline and postvisit surveys, including demographic questions and Likert-type statements, were developed by the authors. The 24-item baseline survey included patient characteristics and two patient preference questions. The 31-item postvisit survey contained the short form of the Rapid Estimate of Adult Literacy in Medicine (SF-REALM)<sup>26</sup> and asked participants to complete the sit-to-stand test.<sup>27</sup> They also answered one of two brief open-ended questions about their CRC screening discussion, depending on whether they made a cancer screening decision.

*Participant Characteristics.* Participants were asked about their *general preference for decision making* using a modified shared-decision making question<sup>28</sup> and a question about *CRC screening preferences:* "Thinking about colon cancer screening, which option would you choose at this time?" Response options were the following: prefer to be screened, would prefer NOT to be screened, or were unsure/don't know. An *appropriate CRC screening preference* was defined as 1) a preference to pursue CRC screening for participants in good health state; 2) any preference for a participant in an intermediate health state; and 3) a preference to forgo CRC screening in the poor health state.

Discussion Measures. We asked participants who reported that they intended to either pursue or forgo CRC screening the open-ended question, "Tell me about how you and your doctor came to that decision?" The participants who did not reach a decision regarding CRC screening were asked, "What led you and your doctor to not make a decision about colon cancer screening?" Participants who did not have a discussion were not asked about why they did not discuss CRC screening. Verbal responses to these questions were summarized by the research assistant and written down. Responses varied from a few words to a few sentences. We collapsed the responses to these two questions into one response set for our discussion analysis and placed participants into 3 groups: 1) intention to pursue screening, 2) intention to forgo screening, and 3) no decision was made. Because the RCT expected to enroll more than 400 participants, we chose to add just these questions to prevent overburdening the participants, while still providing a broad description of discussions.

*CRC Screening Intention.* Because we also wanted to examine the appropriateness of their intentions, we developed a new measure of *appropriate CRC screening intention*. CRC screening *intention* was defined as intention to pursue CRC screening for participants in good health state, discussion about CRC screening for participants in the intermediate health state, and as intention to forgo CRC screening in the poor health state. The idea of appropriate CRC screening for older adults is only appropriate if they will live long enough to see benefit, as recommended by the USPSTF.<sup>1</sup>

# Data Analyses

We organized the presentation of the study analysis and results to follow the natural timeline of a CRC screening decision, from previsit characteristics to during-the-visit discussions to postvisit intentions. Quantitative responses were analyzed using SAS v9.4.

Analyses of Patient Characteristics. We used descriptive statistics to describe patient characteristics of the entire sample. We sought to explore possible associations with discussions. For the purposes of this study, we treated the intervention assignment as an independent variable that occurred before the medical visit and screening discussion. We first used descriptive statistics to determine the frequency of patients who reported having a discussion. We then explored the associations between these characteristics and participants' report of whether or not a discussion took place using bivariable linear regression modeling. Characteristics with a bivariable association of P < 0.15 were included in a multivariable model. We then used a backward selection process to eliminate nonsignificant variables until the multivariable model was finalized. Only characteristics that were still significant at a P < 0.05 were included in the final model. We also explored how many participants who had inappropriate screening preferences—as determined by our a priori categorization scheme-had appropriate screening intentions after a discussion. In this portion of the analysis,

we excluded those who received the DA in order to isolate the effect of a discussion without the influence of the DA. We examined how many patients who initially preferred not to be screened but would likely benefit intended to pursue screening, and how many who initially preferred screening but would likely not benefit intended to forgo screening.

Discussion Domains. We also described participants' report of their discussions. Similar to our previous work,<sup>29,30</sup> we first independently coded the open-ended responses from the survey into qualitative domains. Though familiar with previous literature on the CRC screening discussions, we used a "naïve" or "conventional" thematic analysis of the open-ended responses to ensure we did not ignore potentially important domains undiscovered in prior work.<sup>31–33</sup> Two researchers (CK and AS) then independently read all of the transcripts for domains and developed a framework for coding the responses, including overarching domains, domains, and subdomains. The domains were refined and revised based on readings by the two researchers. Final domains were reviewed and agreed on by the research group. The two researchers then independently coded the openended responses, with the assistance of a third coder (CG). Coding discrepancies were discussed with the group and resolved by consensus over several months.<sup>34</sup> In addition to describing the domains, we also conducted limited quantitative analysis for each domain, including means, proportions, and standard errors, as is common in this type of research.<sup>35</sup>

Intention to Screen Analyses. Last, because we sought to understand the context of CRC screening discussions, we conducted several exploratory analyses. We used descriptive statistics to assess the frequency of each discussion domains that might be associated with screening intentions. These exploratory associations were unadjusted for confounding and were performed to explore the data for possible trends requiring further study. We looked at the associations between the overall content and process domains and intention to be screened using a bivariate analysis. We then explored these domains for differences in their screening intentions using a Pearson's chi-square test, if the cell sizes allowed comparison.

# Results

#### Participant Characteristics

Of the 422 participants in the study, 209 reported discussions about CRC screening and 213 reported no

#### Table 1. Participant Characteristics, n (%)

Characteristics	Total (N = 422)	Discussed CRC Screening (n = 209)	Did Not Discuss CRC Screening (n = 213)	<i>P</i> Value
Age, mean (SD)	76.8 (4.2)	75.9 (4.2)	77.7 (4.1)	< 0.001
Female	248 (59)	125 (60)	122 (57)	0.6
Race				
White or Caucasian	335 (79)	166 (60)	122 (57)	0.7
Black or African American	76 (18)	36 (17)	39 (18)	
Asian American	8 (2)	5 (2)	3 (1)	
Other	8 (2)	2 (1)	6 (3)	
Hispanic	7 (2)	2 (1)	5 (2)	0.45
Educational status				
Some high school or less	30 (7)	15(7)	15(7)	0.38
12th grade graduation	95 (22)	50 (24)	43 (20)	
Some college or associate's degree	97 (23)	44 (21)	53 (25)	
College degree	90 (21)	41 (20)	49 (23)	
Masters, PhD, JD, MD, or other advanced degree	112 (26)	59 (28)	53 (25)	
Literacy score, mean (8-item SF-REALM)	6.8 (0.8)	6.9 (1)	6.7 (1)	0.05
Health group				
Good	149 (35)	95 (46)	54 (25)	< 0.0001
Intermediate	150 (35)	68 (33)	81 (38)	
Poor	125 (30)	46 (22)	78 (37)	
General decision making preference	× /			
Prefers to make the decision alone	79 (19)	38 (18)	41 (19)	0.48
Prefers to make the decision with help from doctor	122 (29)	62 (30)	59 (28)	
Prefers to make the decision together with doctor	198 (47)	100 (48)	98 (46)	
Prefers that doctor make the decision with the participant's help	14 (3)	8 (4)	6 (3)	
Prefers that the doctor make the decision alone	10 (2)	1 (1)	9 (4)	
Colorectal cancer screening preference				
Prefers to get screened	221 (53)	134 (64)	87 (41)	< 0.001
Prefers NOT to get screened	113 (27)	42 (20)	71 (34)	
Unsure	87 (21)	33 (16)	53 (25)	
Received decision aid	212 (50)	122 (58)	89 (42)	< 0.001

SF-REALM, short form of the Rapid Estimate of Adult Literacy in Medicine.

discussion. Of the 209 participants with discussions, 201 had brief reports about their discussions (Table 1). Participants were aged 75.9 years on average. About 60% of participants were White and about 70% had at least some college education. Almost 50% preferred to make medical decisions together with their doctor, as opposed to either making the decision by themselves or letting the doctor make their decisions. After their discussions, 46% (n = 93) of participants intended to pursue screening, 21% (n = 42) intended to forgo screening, and 23% (n = 46) did not make a decision.

# Associations Between Patient Characteristics and Occurrence of CRC Screening Discussions

Among all 422 participants in the study, in bivariate analysis, health literacy, health state, CRC screening

preference, and receipt of the DA were associated with having a CRC screening discussion. Age was also associated, but as it is a component of health state, we did not include it in the final model. In multivariable logistic regression analysis, several factors had greater odds of having a CRC screening discussion, including participants who preferred to pursue screening (odds ratio [OR] 2.3, 95% confidence interval [CI] 1.3, 3.9), were in good health (OR 2.9, 95% CI 1.7, 4.8), and those who had received the DA (OR 2.1, 95% CI 1.4, 3.2).

# Associations Between Inappropriate CRC Screening Preferences and Discussions

Focusing on participants who 1) at baseline had inappropriate CRC screening preferences (i.e., had preferences that conflicted with the likelihood of benefit from screening) and 2) did not receive the DA, of those who *preferred to forgo screening but were likely to benefit*, having a discussion shifted 5 of 12 participants (42%) toward an intention to pursue screening. Of those who *preferred to pursue screening but were unlikely to benefit*, 5 of 14 participants (36%) who had discussions changed their minds and intended not to pursue screening.

# Domains of CRC Screening Discussions

We organized patient responses to each of the openended questions into two overarching domain categories: content and process domains (Table 2). We defined content domains as the information, facts, or issues that participants talked about as being important to the CRC screening discussion. The overarching content domain category included five domains: patient's medical history, CRC screening-related information, timing/frequency of screening, environmental constraints on ability to pursue CRC screening, and patients' values toward screening, each of which had multiple subdomains. Process domains were defined as "when participants spoke about how the discussion proceeded or the process by which a decision was made." We identified three process domains, each of which also had multiple subdomains: the *decision-making* roles of patients and providers, the communication format of the discussion or decision, and insufficient time to have a discussion. Overall, out of 201 participant responses, we found 252 mentions of one of the five content domains (mean of  $1.25 \pm 0.76$  per participant response) and 136 mentions of one of the three process domains (mean of  $0.68 \pm 0.52$  per participant response) (Table 3). More participants mentioned content domains than process domains: 172 participants (86%) mentioned one or more content domains (60 of whom mentioned only content domains) and 131 (65%) mentioned one or more process domains (19 of whom mentioned only process domains).

# Content Domains

Each content domain included at least two subdomains (Table 2). When discussing their *personal medical histories*, participants referenced their gastrointestinal histories, general medical problems, family history, and age and life expectancy. *CRC screening-related information* included six subdomains: CRC screening as part of general preventive care, CRC screening-related process issues, type of CRC screening discussed, risks and benefits of CRC screening, specific mention of using guide-lines or statistics, and need to wait for prior CRC screening results. Reports of *timing/frequency of* 

screening varied from the perception that they were upto-date with screening, to needing screening again based on a particular time interval, to being overdue for screening. *Environmental constraints* also arose in participants' reports of their discussions, primarily including financial and transportation issues. Last, participants talked about their *personal values* toward screening, both positive and negative.

Table 3 shows how often each type of content domain was reported. Ninety participants discussed the CRC screening-related information content domain, 72 participants discussed timing/frequency issues, and 70 participants discussed their personal medical history. Participants also reported discussing content inconsistent with current screening guidelines across multiple domains. Participants reported non-guideline-based age cutoffs and screening frequencies, as exemplified by the statement, "We discussed my age as a factor, that there's no need to repeat it after 70 if it's all normal, though you could repeat it every 10 years instead of every five." They also mentioned friends and other genetically unrelated family members with a history of colorectal cancer screening as important to their discussions, such as "I told my doctor I'd like a colonoscopy...

. My husband passed away from colon cancer." Last, they also reported discussions of symptoms as a reason for CRC screening, which demonstrated a lack of understanding of the difference between diagnostic work-up and screening.

# Association of Content Domains and Screening Intentions

Of the 172 participants who mentioned content domains, 51% intended to pursue CRC screening, 31% intended not to be screened, and 19% were unable to make a decision. In a bivariate analysis, individuals who mentioned any of the content domains had increased odds of intention to pursue screening compared to those who did not mention any content domain (OR 3.9, 95% CI 1.5, 10.1). Similarly, those who mentioned the *timing/frequency* subdomain had increased odds of intention to pursue screening compared to those screening compared to those screening compared to those who did not mention to pursue screening compared to those who did not mention to pursue screening compared to those who did not mention the *timing/frequency* subdomain (OR 14.5, 95% CI 7.0, 30.3).

#### **Process Domains**

The *decision-making role* domain was defined as "the person who made the CRC screening decision" and was mentioned by 63% of the 201 participants. The *communication process* domain, which included decisions made

# Table 2 Discussion Domains

# **Content Domains**

Domain	Define	Subdomains	Example
Personal Medical History	Factors specific to the individual, excluding CRC screening-specific information	Personal gastrointestinal history	The doctor and I decided to schedule the colonoscopy in case my GI
		General medical problems	symptoms didn't resolve. Due to my other health issues, this isn't a top priority at this time. I can have a colonoscopy if I want to.
		Age and life expectancy	The doctor said I'd aged out. It's no longer necessary.
		Family history	There's no family history of colon cancer so the procedure wasn't recommended, given my old age.
CRC Screening-related Information	Factors specific to the CRC screening context	General preventive care	The doctor ordered all of my health maintenance exams, including a referral for a colonoscopy
		CRC screening process	My doctor asked me how I felt about getting screened and accepted me when I said I'd had a bad reaction with the colonoscopy prep, so we decided not to get a colonoscopy
		Screening test type	I'm due for my next screening so I'll complete those stool cards.
		Risks and benefits	I discussed the risks and benefits with my doctor and we mutually decided
		Statistics and guidelines	to hold off for another year. The decision was based on research and current guidelines that recommend I not get screened.
		Waiting on prior screening results	We didn't make a decision yet because I need to check my records first, for the next colonoscopy.
Timing/Frequency	Timing factors about screening intervals or how often screening should occur	Up-to-date	The doctor said I was up-to-date so I don't need screening at this time.
		5-year interval	I had a colonoscopy in 2007 and was told to have one in 5 years and so the doctor recommended I schedule a colonoscopy
		10-year interval	The last time I was screened was 10 years ago.
		Other interval specified	The doctor reviewed my chart and it showed a 3-year recommendation and I last had one done in 2009.
		Overdue for screening	The doctor looked at my records and noticed I was overdue and gave me a referral to set up the appointment.
Environmental Constraints	Factors in a patient's environment perceived as important to their decision	Financial	The doctor recommended having a colonoscopy and I'd like to have it, but I can't for financial reasons.
		Transportation	We will schedule it at my next visit. I have some concerns with transportation I have to work out.
Personal Values	Participants' views/beliefs regarding CRC screening	Positive screening values	I told the doctor I was due, and so I decided to have screening done because it's the wise thing to do.
		Negative screening values	I have a family history of colon cancer but I choose not to look for problems.

(continued)

Table	2	(continued)
-------	---	-------------

Domain	Define	Subdomains	Example
Decision-making roles	Roles of the participant or provider in the decision making process	Participant made the decision with no mention of the provider	It was my decision. I don't think colon cancer screening is necessary.
		Participant made the decision with input from provider	The doctor asked if I wanted one, and I said no.
		Participant and provider made the decision together	The doctor and I came to the decision together.
		Provider made the decision with input from the participant	The doctor said I was due and so I gave tacit approval for the test.
		Provider made the decision with no mention of the participant	The doctor ordered all of my health maintenance exams, including a referral for a colonoscopy.
Communication Format	The process by which the decision was made	Letter	I received a letter from my doctor saying I was due for my next screening, and so I decided I wanted to get screened.
		Phone call	I was overdue for screening as I'd cancelled my last appointment. I'd planned for last year, so my doctor called and set up an appointment.
Insufficient Time to Make Decision	Insufficient time to complete the decision making process		The doctor and I didn't have a chance to finish talking about colon cancer screening.

CRC, colorectal cancer; GI, gastrointestinal.

via letters or telephone calls, was mentioned as part of the discussion by only three participants. Last, six participants mentioned having had insufficient time to make a decision.

Table 3 shows the distribution of process domains by the intention to screen. Forty-nine participants (24%) mentioned their physician in the screening decision, followed by 41 who mentioned themselves in the decision (20%), and 37 who mentioned a mutual decision process (18%). Those who mentioned their provider's role in the decision-making reported statements such as, "My doctor said that they don't recommend colonoscopies past the age of 75, unless there's a reason." Participants who mentioned the mutual process made statements such as, "The doctor and I considered that my father died of colon cancer and I'm less than 75 years old and I was last screened seven years ago."

# Association of Process Domains and Screening Intentions

Of those who mentioned process domains, 59 intended to pursue CRC screening, 49 intended to forgo screening, and 21 were unable to make a decision. Exploratory in nature, differences in intention to be screened emerged by decision-making role. Participants with any mention of a *decision-making role* had increased odds of intention to forgo CRC screening (OR 2.9, 95% CI 1.5, 5.9) as opposed to those with an intention to pursue screening or who did not make a decision. We also found that those that mentioned a mutual process had a slightly lower rate of intention to forgo screening than either participant-sided or provider-sided decision making, but this was not statistically significant (mutual: 10%, participant-sided: 32%, provider-sided: 23%). Those who mentioned provider-sided decision-making role less often made no decision than intended to pursue or forgo screening (13% as compared to 25% and 37%).

# Discussion

This study reports on the discussions with providers about CRC screening that took place among a diverse sample of older adults. In it, we explore the links between patient characteristics and patient-reported aspects of these discussions, and the links between the content and

Domain	Total (N = 201)	Intention to Be Screened (n = 93)	Intention to Not Be Screened (n = 62)	No Decision Made (n = 46)	<i>P</i> Value
Content domains					
Personal medical history	70	26 (28.0)	30 (48.4)	14 (30.4)	0.03
CRC screening-related information	90	42 (45.2)	29 (46.8)	19 (41.3)	0.85
Timing/frequency	72	60 (64.5)	10 (16.1)	2 (4.4)	< 0.01
Environmental constraints	4	1 (1.1)	2 (3.2)	1 (2.2)	0.64
Personal values	16	6 (6.5)	6 (9.7)	4 (8.7)	0.75
Total mentions	252	135	77	40	
Process domains					
Decision-making role					
Participant-sided	41	15 (16.1)	20 (32.3)	6 (13.0)	0.02
Mutual process	37	19 (20.4)	6 (9.7)	12 (26.1)	0.07
Provider-sided	49	23 (24.7)	23 (37.1)	3 (6.5)	< 0.01
Communication format	3	2 (2.2)	0 (0)	1 (2.2)	N/A
Insufficient time to make decision	6	0 (0)	0 (0)	6 (13.0)	N/A
Total mentions	136	59	49	21	,

Table 3 Distribution of Colorectal Cancer Screening Discussion Domains by Intent to be Screened, n (%).

CRC, colorectal cancer.

process of these discussions and screening intentions. Patient preference to pursue screening (as opposed to no preference or preference to forgo screening), self-reported good health state, and receipt of the DA were independently associated with having a CRC screening discussion. Content analysis of the discussions revealed that both the process and content of their discussions were important to patients' intentions. The CRC screeningrelated information domain was the most commonly mentioned content domain. Participants who mentioned timing/frequency of screening as part of the content of their discussion with providers were more likely to intend to pursue screening. Decision-making role, the most commonly mentioned process domain, was associated with increased odds of the intention to forgo CRC screening. Further work is needed to determine whether or not these findings may lead to potential paths to intervening on discussions and hopefully screening decisions. Knowing what happens during a discussion may provide opportunities to change those discussions.

# Associations Between Patient Characteristics and Screening Discussion Occurrence

One interesting characteristic associated with having a CRC screening discussion was patient baseline preference to pursue screening. Consistent with prior work in middle-aged adults, a preference to pursue screening also appears to increase discussions about screening in the over 70 age group.<sup>13</sup> Though exploratory in nature,

we reassuringly found that a discussion with their primary care provider shifted a number of patients toward appropriate final screening intentions. Our previous work found that 43% of 116 highly educated older adults would consider getting CRC screening even if their doctors recommended against it.<sup>29</sup> While we acknowledge that patient preferences matter and providers must elicit them,<sup>36</sup> trying to determine the root cause of those preferences may be even more important. If a patient fears that a decision to forgo CRC screening may cause a provider to withhold other potentially life-prolonging treatments, provider reassurance and support instead of potentially harmful testing without likelihood of benefit may be the better option than ongoing screening. A recent effort to increase CRC screening discussions found that a combined provider/patient-targeted intervention increased CRC screening discussions as opposed to a provider-only intervention or usual care.<sup>37</sup> Our RCT results will help determine if patient-targeted interventions improve individualized screening. Future work will need to examine how to best support older adults with inappropriate preferences and how individualized screening discussions may impact their trust or satisfaction with their physicians.

We were encouraged to find that good health state and receipt of a DA were both associated with having a discussion, a possible sign of individualized screening. The USPSTF encourages providers to individualize their discussions and to discuss screening services only when there is an expected net benefit.<sup>38</sup> Therefore, in the case of CRC screening for older adults, a discussion is warranted particularly for those in good health. However, physicians' abilities to appropriately assess likelihood of benefit and individualize recommendations is imperfect even in hypothetical situations.<sup>39</sup> A recent systematic review suggests that as decision-making difficulty increases, decision appropriateness decreases.<sup>40</sup> Given the importance of physician recommendations,<sup>13</sup> providers' appropriate recommendations may be useful, particularly when patients either prefer screening but are unlikely to benefit or prefer to forgo screening but are likely to benefit. Interestingly, in a recent pilot study among older adults within the Veterans Affairs system, a clinical decision support tool to improve providers' appropriate CRC screening recommendations helped shift three of six individuals in whom screening was likely to be beneficial but who initially did not want screening and three of four who were unlikely to benefit but initially wanted screening.<sup>41</sup> We also found that discussions shifted patients in a more appropriate direction. Our results appear to demonstrate that providers offer CRC screening discussions to those most likely to benefit and that discussions lead to more appropriate screening decisions. Future work will need to examine how to best support providers in their ongoing efforts to individualize screening discussions and recommendations.

# Domains of CRC Screening Discussions

Our analysis reveals a possible framework for conceptualizing CRC screening discussions in older adults and several avenues for improving the appropriateness of CRC screening decisions. While most of the domains we discovered have previously been reported in middle-aged adults in their 50s and 60s, no prior work has presented the detailed framework in older adults reported here. Other work in younger populations has shown provider recommendations,<sup>13</sup> family history,<sup>14</sup> and patient discomfort with the process<sup>7</sup> as important to the screening decision. We found these domains and more in our analysis. Similar to a small qualitative study of primary care providers' CRC screening discussions in adults of unknown ages,<sup>16</sup> we found older adults reported CRC screening-related information as the most commonly discussed content domain. Our finding that the timing/frequency domain was associated with intention to pursue screening may reflect a continuation of the universal screening paradigm of middle-aged adults. Additionally, many older adults favor shorter screening intervals than currently recommended.<sup>42</sup> Patients who discuss timing/ frequency may need more information on the rationale

behind timing/frequency and potentially a shift in discussion to other domains. Interestingly, when participants mentioned decision-making roles, they were less likely to be screened, perhaps due to a shift in the discussion away from the practicalities of screening toward a focus on more patient-centered care. While providers should obviously avoid coercion or manipulation of conversations that mislead patients,<sup>43</sup> it remains to be seen if a structured discussion process where providers deliver an individualized recommendation may improve appropriate, individualized care. Interventions to individualize decisionmaking and screening discussions may change the content or process of those discussions and may help improve the appropriateness of screening decisions.

# Limitations

Our ability to interpret the results of this study is limited because all data were obtained via patient self-report, which may be subject to recall or social desirability biases. Different domains may have emerged from direct observation of clinical encounters. We do not know the extent of discussions nor did we observe what was discussed during visits in which CRC screening did not arise. We did not ask about discussion again at later visits, when other discussions may have occurred. Our sample included more healthy patients, those who preferred CRC screening, and patients who received a DA, limiting generalizability. However, as previously stated, our domains are consistent with those previously reported. Given our aim to assess the breadth of discussions, we did not assess the degree of concordance between researchers and focused more on the insights gained from discussing coding disagreements and refining our coding frames.<sup>34</sup> Several of our analyses are exploratory in nature and should not be taken as the final word in this area of research. We were not powered to assess the effect of a discussion on the final screening intention, nor did we look at whether patients actually underwent screening. Last, none of these associations should be mistaken for causation.

# Conclusions

In sum, CRC screening discussions appeared to occur most often for those who preferred screening, healthier participants, and those who received a DA. Participants reported variation in both content and process aspects of their CRC screening discussions. Different domains are associated with different screening decisions. Future work is needed to determine how to enhance discussions to improve the appropriateness of CRC screening.

#### References

- US Preventive Services Task Force. Screening for colorectal cancer: US Preventive Services Task Force recommendation statement. *JAMA*. 2016;315(23):2564–75. doi: 10.1001/jama.2016.5989.
- Royce TJ, Hendrix LH, Stokes WA, Allen IM, Chen RC. Cancer screening rates in individuals with different life expectancies. *JAMA Intern Med.* 2014;174(10): 1558–65. doi:10.1001/jamainternmed.2014.3895.
- Walter LC, Covinsky KE. Cancer screening in elderly patients: a framework for individualized decision making. JAMA. 2001;285(21):2750–6.
- Breslau ES, Gorin SS, Edwards HM, Schonberg MA, Saiontz N, Walter LC. An individualized approach to cancer screening decisions in older adults: A multilevel framework. *J Gen Intern Med.* 2016;31(5):539–47. doi: 10.1007/s11606-016-3629-y.
- Tariman JD, Berry DL, Cochrane B, Doorenbos A, Schepp KG. Physician, patient, and contextual factors affecting treatment decisions in older adults with cancer and models of decision making: A literature review. *Oncol Nurs Forum*. 2012;39(1):E70–83. doi:10.1188/12.ONF .E70-E83.
- Beeker C, Kraft JM, Southwell BG, Jorgensen CM. Colorectal cancer screening in older men and women: Qualitative research findings and implications for intervention. *J Community Health.* 2000;25(3):263–78. doi:10.1023/a: 1005104406934.
- Chapple A, Ziebland S, Hewitson P, McPherson A. What affects the uptake of screening for bowel cancer using a faecal occult blood test (FOBt): A qualitative study. *Soc Sci Med.* 2008;66(12):2425–35. doi:10.1016/j.socscimed .2008.02.009.
- Dolan JG, Boohaker E, Allison J, Imperiale TF. Patients' preferences and priorities regarding colorectal cancer screening. *Med Decis Making*. 2013;33(1):59–70. doi: 10.1177/0272989X12453502.
- Imaeda A, Bender D, Fraenkel L. What is most important to patients when deciding about colorectal screening? J Gen Intern Med. 2010;25(7):688–93. doi: 10.1007/s11606-010-1318-9.
- Jepson RG, Hewison J, Thompson A, Weller D. Patient perspectives on information and choice in cancer screening: A qualitative study in the UK. *Soc Sci Med.* 2007;65(5): 890–9. doi:10.1016/j.socscimed.2007.04.009.
- Torke AM, Schwartz PH, Holtz LR, Montz K, Sachs GA. Older adults and forgoing cancer screening: "I think it would be strange." *JAMA Intern Med.* 2013;173(7):526–31. doi:10.1001/jamainternmed.2013.2903.
- Shokar NK, Carlson CA, Weller SC. Informed decision making changes test preferences for colorectal cancer screening in a diverse population. *Ann Fam Med.* 2010;8(2): 141–50. doi:10.1370/afm.1054.
- 13. van Dam L, Korfage IJ, Kuipers EJ, et al. What influences the decision to participate in colorectal cancer screening

with faecal occult blood testing and sigmoidoscopy? *Eur J Cancer*. 2013;49(10):2321–30. doi:10.1016/j.ejca.2013.03 .007.

- Feeley TH, Cooper J, Foels T, Mahoney MC. Efficacy expectations for colorectal cancer screening in primary care: identifying barriers and facilitators for patients and clinicians. *Health Commun.* 2009;24(4):304–15. doi:10.1080/ 10410230902889241.
- Wolf AM, Schorling JB. Does informed consent alter elderly patients' preferences for colorectal cancer screening? Results of a randomized trial. J Gen Intern Med. 2000;15(1):24–30.
- Wackerbarth SB, Tarasenko YN, Joyce JM, Haist SA. Physician colorectal cancer screening recommendations: An examination based on informed decision making. *Patient Educ Couns.* 2007;66(1):43–50. doi:10.1016/j.pec.2006.10.003.
- Wee CC, McCarthy EP, Phillips RS. Factors associated with colon cancer screening: The role of patient factors and physician counseling. *Prev Med.* 2005;41(1):23–9. doi: 10.1016/j.ypmed.2004.11.004.
- McQueen A, Bartholomew LK, Greisinger AJ, et al. Behind closed doors: Physician-patient discussions about colorectal cancer screening. *J Gen Intern Med.* 2009;24(11): 1228–35. doi:10.1007/s11606-009-1108-4.
- Berkowitz Z, Hawkins NA, Peipins LA, White MC, Nadel MR. Beliefs, risk perceptions, and gaps in knowledge as barriers to colorectal cancer screening in older adults. *J Am Geriatr Soc.* 2008;56(2):307–14. doi:10.1111/j.1532-5415.2007.01547.x.
- Gurmankin AD, Baron J, Hershey JC, Ubel PA. The role of physicians' recommendations in medical treatment decisions. *Med Decis Making*. 2002;22(3):262–71. doi: 10.1177/0272989x0202200314.
- Kistler CE, Golin C, Morris C, et al. Design of a randomized clinical trial of a colorectal cancer screening decision aid to promote appropriate screening in communitydwelling older adults. *Clin Trials*. 2017;14(6):648–58. doi: 10.1177/1740774517725289.
- Winawer SJ, Zauber AG, Fletcher RH, et al. Guidelines for colonoscopy surveillance after polypectomy: A consensus update by the US Multi-Society Task Force on Colorectal Cancer and the American Cancer Society. *Gastroenterology*. 2006;130(6):1872–85. doi:10.1053/j.gastro.2006.03.012.
- Atkin WS, Morson BC, Cuzick J. Long-term risk of colorectal cancer after excision of rectosigmoid adenomas. *N Engl J Med.* 1992;326(10):658–62. doi:10.1056/NEJM19 9203053261002.
- 24. Katz JN, Chang LC, Sangha O, Fossel AH, Bates DW. Can comorbidity be measured by questionnaire rather than medical record review? *Med Care*. 1996;34(1):73–84.
- Callahan CM, Unverzagt FW, Hui SL, Perkins AJ, Hendrie HC. Six-item screener to identify cognitive impairment among potential subjects for clinical research. *Med Care*. 2002;40(9):771–81. doi:10.1097/01.MLR.0000024610.33213 .C8.

- Arozullah AM, Yarnold PR, Bennett CL, et al. Development and validation of a short-form, rapid estimate of adult literacy in medicine. *Med Care*. 2007;45(11):1026–33.
- Schaubert KL, Bohannon RW. Reliability and validity of three strength measures obtained from communitydwelling elderly persons. *J Strength Cond Res.* 2005;19(3): 717–20. doi:10.1519/R-15954.1.
- Degner LF, Sloan JA. Decision making during serious illness: What role do patients really want to play? *J Clin Epidemiol*. 1992;45(9):941–50.
- Lewis CL, Kistler CE, Amick HR, et al. Older adults' attitudes about continuing cancer screening later in life: A pilot study interviewing residents of two continuing care communities. *BMC Geriatr.* 2006;6:10. doi:10.1186/1471-2318-6-10.
- Kistler CE, Lewis CL, Amick HR, Bynum DL, Walter LC, Watson LC. Older adults' beliefs about physician-estimated life expectancy: A cross-sectional survey. *BMC Fam Pract*. 2006;7:9. doi:10.1186/1471-2296-7-9.
- Grbich C. Qualitative Data Analysis: An Introduction. Thousand Oaks, CA: Sage; 2007.
- 32. Bradley EH, Curry LA, Devers KJ. Qualitative data analysis for health services research: Developing taxonomy, themes, and theory. *Health Serv Res.* 2007;42(4):1758–72. doi:10.1111/j.1475-6773.2006.00684.x.
- Hsieh HF, Shannon SE. Three approaches to qualitative content analysis. *Qual Health Res.* 2005;15(9):1277–88. doi: 10.1177/1049732305276687.
- Barbour RS. Checklists for improving rigour in qualitative research: A case of the tail wagging the dog? *BMJ*. 2001;322(7294):1115–7.
- Morgan DL. Qualitative content analysis: A guide to paths not taken. *Qual Health Res.* 1993;3(1):112–21. doi: 10.1177/104973239300300107.
- Mulley AG, Trimble C, Elwyn G. Stop the silent misdiagnosis: Patients' preferences matter. *BMJ*. 2012;345. doi: 10.1136/bmj.e6572.

- Dolan NC, Ramirez-Zohfeld V, Rademaker AW, et al. The effectiveness of a physician-only and physician-patient intervention on colorectal cancer screening discussions between providers and African American and Latino patients. J Gen Intern Med. 2015;30(12):1780–7. doi: 10.1007/s11606-015-3381-8.
- Sheridan SL, Harris RP, Woolf SH; Shared Decision-Making Workgroup of the USPSTF. Shared decision making about screening and chemoprevention. A suggested approach from the U.S. Preventive Services Task Force. *Am J Prev Med.* 2004;26(1):56–66.
- Dalton AF, Golin CE, Esserman D, Pignone MP, Pathman DE, Lewis CL. Relationship between physicians' uncertainty about clinical assessments and patient-centered recommendations for colorectal cancer screening in the elderly. *Med Decis Making*. 2015;35(4):458–66. doi: 10.1177/0272989x15572828.
- McCleary N, Ramsay CR, Francis JJ, Campbell MK, Allan J. Perceived difficulty and appropriateness of decision making by general practitioners: A systematic review of scenario studies. *BMC Health Serv Res.* 2014;14:621. doi:10.1186/s12913-014-0621-2.
- Schwartz AR, Levin FL, O'Neil JJ, Braithwaite RS. Pilot of decision support to individualize colorectal cancer screening recommendations. *Am J Manag Care*. 2015; 21(7):e439–46.
- Kistler CE, Hess TM, Howard K, et al. Older adults' preferences for colorectal cancer-screening test attributes and test choice. *Patient Prefer Adherence*. 2015;9:1005–16. doi: 10.2147/PPA.S82203.
- Reach G. Patient education, nudge, and manipulation: Defining the ethical conditions of the person-centered model of care. *Patient Prefer Adherence*. 2016;10:459–68. doi:10.2147/PPA.S99627.