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Tuberculosis Treatment Drugs Uganda's Greater Northern Region

By Norah Owaraga

Free TB Treatment Drugs

The greater northern Uganda respondents in a CPAR Uganda Ltd (CPAR) qualitative investigation into pulmonary tuberculosis (PTB) were unanimous in confirming that the Government of Uganda (GoU) provides free PTB treatment drugs to all PTB patients that need and seek them.

"We brought her back to the government hospital. She was enrolled for anti-tuberculosis (TB) drugs. It was free of charge."

"TB patients have been receiving the treatment free and even accommodation (when hospitalised) they are being provided freely."

"For the drugs I did not pay for them. I got the drugs from the main hospital (government hospital)."

"I did not pay, because my elder brother is a VHT (village health team) so he was coordinating with other medical officials from the main hospital. In the main hospital people don't have to pay for medicine."

"Actually, this time, government has put a lot of effort in fighting TB. The first thing in fighting TB, drugs have to be there constantly."

Respondents, Greater Northern Region
CPAR Uganda Ltd Investigation

About the author:

Ms. Norah Owaraga, a cultural anthropologist, is the Managing Director of CPAR Uganda Ltd. Owaraga has a Master of Science Degree in Development Management from the Open University UK. Her first degree is a Bachelor of Arts in Communication Studies from Queen Margaret University, Edinburgh, Scotland, UK.

Accessibility of PTB Treatment Drugs

The greater northern region (including Karamoja, Lango, Acholi and West Nile sub-regions)[1] CPAR investigation respondents not only confirmed that the GoU provides PTB treatment drugs, but they also confirmed that the GoU provides drugs for immunisation of infants against TB, because "***immunisation is also very useful, it is strengthening some of the resistance that we have,"*** they surmised.

The general observation of CPAR northern respondents is that ***"the drugs for ordinary TB are readily available"*** and are more consistently accessed from public hospitals and from a select few hospitals that are owned and managed by the not-for-profit sector. One of the respondents, for example, shared:

> ***"Always I have been referring the clients to the government hospital. Those who are not willing to go to government, I tell them about the hospital owned by a non-for-profit organisation. All those are centres which they can get treatment."***

Access to PTB treatment drugs from privately owned healthcare facilities in the northern region, apparently, is not consistent as it used to be in the past. For example, a CPAR northern respondent clarified as follows:

> ***"Right now as I talk, we are out of stock, like for almost a year. Last week, I went and they told me that we should request direct to the National Medical Stores (NMS). I forwarded our request to the in-charge TB and they told me they were going to try and request. Right now we are not accessing TB drugs to be administered here at our private facility."***

There has been a change of policy in the manner in which the GoU accesses PTB treatment drugs to patients, as a CPAR northern respondent, for example, explained: "***I would like to refer to direct observation therapy (DOT). I think that one (DOT) worked for some time and disappeared. Now they trust patients, they give them drugs (to take on their own unobserved by medical personnel).***

Placing the onus on the patients to be the ones to take the initiative to access treatment drugs, according to CPAR northern respondents, has created two categories of PTB patients. The first is of ***"people when they get TB they feel they should seek for medical treatment, they do not relate so much to other things like witchcraft, or what, maybe in the past, but these days, I see them (going for treatment)"***; and the second of "***some patients that they don't go for the treatment if the TB has been got on them."***

The major reasons as to why PTB patients may choose not to seek treatment from healthcare facilities, according to CPAR northern respondents, include issues related with stigma[2]. Furthermore, among communities of the greater northern region, according to CPAR northern respondents, there is a ***"tendency to think that you can manage most or some of the conditions culturally - locally from home."*** With regard to PTB, according to CPAR northern respondents, the tendency is fuelled by a low TB suspicion index[3].

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[1] *Details on the CPAR qualitative investigation into PTB are contained in its two reports titled:* ***"Research Activity Report on Qualitative Investigation into Tuberculosis in Uganda (2017)"****, and* ***"Findings of Qualitative Investigation into Pulmonary Tuberculosis in the Greater Northern Region of Uganda (2018)."*** *PDFs of both reports are available to download free of charge from the* ***"Tuberculosis page"*** *on CPAR's website www.cparuganda.com*

[2] *The issue of PTB related stigma and how it is manifested in greater northern Uganda is explored in the first briefing:* ***"Tuberculosis the Silent Epidemic in Uganda's Greater Northern Region"*** *in the series of CPAR TB Research Findings Briefings. A PDF is available to download free of charge from the CPAR website.*

[3] *The low TB suspicion index of greater northern Uganda is described in detail in the second briefing:* ***"The Tuberculosis Suspicion Index Uganda's Greater Northern Region"*** *in the series of CPAR TB Research Findings Briefings. A PDF is available to download free of charge from the CPAR website.*

Beliefs which make people to first think of other ailments when they are confronted with PTB symptoms and which make people delay to seek PTB treatment from healthcare facilities or not to seek it all together, apparently prevail amongst communities in the northern region. Some of the CPAR northern respondents, for instance, shared examples of how such beliefs manifest:

> ***"We meet some clients who have had non-medicinal treatment from home, because of the culture. There are people who have tried to use herbs. They have tried to treat a number of conditions with herbs. And they tend to take a little too long to seek treatment from healthcare facilities. An attitude like: "this one is culturally known to do it, even if you go for the medical treatment it may not help, let's use this.""***

> ***"Everyone knows about this, even children. Their mothers first buy them syrups over the counter not prescribed by the doctor and they try treatment at home. When their treatment fails or seems to be failing that is when the second option is going to the clinic. When we ask what treatment they took from home, people often buy first line anti-biotic treatment – someone can buy amoxicillin, if there is no improvement, they change to another name thinking that there will be improvement thereafter."***

The consequence, according to CPAR northern respondents, is that in most cases, by the time PTB patients seek treatment from a healthcare facility ***"they would not be doing very well clinically. By assessment, maybe they already have a lot of chest pains; they already have the fever, body weakness; they have lost weight; and they are not fully functional as before."***

Completion Rates for PTB Treatment

While in significant pain, body weakness and incapacitation, is when PTB patients in the northern region often begin taking PTB treatment drugs, according to CPAR northern respondents, who clarified that ***"you know it is not easy, you have to swallow (drugs) for sixty days, it is not simple"***; and so ***"people don't finish the drugs."***

The side effects of the drugs are another major reason as to why PTB patients apparently fail to complete treatment. Using lived experiences of PTB patients, CPAR northern respondents shared descriptions of the side effects of the drugs:

> ***"All of them (patients on treatment) will complain of dizziness. Others have vomiting if they are not getting used to the medicine. Others reacted to the medicine and they lost hearing. What we call neuropathy, the nerves, they will get a lot of pain – you get up in the morning and you are unable to walk. When you step on the ground you feel like you are stepping on thorns and sharp objects."***

> ***"Somebody treated, declared cured, comes back with a cough. About three of them, all of them I managed to send the samples to Mulago for what we call mycology culture. All of them have shown to be having fungal diseases, which is making them weak and when they are coughing this time they don't cough like TB. The cough is so severe. They get wasted in a shorter time. That fungus it is not TB. Well the drugs you use for treating TB are very difficult drugs, in terms of their compromising the immunity. Now, once immunity drops to a certain point and remember the lung is damaged. And still this fungus also takes advantage of the weak immunity and the damaged lung to develop in your body."***

Persevering through PTB treatment to completion is apparently not for the weak-hearted due to side effects of the drugs. ***"The side effects of the drug, if not well managed, even a very able and most educated person will choose to go and die instead of completing treatment. Because every day they take the medicine, they feel those side effects"***, a CPAR northern respondent, for example, aptly explained.

It does not help matters when PTB patients go to hospital and at times they do not get the drugs, which, according to CPAR northern respondents, is sometimes the case. ***"Supply of drugs is inadequate. Sometimes the patient comes in, doesn't find the drugs at the hospital then there is even no need for the patient to stay there without the drugs";*** and it "***makes them to abort, not just to continue, because when they go to hospital they don't get drugs***."

There are, indeed, instances in the past when healthcare facilities in the northern region did run out of PTB treatment drugs, as was confirmed by CPAR northern respondents:

> ***"The problem with drug stock out is that these clients they do not want to go to the lower health facilities, but when we move around in the lower health facilities the drugs are there and expiring." These clients they come wanting to be treated from the main hospital. They don't want to go to the lower facilities where the drugs are. They have that mindset since they know the main hospital is a big hospital – you know people in the village they will under look those small health centres and their mindset tells them that is where I can get the right treatment, from the big hospital.***
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> ***"When patients are many we run out of drugs, but we pick them (the drugs). At times we get from other districts in Teso sub-region and at times we get from NMS. Drugs are available. The only problem could be to get it in time."***
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> ***"Yes, in case the drug is not there, we often want to run around and pick it quickly so that the person does not break the continuity of treatment. But to be frank, at times we fail to get the treatment and we often refer such patients."***
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> ***"Then the drugs for MDR-TB (multi-drug resistant TB), yes they are there, they are supplied here, with occasional out of stock of one or two items for treatment of MDR-TB."***

It is likely that because of the failure to access drugs and other reasons as well, ***"we actually have a number of those we call "lost to follow-up", those who did not complete treatment and they disappeared"***, suggested CPAR northern respondents.

PTB patients not completing their treatment may be the reason for the evolution of and the prevalence of MDR-TB suspect CPAR northern respondents. For example, as one of them hypothesised that "***the issue of high MDR-TB here is maybe poor treatment of ordinary TB, not to completion, because also the completion rate or the cure rate for treatment here is so low; below the national average."***

To compound the situation, moreover, according to CPAR northern respondents, it is not necessarily easy to trace those PTB patients who ***"abort"*** treatment or have ***"disappeared"*** without completing treatment. An example of how challenging it can be to trace PTB patients that are ***"lost to follow-up"***, for instance, was shared by a respondent as follows:

> ***If you cannot trace somebody using the address of the LC I (village local councillor), you are unable to contact them. Somebody can come to the healthcare facility and use a different name. Then when you now begin looking for that person out in the community they don't know the person.***

Be that as it may, some CPAR northern respondents did share success stories of PTB patients that persevered through the long treatment duration, through the side effects of the drugs and were successfully treated. A respondent, for example, shared their experience of knowing such patients saying that: ***"we have records of success stories of those managed even from here."*** On a personal level, another respondent, for example, shared the experience of a PTB patient that they cared for who ***"after taking her drugs, like for six months after we brought her home and then she recovered."***

Conclusion and Next Steps

As part of the University of St. Andrews led ***"Tuberculosis: Working To Empower the Nation's Diagnostic Efforts (TWENDE)"*** Consortium, from January 2016 to December 2017, CPAR conducted an in-depth qualitative investigation into PTB in Uganda. This briefing is based on a second level analysis of the CPAR TWENDE qualitative data set for the northern region; and, moreover, it contains the findings for only one aspect – PTB treatment drugs in the region. In a series of other briefings, CPAR is sharing its findings on other aspects of PTB in northern Uganda. All its briefings, including this one, CPAR will publish as PDF files that can be downloaded free of charge from its website www.cparuganda.com.

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