



Universiteit
Leiden

The Netherlands

Wartime children's suffering and quests for therapy in northern Uganda

Akello-Ayebare, G.

Citation

Akello-Ayebare, G. (2009, May 20). *Wartime children's suffering and quests for therapy in northern Uganda*. Retrieved from <https://hdl.handle.net/1887/13807>

Version: Corrected Publisher's Version

License: [Licence agreement concerning inclusion of doctoral thesis in the Institutional Repository of the University of Leiden](#)

Downloaded from: <https://hdl.handle.net/1887/13807>

Note: To cite this publication please use the final published version (if applicable).

Chapter Seven

Respiratory tract infections

Introduction

In this chapter, children's viewpoints concerning the prevalence and management of respiratory tract infections are presented and analysed. Children referred to infections in the respiratory system as *aona ki avuru* (cough and flu) and *aona opiu* (tuberculosis). As this study views tuberculosis as a chronic infection of the respiratory system, I adapt the overarching label of Acute Respiratory Infections (ARIs) from biomedicine – to cover cough and flu; but tuberculosis will be examined as a chronic condition which affects the respiratory system. I will not discuss other forms of tuberculosis in this thesis since the only child who discussed his experience with tuberculosis had an infection in the respiratory system. For purposes of this study, flu should be viewed as an episode of influenza.

The rationale for presenting a chapter on ARIs and tuberculosis following discussion of malaria and diarrhoea lies in the fact of ARIs' dual characteristics of presenting with less severe symptoms but with high prevalence. This excludes tuberculosis (TB), which will be discussed as a severe respiratory system infection but with relatively low prevalence among children of primary school age in northern Uganda. Nonetheless a substantial proportion of the children were at a high risk of becoming infected with *Mycobacterium tuberculosis*.

Findings in this chapter are presented under the thematic areas of children's perspectives concerning the prevalence of and medicine use for ARIs and tuberculosis, and how children regarded the severity, symptoms, and disease aetiologies of ARIs. Key informants' perspectives, mainly about tuberculosis prevention and control, will be presented following the children's perspectives. In the analysis I will discuss the dilemmas encountered in the management of tuberculosis in resource poor settings, complicated by the situation of armed conflict and HIV/AIDS. While addressing this issue, I will juxtapose existing interventions in the control and management of tuberculosis for people in Gulu with broader socio-economic factors which contribute to a high prevalence of ARIs and tuberculosis.

7. Findings

7.1. Quantitative data: Prevalence and treatment of acute respiratory infections

Table 7.1: Prevalence of acute respiratory infections within a one month recall (N=165)

Illness	Boys	Girls	Total	P-value
<i>Aona ki avuru</i> (cough and flu)	76	68	144	0.71

Acute respiratory infections constituted a high proportion of health complaints within a one month recall, and there was no statistically significant difference ($P=0.71$) between boys' and girls' experiences.

Table 7.2: Medicines used in treatment of acute respiratory infections within a one month recall (N=165)

Medicines	Boys	Girls	Total	P-values
Red and yellow capsule	53	60	113	0.03
Black and red capsules	24	12	36	0.07
Amox (as called in drug shops)	10	4	14	0.23
Amoxicillin or Tetracycline	87	76	163	0.92
<i>Yat matar ma tye 500 ma wac</i> (white medicine with 500 and tasteless), or Panadol	85	71	156	0.22
Multivitamins (or vitamins)	55	49	104	0.88
Piriton (<i>yat nino matar</i>)	53	42	95	0.46
Action	43	46	89	0.18
Valium (<i>yat nino makwar</i>)	50	29	79	0.01
Septtrin	21	22	43	0.49

Children mainly used antibiotics and analgesics in the treatment of ARIs. As with the prevalence of ARIs, there is no statistically significant difference between boys' and girls' management of coughs and flu, with two exceptions observed in the use of Valium ($P=0.01$) suggesting a stronger likelihood of boys using it than girls and in using the red

and yellow capsules ($P=0.03$) in a one month recall. A slightly higher number of girls ($n=60$) narrated that they used the red and yellow capsules than boys ($n=53$). I will come back to this issue in a chapter focussing on complaints symptomatic of emotional distress.

In the analysis of survey data, I did, however, encounter a dilemma in discussing pharmaceuticals used when multiple conditions were experienced concurrently, or when children experienced multiple illnesses within a one month recall. If children mentioned several illnesses which had affected them within a one month recall, and mentioned using Valium, Piriton, Action, Panadol, and antibiotics, it was not clear which specific pharmaceuticals were used for which particular illness. This issue only became clearer through the triangulation of quantitative data with qualitative inquiries into medicine use. Here is one example: the symptoms of ARIs are sometimes severe and can cause sleep disturbances, therefore Valium or Piriton tablets could both be used in for this purpose, while Piriton was also used to counter the allergic effects of histamine released during an attack of flu. Nevertheless, children also used Valium and Piriton for disturbances by *cen* (evil spirits), deep thoughts, and fear. Children also referred to Valium and Piriton as *yat nino* (medicines for sleep), and these were used for this purpose generally. Therefore, if children mentioned that they had used Valium and Piriton for cough and flu, I discuss them in this section as pharmaceuticals used in the treatment of respiratory infections.

Since available publications, for instance (Hay et al. 2004:1062) suggest that some respiratory system infections are viral in nature, and need not be treated because they are self limiting, in this chapter I discuss the management as opposed to treatment of ARIs such as flu, since recovery could occur even without the use of medications. In addition, where individuals used medications for symptom relief, I question whether they are treating the illness or simply managing it through minimising the severity of symptoms.

Table 7.3: Herbal medicines used for cough within a month recall

Herbal medicine (extracts)	Boys	Girls	Total	P-Value
Mango roots	79	69	148	0.97
Mango bark	75	51	126	0.004

Whereas I indicate here the two herbal medicines, I do it with some caution since children discussed their uses interchangeably. It was however more likely that children used mango tree bark for cough ($P=0.004$) suggesting a strong statistical

relationship in boys' and girls' use of mango bark for cough.

7.2. Qualitative data: Prevalence, symptoms, and management of respiratory tract infections

7.2.1. Prevalence, symptoms, and severity of ARIs from children's perspectives

Episodes and experiences with *aona ki avuru* (cough and flu) were a common occurrence. Children frequently named *aona ki avuru* as common illnesses which they experienced, and by observation in displaced primary schools and night commuters' shelters, symptoms of ARIs were a common occurrence. In children's narratives, however, they agreed that such illnesses were not severe, and frequently the two illnesses 'got cured by themselves'. Ojok, in the prologue of this thesis, did not make it explicit that he had had cough and flu within a one month recall, yet in night commuters' shelters these infections were common, and he and his three siblings exhibited symptoms of ARIs during all interview sessions between July and September 2004. One fourteen year old boy narrated his story of *aona ki avuru* in this way:

Aona ki avuru commonly attack me, but they are not serious. Often, for cough I only need to chew *cwiny lapena* or *cwiny kalatuc* (leaves of pigeon pea or eucalyptus plants) and I will be cured. Sometimes I may take Action tablets, smear *Vickskingo* or use Piriton for flu, but often it goes away by itself.

Although older primary school children ensured some cleanliness during times of illness through the use of handkerchiefs, and some children were observed blowing their noses or coughing outside their classrooms, some unpleasant practices were observed among younger children. Careless coughing, even without covering their mouths in densely packed classrooms, was a common scene, and these practices are linked in this chapter to the high prevalence of ARIs, particularly in classes with children of between five and nine years old.

Through examination of medical record books at GRRH, Layibi, Laliya, and Laroo outpatients units, where malaria was the most frequent diagnosis, in only a few instances were ARIs also registered. In October 2005, only four medical records of children aged eight to sixteen years showed that Valium and Amoxicillin had been prescribed by a clinical officer for cough and flu, and during interviews about how children managed their cough and flu, only twenty-two of the seventy-eight children in one class indicated having been told at Layibi and Laroo health centres to purchase Septrin, Panadol, and Amoxicillin capsules. Perhaps the relative absence of ARIs in medical records was

because children hardly ever sought specialised care for them.

A substantial proportion of children named cough and flu as common illnesses, when listing and ranking common illnesses which attacked them. However, in one focus group discussion with twelve to fifteen year old boys at Noah's Ark night commuters' shelter, they concluded that cough and flu were diseases which were only serious in younger children. One fourteen year old boy told how it was only when the cough was very frequent, and there was pain in his chest, that he bought the red and yellow capsules for cough.

In an exercise to diagrammatically illustrate the common illnesses children experienced in displaced primary schools, cough and flu featured as common illnesses in their drawing. In one class of seventy children at St. Peters Bwobomanam, all children illustrated *aona ki avuru* as individuals with air droplets or particles around the head region. In interview sessions which followed, many children asserted that at the moment of our discussion they had cough or flu or both. However, the episodes were not considered severe since they could still perform their routine activities. Children further told stories of how other children frequently developed a cough after sweeping the dusty classes and school compounds.

In Chapter Five above, I provided an example of how one boy wrote about his experience with malaria within a one month recall, even though at the time of writing his narrative he was experiencing flu and cough. When I inquired about his selective writing, he argued that it was because "flu and cough were not *serious* illnesses. This is because cough and flu do not make people weak like malaria does". Further, he would probably not need medicines in order to recover. Generally speaking, cough and flu were illnesses of lesser importance to children of primary school age, because even children who discussed their recent episodes with cough and flu had first discussed their experiences with other illnesses which were regarded as severe in comparison.

In short, ARIs were highly prevalent among children who participated in this study. They were, however, not regarded as severe. The general agreement was that they were illnesses which went away by themselves and which did not make people weak. Children even continued with their normal 'typical days' while experiencing episodes of acute respiratory infections. Children used both pharmaceuticals and herbals remedies in treating ARIs, and data suggests the use of mainly market drugs, including

pharmaceuticals such as Septrin, Action, Piriton, Valium, Panadol, and Amoxicillin. The various herbal remedies used included *cwiny lapena* (leaves of pigeon peas), *kalatuc* (eucalyptus leaves), and *muyeme ki mupeera* (mango tree and guava leaves). These three herbal remedies were outlined in illness narratives and during presentations in two workshops on common herbal medicines which children used for their illnesses, yet they were not captured in the quantitative survey data. Other remedies mentioned were green *Pepsi*, *Vicksingo*, *Balms*, and other unspecified ointments from India.

7.2.2. Using my experience to explore the management of ARIs

During one focus group discussion with girls aged ten to thirteen years, I was at the time personally experiencing cough and flu, and so I used my own illness to inquire about the severity and treatment of it. One girl aged thirteen years gave this account in response to my inquiry:

Well, you can pray about it. Prayers can heal all illnesses [here I request to be taught how to pray]. But I do not know how to pray. The prayers I was talking about were those often done by the priest at Holy Rosary Catholic Cathedral every Sunday. He prays for the sick, and sometimes sprinkles water on them. But this is how I deal with *aona ki avuru*. I do not use any medicines for those two illnesses. It is because they can be cured by themselves. Even now I have cough and flu. I have not taken any medicine. But I can play, I have been coming to school. At home, I can do all the work which they send me to do. I just leave it to go by itself. But when the cough takes a long time, say one week without curing, then I can drink *kor muyeme* (extracts from mango bark) or chew *cwiny lapena* and *kalatuc* (leaves of pigeon peas and eucalyptus plants).

Another twelve year old girl added to the discussion:

If the cough has taken long, or you are coughing frequently, then you can chew the *cwiny lapena*, *cwiny kalatuc*, or even drink *kado atwona* (extracts from soda ash mixed with salt). The cough will go away within one day. The flu often disappears by itself. Cough and flu rarely make people very sick. You can have them but you will have energy to dig, to cook, to go to school and do whatever you like. It is only when children in class laugh at you and make bad comments when you cough that is when you feel bad.

On the same day, I posed the same question about my ill health with flu and cough in a focus discussion for boys aged eleven to fifteen years. One twelve year old boy first disclosed how he had the same problem, and then mentioned how his neighbour (who sold medicines) had given him two Piriton the previous day, after he had fetched for him a jerrican of water. Another boy, fourteen year old Ojok, elaborated:

There are many medicines you can use for cough and flu. You can drink *kado atwona* (extracts from soda ash) mixed with salt. You can use Amoxicillin capsules if you have money to buy them. Also, other medicines in the shop are *Vicksingo*, Action, and sometimes Valium. But still you can use *cwiny lapena*, *mupera*, and *kalatuc* (leaves of pigeon peas, guava, and eucalyptus).

These are always sufficient in curing those diseases.

Since Ojok was popularly known as *ajwaka* (indigenous healer) by other children, I promised to try out all the therapies he recommended, and so I picked and tasted leaves of pigeon peas and eucalyptus from the school compound. I gradually got better since the cough and flu appeared to be self limiting, though Ojok was happy that I took his advice. Other girls also kept inquiring whether they could bring *cwiny lapena* for me. I mention at this stage that there was a deep internal feeling which I registered as a result of the children's care, which I will call the 'unintended effect' in quests for therapy. For instance, in using the herbal remedies which the children suggested and also brought for me, I perceived my recovery as being more a result of the care they exhibited than from a belief about the efficacy of herbal remedies. Further, in the constant inquiries from the children about whether I needed more of the *cwiny lapena* as opposed to the bitter *cwiny kalatuc*, I felt and recognised the importance of care in situations of suffering, whether with infectious diseases or emotional suffering. I will return to the importance of what I call the 'unintended effect' in quests for therapy for complex forms of psychological suffering.

In a workshop on herbal remedies, twenty out of thirty-two children brought *cwiny lapena* and *cwiny kalatuc* as remedies for cough. For flu, only six children brought Robb and *Vicksingo*. The thirty-two children mentioned that while flu may attack them frequently, it goes away by itself. Sometimes, however, if the children asked what medicine to buy for cough and flu they were given Piriton, Valium, and red and yellow or red and black capsules (Amoxicillin or Tetracycline capsules) from drug shops, clinics, or hawkers who sold medicines in the congested suburbs such as Pece, Cereleno, Kanyagoga, and Kirombe. Only five children bought *Vicksingo* and *Pepsi* (hard green crystalline sweets) during a one month observation exercise in one drug shop at Olailong trading centre in Kirombe suburb. Each of them indicated that the medicines were for cough and flu upon inquiry.

7.3. ARIs disease aetiologies

Children frequently mentioned exposure to dust as the cause of cough and flu. This they knew since they saw that children who were instructed to sweep the non-cemented dusty classrooms started to cough and developed flu shortly afterwards. One child put it this

way:

At home there is no dust since regularly we buy cow dung to smear the floor huts with. Sometimes we use mud to smear floor huts to reduce the amount of dust in huts. The compound is very small, so there isn't much dust. I have flu now since yesterday I was late at school and was punished by being told sweep primary six class. By the end of the activity I was coughing and sneezing.

When children were asked how they prevented cough and flu, numerous answers were given, including sprinkling water in the classrooms before sweeping, and avoiding playing in dust or playing in a compound with a lot of dust. In one focus group discussion with girls aged twelve to fifteen years, they recommended regularly smearing the classroom floor with cow dung, and indeed any other buildings which were not cemented. This helped to minimise the amount of dust and subsequently the likelihood of getting cough and flu.

In another discussion with eight to twelve year old boys, one boy argued as others agreed in unison:

This *aona ki avuru* is common especially in children of P.1 – P.3. Children there do not care about cleanliness. Some of them can just leave the mucus to flow through their noses up to their shirts. Even when they are coughing, they just spit anywhere. Some children cough in front of others. Some even swallow what they have coughed. That is why there is a lot of flu and cough in such classes.

Children's perspectives about the causes of cough and flu pointed to an awareness of the air-borne nature of these infections, which are essentially naturalistic disease etiologies. Although children could not directly attribute these illnesses to particular viruses and bacterial pathogens, it suffices to say that within their level of education and experience it was hardly expected that they would be able to name and link the various microbes to their illness episodes. Perhaps notions of microbes and microscopic disease-causing pathogens also reflect a high level of specialty in knowledge, largely influenced by age and level of education in the medical sciences.

Beyond the common experiences with cough and flu, the children interviewed also knew a type of serious illness which they called *aona opiu*, i.e. tuberculosis. Children indicated a need to avoid people with tuberculosis, and also mentioned how it could be acquired through inhaling cat fur, and from sharing household utensils and even huts or compounds with those suffering from *aona opiu*.

7.4. Children's perspectives concerning the severity of tuberculosis

Tuberculosis (TB) is a respiratory system infection which children considered severe. Tuberculosis was, however, less prevalent among children of primary school age. During the entire ethnographic research, only one child who extensively participated in the study had tuberculosis. Nevertheless, eight of the twenty-four children (33%) who extensively participated in this study were at a higher risk of contracting tuberculosis since they were caretakers of adult kin sickly with HIV/AIDS, infected with an opportunistic tuberculosis infection.

In two workshop discussions on the common medicines used at home, one child brought with him Rifampin tablets which he used for his cough. In his presentation of the medicines, he argued that he had been ordered to stop using *cwiny lapena* and *cwiny kalatuc* at GRRH when he had been diagnosed with *aona opiu* (tuberculosis), and the only medicine for it was Rifampin (Rifampicin). Thirteen year old Okello also argued that he “had used those *yat acholi* (herbal medicines) for a long time, sometimes even using the green capsules (commonly Imodium) and red and yellow capsules (Amoxicillin or Tetracycline) for my cough, but I did not get better”. Following Okello's statement, various children focused their discussion on the severity of *aona opiu* and how it spreads, advising Okello about what he should do, and what other remedies he could use in order to recover. This particular workshop turned out to address the severity of tuberculosis, its perceived disease aetiology, and how Okello could stop spreading tuberculosis to others.

In this discussion, children's perspectives about tuberculosis were detached, focussing on disease aetiology. It is likely that this is due to the fact of their experience-distant perspectives. The tone of the discussion portrays the tuberculosis victim as the ‘other’ and the children seemed not to comprehend Okello's realities. This distant stance in children's viewpoints was, however, not observed in discussions on any other infectious disease which children identified as common. This also tells us about the information available from much anthropological literature which exhibits an experience-distant assessment of the ‘other's’ illness experiences, with the main focus on personalistic disease aetiologies

One twelve year old boy elaborated on the severity of tuberculosis while giving this account:

Aona opiu (tuberculosis) is a very serious disease. In Pece, there is one man whose wife died of *slim* (AIDS), but for him he was healthy for sometime. He even remarried. But with time,

he started coughing, and his coughing was very persistent. He tried to purchase for himself various medicines but did not recover. However, when he went to Lacor Hospital, he was told that he had *aona opiu*. Although he was given so many types of medicines, he still coughed persistently, sometimes coughing just blood only. That is how I know that *aona opiu* is a very serious disease.

One thirteen year old girl shared an experience of a neighbour's daughter who had tuberculosis in order to show its severity:

Her mother says that Acen is about thirty-two years old. The reason why Acen was brought back to Gulu from Kampala was that she was sickly with *aona opiu*. When she was taken to *ot yat adit* (GRRH), she was admitted for a short time and told to go home. She was, however, still coughing. She is very thin and needs help to stand from her bed. She had *aona opiu*. Although she takes medicines like those Okello has, she does not recover. Neighbours, however, keep gossiping about dangers of getting *aona opiu*. Some people say that someone could get *aona opiu* by just crossing the compound and coming close to the hut where that woman sleeps.

In various focus group discussions with children aged nine to sixteen years, sometimes disaggregated by gender, the predominant theme among all children was that *aona opiu* was a serious disease. Furthermore, tuberculosis, the children argued, was caused by the swallowing or inhalation of cat fur. In one session, five boys aged twelve to fourteen years specifically asked Okello whether he had a cat at home, and if so, advised him to get rid of it. Okello, however, insisted that he did not have a cat in his home or his neighbourhood. In the same discussion, children narrowed down their 'advice' for Okello to what to do in order not to spread *aona opiu*:

He should not sit close to others. At home he should sleep in a hut alone. He should use his own cup, plate, and blanket. Above all, since Okello's medicine seemed to work for him, he should never miss a day without taking any of them.

By the time Okello's response below was completed, there was a peculiar silence in the classroom. Here is how he shared his experience:

Perhaps I got this *aona opiu* when I was taking care of my mother last year [2004]. She died of *aona opiu*. Some neighbours say she died of *slim* [HIV/AIDS], since even the soldier whom she had a child with also died last year. It was the child she gave birth to who first died, then later my mother. However, I had to take care of her at hospital. During that time, Ajok was always taking care of my younger sisters and brothers at home. She would also cook and bring food to hospital daily. But I cannot do all what you are telling me to stop *aona opiu* from getting other people at home. We have only one hut for all of us. We have just two blankets for sharing by five of us. We have two cups and three plates. We have been sharing all this. There is no one at home who has got this disease!

The complete silence which followed Okello's narrative was only interrupted by one outspoken eleven year old boy who began by arguing that perhaps Okello had already

infected him with *aona opiu*. However, he added that he may not have, since people often told him that he is very strong (resistant to diseases), and much as the people around him at home sometimes fell sick, he remained healthy. Other children present for the discussion hypothesised that it was because they had not shared cups, plates, or pens with Okello that they were still healthy. Most importantly, they did not have *aona opiu* because they did not have cats at home, and neither did anybody in their neighbourhood.

I closely monitored Okello's medical records which he regularly took with him to Lacor Hospital when he went to collect his medicines. Over a six month period when Okello took Rifampin tablets he exhibited complete adherence. In my follow up visit to Gulu in May 2006, I visited Okello and his health condition had deteriorated substantially. Together with his sister they narrated how, after the six months of taking his medicines, he was told that his chest had not responded to the medicines. The x-ray result showed a black thing in his chest. I organised to take Okello to Lacor for check-ups, and the clinical officer confirmed yet another case of multi-drug resistant tuberculosis (MDR-TB). The hospital was, however, still awaiting the arrival of another line of drugs to combat it. I felt helpless, like the children and the clinical officer and other people who had gathered to watch us. Nevertheless, Okello was again registered for Rifampin medicine, this time with strict advice for him to adhere to the schedule and timing in taking them. In another follow up visit to Gulu in January-February 2007, I traced Okello again. To begin with, I discovered that the brother of their landlady, Aloba, had instructed them to find somewhere else to live as they were becoming a danger to his children, since he had also developed tuberculosis which had been diagnosed at Lacor hospital as MDR-TB. Ajok and Okello were therefore now living at the extreme end of the village with virtually no neighbours. According to Okello, the brother of Aloba – having learnt that the tuberculosis they had was not curable and that there were no medicines in the entire country – instructed them to leave the neighbourhood. He had demolished their huts. That is how they moved to the extreme end of the village to rent a piece of land from the present land owner. Okello and Aloba may therefore have been important sources of infection for MDR-TB. Due to high loss of adult lives in Gulu and northern Uganda, a unique scenario has developed whereby it is children who are the principal caretakers of HIV/AIDS victims, and since HIV/AIDS clients frequently have tuberculosis, it is likely that such children are also exposed to it. Nevertheless, there is hardly any data about the dangers of such children's

exposure to tuberculosis.

While living in isolation, each of the family members had a card and had to regularly report to Lacor Hospital for *isoniazid prophylaxis*. Okello had recovered remarkably compared to my judgement of his condition in May 2006, since he could move unaided and had gained some weight. During another visit in September 2007, each member of the family had a certificate of completion of *isoniazid*, and “Each of them had no traces of active tuberculosis and had perhaps recovered”, said one medical doctor during interviews.

7.5. Tuberculosis as an opportunistic infection for HIV/AIDS clients

Another finding which pointed to the severity of *aona opiu* as a health problem came from three children taking care of their parents, sick due to HIV/AIDS. Their parents had a persistent type of cough which they frequently discussed; it was *aona opiu*, or tuberculosis. Such children often made it clear that even though they did not have cats in their homes, their sickly kin were still affected by *aona opiu*. One eleven year old boy, Abonga, discussed his experience of taking care of his sick mother:

Aona opiu is a very serious disease. My mother has it. Sometimes she can cough for more than one hour until she vomits blood. She had since become very weak and thin. Although she was one time admitted for one month at Lacor Hospital due to that cough and given various medicines, she does not recover. When she was sent home, she kept on coughing. She was also given more medicines which she would take from home. Still she does not recover. She often sends me to call the pastor of BBC (Bridge Builder’s Church) at Laroo to pray for her. When he comes, he makes us kneel down and raise our hands. He first tells us to repent of our sins, before he can chase away the Satan which makes my mother very sick.

Abonga also frequently discussed the difficulty surrounding her mother’s failure to go for more medicines at Lacor Hospital. In yet another discussion, he explained his experience this way:

My mother was admitted two months ago at Lacor Hospital but was told to go back home before she recovered. She was told to go back for more medicines when she completes what she was given. Since she came from the hospital, she has been very weak. She can no longer go and dig or do *leja leja*. She cannot even buy for us exercise books, pens, and school uniforms. Today she was supposed to go for more medicines but she needs 700 Shillings for the hospital and money for transport [about 1000-2000 Shillings by public transport], which she does not have.

Another child aged twelve years discussed in depth her mother’s persistent cough which made her elder brothers go to night commuters’ shelters to sleep:

My mother has *aona opiu*. Although she has been taking medicines, she does not recover. Sometimes she coughs throughout the night. You do not know what to do. I get scared when I see her vomiting blood due to that cough. The landlady threatened to chase us from her hut due to that cough. She said my mother makes a lot of noise for her at night when she wants to sleep. At World Vision, they always tell us not to share plates, cups, food, or a hut with people with *aona*

opiui. But we have only one hut and a few cups and plates. We share all these with my mother. I cannot go to sleep at the night commuters' shelter because it is at night when my mother needs someone to light the lamp for her, to clean her, and to give her medicines.

7.6. Key informants' perspectives about the severity and management of tuberculosis

One doctor was interviewed concerning the extreme fear children have of TB contagion, and about the advice he would give them:

Tuberculosis can be effectively treated within six to eight months with medicines such as Rifampicin and Isoniazid. However, when a patient has been given that medicine consistently for at least two weeks, then it is not infectious anymore. The only thing which that patient needs to do in order to avoid more complicated problems like developing multi-drug resistant tuberculosis [MDR-TB] is for them to take their medicines as prescribed. The major problem we have in Gulu here is that after the patients are discharged from hospital, they *believe* they have recovered, therefore most of them stop taking their medicines. This has contributed to the high incidence rate of MDR-TB in this region. MDR-TB is virtually impossible to manage and at Lacor, there is a policy that facilitates management of those patients without the resistant strains of TB. It is preferred that those with MDR-TB are managed in their communities. MDR-TB is the most dangerous form of TB. Perhaps the children who are taking care of sickly patients are not predisposed to infection, since most of them are in ART programmes, and therefore have taken Rifampin for more than three weeks.

Upon further inquiry concerning how the 'community' is facilitated to manage those with resistant strains of tuberculosis, the doctor gave the example of the Directly Observed Therapy (DOT) project which had been put in place, but which was no longer operating because of lack of funds.

Another doctor in private practice in Gulu, interviewed about the role of *isoniazid prophylaxis* in 'curing' Okello's MDR-TB, responded as follows:

Isoniazid, like Rifampicin, is a first line drug for treatment of tuberculosis. If that boy did not recover after taking Rifampicin, then it would be better to give him a second line treatment for tuberculosis. My experience, even with those very rich people taking ARVs is that, if they do not respond to Rifampicin, they have just been left without any medications. Perhaps, it is because the second line medicines are very expensive. I have not even seen anyone in Uganda taking them.

Further, a clinical officer at Lacor Hospital elaborated on the issues at stake in the DOT project during an interview. The clinical officer, in his own words:

The directly observed therapy was initiated by this hospital five years ago in an attempt to reduce non-adherence rates of our patients. There was also a high increase of multi-drug resistant strains of TB in the clients who did not come back to collect their medicines as were instructed. Often such clients would come back for a refill after realising their TB had become more serious. The DOT project was only active five years ago. Presently however, the hospital is not able to follow up our clients. There are various problems including limited staff, finances, and also the insecurity caused by LRA in our focal communities. There are camps which the DOT project

staff have not tried to visit due to insecurity. The most important problem is lack of facilitation [funds].

In an interview, the coordinator of an HIV/AIDS unit at GRRH elaborated on the phenomenon of increasing episodes of MDR-TB:

MDR-TB is a big problem in Gulu Hospital not only in adults, but also in children. Partly it is because of clients' non-adherence and another problem is that when we diagnose MDR-TB, we have a policy of sending such people home. This is to limit their likelihood to infect other TB clients in the ward with drug resistant strains of tuberculosis. The sad thing is that, about two months ago, I sent home one such case, but after a few weeks a caretaker reported with TB infection similar to the strain in *his* patient. It was MDR-TB. To make matters worse, these persons are living in the communities, which are camps, with poor housing, congestion, and poor sanitation. It is likely that with time the hospital would be confronted with more people with strains of multi-drug resistant TB as first time attendants.

At Lacor Hospital and other state aided health centres, a typical TB unit during the time of the study had a bed capacity of forty patients or less. Although it is a requirement that after such patients are admitted they are closely monitored for the next six months, the clinical officer in charge of Lacor TB unit explained:

We have a policy to admit serious cases of TB for one month. Thereafter, they have to be discharged but they are required to report regularly to the clinic for follow up and refills. In which case progress is monitored and they are given more medicines. Often, however, clients do not adhere to these demands by the hospital. This is because, when we discharge them, most of them think they have recovered.

If Abonga's mother above is representative of clients who do not adhere to the treatment requirements for tuberculosis, then it is clear that the hospitals' policies need to take into account such difficulties.

A substantial proportion of NGOs had programmes addressing the needs of persons affected by HIV/AIDS and tuberculosis, and their general approach was to promote awareness through sensitisation seminars and the dissemination of awareness messages concerning the dangers. For example, one of the counsellors in World Vision's ART programme *counselled* the people taking care of ARV clients, who were exhibiting symptoms of tuberculosis, as follows:

So many of our clients do not only have HIV/AIDS, but also *aona opiu*. My task today is to tell you how to take good care of them, as well as of yourselves. First of all, although the HIV/AIDS virus cannot be easily got through interacting with our clients, TB can easily be spread from one person to another. Its being an airborne disease makes it easy for one person to get it from another sick person. Therefore, you should avoid close contact with them. At home, if possible use another hut so as to avoid constant exposure to infection through sharing one hut and other basic utensils.

Indeed, consistent to the counsellor's advice, available publications suggest that unlike many of the opportunistic infections afflicting those with HIV/AIDS, and unlike HIV infection itself, *Tubercle bacillus* may be transmitted without sustained intimate contact. Viable bacilli are aerosolised by coughing TB patients, and they may remain in the air for hours. Perfectly immunocompetent persons may subsequently inhale these organisms and become infected (Farmer 1997b: 348).

7.7. Discussion

In the interpretation of empirical data about the prevalence and management of acute respiratory infections and tuberculosis, I organise my analysis under three subsections: firstly, I look at the high prevalence of and curative approach to ARIs, then I examine the silence following proximal discussions about tuberculosis (i.e. accounts from tuberculosis patients), and finally, the last subsection links the prevalence of tuberculosis among children to wider socio-economic factors. In analysing the efficacy of curative approaches, I suggest that use of pharmaceuticals in the management of ARIs and tuberculosis serve only as short term approaches, and in some instances I contest such short term approaches, especially where tuberculosis is concerned. Tuberculosis poses various complexities, not only due to the fact that it is a chronic and infectious condition, but also because dire socio-economic conditions, coupled with it being an opportunistic infection in HIV/AIDS clients, play a role in determining the prevalence and the effectiveness of its management among people in the situation of armed conflict.

7.7.1. High prevalence and curative approaches to acute respiratory infections

Empirical evidence suggests that cough and flu were highly prevalent among the study population, but while the frequency of experiences with ARIs was emphasised, its severity was not. ARIs were not seen as life threatening and posed less severe symptoms – with the exception of TB – and were seen to be self-limiting, with individuals recovering without taking any medications. When children did pursue treatment, it was with certain pharmaceuticals, market therapies like *Robb* and *Vicksingo*, and home-made treatments such as soda ash mixed with salt and herbal remedies. This attitude to ARIs could explain why children did not pay much attention to them. It is further likely that for highly prevalent infections, children learned to integrate them into their daily life experiences.

However, children's perspectives suggest that they consider *aona opiu* to be severe. TB presents a severe type of cough because it makes people weak, is persistent, and sufferers cough blood. Further, the fact that people were admitted to hospital, and also

had to take pharmaceuticals for a long period of time, were indicators that *aona opiu* was severe. Apart from Okello who was taking Rifampin (Rifampicin) during the time of study to treat an episode of TB, no other child shared their illness experiences with TB. There were, however, six children in 2005 taking care of parents sickly due to HIV/AIDS and tuberculosis. The link between HIV/AIDS and tuberculosis was made in the late 1980s (Rouillon 1991) and this link is becoming increasingly evident as many TB deaths are due to HIV (Raviglione, Snider & Kochi 1995). That child caretakers of HIV/AIDS clients knew about TB is not surprising. They frequently referred to it as a cough which does not cure, a cough which is persistent, and one that can disturb people during the night, with the occasional coughing up of blood. Such symptoms are at the core of the suffering caused by tuberculosis, and child caretakers of sufferers of HIV/AIDS are at a high risk of contracting it themselves.

In short, cough and flu were common illnesses in wartime children, and children made distinctions between the 'normal cough' and a 'serious cough'. Normal cough and flu were those which they got from dusty areas, or from children who came to school with a cough and passed it on. It did not make them weak, though children laughed at those who coughed in class, and it could be cured by itself. For *aona opiu*, on the other hand, there was a peculiar silence following narratives of individual's experiences with tuberculosis.

7.7.2. Silence following one child's discussion of his experience with tuberculosis

The above sub-title attempts to make explicit the dilemma children were confronted with in discussions about tuberculosis by a child who himself experienced tuberculosis. Interventions with the desired aim of reducing AIDS related mortality through antiretrovirals (ARV) distribution programmes might also draw some lessons from this phenomenon. Unlike discussion sessions about other infectious diseases which commonly affected wartime children, for which children appreciated the short term curative solution of pharmaceuticals, tuberculosis seemed to not exactly fit the pattern. Experiences with tuberculosis resisted simple short term solutions, much as there were efficacious medications such as Rifampin, Isoniazid, and Ethambutol. Even indigenous means of avoiding contracting tuberculosis appeared to border on impractical and detached suggestions, such as the avoidance of cats and cat fur. Hence there was often silence,

especially after listening to a proximal or experience-near narrative about tuberculosis.

Discussions which followed the ‘silences’ seemed to shift to an individual’s need to avoid ‘falling into the trap’ of being exposed; but how could resource poor wartime children, and indeed all people at risk, living in over-crowded conditions with limited resources, prevent infection? Further, I question whether the major operational technique employed by emergency aid institutions and healthcare professionals – of sensitising wartime people at risk, including caretakers of ART clients – is sufficient.

That the infected, the predisposed, and ‘at risk’ children were forced into silence while discussing the dangers of tuberculosis is revealing in a number of ways. Firstly, while an experience-distant stance seems to offer simple solutions, such as avoiding cat fur and not sharing utensils and huts, an experience-near narrative challenges individuals to re-shape their model. One such model is for the infected to ‘take their medicines without fail’; in short, adherence. However, in the promotion of adherence, individuals are confronted with wider socio-economic and political difficulties including abject poverty, crowded living conditions in camps, and insecurity, as well as the deteriorating bodily condition of ART clients, which cannot be ignored. It is clear that being confronted with experience-near accounts makes it harder to suggest preventive ways of dealing with opportunistic infections, including tuberculosis, among ART clients and children. What is more, the major opportunistic infection, tuberculosis, is gradually broadening in scope to affect child caretakers. While it is true that a substantial proportion of people at risk were not aware of the medical-technical details regarding infection, in the main the factors reinforcing the spread and increased infection rates of tuberculosis (including MDR-TB) are of a socio-economic nature. This is consistent with Farmer’s (1997:355) observation that calls for “lifestyle and behaviour” changes are often made to precisely those persons whose agency is most constrained. The critique I pose of contemporary intervention agencies, whose major approach is to sensitise people about the dangers of *Mycobacterium tuberculosis*, is that if the contextual factors of wartime were to be scrutinised by such key players, they may also be forced into silence, and into rethinking their interventions. Failure to do so leads to the suggestion of simple, impractical, and detached solutions.

Unilateral, detached suggestions for the prevention of TB were easily articulated by children who had no direct experience of TB. It was more difficult, however, for children taking care of sickly parents, or for the siblings of Okello, for instance, to effectively

decide upon or even implement preventive measures for TB infection. This is partly linked to their obligations and social roles as healthcare givers. For Adokorach, it was her own mother who was sick, not a stranger, which made it impossible for her to implement preventive measures which would, in effect, signify neglect and alienation of her mother at a time when she needed her most. For instance, her mother needed to be cleaned when she coughed up blood, she needed someone to give her medicines, even at night, and she also constantly needed water to drink; how could Adokorach leave her mother alone to go spend nights elsewhere, such as at a night commuters' shelter? Furthermore, they had few utensils, and had difficulty in getting enough food for the family, thus whatever her mother did not finish would become Adokorach's meal.

In short, it appears that proximal narratives of ways of dealing with ART clients with tuberculosis break all knowledge barriers and rationalities of the inherent needs of people to alleviate suffering. While it is true that children who took care of sickly kin, especially those who had developed TB, knew of the dangers and were the constant targets of awareness messages, their daily life experiences offered few opportunities for implementing the advice in these messages. Okello was well aware of the need to heed the children's advice in the focus group discussion, and the instructions he received at GRRH each time he went for a 'refill' when he was 'taught' how to avoid infecting others. Yet Okello told how he and his siblings had to share only two cups, three plates, and two blankets, and could hardly manage to rent even a single hut for themselves.

7.7.3. Wider socio-economic conditions linked to increased prevalence of tuberculosis

Although the clinical officer in charge of one TB unit attributed non-adherence to patients' perceptions that they had recovered, it is possible that other factors were at play. Findings suggest that many adults admitted to TB wards also had HIV/AIDS. Tuberculosis was therefore just one of the several opportunistic infections and problems they had to deal with. Through visits to various clients of the Presidents' Emergency Programme for AIDS Relief (PEPFAR) and World Vision's ART programme, I found that such persons often lived in camps and municipal suburbs, mostly at a significant distance from Lacor Hospital or other ARV distribution points. Nevertheless, ART clients were required to travel to these ARV distribution points at least twice a month, yet a substantial proportion often had no means to report to the hospital. Explanations commonly given were a lack of transport facilitation, the inability to raise the 700 Shillings each client is required to pay

for each refill, and frequently such clients would be bed ridden in their homes. Similarly, a report by the World Health Organisation estimated that one third of AIDS deaths are due to TB (WHO 1999a). Where HIV has established itself, the prognosis is even worse: in Sub-Saharan Africa, from 1990 to 1999, TB incidence escalated by almost 250%, and poverty remains an overwhelming risk factor for tuberculosis related mortality (Shin et al. 2004:1536). Effective community based tuberculosis control therefore requires comprehensive initiatives that incorporate efforts to address the root causes of disease, notably poverty and the resultant ills (Kironde & Nasolo 2002:276). Similar findings are presented by Farmer (1997b:347), suggesting a patterned occurrence of MDR-TB in the United States afflicting those in homeless shelters and in the inner city, indicative of some of the large scale social forces – including poverty, economic inequality, political violence, and racism – at work in the new epidemic, which begun even before the advent of HIV.

If what experts in tuberculosis suggest about MDR-TB is true – for instance that patients are resistant to three or more first line agents including Isoniazid and Rifampin (Farmer 1997b:348; Shin et al. 2004:1529) – then Okello's tuberculosis was not MDR-TB; in a second follow-up visit, Okello had improved greatly, and in a follow-up visit in September 2007, Okello showed remarkable signs of recovery. He had also received a certificate of recovery and completion of Isoniazid regimen. As Okello's tuberculosis responded to Isoniazid, and he showed improvement, does that not imply that he did not have MDR-TB?

Although TB is easily preventable and can be treated – and even immunised against in children under five years of age with the BCG (Bacille Calmette Guerin) vaccine – there is an emerging trend for TB to be diagnosed in children above five years in northern Uganda. One example is of Okello, above, and his infection was closely linked to his being the caretaker of a kin member sick with HIV/AIDS. If TB spreads through such simple practices as sharing basic household utensils and beddings, and through sharing limited space in congested camps characterised by poor sanitation, then it is concrete to argue that TB will likely affect a substantial proportion of people in Gulu. The children of my study were caretakers of sick kin who could not implement preventive precautionary measures due to the poverty, misery, lack, and difficult socio-economic conditions in which they were embedded.

Conclusion

Empirical evidence suggests a high prevalence of ARIs in children. ARIs were generally regarded as less severe than malaria or diarrhoea, for example, and if children used medications in the management of episodes of ARIs, these included market drugs which provided symptom relief, pharmaceuticals with antibiotic properties including Amoxicillin, Septrin, and Tetracycline, and other unspecified capsules. Children also used painkillers such as Panadol, Action, Hedex, and Painex to minimise the pain caused by ARIs, though more commonly children used herbal remedies.

Beyond the high prevalence and non-severity of common ARIs lies tuberculosis. Children at risk of contracting tuberculosis were those taking care of kin sickly due to HIV/AIDS. All children who participated in this study recognised *aona opiu* as a very serious disease. It was considered severe because they had never seen anyone recover from it, and people needed to take medicines for a long time, yet while they took the medicines, they still appeared sickly. Such people also needed to make frequent hospital visits, or even be admitted to hospital. Attempts to ensure that people at risk practiced preventive measures to avoid contracting tuberculosis were couched in idioms highlighting the dangers of the highly contagious *Tubercle bacilli* and emphasising adherence with medicines. Nevertheless, such approaches met with more difficult challenges of a socio-economic nature. The socio-economic difficulties include, but are not limited to, difficulties in meeting basic needs, poor living conditions, and lack of a basic income which restricts travel possibilities for examination and medication refills. Even attempts to put in place a directly observed therapy project through Lacor Hospital met with difficulties in facilitation due to lack of funding, limited staff, and other problems within the hospital.