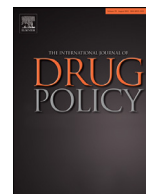




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Research Methods

Lessons learned recruiting a diverse sample of rural study participants during the COVID-19 pandemic



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ABSTRACT

Residents of rural areas have been a hard-to-reach population for researchers. Geographical isolation and lower population density in rural areas can make it particularly challenging to identify eligible individuals and recruit them for research studies. If the study is about a stigmatizing topic, such as opioid overdose, recruitment can be even more difficult due to confidentiality concerns and distrust of outside researchers. This paper shares lessons learned, both successes and failures, for recruiting a diverse sample of rural participants for a multi-state research study about naloxone, an opioid overdose reversal agent. In addition, because our recruitment spanned the period before and after the COVID-19 pandemic in the U.S., we share lessons learned regarding the transition to all remote recruitment and data collection. We utilized various recruitment strategies including rural community pharmacy referrals, community outreach, participant referrals, mass emails, and social media with varying degrees of success. Among these modalities, pharmacist referrals and community outreach produced the highest number of participants. The trust and rapport that pharmacists have with rural community members eased their concerns about working with unknown researchers from outside their communities and facilitated study team members' ability to contact those individuals. Even with the limited in-person options during the pandemic, we reached our recruitment targets by employing multiple recruitment strategies with digital flyers and emails. We also report on the importance of establishing trust and maintaining honest communication with potential participants as well as how to account for regional characteristics to identify the most effective recruitment methods for a particular rural area. Our suggested strategies and recommendations may benefit researchers who plan to recruit underrepresented minority groups in rural communities and other historically hard-to-reach populations for future studies.

Introduction

Recruiting research participants in rural areas can be challenging as rural populations have been identified as a historically hard-to-reach population (Boag-Munroe & Evangelou, 2012). Several factors make recruitment difficult, including geographic isolation, unique cultural and social aspects of rural settings, and low population density (Bigbee & Lind, 2007). In rural communities, researchers are often regarded as outsiders, which creates fundamental distrust of their motives, resulting in low recruitment and participation rates (Lim, Follansbee-Junger, Crawford, & Janicke, 2011). Additionally, the relative lack of anonymity and limited transportation and access to technology, including high-

speed internet, are common barriers when recruiting rural residents (Aylward et al., 2012; Bigbee & Lind, 2007; Lim et al., 2011). For researchers working with rural participants, it is important to consider these factors and apply creative strategies in order to facilitate recruitment (Cudney, Craig, Michols, & Weinert, 2004).

There is limited literature discussing recruitment strategies for rural participants, especially regarding a stigmatizing topic like opioid overdose. Although rural residents account for only 20% of the U.S. population, the opioid overdose death rate in rural areas has increased at a faster rate than in urban areas (Mack, Jones, & Ballesteros, 2017; Rigg, Monnat, & Chavez, 2018). Previous literature from nursing has described factors that can improve recruitment and retention of rural

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Table 1
Number of study participants from various recruitment strategies.

| | Alabama | Iowa | North Carolina | Wisconsin |
|-----------------------------------|------------|-----------|----------------|------------|
| Total participants (N=81) | 40 | 15 | 11 | 15 |
| Pharmacy referrals | 21 (52.5%) | 5 (33.3%) | 4 (36.4%) | 13 (86.7%) |
| Community outreach | 17 (42.5%) | 2 (13.3%) | Not used | Not used |
| Participant or personal referrals | 2 (5%) | 0 (%) | 7 (63.6%) | 2 (13.3%) |
| Mass emails | 0 (%) | 8 (53.3%) | Not used | Not used |
| Social media | 0 (%) | Not used | 0 (%) | Not used |

patients with chronic conditions. These factors included accounting for the importance of outreach efforts like using local recruiters who live in the area, engaging trusted local community members, like physicians, and addressing travel distance and transportation issues (Aylward et al., 2012; Pribulick, Williams, & Fahs, 2010; Young, Barnason, & Do, 2016). A sensitive and stigmatizing research topic can present additional barriers to recruitment due to confidentiality concerns and the relative lack of anonymity in rural areas. Indeed, a study in individuals with substance use disorders found that those living in rural areas were more concerned about the confidentiality of their responses and more reluctant to provide even cross-street addresses compared to those living in urban areas (Rudolph, Young, & Havens, 2017). Potent and pervasive stigma in rural areas was one of the key factors that affected the location where rural participants used opioids and their own strategies to prevent an overdose (Fadanelli et al., 2020).

In this paper, we describe the effectiveness of various recruitment strategies in recruiting diverse rural participants for a multi-state research study on opioid overdose and naloxone. We then provide lessons learned for recruiting rural participants for future research about sensitive topics. Additionally, because recruitment for this study spanned the COVID-19 pandemic, we discuss how recruitment plans were adjusted to address and overcome the unexpected challenges faced during the pandemic.

Naloxone communication study

Our study's purpose was to identify barriers and facilitators to patient-pharmacist communication about naloxone and to explore rural patients' preferences for naloxone discussions. We aimed to recruit rural patients who filled prescription opioids at a community pharmacy and were considered at high-risk of opioid overdose (Dowell, Haegerich, & Chou, 2016) and their caregivers. Caregivers were defined as third parties who obtain naloxone for someone who takes opioids or those who live with a person who they perceive to be at risk of overdose. As the non-white percentage of the population varied significantly between the four states, our goal was to recruit at least 24 (30%) non-white patients and caregivers, which was the average non-white percentage across the four states, to ensure that diverse perspectives on naloxone communication preferences were captured. The final sample included 26 non-white participants (8 patients, 18 caregivers), including 23 African American/Black participants and 3 American Indian/Alaska Native participants. Ultimately, a convenience sample of 81 rural participants (40 patients, 41 caregivers) were recruited from four states: Alabama, Iowa, North Carolina, and Wisconsin. Each of these states has a standing order or statewide standing protocol that allows pharmacists to dispense naloxone to individuals without the need for an individual prescription (Roberts, Carpenter, Smith, & Look, 2019). Rurality was defined based on the 2010 Rural Urban Commuting Areas (RUCAs) (U.S. Department of Agriculture, 2020).

Patients were eligible if they had an opioid prescription with a high daily morphine milligram equivalent (greater than or equal to 50 MME); had an opioid prescription and a co-prescribed benzodiazepine; had an opioid prescription and a naloxone co-prescription; or had purchased naloxone at the pharmacy. Eligible caregivers were not required to live

with the person who they perceived to be at risk of an opioid overdose. Once consent was obtained, a telephone or Zoom interview was scheduled. The interview was audio-recorded, and participants received a \$30 incentive. Interview data were used to develop an online naloxone communication training module for rural pharmacists. The study was approved by the University of North Carolina's Institutional Review Board and reliance agreements were executed for sites in other states.

Recruitment strategies and outcomes

Recruitment took place from November 2019 to November 2020. We organized recruitment strategies into five categories: community pharmacy referrals, community outreach, participant referrals, mass emails, and social media. We started with the community pharmacy referrals as a main modality, and other recruitment strategies emerged as the COVID-19 pandemic evolved (Table 1).

Pharmacy referrals

We engaged rural community pharmacists to refer potential participants. Community pharmacists utilized internal pharmacy records to identify eligible patients and/or caregivers. When potential participants arrived at the pharmacy, the pharmacist briefly introduced the research study and shared a study flyer. If individuals wanted to learn more, pharmacists collected their contact information and shared it with the research team. The conversation regarding the study took place in a private setting, and participants contact information was transferred to the researchers through HIPAA-compliant tools, such as encrypted fax or web-based application (e.g. REDCap). Then, state-specific research team members contacted individuals via email or phone, provided more details about the study, and conducted a formal screening to confirm eligibility. An individual's final decision to participate was not shared with the referring pharmacists to protect confidentiality. We provided pharmacies an incentive (\$500-750 per pharmacy or \$25 per eligible participant who completed an interview) to thank them for their referrals.

This modality was a productive means of recruitment; 26 patients and 17 caregivers were recruited using this method. Since pharmacists were the linkage between patients and the study team, referred patients seemed to trust the researchers, understand the importance of the study, and express a high willingness to participate. Although some patients could not remember their medications at the time of the eligibility screening by study staff, pharmacists had already screened these referrals for medication-related eligibility (e.g., opioid dose, naloxone history, etc.) by utilizing the pharmacy's dispensing records. This strategy's success was also partly due to the fact it was used by all four states for a longer duration compared to other strategies.

Despite its overall success, we encountered several challenges with this modality. Recruitment had to be integrated into the busy workflow of community pharmacists. The COVID-19 pandemic reduced in-person pharmacy visits, which restricted patient-pharmacist interactions and significantly delayed new referrals. In addition, we lost some referrals to follow-up. Although the exact cause is unknown, these individuals might

not have wanted to participate in the research but agreed to offer their contact information to avoid disappointing their pharmacists. Alternatively, individuals may not have recognized researchers' phone numbers and not answered their phones. In addition to robocalls and spam calls, individuals may have been more wary of unknown callers due to an influx of political communications during the 2020 election year. The participants recruited through pharmacist referral tended to give positive feedback on their pharmacists and pharmacy services, which might indicate their responses could be biased compared to others recruited independently without pharmacists.

Community outreach

We also used active recruitment strategies by directly contacting organizations in rural communities in Iowa and Alabama.

Local businesses

Finding a central location that many people in a rural town visit was key. After getting permission from store owners, study staff placed tear-off advertisement sheets in local stores' front windows, and at gas stations. Tear-offs were also posted at several post office community boards, where ads can be placed without need for approval. The tear-off sheets contained a brief study description, inclusion and exclusion criteria, and study contact information. To reduce the impact of stigma, the sheets did not mention the term "overdose". Other areas (e.g., restaurants, community centers) were considered, but due to widespread pandemic-related closings the locations were closed or had limited foot traffic.

The flyers at local gas stations yielded some response even during the pandemic. With limited foot traffic, we were still able to reach potential subjects; 1 patient and 1 caregiver were recruited in Iowa with this method. However, we failed to get any response from rural community stores and post offices. Our flyers may not have received much attention since there were numerous other flyers posted in these locations. Also, even if patrons visited the establishment, they may not have seen the message boards.

Community organization - the National Association for the Advancement of Colored People (NAACP) Alabama Chapter

To utilize grassroots recruitment efforts, we contacted the office of the Alabama NAACP and discussed the purpose and value of the study. We asked how the NAACP could promote the study and ultimately assist in identifying potential participants. The President invited us to attend their next virtual state-level board meeting and share the call for study participants. The electronic flyer was presented at the board meeting and eligibility criteria were shared. The flyer was distributed to all board members and meeting attendees to distribute within their rural communities.

This strategy was useful in Alabama; yielding 5 patients and 12 caregivers. This method capitalized on "word-of-mouth" advertising in several rural communities. Potential participants appeared very interested in the study and more comfortable with participation because the referral was provided by someone they personally knew. This approach was effective despite being 100% online and using an electronic flyer. This strategy enabled us to recruit individuals of color living in rural areas, which helped us achieve a more diverse sample. The NAACP was glad to assist with finding participants and serving as a conduit for both community engagement and scholarly research.

This strategy did involve the greatest amount of personal interaction and one-on-one engagement. Access to committee members and the leadership team required additional time to make the initial connection and build rapport and trust in the community.

Participant referrals

All four states utilized "snowball sampling" or "chain referral" where active participants assisted with additional recruitment either through

referral or sharing the study flyer with others. After completing the interview, researchers asked participants to share the recruitment flyer and/or study staff contact information with anyone else they knew who might be interested in participating. These referrals were then screened for eligibility.

This strategy was fruitful in recruiting 4 patients and 7 caregivers in Alabama, North Carolina, and Wisconsin. Like the pharmacist referral, this method allowed for a similar "warm handoff" by known and trusted individuals to prospective participants. Without prompting, some participants even volunteered to refer others or share the flyer after having a positive interview experience themselves.

This strategy also had limitations. Some participants might have felt uncomfortable broaching the topic of opioids or overdose with others in their social network. For this reason, study staff made it clear they should reach out to others only if they were comfortable doing so. Some participant referrals were ineligible or uninterested in participating after learning more about the study. While an incentivized snowball method has been successful in recruiting stigmatized populations, we decided not to incentivize recruitment due to our participants' privacy concerns (Heckathorn, 1997).

Mass emails

Mass emails were used in Iowa and Alabama. The listserv service at the University of Iowa was used to email about 45,000 people. The email contained a brief description of the study, inclusion and exclusion criteria, and a request to email or call the study team. In Alabama, the Alabama Area Agencies on Aging (AAA) agreed to include the flyer in two issues of their electronic newsletter that reached all 13 AAA Directors and Ombudsman with a readership of over 2,000.

This method was effective at reaching many people easily and quickly. In the final interviews, 3 patients and 5 caregivers in Iowa were identified using this method, although it did not generate any inquiries in Alabama. The emails were easy to distribute and recipients could easily share the study by forwarding the email. This was convenient given many of the initial recipients did not meet inclusion criteria. Email was also unaffected by the pandemic as it did not involve in-person contact.

One of the biggest challenges with this modality was finding participants who met the rural eligibility requirement. Although the subscribers of the University of Iowa listserv included the general public, a large proportion of them were University of Iowa students, staff, and faculty who were not living in a rural area. This resulted in study staff spending substantial time screening ineligible individuals.

Social media

During pandemic lock downs, we pivoted to use Facebook to reach patients and caregivers who might be isolating at home. The Facebook post included the recruitment flyer and directed interested individuals to contact study personnel. The study team did not engage or track prospective participants within the social media platform as it was used only to distribute the flyer (passive recruitment). In order to maintain privacy, the flyer was posted to private community groups in rural North Carolina and Alabama as well as public groups of rural churches in Alabama. The post was configured so it could not be shared and that no one could comment on it, which ensured individuals could not be tagged in relation to the post. Interested participants had to contact the study team via phone or email in order to learn more. Facebook was chosen over other social media platforms due to increased privacy control options such as disabling comments, tagging, and sharing.

This strategy was deemed unsuccessful. Though fairly large (between 2000-8000 members) and highly trafficked Facebook groups were selected with potentially hundreds of views, no study participants were recruited using this method. Though the research team believed that the financial incentive for an at-home interview would appeal to rural individuals who were unable to leave their homes during the pandemic,

Table 2
Lessons learned on recruiting rural participants on a stigmatizing topic.

| | |
|----|--|
| 1. | Engage local health care providers and organizations as recruitment sites <ul style="list-style-type: none"> • Rural community pharmacies, practice-based research networks (PBRNs) • Offer incentives to serve as a recruitment site |
| 2. | Identify and approach trusted local community organizations in rural areas <ul style="list-style-type: none"> • Describe the value of the study • Provide materials that the organization can distribute |
| 3. | Invest in establishing trust and maintaining honest engagement with study participants <ul style="list-style-type: none"> • Describe how their opinions are valuable • Describe how the study will respect privacy and maintain confidentiality |
| 4. | Select recruitment methods for a rural region based on a careful review of that region's characteristics <ul style="list-style-type: none"> • What organizations/businesses do rural community members frequent and trust • Consider both active and passive recruitment methods |
| 5. | Be adaptable to unexpected situations and consider alternative recruitment strategies <ul style="list-style-type: none"> • Be willing to try new strategies – they may work • Do not make assumptions about access to reliable Internet of phone service to allow for remote data collection |

there were likely several challenges that contributed to the lack of this strategy's success. First, private local groups were not specific to patients or caregivers, so many group members were likely ineligible. Secondly, most of the groups required that you live in or have a familial or historical link to the area for which the "local" groups were designed, but staff members did not live in that rural location. Finally, individuals may not have had sufficient trust in or knowledge of the research or university to comfortably disclose private personal or medication-related information, potentially even more so within a social media platform. This may contrast with email recruitment through the university where individuals already have an established relationship with the university and voluntarily signed up for email subscriptions.

Discussion

Rural communities experience significant health disparities (Knapp, Paavola, Maine, Sorofman, & Politzer, 1999); thus, recruiting research participants from rural areas is crucial to understand their experiences and create effective solutions to address their specific health care needs. This paper aimed to contribute to the limited knowledge on effective recruitment strategies in rural areas, by identifying effective recruitment strategies for rural populations that have been underrepresented in clinical research (Winter et al., 2018). We make several recommendations for researchers who seek to recruit rural participants (Table 2).

First, it is important to engage local health care providers and organizations, including rural community pharmacies, as recruitment sites. Community pharmacists are often the most accessible health care professionals in rural communities. Rated as one of the most trusted professionals (Gallup, 2020), pharmacists can build rapport with rural community members who visit their pharmacies an average of 14 times per year (Berenbrok, Gabriel, Coley, & Hernandez, 2020). As such, they are well-positioned to identify eligible patients, introduce studies and eligibility criteria, and provide referrals. Rather than initiating communication with a stranger, potential participants may feel more comfortable communicating with a researcher referred to them by their pharmacist. We worked with community pharmacists in our study because the study was about patient-pharmacist communication on naloxone. Our experience confirmed pharmacists can be a good resource to engage rural participants. We believe it is important to offer community pharmacies a recruitment incentive since referring study participants takes away time from revenue-generating activities. As practice-based research networks (PBRNs) continue to expand beyond physician practices, pharmacy-based PBRNs can serve as a potential resource for connecting researchers with pharmacies that can assist with participant recruitment and referral. One such network, the Rural Research Alliance of Community Pharmacies (RURAL-CP), is exclusive to rural pharmacies (<https://ruralcp.web.unc.edu/>).

One concern with pharmacy recruitment is potential coercion. Participants may feel like their willingness to participate in the study could affect their relationship with their pharmacist or their ability to fill their prescriptions at the pharmacy. When using this recruitment modality, careful consideration should be given to the study protocol and informed consent to minimize the possibility of coercion or undue influence. Pharmacists should be given a recruitment script to ensure that discussions about the study are not coercive, and pharmacists should let potential participants know that their decision to participate will not affect their relationship with the pharmacist or pharmacy. Additionally, researchers should not share names of study enrollees to protect patient confidentiality.

Secondly, we encourage researchers to work with trusted local community organizations in rural areas to assist with recruitment. Several organizations were excited to assist with recruitment and shared that it was only the first or second time that researchers asked for their support. Leaders in these organizations were welcoming once they understood the value of their engagement and support. Working with a local chapter of a large organization like the NAACP proved especially helpful for recruiting diverse participants.

Thirdly, researchers should establish trust and maintain honest engagement with study participants. Gaining access to rural communities and individuals that might be reluctant to speak with an unknown individual proved to be a challenge in our study. Some participants shared their privacy concerns, especially as it related to others learning about their use of opioids in their close-knit community. Others shared they were concerned they were not qualified to assist with scientific research. We found that discussing the need for every participant's feedback and contribution was key to recruitment success. We tried to assure individuals that their perceptions were valued and that there were no right or wrong answers to interview questions. It was also important for researchers to provide timely follow-up with eligible individuals to keep them interested in participation and address any concerns or questions.

Fourth, we recommend selecting recruitment methods for a rural region based on a careful review of that region's characteristics. We found some strategies, like passive recruitment, were successful in one state but not others. For example, in Iowa, the use of email was a productive recruitment strategy, and this could be due to the community's familiarity with research recruitment emails from the university. The emails were sent through the University of Iowa and the university partners with critical access hospitals in rural areas, which are trusted organizations in rural Iowa. There are many rural community members that commute to work at the University or its outlying clinics, which may have contributed to the success of email recruitment. In Alabama, personal and community outreach were effective methods for recruitment. Finding a foothold in the community was key to building trust and rapport. Once the researchers had support from trusted community leaders, word-of-mouth referrals increased. This also greatly assisted in reaching and enrolling underrepresented minority study participants. Building

initial trust and demonstrating why the researchers valued the perspectives of community members was successful after previous efforts, like passive social media postings, had failed.

Lastly, researchers need to be adaptable when unexpected situations arise and consider alternative recruitment strategies. As the pandemic unfolded, we needed to shift recruitment and data collection to adhere to public health and IRB guidelines. While in-person data collection through community pharmacy referrals was the primary recruitment strategy, adding various active and passive strategies allowed us to reach more people to achieve our recruitment goal during the pandemic. We noticed as recruitment progressed, there was a shift from reluctance to participate in the online interviews to more openness to the online format. We postulated that increased participant comfort with telehealth and the use of technology to connect with others led to this change.

There are limitations in applying these lessons learned to other studies due to the scope of this study. Recruitment did not include all opioid users as those who misuse opioids are less likely to utilize pharmacy services to obtain their opioids. To reach these populations, other modalities of recruitment may be more successful than those discussed here. There was a lack of systematic sampling of those who use opioids in rural areas which limits our knowledge of whether or not this is a representative sample. Due to privacy concerns it was not possible to systematically recruit patients using medical or pharmacy records. This is a limitation but representative of real-world situations.

Traditionally successful recruitment methods such as incentivized recruitment was not feasible in this population due to lack of opioid use disclosure to friends, family, or peers among patients with prescribed opioids. Utilizing a University listserv was helpful in some populations and not in others, limiting its overall usefulness. While emails may reach many ineligible people, the surrounding community can also be reached this way. While this method was useful in Iowa due to the geography and diversity of listserv members, this is not the case for all University listservs.

Conclusion

Though rural participants can be hard-to-reach and rural areas pose unique recruitment barriers, several different recruitment modalities can help researchers identify, contact, and recruit a diverse sample. Overlooked, yet valuable strategies, such as utilizing rural community pharmacists and local community organizations, can help to overcome known barriers by providing a warm handoff from an accessible and trusted community member. In spite of distant locations, stigmatizing topics, or unforeseen circumstances such as global pandemics, recruitment protocols can be adapted to reach rural participants. Our suggested strategies and recommendations may benefit researchers who plan to recruit underrepresented minorities, including those living in rural communities.

Declarations of Interest

The authors declare that they have no known competing financial interests or personal relationships that could have appeared to influence the work reported in this paper.

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