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Double Identity Clients: Reality of Non-disclosure and its Implications for HIV and AIDS Treatment in Uganda

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Abstract

Uganda, ravaged by HIV and AIDS started administering Antiretroviral Therapy (ART) in public health facilities in 2004. Being a new phenomenon, several things were not known about ART in resource limited settings. This paper presents challenges and implications of inaccurate identity and addresses of ART clients to different HIV care and treatment interventions in the country. Specifically it presents a challenge of tracing ART clients in their homes when they miss their scheduled clinic appointments, especially in the early days after enrolling on ART or when they finally drop out of care.

Using a longitudinal study design, most data used in this paper was collected using exit interview schedules (at baseline in October 2008) and in-depth interviews (administered twice in 2011 and 2013) with one hundred ART clients. Supplementary data used included document reviews and key informant interviews conducted in 2016. The study participants were ART clients accessing treatment from Mbarara regional referral and Iganga district hospitals.

Findings show that twenty five of the one hundred clients could not traced. It turns out that these twenty clients were "double identity clients". Existence of double identity clients is not only a recipe for disharmony between sexual partners but could also lead to sub- optimal or non- adherence if doses are missed.

The study arrived at the conclusion that stigma and discrimination of HIV+ individuals still exists thirty five years into the epidemic. Double identity ART clients casts some doubt on the accuracy of national ART figures.

Key Words: HIV/AIDS; Treatment; Double Identity; Disclosure;Uganda

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Introduction

The first HIV and AIDS cases in Uganda were first reported in 1982 in two small fish landing villages of Kasensero and Lukunya, found on the shores of Lake Victoria (Serwada, D. et al., 2000; Hooper, 1990; Neema, S., 2004; Rwabukwali, C., 2007; Uganda AIDS Commission (UAC), 2006). Myths and misconceptions surrounded the cause and etiology of the epidemic with some believing that HIV and AIDS was caused or was an act of witchcraft (Okware, S., 2001).

By the early 1990s, the HIV prevalence rate was reported to have been as high as 30 per cent among women in urban areas and 3 per cent among rural women (MoH, STD/ ACP Report, 2000). Combined macro and micro responses after the peak, helped reduce and eventually stabilize the epidemic with the Uganda AIDS Indicator Survey giving the average HIV prevalence rate as 6.7 per cent[1] (UAIS; 2012).

With no known cure, the government of Uganda with support from health development partners, multinational and international organizations (USAID/PEPFAR, NORAD, WHO, DFID and GFTAM) started administering Antiretroviral Therapy (ART) in public health facilities in 2004 (National Antiretroviral Treatment and Care Guidelines for Adults and Children, 2008). Introduction of ART in public health facilities came with its attendant challenges. Some of these challenges as highlighted in national guidelines (2008) included: (i) late initiation of ART; (ii) prevalent concurrent infections; (iii) drug stock outs; (iv) loss to follow up; and (v) inadequate health infrastructure among others. It must be noted, however, that most of the above challenges have been adequately addressed given the current total ART enrollment figures, from 135,000 in March 2008 (MoH, 2016) to 750,000 by 2014 (UAC, 2015; and World Health Organization, 2014, "Technical Report," July 2014).

While ART coverage in Uganda has been steadily increasing, poor adherence remains a persistent challenge. This has led to poor treatment outcomes especially poor viral suppression, increased morbidity and mortality. Poor adherence has been linked to: low patient retention in care, non-disclosure of HIV status, stigma and discrimination among other challenges.

In order to improve adherence to care and treatment services being provided in both private and public health facilities, a number of strategies have been piloted. Strategies with the strongest evidence to increase retention in care and enhanced adherence for those on antiretroviral therapy (ART) included task-shifting to nurse-based and peer health worker care as well as adherence support through counseling, education, and SMS messages (Scanlon & Vreeman, 2013), an extended counseling program involving one post-test visit

and monthly two-hour home visits (Muhamadi, L., Tumwesigye, N., Kadobera, D., Marrone, G., Wabwire-Mangen, F., Pariyo, G., Ekstrom, A., 2011). Other tested strategies to improve adherence include: psychosocial support, disclosure, help of an adherence buddy whose role it is to remind the patient to take their medicine daily, home visiting and directly observed therapy by a community health worker or buddy and support groups which provide both emotional support and education (ANECCA, 2016).

While the above strategies have been found to be effective in as far as retention of ART clients in care and enhance adherence to ART there are a number of challenges that may make it difficult to scale them up in the community. One challenge, which is the focus of this paper, is the inaccurate or false identities and addresses that some persons living with HIV (PLHIV) and ART clients use to access services at the different health facilities. Inaccurate or false identities are meant to hide the PLHIV or ART client from direct or indirect HIV disclosure to spouse, significant other and the community.

There is no doubt that HIV disclosure offers PLHIV benefits like better or improved adherence to ART and assurance of social support (Evangeli and Wroes, 2017). Yet the above benefits notwithstanding, HIV disclosure has not been fully practiced in resource limited settings. This paper argues that correct and accurate identity of ART clients is very critical in harnessing community based interventions meant to enhance ART outcomes and ensure safe-sexual practices among PLHIV.

Borrowing from the consequence theory of HIV disclosure, the paper interrogates why some ART clients have not disclosed their HIV status by the time of enrolment on ART. It also tries to understand why some ART clients choose to hide their true identity when accessing treatment. Findings presented in this paper show that the consequence theory of HIV disclosure as propagated by Serovich (2001) and anchored in the social exchange theory (Thibaut and Kelly, 1959) plays out differently in different settings and stages of HIV prevention and treatment. Decisions of HIV disclosure or non-disclosure are driven by fear (of disclosing) and optimism occasioned by availability of ARVs and positive treatment outcomes.

Research questions that guided this study were: (i) what role does accurate identification at commencement of treatment play in tracing or following up clientsat their homes; (ii) what are some of the challenges of following up or tracing ART clients in their homes in order to ensure enhanced adherence; (iii) why are some ART clients reluctant to give correct/ accurate information regarding self? and (iv) why have some ART clients not disclosed their HIV status and

enrollment on ART to their spouses or significant others?

Methods

Findings presented in this paper are largely extracted from a bigger doctoral study conducted between October 2008 and September 2013 and key informant interviews conducted in 2016. The doctoral study adopted a longitudinal study design. ART clients who participated in this study were recruited at Mbarara regional and Iganga district hospitals. After recruitment ART clients were traced to their homes in the surrounding districts of Ntungamo, Bushenyi, and Isingiro (for clients accessing treatment at Mbarara) and Kaliro, Bugiri, and Mayuge districts (for those accessing treatment at Iganga). Primary respondents of this study were active ART clients who had been on ART since December 2003, before ART was rolled out in public health facilities and those that were scheduled to be initiated into treatment. Complementary data was collected from health workers at the two health facilities.

Selection of ART clients followed random exit interviews conducted at the two health facilities. The exit interviews helped in compilation of a "where are they now" inventory (Kirumira and Bateganya, 2003) that was to be used during the tracing of ART clients at their reported addresses. The inventory had variables such as: ART number, name, age, duration on ART, sex, health facility where ART is accessed, village, cell phone number (if any), and local council chairperson. With a completed "where are they now" inventory the research team comprising of the researcher, one assistant and a counselor started tracing one hundred ART clients. Permission to trace/visit clients in their homes was sought using an informed consent form read out to the client during the administering of the exit interview at the health facility.

Tools used to collect data for this paper included; an exit interview schedule (conducted at baseline in October 2008), an in-depth interview guide (administered twice to the same ART clients in September 2011 and September 2013) and a status tracing tool. Secondary data such as the SOPs and treatment guidelines was used to triangulate and confirm if enrollment process was made in 2015 and 2016.

ART clients who were the primary respondents of this study were interviewed four times between October 2008 and September 2013. The one hundred ART clients were traced on the basis of a "three-step model". The first step was to locate the ART client using information collected during exit interview. Step two was to locate the ART client through local leaders whose particulars were captured on the "where are they now" inventory (without disclosing exactly why we wanted to get in touch with these people, due to the confidentiality promise we made to ART clients at first interaction). Step three was locating or tracing ART

clients who were not found in the villages on the basis of information provided to the health facilities they attended.

This study upheld ethical requirements. The study protocol was approved by the Uganda National Council of Science and Technology (UNCST). It was also cleared by the research and higher degrees committee of the Department of Sociology and Anthropology and that of the Faculty of Social Sciences of Makerere University. A counselor was part of the research team and was present during all interactions with ART clients. This was done to guard against any emotional and psychosocial discomfort that could have arisen as result of the research team's engagement with ART clients.

Permission to participate in the study was sought at three levels namely: the district, hospital (administration) and individual clients. Informed consent forms translated into Runyankore and Lusoga were used before interviewing ART clients. All interactions were conducted in the relevant local language, if the client did not want it conducted in English.

Results

One hundred ART clients were interviewed and information for the ART clients' inventory was collected. The information captured included: name, village, phone number, age, marital status, and ART number. All ART clients accepted to be traced and interviewed at home. While all the one hundred ART clients consented to being traced to their homes, the researcher managed to locate 75 clients only. The remaining twenty five clients could not be traced by use of the registered cellphones nor could they be found at the addresses (villages) provided at recruitment during the exit interviews; but they were available at the health facilities because they went back for refills and reviews. The focus of this paper is therefore on these twenty five ART clients who were neither found at their given addresses nor could they be reached through the given cellphone contacts.

Sixteen of the clients who could not be physically located at the provided home addresses were female while the remaining nine were male. Of these, a majority of them, nineteen (19) were married while five (5) and were widowed and one was divorced. Twenty of these clients were aged between 21and 40 years while 5 were in the 41-55 age bracket. Majority (12) clients had primary education while four had secondary education, while nine (9) had none. Eighteen (18) clients lived in rural areas, while seven (7) were from urban centres. The summary of the socio-demographic characteristics are attached as Appendix 1.

A confirmatory check of the untraced twenty five (25) clients at the respective health facilities where they accessed treatment, showed that all data collected at recruitment and fed into the "where are they now"

inventory, was accurate and consistent with the data in their personal files. In the context of this study, the untraced twenty five (25) clients, whose personal information and data had been accurately captured, came to be known as "double identity ART clients". The data on these double identity clients at the health facilities showed that they continued to come for refills and reviews as required and as instructed. These double identity clients were adherents in as far as keeping appointments were concerned. It was further established that the 25 double identity clients were active members of HIV+ support groups at the respective health facilities.

Most (eighteen) of the double identity clients reported that they had neither disclosed their HIV+ status nor their enrollment on the ART to any significant other in the families or the communities where they lived. Some excerpts from different interviews held with double identity clients attending reviews and refill sessions are presented below. A female client reported that:

> I have not told (disclosed) anyone that I am HIV+ or even on medication. Coming here is purely something that I want no one to know about. I would have liked to share or disclose to someone but the conditions are yet not good..... (Malia, 34 year old female, Iganga Hospital).

Another female ART client said:

> ...my brother, though we are advised to disclose our status to someone at home or in the community, it is not easy. You don't know exactly how the person you disclose to will handle it. Even to my spouse, it is not straight forward. I have not told (disclosed) him but maybe I will in future, for now benefits of disclosing are few if not none... (Musimeenta, 46 year old female)

Male double identity clients said as much as some excerpts below show:

> Disclosing is a good thing but I haven't done it and know some friends who are on ARVs who have not done so. ...it's true they encourage us to disclose to our spouses or close family members but I have never done so. I will think about it now that there are many HIV+ people in the country. Every time you come here you find them seeking for services... (Topher, 39 year old accessing treatment from Iganga Hospital)

Aloni, a 29 year old ART client from Nyamitanga, Mbarara said:

> Disclosing for sure, I have not done. Each time I want to do so something stops me. It is not easy to, besides I know my friends at this health facility who have not told anyone be it wife, children or any other relative.

Stigma and discrimination was reported as the main reason for not disclosing their HIV status to anyone at home or the communities in which they live. Other reasons for non-disclosure were; fear to create any unwanted reaction from spouse and treatment optimism associated with ARVs. Reasons for non-disclosure are presented below.

Discrimination and stigma was a reason for non-disclosure. One

excerpt among the many highlighting this is from Topher. He noted that:

> Discrimination and stigma are real. Our community is closely knit we know each other so deeply. Disclosing to anyone is likely to be counterproductive. Discrimination and mouth pointing (a gesture used instead of finger pointing) do exist. It happened in the neighbouring village so I have an example, it is based on "bwino" (evidence). So rather than experiencing the same treatment .... (Topher, 39 year old male accessing treatment from Iganga Hospital)

Fear of not creating marital disharmony was another reason for non-disclosure. A male ART client noted that disclosure would lead to some level of disharmony in the home. He said:

> I have not disclosed to my wife because I don't want to create disharmony in our marriage. We have been together without any disagreements but disclosure may change all that. I think everything will come out at some point. It won't be after disclosing but conditions will "reveal "our HIV status. At that point we will handle it depending on the reaction I get. (Aloni, a 29 year old ART client from Nyamitanga, Mbarara)

Treatment optimism arising from the availability of ARVs in the public health facility was another reason cited by many double identity ART clients for non-disclosure. Musimeenta, the 46 year old female who said there were no benefits of disclosing noted that:

> Availability of ARVs in most health facilities has contributed to my and many other HIV+ persons non-disclosure. With the ARVs now, persons living with HIV (PLHIV) can live longer. The treatment (ART) has reduced the symptoms and other effects of AIDS. ARVs have given PLHIV the confidence to live without caring much about who would care for them incase their health condition deteriorated.

Double identity clients were created in two main ways. First, an individual register names different from their ordinary names used at home. For example, one may be known as Fred at the health facility where he seeks treatment but he John in the village where he lives. This practice helps the individual block any attempts to trace such an individual by name the purported place of residence or at either at the health facility. Since a name is a key identifier of people, by implication Fred and John in our example are two different persons.

The second way in which double identity clients were created was by giving a true name but a wrong address (village) and phone number. This distorted information given by design, made it hard to trace such ART clients.

At the time of the study, though some ART programs preferred that an HIV+ initiating on ART came with or disclosed to a spouse or significant other, it was not mandatory to do so in the mainstream public health care system.

Discussion

Existence of double identity clients came out of a desire by persons who were not interested in disclosing their HIV sero-positive status to their significant others at home and/or in the communities in which they live. Significant others is used here to include a spouse or a lover, close kin or the community. It is evident that stigma and discrimination persist in communities. The non-disclosure reported among double identity ART clients due to "fear of stigma" was also reported in another multi-country study (Hardon, A. et al., 2013). On the basis of the findings of this study, it is instructive to note that thirty five years into the epidemic, HIV/AIDS remains stigmatizing to some ART clients. In order to avoid being stigmatized and the attendant consequences, some ART clients have chosen to have a double identity rather than disclose their HIV sero-positive status.

A close scrutiny of the double identity ART clients shows that the majority (18) lived in rural areas while seven lived in urban areas. That the majority of double identity ART clients were found in rural areas, says volumes about the challenges ART clients are likely to face if their HIV status was directly disclosed by themselves or indirectly disclosed by another person or through gossip. The closely knit community and their social structure makes it difficult to keep PLHIV's status a secret and thus suffer certain consequences. Fears of creating disharmony between spouses and discrimination and stigma were consequences that double identity ART clients wanted to avoid.

The fact that all double identity ART clients were found to be active in post-test clubs (PTCs) and other peer psychosocial support groups of PLHIV at the health facilities provides an insight on the state of stigma and discrimination in some communities in Uganda. With a mature HIV epidemic in its fourth decade, stigma and discrimination persist. This finding is consistent with another study conducted in eastern Uganda (Mburu, G., et al., 2013). Involvement and participation in PTCs and other peer groups at the health facilities offers the individual ART client peer support and a sense of "sameness" and "normality" with other PLHIV. This partly helps the double identity clients gain self-confidence and ultimately reduces self-stigma (Mburu, et al., 2013).

One quarter (25) of all ART clients of the 100 included in the study seems to negate the HIV disclosure theory which contends that disease progression triggers disclosure (Serovich, 2001). Existence of double identity clients in resource limited settings, such as Uganda, partly attributed to scaled up access to ART and the reported positive treatment outcomes has meant that many clients can choose not to disclose their sero-positive status and medicine taking to anyone in the comfort that if they

diligently adhered to medication there is no need to disclose to anyone. To some degree, efficacy of ARVs and associated treatment optimism (Wamoyi, J. et al., 2011) seem to have "replaced" benefits of disclosing to kin and other forms of social support.

At a programmatic level, existence of double identity clients seems to expose some loopholes in Uganda's health care delivery system. For example, though in the early years of HIV counselling and testing and treatment some programs encouraged HIV+ persons to disclose to their partners (Hardon et al, 2013), findings from this study are consistent with others done in Africa (Bobrow, E. A. et al., 2008; and Varga, C. A. et al., 2006) that this advice was not taken by some HIV+ individuals. Our study shows that eighteen out of twenty five double identity ART clients had not disclosed to their partners. Some clients confided to the research team that they at times "hire" spouses or next of kin in order to "fulfill" the requirement. This problem is exacerbated by lack of a national identification system. Though identification is requested before one accesses treatment, lack of national identification systems "aids" in form of identity cards some clients thus have an opportunity to register under fictitious names, hence the double identity ART clients.

The loopholes reported above coupled with double identity clients may in the process help some HIV+ persons to severally register for ART at different centers. This has implications for the accuracy and validity of figures and statistics of persons currently on ART in the country. These statistics are key outcome indicators for the scale up of ART in the country.

Furthermore, existence of double identity clients has implications for adherence to medication. Non-disclosure to spouse may affect a clients' adherence since one may not take medicine in the presence or knowledge of the other. In addition to this, it may be hard for women to honor appointments for refills and reviews due to lack of transport if they depend on men for money or inability to make decisions to go to attend a session at the health facility because of power imbalance between men and women.

Double identity ART clients could easily become sub-optimal or non-adherents should they, for any of the above reasons fail to make it to the health facility. Sub-optimal or non-adherence to ART causes poor viral suppression; poor health status and consequently death of clients. Non-viral suppression leads to development of drug resistant mutations of HIV causing faster ineffectiveness of the available treatment regimens, making it difficult to achieve epidemic control (MoH, 2016).

The finding that double identity clients did not disclose their HIV status for fear of creating disharmony and tension between couples or persons living together in marriage

which is consistent with findings in Zambia (Sanjobo N, Frich JC and Fretheim A (2008)), gives an insight into some challenges HIV care and treatment interventions face in closely knit communities where the extended family is still an important component of the social structure. Non-disclosure of double identity ART clients could have happened with the knowledge that the HIV Testing Services (HTS) policy (2016) on disclosure upholds that disclosing of a client's HIV status should be done with his/her informed consent. The policy instructs health workers to implore HIV+ individuals to inform or disclose their status to their sexual partners. What the HTS policy seems to do is a navigation of a seemingly delicate balance between clients' rights (to privacy and confidentiality) and the need for HIV+ individuals and their spouses to enjoy benefits of HIV disclosure.

Double identity appears to be a coping mechanism of some clients who want to access ART yet still want to maintain their other known identity and status in the community. It further shows that such double identity clients understand and appreciate what ART entails since all double identity clients records at the health facilities showed that they continued to come for reviews.

While the seventy five per cent tracer rate in this study is consistent with other studies that employed a tracer methodology (Kirumira and Bateganya, 2003; Dalal, R. P. et al., 2008) there are some lessons to be learned for HIV and AIDS treatment in resource limited settings. Double identity ART clients highlight some of the challenges that home based care programs are likely to face when it comes to making home visits. This may also be true for health facility based HIV and AIDS treatment where counselors and other health workers for any one of these reasons namely; lost to follow up, adverse reactions from medication or dishonoring scheduled appointments and reviews decide to visit such clients at their homes.

Methodologically, due to double identity clients, some ART clients in longitudinal studies and operations research that involve making home visits could be problematic since a big percentage, in this case up to twenty five percent may not be traced. This could have implications for sample size and amount of time to be spent doing a given study or intervention.

Conclusion

Failure to trace some ART clients at purported home addresses and cellphone numbers given during exit interviews and registered at the health facilities attended brought to light the existence of "double identity clients". Double identity ART clients arose partly because the affected people did not want to disclose their sero-positive status to people they were required to by health workers. Existence of double identity clients highlights a number of issues that may impact the overall performance of the ART program. One, though

HIV+ persons have come forward to enroll for ART some of them do not want others to know they are on medication. This has implications for adherence to medication as clients who have not disclosed are likely to skip doses due to the need to conceal their medicine taking. Two, stigma and discrimination of HIV+ persons still exists three and a half decades into the epidemic in Uganda. Thirdly, success of home based care and other programs is likely to be hampered by double identity clients. Lastly, double identity ART clients in a situation where all citizens are yet to have a national identity card may lead to multi enrollment and thus cast doubt on the accuracy and validity of national ART figures. Planning based on inaccurate data is a recipe for wastage of scarce resources that could have been used optimally.

Recommendations

So as to streamline accuracy of individual client records in ART programs across programs, there is need to use national identification documents. Furthermore, such records should be linked. This will eliminate double enrollment and ensure accurate data that can be used for effective programming.

Continued existence of stigma and discrimination clearly undermines efforts to control the HIV and AIDS epidemic. In order to contribute substantially to efforts to contain the epidemic, there is need to commission more rigorous sociological studies that will be tasked with unpacking the underlying drivers of stigma and discrimination.

Since inaccurate names and/or addresses make it difficult to trace or locate double identity ART clients to their homes, such programs across the country should strive to ensure that all avenues and conditions that are likely to lead to sub-optimal or non-adherence to medication are addressed.

Competing interests

The authors have no competing interests and therefore declared none.

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Note

[1] At the time of review of this paper the Uganda Population-Based HIV Impact Assessment (UPHIA) survey (2016) preliminary data released in August 2017, showed that HIV prevalence had reduced to 6.0%

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Abbreviations

ACP	AIDS Control Program
ART	Antiretroviral Therapy
ARVs	Antiretroviral
MOH	Ministry of Health
MR	Medical Records
PTC	Post Test Club
SIDA	Swedish International Development Agency
SR	Self Report
UAC	Uganda Aids Commission
UAIS	Uganda AIDS Indicator Survey
UNCST	Uganda National Council of Science and Technology
UPC	Unannounced Pill Count

Appendix: ART Clients' Socio-demographic Characteristics

Characteristic N=25	
Sex	
Female	16
Male	9
Marital Status	
Married	19
Widow(ed)	4
Separated/divorced	2
Age of Respondent	
21- 26	3
27-33	8
34-40	9
41-47	2
48-54	2
55+	1
Education	
None	9
Primary	12
Secondary	3
Post-Secondary	1
Employment	
Salaried	2
Self employed	6
Peasant	17
Location	
Urban	7
Rural	18
Children	
Yes	21
No	4