




# 'We did not even know it was tuberculosis': a qualitative evaluation of integrating tuberculosis services into paediatric entry points in the CaP-TB programme in Cameroon and Kenya

Leila Katirayi,<sup>1</sup> Rose Masaba ,<sup>2</sup> Boris Tchounga ,<sup>3</sup> James Ndimbii,<sup>1</sup> Muhammed Mbunka,<sup>3</sup> Millicent Ouma,<sup>2</sup> Kelia Olughu,<sup>4</sup> Jenna Siehien,<sup>4</sup> Saint Just Petnga,<sup>3</sup> Martina Casenghi,<sup>5</sup> Gordon Okomo,<sup>6</sup> Anne-Cecile Zoung-Kanyi Bissek,<sup>7</sup> Appolinaire Tiam,<sup>1</sup> Lise Denoeud-Ndam ,<sup>5</sup> The INPUT study team

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For numbered affiliations see end of article.

**Correspondence to**  
Dr Lise Denoeud-Ndam;  
ldenoed@pedaids.org

## ABSTRACT

**Introduction** Paediatric tuberculosis (TB) is often undiagnosed and under-reported. The Catalysing Paediatric TB (CaP-TB) programme provided integrated and decentralised TB screening and diagnosis services through multiple paediatric care entry points. This qualitative evaluation explores acceptability of the CaP-TB programme and existing knowledge and perceptions of paediatric TB. **Methods** A descriptive qualitative study was conducted in four sites in Kenya and six sites in Cameroon. 54 in-depth interviews were conducted with caregivers, community workers (CWs) and CaP-TB programme managers, and 7 focus group discussions with healthcare workers (HCWs) and CWs. Thematic analysis identified emerging recurrent themes across participants' responses. Data were coded by using MAXQDA V.12. Data were collected during March–September 2021. **Results** Caregivers were often not aware that children were at risk for TB. HCWs reported limited knowledge about paediatric TB prior to CaP-TB. Sometimes caregivers refused to have their children tested for paediatric TB, and this was often related to a lack of awareness of paediatric TB and free services, concerns about the testing procedure and treatment and fear of stigma. TB was referred to as disease of 'shame,' associated with poverty and poor hygiene. The CaP-TB programme increased HCWs knowledge about symptoms of paediatric TB and motivation to investigate children with clinical presentations consistent with possible TB. Adding screening at all entry points was perceived to be beneficial to caregivers who would not have felt comfortable bringing their child to a TB unit. HCWs also discussed the increased workload with CaP-TB, challenges with medication stock-outs and a need for additional training. **Conclusions** CaP-TB illustrated the positive impact of decentralised paediatric TB services, including addressing the awareness and knowledge gap among caregivers and HCWs. Multiple entry points increased opportunities for identification of paediatric TB and increased caregiver comfortability with their child being tested for TB. **Trial registration number** NCT03862261.

## WHAT IS ALREADY KNOWN ON THIS TOPIC

- ⇒ Paediatric tuberculosis (TB) remains a significant public health challenge, often going undiagnosed and under-reported.
- ⇒ The stigma attached to the disease, coupled with limited awareness among caregivers and healthcare workers (HCWs), has hindered effective management and control efforts.

## WHAT THIS STUDY ADDS

- ⇒ The Catalysing Paediatric TB (CaP-TB) programme aimed to address these gaps through a decentralised approach to TB screening and diagnosis.
- ⇒ This qualitative evaluation reveals CaP-TB's success in increasing awareness of paediatric TB among caregivers and HCWs.
- ⇒ Multiple entry points increased opportunities for identification of paediatric TB and increased caregiver comfortability with their child being tested for TB.

## HOW THIS STUDY MIGHT AFFECT RESEARCH, PRACTICE OR POLICY

- ⇒ The findings underscore the importance of decentralised TB services and integrated care models in paediatric settings.
- ⇒ Furthermore, the study highlights the urgent need for community-level education and stigma reduction efforts. Addressing misconceptions surrounding TB and promoting early assessment among caregivers are crucial steps in combating paediatric TB effectively.
- ⇒ The insights from this study can inform policy decisions aimed at scaling up decentralised TB services and implementing targeted education campaigns to reduce stigma and improve access to care for paediatric TB patients.

## INTRODUCTION

Tuberculosis (TB) is a leading cause of death among children globally, with an estimated one million cases diagnosed annually.<sup>1</sup> Sub-Saharan Africa disproportionately contributes to the global burden of paediatric TB cases.<sup>1,2</sup> Cameroon and Kenya are among the 30 highest TB burden countries globally.<sup>1</sup> Previous research has indicated that TB could be a more common cause of morbidity and mortality in children with pneumonia than recognised.<sup>3</sup>

Paediatric TB is often undiagnosed and under-reported due to poor access to healthcare, late diagnosis and poor disease management.<sup>4</sup> A study conducted in Kenya shows that Paediatric TB case identification in children 0–14 years was about eight times less than that of adults.<sup>5</sup> These shortcomings may also be attributed to insufficient awareness or understanding of paediatric TB, difficulty in collecting appropriate samples for diagnosing TB in children, and a lack of training in paediatric TB diagnosis and care among healthcare workers (HCWs).<sup>6,7</sup> TB diagnosis in children is critical to reduce the associated mortality and morbidity.<sup>8</sup> Most children who are promptly diagnosed and started on treatment thrive when they are treated.<sup>9</sup>

In many sub-Saharan African countries, including Cameroon and Kenya, diagnosis and treatment of children with TB are centralised at higher level of care, making both case identification and treatment more difficult.<sup>10</sup> A patient pathway analysis conducted in Cameroon shows that about 46% of TB patients initially seek care from primary healthcare facilities with limited TB services while only 18% seek initial care from higher-level facilities.<sup>11</sup> In Kenya, a 2017 study reported that nationally, 43% of patients encountered at least one TB diagnostic technology at the point of care initiation. In urban areas, 47% of initial visits were at facilities with TB diagnostic capabilities, but this dropped to 42% in rural areas.<sup>12</sup>

Decentralisation and integration of service delivery have been suggested as a strategy to increase case identification and improve TB treatment for children.<sup>10,13</sup> Paediatric entry points such as Maternal, Neonatal and Child Healthcare/under-5 clinics, outpatient clinics for children, paediatric ART clinics and nutrition rehabilitation clinics represent principal entry points for children and present an opportunity for integration. Previous findings from the literature show that integrating TB services into other services such as HIV services was feasible and improved TB case detection and management.<sup>14,15</sup> In response to the challenges related to identifying and managing paediatric TB, the Elizabeth Glaser Pediatric AIDS Foundation (EGPAF) designed the Catalysing Paediatric TB (CaP-TB) programme. The programme focused on reducing paediatric TB morbidity and mortality through improved paediatric case detection and treatment. The CaP-TB programme initiated TB screening at all paediatric entry points at selected facilities using a hub-and-spoke model. ‘Hubs’ were higher-level facilities, such

as hospitals, and ‘spokes’ were lower-level facilities, such as health centres. Hubs and spokes supported each other, with spokes sending diagnostic samples to the hubs, and hubs then sending diagnostic results back to the spokes. The hub sites used more complex procedures to collect TB samples, conduct laboratory investigations and treat complicated cases of TB. The programme is intended to significantly increase the number of children screened for TB and strengthen treatment services. Facilities participating in CaP-TB received additional training on how to screen for paediatric TB, how to collect specimens such as nasopharyngeal aspirates and gastric aspirates for molecular GeneXpert testing and learnt the treatment algorithm for paediatric TB. The CaP-TB programme involved trainings, supportive supervision, job aids and logistical support that were all tailored to the different levels of care.

A stepped-wedge cluster-randomised study was designed to assess the effect of the CaP-TB model compared with the standard of care.<sup>16</sup> The study included a qualitative evaluation to explore the programme’s acceptability and feasibility. This paper explores the results of the qualitative evaluation, helping to understand the landscape of paediatric TB in Cameroon and Kenya, including knowledge and perceptions regarding paediatric TB among caregivers and HCWs’ knowledge and practices regarding paediatric TB before and after the introduction of the CaP-TB programme.

## METHODS

### Study design

This was a qualitative study using in-depth interviews (IDIs) and focus group discussions (FGDs) to collect data.

### Site selection

Data were collected from two spoke sites and three hub sites in Homa Bay, Kenya. Data were collected from two spoke sites and four hub sites in Centre and West Cameroon. Sites participating in the CaP-TB programme were purposively selected due to their high volumes of paediatric TB cases.

Most hub sites had more than 100 staff, but only 15–20 were involved in TB activities. Spoke sites had about 20–25 staff overall and about 6–8 staff involved in TB activities.

### Sample size considerations

Across the 6 sites in Cameroon, approximately 4–5 IDIs with caregivers and 1 IDI with a programme manager (PM) were planned for each site. In Kenya, IDIs with caregivers were conducted at four sites while additional sites were included to ensure the sample size for the PMs was reached. FGDs were composed of 5–12 participants and 3–4 FGDs were conducted with HCWs and in Kenya, with community workers (CWs). These ranges were selected to ensure enough data were collected to be able to sufficiently describe the experiences at each of

**Table 1** Overview of IDIs and FGDs by study group

Study population group	Kenya*	Cameroon†	Total
Caregivers	20 IDIs	24 IDIs	44 IDIs
HCWs	3 FGDs	4 FGDs	7 FGDs
CWs	4 FGDs (1 per site)	N/A	4 FGDs
Programme managers	4 IDIs (1 per site)	6 IDIs (1 per site)	10 IDIs

\*Kenya sites: Homa Bay County Referral Hospital, Makongeni Sub-County Hospital, Marindi Health Center, Ndhiwa Sub-County Hospital, Magina Health Center, Kiasa Dispensary, Kendu Bay Sub-County Hospital, Wagwe Health Centre and Kandiege Sub-County Hospital.

†Cameroon sites: Akonolinga District Hospital, Soa District Hospital, Fouban District Hospital, Palais des Rois Bamouns Private Hospital, Dschang District Hospital and Lepi Health Center. CWs, community workers; FGDs, focus group discussions; HCWs, healthcare workers; IDIs, in-depth interviews; N/A, not applicable.

the different health facility levels for the various participant groups. Previous literature has determined that saturation is reached at 10–12 IDIs and at 3–6 FGDs per homogeneous group.<sup>17 18</sup> See [table 1](#) for an overview of the data collected.

### Study population and recruitment

All children participating in the CaP-TB programme were under the age of 5 years. The study collected data among caregivers with TB-presumptive children who had gone through TB investigations (some with TB ruled out and some with diagnosed TB). For each location, eligible participants were randomly selected to participate in IDIs using an Excel randomisation list. If less than five eligible children were found in a site, all of the location's children were invited to participate. If the total sample size for a country was not met after selecting five children, additional children were invited from the country's bigger sites. If a caregiver was not reached after reasonable efforts, they were replaced by the next caregiver, as ordered in the randomisation list.

HCWs from the selected study sites and directly involved in TB diagnosis or treatment activities that were introduced as part of the CaP-TB integrated services model were invited to participate in FGDs. HCWs provided insight into the facility experience and highlighted the barriers and facilitators of implementing the CaP-TB programme. In Kenya, CWs were invited to participate in FGDs if they had supported paediatric TB service delivery activities at the selected sites for at least 6 months in the previous year. CWs were not interviewed in Cameroon, as they were not involved with TB service delivery. The Kenyan CWs gave insight into the general understanding of integrated TB services and the overall perception of this integration within the community.

Eligible HCWs and CWs were identified by CaP-TB programme officers and nurses-in-charge. In Cameroon,

all eligible HCWs were randomly selected. When there were more than 12 eligible participants, the names were written on a piece of paper and randomly selected from a bag. In Kenya, the CaP-TB programme officers identified HCWs and CWs available for the FGDs and contacted them based on their availability. The INPUT study nurses assisted the qualitative team in contacting and inviting the selected HCWs and CWs to participate in the FGDs. If the HCWs/CWs were interested in participating, they were told to come to the health facility on a certain day/time. If they declined, additional names were selected following the above procedure. A minimum of five participants were required for each FGD. If there was an insufficient number, additional HCWs and CWs were invited to participate from neighbouring INPUT study sites.

PMs were facility staff, employed by the Ministry of Health (MOH), who were the most closely involved in the oversight of the unit in which the CaP-TB intervention was being implemented. These included the district medical officer, TB coordinators at county and subcounty levels and other positions of authority. IDIs were used to gather their high-level viewpoints regarding the CaP-TB programme's integration within the facility. They were selected by the facility director using the eligibility criteria and if eligible, contacted by either the TB nurse or directly by the qualitative staff. An overview of the data collected by study group is provided in [table 1](#).

### Study preparation

IDI and FGD guides were designed in English and translated to French for Cameroon. In Kenya, the caregiver tools designed in English were further translated into Dholuo. There was no need to translate other tools since the HCWs, CWs and PMs' professional trainings are done in English in Kenya. Study materials were piloted at study sites not participating in the qualitative component. Sample participants were informed that the information collected during this pilot period would not be used in the study.

### Enrolment and data collection

Data were collected in Cameroon and Kenya from March to September 2021. All IDIs and FGDs were collected by three research assistants in Cameroon and two research assistants in Kenya, all of which had prior experience in qualitative data collection. Data collection was supervised by two qualitative researchers employed by EGPAF (one in each country). They were both males who had obtained a master's in public health degree in social science or related field and several years of experience in qualitative work. Each of the study teams had at least one research assistant from each of the data collection areas, which decreased the challenges of an outsider projecting their perspectives. All transcripts were reviewed by the team supervisor to ensure translations captured accurately captured the participant's statements, without being summarised or simplified by the research assistant. The teams had not established a relationship with participants

prior to study commencement. Interviewers were trained on the study protocol, human subject research ethics and qualitative data collection methods.

The IDIs involved one research assistant and one study participant and lasted around 30–40 min. The FGDs were composed of 5–12 participants, with 1 discussion moderator and one note-taker, and took 90–120 min. Both IDIs and FGDs used a semistructured guide. IDIs were offered in the participant's preferred language and FGDs were conducted in the language that was the most appropriate for the region. All IDIs and FGDs were conducted at the health facility in private rooms, except for one interview which was conducted over Zoom in Cameroon due to COVID-19. Written informed consent was obtained from all study participants before data were collected. For illiterate participants, a witness signed a consent form certifying that the participant had read the consent form and voluntarily agreed to participate in the study.

### Data analysis

Data were analysed using thematic analysis. Audio recordings from the IDIs and FGDs were simultaneously transcribed and translated into English in Microsoft Word. The qualitative lead investigator and two study analysts developed a code list. The code list was created using a combined deductive and inductive approach that identified codes responding directly to the study questions while still allowing codes to emerge from unanticipated findings. Creating a code list involved each of the three individuals reviewing a subset of transcripts, identifying codes and drafting a code list separately. After reviewing the three code lists, a code list was created based on a combined version of the three lists. The code list was then compared against the data collection tools to ensure that any data resulting from the questions would fit within the code list. Emergent codes were identified through the coding process. When a segment of text did not fit within the current codes and was determined to be critical to answering the research questions, new codes were created. Throughout the coding process, the analysts were in contact with those who collected the data, discussing their interpretation of the results, in an effort to minimise bias. In addition, one of the field supervisors, joined the analysis team to help oversee interpretation of the data. Transcripts were analysed using the qualitative analysis software programme MAXQDA V.12. To ensure intercoder reliability, a subset of transcripts was coded by both research assistants and compared line by line to ensure uniform coding. Any discrepancies were discussed and resolved, sometimes resulting in modifications to the code list. After coding, code reports were generated for each code and data were analysed by study population group. Data were summarised through descriptive, text-based summaries and tables. Data were carefully reviewed by investigators to identify recurrent patterns and themes and to establish recommendations to improve the integration of TB services into paediatric care services.

### Patient and public involvement

Patients or the public were not involved in the design, or conduct, or reporting of our research. Patients and healthcare providers were involved during study preparation, by piloting the study tools.

## RESULTS

### Study population

Table 2A–C presents the demographic data of participants, including caregivers, HCWs, PMs and CWs.

### Findings

The results were organised into eight broad themes: knowledge about paediatric TB; beliefs about TB and stigma; health-seeking behaviours with paediatric TB; perceptions about paediatric TB diagnosis; impact of integrating TB services into paediatric care; facility-level challenges implementing CaP-TB and recommendations. The citation line includes country, gender and category (caregiver, HCW, CW or PM).

### Knowledge about paediatric TB

In Kenya and Cameroon, while most caregivers, CWs and HCWs were aware that TB was an airborne disease, many of the caregivers still did not understand that children were at risk for TB.

...it was believed that TB was for adults and even up to now, parents or caregivers are having a hard time agreeing that their children might have TB. (Kenya, CW, female, K-10-W-FGD-01-P05)

### Beliefs about TB and stigma

A few CWs and HCWs in Kenya and some caregivers in Cameroon explained that TB was referred to as a disease of 'shame' since it was associated with poverty, poor hygiene and a lack of access to food or housing.

Those who were likely to have TB according to the community were the poor. That TB was not for the rich. (Kenya, CW, male, K-30-W-FGD-01-P01)

Some caregivers and CWs attributed misinformation about paediatric TB to their community members, family and friends. HCWs and CWs stated that even after being informed about paediatric TB, some community members continued to believe that children were unable to contract TB.

In both countries, there was stigma associated with TB, with it being reported as more of a problem in Kenya. Some caregivers said they had hidden their child's diagnosis from others.

You do not want people to know that your child has something like that [TB], so people will also be afraid to even hold your baby. So, you will be all alone.... You prefer to be alone before you are put on medication because of the fear that people will spread to other people that you have TB...you know it is something that you feel yourself when they say that such and such a person has TB. So in the community people are afraid to get close to you, to come near

**Table 2** (A) Caregivers' demographic information; (B) healthcare workers' and programme managers' demographic information and (C) community workers' demographic information

<b>(A)</b>			
	<b>Kenya N=20 n (%)</b>	<b>Cameroon N=24 n (%)</b>	<b>Total (Kenya and Cameroon) N=44 n (%)</b>
Age (years)			
Mean (SD)	30.3 (11.2)	36.3 (12.1)	33.6 (11.9)
Age of child (months)			
Mean (SD)	24.7 (17.0)	27.1 (13.8)	26.0 (15.2)
Duration of TB treatment (weeks)			
	N=15*	N=17*	N=32*
Mean (SD)	12.4 (5.8) Min: 4 weeks/max: 24 weeks	4.4 (1.5) Min: 0 weeks/max: 6 weeks	8.2 (5.7)
Gender			
Female	19 (95.0)	17 (70.8)	36 (81.8)
Male	1 (5.0)	7 (29.2)	8 (18.2)
Marital status			
Single	1 (5.0)	11 (45.8)	12 (27.3)
Married	19 (95.0)	13 (54.2)	32 (72.7)
Education			
Below primary	7 (35.0)	0 (0)	7 (15.9)
Primary	7 (35.0)	7 (29.2)	14 (31.8)
Secondary	5 (25.0)	15 (62.5)	20 (45.5)
University	1 (5.0)	2 (8.3)	3 (6.8)
<b>(B)</b>			
	<b>Kenya n (%)</b>	<b>Cameroon n (%)</b>	<b>Total (Kenya and Cameroon) n (%)</b>
Healthcare workers			
	N=23	N=36	N=59
Age (years)			
Mean (SD)	32.9 (3.6)	37.1 (9.2)	35.4 (7.7)
Duration of providing CaP-TB services (months)			
Mean (SD)	19.2 (5.6)	14.5 (10.0)	16.3 (8.8)
Gender			
Female	10 (43.5)	22 (61.1)	32 (54.2)
Male	13 (56.5)	14 (38.9)	27 (45.8)
Cadre			
Clinician (physician and non-physician)	16 (69.6)	7 (19.4)	23 (39.0)
Laboratory position	3 (13.0)	7 (19.4)	10 (16.9)
Nursing position	4 (17.4)	22 (61.1)	26 (44.1)
Programme managers			
	N=4	N=6	N=10
Age (years)			
Mean (SD)	38.3 (3.9)	40.7 (9.0)	39.7 (7.2)
Duration of service at this facility (months)			
	N=3		
Mean (SD)	80.0 (30.2)	40.0 (32.1)	53.3 (35.7)
<b>(C)</b>			
	<b>Kenya N=38 n (%)</b>		
Age (years)			
	N=37		
Mean (SD)	39.1 (10.2)		
Duration of service (months)			
	N=37		

Continued

Table 2 Continued

(C)	
	Kenya N=38 n (%)
Mean (SD)	23.9 (11.8)
Gender	
Female	26 (68.4)
Male	12 (31.6)
Cadre	N=37
Community health volunteer (CHV)	17 (45.9)
Cough monitor	9 (24.3)
CW	2 (5.4)
Multiple†	6 (16.2)
Other‡	3 (8.1)

\*Five TB-presumptive children in Kenya and seven in Cameroon were not diagnosed with TB.  
†Multiple includes CHV/cough monitor, CHV/cough monitor/CW, cough monitor/CHV/adherence and/or CHV/TB linkage assistant.  
‡Other includes linkage assistant, peer educator—chest clinic and TB ambassador.  
CaP-TB, Catalysing Paediatric TB; CW, community worker; TB, tuberculosis.

you because they know that TB is spread through the air. (Kenya, caregiver, female, K-10-C-IDI-07)

### Health-seeking behaviours with paediatric TB

Many HCWs in Cameroon and CWs in Kenya stated that their knowledge about paediatric TB was very limited prior to the CaP-TB programme. In both countries, HCWs, CWs and PMs observed a significant increase in paediatric TB screening following the implementation of the CaP-TB programme.

Since the inception of the follow-up of pediatric tuberculosis here, it has facilitated our job. We have diagnosed easily, many children who had tuberculosis and we have placed them under care easily, compared to what obtained in the past [number of children initiated on treatment previously]. (Cameroon, HCW, female, 10-A-H-01-P51)

Many caregivers in Cameroon and an HCW and a programme manager in Kenya explained that providing free paediatric TB services is one of the main facilitators for caregivers' accepting of TB screening and treatment. Previously, cost had been a barrier for some families.

But currently when you tell them that this one is going to be done free for you, they agree so most of the time... ideally it has helped us a lot. (Kenya, HCW, female, K-10-H-FGD-01-P04)

### Perceptions about paediatric TB diagnosis

In Kenya and Cameroon, some HCWs, CWs and PMs explained that caregivers occasionally refused screening for paediatric TB, leading to missed opportunities for TB identification and treatment.

... It is true that we have to do with patients who do not even accept that the child coughs...the child shows signs of the disease. What they generally do is, when we say the

child has a cough and should be tested [diagnosed], the parents would say 'No, I don't think so, because my child has always had a cough which I have been managing myself'. So, parents are also the problem. (Cameroon, HCW, female, 10-A-H-01-P45)

Reasons for parental refusal included a lack of awareness of paediatric TB, believing TB symptoms were other common illnesses, concerns about the diagnosis procedures and fear of stigma.

In Cameroon, one PM attributed caregivers' refusal of TB screening to their denial that their children's symptoms could potentially be TB.

...They always start by telling us that, it is not it (tuberculosis) and they would go [leave the facility]. It is when it [cough] persists that they would come back and tell you, 'You might be correct, let's try what you said', but at the beginning...at the first diagnosis (Sighs and laughs) they don't agree...they don't agree. They [the parents] would tell you, no, 'it might be a bronchitis, it is pneumonia'... they know big terms ehh, but they cannot tell you that it is tuberculosis, because they think that it is for adults, and when one has tuberculosis he is isolated, it is six months, it is many days... 'How can I isolate this child?...it cannot be it'... (Cameroon, program manager, 10-A-P-48)

Many caregivers, HCWs, CWs and PMs mentioned that prior to presenting at a CaP-TB facility, caregivers sought care at other locations, including local drug stores at the onset of their child's symptoms. Several caregivers in both countries attributed this decision to seek care elsewhere to the belief that symptoms were evident of other diseases, such as malaria, cough or pneumonia.

While at the village he used to get sick and my mother used to take him to the hospital and give him medicine.

She thought that it was just malaria. So, when I brought here and he got tested he was found with that disease [TB]. He got sick many times. They just gave him medicine. They bought Coartem. For the cough they bought him haemoglobin to drink. The hospital that he normally went to was just a dispensary. (Kenya, caregiver, female, K-12-C-IDI-03)

Some HCWs in Kenya and Cameroon explained that requiring children to fast for the diagnostic procedures (eg, gastric aspirate) and needing them to return to the facility the next day for the procedure, resulted in some patients not returning. In Kenya, a PM explained that teamwork and tracing defaulters were employed as mitigation strategies.

You can give a mum a TCA [to come back again] to come tomorrow before breastfeeding the child. So, it becomes a challenge to the mum, bringing the child to the facility without being breastfed. So, it is like they keep on postponing until you go look for them physically. They tell you that they had to breastfeed the baby because the baby was crying. But not a great percentage usually deny their children to be tested. (Kenya, HCW, female, K-30-H-FGD-01-P08)

Concerns about having to isolate and therefore alerting others to the child's infection also raised concerns about stigma.

Maybe to add on, I think stigma is still a challenge and that is why when you want to take a specimen, they may not accept easily because there is that essence of you need to stay isolate. (Kenya, HCW, female, K-20-H-FGD-01-P01)

### Impact of integrating paediatric TB services

Many CWs in Kenya and HCWs in Cameroon praised CaP-TB for increased case identification. These participants explained that the CaP-TB programme increased HCWs' motivation to investigate children with clinical presentations consistent with possible TB. Furthermore, the CWs and HCWs in both countries stated that prior to the CaP-TB programme, there were many missed opportunities in TB case identification, resulting in many avoidable deaths.

For example, in a child who has a fever. Maybe without the CaP-TB project we might bypass the disease during the search for this disease in some patients, but with the screening manual which is always in front of the doctor, it keeps reminding us that we have to look for the symptoms in the patient that has been sent to us. (Cameroon, HCW, male, 20-S-H-01-P34)

In both Kenya and Cameroon, most participants believed that TB service integration into routine paediatric services increased caregivers' satisfaction with care outcomes and reduced TB mortality in children.

A lot of awareness has been created in the community so most parents and the community members have the know how on the signs and symptoms. So, when they see these

things in children they know the actions they should take. (Kenya, CW, male, K-10-W-FGD-02-P04)

A caregiver in Kenya explained that TB screening at all paediatric care entry points was beneficial to children whose parents had fears or concerns about taking their children for TB diagnosis.

That is good because there are some parents who fear testing their children for TB but if they find that screening is done within all the departments at the facility...that will help them ... It cannot have any challenges because TB screening is free... (Kenya, caregiver, female, K-10-C-IDI-02)

Although the majority of caregivers supported the TB service integration into routine paediatric services, one caregiver in Kenya was the exception. This caregiver explained they preferred to receive care and treatment for the specific service they came for and expected to receive no additional services.

It is not good because you left the house to go to clinic and they also test TB. If you wanted to go for both it is okay. If you only went for clinic you should just go for the clinic then go back home. Even if you went for the TB test, just test TB only then go back. (Kenya, caregiver, female, K-30-C-IDI-04)

A few PMs (two in Cameroon and one in Kenya) acknowledged that CaP-TB had increased the workload since there were greater needs for supervision, time spent with the patient and documentation.

CaP-TB has made me speak a lot. It's exhausting because you have to persuade the patients. You also have to persuade the staff... Every day trying to persuade first the staff, then the patient ... you waste time filling in the forms and also chatting because you have to come every time to say but why don't you screen the patients? You have to do it, don't you, don't you, don't you see that? The same talks every day is exhausting, you know? Yes, trying to, trying to get everyone into the swing of things. (Cameroon, program manager, 32-F-P-78)

In Cameroon, a few HCWs reported that providers were not motivated to implement the project, leading to missed TB screening opportunities. However, this challenge with providers' motivations was not reported in Kenya.

Work has increased at the reception. We have a new register. They have added the registers and the fact that all children are absolutely screened has increased the workload. That is a negative impact (Laughs). And the fact that the personnel is not motivated...that should be highlighted, yes. The fact that the personnel are not motivated disturbs. (Cameroon, HCW, female, 10-A-H-01-P51)

### Facility-level challenges implementing CaP-TB

One facility-level challenge mentioned by several caregivers, HCWs and PMs was an insufficient supply of paediatric TB medications. A HCW in Kenya stated that paediatric drug shortages were a major challenge in their

facility. Additionally, a few caregivers, HCWs and PMs explained that the insufficient supply of paediatric TB medications led to adjusting adult formulations for children. Children's refusal and difficulty swallowing medications were the most common challenges with paediatric treatment.

...there was a shortage in the medications of children... but she was sick, she had to, we had to start the treatment. We were obliged to, to break that of adults. (Cameroon, caregiver, female, 10-A-C-50)

A few HCWs and PMs in Kenya and Cameroon attributed shortages of paediatric TB drugs to their site's existing paediatric TB medications expiring. However, in addition to medications expiring, one HCW and two PMs in Kenya mentioned other causes for insufficient supplies of paediatric TB drugs, including delays with customs' clearance, gaps in reporting stockouts and challenges with management at the MOH and Kenya Medical Supplies Authority.

...it stopped for only two months when there was a delay on clearing at the port. So, we had that challenge of which pediatric drugs was out of stock... and also the short expiry that is why you find that we were trying to...use the conventional one, the adult one and advise the caregivers to split but it was just for a short while. Only a month. (Kenya, HCW, male, K-30-H-FGD-01-P05)

Another challenge within the CaP-TB facility mentioned by many PMs and a few HCWs was an inadequate number of staff to complete the required work and a lack of skills. PMs and HCWs explained that although training was adequate, there were constant changes in staff with frequent transfers, resulting in some staff not receiving the required training. One HCW suggested that trainings be conducted more regularly.

CaP-TB has to understand as time passes by.....there is recycling to be done because there are new doctors, new nurses who need this training ... If we could do recycling every three months or six months. (Cameroon, HCW, female, 10-A-H-01-P50)

Furthermore, some HCWs and PMs in both countries explained that the staff selected to receive specialised training were not always available to perform the needed procedures, resulting in delays in care.

There were moments when the aspirator had to be used automatically and eh...eh... the doctor who was trained was not available. (Cameroon, HCW, female, 20-S-H-01-P33)

## Recommendations

Four main recommendation areas were identified: strengthening community sensitisation and awareness of paediatric TB; providing more staff; task shifting and engaging more community HCWs to identify patients in the community.

Several caregivers, CWs, HCWs and PMs mentioned the need to increase awareness of paediatric TB within

the communities, with some suggesting disseminating information about paediatric TB through media such as religious gatherings, community leaders and home visits.

Yes, we can even use the CHVs in the community to pass the information across. The CHVs are always there; in the church, in the market. So, they can get the information through the CHVs easily. (Kenya, CW, female, K-30-W-FGD-01-P10)

A few caregivers, CWs and HCWs explained that increasing sensitisation of paediatric TB would help demystify TB, ensure individuals were informed and could recognise when people in their community should seek TB diagnosis for their child and reduce the stigma associated with TB.

So, when we sensitize the community on pediatric tuberculosis, then the parents will have the knowledge that when the child has a cough and has fever and the body just getting weak. Then they will have the thought of going to the hospital instead of giving the child traditional herbs. (Kenya, CW, female, K-10-W-FGD-01-P05)

In Cameroon, many caregivers explained that their willingness to have their child screened was motivated by the diagnosis being done at no-cost to them. In Kenya, one CW suggested that sensitisation efforts should include making community members aware that TB screening and treatment services were free.

The message we can pass across is just that this disease is being treated free of charge so the children who have it should be brought to the health facilities for treatment so that it does not spread so much. (Kenya, CW, female, K-10-W-FGD-02-P02)

A few caregivers and CWs also suggested the programme includes community-based and home-based TB screening services by CWs who are already working the community.

There is a certain group that always go round to look... to test for, for this thing... they always say, is it measles, is it measles or what like that. So that whenever they come across any child that is having such type of thing sickness, they will then call to higher level so that they will come and collect the child. So, for me, I think that we should do so... we should also maintain that on TB patients. (Cameroon, caregiver, male, 30-F-C-64)

Although respondents indicated a need for additional personnel in both countries, the recommendation was expressed more frequently by respondents in Kenya. In Cameroon, the need for additional staff was suggested in relation to improving facility logistics' management and disaster prevention management. In contrast, Kenyan participants need for the additional personnel stemmed from the facility workload and specific needs, such as wanting additional cough monitors.

One is to employ more of cough monitors to help us in screening, second is also to employ or bring me back my staff who went on transfer that would be able to help. (Kenya, HCW, male, K-20-H-FGD-01-P03)



In some sites, only physicians were trained for sample collection. In Cameroon, one PM suggested task-shifting, with training more nurses to perform sample collection procedures since they had more time available and could master the necessary skills with the training. This could help address the lack of trained staff.

Everyone should have been trained to be able to use ‘nasopharynges’ because most of the time it is the gastric probing that is used to collect sample, and normally, only doctors are supposed to perform this method of sample collection... I would like that all the nurses be trained to perform or do gastric probing because most of the time the nurses are more available in the hospital than the doctors. (Cameroon, program manager, 20-S-P-33)

In Cameroon and Kenya, a few HCWs and PMs recommended that CaP-TB services be extended to additional health facilities to improve accessibility, especially for patients who had to travel far and incur expensive travel costs.

It should even be present in all health institutions... CaP-TB should be implanted everywhere....children are received everywhere, ... If it is selective, that is, only in district hospitals, more and more children go to conventional and private hospitals such children would be lost. But if the service is implemented everywhere they would be, it would save many children. (Cameroon, program manager, 20-S-P-33)

## DISCUSSION

This study identifies large gaps in knowledge of paediatric TB among both caregivers and HCWs, perceived benefits of decentralising services and recommendations to improve paediatric TB identification and treatment.

### Knowledge gaps

Lack of knowledge of paediatric TB has been well documented in previous research. One study in Cameroon found that one-third of the study participants did not know that TB is transmitted through the respiratory route and 11% did not know how TB is transmitted at all.<sup>19</sup> Without knowledge about TB symptoms, those infected with TB may not seek diagnosis and treatments, potentially resulting in transmitting the disease to others.

Lack of knowledge regarding paediatric TB was the main contributing factor as to why parents in this study did not have their children assessed for TB. Symptoms of paediatric TB can often be mistaken for other illnesses, such as malaria, a ‘normal’ fever, etc.<sup>20</sup> Patient knowledge and beliefs are critical in encouraging caregivers to bring their child for diagnosis, present for medication if diagnosed and adhere to treatment.

In our study, participants generally agreed to TB screening and diagnosis procedures, yet some did not return the following day for the diagnostic testing of their children. This could have been due to concerns about fasting prior to the test, transportation or other challenges. Previous studies have documented resisting

diagnostic testing due to fear of being observed receiving TB treatment, fear of being diagnosed with drug-resistant TB and denial of TB diagnosis.<sup>21</sup>

Stigma may have also discouraged caregivers from returning to having their child tested for TB. Previous research has linked TB to ‘dirtiness’, with some explanations going beyond socioeconomic factors and reflecting more morally sanctioned behaviours, like smoking, drinking and having multiple sexual partners.<sup>22</sup> A Knowledge-Attitudes-Practices (KAP) survey in regions in Cameroon found that a large number of respondents also mistakenly indicated that TB could be transmitted through eating from the same plates and contact with the same objects.<sup>19</sup> Such misbeliefs can increase stigma and fear in the community. TB and HIV coinfection is common, which further exacerbates negative TB perceptions, and a previous study found that participants reported being fearful to test for TB, lest it also result in an HIV-positive diagnosis.<sup>20</sup>

Previous research has also documented a lack of HCW knowledge about paediatric TB. One study in Tanzania reported that TB was rarely suspected in children but acknowledged that they probably saw very little paediatric TB because they were not able to diagnose it.<sup>23</sup> The Tanzania study reported that TB was typically differentiated from more common acute diseases on the basis of being severely sick and unresponsive to treatment.<sup>23</sup> The Tanzania study also reported that HCWs felt that it was difficult to distinguish HIV and malnutrition from TB and believed that only the hospital had the ability to differentiate between the two conditions.<sup>23</sup>

A study in Kenya reported that reluctance to diagnose TB was often linked to underlying beliefs that children do not usually get TB.<sup>24</sup> A multicountry KAP survey on childhood TB found that HCWs have overall limited knowledge and little practice with paediatric TB diagnosis. The study found that half of the respondents in Cameroon, Cote d’Ivoire and Sierra Leone disagreed or strongly disagreed that any child attending an outpatient department should be systematically screened for TB.<sup>25</sup>

Specific concerns included symptom overlap with other childhood illnesses, a lack of reliable diagnostic tests and difficulty obtaining samples for diagnosis, particularly when procedures were invasive, such as gastric aspirates.<sup>24 26</sup> A multicountry KAP survey on childhood TB reported that HCWs would rather rely on ‘objective’ laboratory findings, than their own ‘subjective,’ clinical findings.<sup>25</sup> The treatment of paediatric TB is also complex. The need to calculate paediatric doses by weight increases the risk of dosing errors.<sup>27</sup>

One study reported that stigma regarding TB made some HCWs reluctant to diagnose paediatric TB, out of fear of upsetting the caregivers.<sup>24</sup> This study hypothesised that some of the reluctance to give a TB diagnosis was the association with HIV, as HCWs feared it may lead to emotional burden.

### Perceived benefits of decentralising services

Decentralisation has previously been identified as a potential solution for increasing paediatric TB case identification and treatment. A study in Uganda found that the decentralisation and strengthening of child TB services in Uganda was associated with a significant increase in case notifications and improved treatment outcomes for paediatric TB cases, which was primarily due to the increased proportion of cases identified at periphery facilities.<sup>28</sup> The Uganda study also found that a significant increase in the treatment success rate of children treated for TB and a significant decrease in proportions of death and treatment failure, which was primarily attributed to the increased numbers of trained HCWs.<sup>28</sup>

Previous research has found that even when caregivers have been provided with referral slips, they sometimes choose to not attend the referred facility out of concerns regarding transportation cost and lost working hours and may wait until the symptoms are very severe.<sup>23</sup> One of the key components of the CaP-TB programme was the decentralisation of TB diagnosis and treatment offered at the lower-level facilities. Through a hub-and-spoke model, samples instead of the patients were transported, thus limiting caregivers' transportation costs and extended travel times.

The CaP-TB programme also provided a critical feedback loop between the hub-and-spoke sites. Previous research has documented the lack of communication from tertiary-level facilities once patients have been referred, resulting in lack of awareness of the TB burden in the community.<sup>23</sup>

The CaP-TB programme also highlighted the need for additional resources to adequately support paediatric TB efforts. Sub-Saharan Africa has historically faced a shortage of HCWs and adding additional roles and responsibilities to staff further exacerbates the burden on the existing health-care system.

### Recommendations

Results from this study highlight the need for further community education on the symptoms of paediatric TB, what TB screening and diagnosis entails, the benefits of starting treatment early, and where to go for diagnosis while also emphasising that TB services are free. In another study, providers suggested that community-based health education can reach more people and have a greater impact, especially by strengthening the role of the CW to educate families in the community.<sup>29</sup> Expanding community-based services, with CW screening and following-up of child contacts is one method of addressing the challenges caregivers report related to time and distance to go to a clinic.<sup>29</sup> In Cameroon, it was identified that the rural populations need additional information about paediatric TB.<sup>19</sup>

Additional training and support are needed for the HCWs, not only to increase their comfort with diagnostic testing but also to enable them to provide adequate counselling to the caregivers of children at risk of TB and HIV and help them understand the benefits of early diagnosis and treatment for both diseases. The multicountry KAP survey reported that more than two-thirds of study respondents reported insufficient training in paediatric TB.<sup>25</sup> Other research has

highlighted the importance of simple diagnostic tools and guidelines for screening children and improving TB case detection.<sup>23</sup> Training should increase awareness of the burden of childhood TB and expand the knowledge of clinical signs and symptoms, with emphasis on early symptoms and a timely referral.<sup>23</sup> It is also important to ensure that the HCWs are knowledgeable and understand the guidelines for screening children. In Tanzania, HCWs were unaware of the clinical score chart included in the Tanzania NTL manual.<sup>23</sup>

Additional resources, in terms of adequate supplies of paediatric formulas, are also needed. Although the CaP-TB programme intended to procure paediatric, child-friendly, fixed TB drug combinations, during the study there were drug shortages reported in both countries, resulting in the use of adult formulations for children. Caregivers described challenges with administering adult formulations to their children, especially if they had to split adult tablets, which exposed the bitter taste of the medicine. The process of preparing paediatric doses by crushing adult medications makes the taste more bitter.<sup>27</sup> The lack of child-friendly drugs has been found to lead to incorrect dosing.<sup>27</sup>

The CaP-TB training ensured that HCWs were aware of the challenges that caregivers experienced administering the medication to their child. Educating HCWs about such challenges could help them prepare caregivers in order to anticipate and assist in possible adherence issues and facilitate success.<sup>26</sup>

One of the main strengths of this study is the multicountry and multiregion design, gathering feedback from many different geographic areas. Also, the study gathered perspective from many different groups, allowing the authors to be able to triangulate findings across groups and provide overview of the existing knowledge and perceptions of paediatric TB and the acceptability of the CaP-TB programme. The main limitation of this study is that no interviews were held with caregivers who rejected having their child assessed for TB and this group may have had a different perspective. Additionally, caregivers were only recruited from the health facility and those in the community who do not access the facility may have also had a different perspective.

### Conclusions

Paediatric TB disease is a highly stigmatised disease that requires additional education at community and health facility levels. The CaP-TB programme highlighted the many opportunities for increased case finding, diagnosis, and successful treatment by decentralising paediatric TB care to routine paediatric service sites and providing free-of-charge TB services. The CaP-TB programme contributed to increased awareness of paediatric TB among both caregivers and HCWs and showed high acceptability by both groups. The programme also identified a need for efforts at the community level to encourage caregivers to assess their children for TB and decrease the stigma and shame surrounding a TB diagnosis.

### Author affiliations

<sup>1</sup>Elizabeth Glaser Pediatric AIDS Foundation, Washington, District of Columbia, USA

<sup>2</sup>Research, Elizabeth Glaser Pediatric AIDS Foundation, Nairobi, Kenya

<sup>3</sup>Public Health Evaluation and Research, Elizabeth Glaser Pediatric AIDS Foundation, Yaoundé, Cameroon

<sup>4</sup>Global Health, The George Washington University Milken Institute School of Public Health, Washington, District of Columbia, USA

<sup>5</sup>Elizabeth Glaser Pediatric AIDS Foundation, Geneva, Switzerland

<sup>6</sup>Kenya Ministry of Health, Homa Bay, Kenya

<sup>7</sup>Ministry of Health, Yaounde, Cameroon

X Rose Masaba @rose Masaba

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#### ORCID iDs

Rose Masaba <http://orcid.org/0000-0003-1801-7938>

Boris Tchounga <http://orcid.org/0000-0002-8747-9610>

Lise Denoeud-Ndam <http://orcid.org/0000-0002-9482-1461>

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