

HOW SOCIAL UNDERSTANDINGS OF HIV STIGMA IN UGANDA SHAPE PEOPLE'S
TREATMENT

By

ZULEMA DOMENICA IBOA GARCIA

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Abstract

This study examines the ways in which social understandings of HIV stigma in Uganda shape people's treatment drawing on Goffman's theory of stigma. The research was conducted at St. Francis Health Care Services, a non-governmental organization in Uganda founded in 1998. It involved a two-pronged study, which included both quantitative and qualitative research methods using a community-based framework. For the first leg of the study, I collected data on 2,027 patients regarding their sex, age, marital status, district, original regimen, and antiretroviral treatment status using medical records. For the second leg, I interviewed 20 participants and conducted three focus group discussions with 25 participants (with the assistance of an interpreter). The results showed that when community members and relatives stigmatized patients, patients managed their stigma by controlling to whom to disclose their status. Patients decided whether to receive treatment after stigmatization by others and after carefully assessing prevalent myths regarding the human immunodeficiency virus (HIV). Discredited HIV individuals faced more direct and overt stigmatization while discreditable HIV people internalized stigma more often. The results also showed that some participants had positive experiences with identifying their illness, as it improved people's health and provided them with the opportunity to pass as "normal."

Introduction

Human immunodeficiency virus, also known as HIV, is highly stigmatized around the globe. According to the *Prevention Gap Report* in 2015, about 1.5 million people were living with HIV in Uganda, and an estimated 28,000 Ugandans died of acquired immunodeficiency syndrome (AIDS)-related illnesses. As of 2015, the HIV prevalence among Ugandan adults (aged 15 to 49) was about 7.1%. In other words, approximately 1 out of every 14 adult Ugandans carry the HIV virus. However, there has been an overall decline in the number of people diagnosed with AIDS in Uganda (UNAIDS 2016).

One of the most critical contributions to combatting this infectious disease was the creation of the AIDS Information Center Uganda, which was established by the Ministry of Health in collaboration with other organizations, including the AIDS Support Organization, the National Blood Bank, Uganda Red Cross, Nsambya Home Cross, and the Uganda Virus Research Institute (AICUG 2017). However, despite community outreach of these organizations, there remain disparities around accessing appropriate treatment (UAC 2015), since access to quality affordable health-care does not exist for the majority of people who live in rural Uganda (Singh et al. 2015).

In 2006, the World Health Organization published a report on the challenges of antiretroviral treatments (ART) using studies from Botswana, Tanzania and Uganda. ART is a treatment for HIV that can prolong and improve patient's lives while reducing the likelihood of HIV transmission (Assefa et al. 2014). According to this report, Uganda pioneered the use of ART in sub-Saharan Africa in 1996 (Hardon et al. 2006), but few people could afford ART (even though AIDS became the second highest cause of death following malaria). With the help of foreign aid, the challenges of high cost of healthcare were mitigated. Hardon et al. (2006), for

example, explain that antiretroviral drugs (ARVs) became more widely used in Uganda when the Global Fund and the US President's Emergency Plan for AIDS Relief supported the delivery of ART for people with AIDS. According to Singh et al. (2015:638-9), "Although government facilities are theoretically free of charge, costs are often incurred for transport to the clinic or hospital, and to ensure that the patient is attended to in a timely fashion, and for medication and for basic necessities, including food, water, and supplies." Despite the fact that the majority of available health-care in Uganda is free another challenge that might affect care is stigma.

While stigma is widely explored among sociologists, much of the research regarding HIV examines patients' experiences with stigma. However, these studies rarely discuss the implications of stigma management in relation to treatment. Thus, in this study I ask; how do social understandings of people with HIV in Uganda shape their treatment? To answer this question, I examine the attitudes and experiences of patients receiving treatment at St. Francis Health Care Services, a non governmental organization whose mission is to limit the spread and social impact of HIV/AIDS, through education while providing medical and counseling services among affected Ugandans. My research contributes to the sociology of stigma by analyzing how people with HIV manage stigma when deciding to receive treatment and while they are actively receiving it. Furthermore, my study sheds light on patients' positive experiences identifying their illness. I conducted twenty in depth, semi-structured interviews and three focus group discussions during July 2017, studying a sample of 45 HIV patients registered in the ART program at St. Francis in Uganda. I also reviewed medical data on over 2,027 patients who had enrolled in the ART program from January 2011 to December 2016.

Using an inductive approach, I found that stigmatization is highly rampant among Ugandan communities. While some stigmatized patients internalized the stigma others managed

their stigma by controlling to whom to reveal their status. After experiencing stigmatization by others and assessing prevalent myths regarding HIV, patients decided whether to receive treatment. Discreditable people with HIV internalized their stigma more often, while discredited individuals with HIV faced more direct and blatant stigmatization. Finally, the results showed that identifying one's illness could also lead to positive experiences, as it improved patients' health and provided them with the opportunity to pass as "normal."

In the following section, I include a literature review that outlines existing knowledge on stigma and stigma management. Succeeding the literature review, is the methods, findings, discussions and conclusions sections.

Literature Review

HIV stigmatization is highly common among people living with the disease, which is a barrier preventing effective responses to HIV (Feyissa et al. 2012). To help understand the social understandings of HIV stigma, this study uses Erving Goffman's theories, whose work is one of the most influential explorations of how stigmatized individuals navigate their own lives. Goffman (1963:3) defines stigma as an "attribute that is deeply discrediting" and "a process by which the reaction of others spoils normal identity." The term "spoiled identity" simply refers to a person's stigma excluding them from full social acceptance. Fundamental to Goffman's (1963) notion of stigma is the issue of social relationships. Rather than focusing solely on the attribute itself, Goffman (1963) explains that it is necessary to understand how social relationships transform a characteristic into a stigma.

In his book, Goffman (1963) postulates three different types of stigma, which are bodily deformities stigma, character traits, and tribal stigma. Furthermore, Goffman (1963) suggests that the experience of stigma differs depending on how well one can conceal the stigmatized

attribute. Stigma that can be concealed or unknown refers to discreditable people, while the term discredited relates to people whose stigma is clearly visible or known (Goffman 1963; Chaudoir, Earnshaw, and Andel 2013). Given these definitions, an HIV person could either be classified as a discreditable with a character flaw, a discredited individual with a physical flaw or a mixture of these two combinations. For example, rashes are a common symptom of HIV, which are extremely visible when not treated appropriately. Hence, a person with a rash would be considered discredited and identified as tainted. On the other hand, individuals receiving treatment often have no rashes, in which case they can pass for “normal.” Thus, their stigmatized identity is hidden and relates to character traits, which can only be known if disclosed. Because of this, the discredited are also more likely than the discreditable to face stigmatization at the individual level (Chaudoir et al. 2013).

Other studies investigating visible (African American race) and concealable stigmas (sexual minority status and bulimia) offer evidence suggesting that the discredited feel higher self esteem (Frable et al. 1998) and less internalized stigma than the discreditable (Cook et al. 2011; Hatzenbuehler et al. 2009). In a study conducted in South Africa on people living with HIV, Judgeo and Moalusi found that “The participants with the discreditable stigma internalized society’s prejudice towards those living with the virus. As a result, the participants relied on self-isolation and social withdrawal to cope with enacted stigma” (2014:76). They were able to manage their stigma by completely isolating themselves. Chaudoir et al. (2013), describe internalized stigma as the degree to which people feel self-loathing or shame because of their stigma. According to a study conducted by Ashley Wynne et al. (2014), those with TB would rather not seek treatment for fear of being diagnosed as HIV-positive and those with HIV fear being recognized at an HIV clinic. Despite not having HIV, TB patients internalize HIV stigma

to the point that they rather not receive treatment. Similarly, patients who have already been diagnosed with HIV and know their status can also be considered discreditable. In either case, stigmatization contributes to poor adherence for both TB and HIV patients by delaying patients from seeking treatments for their illnesses (Wynne et al. 2014.)

Although some people may not want to seek health services, HIV patients who decide to receive ART treatment benefit largely both in their physical and mental health. Research has shown that an increase in social capital reduces the amount of stigmatization present in patients' lives (Muriisa et al. 2011). Increasing the availability of ART programs has been associated with improvements in internalized stigma and psychosocial health. Over time, internalized stigma decreases with the use of ART programs, with the largest decline after the first two years of treatment (Tsai et al. 2013). This is due to the interdisciplinary nature of these programs, offering a multitude of services. Assefa et al (2014:7) describe, "in addition to counseling services...health facilities with high levels of retention were providing other services such as defaulter tracing and outreach services." The counseling portion provides social support.

Masculine and feminine roles are a big factor when discussing HIV stigma within romantic relationships. For women, "doing" femininity, means using the health care system; however, for men, "doing" masculinity, means not seeking help, engaging in risky behaviors, and ignoring health symptoms. Therefore, women tend to use the health care system more than men (Courtenay 2000). Even though polygamy is legal in Uganda, only men are endowed the right to have multiple wives (Shay 2010). In a study conducted by Muldoon et al., they found that polygamous men compared to single spouse men were "more likely to report unprotected sex with an unknown sero-status partner" (2011:933). Furthermore, the study also found that men involved in polygamous relationships reported controlling sexual decision-making more

than single spouse men. Men are not only able to sleep with multiple women; they also choose to not disclose their status, which puts women at higher risk. In fact, the greatest risk for HIV infection for women was their husband's extramarital sexual activities (Parikh 2007). In addition, women who depend both socially and economically on their husbands or sexual partners are less likely to be able to negotiate with their partners about condom use or asking them about their sexual relationships outside of their marriage.

Mburur et al. (2014) found that HIV stigma and masculinity do not exist as isolated variables, but rather as intersecting phenomena that influence men's participation in Ugandan HIV services. According to their analysis, stigma threatens masculine perceptions of independence, emotional control, and respectability. They concluded that reduction interventions regarding stigma are necessary within HIV programs to target both structural and social drivers of stigma to increase involvement in HIV services. In addition to this, they propose that gender transformative intervention measures should be taken. The intent of these measures is for men to reconstruct their male identities while rejecting the parts of masculinity that inhibit their access to HIV services (Mburur et al. 2014). To help increase participation in treatment programs, they introduce three measures. Firstly, community conversations led by HIV programs should aim to educate men and women about the negative consequences of adhering to masculine notions. Ideally, they should increase uptake of protective sexual behaviors and increase seeking help. Secondly, HIV programs should collaborate with peer support groups to target HIV-positive men and their families to increase livelihood interventions. Lastly, they recommend that social support networks should help men manage stigma (Mburur et al. 2014).

Drawing on Goffman and the literature on stigma management, I analyze people's experiences negotiating stigma and disease in relation to their treatment. Goffman (1963)

describes stigma as the process by which others reaction spoils a person's normal identity. Extending on the literature, I examine how a person with HIV comes to terms with the notion of their own "spoiled identity" in order to seek treatment. While Muldoon et al. (2011) and Parikh (2007) discuss the gap between men in women when it comes to their sexual freedom, I build on these studies by demonstrating that women have autonomy in their relationships by choosing to leave their husband or partners with the support of family members. As I will show, Goffman's theory on stigma is useful because it provides a theoretical framework to understand the intrinsic relationship between stigma and treatment. The analysis contributes to the literature on stigma, stigma management, and HIV treatment by assessing how individuals cope with their illness and may sometimes even experience positive outcomes by identifying their disease.

Methods

The research involved a two-pronged study conducted at St. Francis Health Care Services in Uganda. It included both quantitative and qualitative research methods using a community-based framework. The first part of the project took five weeks to complete and was strictly quantitative. I reviewed medical registrars (medical record books), patient files, and the electronic medical record (EMR) system for patients enrolled in the antiretroviral therapy (ART) program from January 2011 to December 2016. For the second part of the study, I conducted 20 in-depth, semi-structured interviews and three focus group discussions from July 10, 2017 to July 21, 2017.

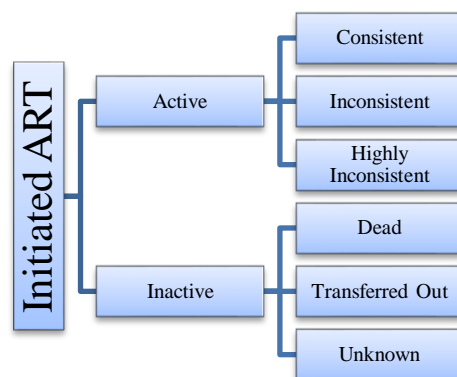
Medical Record Review

While the clinic has an EMR system, it is not kept up to date and much of the information is inaccurate when compared to the hard copy patient files and medical registrars. To construct an accurate and robust data set, I verified all the information using three types of records (the

registrars, hard copy patient files, and electronic medical records). I extracted demographic data on over 2,027 patients regarding sex, age, marital status, and district, among other characteristics from these sources. Additional information about the patient's treatment was also recorded, such as the date they started the ART program, their original regimen, their status in the ART program, and general notes about the patient. While collecting the data, I created individual codes for this information and input them into an Excel spreadsheet.

Figure 1, as seen below, displays a flow chart of the possible outcomes for a patient's ART program status. This chart was used to identify potential participants for the interviews and focus group discussions. Identifying how often patients missed their clinic follow-ups provided me with a basis to formulate questions regarding their treatment and the experiences they may have with their HIV. Active patients were those still enrolled in the ART program, meaning they attended their clinic follow-ups while inactive patients were those who had completely dropped out of the ART program, as of May 2017.

Within these two categories, three sub-categories were formed. Under the active status, a patient was considered consistent if they had made 100% of their treatments, inconsistent if they had lost/dropped one appointment since their initial start date, or highly inconsistent if they had lost/dropped at least three appointments in a span of 12 months starting from their initial start date. Depending on how far a patient lived from the clinic, patient appointments ranged between every two weeks to once every three months. Three reasons were given for a patients' inactive status, which included death, transfer to another facility, or unknown. I gathered this information by reviewing all of the patients in the medical registrar during the indicated five-year time span.

Figure 1: Patient's Status in the ART Program

Interviews and Focus Groups

For the second prong of the study, I conducted twenty in-depth, semi-structured interviews and three focus group discussions, from July 10, 2017 to July 21, 2017, studying a sample of 45 HIV patients enrolled in St. Francis' ART program. I audio-recorded the interviews and focus group discussions for analytical purposes, with participants' permission. With the assistance of an interpreter, the same questions were asked during the interviews and focus group discussions, starting with general demographics and proceeding to more specific questions about their experience with their illness and treatment. My approach allowed me to ask follow-up questions and enabled participants the freedom to express their experiences, providing richer and deeper findings. A copy of the demographic information sheet, with questions that I asked participants, can be found in the Methodological Appendix (in English and Luganda). Interpreters were compensated 15,000 schillings (\$4.28) per day.

Interview participants were selected based on a stratified sampling method. Using the quantitative data collected in the first part of the study, I created selection pools in Excel, starting with the following eligibility criteria: the patient had to be alive and over the age of 18 years old at the time of registration as indicated by the medical registrar. Any person whose age was

missing from the main registrar was eliminated from the main selection pool. Once this new list of eligible patients was created, I separated active patients from inactive patients. Next, within the active patient pool (consistent and inconsistent patients), I created a sheet with a list of active females and another sheet with a list of active males. I did the same for the inactive pool (patients who had transferred out or dropped for unknown reasons), but also went a step further by creating two more lists. On two different sheets, I separated females who had dropped for unknown reasons as well as males who had dropped out for unknown reasons.

After creating the selection pools, I created a list of active male and female participants and another list of inactive male and female participants from which to sample for interviews. The “gatekeepers” I established were counselors who interacted with patients everyday. They were in charge of contacting participants via phone or in person, informing them about the study, and scheduling them for either interviews or focus groups. To supplement the cost of phone calls, counselors were given 30,000 (\$8.57) schillings for airtime. As many of the individuals’ files either had missing contact information or none at all (or some patients had passed away), I supplemented the stratified sampling list of participants with additional patients. Additional participants were gathered on ART clinic days (days that are entirely for HIV-positive patients to come for treatment), which were every Tuesday and Thursday. On ART clinic days, patients visited for routine health issues such as picking up drugs, speaking to a counselor, and/or consulting with a doctor.

All interviews were face-to-face and took place at the clinic and in the field. They lasted anywhere between 30 minutes to an hour. For those conducted in the field, drivers were compensated 30,000 schillings (\$8.57) per day. In total, 20 participants (9 males/11 females) were interviewed for about an hour. Of these 20 participants, 12 (5 males/7 females) were

interviewed on site and 8 (4 males/4 females) were interviewed in the field. Interview participants received between 10,000 schillings (\$2.86) and 15,000 schillings (\$4.28) as travel compensation.

To recruit participants for focus groups, counselors approached potential candidates who met the eligibility criteria on ART clinic days, and asked them if they were willing to volunteer their time to be part of the study. Each focus group discussion was conducted face-to-face and was composed of a different number of participants. These discussions lasted from an hour and a half to two hours. In total, there were 25 participants in three separate focus group discussions, which were as follows: 11 (6 males/5 females), 8 (4 males/4 females) and 6 (2 males/4 females) respectively. In addition to receiving 15,000 schillings (\$4.28) in travel compensation, focus group participants received snacks and refreshments during the sessions.

In total, 45 HIV-positive adults (21 males/24 females) between the ages of 20 and 64 were included in the qualitative portion of the study (interviews and focus groups). More detailed information regarding participant demographics can be found in Tables 1-4 in the Methodological Appendix. To preserve confidentiality, I gave each participant a pseudonym, and I use these pseudonyms throughout this study. To analyze the data, I manually transcribed 347 pages, which included all twenty interviews and three focus group discussions verbatim. From these transcripts, I performed topical coding and used a grounded theory approach to interpret the findings. Since I often used an interpreter for interviews and focus groups, the quotes provided in the results section are in English with the understanding that for some participants this is a translation.

Results

The percentage of active patients ranged from 59% to 70% in 2011 to 2016.

Stigmatization when Receiving Treatment

Several participants stated how people often refuse to share food or drinks with them since they were HIV-positive. Earnest describes that this troubling issue occurs frequently within schools: “Even today they have people who don’t want to use a cup, a small cup, with someone who is HIV-positive... I even remember, at one moment I even refused to take medication...for like three weeks.” His refusal to take his medication was to conceal his status from other students due to the treatment he had witnessed towards people with HIV. Brenda reinforces Earnest’s point by explaining, “There are myths that people will contract HIV if they share drinks, food, and children playing with other kids.” These types of interactions deter participants from disclosing their status to friends or community members. Additionally, patients may isolate themselves from others during meals to avoid public humiliation. Isolation significantly affects patients’ health, as they may also decide to skip meals or not take their prescribed medication, as was the case with Earnest.

One young woman, Joanita, explained why she chose not to take her medication following her diagnosis: “For the first quarter when [I] had just tested [I] took around six months when [I] had not yet started taking medication because [I] was stigmatized [I] used to fear, ‘How can they see me?’” In order to avoid being identified as HIV-positive by members of their community, several patients, including Joanita, chose to receive care far away from their hometowns. Davis describes, “When [I] got to know that [I] was HIV-positive [I] refused to go to the nearby hospital [I] decided to come this side...[to avoid] the other scenarios.” The other scenarios he describes are being recognized by community members and having them spread rumors about him. As a result, participants often prefer to travel long distances to avoid such situations. Furthermore, these long commutes are a financial burden on patients and decrease

their overall quality of care given the strain it puts on them. Transportation to distant healthcare providers is considered a significant obstacle to attending clinic follow-ups, and this issue stems from a larger, more ingrained problem: fear of exposure.

Sarah who is 22 explains how people assume that young HIV-positive women who are prostitutes: “No one wants to be a friend to that person...you are taken to be as a prostitute. Where did you contract HIV at that age?” When asked how these comments made her feel she responds, “It inflicts pain on [me] because such a condition is for everyone...[you] laugh at [me] today and tomorrow you contract it also.” Overall, the experience of being stigmatized while receiving treatment had the greatest effect on patients’ willingness to seek and continue care.

In order to cope with their status, respondents described different methods used to mitigate negative experiences. The most common method pertained to varying levels of HIV status disclosure, ranging from full disclosure to not telling anyone. Other approaches involved ignoring negative comments, responding to people’s remarks, dedicating time to educating communities about HIV, or volunteering for St. Francis. For example, Joshua describes how he is able to cope with people’s perceptions on HIV:

Stigma is not good because whenever you talk about that person you be devaluing that person, you be demoralizing that person. And today its me and tomorrow it can happen to you...You don’t know if that person will help you in the future, so it causes a lot of chaos so it should not be advised for someone to stigmatize someone.

The statement indicating, “today it’s me, tomorrow it’s you” was repeatedly used by participants during interviews and focus group discussions. Many patients used this statement to overcome feelings of neglect and harassment. By acknowledging that nobody is immune to the illness and that it can be contracted by anyone engaging in sexual relations, people living with HIV are able

to mitigate the effects of negative comments directed towards them. While the participants with HIV know that “today” they must live with the illness, individuals ostracizing them might contract the disease “tomorrow”; therefore, it is necessary to treat everyone with dignity and respect since people do not know if they will become infected.

Some participants were involved in polygamous relationships while others in monogamous ones. In either case, they spoke about issues of disclosure. Joshua also explains how he is free to disclose his status to anyone except girlfriends: “because when you disclose [your status] that person won’t accept you.” However, Joshua also discusses that he has disclosed his status to his wife. Choosing to disclose status to one’s husband or wife shows that they trust that they will continue to stay with them and provide them with the social support they need. On the other hand, failing to share one’s status with intimate partners contributes to the spread of HIV. Not only will their extramarital partners contract the illness, but also their sexual partners.

Patients expressed reluctance and feeling uncomfortable communicating their HIV status with their bosses because in many cases, they may find themselves in a lose-lose situation. Therefore, when their work required them to travel long distances during their designated clinic day, they were unable to pick up their treatment or be checked by a doctor. These kinds of understandings in the work setting are what end up spreading HIV. When patients miss their clinic days due to work, they are unable to receive their refills or be checked up by a doctor. However, if patients decide to disclose their status to their employers they are at risk for losing their job, which contributes to a completely different realm of obstacles. For example, if they lose their jobs, they will be unable to pay for their transportation to the clinic or provide for their families contributing to an endless cycle of inadequate and unfair access to treatment. By choosing not to disclose their status to anyone, patients felt that they were being protected from

experiencing ridicule. Participants explained how they were too afraid to let others know of their status for fear of isolation. They also believed that people would be unwilling to help.

In a few extreme cases, participants chose to not disclose their own status and harass others for being HIV-positive in order to save themselves from exposure. For example, Daphine describes how people have expressed negative attitudes towards her when she picks up her medication. Some examples of things people have said to her are, “They are sick, they are dead, they are ill...she is nothing.” She then explains, “Yet for themselves they...[ask others to] collect the drugs from somewhere...but far.” In other words, Daphine assumes that the same people exclaiming that she is a dead person walking will also ask someone else to pick up drugs far away. Not only do these individuals rely on others to collect their medication, they do not want them to be anywhere near their hometown to erase all trace of their illness. In turn, this can negatively affect people’s ability to manage HIV in more than one way. For example, people who share similar experiences to Daphine may not want to be harassed every time they pick up their medication, so they decide to stop collecting it. On the other hand, if a person with HIV is relying on someone else to pick up his or her medication from far away the person helping him or her may not always have the money or time to be able to commute to the medical center.

Alternatively, other participants mentioned that they chose to selectively disclose their status to close family members or friends, but not to neighbors or community members. Joanita explains why she prefers that the general community not know about her diagnosis:

It’s not good to tell them because they can decide to gang up [on you and] make a point [to] start talking about you like ‘that one is HIV-positive’ and then they laugh at you.

That causes inflicted pain not only on your life but in the internal person... Some of those people isolate us, who are HIV-positive; they don’t want to associate with us.

These types of attitudes may contribute to feelings of isolation for people living with HIV, thereby preventing them from receiving the appropriate treatment. When others ridicule people with HIV it compromise their care, which contributes to the spread of the disease. For instance, someone may not go to pick up their medication if it meant that they would expose themselves to the community. Therefore, they would no longer be taking the necessary precautions to mitigate the spread of HIV.

Some participants explained that they had no reservation about disclosing their HIV status. Vianne who likely felt as though his family would be supportive regardless of his status, describes how his family reacted to his disclosure, “The attitude from [my] relatives was not bad because they also even helped [me]...these people gave [me] an outreach they could contribute for...the transport to go and collect the drugs so it was a positive...reaction.” By disclosing his status, he realized that he had a strong support system, which helped him manage stigmatization from others. Despite the rumormongering in his community, the support he received from his family gave him the courage to start helping and educating relatives and community members. Having a supportive reaction towards people with HIV could potentially increase disclosure, which would in turn decrease the spread of the disease since more people would be more informed on the proper precautions to take to not contract the illness.

Deciding to Receive Treatment: Myth or Truth?

Participants’ revealed various reasons as to why they decided to seek treatment. Their explanations also uncovered prevalent myths and lack of information regarding HIV. An example of such myths is the idea that people who are HIV-positive are essentially dead people walking. Esther mentions that people have said to her, “you are going to die.” She then explains how other people discourage those who talk to her or people with HIV “[not to] talk to those

dead bodies.” Similarly Sauda describes how many of the individuals she encourages to be tested refuse because they believe that when they are tested HIV-positive they will lose all faith in life.

‘When you get tested and know that you are HIV-positive you lose hope’... ‘Nothing you can contribute towards the development of anything when you are HIV-positive’...many people...say... ‘for me I don’t need to go for HIV testing because when you go for testing you are going to be demoralized’... ‘for me if I am tested positive I rather kill myself.’

Having HIV is considered a death sentence, which is why people often rather not know their status and decide not to be tested. Ironically, this death sentence myth affects people to the extent that they do not even want to continue living. Moreover, when a person is told that if he or she is tested positive they will no longer have anything to provide to society, it contributes to a general lack of understanding about the disease and severely damages a person’s self worth. Thus, believing such unreliable statements greatly affects a person’s willingness to seek treatment. Joanita explains: “[I] had a myth that whenever you contracted [HIV] that’s the end of your life, so [I] used to fear that thinking that [I] was going to die.” Contracting HIV is not a death sentence, as proven by individuals with HIV who have lived several years by regularly taking their medication. However, people lack knowledge about HIV, which may in itself make it more likely that they will die because they do not receive treatment.

Another prevalent myth that exists is that HIV is contagious by touch. The myth originates from the fact that a visible sign of this disease are intense skin rashes and people believe that the illness can be transmitted through these rashes, which is not true. Joshua describes, “Back in the days there was a lot problems with skin rash...[it] could ignite a lot of conversations among the community [as] it was a very serious, serious sign... people would always keep eyes on you on you. Whenever they saw you have any skin rash.” Individuals keep

a close watch for skin rashes, as was a way to identify people with HIV. Since people with rashes know that others think that they can transmit the disease through contact, they may be afraid of others seeing them, which in turn may make them reluctant to pick up medications or go to the clinic. While in some cases, individuals may decide to suffer in isolation; in an alternative situation, others might decide to receive treatment to get rid of the skin rashes. Those who seek treatment, do so in order to be able to pass as “normal.” In other words, they wish to not be able to be identified as having the disease. In both cases, individuals with HIV and persistent rashes wish to not be ostracized from society for how they look.

When it comes to relationships, many individuals believe that it is sometimes necessary to keep their status concealed to keep their significant other. They assume that if they disclose their status willingly or if they accidentally run into their partner at the clinic, their lover will no longer want to be with them. Partners may also automatically jump to the conclusion that the person with HIV has been cheating. While these scenarios are not necessarily always the case, these types of beliefs hinder people from obtaining care. As a data clerk, Earnest describes a situation he witnessed regarding partners not disclosing their status at the clinic he works at:

You will leave home saying I'm going in the market. If you are going to pick what? Medication. Me I will tell you I am going to work, yet I am going to pick medication. Now a lot of confusion comes when you find me on the line... where the problem is going to come from eh everyone be like you are the one who transmitted to me you are the one you are the one, so at the end of the day they are going to accuse one another.

Conversations like these may contribute to Ugandans' reluctance to be tested and seek treatment at the clinic. For one, as Earnest illustrated they may fear running into a partner, which would lead to an awkward encounter. People may want to avoid tension in their relationships and the

blaming that ensues following the revelation. Women especially may suffer from harsher repercussion due to gender roles in Uganda. Ultimately, they will be most impacted by gender-based violence if their partners find out about their status.

While some individuals put their treatment above everyone else, they still realize how others may not be as willing to do the same, which unfortunately contributes to the spread of HIV. When asked if she would feel more comfortable receiving treatment if she knew for certain that nobody she knew would recognize her, Zura responded: “It’s [my] life first, not friends first. Men have side lovers...They fear... ‘my lover to see me collecting drugs,’ so they have someone else collect their drugs.” These types of situations are also common in the field. By having another person pick up the medication, people are saving face so that their potential lovers do not find out about their status. Vianne expresses a similar sentiment by stating, “Men may be having a lover or wants to engage somebody and somebody is near the station where he collects the drugs...he doesn’t want to go to be revealed there to be seen taking drugs from that station because his lover may think of another thing.” Zura and Vianne’s statements are representative of what many participants’ had to say about the impact romantic partners had on deciding to receive treatment. What many individuals fail to take into account is that not everyone will have the same response and that at the end of the day communication and honesty are crucial components to healthy relationships. However, rather than take the risk of losing their partners, they decide its better to hold off on their treatment, which ends up spreading the disease.

Many patients reported that before going in to be tested at the clinic they would go to traditional herbal doctors, as they thought they had been bewitched. During one of the focus group discussions, Caroli explains how her family members believed that her sudden illness had been due to witchcraft: “In the beginning the family member thought that she was being

bewitched and they would used to go to witch doctors seeking all types of local herbs.” Although Caroli was unaware of her HIV status, her husband was aware of his own. By not disclosing his status, the husband was hindering his wife’s ability to seek treatment and become healthier. He also contributed to the lack of understanding about the illness by keeping silent. When Caroli’s siblings contracted HIV, they convinced her to start taking medication and move in with her father. These types of family support networks allow women to focus primarily on their health without having to worry about how they are going to care for themselves or their children.

In some cases, participants encourage individuals to be tested since they have already gone through the experience. Esther recalls that she often hears people automatically assuming they have been cursed: “For me, ‘oh I have something here, I am bewitched.’” When she hears this, she quickly encourages them to go to the clinic instead of focusing on the idea that they are bewitched. Daphine explains a situation, where a family thought that their relative had been cursed, so they did not seek medical attention for curing the person: “They lost them because of not knowing because they said that they were bewitched.” In these types of situations, people are making deadly decisions by dismissing medicine and assuming witchcraft is the culprit.

Some individuals attempt to convince people to stop taking medication and seek herbal treatment. Kato describes how individuals would either advise him to stop taking medication or switch to herbal medication. “Even when you take medication you are going to die, it does not cure...Why don’t you change from medication to herbal medicine? Because there are those ones who uses herbal.” Some people believe that herbal medicine is more effective than medication. This common myth comes from the fact that many of the medications have side effects when you first start taking the treatment. It is also recommended for people to take their medication with a meal; however, many people cannot afford to have a meal every time. Because of this, they often

become dizzy after taking their medication, which is not a side effect of herbal medicine.

Individuals may also not want to deal with the amount of pill burden that comes with the ART treatment. All of these reasons contribute to why people may choose to take the herbal route over medicinal treatment, which unfortunately contributes to a lack of understanding and potentially causes preventable deaths.

Positive Experiences with Identifying Illness

Researchers often focus on the negative implications of a patient's HIV diagnosis and how it affects their life for the worse, which fails to account for how often people can experience their diagnosis in positive ways. While the diagnosis itself can be frightening news to patients, participants frequently expressed relief after beginning their treatment. Participant's experienced several positive changes not only in their physical health, but also their mental health. Earnest, who was diagnosed at birth, describes how as he's grown older HIV has given him confidence:

It has empowered me to be a leader...it has restored my dignity...People do respect me in the community because it has shaped me how myself positively positive. It has showed me the various ways I'm supposed to live as a good citizen.

Patients are empowered in the process of identifying and accepting their illness. Furthermore, coming to terms with their illness allows patients to find meaning in life. In a similar experience, Brenda discusses: "[I] got courage... [I have] built confidence in [myself] in a way that [I] know that having HIV does not mean [I] am going to die tomorrow." By accepting their status, patients can educate their communities and serve as role models, thereby dismantling negative myths that pervade several Ugandan communities.

Vianne, a rural farmer, talks about how sharing his status and story with others, he shows them that it is possible to live a happy life with HIV. In his own words he states that he is an

“exemplary” example. Furthermore, he explains how there was a big change in his life when he was diagnosed. Before his diagnosis he says that he had a lot of body weakness and rashes, which is no longer the case. He describes, “[I am] now okay [I] can do [my] work. [I] go in the farm and the garden...you see me and you can’t know what status I am.” As a farmworker, his only way of generating income is through physical labor. It is therefore imperative that his health be in good state. With the disappearance of his rashes, his status becomes invisible to the naked eye, providing him the autonomy to disclose his status. Daphine also states that her life changed for the better: “There is a positive change. When [I] walk, people can’t even tell that [I am] HIV-positive.” For many, the biggest benefit for receiving treatment (other than being alive) is not being treated as an alien by others. Individuals such as Daphine and Vianne, acknowledge that on medication people cannot tell when someone is HIV-positive. Since individuals start passing, they experience less stigmatization in their communities. This provides them with the opportunity to willingly disclose their status if they so choose.

Participants describing the positive changes associated with identifying their illness predominantly speak about their overall health. Once people have identified their illness and start receiving treatment they are able to regain strength and their rashes disappear. Because of this, they are able to hide the fact that they are HIV-positive since they are able to pass as “normal.” Doing so, allows people to feel more confident in their lives and less ostracized from society.

Esther explains, “After knowing [my] status of life [I] started planning strictly for [my] children...and there is an improvement... [I] changed [my] behavior and how [I] would spend [my] money.” By finding out about her HIV status, Esther was able to make the appropriate changes in her life to support herself and her children. Identifying ones illness can provide patients with a sense of purpose and direction since they now realize the importance of being

healthy. When people experience such positive outcomes, they are keener to spreading the word about the successfulness of receiving treatment. Furthermore, others are more willing to listen to them if they can see for themselves the impact treatment has on individuals self esteem, personal life style and overall health.

Discussions and Conclusions

Despite having a qualified team of medical professionals and a psychosocial support team, high levels of stigma have led to poor treatment experiences for patients at St. Francis. For this reason, identifying how social understandings of people with HIV in Uganda shape their treatment is crucial for the betterment of patient care. The results clearly show that patients manage their stigma by controlling to whom to disclose their status to and by acknowledging that nobody is immune to the illness. After assessing prevalent myths regarding HIV and experiencing stigmatization by others, participants decided whether to receive treatment. In some cases, individuals who believed there was no hope for survival decided not to receive treatment unless encouraged otherwise by success stories. People who identified themselves as “free” often served as advocates and educators within their communities. This call to action is just one among many other examples regarding positive outcomes from patients identifying their illness.

However, the most important outcome for many is the notion of passing as “normal,” which provides individuals with the autonomy to willingly open up about their experiences with HIV.

Some of the challenges faced in this study involved identifying inconsistencies in data management regarding the registrars and EMR system. Moreover, the language barrier made it difficult to fully comprehend the participants, even with the help of an interpreter. Clarifying information with staff and debriefing with the interpreter after interviews and focus group discussions helped to mitigate these challenges. A large benefit to conducting the research

through a community-based approach was the creditability that was attributed to my research due to my partnership with FSD and St. Francis. The community was very receptive and willing to be a part of the focus groups and interviews. Additionally, the host organization provided an immense amount of support from doctors, data managers, nurses, and staff members.

The experiences of patients with HIV, requires further research. While socioeconomic status, health, and care dissatisfaction were found to impact patients' treatment, they fell outside the scope of this project. Future research should therefore examine how these factors relate to stigma. For example, some health factors that should be explored are alcoholism, malnutrition, forgetfulness, etc. Other studies regarding socioeconomic status should consider transportation and economic instability. Additionally, this study was conducted at a medium sized medical clinic, where patients interact with most of the staff, ranging from counselors to doctors. Future studies should examine the attitudes of patients with HIV at larger medical institutions, which likely have different patient-staff interactions and process for receiving treatment.

The results of this study have policy implications relating to reducing stigmatization and its consequences. Addressing these issues will allow people will feel more willing to be tested, receive treatment, and continue their care. Moreover, it will improve the overall quality of treatment, as patients will no longer fear scrutiny from people in their everyday lives. Hence, I recommend that St. Francis partner with volunteers to inform rural communities about HIV. More specifically, they should conduct workshops on site, in schools, or public spaces to teach people about ART treatment, HIV stigma, the resources available at St. Francis, and how any signs of illness should be addressed immediately by being tested.

Additionally, to inform people about the negative effects of rumor mongering and debunking myths; St. Francis' volunteers should hold educative theatrical performances. This

idea was brought up during focus group discussions and interviews. While there are several campaigns in Uganda aimed to decrease the prevalence of HIV, they typically involve informational posters. Given that many Ugandan's affected by this disease are illiterate, an important component about the impact of performances is that it does not require individuals to be able to read. Some of the participants explained how successful these kinds of initiatives at St. Francis have been for younger generations. To support HIV patients, in addition to continuing the counseling services, St. Francis can establish peer-buddy systems or support groups to help patients who are feeling stigmatized or depressed. Ultimately, by implementing these types of recommendations, clinics can help mitigate stigmatization in the communities and potentially save more lives.

Applying Goffman's theoretical framework on stigma in combination with the literature on stigma management, I examine people's experiences managing stigma in regards to their treatment. Stigma, as described by Goffman (1963), is the process by which others reaction spoils a person's normal identity. This study highlights how a person with HIV comes to terms with the notion of their own "spoiled identity" in order to seek treatment. Adding to this field of study, I assess how individuals cope with their illness and even experience positive outcomes by identifying their disease. Extending on the literature, I examine how romantic relationships affect patient's willingness to receive treatment and the role that both men and women play when it comes to their health as well as their partner's health. The analysis contributes to the literature on stigma, stigma management, and HIV treatment by demonstrating the intrinsic relationship between stigma and treatment.

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Methodological Appendix

Interview Schedule

(A) Demographic Information Sheet in English and Luganda:

1. District/*Distulikiti*:
2. Primary Language/*Olulimi Oluzaalwa*:
3. Languages Spoken/*Ennimi z'oyogera*:
4. Age/*Emyaka Gyo*:
5. Sex/*Obutonde*:
6. Educational Attainment/*Obuyigilize*:
7. Occupation/*Omulumu Gwo,kola*:
8. Marital Status/*Oli mufumbo*:
9. Religion/*Ediini yo*:
10. Number of Children/*Abaana B'olina*:

(B) Questionnaire in English and Luganda:

1. What made you want to seek the services available at St. Francis Health Care Services?

1. Kiki ekyakuleetera okujja okufuna obujjanjabi ku St. Francis Health Care Services?

2. Have you missed any appointments? If so, why?

2. Wali elemedwaako okujja okukima eddagalyo? Bwekiba kituufa kyaava kuki?

3. What obstacles, if any, have kept you from attending clinic follow-ups?

3. Miziziko ki gwe wali ossanzo ejikulemesa okudda mu dwaiiro okulaba omusawo.

4. Some people choose to completely stop receiving care. Have you? If so, why? If not, have

you considered doing so?

4. *Abantu abamu basalawo okulekera ddala okufuna okubudaabudibwa. Wali osazeewoko bwotyo nga ggwe? Oba wali okilowoozezzako okulekeraawo okufuna okubudaabudi bwa?*
5. What, if anything, do you think St. Francis can do to ensure people do not miss appointments or stop their treatment?
5. *Olowooza St. Francis kiki kyesobola okukola okusobola okutangila abantu obutayosa okulaba oba okulekera okufuna obujjanjubi?*
6. How do you think St. Francis can improve the delivery of treatments?
6. *Ngeri kyi gyolowooza St. Francis gyeyinza okulongosaamu empereza yobujanjabi?*
7. In what ways has your life changed since your diagnosis?
7. *Obulamubwo bulina engeli gye bwakyuukako okuva lwewasangibwa nobulwadde?*
8. Who, if anyone, have you told about your diagnosis? If you shared with someone, why did you choose to do so? If you have told no one, why not?
8. *Olina gwewali obuliddeko kubulwaddebwo, bwoba oyina gwewali obuliiddeko, lwaki wasalawo okumubuliirako, ate bwoba tobulirangako muntu yenna nsonga eyakugaana?*
9. Is there anyone that you would prefer never learned about your diagnosis? If so, who and why would you prefer they not know?
9. *Waliwo omuntu yenna gwo 'tandiyagadde amanye ku bulwaddebwo, bwekiba kituufu ani oyo, era lwaki te wadiyagadde amanye?*
10. Would you be more willing to receive treatment if you knew that you would not encounter someone you know? If so, why? If not, why not?
10. *Wandiyagadde okweyongera okufuna obujjanjabi singa omanya nti to 'jja kuisinkana muntu gwomanyi, bwekiba bwekityo lwaki, bwekiba ssikyo era lwaki?*

11. How do people in your community perceive and treat those with HIV? Have these perceptions and actions affected your life? If so, how?

11. Abantu bo 'mokitundukyo batwaala batya oba be 'yisa batya ku balwadde ba 'kawuka

Enne 'yisa yaabwe ne bikolwa byabwe biyina engeri gye 'bikosaamu obulamubwo?

Bwekiba kyekyo egerikiyi gyekikosaamu?

*Tables***Table 1: On-Site Interviews**

Pseudonym	Ugandan District	Primary Language	Languages Spoken	Age	Sex	Educational Attainment	Occupation	Marital Status	Religion	Number of Children
Earnest	Buikwe	Luganda	4	20	M	University	Data Clerk	Single	Muslim	0
Davis	Kayunga	Luganda	2	27	M	None	Fisher	Married	Christian	2
Joshua	Buikwe	Luganda	4	34	M	Primary Seven	Peasant	Married	Catholic	4
Kato	Buikwe	Luganda	3	35	M	Senior Two	Traditional Herbal Doctor & Carpenter	Married	Muslim	11
Alfred	Iganga	Lusoga	4	38	M	Primary Seven	Truck Driver	Married	Muslim	5
Fazira	Buikwe	Luganda	2	47	F	Primary Five	Tailor	Widow	Muslim	6
Betty	Buikwe	Luganda	3	30	F	Senior Three	Prostitute	Married	Born Again	1
Claire	Jinja	Lusoga	2	50	F	Primary Seven	Peasant	Divorced	Protestant	5
Joanita	Namutumba	Luganda	3	27	F	Primary Six	Aromatherapy & Masseuse	Single	Protestant	1
Brenda	Kamuli	Luganda	2	40	F	Primary Six	Fisher	Married	Catholic	4
Teddy	Buikwe	Luganda	2	39	F	Senior Three	Shop Keeper and Bartender	Single	Protestant	1
Tabiat	Mukono	Lunyrwanda	5	42	F	University	Technical Professor	Widow	Muslim	4

Table 2: Field Interviews

Pseudonym	Ugandan District	Primary Language	Languages Spoken	Age	Sex	Educational Attainment	Occupation	Marital Status	Religion	Number of Children
Ben	Buikwe	Luganda	2	52	M	Senior Four	Farmer	Divorced	Catholic	8
Zura	Buikwe	Luganda	1	40	F	Primary Six	Farmer	Widow	Catholic	6
Edwin	Buikwe	Luganda	1	40	M	Primary Two	Farmer	Married	Protestant	4
Daphine	Buikwe	Luganda	1	35	F	Primary Seven	Farmer	Separated	Born Again	0
Joseph	Buikwe	Lusoga	2	45	M	Primary Two	Casual Labor	Widow and Separated	Muslim	5
Hadija	Buikwe	Lusoga	3	37	F	Primary Six	Farmer	Separated	Protestant	6
Vianne	Buikwe	Luganda	1	43	M	None	Farming & Animal Rearing	Separated	Protestant	2
Esther	Buikwe	Luganda	1	32	F	Primary Three	Farmer	Married	Adventist	7

Table 3: Focus Groups

Focus Group 1										
Pseudonym	Ugandan District	Primary Language	Languages Spoken	Age	Sex	Educational Attainment	Occupation	Martial Status	Religion	Number of Children
Fahad	Iganga	Lusoga	2	38	M	Senior Two	Peasant	Married	Catholic	5
Hassan	Bujiri	Lusoga	2	49	F	Primary Six	Peasant	Widow	Muslim	0
Jeremiah	Kayunga	Luganda	2	47	M	Primary Seven	Peasant	Married	Christian	9
Raymond	Buikwe	Luganda	2	64	M	Primary Seven	Farmer	Married	Protestant	6
Rebecca	Mayuge	Lusoga	1	47	F	Primary Four	Peasant	Widow	Protestant	10
Sarah	Kayunga	Luganda	2	22	F	Senior One	Hair Dresser & Cosmetics	Single	Protestant	1
Isaac	Jinja	Lusoga	2	50	M	Senior Six	Data Clerk	Divorced	Catholic	5
Ronnie	Jinja	Lusoga	2	41	M	Primary Five	Constructor	Married	Catholic	6
Zaing	Buikwe	Luganda	1	25	F	Senior Six	Vendor	Single	Catholic	2
Mayi	Buikwe	Mugiso	2	58	F	Primary Four	Peasant	Divorced	Protestant	0
Timothy	Jinja	Lusoga	2	50	M	Primary Seven	Mechanic	Married	Muslim	9
Focus Group 2										
Pseudonym	Ugandan District	Primary Language	Languages Spoken	Age	Sex	Educational Attainment	Occupation	Martial Status	Religion	Number of Children
Immy	Buikwe	Luganda	2	37	F	Primary Four	Peasant	Divorced	Protestant	1
Joyce	Buikwe	Luganda	1	39	F	None	Farmer	Widow	Catholic	4
Emmanuel	Jinja	Lusoga	4	44	M	Senior Six	Tailor	Married	Protestant	3
Joan	Buikwe	Lusoga	2	40	F	Primary Four	Peasant	Married	Muslim	6
Rita	Buikwe	Lusoga	5	57	F	Primary Seven	Peasant	Widow	Muslim	6
Angelo	Jinja	English	3	26	M	Senior Six	Unemployed	Single	Catholic	0
David	Buikwe	English	4	53	M	Senior Six	Tailor	Separated	Catholic	3
Robert	Mayuge	Lusoga	4	50	M	Senior Four	Retired Policeman	Divorced	Catholic	5
Focus Group 3										
Pseudonym	Ugandan District	Primary Language	Languages Spoken	Age	Sex	Educational Attainment	Occupation	Martial Status	Religion	Number of Children
Sauda	Buikwe	Lugwere	2	50	F	None	Unemployed	Married	Muslim	7
Abdul	Jinja	Swahili	7	34	M	Primary Four	Retired Soldier	Divorced	Muslim	3
Mutwalibu	Kampala	Luganda	6	39	M	Senior Six	Driver	Married	Catholic	2
Shadia	Iganga	Luganda	3	51	F	Primary Two	Housemaid	Separated	Protestant	4
Robina	Buikwe	Swahili	5	33	F	Senior One	Housemaid	Married	Catholic	4
Caroli	Buikwe	Luganda	3	45	F	Primary Four	Tailor	Separated	Muslim	4

Table 4: Sample Summary

Data Characteristic	Count
Gender	
Female	24
Male	21
Age	
18-29	6
30-39	14
40-49	14
50-59	10
60-69	1
District in Uganda	
Buikwe	25
Jinja	7
Iganga	3
Kayunga	3
Mayuge	2
Mukono	1
Namutumba	1
Kampala	1
Kamuli	1
Bujiri	1
Primary Language	
Luganda	24
Lusoga	14
English	2
Swahili	2
Mugiso	1
Lunyrwanda	1
Lugwere	1
Number of Languages Spoken	
One	8
Two	19
Three	7
Four	6
Five	3
Six	1
Seven	1
Religion	
Catholic	14
Muslim	13
Born Again	13
Christian	2
Protestant	2
Adventist	1

Marital Status	
Married	18
Never Been Married	6
Divorced	7
Widowed	7
Separated	7
Eudcational Attainment	
None	4
Primary Two	3
Primary Three	1
Primary Four	6
Primary Five	2
Primary Six	5
Primary Seven	8
Senior One	2
Senior Two	2
Senior Three	2
Senior Four	2
Senior Six	6
University	2
Occupation	
Farmer or Peasant	19
Data Clerk	2
Fisher	2
Traditional Herbal Doctor/Carpenter	1
Driver	2
Tailor	4
Commercial Sex Worker	1
Aromatherapy/Masseus	1
Hair Dresser/Cosmetics	1
Constructor	1
Vendor	1
Mechanic	1
Casual Laborer	1
Unemployed	2
Retired	2
Housemaid	2
Shop Keeper/Bartender	1
Technical Professor	1
Total Participants	45