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Health care worker perspectives on TB case finding and HIV services among pediatric TB patients in Tanzania

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SUMMARY

BACKGROUND: Tuberculosis (TB) and human immunodeficiency virus (HIV) infection in children are of concern due to the high morbidity and mortality they engender. Tanzania is working to improve TB and HIV case identification and treatment, as well as linkage of TB and HIV care in pediatric patients.

METHODS: In-depth interviews were conducted in March 2016 at 10 high TB burden clinics in five districts of Tanzania to identify the barriers to pediatric TB diagnosis and HIV care. Health care workers (HCWs) at TB clinics who provided informed consent were administered interviews which were analyzed.

RESULTS: Of 41 HCWs interviewed, 26 reported receiving pediatric TB training. Barriers to TB diagnosis included low community awareness, stigma and late presentation to the clinic. Barriers to HIV testing included children attending the TB clinic with someone who was not their parent/guardian and shortages of HIV rapid test kits. HCWs stressed the need for improved community education because it was perceived that some caregivers did not understand the importance of prompt TB and HIV treatment in children (although most were eager for a resolution of their child's illness).

CONCLUSIONS: Efforts are needed to ensure effective TB and HIV diagnosis and treatment of children, provision of broader HCW and community education, enhanced TB-HIV contact tracing, and ensuring a continuous supply of HIV rapid test kits.

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RÉSUMÉ

La tuberculose (TB) et l'infection par le virus de l'immunodéficience humaine (VIH) chez des enfants sont une source de préoccupation en raison de leur morbidité et de leur mortalité élevées. La Tanzanie agit afin d'améliorer l'identification des cas pédiatriques de TB et de VIH, leur traitement et le lien avec la prise en charge du VIH.

Des entretiens approfondis ont été réalisés en mars 2016 dans 10 centres TB très affectés de cinq districts de Tanzanie afin de comprendre les obstacles au diagnostic de la TB pédiatrique et à la prise en charge du VIH. Les agents de santé (HCW) des centres TB ont fourni un consentement éclairé et ont réalisé les entretiens qui ont ensuite été analysés.

Sur les 41 HCW interrogés, 26 ont dit avoir eu une formation en TB pédiatrique. Les obstacles au diagnostic de la TB ont inclus la faible sensibilisation de la communauté, la stigmatisation et une présentation tardive au centre. Les obstacles au test VIH ont inclus le fait que les enfants sont venus au centre avec une personne autre que leur parent/responsable et les ruptures de stock de kits de tests VIH rapides. Les HCW ont souligné le besoin d'améliorer l'éducation des communautés car ils ont réalisé que certains adultes responsables des enfants ne comprenaient pas l'importance d'un traitement rapide de la TB et du VIH des enfants même si la majorité avait hâte que la maladie de leur enfant soit guérie.

Des efforts sont requis afin d'assurer un diagnostic et un traitement efficaces de la TB et du VIH des enfants, notamment la mise en œuvre d'une éducation plus vaste des HCW et des communautés, d'une meilleure recherche des contacts TB-VIH et de la fourniture continue des kits de tests VIH rapides.

RESUMEN

La tuberculosis (TB) y la infección por el virus de la inmunodeficiencia humana (VIH) en la población pediátrica son motivo de preocupación debido a su alta morbimortalidad. En Tanzania, se trabaja en la actualidad con fin de mejorar la detección de casos y el tratamiento de la TB y la infección por el VIH en los niños y promover su vinculación a los servicios de VIH.

En marzo del 2016, se llevaron a cabo entrevistas exhaustivas en 10 consultorios de TB con alta carga de morbilidad por TB en cinco distritos de Tanzania, con el objeto de comprender los obstáculos al diagnóstico de la TB y la atención de la infección por el VIH en los niños. Los profesionales de salud (HCW) de los consultorios de TB aportaron su consentimiento informado y respondieron a las entrevistas, a las cuales se aplicó un análisis de contenido.

De los 41 HCW entrevistados, 26 afirmaron haber recibido capacitación en materia de TB pediátrica. Entre los obstáculos al diagnóstico de la TB se mencionaron la escasa sensibilidad de la comunidad, la estigmatización y el retraso en acudir al consultorio. Se refirieron como barreras a la prueba del VIH el hecho de que el acompañante del niño al consultorio no era uno de sus padres ni su tutor y los desabastecimientos de los estuches de pruebas rápidas del VIH. Los HCW destacaron la necesidad de mejorar la educación comunitaria, pues percibían que algunos cuidadores no comprendían la importancia de la rapidez del tratamiento de la TB y la infección por el VIH en los niños, aunque la mayoría estaba impaciente de obtener su curación.

Se precisan iniciativas que procuren un diagnóstico y tratamiento eficaces de la TB y la infección por el VIH en los niños y que incluyan una educación más completa a los HCW y a la comunidad,

el reforzamiento del seguimiento de los contactos de casos de coinfección por TB-VIH y la garantía de un suministro ininterrumpido de estuches de pruebas rápidas del VIH.

Keywords

pediatric; tuberculosis; HIV/AIDS; HCWs

TUBERCULOSIS (TB) IN CHILDREN aged <15 years, particularly those living in high human immunodeficiency virus (HIV) and TB burden regions such as sub-Saharan Africa, is a major public health concern. In 2016, an estimated 1 million children became ill with TB and 250 000 children died because of it.[1] The burden of TB among children is greatest in low-resource settings, in which children can account for 15–20% of all TB cases.[2]

Tanzania is among the top 30 high TB burden countries worldwide.[1] In 2015, the national TB incidence rate was 306 per 100 000 population, and 62 180 cases of TB were reported to the Tanzania National Tuberculosis and Leprosy Programme (NTLP), 5699 (9.4%) of whom were children aged <15 years.[3,4] However, a study in Mwanza, Tanzania, showed a large gap between the reported incidence of TB in children aged <5 years and household exposure of children to adults with TB. This finding would lead to a higher theoretical incidence of early childhood TB, and suggests that underdiagnosis of pediatric TB is common.[5] In addition, the first national TB prevalence survey in 2012 reported a case detection rate of as low as 42%, suggesting undiagnosed children in the community.[6] Only 6.9% of children aged <5 years who were household contacts of bacteriologically confirmed TB cases were estimated to be receiving isoniazid preventive treatment (IPT) in 2015.[3]

In 2015, the prevalence of HIV infection in Tanzanian adults was 4.7%, and an estimated 91 000 children aged 0–14 years were living with HIV.[7] In 2015, 96% of children notified with TB were tested for HIV, and 29% were identified as HIV and TB co-infected cases. Among notified co-infected children, 97% were registered for HIV care services, 98% were initiated on cotrimoxazole prophylaxis therapy, and 87% were initiated on or were undergoing antiretroviral therapy (ART) at the time of TB diagnosis.[3,4] These data suggested the need to increase ART rates in children.

The Tanzanian government has made substantial efforts to train health care workers (HCWs) in pediatric TB and HIV management. Nevertheless, challenges that remain in pediatric TB case identification and HIV testing, and linkage to ART experienced by front-line HCWs are not well known. Few studies have assessed the staff perspectives on TB and HIV integration.[8]

To address this gap, we conducted a qualitative study. We interviewed HCWs to understand the challenges they encounter in diagnosing and treating TB and HIV among children. This would help to further strengthen TB and HIV case management among pediatric populations in Tanzania.

STUDY POPULATION AND METHODS

In March 2016, five NTLP districts with a high TB burden were selected purposefully by study investigators to include urban and rural areas. Ten health facilities (two per district) were included based on the child TB burden in these regions. In each region, the district health facility was included because it had the highest number of children registered for TB care; a second, lower-level health facility was also selected. In Tanzania, TB clinics are staffed primarily by clinical officers and nurses who can diagnose and treat TB. Patients are referred from HIV clinics, Well Child clinics, or any service point where clinicians suspect a child may have TB. All health care providers working in the TB clinics at the selected facilities were invited to participate in one-on-one in-depth interviews. To be eligible for study participation, providers had to work full time at the facility and be able to provide verbal informed consent. HCWs interviewed were those present during the study period.

Verbal informed consent was given by providers before the start of the interview. Interviews were conducted in a quiet, private space by a trained interviewer, who was not a Ministry of Health employee. In-depth interview guides were used to conduct interviews in the participants' language of choice (English or Kiswahili). Interviews were audio-recorded, transcribed verbatim, and translated into English for analysis. Key questions included reasons for the failure to identify TB in children, recommendations on how to improve TB identification, reasons for not offering HIV testing to children with TB, challenges to HIV testing, and recommendations on how to improve HIV testing.

Data were analyzed using an iterative coding process. A codebook was developed a priori based on the objectives of the study, and additional themes were added based on the context of the responses.[9] The transcripts were coded manually. Three socio-analysts applied the codes to the transcripts independently. Regular meetings were held to discuss discrepancies among the three analysts until consensus was reached. Brief summary statements with representative quotes were developed for each theme and subtheme.

Ethics approval

The study protocol was approved by the US Centers for Disease Control and Prevention (Atlanta, GA, USA) and by the National Health Research Committee of the Ministry of Health, Community Development, Gender, Elderly and Children (Dar es Salaam, Tanzania).

RESULTS

Overall, 41 HCWs were interviewed, of whom 25 (61%) were clinicians (Clinical Officers and Medical Officers) and 16 (39%) were nurses. The HCWs had worked an average of 5.7 years in the current TB clinic and 6.7 years in the field of TB. Of the 41 participants, 33 (80%) reported receiving training in TB, whereas 26/41 (63%) participants had received training in pediatric TB. Eighteen (44%) participants had received training since 2015 after the NTLP updated the national pediatric guidelines to emphasize the need to use a pediatric scoring chart. The majority of participants (38/41, 93%) had copies of the current National Pediatric TB Guidelines.[10]

When asked about the methods used to diagnose TB in children (with the opportunity to report more than one method), 24/41 (59%) reported basing their diagnosis on clinical judgment, 20/41 (49%) on microscopy results, 13/41 (32%) on radiology reports, 19/41 (46%) on the pediatric score chart, and 3/41 (7%) on gastric aspirate results. All interviewed HCWs reported that they routinely ask adult TB cases about children with whom they are in contact. Key responses from the interviews are indicated below and organized by theme.

Services used to treat tuberculosis

Reasons for delayed care seeking or late presentation of children with tuberculosis

1 Low community awareness: HCWs perceived that one of the main barriers for caregivers not bringing TB-exposed children to a health facility was the belief within the community that children cannot get TB. They also sought treatment from other avenues, including traditional healers, before going to TB clinics.

> Firstly, some people do not believe that children can have TB, so once the child develops the TB symptoms they don't bring him to hospital, instead they go to pharmacies and private dispensaries. They bring the children to the hospital after their initiatives fail. Once you listen to their explanations, you realize that the child has TB. (Nurse)

2 Stigma, causing caregivers to delay bringing children to the health facility: HCWs also reported that stigma surrounding TB made community members reluctant to seek care. Because TB is an infectious disease and is associated with HIV, a sexually transmitted disease, HCWs perceived that stigma may have led some families to delay seeking care for their child.

> We face challenge with the caregivers, the child might be ill for such a long time but they don't bring them to the hospital for fear of stigma. By the time they bring the child we find the child is in bad condition, for this case then we have to make close follow-up to this caregiver. Secondly, once the children are already in bad condition, some mothers tend to feel shy to bring them to the hospital. (Clinician)

Reasons for the failure to identify tuberculosis

1 Difficulty diagnosing tuberculosis in children: Once the child was brought to the health facility, HCWs mentioned difficulty in diagnosing TB because children do not usually produce sputum and have paucibacillary disease. As a result, their symptoms may be attributed to a different problem such as pneumonia or other respiratory illnesses.

> It is not easy to recognize the symptoms. It is also difficult to get sputum from a child. (Clinician)

Ways to improve tuberculosis identification and pediatric contact tracing suggested by health care workers

1 Emphasize the importance of tracing the pediatric contacts of adult TB patients: HCWs suggested that they should work to ensure that all children living in

households with adult TB patients be traced and brought for TB screening. This should start by educating and encouraging adult TB patients to bring their children to the health facility for screening.

> Health workers should ask people with TB about their family members, particularly children. (Nurse)

HCWs reflected that many of the adults receiving TB-HIV education during TB clinic visits were willing to bring their children to the facility for TB screening; however, this was not being emphasized routinely at every clinical encounter with the TB patient. Some providers suggested that a more active approach, including household visits, was needed to ensure that children are screened for TB and receive IPT.

2 Ensure engagement of all healthcare workers in tuberculosis care: HCWs called for all facility providers to be cross-trained in recognizing the signs and symptoms of TB in pediatric patients as well as how to screen for TB in these patients to maximize TB case identification among children.

> To provide training to all service providers who deal with children, for example at OPD [Outpatient Department], RCH [Reproductive and Child Health] and at the children's clinic ward. Doing this will help to identify many children with TB. (Nurse)

3 Engage pharmacists, drug vendors and traditional healers and ensure training and sensitization among community members: Some caregivers visit traditional healers to treat their child's TB symptoms before seeking health services at a clinic or hospital. HCWs, therefore, recommended training these individuals to recognize the signs and symptoms of TB so they could refer children with symptoms to a health facility (Table 1).

> To involve pharmacists, traditional healers and community health care workers to refer children to this clinic once they find the children with TB symptoms. Doing all of these will help to identify many children with TB. (Nurse)

Care and treatment services for human immunodeficiency virus infection

Reasons caregivers may not want their child tested for human immunodeficiency virus

HCWs noted that it is rare to encounter a caregiver who refuses HIV testing for their child. Those who had encountered caregiver reluctance cited reasons, including implications of the child's status for the parent's HIV status and lack of knowledge about HIV transmission and the importance of prompt treatment.

1 Concern that the child's human immunodeficiency virus status would reveal the parent's status—Caregivers understood that their children's HIV status could potentially reveal their own status, particularly if the caregiver was the biologic mother of the child. Other caregivers expressed concern about how their child would react upon learning that the parent had transmitted HIV to their child.

> Most of them are afraid to be questioned by their children about what happened that the child is HIV positive. To them it is very stressful. I once met a certain woman who attempted to commit suicide because her child was embarrassing her by asking why did she infect him with HIV. (Clinician)

2 Lack of knowledge about the transmission and importance of prompt treatment of human immunodeficiency virus infection in children:

> Some of them believe that getting early information they will have long time to plan so they just wait for a child to grow and will test even later. (Clinician)

Reasons healthcare workers may not test for human immunodeficiency virus —Most HCWs noted that they try to test all children for HIV at the TB clinic. However, HIV testing is not offered in some situations as described below.

1 The child is not accompanied by a parent or caregiver and/or has not attained the age of consent: In Tanzania, the minimum age of consent for HIV testing is 15 years.[11] Of 39 HCWs, 19 (49%) responded that they would not offer HIV testing to a child accompanied by an adult family member who is not the parent.

> For instance, if the child is under 15 and is brought by the person who is not his parent or a caregiver, I cannot test him. (Clinician)

HCWs described several exceptions whereby a child aged <15 years can be tested for HIV without the consent of a parent or a caregiver. These exceptions were if the child 1) had signs or symptoms of an HIV infection (12/41, 29%), 2) was engaged in sexually risky behaviors (8/41 20%), 3) was pregnant (4/41, 10%), 4) was married (4/41, 10%), or 5) was already a parent (1/41, 2%).

> In case the child is sick or s/he wants to get married, I can provide direct HIV testing to a child who can understand. In case the child has no caregiver, for example, there are those who are being neglected at hospital… if the child was neglected and raised by someone who is not the family member, then I can provide the service. (Clinician)

HCWs did not identify a particular age that was specifically challenging for HIV testing, noting instead that all children were difficult to test due to consent issues.

> The age between 0–16 years because you cannot test them without parents' consent. (Clinician)

When asked about the youngest age at which HCWs would disclose HIV status directly to a child, 12/34 (35%) stated 10–14 years, 10/34 (30%) stated 15–16 years and 12/34 (35%) stated 17–18 years. National guidelines recommend that disclosure should begin at 4–6 years of age, with full disclosure by 8–10 years.[12] That one third of providers stated they could only provide results directly to children aged 17–18 years is a matter of concern, given that the age of consent is 15 years.

2 Stock-outs of human immunodeficiency virus rapid test kits: Stock-outs of rapid HIV test kits was reported as another reason why HIV testing was sometimes not provided to pediatric TB patients.

> Yes, if there is no HIV testing kits. I have come across this case several times, the supply of testing kits is not constant, and sometimes we miss them. (Nurse)

The primary way identified to increase HIV testing and linkage to TB care was the education of community members, caregivers and service providers on the importance of seeking prompt identification and treatment of pediatric HIV. For facilities that had experienced HIV test kit stock-outs, ensuring a continuous supply of rapid test kits was recommended (Table 2).

DISCUSSION

We observed that there were still challenges in TB case identification and linkage to HIV services among children in Tanzania.

Diagnosis and treatment of childhood tuberculosis

Due to diagnostic challenges and non-specific symptoms, TB illness in children is often missed or overlooked.[13,14] This has been reported in many studies, so there is thus a need to find for new diagnostic procedures that are effective in children, as well as to optimize the use of existing technologies such as Xpert® MTB/RIF (Cepheid, Sunnyvale, CA, USA).[15] At the time of this study, Xpert use remained limited (primarily to research institutions). Although the pediatric score chart was designed to be a simple tool to help diagnose pediatric TB, many HCWs had not yet been trained in its use. Gastric aspirates were not widely available at the time of this study and are usually available only in inpatient settings.

HCWs also reported low community awareness of pediatric TB and delayed care-seeking, high stigma associated with TB, and caregivers presenting children for TB evaluation in the late stages of illness to be barriers in diagnosing pediatric TB. These observations are in accordance with a study in Tanzania which found that 48% of individuals diagnosed with TB sought care at a health facility ≥3 times before receiving a TB diagnosis.[16] A study in adult TB patients concurred with the HCW perception that patients first self-treated with over-the-counter medications and that the TB diagnosis was delayed due to misinterpretation of early symptoms.[17] A study by Yeap et al. also identified very late diagnosis after prolonged illness as a challenge to TB diagnosis in children.[18] In a cohort of TB patients in Zambia, 86% reported experiencing stigma related to TB and HIV,[19] which has been recognized as hindering TB care-seeking.[20,21] Although we did not assess patient perspectives, ensuring that the clinical setting is free from the judgmental attitudes of HCWs is essential to improving uptake of TB and HIV services by children.[22] Nevertheless, even in the absence of poor care, patients and caregivers can still experience ‘anticipated stigma,’ i.e., the expectation or fear of stigma).[19] A study in Tanzania found that primary health care staff perceived childhood TB to be uncommon and TB was rarely considered a likely differential diagnosis.[23] Community education is needed to emphasize the importance of early treatment for pediatric TB and to dispel the misconceptions that contribute to TB stigma.

Adams et al. focused on HCW training in pediatric TB in Tanzania. They found that three times as many trained as untrained HCWs reported having ever prescribed IPT to a child ($P < 0.05$), data that support the argument that training can lead to improved practices.[24] Enlisting traditional healers and pharmacists to improve TB detection has also been shown to be an effective strategy.[25]

Considering the challenges in diagnosing TB in children, contact tracing is critical to ensure that children are prevented from developing active TB disease through screening and provision of IPT.[13] Passive contact tracing has severe limitations in terms of pediatric contacts not attending the clinic to be assessed. Whenever possible, active case finding strategies should be prioritized and accompanied by appropriate training, tools and staffing.[26] Careful attention to child contact management can ultimately lead to reduced morbidity and mortality in children.[27]

Human immunodeficiency virus testing in tuberculosis settings

HCWs cited certain facility barriers to providing HIV testing. These were a lack of parent or caregiver presence during testing, HIV rapid test kits, and clear understanding of HIV testing and counseling (HTC) guidelines regarding testing of children under the age of consent. Similar studies also found that the main reason given by HCWs for not offering provider-initiated testing and counseling in children were the perceived unsuitability of the accompanying guardian to provide consent for HIV testing on behalf of the child, as well as a lack of availability of staff and of HIV rapid test kits.[28] Pediatric HTC requires an adequate supply of essential commodities, including rapid test kits and reagents, but HCWs reported frequent stock-outs of these commodities. Regular monitoring and management of the entire supply chain system—including stock levels, forecasting, procurement, storage and delivery— is critical to address these gaps in the supply chain.

HCWs noted that some caregivers were reluctant to have their child tested for HIV because it could result in inadvertent disclosure of the parent's own status and because they were unsure how the child would react to learning that the parent had transmitted HIV to them. In line with our study findings, several other studies have noted that the fear of stigma and discrimination as well as misconceptions surrounding HIV and the acquired immune-deficiency syndrome deter HIV testing, but that recognition of current poor health and interest in getting well encouraged HIV testing.[28,29] Kigozi et al. reported that patients were receptive to additional community education, and cited it as a way to increase HIV testing in persons with TB.[31]

This study had two main limitations. First, as the clinics were purposefully selected, the findings may not be generalizable to other settings within and outside of Tanzania. Second, although HCWs were interviewed for their perspectives, their practices were not observed directly. However, the facilities included were high-volume and located in high HIV burden regions, where many children with TB live.

Despite the limitations mentioned above, our study has two clear public health implications in the area of TB and HIV services for children in resource-constrained environments: 1) the need to address health system barriers, and 2) to provide community education on the

importance of pediatric TB and HIV testing and treatment. An urgent area for additional research is identifying the best way to improve diagnostic options for TB in children because the identification of TB in children remains challenging.

CONCLUSIONS

Effort is needed to ensure effective TB and HIV diagnosis and treatment in children. Strategies include providing HCW training in recognizing the signs and symptoms of pediatric TB and supportive supervision for pediatric HTC, community education on the importance of seeking early treatment for pediatric TB and HIV, and ensuring a continuous supply of HIV rapid test kits to reduce morbidity and mortality in this vulnerable population.

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Table 1

HCW recommendations to improve TB diagnosis in children

TB diagnosis in children
Challenges
Reasons why caregivers delay seeking health care services for their child: passive TB contact tracing, stigma, and the misconception that TB cannot affect children
Reasons for non-identification of TB: difficulties faced by providers in diagnosing TB, and possible misdiagnosis
Solutions
Caregiver solutions: community awareness activities, strengthening TB contact tracing, and training traditional healers in TB symptom referrals
Facility solutions: HCW training on TB diagnosis, and TB screening training for all departments/HCWs

HCW = healthcare worker; TB = tuberculosis.

Table 2

HCW recommendations to improve HIV testing and linkage to care in children with TB

HIV testing and linkage to care in children
Challenges
Reasons caregivers may not want the child tested for HIV: inadvertent disclosure of parent's HIV status, as well as a lack of knowledge about HIV transmission and the importance of prompt treatment
Reasons healthcare workers may not test for HIV: child at the facility with no parent or caregiver, and stock-outs of HIV test kits
Solutions
Caregiver solutions: education of community members and caregivers
Facility solutions: additional training on HIV testing guidelines, consistent provision of HIV test kits

HCW = healthcare worker; HIV = human immunodeficiency virus; TB = tuberculosis.