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Briefing on Research Findings
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'Tuberculosis Attitude' in Uganda's Greater Northern Region

By Norah Owaraga

Tuberculosis a Burden of Attitude

"This is an important brief. There is hardly any better way of communicating that the tuberculosis (TB) problem in our country (Uganda) is more social than medical."

"This work certainly provides a window into some of the challenges in TB care. The stigma issue seems particularly striking to me."

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

In this, its 8th briefing on its research findings on PTB, CPAR shares what needs to be done in order to address Uganda's attitude towards PTB and to end PTB as it was recommended by its Greater Northern Uganda respondents in its qualitative investigation into PTB that it conducted in Uganda from 2016 to 2017. Specifically, such attitudes that drive the TB-HIV-AIDS association and that drive the deployment or not of human resources for PTB healthcare.

The TB-HIV-AIDS Association

In greater northern Uganda (Karamoja, Lango, Acholi, and West Nile), according to CPAR northern respondents, henceforth to be referred to as respondents, a major driver of PTB related stigma is PTB's association with HIV and AIDS; particularly, the belief that:

"Where there is TB, there is HIV
and
where there is HIV, there is TB"

About the author:

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According to respondents of CPAR's qualitative investigation into PTB[1], the 'TB-HIV-AIDS association' fear that their fellow community members have is hinged on the fear that if one is confirmed a PTB patient, others will automatically think that the PTB patient is also infected with HIV and is therefore ***"finished.[2]"*** Respondents explained why and how this particular kind of fear prohibits community members to come out, to be tested, and for their PTB status to be confirmed; for example one them clarified:

> ***"They (community members) know that HIV cannot be treated and cured. It is like a death sentence. Here (in the region) they use the word (to describe HIV and AIDS) which means that it is just controlled, but it will not heal. And that you (person infected with HIV or an AIDS patient) are most likely going to infect other people. Even your woman or your husband will run away, because the woman will fear to die or the man will fear to die[3]."***

Whereas, according to respondents, within the minds of their fellow community members the two infections, HIV and TB, have come to be closely associated, ***"the Government is putting much interest in HIV than in TB",*** and moreover, according to respondents***, "we need to sensitise people that TB is curable unlike HIV and AIDS."***

Respondents do appreciate that the Government has recently begun to spread the word about PTB, even though, according to respondents, the Government's chosen method of doing so is wanting. This is because, according to respondents, "***they (Government) have put adverts on the radio stations, but not all radio stations carry the adverts, very few radio stations do so";*** and there is also the fact that ***"in the village not all people have radios."*** Thus, respondents are of the view that people ***"miss some information, like health education messages to avoid the spread of TB in the community"***, because, in addition, even though some ***"have radios, but some of us have no time of hearing adverts. You find (adverts are broadcast) when you are going to work and you come back very late and go straight to sleep."***

Generally, in addition, according to respondents, in their region ***"people don't follow announcements on radio"*** and so they recommend that the campaign to end PTB in their region should incorporate the following:

> ***"We should put posters with photos explaining those things in a position that our local people can see, like the health centres; in schools; and also put in halls people go for gatherings."***
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> ***"The best thing that we can do right now, is to get a cluster of people in each and every sub-county, where they go and sensitise – playing drama."***
>
> ***"What they do in AIDS Information Centre is they have a recorded CD or DVD then they put it on a projector for people to watch (information dramas) – moonlight viewing."***
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> ***"We should use the media in our local language that our common man and a common woman who does not know English can understand."***

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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 views of *CPAR northern Uganda respondents on TB related stigma, including the TB-HIV-AIDS association are contained in CPAR's first briefing in its series of briefings on its TB Research Findings, which is titled:* ***"Tuberculosis the Silent Epidemic in Uganda's Greater Northern Region."*** *A PDF is available to download free from the CPAR website.*

[3] *The views of CPAR northern Respondents on the plight of stigmatised TB patients in their region are captured in CPAR's fourth briefing in its series of briefings on its TB Research Findings which is titled:* ***"Social Support and Tuberculosis Uganda's Greater Northern Region."*** *A PDF is available to download free from CPAR's website.*

Human Resources for PTB Healthcare

"***TB is almost becoming a neglected disease"*** in terms of the provision of diagnostic services[4]; in the management of diagnostic services[5]; and in accessing PTB treatment drugs[6], this is according to respondents. Another area which respondents pointed out as being an example of PTB being a neglected disease is in the provision or not of human resources for PTB healthcare in their region. This status quo, neglect of PTB, according to respondents, is likely because of the insufficient knowledge that their leaders have of PTB. For example, a respondent explained:

> ***"I must admit that the political leadership (in the region, at district local government level) are not very knowledgeable about TB. Me, I always sit for meetings, people don't normally bring issues of TB out clearly. Okay. It is maybe during some workshop organised by the health department and must be specific on TB. We always talk more about HIV, but not TB."***

And yet, according to respondents, ***"community leaders should be able to educate our people on TB";*** in particular the LC1s (village councillors). Respondents, furthermore, are of the view that ***"the institutions of government, like schools; the churches where there are congregations; and the traditional leaders, in their gatherings, all should be able to create awareness."*** This, according to respondents, is ***"the only (more sustainable) way we can make people to be aware – verbally (through verbal face-to-face communication)."***

In the past PTB was better managed, according to respondents, because there were sufficient human resources that were recruited and deployed by Government to handle TB healthcare. "***Those days there were TB extension workers. Yes, they were government workers,"*** for example, a respondent emphasised; while at the same time decrying the fact that "***now there are no TB extension workers."*** In addition to no longer having TB extension workers, respondents gave other examples to describe the poor state of human resources for PTB healthcare in their respective healthcare facilities, including:

> ***"The human resources for health to manage TB, all of them are programme staff (staff members of specific donor-funded programmes)", with a few exceptions of nursing staff from here (a Government hospital)."***

> ***"We have only one physician who is supposed also to cover TB and you know monitoring TB cases is labour intensive – the physician should have a one-on-one with every patient. And if the patients are too many, definitely the quality of service drops."***

Better allocation of sufficient human resources to PTB healthcare, according to respondents, would ***"help us clean the stigma,"*** so that ***"you see that once you are on treatment, accept you are on treatment."*** It is against this background, that respondents recommend that there is a need to ***"identify, maybe incorporate village health teams to identify persons (infected with PTB)."*** They further recommended that "***if we could have persons trained specifically for TB, yes you can be a health worker, but you train on TB so that you can really follow up TB cases up to the person's home, we shall manage TB appropriately."***

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

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

[6] *The views of CPAR northern Respondents on the supply and accessibility of PTB treatment drugs in their region are captured in CPAR's third briefing in its series of briefings on TB Research Findings, which is titled:* ***"Tuberculosis Treatment Drugs in Uganda's Greater Northern Region."*** *A PDF is available to download free from CPAR's website.*

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 – the 'tuberculosis attitude' in the region. In a series of other briefings, CPAR has shared its findings on other aspects of PTB in northern Uganda. All of 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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