



Qualitative Analysis of Colorectal Cancer Screening in Rural Nebraska

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Abstract

Compared to urban residents, rural populations are less likely to engage in colorectal cancer (CRC) screening. As part of a statewide cancer needs assessment, we aimed to elicit rural perspectives about CRC screening and resources. We conducted three focus groups with rural Nebraska cancer survivors and caregivers ($N=20$) in Spring 2021 using a collective case study design. Participant awareness of and knowledge about CRC screening methods varied across focus groups; overall, 95% of participants had heard of colonoscopy. Participants were less familiar with fecal tests and had confusion about them. Colonoscopy was associated with negative perceptions regarding the time, cost, and discomfort of the preparation and procedure, but some providers did not discuss alternative methods unless the patient resisted colonoscopy. Healthcare providers played a key role educating rural communities about CRC screening recommendations (age, risk) and testing options and being persistent in those recommendations. CRC awareness campaigns should include a variety of communication channels (TV, radio, billboards, health fairs, churches, healthcare settings). Promotion of CRC screening should include education about screening age guidelines, alternative test types, and informed decision-making between provider and patient regarding preferred screening methods based on the pros and cons of each test type. Individuals with a family history of colon issues (Crohn's disease, CRC) are considered high risk and need to be aware that screening should be discussed at earlier ages.

Keywords Cancer screening · Colorectal cancer · Focus group · Qualitative analysis · Rural health

Introduction

Cancer services are underused by rural residents in the United States (US) [1]. Rural residents often need to travel long distances to obtain cancer screening, diagnostic services, and treatment, and weather-associated road conditions and lack of public transportation may further impede care [2]. Additionally, healthcare accessibility, especially specialized cancer care, is aggravated by low socioeconomic status

and lack of health insurance [1]. Such accessibility issues are associated with adverse cancer outcomes for rural compared to urban residents, including later stage of diagnosis and higher mortality rates [1] and poorer quality of life [3]. A US cancer registry study showed that incidence rates of cervical, lung, and colorectal cancer (CRC) were significantly higher among rural residents [4]. Furthermore, a study of Medicare recipients found that rural versus urban cancer patients had worse health-related quality of life including poorer vitality for CRC patients [3].

CRC is a major health concern in the US, with approximately 150,000 people newly diagnosed and 50,000 deaths in 2021. It is ranked third among cancers for new diagnoses and second leading cause of deaths [5]. CRC screening measures can reduce the incidence of CRC by identifying (and removing during endoscopy exams) pre-cancerous polyps. Screening can also identify cancer in earlier stages when it is more treatable and individuals have better survival rates. Therefore, screening plays an important role in state and national cancer prevention and control efforts.

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In May 2021, the US Preventive Services Task Force (USPSTF) released the final CRC screening recommendation statement, extending recommended screening to ages 45–49 for those at normal risk and maintaining screening recommendations for ages 50–75. Screening for age 76–85 is not generally recommended but may be determined on a case-by-case basis. The recommended screening intervals depend on the screening method: high sensitivity guaiac fecal occult blood tests (HSg FOBT) or fecal immunochemical test (FIT) every year, stool DNA-FIT every 1 to 3 years, computed tomography (CT) colonography every 5 years, flexible sigmoidoscopy every 5 years, flexible sigmoidoscopy every 10 years plus annual FIT, or colonoscopy every 10 years [6].

Odds of CRC screening are lower for rural vs. urban residents [7]. In Nebraska, rural primary care patients were less likely to be up-to-date on CRC screening than their urban counterparts (74.4% vs. 88.1%) and colonoscopy use in the past 10 years was significantly lower among rural patients (71.9% vs. 87.5%) [8]. However, rural–urban difference in the use of FOBT was not statistically significant (rural: 12.4%; urban: 7.5%) [8]. Moreover, results showed several misconceptions are present regarding CRC screening: a lower proportion of rural patients stated that they can prevent themselves from getting CRC (41.3% vs. 55.8%); they would live no longer than 5 years with CRC (8.2% vs. 15.5%); and CRC screening costs too much (34.7% vs. 18.0%) [8].

As part of a statewide cancer needs assessment, team members at the University of Nebraska Medical Center (UNMC) collaborated with the Nebraska Comprehensive Cancer Control Program (NECCCP), Nebraska Cancer Coalition (NC2), and four rural cancer centers to conduct focus groups with cancer survivors and caregivers to learn about CRC screening. A person is considered a cancer survivor from the time of diagnosis, regardless of whether the person is actively receiving treatment, so we used the terms patient and survivor somewhat interchangeably. Because survivorship care is an integral component of cancer care, often with increased contact with the health care profession for continued monitoring of cancer status, treatment, and long-term side effects, we were interested in learning more about cancer survivors' and caregivers' experiences and perceptions about CRC screening. We assumed that this population of cancer survivors and caregivers might be better informed than the general population on the topic. Prior focus group studies have focused on cost, fears, attitudes, and beliefs associated with CRC screening [9, 10]. Our questions were as follows: (1) What factors impact CRC screening in rural communities? and (2) What are suggested strategies to improve CRC screening in rural communities?

Methods

The UNMC Institutional Review Board deemed this qualitative collective case study [11] non-human subjects research as part of an institutional needs assessment. Prior to the beginning of each focus group, the purpose of the group was reviewed along with how information would be shared and the rationale for recording the session.

Team

The female assessment team consisted of cancer epidemiologists (KLR, SWG), a qualitative researcher (DD), public health students (JR, KN), a community outreach program coordinator (LBL), and cancer program administrators (TR, LS). Three members were present at each focus group filling the roles of facilitator (KLR), polling (JR, LBL), and notetaker (SWG, LBL, KN). Prior to initiating data collection, we held two practice sessions with public health students.

Setting

Cancer centers were located in central and western Nebraska counties classified 3–5 on the Rural–Urban Continuum Code, in cities with populations ranging from 25,000 to 51,000 and serving small outlying communities. Data collection occurred between February and May 2021. All focus groups were held virtually due to COVID-19 restrictions.

Recruitment and Eligibility

Cancer center staff distributed recruitment flyers at clinic appointments and support groups and posted copies in lobbies. The flyer stated the study purpose, topics, eligibility criteria (30 years and older, cancer patient/survivor or cancer caregiver, and Nebraska resident), and compensation (\$40 gift card). Age 30 is outside the screening guidelines but encompass adults who may be caring for aging family members. The flyer contained assessment team contact information; later versions also had a QR code and web address for a screening survey administered through REDCap (Research Electronic Data Capture). The survey included age and residence screening questions to confirm eligibility and collected name, contact information, and general availability for the focus group. A team member contacted potential participants who had completed the survey to schedule the focus groups and to offer Zoom tutorials for any who were unfamiliar with the technology.

Procedure

Zoom is a cloud-based video conferencing platform accessible via computer or a free app. It also allows phone call-in. Zoom enables pre-built polling questions with point-and-click response. Sessions lasted 75 to 90 min and had 6–8 participants per group. Sessions were audio and video recorded and included built-in poll questions. In two instances, a survivor/caregiver dyad participated using one device. In those situations, poll responses were electronically captured for one participant and verbally reported for the other. Participants were instructed to keep their cameras on throughout the session. At the conclusion, participants were encouraged to contact the team if they had any questions or concerns. Gift cards were mailed within 2 weeks of the session.

Facilitation Guide

Team members (KLR, SWG, JR) and NECCP set the scope and general content of the facilitation guide, which was then modeled on a health needs assessment [12], with editing input solicited from the participating cancer centers. The guide attempted to balance participant engagement with time constraints. It was divided into two main sections plus a short conclusion: (1) general cancer experiences (general community health status, cancer diagnosis and treatment, and sources of cancer-related information) which is reported elsewhere [13] and (2) CRC screening (Online Resource 1). The guide included open-ended discussion questions, prompts, and probes with some marked as “time permitting.”

Coding and Analysis

A professional transcription service created verbatim transcripts from the audio recordings, which were reviewed by the team for accuracy. Analysis was based on a directed content analysis approach [14] with several processes implemented to ensure data validity and trustworthiness [15]. We maintained Word documents (transcripts, annotations, codebook, meeting notes) with editing software (track changes, comments) saved to a shared file repository that tracks document edits to serve as an audit trail for dependability and confirmability. SWG deductively developed broad initial codes from the guide and reviewed them with KLR. They served as primary reviewers and independently handled initial coding and analysis, inductively adding subthemes and reconciling differences across multiple rounds of review to develop a codebook, which was used for analysis of remaining transcripts. Subthemes were added when content did not fit into existing codes to ensure data saturation. Triangulation was achieved via regular check-in with the extended team for credibility and to ensure alignment. Thick description was used to contextualize the findings for transferability.

Results

Seven of the 27 people who completed the screening did not participate, including a physician testing the registration process before sharing flyers with patients, three individuals who were unresponsive to multiple contact attempts, one with a scheduling conflict, and two no-shows. Of the 20 participants, most ($n = 16$) self-identified as survivors, one of whom reported dual roles (survivor and caregiver), and the remaining 4 were caregivers. Two sessions included spousal dyads in which one spouse cared for the other. In such cases, the type of cancer was reported only for the survivor. Participants indicated the following cancer diagnoses: bladder, breast, lung, lymphoma, multiple myeloma, and prostate (Table 1).

Participants had many thoughts about factors impacting CRC screening. Most focused on negative aspects or barriers, although some also identified factors that promote screening. These factors were grouped into the following themes: information and awareness, role of healthcare providers, perception and attitude, and test-specific factors (Table 2). Participants also provided suggestions to improve messaging and CRC screening uptake. Based on the poll results and participant discussion, health education about CRC varied geographically in terms of testing types and level of awareness (Fig. 1).

Information and Awareness

Information and awareness primarily centered on screening knowledge—guidelines, tests, and sources of information

Table 1 Focus group participant characteristics

	Total ($n = 20$)	FG #1 ($n = 8$)	FG #2 ($n = 6$)	FG #3 ($n = 6$)
Gender				
Female	16	7	5	4
Male	4	1	1	2
Role*				
Patient/survivor	16	7	5	4
Caregiver	5	2	1	2
Cancer type*				
Breast	11	7	1	3
Lung	2	1	1	
Bladder	1	1		
Multiple myeloma	2		2	
Lymphoma	2		1	1
Prostate	1			1

*Participants could indicate multiple responses for roles and cancer types

Table 2 Themes, subthemes, and example quotations

Themes and subthemes	Quotation
<i>Information and awareness</i>	
Knowledge of screening guidelines	<ul style="list-style-type: none"> • You don't hear about that you should, it's not, you know now you hear about mammograms and stuff all the time, but out there [in Omaha] you didn't hear about that nearly as much as out here. (FG1, female, survivor, breast cancer) • I have been keenly aware about mammograms and that sort of thing, but I haven't really seen much of anything on colorectal for instance. (FG1, female, survivor, breast cancer) • "I'm assuming the older population are having their providers suggest for them to do that as part of their routine doctor visits, but I don't think that people in their 40's or 50's are aware of when that is supposed to happen." (FG1, female, survivor, breast cancer) • My dad died of metastasized colon cancer and I think at least two of his brothers did too... He specifically said, I will tell all you children if you can even go sooner than 50; do it as soon as you get through this. All of us have had a colonoscopy done, as he was very adamant about it and I am very religiously keeping up with that. (FG1, female, survivor, breast cancer) • My husband does have a family history of colorectal cancer, so he made sure he got his screening done. (FG2, female, survivor, multiple myeloma) • I've heard of it, I guess, but that's about it. (FG3, male, survivor, lymphoma; sister is CRC survivor)
Knowledge of screening tests	<ul style="list-style-type: none"> • All I've heard of is the colonoscopy, quite honestly, and just now that they have come out with that Cologuard on TV. (FG1, female, survivor, breast cancer) • I've never done [CRC screening] and I would choose probably to do the colonoscopy with my family history. (FG1, female, survivor, breast cancer) • Which one of these would be the Cologuard? (FG3, male, survivor, prostate cancer) • FOBT...I think that is just like the little cards. I'm a nurse too. And there are the little cards that you just check for blood, but I'm not sure about the Cologuard, which one. (FG3, female, survivor, breast cancer) • It's kind of nice to work with someone that actually does [information meetings about Cologuard] on the side as well as the people that work in the clinic, but she is pretty good at explaining everything about it. I went to one of her meetings and it was very informational. (FG3, female, survivor, breast cancer) • I know that my mom, I think her oncologist brought it up to her about the Cologuard since she hadn't had a colonoscopy yet and I imagine it was because she did not want a colonoscopy is why it was brought up, but I kind of talked her into doing a colonoscopy instead, just because I had heard of a few patients that had done Cologuard and had had colon cancer and I didn't want to have to worry about that. (FG3, female, caregiver, breast cancer)
Sources of CRC and CRC screening information	<ul style="list-style-type: none"> • A lot of your TV celebrities are talking about it on the morning show like Al Roker and all the guys that are promoting, what cancer month is it, whatever, they talk about it so when more famous people are talking about it, I think it brings people more aware (FG1, female, survivor, breast cancer; caregiver, lung cancer) • TV with their advertising and a lot of that and then the physicians. I mean being in the cancer center, you know you hear about that, but that's exactly what I was thinking is that the celebrities are now coming and saying Hey, I went and had this test done and it's super easy or you know I was diagnosed with this, I think that is really helping the word get out (FG1, female, survivor, breast cancer) • I've never see any like information at a clinic for that. There is a lot of prenatal stuff and you know where we go is a family practice and they deliver babies and stuff there, but I've never really noticed anything in our doctor's office for that screening at all (FG1, female, survivor, breast cancer) • My annual physical and even during my physical exams; but usually just in general, when I go to my annual checkup at my primary care physician (FG2, female, caregiver, breast cancer; caregiver, lung cancer)

about CRC and CRC screening. Some participants had a general lack of awareness about CRC, indicating that "it's something that nobody likes to talk about," although many participants knew someone who had CRC, including

family and community members. Discussion also revealed misinformation about CRC, reflecting a misunderstanding of risk factors and the relationship between CRC and other types of cancer.

Table 2 (continued)

Themes and subthemes	Quotation
<i>Role of healthcare providers</i>	
Recommending screening	<ul style="list-style-type: none"> • When they tell me to do it, I will probably do it (FG1, female, survivor, breast cancer) • When I turned 50, I mean there was not an option; you will go have this done and he is a wonderful doctor... He is not mean or anything, but this needs to be done and I have had it done every—well they notify me when I am up for my next one and I have just always had it done. (FG1, male, caregiver, breast cancer) • I think a lot of it is the doctors, too. I used to go to a doctor that he never, honestly never mentioned colonoscopy, shingles shot, nothing. Nothing preventative. He never mentioned it. I went to a new doctor and first thing he did was schedule a colonoscopy and a shingles shot. You know, all of the preventative stuff. (FG1, female, survivor, breast cancer) • Primary care physician also and then also my oncologist keeps track to be sure that I keep coming back for them. (FG2, female, survivor, MALT lymphoma) • Primary care during my annual or the oncologist. (FG2, female, survivor, multiple myeloma) • Primary care and now that I'm past 75, I don't have to worry about it. One perk of getting older. No colonoscopy. (FG2, male, survivor, lung cancer) • Mom was like 65 before she got her first colonoscopy and that was only because I persisted and that was after her cancer diagnosis. She told me, and I don't know how true this is, but she told me her primary care physician never brought it up to her so she didn't think it was necessary. (FG3, female, caregiver, breast cancer) • I've only ever had one colonoscopy and that was when I was 55. I really don't know why. It really wasn't brought up much after that (FG3, male, survivor, prostate cancer) • I'm over 45, but I am actually after all of my radiation and starting the med, I have a consult for a colonoscopy already set up and scheduled, but I haven't had one yet. (FG3, female, survivor, breast cancer) • There are a lot of colon problems in our family, so they thought it was probably a good idea. I don't prefer to have one to be honest with you, but my physician keeps harping on me about it so now I have a consult which is good, I guess. (FG3, female, survivor, breast cancer) • [PCP] kind of harassed me until I finally said okay, I'll get one. (FG3, female, survivor, breast cancer)
Educating about screening options	<ul style="list-style-type: none"> • I was just recommended to get [colonoscopy]. If there were other options, the doctor didn't mention any. That was just kind of standard procedure at the time so that was the route that we went. (FG3, male, survivor, prostate cancer) • I didn't want to do another colonoscopy. So we went that route instead [he asked his doctor about Cologuard] (FG3, male, survivor, prostate cancer)

Knowledge of Screening Guidelines

Although a few participants knew CRC screening should begin at age 50, most did not. They reported a general lack of knowledge about screening guidelines. One participant thought rural areas may have more people who lack awareness of the need for CRC screening. Multiple participants made unfavorable comparisons between CRC and breast cancer screening awareness, with comments such as “You don't hear about that you should. It's not...[like] mammograms.” Interestingly, participants with a family history of colon problems (CRC, Crohn's disease) were more familiar with CRC and colonoscopy but some were still misinformed. For example, a male survivor in his 30 s indicated that he had a family history of CRC and said it's “probably something in...future to get screened for” but he was unaware that he should begin screening before the general age guidelines

due to his family history risk. In contrast, others with a family history were more knowledgeable and made sure to get screened.

Knowledge of Screening Tests

Based on polling, only one participant was unfamiliar with any type of CRC screening test. All others knew about colonoscopies. Several participants expressed unfamiliarity with options other than a colonoscopy, and there was confusion about fecal tests. Multiple participants specifically mentioned Cologuard, which is the only Food and Drug Administration-approved stool DNA screening test for CRC currently available in the US market. Despite name recognition, they did not know how to classify Cologuard for the poll. They knew it was an at-home stool test but did not identify it with DNA testing. Thus,

Table 2 (continued)

Themes and subthemes	Quotation
<i>Perception and attitude</i>	<ul style="list-style-type: none"> • “It is an old person disease.” (FG1, female, survivor, breast cancer; caregiver, lung cancer) • People think it’s a joke, it’s an old man disease. (FG1, female, survivor, breast cancer; caregiver, lung cancer) • I think you’re right. I think people do think it is an old person’s thing. You don’t want to do it. (FG1, female, survivor, breast cancer) • I know that the screening is important because you know most of the time, like you say, it’s a joke and then when they find out, then it’s fatal, I mean it’s done. (FG1, female, survivor, breast cancer) • As a big joke, I think a lot of people laugh about it, but I think they’re scared about it and they don’t want to do it. (FG1, female, survivor, breast cancer; caregiver, lung cancer) • Uninformed ignorance. I mean, to make a joke out of something like that is so ridiculous and so childish, but that is what I hear all the time and you know, I don’t know how to present that differently, but probably does need to be presently differently somehow (FG1, female, survivor, breast cancer) • Just a general reluctance of people to say ‘I’m fine.’ Especially guys; we have this thing, no matter what it is; it’s going to be fine. It’s a guy thing (FG2, male, survivor, lung cancer) • Those of us of a certain generation grew up on this popular meme on Facebook right now. I died once when I was five-years old. Mom said walk it off. That is the way it was in our generation, you know? You didn’t think about these things. (FG2, male, survivor, lung cancer) • Just a general reluctance of certain age groups to subject themselves to medical procedures. I’m just speaking for especially guys; speaking from a guy’s standpoint. We are just kind of stubborn that way. (FG2, male, survivor, lung cancer) • Oh it’s probably not a risk for me so I don’t know if I need to be screened and I’ll get it later kind of a thing. (FG2, female, survivor, multiple myeloma) • Men are not as apt to do it as probably females are. They just don’t think they have the time or it’s not going to happen to them. (FG2, female, survivor, multiple myeloma)
<i>Test-specific factors</i> Colonoscopy	<ul style="list-style-type: none"> • So many horror stories about the laxatives you have to take to get yourself cleaned out so you can have the procedure the next day (FG1, female, survivor, breast cancer; caregiver, lung cancer) • I think a lot of people say ‘I don’t want to take that medicine, I don’t want to have to poop, poop, poop and go and have this done’ (FG1, female, survivor, breast cancer; caregiver, lung cancer) • Quite frankly the comments that I hear, I don’t want to go in and have any doctor playing with my butt and I’m glad I’m asleep so I don’t hear them talk about you know and all that stuff (FG1, female, survivor, breast cancer) • Invasive procedure, I mean a colonoscopy requires you to go into the hospital for the procedure. I find there are a lot of people who financially can’t afford it. Even with insurance, your copays, you can go in and come out with a pretty hefty bill (FG2, male, survivor, lung cancer) • the prep. When you have to go through all of that prep (FG2, female, survivor, MALT lymphoma) • That was my comment too was the horror stories about the prep and just the inconvenience in having a day or two of discomfort before, during and the time of being busy. (FG2, female, caregiver, breast cancer; caregiver, lung cancer) • I didn’t get screened as soon as recommended and part of that was a time issue, probably that prep that was talked about. (FG2, female, survivor, multiple myeloma) • A lot of people are just scared of having their routine colonoscopies done. I mean it’s something that nobody likes to talk about and the bowel prep is unpleasant, just in being a nurse; that is what patients have discussed in the past. (FG3, female, caregiver, lymphoma) • Uncomfortable and some people think it is an embarrassing situation. (FG3, female, caregiver, lymphoma)

Table 2 (continued)

Themes and subthemes	Quotation
Fecal tests	<ul style="list-style-type: none"> ● I did the Cologuard test this year instead of the colonoscopy and you know, it's so much easier. I kind of wondered if it was really going to be as accurate, but they say that it is pretty accurate (FG1, female, survivor, bladder cancer) ● According to the television commercial, I mean it's 90% effective, is what it is so that is the route I decided to go then (FG3, male, survivor, prostate cancer) ● Convenience of the Cologuard because they're at home and it is more private than first being at the hospital you know outpatient to have that done (FG3, female, survivor, breast cancer)
<i>Suggestions to improve CRC screening</i>	
Increasing awareness	<ul style="list-style-type: none"> ● If you're sitting in their waiting room for 15 or 20 min for him to come in there, it gives you something to read and it's beneficial and it might turn on some lightbulbs for a lot of people. (FG1, female, survivor, breast cancer) ● I think we are the same thing like in the offices and stuff... I mean the same places where they will promote like the prenatal classes or the diabetes classes or those types of health management type things, I think if there was maybe some more information, like she said, hey, do you know this, kind of a thing out with things that people would maybe start picking it up. (FG1, female, survivor, breast cancer) ● I don't think I would in a waiting room in the clinic, I don't think I would go look at the brochures. I would look at them once I get into the doctor's office and I'm waiting for him. (FG1, female, survivor, breast cancer) ● At the cancer center, and at the Women's Healing Center, physical therapy places, they do what is called stall stories. (FG1, female, survivor, breast cancer) ● There is no more Relay For Life, but I thought that was really a good opportunity to get people to talk about this, a mini-health fair inside that, but I think it is, you really need to have a person who has it to talk to another person. (FG1, female, survivor, breast cancer; caregiver, lung cancer) ● Target the media that people of the targeted age that you want to reach, if you could figure out if that's radio or, I know you can figure it out. I'm a radio listener. I don't do much TV... maybe a blitz of it. (FG2, female, survivor, multiple myeloma) ● I think colon cancer has its own month dedicated to it. There are a lot of billboards that would be accessible; people drive by through the middle of town that they could visually see every day or just giving flyers to physician clinics to hand out to their people on a day-to-day basis throughout that month. (FG3, female, caregiver, lymphoma)
Messaging	<ul style="list-style-type: none"> ● I think it is the public perception of the whole thing that somehow needs to be addressed on, I don't know, on a mature level... it somehow needs to be addressed differently in the serious manner because it is a very serious thing and it needs to be addressed as such, but I really have no idea how to do that (FG1, female, survivor, breast cancer) ● Take the sexual connotation out of everything... how we remove that from it, I don't know (FG1, female, survivor, breast cancer) ● To re-educate about the better programs, the better tests and strategies to prepare for the test and maybe better information about that so it's not such a feared situation. (FG2, female, caregiver, breast cancer; caregiver, lung cancer) ● A little more awareness like they do for...breast cancer, mammograms, like maybe dedicate a month you know? Fliers up in offices or dedicate a month awareness so it's time to get your colonoscopy; do it on your birthday, that's kind of a good way to do it you know, give yourself that birthday present so that you have time for family and grandkids and all of that good stuff in your retirement age. (FG2, female, survivor, multiple myeloma) ● Perhaps that there are some other options other than that GoLytyly prep...it was much easier tolerated than the GoLytyly. (FG3, female, caregiver, breast cancer)

Table 2 (continued)

Themes and subthemes	Quotation
General community needs	<ul style="list-style-type: none"> • A lot of this is preventative and a lot of insurance doesn't like to pay for stuff like this so I think a lot of people who may not have great insurance or don't have insurance, don't have some of these tests done so I think money is the other key factor as to why people don't get tested for certain things (FG1, female, survivor, breast cancer; caregiver, lung cancer) • Our community needs to work with is the other cultures and let them be aware this can happen to them (FG1, female, survivor, breast cancer; caregiver, lung cancer) • Access to information that just told you just this type of cancer, this is the age and time that you should be, you know, checking into it because some people, I mean, don't even see a primary care physician routinely until they get older (FG1, female, survivor, breast cancer) • We need to get that information to the different, I don't know if it's churches...stores of the different ethnic groups and stuff (FG1, female, survivor, breast cancer) • Our different cultures and our different language is a big road block (FG1, female, survivor, breast cancer; caregiver, lung cancer) • Get a doctor who is bilingual who has an office down there and can talk to people and make it an open clinic type. (FG1, female, survivor, breast cancer; caregiver, lung cancer) • I don't know if it is just for dentists like once or twice a year, they go to, I think it's Lincoln, and they will do work for nothing on people who can't afford it. (FG1, female, survivor, breast cancer) • Finances...some of those things [nurse navigation, grocery and gas assistance] need to be maybe expanded a little bit and make sure that people know how to connect with them a little more because that was hard, you know? (FG1, female, survivor, breast cancer)

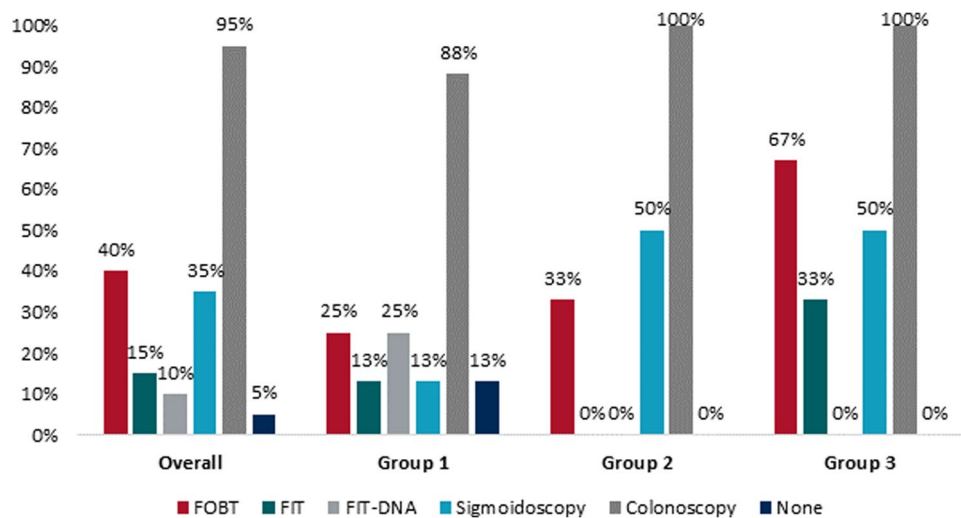


Fig. 1 Colorectal cancer screening tests recognized by participants. Note: participants could select multiple responses. Descriptive caption for accessibility: Image of vertical bar chart representing percent of participants who had heard of each type of colorectal cancer screening test, grouped by focus group. Overall: FOBT=40%, FIT=15%, FIT-DNA=10%, sigmoidoscopy=35%, colonos-

copy=95%, none=5%; group 1: FOBT=25%, FIT=13%, FIT-DNA=25%, sigmoidoscopy=13%, colonoscopy=88%, none=13%; group 2: FOBT=33%, FIT=0%, FIT-DNA=0%, sigmoidoscopy=50%, colonoscopy=100%, none=0%; group 3: FOBT=67%, FIT=33%, FIT-DNA=0%, sigmoidoscopy=50%, colonoscopy=100%, none=0%

the poll results reflected misclassification as FOBT or FIT. Participants were also uncertain about the accuracy of stool-based tests, although one older male started using Cologuard after he heard it was highly accurate.

Sources of Screening Information

Participants primarily received information about CRC screening from primary care physicians (PCP) and their

local cancer center. Others worked in healthcare settings and received information about screening tests at work. In addition to TV ads, some participants had heard TV celebrities such as Al Roker talk about CRC during CRC Awareness Month. Others did not know there was a month dedicated to CRC awareness and suggested creating one to promote awareness.

Role of healthcare providers

Healthcare providers appeared to play a key role in educating rural communities (and more specifically their patients) about CRC screening in terms of recommending screening and educating about screening options.

Recommending Screening

Some participants believed that older adults may be more aware of CRC (compared to younger people) because healthcare providers tell them to get screened. Several participants indicated that they wait to be told that a screening is needed. Specifically, they mentioned a PCP recommending cancer screening or reminding when (how often) to do it. Other participants pointed out that PCPs are not consistent about recommending screening. One survivor older than age 75 had a colonoscopy at age 55 and “it really wasn’t brought up much after that.” He expressed gratitude that he was now old enough to no longer need to worry about it. Participants thought younger (versus older) doctors were more likely to focus on preventative care and were more likely to recommend cancer screening in general. A caregiver described how she insisted her mother get a colonoscopy, but the mother “didn’t think it was necessary” because the PCP never recommended it. Participants felt the persistence and insistence of the PCP also impacted CRC screening. Participants used words such as “insist,” “harping,” and “harassed” to describe the PCP’s approaches to pushing patients to get a colonoscopy.

Educating About Screening Options

Several participants reported that colonoscopy is the recommended screening method, and discussions about alternative screening methods did not occur until they expressed hesitancy about colonoscopy. One older male indicated that for his first CRC screening, his PCP “just recommended to get [colonoscopy]. If there were other options, the doctor didn’t mention any.” When it was time to repeat the screening, “I didn’t want to do another colonoscopy.” He had seen TV ads for Cologuard, so he asked about that and “we went that route instead.” Likewise, a caregiver reported that her mother refused to get a colonoscopy, and only then did the

PCP mention the alternative, non-invasive fecal test, which the mother agreed to do.

Perception and Attitude

The general opinion was that CRC is perceived as an “old person disease” and more particularly “an old man disease” with low perceived personal risk. “I’ll get [screened] later.” However, one participant pointed out that such attitudes lead to situations in which “when they find out, then it’s fatal.” An older male cited both generational and gendered attitudes characterized by “Mom said walk it off” in which health problems do not need to be addressed unless they are causing severe distress, particularly among males who have an “I’m fine” attitude. He felt such an attitude meant older people were less likely to be screened. Additionally, CRC was “something that nobody likes to talk about” and is often the subject for embarrassment and jokes, particularly related to colonoscopies.

Test-specific Factors

Colonoscopy

Although nearly all participants had heard of a colonoscopy, they did not have positive comments about it. Several participants said people were scared of the colonoscopy preparation and procedure, describing the bowel prep as “unpleasant,” “uncomfortable,” “inconvenient,” and time consuming. Additionally, sexual connotation and embarrassment of the procedure make people reluctant to undergo screening. The procedure is invasive, requires patients to go to the hospital, and is costly. An older male survivor noted, “there are a lot of people who financially can’t afford it. Even with insurance, your copays, you can go in and come out with a pretty hefty bill.”

Fecal Tests

In comparison, fecal tests such as Cologuard were perceived as convenient, easy, and private. One survivor commented that he decided to use Cologuard when he found out that it was 90% effective.

Suggestions to Improve CRC Screening

Participant suggestions to improve CRC screening focused on increasing awareness (dissemination methods), messaging suggestions, and addressing general community needs.

Increasing Awareness

Participants disagreed about methods of educating the public. Several people suggested that CRC outreach should follow other clinic-based education campaigns (e.g., prenatal/childbirth information, breast cancer awareness of mammograms, diabetic education) with posters and brochures in the clinic waiting and exam rooms. Others did not think those methods would be effective. Another suggestion was to incorporate CRC awareness into a local health education outreach method used by one of the cancer centers called “Stall Stories” in which laminated educational materials are posted in healthcare restroom facilities. They suggested using church groups, having a presentation with the monthly senior citizen informational dinners in which guest speakers present on different topics, and getting the community’s Relay for Life back. A participant suggested that the Relay for Life mini-health fairs provided opportunities for in-person contact with someone who had personal experience with CRC, which would be an effective method of increasing awareness. Other suggestions included using media preferred by the target age group (a “radio blitz”), billboards, and targeted media during CRC awareness month.

Messaging

Ideas for messaging included the need to convey that CRC is not a joking matter and to remove the sexual connotations from CRC and colonoscopy. However, participants did not have concrete ideas about how to accomplish this. One participant suggested using birthday reminders about getting screened such as “Give yourself a birthday present so that you have time for family and grandkids.” Participants cited the need for general education about CRC and the screening guidelines, so patients do not rely solely on doctors to tell them when to be screened. Other messages included a focus on letting the community know newer bowel preparation medications are more tolerable, and that there are alternative tests available (Cologuard).

General Community Needs

Participants were sensitive to cultural diversity factors related to accessing primary health care and cancer screening. They identified the need for better primary care for minority populations, specifically the Latinx population but extending to the wide diversity of cultures in their community associated with the meat packing industry. They noted the difficulty in providing culturally and linguistically tailored healthcare and suggested recruiting more bilingual PCPs and offering free or low-cost primary care clinics, even if only available once or twice a year, modeled on dental clinic outreach in the area. Financial assistance was also

mentioned. Such actions, they believed, would improve the basic health needs in the community and increase preventative care, including CRC screening. The general public needed more education about cancer screening guidelines (ages, tests) because some people do not see a physician regularly and therefore are not told to be screened.

Discussion

Our focus groups conducted with rural Nebraska cancer survivors and caregivers found widespread awareness of colonoscopy as a CRC screening method but general lack of understanding of other test options despite some name recognition of Cologuard. Participants indicated that CRC screening information primarily came from physicians, who play a key role in educating and recommending, even urging, CRC screening. However, not all physicians recommend screening nor do they present alternatives to colonoscopy to all patients. Several participants noted that discussion of stool-based tests only occurred when colonoscopy was resisted. Having a personal connection with CRC (family history, knowing someone who died from CRC) increased general awareness but did not always seem to translate into knowing or meeting screening recommendations. Although not specifically mentioned by participants, their comments about perceptions and barriers to screening indicate that information is also passed within the community by jokes and comments about the colonoscopy preparation and procedure, and that this type of negative information is the most difficult to overcome.

Our results are similar to previous studies about CRC screening which found that financial burdens including cost and insurance coverage [9], fear and embarrassment, lack of perceived need (low perceived risk), and lack of provider recommendation hinder CRC screening [10]. We also found that specific qualities of the screening measures were important [10]. Unlike prior studies, we did not identify fear of diagnosis [9], fear of burdening family [9], health care delivery system or logistical issues [10], or cultural beliefs [10].

Provider recommendations are a crucial factor to increase CRC screening. Based on our results, participants lacked knowledge of fecal tests and they relied on PCP screening recommendations. Stool-based test are easy to perform, low cost, and non-invasive compared to colonoscopy, which address some barriers to CRC screening. Some patients prefer fecal tests versus a colonoscopy [16]. Therefore, providers ought to discuss all screening options with patients to promote shared decision-making based on patients’ needs, resources, frequency of testing, and preferences.

Our study participants suggested measures to improve CRC screening such as clinic-based education campaigns in restrooms, clinics, or waiting areas, use of church groups

to increase awareness, and mass media (radio, billboards) targeted to the age group. Prior studies suggested one-to-one or group educational interventions, reminders, mass communication approaches, and provider-patient communication [17, 18].

Need for Theoretical Underpinning for Interventions

Our study indicated that increased general awareness of CRC did not translate into knowledge about risk, screening guidelines, or even screening behavior. Screening behavior is complex and involves individual, interpersonal, and systems-level factors. As such, interventions to promote CRC screening should be theoretically grounded. Systematic reviews focused on cancer screening interventions include an examination of constructs related to informed decision-making [19] and focused specifically on the use of Health Belief Model constructs for CRC screening [20]. Another systematic review of CRC interventions examined specific intervention components but did not report the underlying theoretical frameworks [21]. The literature on breast cancer screening is well-developed and includes many theoretically grounded intervention studies which would be informative for CRC screening programs. A scoping review conducted on rural breast cancer screening [22] identified the following theoretical frameworks being used: social learning theory, PRECEDE-PROCEED, Transtheoretical Model, communication-behavioral change model, and community organizational model.

Intersectionality of Rurality and Minority Status

Our focus groups highlighted the need for additional support of minority populations in rural communities. Rates of CRC are greater in rural vs. urban communities [4], but less is known about the intersectionality of rurality and minority status [23]. In their review study, Zahnd and colleagues discussed the need to focus increased efforts to understand and address the cancer disparities experienced by racial/ethnic minority populations living in rural communities [23]. They recommended research that examines how best to deliver the evidence-based practices to reduce health disparities in these populations, and we concur with their recommendations.

Strengths and Limitations

Strengths of our study include representation of multiple types of cancer and participants from multiple cancer centers serving areas of rural Nebraska. However, despite working with a cancer center in the western panhandle, we were not able to recruit participants from the sparsely populated frontier areas of the state. Of Nebraska's 93 counties, 48 are classified as rural and 31 as frontier (< 7

residents per square mile) [24]; 62 counties are state-designated shortage areas for family practice [25], which is determined mainly by the population-to-physician ratio. These are areas where structural barriers such as travel, cost, and provider availability may be greater. Additionally, we did not specifically ask participants to report their CRC screening history.

Conclusions

Participant awareness of and knowledge about CRC screening methods varied across focus groups. Colonoscopy was the most widely known test but was associated with negative perceptions regarding the time, cost, and discomfort of the preparation and procedure. Promotion of CRC screening should include education about alternative test types, and informed decision-making between provider and patient regarding preferred screening methods based on the pros and cons of each test type. Individuals with a family history of colon issues (Crohn's disease, CRC) are considered high-risk and need to be aware that screening should be discussed at earlier ages.

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Declarations

Ethics Approval This was a focus group study conducted as part of an institutional needs assessment. The UNMC Institutional Review Board deemed this study as non-human subjects research.

Informed Consent Participants gave verbal permission for recording at the outset of the focus group.

Conflicts of Interest The authors declare no competing interests.

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