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Department of Sociology

BIDS

The Socio-Economic impacts of Stigmatization on young women (16-24) infected with HIV in Accra, Ghana (Ridge hospital)

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Bachelor Thesis: UTKV03, 15 hp

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ABSTRACT

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This study sought to explore the socio-economic impacts of stigmatization on young women (16-24) infected with HIV in Accra, Ghana (Ridge hospital). Qualitative study was performed with five young women 16-24 infected with HIV attending HIV clinic at Ridge hospital. Interviews were conducted to explore respondents' perception of stigmatization and discrimination based on their HIV status and gender, economic burden posed on victims as a result of the HIV infection, and investigate any changes in the victim´s social participation following realization of their HIV infection.

The respondents reported that stigma and discrimination have a negative impact on their socio-economic status. There is a fear of future refusal or dismissal from work due to their HIV status, a fear of economic and social suffering due to family and spousal neglect, as well as many other challenges associated HIV and pregnancy. Some respondents were able to cope with their current situation through self-confidence, adequate pre and post HIV counseling and testing, and social and economic support from family and hiding of HIV status.

Stigma and discrimination was a huge problem that all the respondents reacted to as being an obstacle to their social and economic wellbeing. A model was developed from the findings that explain the stages that potential interventions can focus on to help alleviate this burden. This model was based on the findings that respondents perceived the effects of stigma and discrimination at two levels: current and future burdens. Beneath these lies a third level that helps them to cope.

Keywords: Economic, HIV/AIDS, Young women, stigmatization, discrimination, Psycho-social, Accra (Ghana).

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Chapter 1: Introduction

The Human Immunodeficiency Virus (HIV), the virus that causes AIDS was first reported in 1981, but after 31 years the disease had killed almost 30 million people through HIV related causes and more than 34 million people are currently living with HIV and AIDS (UNAIDS 2012a). HIV prevalence among young women is becoming very high. In Sub-Saharan Africa where the epidemic is worst, young women or girls between the ages of 15-24 constitute three quarters of the young infected with HIV. It is estimated by the UNAIDS that every minute a young woman is infected with HIV (UNAIDS 2012b). If this is not given urgent attention, the situation is going to get worse. Young women are the most vulnerable of being infected with the disease due to factors like gender inequalities, gender-based violence, biological susceptibility, and vulnerability of the key population (UNAIDS 2012c). The most recent report on HIV from South Africa shows that about 28% of young women in the universities are infected with the HIV virus (Globalpost.com). The pace at which the young, especially women, are infected with HIV is very alarming and also dangerous for future development, especially in sub-Saharan Africa (UNAIDS 2012 d). Apart from the fact that young women have been tipped as the most vulnerable in the sub-population with an increased risk of being infected with the virus, they also face the double-burden of being the most affected socio-economically by HIV infection (UNAIDS, 2012f). Despite these socioeconomic challenges, young women infected with HIV are highly stigmatized both within the society and in the labour market. Though HIV is currently in its third decade since its discovery, research shows stigma surrounding HIV and AIDS remains very high in both developing and developed countries (Busza, 1999; CDCP, 2000; Herek, Capitanio, & Widaman, 2002; London & Robles, 2000; Taylor, 2001).

There has been very little research done by interest groups like the UNAIDS and the other UN joint teams on reducing HIV stigma and discrimination and its effects on the socio-economic status of its victims. Though the article by UNAIDS and Kayeyi *et al* showed some successful cases of countries that are benefiting from programs focused on reducing stigma and discrimination among people living with HIV and AIDS, there is absolutely more work to be done on the effects stigma and discrimination have on its victims in their social and economic life. Other researchers have worked on stigma and discrimination associated with HIV (Brooks et al., 2004, Garrido et al., 2007, Liu et al., 2012) but as of this moment very little

research has been done on the topic in connection with young women in the sub-Saharan region (Nattabi et al., 2012, Nattabi et al., 2011, Tsai et al., 2011), specifically Ghana (Poku et al., 2005, Mwinituo and Mill, 2006). It has been openly acknowledged from this epidemic that stigma and discrimination are critical obstacles towards universal access to prevention, treatment, care and support for people living with HIV and AIDS (UNAIDS 2007e &2012e). Therefore this research seeks to explore the perception of young women (16-24) on the impacts of stigmatization on their socio-economic status that are infected with HIV.

Purpose / Objectives of the thesis

The overall aim of this study is to explore the perceived impacts of stigmatization on women infected with HIV attending HIV clinic at ridge hospital in Accra, Ghana. To achieve this aim, the following research questions were designed.

Research question(s)

- To explore victims' perception and experiences on their HIV status and gender
- To investigate any economic burden posed on victims as a result of the HIV infection.
- To investigate any changes in the victim´s social participation following realization of their HIV and health status.

Limitations

My sixth semester in the bachelors in development studies was incorporated with my internship and bachelor thesis. The internship took place at the UNAIDS country office in Ghana. The internship was quite demanding, since there was a lot of ongoing activities in the UNAIDS office concomitantly with Ghana Aids Commission. I also needed to complete the tasks I had been personally assigned. Therefore very limited time was available for me in conducting the interviews for my thesis project for spring 2013. As a result of having an internship and conducting interviews within a limited period of time and the intensive nature of every interview, I was only able to conduct a few interviews. If I had more time I would

have included other hospital departments with HIV and AIDS clinics in my research work to get more respondents. Also being a nurse gave me the advantage to win the trust and confidentiality of participants throughout the interview process since they have developed some trust for health workers and believe they understand their situation more than any other group or individuals in the society. Again, since the whole process from the internship to the interviews was self-sponsored, at a point the lack of resources limited me from interviewing more people as my financial situation became quite constrained especially with transportation from one end to another which is very expensive in Accra (Ghana). I therefore advise future researchers in this field to make sure they spend and devote more time in the field for their research. They should also be aware that things can get pretty bad on the field economically and socially. Therefore they need to be prepared towards some of these unforeseen eventualities (Chambers, 1981). Very little research has been done on HIV stigmatization and its socio-economic effects on young women between the ages of 16-24, which made it quite challenging for me in my literature review. That notwithstanding, I still ventured to research the effects of stigmatization on the socio-economic situation of these already vulnerable young women to try and shed more light on their situation.

Survey of the field

The HIV and AIDS Pandemic have been on the increase since its discovery in the early 1980s with sub-Saharan Africa most affected. It has become a great concern for public health care and world leaders due to its social, human, mass media and economic impact (Gonzalo *et al* 2009). The economic and social impact of the HIV/AIDS epidemic in sub-Saharan Africa has attracted attention from different stakeholders with the hope of combating the epidemic (UNAIDS 2012). This has led to the involvement of stakeholders and governments incorporating new and more effective antiretroviral treatments which will change the disease pattern with positive impacts on survival and quality of life. There have been great involvements and contributions by the pharmaceutical industry through research into highly active drugs for people living with HIV and AIDS. HIV and AIDS is now referred to as chronic and controlled disease because these developments. This has also decreased absenteeism from work with regards to PLHIV, increased social wealth which will lead to increase in economic growth (Gonzalo *et al* 2009).

In a study done by Jefferis *et al*., in Botswana, it was shown that HIV/AIDS significantly reduces economic growth and also increase household poverty. They concluded that the

impact is so severe that it is affecting the whole world economy, especially the sub-Saharan region which is most highly affected and most likely to pull the uninfected population into poverty. But with the support of governments in the provision of antiretroviral therapy, the negative effects on victims and family have reduced (Jeffris *et al.,* 2008).

According to a survey done in Nigeria by Ajay *et al*., households infected by HIV/AIDS´ expenditures on health care are more than half of their monthly incomes. Also their attention is diverted from income earnings to care giving. The family's attention will also be taken away from other important activities such as education, good nutrition, personal hygiene etc (Ajay et al 2008). Another study conducted by Tiyou et al in Jimma zone Southwest Ethiopia concluded that food insecurity is a great problem among HIV-infected individuals receiving antiretroviral treatment (ART) (Tiyou *et al* 2012).

According to the study done by Glynn et al in both Kenya and Namibia, it was concluded that young women have a higher prevalence of HIV and AIDs than their fellow counterparts, young men. The study found that the prevalence rate among women was six times that of sexually active male counterparts within 15-19 years age group and three times within 20-24 years age group (Glynn *et al* 2001).

A study conducted in East, Central and Southern Africa shows that neighborhood educational attainment is found to be a strong determinant of HIV infection in both the rural and urban areas. The study concluded that HIV prevalence substantially decreased in neighborhoods with increasing levels of education, due to reduced stigmatization and discrimination (kayeyi *et al* 2009). This indicates that the better a society understands HIV and AIDS and its related issues, the less stigmatized the condition becomes. Therefore, the majority of the population will feel more secure in receiving voluntary counseling and testing services because they will feel less threatened due to reduced stigma. This may help the prevalence rate to reduce since they will take the necessary precautions to take care of themselves and less likely to pass the virus to others.

All these point to the fact that more attention and effort should be directed toward the reduction of stigma and discrimination in others to be able to prevent and treat HIV and AIDS. "*Since the beginning of the HIV epidemic, stigma, discrimination, and gender inequality have been identified as major obstacles to effective responses to HIV. Yet there has never been serious political and programmatic commitment to doing anything about them.*"

(Peter Piot, Executive Director, Joint United Nations Program on HIV/AIDS). This makes it a essential to devote more resources, time, and energy in reducing stigma and discrimination as a head way in combating HIV and AIDS.

The literature above is the previous works done by other scholars that my research will be based on. This research examines the higher prevalence rate among young women than their fellow male counterparts, the extra socio-economic burden that HIV and AIDS brings upon its victims, the effects stigma and discrimination have on its victims, and how neighborhood education on HIV and AIDS reduces stigma and discrimination on its victims and why it should be a critical part of world leaders and national stakeholders in the HIV response. All this research in one way or another supports or helps me answer my research questions by enriching it with the already available literature on stigma and discrimination against people living with HIV and AIDs. These background literatures helped me to frame and organize my research questions, design my interview guide and interpret my findings.

Structure of the Thesis

Chapter 2 of the thesis deals with the research design and method used in the study, followed by ethical and methodological consideration and the setting of the study. The researcher discusses the research method used and rationale for its use, the study area and the target population of the study, the sampling and the data collection.

Chapter 3 is mainly devoted to the review of applicable theory on stigma and discrimination, including: the definition of stigma and discrimination, HIV and AIDS related stigma and discrimination, and the nature of HIV and AIDs related stigma by incorporating the theory of Erving Goffman on social stigma.

Chapter 4 and 5 will focus on the analysis of the results and the findings and will be followed by the conclusion.

Chapter 2 Method

Research design and method

The study used qualitative study to help obtain an in-depth knowledge (Punch, 2005 p141-142), better understanding, and probably a new discovery of the socio-economic effects of stigmatization on young women. Qualitative study is always very difficult to generalize and replicate due to its small sample size, most unlike quantitative study, which due to its nature and design usually incorporates large numbers and statistically reliable generalizations (Punch, 2005 p 141-148). The aim of the study is not to generalize, but to gain an in-depth knowledge while hoping to discover new information (Punch, 2005 p 145-148) on how stigmatization and discrimination affects these young women infected with HIV. The study employed a qualitative research approach where five young women between 16-24 years of age were interviewed. This particular age group and gender was chosen because of their vulnerability which makes them susceptible to HIV and the magnitude of the social and economic impact the disease have on them (De Bruyn, 1992). Also at this age group most of the time the individual is in school, not employed and even not married which makes the effects more severe on them. Five young women infected with HIV were interviewed face-to-face using in-depth and semi-structured interviews. Due to the sensitive and confidential nature of the topic there was no focus group discussion. The interviews were recorded and short notes were taken to keep up with the interviews. Permission was sought from each participant before the recordings were made (Punch, 2005 p172). Four of the interviews were conducted in Twi; the local dialect, which I can speak and write fluently, then later was transcribed to English. Only one of the interviews was conducted in English. The interview sessions took 30 to 40 minutes with each respondent. The interview process took five days; one respondent was interviewed in a day and after the interview the audio was transcribed (Punch, 2005, p 174-175) in the evening to help me improve for the next interview. Participants were assured that their identities will be kept secret and that they are entitled to drop out at any point of the interview process (Punch, 2005). Participants were told (respondent) will be used to represent them and not their names due to the sensitive nature of the topic. Using qualitative study I was able to gain a descriptive detail and in-depth knowledge and understanding on how stigmatization and discrimination affects the socio-economic status of young women infected with HIV first hand through the interview process (Punch, 2005 ch9). Due to the sensitive nature of the topic in some instances where the

respondents were feeling uncomfortable, the question was not asked again. Also I was limited to only interview a few (five) people due to the nature of the method, which takes much time. This makes it impossible to generalize the results obtained from the field to the entire population of HIV infected young women in Ghana. After getting the notes from the interviews ready, examination was done on how the interview notes answered my research questions through coding (Punch, 2005, p.57). During coding, some themes stood out and were addressed by all the respondents with much passion. (Stigmatization and Discrimination, current and future employment and economic situation and marriage with regards to people living with HIV and AIDS) (Punch, 2005, p.176). The respondents' responses helped me very much to answer the research question.

These interview questions were asked to help me address the problem and my objectives.

Ethical and methodological consideration

Ethical approval for the study was obtained from Ghana National Aids Control Program (NACP). Permission was sought from the medical superintendent at the Ridge Hospital and the nurse in charge at the HIV centre in the hospital (Punch, 2005p276-277). Participants were made aware that their identity would not be revealed in the paper and their participation was voluntary. Participants were informed that they could withdraw their participation at any point without any explanation or any personal consequences (ibid). None of the participants was given a gift or stipends. Due to the sensitive nature of the topic respondents were assured a higher degree of honesty and confidentiality between them and me (Punch, 2005 ch10). Before any of the interviews began, the participants were briefed on the motives behind conducting the research and also informed that the research results were going to be used for my thesis and will be published in the university database (Bryman, 2008 ch5, Holiday, 2007 ch7). Also the respondents were told that either symbols or letters would be used to represent them in the writing of the thesis such as respondents 1-5 (R1-R5) (Punch, 2005 ch10).

Setting

My internship took place at UNAIDS country office in Accra, Ghana. Ghana is a country located in West Africa bordered by Cote d'ivoire to the west, Togo to the east and Burkina Faso to the north. Ghana's population growth rate is at 2.2%, total fertility rate is 4.15 children born per woman, infant mortality 40.9 deaths/1,000 live births, life expectancy 61.45

years (2012 est. http://www.indexmundi.com/ghana/demographics_profile.html). The total population is estimated to be 24.2 million. Total estimate of people living with HIV in number cumulatively is 225,478 made up of 100,336 males and 125,141 females (Ghana Aids Commission 2013). The national prevalence for 2011 was estimated to be 1.5%. Annual HIV and AIDS related deaths was 15, 262 with 2,079 of them children. The prevalence rate among the most at-risk population is men who have sex with men (MSM), lesbians, and female sex workers (FSW) (Ghana Aids Commission, 2012). Ghana has ten regions in total; the prevalence rate differs from one region to another with the northern region having the lowest prevalence rate of 0.3% and the central region with the highest prevalence rate of 4.7% of the regional population (Ghana Aids Commission, 2012). Accra is the capital of Ghana, with the third highest prevalence rate of 3.2%. The prevalence rate among pregnant young women aged 15 – 24 was 2.0% in 2010 and 2.1% in 2011(Ghana Aids Commission, 2012).

During the internship I had the opportunity to conduct my research interviews at the Ridge hospital in Accra located in north ridge with young women living with HIV. Ridge hospital was chosen for this particular study because of the high amount of people living with HIV (PLHIV) who come for counseling, medication and other issues concerning HIV and AIDS. I was given an office room for the interview process. The respondents were very comfortable in answering the questions without any interruption by the hospital staff.

Chapter 3: Theory-Stigma and discrimination

Goffman´s theory of social stigma will be used in this thesis to understand the concept of stigmatization.

Goffman´s theory explains stigma as social or individual attribute that is "devalued" and "discredited" in a particular way (Goffman 1963). The stigmatized individual according to Goffman is "disqualified" from full social acceptance. This means that the stigmatized individual is marginalized and different from the others and therefore needs to be isolated. Goffman divides the individual's relations with stigma into three categories.

- The stigmatized (individuals bearing the stigma)
- The normal (those who do not bear the stigma)
- The wise (individuals among the normal who the stigmatized identifies as wise).

Goffman identifies the virtual and actual social identity as categories, society use to identify stigma. Virtual social identity is the assumption made on the individual on the first interaction with them and actual social identity is the attribute that can be proved due to interaction with the individual for a long time (Goffman, 1963 ch1 p 11-12). Sometimes the wise may be stigmatized in another social context for being wise.

According to Goffman, stigmatization does not occur in isolation, either an individual is the stigmatized, the normal, or the wise (Goffman 1963 ch1).

Discrimination comes about as the end result of stigmatization. According to the Oxford dictionary discrimination is the "unjust or prejudicial treatment of different categories of people, especially on the grounds of race, age, or sex: victims of racial discrimination" (Oxford dictionary, http://oxforddictionaries.com).

The word stigma originally referred to a tattoo mark or brand on Greek slaves who had polluted and so should be avoided in public places (Goffman, 1963 p11). Though HIV and AIDS did not exist at the time Goffman originally described the three different types of stigma, HIV-related stigma can still be included in in the category where the individual character is perceived as weak and unnatural (same as alcoholism, homosexuality, unemployment and suicidal attempt etc).

HIV and AIDs related stigma is referred to as prejudice, negative attitude, abuse and maltreatment directed towards individuals infected with HIV or AIDS and the individual group or community they associate themselves with. This manifests in the form of poor treatment in their health care and education, erosion of rights, maltreatment, violence against them, and rejection (Avert.org). Stigma related to HIV and AIDS came about as the disease in the beginning was seen as deadly and the stigma attached to it was inevitable.

AIDS stigma has also increased the negative attitude towards female sex workers, the gay population, and intravenous drug users as they are the most at risk population of getting infected with the virus. To an extent, AIDS related stigma affects the well being of people living with HIV and AIDS, their family, loved ones, caregivers (Haber et al., 2011, Mwinituo and Mill, 2006), volunteers, and even health professionals. This affects and greatly influences people`s personal interest in counseling and testing and even openly disclosing one`s status., It has even gotten to the point that sometimes people living with HIV believe they got the infection because of the sins of their ancestors or curses sent on them for what they have done or might have done in their first world (Goffman, 1963 ch 1).

There have been several factors that have caused and sourced the HIV and AIDS related stigma and discrimination. There have been several situations were HIV and AIDS have been associated with poverty, gender, sexuality, class and race (Herek *et al* 2002). The initial preconceived ideas that were associated with HIV as a contagious disease, death, horror, crime, otherness, guilt, shame, war, punishment etc worsened the fears and made stigma and discrimination against people living with HIV legitimate (Avert .org).

There are other causes and sources of HIV and AIDS-related stigma and discrimination. This includes sexuality, gender, ethnicity, witchcraft, class and occupation (UNAIDS 2007e).

The most common mode of transmission of HIV is through sexual intercourse, which makes HIV related stigma on sexuality very high and the most common. Therefore any deviation among a group of people from the generally accepted societal norms increases stigma. Example: prostitution, homosexuality (lesbians and gays) and promiscuity (Avert.org).

Gender according to eldis refers to "the socially constructed roles of and relations between men and women" (eldis.org). HIV and AIDS–related stigma and discrimination have also being attributed mostly to the gender of the individual. Women are more prone to being infected with HIV and its related stigma and discrimination due to pre-existing inequalities among men and women with regards to education, employment, cultural and social disadvantages, inequalities in relationships, socio-economic stress, and unequal access to information and service (Centers for disease control and prevention, 2008).

HIV and AIDS related stigma and discrimination with regards to ethnicity and race have been associated with minority and marginalized groups in the society. Some race and ethnicity has been attributed to HIV and AIDS and its related stigma. A survey by the centers for disease control and prevention on HIV and AIDS among women showed that in 2005 black women accounted for 66% of women diagnosed with HIV and AIDS, 17% in white women, 14% in Hispanic women, 1% in Asian Pacific Islander women and 1% in American Indian Alaska native(ibid).

Class and Occupation: HIV and AIDS related stigma and discrimination are mostly been characterized as the disease of the poor and marginalized ones, due to the hardship the disease brings upon its victims especially the poor.

Goffman`s theory has been used to understand the process of stigmatization and discrimination as perceived by the respondents and how this consequently impacts their social and economic lifestyle and status in society. Goffman's theory on stigmatization emphasizes the importance of analyzing and accessing stigma in terms of relationships rather than

individual traits or attributes (Goffman, 1963 ch 1). A study done in Haiti on understanding and addressing AIDS-related stigma incorporating Goffman's theoretical framework found that improvement in clinical service can raise quality of prevention service, boost staff morale, and reduce AIDS-related stigma (Castro and Farmer, 2005). The study found that those individuals who were infected with HIV and AIDS that had become very ill because of lack of access to treatment were stigmatized more than the individuals who were on treatment and able go about their normal duties (Castro and Farmer, 2005).

Chapter 4

Analysis of results

Five young women were interviewed for the thesis; the first respondent is a mother of two children and currently separated from the partner. She ended her education at the junior high school, and at the time of the interview was involved in petty trading. The second respondent has a three years old child and a partner whom she is planning to get married to. She was not able to complete junior high school education since she got pregnant. She sells pastries in a school compound. The third respondent is a student at the tertiary level. The forth respondent also ended her education at the junior high, and at the moment is not working and relies on family support. The fifth respondent has completed her senior secondary education and is planning to write an international exam to be able to study medicine abroad. Each of the five young women between the ages of 16-24 interviewed had different views or experiences about the issues discussed but almost all of them had disheartened issues concerning stigma and discrimination in the society, future employment, marriage etc.

The participants expressed concern about their future employment; they all had a fear of being stigmatized and discriminated in their future employment. At the time of the interviews two of the respondents were still in school (R3 and R5), R4 unemployed, R1 quite weak and could not trade as much she could and only R2 was working actively. She was selling pastries in a school campus where she had fears of being sent away if the authorities came around to do medical examination including HIV test on them. This has left her in greater fears since one day she will be fished out and will not be able to hide any more. The participants continued to describe how stigmatization and discrimination are going to affect their economic and social life if their status is made known to the public.

R1 "now that I am infected with HIV, I have not been able to look after the kids very well as I used to. I am not able to walk for long distance as I used to in selling of the alansa (fruits), our nutritional value has decreased due to my condition and even with their education"

This conforms to the study by Jefferis *et al* and Ajay *et al* as HIV reduces economic growth and decreases household income (Jefferis *et al*, 2008). Attention is also taken away education, nutrition and personal hygiene (Ajay *et al,* 2008). Being infected has prevented her from trading actively as she used to do previously and also not being able to take care of her children as she used to do. This can also affect the children`s up bringing due to lack of social and economic support.

R3 "*Sometimes when I reflect on my condition it strikse me about how people living with HIV (PLHIV) are being laid off from their job which they need the most in their current condition, HIV is not contagious it is just like any other disease such as malaria or cancer you can die at anytime. This makes me scared for future employment*".

This confirms the negative attitude people living with HIV know the labour markets have on them. This can be illustrated by Goffman's theory as people living with HIV (stigmatized) are polluted and contagious and for that matter should not be accepted in public places (Goffman, 1963 ch1 p1). This finding is confirmed by a study by Liu et al. that interviewed 156 employers in Chicago, Beijing and Hong Kong and found HIV related stigma as a strong predictor of unemployment of people living with HIV and AIDs. In the above study, the two main reasons that contributed to employers unwillingness to interview people living with HIV and AIDS were: their fear of contagion and their perception of the competence possessed by the latter (Liu et al., 2012). Contagion has been widely reported to contribute to public stigma against people living with HIV (Rao et al., 2008, Bogart et al., 2008).

R 2"If not because of the infection I would have been working with some white men from abroad. I got the chance to cook and care for the children of some white men from abroad and their families, through my mother's help, but because they have to check for your HIV status before being employed. I was eliminated since I tested positive for HIV".

As described by Goffman immediately a discreditable aspect becomes visible, the stigmatized individual risks losing rights to virtually everything. At this moment the individual feels she has no right to work or do any economic activity since she is HIV positive (Goffman, 1963

ch1). Since she does not know or have access to any law in the labour market that supports people living with HIV and AIDS like her.

R2 "Since am selling pastries on a school compound, we were told by the authorities to do HIV test but always I try to excuse myself, as some people have already been sacked from the compound from selling, we are told they will be coming again to check again, this time I do not think I will be able to exempt myself meaning very soon am going to eliminated also, unless a miracle happens".

As found in previous studies, although some people living with HIV and AIDS successfully manage to enter the workforce, most are faced with barriers throughout the process of seeking and maintaining their employment (Blalock et al., 2002, Braveman et al., 2006).

From the minute there is mistrust in the society, an individual at the edge of being discriminated develops their social interaction skills to prevent themselves from being visible (Goffman, 1963 ch1). Very few have disclosed their status to even their very close family due to the fear of being discriminated while none of the respondents is willing to make their status known to the public. Respondents were able to disclose their status to their immediate family who are supporting them and believe will not stigmatize and discriminate against them.

R1"No I have not being discriminated against just because my status is not known to the public or anyone. I believe if my status is made public, I will definitely be discriminated".

The respondent believes that she has not been discriminated just because her status has not been known to the public. But if there is the need to reduce stigma and discrimination, then there should be some form of desire for the individual to disclose his/her status without any stigma or discrimination. This is supported by the study done by Kayeyi *et al* in East, Central and Southern Africa that shows that HIV prevalence substantially decreased in neighborhoods with increasing level of education, due to reduction in stigma and discrimination (Kayeyi *et al* 2009). When people living with HIV feel they are accepted in the society, I believe they will try as much as they can to prevent themselves from spreading the virus to other people and also save themselves from attracting the different forms of the virus to worsen their case. People in the society will also be motivated to check their status and commence treatment if they are positive (Kayeyi *et al* 2009, Herek, *et al 2002*).

R2 "Among my family is only my mother who is aware of my status, I know if the rest of the family gets to know of my status they will discriminate against me. They will not even allow me to even get closer to them and even the community I live in and my neighbors will not even patronize my food if my status is made public to the ".

P3 "my social activities have been cut off when am in such places I do not feel easy and redrawn"

As described by Goffman the "stigmatized" individual will prefer to stay alone indoors to be depressed and isolated and to prevent any face to face interactions with the normal, than to go to public places where the "normal" will stigmatize and discriminate against them. (Goffman 1963).

P5"actually I will not say it has changed because, I was infected at a very young age and by that time did not know what really HIV was until now that I have been counseled, it did really restrict my social activities with my friend but when I realized that I was kind of different from other children because I was always taken medication which made me rethink about my condition and started to read more about my condition and the virus. Though sometimes am scared and want to redraw myself from people, other times try going to some of the activities".

As Goffman described the stigmatized individual will try as much as they can to get all the necessary knowledge, help and advice about their condition to improve their life and their status (Goffman, 1963 ch1).

R4 "Am not that close to my neighbors but I know that if I disclose my status to them they are going to discriminate against me" "my parents are dead its only one of my Aunty who knows of my status and has been supporting me. She does not discriminate against me, she has even told a pastor to be praying for me".

R5 " the people in my neighborhood are not aware of my status not even my friends because immediately they become aware that is going to be the end of your life, they will stigmatize and discriminate against you and will die slowly through discrimination, I therefore strongly belief that it is advisable not to make your status known to the public".

R3 "Even if it was me, I would not even get closer to the person infected with HIV before I was educated on the virus and how it works. Even when I got to know of my status, I did not want to share anything with my family members for fear of infecting them also. But after having been counseled, my perception has changed. Therefore, I know people will discriminate against me unless they are all educated and given the necessary counseling needed. It is natural and human for them to do that, therefore it should be the government's priority in educating the total population on HIV and AIDS and how it works."

The respondent accepts that before people are educated on HIV and AIDS to know and understand it (mode of transmission, treatment, support, and care for people living with HIV and AIDs), stigma and discrimination against people living with HIV and AIDS will not be eliminated or even minimized in the society. This situation adds up to what Goffman explains as a way forward in reducing stigmatization: to get respectable people in the society who are part of the normal and also deeply accepting of the stigmatized to be the voice of the stigmatized. This can be accomplished by helping to present cases of the stigmatized (their achievements, their situation and conditions, how they are affected by the stigma, how they are able to adjust to their situation, maltreatment by the normal, and how they feel) through advertisements and distribution of leaflets etc (Goffman, 1963 p 37). In chapter 3 of Goffman, it is explained that the stigmatized should assume the normal to be ignorant rather than malicious when discussing the rules the stigmatized should follow when handling the normal (Goffman 1963 ch3). An example of this situation was how comfortable the people living with HIV and the other minority groups felt when they were at UNAIDS country office in Ghana where I was doing my internship for the spring semester.

Due to the vulnerable nature of women in the society, in cases where the woman is the first to know their status most likely through pregnancy or from the affected individual, their partners and family members abandon them and their children in most cases, leaving the woman without any means to support her and the immediate family.

R1 "When it happened that I have reduced in weight, the boyfriend with whom I have two kids with went for another woman, neglecting me and his children. If I tell him that I found out I am HIV positive and therefore he needs to go check his status, he will go and tell my family and the town where I come from and that I have HIV, which will prevent me from going there."

Stereotypes related to HIV and AIDS and its transmission modes continue to have deleterious effects on women and other minorities like homosexuals, lesbians, IV drug users, and prostitutes as the primary modes of transmission. This situation prevents women and the most at risk individuals from practicing safe sex since by using condoms one will be labeled as a prostitute. Consequently, they will avoid frequently checking their status, which offers them the opportunity of getting the necessary or appropriate medication if tested positive for HIV or for other opportunistic infections.

R3"It is kind of embarrassing the reactions people begin to show immediately when they get to know of your status. You are known to be a bad girl moving from one man to sleeping with another. Nobody wants to speak to you which is very sad because married couples even get infected with HIV."

All the participants, like other young women in their age group, wished to be married and have children, but were faced with the fear of the challenges that their situation presents.

HIV positive women have been shown to have a higher risk for pregnancy-related complications such as spontaneous abortions, perinatal mortality, premature births, and the chance of giving birth to an HIV positive child.

R3 "I definitely want to get married. It's going to be very difficult for one to disclose his/her status to his/her partner. I want to keep it a secret from my partner or husband. But maybe when I become pregnant in future, my status will become known to him. Also, if I do not disclose before we get involved, I might infect him and affect the marriage".

R4 "I do not have any partner at the moment; I have decided to wait for sometime before I get someone. I know it's going to be difficult finding a husband who knows I am HIV positive"

R5 "Sometimes I get worried about my future marriage and children and my mother too is very worried. But after being counseled she is okay and I am also fine. It is difficult but when you get counseled then you calm down since at least there have been other positive couples who have been able to give birth to healthy children and are living happily. I know it will be okay when the time comes ".

The above findings are supported by a study conducted among people living with HIV in northern Uganda. The study found that although many women living with HIV desire to be married and have children, they are confronted with various challenges including social and

cultural obligations, as well as stigma and discrimination. They found that stigmatizing behaviors such as abuse and desertion and agents of stigmatization (families, communities and health systems), either directly or indirectly promoted or discouraged their desire to have more children (Nattabi et al., 2012).

External support to these women was seen to positively influence their economic situation and help them to cope better.

R5 "Economically, there has not been any difference before and after I became infected with HIV. I still receive supports from my loved ones, my mother abroad and my grandmother who is really supporting me back home."

Also, support in the form of counseling from the health services staff, the general public, and close relatives also help these women to cope with their psycho-social challenges.

R5"The public should know that people infected with HIV are also human like anybody. What we need is attention from the public to open up their arms and accept us."

High level of self-confidence was also seen as an important ingredient to cope with both current and future burdens posed by stigma and discrimination as a result of the HIV infection.

R5"I believe I can continue my education to any level or point I want to, the only thing is to psych yourself that HIV is not a death sentence. Even an individual who is not HIV positive can get malaria and die, while an individual with HIV will be alive. The first thing for people living with HIV to do is to do away with self-guilt and self-stigmatization and hope there is a life ahead of you. Now, the medications are very effective for the individual to leave strong and have a normal life. I myself want to be a doctor in future, and therefore I do not want the issue of being infected with HIV to obstruct me. I have to stay focused and study very hard to become the doctor I want to be."

This statement by the respondent is an exemplarily way Goffman explains how the stigmatized person responds to their situation by seeking medical help to make a direct attempt to correct what he /she sees as the objective basis of their failing and also working very hard to achieve much in life to prove to society and others that they can do the same things and that they are not failures (Goffman, 1963 p 18). The respondent is seeking

treatment to make herself become healthy and strong and is determined to work very hard to fulfill her dreams of becoming a doctor.

Chapter 5

Conclusions:

The aim of the study was to explore the perceived impacts of stigma and discrimination on young women (16-24 years) infected with HIV on their socio-economic status. Throughout the interviews, stigmatization was one issue that all the respondents reacted to as a big problem when it comes to HIV and AIDS. With reference to the results I got from the respondents, stigma and discrimination are obstacles blocking the provision and uptake of prevention, treatment, care, and support. Goffman's theory of stigma has a significant relevance on the empirical findings of the paper. In a nut shell, Goffman explains the importance of educating of 'the normal' (*the individuals who stigmatize*) on the conditions of the stigmatized, how they feel when stigmatized and examples of those who are stigmatized but have been able to make a difference in the society, as the best way of reducing stigma to certain conditions that prevail in the society. The findings of this study also support Goffman's theory of educating the society on stigmatization and its effects. This study also recommends that such education should be provided at the different levels of society where stigma and discrimination happen among family members, individuals, communities, institutions, government policies and practices, media, and friends.

From this study, it was found that participants perceived the effects of stigma and discrimination on two levels; the current and the future burdens, but beneath this is a third level that helps them to cope with their situation (as illustrated in model 1). This model is very important in understanding the target points for interventions to be able to help these vulnerable women. Interventions can target any of the stages identified in this model by:

1. Increasing support to these women and providing them with other alternatives to help them cope with their situation.

2. Providing interventions and policies that can help reduce the current economic and social burden they face as a result of their HIV status.

3. Providing interventions and policies that will help them cope better with their future economic and psycho-social challenges.

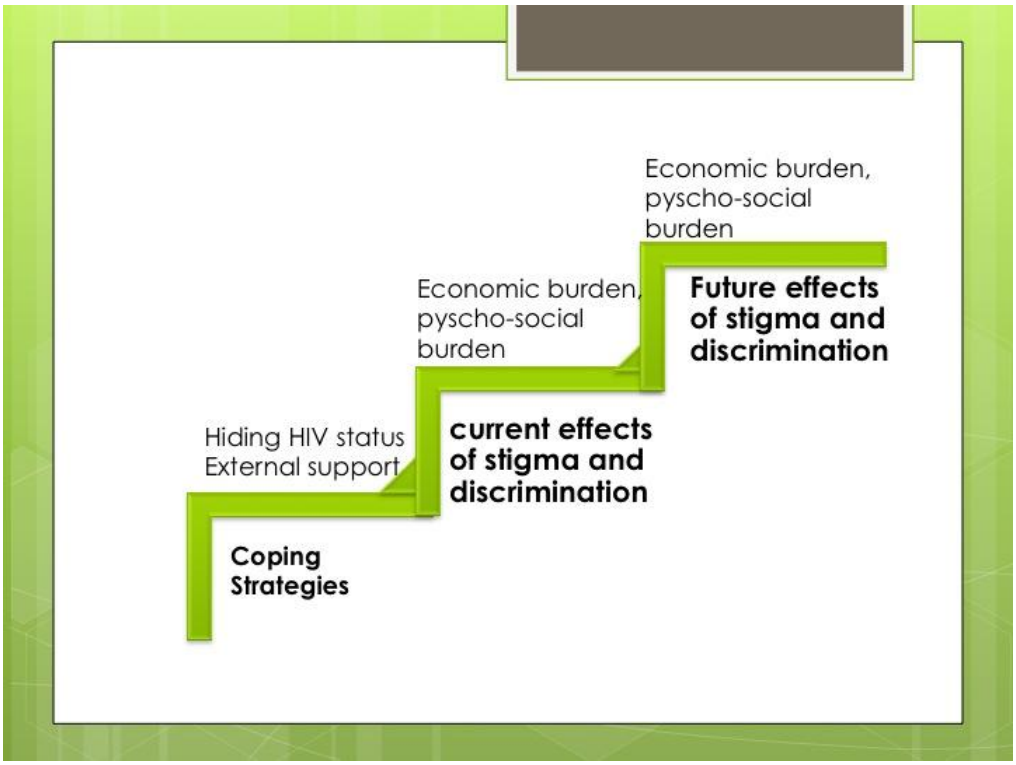

Figure 1: Stages at which policy makers and interventionists can intervene to curb the psycho-social and economic burden posed by stigma and discrimination on young women infected with HIV.

With reference to the findings in this study, there are some important issues that need to be tackled.

Firstly, there is the need to intensify the education of HIV and AIDs to the public and also the importance of making the general population aware and convinced about the mode of transmission which is not through social contacts such as a handshake, a hug, or any form of social gathering and that transmission is also not contagious as it seems to be. The education can start from the very early stages in the primary schools to high schools and universities, about how people living with HIV are living healthy lives and may even live up to their biological life spans. The public should also be educated about the success stories of people living with HIV.

Secondly, human rights laws governing the labour market should be reinforced so that people living with HIV will be secured in their work so far as they are able to do their work

effectively and they should not be discriminated based on their HIV status. This will even reduce their current psychological problem of always thinking about the fear of the future work place stigmatizing against people living with HIV.

Thirdly, there is the need to strengthen the social system so that young women who are not yet in the labour market and are infected with HIV can be supported by family and also the government through good social policies, especially concerning people living with HIV.

These three points or measures need to be put in place by governments, stakeholders, and international bodies, like the UNAIDS and the joint UN team on HIV and AIDS, otherwise it will be very problematic to the achievement of zero new HIV infections, zero stigmatizations, and zero HIV related deaths, which are very important public health goals.

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Appendix

The following open-ended questions were used as a guide during the interview process.

- Have you ever been stigmatized or discriminated based on your HIV status -by: family, spouse / partner, friends, employers, neighbors, hospital staff, teachers, Church members and church leaders?
- How has your participation social activities change before and after realization of HIV status?
- Has there been any extra economic burden as a result of the HIV infection?
- How has the HIV infection affected your current and future economic engagements/activities?
- How has the infection affected your education?
- Do you have any plans of getting married in future?

- How do you think the disease is going to affect your marriage plans?
- Do you want to give birth to your own babies in future?