



Planning, implementing, and evaluating morbidity management and disability prevention (MMDP) using community-based research with patients and frontline service providers in Nigeria

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Key messages

Nigeria bears a disproportionately higher burden of Africa's neglected tropical diseases (NTDs). For many of the people affected, a lack of access to morbidity management and disability prevention (MMDP) services and delayed identification often result in significant physical and psycho-social impacts.

NTD intervention programmes have predominantly focused on preventive treatment through mass administration of drugs (MDA). However, there are critical gaps in addressing the needs of people affected by NTDs, particularly as we move to a post-elimination phase. Sadly, most frontline healthcare workers lack the requisite training, knowledge, and resources to provide adequate care and management of these conditions, while in communities, a lack of awareness of the disease, socio-cultural beliefs, and stigma often hinder access to care.

Using a community-based participatory research (CBPR) approach, we identified several social and structural barriers to accessing health services for persons affected. Working with health systems stakeholders, affected persons and community health workers as co-researchers, we collaboratively generated potential solutions to address these challenges. Two areas for intervention were prioritised as awareness within the community and training of health workers in case management of NTDs, including a component on stigma and providing sensitive care. Intervention was co-designed and evaluated using a mix of participatory data collection approaches.

Formative research findings showed barriers to accessing healthcare services included poor knowledge of the cause of illness, misinformation, cultural or traditional beliefs, poor health literacy, fear of surgery, long distances, difficult terrain, lack of transport, and stigmatising attitudes of health workers.

Learnings from this study showed that routine health programmes such as MDAs can be adjusted to incorporate new MMDP intervention ideas to address the barriers to health services for persons affected with NTDs. This was possible from our experience with Benue State (which had no funds for MMDP programme), where training intervention for health workers using revised health worker training guide were incorporated into MDA planning process and then co-delivered during MDA. MDAs, therefore, hold potential for being more than just a platform for routine distribution of medicines, as they can also serve as a channel for implementing changes that impact on overall NTD programming.

Planning and evaluation of new health interventions can become more inclusive, participatory, and effective, through engagement of different stakeholders such as NTD researchers, programme planners and affected persons who bring their unique experiences, strengths and perspectives into the intervention planning process, ensuring their voices are heard.

The CBPR approach from this study was very well received, and effective in redressing hierarchies and in managing the power dynamics within the research team. The participation of affected persons and community health workers as co-researchers at all points in the research cycle, including during participatory data analysis, enabled individuals who are deeply embedded in communities and with significant lived experience to shape emerging themes, provide contextual insights, and ultimately bolstered their confidence in shaping the design of health interventions that are beneficial to them.

Background

Nigeria accounts for one fourth of Africa's neglected tropical diseases (NTDs) burden, which affects the most marginalised and poorest communities in the world (Yashiyi, 2019). A critical need of affected people is a lack of access to MMDP services, resulting in delayed identification with significant physical and psycho-social impacts. Affected persons often attend treatment at health facilities at the latter stages of disease once symptoms become severe and have the potential to cause life-altering morbidity and disability.

In most NTD programmes, issues commonly exist that implementers or beneficiaries can solve, but are usually not given the opportunities to proffer solution. This research sought to evaluate and develop MMDP services in Nigeria to be responsive to patient and provider perspectives using community-based participatory research approaches in a participatory action research cycle.

Methods

The study design was community-based participatory research (CBPR) with a mix of different qualitative research approaches. CBPR involves respectful collaboration, mutual dialogue, shared decision-making among community members in planning, data collection, analysis and dissemination (Greenwood et al., 2016). CBPR was implemented within the framework of a participatory action research (PAR) cycle, fully integrated with the Federal Ministry of Health's natural programme planning and implementation process. This approach enabled co-researchers, including people with disabilities, to identify key problems and solutions to modify policy and programmes to best meet their needs, as well as participated in creating that change.

Setting: Kebbi and Benue states, Nigeria

Kebbi State was selected for having an existing MMDP programme, while Benue State was selected because an MMDP programme was being planned to commence there. LGAs that reported relatively low therapeutic coverage were identified through analysis of existing programmatic data in collaboration with the State Ministry of Health and six were selected from the two states (3 LGAs respectively).

Research phases

The research was conducted in the four phases, as shown in figure 1:

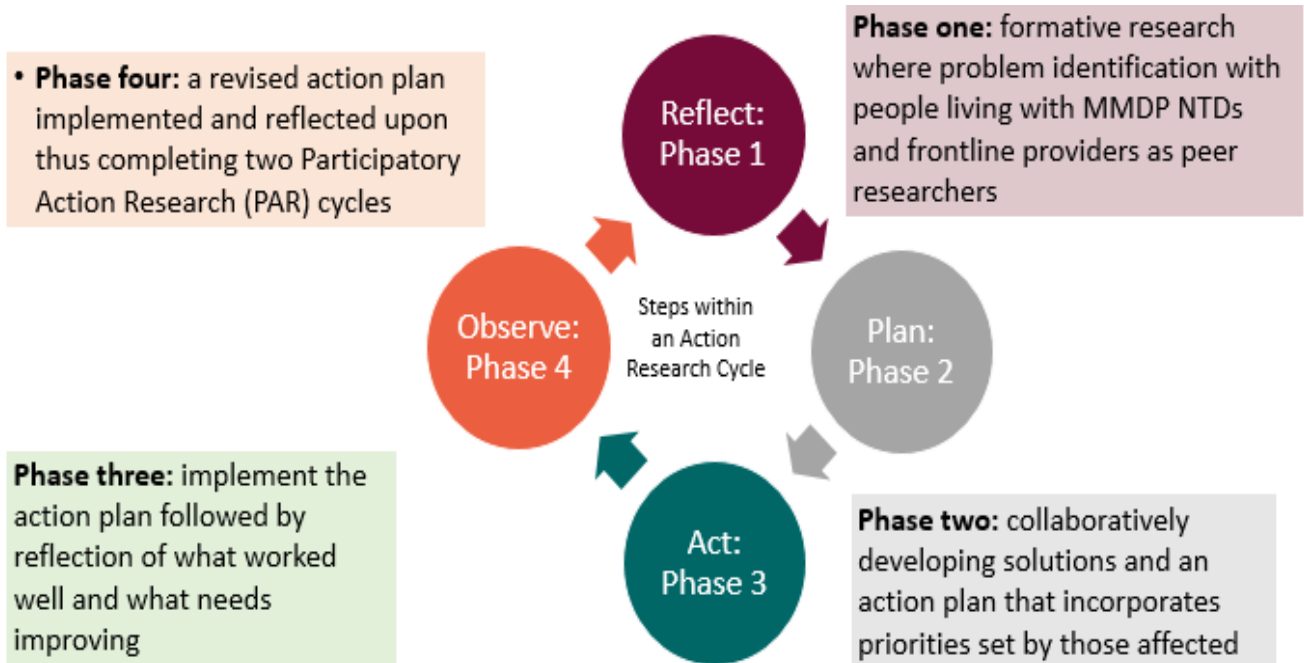


Fig.1 Phases of research

Data collection

Data were collected for only two of the phases as summarised in table 1. A predesigned discussion guide was used to collect qualitative data during the formative research, while questionnaires were developed to evaluate health workers' knowledge during the evaluation of their training.

Table 1: Data collection for each of the research phases

Phases	Objectives	Data collection activities
Formative research	Understand the lived experiences of persons affected by NTDs.	12 illness narratives with patients. 12 interviews with household family members.
	Explore the barriers to accessing healthcare services.	6 focus group discussions (FGDs) with affected patients. 12 FGDs with community health workers. 12 FGDs with clinic-based providers.
Evaluation of intervention	Evaluation of health worker training using the training guide.	Pre-test and post-test (after training and six weeks). 4 FGDs with trained frontline health workers (FLHWs) after 3 weeks. 4 FGDs with trained FLHWs after 6 weeks. 12 narratives with FLHWs.
	Evaluation of information, education and communication (IEC) materials.	13 FGDs with stakeholder groups: community leaders, religious leaders, youth leaders, women leaders, health workers, persons affected.

Data analysis

Qualitative data: FGDs, narratives and reflective workshops were recorded digitally and transcribed verbatim into English. Data was analysed thematically using a framework approach. For the formative research, the Levesque framework approach was used. This coding framework was applied to the data using NVivo; charts were developed, which summarised the data analytically by themes and states.

Quantitative data: pre, post, and six-week tests were analysed using comparison of mean scores, t-tests and a one-way analysis of variance (ANOVA) conducted in Stata. Participants with incomplete test scores – missing either pre, post or late post test scores were dropped from the analysis. Post-training evaluation forms were analysed using simple descriptive percentages.

Research findings

Research findings are presented for each of the research phases:

Phase 1: formative research

Formative research was conducted with co-researchers (persons affected with NTDs, frontline health workers and family members of persons affected) to collaboratively identify the challenges associated with living with NTDs and explore the various barriers to accessing healthcare services.

Findings from the formative research about patient health seeking pathway were based on the Levesque framework, presented from both the patients' and healthcare workers' perspectives.

Table 1: shows the findings from formative research from both patient and health workers' perspectives

Patients' perspective	Health workers' perspective
<p>Ability to perceive: Patients viewed the cause of their illness through the lens of dominant belief systems that are deeply rooted in traditional / religious beliefs. Misinformation was a reason that deterred the need to seek treatment.</p>	<p>Approachability: Affected persons were less likely to approach health services due to being unaware about diseases and services available to them, including lack of information from health workers.</p>
<p>Ability to seek: Many affected persons had the feeling of being ashamed to attend health facilities, for fear of exposing their condition, which puts them at risk of being ostracised by family and community members. Worsened by stigma, affected persons are usually isolated, leading to anxiety and depression.</p>	<p>Acceptability: The gender of health care providers was reported as a critical factor in persons accepting treatment, health workers having a key role in supporting patients to gain their trust and accept health care.</p>
<p>Ability to reach: Although affected persons may be able to perceive the need to seek healthcare, many are unable to physically reach health facilities, due to long distances and difficult terrains. Physical mobility of affected persons was mentioned widely as a hindrance to accessing healthcare.</p>	<p>Availability and accommodation: Lack of trained health workers and ill-equipped facilities hinder the ability to provide appropriate healthcare. Structural barriers were also highlighted as challenges in service delivery. Poor working environments can result in unmotivated staff.</p>
<p>Ability to pay: Poverty is a priority challenge for many, both health workers and cases. Many affected persons described growing up in low-income households in the illness narratives. The physical impact of these illnesses often results in debilitating symptoms, which render many patients unable to work.</p>	<p>Affordability: The financial and opportunity costs of health workers shape access to health services, due to their availability and motivation to provide services. Poverty affects the majority of affected persons, rendering many unable to afford treatment.</p>
<p>Ability to engage: Individuals are more likely to gain better access to care and health information if they had a wider social circle through support from family, neighbours, and friends. Affected persons reported frustration and desperation of seeking care from informal and formal healthcare sectors. Confidence and trust in the health provider were factors that enabled patients to continue to seek care.</p>	<p>Appropriateness: The lack of clinical knowledge and training on case management diseases were major challenges faced by health workers. Poor attitudes serve to discourage patients from continuing treatment.</p>

Phase 2: Dissemination of findings and solution generation

Following analysis of the formative research data, a dissemination workshop was held to present findings of formative research with programme implementers. Cartoon illustrations were used to facilitate the discussions on the findings of the formative research. Potential solutions to address the gaps and barriers to healthcare seeking were collaboratively discussed with affected persons and community health workers.

Prioritisation of solutions to address these barriers were generated, and action plans were developed.

Phase 3: Intervention design

A nine-person intervention working group, made up of co-researchers including FLHWs, persons affected, senior researchers from Sightsavers, and SMoH/LGA teams, was set up to develop and implement the intervention.

Kebbi State

Two areas were prioritised for intervention in Kebbi State:

1. Sensitisation within the community using revised IEC materials and short video clips. New IEC materials (digital flipbook and posters) were developed using some of the cartoon illustrations. The key message from the materials was about sensitising and raising awareness about NTDs – the causes, agents, and available treatment of these conditions at the health facility.
2. Training of health workers in NTDs case management, using a revised health workers training guide, which incorporated information on mental health, gender sensitisation, and NTDs in general. It contained three key messages: be aware, be empathetic and be supportive. There were also additional messages about home-based care, gender sensitive care, NTDs, and disability.



A: Revised IEC Materials for community awareness



B: Revised Health workers Training Guide

Benue State

Three intervention areas were prioritised for integration into the MDA process: revision and updating of IEC materials, to include key messages for dissemination of information on NTDs in the community, with cartoon illustrations adapted as part of IEC materials; integrated training manual for health workers, to include information on MMDP and water, sanitation and hygiene initiatives (WASH); and home-based care training for caregivers.

Phase 4: Implementation and evaluation of intervention

Piloting of intervention

The intervention implemented were health worker training and validation of the IEC materials. The intervention was piloted and evaluated in one LGA of Kebbi State. Zuru LGA was chosen, it being one of the LGAs where the formative research was conducted.

The training of health workers was facilitated using the revised health workers' training guide over two days, with 47 participants in attendance. Training featured sessions on identification and management of NTDs, as well as practical sessions.

In Benue State no intervention was carried out.

Evaluation of intervention (health worker training guide)

Pre- and post- test evaluation of health workers' knowledge: Table 3 shows the test scores from the pre-test, post-training test, and six weeks after training among trained FLHWs to assess their knowledge change. It shows a statistically significant increase in knowledge change from baseline to post-test.

Baseline (pre-test) score	Post training test score	6 wks post test score	F-test
17.8/39 (46%)	21.9/39 (56%)	26.7/39 (68%)	F=31.3, p<0.001

FGDs and narratives with health workers

Findings from FGDs / narratives with FLHWs showed that health workers' experienced behaviour changes because of training. Findings showed improved health workers' attitude and understanding of an affected person's illness, as well as empower during patient interaction and referrals. Health workers expressed increased confidence and scope in managing NTDs, as well as bolstered confidence in educating community members.

Health workers also expressed satisfaction with the content of the training, including the training guide, the presentation slides, and practical demonstrations, as they helped information retention. The manual was found to be very useful as a reference material to consult when faced with any patients with symptoms of NTDs, as well as to cascade training to colleagues, leading to reduced workloads. They did opine that training guides should be produced with more durable material and, if possible, in the form of a table calendar (flipchart format) for easy referencing.

The inclusion of stigma and gender sensitivity information into the training guide equipped FLHWs with skills and knowledge to educate community members about stigmatisation, and

to provide support to affected persons. During a reflective section, health workers expressed that training be conducted periodically, not just a one-time occurrence, which can be achieved by integrating the training of health workers about MMDP into the MDAs process going forward.

FGDs and narratives with community leaders (evaluation of IEC materials)

Participants were generally happy with the simplicity of the language used in the IEC materials. Some, however, felt the use of only Hausa language for the posters and flipbook was insufficient, especially in the communities where locals only understand / read in the local dialect.

The use of community leaders and community health extension workers (CHEWs) to distribute the IEC materials was favoured; posters can be placed in public places (churches, schools, mosques etc). They also favoured the use of social media as an effective means of distributing the videos, especially with people who have access to an internet-enabled device.

Illustrations in the IEC materials were relatable, especially among affected persons, and helped in reducing stigma around the conditions. However, some participants believed the IEC lacked the additional information that would be helpful in explaining causes of disease. Participants also expressed the need to replace all cartoon illustration with real pictures of human photographs on the poster, for better understanding and appreciation.

Other observations included: length of videos to be less than one minute, align pictures with the message or diseases being displayed, include English subtitle when speaking in local language, cartoon illustrations can be made into animation to make them more interesting and interactive, ward development channels (WDC) should be added as part of the distribution plans.

Recommendations

Using the CBPR approach to continue wider engagement with persons affected, FLHWs and community groups when designing and implementing health systems interventions; the voices of these community groups often provide broader insight on how interventions can be best implemented in those settings.

Utilising the already existing MDA platform for integrating innovative health systems interventions (e.g. training of health workers on MMDP, using the health workers' training guide from this study) can be conducted during MDA (create extra days for this training during preparation). This will provide health workers an avenue for much-needed refresher training on management and care of NTDs.

Greater sensitisation/mobilisation at community levels to address barriers and perceptions about NTDs, using innovative tools such as the revised/evaluated IEC materials and digital flipbook developed from this study.

The need for refresher trainings for FLHWs in the care and management of NTDs, using a revised training guide such as the health workers' training guide from this study, which addresses aspects of care, including inclusion, stigma, and gender sensitivity.

Conclusion

The CBPR approach has helped in identifying barriers to accessing healthcare services by affected persons from their perspective and the perspective of health workers, as well as in developing a suitable intervention that addresses these barriers in a mutually benefiting way.

The intervention developed with co-researchers proved highly effective, of good quality, and useful to health workers. Evaluation results also showed improvement in health workers' confidence and scope of disease management.

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We work with partners in low and middle income countries to eliminate avoidable blindness and promote equal opportunities for people with disabilities.

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