

Re-visiting the ART-naïve subset for linkage to HIV services: does COVID-19 pandemic offer opportunities?

'I hear stories that when you start taking HIV medicine, you will get worse than you were. And the only thing I hear about HIV on TV is take medicine, take medicine [ART]. They do not talk about where we can go to get medicine or how we can get treatment when parents are not looking. When I think of 'lining up' in the waiting area and being called out by name, I feel like I will be ashamed. I wish there was a way I could access medicine away from the health facility, then I would enrol for treatment.' Aaron, 20 year old Ugandan living with HIV/AIDS

Unfortunately, this sentiment is still familiar to the car; are says Phoebe Nabongo, a lead HIV/AIDS counsellor in the Prevention Care and Treatment (PCT) department at the Infectious Diseases institute (IDI), an HIV centre of excellence and recipient of the US Presidents Emergency Plan for AIDS Relief (PEPFAR). Phoebe leads a team of health workers mandated to trace people living with HIV/AIDS (PLHIV) and link them to care.

As a contribution to the ambitious UNAIDS 90-90-90 treatment target for 2020 to help end the AIDS epidemic, IDI is providing comprehensive care and treatment to 8,900 PLHIV in the PCT department alone. IDI's Health Systems Strengthening (HSS) Department cares for about 319,000 PLHIV in care across the three regions of West Nile (40,547), Mid-West (64,021) and Kampala region (Kampala and Wakiso - 215,427), as of September 2020. These statistics constitute 27.3% of Uganda's known population of 1.2 million PLHIV including at-risk populations of men who have sex with men, female sex workers, and people who use drugs (PWUD). IDI's Programs offer a myriad of HIV services to these populations at their clinics located at Mulago National Referral Hospital, KCCA HIV clinics, several regional referral hospitals and at IDI Kasangati.

On 30 January 2020, the WHO declared the outbreak of coronavirus disease (COVID-19) a Public Health Emergency of International Concern and global pandemic on 11th March, 2020. Uganda registered her first case on 21st March, 2020. The impact of COVID-19 on PLHIV and their access to care and treatment remains largely unknown. Uganda, like many countries entered into phased lockdown in the early stages of the pandemic. This included a ban on public transport since 25th March, 2020 and eventually a ban on private transport by on 30th March, 2020. This meant many PLHIV would not access much needed routine care including access to antiretroviral therapy (ART). Then, with the rapidly escalating numbers of COVID-19 patients, attention to this new global threat took precedence over any known existing threats in medical facilities. At IDI, the teams responded to these widespread HIV care disruptions by decentralising HIV services including ART distribution and blood draws for viral load monitoring.

Dr. Ddungu believes that, "HIV/AIDS is a social disease and like other social stereotypes, it comes with stigma and discrimination. Whether we feel or anticipate stigma, affects all dimensions of living with HIV/AIDS at individual, community and broader levels of society. This is why we refer to PLHIV as *friends* at IDI. It is important for all concerned citizens, including families, community leaders, media and the public to understand HIV associated



stigma and its consequences. For instance, irresponsibly disclosing someone's positive HIV status may significantly affect his or her decision to access to or continue HIV care. It is important to understand that not all PLHIV embrace care as soon as they become aware of their HIV positive status. Indeed, many may take months to years often being awakened by deleterious conditions associated with worsening HIV disease. The ART-naïve PLHIV that delay to initiate treatment or those who default for certain periods off ART and develop certain HIV associated illnesses due to severe immune destruction are referred to as individuals with 'advanced HIV disease'. Individuals with advanced disease represent a subset of PLHIV who are very sick or immune-suppressed (very low CD4) and require rigorous care and intense monitoring/follow up. They often include PLHIV who are not taking ART until they notice or suffer severe HIV associated illnesses like TB, Meningitis among others. This category of PLHIV are a unique subset that calls for utmost empathy and support to enable them re-engage or enrol into care to initiate ART. It is

important to note that ART-naïve *friends* with advanced HIV exist among all age categories including children (2-11 years old), adolescents (12 – 19 years old) and adults (20 years and above). This calls for everyone's concern and participation in fostering linkage to HIV services during and beyond especially during this COVID-19 pandemic."



Phoebe shared her experiences working with ART-naïve clients in PCT clinic at IDI. Her team often traces ART-naïve *friends* through other PLHIV who are receiving care and treatment at the IDI Clinic, or through assisted partner notification (APN) strategies. The unique ART-naïve subset is a source of helpful perceptions that could enrich Community Engagement strategies for HIV services. Phoebe concurs with Dr Ddungu that the 'stay home/work from home' strategies for controlling community transmission of COVID-19 offers a unique opportunity for health workers to re-visit the issue of linking ART-naïve *friends* to HIV services – in protected settings of their communities. Phoebe shared her re-recollection of perceptions of ART-naïve *friends* as well as suggestions they felt would facilitate enrolment into HIV care and treatment.

Community based caregivers who guarantee confidentiality:

Non – disclosure of HIV status to significant others was a perceived barrier to initiating ART, especially if the ART-naïve *friend* was an adolescent or a spouse who had not yet disclosed their HIV status to family members or spouse respectively. Other ART-naïve *friends* mentioned a need for community based psychosocial support to accept and cope with their HIV positive status.

Reassurance that the side effects of ART will not give away their HIV status to their family and community:

The fear that ART has visible side effects like falling ill or gaining weight that they cannot justify exists to date. ART-naïve friends feel that ART-related side effects will cause suspicion among people and family members who have no idea about their HIV status.

Recommendation - District and community based meetings discussing COVID-19 issues maybe an excellent avenue to address issues to allay fears with facts on ART.

Community based ART-refills:

Before the COVID-19 pandemic, ART-refills took place at public health facilities. Some ART-naïve friends who live far away from health facilities often contemplate initiating ART because of high costs of transportation to and from the clinic for refills while a few will prefer to travel so far due to stigma.

Recommendation - With decentralized HIV services during COVID-19 pandemic, transportation costs for ART refills should no longer be an obstacle to reckon, if COVID-19 mass messaging incorporates promotion of HIV services at community-based refill pharmacies/drug shops.

Co-pay and Convenience clinics:

The PCT program innovated a Young Adults Clinic at its Mulago National Referral Hospital premises, in response to stigma and discrimination by adults against adolescents and young people on ART. In addition, Convenient and Co-pay clinics were set up. Since the young adults face unique challenges, separating them from the adults allows for Adolescent adult friends who perceive themselves as community leaders and opinion shapers but confronted. Adolescent centered services with improved stigma and the fear improved outcomes of discrimination care. IDI set up a Convenient and Co-pay Clinic for adult friends who preferred to access services out of hours but were also confronted with stigma and the fear of discrimination especially if they were opinion shapers and community leaders.

Recommendation - Cohorting or grouping of patients and offering a targeted service in safe settings, is an area that can be grown in HIV services.

Remote Trainings and Mentorships for Counselors and Health workers:

Like other organizations globally, IDI has turned to online and offsite trainings and mentorships to deliver continuing medical education during the COVID-19 pandemic. Phoebe believes that it is a unique opportunity to tag these topics addressing myths and misconceptions about ART and enrolling ART-naïve friends alongside COVID-19 messaging. Phoebe's suggestions are based on her recollection of conversations with ART-naïve friends who later enrolled for ART, who said that they were biased against treatment and regular viral load tests because they were told that ART will trigger tumors in the stomach, cause cancers, lower their libido or even cause infertility. Misconceptions and myths about enrolling for ART contribute to poor healthy seeking behavior with negative outcomes.

Recommendation - Linking key messages on timely initiation of ART among ART-naïve friends to remote trainings and mentorships may be beneficial to HIV service delivery during this period of the COVID-19 pandemic.

Conclusion

- The new way of life brought about by the COVID-19 pandemic may have created an excellent opportunity to re-strategize for better linkage of ART-naïve PLHIV to care and treatment.
- COVID-19 lock downs and risk communication platforms may have a lot to offer the Ministry of Health and its partners.
- Mutual benefits and learning may exist through a two-way interaction between health care providers and community members about the dangers of 'advanced HIV disease'.

Contributors- Ahmed Ddungu, Phoebe Nabongo, Isaac Lwanga, Noela Clara, Owarwo-PCT Program.

Writer-Caroline Asimwe, Documentation Specialist



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