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COUNTDOWN
Calling time on Neglected Tropical Diseases

Nigeria Situational Analysis | Brief 1

Community Engagement in Neglected Tropical Disease Treatment in Nigeria: Rethinking the needs of varying contexts

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The COU**NTD**OWN project conducted an NTD situational analysis between February and April 2017 in Kaduna and Ogun States, Nigeria. The study consists of a literature review, a policy review and a qualitative component. Findings were triangulated and synthesised into key outcomes, presented in this series of 4 briefs. This brief presents results regarding community engagement successes and challenges as perceived by stakeholders at all levels of the health system (National, State, Local Government Area (LGA) and Community) in Nigeria. More about the situation analysis methods can be found in the Executive Summary (web address).

Involving the community as primary stakeholders in NTD implementation can help attain and sustain wider treatment coverage[1]. In Nigeria, NTD programme implementation—specifically mass administration of medicines (MAM)—draws heavily on the community-directed intervention (CDI) model. **MAM is designed to engage community input through advisory committees or coalitions that are involved in decision making.** These groups nominate and reward their own community-based distributors, who assist in tailoring interventions towards specific target groups[2,3]. As the community are both the target of the intervention and a primary stakeholder in its implementation, their engagement in the programme at all levels is crucial.

Findings: Community engagement is critical for success

The CDI approach, which underpinned the response to onchocerciasis, is based on community involvement and ownership. It is the standard model for all NTD MAM activities in Nigeria, though the CDI model has evolved to allow for the integrated distribution of some medicines.

Key Messages

- Disrupting factors such as community fatigue of the NTD programme, requests for incentives by community leaders, and religious or spiritual beliefs surrounding NTDs, challenge community mobilisation efforts, resulting in reduced programme acceptance and uptake.
- The decline of visible morbidity associated with NTDs (a key programme success), combined with persistent beliefs in traditional causes and treatments, leads to low perceived need for Mass Administration of Medicines (MAM) and contributes to the rejection of MAM in some communities.
- Side effects and severe adverse events after MAM lead to anxiety about the NTD programme and can cause rejection of MAM. Effective implementation of pharmacovigilance guidelines (particularly for praziquantel), can overcome such challenges.
- The perception of more immediate development needs, such as food, drinking water, or infrastructure, are barriers to community engagement with the NTD programme. Communities desire a more holistic approach to development.
- The community engagement strategy, which contributed to past success in programme acceptance, is no longer meeting all the needs of varying and emergent contexts.

National officials have been satisfied with CDI and felt it laid a strong foundation for all NTD intervention delivery. **All national level interviewees stressed the importance of community engagement for the successful implementation of the CDI strategy** in Nigeria. They perceived that strong community engagement was due to 1) framing onchocerciasis as a leading cause of low quality of life, 2) committed health workers who provided education on the causes and consequences of the disease at the community level, and 3) the visible impact of disease within communities.

A holistic development approach will help sustain and attain positive MAM outcomes

In Kaduna State, strategies for community engagement had been successful for many years, as reported by actors at all levels of the health system and reflected in treatment data. Infrequent implementation of the relatively new NTD programme in Ogun State led to much lower levels of community engagement overall.

However, community directed distributors (CDDs) in both Ogun and Kaduna States reported a reduction in community engagement and acceptance of NTD interventions. They attributed this to competing community priorities such as better infrastructure, provision of food, safe drinking water, and fertilisers. Poverty was frequently cited as the main concern of the target communities.

'if we get to the community some of the elders will say they are hungry and we are giving them drugs do we want hunger to kill them, do we want them to use the drug on an empty stomach'

Participatory meeting with CDDs, Abeokuta North LGA, Ogun State

Informants perceived that communities were more reluctant to accept MAM and engage with the NTD programme when other development needs were not being addressed. This suggests an integrated, multi-sectoral approach could contribute toward attaining and sustaining positive MAM outcomes.

Factors affecting implementation of the Community-Directed Intervention model

CDI successful model for community engagement

Disrupting factors reducing community engagement

Rural homogeneous populations

Alternative contexts: urban, border regions

Mobilisation on effects of NTDs

Decrease in morbidity; changing priorities

Involvement of community structures and leaders

Community fatigue, demotivated staff, leaders expect incentives

Community engagement

Poor management of side effects of newly integrated medicines

Programme acceptance and uptake

Declining NTD associated morbidity threatens engagement

Frontline health facility staff in Kaduna and CDDs in Ogun reported that some communities had a strong memory of onchocerciasis-related blindness. Understanding that MAM could prevent this disability made community members likely to accept it. However, the converse was more common. **A key success of the NTD programme is a significant reduction in morbidity prevalence due to NTDs. Participants reported that communities perceived less need for MAM over time and were therefore wary of taking it**, although treatment is still required. Community engagement was difficult, programme acceptability was low, and there were many refusals by community members to take medicines during distribution.

Furthermore, **in Ogun, medicine refusal was exacerbated by attribution of NTDs to non-medical causes**, and beliefs that traditional treatments were more appropriate. This resulted in community perceptions that the medicines were not beneficial. In Kaduna, the deworming programme had initially been challenged by traditional beliefs but community sensitisation and mobilisation led to programme acceptance.

'For instance, a lot of people might believe that whoever contracted lymphatic filariasis had stepped on something diabolical and treatment must be spiritual'

Participatory meeting with CDDs, Abeokuta North LGA, Ogun State

The acceptability of medicines was higher where there were evident intrinsic benefits to the community members. In some instances, these were known to be true ancillary benefits such as reduction in bed bugs and lice. In others, these were linked to community perceptions such as descriptions of enhanced sexual performance.

Poor management of side effects leads to rejection of MAM; implementation of pharmacovigilance guidelines and tailored community sensitization efforts can help

Side-effects (mainly vomiting and dizziness) and in some rare cases severe adverse events (SAEs) were often cited as a factor that decreased acceptability of MAM and led to high levels of refusals. In some cases, community members reported experiencing these side-effects themselves; in other cases, they reported hearing about side-effects at the community level. Side effects were most commonly related to praziquantel (PZQ). However, **with integration of PZQ distribution to other MAMs, poor management of side effects could potentially compromise the coverage for all NTD treatments.**

'*rejection of medicines due to side effects such as vomiting, dizziness…big size of the drugs and some believe that it is for family planning'*

Participatory meeting with teachers, Igabi LGA, Kaduna State

In Ogun State, some parents asked their children not to accept PZQ. Only children whose parents had consented were treated. Teachers described how they were approached by angry parents following the distribution of PZQ, and they found it difficult to manage when children experienced side-effects after MAM. Such situations demotivated teachers and led them to believe that health workers were in a better position to deliver the programme.

In Kaduna, intensive advocacy with community leaders and immediate actions in response to side effects using the pharmacovigilance guidelines have significantly reduced community fears and led to higher programme coverage. A collaboration with the Ministry of Information has produced jingles to educate communities on the need to feed children adequately prior to MAM, and has helped to increase community willingness to accept PZQ.

'We went round to sensitize the people as to why they had the reactions and even liaised with the state media which rectified the problem of refusals'

LGA Primary Health Care Director, Kaduna State

Challenges with community sensitisation negatively impact MAM acceptability and coverage

In some contexts where the NTD programme had been implemented for many years (sometimes over 27 years), community and programme staff fatigue led to complacency and ineffective community sensitisation. This was particularly detrimental when PZQ MAM was integrated into other NTD programmes without adequate community sensitisation around side effects and their management.

'They are really complaining about praziquantel they even said that a child died as a result of taking praziquantel'

Participatory meeting with FLHF staff, Ikara LGA, Kaduna State

'in the past community leaders were all involved in passing the information to their people. Unfortunately, the level of information about this program in the subsequent years has reduced and that is why we have serious challenges with people accepting the drugs as compared to that year'

Participatory meeting with CDDs, Ijebu East LGA, Ogun State

Frontline health facility staff reported that the communal structures of rural communities in Kaduna helped with mobilisation, particularly when community leaders were engaged. In both Sates, however, there was an expectation of remuneration for the community leaders due to the comparison of the NTD programme with other health programmes (such as polio), where community gatekeepers were incentivised. Since community leaders and gatekeepers play a key role in community mobilisation and sensitisation, their poor motivation and non-participation have a negative impact.

'There is no full participation of the community leaders, most of them are expecting incentives from us before they participate because they do get from polio programme and they expect the same from the NTD programme too for that they don't give us much support during the exercise'

Participatory meeting FLHF staff, Ikara LGA, Kaduna State

Community mobilisation was reported to be particularly challenging in the areas where there were no rural community structures, or where there were difficulties in access due to challenging geography or security issues.

Ogun workshop with Community Drug Distributors

Key informants made a number of suggestions on how to access difficult to reach populations through continuous mobilisation in communal gathering points and more targeted sensitisation strategies tailored to the community needs.

'Some people come out to the towns only on market days or other special days, a lot of them are strangers. Since information does not cut across everywhere education about these drugs should be extended to them whenever they come.' ***LGA Education Secretary, Ogun state***

Limited time for community mobilisation was also described as a major barrier to effective community participation. This was often due to the delays in the delivery of medicines to the lower levels of the health system, or a very short period between the training and distribution (sometimes only a couple of days). As a result, frontline implementers are left with little time to engage with the communities prior to MAM. It also leaves limited time for the adaptation of messages for different contexts and community groups.

'On the basis of religion, some people believe that the medicine is not good and they run away from it, I mean the pupils. They told us that their parents have instructed them not to collect any drug in school. So based on their belief, based on their religious belief they didn't take it'

Participatory meeting with teachers, Abeokuta North LGA, Ogun State

Recommendations

At all levels of the NTD programme in Nigeria there is a commitment to community engagement and a recognition of communities as a primary stakeholder in the MAM implementation. This study found that community engagement, the key principle that has historically underpinned MAM has become less effective in many Nigerian contexts and **reduced community engagement negatively impacts the acceptance of medicines**. There is therefore a need to:

1. Research and update community sensitisation and mobilisation strategies which address importance of NTDs and the risk of regression from elimination targets. **It is particularly important to stress why treatment matters in contexts where morbidity is invisible and where there are many competing community priorities.** For example, in the areas where there is a low perceived need for MAM, patient advocates could be a useful tool in enhancing community awareness regarding the impact of NTDs.

2. Explore factors that contribute to poor motivation of health workers and CDDs in the delivery of community sensitisation and mobilisation activities and understand what can be done to re-motivate these cadres.

3. Evaluate community structures that are available in rural and urban settings, and migrant/border populations that would be most appropriate for mobilisation and sensitisation activities, and how these structures could be motivated to participate without financial incentives.

4. Review new and existing sensitisation and mobilisation materials to understand how they could be innovatively applied to increase programme awareness and engagement in all contexts; rural, urban, migrant and others.

5. Identify strategies for the continuous training and supervision of CDDs, teachers, and health staff to ensure strict **adherence to pharmacovigilance guidelines and in providing advice regarding the management of side effects** and SAEs associated with MAM.

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COUNTDOWN (grant ID PO 6407) is a multi-disciplinary research consortium dedicated to investigating cost-effective, scaled-up and sustainable solutions to control and eliminate the seven most common NTDs by 2020.

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