Facilitators and Barriers to Research Participation in Rural Communities

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Abstract

This study addresses the underrepresentation of rural communities in research by examining facilitators and barriers in two rural Mississippi counties, emphasizing the need for context-specific exploration. Utilizing focus group interviews with Community Advisory Board members from the health-oriented RURAL Cohort Study, the research explores relationships, trust, and communication as key themes influencing participation. Strong community bonds are both a facilitator and a barrier, emphasizing the importance of preserving close-knit ties. Trust, built through training and community recognition, is crucial, while mistrust rooted in historical concerns poses a significant barrier. Communication transparency and strategic engagement are fundamental, with physical spaces prioritized for recruitment. The study identifies hard-to-reach populations, highlighting the challenges of traditional outreach methods. Achieving the target participant number is seen as both feasible and meaningful, reflecting community commitment. Overall, the study provides nuanced insights for effective and culturally sensitive research engagement in rural communities, contributing to region-specific literature.

KEYWORDS: barriers, community engagement, facilitators, focus groups, rural research

Introduction

Historically, rural communities are underrepresented in research (Winter et al. 2018). Barriers to engaging them in research are multifaceted, encompassing challenges such as remote locations, longer travel distances to health care sites, increased travel costs, economic stagnation, and technological disparities (Hart, Larson, and Lishner 2005). Notably, rural residents exhibit paradoxically high levels of self-rated health but are often skeptical about medical tests, fostering hesitancy toward research (Morgan, Fahs, and Klesh 2005; Ramachandran 2018). Geographical remoteness, unintentional exclusion by researchers, and limited internet access further contribute to lower participation rates (Arcury et al. 2005). Additionally, socioeconomic factors like lower income, lack of health insurance, and higher unemployment decrease participation rates (Bolin et al. 2015). Cultural differences and mistrust of research institutions are also recognized as significant barriers (Braunstein et al. 2008). These barriers illustrate the intricate landscape researchers encounter in recruiting and retaining participants in rural areas.

From 1999 to 2015, all-cause mortality rates decreased, but the rural-urban gap widened, favoring urban areas—a phenomenon termed the "rural mortality penalty" (Richman et al. 2019). The rural South notably exhibits elevated mortality rates across the top ten causes of death. Mississippi is among the most rural and economically challenged states, housing some of the poorest counties in the rural South, particularly within the Appalachia and Mississippi Delta regions, which exhibit the lowest life expectancy nationwide (Ramachandran 2018). In response, the Risk Underlying Rural Areas Longitudinal (RURAL) Study, a pioneering, observational population-based study funded by the National Institutes of Health's National Heart, Lung, and Blood Institute [Note from author: Very important nuance here, the National Heart, Lung, and Blood Institute is one of the 22 institutes under the National Institute of Health,] focuses on the poorest vulnerable communities in the rural South, specifically the Appalachia and Mississippi Delta regions. Two Mississippi counties forming the Mississippi Core of RURAL Cohort Study, led through the University of Mississippi Medical Center , were selected among the ten counties spanning four states (Alabama, Louisiana, Kentucky, and Mississippi). This six-year study aims to advance health-disparities research by comprehensively understanding the rural-mortality penalty. It also seeks to identify targets for health-system reform, comparing low-risk and high-risk counties with similar poverty levels, racial makeup, and rurality, offering crucial insights for addressing rural health challenges (Ramachandran 2018).

Understanding the facilitators and barriers to research participation is vital for discerning methodologies in rural research and avoiding counterproductive practices. Such insights are pivotal for crafting nuanced interventions addressing health care challenges in a context-specific manner.

Building on the RURAL Cohort Study's objectives, this research note explores research facilitators and barriers in two rural Mississippi counties. Recognizing the need for a context-specific examination of rural communities, we employ varied methods, prioritizing community engagement to amplify community voices, and utilizing focus group interviews to delve into qualitative insights not presently found in literature. This is supported by Richman et al.'s (2019) call for research in rural communities to consider their distinct characteristics. Using focus group interviews as the primary data collection method adds methodological diversity, capturing both individual perspectives and shared experiences within the community, which is essential for inclusive representation of rural populations in scientific research. The qualitative nature of the study aligns with the aim of comprehensively exploring participants' "why," "how," and "what" aspects of research participation, acknowledging them as experts in their experiences and perceptions.

Methods

This descriptive qualitative study utilized focus group interviews, chosen over individual interviews for their distinct advantages in capturing the intricacies of group dynamics (Kitzinger 1995). Recognizing the inherent value placed on community participation in rural settings (Kenny et al., 2015), focus groups offer a unique platform for actively engaging participants and unveiling collective perspectives.

Participant Recruitment

This study employed purposeful sampling to engage information-rich participants. Community Advisory Board (CAB) members in each county had been active with RURAL Cohort Study for two years. We therefore ensured the inclusion of individuals with expertise and experience in the "why," "how," and "what" aspects of research in their communities. We invited CAB members from both counties through email (followed by a telephone call to those who did not respond to the email). A total of eight CAB members accepted our invitation to participate in the focus group interviews. Sample size in qualitative research is ultimately a verdict based on evaluating the quality of the data collected against the purpose, method, and intended product of the study. Saturation emerges as similar responses are repeated within and among focus groups.

Data Collection

The study protocol received approval from the University of Mississippi Medical Center Institutional Review Board. All focus group participants (FGPs) provided written and verbal consent. Data collection utilized interview questions developed by the research team.

Table 1: Focus Group Interview Questions

- **On Facilitators:**
  o   What are some current strengths of your County that make it easy to participate in research?
  o   Together, how can we make the best use these strengths?

- **On Barriers:**
  o   What problems/challenges do you currently see in your County that may hinder participation in research?
  o   Please describe approaches that would help overcome hinderances to research participation in your County.

- **On Reach and Effectiveness:**
  o   How meaningful is it to you for the RURAL Cohort Study to reach the desired number of participants?

- **On Community Engagement Approaches and Reach:**
  o   What approaches do you recommend for getting the word out to people in your County with information about the RURAL Cohort Study?
  o   What are the most effective approaches for reaching persons ages 25-40 in your County with information about the upcoming Study?
  o   Studies have shown that women are more likely to participate in research than men. What are some effective ways we can reach men in your County to invite them to participate in the RURAL Cohort Study?

- **What more would you like to share with us about research participation?**

Conducted on a virtual platform due to the COVID-19 pandemic, each interview lasted 50 to 60 minutes and involved only CAB members, the investigator, and the research team. The interviews were audio-recorded and transcribed verbatim by the research team with identifiable information removed.

FGPs were invited to share their experiences related to research in their community, as well as their concerns and ideas for promoting participation. Follow-up questions were utilized as needed to provide

clarity and expand responses. Weighing the quality of the data collected against the purpose, method, and intended product of the study, the research team deemed the data collected in the two focus groups to be sufficient exploration of the facilitators and barriers to research participation among CAB members in these two Mississippi counties.

Data Analysis

The research team used thematic analysis, a widely recognized qualitative research method, to systematically identify, analyze, and report themes emerging from the data. Thematic analysis is well-established for its flexibility in capturing and interpreting patterns within qualitative data (Braun and Clarke 2006). In this study, first-cycle analysis was conducted manually and independently by three researchers, aligning with best practices in ensuring reliability and credibility (Nowell et al. 2017). Codes were derived from common responses or descriptors appearing in the transcripts. These codes were organized into themes through a collaborative process and researcher consensus was achieved through iterative discussions. The entire team contributed to refining interpretations and enhancing the robustness of the analysis. The investigator subsequently synthesized the research team's input into final themes and subthemes. Throughout this process, a data-file worksheet facilitated the contextualization and organization of codes and themes, ensuring transparency and rigor in the analytic process.

Results

A total of eight CAB members participated in two separate focus groups: four African American women, two White women, and two African American men ages 30 to 49 who had lived in their respective counties most of their lives. Most (six; 75 percent) were in the 45 to 69 age category, and most (six; 75 percent) were female. Half of the participants reported lifelong residence or working in the county all their lives, and a majority (seven; 87 percent) had completed graduate or professional education. Six participants were currently working and two were retired. Their occupations were retired community health educator, nurse practitioner, physician, self-employed business owner, retired youth coordinator, program specialist in a community-based organization, a university US Department of Agriculture Extension agent, and a county supervisor.

The narrative data revealed the following three themes reflecting both facilitators and barriers to participation in research: (1) relationships, (2) trust, and (3) communication. These themes could be viewed as a facilitator and as a barrier depending upon the context provided by the participants. Each theme, along with its associated subtheme, are detailed in the sections below.

Facilitator and Barrier: Relationships

FGPs emphasized the importance of relationships in research participation, highlighting strong community bonds as a key facilitator. Conversely, the lack of connections can be a potential barrier. The close-knit fabric characterizing their communities was a perceived strength, with participants valuing the preservation of this distinctive quality. This highlighted the advantage of the small size of their communities in cultivating robust relationships that in turn enhance engagement in research initiatives. As one participant expressed, "[county] is comprised of several small knit close communities . . . lots of tight-knit relationships . . . folks know each other . . . if there is something going on, where involvement is community wide, there are folks in the community that can facilitate." Another participant's perspective was, " [In] smaller rural towns where people know each other . . . there's a close-knit relationship, I think that people tend to be more hospitable and more supportive of each other."

FGPs emphasized the necessity for community involvement throughout the research cycle. Echoing a participant's sentiment, active engagement of both community leaders and members is crucial for

successful community relationships and partnerships. One participant underscored the importance of inclusivity, stating,

> Making sure everyone is at the table when you [begin] programming, bringing the resources to the community, and making sure that we reach the decision makers in town . . . to make sure that people who are decision makers are at the table and the community is aware of the time place and the events . . . so that everybody's on the same page.

Subtheme: Familiarity. FGPs placed value in research investigators establishing connections with influential figures in their community, prioritizing familiarity over formality. The creation of the CAB emerged as central to this objective with participants unanimously underscoring its importance. FGPs consistently emphasized the need for high recognition of the research investigators, especially the Principal Investigator (PI), within county leadership and community circles. Notably, one participant stressed the importance of demonstrating unity among the PI, research investigators, and CAB members to enhance community acceptance of the study. "By going into the [local community group] and talking to them with [PI] and having us there they can recognize people in the community and . . . [be more] willing to accept the study as we're doing."

Facilitator and Barrier: Trust

Participants underscored the significance of investing time and resources in thorough training and empowerment of CAB members as experts in the research subject matter. Establishing trust within the community was identified as crucial for fostering authentic community partnerships and conducting effective research.

FGPs pointedly highlighted the trust gained from their community's recognition and expressed their readiness to leverage their societal standing to facilitate coordination between the community members and the research team. One participant articulated this sentiment, stating:

> Because we are in the community, people know our face. It would probably be safe to say a great deal of them trust us . . . it's going back to that trust factor and making sure that you understand how important. We can work along with you all to move this forward as that connection between you guys and the community.

Subtheme: Limited knowledge and mistrust. FGPs identified mistrust as a pervasive barrier to research participation, citing concerns about researchers entering, collecting data, and leaving without feedback or information on the application of the collected data. This sentiment, rooted in historical indiscretions and perceived dishonesty of researchers, particularly affects minorities in their community. Participants stressed the "outsider" perception of researchers, emphasizing the importance of conducting research with, rather than on, their communities. One participant articulated the impact of community involvement in dispelling mistrust, stating,

> [to researcher] . . . even though you're coming from [surrounding city] you're still considered an outsider . . . when people in the county see their own residents participating, you know, like [name of CAB member] and [name of CAB member] and me showing up at these events that makes a big difference because that way, if you can make them trust you they're more likely to participate.

FGPs emphasized the need for researchers to be cognizant of historical misconduct to prevent a repetition of past grievances, ultimately preserving trust. They consistently reiterated mistrust, lack of familiarity with

the research process, and uncertainty about research outcomes as significant barriers. One participant suggested targeted efforts to address this specific group's apprehension and increase participation:

> There's a certain demographic that has more . . . fear surrounding research . . . and it's because of some unethical practices in the past, so I really think that there are certain people that we need to probably focus on targeting more because they will be less likely to participate.

Furthermore, another participant emphasized unfamiliarity with the research process among community members, accentuating a critical gap in knowledge:

> Distrust may just come from how the data may be used on the other side of it, and again just specifically mentioning comments from folks who you know may fear that the results, the data . . . may be used to paint a negative light of their community.

Another participant highlighted how unfamiliarity contributes to uncertainty about trusting the research:

> The biggest thing is just people not being familiar with that type of . . . process and what it entails, and . . . whether it is something that . . . they can trust or not trust, or you know just kind of what it requires of them and just not having knowledge about it.

Facilitator and Barrier: Communication

Ensuring clear and transparent communication emerged as a fundamental theme. Specifically, FGPs underscored the necessity for investigators to transparently convey how and why the collected data would be utilized to inform future health practices or interventions within their community:

> Being very upfront and very open about the goals for information for the research [and being] very clear about the sources of the research, [and] the source of the funding [for] the research. The folks who are going to be using the data . . . what they're going to be using it for.

There were two subthemes addressing communication: transparency and strategic engagement.

Subtheme: Transparency. Transparency was particularly salient, with participants advocating for clear and consistent communication regarding the goals and purposes of the research project. One participant highlighted the importance of clear communication about the potential benefits for participants, suggesting that a transparent articulation of these benefits could mitigate existing barriers:

> All the communications are clear about the benefit to a potential participant if they see a clear benefit, you know, for them, you know as that's being communicated . . . it's more likely that they won't fortify . . . whatever barriers may be there.

Subtheme: Strategic engagement. The development of a strong rapport by the PI within the community emerged as a key factor in enhancing community involvement. One participant stated, "going to go into the community where they are located is the best way and having [PI] come." highlighting the significance of the PI physically entering the community, among the most effective approaches for fostering community engagement.

Furthermore, FGPs expressed the belief that the PI's active involvement, particularly through talks and transparent communication about research expectations, played a crucial role in sustaining engagement.

FGPs highlighted the effectiveness of "going where the people are," prioritizing physical spaces such as barber shops, local clubs, organizations, and community centers for optimal recruitment and retention. While recognizing the potential of social media, the consistent sentiment emphasized reaching research targets through active engagement in familiar spaces, aligning with the concept of "going to the people rather than them coming to us."

Hard to Reach Populations

From the FGPs responses, it was evident that individuals ages 25 to 40 and men may be considered hard-to-reach populations. One participant emphasized the challenges in reaching the age group of 25 to 30, highlighting their heavy engagement with social media platforms such as Instagram and Facebook. The quote, ""I know the twenty-five-year-old's [are not] readers [unlike] the seasoned ones who like the [news] paper . . . You know they are on Instagram and Facebook, they do that," suggests the difficulty in traditional outreach methods for this demographic. Additionally, another participant underlined the need to target young people at specific events like trail rides, blues shows, and racetracks, indicating a preference for more unconventional approaches to engage this population. "I'ma tell you where young people are from what I can see. They're at these trail rides, blues shows and they at the racetrack. That's where they are . . . and we gon have to go there."

Regarding men as a potentially hard-to-reach population, the suggestion of targeting sporting events, particularly football games, and male fraternities acknowledges where men within the community gather. Repeated emphasis on tailgating events underscores the importance of visibility and accessibility to attract men's attention within the community.

"Setting up a tailgate spot at football games . . . would probably be a big thing for like visibility from that standpoint." Another participant remarked, "Target fraternity groups that have some influence in the community . . . They have other men's groups . . . so try to find those groups [that] can influence . . . some participation."

Reaching Target Number of Participants

The FGP responses strongly conveyed the meaningfulness of reaching the target number of participants in the study. They collectively expressed an optimistic stance toward the target number, acknowledging both its feasibility and importance. "I think that that's a great number if you set a goal for that. You had a reason for [target number] so that's your goal then use it and get more if necessary . . . the more the better." And as another participant stated, "I'm just happy that we got some individuals that are interested in it and supporting it . . . shoot for the moon, if you don't get it you'll be in a number of more than what you started off with."

One participant mentioned community competitiveness, suggesting exceeding the target number was not only plausible but also a testament to the community's commitment. Another participant highlighted the target number's significance, stating that achieving it would signify effective dissemination of research information.

> [Goal] number is very important because to me saying that we have basically succeeded . . . because when you meet the target number it means that the work that we've been doing up until actually doing the research has been effective.

Furthermore, participants stressed the target number's importance for accurate and representative data in the diverse experiences of rural areas. Meeting or exceeding the target number is seen not just as a numerical achievement but as a measure of the study's impact, outreach, and community engagement. These perspectives highlight the value of achieving the desired participant count for comprehensive and

reliable information from county residents. "It will mean a lot to [name of county] to see what our problems are and what our strengths are with health . . . I think it would help them understand the importance of being healthier than what we really are." According to a different participant, "When it comes to all kinds of things, including health outcomes . . . I think, making sure that that number is achieved is going to be very important to making sure there's proper representation."

Conclusion

This study identified three overarching themes—relationships, trust, and communication—as key factors influencing research participation in rural communities. These themes, identified through narrative data provided by FGPs, exhibit a dual nature, functioning as both facilitators and barriers depending on the contextual dynamics reported by participants. Along with associated subthemes, they provide valuable insights and confirm the nuanced nature of research participation in rural settings.

Strong relationships were pivotal for research participation, particularly within small, close-knit communities. The absence of such connections was recognized as a potential barrier. Participants valued preserving the distinctive close-knit fabric of their communities. Their focus on community involvement throughout the research cycle, both from leaders and members, not only promotes inclusivity but also strengthens connections among community members, aligning with their core values. Additionally, familiarity is valued, advocating for research investigators to establish connections with influential community figures, prioritizing familiarity over formality.

Trust is crucial, and participants emphasized the need to invest in and empower selected CAB members through thorough training. Participants noted that leveraging their societal standing as well-known figures can facilitate coordination between the community and the research team. Mistrust, stemming from historical indiscretions and perceptions of researcher dishonesty, disproportionately affects minority communities and was identified as a significant barrier. Overcoming this requires dispelling mistrust through community involvement and conducting research with, rather than on, their communities.

Communication, specifically through transparency and strategic engagement, is fundamental. Participants stressed the importance of clear, consistent communication about research-project goals. A strong rapport by the PI in the community, achieved through active involvement and transparent communication, enhances community engagement. Physical spaces like barber shops, local clubs, and community centers are valued for recruitment and retention, aligning with the concept of "going where the people are."

The identification of hard-to-reach populations, particularly individuals ages 25 to 40 and men, underscores the challenges in traditional outreach methods. Targeted efforts, including social media engagement and innovative approaches, tailored to the community's lifestyle, are paramount for effective engagement.

Finally, participants placed a significant emphasis on reaching the target participant number. Seen as both achievable and surpassable, it is a meaningful indicator of community involvement in the study.

These findings indicate that successful engagement of rural participants in research requires strategic and deliberate groundwork, demanding a profound understanding of the unique facilitators and barriers within each community.

Moreover, this investigation highlights the significance of meeting research goals in rural communities. Leveraging their tight-knit social bonds, these communities serve as staunch advocates for one another. By synergizing this advocacy with external resources from research teams, perceived barriers such as transportation challenges, limited access to healthcare, and educational gaps can potentially be overcome.

This study provides a region-specific, qualitative exploration of the facilitators and barriers to research participation in rural communities. It enriches the field with in-depth insights, community voices, and

practical implications that can contribute to more effective and culturally sensitive approaches in research engagement.

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