





# Effect of Disclosure and Social Support on Change in Childbearing Intentions among People Diagnosed With Hiv

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<u>Abstract</u>: - Majority of PLWHA remain sexually active, reproduction among PLWHA are clinical and concerned more on transmission prevention rather than childbearing plans and intentions. There are limited data on childbearing intentions of PLWHA, especially when comparing those whose sexual partners and/or significant others are aware of their HIV status. The study used Information-Motivation- Behavioural Skills Model and Theory of Planned Behaviour in analysing relationship between disclosure and change in sexual behaviour/childbearing intentions among known HIV patients.

A cross sectional study of PLWHA attending care and treatment centre was conducted using both quantitative and qualitative methods of data collection. Selected subsamples of the survey respondents participated in in-depth interviews and 13 were interviewed. Descriptive statistics were calculated to determine rate of disclosure and other outcomes.

Respondents were between the ages of 20-49, belonged to one religious group or the other, a large percentage (56.7%) had secondary education, majority; 90.9% revealed their HIV status to at least one person whereas 50.6% disclosed to their sexual partners. Female respondents disclosed to sexual partners than males (64.2% versus 37.2%, respectively). Doctors/health professionals gave the overall greatest source of support. Only 24.7% reporting abstinence in 12 months while only 20 (9.4%) changed their reproductive intentions after disclosure.

Majority reported receiving more social support after disclosure; disclosure was related to changes in sexual behaviour but not related to childbearing intentions. The study suggests that counsellors and Healthcare providers should provide accurate reproductive health information to guide PLWHA in making informed choices regarding their reproductive goals.

<u>Keywords</u>: Disclosure, Social Support, Change, Sexual Behaviour, Childbearing Intentions

# 1.1 Background to the Study

People diagnosed with HIV, especially newly diagnosed (Index) cases are faced with so many challenges, one of which is the disclosure of status. They undergo a transition to a new sense of self-identity/self-evaluation and perception as they incorporate HIV/AIDS into their lives and as they interact with others (Russell and Seeley 2010). Disclosure can help modify the high-risk behaviours of partners who may not be infected but were unaware of their exposure to HIV; it will also allow HIV positive women make reproductive choices that will offer them safe fertility options including

prevention of mother to child transmission (PMTCT).

A matter of sexuality is a key aspect of lives of people living with HIV and AIDS (PLWHA); after all, PLWHA have a right to a satisfying sex and reproductive life (Segurado and Paiva, 2007). While some PLWHA may decide to stop sexual activities after their HIV diagnosis, others continue to have sex. The importance of disclosure in shaping sexual and reproductive behaviour of PLWHA cannot be overemphasized, not in the least because in heterosexual relationships, sex and reproduction is a dual undertaking between both partners, with differential power relations that tend to favour men.

Studies in the developed world show that over 70% of PLWHA remain sexually active (Crepaz and Marks, 2002), therefore policy makers and healthcare providers have a responsibility to support PLWHA and their partners in protecting their sexual and reproductive health (Cooper et al, 2009; Segurado and Paiva, 2007).

Anti-retrovirals (ART) use also bring new hope for PLWHA; a phenomenon referred to as "treatment optimism" (Kennedy, O'Reilly, Medley and Sweat, 2007), which encourages PLWHA to strive a return to normalcy after a period of initial turmoil (Baumgartner 2007; Carricaburu and Pierret 1995; 2002). Resumption of Kralik, sexual and reproductive lives by PLWHA is reflective of their pursuit for normalcy after disruption to their identity (Smith and Mbakwem, 2010). This however poses a great risk for PLWHA, their partners and possibly their unborn children without disclosure of status. Safe sex and reproductive decisions may be particularly difficult for people in spousal/ intimate/regular sex relationships and can only be negotiated with cogent reason(s) which may not be possible without disclosure of HIV status. It is difficult and almost impossible for a female PLWHA in Sub Saharan Africa (SSA) to negotiate safe sex (Mbizvo and Bassett, 1996) or make reproductive choices (Varga, 2003) except for very cogent reasons like disclosure of a positive HIV status, thus making women in SSA particularly more vulnerable to "risky" sexual and reproductive behaviour or HIV infection (Kalipeni, Oppong, and Zerai 2007; Mill and Anarfi, 2002).

Being newly diagnosed with HIV in the context of treatment optimism will throw more light on how PLWHA, incorporate disclosure to work together with their families and social networks, to manage their new status in general and sexual and reproductive lives in particular. This study was undertaken to understand how PLWHA went about disclosing their HIV status, facilitators or inhibitors of such disclosures, the typical course of these disclosures. outcomes and impact of such disclosures in terms of change in sexual and childbearing intentions.

### **1.2 Statement of Problem**

Coping with the disease, Stigmatization; disease management cost; access to social support in illness as well as sex behavours and childbearing intentions is essential to PLWHAs, Most PLWHAs in SSA are in their prime child-bearing and rearing years, many are already parents who live in a context where a high premium is placed on parenthood (Cooper, Harries, Myer, Orner and Bracken, 2007). In contrast to the general population, people who know they are HIV infected have additional issues to consider, such as potential health risks for (re)infections, vertical transmission of HIV and potential orphaning of existing and future children.

For some PLWHA, meeting family and social obligations concerning reproduction may be more important than the risk of HIV transmission (Cooper et al, 2007). For other PLWHAs, however, their health status and risk of HIV transmission might dissuade them from wanting a/another child. These issues present PLWHAs with a dilemma of either risking vertical and/or horizontal transmission of HIV or setting aside fertility desires.

Safe sex negotiation and planned reproductive choices requires a joint involvement of both partners and can only be possible for PLWHA whose partners are aware of their positive HIV status; thus making disclosure a key issue in preventing MTCT and new infections among negative partners of PLWHAs (discordancy). Urban prevalence of HIV is higher than rural in all geopolitical zones in Nigeria, this is a public health concern and it particularly indicates Lagos State; being a mega city as a hot spot for HIV prevention intervention. Although there has been a general decline of adult prevalence in the country as well as in Lagos State (5.2% to 3.3%); reports of new infections remains a major cause for worry. Within the state, mega areas like Ajegunle are hotspots for HIV infections considering the high population therein and large number of brothels and sex workers.

Meanwhile Most studies on reproduction among PLWHA are clinical and concerned more on transmission prevention rather than childbearing plans and intentions. There are limited data on

childbearing intentions of PLWHA, especially when comparing those whose sexual partners and/or significant others are aware of their HIV status and those who have or are yet to disclose in urban areas of resource poor settings, hence the need for a study of this nature.

# **1.3 Research Questions**

The questions addressed by this study include the following:

- 1. To what extent has PLWHAs' in Ajegunle, Lagos State disclosed their status to sexual partners or significant others?
- 2. What are the factors associated with disclosure of positive HIV status to a sexual partner?
- 3. Do PLWHAs receive social support after status disclosure?
- 4. How does disclosure of positive HIV status influence the sexual behaviour and childbearing intentions of PLWHAs

# 1.4 Objectives of the Study

The general objective of this study is to explore disclosure of HIV status, change in sexual behaviour and childbearing intentions of PLWHAs in Ajegunle, Lagos. The specific objectives are to:

- 1. Assess the extent of positive HIV status in Ajegunle, Lagos State.
- 2. Discuss the factors influencing disclosure of positive HIV status in Ajegunle, Lagos State.
- 3. Examine the extent of social support received as a result status disclosure in Ajegunle, Lagos State.
- 4. Explain the changes sexual behaviour and childbearing intentions of PLWHA following disclosure of status.

### 1.5 Justification for the Study

Available evidence shows that about 50% of all HIV infections in SSA occur in discordant couples already in a stable relationship (UNAIDS, 2010, 2015). This is an indication of the need to shift from the conventional focus of addressing risky behaviour in isolation, after all, several PLWHA remain sexually active thus highlighting the need to pay closer attention to sexual and reproductive health (SRH) needs of PLWHA (Barnett and Whiteside, 2006; Evans and Lambert, 2007; Stillwaggon, 2002; 2016). This is clearly essential as sexual and reproductive lives of PLWHA extend beyond the PLWHA circle to involve their positive or negative partners as well as their unborn children.

The importance of a study of this nature in the selected location cannot be downplayed; urban slums like Ajegunle in Lagos state are characterised by overcrowding, insecurity, poor housing and sanitary conditions, lack of basic social amenities and infrastructure, extreme poverty, high unemployment levels, crime, low educational levels. These conditions combine to produce poor health outcomes for slum residents.

This study responds to this challenge by documenting the extent of positive HIV status disclosure, outcome of positive HIV status disclosure to the sexual partners (an important factor in HIV prevention) and how it influences change in sexual behaviour and reproductive intentions in an urban setting (including urban slum dwellers) of a developing country. This information is expected to be helpful to policy makers and program managers in developing and strengthening strategies to address issues of HIV discordance and MTCT.

Considering the fact that the majority of PLWHA are of reproductive age and the main modes of HIV transmission in Nigeria are heterosexual and motherto-child transmission, the understanding of sexual behaviour and reproductive decisions of PLWHA is crucial for HIV prevention and their quality of life. reproductive Understanding sexual activity, intentions and intentions among PLWHA is necessary to help them enjoy their sexual lives and achieve reproductive goals without sacrificing the health of their partners, their children and their own health. It is expected that findings generated from the study will also contribute to the understanding of factors influencing sexual activity and childbearing intentions of PLWA which will in turn aid programme designs that will address needs of PLWHA.

### 1.6 Study Scope and Limitations

The study covers people who are known PLWHA who are attendees of HIV clinic for treatment.

Children and PLWHA under reproductive age were not considered in the study because they may not be capable of making disclosure and sexual/reproductive decisions individually. By sampling PLWHA resident in a geographically delineated urban slum setting, Ajegunle; an urban slum, a contextual risk environment is identified, with its own set of socio-cultural, economic and environmental conditions likely to have an impact on disclosure decisions outcomes of PLWHA. These contexts include: reproductive factors (no of children), personality of the individual and his or her social network (e.g., based on the availability and supportiveness of friends, intimate partners, family of origin, extended family, co-workers, and health providers); the nature of the social environment, the relational, temporal, and personal contexts in turn, affect the endorsement of reasons for and against HIV disclosure as posited by the Information-Motivation-Behavioural skill theory and Theory of Planned Behaviour.

This study has some limitations; results depended on each PLWHA's self-report and were not verified by their partner. We cannot rule out social desirability bias where PLWHAs reported what they think the society expects. Secondly, it is essential to note that self-reporting about sexual behaviours may be subject to reporting bias. There is evidence of social desirability bias, that is, where people tend to conceal or underreport socially proscribed sexual behaviour such as extra-marital and homosexual relations (Gregson et al. 2002).

Nonetheless, conscious efforts were made by the interviewer who is aware of procedures of securing the comfort, trust, and cooperation of respondents, even though social desirability bias cannot completely be eliminated. It is important to note that sexual behaviour in the 12 months preceding the interview may not sufficiently replicate lifetime sexual behaviour and experience. It is also possible that some people might not recall certain sexual practices that occurred during this time period. Also, sexual practices were just a snapshot picture in the previous 12 months, thus limiting its ability to track changing sexual behaviour and childbearing desires with duration of HIV and disclosure.

# 2.0 Brief Literature Review and Theoretical Framework

A brief review of existing studies on disclosure of positive status among PLWHA and its implication on sexual and reproductive lives of PLWHA in relation to the study's research questions is thus provided. Efforts are made to discuss factors related to HIV disclosure as rationale of the research questions and objectives, identify the gaps in the literature that the study sets out to fill and provide a conceptual framework for the study.

# 2.1 Positive HIV Status Disclosure

For most people disclosure is a gradual process that happens over time and that raises several issues, including the rights of People Living with HIV and AIDS to control their own personal information and their right to confidentiality and privacy (Mathews, Coetzee, Zwarenstein, Lombard, Guttmacher and Oxman, 2002).

Numerous factors have been associated with status disclosure, Greenberg (2000) states that although HIV positive people do not want to disclose their status, they are however motivated to do so because of one factor or the other; these could inlcude but not limited to: sense of ethical responsibility, concern for partners health, failing health or severity of illness, need for social support to cope with the diagnosis and to alleviate stress associated with non-disclosure.

# 2.2 Sexual Behaviour and Experiences of PLWHA

HIV infection until recently (when ARTs were made available and) implied a death sentence, it was as at then, more important to focus on interventions that provided medical, financial and moral support to PLWHA, rather than giving considerations to their sex or reproductive lives. Meanwhile, access to ART in itself meant improvements in health and quality of life among PLWHA and of course in sexual activity (Kennedy et al., 2007). Evidence from the global North shows that over 70% of PLWHA are sexually active, (Crepaz and Marks 2002) implications of unsafe sexual behaviour amongst PLWHA include the possibility of: infecting their sexual partners with the virus; re-infection with multiple strains of HIV; and, transmission of drug resistant strains (Courtenay-Quirk, Cari, Jun Zhang and Wolitski 2009; Maclachlan, 2007

The rise in "risky" sexual behaviour amongst ART users has been attributed to the phenomenon referred to as "treatment optimism" or "disinhibition" (Kennedy et al., 2007). This refers to a situation where PLWHA believe that since ART reduces their viral load to undetectable levels, they are well and no longer infectious (Kennedy et al. 2007). In short, treatment optimism has the potential to increase risky sexual behaviour, the variable in the context of childbearing intentions is however unclear; a gap this study is set to fill.

# **2.3 Disclosure and Change in Sexual Behaviour** /Reproductive Intentions

Literature shows that perceptions of self- identity and lived experience have implications on sexual and reproductive behaviours of PLWHA (Smith and Mbakwem, 2010). Living with a chronic illness can to lead to a biographical disruption of the self (Bury, 1982) and the need for reconstruction mechanisms to return to a more normal state (Carricaburu and Pierret, 1995; Kralik, 2002).

The study of reproductive desires and intentions and sexual health among PLWHA is very crucial because HIV can be transmitted in the same way that pregnancy is achieved, that is, through unprotected hetero-sexual intercourse. Thus, unprotected sex among PLWHA, in order to conceive, carries the risk of transmitting HIV to sexual partners and subsequently to children during birth or breast feeding, Also, reproductive decisions made by PLWHA and their partners have long-term consequences for the survival and wellbeing of their families and society at large (Hosegood, 2009).

Studies in SSA have identified a relationship between disclosure of HIV status to sexual partners and change in sexual behaviour (Akanni and Erabor, 2006; Amoran, 2012; Daniel and Oladapo 2001; Salami, Ogunbodede and Desalu, 2011.). Still, effects of HIV/AIDS on fertility and the childbearing intentions and preferences among PLWHA are poorly understood. Studies on reproduction and fertility have been mainly biological, focusing on the negative effect of HIV infection on the ability to conceive or carry a pregnancy to term (Darak, Janssen, and Hutter, 2011, Kazuyo, Mumah, Mutua and Cleland 2019; Wajesa and Coast 2014)

# 2.4 Theoretical Framework

This study is based on the framework of Information-Motivation- Behavioural Skills Model (IBM) (Fisher and Fisher, 1992; Fisher et al., 2006) and Theory of Planned Behaviour (TPB) (Ajzen and Madden, 1986). These theories are employed in analysing factors related to disclosure and change in sexual behaviour/childbearing intentions. The IMB model was proposed by Fisher and Fisher (1992) to explain HIV related behaviours, this model identifies three primary constructs that influence behaviour change: Information and knowledge about the behaviour; the individual's motivation to perform the behaviour; and the behavioural health skills needed to engage in a given health behaviour, as specific individual determinants of behaviour and behaviour change. The constructs of the Information-motivation-behavioural skills model (IMB) provide a platform to design interventions that help to induce change in the pattern of health behaviour and plan preventive public health programs. The 'information' component targets understanding of the concepts that lead to behaviour change and the ways and means of achieving the behaviour change.

The Theoryof Planned Behaviour (TPB) is developed by Fishbein and Ajzen (1975) in Green and Kreutere, (1991). It defines the links between beliefs, attitudes, norms, intentions, and behaviors of individuals. According to this model, also known as theory of reasoned action; a person's behavior is determined by its behavioral intention to perform it. This intention is itself determined by the person's attitudes and his subjective norms towards the behavior. Fishbein and Ajzen defines the subjective norms as "the person's perception that most people who are important to him thinks about performing the behavior in question"

# 3.0 Methodology

# 3.1 Study Area

Ajegunle is a major informal settlement, often referred to as 'jungle city' with a multi-ethnic population. It is the most populated slum in Lagos State. Ajegunle has a population density of 750 the highest of all slums in Lagos state. Ajegunle is situated in Ajeromi/Ifelodun local government, the second largest local government in Lagos state. In Ajegunle, it is normal to find the assistant manager of a bank, the insurance marketing executive, mingling with factory and construction workers, even hawkers of Gala at a local drinking bar (popularly known as beer parlour), after a hard day's job; as is the character of the consummate ghetto man.. It may be noteworthy that Ajegunle records the highest number of brothels in the Lagos state (Ajeromi-Ifelodun Local Government Health Reports 2010, 2013).

# 3.2. Research Design

A cross sectional study of PLWHA attending care and treatment centre was conducted using both quantitative and qualitative methods of data collection. Officials of Ajeromi General Hospital Ajegunle (AGHA) VCT Centre were contacted to assist with participant recruitment. Officials of AGHA were approached and an explanation was given about the study, its purpose, objectives, and all the planned activities. Permission was sought from them to assist with recruitment of participants. After the participants granted permission and were comfortable enough, the researcher was then introduced to them. Only individuals, who volunteered and met the admission sample criteria, were recruited for the study. The participants were drawn from the database because they were already identified as people living with HIV/ AIDS.

As an integrative strategy, this study selected subsamples of the survey respondents to participate in in-depth interviews (IDIs). IDIs were purposively selected from questionnaire respondents on the basis of their understanding of questionnaire and willingness to provide deeper answers to buttress their points. There are few guidelines as to how one should proceed in selecting cases for qualitative follow-up from quantitative studies, and for mixed methods sequential design include either selecting typical cases or outlier (extreme) cases for follow-up (Ivankova, Creswell and Stick, 2006). This study selected typical cases from the survey for follow-up in- depth interviews so that quantitative results can be better explained with qualitative analysis. This resulted in a total of 21 typical cases identified from the survey sample. Out of an initial sample of 21, only 13 were interviewed.

# 3.3 Data Management and Analysis

QuantitativeData were edited, cleaned, coded, entered and analyzed using SPSS version-16.0 Descriptive statistics were calculated to determine rate of disclosure and other outcomes. Odds ratios and 95% confidence intervals were used to determine the significance and degree of association between dependent and independent variables. To identify independent associated factors multiple logistic regression were employed.A logistic regression model was produced with disclosure and non-disclosure as outcome variable identifies associated factors. Multiple logistic regression models well used to identify the factors related to disclosure.Statistical analysis described socioeconomic, diagnostic and disclosure probabilities of the respondents. The qualitative analysis involved the categorization of responses into the objectives of the study, which they match. The open code content analysis was adopted to transcribe recordings followed by examination and isolation of various responses according to the respective objectives, in regard; some transcribed opinions this of respondents were reported to compliment the quantitative data.

# **3.4 Ethical Consideration.**

Ethical principles were adhered to and the research was conducted in an ethical manner, participants were informed of the study and invited to participate in the study by officials of AGHA VCT centre. Information sheets about the study, purpose, and significance were read and given to participants to allow them to make an informed decision about their participation in the study. Participants were informed that participation was on a voluntary basis. They were informed about possible advantages and inconveniences of participating in the study, and that they could withdraw at any time. After the participant agreed to participate in the study, they signed consent forms. Information about the participants were kept confidentially as only the person involved in the study had access to it. Individual in-depth interviews were conducted in private settings. Anonymity was maintained by the allocation of numbers and for each participant instead of using their real names. The risks associated with participating in the study, such as emotional upsets were kept minimal. In the event of an emotional breakdown during individual in-depth interviews, research assistants attended to such clients. No information was collected that did not relate to the study.

# 4.0 Findings

# **4.1 Socio-Demographic Characteristics of Survey Respondents**

The socio-demographic characteristics of the study participants are summarized in Table 1. Data were collected from 430 respondents who have tested positive to HIV, 176 (40.9%) of the respondents were between the ages of 26-35, followed by those between 36 to 45 years of age, 129 (30%), then 73 (16.9) less than 25 years of age and the remaining 52 (12.1%) were above 45 years of age. An implication of this is that the majority of the respondents were in their prime and reproductive age; this is a reflection of NACA's (2010) report about HIV infections in Nigeria that majority of the new infections occur in persons who are within the reproductive age, a subpopulation that includes singles as well as cohabiting or married sexual partners.

All the participants belonged to one religious group or the other, with the majority of 232 (54.0%) being Christians, 198 (46.0%) being Muslims. Background information on religion is essential as people view religion as an important aspect of life. To a large extent, religion plays an important role in dealing with people who have problems, including those who are infected and affected by HIV/AIDS through spiritual counseling and material support, and could provide the basis for people's reason for disclosing their HIV positive status in order to access prayers, care and support.

Respondents' educational level ranged from primary school, secondary school and tertiary institutions. The majority 244 (56.7%) had secondary education, 98 (22.7%) had tertiary education, and the remaining 88 (20.6%) respondents had none or only primary education. This statistics provides a reflection of the literacy level picture of urban slum dwellers. This population can be described as a semi-literate population. Majority 296 (68.9%) indicated that they reside (married or cohabiting) with their sexual partners, since the study included individuals in sexual relationships, marital-like or otherwise, formal or informal; cohabitation pattern was considered more relevant than nature of union once the participant had sexual relationships. Another 19 (4.4%) reported being widowed or divorced while the remaining 15 (3.5%) of the respondents claimed to be single or never married to their sexual partners. It can be said then, that quite a number of PLWHA do live with their sexual partners after testing positive to HIV. A total of 337 (78.4%) respondents reside within Ajegunle area, and of the total sample, 93 (21.6%) reside outside Ajegunle; the fact that people who resided outside Ajegunle come for HIV care and treatment in Ajegunle may suggest that PLWHA choose to attend HIV clinics outside their vicinity for one reason or another. For the qualitative study, participants' age range was between 26 and 48 years. This age range fell well within the age criteria for inclusion into the study. There were more females than males, with four out of thirteen participants being males. Almost all participants and their partners were educated, with two having tertiary education and others having secondary education. Almost all respondents demonstrated difficulty /hesitation in describing the pattern of relationship with partners before knowledge of positive HIV status; with seven saying "okay", five "alright" and one individual said "so..so". Only one out of thirteen participants was unemployed. All participants reported their health as being 'okay' or 'good' and some had children with their current partner or from a previous relationship. All participants are either at stage I or II of HIV

infection, all have had more than one sexual partner respondents were not sure of partners HIV status.

in their lifetime, two reside outside Ajegunle or all

**Table 4.1:** Socio-demographic characteristics of the respondents, Ajeromi General Hospital, Ajegunle

 Lagos August 2010

Variable	Frequency	Percentage (%)
Age (years)		4.0
15-24	17	59.2
25-34	255	36.8
35 and above	158	
Education		20.6
None/Primary	88	56.7
Secondary	244	22.7
Tertiary	98	
Residence Pattern		68,2
Residing with partner	296	29.5
Living alone	64	2.3
No response	10	
Family Income per month (in Naira)		53.7
$\leq 15\ 000$	231	6.1
15 000 - 30 000	26	11.2
31 000 above	48	29.0
None/ Unstated	125	

Religion		
Islam	198	46.0
Christianity	232	54.0
Marital Status		
Married/Cohabiting	316	73.5
Widowed/Divorced	19	4.4
Single/Never Married	95	22.1
Currently living with partner		
Yes	306	83.2
No	124	16.8

# **4.2 HIV Status Disclosure Rates.**

On the one hand disclosure has been associated with safer sex, treatment adherence and social support provision (Gielen et al., 2000; Izugbara and Wekesa, 2011). On the other hand disclosure has been found stigmatizing elicit attributes such to as discrimination, rejection and other negative reactions (Carricaburu and Pierret, 1995; Anderson and Doyal, 2004; Paxton, 2002). Despite its importance, documentation of the actual process (when and how) of disclosure and its consequences remain largely insufficient (Chaudoir, Fisher, and Simoni, 2011). The majority (90.9%) of PLWHA in this study reported that they had disclosed their HIV status to another person apart from health care providers and researchers.

A total of 404 (90.9%) of the respondents revealed their HIV status to at least one person. This indicates a high disclosure rate in the area. The high general disclosure rate (90.9%) is almost similar to those reported by Akanni (2006), but the sex partner disclosure rate is far higher than that reported by Salami et al (2011) which is 39.5%. Studies among PLWHA report different rates of disclosure; for example 88% of PLWHA in the US had at least disclosed their status to a friend or family member (Kalichman et al., 2008) and 95% of PLWHA had disclosed to someone in Uganda (Ssali et al., 2010). The high rate of disclosure may possibly be traced to the fact that respondents for the study are known who belonged to one support group or the other and who are attendees of HIV care services.

The proportions of those who disclosed to sexual partners were almost evenly split, with 218 (50.6%) of the respondents disclosed their positive result to

their sexual partners and the remaining 49.4% did not. Female respondents disclosed to sexual partners than males (64.2% versus 37.2%, respectively).

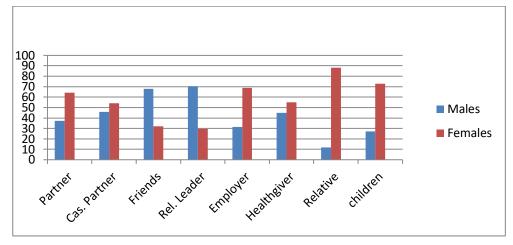


Figure 1: Disclosure Rates by Gender among Respondents

# Network/General Disclosure

Only 100 (23.3%) of respondents told their friends about their HIV status, 391(90.9%) inform health caregivers of the HIV status. 314(73.2%) of the respondents had disclosed to the religious leaders, 36(8.4%) to their employers; and 137(31.9%)claimed to have disclosed to a relative. Meanwhile, among the 228 respondents who reported having other casual sex partners than their regular sex partners, only 37(16.2%) disclosed their positive HIV status to their casual sex partners. Also, only 11 (5.2%) of the 212 respondents who have children revealed their positive HIV status. Responses from IDI respondents indicated that only few respondents have not disclosed to at least one person other than caregivers, although only four persons claimed to have revealed their HIV status to their partners. Many of the respondents claimed to have delayed disclosure to anyone, according to their reports; as reported by a respondent:

My closest friend is aware of my HIV status, we tell each other everthing no matter how terrible it is, I also todl my mum recently.

### (IDI; Anonymised, Single, fFemale, 29 Years)

A respondent recalled:

I told my pastor, it is only God that can cure HIV.

(**IDI; Anonymised, Seperated, Male, 44 Years**) Another also said: I have a friend who is so close to me, she would have known eventually if I did not inform her. We do things together. . (**IDI, Seperated, Female, 42 Years**)

### 4.3 Reasons for Disclosure

Several (in some cases multiple) reasons were reported for disclosing their status; 200 (46.5%) of the respondents claimed they decided to disclosed because of the perceived benefits of disclosure, 316 (73.5%) respondents were encouraged to do so by others, care givers motivated 181 (42.1%), the perceived risk of non-disclosure made 160 (37.2%) disclose their status; and 91 (21.2%) felt they had no option than to disclose their status. Other factors mentioned leading to disclosing one's HIV positive status in the space provided include the following: deteriorating health status, accessing medical care services. Prevention of Mother Child to Transmission of HIV (PMTCT), need for emotional and psychological support, need for more information about HIV promoting HIV /AIDS awareness, to encourage partner to check for HIV status; to negotiate safer sex and 'to feel better'.

# **4.4 Disclosure Outcomes: Social Support, Change in Sexual Behaviour and Childbearing Intentions**

### 1. Social support

Outcome of disclosure was measured in terms of perceived social support received from disclosure recipients. Social support was measured for eight

possible relationship categories in an individual's social network; although perceived level of social support may be clouded and may be a function of expectations. Individuals may be disappointed when they received less or more social support than expected from the person disclosed to, this may affect their judgment of the social support provided had increased, decreased, or remained the same after disclosure of HIV status for each relationship category.

For all relationships, the majority of individuals reported receiving more support after disclosing their HIV status (69% of all types of support given) as opposed to the same amount of support (22%) or less support (9%). Also, results revealed that the greatest increase in support was reported to have been received from friends (84%), followed closely by doctors (83%), religious leaders (83%) and family members (81%). Figure 4.12 describes percentage of social support received by respondents. This an indication that social support received after disclosure of HIV increases generally. According to a participant's narrative:

They have been supportive; my pastor has been very kind.

# (IDI, Separated, Male, 44 Years)

A similar report was that:

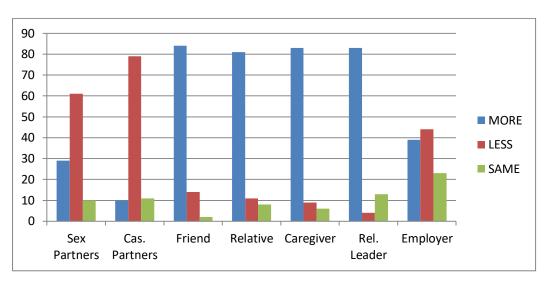
Most of the doctors are my friends; they call to check on you when you don't show up for your drugs, they are very nice

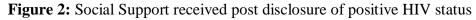
### (IDI, Single, Female 33 Years)

A respondent added:

My friend and cousin that are aware are very nice; sometimes my cousin follows me to the clinic for my medications. The VCT people are good people too, they relate with us as if HIv is no big deal

# (IDI; Anonymised, Single, Female, 29 Years)





Furthermore, the study was interested in knowing which social network members were providing the most amount of support to the majority of the HIVpositive individuals in this study's sample. Participants were allowed to choose multiple support sources of the eight relationship categories. In most respondents, Doctors/health professionals gave the overall greatest source of support with 25% of all support being provided by health professionals. Immediate families were reported to be supportive for 20% of individuals, and friends supported 16% of HIV-positive individuals. Fig.3 describes the overall percentage of social support.

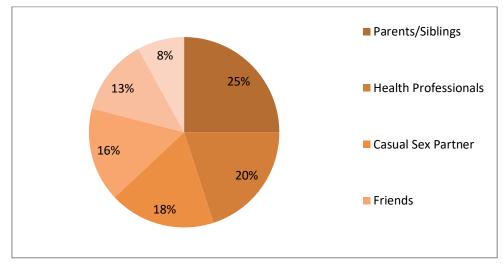


Figure 3: Overall percentage of social support.

# 4.5 Sexual Activity among Respondents

Both the quantitative and the in-depth qualitative interviews with PLWHA methods were utilised to gather information about sexual behaviour of PLWHA before and after disclosure of status to sexual partners. The quantitative data provide the magnitude of sexual activity and its variations. Qualitative data from the in-depth interviews provides more in depth explanations. Among the respondents, the majority 324 (75.3%) of PLWHA reported having sex in the previous 12 months; of these, 176 (54.3%) are males and 148 (45.7%) are females. Only three of the participants for qualitative study claimed to have abstained from sex in the past 12 months prior the interview.

Findings from this study reveal higher sexual activity among men (54.3%) than women 945.7%); Njogu and Martin (2005), and Wakesa (2014), have similarly documented higher reported sexual activity among men (not necessarily PLWHA) in comparison to women. Probable justifications for expected and observed gender differentials in sexual activity may be reporting bias; reporting of sexual activity is influenced by socio-cultural beliefs in SSA (Caldwell, Caldwell, and Quiggin, 1989).

Findings from this study reflect other studies' findings that PLWHA are sexually active and that HIV infection does not eliminate their sexual desires. Studies elsewhere, though with different time frames, report sexual activity for PLWHA, including 59% in the preceding 3 months in the Caribbean (Allen et al., 2010) and 45% in the

preceding six months in Mombasa, Kenya (Sarna et al. 2008).

In this study, the following were received from the field:

The truth is, this thing is part of life, more so you cannot do without sex for too long; it is not possible. (IDI; Anonymised, Separated, Male, 41 Years).

Other participants also said concerning their sexual activeness:

• Yes, I have had sex. It is something you cannot avoid completely

### (IDI; Anonymised, Married, Female, 41 years)

• Ah..... one cannot say because you eat one food and is turning your stomach then you will not eat again, I do it oooooo......( laughs)

### (IDI; Anonymised, Separated, Male, 48 years)

Principles of masculinity and femininity may account for differential sexual activity between men and women. In African societies, cultural expectations that women should take a passive role and men take a dominant role can influence the reporting of sexual behaviour (Varga, 2003). As noted by a participant in the study, total abstinence may be difficult to observe.

According to a participant, it is the nature that dictates and once both parties want it, then it can't be rejected:

It's hard not to have sex at all; even when you want to take your mind off it the body will call for it; i do it once in a while.....you know..... When he wants it and you want it to the body will still want life... (**IDI;Anonymised, Married, Female 41 years**)

Another participant also felt that abstaining from sexual intercourse is not necessary:

There's no way one will not do it oo..... Having this disease is not the end of life now, I do it (well well), although not like before, but whenever I want it, I do it

# (IDI; Anonymised, Male, Seperated, 42 Years)

To assess level of sexual activeness among respondents; respondents were asked to give an idea of last time they had sex; responses ranged from days (n=67; 20.7%) to weeks (n=196; 60.5%) and the remaining 61(18.8%) mentioning months.

Among the respondents for quantitative data, 106 (24.7%) of PLWHA in the survey was sexually abstinent in the last 12 months. A related study by Chama, Morrupa, and Gashau, (2007), found comparable rate of 24% of sexual abstinence. The in-depth interviews helped to understand the circumstances that led to some PLWHA to remain sexually inactive. Reasons for abstinence was not captured in the quantitative data, but was probed among participants of the IDI. Participants' accounts revealed that some PLWHA understood positive living that was discussed during ART adherence counselling.

No o; they (doctors) did not say it plain (directly) like that, you know how they talk now...(laughs) He said "you have to watch the way you do 'it' for now; I mean the number of times you do it, so that you can conserve your energy, you must not stress yourself too much henceforth, so that you will not breakdown". I thank God (I) am still alive, I just want to take care of myself, I can't waste my energy on that for now.

# (IDI; Anonymised, Separated, Female, 41 Years)

The truth is that I am not as strong as I used to be, I've lost energy and caused issues with my former girlfriend. I can't stress myself because yourself and yet the body has not regained full strength. I decided to concentrate on my medication first. If it is sex I will do it in the future.

# (IDI; Anonymised, Separated, Male, 38 years)

# 4.6 Change in sexual Behaviour

Respondents were asked whether or not they took precautionary steps to protect against HIV transmission after testing and after disclosing their HIV status to sexual partners. Participants were asked to recall if they made the following sexual behaviour changes post-test and post-disclosure: abstained from sex, always used condoms, used condoms more frequently, changed the way they selected sexual partners, limited the total number of sexual partners, or became monogamous. The most frequent change in sexual behaviour with regard to safer sexual interactions pre disclosure was that 62.1% of participants decided to have sex with only one partner, followed by using condoms during every sexual interaction (55.4%), using condoms more often (60.3%), reducing the number of sexual partners (16.1%),changing partner selection abstaining from sex (19.6%) (54.2%), and maintaining frequency of sex (24.2%).

After disclosure, the majority (82.3%) of participants asked their partner to get tested. The most frequent change in sexual behaviour with regard to safer sexual interactions was that 81.2% of participants decided to have sex with only one partner, followed by using condoms during every sexual interaction (63.7%), using condoms more often (58.7%), reducing the number of sexual partners (56.2%), changing partner selection (54.3%), maintaining frequency of sex (40.6%) and abstaining from sex (19.6%). Averagely, individuals who eventually told their partner made more positive behaviour changes after receiving their HIV test results compared with those who never disclosed to their sexual partner. Fig.5 shows behaviour change pre and post disclosure among respondents.

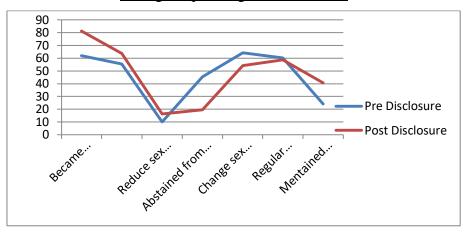


Figure 5: Sexual Behaviour pre and post disclosure among respondents.

# 4.7 Childbearing Intentions and Change in Reproductive Behaviour/Intention as a Result of Disclosure among PLWHA

Findings of this study revealed a high level of sexual activity among PLWHA, further highlighting the existence of reproductive health needs among this population. A total of 282 (65.6%) of the respondents reported no intention of more children, while the remaining 148 (34.4%) claim to have plans of having more children. To assess the possible effect of disclosure on change in childbearing intentions, respondents were asked to recall if the childbearing intention they had after knowing their HIV status remained same after disclosing their status to their sexual partners.

Among the disclosers; majority, 197(90.6%) did not change their reproductive desires after disclosure while only 20 (9.4%) changed their reproductive intentions after disclosure; an indication that disclosure did not necessarily change childbearing intentions of PLWHA. A possibility however, is that childbearing intentions may be a reason for not disclosing as reported by a respondent:

There is no point telling him, afterall there are two children already. He had one child before we met and I had one for another man before. We are struggling to cater for them so we agreed not to have children now. We use condom anytime we do it, so no need for that now.

(IDI; Anonymised, Married, Female, 41 Years)

Regardless of the fact that about half of respondents revealed their status to their sexual partners, 31(14%) of those who disclosed to their partners already had sex with their partner before revealing their results to their partner (delayed disclosure); this is a worrisome occurrence. Also, the methods of HIV status disclosure varied among participants as 190 (86.8%) of the discloser told their partners directly while the remaining 28 (13.2%) used the indirect method. Findings from the qualitative revealed that most disclosers had to go through the process of considering modes of delivering the news; and finally delivering the news.

Majority of HIV-positive individuals reported receiving more social support after disclosure, which is important, given the negative stigma surrounding the disease. Social support has been linked to many positive outcomes such as buffering psychological and emotional distress, promoting more adaptive HIV coping strategies such as spiritual resilience and community involvement and even positive effects on the immune system, which in turn influence mortality risk and survival. (Deribe et al, 2008) Meanwhile, some of individuals who disclosed to their sexual partners were met with less support. Because decreases in social support may have tangible effects on quality of life and disease trajectory, further research is needed to specify the (suspected) reasons why these individuals received less support.

The findings showed that majority of PLWHA were sexually active in the last twelve months. Though sexually functional, some PLWHA reported that their desires were diminished and their sexual

#### Conclusion

activities less frequent and satisfactory. Their sexual experience is plagued with fears about HIV transmission and status disclosure, loss of sexual interest and libido, concerns about their sexual performance and partner rejection.

The conclusion from analysis of findings is that there is sex after HIV infection for the majority of PLWHA, disclosure of HIV status to sexual partners needs to be encouraged and the need for PLWHA to express themselves sexually needs to be recognised as their right and supported. Conclusively, disclosure was related to changes in sexual behaviour and was probably a baseline factor for disclosure to sexual partners in the first place; but not related to childbearing intentions.

# Recommendations

An institution that will mainly focus on handling support and managing disclosure outcomes and management should be put in place, access to such institutions could be through internet, phone calls, and where desired, through physical appearance, so as to protect and guarantee the confidentiality of clients. It is recommended that counsellors should be encouraged to help PLWHAs to develop an individualized disclosure plan especially targeting younger women  $\leq 25$  years, those who are within childbearing age and those who didn't discuss with partners before testing. Healthcare providers should provide accurate reproductive health information, free of personal bias; this will guide PLWHA in regarding making informed choices their reproductive goals.

# References

- 1. Ajeromi-Ifelodun Local Government Health Reports 2010, 2013
- Ajzen, I., and Thomas, J. M. 1986 Prediction of goal-directed behavior: Attitudes, intentions, and perceived behavioral control. Journal of Experimental Social Psychology 22 (5):453-474.
- **3.** Akani, C. I. and Erhabor, O. 2006. Rate pattern and Barriers of HIV Serostatus Disclosure in a Resource –limited Setting in the Niger Delta of Nigeria. Tropical Doctor, 36(2): 87-89.

- **4.** Allen, C. F., Y. Simon, J. E, and Simeon, D.T. 2010. Factors associated with condom use: economic security and positive prevention among people living with HIV/AIDS in the Caribbean. AIDS Care 22 (11):1386-1394.
- Amoran, O. E. 2012 Predictors of disclosure of sero-status to sexual partners among people living with HIV/AIDS in Ogun State, Nigeria. Niger J Clin Pract 2012;15:385-90
- **6.** Anderson, J., and Doyal, L. 2004. Women from Africa living with HIV in London: a descriptive study. AIDS Care 16 (1):95 105.
- Barnett, Tony, and Whiteside A.. 2006. AIDS in the Twenty-First Century: Disease and Globalization. Second Edition ed. New York: Palgrave Macmillan
- Bartos, M., and McDonald, K. 2000. HIV as identity, experience or career. AIDS Care 12 (3):299-306.
- **9.** Baumgartner, Lisa M. 2007. The Incorporation of the HIV/AIDS Identity Into the Self Over Time. Qualitative Health Research 17 (7):919-931.
- 10. Bunnell, R.E., Mermin, J.H, De Cock, K.M. 2006. HIV prevention for a threatened continent. Implementing positive prevention in Africa. Journal of American Medical Association; 296(7):855-858.
- **11.** Bury, Michael. 1982. Chronic illness as biographical disruption. Sociology of Health & Illness 4 (2):167-182.
- Caldwell, J. C., Caldwell, P and Quiggin, P. 1989. The Social Context of AIDS in sub-Saharan Africa. Population and Development Review 15 (2):185-234.
- **13.** Carricaburu, D. and Pierret J. 1995. From biographical disruption to biographical reinforcement: the case of HIV-positive men. Sociology of Health & Illness 17 (1):65-88.
- 14. Chama, C., Morrupa, J. and Gashau, W. 2007. Sex and reproduction among HIV- infected people in Maiduguri, Nigeria. Journal of Obstetrics & Gynaecology 27 (8):812-815.
- **15.** Chaudoir, S. R., Fisher, J.D and Simoni, J. 2011. Understanding HIV disclosure: A review and application of the Disclosure Processes

Model. Social Science and Medicine 72 (10):1618-1629.

- 16. Cooper, Diane, Jane Harries, Landon Myer, Phyllis Orner, and Hillary Bracken. 2007. "Life is still going on": Reproductive intentions among HIV-positive women and men in South Africa. Social Science & Medicine 65 (2):274-283.
- **17.** Cooper, Diane, Jennifer Moodley, Virginia Zweigenthal, Linda-Gail Bekker, Iqbal Shah, and Landon Myer. 2009. Fertility Intentions and Reproductive Health Care Needs of People Living with HIV in Cape Town, South Africa: Implications for Integrating Reproductive Health and HIV Care Services. AIDS and Behavior 13 (supplement 1):38-46.
- Courtenay-Quirk, Cari, Jun Zhang, and Richard Wolitski. 2009. Intentional Abstinence Among Homeless and Unstably Housed Persons Living with HIV/AIDS. AIDS and Behavior 13 (6):1119-1128.
- **19.** Crepaz, N. and Marks, G. 2002. Towards an understanding of sexual risk behaviour in people living with HIV: A review of social, psychological and medical findings. AIDS, 16:135-159
- **20.** Daniel O.J and Oladapo O.T 2011: Selfdisclosure of HIV sero-status to sexual partner in Nigeria
- **21.** Darak, Shrinivas, Fanny Janssen, and Inge Hutter. 2011. Fertility among HIV-infected Indian women: the biological effect and its implications. Journal of Biosocial Science 43 (01):19-29.
- 22. Deribe K, Woldemichael K, Wondafrash M, Haile A, Amberbir A. (2008) Disclosure experience and associated factors among HIV positive men and women clinical service users in southwest Ethiopia. BMC Public Health. 8:81.
- 23. Eliud Wekesa, Ernestina Coast (2014) Fertility Desires among Men and Women Living with HIV/AIDS in Nairobi Slums: A Mixed Methods Study. PLoS One. 2014; 9(8): e106292.
- 24. Kazuyo Machiyama, Joyce N. Mumah, Michael Mutua, John Cleland (2019) Childbearing

desires and behaviour: a prospective assessment in Nairobi slumsBMC Pregnancy Childbirth. 2019; 19: 100. doi: 10.1186/s12884-019-2245-3

- **25.** PMCID: PMC6437922
- **26.** Evans, Catrin, and Helen Lambert. 2007. The limits of behaviour change theory: Condom use and contexts of HIV risk in the Kolkata sex industry. Culture, Health & Sexuality 10 (1):27-41.
- 27. Fisher, J. D., W. A. Fisher, K. R. Amico, and J. J. Harman. 2006. An information- motivation-behavioral skills model of adherence to antiretroviral therapy. Health Psychology 25 (4):462-473.
- 28. Fisher, Jeffrey D., and William A. Fisher. 1992. Changing AIDS-risk behavior. Psychological Bulletin 111 (3):455-474.
- **29.** Gielen, Andrea, Linda Fogarty, Patricia O'Campo, Jean Anderson, Jean Keller, and Ruth Faden. 2000. Women living with HIV: Disclosure, violence, and social support. Journal of Urban Health 77 (3):480-491.
- **30.** Green L,W and Kreuter M.W 1991 Health promotion planning, an educational and
- **31.** Greenberg, J. 2000. The impact of disclosure of mixed HIV Status of support, relationship satisfaction and psychological Distress for male mixed status couples. Accessed from www.informaworld.com/index.
- **32.** Gregson, Simon, To Zhuwau, Joshua Ndlovu, and Constance Nyamukapa. 2002. Methods to Reduce Social Desirability Bias in Sex Surveys in Low- Development Settings: Experience in Zimbabwe. Sexually Transmitted Diseases 29 (10):568-575.
- **33.** Hosegood, Victoria. 2009. The demographic impact of HIV and AIDS across the family and household life-cycle: implications for efforts to strengthen families in sub-Saharan Africa. AIDS Care 21 (sup1):13-21.
- 34. Ivankova, Nataliya V., John W. Creswell, and Sheldon L. Stick. 2006. Using Mixed- Methods Sequential Explanatory Design: From Theory to Practice. Field Methods 18 (1):3-20.
- **35.** Izugbara, Chimaraoke O., and Eliud Wekesa. 2011. Beliefs and practices about antiretroviral

medication: a study of poor urban Kenyans living with HIV/AIDS. Sociology of Health & Illness 33 (6):869-883.

- 36. Kalipeni, Ezekiel, Joseph Oppong, and Assata Zerai. 2007. HIV/AIDS, gender, agency and empowerment issues in Africa. Social Science & Medicine 64 (5):1015-1018.
- 37. Kennedy, C., K. O'Reilly, A. Medley, and M. Sweat. 2007. The impact of HIV treatment on risk behaviour in developing countries: A systematic review. AIDS Care 19 (6):707 720.
- 38. Kralik, Debbie. 2002. The quest for ordinariness: transition experienced by midlife women living Lekas, Helen-Maria, Karolynn Siegel, and Jason Leider. 2011. Felt and Enacted Stigma Among HIV/HCV-Coinfected Adults: The Impact of Stigma Layering. Qualitative Health Research with chronic illness. Journal of Advanced Nursing 39 (2):146-154.
- **39.** Maclachlan, Ellen W. 2007. Factors that Influence Risk Behaviour in HIV Infected Women Receiving Antiretroviral Therapy in Kampala and Masaka, Uganda. PhD Thesis, Public Health, Oregon State University, Oregon.
- **40.** Mathews C, Coetzee N, Zwarenstein M, Lombard C, Guttmacher S, Oxman A, et al. (2002)A systematic review of strategies for partner notification for sexually transmitted diseases including HIV/AIDS. Int J STD AIDS 13:285-300.
- **41.** Mbizvo, M. T., and M. T. Bassett. 1996. Reproductive health and AIDS prevention in sub-Saharan Africa: the case for increased male participation. Health Policy and Planning 11 (1):84-92.
- **42.** Mill, Judy E., and John K. Anarfi. 2002. HIV risk environment for Ghanaian women: challenges to prevention. Social Science & Medicine 54 (3):325-337.
- **43.** Njogu, W., and T.C. Martin. 2005. The persisting gap between HIV/AIDS knowledge and risk prevention among Kenyan youth. Genus 62 (2):135-168.
- **44.** Paxton, S. 2002. The paradox of public HIV disclosure: Psychological and Socio-medical

Aspects of AIDS/HIV. AIDS Care 14 (4):559-567.

- **45.** Russell, Steven, and Janet Seeley. 2010. The transition to living with HIV as a chronic condition in rural Uganda: Working to create order and control when on antiretroviral therapy. Social Science & Medicine 70 (3):375-382.
- **46.** Salami, K.A, Fadeyi, A, Ogunmodede, J.A. and Desalu O.O 2011 Status Disclosure among People Living With HIV/AIDS in Ilorin, Nigeria. West African Journal of Medicine Vol 30, No 5
- 47. Sarna, A., S. M. F. Luchters, S. Geibel, S. Kaai, P. Munyao, K. S. Shikely, K. Mandaliya, J. van Dam, and M. Temmerman. 2008. Sexual risk behaviour and HAART: a comparative study of HIV-infected persons on HAART and on preventive therapy in Kenya. International Journal of STD and AIDS 19 (2):85-89.
- **48.** Segurado A.C, Paiva V. 2007. Rights of HIV positive people to sexual and reproductive health: parenthood.Reprod Health Matters. May;15(29 Suppl):27-45.
- **49.** Smith, Daniel Jordan, and Benjamin C. Mbakwem. 2010. Antiretroviral therapy and reproductive life projects: Mitigating the stigma of AIDS in Nigeria. Social Science & Medicine 71 (2):345-352.
- **50.** Ssali, S. N., L. Atuyambe, C. Tumwine, E. Segujja, N. Nekesa, A. Nannungi, G. Ryan, and G. Wagner. 2010. Reasons for disclosure of HIV status by people living with HIV/AIDS and in HIV care in Uganda: an exploratory study. AIDS Patient Care and STDs 24 (10):675-681.
- 51. Stillwaggon, E. 2002. HIV/AIDS in Africa: Fertile Terrain. Journal of Development Studies 38 (6):1 - 22.
- **52.** Stillwaggon, E. 2006. AIDS and the Ecology of Poverty. New York: Oxford University Press.
- **53.** UNAIDS (2010) 'UNAIDS report on the global AIDS epidemic'
- **54.** Varga, Christine A. 2003. How Gender Roles Influence Sexual and Reproductive Health Among South African Adolescents. Studies in Family Planning 34 (3):160-172.