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Caregiver perspectives on TB case-finding and HIV clinical services for children diagnosed with TB in Tanzania

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Abstract

Caregivers of children with tuberculosis (TB) and HIV play a critical role in seeking healthcare for their children. To assess the perspectives of caregivers of pediatric TB patients, we conducted 76 in-depth interviews at 10 TB clinics in 5 districts of Tanzania in March 2016. We assessed how the child received their TB diagnosis, the decision-making process around testing the child for HIV, and the process of linking the child to HIV treatment in the event of an HIV diagnosis. Caregivers suspected TB due to cases in their family, or the child being ill and not improving. Most caregivers noted delays before confirmation of a TB diagnosis and having to visit multiple facilities before a diagnosis. Once diagnosed, some caregivers reported challenges administering TB medications due to lack of pediatric formulations. Reasons for accepting HIV testing included recurrent illness and HIV symptoms, history of HIV in the family, and recommendation of the clinical provider. Caregivers described a relatively seamless process for linking their child to HIV treatment, highlighting the success of TB/HIV integration efforts. The multiple clinic visits required prior to TB diagnosis suggests the need for additional training and sensitization of healthcare workers and better TB diagnostic tools.

Keywords

Tuberculosis; HIV; Tanzania; children; qualitative; linkage to care

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Introduction

Tuberculosis (TB) remains the most common opportunistic infection in people living with HIV including children (WHO, 2018). Early diagnosis and treatment is critical to reduce mortality and morbidity (Martinson et al., 2009; Newell et al., 2004). Globally, Tanzania is among countries with the highest TB burden in the world (WHO, 2016). In 2015, 5481 (96%) children diagnosed with TB were tested for HIV and 1613 (29%) of these children were co-infected with HIV and TB. Of the children who tested positive for ǁHIV, 1406 (87%) were on anti-retroviral therapy (ART) (NTLP annual report, 2015).

Caregivers are the main gatekeepers for children's ability to access testing and treatment for TB and HIV (Chileshe & Bond, 2010; Murray et al., 2017). Among adults living with TB and HIV, challenges associated with accessing diagnosis, care and treatment of both illnesses including pill burden, stigma, and poor linkage to care have been documented (Chileshe & Bond, 2010; Gebremariam, Bjune, & Frich, 2010; Okot-Chono et al., 2009; Wachira et al., 2014). Less is known about challenges that caregivers experience managing care for children with TB and HIV (Legido-Quigley et al., 2013). This evaluation assessed barriers and facilitators caregivers encountered in accessing TB/HIV care for their child.

Materials and methods

In-depth interviews were conducted with caregivers of pediatric TB patients less than 15 years of age. Caregivers were identified by healthcare workers and conveniently sampled from 10 TB clinics in 5 high-burden TB districts of Tanzania (Temeke, Ilala II, Morogoro, Tanga, and Shinyanga). Caregivers were eligible for study participation if they accompanied a child diagnosed with TB within the past year, were above 18 years of age, and provided informed consent.

The in-depth interview guide was developed based on a socioecological framework (Figure 1) as an empirical model of health action (Cummings, Becker, & Maile, 1980). The socioecological framework examines external factors that influence individual health-seeking behavior at the interpersonal, health system, community, and public policy levels (Baral, Logie, Grosso, Wirtz, & Beyrer, 2013; Mugavero, Norton, & Saag, 2011). Key issues addressed during the interview included the process of obtaining a TB diagnosis for their child, the HIV testing services offered to their child, and if HIV-positive, how the child was linked to HIV treatment services.

Interviews were conducted in Kiswahili. Audio recordings were transcribed and translated into English. Key information related to TB treatment and HIV status was abstracted from the child's TB treatment card. Codes were developed *a priori* based on the objectives of the study using a directed content analysis approach (Hsieh & Shannon, 2005). Additional inductive themes were identified and added to the codebook (Bernard, 2000; Corbin, 2007).

Ethics approval

This project was reviewed by the US Centers for Disease Control and Prevention (CDC) and determined to be public health program evaluation and not human subjects research

requiring institutional ethics board review; it was also reviewed and approved by the National Health Research Committee of the Ministry of Health, Community Development, Gender, Elderly and Children (MOHCDGEC) Tanzania.

Results

A total of 76 caregivers were interviewed. A description of caregiver characteristics and those of their children is provided in Table 1. Information related to HIV testing and treatment is in Table 2. Key respondent themes are outlined in Table 3 and in the text below.

Caregivers' experience of child's TB diagnosis and treatment

Caregivers gave several reasons for suspecting their child had TB, with the most common being another family member had TB. Caregivers also mentioned suspecting TB because their child was ill and did not improve even after visiting multiple healthcare facilities or having repeated clinic visits for treatment. Several caregivers noted seeing educational information that alerted them to the possibility that their child may have TB.

Once their child had received a TB diagnosis, most caregivers 51/76 (67%) reported no challenges starting their child on TB medications. Of those caregivers who experienced challenges, the most common was the lack of pediatric drug formulations for TB, taking medications consistently, and financial difficulties that hindered their ability to buy nutritious foods while the child was on TB treatment.

Caregivers' experiences with child's HIV testing and treatment services:

Of 76 children, 38 (50%) were living with HIV; 33 (43%) were HIV-negative, and 5 (7%) had an unknown HIV status. Of the 38 children who tested HIV-positive, 34 (89%) were on anti-retroviral treatment for HIV. Only four children had been told their HIV status. The majority of caregivers, 60/69 (87%) reported no challenges obtaining an HIV test for their child. Among those who reported a challenge, the main reported was worry associated with receiving an HIV-positive test result. Mothers, in particular, felt sadness and guilt for passing HIV onto their child. Although some caregivers, who were not the child's biological parent reported that the health care provider asked why the parent was not present for the HIV test, this did not appear to be a barrier for getting the child tested for HIV. Caregivers gave several reasons for agreeing to have their child tested for HIV including frequent illness, a family history of HIV, and receiving a recommendation by a clinical provider.

Caregivers of HIV-positive children mentioned peace of mind, improved health and a resolution of extended illness as the main benefits for knowing the child's HIV status. Most caregivers described a streamlined process for enrolling their child in HIV treatment services with initiation of treatment occurring on the same day of HIV diagnosis.

Discussion

Caregivers reported multiple delays in receiving a TB diagnosis for their children, occasioned by multiple hospital visits and deterioration of the child's health before a TB diagnosis was made. This study found that patient education through written materials

motivated caregivers to seek TB and HIV testing for their children. Potential implications of these findings include educating caregivers about the signs and symptoms of TB and HIV during routine healthcare visits and through community mobilization efforts. In addition, better tools for diagnosing pediatric TB are needed. Availability of pediatric formulations of TB medications are also needed to ensure children complete TB treatment.

Among caregivers whose children were HIV-positive, most reported that their child's health had improved after receiving an HIV diagnosis and starting ART. Most children were started on HIV treatment the same day they received their HIV diagnosis, which highlights the successful integration of TB/HIV services and scale-up of same-day ART initiation for children in Tanzania (Mavegam, Pharr, Cruz, & Ezeanolue, 2017). Other studies have found that the prospect of gaining good health is a motivating factor to start and continue ART (Kumwenda et al., 2011; Wachira et al., 2014). Strengthening counseling messages on the benefits of early initiation of ART to ensure the child's normal growth and development may be encourage caregivers to initiate and adhere to HIV medications.

Only 4 of the 37 HIV-positive children in this study were aware of their HIV status, These rates are lower than a study in Tanzania that found a disclosure rate of 32.6% (Nzota, Matovu, Draper, Kisa, & Kiwanuka, 2015). This is of interest as other studies have cited the association of lack of pediatric disclosure with poorer adherence to HIV medications (Kigozi et al., 2010; Vreeman, Gramelspacher, Gisore, Scanlon, & Nyandiko, 2013). Family-centered care (Luyirika et al., 2013), a patient-centered approach (Wachira et al., 2014), and healthcare worker training (Kalembo, Kendall, Ali, & Chimwaza, 2018) may help facilitate disclosure. Some caregivers reported feeling shame that they had passed HIV to their child. This concerns have also been cited in other studies (Kigozi et al., 2010). Efforts to address HIV-related stigma should also be addressed (Vreeman et al., 2013).

This study was conducted in a limited number of facilities. As such, results may not be generalizable to other facilities within Tanzania or other contexts. Moreover, a selection bias may be present as caregivers were already connected into care and may be more sensitized to the need for HIV and TB treatment than other caregivers.

Conclusions

This study demonstrated the challenges that caregivers experience in receiving a TB diagnosis for their child. The multiple clinic visits required prior to TB diagnosis remains a concern and suggests the need for additional training and sensitization of healthcare workers and better TB diagnostic tools. HIV testing and treatment were easier to access and likely reflects the success of TB/HIV integration efforts. Reasons for accepting HIV testing included recurrent illness and HIV symptoms, history of HIV in the family, and recommendation of the clinical provider.

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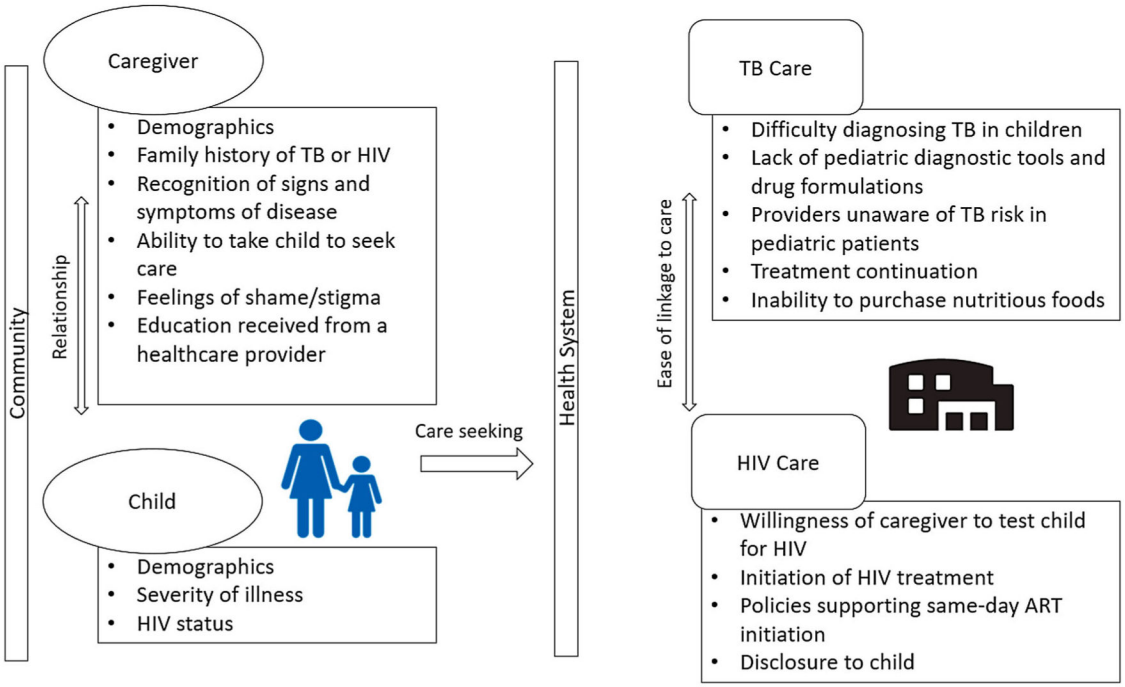

Figure 1.

Socioecological framework summarizing perspectives of caregivers of children diagnosed with TB in Tanzania on TB and HIV diagnosis and treatment.

Table 1.

Characteristics of caregivers and their children with tuberculosis (TB) who completed in-depth interviews (*N* = 76)

Characteristic	*n* (%)
Median Number of adults ≥15 in household	3.3
Median Number of children <15 live in household	2.5
Age of Caregiver	
18–24 years	9 (12%)
25–34 years	33 (43%)
35–44 years	18 (24%)
>45 years	16 (21%)
Sex of Caregiver[*]	
Female	60 (79%)
Relationship with Child	
Parent	56 (74%)
Grandparent	6 (8%)
Aunt/Uncle	11 (14%)
Sibling	3 (4%)
Age of Child	
0–5 years	41 (54%)
6–10 years	18 (24%)
11–15 years	17 (22%)
Sex of Child	
Female	31 (41%)
Type of TB[*]	
Pulmonary TB (PTB)	53 (70%)
Extrapulmonary TB (ETB)	22 (29%)
Sputum smear status[*]	
Smear (+)	28 (37%)
Smear (−)	2 (3%)
Smear not done	13 (17%)
Patient Type[*]	
New	71 (94%)
TB Treatment Relapse	3 (4%)
Transfer in	1 (1%)
How long child receiving TB Treatment[*]	
<2 months	25 (33%)
2–6 months	41 (54%)
>6 months	1 (1%)

[*] Missing data includes: Sex 1 (1%), Type of TB 1 (1%), Sputum smear status 33 (43%), Patient type 33 (43%), and How long receiving TB treatment 9 (12%)

Table 2.

Caregivers' experience with HIV testing and linkage to care for children receiving tuberculosis (TB) treatment ($N = 76$).

	N	*n* (%)
Child offered HIV test as part of TB care	76	68 (89%)
Offered HIV test prior to visiting TB clinic	31	19 (61%)
If yes, where offered test?		
Inpatient	16	8 (50%)
Dispensary	16	2 (12.5%)
Pediatric Clinic	16	2 (12.5%)
MCH Clinic	16	2 (12.5%)
Outpatient Department	16	2 (12.5%)
HIV Status Of Child[*]		
HIV Positive	76	38 (50%)
HIV Negative	76	33 (43%)
Age of HIV Positive Child		
0–5 years	38	16 (42%)
6–10 years	38	13 (34%)
11–15 years	38	9 (24%)
On Antiretroviral Treatment for HIV	38	34 (89%)
On Co-trimoxazole Therapy	38	36 (95%)
Encountered Challenges Getting Tested For HIV (% yes)	69	9 (13%)
HIV Test Result Has Been Disclosed To Child	37	4 (11%)

[*] Missing data includes: HIV status of child 5 (7%)

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Table 3.

Illustrative quotes for the themes identified related to caregivers' perspectives on TB case-finding and HIV clinical services for children diagnosed with TB in Tanzania.

	Caregivers' experiences with child's TB diagnosis and treatment
Process of seeking care for TB	"My sister and my first born had TB before. After some time my child started to get high fever and coughing and he sweats a lot at night. I sent him to the hospital and was given medicine but he did not recover. Then I decided to take him to the hospital and asked the doctor to perform an X-ray in order to know what was the problem. After testing, he was diagnosed with TB." – 30 year old mother of 6 year old boy
	"I decided to bring her here although there are a lot of procedures and it is time consuming; that is why others give up. It was May. I remember I was going to court for my late daughter's will. But I also managed to attend clinics for my child. So from June we started coming here, until October when she was tested and started medication" – 64 year old grandmother of 6 year old girl
	"I once went to hospital where I saw an advert about TB symptoms; I realized that she had all the symptoms I saw at hospital, so I decided to take her to hospital for testing. She had regular fever, coughing and vomiting. Generally she had all the symptoms I saw; she had four out of five symptoms I saw." – 28 year old mother of 3 year old girl
Challenge in TB treatment	"Mostly it is financial-related, because I need money to buy her food that was recommended by the health care workers … I even came here to the regional chief medical officer to ask him for help so I can buy some fruits for my child" – 64 year old grandmother of 6 year old girl
	Caregivers' experiences with child's HIV testing and treatment services
Process of HIV testing	"Firstly, she [the healthcare provider] asked why I brought him while I'm not his mother. I told her that he is my grandchild. Then she asked if I will be ready to receive his HIV testing results and if I'm ready to take care of him. I told her that I am ready to care of him until he recovers" – 65 year old grandmother of one year old boy
	"He had regular illness including high fever so I decided to come here at the government hospital for HIV testing. He had fever and coughed regularly" – 42 year old mother of 13 year old boy
	"I decided to test him because I was aware that his mother was HIV positive, also because of his regular illness. Previously I saw my neighbor's child died because their parents delayed to bring him to hospital; so I was afraid this boy might die if I didn't bring him to hospital. I was very courageous to bring him to hospital because I'm also infected and I'm using ARVs." – 47 year old grandmother of one year old boy
Implication of HIV testing and treatment	"I was so devastated, my heart was broken. To me, being positive, it's ok. But my son … I was heartbroken and so depressed. That info made me very sick. I remembered I was admitted at the hospital." – 32 year old mother of 4 year old boy
	"After testing him I have benefited, because I'm aware of my child's status. I know how to treat him, how to take care of him" – 32 year old mother of 7 year old boy
	"I benefited because she is alive. I would have lost her if I didn't know. It is good to know the child's condition because she was unhappy when she was sick. This can lead her to fail to proceed with schooling" – 64 year old grandmother of 6 year old girl
Process of starting HIV treatment	"He started medication the same day he was tested" – 42 year old mother of 4 year old boy
	"They told me because he is a child, I should start the medication straight away" – 31 year old father of 3 year old boy