

Stigma hinders couples with HIV and AIDS in rural Uganda from accessing services

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A TASO officer looks on as a client fills in a medical form. (Photo courtesy of TASO).

In 2009, over 2.6 million HIV infections occurred in the world, with most of them in sub-Saharan Africa, where most transmission is heterosexual (UNAIDS, 2010). In the three centres of The AIDS Support Organization (TASO) Eastern region covering Soroti, Mbale and Tororo districts, 63.4 per cent of the organisation's clients were reported by the management information system in 2009 to be having a stable sexual partner with a 93.5 per cent reported disclosure rate.

However, only 20.8 per cent of clients seek HIV-related services as couples. This study sought to establish why high rates of client disclosure to their sexual partners have not translated into increased uptake of services for couples.

Rationale of the study

Scaling up HIV prevention, access to care, support and treatment among couples living with HIV is a key strategy to reducing new HIV infections and improving adherence to treatment. The majority of TASO clients, who have regular sexual partners, reported to have disclosed their HIV sero-status to their sexual partners, although most of those reported to have disclosed do not seek HIV-related services as couples.

This qualitative study aimed at finding out client and provider-related factors that hinder uptake of HIV and AIDS services for couples.

Eight focus group discussions involving men and women were done. The discussions were separate and of mixed sexes, but did not include couples. Also, 14 interviews with key informants were undertaken. These comprised of four counsellors, six expert clients (clients' council representative selected by clients through secret ballot), one district health officer and three day care supervisors (HIV-positive person who supervises clients' representatives and drama) in Soroti, Tororo and Mbale districts.

Reasons for non-disclosure

Most counsellors, expert clients, day centre supervisors and the majority of clients emphasised that community stigma results in fear of village mates, relatives and friends seeking to know their HIV sero-status. This is a major obstacle to accessing services as a couple although women are more open about their sero-status than men.

Men fear being pin-pointed especially when they want to have other sexual partners.

"Some clients have 'side dishes' (other sexual partners) especially the men, hence fear collision of the 'side dish' and the spouse at the service centre," noted a woman in a third focus group discussion in Tororo. "Most of us fear our relatives and other friends knowing our sero-status because they will say we are dead and they will stop supporting us. They say supporting people living with HIV is a waste of time and money," an expert client from Soroti noted.

Some people have not disclosed their status to family members, employers, partners and their friends, hence fear associating with HIV service providers. Reasons for non-disclosure included being accused of infidelity, and having quarrels and disagreements at family level. These also hamper uptake.

"Blaming each other for bringing infection especially if you tested positive first is a factor hindering couples from accessing services together," a man said during an FGD in Mbale.

Lack of money and long distance

Lack of money for transport and poor transport systems from villages to the HIV and AIDS clinics also hinder couples from accessing services together.





Although such conferences have addressed stigma and discrimination, many people do not still access HIV and AIDS services due to self-stigmatisation. (Photo courtesy of SAfAIDS)

"Some clients cannot afford transport costs because they don't have incomes hence (they) a couple cannot visit a health facility together. One of them has to make the trip as they raise money to enable the other to do it later. Most people in the communities are poor," a TASO counsellor said.

This is compounded by the fact that service centres are far. In some cases, they are located 75 kilometres away from the clients. This contributes to low uptake of services.

"A one-way bus ticket to the health facilities can cost up to Uganda shilling 1,000 and a similar amount for the return journey brings the total to 2,000 Shillings (\$0.43) — an amount that is worth a meal. Most poor families will prioritise food for their families over health," an expert client said.

Long waiting time

A lot of time is wasted at service centres as clients wait to be served. This discourages most couples who become impatient. Also, retrieving clients' files takes long. Most clients in FDGs as well as key informants emphasised that missing client files contributed to long waiting. This hinders couples from seeking services together.

"It can be very frustrating, say, for a couple when one has his or her file available and the other's file is missing. This leads to one being treated early. There are instances where the one who has been treated has to wait for hours for the partner to be treated especially when they share transport, in this case, the bicycle," a respondent said.

Most clients emphasised that couples often have different clinic appointments and from different service locations. "My partner gets septrin at the centre whereas I get my antiretroviral drugs at community drug distribution points." Having different counsellors at the HIV and AIDS clinic is also an obstacle for couples to visit clinics or service points together.

Attitudes of service providers and clients

Service provider and client negative attitudes were identified by counsellors, day centre supervisors, expert clients and most clients in the discussions as factors hindering couples from visiting service centres together. A client noted: "Negative staff attitude like 'barking' at a male client in the presence of his wife and asking sensitive questions like 'you know you are HIV-positive, why did you again get pregnant' discourages couples from seeking services together."

These study findings were disseminated to both clients and staff in order to improve uptake of couple services.

Conclusion

Client-related factors that hindered couples from accessing HIV services jointly were nondisclosure, accusation of infidelity, lack of money for transport, and long distance to the service centres. Service-related factors that undermine use of facilities were long waiting times, different clinic appointments and negative service provider attitude. Therefore service providers should come up with incentives like faster service delivery for couples, couple-friendly services like coinciding clinic dates, offer continuous comprehensive counselling to PLHIV and scale up the communitybased model of service delivery to improve accessibility.

Reference

¹UNAIDS report on the global Aids epidemic, 2010

Lessons Learnt

- Accessing services as a couple enhances HIV and AIDS prevention, care and support but community stigma, non-disclosure, blaming (discordance is attributed to infidelity by the positive partner) and misunderstandings leading to quarrels among couples need to be addressed by continuous HIV and AIDS sensitisations, continuous home-based care and support programmes. This will help in addressing stigma-related issues among couples.
- Lack of money and longer distance to service points hampers uptake of HIV and AIDS services for couples and therefore more community-based service models should be scaled up to help couples to address financial barriers and improve access.
- Better record keeping mechanisms and retrieval of files a day before clinic days will minimise the issue of missing files while streamlining couple appointment will enhance access to services.

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HIV and gender workshop for women undertaken by SAfAIDS. (Photo courtesy of SAfAIDS)