


Distance and Transportation Barriers to Colorectal Cancer Screening in a Rural Community

Journal of Primary Care & Community Health
Volume 14: 1–5
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DOI: 10.1177/21501319221147126
journals.sagepub.com/home/jpc


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Abstract

Rural residents in underserved areas face many barriers to health services, including colonoscopies for colorectal cancer (CRC) screening, but rural healthcare providers may assist patients navigating these challenges due to familiarity with local contexts. In 2017 to 2018, we interviewed clinical practitioners and staff ($n = 40$) at 13 primary care and gastroenterology locations across rural Southern Illinois. We used a semi-structured interview guide that addressed system, provider, and patient levels including domains related to barriers, facilitators, and needs for intervention. This article focuses on 3 main elements related to distance and transportation that emerged from inductive coding. First, providers described long distance travel for care as normalized but not necessarily preferable. Second, they identified and described distance-related challenges specific to CRC screening, and third, providers discussed strategies, mostly related to transportation, they use to navigate those challenges. Finally, they suggested a variety of broader solutions to reduce distance and transportation barriers to screening. Overall, distance to care remains a challenge to increasing CRC screening and contributes to disparities in rural communities. To increase early detection and reduce rural cancer disparities, efforts to increase screening and follow-up must address ways to help patients and providers navigate this distance within their local communities and contexts.

Keywords

rural healthcare, colon cancer, cancer screening, implementation

Dates received: 15 June 2022; revised: 30 November 2022; accepted: 2 December 2022.

Introduction

Rural residents frequently face fewer and more dispersed options for healthcare compared to urban and suburban residents.^{1,2} Pervasive and persistent poverty in rural areas exacerbates challenges associated with distance, given the need for gas money, access to a working car, and travel time.^{2,4} Colorectal cancer (CRC) screening is an illustrative example of access challenges faced by rural residents.⁵⁻⁷ While several guideline-adherent options for CRC screening exist in the United States, colonoscopy is often recommended and is required diagnostic follow-up if a stool blood test is positive.⁸ Per capita, there are fewer trained colonoscopy providers in rural areas, meaning fewer choices and longer distances for patients.⁵ Many endoscopists require pre-colonoscopy appointments and mandate patients have an adult escort to drive them home after colonoscopy (because of sedation). Distance to specialized care has been named as a barrier for

people living in rural areas.⁹ Although this may be normalized for many people, we wanted to explore how providers recognize and work to overcome this barrier with their patients in order to provide CRC screening.

Rural Southern Illinois, our research location, has persistently high CRC mortality, and CRC trends in this region have remained stable while declining elsewhere.^{10,11} The health system service area and Mississippi Delta CRC hotspot are far larger than the region of focus discussed

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here, although it has been identified as a region where CRC screening interventions can have significant impact. As an initial step in designing an evidence-based strategy to promote CRC screening in rural primary care practices, we conducted a qualitative study with healthcare providers to understand the clinical setting and community needs. Here, we focus on transportation and distance issues identified by healthcare providers as they described CRC screening and follow-up processes in these communities.

Methods

As pre-implementation research for a stepped-wedge trial to promote CRC screening and follow-up (NIHR01CA233848), we partnered with a rural health system to conduct semi-structured interviews at 13 healthcare delivery locations in Southern Illinois (11 primary care practices; 2 colonoscopy sites). The health system service area is predominantly rural and medically underserved; several practices are designated rural health clinics. We used maximum variation sampling to select clinics of varying sizes located in rural, small town, and metropolitan locations across the service area.

Trained interviewers conducted interviews and short demographic surveys with participants (ie, people involved with screening) in English. The semi-structured interview guide asked about CRC screening approach, referral processes, barriers and facilitators, and feasibility and acceptability of potential interventions. To facilitate participation, we interviewed providers in groups or individually per their preference and availability. Interviews lasted 10 to 60 min. Most interviews were audio-recorded, but a few participants preferred not recording and we took extensive notes using a template. Flexibility enhanced our approach because it encouraged participation: our methods adjusted to fit providers' schedules and comfort, cultivating rapport for sustained partnership. We acknowledge that this flexibility shaped the responses we received and limited some comparative approaches.

Recordings were transcribed verbatim; de-identified transcripts and field notes were analyzed in NVivo12 using a combined deductive and inductive coding approach, developing and refining the codebook through team discussion of transcripts. All transcripts were double-coded with discrepancies reconciled through consensus. While not originally in the interview guide, distance and transportation emerged as topics in 16 of 21 transcripts. Other identified barriers included patient and provider time for discussion around screening, individual-level patient barriers (eg, lack of knowledge, concerns about completing screening), cost concerns, competing priorities for patient care, and working in a medically-underserved area. Here we focus on the distance and transportation codes, with content and interpretations confirmed through cross-checking with other codes.

Table 1. Descriptive Characteristics of Study Participants (n=40) Recruited From a Rural Health System.

Demographic characteristics		N (%)
Gender	Female	29 (72.5)
	Male	7 (17.5)
Age	<30 years	4 (10)
	30-49 years	15 (37.5)
	>60 years	17 (42.5)
Job role	Physician, Physician Assistant	9 (22.5)
	Nursing and other clinical	16 (40.0)
	Administrative or support role	11 (27.5)
	Involved in clinical care delivery	25 (62.5)
	Involved in organizational decision making, management of operations or programs	27 (67.5)
Time at Health Center	≤3 years	9 (22.5)
	4-10 years	14 (35.0)
	>10 years	13 (32.5)

Race/ethnicity was not asked to protect confidentiality of respondents. Some response categories were collapsed if cell sizes were small to protect confidentiality. Values do not add up to 100% because 4 respondents did not complete the survey.

University and healthcare system Institutional Review Boards approved this study. At the request of the healthcare partner, we did not offer participant incentives beyond refreshments. All participants provided verbal consent before interviews.

Results

We interviewed 40 participants from 13 practices, representing a range of healthcare providers (Table 1). We interviewed 13 participants individually, 6 participants in pairs, and 21 across 4 group sessions. Based on this analysis, we describe 3 elements of distance and transportation in CRC screening and provider recommendations to address these challenges. We noted (1) the production and normalization of long distances to care; (2) specific challenges of distance and transportation in these rural settings; (3) provider attention to navigating distance and transportation challenges. These are described below with supporting quotes in Table 2.

Production and Normalization of Long Distances

Long distances are required to access many services in this area. Providers discussed how community-level factors influenced local healthcare access, including loss of local industries that reduced populations and increased poverty. These changes affected patient volume and led to reduced healthcare and pharmacy services in those areas. Attempts

Table 2. Exemplar Quotes for the Identified Areas of Transportation and Distance Challenges in Accessing CRC Screening.**Production and normalization of long distances**

Well, it's just—it's just been a way of life for this community, I think.

People at this practice, they don't seem to have any problem with jumping over to [another town]. They're just used to it.

. . . a lot of them don't wanna go miles away home. They want to stay local. And that's what pushes these [appointment] dates out.

Specific challenges of distance and transportation

Transportation here is just a . . . a huge issue as far as, you know, we're not in the city. We don't have any kind of public transportation or bus system.

[Patients say,] "I don't want [to go] any farther," you know, gas money is an issue.

Right, and like I said, there's some [ride services] that only make one run, and if your appointment's at one o'clock, you've gotta be there on the bus at 7:00 a.m., and then wait until—

Provider attention to navigating distance and transportation challenges

[This health system] is fairly good with transportation because transportation is usually a big one. . . . they try to set up [patients] with transportation as best as possible.

We'd probably have to arrange transportation at least 3 weeks in advance, so . . . we don't never say, "Oh next week sounds good" [for an appointment].

We call [one transportation group] and generally, it's like "you have to call this [other] one.." 'oh, no, you'll have to call that one," like 2 h on the phone just to make one appointment for a patient.

to stay healthy were complicated by subsequent loss of grocery stores (where prescriptions are often filled) in some communities. Providers described how these trends produce additional transportation burdens as distances increase. One interviewee noted, "We have [had] no grocery store for over 2 years. . . If you can't find it at the Dollar General, you don't eat it." Disinvestment and subsequent community changes produced and, over time, normalized long distances as a "way of life" for residents, something necessary but not always preferable.

Providers simultaneously perceived that some patients did not *want* to travel for healthcare, as one interviewee phrased it, "They want to stay local." This was framed as an individual and affective choice, but also one related to barriers. For CRC screening, interviewees emphasized that both community- and individual-level transportation factors were critical for understanding the needs of their patients and together "hinder us from pushing through a lot of our screens." This multilevel contextual understanding is important for developing interventions.

Specific Challenges of Distance and Transportation

Many interviewees linked CRC screenings challenges regarding long distance with patient socio-economic and family situations. Transportation barriers included not having gas money or a reliable vehicle. Because patients must have an adult companion during the procedure to escort them home, providers noted that long distances cause a colonoscopy to consume an entire day for both patient *and* companion. Another provider said: "sometimes you get patients, they want to have it done, but they are alone. They have no support. They have no family, and

they want to—we cannot do it because there is nobody to drive them back."

Provider Attention to Navigating Distance and Transportation Challenges

Providers helped patients navigate these distances and described transportation planning as complex and time-consuming. First, someone must identify who needed transportation. Most practices use targeted approaches, keeping lists of patients or focusing on patient types, such as "older people [who] don't drive." Second, interviewees relied on case managers, coordinators, or nurses to assist patients with transportation. Helping patients determine if distance would be an issue and identifying transportation options required knowing patients' home locations, screening facility locations, appointment times, and insurance carrier. One interviewee described "hours" calling transportation companies for one patient. Finally, while providers wished to assist with transportation, availability of transportation supports varied across region, practice, and patient eligibility. Some practices offered travel payment assistance, but this was not an option for all, as this region generally lacks taxis, ride sharing, and public transit.

Organizing transportation did not eliminate distance-related challenges. Providers described some transport options as unreliable (eg, "no-show" or late rides), causing patients to be late or miss appointments, go through unnecessary colon preparation, or experience substantial wait-times pre- or post-appointment based on transport schedules. Additionally, arranging transportation influenced scheduling of colonoscopies, as many transportation providers required several weeks' notice or had limited operational hours.

Provider Recommendations to Address Distance and Transportation

Interviewees offered recommendations to address distance and transportation barriers, yet they also recognized funding and logistical constraints that had impeded such efforts in the past and could prevent sustainability. Suggestions included having additional navigators or case managers help patients resolve transportation barriers. One clinic suggested purchasing a vehicle to transport patients, and another suggested providing gas cards. Others wished to reduce travel distance, with ideas such as bringing gastroenterologists to the region (permanently or visiting) and training local non-gastroenterologists in colonoscopy.

Discussion

We conducted semi-structured qualitative interviews at rural health practices as a pre-implementation step in the design of a CRC screening intervention. We aimed to understand the engagement of rural practices with screening and co-create an intervention adaptable to local processes, needs, and resources. Our data suggest that long travel distance to CRC screening was a recurrent barrier, that arranging transportation took significant effort and resources, and that transportation-specific challenges that were outside of the control of providers created hardships for patients. Our findings offered several considerations for our intervention and valuable insights for healthcare providers, support staff, researchers, and others concerned with rural cancer detection and prevention.

First, rural regions are often medically underserved and have limited access to medical care, specialty services, and pharmacies.^{5,6} Similar to previous findings,¹² interviewees remembered a time with more healthcare providers, more healthful alternatives, and better livelihoods; thus, local and regional histories demonstrate that scarce healthcare resources were not immutable components of rural life and context is dynamic. They noted that longer distances were produced by political and economic changes over time, while recognizing that long distances have become normalized in rural residents' lives. Simultaneously, the persistent poverty that influences these contexts also can make such travel difficult or impossible. This aligns with existing work documenting how distance and transportation impede health care and CRC screening,^{2,4,9,13,14} as well as the seeming acceptance of these constraints by many rural residents.⁷

Second, healthcare providers and support staff emphasized that distance and transportation barriers to CRC screening are multi-factorial and solutions need to be as well. Time (eg, travel, procedure) and cost beyond medical bills (eg, lost wages, gasoline) are established barriers to CRC screening,^{3,13-15} and mobilizing resources to address these issues is necessary to achieve screening

goals. Even a completed colonoscopy may lead to additional time-consuming and expensive procedures, diagnoses, and concerns.¹⁶

Third, interviewees described frustrations trying to link patients with colonoscopies. They attempted to address challenges of distance and transportation by combining multiple approaches. Rural settings have limited numbers of healthcare providers, and assisting patients as they navigate the challenges of CRC screening without sufficient structural support further taxes scarce resources. Our research highlights the work this required from care providers and support staff as well as the mental and emotional toll for all involved.

Finally, interviewees suggested several potential solutions for addressing the above challenges. Some solutions require significant investments to hire staff, purchase vehicles, or create and maintain new facilities. However, there were smaller-scale suggestions that were viable given resource constraints in this rural and medically underserved region. Building on these suggestions, we partnered with the health system to develop a transportation resource guide tailored to local settings. This collaborative and targeted transportation resource guide is one component of the larger stepped-wedge intervention to increase CRC screening in this rural, under-resourced region with pervasive and persistent poverty.

A strength of our research includes using these interviews to build rapport as we learn from community members. Our solutions incorporate local contexts and challenges, and are more likely to be adopted because they were developed in collaboration with the people who will use them. A limitation is that provider perceptions of patient challenges with distance and transportation reflect only one perspective. To address this we then interviewed patients and their families, who offer critical knowledge about informal, familial, and social network efforts to meet household health care needs such as screening.¹⁷

These results, based on provider interviews, affirm existing data on the challenges of distance and travel for CRC screening, particularly for rural residents.¹³⁻¹⁵ We recognize that many of these challenges persist and have been exacerbated during the COVID pandemic. While our approach may not reduce distances (this requires policy change), we can assist people navigating cancer prevention and screening. Addressing distance and transportation as part of equitable access to care is vital for the U.S. to achieve larger goals for improved health.

Acknowledgments

We want to thank the participants who agreed to be interviewed for this study. We thank Drs. Graham Colditz and Marci Moore-Connelley for their support and effort in building this collaboration. Additionally, we want to thank (in alphabetical order): Channele Chua, Sonya Izadi, and Brandon Smith.

Declaration of Conflicting Interests

The author(s) declared no potential conflicts of interest with respect to the research, authorship, and/or publication of this article.

Funding

The author(s) disclosed receipt of the following financial support for the research, authorship, and/or publication of this article: This work was supported by NIH grant U01CA209861 (PI: James) and R01CA233848 (PI: James). KMNL's and MWLT's time was supported by T32CA190194 (MPI: James/Colditz), Siteman Cancer Center and the Foundation for Barnes Jewish Hospital provided additional support. MWL-T was also supported by a Northwestern University Clinical and Translational Sciences Institute award (UL1TR001422), the Respiratory Health Association of Metropolitan Chicago awards (RHA2020-01), a National Institutes of Health's National Institute on Aging (P30AG059988), and funds from the Northwestern University Center for Community Health.

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