A qualitative exploration of barriers to "test and treat" for HIV in geographically isolated fishing communities of Rakai, Uganda

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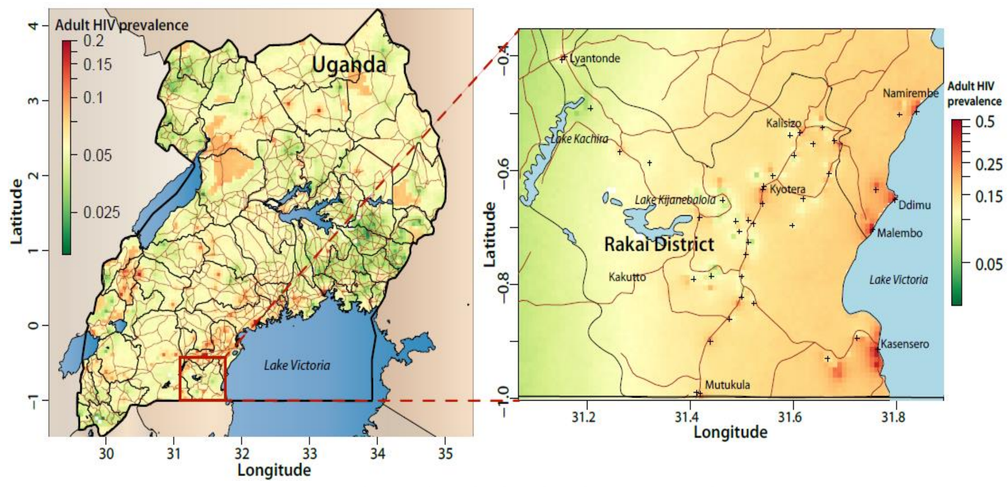
ALPHA NETWORK
Analysing Longitudinal Population-based HIV/AIDS data on Africa

Introduction

- The “test and treat” policy is now recommended for key populations in Uganda. These include fishing communities in Rakai, south-west Uganda, where adult HIV prevalence is around 40% and incidence estimated at 3.9 per 100 person-years.
- Delivery of “test and treat” occurs through the Ministry of Health and PERFAR-supported district-led programming (DLP). The tenets of DLP include structuring HIV care around the traditional formal health facilities.
- As part of a broader comparative study being undertaken by the ALPHA Network to explore ‘bottlenecks’ in accessing HIV care services, we aimed to document the HIV care-seeking experiences of patients along the treatment cascade in the context of “test and treat” roll-out.



Location of Rakai District - Uganda

Fishing boats set for night duty

Methods

- Fisherfolk were purposively sampled from HIV counseling, ART clinics and Rakai Community Cohort Study (RCCS) databases. Participants included family members of HIV deceased persons and people living with HIV (PLHIV) at different stages of the care continuum (diagnosed but not initiated, initiated on ART for different durations, and ART defaulters).
- Sixteen in-depth interviews (see Table 1) were conducted using semi-structured topic guides, which were iteratively developed and covered individual, community and programmatic factors that might influence HIV care-seeking.
- Using a framework analysis, with a thematic approach, we coded and mapped barriers to accessing HIV services and examined their influence on the implementation of “test and treat” in Rakai.
- The study was approved by local and international ethical review boards.

Key variables	Male	Female	Overall
Number of participants	9	7	16
Average age	29	28	29
Married	5	4	9
Unmarried	3	4	7
Occupations			
Fisherman	5	0	5
Business man/Woman	1	2	3
Boat maker	1	0	1
Peasant Farmer	1	1	2
Hair Dresser	0	1	1
House wife	0	2	2
Bar Owner	1	1	2

Table 1: Key Demographics for participants

Results

A number of factors, arranged into four thematic areas, deterred patients from care-seeking, and meant they reached health facilities when they were ill rather than 'promptly', as per the “test and treat” policy:

1. Lack of affordable transport: Many participants lacked access to affordable transport. As a consequence, their clinic attendance became irregular and they instead relied on sharing medication with other PLHIV in their communities, as explained by this family member*: “we always faced a challenge of getting transport to the health facility. The sex worker I have talked about who advised him to share ARVs with him did it because there was no transport to go to the health facility for ARVs”* (Male, 30 yrs, Family Member of HIV deceased).

2. Long distances to health facilities: Health facilities are located far from these isolated fishing communities and are not accessible by foot or bicycle. The time taken to travel to the facilities and queue for medication was sometimes equated with lost earnings. Accessing facilities was especially problematic when PLHIV were symptomatic or lacking practical support from loved ones and community members, as reflected by this client: *“The distance from Ddimo* [fishing village] *to Rakai Project is too long and you cannot walk this distance on foot. At the same time you cannot ride a bicycle. … I will not walk on foot. When I am sick, I might get someone who can volunteer to collect the medicine on my behalf but the only problem is that I cannot walk on foot”* (Male, 27 yrs old, Recently Initiated).

3. Anticipated stigma: Many PLHIV anticipated being devalued if others knew they were HIV+. The fear of being seen going to clinics and taking medicine within the community meant care-seeking was often forgone.

4. Being asymptomatic: Some PLHIV were reluctant to start or continue ART as they believed “treatment is for people who are sick”: *“I was told I have akawuka (virus causing Aids) but I am not sick …I feel well with no medical need”* (28 yrs old, Initiated not retained).

Conclusions

Despite the introduction of “test and treat”, health education and the availability of HIV care services at catchment health facilities, trajectories of HIV care in this setting remain characterized by delays in reaching services due to socio-cultural and logistical barriers. Service decentralization will be essential to reduce distances that patients are expected to travel if “test and treat” policies are to be successful in Rakai.

Rakai Health Sciences Program
Improved Health Through Research

AIDS 2016

This study was made possible with support from: The Wellcome Trust (085477/Z/08/Z) and The Bill and Melinda Gates Foundation (OPP1082114).

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