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A QUALITATIVE STUDY OF THE BARRIERS HIV POSITIVE YOUTH IN ATLANTA FACE IN DISCLOSING THEIR STATUS

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An Abstract of

A thesis submitted to the Faculty of the

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ABSTRACT

A QUALITATIVE STUDY OF THE BARRIERS HIV POSITIVE YOUTH IN ATLANTA FACE IN DISCLOSING THEIR STATUS

BY LOUISA ASARE

Background- HIV remains a major global public health issue with approximately 36.7 million people worldwide infected, with 30% of all new HIV infections globally estimated to occur among youth. Since there is no cure for HIV, one way to avoid HIV infection is to prevent viral transmission. Advocating for HIV positive people to freely disclose their status has been shown to have a direct impact on preventing transmission as it facilitates risk-reduction strategies. This study aims to identify barriers HIV positive youth face to status disclosure and to recommend interventions to facilitate voluntary status disclosure.

Methods- This was a qualitative study based on secondary analysis of data collected by in-depth interviews of HIV positive youth. MaxQDA12, a qualitative data analysis software, was used to aid in developing codes and subsequent themes that led to the development of a conceptual framework to identify and describe barriers to HIV status disclosure

Results- The main barriers to status disclosure participants faced were Racism, Stigma and Homophobia from both family and society, and these were experienced in enacted, internalized and anticipated forms.

Conclusions- Though laws exist in certain places to mandate HIV status self-disclosure, these sometimes undermine public health efforts by having the opposite effect. Identifying barriers to voluntary status self -disclosure can help in the development of interventions that will ensure that HIV positive people have a safe space to express themselves, disclose their status and fully participate in society.

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Finally, to my children, who perhaps paid the greatest price to enable their mother to attain this degree…thank you… and I hope this inspires you to reach beyond the glass ceiling in pursuit of your dreams.

Author

LOUISA ASARE

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1. Introduction

In 1983, a virus called the Human Immunodeficiency Virus was discovered.[1] This virus was the cause of a disease that caused severe devastation to humanity by weakening the human immune system. Thirty-five years later, humanity is still dealing with this virus. Thankfully, the days where an almost death-sentence is passed on an individual the moment an HIV diagnosis is reached are over mainly due to the discovery of highly active antiretroviral therapy (HAART). HAART is a multi-drug combination therapy for the treatment of HIV and has successfully reduced the death rate from HIV by 50 to 80%, changing HIV from an almost certain death sentence into a manageable chronic disease.[2]

However, we are still dealing with the fact that 35 years on there is still no cure for HIV and it remains a major global public health issue. According to the UNAIDS, there were approximately 36.7 million people worldwide living with HIV/AIDS at the end of 2016. New people are being infected every day, with about 5,000 new infections per day.[3] Not all infected people have access to or are retained in care–as of November 2017, only 54% of adults and 43% of children living with HIV were receiving lifelong antiretroviral therapy (ART).[4]

Since there is no cure for HIV, the best way to avoid HIV infection is to prevent viral transmission. There are many ways in which the virus can be transmitted, these include sexual transmission, vertical transmission-where untreated infected mothers pass on the infection to their babies during labor, delivery or breastfeeding, transmission via contaminated objects that encounter blood e.g. use of contaminated intravenous needles-commonly seen among IV drug users, and rarely due to contaminated surgical instruments or blood transfusion. Among these routes sexual transmission is still the most common route of infection worldwide.[5]

Groups at risk of infection include women (especially pregnant women), children, sex workers, injection drug users, men who have sex with men (MSM) and the transgender population. The level of risk of each of these groups depends on a lot of factors including geographic location, as well as cultural and societal norms. For example, in sub-Saharan Africa, heterosexual transmission of HIV is the most common route of transmission and women are at higher risk of HIV infection.[6]This is mainly due to most cultural practices and norms that disempower women and subject them to the authority of men.[7]This leaves them with little choice over their sex lives. However, in the United States, the opposite holds true where anal sexual transmission of HIV is the most common route of infection and the most vulnerable population are men who have sex with men (MSM).[8]

Particularly in the southern states of USA like in Georgia, there is a high burden of HIV, with research approximating that in 2014, 50% of new HIV infections in all of USA occurred in the southern states.[9]

In Georgia, as at 2014, 46,870 people were living with HIV. 75% of these people were men, and 25% were women. 69% of infected people were black, 7% Hispanic/Latino, and 20% white.

The figures below demonstrate routes of transmission by gender of people living with HIV in Georgia.[10]

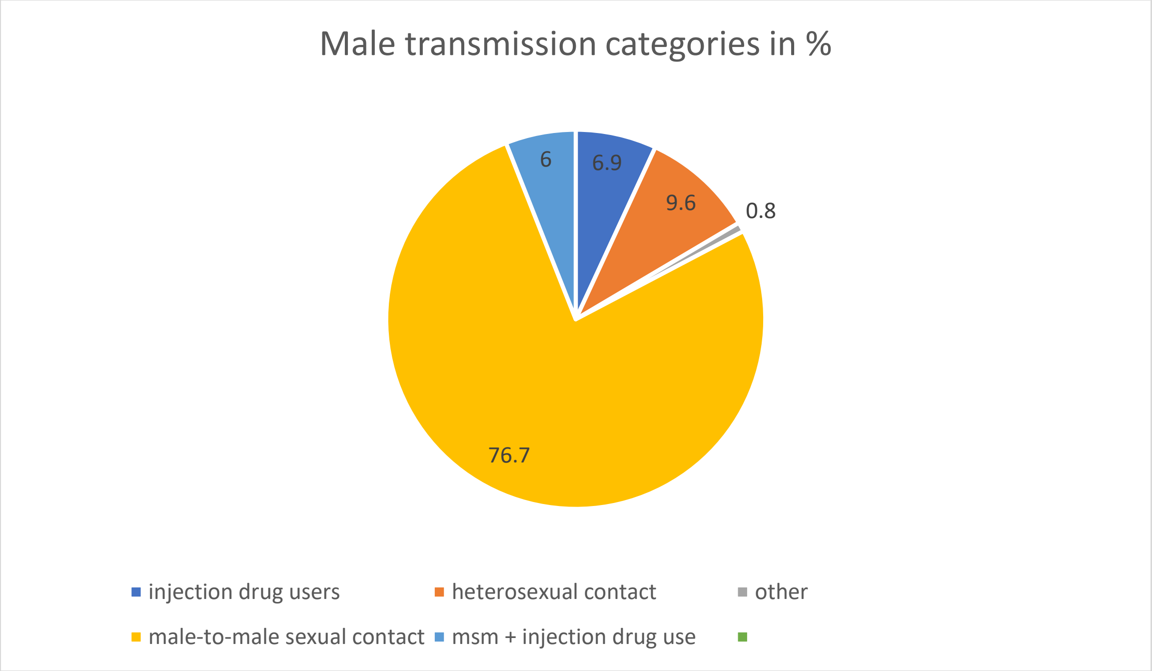

Figure 1: Male Transmission Categories in %

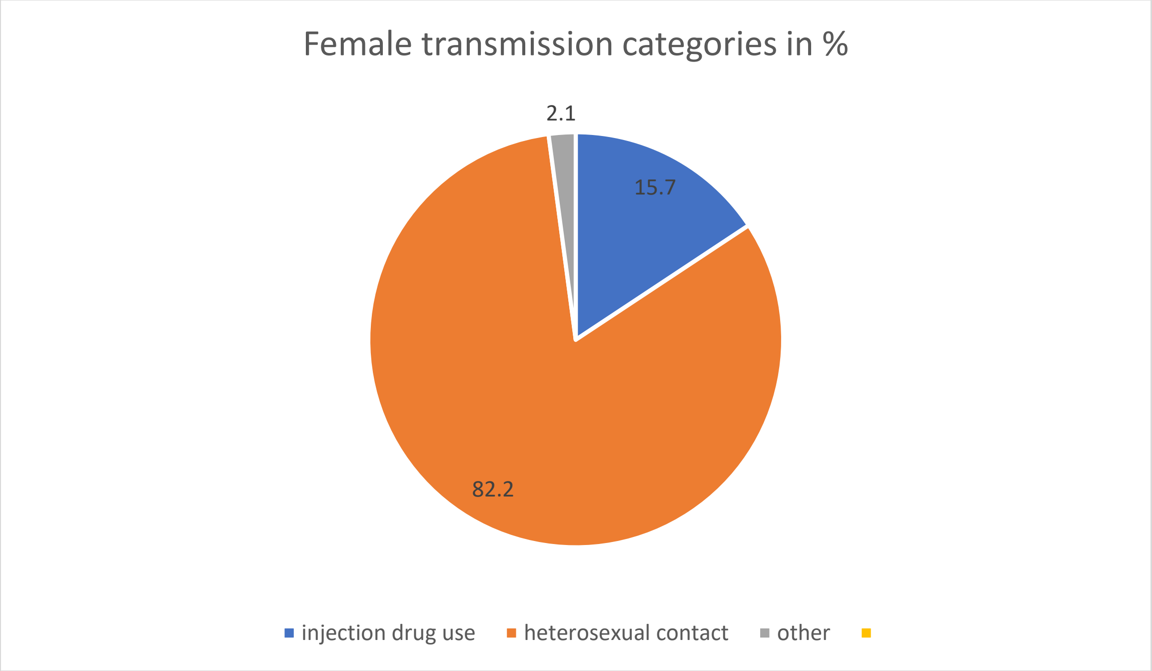

Figure 2: Female Transmission Categories in %

From the figures above, sexual contact is also the highest route of transmission of HIV in Georgia.

Factors driving the high rates of HIV infection in Georgia include poverty. According to the United States Census Bureau, the southern parts of the USA is home to the nation's largest number of people living in poverty, as depicted in figure 1.3 below. For Georgia in particular, the percentage of people living in poverty is estimated at 16% a number higher than the national average of 12.7%. Many lack health insurance and Georgia is one of the states that did not expand Medicaid. Thus, a lot of people cannot access care.[11][12]

One of the ways to decrease the spread of HIV is through behavioral interventions such as status disclosure. According to a study by Atuyambe et al, "Disclosure of HIV status supports risk reduction and facilitates access to prevention and care services"[13]

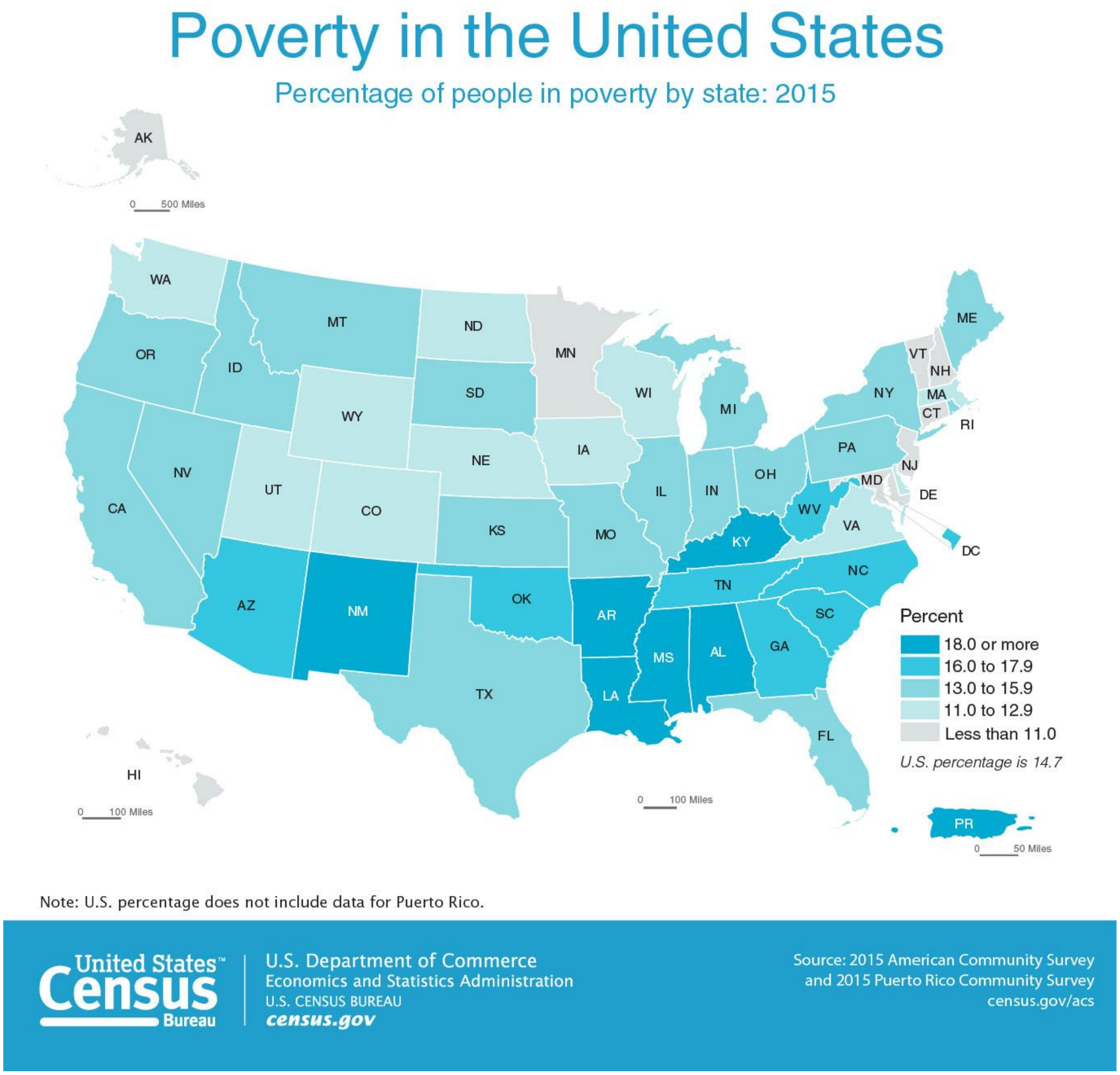

Figure 3: Poverty in the United States[i]

HIV status self-disclosure specially to intended sexual partners is a behavioral way of HIV prevention.[14]HIV status disclosure has been a long-discussed topic in both academic study, public health and clinical care of HIV patients. Advocating for HIV positive people to freely disclose their status especially to their sexual partners has been shown to have a

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[i] From the website of United states Census Bureau

direct impact on preventing transmission as it facilitates risk-reduction strategies in both parties e.g. increasing condom usage and encouraging ART uptake.[15][16]Though there is not much literature on HIV status disclosure to non-sexual partners, it can be inferred that in the absence of stigma and negative reactions, disclosing status to non-sexual partners including family and friends could help them realize HIV is not a distant disease that affects strange people, but that anyone including them, can also be affected. This could potentially inspire them to take precautionary measures to protect themselves from HIV infection. Indeed, status disclosure, in the absence of stigma, helps to provide the much-needed support system for the HIV positive patient and helps them deal with the diagnosis, treatment and overall helps in improving the quality of life of HIV patients, subsequently helping their retention in care and ultimately reducing spread.[17]It is therefore imperative that more work is done to reduce stigma in society to facilitate this.

This paper focuses on HIV status disclosure as a behavioral means of HIV prevention, barriers people face with respect to HIV status disclosure and recommendations on how to overcome these barriers to prevent HIV transmission in the long-term.

1.1 Study purpose and significance

Disclosure of HIV status has the potential to support risk reduction, facilitate access to care and increase support for the patient. However, there are many people who are not willing to disclose their status for many reasons. The purpose of this study is to identify the barriers that people face with respect to HIV status self-disclosure. In the future, we hope this will enable people living with HIV to overcome these barriers and freely disclose their status to others, ultimately assisting in prevention of HIV transmission.

1.2 Research Question

What are the barriers HIV positive youth in Atlanta face with respect to HIV status self-disclosure?

2. Literature review

2.1 Introduction

As stated in the previous chapter, the purpose of this study was to determine the factors that influence HIV status self-disclosure in HIV positive people. HIV status self- disclosure is an important aspect of behavioral interventions, aimed at preventing the spread of HIV and it is important to know what factors affect and serve as a barrier to one's decision to disclose their status.

2.2 Epidemiology of HIV

The WHO estimates that as at 2016, more than 70 million people worldwide had been infected with HIV and about 35 million people had died of HIV.[18]Worldwide, there are certain key populations, which are UNAIDS defines as "groups that are particularly vulnerable to HIV and frequently lack adequate access to services."[19]They often face legal or social issues e.g. stigmatization or criminalization of their behavior, that increases their vulnerability to HIV and decrease their access to care. These groups include men who have sex with men, people who inject drugs, sex workers and transgender people.[20]Their prevalence compared to the general population is demonstrated in the figure below[21]

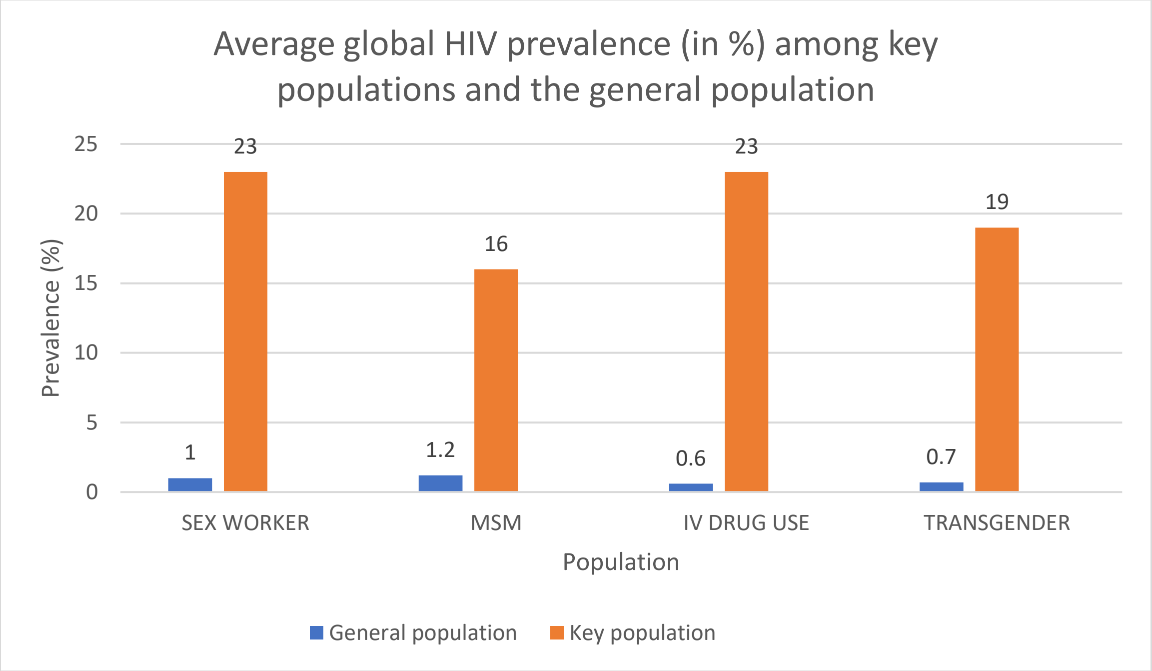

Figure 4: Average global HIV prevalence (in %) [ii]

There are also groups that fall in the category known as Vulnerable populations**.** These are defined as "people who are particularly vulnerable to HIV infection in certain situations or contexts, e.g. adolescents, orphans, street children, people with disabilities and migrant and mobile workers. These populations are not affected by HIV uniformly across all countries and epidemics."[22]It is important that all these populations be it key populations or vulnerable populations be given special attention in the efforts towards prevention of HIV spread.

HIV.org, the United States federal government's leading source of information about HIV, states that in the U.S, as of 2016, the number of new HIV infections were 37,600, while the number of people living with HIV were over a million. Out of those infected with

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[ii] From WHO: Key populations: Demographics, Epidemiology, Epidemic Drivers (pdf)

HIV,15% do not know they have the infection. Though the annual rate of new infections in the US fell about 5% between 2011 and 2015, the decrease was uneven across various demographics and certain populations as described above.[23]

The figure below depicts HIV prevalence and incidence in USA from 1980-2010

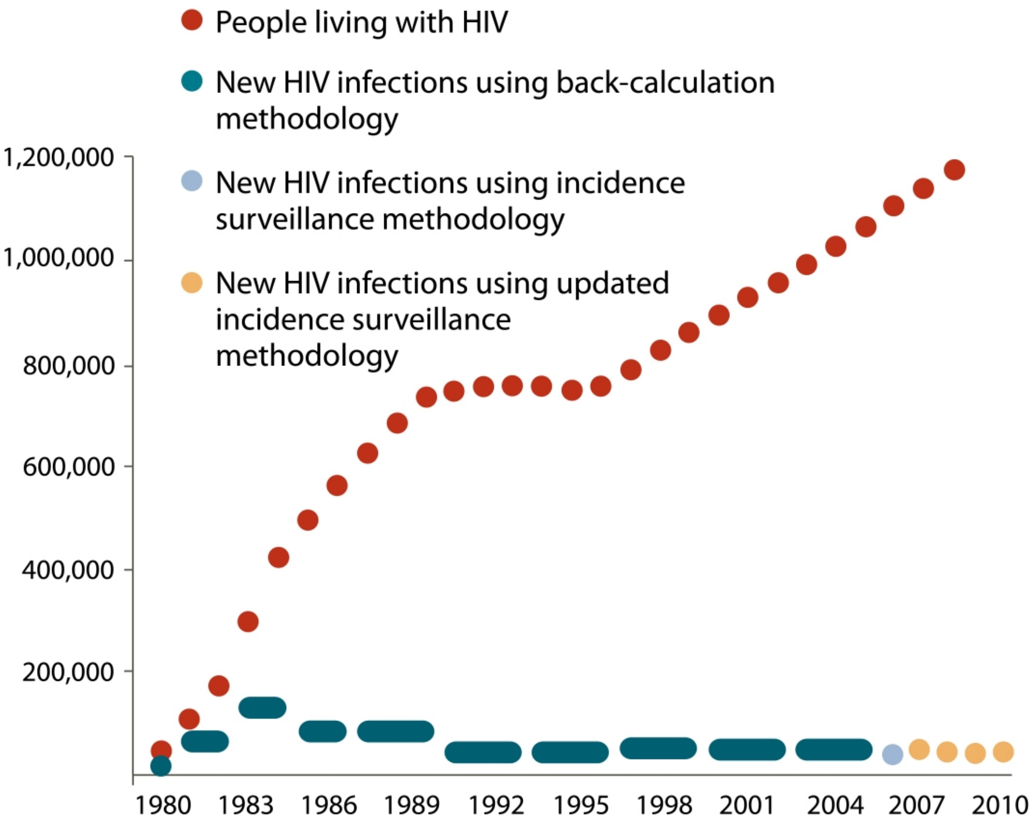
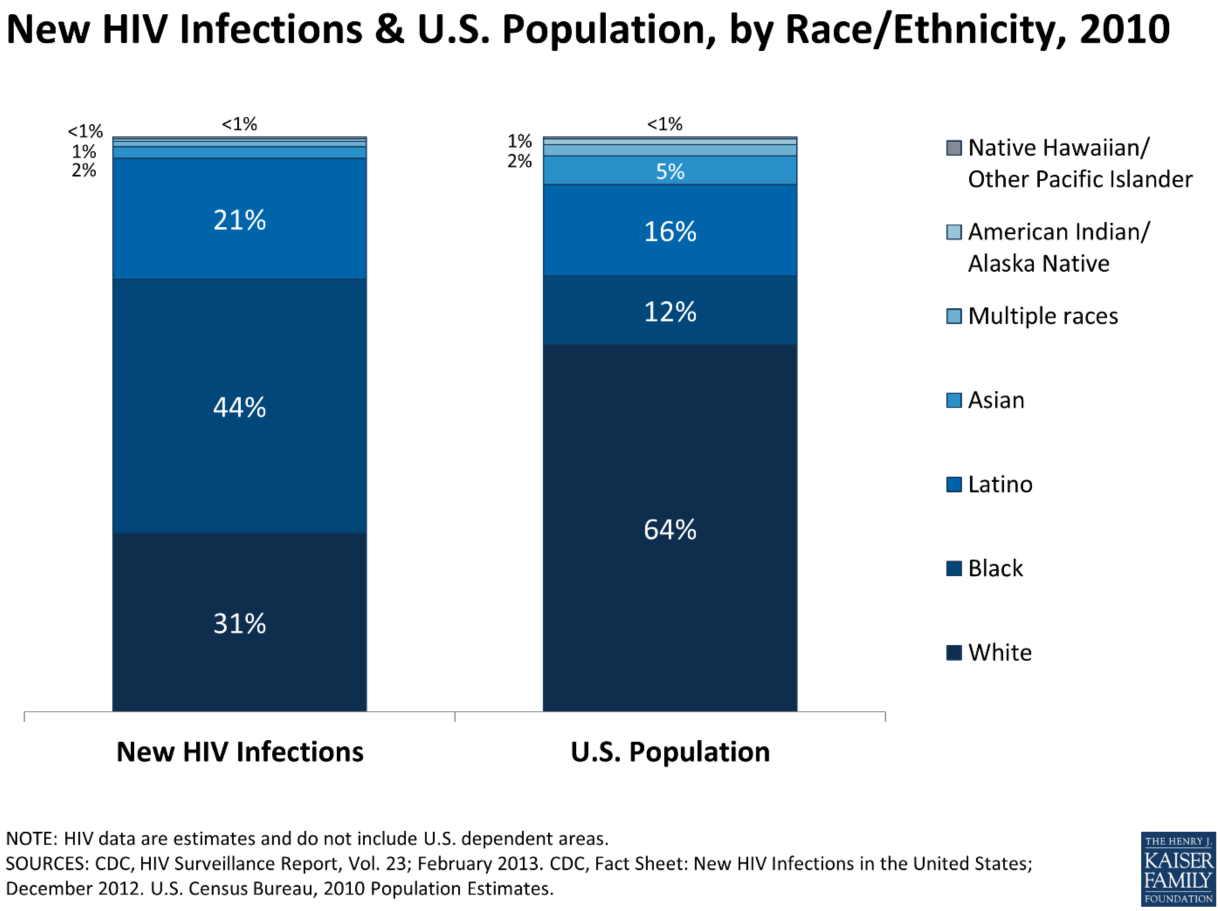


Figure 5: HIV prevalence and incidence in USA from 1980-2010[iii]

[iii] From CDC.GOV

The figure below also depicts new HIV infections in USA by race or ethnicity



New HIV Infections & U.S. Population, by Race/Ethnicity, 2010

NOTE: HIV data are estimates and do not include U.S. dependent areas.
SOURCES: CDC, HIV Surveillance Report, Vol. 23; February 2013. CDC, Fact Sheet: New HIV Infections in the United States; December 2012. U.S. Census Bureau, 2010 Population Estimates.

Figure 6: New HIV Infections & U.S Population by Race/Ethnicity,2010[iv]

[iv] From CDC HIV surveillance supplement report Vol 23, Feb 2013

Below is also a figure depicting HIV incidence among key populations in the USA.

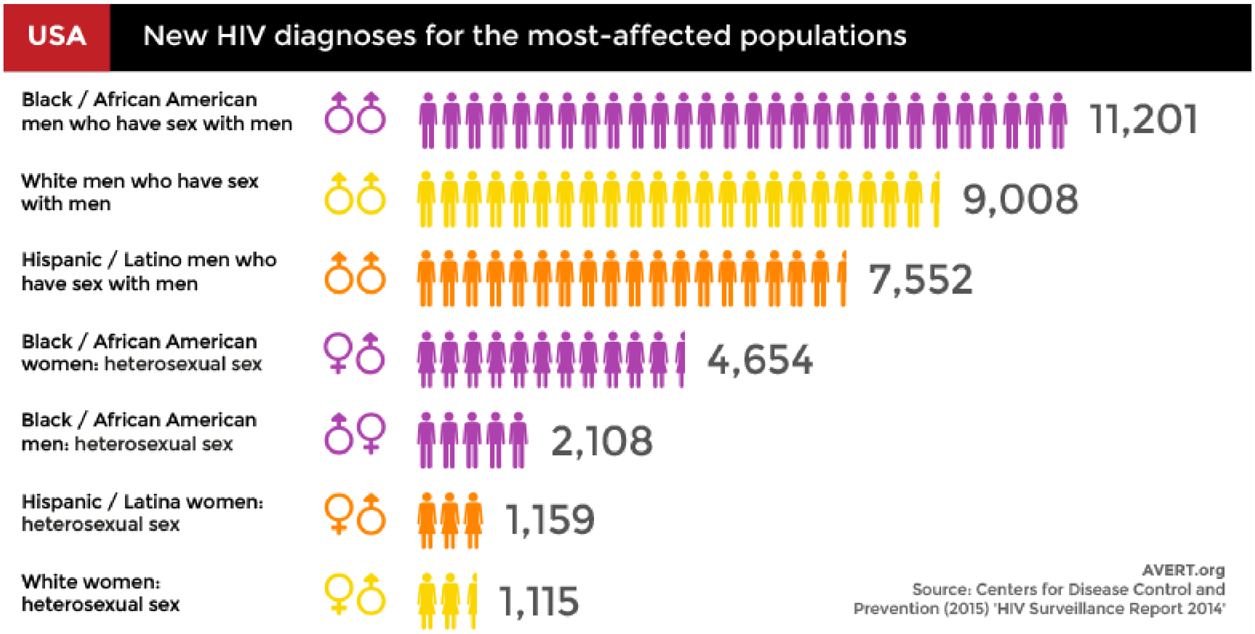


Figure 7: HIV incidence among key populations in the USA[v]

With respect to the state of Georgia, among the 50 states in the United states, Georgia ranks 5th in overall burden of HIV infections.[24]In Georgia, the rate of black males living with an HIV diagnosis is 5.8 times that of white males, whilst the rate of black females living with an HIV diagnosis is 12.6 times that of white females.[25]Other statistics concerning the state of Georgia and HIV have already been discussed in the previous chapter.

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[v] From Avert.org: Source CDC HIV surveillance Report 2014

2.3 Mode of HIV transmission

These modes of transmission as previously mentioned in the preceding chapter include transmission through sexual intercourse, vertical transmission from mother-to-child either in labor and delivery or through breastfeeding, injection drug use and rarely through blood transfusions or other medical procedures.[26]

2.4 Factors associated with the spread of HIV

There are many factors implicated in the spread of HIV. Many of these factors are social, economic or cultural in nature. Whilst some of these factors cut across demographics, others are peculiar to certain populations. These factors include poverty, gender inequality, homelessness, substance abuse, lack of education and poor access to HIV testing.[27]

2.5 HIV status disclosure

HIV status disclosure is defined as "the process of revealing a person's **HIV status**, whether **positive** or negative. **HIV status** is usually disclosed voluntarily by the index person, but it can also be revealed by others with or without the index person's consent."[28]Thus HIV status self- disclosure refers to the index person revealing his or her own HIV status.

Globally, research on HIV serostatus disclosure has primarily focused on HIV-infected adult men and women within HIV testing and treatment clinic settings.[29]However **the issue of status** disclosure should go beyond the borders of the clinic as it is critical in the fight against HIV as an effective method of preventing spread. It is also seen as a way of 'normalizing' HIV with the aim of decreasing stigma and encouraging acceptance of HIV positive people in society.

2.6 Advantages of HIV status disclosure

HIV partner disclosure may facilitate social support, improve psychological well-being among HIV-infected individuals, and promote HIV testing and HIV prevention among their sexual partners.[30]Research also points to a long- term advantage of treatment adherence in those that can freely disclose their status as they tend to have more support.[31]

2.7 Status disclosure and HIV Criminalization

There are structural interventions in the form of laws that govern HIV status disclosure in various parts of the world. These laws fall under HIV criminalization, which the HIV justice network described as " the unjust application of the criminal law to people living with HIV based solely on their HIV status – either via HIV-specific criminal statutes, or by applying general criminal laws that allow for prosecution of unintentional HIV transmission, potential or perceived exposure to HIV where HIV was not transmitted, and/or non-disclosure of known HIV-positive status."[32]According to a report by the HIV justice network, currently HIV criminalization is active in 72 countries worldwide, whilst 34 states and two US territories also engage in HIV criminalization.[33]

Indeed, one would think that the criminalization of HIV non-disclosure among others would serve as an effective preventative public health strategy to reduce new infections. However, research has shown that HIV criminalization exacerbates racial and gender inequalities, negatively impacts sexual and reproductive rights and also negatively impacts testing and disclosure.[34]These concerns have been reiterated by the American Psychology Association which has described HIV criminalization as dehumanizing and disproportionately affecting those who are already marginalized in society.[35]As an example, some countries have taken advantage of HIV criminalization laws to persecute homosexual and transgender people as well.[36]

2.8 Current rates of disclosure and associated problems

Among studies in the developed world, rates of HIV status disclosure to sexual partners ranged between 42% to 100%. For the developing countries, the rates of disclosure were notably lower than rates reported from the developed world. The rates ranged from 16.7% to 86%.[37]

In a study among MSM in the US, for those who disclose their status, Sullivan et al found that differences in disclosure rates varied based on factors like sero-status, relationship status, and number of sex partners. They stated that, "More importantly, rates of disclosure to primary sex partners ranged from 67% to 88%, suggesting that nearly one third of main sex partners were not disclosed to and were at risk of contracting HIV, whereas a pattern of even lower disclosure among casual partners was evident. As the number of sex partners increased, the likelihood of disclosure to all sex partners decreased, ranging from one quarter (25%) to slightly over half (58%).[38]In a sample of HIV infected men and women in the U.S, Kalichman et al, found that men who had not disclosed to partners indicated lower rates of condom use during anal intercourse."[39]

In the study titled Ethnic differences in HIV disclosure and sexual risk, Bird et al, found that that African-American MSM are less likely than White MSM to disclose their HIV status to sexual partners. Reasons given included the fact that African-American men belonged to riskier sexual networks where it is not that they have more sexual partners but rather their pool of sexual partners contains more infected people.[40]

All the above research alludes to the fact that certain barriers exist that prevent HIV positive people from disclosing their status and the aim of my study is to identify these barriers and recommend solutions to overcoming them.

3. Methodology

This was a qualitative study based on secondary analysis of data collected by in-depth interviews of HIV positive patients that attended the IDP-Ponce Clinic. The study was conducted in the summer of 2017. Out of the interviews conducted, eight were selected for data analysis since at that number, saturation had been reached and not much additional information was derived from subsequent interviews. The interviews were conducted by well-trained interviewers using structured interview questionnaires and patients' consent was sought before the interviews were conducted.

The interviews were de-identified and transcribed verbatim prior to analysis to ensure excellent quality data. The high quality of the data and transcription was evident by the presence of long responses and slang words used by the participants that were in the transcript.eg. *'But, then you know, after doing all the research and all the pampers(pamphlets)…the pamper(pamphlets) thing-y…'* The use of the slang 'pampers' here by the participant is included in the transcript though the actual meaning is put in bracket. Secondly, the participant responses were lengthy, detailed and rich. Particularly in the areas where questions were asked about their experiences when first diagnosed with HIV, the participants gave in-depth long personal responses – e.g., a response could take about half a page. This showed that the participants gave relevant answers to questions, contributing to good data quality. Thirdly there was an abundance of use of personal pronouns like 'I' and 'me', which gave an indication of the emic perspectives of the participant e.*g "So that's when* ***I*** *started getting worried, getting scared and stuff like that. But after that, it still didn't affect* **me**, ***I*** *didn't think it did.* ***I*** *mean not until* ***I*** *got to the age of dating that's when it started to affect* **me** *more because* ***I*** *realize that how many* *people put so many stigmatisms on HIV people. And* ***I*** *didn't know nothing about that either. So experiencing that at a young age was crazy also. And so,* ***I*** *guess, you can say it has be a roller coaster ride through the years*." Again, in the interviews, the presence of great probes also elicited detailed responses from the participants e.g. *'tell me more', 'how do you mean'*-these succeeded in getting the participant to give more information about a response. Also, as proof of excellent quality, interviews were participant dominated, where the ratio of interviewer-to -participant response were about-30 :70.

4. Data Analysis

A Grounded Theory approach was used to analyze the data. This approach included the iterative methods of reading, creating memos creating codes and developing common themes, to develop a conceptual framework to understand the barriers HIV positive people in Atlanta had when it comes to HIV status disclosure. MaxQDA12, a qualitative data analysis software, was used to aid data analysis. A thorough analysis of the memos therefore helped to generate codes, which identified common themes running through the participants' responses. Codes that were generated included a parent code of discrimination, under which sub-codes included stigma, homophobia and racism. Another parent code identified was support system and within that were sub-codes family support and friends' support. An analysis of these codes then helped to generate themes where comparisons could be made among the respondents.

With regards to comparison methods, to appreciate the scope of each participant's unique experience, cross case analysis was used to analyze each person or each case's experience. Subsequently, to identify similarities and nuances that may exist within experiences, participants were grouped in various categories namely gender, relationship status, employment status, age of HIV acquisition, sexual orientation and race. The data was then analyzed to compare the experiences of diverse groups (e.g males vs females) when it came to status disclosure and its barriers. For both methods of comparison, inductive and deductive methods were used. Inductive comparative methods were used based on demographic differences that existed among the participants e.g. difference in experience between male and female respondents. With respect to deductive methods, these were derived only after thorough reading of the data which revealed that differences in experiences that were not so obvious before reading the data(e.g age of acquisition of HIV or sexual orientation).

Finally, after the above rigorous exercises, a conceptual framework was developed to identify and describe barriers to HIV status disclosure. This was done through conceptualization, where certain techniques were used to identify the big picture and understand what the data was conveying. An ‘x-ray view’ was used to isolate the essential backbone or relevant data from all the clutter of other things said by the participants during the interview. Subsequently, using a matrix of codes approach, the various categories were linked to the central theme that came up in the data to aid in getting the big picture or central message in the data. This aided in constructing a conceptual framework to answer the research question. The conceptual framework was verified by ensuring that the concepts and relationships shown in the conceptual diagram were grounded in the data. This was done by repeatedly reading the data to ensure that emerging themes were consistent across board. Alternative explanations were also tested and compared with the data, but those explanations failed to validate the theory drawn from the various categories and concepts.

5. Results

The following section provides a summary and analysis of participant responses about their experiences with respect to barriers they face in disclosing their HIV status to both family and non-family members of society.

5.1 Demographics

Of these eight individuals, five were male, three were female, three were born with HIV and five acquired HIV later in life. Ages ranged from twenty-four to twenty-five years. Seven participants identified as African-American whilst one identified as an African. Of the participants, three were MSM, one was a male bisexual, one was a male heterosexual, one was a female homosexual or lesbian and two were female heterosexuals. All but one participants were employed. Five participants were single whilst three were in stable relationships. All participants were HIV positive and were currently on ART.

FILE NAME	GENDER	AGE AT IDI	AGE DIAGNOSED	RACE	SEXUAL ORIENTATION	EMPLOYMENT STATUS	RELATIONSHIP STATUS
ID 20	MALE	24	14	AFRICAN-AMERICAN	HOMOSEXUAL	EMPLOYED	SINGLE
IDI 36	MALE	24	18	AFRICAN-AMERICAN	HOMOSEXUAL	EMPLOYED	SINGLE
IDI38	MALE	25	19	AFRICAN-AMERICAN	BISEXUAL	EMPLOYED	SINGLE
IDI40	MALE	25	17	AFRICAN-AMERICAN	HOMOSEXUAL	EMPLOYED	SINGLE
IDI 54	MALE	24	AT BIRTH	AFRICAN-AMERICAN	HETEROSEXUAL	EMPLOYED	IN A RELATIONSHIP
1DI 57	FEMALE	N/A	AT BIRTH	AFRICAN-AMERICAN	HETEROSEXUAL	EMPLOYED	IN A RELATIONSHIP
IDI 60	FEMALE	25	17	AFRICAN	HETEROSEXUAL	UNEMPLOYED	IN A RELATIONSHIP
IDI 63	FEMALE	24	AT BIRTH	AFRICAN-AMERICAN	LESBIAN	EMPLOYED	SINGLE

Figure 8:Demographics Table

5.2 Barriers to disclosing HIV positive status

Stigma- Of the 8 participants that were interviewed, they all had experienced stigmatizing behavior from others due to their known HIV positive status. This included stigma from both family members as well as the society at large. For one person, the fact that he was discharged from the military due to his status alone was very stigmatizing and depressing for him. For another person, this was her description of stigmatizing behavior from her family:

"So, it was like I was like this strange thing in the house you know? So it was kind of hard. Yeah, I didn't cook, like you know? Not being allowed to do much activity in the house or I had to use gloves or just some like weird things that you would not expect. So, it was kind of hard."

Another talked about a general reaction from people:

"everybody still is like, 'Uh, you're sick and you got the bug and you got the package and you got the project and you got the house and the…', whatever name they got for it, they got some new names. It's just that you are like Ebola. "Get away from me."

Other participants had not experienced stigma directly, but had been warned by loved ones not to disclose their status to avoid discriminating treatment from other people.eg a patient born with HIV was told this by his mother:

"If you tell people this, they going to treat you different." …………"They are going to treat you more different than they treat you that you're black, facts. Because even the black kids are going to treat you different."

Another participant also disclosed the fact that in hearing other people speak very disparagingly about HIV, he was afraid to inform his friends that he was HIV positive. This is reflected in the response below by one participant:

"Everybody I know. I have got, um, like just be little comments here and there that kinda make me – it's like it plays in the back of my head every time I get ready to tell somebody. "

Thus, the experience of stigma was both a direct and indirect one, which ultimately negatively affected a person's decision to disclose his status.

With respect to comparisons, both male and female; gay and straight; born with HIV or acquired later in life, employed or unemployed, single or in a relationship had all experienced stigma at one point in their life and this greatly influenced their willingness to disclose their status.

There were however nuances that existed within these comparison groups. Gay HIV positive people among the participants expected to receive more stigmatizing behavior for being HIV positive because they were gay. Though they did not give examples of direct experiences they had, it was more of an anticipatory thing. This was reflected in statements such as:

"People, talking to them about it, the stigmatism, being gay, being black, being in America, being a man, it's like five strikes already there. You know. "

Another nuance existed for the participants born with HIV compared to those who acquired it later in life, where family members were less stigmatizing compared to the experience of those who acquired it and told family members. For both employed and unemployed, apart from the experience of the participant in the military, none of the participants felt the need to disclose their status to their employers hence did not experience any stigma in that regard.

Finally, for those who were in a relationship, they did not experience any stigma from their partners (who all happened to be HIV negative). Single participants talked of disclosing their status only when they felt a sexual encounter with someone was more likely. However, it appeared they were more comfortable disclosing their status through a dating app or through the internet before meeting the person rather than disclosing status in person.

Racism-All 8 participants were black and all alluded to the fact that being black made it more difficult to disclose their status to others. However, in this instance, others refers to non-family members. The experience of racism as a barrier to status disclosure was generally an anticipatory effect. None of the participants had direct examples of where being black and being HIV positive resulted in obvious discriminatory behavior. Instead they all allude to the specific examples of being treated badly because of being black as a reason why they would be treated badly if they disclosed their status as HIV positive. One participant summed it up like this:

"I'm a male. I'm black. I'm gay……….. I'm HIV positive. Might as well put a gun to my head. I'm everything that America doesn't want."

Another participant alluded to being shunned at school but because she was black, was not sure if it was due to her color or because they knew she was HIV positive.

Homophobia-Just like racism, the homosexual participants in this study also regarded being gay as a barrier to disclosing their HIV status. A nuance that existed however is the fact that they were ready to disclose their status provided they anticipated a sexual encounter. However generally due to homophobic treatment they suffered, they also anticipated being treated badly if their HIV status was disclosed. What was interesting about this theme of homophobia was the fact that these participants also feared worse treatment even from their own family. Unlike the experience of race where it was rare to experience racism from your own family, the homosexual participants anticipated discrimination if either or both homosexual orientation and HIV status were revealed to both family and non-family members.

I : Okay, so how is it being around your family, like -

P : It's awkward. It's awkward and it's lonely

I : Do you ever think you will tell them your status?

P: Well I have got to tell them I'm gay first. But you know, that would be – no, that's not going to work.

In comparing the experiences of gay participants, they were all single hence a comparison could not be made with respect to their experiences as single or attached people. Their employment status also did not make a difference to their experiences. Both male and female homosexual had similar experiences with regards to status disclosure.

In comparing the experiences of heterosexual to homosexual participants, the experiences of the latter were solely based on stigma and or racism being tied to status disclosure, but it seemed sexual orientation was not a barrier to status disclosure, unlike for homosexuals.

Support system: This theme was divided into family support as well as friends' support. The aim was to find out if lack of a support system served as a barrier to disclosing HIV status.

With respect to family support, all three people born with HIV admitted having a great family support system. They did not have to disclose their status because these family members already knew thus making it easier for them. However, there was no direct evidence that this existing support system made it easier to disclose their status to other non-family members. For those who acquired HIV later in life, though most alluded to having family support, it was not in relation to HIV status because they had not told family members of their status or had told very few. This refusal to disclose status to family members was due to fear of losing family support due to homophobia and or stigma.

With respect to support of friends, all participants in a relationship found it easy to disclose their status to their stable partners whilst single participants would only disclose to people they were about to have a sexual encounter with. Regarding platonic friendships, except for 1 participant, all other participants had close friends that they had disclosed their status to and spent time together with. However, the presence of these friends was not necessarily identified as something that helped to disclose their HIV status to other people.

The above results are depicted in Fig 5.1 as a conceptual diagram:

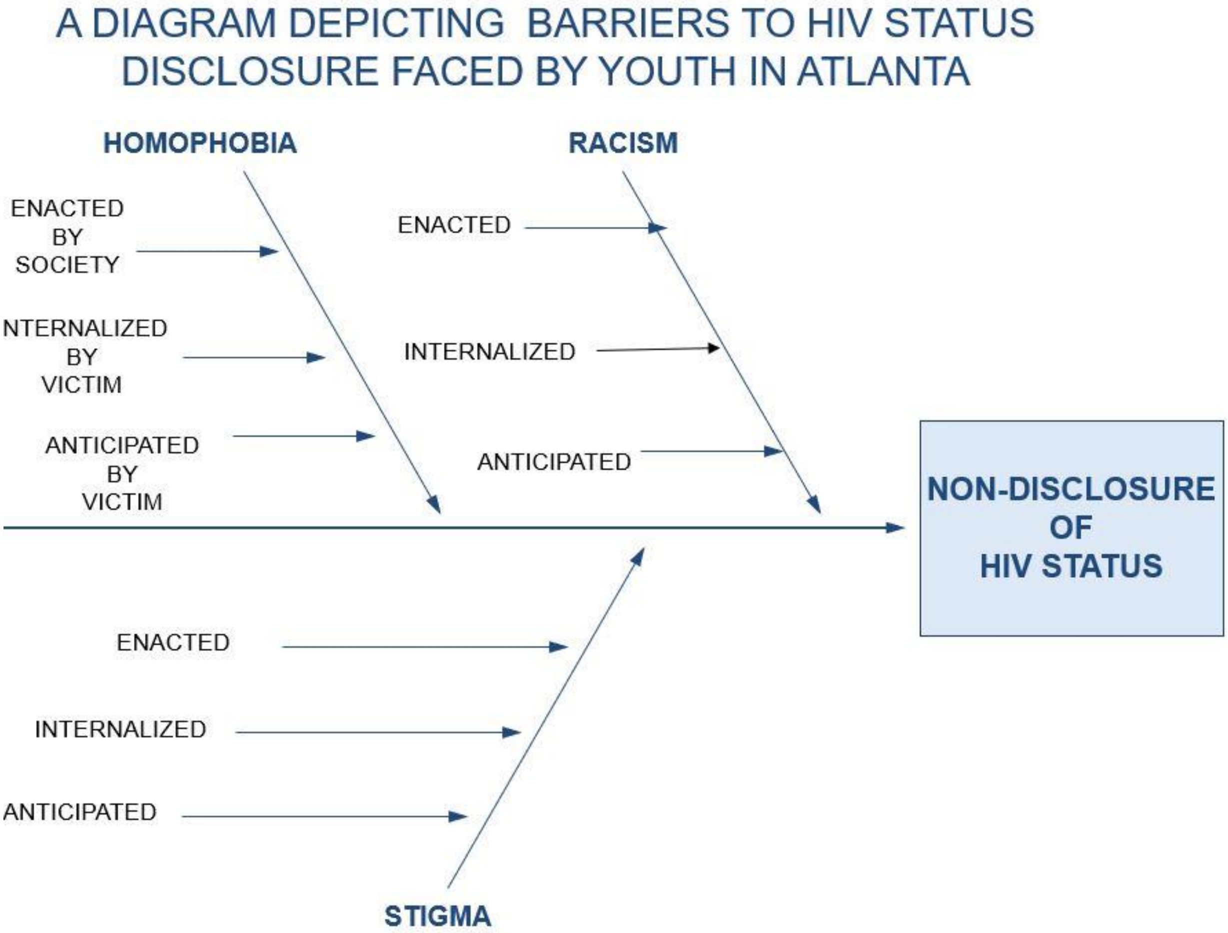

Figure 9:Barriers to HIV Disclosure

6. Discussion

6.1 Discussion

The purpose of the study was to identify and understand the barriers that HIV positive people faced with respect to HIV status self- disclosure to society in general. This study focused on status self-disclosure to both familiar or close family and friends as well as to the public in general. Previous studies have already been done on the roles that racism, stigma or homophobia play in HIV prevention. E.g. one study talked about racism, homophobia and stigma, but this was limited to just the black MSM population.[41]Other studies have also focused individually either on just racism, homophobia, or stigma, or have limited themselves to specific populations e.g. barriers faced by Latinos only[42] or by women only[43]etc. However, this study was a general study for both male and female HIV positive people, irrespective of mode of HIV acquisition, sexual orientation or ethnic origin. Due to its more diverse target population, this study was able to capture nuances in these common experiences already talked about in previous research. Thus,our findings can add to already existing knowledge about the effects of various forms of discrimination, on HIV prevention.

In discussing our findings, the main barriers to disclosure that were identified in our analysis were homophobia, racism and stigma. These barriers were derived inductively from the interview process of the research. However, it is important to note that these experiences were suffered externally or enacted, internalized as well as anticipated based on the responses of the participants, e.g. those who experienced external stigma also revealed characteristics of anticipated as well internalized stigma, likewise similar experiences with racism and homophobia.

Other points in the results noteworthy of discussion are the nuances that existed in these barriers or experiences that participants faced.

For example, one would have expected that generally, HIV positive patients would have an easier time disclosing their status to family or perhaps close friends compared to the rest of society. However, the results varied particularly with regards to the barrier of stigma.

People who were born with HIV seemed to have more family support, sympathy and understanding and they didn’t have to necessarily self-disclose as the family members got to know of their status through other means. This it seemed made it easier for those born with HIV to disclose status to others. For the participants who were born with HIV they seemed to find it easier to disclose their status to non-family members and seemed to brush off or seemed to be able to easier handle any stigmatizing behavior.

Participants that acquired HIV later however faced the same barriers with family members as they faced with the general society. Some due to the fear of stigma were either alienated from their families or interacted with them without revealing their HIV status.

Another nuance that existed in the research results were the experiences of heterosexuals compared to LGBT population. The LGBT participants had a lot of internalized and anticipated discriminatory feelings that transcended beyond their sexual orientation, compared to their heterosexual counterparts.

6.2 Significance of findings and implications in Public health

These 3 barriers discussed above points to the fact that experiences of stigma, racism and homophobia have a very potent effect on HIV positive people and play an incredibly significant role in influencing HIV status disclosure as well as influencing other aspects of HIV prevention and care.

Various interventions aimed at improving status disclosure are either being practiced or have been studied but they either have their limitations or need to be practiced on a larger scale. E.g. a randomized control trial on a digital intervention to promote HIV status disclosure among both HIV positive and HIV negative MSM in the USA was done in 2009, where participants watched videos on the importance of status disclosure and engaged in critical thinking. A follow-up was done 3 months later and questionnaires were administered to find the rate of status disclosure[44].Though the study discovered an increase in the rate of disclosure, considering that of the 522 men who completed the online intervention only 72 were HIV-positive and knowing that the barriers HIV positive people face is different from that of HIV negative people, more studies need to be done to evaluate the effectiveness of this intervention targeting only HIV-positive participants. Other interventions that exist in various places include group counselling among HIV positive people on disclosure[45], discordant couples counselling,[46]and the development of structured support groups[47]all with the aim of facilitating HIV status disclosure.

This study hopes to propose more interventions to promote status disclosure based on our research findings.

For example, with respect to our findings on the experiences of stigma endured by participants, one can infer that if as a society we are more open, accepting and understanding of HIV positive people by doing away with stigma, we empower them to take the necessary responsibility in preventing disease spread through free status self-disclosure. It also helps to strengthen their psychological wellbeing in being able to handle discriminatory behavior from non-enlightened people. The nuances found in this study also informs us as public health personnel to do more in terms of education of family members of HIV positive people, particularly those who acquired it later in life. Usually one would expect the family to be the first point of contact in terms of support but if one faces or expects to face stigma from family particularly because they acquired HIV later in life, it makes it difficult for HIV patients to have the support needed to deal with the diagnosis, enter and stay in care. This study recommends interventions such as more public health educational sessions and special peer-group meetings being organized in various places of care of HIV positive people to engage with family members, educate them and involve them in the care of HIV positive patients. This will go a long way to retain them in care and ensure fidelity with respect to ARVs and safe practices.

With respect to the experiences of racism, so much work has already been done on racial awareness campaigns to draw society’s attention to the harmful effects of racism and indeed a lot of studies have talked about racial disparities in healthcare. However, these studies are usually restricted to clinical settings. From this study, it is clear the role racism plays in HIV status disclosure and its consequences. There are many more infectious and non-infectious diseases that have the potential to spill-over into epidemics if racism is not effectively dealt with in public health. Attention to the harmful effects racism has both on the victim as well as the long-term effect on the general society must be addressed. Special attention must be paid to non-Caucasian populations in any public health intervention and racism must be addressed and discussed with these populations. Public health institutions must incorporate trainings on inter-cultural awareness and competence to enable practitioners to effectively understand these vulnerable populations, effectively reach them and have a relevant impact on them.

Thirdly, with regards to the study findings on the barriers faced by the LGBT population, there is no doubt that within the universal group of HIV positive patients, attention must be paid to the LGBT group which is more vulnerable compared to others due to the undue enacted as well as internalized discrimination they experience. The situation is even worsened when the individual is also of non-Caucasian race. Public health practitioners and clinicians alike need to pay close attention to such patients. In the clinical setting, the patient may be presenting with a symptom, but the social history of the patient may throw more light on his or her current health and addressing their needs together with social workers may yield better health outcomes for such patients.

In the field of public health, we cannot use a one- cap- fits all approach with respect to HIV interventions. We need to customize our interventional approached to meet each vulnerable population at the point of their needs and address limitations peculiar to their situation. More resources need to be pumped particularly into education of the public on the harmful effects of discrimination against HIV patients not just based on their HIV status but also based on their ethnic origin or sexual orientation. Particularly with respect to HIV status disclosure, where previous discussion above has pointed out the limitations of HIV criminalization, it is obvious that voluntary self- disclosure, is a better option which has the potential to yield more results in the long-term goal of promoting safer sexual practices and reducing spread of HIV.

Finally, an important finding from this study is how it exposed the need to optimize the role of mental health in dealing with HIV positive people. Again, considering that some of the barriers that these participants faced were not enacted but rather internalized, it points to the fact that perception may not necessarily be equal to reality and patients will need to be counselled on ways to overcome these psychological barriers to fully take charge of their health and partake in society.

7. Challenges and Limitations of the study

7.1 Time

Qualitative study is time consuming. Though this may not necessarily be a challenge or limitation, it sometimes requires more work on the part of the researcher compared to quantitative research e.g. the data collection was via one-on-one in-depth interview with each participant after which the interview needed to be transcribed verbatim. Data analysis also takes time as the software MAX QDA does not analyze the data by itself (unlike SAS or STATA software) but rather only helps to identify themes through repeated reading, memo writing and coding of transcripts. Thus, more time is needed to inductively and deductively analyze the data to come out with results.

7.2 Early saturation

Due to the demographic distribution of HIV in Atlanta, saturation in this study was reached early in this study. All participants were black, and half were LGBT . One may argue that this does not give an accurate representation of people living with HIV as there were no other races present in the participants. This was a concern as it implied that our results may not necessarily be generalized. None the less, since the black LGBT demographic does represent a substantial proportion of people suffering from HIV worldwide and particularly in Georgia, it is believed that our research results are still credible. Also considering that the research is of qualitative nature, generalizability is not the goal. The aim of qualitative research is usually to gain a more personal understanding of the phenomenon under investigation and the results can potentially contribute valuable knowledge to the scientific community.[48]

7.3 Reflexivity

Being of black ethnicity (though from a different background as an African migrant) and being a health professional, I had to apply a lot of reflexivity to allow data speak to me rather than rely on my previous knowledge or similar experiences to draw conclusions for the participants. I had to apply a lot of reflexivity to separate my own beliefs, expectations and interpretations from the information the participants were giving, to accurately report what was being demonstrated in the data by participants and not my own deductions and assumptions

8. Conclusion

There is no doubt that HIV status self -disclosure is vital in the fight against HIV. As previously stated, disclosure of HIV status supports risk reduction, facilitates access to care and increases support for the patient.

Though laws exist in certain places to mandate HIV status self-disclosure, research shows that forcing people to involuntarily disclose their status is ineffective and even has the opposite effect of undermining public health efforts in some of the cases. Numerous studies have been done on the rates of status disclosure across various demographics and factors that influence disclosure within certain contexts. However, more needs to be done to encourage people to freely and voluntarily disclose their status without fear of prosecution or discrimination and more research is needed to identify the barriers that people face to HIV status self-disclosure, irrespective of ethnic origin, mode of HIV acquisition or sexual orientation.

Identifying barriers to self -disclosure is the first of many steps to ensuring that HIV positive patients have a safe space to express themselves, disclose their status and enable them to fully participate in society and contribute their quota to mankind and my study hopes to contribute to this need.

9. Glossary

Term	Explanation
HIV	Human Immune Deficiency Syndrome
MSM	Men who have Sex with Men
LGBT	Lesbian, Gay, Bisexual, Transgender
HAART	Highly Active Antiretroviral Therapy
VCT	Voluntary Counselling and Testing
Stigma	A strong lack of respect for a person or a group of people or a bad opinion of them because they are or have done something society does not approve of.[49]
Racism	Racism is the practice of discriminating against people based on their race, national or ethnic background.[50]
Homophobia	An irrational hatred or fear of homosexuals or homosexuality.[51]

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