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Colorectal Cancer Health Disparity among African Americans - A Qualitative Study at the Community Level, Exploring the Connection between Low Access to Resources, Diet, and Colorectal Health

Eryn K. Matich[1], Rachel Hale[2], Nicola Spencer[2], M. Kathryn Stewart[2], L. Joseph Su[3#], Ping-Ching Hsu[1#]

[1]Department of Environmental and Occupational Health, College of Public Health, University of Arkansas for Medical Sciences, Arkansas, USA

[2]Department of Health Policy and Management, College of Public Health, Translational Research Institute Community Engagement team, University of Arkansas for Medical Sciences, Arkansas, USA

[3]Department of Epidemiology, College of Public Health, University of Arkansas for Medical Sciences, Arkansas, USA

[#]**Corresponding author-1:** L. Joseph Su, Department of Epidemiology, College of Public Health, University of Arkansas for Medical Sciences, Little Rock, Arkansas, USA

[#]**Corresponding author-2:**Ping-Ching Hsu, Department of Environmental and Occupational Health, College of Public Health, University of Arkansas for Medical Sciences, Little Rock, Arkansas, USA

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Abstract

Background: Colorectal Cancer (CRC) is the second leading cancer-caused death among men and women combined in the United States (US) but is preventable with screening. A CRC health disparity exists among African Americans (AAs). This disparity is particularly evident in rural areas, including in the Mississippi River Delta, but is not explained solely by lower screening. Studies have suggested that differences are associated with socioeconomic status, screening, and exercise. Research in Arkansas is needed on determinants of disparities to develop actionable prevention strategies.

Methods: A Community Review Board (CRB) was used, which is a meeting where lay community members are experts based on experience with the topic or knowledge of the population and provide feedback. Two CRBs of AAs age 45-75 were conducted in rural and urban Arkansas communities to understand perspectives on CRC and screening. We discussed their willingness to participate and barriers. Differences in viewpoints were documented and compared.

Results: CRB experts indicated their willingness to listen to other community members. More of the urban experts had previous CRC screening than rural experts. Rural experts preferred results dissemination in an open discussion format. Experts thought communities could benefit from information related to these topics. Additionally, the rural experts were more comfortable discussing CRC with family.

Conclusions: Community experts mentioned the need for more information about CRC and screening; therefore, we will hold forums with Arkansas communities to discuss these topics to inform and learn more. We used the feedback to improve our project.

Keywords: Colorectal cancer; Community review board; Diet; Screening

Introduction

Colorectal cancer (CRC) is the second leading cancer cause of death among both men and women in the United States (US) [1]. CRC is preventable through early treatment of disease found during screening [2], however, the screening rate among adults age 50-75 in the US is only 67% [3]. Although CRC incidence and mortality rates are gradually decreasing in the US [4], some regions remain CRC mortality hotspots in which these counties average CRC mortality rates are 40% higher than those of counties not included in these hotspots [5]. These hotspots are mainly rural or lower Socioeconomic Status (SES) regions, with the largest hotspot located in the Lower Mississippi River Delta, including portions of Arkansas, Illinois, Kentucky, Louisiana, Mississippi, Missouri, and Tennessee [5]. Among racial ethnic groups in the US, African Americans (AAs) have the highest CRC incidence and mortality rates [6]. Factors contributing to this CRC health disparity are unclear and may be explained, at least partially, by SES [7,8]. More AAs are living in poverty than non-Hispanic whites (NHWs) [9] and may experience less access to health care such as screening facilities [7], less continuity of care, lower trust in providers [10], and more likely to be uninsured [11], leading to lower screening rates, late diagnosis, and higher mortality from CRC. Interestingly, there was a higher percentage of CRC screening test usage among AAs (67.6%) compared to NHWs (65.1%) in Arkansas [12], although the mortality rate for AAs is 40% higher than NHW [6]. The average CRC screening rate in Arkansas in 2014 was 59.9% [13]. This raises the question of what other factors may play a contributing role.

CRC incidence has also been found to be associated with lifestyle factors and co-morbidities. Some examples of these associations include consumption of red [14] and processed meat [14], alcohol use [15], smoking [16], low physical activity [17], obesity [18], inflammatory bowel disease [19], and type 2 diabetes [20]. Other factors may include less access to resources such as fitness facilities and grocery stores with healthy options. Food insecurity is defined as a household-level economic and social condition of limited or uncertain access to adequate food by the US Department of Agriculture. Food insecurity is associated with a poor diet [21] and risk of cancer death [22]. These complex determinants deserve further exploration. Previous studies have analyzed the associations between diet and colorectal cancer using self-report surveys and metabolomics analyses but typically are analyzed in blood samples. In addition, most previous studies have not analyzed the role that certain SES factors play in these associations. The focus of the proposed project is to understand whether certain dietary habits related to SES will be reflected in stool metabolites and colorectal health, to inform at-risk communities, especially those with limited access to resources and food insecurity. However, recruitment of research participants in rural, underserved communities is often a challenge [23-25], particularly regarding stigmatized issues [26,27]. Understanding the attitudes among AAs living in rural Arkansas is important in adapting research project designs. This paper describes work we carried out to better understand community perspectives on these issues related to lower recruitment numbers and the knowledge and opinions of these underserved AA communities.

Methods

Project Design

We used an engagement approach known as a Community Review Board (CRB). A CRB is a one-time meeting with community member experts who have experience with the research topic or community in which these experts provide feedback to the researcher on their study [28]. These CRBs are not considered focus groups because they are a rapid assessment approach to gathering community input. We used CRBs to gain insight into the communities' perspective about a study proposed to analyze the association between diet with stool metabolites and colorectal health. Community experts from the urban city of Little Rock (Pulaski County, Central Arkansas) and the rural community of Helena (Phillips County, Lower Delta region of Arkansas) were recruited within a one month period of time prior to the scheduled CRBs and oriented by members of the Translational Research Institute (TRI) Community Engagement (CE) team at the University of Arkansas for Medical Sciences (UAMS) and invited to attend a CRB to discuss the proposed project. During the CRBs, the researcher presented about the project and background, and then the CE team asked the experts about the knowledge and attitudes of their community regarding CRC, screening, and the project.

Community Experts

Sixteen AAs aged 45-75 who live in or near the Little Rock or Helena communities were recruited within a period of about one month prior to the scheduled CRBs. Typically these experts are recruited from those who have previously participated in CRBs through the CE team. Experts were compensated for their time. For these CRBs, the UAMS TRI CE team recruited AAs ages 45-75 including a mixture of people who had and had not received a colonoscopy. The purpose of the CRB was to speak to community members to find out their thoughts on colonoscopy, determine the reason behind any hesitancy, gauge their willingness to participate in a research project about the colon, and gain feedback about the study from these community members. These community members' life experiences make them experts in the topic and more than qualified to answer questions about the topic at hand.

Setting

These CRBs took place at the Bessie Hunt Education Center in Helena and the Hillary Clinton Children's Library in Little Rock. These locations were easily accessible to community members, have private conference rooms with tables and chairs for the experts to sit and a projection screen for the researcher to present.

Data Collection and Analysis

Discussions were audio-recorded for accuracy, and word-for-word quotes and notes were taken by the CE team. The questions posed for discussion with the experts included:

What would be the best way to communicate study results and conclusions to the community?;
How would the community prefer to answer survey questions? And how long would the community be willing to spend on this?;
If someone from the community was already scheduled to receive a colonoscopy, would they be willing to participate in the study (arrive early for the survey)? If no, why not? What could we do to increase participation?;
Does your community feel comfortable discussing CRC with your family (for example, asking if anyone in the family has or had CRC)? If no, why not?;
Have you been screened for CRC since turning 50? If yes, what type of screening? If no, why not?

These questions were developed for these CRBs that the CE team organized.[28] Only these five questions were planned to be asked in relation to the project and topic in order to leave time for discussion among the experts. We did not ask questions related to SES, diet or stool metabolome which will be analyzed in the proposed research study. This is because we were trying to get feedback about the overall study design and the community knowledge and perspective of CRC and screening from these CRBs. A rapid assessment approach was used in gathering community input. In-depth qualitative analysis or theoretical frameworks were not used to analyze the data. Input from the experts was summarized and organized to report the community experts' responses. Due to the need for rapid turnaround, we did not have time for these notes to be reviewed by the experts for control and correction.

Results

Description of Community Experts (Demographics)

Sixteen AA community experts were recruited for these CRBs, including 13 women and three men. There were five women and one man at the Little Rock CRB and eight women and two men at the Helena CRB. The average age of experts were 54.8 (range: 47-68) and 56.6 (range: 46-69), in Little Rock and Helena, respectively.

Results Dissemination

What would be the best way to communicate study results and conclusions to the community?

Based on the discussion of the experts, it seems that there are two proposed groups of ideas: individual, direct communication, or community, open discussion. The experts in Little Rock seemed to prefer individual, direct communication and some proposed methods were calls, email, or mail. In contrast, in Helena, the experts preferred a more open community discussion. Some of their suggestions included a town hall or meeting located at a community center or church because "people in this community are more willing to listen to someone they relate with and know." They also suggested we advertise for these discussions through radio, flyers, local newspaper, and social media.

Survey Method

How would the community prefer to answer survey questions? How long would the community be willing to spend on filling out the survey?

Most experts in Helena (seven out of ten) said they would prefer to fill out the survey electronically such as on a computer or tablet. The remaining experts in Helena preferred to fill out the survey on paper. In Little Rock, there was no preference between paper and electronic surveys. In Helena, a shorter survey time was preferred at ten minutes or less. In Little Rock, the experts thought that their friends would be willing to spend up to 30 minutes sharing this information.

Willingness to Participate

If someone from the community was already scheduled to receive a colonoscopy, would they be willing to participate in the study (arrive early for the survey)? If no, why not? What could we do to increase participation?

Most experts answered that they would be willing to participate and have a stool sample collected if they were already scheduled for a colonoscopy (all ten experts in Helena and five out of six in Little Rock). The experts in both towns also believed that their friends would be willing to participate in the study. In addition to their willingness to participate, a majority of the experts were willing to arrive early to complete the survey (eight out of ten in Helena and all six experts in Little Rock). Also, the experts in both locations believe that their friends would be willing to come early for the survey.

Discussion of Colorectal Cancer

Do people in your community feel comfortable discussing CRC with family (for example, asking if anyone in the family has or had CRC)? If no, why not?

The experts in Helena all agreed that they were comfortable discussing CRC with their friends and family and that they believed their community is comfortable discussing this. Meanwhile, experts in Little Rock discussed how they felt uncomfortable discussing this sensitive topic with their family and friends. In addition, an expert in Little Rock mentioned that their husband had polyps, and they were "Scared to get screened because they don't do doctor stuff," and the rest of the experts agreed that they do not often go to the doctor. Also, one expert from Little Rock stated that "the AA community does not talk about what they have and often do not know how other people die." It was also suggested by the experts in Little Rock that we "need to talk to the community to get them more comfortable about this topic."

Previous Colorectal Cancer Screening

Have you been screened for CRC since turning 50? If yes, what type of screening? If no, why not?

The Helena experts needed clarification to understand what type of screening we were asking about, and so we further explained the types screening. In Helena, four of the ten experts had received a CRC screening, and two specifically stated that they had provided a stool sample which may have been for a Fecal Immunochemical Test (FIT) or other stool-based tests. In Little Rock, five out of six experts stated that they had received a CRC screening, but none had used a FIT. The experts who had not been screened mentioned many reasons ranging from health insurance issues to lack of understanding when it came to the colonoscopy bowel prep, and finally, the most common reason was fear of the result. The remaining experts stated that they were apprehensive due to a few reasons, such as the location of the camera and the taste of the bowel prep.

Other Discussions

Much of the discussion outside of answering questions had to do with colonoscopies or CRC screening. Many of the experts expressed their concerns about colonoscopies and the bowel prep. In addition, many of the experts had previously had colonoscopies and provided some of their experiences. One common worry among many of the experts was the bowel prep drink. Another type of CRC screening, called a FIT, was also discussed briefly. The experts at the Little Rock CRB seemed unanimous to have not previously used a FIT and did not want to use it in the future. In addition, in Helena, an expert stated that "there is miseducation in this community because they don't have anyone to provide and facilitate this information."

Also, a researcher raised the question, "If we asked you to recruit one person to the study - what kind of objections would you meet?" Some of the responses related to fear, lack of education, and discomfort. Another point raised by a couple of experts was that "many older people in the AA community do not go to the doctor unless they are sick."

Another topic of discussion raised by a researcher was potential distrust in the AA community towards NHW doctors. Some of the discussion included comments about how some members of the community trust NHW doctors more than AA doctors, while the opposite is true of some community members. Another community expert shared that "back in the 1980s, there was more prejudice towards AAs, and therefore some doctors did not take care of them as well." These racial differences, concerns, and discrimination based on race could have an effect on the level and quality of care that these AA people are receiving. Previous studies have shown that the higher CRC incidence and mortality rates among AAs as compared to other races are related to lower screening rates (potentially because of lack of available resources), leading to later stage diagnoses and poorer response to chemotherapy if the AA CRC patient received chemotherapy or radiation at all [29].

Along with the discussion during the CRB, the experts were asked to give feedback about the CRB and the project. Some of these comments were related to the information they learned during the discussions, such as: "I think this is a great thing that our community needs, especially because we need more help to stay healthy." The experts were also asked about the challenges they thought we would have. Some of their expert opinions included: "Just getting the people to understand that this is a way to help you live a good and healthier life. Some people are not accustomed to eating healthier." Finally, they were asked what they would like to see the researchers do differently. Some of the feedback included: "I would like to see the researcher get back with the community to show a difference in the research when they finish."

Barriers and Facilitators to Research Participation

The community experts provided important information on how to increase participation from these communities. Their main advice was to advertise for the study through radio, local newspaper, and social media. A majority (seven out of ten) of the experts in Helena use Facebook, and they believe that other members of the community do as well. They also expressed interest in receiving brochures to share with friends and family about this project and the information we discussed. This suggests that there is strong trust among community members and that recruitment through trusted members of the community for the project would be advantageous.

Application of Community Experts' Feedback to Study Design

These CRBs obtained input from community experts on the proposed project related to CRC and screening. The targeted population comprised AAs age 45-75, and the CRBs were held in the cities of Little Rock and Helena, Arkansas. We were able to get great feedback about the project from the experts, along with answers to our questions related to their opinions and knowledge of CRC and screening. Based on the input from the experts, we believe that our study design will be successful at recruiting AA and NHW participants' age 50-75 who are already scheduled for a colonoscopy. We have also added a community forum component to our study design in order to inform and discuss with Arkansas communities about CRC, screening, and the study results. We hope to further learn from these community forums how best to encourage people about the importance of CRC screening for prevention and early detection. The goal is to be able to use these discussions and feedback from the forums to design new research projects around the discussed needs of the community and to design communications and messaging to raise awareness around the topics of CRC and timely screening for prevention and early detection. The information gained from these forums will allow us to use these discussions and future community forums to share information and evaluate attitudes before and after the forums.

From these discussions, we conclude that these communities need more accurate information at their disposal, and the community-based discussions or forums seem to be an appropriate route to at least partially meet that need. With researchers and colorectal specialists present in the forums, information about CRC and screening can be disseminated while the community members express and discuss their views and experience and learn from each other. The knowledge gained at these forums will allow Arkansans to have more information about this disease and how it can be prevented through active screening and a healthy diet, and therefore potentially lower their risk of CRC. Based on the feedback of the experts, the information they received was useful, and they expressed the desire to share this information with their friends, family, and community to promote discussion and timely screening.

Discussion

Main Findings

Little Rock is an urban community in Central Arkansas, while Helena is a rural community in the Lower Delta region of Arkansas. From the CRBs in both areas, we found that there were some similarities and differences between these older AA communities in Arkansas.

A majority of the community experts from both locations agreed that they would be willing to participate in the research study if they were already scheduled to receive a colonoscopy, and most said that they would come early for the survey as well. Some of the differences include their preferences for survey method and length of time, the method to disseminate results, previous CRC screening history, and comfort with discussing CRC with friends and family.

For results dissemination, in Little Rock, the experts expressed that they would prefer individual methods such as a phone call, or a document by email. This differs from Helena, where the preference for results dissemination was in a community and open setting such as a town hall or community meeting. The experts in Helena were more likely to believe something if it came from another community member as opposed to an outsider or researcher.

Another difference was the percentage of the experts who had previously been screened for CRC. In Helena, only 40% of the experts mentioned that they had been screened for CRC, while in Little Rock, the majority (83%) of the experts had previously had a CRC screening. This group of individuals does range in age from 46-69, and the previous American Cancer Society recommendation was that adults age 50 and older get screened for CRC, so that may explain why some of the younger experts had not yet been screened. But these differences in screening seem to match the results of many studies about the difference in screening use between urban and rural communities [30-32]. Many health professionals and researchers have focused on increasing the screening in underserved, low SES, rural communities with other methods of CRC screening, including FIT or other stool-based tests as opposed to colonoscopy [33,34].

Finally, the last difference observed between the two groups was their feelings about discussing CRC with their friends and family. In Helena, the experts unanimously agreed that they were comfortable discussing CRC with their friends and family and believed that members of their community were as well. While in Little Rock, the opposite was true in that they did not feel comfortable discussing CRC with friends and family. The experts at Little Rock mentioned that in their culture, they do not go to the doctor unless they feel sick, and therefore things like this are not discussed in the community. They seemed more comfortable discussing this topic at the end of the CRB than at the beginning. They expressed that the AA communities in Little Rock could benefit from hearing this information and discussing it as well to become more comfortable and informed.

Strengths

The strengths of this study are that based on the discussion during this CRB, we could compare these urban and rural communities to see what might relate to the CRC mortality hotspot in the Delta [5] and what we find in common amongst these communities may relate to their health disparity [6]. Through these CRBs, we learned that the biggest hurdle to getting these communities to participate is convincing them to get a colonoscopy. Those who are already scheduled to receive one would most likely participate. Additionally, the fear related to a colonoscopy seems to be related to the bowel prep liquid and not wanting to know the diagnosis. Also, we were able to observe some major differences between these two groups with regards to the survey, results dissemination, past CRC screening, and comfort discussing CRC with friends and family.

Limitations

This study only recruited 16 community experts and was not equally distributed when it comes to gender (13 women and three men) or geographic location (six in Little Rock and ten in Helena). It is possible that the views and experiences of these experts do not represent others in their communities. We understand that this number is not sufficient to prove conclusively that these differences are present between these communities. We hoped to use these CRBs as a method to gain feedback from these communities to ultimately make changes and improve upon our proposed research project. We also plan to hold similar community discussions in the future to get a larger population size discussing similar topics. In addition, these CRBs are not considered focus groups because they are more of a rapid assessment approach to gathering community input. Therefore, the recorded audio is not transcribed, sorted based on codes, or analyzed in a qualitative manner. Because of this, we are only able to report on the discussions that occurred to hypothesize relationships between these rural communities in the Delta and their higher CRC mortality [5] and AAs in general and their increased CRC incidence and mortality rates [6]. If we wanted to analyze the feedback of these experts in a more qualitative manner, we would need to recruit more experts, observe these discussions for a more extended period of time, transcribe, code, and analyze those discussions to improve our understanding.

Conclusions

In conclusion, at-risk communities in Arkansas remain under-informed about CRC and screening. This discussion and analysis provide ideas on how to best discuss these topics and inform these at-risk communities about CRC and screening as well as feedback about improvements that could be made to the described project. Strategies focused on open discussion about the project, CRC, and screening with guided questions in order to have open communication about the experts' understanding and what they would like to know. Based on these discussions, we have added a forum component to our project to discuss with Arkansas communities about CRC and screening as well as inform these communities about the results of the project.

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Declarations

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Conflict of Interest

None declared.

Ethics Approval

The CE team requested a Letter of Determination from the UAMS Institutional Review Board (IRB) regarding the CRBs. The IRB determined the CRBs are exempt from IRB review because they were not considered human subjects research, and therefore no informed consent was required (waived). The need for ethics approval was waived because the IRB functions as the entity providing ethics approval. However, the CE team provided verbal assurance to the community experts that their personal information would not be shared with the researcher unless they give permission. In addition, they made it clear to the experts that they are not research participants.

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