

Challenges and lessons learnt in the recruitment of rural residents for a diabetes screening program — the TREND project

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Abstract

Objective Conducting diabetes screening programs in rural areas represents unique challenges with respect to participation of the rural residents. This study focussed on understanding the real-life challenges encountered and lessons learnt in the recruitment of rural residents for a population-based cross-sectional study in Tamil Nadu, South India.

Methods In-depth interviews (IDIs) were conducted among a multidisciplinary research team comprised of field investigators ($n = 8$), field technicians ($n = 8$), telemedicine technicians ($n = 2$), and site coordinator ($n = 1$) who worked in the TREND study (Telemedicine PRoject for screENing Diabetes and its complications in rural Tamil Nadu). The IDIs explored the real-life challenges and potential strategies used to facilitate a high response rate in the recruitment of rural participants through a semi-structured guide. IDIs are conducted for 35–40 min and recorded after obtaining consent from each staff. The recordings were then transcribed into text, coded, and analysed using thematic analysis through NVIVO software version 10.0.

Results A total of 10 IDIs were conducted. Seven major themes such as lack of awareness; transportation issues; stigma — fear of being diagnosed with diabetes; distrust on healthcare providers; cultural beliefs and practices; language barriers; and competing priorities were identified as the reasons for inactive participation. Building rapport and trust, patience and counselling skills aided the staff to handle non-respondents. Display of pamphlets in the public places, the village head's support in campaigning, helped in the active participation of rural residents.

Conclusion By identifying and addressing barriers to participation, healthcare providers and community stakeholders can work together to improve the health of rural communities.

Keywords Challenges · Recruitment · Screening · Diabetes · Rural · TREND · Tamil Nadu

Introduction

Diabetes is a chronic disease that affects millions of people worldwide, and its prevalence continues to increase, particularly in low- and middle-income countries [1]. According to the World Health Organization (WHO), diabetes has become one of the leading causes of death worldwide, with an estimated 4.2 million deaths in 2019 [2]. The recent estimates of the nationally representative Indian Council of Medical Research-India Diabetes (ICMR-INDIAB) Study based on 31 states/union territories of India reported that 101 million adults now have diabetes [3] which is much higher than the earlier estimates of IDF, Diabetes atlas 10th edition [4]. The ICMR-INDIAB study reported the overall prevalence of diabetes to be 11.4% and prediabetes to be 15.3%, while the prevalence in rural areas reported to be 8.9% [3]. Though the prevalence of diabetes continues to be higher in urban

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areas when compared to rural areas of India, there are strong evidences which shows that rural areas are fast catching up with the increasing prevalence of diabetes in the recent years [5–8]. As the prevalence of diabetes increases in rural areas, it is important to focus on the effective diabetes screening for diabetes, to uncover the large numbers of undiagnosed diabetes [9].

Early detection through screening has been shown to improve health outcomes in individuals with diabetes, including reducing the risk of complications and improving the quality of life [10]. However, diabetes screening programs in India face several challenges, which can limit their effectiveness in identifying individuals at risk of developing diabetes or those with undiagnosed diabetes. These challenges include limited access to healthcare services, low awareness of diabetes and its risk factors, cultural beliefs, and limited resources for diabetes screening and management [11]. As the research team holds the primary responsibility in the recruitment of the study participants for any kind of screening programs, interviewing them can provide valuable insights on the recruitment process, including the strategies used to recruit participants, barriers to participation, and solutions to overcome these barriers [12]. Understanding the recruitment challenges can help in conducting effective diabetes screening programs [13]. Hence, in this study, we aim to describe the challenges encountered and lessons learnt in the recruitment of rural residents for a diabetes screening program.

Methods and Materials

Study design: The **Telemedicine P**roject for **screENing Dia**betes and its complications in rural Tamil Nadu (**TREND**) study was a large cross-sectional study conducted in 30 villages of Chengalpattu and Kancheepuram districts of Tamil Nadu state to assess the prevalence of diabetes in the rural South Indian population which involved 15,091 individuals between 2018 and 2021. The multidisciplinary research team consisted of 19 staff including field investigators ($n = 8$), field technicians ($n = 8$), telemedicine technicians ($n = 2$), and a site coordinator ($n = 1$).

Study team

The study staff was recruited from nearby local villages who have qualified with a relevant basic undergraduate degree and who reflect the socio-cultural background of the rural community. The field investigators were responsible for administering questionnaires and anthropometric measurements. The field technicians were responsible for biochemical testing and storing of sample procedures. The telemedicine technicians were responsible for screening diabetes

complications in the telemedicine van, while the site coordinator was responsible for the smooth co-ordination of the study at each village. The study team was fluent in Tamil, the local language, and received intensive training in the study testing procedures before the commencement of the study and at every 6 monthly intervals.

Study tool

For conducting in-depth interviews (IDIs), semi-structured IDI guide (Supplementary Table S1) was meticulously crafted which specifically aimed to gather insights regarding the program's efficacy, benefits, delivery mechanisms, and sustainability measures. This guide was designed to delve into the viewpoints of multidisciplinary team concerning various aspects of the screening program. The IDI guide was pilot-tested before the collection of data to ensure the understandability of questions to participants. This crucial step ensured that the questions included in the guide were comprehensible, relevant to the participants' experiences in the study program. Their perspectives provided valuable input for evaluating and improving the screening program, ultimately contributing to its overall success and sustainability.

Data collection

A total of 10 IDIs were carried out from June to July 2022 within the multidisciplinary research team of the TREND study. These interviews were conducted after the completion of the TREND study in the year 2021 as this period was deemed suitable for extracting insights on the challenges faced and strategies employed in engaging rural participants for a diabetes screening program. The interviews were facilitated by the primary researcher, who had received training for this purpose, along with a designated note-taker. These interviews were conducted in the local language to ensure clear communication and understanding between the interviewees and the interviewers. To create a conducive environment for open discussion, the interviews took place in a separate room. This ensured privacy and comfort for the study staff, enabling them to freely share their insights and experiences regarding the probed questions. During the interviews, a digital recorder was positioned in the centre of the table to capture the conversation accurately. This recorder was used to facilitate the transcription process and to ensure that no valuable insights were missed during the interviews.

Before commencing each in-depth interview (IDI), consent was obtained from the study staff participating in the interviews. This ensured that they were fully aware of the recording process and voluntarily agreed to participate. Following the completion of each IDI, the interviewers initiated the transcription process promptly. This involved transcribing the recorded conversations verbatim into written text,

allowing for a detailed analysis of the data. After conducting a total of 10 IDIs, thematic saturation was achieved. This means that no new or significant information was emerged from the interviews, indicating that a comprehensive understanding of the challenges and strategies related to involving rural participants in the diabetes screening program had been attained. As a result, further interviews were not considered necessary. Thematic saturation served as a criterion for determining the sufficiency of data collection, ensuring that the research objectives were adequately addressed. The findings were representative of experiences encountered during the study period by the study team.

Data analysis

The audio recordings of the interviews were transcribed verbatim, ensuring that the original language, including key terms, phrases, and local proverbs, remained unchanged. This approach preserved the authenticity and richness of the data. After the transcription, the primary researcher meticulously reviewed the transcripts to ensure accuracy and completeness. Thematic analysis was employed to analyse the data, through NVivo software version 10.0. This analysis involved identifying patterns, themes, and meanings within the data. Two independent coders, referred to as moderator 1 and moderator 2, were involved in the analysis process. The coding process involved both deductive and inductive approaches. The deductive approach used for identifying codes anticipated from existing literature, while the inductive approach allowed for the identification of new codes that emerged directly from the data. Once the initial coding was completed, emerging themes were reviewed by all

authors. Through multiple discussions, notes, and memos, the authors collaboratively grouped the codes into the most prominent themes. Throughout the analysis, the moderators continuously observed for confirmatory and contradictory evidence of the identified themes. This iterative process helped ensure the reliability and validity of the findings.

Results

Recruiting rural participants for diabetes screening programs posed several challenges that can encumber program success. The thematic content analysis led to the identification of major key issues that impact the study participants' recruitment. On further analysis, these major issues were consolidated into seven main themes that mapped onto major components of the study: (1) lack of awareness, (2) transportation issues, (3) stigma, (4) distrust of healthcare providers, (5) competing priorities, (6) cultural beliefs and practices, and (7) language barriers. In some villages, the recruitment team encountered barriers at each of the seven levels identified, although they differed from village to village. Themes and word cloud obtained from the study on challenges and the lessons learnt are described in Figs. 1 and 2.

Lack of awareness

Challenges

One of the major challenges in recruiting rural participants for diabetes screening programs was the lack of awareness about the program. Most of the staff from the multidisciplinary

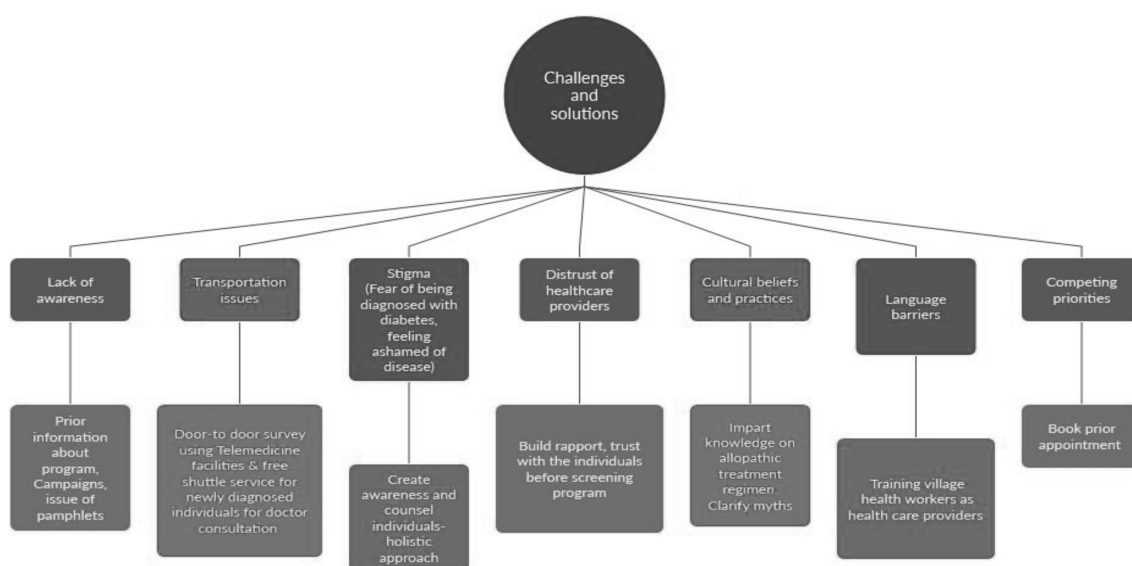


Fig. 1 Themes of barriers and solutions in the recruitment of rural population for a diabetes screening program



Fig. 2 Word cloud depicting the multidisciplinary research team's experiences on the challenges encountered and solutions obtained in the screening of rural population

research team reported that rural residents were not aware of the importance of diabetes screening programs due to inadequate promotion, low literacy levels, and limited access to health information sources and this was identified as one of the reasons for non-response. The spread of false messages and lack of awareness hindered the participation of the rural residents in the program and led to missed opportunities for early detection and intervention.

Lessons learnt

Prior information about the screening program such as announcing the date, time, and venue boosted participation. This was done with the support of the village head. A notification letter in the local language with the details of venue, date, and time was countersigned by the village head and stuck in the village office so that the rural residents are aware of the screening program in advance. A diabetes awareness pamphlet was developed in the local language and was distributed to each household before the day of screening. Detailed information regarding diabetes and its complications, the rising prevalence of diabetes, and program benefits were included in the pamphlet and displayed in common public places such as public distribution systems, village administrative offices, provision stores, and tea shops thereby creating awareness and improving the response for the participation.

Transportation issues

Challenges

Majority of the staff reported transportation as a significant barrier to accessing healthcare services in rural areas as they live far from healthcare facilities, and public

transportation may be scarce or non-existent. That was the major reason for the increasing prevalence of diabetes in the rural population. Most of them agreed that transportation of individuals with diabetes for further treatment was challenging.

Lessons learnt

A strong study design, i.e. door-to-door survey was the major enabler for the highest participation in the screening program. Furthermore, telemedicine facilities aided in avoiding missed appointments for healthcare services and increased participation.

Stigma

Challenges

Nearly half of the staff reported the prevailing stigma associated with diabetes. The rural population felt discouraged from participating in diabetes screening programs as they have the fear of being diagnosed with diabetes if they get tested in screening camps. It was reported that the majority of the rural residents often view diabetes as a personal failure or a consequence of poor lifestyle choices leading to feelings of embarrassment and inadequacy. This perception made individuals feel ashamed and reluctant to participate in diabetes screening programs.

Lessons learnt

To overcome these stigmas, the study team educated the rural communities about diabetes. Several informal public awareness talks were given to impart knowledge on diabetes in the places (100-day work scheme) where people mostly gather. Individual counselling also helped in overcoming misconceptions and beliefs about diabetes.

Distrust of healthcare providers

Challenges

Most of the staff reported that distrust of healthcare providers was the major reason for non-response to screening programs. Rumours; use of abusive words; misconceptions about blood tests, i.e. the spread of diseases; misconceptions about free screening programs; and past negative experiences with medical care facilities stemmed trust on the whole.

Lessons learnt

Building rapport and trust was the major facilitator. After understanding the reasons for distrust, the study team followed a more targeted approach to encourage participation in screening programs which includes providing culturally sensitive, language-appropriate health education, addressing past negative experiences, and involving village heads in healthcare initiatives.

Competing priorities

Challenges

Half of the study staff reported that rural residents often faced competing priorities that made them prioritize diabetes screening. These competing priorities include work, family responsibilities, and other health issues, particularly if they do not perceive diabetes as a significant health concern and cultural beliefs that discourage seeking medical attention until symptoms become severe.

Lessons learnt

To encourage and promote participation, the study team visited each village resident before the day of the screening campaign. Study pamphlets were distributed to each household to create awareness about diabetes. Emphasis was made on free screening tests, door-door screening, free transportation services to and from screening locations in case of bigger villages, and extended screening hours to accommodate work schedules.

Cultural beliefs and practices

Challenges

All the study staff agreed that cultural beliefs and practices were other significant barriers for the participation in a diabetes screening program. Traditional beliefs about health and illness, including the use of traditional therapists and remedies, affected the willingness of rural populations to participate in diabetes screening programs. Few of the rural residents felt diabetes is a punishment for past sins, and looking for medical care was considered redundant or a sign of weakness. Additionally, the use of traditional remedies for diabetes, such as herbal remedies, was more effective and less harmful than current medicine.

Lessons learnt

The cultural barriers for diabetes screening were identified and addressed by the healthcare providers through counseling. It is important to emphasize that healthcare providers

do understand and respect their cultural beliefs and practices. Creating peer support groups of individuals with self-reported diabetes was also effective in increasing participation rates as they were ready to share their life experiences in diabetes management.

Language barriers

Challenges

Language barriers were the least reported challenge. Though the rural population speak regional languages or dialects, they may not be fluent in the official language of the state, which is typically used in healthcare settings. The lack of language proficiency leads to misunderstanding and miscommunication between healthcare providers and rural residents, which also affects the quality of care and the willingness to participate in diabetes screening programs. Some of them were reluctant to seek care or participate in screening programs if their distress is being misunderstood or not being able to communicate their concerns effectively.

Lessons learnt

To address language barriers, the study team provided elaborate information about the study procedures and ensured that communication with them was effective and clear. This involved the use of study materials translated into local language, including study questionnaires, consent forms, patient information sheets, pamphlets, and brochures, to help patients understand the importance of diabetes screening and management. Majority of the study staff that belonged to the rural study areas were recruited and trained as field investigators. In addition, the cultural and linguistic needs of the study population such as using simple, jargon-free language and avoiding medical terminology that may be unfamiliar to the study population were considered.

New emergent themes

Some of the newly emerged themes were identified from the IDIs conducted among multidisciplinary research teams in terms of staff level benefits/program levels benefits and were categorized into (1) connecting communities, (2) innovative outreach, (3) empowering women, and (4) digital inclusion.

Connecting communities The staff members were encouraged by the project lead to create mutual partnerships with local primary healthcare centers, village panchayat heads, village administrative officers, and leaders to create a more holistic and comprehensive approach to recruitment. Building trust and relationships with rural communities and the feedback given by them helped in the improvement of the program.

Innovative outreach Frequent study team meetings by the team head showed ways for the staff members to come up with creative and innovative ways to reach and engage with rural populations. The village head was informally aided in the mass communication of screening camp dates through a traditionally followed messenger system called “Dandora” (a localized communication system to disseminate important instructions to the residents of a village through village assistants). This in turn was noted trustworthy, and many non-respondents reverted to the screening camps for further blood tests.

Empowering women Focusing on strategies to target women participants in each household from rural areas boosted the active participation as the majority of the non-respondents were influenced due to past negative medical experiences.

Digital inclusion Staff members were invigorated to explore the use of technology, to manage the entries of daily recruitment status in the common data share point which in turn helped in the further follow-up of the non-respondents. Continuous engagement and monitoring of daily recruitment status further enhanced the increase of the daily recruitment count.

Discussion

This qualitative study has provided important insights on the real-world challenges encountered and lessons learned when recruiting rural residents for a diabetes screening program, as seen through the eyes of a diverse research team. The main challenges faced and approaches adopted to ensure active involvement of rural residents are summarized as follows: lack of awareness, transportation issues, stigma, distrust of healthcare providers, competing priorities, cultural beliefs and practices, and language barriers were the challenges encountered. To address these, strategies such as creating awareness about the disease, using posters or pamphlets for promotion, providing flexible schedules for the screening camps, establishing rapport and trust, patience, counselling, considering cultural beliefs and practices, providing clear information on the study procedures in a simple language, and promotion of screening camps through village leaders were the potential strategies aided for the successful recruitment. Researchers strongly recommend that developing trust with participants, involving community members, and implementing effective recruitment tracking mechanisms are crucial strategies for successful recruitment [13, 14].

Earlier studies underscore that assessing the healthcare provider’s belief is important as it can directly impinge on the willingness of potential participants for screening [15,

16]. Likewise, evidence from the study conducted on cervical cancer screening in rural Tamil Nadu highlighted that enhancing health literacy via community awareness can mitigate low participation rates in screening programs [17]. In addition, a review addressing facilitators and barriers to the screening of South Asians in health research studies identified language barriers, fear of adverse health screening outcomes, and mistrust of research as commonly associated challenges, which resonated with findings of our study [18]. A study on assessing the recruitment strategies for a weight management program in rural populations reported partnering with community health centres, social support, and free transportation are reasons for the successful retention of study participants [19]. In our study, collaborating with community village leaders to disseminate information regarding screening schedules emerged as the most effective strategy in achieving our desired recruitment targets. This strategy capitalized on established community networks and local leadership, fostering trust and engagement among residents.

Evidence from a previous study highlights the significance of fostering trust and providing complimentary transportation aided in facilitating successful recruitment and a high response rate for a diabetes retinopathy screening model among both rural and urban in developing nations [20]. Similarly, in our study, establishing trust and developing rapport with rural residents served as a pivotal approach during the initial phases of the recruitment, which extended over a span of 3 years. To surmount barriers to participation, the team exercised patience, consistency, and employed counselling techniques, eventually nurturing an environment wherein rural participants felt increasingly at ease in sharing their personal narratives with the research team. While the process of building rapport and trust may be time consuming and energy-intensive, it lays a robust groundwork for executing subsequent interventions and contributes to the long-term sustainability of the program.

In our study, majority of the non-respondents preferred traditional medicine over modern medicine due to various factors such as easy availability, low cost, and less side effects. In line with this, evidence has shown that approximately 80% of individuals in developing countries rely on traditional remedies as their primary solution for various health issues [21, 22]. One of the study findings emphasize the importance of establishing relationships with community leaders as an effective strategy for overcoming recruitment barriers as reported by earlier studies [23]. In the present study, to encourage active participation in the screening program, some of the local community volunteers were involved in distributing posters and informative pamphlets which resulted in improved understanding of the disease, and similar outcomes were observed in a different study on assessing healthcare providers’ perspectives on screening for gestational diabetes mellitus [24]. These approaches can

contribute to the cultivation of trust and rapport with the rural population, facilitate the dissemination of diabetes-related information in a culturally sensitive manner, and encourage community involvement in diabetes prevention initiatives.

Conclusion

In rural India, barriers to diabetes screening include lack of awareness, misconceptions, distrust of healthcare providers, competing priorities, and cultural beliefs. Overcoming these challenges necessitates tailored interventions such as culturally sensitive health education, strengthening rural healthcare infrastructure, and implementing free diabetes screening initiatives. Engaging community leaders, utilizing posters, and fostering community participation are effective strategies for enhancing diabetes prevention and management in rural areas.

Strengths and limitations

This qualitative study aided in an in-depth understanding of the challenges and lessons learnt in recruiting rural populations for diabetes screening programs and provided rich, detailed data and a more nuanced understanding of the factors that affect recruitment. Significance of the study lies in its ability to put these findings into context by delving into the cultural and social dynamics that influence recruitment in rural areas, thereby guiding the development of targeted and culturally sensitive recruitment strategies. Flexibility in data collection allows for the exploration of new themes and ideas which have not been uncovered through a more structured research approach. It is highly meaning-centric which prioritizes the perspectives of the participants and cannot be generalized to the wider population. Limited sample size, time, and resource constraints are some of the limitations of this study. Furthermore, it is essential to consider the viewpoints of non-respondents and community leaders to enhance the triangulation of study findings regarding non-participation, a factor that has been inadequately addressed in the current study.

Supplementary Information The online version contains supplementary material available at <https://doi.org/10.1007/s13410-024-01342-4>.

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Author contribution VM, CP, RMA, and RP conceived the study, provided scientific inputs, and reviewed the manuscript critically for important intellectual content. RP and NL were involved data acquisition and execution of the field work. NL conducted the literature search, data transcription, and coding and was involved in manuscript preparation, editing, and revision of the drafts. RP reanalysed the coding of NL

for data accuracy. HR reviewed article and provided inputs wherever necessary. RMA and RP provided substantial contributions to the interpretation of data and revision of the manuscript. VM and RP are the guarantors of this work and had full access to all the data in the study and take responsibility for the integrity of the data and the accuracy of the data analysis. All authors read the final draft of the article and contributed to it.

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Data Availability The dataset will be available upon request unless there are legal or ethical reasons for not doing so.

Declarations

Ethical approval This study was approved by the Institutional Ethics Committee of the Madras Diabetes Research Foundation, Chennai, India (MDRF/NCT/04-03/2022).

Informed consent disclosure Informed consent was obtained from all patients for being included in the study.

Conflict of interest The authors declare no competing interests.

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