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Briefing on Research Findings
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‘Tuberculosis Economics’ in Uganda’s Greater Northern Region

By Norah Owaraga

The Tuberculosis (TB) Economic Burden

“This is an important contribution to our efforts and I hope that those responsible for designing the control strategies (for TB) will listen carefully.”

“I am interested to hear about whether there's a possibility to support addressing some of these questions on the ground!”

“I'll be very curious to read what ideas you may have for intervention.”

These comments are part of the feedback from health care practitioners in response to the first research findings briefing on pulmonary TB (PTB) by CPAR Uganda Ltd (CPAR).

In this, its 7th research findings briefing on PTB, CPAR, therefore, shares what needs to be done to end PTB in greater northern Uganda (Karamoja, Lango, Acholi, and West Nile), as it was recommended by CPAR respondents from greater northern Uganda who participated in its qualitative investigation into PTB that it conducted in Uganda from 2016 to 2017.

The focus in this CPAR 7th PTB research findings briefing are the recommendations of CPAR greater northern Uganda respondents related to economic issues associated with PTB health care services - the accessibility or not of diagnostic services contextualised within the economic status of the communities in the region.

About the author:

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Economic Burden from Perspective of Presumptive PTB Patients

Greater northern Uganda respondents in a CPAR qualitative investigation into PTB[1], henceforth to be referred to as respondents, confirmed that there are presumptive PTB patients within their communities ***"who are out there, they are already coughing and are able to spread TB"***, but are ***"not coming out fully for the tests"*** to confirm whether they are infected with PTB or not. A plausible reason as to why presumptive PTB patients are not coming out to be tested, according to respondents, is due to prohibitive PTB diagnosis costs that they are required to bear.

A presumptive PTB patient who is unable to access free services from government health care facilities and has to utilise private health care facilities in order to access PTB diagnostics has to bear ***"a lot of costs involved in testing for TB,"*** observed respondents, who gave examples of such costs as those for:

Sputum Analysis, which ranges from Ug.shs. 10,000/= to over Ug.shs 100,000/= as follows:

> ***"Sputum analysis may be from Ug.shs. 10,000/= to Ug.shs. 30,000/= depending on the facility."***
>
> ***"Sputum analysis you pay Ug.shs. 20,000/= - the gram stain, that is when you are expecting a bacterial infection; and the ZN (Ziehl-Neelsen), that is now testing for the AFBs (Acid-Fast Bacilli), which is for TB, which causes TB. So, the whole test costs Ug.shs. 20,000/= - Ug.shs. 10,000/= for the gram stain and Ug.shs. 10,000/= for the ZN."***
>
> ***"They don't do sputum analysis once. That is why, actually, it can even go up to Ug.shs. 40,000/=. They (presumptive PTB patients) have to pay for sputum analysis, like three to four times."***
>
> ***"And then the GeneXpert, well, the whole thing (testing) can cost over Ug.shs. 100,000/= in all."***

Chest X-Rays range from Ug.shs. 10,000/= to Ug.shs 25,000/= as follows:

> ***"And then the doctor has also to request for x-ray, that one now you go to the radiology department. For x-ray it depends, but the chest x-ray here is Ug.shs. 25,000/=."***
>
> ***"The x-ray charge ranges from Ug.shs. 15,000/= to about Ug.shs. 20,000/=; or may be Ug.shs. 25,000/=."***
>
> ***"X-rays are somehow between Ug.shs. 10,000/= to Ug.shs. 15,000/= or Ug.shs. 20,000/=, like that."***
>
> ***"The x-ray was done at a private clinic downtown and was done at Ug.shs. 20,000/=."***

Chest Surgery at Ug.shs 450,000/= as follows:

> ***"After x-ray she was identified as having water, I don't know how they call it in medical terms, water in her chest. We took her to a surgeon at the private hospital, that water was operated and withdrawn. For the operation we paid Ug.shs. 450,000/=."***

According to respondents, ***"patients may have to pay around Ug.shs. 60,000/= for TB testing"***; while others may pay much more, for example, as shared by a respondent that when "***finally they found I had TB, It took me some lump sum money. It cost me like Ug.shs. 800,000/=, I paid for the testing."***

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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*

Presumptive PTB patients' ability to bear the cost of PTB diagnosis varies, according to respondents, who noted that private health care facilities ***"have clients of two categories. We have the people who are insured by maybe some organisation, we send the invoice to their organisation which is paying for them. And for other community members around they pay for themselves."*** Reportedly, some community members ***"have the money, they do pay";*** however, some cannot fully cover the necessary diagnostic costs, so ***"if you can afford only one test, we can do that one test. The other one we make a request and send you to referral (government referral hospital) so that they can help you freely."***

Respondents further shared that while they ***"have not really had situations where the patient was not able to pay, most of the patients are paying, but others do pay with difficulties."*** The reason why others pay for PTB diagnostic services with difficulty is because of "***the poverty in our villages"***, surmised respondents. In addition to indicators of poverty, such as the inability of some PTB patients to complete PTB treatment because of food insecurity[2], respondents explained the indicators of poverty in their region thus:

> ***"You will get people packed up together. They do not have a proper place for accommodation. They are packed in one house – ten, twenty people."***
>
> ***"You see most areas, when you look at the structural designs there are more grass thatched houses there.***
>
> ***"You see that the majority of the slum areas are there. When you go to the other division you will also see a slum structure emanating. Those are the signals of poverty."***

Poverty in their region is also ***"a transmission mode"***, according to respondents, because the living conditions of poor people, as described above, ***"make the transmission of TB easy."*** Respondents, therefore, recommend that ***"just to save the community around, the Government has to help. Maybe, if they (Government) could help private hospitals with reagents for testing TB also, (presumably as Government does for HIV tests), we, (private healthcare facilities), would even test for TB freely."*** This is because, according to respondents, there are those within their communities who are living in poverty and ***"who cannot afford to pay for the tests"***, but could be more easily assisted at private health care facilities. ***"If Government could really help private settings also, because I know government settings they give them those reagents,"*** respondents plead. This plea, in addition, according to respondents, is because government facilities in the region have insufficient capacities to test for TB[3] and have challenges managing TB diagnostics[4].

In terms of addressing the food insecurity challenge, respondents are of the view that some of the interventions by the Government and other development partners are using the ***"wrong approach of providing nutrition for TB patients who are hospitalised, even though it sounds so beautiful."*** Respondents criticise the approach of providing food or food rations to PTB patients, because, according to them, it perpetuates an unhealthy dependency, since ***"down in the community people don't have food. Yes, there is a food crisis. Someone will demand to get to be treated here for that purpose. It is not sustainable."*** Respondents thus recommend that ***"the more sustainable ways would have been what I can call enabling these families who have the patients to have a particular defined means of producing this food themselves."***

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[2] *The views of CPAR northern Respondents on the impact of food insecurity on PTB treatment completion rates are captured in CPAR's fourth briefing in its series of TB Research Findings Briefing, which is titled:* ***"Social Support and Tuberculosis in Uganda's Greater Northern Region."*** *A PDF is available to download free from CPAR's website.*

[3] *The views of CPAR northern Respondents on TB diagnostic capacity in their region are captured in CPAR's fifth briefing in its series of TB Research Findings Briefing, which is titled:* ***"Capacity to Test for Tuberculosis Uganda's Greater Northern Region."*** *A PDF is available to download free from CPAR's website.*

[4] *The views of CPAR northern Respondents on TB diagnostic management in their region are captured in CPAR's sixth briefing in its series of TB Research Findings Briefing, which is titled:* ***"Managing Tuberculosis Diagnostics Uganda's Greater Northern Region."*** *A PDF is available to download free from the CPAR's website.*

Economic Burden from the Perspective of Local Governments

> ***"Now as we are focusing on preventive measures, I think there are certain things we need to look at first - improving infrastructure throughout the lowest, nearest point to the patient. Not saying "we have a regional centre", not saying "we are building this mega structure here". Look out to the community, if you are sick there, can you walk to the nearest health facility and get the quickest service, just like someone sitting in Mulago (National Referral Hospital)? That is the problem. If we are to talk about the budget needs, it is a big one,"*** assessed a respondent.

It is the general view of respondents that their respective district local governments (DLGs) are ill-equipped for PTB health care management, as, for example, can be deduced, according to them, from the fact that in some cases they do not have the drugs to treat PTB, especially so for Multi-Drug Resistant TB (MDR-TB) and they have to refer patients. A respondent, for example, testified:

> ***"In case we don't have medicine at that time for MDR-TB you would have to transport the patient to Mulago. The problem is appropriate vehicle to refer them. We can't put them in the bus. We must get a pickup (truck) for them to sit and refer them. We usually refer to the national TB centre. But that is not encouraged, because you are now moving around a dangerous disease. It is easier to bring the medicine – source for the medicine and bring it here than sending the person there."***

Respondents testified that DLGs have insufficient infra-structure, such as the necessary ambulances for transporting patients inflicted with highly infectious diseases such as PTB; they have to source for and use pickup trucks to refer patients long distances – hundreds of kilometres – from their region to the national referral hospital that is located in the capital city, Kampala.

DLGs and the Uganda Government, as a whole, according to respondents, are poor and are unable to afford TB diagnostic machines, such as the GeneXpert, which they were ***"told the machine is very expensive"*** and the Government ***"can't even now afford it. Okay they can afford it, but sometimes you know the Government has so many things they are doing. When they have a chance of getting funds from outside, maybe like a donation that is when they can afford that."***

This status quo - Government not allocating domestic resources to PTB health care management and depending on external donations - according to respondents, sometimes brings added challenges to DLGs in the form of inappropriate or insufficient machines being donated to them and which, in turn, come with strings attached. For example, a respondent explained:

> ***"This country depends on implementing partners – donors' money, which is a fact. What they say, a beggar has no choice. A person says: "am going to give you this" and you might find that this person has vested interest. I will give you an example. A donor country were the ones supporting it (purchase and supply of machine), they said that "you are going to buy a machine of bigger capacity"; a donor country product. There was a string attached that "you will get this from our donor country", now we have a high capacity machine that is underutilised."***

Other strings attached by donors to their donations of PTB diagnostic machines, according to respondents, include, for example, extra and somewhat unethical demands from donors, such as the donors having open and regular access to PTB patient data. ***"Now, with the entry of the donor (who donated the GeneXpert machine), the data of TB is being presented to the donor every Friday, at worst every Monday"***, for example, shared a respondent. Nevertheless, respondents appreciate that in demanding for patient data to be systematically collected and shared the donor, in fact, ***"is doing Government work. The government of Uganda uses this project (donor funded project), otherwise without the approval of the Government of Uganda, these projects won't go on."*** And so, according to respondents, whatever the donors are doing they are doing for and as directed by the Government.

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 – 'TB economics' 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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