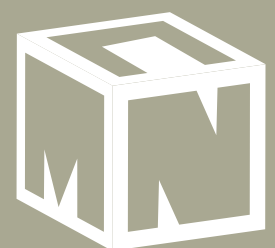

ACCESS FOR ALL

VOLUME 2:

What factors influence access
to community-based treatment
of severe acute malnutrition?

CHLOE PUETT, SAMUEL HAUENSTEIN SWAN & SAUL GUERRERO



COVERAGE MONITORING NETWORK

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Volume 2 of the Access for All series aimed to contribute to the emerging body of evidence on barriers to SAM treatment services by offering insights and experiences related to the top community-level barriers.

To do so, several analyses were conducted. First, this volume examined over 40 coverage assessments carried out by the Coverage Monitoring Network (CMN) in over 20 countries to identify common barriers to access and understand how these vary according to programmes and contexts. Next, the public health literature was reviewed to determine whether these barriers were unique to SAM treatment services. Finally, the volume incorporated findings from three country case studies in Ethiopia, Kenya and Pakistan, designed to provide complementary qualitative data and analysis on access to community-based SAM treatment, and giving a human perspective on barriers and their effect on the lives of those seeking care.

The analysis carried out on CMN-supported coverage assessments (n=44) found that the five most frequently reported barriers to access across all interventions were:

1. Lack of knowledge of malnutrition
2. Lack of knowledge of the programme
3. High opportunity costs
4. Distance to site
5. Previous rejection.

Without exception, these barriers were found to also have influenced other public health programs. Findings from the three country case studies described program and beneficiary experiences with the top five barriers identified from coverage assessments. These experiences varied to some extent with program and cultural context, suggesting that while barriers are common across programs, their causes are not only context-specific, but also household and community-specific. Findings indicate that some of the most significant barriers to access are linked to the scale-up of SAM treatment services. These include lack of awareness due in large part to limited sensitization efforts, and high opportunity costs due to services (even when decentralized and integrated into the existing health system) being located at a distance from communities.

VOLUME THREE will further explore the implications of these findings for how SAM treatment services are delivered, based on experiences of other public health interventions in addressing similar barriers.

The CMN project is an inter-agency initiative to improve nutrition programmes through the promotion of quality coverage assessment tools, capacity building and information sharing



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The first volume of this series explored the question of whether community-based treatment of severe acute malnutrition (SAM) at scale could meet global needs. To answer this question, the performance (in terms of clinical outcomes, coverage and cost-effectiveness) of community-based SAM treatment over the period between 2000 and 2013 was reviewed. Based on this analysis, the report concluded that:

1 *SAM cases admitted into treatment services today are as likely to be successfully cured as they were a decade ago.*

2 *In spite of their dependency on context-specific operational factors, MoH delivered community-based SAM treatment services continue to be cost-effective interventions.*

3 *The capacity of treatment services to meet global SAM needs depends on coverage being significant and consistently improved.*

But how can the coverage of community-based SAM treatment services be improved? Generally speaking, improving coverage requires an increase in the availability of services (i.e. increase in the number of health facilities offering SAM

treatment services) (1). Making treatment services available, however, is not the same as making them accessible to those who need them. The high number of coverage failures (<50%) reported by treatment services over the last few years (and detailed in Volume 1) suggests that to truly maximise the proportion of SAM cases receiving treatment, services must be made both available and accessible. And to do so, it is essential to identify, analyse and understand the barriers which determine access to such services. This type of coverage analysis for health services as a whole is not new (2-5), but research focusing specifically on SAM treatment is limited (6,7).

Volume 2 of this series aimed to contribute to the emerging body of evidence on barriers to SAM treatment services by offering insights and experiences related to the most-common community-level barriers. To do so, this volume explored over 44 coverage assessments from over 21 countries to identify common barriers to access and understand how these vary according to programmes and contexts. The paper also built on the findings of three country case studies designed to provide complementary qualitative data and analysis on access to community-based SAM treatment, giving a human perspective on nature of the barriers and their effect on the lives of those seeking care.

Since 2012, the inter-agency Coverage Monitoring Network (CMN) has assessed the coverage of community-based SAM treatment services around the world. Between July 2012 and June 2013, a total of 49 coverage assessments were carried out with the support of the CMN in 21 countries, or approximately a third of all countries implementing community-based SAM treatment services today (1). Of those assessments analysed (n=44), 84% were carried out in Africa¹, with the remaining 16% in non-African settings (see Annex I). The coverage assessments were predominantly (79.5%) undertaken in MoH-integrated services (with varying degrees of NGO support), with fewer (20.5%) undertaken in NGO-delivered programmes. As part of these assessments, caregivers of children with SAM who were not enrolled in a treatment programme were asked to cite the reasons for non-attendance. The first five barriers² recorded by each assessment were included in the coverage assessment reports, and the combined list from all assessments were analysed. The analysis was carried out on all assessments combined (to produce the overall list of common barriers) and according to type of implementer (NGO or MoH), coverage performance (> or < 50%) and program contexts (urban, rural or camp setting). This process identified the most common barriers, but additional research was required to better understand the barriers themselves. To do so, the CMN brought together the findings from three case-studies.

Two of the case studies focused on community-based SAM treatment interventions; an NGO-implemented programme in Tando Mohammed Khan and Badin districts (Sindh Province), Pakistan and a MoH-integrated service in Tigray Region, Ethiopia. These interventions were selected for a variety of reasons. First and foremost, they represent both of the two distinct time periods of development of SAM treatment (as outlined in Volume 1); a community-based program implemented by an NGO and a program where SAM treatment services were integrated by the MoH into other existing health services. They also rep-

resent different geographic regions (Africa and Asia) with distinct cultural perspectives. Both interventions were considered to be "successful" either due to results of recent coverage surveys or strong integration achieved with the health system. In using these criteria to select well-performing programmes, the aim was to assess the barriers that continue to arise even within a functional programmatic environment. Within these two interventions, the same analysis was conducted, using qualitative methods to assess community perspectives on the factors promoting and preventing access³. To get different perspectives on barriers to access, focus group discussions and semi-structured interviews were conducted with a variety of stakeholder groups, including community leaders, care providers and program beneficiaries. Particular focus was placed on identifying caregivers of children who had stopped attending, or defaulted from, the programme, in order to understand the barriers that ultimately prevent attendance in a variety of program contexts. These households came from areas of the program that were purposively selected as having either supportive or challenging program environments (see Annex II for more details on the methodology used in Pakistan and Ethiopia).

The third case study focused on one community-based SAM treatment intervention in West Pokot, Kenya. The MoH-integrated SAM treatment services cover the entire county including semi-dry grassland and mountainous areas with high annual precipitation which contribute to the creation of a complex set of barriers to access. The fieldwork focused on a small region around Singor, the administrative capital, an area chosen for its location between both highland and plains livelihood systems. The study, carried out as an extension of a coverage assessment, included both current and past beneficiaries as well as defaulters, and relied mainly on self-selected and voluntary focus group discussions (disaggregated by gender). Each FGD used constructed groups with similar composition; female groups comprised caregivers of current and/or past SAM cases, whilst male groups were selected on the basis of

¹As defined by the World Health Organisation. They were carried out in Burkina Faso, Cameroon, Chad, Democratic Republic of Congo, Ethiopia, Ivory Coast, Kenya, Mali, Mauritania, Niger, Nigeria, Rwanda, Senegal and South Sudan.

²While some of the findings may also apply to treatment of moderate acute malnutrition (MAM), analysis of barriers for MAM treatment or prevention services was not the purpose of this analysis.

³Because defaulters were preferentially sampled, findings therefore do not represent problems faced by all participants in each program, and negative findings do not reflect poorly on the well-performing programs selected. Rather, the challenges outlined in this report represent those households that encountered barriers, often within very challenging programmatic environments including geographically inaccessible areas.

their link to the “male-to-male” outreach component of the nutrition information project⁴. The data was collected using standardised Participatory Rural Appraisal (PRA) tools, including a seasonal calendar, future fantasy mapping, and preference ranking (pair-wise and by ways of forced periodization). The findings were triangulated with NGO and MoH staff.

Finally, a broader literature review was conducted on barriers to access affecting other public health interventions in

resource limited settings. This literature review identified barriers to access to preventative and curative services in the following public health intervention areas: malaria, HIV, tuberculosis, vitamin A, deworming, immunisations, family planning, maternal health and pneumonia, with a particular focus on synergies with the barriers to access to SAM treatment. The findings of this literature review are included in Volume 2 and 3 of this series.

BOX 1 » Case Study Services at a Glance

PAKISTAN

The project was implemented by Action Against Hunger, and had Outpatient Therapeutic Programme (OTP) sites at 11 out of 16 Union Councils⁵ (UC) within Tando Mohammed Khan and Badin districts. Services for both SAM and moderate acute malnutrition (MAM) were provided, but this analysis focuses on services for SAM. Program staff provide services weekly at the OTP site, while Community Nutrition Volunteers (CNVs) would assist with screening and sensitizing communities, and following up absentees. Each CNV had a catchment area of around 5 villages, within 5-10 km from their home. Each OTP delivered services from one static site and two satellite sites. Satellite sites were chosen based on where most beneficiaries lived, in order to bring services closer to the community. A coverage assessment conducted in February 2013 across the entire project area (11 out of 16 UCs) estimated that 62.6% of SAM cases to be covered (8).⁶

ETHIOPIA

The services were delivered by the MoH, with varying degrees of support from Concern Worldwide (from simple training, reporting, and supervision to more involvement in terms of staff, supplies, logistics) in different woredas⁷. The Concern Worldwide project was funded by the World Bank and Japan's Social Development Fund. Services were delivered both at Health Posts, which were closer to the community level and delivered basic health services, and at district-level Health Centres. The program was implemented within national health services using two levels of community-based health workers. Health Extension Workers (HEWs) are formal salaried workers within the health system; they provide treatment for SAM as part of a Health Extension Program containing 16 packages on topics such as hygiene, family health, disease prevention and control, and health education. The Women's Development Army (WDA), is a team of community-level volunteers engaged in sensitizing and mobilizing communities, as well as tracing defaulters among 30 households in their villages.

KENYA

The services were delivered by the MoH with support from Action Against Hunger (funded by ECHO and UNICEF). Pokot County lies in Rift Valley province, bordered to the North, East and West by the Arid and Semi-Arid regions of Karamoja and Turkana. The ECHO-funded programme, 'Capacity Building for Emergency Nutrition Response in Northern Rift Valley Province,' focuses on capacity building for emergency nutrition response, targeting children under 5 years, and in pregnant and lactating women. Action Against Hunger, together with the District Health Management Team, work on building the capacity of local health services to provide SAM treatment in all health facilities. As part of the package of interventions, ACF supports communities activities including the creation and strengthening of “women-to-women” and “men-to-men” groups tasked with improving awareness about treatment services. A coverage assessment conducted in September 2012 across the entire programme area estimated that 33.5% of SAM cases are covered (9).⁸

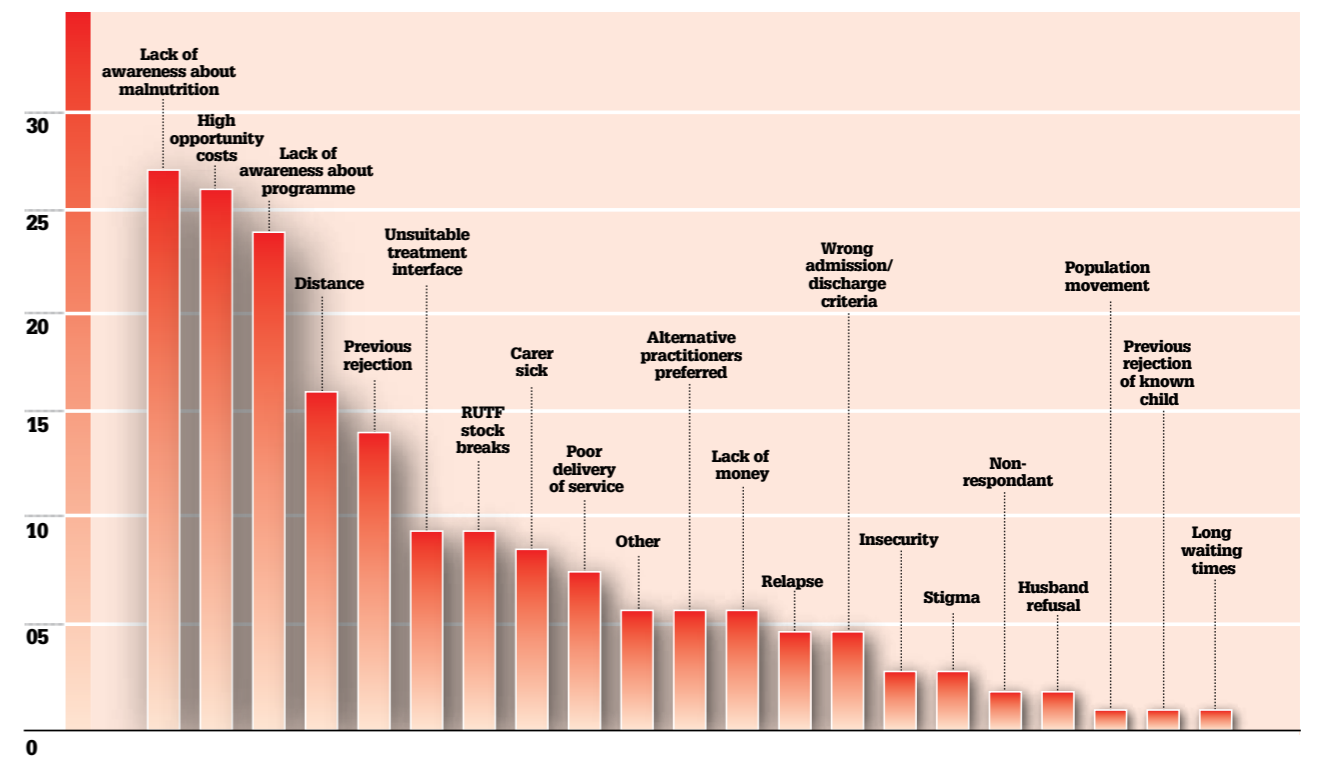
Understanding Barriers to Access affecting Community-based SAM Treatment

The analysis carried out on CMN-supported coverage assessments in 21 countries (n=44) found that the five most frequently reported barriers to access across all interventions were: lack of knowledge of malnutrition, high opportunity costs, lack of knowledge of the programme, distance to site and previous rejection. These account for 58.9% of all barriers reported. If only the primary barrier from each programme is considered, the first two barriers (lack of awareness about malnutrition and treatment programmes) account for 54.5% of reported

barriers. These findings largely support the results of an earlier study also based on coverage assessments and corresponding questionnaire results with caregivers of non-covered cases. That study, based on a smaller sample of coverage assessments (n=12), focused primarily on NGO-delivered programmes implemented between 2004 and 2006 across five countries. The analysis relied on questionnaires carried out with 1,696 caregivers of non-covered cases (6). While the outputs of each analysis vary, the results show a similarity in barriers to access.

FIGURE 1

Top 5 barriers to access from each assessment



Source: CMN Database

⁴ Given that the study participants were selected due to their relation with the treatment services, a bias was introduced in terms of their perceived barriers to access and the importance of “awareness” about services and the condition in particular.
⁵ Union Councils are district subdivisions in Pakistan, and can include either cities or a large village and surrounding areas.

⁶ Period coverage (based on current & recovering cases) was used in this assessment.
⁷ Woredas are the third-level administrative divisions of Ethiopia. Woredas are composed of a number of wards (kebele), or neighbourhood associations, which are the smallest unit of local government in Ethiopia.
⁸ Point coverage (based on current cases only) was used in this assessment

Although the same barriers were identified by both analyses (see Figure 1 and Table 1) their reported frequency (or relative importance) does differ. Part of this has to do with the fact that some of the assessments included in the earlier study measured coverage of

BOX 2 » Labelling Barriers to Access

The nomenclature used to report on barriers to access in SAM treatment services has evolved over the last decade. Some labels have been replaced, and others have been simplified to facilitate comparative analysis. The following list provides further insights into the meaning and changes made to key classifications:

- **Lack of knowledge of programme:** this is also referred to as “not aware of the existence of the programme”.
- **Lack of knowledge of malnutrition:** this is also referred to as “condition not recognised as malnutrition”.
- **Opportunity Costs:** the term is used to describe the decision made by caregiver not to attend treatment services because the direct/indirect costs and implications of doing so (e.g. loss of income, agricultural yield, etc.) are perceived as too high. This is also referred to as “carer busy”.
- **Unsuitable treatment interface:** the term is used to describe a case that seeks treatment/is enrolled in a related treatment service at the health facility (e.g. Malaria treatment) but in spite of its nutritional status, it is not identified as being eligible for SAM treatment.
- **Poor delivery service:** the term is used to describe poor customer (caregiver) service provided at health facility level.
- **Relapse:** the term is used when a child has been discharged and cured but found to be malnourished again but has not been enrolled in the treatment programme.
- **Wrong admission criteria:** the term is used to describe the enrolment of the case into the wrong service (e.g. MAM instead of SAM treatment) or when eligibility criteria (e.g. oedema) are not used to enrol into SAM treatment services.

both MAM and SAM treatment services operating together (as early Community-based Therapeutic Care, CTC, projects often did). Thus, some of the distinct dynamics affecting access to MAM treatment (10) are also reflected in this analysis. But the discrepancy also reflects changes in the policy environment, protocols used and overall design of community-based SAM treatment services⁹. Thus, whilst variations in their relative importance reflect the changes and evolution of treatment services, the same type of barriers have continued to shape access to community-based SAM treatment over the years.

But do these barriers affect all community based treatment services equally? To understand how these barriers vary across different contexts, the results of CMN-supported assessments were further analysed in relation to the type of context (rural, urban and camp), implementer (MoH-integrated services versus NGO-implemented projects) and overall performance (< or >50% coverage) of the service in question (see Annex III).

No significant variation was observed between rural and urban contexts with the exception of stigma which featured more commonly in urban settings. The results from camp settings did reveal major variations, with awareness about malnutrition and treatment services dropping from the five most frequently reported barriers. In terms of implementers, no major variation was found in the five most common barriers to access reported by MoH-integrated services and NGO-implemented projects; only the 5th most common barriers varied, between MoH-integrated services (“previous rejection”) and NGO-implemented projects (“lack of money”). In terms of overall coverage performance, the analysis found virtually no change in the top-five barriers identified but some differences in their relative importance (ranking). In programmes with coverage of >50%, “lack of awareness about malnutrition” drops from the top-three list of barriers whilst in services with coverage <50%, distance and RUTF stock-outs are included in the list of top-five barriers reported (see Annex III).

Overall, the results show the same barriers affecting community-based SAM treatment services with minimum variation across contexts. What is more, the findings of the literature review also found that these barriers also affect other interventions, including services for Malaria, HIV/AIDS, Tuberculosis, Pneumonia, Deworming, Vitamin A, Immunization and Family planning and maternal health (see Table 2).

⁹ The decrease in the number of cases citing rejection as a reason for non-attendance, for example, is partly the result of the gradual adoption of common referral and admission criteria. The increases in the occurrence of other barriers (such as RUTF stock-

outs) in turn reflect the expansion of supply networks and the integration into national systems supplying health services.

The coverage assessments supported by the CMN provide an indication of which barriers to access predominate for SAM treatment, and the review of the literature on barriers to other public health interventions indicates that these barriers are not specific to SAM treatment services. But why and how do these

barriers emerge in the first place? Are they recognised and tackled by service providers, and if so, how? Building on the qualitative data generated from coverage assessments and the results of the three case studies, this review will profile the five most common barriers and explore the way caregivers experience them¹⁰.

TABLE 1 » Reasons for non-attendance in 12 surveys - ranked by modality¹¹

| REASON FOR NON-ATTENDANCE | NUMBER OF SURVEYS | | | |
|---|----------------------|------------------------|------------------------|------------------------|
| | Number in top 3 rank | 1st most common reason | 2nd most common reason | 3rd most common reason |
| Previous rejection | 9 | 7 | 2 | 0 |
| Condition not recognised as malnutrition | 6 | 2 | 3 | 1 |
| Carer sick | 4 | 0 | 3 | 1 |
| Not aware of the existence of the CTC programme | 3 | 1 | 0 | 2 |
| Distance to sites | 3 | 1 | 1 | 1 |
| No belief in the CTC programme | 3 | 1 | 1 | 1 |
| Carer busy | 3 | 0 | 1 | 2 |
| Relapsed | 3 | 1 | 1 | 1 |
| Other reasons | 2 | 0 | 1 | 1 |
| Childcare obligations at home | 2 | 0 | 0 | 2 |
| Shame | 1 | 0 | 1 | 0 |
| Total* | | 13 | 14 | 12 |

* Each column should add up to the total number of programmes surveyed (12). The 1st & 2nd most common reason columns add up to 13 and 14 respectively, due to ties where two reasons received equal mention.

Source: Guerrero, et al (6)

TABLE 2 » Barriers to access experienced by other public health interventions

| BARRIERS | MALARIA | HIV/AIDS | TB | PNEUMONIA | DEWORMING | VITAMIN A | IMMUNISATIONS | FAMILY PLANNING & MATERNAL HEALTH |
|--|-------------------|-------------------|-------------------|-------------------|-------------------|-------------------|-------------------|-----------------------------------|
| Distance | Yes ¹¹ | Yes ¹² | Yes ¹³ | Yes ¹⁴ | Yes ¹⁵ | Yes ¹⁶ | Yes ¹⁷ | Yes ¹⁸ |
| Lack of knowledge of services | Yes ¹⁹ | Yes ²⁰ | Yes ²¹ | Yes ²² | Yes ²³ | Yes ²⁴ | Yes ²⁵ | Yes ²⁶ |
| Lack of knowledge of disease/condition | Yes ²⁷ | Yes ²⁸ | Yes ²⁹ | Yes ³⁰ | Yes ³¹ | No | Yes ³² | Yes ³³ |
| Caregiver busy/ opportunity costs | Yes ³⁴ | Yes ³⁵ | Yes ³⁶ | Yes ³⁷ | Yes ³⁸ | No | Yes ³⁹ | Yes ⁴⁰ |

NB: The frequency of experience has not been noted, but a ‘yes’ indicates it has been reported in the literature. These barriers represent both past and on-going barriers to treatment. This is not an exhaustive list, but represents the barriers described in the literature.

¹⁰ The relative ranking of the barriers used in the report reflects the findings of coverage assessments supported by the CMN and not necessarily the specific ranking found in the three field locations. The authors acknowledge that families and households experience these barriers differently from one location to another,

and also from one season to another.

¹¹ In that study, the authors described modality as “...the number of times that an issue was mentioned as a primary reason across all programmes” (6)

Lack of Knowledge of Malnutrition & Treatment Services

In almost all of the CMN-supported coverage assessments analysed, lack of knowledge of malnutrition and/or treatment services were identified as leading barriers to access. The recurrent appearance of these barriers reflects the complexity surrounding local aetiologies of malnutrition and the challenges facing treatment services wishing to establish themselves as a key pathway to treatment for the condition. Whilst communities often have a basic understanding of the role of the immediate causes of malnutrition, local understandings (and corresponding pathways to treatment) are also influenced by “traditional” beliefs and/or misconceptions (41). The study in Ethiopia found examples of caregivers attributing the onset of the condition to a number of causes including the use of birth control medication. The study also found significant evidence pointing towards the use of Traditional Health Practitioners (THPs) as the first tier for seeking treatment. Local specificities aside, the results from coverage assessments and the three country case studies suggest that the way SAM is perceived by caregivers and the way it is understood by those treating it can be different. This divergence is particularly important because it plays a role in health seeking behaviour, not only for SAM treatment but for a number of other health services.

“Awareness is a major issue, about malnutrition, why it is bad, how to prevent it. People think their child is OK.”

DIRECTOR OF HEALTH CENTRE, ETHIOPIA

“My child looks OK to me, but not to you!”

BENEFICIARY, DEFAULTER, ETHIOPIA

“It is difficult to understand that my son is sick because he does not behave in a sick way. However I do know that he does not have enough nutritious food to eat”

BENEFICIARY, KENYA

Community-based SAM treatment interventions were originally designed to proactively address this by raising awareness about the condition and the treatment services available (42). Successful sensitisation initiatives used in early community-based SAM treatment programmes targeted key community figures, including local leaders, THPs and community groups (43). In Ethiopia, the research found many of these key community figures being recognised and incorporated into sensitisation efforts today;

“[To sensitize communities], we have a community conversation with 25-30 people. Most of the participants are religious and community leaders. We demonstrate how to prepare complementary foods and provide education about OTP and breastfeeding.”

HEALTH EXTENSION WORKER, ETHIOPIA

In Kenya, the study also found examples of how communities can become the primary interlocutors in this process. Woman-to-Woman and Man-to-Man groups were created to bring together caregivers of current or past SAM cases with other community members with no prior exposure to the condition. In these fo-

ums, participants could explain in their own terms what it meant to deal with SAM and explore issues of access and treatment.

Mainstreaming these kind of sensitisation activities into community-based SAM treatment services worldwide is crucial, but it faces predictable challenges. First, effective sensitisation requires an understanding of the communities they target and local or “traditional” beliefs associated with the condition so as to adapt them to user’s needs (44). In some contexts NGOs are supporting governments in developing context-specific sensitisation material (45), but these kinds of initiatives are rare (46). Second, when carried out, sensitisation initiatives are generally developed as short, one-off campaigns, rather than on-going dialogues with communities over time. Third, getting the word out to all communities is particularly challenging in sparsely populated areas. In many places where integrated SAM treatment services operate, the broader health system does not reach all communities (47).

Additionally, a lack of strong public health and educational infrastructure (i.e. schools and community health programs) can lead to limited awareness about the general benefits of health, hygiene and nutrition (48) and how to best participate in the program by following protocols. In underserved areas, a lone CMAM program will face particular challenges in achieving positive outcomes.

Community-based SAM treatment services entrust awareness-raising to community outreach workers, many of them working on a voluntary basis. When these workers are formally recognised and linked to national health services, the results can be positive. In Ethiopia, for example, the study found that the recognition of the Women’s Development Army by the health system, and the partnership between the WDAs and SAM treatment services helped improve awareness about the service and raise its profile. But if there are advantages to working with established volunteer networks, there are also practical drawbacks. In Pakistan, for example, the study found that the reliance on Community Nutrition Volunteers operating on a voluntary basis made it difficult for them to dedicate the time necessary to cover their assigned catchment area. This had consequences for the way sensitisation was effectively done, with a prioritisation of larger, more accessible and/or more densely-populated settlements, over smaller and more marginal settlements.

“We have covered 70%. Due to distance we cannot cover all villages. According to population, we have covered most big population-based villages.”

PROGRAM STAFF, PAKISTAN

“Some people come from distant hills we would like a mobile supply to take supplies to these remote villages, such as on a motorcycle or bicycle.”

COMMUNITY HEALTH WORKER, KENYA

This means that information about malnutrition and treatment services remains limited to larger, more easily accessible areas that were located closer to the volunteers’ homes and to the program sites. This pattern of spatial awareness is in turn reflected in the spatial distribution of coverage of SAM treatment services (49).



JOSEPH NGOLEMWAI, A WIDOWER FROM WEST POKOT, KENYA SAYS THAT

“...it is difficult to understand that my son is sick because he does not behave in a sick way. However I do know that he does not have enough nutritious food to eat. Now I will go back to the centre and see what else they can do for him.”

High opportunity Costs

Opportunity costs were another commonly cited reason for non-attendance in many of the CMN-supported coverage assessments. The term is used to describe the decision made by caregivers not to attend treatment services because of the direct/indirect costs and the implications of doing so are perceived as being too high. Opportunity costs are fundamentally about balancing the need to seek care with other (often equally pressing) responsibilities which can include tending the fields during harvest time, taking care of other family members (including the elderly and other children at home), tending cattle, attending market day and fetching water. For many households, seeking care for SAM comes at the end of a longer chain of events to address health conditions that have led to SAM in the first place, making the opportunity costs for SAM cumulative. The study in Pakistan found examples of this.

"We took our child to a doctor to receive treatment for cholera. We went to the doctor every day for 15 days. It was 25 minutes each way and the rickshaw cost 20 Rs (c. US\$0.20). We paid 1,000 Rs. (c. US\$10) on a daily basis for medications, IV solutions for dehydration, and doctor's fees. On the last day, we didn't pay for rickshaw fare, and the doctor didn't forgive us the fees. We walked home. We sold all our goats and our gold for the health of our child. After recovering from cholera, the child was admitted to the OTP."

BENEFICIARY, RECOVERED, PAKISTAN

The high opportunity costs can also trigger a vicious cycle in which caregivers delay attending treatment services, which often leads to a deterioration of the condition. This in turn requires inpatient care which drives the opportunity costs even further.

"I closed my shop because I went to Adwa for treatment [at the Therapeutic Feeding Unit*]. My livelihood was weakened. I give priority to my child and work less, my shop is almost closed. Before, I would make 100 birr (c. US\$5) profit per day if the market was fine."

BENEFICIARY, RECOVERED, ETHIOPIA

"While I was staying for two weeks with my firstborn at the stabilisation unit* for treatment my other girl was left alone at home. When I returned home she was sick and malnourished and I had to return to the stabilisation unit because of her."

BENEFICIARY, KENYA

Opportunity costs not only vary for different households, but also fluctuate seasonally (50). In Kenya, for example, the study participants consistently highlighted the difficulties in accessing treatment during the rainy season, when river crossing becomes more hazardous and road access less predictable. In Pakistan, Kenya and Ethiopia, study participants reported that attending the program was most difficult during the harvest season, when the caregivers' workload increases and absences and defaulting become more common. During this season, individuals and families migrate to other towns or far away fields

for extended periods of time. Seasonality influences opportunity costs in a more predictable way, but many of the factors that ultimately make the costs of attending too high are unpredictable and more personal. Factors such as pregnancy, death or illness of a family member can affect a caregiver's participation.

"After I attended three times I stopped coming here because my mother was sick. I was responsible to provide care. Also my other children go to school, so we don't have time to take this child to OTP. I have many children and my mother to care for."

BENEFICIARY, DEFAULTER, ETHIOPIA

"During the livestock migration our women are alone in the villages, they cannot leave to attend weekly follow up there is no one to take care of the siblings and elders"

BENEFICIARY, KENYA

These personal issues can be particularly difficult for women who have lost spousal support. In Ethiopia and Pakistan, female caregivers who were widowed or divorced (and lacked livelihoods opportunities and other public safety nets) were found to face more challenges. Pregnancy has also been commonly identified as a major factor impeding a caregiver's ability to travel from her house and attend the program.

Service providers and beneficiaries have found ways of reducing the opportunity costs of accessing SAM treatment services. When dealing with barriers beyond the regular scope of an intervention, successful programmes tend to maintain flexibility to provide any additional support possible to beneficiaries during these times. This flexibility can include changes in visiting schedule (opening on weekends, earlier/longer hours of operation, etc.), holding distributions every two weeks, or even home visits.

"We recommend changing the follow-up time to every two weeks. We come from far, two or one hour. Also we are busy with harvest [and during the] rainy season. This is a point we wish to improve in the future."

GROUP DISCUSSION WITH RECOVERED BENEFICIARIES, ETHIOPIA

"We asked staff to make it easier for us to come, because we were spending money on transport to attend. They then gave us rations [every two weeks]."

BENEFICIARY, RECOVERED, PAKISTAN

The decision to seek care is based on an individual cost-benefit analysis that pitches the costs against the perceived needs and confidence in the potential gains. In this process, caregivers also balance individual versus household needs. As the recovery of the child starts to be visible and recognisable, and the life-saving urgency of the first weeks fades, the trade-off changes and the costs become harder to justify (34-40). The capacity of community-based SAM treatment services to ensure continuous adherence (and thus coverage) depends largely on its capacity to recognise these shifts and to reduce opportunity costs for caregivers.

* Therapeutic Feeding Units, also known as Stabilisation Centres or Units, are in-patient facilities (commonly found in district hospitals) where complicated cases of SAM are treated until they can be transferred to outpatient services.

**NANCY LOMWAI,
A MOTHER OF TWINS IN
WEST POKOT, KENYA SAYS**

“ Carrying two babies is very heavy. I can take a motorbike for some of the journey but I do not have enough money to go the whole way. It is very tiring. If I would have other children at home I could not come here



Distance

In spite of the gains made with the decentralisation of SAM management from hospitals to health facilities, for most caregivers accessing treatment still implies travelling significant distances (51). Although the evidence from CMN-supported assessments is clear about the prominence of distance as a barrier to access, defining levels of acceptability regarding distance is more complex. Early community-based SAM treatment models clearly specified the need to place service delivery points within 3-hour walk (or one day round-trip) of the targeted populations (52). Yet, study findings from Ethiopia, Kenya and Pakistan found variations in community's perceptions. Whilst caregivers living three to four hours from treatment sites declared this to be too far, many people living one hour away also deemed the distance prohibitive for regular attendance.

The variations in perceptions reflects the close links between distance and the notion of opportunity costs; the acceptability of allocating time (and sometimes transportation fees) to cover large distances is determined largely by how else that time could be spent. The study found instances in which time-consuming domestic tasks such as fetching water made relatively shorter walks to the treatment sites too time-consuming.

"Some people walk 6-7 hours round-trip to fetch water. So there is no time to go to OTP."

COMMUNITY LEADERS, ETHIOPIA

The concept of distance also involves a range of other elements including cultural norms, security, topography, road quality and lack of transportation options (53). And as with opportunity costs, distance as a barrier to access varies seasonally. The study results from Ethiopia and Pakistan also reflected the role of distance and the multi-faceted ways in which this is assessed.

"Distance is a problem all times of year, but mostly in the rainy season. There is no proper transport, only rickshaw. There is no proper road."

COMMUNITY LEADERS, PAKISTAN

"We face a difficulty to come because the site is so far from our house [3 hours]. I never come alone without my husband; when the site was closer I would come with other women. During the rainy season, the road is slippery and even flooded. There is also a distance problem, during the walk we feel exhausted, and we also carry the children."

BENEFICIARY, DEFAULTER, PAKISTAN

Seasonality also brings migration. In Pakistan, the study found that seasonal migrants moved from one area to another throughout the province. This led to differences in access, and higher numbers of defaulters for this group at certain times of year.

"We are migrating and the program is not migrating [with us]."

BENEFICIARY, DEFAULTER, PAKISTAN

SAM treatment services have attempted to tackle this barrier in several ways. In Ethiopia, for example, the integrated services were further decentralised to Health Post level. By moving further down the health system, and using facilities closer to communities, the issue of distance was noticeably improved. In Pakistan, the NGO-implemented programme relied on satellite sites that were located closer to the beneficiary population. Changing the location of treatment services is only part of the solution. In Ethiopia, the study found evidence to suggest that improved linkages with the WDA (responsible for sensitizing communities even in more remote areas) also proved pivotal in informing and mobilising communities to attend services. All of these measures ameliorate the issue of distance but are often insufficient to ensure access.

Previous Rejection & Staff/Beneficiary Interface

High coverage is as much about identifying and enrolling cases as it is about retaining them until the treatment is completed. Given the efforts made by caregivers to access treatment, the manner in which they are treated by service providers and the way in which treatment features are explained can become a key deciding factor for their continuing attendance. Yet, as the findings from CMN-supported coverage assessments reveal, beneficiary/staff interface and rejection remain a key barrier to access.

The issue of staff/beneficiary interface starts with how admissions are made and communicated. The degree of rejection taking place in community-based SAM treatment services has traditionally been linked to the degree of homogenisation between the referral and admission criteria. In the early years of community-based SAM treatment, national protocols would often encourage the use of different referral (mostly based on Mid-Upper Arm Circumference) and admission criteria (mostly based on Weight for Height). This discrepancy resulted in high numbers of cases being rejected, which in turn accounted for the prominence of rejection as a key barrier in early studies (5). In recent years, national guidelines have changed, incorporating both MUAC and Weight for Height as official criteria for admission. In spite of these policy changes, a number of practical challenges remain. First, service providers often encourage the use of different thresholds (e.g. MUAC of 120mm) for referral as a way of identifying not only eligible cases but also those “at risk”. Inadequately explained rejection of these “at risk” cases results in frustration which in turn prevents future attendance when the child’s condition deteriorates (54). In other contexts, health workers erroneously admit cases that meet both criteria resulting in the exclusion/rejection of eligible cases (55).

Staff/beneficiary interface and communication remains equally important and equally challenging once cases are enrolled. In Kenya for example, the study found that whilst caregivers were generally positive about the quality of service, they were unclear about the expected length, frequency and nature of treatment. This general lack of understanding about the treatment cycle forces caregivers to evaluate opportunity costs (including household and economic decisions) based on insufficient information. Similar problems have also been found with the practical guidance provided on the use of RUTF. Several of the caregivers consulted during the study mentioned that their children did not accept RUTF, and some would have diarrhoea and vomiting after consuming it. Many of these mothers therefore stopped giving the RUTF to their child, and/or defaulted from the programme.

"A main reason for default is the reluctance of mothers: they think that RUTF doesn't work for their child."

HEALTH EXTENSION WORKER (HEW), ETHIOPIA

"At first my child had a good appetite. After 5 weeks she refused to eat so I stopped going... She lost her appetite. She didn't even want to see the sachet."

BENEFICIARY, DEFAULTER, ETHIOPIA

Avoiding confusion and improving awareness about the optimal use of RUTF requires time and space for meaningful engagement between staff and beneficiaries. Yet, many of the MoH-integrated services for SAM treatment are implemented within a large government infrastructure, with a limited amount of resources. These services often rely on overburdened community-based health workers (56). The service delivery model (which maintains many of the structural features of the NGO-delivered structure), funnels all SAM cases towards a limited number of facilities, forcing these under-resourced, overburdened and often demotivated health workers to deliver treatment to a high number of cases per week. This not only increases the waiting times (57) but also decreases the amount of time available for communicating with each caregiver. Whilst rejection and staff/beneficiary interface are influenced by the levels of supervision and motivation (63), improving the quality of this key interface between SAM treatment services and caregivers will remain inexorably linked to staff/beneficiary ratios and the corresponding time that staff are able to allocate to each service user.



A caregiver whose child was enrolled in the CMAM program discusses her experience with a data collector in Tigray Region, Ethiopia

Photo: Chloe Puett

RUTF Stock-outs

Decentralised, community-based SAM treatment requires a robust and dynamic supply system capable of delivering Ready-to Use Therapeutic Food (RUTF) where and when it is needed. The identification of RUTF-stockouts as a key barrier by coverage assessments, however, suggests that logistics and stock management systems are struggling under the pressure of expanding services.

Supplying RUTF is complicated by two key factors. The first challenge relates to using national supply chains to transport RUTF to a high number of service delivery units across countries, with different people responsible for its distribution and management at different levels (59). The second challenge relates to the volume of RUTF. Unlike other medicines, RUTF is a heavy commodity, with high volume and weight of supply per child treated, requiring large transport and storage units. For this complex supply chain to ensure a continuous supply, reliable projections need to be generated and communicated across all levels of the supply chain, in a manner that accounts for variable delivery timeframes.

Breaks in the RUTF supply chain can have a significant impact on attendance and coverage. Repeated stockouts contribute to community-based SAM treatment services being perceived as unreliable, and to significant increases in length of stay, absenteeism and defaulting (60). There is also evidence

that services that experience repeated RUTF stockouts also achieve significantly lower levels of coverage (61). In Kenya, health workers and beneficiaries identified stockouts as an important factor in their opportunity-cost analysis and in how assessments of acceptable distance to travel.

"People are patient and do not complain though even though some have come here from very far away. We have not had supplies for two months some of the mothers will not return for a second or third time."

COMMUNITY HEALTH WORKER, KENYA

In Ethiopia, the study found that whilst stock-outs had had the anticipated effect of interrupting service delivery, the impact of this occurrence on defaulting rates was less pronounced than would be anticipated. This was due in large part to the involvement of the community-based staff; using a carefully developed communication system¹² between service providers and caregivers, changes in RUTF supply were effectively communicated and defaulting was mitigated during stockouts. In addition, service providers helped communities to endure the absence of RUTF, by offering guidance on how to protect the child’s nutrition status using foods available at home.

"Sometimes there was an interruption of supply. I prefer to give my child complementary food at home until they bring more RUTF."

BENEFICIARY, RECOVERED, ETHIOPIA

Ensuring continuous access to SAM treatment services and products is essential to maintain community trust and utilisation of services.

¹² Each WDA member was responsible for sensitizing 30 households in her community. For every 5 of these households, one mother serves as a focal point to convey information and concerns to the WDA, creating a "1:5 network". The WDA members then met regularly with a HEW to convey this information "upwards" and HEWs followed up with household visits as needed.

The findings from both the analyses of coverage assessments and the field studies provided valuable insights into the range of (often interconnected) barriers to access affecting community-based SAM treatment interventions. While these barriers are common across SAM treatment programs, their causes are not only context-specific, but also household and community-specific. As community-based SAM treatment services expand globally, offering services that are accessible to all will always remain a challenge. But the findings of this analysis suggest that improving access to community-based SAM treatment services must start with improving fundamental aspects of service delivery.

Raising awareness about SAM and the availability of treatment was a key feature of the original model of community-based SAM treatment (Community-based Therapeutic Care, CTC). The early implementation of the model by NGOs (and at a smaller scale) allocated the time and resources required to understand community perceptions and develop community mobilisation strategies that were culturally-appropriate and context-specific. However, the integration of SAM treatment into MoH services, appears to have neglected these essential elements of the model and failed to consider the challenge of their integration into health systems with competing demands and limited resources. The findings of this study suggest that, exceptional cases aside, sensitisation has been largely ignored in the scale-up of community-based SAM treatment.

Adequately sensitising communities about SAM to promote change in treatment-seeking behaviour is a long-term process. Imparting knowledge to communities about new services requires that trust is built, both in the service itself, and in the system delivering it. While this volume has cited the common issue of overburdening health workers, previous research also shows that formalising community health workers' positions within the health system, with the level of professionalisation that this entails, is a good way to improve motivation of these workers (58). This integrated approach is crucial for achieving sustainability and scale of services, and it has shown most suc-

cess in countries with strong health systems and supportive policy environments (62). Yet in many countries needing SAM treatment services, health systems are weak and fragmented; in such environments community health workers require adequate external support to deliver quality services, and the level and type of support needed will vary by context (63).

Part of the support must come from communities themselves. In areas underserved by the formal health system, the enduring relevance of Traditional Health Practitioners (THPs) is as much about local beliefs as it is about their services being offered closer to the community. Integrating THPs into the cadre of community workers supporting the identification and referral of SAM cases has been shown to produce positive results (52) and should be further explored. Promoting the involvement of established or ad hoc community groups (such as the Men-to-Men group in Kenya) to support SAM treatment services has also produced positive results and must be encouraged. Bringing about more active community involvement will also require innovative ways of incentivising their participation. Experiences from other public health interventions that have successfully introduced sustainable income generating activities (IGAs) (64) and/or other measures for horizontal solidarity¹³ to support communities' involvement must be reviewed and explored to replace the volunteer-based model that has ultimately proven so ineffective and unsustainable (65).

Translating improved awareness into changes in health seeking behaviour and access to SAM treatment services will require more than an improvement in community sensitisation. Whilst the decentralisation of treatment services to health centres/posts has reduced barriers to access (vis-à-vis centralised services at hospital level), it has not eliminated them. In large, sparsely populated areas the available health infrastructure is often limited and this has effectively put services beyond reach for many communities. The large distances between communities and health facilities contribute to raising the opportunity costs of accessing treatment, effectively "pricing out" many affected households. What is more, the reliance on what is often

¹³Such as incorporating saving objectives in Cash-for-Work programmes to establish self-administered hardship funds.

only a handful of facilities for large geographical areas, means that already overburdened staff are often unable to provide a desirable quality of care to each caregiver and patient seeking care, or to adequately sensitize communities. Community-based SAM treatment at health centre/post level is often still too far and the opportunity costs too high for many affected households.

Service providers can introduce relatively small changes that can have a notable effect on opportunity costs, including the reduction of waiting times on site, the introduction of bi-weekly attendance¹⁴ and improved communication with caregivers about the expected length/treatment progress. These measures, however, are unlikely to bring about the dramatic improvement in access that is needed. Study participants in Ethiopia, Kenya and Pakistan highlighted the need to improve access to treatment services by decentralising treatment services further. There is an emerging body of evidence suggesting that SAM treatment can be successfully delivered by community health workers (66). There are, however, practical considerations that will influence the capacity of treatment services to reach out to communities. In the case of SAM treatment, persistent challenges in the RUTF supply chain must be understood and innovative solutions developed if further decentralisation will be logistically viable. The search for solutions to this and other challenges is one that may be comparatively new for community-based SAM treatment but one that other public health interventions have extensively explored over the last few decades. Reviewing these experiences is a key step to identifying evidence-based alternatives for improving access and unlocking the potential of community-based SAM treatment.

VOLUME THREE of this three-part series will look more closely at the experiences of other public health interventions in addressing these and other barriers. This final volume will review available evidence to tackle the question, what can community-based SAM treatment learn from other public health interventions about community-based action to improve access and coverage?

¹⁴ NGO-delivered programmes may go further, by relocating service delivery points (e.g. markets, churches, water points, cereal mill, etc.) to enable caregivers to optimise their visits by merging them with other periodic tasks.

Annex 1: Coverage Assessments

| CMN-supported programmes (July 2012 - June 2013) | | | |
|--|------------------------|-----------------|--------------------------|
| COUNTRY | LOCATION | TYPE OF CONTEXT | NGO-DELIVERED PROGRAMMES |
| Afghanistan | Kabul | Urban | |
| Burkina Faso | Manni (district) | Rural | |
| Burkina Faso | Bogande (district) | Rural | |
| Burkina Faso | Yako | Rural | |
| Burkina Faso | Pama | Rural | |
| Cameroon | Maroua Urbain District | Urban | |
| Chad | Batha Region | Rural | |
| Chad | Bahr el Gazal | Rural | |
| Chad | Iriba | Rural | |
| Chad | Kanem | Rural | |
| Chad | Kanem | Rural | |
| DRC | Kisantu | Rural | |
| DRC | Kasai Oriental | Rural | |
| DRC | Opala | Rural | • |
| DRC | Bafwasende | Rural | • |
| Ethiopia | Dolo Camp | Camp | • |
| Haiti | Port-au-Prince | Urban | |
| Ivory Coast | Danane | Rural | • |
| Ivory Coast | Zouan Hounien, Tonkpi | Rural | • |
| Ivory Coast | Toulepleu | Rural | • |
| Kenya | Nairobi | Urban | |
| Kenya | Nairobi | Urban | |
| Kenya | Nairobi | Urban | |
| Kenya | Garbatulla | Rural | |
| Kenya | Isiolo | Rural | |
| Kenya | Laikipia County | Rural | |
| Mali | Kita, Kayes | Rural | |
| Mauritania | Guidimakha | Rural | |
| Nepal | Saptari District | Rural | |
| Niger | Keita | Rural | |
| Niger | Gaya | Rural | |
| Niger | Mayahi, Maradi | Rural | |
| Niger | Zinder | Rural | |
| Nigeria | Katsina | Rural | |
| Pakistan | Tando Mohammad | Rural | • |
| Rwanda | Gisagara | Rural | |
| Senegal | Matam | Rural | • |
| Senegal | Matam | Rural | • |
| Somalia | Garowe | Camp | |
| South Sudan | Kapoeta | Rural | • |
| South Sudan | Awel West | Rural | |
| Sudan | W. Darfur | Camp | |
| The Philippines | Mindanao | Rural | |

Annex 2: Methods used in primary data collection: Pakistan & Ethiopia

This study was conducted in order to better understand the barriers to access which households face even within a well-performing CMAM program.

DATA COLLECTION

Data was collected between May and July 2013. Informed consent was obtained from all respondents before beginning discussions.

SAMPLING AND PARTICIPANT SELECTION

Three program areas from each country and the OTP sites within them were purposively selected, based on default rates from program monitoring data, to capture a variety of program environments. These included areas with a more supportive program environment (in terms of support received from partners or duration of implementation) and more challenging environments (high and low population density, challenging topography, agricultural productivity). Within each program, a minimum of 10 defaulted and recovered beneficiaries were consulted from a variety of program sites. Households of recovered children were randomly selected where possible using registration records. Defaulter households were purposively selected, and efforts were made to locate all defaulted households in each area for discussions. In the catchment area of each site selected, individual and group discussions were conducted with program staff, community leaders, and other community members. Table 4 outlines the number of group discussions and individual interviews conducted with different types of respondents in each country.

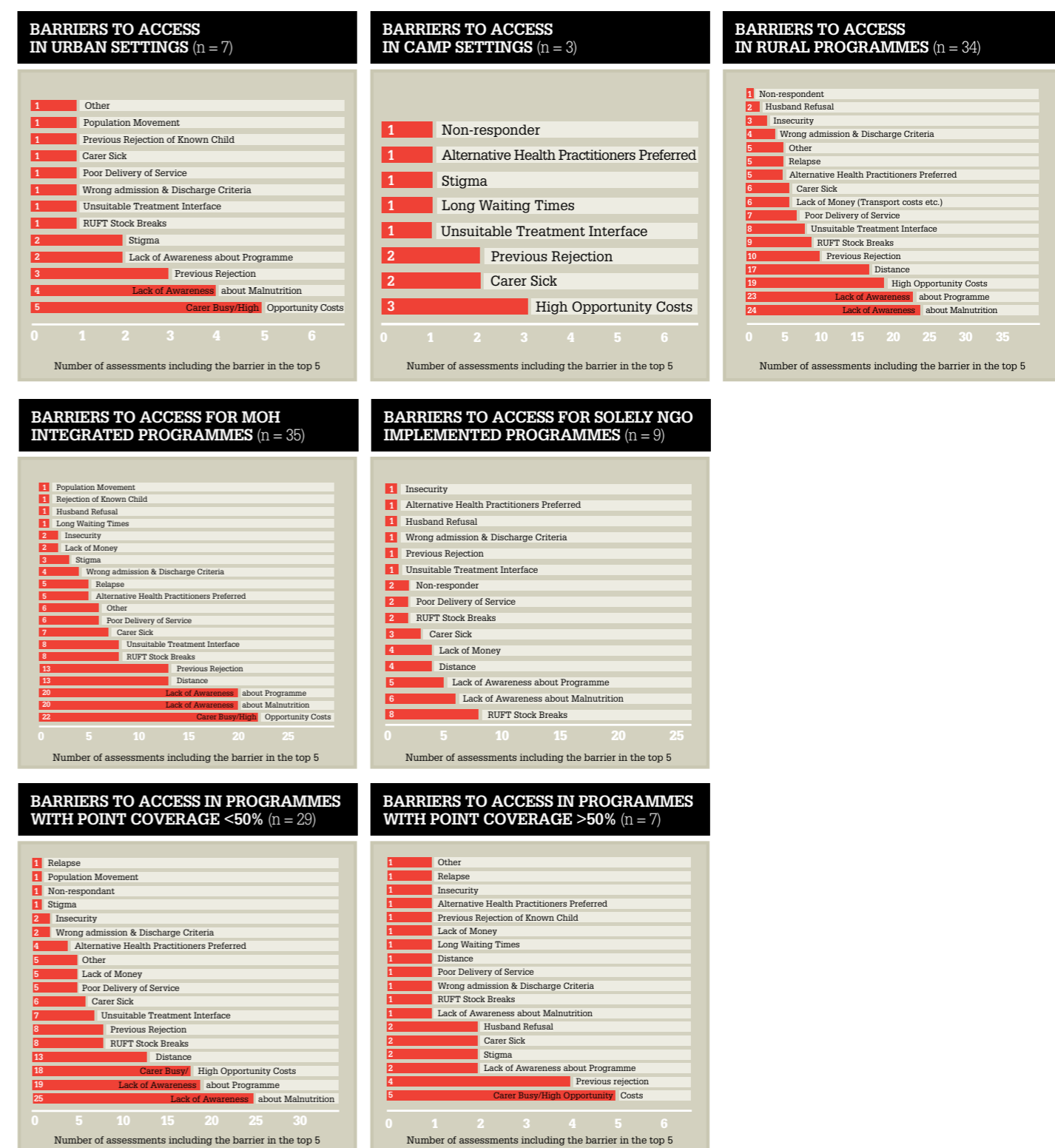
| RESPONDENTS | ETHIOPIA | | PAKISTAN | |
|-------------------|----------|------------|----------|------------|
| | Group | Individual | Group | Individual |
| Program staff | | 13 | 6 | |
| Community members | 4 | 7 | 3 | |
| Beneficiaries | | | | |
| - Recovered | | 16 | | 11 |
| - Defaulted | | 21 | | 10 |
| - Non-beneficiary | | 1 | 2 | |

In Ethiopia, community-based MoH staff were busy with training sessions and other work-related activities during the first round of data collection. Therefore data collection was extended and the number of beneficiary households consulted in Ethiopia is higher. No such challenges were encountered in Pakistan, and the sample included represented the characteristics and barriers of the general program beneficiaries.

DATA ANALYSIS

Qualitative thematic analysis was conducted in Microsoft Word. Quantitative data on beneficiary characteristics was analysed in Microsoft Excel, to describe and compare characteristics of households experiencing different barriers.

Annex 3: Barriers to Access - By Type¹⁵



¹⁵Given the difference in sample size between all three contexts, these results should be interpreted with caution.

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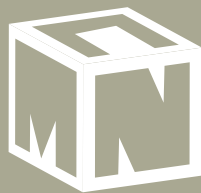
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