End 90,000 people getting Tuberculosis annually in Uganda

Research Team

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Research Assistants: 10 university students from disadvantaged backgrounds under the mentorship of the principal investigator.

Action Research Project Summary

CPAR Uganda proposes to contribute to ending pulmonary tuberculosis (TB), by conducting research and generating qualitative empirical data that is urgently needed to enable policy makers to fully appreciate the traumatic suffering and the cost burden that households of TB patients in Uganda currently bear. Uganda is a high TB burden country in which over 90,000 people are infected with TB annually (1). Our CPAR Uganda theory of change is that the right help to TB patients and their households; and the implementation of the right disease management protocols can stop the spread of TB via implementing appropriate TB interventions, which are designed based on good quality data.

The Challenge

Uganda's 45.9 million people (2) are at high risk of contracting TB and dying from this infectious killer disease, which is preventable and curable. Every day 30 people die of TB in Uganda (1). Persons most afflicted and affected by TB are among the poor, whose households Hon. Rukia Nakadama (1) observed "experience out-of-pocket expenditure (on TB diagnosis and treatment related costs) of up to 53 percent of their income." Such costs to cover travel to and from distant health facilities to access TB services and to get medication; nutrition expenses on recommended diets for TB patients on medication, since the drugs are strong; and income loss during which the TB patient is weak and is unable to work and or is in isolation to avoid spreading the disease.

And so, whereas, CPAR Uganda appreciates that the Government of Uganda bears the huge costs of providing free TB treatment drugs to all who are afflicted with TB and seek treatment, the afflicted must bear the significant other costs related with accessing and taking the drugs (3). It is no wonder that 73 percent of participants in the Quality of TB Services Assessment in Uganda (4) included nutritional support or food basket; and 70 percent included transport assistance among "support services that TB patients found most helpful for their treatment." Of great concern, however, is that at the time of the assessment it was found that only 11 percent of TB patients had ever received nutritional support or food basket; and only eight percent had ever received transport assistance.

CPAR Uganda is persuaded by the thesis that when TB patients are unable to meet the TB treatment related costs, the risk that they will not adhere to and complete treatment is high. With catastrophic consequences to them, including ultimately dying prematurely; to their households enduring costs related to prolonged TB patient recovery time; to Government, especially if the TB patient develops multi-drugs resistant TB (MDR-TB) for which the treatment costs are fifty times higher than those of treating ordinary TB; and to the general public, the risk of getting infected with MDR-TB is increased. MDR-TB is harder to treat, takes longer to treat and its treatment regime has far worse and sometimes irreversible negative side effects. For example, "severe depression, anxiety or psychosis is usually due to terizidone or cycloserine (drugs used to treat MDR-TB). Symptoms include: panic attacks, hearing voices or seeing things that do not exist, paranoia and coma (5)."

Due to under-funding of TB research (6), there is insufficient qualitative empirical data to enable policy makers to fully appreciate the traumatic suffering and the cost burden that TB households bear. Inappropriate interventions are the norm. Case in point, the suggestion: "targeting (TB) affected households for government poverty reduction programs such as the (PDM) Parish Development Model (1)." PDM funds are intended for income generation and "in order to access services under the PDM, the subsistence households will be organised into common Enterprise Groups that are engaged in a common income-generating activity within their locality (6)." How might this work then for TB patients bedridden, in isolation and whose bodies are daily weakened by the battering from TB medication?

CPAR Uganda Proposed Solution

- Raise 20 million shillings (USD 5,436) and invest it to conduct qualitative investigations in five districts (Wakiso, Pallisa, Soroti, Moroto and Gulu) in five sub-regions (Buganda, Bukedi, Teso, Karamoja and Acholi) to generate good quality data, the basis on which suitable and adaptable technologies may be developed to fight TB. Focused on ameliorating crippling cost burdens that TB households bear that are associated with seeking for TB diagnostic services and with adherence of patients to TB treatment regimes.

- Mentor ten university students from disadvantaged backgrounds and endow them with transferrable skills in conducting empirical qualitative research studies; and to become the spokespersons for their respective communities advocating for public services provision, starting with TB services.

- Proactively design and conduct empirical knowledge and fact-based policy advocacy campaigns for financial relief aid provision to TB indigents.

Longer-Term Project Impact

End TB in Uganda. CPAR Uganda's expectation is that this project will heighten urgency among policy makers to ensure allocation of requisite funding towards the fight against TB. Enabling accessibility of TB diagnostic services at the grassroots, which will reduce resources poor households spend seeking TB diagnostic services. Reduce time it takes to confirm TB infection, therefore reduce the rate of spreading TB, consequently, the number of TB patients and households needing financial relief for TB treatment will reduce and or will be no more. This, indeed, is among the milestones for the World Health Organisation's End TB Strategy (2016-2025), "zero TB patients and their households facing catastrophic costs due to TB (6)."

Project Concept Author

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