Children’s role in enhanced case finding in Zambia

V. Bond,*† L. Chilikwela,† M. Simwinga,*† Z. Reade,‡ H. Ayles,†§ P. Godfrey-Faussett,§ J. Hunleth¶

*Health Policy Unit, Department of Public Health and Policy, London School of Hygiene & Tropical Medicine (LSHTM), London, UK; †ZAMBART Project, University of Zambia, Lusaka, Zambia; ‡Department of Social Anthropology, University of Cambridge, Cambridge, §Clinical Research Unit, Department of Infectious and Tropical Disease, LSHTM, London, UK; ¶Anthropology Department, Northwestern University, Evanston, Illinois, USA

OBJECTIVE: To evaluate information dissemination by children and attitudes among children towards a school-based tuberculosis (TB) reduction strategy that asked children to address TB symptoms, testing and stigma in their homes.

SETTING AND DESIGN: Qualitative research was conducted with schoolchildren before, and 2 years into, an intervention to promote early detection of TB using sputum microscopy in Zambia. The baseline study in 2005 involved 38 children at five sites. The evaluation in 2008 included 209 children in schools at four sites. Research with schoolchildren included discussions, drawings, role plays and narratives.

RESULTS: The baseline study revealed children’s enthusiasm to learn about TB and the human immunodeficiency virus (HIV), but it also revealed children’s anxieties about the possible conflicts related to discussing HIV and TB with adults. Children in the evaluation demonstrated more accurate knowledge about TB and HIV than in the baseline study. Children were enthusiastic about discussing TB and HIV at home. Their responses suggested that they did so with respect and adult approval, circumventing the intergenerational conflict expected during the baseline study.

CONCLUSION: The present study demonstrates that schoolchildren have a role to play in enhanced case finding. Schoolchildren are already familiar with TB in areas of high burden, but they need more information about the link between TB and HIV and about antiretroviral treatment.

KEY WORDS: case finding; health education; children

ENHANCING CASE FINDING of infectious tuberculosis (TB) is a pivotal TB control strategy. The present study looks at whether children have a role in improving case finding of infectious TB at the community level, drawing on an evaluation of an intervention involving children in Zambia. This intervention also attempts to understand the role that children may play as TB and HIV/AIDS (human immunodeficiency virus/acquired immune-deficiency syndrome) health promoters.

New understandings of children’s health agency are emerging; recent research has labelled children as ‘health change agents’ who have the ability to influence adult behaviour. In practice, children’s actions as health promoters typically revolve around the promotion of behaviour change to prevent diseases that affect them directly, such as malaria, diarrhoea and schistosomiasis. While school programmes in Southern Africa attend to TB education to some extent, they rarely consider children as health change agents in the TB epidemic.

Zambia has a high TB incidence rate (506 per 100,000 population in 2007), as well as a high HIV prevalence of 15.2% among 15–49-year-olds. Seventy per cent of TB patients are co-infected with HIV. Bond and Nyblade argue that HIV has deepened TB-related stigma in Zambia, relaying how the biosocial association of TB with HIV/AIDS has created an environment in which sufferers face blame, mistreatment and deprivation. There is also a profound silence around these diseases, and an absence of discussion with children about TB and HIV/AIDS. Researchers suggest that, within these silences, children have unaddressed fears, anxieties and experiences that undermine attachment and competence unless they are able to discuss them with a confidant.

The research for this article builds on recent HIV/AIDS research findings that demonstrate that children play a direct role in biomedical and household level disease management. Social scientists have suggested that children’s labour within and movement between Southern African households provides a critical coping strategy for households dealing with HIV/AIDS. In Uganda, children offer significant contributions as ‘medicine companions’ in encouraging adult adherence to antiretroviral treatment (ART) (Amuron B et al. Presentation at XVII International AIDS Conference, Mexico 2008). A community randomised trial (Zambia and South Africa TB and AIDS
Reduction Study (ZAMSTAR) engaged schoolchildren in an intervention called ‘enhanced case finding’ (ECF), which has been implemented in 12 sites (eight in Zambia, four in South Africa) since July 2006. The intervention uses social mobilisation activities to promote the early detection of TB, facilitating diagnostic access through direct submission of sputum both at local health clinics and through mobile sputum collection points. Within schools, key messages on TB, stigma and HIV are tailored to children’s comprehension and cognitive levels. The approach includes drama, health education, games, educational activities (quiz, debate, drawing and colouring) and IEC (information, education, communication) materials. Children are encouraged to find opportunities in their homes and the community to disseminate information on TB and stigma. Each school is visited four times a year and sputum collection points are set up in or close to the schools for 2 weeks after social mobilisation. A qualitative evaluation of children’s involvement in ECF was carried out in four Zambian ECF sites in 2008.

**STUDY POPULATION AND METHODS**

In 2005, focus group discussions (FGDs) were held in schools before implementing the intervention. As a component of the baseline study, 38 schoolchildren (19 girls and 19 boys aged 11–18 years) in five sites across five Zambian provinces took part in a discussion of, among other topics, how adults might respond to children advising them to test for TB. In 2008, a qualitative evaluation was carried out in eight schools in four sites (one government-run basic school and one community school—set up by non-governmental actors to provide increased access to education for vulnerable children—in each site) to assess the appropriateness of engaging children in intensified case-finding. The Table summarises the profile of the participating children; there were 133 younger children (aged 10–14 years) and 76 older children (aged ≥15 years). All children had participated in the ECF intervention, half recently (in the preceding 2 weeks) and half less recently (more than a month before the evaluation). Teachers and local ECF assistants at each school selected approximately 15 girls and 15 boys who had participated in the intervention to attend the two research sessions.

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<th>Table: Study population</th>
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<tr>
<td><strong>Age range years</strong></td>
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The University of Zambia’s Ethics Committee gave clearance for the baseline and evaluation studies. These protocols did not include obtaining informed consent from parents. Once the school authorities had given permission, class teachers selected girls and boys, aged ≥10 years, from a range of years and classes. Selected children gave verbal assent to participate in 2005 in the FGDs and in 2008 in 1-hour sessions at the end of two school days. Children’s names were removed from drawings. Research was carried out by a social science research assistant, the ECF research assistant, and at least one other local researcher or volunteer. Children were sex segregated and details on children’s age, class, contact with the local clinic (date and reason for last contact) and orphan status were collected.

The research methods were designed to maximise participation under time constraints. Methods included two sets of drawings and/or a written narrative, a dice game and a drama exercise. Children made two sets of drawings: one focused on where someone with TB symptoms could go for help, and the other, done as homework between the two sessions, on the response of adult household members to children discussing TB with them. The drawings were discussed with each child individually to elicit their meaning. Several older children chose to write a narrative instead of drawing. In the dice game, children took turns throwing a large foam dice with pictures on each side that dictated the types of questions they were asked or if they were to ask their own questions about TB and HIV (which were answered by other students and the researchers). For the drama exercise, groups of children prepared role plays depicting the reactions of a range of household members (stepmothers, grandparents, elder brothers/uncles or parents) to a child telling them about TB symptoms, diagnosis and treatment. A member of the research team recorded the children’s responses and general observations in each session. This documentation was shared with other research facilitators the same day, and additional observations added.

After the research had been conducted in each site, the data were entered, filed, scanned (if necessary) and a report written up by the lead research assistant and participating researcher/s. The analysis of the data from all sites was carried out by researchers working in a group and in pairs to pull out, contextualise and interpret emerging themes, guided in part by doctoral fieldwork on the role of children in managing TB being carried out by JH and in other literature. Wider observations of ECF in the community also provided material for this analysis.

**Limitations of the study**

The study was limited by a number of factors: relatively rapid fieldwork; including only children who were directly involved in the ECF intervention; a tendency to select high performing children; being unable...
to link the recordings of FGDs, dice games and drama exercises to different age groups; an emphasis on participatory methods (for critical appraisals of participatory research methods with children, see Backett-Milburn 1999 and Gallacher 2008); conducting research in didactic school settings; and the possible suppression of information about alternative treatment options.

RESULTS

Familiarity with the clinic
Almost half of the children reported having attended the local clinic for their own health within the 2 years prior to the research. Only 12 girls and five boys reported never visiting the clinic. Children’s drawings demonstrated their familiarity with the clinic set up, including accurate depictions of the laboratory, pharmacy, voluntary counselling and testing (VCT), TB corner and other features (see Figure 1). Several children drew the clinic as it fit into the wider topography of their residential area (see Figure 2).

Sources of information
The baseline FGDs indicated that schoolchildren learn about TB from school clubs, television, community drama performances, clinics, parents and observation (as a 17-year-old boy put it, ‘listening from people when they talk’). Learning about TB through joining a ‘club’ was mainly mentioned by older children. Schoolchildren were adamant about wanting to learn more about TB at school. Children mentioned wanting to learn about TB transmission, prevention and care, and the differences between TB and HIV. A 13-year-old girl said she would like to learn ‘how we can look after patients in our own homes’. The number of children with personal experience of TB was evident from the baseline; seven of the 38 children mentioned a TB patient in their family.

The evaluation revealed that children gained significant information about TB from ECF activities. They recalled activities in schools (health talks, colouring, debates and quizzes), community drama performances (where children are often the majority in the audience), health talks at the clinic (usually these children were very young), and ECF-sponsored megaphone messages in their communities. They also learnt about TB from relatives and daily observation. The ECF activities only targeted children in schools. This was evident at community drama performances, where children were overlooked in question/answer sessions and were not given health education leaflets.

Knowledge of TB
In the baseline, children demonstrated wide-ranging and accurate knowledge about TB transmission, symptoms, treatment options, the burden of care and cure. Younger children were less sure about diagnosis, length of TB treatment and the link between TB and HIV. Older children were more likely to recall discussing the latter in their households. They also recounted more biomedical details, for example describing the difference between pulmonary and extra-pulmonary TB. In the evaluative research, schoolchildren demonstrated more confidence and accuracy when answering questions about TB and HIV. At home, they recollected talking about TB symptoms, sputum diagnosis,
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where to go to submit sputum, TB treatment, the difference between TB and HIV and that TB could be cured.

Children recalled TB symptoms in detail during the evaluative research. They especially pointed out that coughing was painful, persistent and prolonged (‘more than 2 weeks’) and produced blood. TB patients were often depicted by younger children as extremely thin, bedridden and needing to be accompanied to the clinic and admitted to hospital. Some descriptions were overlaid with sensational accounts (for example, extreme frailty).

There was a widespread understanding that TB is airborne and transmitted when people with TB cough or sneeze. Although transmission was described as occurring at home, the community and the clinic, moral evaluations of TB sufferers were evident in children’s association of TB transmission with smoking, drinking, sex and working in the mines. Further, TB transmission was blamed partly on people ‘coughing anyhow’. Children mostly showed people with symptoms going to the local clinic (see Figures 1 and 3). In two sites, the children discussed the hospital. Witch-doctors, a private clinic and home-based care each featured once. People either self-referred or were directed to the clinic by others. There was a strong sense of community diagnosis, usually by adults (friends, stallholders, teachers), but occasionally by children. Younger children portrayed themselves telling friends to go to the clinic as illustrated by Figure 3, but would not show themselves directing adults to the clinic, unlike older children, especially boys, who either drew or wrote about advising sick adults to be tested for TB. In one drawing, a 15-year-old boy draws ‘a young person advising an older person where he can go to test for TB’. And in a narrative, a 15-year-old boy relates, ‘When I was taught about TB and HIV, I knew my aunt was suffering from TB. I advised her to go to the clinic so her sputum can be examined. I also told her about the symptoms of TB’. Another 16-year-old boy reported telling his mother who was sick that ‘you shouldn’t waste time but you should go to the clinic and get tested for TB’.

Most children were familiar with the process of testing for TB by examination of sputum. Particularly in those schools with recent ECF activity, detailed descriptions of the process of submitting sputum were given, including the project’s system for collecting sputum at open access points and the specifics of producing and transporting sputum samples (see Figure 4). Children knew details about the prescription and taking of drugs (including differences in children’s and adults’ doses). They explained that it was important not to drink alcohol or smoke while on treatment, to take drugs with food and to complete treatment. A 16-year-old boy inserted this directive in his essay on TB: ‘I want to urge you guys out there, especially youths, avoid TB by stopping smoking straight away and drinking, let’s all stop TB, parents, grandfathers, teachers, nurses, doctors, pastors and grandmothers’. Children had considerable faith in TB medication, explaining the links between TB treatment and recovery. A 15-year-old boy, using the words of a person suffering from TB, said: ‘am coming from Zambart to
get my medication, am now feeling much better and stopped coughing since I started my TB treatment. In their drawings, children portrayed individuals who completed their courses of TB treatment as gaining weight and resuming normal activities. Figure 4, for example, shows a person suffering from TB who was coughing blood and bedridden. By the end of the sequence, the person is recovering with the help of medication and food.

Children often provided accurate biomedical information and public health messages about the difference between TB and HIV, saying HIV is not airborne, involves more symptoms and is incurable. Children offered statements such as: ‘It’s hard to tell if someone has HIV’ (14-year-old boy); ‘Someone can get TB through the air. It is true anyone can have TB. It is not only people who are [HIV] positive’ (13-year-old girl).

Only a few younger children were aware of the link between TB and HIV. Older children more often described why TB was associated with HIV. For example, Figure 1 shows a clinic layout that conveys referral between TB and HIV services. In the dice game, responding to questions on the latter and whether there was treatment for HIV, children gave conflicting information about ART, especially the length of treatment and whether or not it cured HIV. Only two drawings by older children captured ART: one showed a boy living with HIV and receiving ART, and the other depicted a woman being advised to go for VCT, and then put on a nutritious diet and given ART.

**Flow of information within the household and beyond**

The reaction of schoolchildren in the baseline to the proposed idea that they should talk to adults at home about TB was overwhelmingly negative. They said that adults did not listen to children and did not wish to be controlled by children. They anticipated trouble at home: ‘they would say that it’s none of your business’; ‘they can refuse and beat you’; ‘they would say you can’t tell me what your teachers lie to you [about]’.

Children responded very differently during the evaluation. They embraced the opportunity to be proactive. If they were not initially granted a platform to talk about TB and HIV, the research suggests that they did not give up, but were careful and respectful in their approach (see Figures 5 and 6). In their drawings and dramas, children knelt on the ground when talking to adults to demonstrate respect. Some children depicted approaching their parents for approval to continue learning about TB and HIV (it was of note that 92 of the 209 school children participating in the evaluative study were not staying with their parents). Children portrayed female relatives as most approachable and male relatives and stepmothers as less approachable. Older boys found it easier to get the attention of their relatives. In a 12-year-old girl’s narration of her drawing, she explains: ‘When I tell my brother about TB, he shouts at me and tells me he doesn’t want me to tell him anything about TB. He shouts at me in anger’. Upset by his reaction, she appeals to her mother, who listens to her carefully and responds: ‘It is good you are learning about this’.

Most reactions were positive, praising the ECF intervention or the child and encouraging them to share information with others in the community, particularly among their peer group. One 11-year-old son was praised by his father: ‘you are a good boy for learning such kind of information’; another 13-year-old girl reported, ‘I told my mother and my elder sister what I have learnt and she said, “This will make other friends who have left school admire you”’. Occasionally the responses were dismissive—adults were too busy, disinterested or unresponsive—but there is little evidence that it led to much conflict. Older
children, especially boys, were often asked questions about TB by their parents or guardians and were sometimes asked for literature. The information given by children was not confined to the household, but sometimes passed on to other relatives, friends in the community and even to strangers who looked ill (see Figure 3).

**DISCUSSION**

The findings reveal that there are few forums for children to discuss TB and HIV. Involving them in the ECF intervention facilitated discussion at school and at home. Although the hierarchy at home meant that children’s voices were at times muted, parents or guardians were often interested in what the children were learning about and valued learning in general, and would sometimes go on to ask older children for more information. Children were also good at navigating social conventions and hierarchies and were careful with how they disseminated information (see Figures 3, 5 and 6). For example, children reframed the ECF intervention as a ‘school club’—a more socially acceptable form for themselves and their parents. Being educated about TB and HIV was viewed as a status symbol for children. Children’s depictions of their discussions with parents were overwhelmingly positive. They depicted and discussed interactions with mothers that were exceptionally touching (see Figure 5).

To carry out their task, children’s own knowledge of TB had to be sound. The ECF intervention effectively equipped children with more detailed information on TB symptoms, sputum diagnosis, transmission and treatment than they had encountered at home. According to a few older children, this led to those they approached seeking a TB test. The contribution of children is most obvious in referral, and the detailed knowledge they most recalled surrounded symptoms and testing.

Children demonstrated considerable faith in TB treatment, with strong images of how people regained health once on treatment (see Figure 4). They were careful to disassociate TB and HIV, but in doing so, the link between TB and HIV was less well understood among younger children. Their knowledge of ART was very limited. This may in part reflect the deliberate focus on TB in the ECF intervention and the difficulty of creating the association and the distinction between TB and HIV.

It was nevertheless evident that the physical frailty that accompanied TB frightened younger children; implicit in this is the fear that TB could lead to death. The shame and blame around TB transmission were marked in the children’s discourse; these are common associations in Zambia that also resound in adult perceptions at the same sites. Combined with the pragmatic, though isolating, cough hygiene measures advocated by children, these perceptions could reinforce TB-related stigma.

**CONCLUSION**

Most of the interventions that utilise children as ‘health change agents’ revolve around diseases that directly affect children, such as malaria and schistosomiasis. This intervention is unusual in that it aims at getting children to address a disease that they suffer at a much lower incidence than adults but that impacts their lives enormously, particularly in high HIV prevalence settings. The research indicates that schoolchildren do have a role to play in enhancing TB case finding in Zambia by building on their observations of TB in the community and their personal experiences with TB. Children are eager to act as communicators and use their information pragmatically rather than indiscriminately. Their own knowledge base was sharpened by the intervention; many household members seemed to value this and support the initiative.

Children’s roles are probably confined more to expanding knowledge than to active case finding. The children’s drawings and narratives imply that people were most often referred by adults or took themselves to be tested, with the exception of older boys who suggested that they had the social authority to strongly advise sick adults to be tested for TB. It nevertheless bodes well for children’s own lives and future that they are well informed about TB. Working with schoolchildren is also a relatively manageable health intervention, and one potential future intervention would be to integrate TB into the standard curriculum (similarly to malaria and other diseases).

There are some caveats: children need to be provided with more support about how to talk to different adults. More awareness of TB stigma, of the link between TB and HIV and of ART is also needed. Finally, children’s astute understanding of the burden of care and their role in the management of TB in contexts of poverty, HIV and overstretched health systems warrants more in-depth investigation and exposure.

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El estudio de referencia a revelado un entusiasmo de los niños por aprender sobre la tuberculosis (TB) y el VIH, pero ella a también revelado la crinente de los niños al sujeto de cocias que la discussion del VIH y de la TB con des adolescentes lo podrían sospechar. Chez los niños dans l’evaluation, una connaissance plus prccise au sujet de la TB y du VIH es apparue que chez les enfants dans l’étude de base. Ils ont été enthousiastes au sujet de la discussion concernant la TB y el VIH a leur domicile. Lesurs responses ont suggéré qu’ils l’ont fait avec le respect et l’approbation des adults en évitant el conflicto intergeneracional atendido al curso de l’étude inital.

CONCLUSION: Cette étude démontre que les enfants des écoles ont un rôle a jouer dans el renforcement du dépistage des cas. Les enfants sont déjà informés de la TB dans les zones a fardeau élevé, mais ils ont besoin d’une information plus importante au sujet des liens entre TB y VIH a el sujeto del tratamiento antirretoviral.

OBJETIVOS: Evaluar la difusión de la información sobre la tuberculosis (TB) en los niños y las actitudes frente a una estrategia escolar de disminución de la TB, en la cual se solicitó a los niños que comentaran en sus hogares temas como los síntomas de la enfermedad, las pruebas diagnósticas y los stigmatisms relacionados con ella.

MARCOS DE REFERENCIA Y MÉTODOS: Se llevó a cabo una investigación cualitativa en niños escolarizados antes y 2 años después de una intervención que promovía la detección temprana de la TB mediante examen microscópico del esputo en Zambia. En el estudio inicial en el 2005 participaron 38 niños en cinco centros. En la evaluación del 2008 participaron 209 niños escolarizados en cuatro centros. La investigación con los niños comprendió discusiones, dibujos, juegos de representación y relatos.

RESULTADOS: En el estudio de referencia se observó un gran interés de los niños por aprender sobre la TB y la
infección por el virus de la inmunodeficiencia humana (VIH), pero también reveló su angustia por el conflicto que podría desencadenar el hablar con los adultos sobre estos temas. Los niños en la evaluación demostraron un conocimiento más preciso sobre los temas que los niños en el estudio de referencia. Los niños se mostraron entusiastas con respecto a la discusión de estos temas en los hogares. Sus respuestas indicaron que lo habían logrado con el respeto y la aprobación por parte de los adultos y que habían superado el conflicto intergeneracional temido durante el estudio de referencia. 

CONCLUSIÓN: Con el presente estudio se pone en evidencia que los niños escolarizados pueden cumplir una función de refuerzo en la búsqueda de casos. Los niños ya están familiarizados con la TB en los entornos con alta carga de morbilidad, pero pueden necesitar más información sobre la asociación entre la TB y la infección por el VIH y sobre el tratamiento antirretrovírico.