PILOT INTERVENTION TO INCREASE HIV STATUS DISCLOSURE TO SEXUAL PARTNERS AMONG PLHIVS AT A MUWRP SUPPORTED HEALTH UNIT IN KAYUNGA DISTRICT, UGANDA.

BY

SOLOME MUKWAYA (BA, MA -DEVST STUDIES, PGD PPM)
MakSPH-CDC HIV/AIDS FELLOW

APRIL 2011
# TABLE OF CONTENTS

ACKNOWLEDGEMENTS .......................................................................................................................... iv  
ABSTRACT .................................................................................................................................................. v  
ABBREVIATIONS AND ACRONYMS ....................................................................................................... vi  
OPERATIONAL DEFINITIONS .................................................................................................................. vii  
1.0 INTRODUCTION AND BACKGROUND ................................................................................................... 1  
1.1 Introduction ........................................................................................................................................... 1  
1.1 Background ........................................................................................................................................... 3  
2.0 LITERATURE REVIEW ............................................................................................................................ 4  
2.1 Introduction ........................................................................................................................................... 4  
2.2 The Process of HIV Status Disclosure ................................................................................................... 4  
2.3 HIV Status Disclosure Approaches ....................................................................................................... 5  
2.4 Benefits of disclosure ............................................................................................................................. 5  
2.5 Barriers to disclosure ............................................................................................................................. 6  
2.6 Disclosure Outcomes ............................................................................................................................. 6  
2.7 Interventions to promote HIV Status Disclosure ................................................................................... 7  
2.8 Conclusion ........................................................................................................................................... 8  
3.0 PROBLEM STATEMENT, JUSTIFICATION AND CONCEPTUAL FRAMEWORK .............................................. 8  
3.1 Problem Statement ................................................................................................................................ 8  
3.2 Justification .......................................................................................................................................... 9  
3.3 Conceptual Framework .......................................................................................................................... 10  
4.0 STUDY OBJECTIVES .............................................................................................................................. 11  
4.1 General Objective ................................................................................................................................ 11  
4.2 Specific Objectives ................................................................................................................................ 11  
5.0 METHODOLOGY ..................................................................................................................................... 12  
5.0.1 Study area ........................................................................................................................................ 12  
5.0.2 Study population ............................................................................................................................... 12  
Phase 1: Understanding the Problem ......................................................................................................... 12  
5.2.1 Study design ................................................................................................................................... 12  
5.2.2 Study Methods and Sample size ...................................................................................................... 12  
5.2.3 Sampling Procedure ........................................................................................................................ 12  
5.2.4 Data collection .................................................................................................................................. 13  
5.2.5 Data Management ........................................................................................................................... 14  
Phase 2: Intervention and Evaluation ......................................................................................................... 14  
5.3 Intervention .......................................................................................................................................... 14  
5.3.1 Intervention description ..................................................................................................................... 14  
5.3.2 Target .............................................................................................................................................. 15  
5.3.3 Sampling Procedure ......................................................................................................................... 16  
5.3.4 Outputs .......................................................................................................................................... 16  
5.3.5 Activities/ strategies ......................................................................................................................... 18  
5.3.6 Implementation ............................................................................................................................... 18  
5.4 Evaluation ............................................................................................................................................ 19  
5.4.1 Study Design ................................................................................................................................... 19  
5.4.2 Study Methods and Sample size ...................................................................................................... 19  
5.4.3 Study variables ................................................................................................................................ 20  
5.4.4 Sampling Procedure ......................................................................................................................... 21  
5.4.5 Inclusion and exclusion criteria ...................................................................................................... 21  
5.4.6 Data collection .................................................................................................................................. 21
5.4.7 Quality control .......................................................................................................................... 22
5.4.8 Data management .......................................................................................................................... 22
5.4.9 Ethical Considerations .................................................................................................................. 23
5.4.10 Study Limitations ....................................................................................................................... 23
6.0 RESULTS ....................................................................................................................................... 24
6.1 Barriers, Benefits and Skills of Disclosure of HIV Status to Sexual Partners by PLHIVs .......... 24
   6.1.1 Background ............................................................................................................................. 24
   6.1.2 Understanding of HIV Status Disclosure to Sexual Partners .................................................. 24
   6.1.3 Benefits of HIV Status disclosure to sexual partners ............................................................... 26
   6.1.5 Skills for HIV Status disclosure to Sexual Partners ............................................................... 28
   6.2 Preliminary Evaluation of a Pilot Intervention to Increase HIV Status Disclosure to sexual partners among PLHIVs ................................................................. 29
       6.2.1 Baseline Findings on Disclosure of HIV Status to Sexual Partners ........................................ 31
       6.2.2 Post Intervention Findings on Disclosure of HIV Status to Sexual Partner in Bbaale HCIV and in the control -Kangulumira HCIV ........................................................................ 33
7.0 DISCUSSION .................................................................................................................................. 36
8.0 SUMMARY, CONCLUSIONS, AND RECOMMENDATION ............................................................ 39
9.0 References ...................................................................................................................................... 42
APPENDIX 1: Draft Questionnaire ......................................................................................................... 45
APPENDIX 2: Draft KII and FGD guide ................................................................................................. 48
APPENDIX 3: Draft consent form .......................................................................................................... 49
APPENDIX 4: Guideline for HIV status Disclosure to Sexual Partners ............................................. 50

**LIST OF TABLES**

| Table 1: Baseline Characteristics                                                                 |
| Table 2: Assessment of Future Disclosure of HIV Status to Sexual Partner in Bbaale HC IV & Kangulumira HCIV |
| Table 3: Pre and Post intervention results of the pilot intervention |

**LIST OF FIGURES**

- Figure 1: Conceptual Framework
- Figure 2: Benefits of HIV status disclosure to Sexual Partners
- Figure 3: Barriers of HIV status disclosure to sexual partners
- Figure 4: Change in HIV Status Disclosure to sexual Partners at Baseline as Compared to Post Intervention
- Figure 5: Plan to Disclose at baseline as compared to post intervention
- Figure 6: Discussions on disclosure at Baseline compared to Post Intervention
- Figure 7: Plan to discuss disclosure at baseline compared to post intervention
DECLARATION

1. Solome Mukwaya do hereby declare that this programmatic/research report entitled Pilot Intervention to Increase HIV Status Disclosure to Sexual Partners among PLHIVs at a MUWRP Supported Health Unit In Kayunga District, Uganda, has been prepared and submitted in fulfillment of the requirements of the MakSPH-CDC HIV/AIDS Fellowship Program and has not been submitted for any academic qualifications.

Signed …………………………….. Date…………………………………….. 
Solome Mukwaya, Fellow

Signed …………………………….. Date…………………………………….. 
(Mark Breda) Host Institution Mentor

Signed …………………………….. Date…………………………………….. 
(Dr. Lynn Atuyambe) Academic Mentor
ACKNOWLEDGEMENTS

I acknowledge the support, encouragement and advice from my Host Institution mentors Mr. Mark Breda, and Dr. Fred Magala. I appreciate their receptiveness and effort in providing opportunities for me to learn and explore new areas in HIV prevention, Care, and Treatment. I further acknowledge the advice, time and concern from my academic mentor Dr. Lynn Atuyambe. My appreciation also goes to the roaming mentors especially Dr Fredrick Makumbi, the fellowship programme office for the continued and untiring support. I acknowledge the support and enthusiasm of all Makerere University Walter Reed- PEPFAR program staff. I thank all those who have provided support and motivation in one way or another. Finally, I acknowledge the support my family and from fellow fellows.
ABSTRACT

Background: The average rate of HIV status disclosure to sexual partners is 49% and 79% in developing countries and developed countries respectively. Non-disclosure of HIV status compromises HIV prevention interventions.

Objectives: The main objective of this study was to pilot and evaluate an innovative new approach through the diffusion of innovations theory (DIT) to increase HIV status disclosure to sexual partners among HIV positive clients.

Methodology: Based on a qualitative assessment to establish barriers, benefits and skills for HIV status disclosure to sexual partners, a small group (25 people) intervention targeting HIV positive clients was designed and implemented at Bbaale Health Centre IV, with Kangulumira Health Center IV serving as a control. At Bbaale Health centre IV, a select group of 25 persons was randomly selected to receive the intervention with the assumption that this intervention when implemented among a small group would not only benefit the participant but would through peer networks spread out to the bigger population. For preliminary evaluation of this intervention, baseline and post intervention data was collected from both the intervention and control groups from a sample of 196 persons (n=196) at baseline and the same number (n=196) at post intervention.

Results: qualitative research established i) the need to define disclosure to sexual partners ii) the need to broaden the benefits beyond the ability to access treatment, partner protection, partner support and include benefits such as PMTCT among others. ii) Need for strategies to counteract the main barriers such as fear of being blamed by partners, abandonment, loss of economic support, physical and emotional abuse. Preliminary assessment results from a sample of 196 clients at baseline and the same number at evaluation showed that the intervention significantly increased the disclosure of HIV status to sexual partners.

Conclusions: 1) diffusion of information through a small group intervention can through a ripple effect increase HIV status disclosure to sexual partners in a health care system and ultimately reduce transmission of HIV. 2) Interventions that are population driven and make individuals agents of change within their peers can be effective.3) The diffusion of Ideas/innovations can lead to quick outcome turn around.

Recommendations: i) For conclusive results, it is recommended that an evaluation be carried out at least 3-6 months after the intervention ii) Subsequent studies should establish the ideal ratio of small groups to population required for effective diffusion

Program and policy implications: This intervention increases disclosure of HIV status to sexual partners at minimal cost. However, for effective prevention, it would need to be coupled with other prevention support programs especially for sero-discordant couples.
ABBREVIATIONS AND ACRONYMS

AIDS: Acquired Immune Deficiency Syndrome
ART: Antiretroviral Therapy
FGDs: Focus Group Discussions
GIDs: Group Interactive Discussions
HCIVs: Health Center IVs
HIV: Human Immunodeficiency Virus
KII: Key Informant Interviews
MoH: Ministry of Health
MUWRP: Makerere University Walter Reed Project
PINs: Peer Influence Networks
PLHIV: People Living With HIV and AIDS
PP: Positive Prevention
RCT: Routine Counseling and Testing
UNAIDS: The Joint United Nations Programme on HIV/AIDS
VCT: Voluntary Counseling and Testing
WHO: World Health Organization
**OPERATIONAL DEFINITIONS**

<table>
<thead>
<tr>
<th>HIV Status Disclosure:</th>
<th>HIV status disclosure is the process of revealing one's status to sexual partners, family, friends, health care providers or the community. It could be voluntary or involuntary, direct or indirect.</th>
</tr>
</thead>
<tbody>
<tr>
<td>HIV Status Disclosure</td>
<td>HIV status disclosure to sexual partners is the process of revealing one's status to sexual partners. It could be voluntary or involuntary, direct or indirect, full or partial.</td>
</tr>
<tr>
<td>to sexual partners:</td>
<td></td>
</tr>
<tr>
<td><strong>Full disclosure</strong></td>
<td>This is disclosure of HIV status to all persons (sexual partner, community, family, etc)</td>
</tr>
<tr>
<td><strong>Partial disclosure</strong></td>
<td>This is the disclosure of HIV status to some individuals and not to others.</td>
</tr>
<tr>
<td><strong>Expert clients/ Peer</strong></td>
<td>HIV Positive persons who have been with the health center for a substantial period of time and serve as volunteers at the health centers. They are involved in client follow up activities, and various other activities at the health center including counseling.</td>
</tr>
<tr>
<td><strong>Counselors:</strong></td>
<td></td>
</tr>
<tr>
<td><strong>Positive Prevention:</strong></td>
<td>PP programs focus on empowering and involving People Living with HIV and AIDS as key partners in the effort to reduce HIV. PP supports prevention through promoting sero-discardance; HIV status disclosure and knowledge of partner sero-status; sex and sexuality issues addressing childbearing choices; Family Planning, PMTCT; facilitates Testing and counseling, Provides ART, Behavior change among others.</td>
</tr>
<tr>
<td><strong>Treatment Clubs:</strong></td>
<td>These are formal groups of HIV positive persons on treatment at the different health facilities. They are avenues for bringing HIV positive persons together to share experiences and challenges, and they are avenues for providing continued counselling on adherence, positive prevention, positive living and general health for HIV positives. There are 6 treatment clubs at the 6 health units with over 1000 people in total.</td>
</tr>
<tr>
<td><strong>Disclosure counseling:</strong></td>
<td>This is an effort to convince HIV positive persons to disclose their HIV to their sexual partners with the sole aim of reducing</td>
</tr>
</tbody>
</table>
transmission of the virus.

**ART Clinic Day**  
Once a week each health center holds an ART clinic day at which HIV positive persons attending the particular clinics turn up from reviews, drug refills among others.
1.0 INTRODUCTION AND BACKGROUND

1.1 Introduction

The number of people living with HIV worldwide in 2008, reached an estimated 33.4 million which was more than 20% higher than the number in 2000, and the prevalence was also said to be roughly threefold higher than in 1990 (UNAIDS and WHO, 2009).

As of 2008, in Sub-Saharan Africa 24.4 million people where living with HIV, up from 19.7 million in 2001. There were 1.9 million new infections, down from 2.3 million in 2001 and a prevalence rate of 5.2% which was down from 5.8% in 2001. (UNAIDS and WHO, 2009). The same report shows that all regions in the world have a prevalence rate of 0.6% and below except sub-Saharan Africa.

Approximately 130,000 Ugandans are infected with the HIV virus every year. The Uganda government's national HIV/AIDS strategic plan predicts that the number of HIV positive Ugandans will rise from 1.1 million in 2006 to 1.3 million in 2012. (Kelly, 2008). To counteract the predictions of rise in HIV transmission, prevention interventions focusing on prevention with positives are now being looked at as a priority. One of the most important strategies for HIV prevention is through HIV status disclosure to sexual partners.

Sex without disclosure of HIV status is a common happening among PLHIVS (Ciccarone et.al, 2003). It is indicated that up to 25% to 30% of PLHIVs continue to have unprotected sex, at times without informing their sexual partners, who may be of negative or unknown serostatus (Kalichman, 2000).

There is little information on the general rates of HIV status disclosure however, rates of disclosure in the developed world among women are said to range from 42 to 100% (WHO, 2004; WHO, 2003) compared to the developing countries which is 16.7% to 87% (Paulini et.al, 2006; WHO, 2004; WHO, 2003). Furthermore, the average rate of HIV status disclosure to sexual partners was 49% and 79% in developing countries and developed countries respectively (WHO, 2004). Ironically, HIV incidence in the developing world is higher than in the developed world while disclosure is lower which is worrying for HIV prevention interventions.
Evidence suggests that HIV status disclosure can prevent HIV transmission. A study in South Africa examined HIV serostatus disclosure and its relationship to risky sexual behaviours and established that 78% had not disclosed their HIV serostatus to their sexual partners and 46% had no knowledge of their sexual partner's serostatus. It further established that those who did not disclose were more likely not to use condoms and to have multiple sexual partners. It was established that being in a married relationship, having multiple partners and non-use of condom at last sex were significantly associated with non-disclosure of HIV serostatus (Olley et. al, 2004). Hence the need to prioritise self-disclosure among PLHIVs for HIV prevention.

Despite evidence on the benefits of HIV status disclosure to sexual partners in HIV prevention, the rates of disclosure remain low in most countries in Africa and Uganda in particular.

“Ninety percent of Ugandans do not know the HIV status of their sexual partners. A study done by the Uganda AIDS Commission in seven districts indicates 64% of people who tested did not disclose their status to their partners.” (New Vision, 27th November 2009)

A study carried out among 1,092 TASO clients in Eastern Uganda showed that 69% had disclosed their HIV serostatus to their most recent sexual partner (King et.al, 2007) implying a non disclosure rate of 31%.

Between 2003 and 2006, 43% of PLHIVs in Mitiyana (Central Uganda) attending posttest care had disclosed their status to sexual partners and family (Kadowe and Nuwaha, 2009). This implies a non disclosure rate of 57%

The Uganda Modes of Transmission report shows that 43% of all new infections were among people in discordant monogamous relationships (UAC, 2009). In addition to this, key drivers of the epidemic according to the National Strategic Plan include: Discordance with partner: Lack of knowledge of status and poor disclosure, (UAC, 2007). All these underscore the importance of disclosure which in turn leads to couple testing and counseling, condom use and other risk reduction behavior.

Unpublished routine data from MUWRP supported health units in Kayunga district shows that over three quarters of clients do not know their partners HIV status, implying that they had not disclosed their status, neither had they tested together. This has direct
implications on HIV prevention and transmission hence the need to establish levels of HIV status disclosure to sexual partners and implementation relevant interventions that promote HIV status disclosure to sexual partners

1.1 Background

Makerere University Walter Reed Project (MUWRP) is a non governmental, not for profit partnership between Makerere University and the US Military HIV research Program for the purpose of conducting HIV research and related activities in Uganda. MUWRP was established in 2002 as a result of a memorandum of understanding between Makerere University and The Henry M Jackson Foundation.

The MUWRP PEPFAR programmes mandate is to strengthen systems through building the capacity of health centres to manage the growing number of HIV/AIDS patients. The programme provides treatment, care and support (counselling, nutritional and general health education, and livelihood support as well as prevention services to the HIV/AIDS patients) through the government health centres in a sustainable manner.

The programme works with the Kayunga and Mukono District Local Government Administrations in supporting a full range of HIV prevention, care and treatment programs in the district. The programme currently works with 6 clinic sites and supports them through provision of drugs, technical support, capacity building of staff, improvement of infrastructure, support to treatment clubs and farm groups. Within her structures, MUWRP PEPFAR Programme has two major arms: prevention and treatment. Under the prevention arm, the programme provides house to house VCT, routine counselling and testing, Medical Male Circumcision and prevention outreaches. Under the treatment arm, the programme provides ART and cotrimoxazole to HIV positive clients at the ART clinics and Post Exposure Prophylaxis services. Disclosure falls under both the prevention and treatment arm where disclosure counselling is provided whenever an individual tests positive. At the ART clinics, that occur once or twice a week, disclosure counseling is part of the package that is provided among other prevention services.
MUWRP programme interventions to promote disclosure mainly include counseling at the health centres before starting ART. On the house to house programme, once a couple is tested and is found to be discordant, there is a programme in place to convince them to disclose their status with the ultimate hope that disclosure of status will lead to use of risk reduction strategies in the relationship among which is condom use. Furthermore, to promote disclosure at health centres preferential treatment is given to partners of already tested individuals.

2.0 LITERATURE REVIEW

2.1 Introduction

This section explores the various aspects of HIV status disclosure. Discussed are the process of HIV status disclosure, approaches to disclosure, benefits of disclosure, barriers to disclosure, and outcomes of HIV status disclosure as well as interventions to promote disclosure to sexual partners. Also discussed in this section is the diffusion of innovations theory that explains how messages diffuse from a smaller group into the wider population.

2.2 The Process of HIV Status Disclosure

The process of HIV status disclosure is a six step process that involves the individual accepting the diagnosis, they then assess their disclosure skills, and decide whether it is important to disclose to persons in their social network. At this point, the individual decides who to disclose to and evaluate the circumstances for disclosure this includes barriers to disclosure. They then anticipate the reactions of the potential recipients as compared to the benefits and finally identify reasons for disclosure to different persons (WHO, 2003, King et al 2008, Kimberly, 1995). It is therefore important to facilitate the disclosure process so as to attain the desired outcome of HIV status disclosure to sexual partners among others.

Couples who test individually are more likely to disclose to persons other than their spouses and even when they do disclose to their partners they may take as long as two years to do so (UAC, 2007). In further support of this statement, a Study with TASO clients in eastern Uganda showed that disclosure of HIV-status was associated with being married, having attended the clinic for more than 2 years, increased condom
use, and knowledge of partner’s serostatus (King et.al, 2008). It is therefore important to design interventions that can speed up the process of HIV status disclosure to sexual partners. WHO (2003) recommends more research to identify factors associated with disclosure to allow for the development of counseling tools that can be used to counsel individuals based on their needs.

2.3 HIV Status Disclosure Approaches

Disclosure can be done in three forms: direct disclosure, indirect disclosure and third party disclosure. Each of the types of disclosure work best for different individuals in different situations. Disclosure can be direct, indirect, or assisted/third party disclosure. The choice of disclosure that appeals to the clients depends on the individual foreseen challenges/ barriers to disclosure. A study in Eastern Uganda showed that 55% of the participants used direct disclosure, 27% used indirect and 18% used assisted (King et. al, 2008). It was further noted that those who had not disclosed, hoped to use assisted disclosure using third parties as their option for disclosure. (King et.al. 2008). This ultimately implies that there is need to understand disclosure needs of PLHIVs and design interventions that respond to these needs.

2.4 Benefits of disclosure

Evidence suggests that HIV Status disclosure to sexual partners serves as an HIV prevention intervention through the reduction in risk of transmission. A mathematical model for assessing the HIV transmission risk reduction effectiveness of sero status disclosure found that disclosure reduces the risk of HIV transmission by between 17.9% and 40.6% relative to no disclosure (Pinkerton et al., 2007).

Disclosing HIV test results to one's sexual partner allows the partner to engage in preventive behavior as well as the access of necessary support for coping with positive serostatus. It is further said that disclosure may motivate partners to seek testing or behavior change, and ultimately decrease the transmission of HIV (Kebede Deribe et al.,2008, Kalichman and Nachimson, 1999). Studies further show that disclosure of serostatus to sexual partners leads to risk reduction behavior, increased care-seeking/ treatment behavior, less anxiety, social support, and motivation to
plan for the future (King et al., 2008, Medley et al., 2003, WHO, 2003 and Lauren et al., 2009). This evidence affirms the central role of HIV status disclosure to sexual partners in HIV prevention and the need to support PLHIVs in easing the process for their wellbeing and ultimate reduction in transmission to sexual partners.

2.5 Barriers to disclosure

Despite the evidence of HIV sero status disclosure to sexual partners, PLHIVs who may wish to disclose are faced with various barriers that delay disclosure. Evidence shows that individuals fail to disclose their sero status to sexual partners because of barriers that range from fear of stigma, violence, rejection, and blame, loss of economic support, physical and emotional abuse, discrimination, to disruption of family relationships among others (Medley, 2004). Further, the potential for rejection, abandonment, physical and emotional abuse, and other adverse consequences creates substantial barriers to disclosing HIV status. (Bayer, 1996). These barriers prevent PLHIVs from disclosing their HIV status to their sex partners. No studies have been done in Kayunga district to establish the barriers to HIV status disclosure. However, based on the need to promote disclosure, interventions that help PLHIVs to overcome the existing barriers are important to enable disclosure.

2.6 Disclosure Outcomes

Disclosure is said to be an important public health goal because it leads to partner testing, behavior change and ultimately decreased HIV transmission. It further leads to increased opportunities for social support, increased access to treatment (WHO, 2004). UNAIDS further ascertains that disclosure is an important prevention goal (UNAIDS, 1997). Disclosure of HIV status to sexual partners is intended to promote partner testing and encourage persons to practice safe sex.

Risk reduction strategies are said to arise naturally in the context of disclosing HIV status (UAC, 2007). Partner testing, disclosure and condom use are interrelated aspects of positive prevention. Partner testing in itself helps ease disclosure and create a situation of dual responsibility for protected sex. To emphasize this relationship, mathematical modeling was done and it established that disclosure directly relates to condom use (Pinkerton et al., 2007).
Given the outcomes of HIV status disclosure to sexual partners, it is clear that it plays a pivotal role in prevention activities and efforts should be made to promote sero status disclosure to sexual partners.

2.7 Interventions to promote HIV Status Disclosure

Group interventions have been used to promote HIV Status disclosure. A comparative study on disclosure among persons attending community groups and home based care showed that persons who attended these were more accepting and did not find disclosure of their status difficult, and had disclosed their positive HIV status to more people than those who were not in any programme (Ncama, 2007).

Couple counseling has also been promoted as a strategy to minimize adverse social outcomes associated with disclosure of HIV status. Couple counseling did not increase the risk of adverse social events associated with HIV disclosure and helped individuals to mutually find out their partner’s status. (Semrau et al., 2005)

A 2005 study showed that interviews highlight the experiential opportunities that group interventions offer with respect to HIV knowledge, social support, HIV disclosure skills, and HIV risk reductions. Participants talked highly of their experiences in group-level interventions, suggesting that they should be considered an important prevention strategy for people living with HIV. (Hyde et al. 2005)

In Uganda, there have been various efforts to promote HIV status disclosure especially after realizing that the HIV epidemic was on the rise especially amongst married couples or those in long-standing relationships. One intervention is the push for an HIV prevention and Control Bill that makes testing mandatory for specific cases. It encourages HIV-positive people to inform their partners about their status and then go on to ensure prevention and treatment measures. It further gives medical personnel the power to disclose HIV status to sex partners in the event that the individual fails to disclose. (http://www.medicalnewstoday.com/articles/133172.php)

Despite these interventions, there are still low levels of HIV status disclosure and there is need for more innovative approaches to promote disclosure particularly to sexual partners.
2.8 Diffusion of innovations theory (DIT)

This theory explains how innovations (ideas, behavior) are taken up in a population. It further explains that the ability of a population to take up an innovation depends on its relative advantage, ease of use, and observable benefits. The easier it is for individuals to see the results of an innovation, the more likely they are to adopt it and also stimulate peer discussion of a new idea (Mahajan et.al 1990). With DIT, change can be promoted faster and easily in a community through a domino effect which explains that one small change will create a similar change among others (Rogers, 1995).

2.8 Conclusion

There have not been many interventions that are specifically focused on increasing disclosure of HIV status to sexual partners among the clients at MUWRP Kayunga site. This group intervention focusing on counteracting barriers to disclosure, emphasizing the benefits of disclosure and building disclosure skills among PLHIVs will be among the first and given the evidence of the success of similar interventions elsewhere is predicted to work. Basing on the outcomes of HIV status disclosure, this intervention will be a small group intervention supported by DIT which assumes that an innovation or knowledge among a small group diffuses into the networks and wider group. It will focus on easing the process of disclosure through skills building using interactive group discussions.

3.0 PROBLEM STATEMENT, JUSTIFICATION AND CONCEPTUAL FRAMEWORK

3.1 Problem Statement

HIV sero status disclosure rates among clients attending clinics at the MUWRP supported sites is not fully known, but available data suggests that it is very low. Unpublished reports for the first quarter of 2010 among clients who visited health centers in Kayunga showed that only 23% of the 4867 repeat testers knew their partners HIV status. The high lack of knowledge about partner’s sero status may be an indicator that they too did not disclose to their partners. Lack of knowledge of a partner’s sero status may lead to risky and unsafe sexual practices such as low condom use, which risky behaviors may result in increased risk of HIV transmission
to the negative partner(s), re-infection in the positive partner, thus further driving the HIV/AIDS pandemic. If not mitigated, the increase in HIV transmission can result in increased number of HIV-infected persons that will further strain the health systems.

Recent information suggests that there is a decline in the global funding for AIDS treatment, which will further lead to increased risk of morbidity, and mortality among the HIV-infected.

As a potential mitigating factor, HIV sero status disclosure has been shown to be associated with reduced HIV transmission, but disclosure rates are still very low in many settings. Although factors associated with low levels of disclosure are known, there are limited or no effective disclosure related interventions that have been implemented in these rural and poor resource constrained settings to address this challenge.

I, therefore designed, piloted, and evaluated an innovative HIV sero status disclosure related intervention that was geared towards increasing the levels of partner disclosure. This intervention was based on improving or addressing the barriers to disclosure as stated by ART clients at the health facilities. First I carried out FGDs to establish barriers and status of disclosure among ART clients. I used these findings to design a counselling guide with messages whose primary focus was to promote HIV sero status disclosure to sexual partners. This proposed small group intervention was therefore focused on enhancing tailored counselling messages in order to promote couple discussions on disclosure, planned disclosure and ultimately increase HIV status disclosure.

3.2 Justification

HIV Status disclosure to sexual partners among HIV positive clients is a national priority area in the reduction of new HIV/AIDS infections in Uganda (UAC, 2007). In line with the national standing, the planned activity is an effort to increase HIV status disclosure to sexual partners which would eventually lead to knowledge about partner’s sero status which may lead to reduced HIV risk related behaviour and safe sexual practices such as increased condom use, which may result in reduced risk of
HIV transmission to the negative partner(s), reduced possibility of re-infection in the positive partner, thus contributing to the mitigation of the HIV/AIDS pandemic.

This pilot points to a possibility of a cheaper, sustainable, and effective alternative for promoting HIV status disclosure. This small group approach could be replicated to promote other prevention activities by prevention programmes.

Based on the above exposition, it is clear that HIV status disclosure to sexual partners is an important starting point for HIV prevention efforts and therefore, the proposed intervention is a justified effort towards slowing the transmission of HIV.

3.3 Conceptual Framework

HIV status non disclosure to sexual partners is among others caused by service as well as social cultural barriers. The major service barriers include lack of disclosure skills and lack of knowledge on positive reasons for disclosure, limited disclosure counseling time. Socio-cultural barriers to disclosure range from fear of rejection and stigma to demographic/ personal factors. The Intervention is based on the assessment of barriers to disclosure, disclosure skills, and benefits of disclosure counseling. The conceptual framework highlights the methodology of the intervention. It will have a control and
intervention group that will be the subject of the pretest (baseline) and posttest (Evaluation). The intervention group will further be divided into a small group of 20-25 persons, within which a series of 4 disclosure counseling and training sessions will occur. Midway this small group training, a mini assessment will occur to measure for within individual changes and thereafter the remaining 2 training sessions will occur. This intervention assumes that based on the diffusion of innovations theory, the outcomes of the intervention will spread wider than the small group into the wider networks of PLHIVs, with the intervention group serving as a communication channel.

4.0 STUDY OBJECTIVES

4.1 General Objective  
To pilot and evaluate an intervention to increase HIV status disclosure to sexual partners among HIV positive clients at a MUWRP supported health unit in Kayunga district.

4.2 Specific Objectives  
Phase 1: understanding the problem  
1. To identify barriers, benefits and skills of disclosure of HIV status to sexual partners by PLHIVs.

Phase 2: Intervention and Evaluation  
1. To implement a small group intervention to facilitate HIV status disclosure to sexual partners among PLHIVs  
2. To evaluate the effectiveness of a small group intervention program for increasing HIV status disclosure to sexual partners among PLHIVs
5.0 METHODOLOGY

5.0.1 Study area

This study was carried out at 2 health center IVs that receive support from MUWRP that is Kangulumira Health center IV and Bbaale Health center IV (one serving as a control group and the other the intervention arm respectively).

5.0.2 Study population

This study was conducted among HIV positive clients of age (18-45) that receive treatment within the selected health facilities. The age group was selected based on the fact that it covers both the male and female reproductive age group that are highly sexually active and is in line with PEPFAR age group classifications.

Phase 1: Understanding the Problem
Identifying barriers, benefits and skills of disclosure of HIV status to sexual partners by PLHIVs.

5.2.1 Study design

This was a qualitative study with four focus group discussions with PLHIVs (2 FGDs for men and 2 for women) and 6 key informant interviews with the counsellors at the health facility were carried out at the two health centers, Kangulumira health centre IV and Bbaale health centre IV.

5.2.2 Study Methods and Sample size

The qualitative sample size constituted of 4 FGDs each with 8-10 persons. There were 2 FGDs comprising of women and 2 FGDs comprising of men. The KII's constituted of 3 health centre staff and 3 peer counsellors.

5.2.3 Sampling Procedure

Study sites
Study site selection was done purposively to include the two sites that are Health Center IVs that provide HIV care and Treatment and receive support from MUWRP. This is because the two are the only Health Center IVs in Kayunga District that receive MUWRP Support. Selection was also based on the fact that one served as an intervention group and the other a control arm, the two were the only sites that were similar in characteristic with regard to the standard health package provided by Health Center IVs. Study sites were therefore Kangulumira Health Center IV and Bbaale Health Center IV.

Participants

The sampling was open (purposive); the first contact selection was the first client that walked into the health centre on a particular clinic day that met the inclusion criteria. After that, every 3rd person that walked into the health centre and registered at the HIV clinic was a possible candidate as long as they fulfilled the selection criteria. They were approached and briefed about the study and its purpose, asked if they were willing to participate. The content of the consent form was read out to them, were asked if they understood and given an opportunity to ask questions for clarity. They signed the consent form if they agreed to participate and the research assistant then interviewed them.

5.2.4 Data collection

Focus group discussions (FDGs): 4 FGDs were conducted with study participants each constituting of 8-12 persons. The participants with similar characteristics but segregated by gender to ensure that gender concerns were captured constituted an FGD. During the FGDs, the facilitators guided the discussions into various topics assisted by an FGD guide. The FGD was conducted at one Health Center at the stipulated clinic days. To enhance the quality of reporting and presentation of findings, tape recording and transcribing of the FGD proceedings were done. Recording of the FDG proceedings was done after seeking consent of the respondents.
**Key Informant Interviews (KII):** 6 KIIIs were carried out at the clinic where the intervention was implemented. KIIIs were done with peer educators and counselors.

**Data collection tools**

Tools included a KII guide and FGD guide translated to Luganda and back translated to English to be able to avoid misinterpretation. Final copies of the tools were photo copied and centrally kept by the overall supervisor (fellow). On completion of each interview, consistency and accuracy were ensured. Each assistant checked for completion of the questionnaire before leaving the site. The supervisor checked collected data for any ambiguities.

**5.2.5 Data Management**

**Data Management**

Audio taped files were transcribed and typed in and edited in Microsoft word. The transcribed document was later organized into themes; responses were tallied and later on analyzed with the unit of analysis as the group.

**Phase 2: Intervention and Evaluation**

**5.3 Intervention**

*Implementation of a small group intervention to facilitate HIV status disclosure to sexual partners among PLHIVs*

**5.3.1 Intervention description**

There were incremental dosages of the messaging divided into a series to include understanding disclosure, barriers to disclosure, benefits of disclosure, and how to disclose (skills). The first session was on understanding disclosure, a week later the second session on barriers to disclosure and how to overcome them took place. A week later, the third session on benefits of HIV status disclosure to sexual partners took place and finally in the fourth week a detailed practical session on disclosure skills took place.
The mode of delivery involved interactive methods among a small group of people of approximately 25 people with the belief that concentrating on a few would create a situation where the message would diffuse to the entire group based on the diffusion of innovations theory.

The participants were preselected randomly. At selection, no information was provided regarding any form of compensation, however, a detailed account of the background to the intervention, activities to be carried out as well as length of the intervention were provided. This information was first given at individual level and later as a group. The participants were then asked if they would be able to attend all sessions and arrive on time (by 9:00am) which was part of the inclusion criteria. At this point the consent form was signed and all participants provided with the first session date.

The sessions were all delivered by professional counselors who focused on letting the participants direct the topics of discussion in terms of letting them ask questions, seek clarity, disagree with views presented and then eventually clarified these views, myths, and perceptions as well as gave a wrap up of the entire session. Each session merely had facilitators and it was ensured that there were at least 2 facilitators at each of the sessions.

It is important to note that disclosure counseling is standard of care and is provided at the Health Center IVs and therefore this intervention did not involve withholding of information but was an addition to what was already in place. This intervention was guided by the diffusion of innovations theory that assumed that a small group intervention would spread out to the wider populace. The intervention was through interactive mechanisms such as Group interactive discussions.

It was assumed that outcome would increase with an increasing dose of the intervention. Each session took a maximum of 1 hour and was facilitated by 2 counselors or health educators. In this intervention, the participants were the agents of change and were asked to let their colleagues know about this intervention.

5.3.2 Target

The Target population were the HIV positive clients of reproductive age (18-45) attending the Bbaale Health Center IV in Kayunga district. However, the intervention
was amongst a select cohort of 20-25 clients that consented to be a part of the intervention.

5.3.3 Sampling Procedure

PEPFAR adopted the approach of small group (25 persons) interventions with the idea that these are effective in getting the message across of individuals. As a result of this, many prevention activities have taken on this approach. This intervention chose to take on small groups so that their effectiveness can be evaluated. The actual selection of participants was done by simple random sampling. Selection was at two levels, that is the group level and the individual level.

Group selection

Notes with numbers doubling the actual number of groups formed at the health center that day. (ie there were 6 groups and 12 notes were written on) were written in order to ensure equal opportunity of each group to be selected. Only one of the notes had “selected” written on it. We then asked a representative from each of the groups to select a note. The group that selected the note that says “selected” became the intervention group.

Individual selection

The members of the group selected were each asked if they were able to consistently return to the Health Center for four consecutive health talks as well as evaluated for other inclusion criteria such as age. For each member that declined, a replacement was randomly got from one of the other groups.

5.3.4 Outputs

9.5.1 A reviewed disclosure counseling guide (see appendix 5).

Step 1: Qualitative research

First a qualitative research using FGDs and KIIIs was carried out to establish peoples understanding of HIV status disclosure, the barriers experienced or heard about, the benefits of disclosure to sexual partners as well as the gaps in skills needed to
disclose. Based on this exploration, the results were used to develop the themes and topics for a disclosure counseling guide.

**Step 2: Guide Development**

A team was constituted to develop the guide further. The team was of six persons that met once to further suggest how the content should be presented. This team constituted of counselors and Walter Reed staff involved in the facilitation of disclosure at the health centers. This was to ensure that the messaging did not contradict the already existing messages.

Other data was reviewed from other literature, the national pre-ART counseling guidelines as well as WHO and Ministry of health approved counseling tools at the health centres.

All this information was collated to develop the draft guideline which was further forwarded for review.

**Step 3: Review**

The draft guide was further reviewed by Walter Reed PEPFAR program manager and the coordinator as well as four Walter Reed experienced personnel, external resource persons from TASO, to ensure that the content was accurate as well as useful, clear, simple, and ready to use.

**9.5.2 Disclosure counseling done at one Health Center. (See appendix 6)**

**Registration**

Registration was done on arrival with each participant writing down their name and signing.

**Sessions**

Each session was a minimum of one hour and a maximum of one hour and a half. The disclosure counseling was subdivided into four session with each session feeding into the subsequent sessions. The sessions were as follows 1) understanding disclosure 2) barriers to disclosure and practical skills to overcome them 4) benefits of disclosure (why should one disclose)
Using the developed document as a guide, for four weeks once every week, one of the sessions was delivered by two counselors. Each session was practical and interactive. Questions were encouraged, role plays, and testimonies.

**Exclusion**

It was a requirement made clear from the start that each participant had to attend all sessions until the end. Clients who missed one of the sessions were not allowed to be a part of the subsequent sessions.

**Key message**

At the end of each of the sessions, participants were asked to inform their colleagues/peers of what had transpired in the session. They were asked to share as much information as possible. This was meant to ensure that the valid skills to enable disclosure diffuse into the entire populace,

### 5.3.5 Activities/strategies

**Develop disclosure counseling manual**

**Activities**

1) Constitute a team to review the manual  
2) 3 guideline development meetings  
3) Print final guidelines

**Carry out small group disclosure counseling at clinic days**

4 counseling sessions with in a period of 1.5 months were carried out at one health centre (Bbaale HCIV). The Topics included a) understanding HIV Status Disclosure b) Benefits of HIV status disclosure to sexual partners c) Skills for HIV status disclosure to sexual partners d) barriers to disclosure to sexual partners.

### 5.3.6 Implementation

Implementation was done through interactive methods such as group interactive discussions, experience sharing, role plays and question and answer sessions.
Facilitation of these sessions was done by qualified and experienced persons to ensure that the message was passed on as should be.

5.4 Evaluation

_Preliminary evaluation of the pilot intervention to increase HIV status disclosure to sexual partners among PLHIVs_

5.4.1 Study Design
The study design was a pre-post design with a control. In this study, the proportion of those disclosing was measured, comparing the intervention and control. Among the intervention group, there were three observation points. Among the control arm there were two data collection points.

The intervention was among a purposively selected group of 25 within a period of approximately 2 months. After 4 weeks of the intervention, a quick midterm evaluation was conducted to assess any changes in disclosure. After another four weeks (at end of the intervention) a preliminary evaluation was done for the selected sample size, the 25 persons included in the intervention inclusive. The end term evaluation was also conducted among the control group with a similar sample size as at baseline. The preliminary evaluation was an exact replica of the baseline assessment with the same population size and study design with the assumption that the information from the small groups would diffuse to the entire population.

Validity and reliability
Validity was ensured by having measurements that address the full domain of the phenomenon (Disclosure) being measured and having exhaustive questions.
Reliability was ensured by use of data quality control measures, using standardized instruments, meticulously training of the observer/interviewer and by ensuring that there were standardized conditions under which participants were being interviewed. To ensure internal consistency, there was a control group.

5.4.2 Study Methods and Sample size
Sample sizes used in the study were calculated based on the assumptions of the outcome and rates of disclosure/ non disclosure from regional and national statistics
A study carried out among 1,092 TASO clients in Eastern Uganda showed that 69% had disclosed their HIV sero status to their most recent sexual partner (King et al., 2007).

The Sample size was calculated using the formula:

**Sample Size Calculation**

Based on outcome and proportion of respondents disclosing from regional and national statistics. 43% of persons attending posttest clinic in Mitiyana had disclosed (Kadowe and Nuwaha, 2009).

\[
2N = 4(Z_\alpha + Z_\beta)^2 \frac{p(1-p)}{(P_c-P_I)^2} \quad \text{(Lawrence et al, 1998)}
\]

- \(Z_\alpha = 1.960\) critical value (extracted from standard table)
- \(Z_\beta = 0.84\) corresponds to the power \(1-\beta\) (e.g., if \(1-\beta = 0.80\), \(z_\beta = 0.84\))
- \(P_c = 43\% 0.43\) participants expected to disclose in control group
- \(P_I = 63\% 0.63\) participants expected to disclose in Intervention group
- \(P = 0.53\) mean of \(P_c\) and \(P_I\)

\[
2N = 4(1.96+0.84)^2 0.53(0.43)/(0.43-0.63)^2
\]

\[
2N = 195
\]

\[
N = 98\text{ per group}
\]

This formula is selected because it assumes two independent samples and is able to calculate an equivalent sample size for both the control group and the intervention group.

**5.4.3 Study variables**

**Dependent variables**

The dependent variable in this study is HIV status disclosure to sexual partners.

**Independent variables**

Some of the Independent variables will include;

a) age,

b) gender,

c) discussion about disclosure

d) marital status

e) Knowledge of partners HIV Status

f) Time since first HIV positive test

g) Benefits of HIV status disclosure to sexual partners
h) Barriers to HIV status disclosure

5.4.4 Sampling Procedure

Study sites

Regarding the selection of study sites, this was done purposively to include the two sites that are Health Center IVs that provide HIV care and Treatment and receive support from MUWRP. This is because the two were the only Health Center IVs in Kayunga District that received MUWRP Support. Also based on the fact that one was an intervention group and the other a control group, the two were the only sites that were similar in characteristic with regard to the standard health package provided by Health Center IVs. Study sites were therefore Kangulumira Health Center IV and Bbaale Health Center IV.

Clients

The number of clients recruited for the baseline and Evaluation of the intervention per health facility were equal as shown by the sample size calculation. Selection of clients at each facility was done by systematic random sampling using the daily registers as the sampling frame at the selected health facilities. Depending on the number to be interviewed per site per day, every nth person in the register on that day was selected to participate. Given the limitation in time, this activity was accomplished within 10 days.

5.4.5 Inclusion and exclusion criteria

The clients included in this study were;

a) All adult clients within the reproductive age group (18-45) that attend the ART clinic on clinic days

Those excluded were

a) Those were too ill to sit through an interview.

5.4.6 Data collection

*Preparation for data collection;*
Preliminary visits were made to the selected study sites to seek official permission to conduct the activity. During these visits, the programmatic objectives, ethical procedures and administrative issues were explained to the health facility in-charge.

*Pretesting the tools:*

Before the baseline, a pretest of the tools was conducted to assess the suitability of the data collection tools and an exploration of other field situations was noted. The pretesting was the basis for any revisions in the tools or procedures. Respondents who participated in the pre-test were not included in the real data collection.

*Interviews:*

After identifying eligible respondents, a brief consenting procedure was conducted. Thereafter semi-structured questionnaires were administered by the researcher face to face with the clients at both baseline and evaluation stage to eligible respondents both in the control and intervention group. The interview was conducted in either English or Luganda. Immediately after data collection, field editing was done by the researcher to sort out any incompleteness issues with the respondent.

5.4.7 *Quality control*

**Selection and training of Research Assistants**

Criteria for selection of field staff (Research Supervisors and Research Assistants) included fluency in spoken and written Luganda because the local language spoken in the area of study was mainly Luganda. Other criteria for selection of Research Assistants included prior experience in conducting social research studies and attainment of at least a degree in Social Sciences. Gender balance was also a major consideration in hiring the field staff.

5.4.8 *Data management*

**Data Management**

A data capture template with complete validation checks and skip patterns was designed and thereafter data captured in Epi Info 2000 Software. Data was entered following double entry procedures which enhanced thorough cleaning. The two entries were compared for all differences and the cleaned to generate one similar dataset
which was exported to Spss for analysis. At this phase, relevant data manipulations such as merging or combining of some variables to derive others was done concurrently. All the data was password protected to ensure privacy of the information and as criteria to adhere to ethics.

5.4.9 Ethical Considerations

Formal authorization and ethical approval was sought from the intended study sites and clearance was obtained from the DPH Higher Degrees, research and ethics committee and Uganda National Council of Science and Technology.

A consent form was given to the service providers and the caregivers to seek their consent prior to their participation in the study.

Participants were informed about the need for voluntarily participation they were informed that they are free to withdraw from the study at any time. They were informed about the importance of the study and its intentions of increasing HIV status disclosure to sexual partners.

5.4.10 Study Limitations

i) Issues of desirability were inevitable given that the intervention was done at the health centre and therefore clients might have felt obliged to respond in the affirmative when asked if they had disclosed their status to sexual partners.

ii) The time period between intervention and evaluation is too short and may not be able to show significant changes in HIV status disclosure. However, it is thought that this preliminary evaluation will be able to detect indicators to change. I recommend that the host institution carries out a further evaluation at least 6 months after the intervention.
6.0 RESULTS

6.1 Barriers, Benefits and Skills of Disclosure of HIV Status to Sexual Partners by PLHIVs.

6.1.1 Introduction

The findings presented are as a result of a triangulation of information from the 6 key Informants and 4 focus group discussions. The findings are presented under the following thematic areas:

- Understanding of HIV status disclosure to sexual partners
- Barriers to HIV status disclosure to sexual partners
- Benefits of HIV status disclosure to sexual Partners
- Skills of HIV status disclosure to sexual partners

6.1.2 Understanding of HIV Status Disclosure to Sexual Partners

Understanding of HIV status disclosure to Sexual Partners is important for one to be able to take the step and disclose.

In this study, focus group participants were asked about their understanding of HIV status disclosure to sexual partners. Most participants indicated that they clearly understood what HIV status disclosure to sexual partners meant. However, most participants were quick to define it based on their own experiences. The most common definitions that came up were; family misunderstandings, protection, treatment access, and awareness of partners HIV Status.

It was common for participants to mention their understanding of HIV status disclosure as related to misunderstandings with the partner.

“It is very difficult to disclose to your partner and she stays and its only one of a kind that can stay after being disclosed to positive HIV test results. It is only the bewitched who stay with an HIV positive husband.” (FGD Kangulumira HCIV).

Many confessed to understanding it as a sure way of being left by their wives and therefore considered it as an undesirable situation.

“I came here for an HIV test, went back home and told my dear – my wife I got some problems, I am HIV positive. I told her you know also go and test, when she tested, she was HIV negative and said in such a situation, running away is the only protection
She immediately left me so then I also let her go and remained with my virus” (Male FGD Bbaale HCIV)

Women too just like the men defined HIV status disclosure to sexual partners based on their own experiences. Many agreed to the definition of disclosure as more of misunderstandings, some testifying that it had caused them problems in their homes.

“For me it brought me problems I had been with my husband for 24 years with 5 children and the last child was falling sick a lot so I went to test I was told I was positive and asked him to go and test yet he works with the ministry of health, he refused to test and for 2 years he stopped me from going to the Dr. I left after 2 years with 3 of the 5 children and he doesn’t check on us or pay their fees. In my understanding, it is a problematic thing because it made me lose my marriage.” (Female FGD Participant, Bbaale HCIV)

Furthermore, the male as well as the female FGDs repeatedly defined HIV status disclosure to sexual partners as protection or reduction of transmission. They agreed that once one disclosed their status to their sexual partner, it was synonymous with protecting them from acquiring the virus.

“I told my husband I am HIV positive, he then tested but was found negative and now we use condoms”. (Female FGD Participant, Kangulumira HCIV)

There was also a tendency to define disclosure to sexual partners as treatment access. Though the female FGDs hardly brought out the issue of treatment as definitive of partner disclosure, the male FGDs, many times related disclosure to sexual partners to treatment access. There was argument among the men that disclosure of status to sexual partners meant access to treatment for self, for partner and adherence to treatment and was therefore a big reason and definition for disclosure to sexual partners.

“To tell your partner your status so that you manage to stay on the treatment that has been given to you and to make your partner aware to strengthen her that you are not dying soon.” (Male FGD Participant, Bbaale HCIV)

There was also a definition of disclosure as awareness many said that it is meant to create awareness to the partner that they may also have the HIV virus and should therefore test to verify.

Though hardly mentioned by both the male and female FGDs, Other ways in which disclosure was understood was as among others, provision of hope, partner support, testing and a few related it to PMTCT with not much support from colleagues.
6.1.3 Benefits of HIV Status disclosure to sexual partners

Most women though attesting to the benefits of HIV Status disclosure to sexual partners had their doubts about it being fully beneficial. With every benefit they mentioned they had doubts as to whether there were full benefits of disclosure.

The ability to access treatment was mentioned by both the FGD’s and KII’s as a benefit of HIV status disclosure to sexual partners. They said that once they disclose their status to their partners, they would not only freely pick up drugs but also take drugs as prescribed by the health workers with constant reminders from their partners.

“For me what helped me disclose was the medicine, the fact that I needed to take the medicine at specific times. It sometimes gets confusing and I needed someone to keep reminding me.” (Male FGD participant, Kangulumira HCIV)

“Disclosure is important for moral support since the partner can help you to collect drugs from the health centre.” (KII respondent, Bbaale HCIV)

Amongst the male FGDs, the other benefits of HIV Status disclosure to sexual partners included protection of the partner, access to treatment and testing. However, just like in the female FGDs, there was an agreement that despite the benefits, there is a mix of benefits and harms from HIV status disclosure.

Other benefits mentioned though with not much consensus were PMTCT, reduced fear, gaining partner support and care.

The FGD results with regard to the benefits of disclosure of HIV status to sexual partners were similar to the results from the interviews carried out from 196 respondents at the health centers.
Figure 2: Benefits of HIV status disclosure to Sexual Partners

In line with the FGDs, the results from the questionnaire revealed that the benefit received from disclosure of HIV status to sexual partners as reported in the two HCIV(s) showed that clients perceived benefits of disclosure included an improvement in access to necessary medical treatment and care which accounted for 22%. The second benefit was HIV risk reduction with partners due to disclosure this accounted for 17% followed by increased partner support which accounted for 17% of the responses. Disclosure of HIV status to sexual partner encourages partners to get tested and this accounted for 13% and HIV status disclosure to sexual partners increased the opportunities to plan for the future 10%.

6.1.4 Barriers to HIV status disclosure to sexual partner

Female FGDs and KIIIs had consensus that fear of being left by the partner was a barrier to HIV status disclosure to sexual partners. However a few people mentioned that they could not disclose because the partners would blame them and also there would be family instability. There were also sentiments mainly amongst the female FGDs that the desire to have children was a hindrance to disclosure to sexual partners

“I want to have children and if I disclose I will be unable to find a man willing to engage in sexual practices without a condom. How then will I have a child?” (Female FGD Participant)
Among the male FGDs and KIIIs there was consensus that the main barriers to disclosure are that they would be left by their partners, would be blamed for infecting their partners and even there was a possibility of being murdered by their partners.

![Figure 3: Barriers of HIV status disclosure to sexual partners](image)

In line with the FGD results, Clients who responded to the questionnaire preferred to keep private their HIV status due to mainly the fear of being blamed (20%) and abandoned (15%). A few expressed that they did not disclose their HIV status because it would cause family disruptions, loss of economic support and finally physical and emotional abuse.

“The issue of abandonment is the most common, many people fear to be abandoned by their partners especially at such a low time in their lives. Because of this, they keep quiet and assume that their partners are already infected anyway, so what’s the use of disclosing.”

6.1.5 Skills for HIV Status disclosure to Sexual Partners

When asked about skills that enhance disclosure of HIV status to sexual partners, clearly there was not much discussion amongst the male FGDs as well as the female FGDs. However, there was a predominant mention that participants overwhelmingly agreed that for one to be able to disclose their HIV status to their sexual partners they need to go through counseling and education. It was agreed that disclosure counseling and education is a major reason that people find it easy to disclose to sexual partners since this process provides skills.

“It became easier because of the educational sessions and counseling I got from here after testing for HIV. That talk made me stronger and it made me bold and confident. I then was able to tell my wife and my relatives.” (Male FGD participant, Bbaale HCIV)
Knowledge of the Partners status was also mentioned by the groups as a factor that eases disclosure to sexual partners.

“My husband was already positive and i was his treatment supporter. I was encouraged to test by the messages given and the availability of treatment. I was negative for 3 years …I am hurt because he transmitted the virus to me but is still promiscuous.” (Female FGD Participant, Bbaale HCIV)

Also overwhelmingly mentioned by both men and women was that to be able to disclose HIV status to sexual partners it is important to test together which implies that the results are received together. FGD participants thought this was an easier way of encouraging HIV status disclosure to sexual partners.

“What helped me was that we went together to test, then we were counseled together and they disclosed to us together. This eased disclosure a lot for me.” (Male FGD respondent, Kangulumira HCIV)

The KIIIs mentioned that couple testing, health talks and good timing for disclosure were key skills for disclosure to sexual partners. The KIIIs also mentioned the ability to use health workers to support one to disclose as a required skill for disclosure. The KIIIs further mentioned that there was need to have IEC material as a facilitator for disclosure

“One must have as much information about being HIV positive and what it means before disclosing to the partner. An individual who discloses is meant to provide moral support to the person to whom they disclose.” (KII, Bbaale HCIV)

6.2 Preliminary Evaluation of a Pilot Intervention to Increase HIV Status Disclosure to sexual partners among PLHIVs

To enable a preliminary assessment of the intervention in the short run, the researcher adopted a questionnaire that had questions on the primary and secondary outcomes of the disclosure. Surveys were administered to a randomly selected group at each site prior to the intervention activities (n= 98 Bbaale and n= 98 Kangulumira), and after the intervention had been ongoing for 1.5 months (n= 98 Bbaale and n= 98 Kangulumira).

Participants ranged in age 18 to 45 years. All participants (n= 216) were HIV positive and attending the two selected health centers of Bbaale HC IV and Kangulumira Health center IV in Kayunga district. Most respondents had been attending the clinic just as long as they had been diagnosed as HIV positive.
Table 1: Facility characteristics

<table>
<thead>
<tr>
<th>Facility characteristics</th>
<th>Intervention Bbaale HCIV</th>
<th>Control Kangulumira HCIV</th>
</tr>
</thead>
<tbody>
<tr>
<td>No of Medical doctors</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>Clinicians</td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td>Nurses/ midwives</td>
<td>4</td>
<td>4</td>
</tr>
<tr>
<td>HIV counselors/ educators</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>External Support</td>
<td>1</td>
<td>1</td>
</tr>
</tbody>
</table>

Table 2: Baseline demographic characteristics

<table>
<thead>
<tr>
<th>Variables</th>
<th>Intervention % (freq)</th>
<th>Control % (freq)</th>
<th>P-Value</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Age</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Mean age (SD)</td>
<td>34 (7)</td>
<td>33 (6.5)</td>
<td>0.358</td>
</tr>
<tr>
<td><strong>Age group</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>18-29</td>
<td>23 (22)</td>
<td>30 (27)</td>
<td></td>
</tr>
<tr>
<td>30-39</td>
<td>43 (40)</td>
<td>52 (47)</td>
<td></td>
</tr>
<tr>
<td>40-49</td>
<td>34 (32)</td>
<td>19 (17)</td>
<td>0.061</td>
</tr>
<tr>
<td><strong>Sex</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>27 (25)</td>
<td>22 (20)</td>
<td>0.497</td>
</tr>
<tr>
<td>Female</td>
<td>73 (69)</td>
<td>78 (71)</td>
<td></td>
</tr>
<tr>
<td><strong>Marital status</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Never Married</td>
<td>13 (12)</td>
<td>24 (22)</td>
<td>0.124</td>
</tr>
<tr>
<td>Married</td>
<td>71 (67)</td>
<td>60 (55)</td>
<td></td>
</tr>
<tr>
<td>Widowed/divorced/ separated</td>
<td>16 (15)</td>
<td>15 (14)</td>
<td></td>
</tr>
<tr>
<td><strong>Time since first diagnosis</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>1 year</td>
<td>35 (33)</td>
<td>33 (31)</td>
<td></td>
</tr>
<tr>
<td>2 years</td>
<td>46 (43)</td>
<td>41 (37)</td>
<td></td>
</tr>
<tr>
<td>3 years</td>
<td>19 (18)</td>
<td>25 (23)</td>
<td>0.603</td>
</tr>
<tr>
<td><strong>Time since started attending the clinic</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>1 year</td>
<td>44 (41)</td>
<td>40 (36)</td>
<td>0.763</td>
</tr>
<tr>
<td>2 years</td>
<td>39 (37)</td>
<td>40 (36)</td>
<td></td>
</tr>
<tr>
<td>3 years</td>
<td>12 (16)</td>
<td>21 (19)</td>
<td></td>
</tr>
<tr>
<td><strong>Knowledge of Partners status</strong></td>
<td>63 (59)</td>
<td>63 (57)</td>
<td>1.00</td>
</tr>
<tr>
<td>Disclosure</td>
<td>71 (70)</td>
<td>70 (68)</td>
<td>0.839</td>
</tr>
</tbody>
</table>
An overview of the demographic characteristics as shown in tables 1 and 2 show that there were no significant differences in baseline characteristics between the intervention and control groups as further shown by the various p-values.

### Table 3: Demographic characteristics at follow up

<table>
<thead>
<tr>
<th>Variables</th>
<th>Intervention % (freq)</th>
<th>Control % (freq)</th>
<th>P-Value</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Age</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Mean age (SD)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Age group</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>18-29</td>
<td>25(24)</td>
<td>30 (29)</td>
<td>0.630</td>
</tr>
<tr>
<td>30-39</td>
<td>45(43)</td>
<td>45(44)</td>
<td></td>
</tr>
<tr>
<td>40-49</td>
<td>30(29)</td>
<td>25(24)</td>
<td>0.630</td>
</tr>
<tr>
<td><strong>Sex</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>38(36)</td>
<td>24 (23)</td>
<td>0.043</td>
</tr>
<tr>
<td>Female</td>
<td>62 (60)</td>
<td>76(74)</td>
<td></td>
</tr>
<tr>
<td><strong>Marital status</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Never Married</td>
<td>11 (11)</td>
<td>8(8)</td>
<td>0.613</td>
</tr>
<tr>
<td>Married</td>
<td>82(79)</td>
<td>82(80)</td>
<td></td>
</tr>
<tr>
<td>Widowed/divorced/separated</td>
<td>6(6)</td>
<td>9(9)</td>
<td></td>
</tr>
<tr>
<td><strong>Time since first diagnosis</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>1 year</td>
<td>49 (47)</td>
<td>28(27)</td>
<td>0.015</td>
</tr>
<tr>
<td>1&lt;3 years</td>
<td>29(28)</td>
<td>34(33)</td>
<td></td>
</tr>
<tr>
<td>3+ years</td>
<td>22(21)</td>
<td>38(37)</td>
<td></td>
</tr>
<tr>
<td><strong>Time since started attending the clinic</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>1 year</td>
<td>51(49)</td>
<td>33(32)</td>
<td>0.015</td>
</tr>
<tr>
<td>1&lt;3 years</td>
<td>31(30)</td>
<td>34(33)</td>
<td></td>
</tr>
<tr>
<td>3+ years</td>
<td>18(17)</td>
<td>33(32)</td>
<td></td>
</tr>
<tr>
<td><strong>Knowledge of Partners status</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Disclosure</td>
<td>72(69)</td>
<td>75(73)</td>
<td>0.627</td>
</tr>
<tr>
<td></td>
<td>88(84)</td>
<td>76(74)</td>
<td>0.061</td>
</tr>
</tbody>
</table>

At follow up, the intervention and control group had similar characteristics.

**6.2.1 Baseline Findings on Disclosure of HIV Status to Sexual Partners**

*Primary outcomes of HIV Status disclosure to sexual partners*

The findings from the baseline study indicated that in a sample of 196 respondents 71% (139/196) had disclosed their HIV status to sexual partners. At health unit level, the rate of disclosure of HIV status
was not significantly different, with 71% in Bbaale HCIV and 70% in Kangulumira HCIV having disclosed, see figure 4.

**Secondary outcome measures**

Responses indicated that the clients from Bbaale HCIV who plan to disclose their HIV status to sexual partners was twice as those in Kangulumira as shown by 61% and 31% respectively. Responses showed that at both health centers the clients who had discussed disclosure were 18%. They however showed the interest in discussing their HIV status in future with 71% in Bbaale HCIV Planning to discuss disclosure and 45% in Kangulumira HCIV as shown in Table 2 below. Clients not discussing disclosure with their sexual partners could be because they don’t know what and how to discuss, indicating that interventions should be focused on equipping individuals with skills to promote disclosure.

**Table 2:** Assessment of future disclosure of HIV status to sexual partners at Bbaale HC IV & Kangulumira HCIV

<table>
<thead>
<tr>
<th>Assessment Areas</th>
<th>Bbaale HCIV</th>
<th>Kangulumira HCIV</th>
</tr>
</thead>
<tbody>
<tr>
<td>Plan to disclose HIV status to sexual partners in future</td>
<td>61%</td>
<td>31%</td>
</tr>
<tr>
<td>Discussed disclosure with your partner in past 12 months</td>
<td>18%</td>
<td>18%</td>
</tr>
<tr>
<td>Plan to discuss HIV Status disclosure with your sexual partner</td>
<td>71%</td>
<td>45%</td>
</tr>
</tbody>
</table>
6.2.2 Post Intervention Findings on Disclosure of HIV Status to Sexual Partner in Bbaale HCIV and in the control -Kangulumira HCIV.

Figures 2, 3, 4, and 5 below show changes in HIV status disclosure, planned disclosure, discussions about disclosure and planned discussions on disclosure before and after the intervention.
Fig 4 shows a 7% increase in disclosure of HIV status in the intervention group and a 6% increase in the control group. The change in the intervention group is significant with a p-value of 0.061. The change in the control group is not significant but could be described as a natural change that occurred due to the already existing interventions such as the continued health education, group counseling sessions and the monthly treatment clubs.

For the secondary outcomes i.e. plan to disclose, discussion on disclosure, though the changes were not significant, there was a 5% and 52% increase respectively in the intervention arm compared to a 1% and -1% increase respectively in the control arm. Clearly there was a bigger increase in the intervention group. The secondary outcome plan to discuss disclosure showed that there was an 11% reduction in plan to discuss disclosure in the intervention arm while there was a 7% increase in the control group. This reduction in plan to discuss disclosure after the intervention had been implemented could be explained by the fact that those who initially planned to discuss disclosure could have quickly been prompted to discuss due to the intervention.

**Assessment of Outcome Measures**

While controlling for age, gender, knowledge of partners status and time since one knew they were positive, primary outcome HIV status disclosure and the secondary outcomes Discussions on disclosure, plan to disclose, and plan to discuss disclosure were assessed. This was done by computing proportions, odd ratios and confidence intervals based on the baseline as well as post intervention findings as shown in table 3.

**Table 4:** Pre and Post intervention results of the pilot intervention

<table>
<thead>
<tr>
<th>Variable</th>
<th>Baseline</th>
<th>Evaluation</th>
<th>95% CI</th>
<th>OR</th>
<th>Difference OR (i)- OR (c)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Disclosure of HIV Status</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Intervention N=98</td>
<td>71.4% (70)</td>
<td>88% (86)</td>
<td>1.40; 9.41</td>
<td>3.63</td>
<td></td>
</tr>
<tr>
<td>Control N=98</td>
<td>70.1% (68)</td>
<td>76% (74)</td>
<td>0.42;1.98</td>
<td>0.91</td>
<td>2.72</td>
</tr>
<tr>
<td><strong>Discussion on disclosure</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Intervention N=28</td>
<td>18% (5)</td>
<td>25% (3)</td>
<td>0.18;6.37</td>
<td>1.06</td>
<td></td>
</tr>
<tr>
<td>Control N=28</td>
<td>18% (5)</td>
<td>17% (4)</td>
<td>0.21;4.15</td>
<td>0.93</td>
<td>0.13</td>
</tr>
<tr>
<td><strong>Plan to disclose</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Intervention N=28</td>
<td>71% (20)</td>
<td>75% (9)</td>
<td>0.32;10.67</td>
<td>1.83</td>
<td></td>
</tr>
<tr>
<td>Control N=29</td>
<td>45% (13)</td>
<td>46% (11)</td>
<td>0.36;3.76</td>
<td>1.16</td>
<td>0.67</td>
</tr>
<tr>
<td><strong>Plan to discuss disclosure</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Intervention N=28</td>
<td>61% (17)</td>
<td>50% (6)</td>
<td>0.15;2.82</td>
<td>0.66</td>
<td></td>
</tr>
<tr>
<td>Control N=29</td>
<td>31% (9)</td>
<td>38% (9)</td>
<td>0.47;5.66</td>
<td>1.62</td>
<td>-0.96</td>
</tr>
</tbody>
</table>

**Disclosure of HIV Status**

After the intervention, disclosure in the intervention group increased by 17% compared to that in the control which increased by 6%. The odds of individuals disclosing after the intervention are 3.6 folds or times the odds of disclosing before the intervention. These results are attained after controlling for age, gender, knowledge of partners status and sex. The confidence interval of 1.4; 9.4 implies that the intervention is significant.
Secondary Outcomes
Although there was a bigger increase in the secondary outcomes discussion about disclosure and plan to disclose in the intervention arm compared to the control, this difference was not significant. However, for the secondary outcome plan to discuss disclosure, there was a reduction in this variable in the intervention arm thus giving a negative P-value (-0.96) which could be explained by the fact that the intervention could have prompted clients to actually discuss disclosure thus the reduction in plan to discuss disclosure.

Table 5: showing adjusted disclosure levels in the intervention arm

| HIV status disclosure | IRR  | Std. Err. | P>|z| | [95% Conf. Interval] |
|-----------------------|------|-----------|-----|---------------------|
| studyarm_1            | 1.206| 0.067     | 0.001 | 1.081  1.345        |
| Age category 1        | 1.119| 0.0811    | 0.120 | 0.971  1.290        |
| Age category 2        | 0.99 | 0.0827    | 0.943 | 0.844  1.1702       |
| Sex                   | 0.975| 0.0574    | 0.663 | 0.868  1.094        |
| Marital status 1      | 1.955| 0.508     | 0.010 | 1.175  3.253        |
| marital status 2      | 1.715| 0.578     | 0.110 | 0.886  3.320        |
| Partner status        | 1.825| 0.265     | 0.000 | 1.373  2.426        |
| clinic duration 1     | 1.137| 0.183     | 0.425 | 0.829  1.559        |
| clinic duration 2     | 1.259| 0.242     | 0.231 | 0.864  1.836        |
| Time since diagnosis 1| 0.946| 0.153     | 0.732 | 0.690  1.298        |
| Time since diagnosis 2| 0.886| 0.171     | 0.529 | 0.607  1.293        |

The table shows that in the study arm, that is the intervention group (Bbaale HCIV) after the intervention had been implemented and after adjusting for age, sex, marital status, knowledge of Partners HIV status, duration since individual started coming to the clinic and time since diagnosis, the p-value was 0.001 with a confidence interval of 1.081; 1.345, implying that there was a significant change in disclosure in the intervention arm. This implies that the pilot intervention significantly improved/ increased HIV status disclosure to sexual partners.
7.0 DISCUSSION

Introduction
With the low levels of HIV status disclosure, there was an urgent need to develop interventions to promote disclosure to sexual partners. The primary aim of this study was to develop a pilot intervention to increase HIV status disclosure and test the effectiveness of this small group behavioral intervention to increase HIV status disclosure to sexual partners among people living with HIV in a health care setting. The significance of this study was that the results would have important implications for future HIV prevention efforts among people living with HIV first in Uganda and the rest of sub-Saharan Africa. This study was not without limitations. One of the limitation of this study is that it is a pre intervention and post intervention comparison design and uses self-reported behaviors as indicators of intervention efficacy rather than measuring new cases of HIV. A long-term objective therefore is the need to more accurately determine whether the peer-driven behavioral intervention model actually does reduce the incidence of HIV infection. Future studies will need to consider using randomized controlled trial designs to effectively measure the effectiveness of this intervention. Despite these limitations, very important findings were highlighted with regard to the Pilot intervention, its design and disclosure to sexual partners as is highlighted in the discussion below.

Intervention Description
Based on a qualitative assessment to establish barriers, benefits and skills for HIV status disclosure to sexual partners, a small group intervention targeting HIV positive clients was designed and implemented at Bbaale Health Centre IV, with Kangulumira Health Center IV serving as a control. At Bbaale Health centre IV, a select group of 25 persons was randomly selected to receive the intervention with the assumption that this intervention when implemented among a small group would not only benefit the participant but would through peer networks spread out to the bigger population of PLHIVs that attend the health centre. This idea was based on the diffusion of innovations theory (DIT). This theory explains how innovations (ideas, behavior) are taken up in a population. The easier it is for individuals to see the results of an innovation, the more likely they are to adopt it and also stimulate peer discussion of a new idea (Mahajan et.al 1990). With DIT, change can be promoted faster
and easily in a community through a domino effect which explains that one small change will create a similar change among others (Rogers, 1995). There were incremental dosages of the messaging divided into a series to include understanding disclosure, barriers to disclosure, benefits of disclosure, and how to disclose (skills). The sessions were divided into four sessions implemented on a weekly basis.

The mode of delivery involved interactive methods among a small group of people of approximately 25 people with the belief that concentrating on a few would create a situation where the message would diffuse to the entire group based on the diffusion of innovations theory. It was assumed that outcome would increase with an increasing dose of the intervention.

**Understanding Disclosure**

Interventions intended to promote HIV Status disclosure should first ensure that the target population have a clear understanding of disclosure, clearly highlight all the benefits of disclosure as well as highlight the possible dangers/ barriers and how to counteract them. Based on the results of this study, this approach has proven to be effective in ensuring a good understanding of disclosure, skills and an increase in actual sexual partner disclosure rates. These results rhyme with results of other studies that established that clients that had regular counselling were more likely to disclose just like those with good communication skills (Kadowa et.al, 2009).

**Benefits and Barriers of disclosure**

This study revealed that the more people know about the benefits of disclosure and the barriers to disclosure and how to work against them, the more they disclosed. The pilot intervention dedicated a session to discussions on these issues. Results of the preliminary evaluation of the pilot intervention showed a significant increase in disclosure to sexual partners after implementation of the intervention. This change is attributed to the design of the intervention which took into consideration the benefits, barriers and skills of HIV status disclosure to sexual partners. These results are in line with other studies that established that HIV positive persons exposed to continuous counselling where more likely to disclose (Rosa et.al, 1998, sowell et.al,2003). This is probably because they get to understand all the benefits, barriers, skills and other tenets included in disclosure counselling.
Small group interventions (Model of the Pilot intervention)

Results of this study suggest that this intervention though implemented amongst a small group of people is effective in promoting HIV status disclosure to sex partners not only in the smaller group but among the larger group of peers which can be explained by the diffusion of innovations theory. Based on the highlighted findings, public health interventions especially with limited resources could incorporate the diffusion of innovations theory to use minimal resources and have a larger effect with regard to disclosure of HIV status to sexual partners for prevention purposes especially in a health care setting. This kind of intervention is applicable mostly among close knit communities that have regular interactions thus the opportunity to pass information from one to another.

To further affirm the effectiveness of the diffusion of Innovations Theory as established by this small group intervention, interventions elsewhere with this theory as the basis have been shown to achieve similar good results. In Haiti, a United States Agency for International Development effort to conduct HIV prevention education in rural villages had results that exceeded campaign objectives by 124%. In Nepal, where vitamin A deficiency contributes to very high rates of infant and maternal mortality, the innovation of kitchen gardens was diffused among households through neighbor social modeling, and had great results. (Dearing, 2009)

Diffusion of Innovations theory was central to one of the most effective HIV/AIDS prevention programs to date: STOP AIDS in San Francisco. STOP AIDS began by conducting focus groups but then the founders realized that the focus groups were having a strong educational effect, as men shared information(diffused) about HIV prevention. STOP AIDS then employed a group of outreach workers from the gay community to conduct small group meeting in homes among other places which launched the diffusion process thus unintendedly reaching 30,000 men. (Bertrand, 2004)

Small group interventions are low cost. The diffusion of innovations theory goes a long way in promoting the effectiveness of interventions on small groups which reduce the cost of implementing the intervention. Such interventions that have the potential to spread out to the entire community despite being implemented amongst a smaller group are favourable for communities that lack resources to intervene widely.
Implications/ applications of the intervention
This study implies that since small group intervention are less costly than intervening in an entire community; they through the diffusion of innovations theory can be used to implement prevention interventions as well as other behavioural interventions. It further implies that resource scarcity should not be looked at as a hindrance to implementation of HIV prevention interventions since it has been shown that an intervention can be implemented among a small group and it spreads out to the entire community in equal proportion.

8.0 SUMMARY, CONCLUSIONS, AND RECOMMENDATION

8.0.1 Summary
HIV status disclosure to sexual partners is important in the reduction of the transmission of the virus. It is therefore advisable for persons involved in HIV prevention activities to design interventions focused on prevention of this primary transmission to the sexual partner. The piloted intervention a standard counseling and education tool to equip clients with skills to disclose was developed and implemented in 4 sessions among a select group of 25 clients. This intervention is based on the diffusion of innovations theory which assumes that the effect of the small group intervention will spread into the wider population. Subsequently, preliminary assessment results from a sample of 196 (n=196) clients at baseline and the same number at evaluation showed that the intervention increased the disclosure of HIV status by 17% (from 71% at baseline to 88%) in the intervention group (n=98) compared to a 5% (71% to 76%) increment in disclosure in the control group (n=98). The odds of disclosure in the intervention arm are 3 folds the odds of disclosure before the intervention.

8.0.2 Conclusion
Understanding disclosure based on personal experiences is misleading since some individuals have very bad experiences of disclosure to their partners and therefore define disclosure in a negative way. Disclosure without appropriate preparation and appreciation of the benefits is an issue counsellors need to focus on since learning from peers who were
not counselled and therefore only share their negative experiences is bound to turn out as a barrier to disclosure of HIV status to sexual partners.

HIV positive persons need to be exposed to all the benefits of disclosure of their status to partners so that however insignificant the benefits, individuals can relate to at least one benefit and therefore be implored to disclose their status. Individuals need to see the good in disclosing their HIV status to their sexual partners as a trigger for disclosure.

Interventions to promote HIV Status disclosure need to focus on counteracting barriers to disclosure of status to sexual partners. Though the common barriers to disclosure to partners are similar in the various communities, it is still important to tailor interventions to particular communities and focus on the needs and disclosure environment of that particular community.

Small group interventions for HIV prevention that base on the diffusion of innovations theory are a sure way to get interventions to communities with minimal resources invested. The diffusion of Innovations Theory which is behind the intervention evaluated in this paper has been proven to work. Once an intervention is implemented amongst a small group of peers, it is bound to diffuse to the rest of the peers that have not been direct beneficiaries of the intervention. This study did not however establish the ideal ratio of community to intervention. Its advisable to establish the ideal number of people compared to community size to which an intervention should be implemented for it to be effective.

8.0.3 Recommendations
A common understanding of HIV Status disclosure to sexual partners, its benefits and barriers should be the start point of discussions on disclosure. This information as well as support in terms of disclosure skills will motivate and give confidence to individuals to disclose their HIV status to their sexual partners as can be illustrated in the pilot intervention that is the basis of this report.

Interventions to promote HIV status disclosure to sexual partners must also be tailored to the particular communities for which they are intended. Baseline information on the understanding of disclosure and gaps/ barriers to disclosure should be attained so that the content of the interventions are relevant to the communities for which they are intended.
Small group interventions for HIV prevention should be proportionate to community size and participants encouraged to disseminate received information for it to be able to diffuse into the whole population and thus attain the intended impact.

Small group interventions for HIV status disclosure to sexual partners are an effective approach to promote HIV Status disclosure to sexual partners especially in resource constrained settings and should therefore be an approach borrowed by public health programs to implement low cost interventions with maximum benefits.
9.0 References


James W. Dearing. 2009. Applying Diffusion of Innovation Theory to Intervention Development


Julianne M. Serovich, Sandra Reed, Erika I. Grafisky, and David Andrist, An Intervention to assist Men Who Have Sex With Men Disclose Their Serostatus to Casual Sex Partners Results From a Pilot Study, Aids educ prev. 2009 june; 21(3): 207–219.


and women clinical service users in southwest Ethiopia, BMC Public Health. 2008; 8: 81. Published online 2008 February 29.


WHO. 2003. Gender dimensions of HIV status disclosure to sexual partners: Rates, barriers and outcomes; A review paper.

**APPENDIX 1: Draft Questionnaire**

**Assessment of the state of HIV status disclosure**

| Health center | ____________________________ |
| Research assistants initials | ____________________________ |
| Date | (dd/mm/yy) |
| Respondents name (one name is good if preferred) | ____________________________ |

<table>
<thead>
<tr>
<th>NO.</th>
<th>QUESTIONS</th>
<th>CODING CATEGORIES</th>
</tr>
</thead>
<tbody>
<tr>
<td>101</td>
<td>Gender of the respondent</td>
<td>1. Male 2. Female</td>
</tr>
<tr>
<td>104</td>
<td>How long is it since you were diagnosed as HIV positive?</td>
<td>1. 1 year 2. 2 yrs 3. 3 yrs 4. &gt;3 years</td>
</tr>
<tr>
<td>105</td>
<td>How long have you been attending the clinic?</td>
<td>1. 1 year 2. 2 years 3. &gt;2 years</td>
</tr>
<tr>
<td>106</td>
<td>In the past 3 months, have you disclosed your HIV status to your sexual partner?</td>
<td>1. Yes 2. No</td>
</tr>
<tr>
<td>107</td>
<td>In the months ahead do you plan to disclose your HIV status to your sexual partner?</td>
<td>1. Yes 2. No</td>
</tr>
<tr>
<td>108</td>
<td>In the past 2 months, have you discussed HIV status disclosure with your partner?</td>
<td>1. Yes 2. No</td>
</tr>
</tbody>
</table>

**Objective 1: Levels of HIV status disclosure to sexual partners**
<table>
<thead>
<tr>
<th>Question</th>
<th>Option 1</th>
<th>Option 2</th>
</tr>
</thead>
<tbody>
<tr>
<td>109 Do you plan to discuss HIV status disclosure with your sexual partner?</td>
<td>1. Yes</td>
<td>2. No</td>
</tr>
<tr>
<td>110 Do you know your partner’s HIV status</td>
<td>1. Yes</td>
<td>2. No</td>
</tr>
<tr>
<td>111 If yes, did your partner disclose to you in person?</td>
<td>1. Yes</td>
<td>2. No</td>
</tr>
</tbody>
</table>

**Objective 2 and 3: Perceptions, barriers, benefits and Knowledge**

<table>
<thead>
<tr>
<th>Question</th>
<th>Option 1</th>
<th>Option 2</th>
</tr>
</thead>
<tbody>
<tr>
<td>112 If a person learns he/she is infected with the HIV virus, should the person be allowed to keep this fact private away from sexual partners?</td>
<td>1. Yes</td>
<td>2. No</td>
</tr>
<tr>
<td>113 If kept private why?</td>
<td>1. Loss of economic support</td>
<td>2. Blame</td>
</tr>
<tr>
<td></td>
<td></td>
<td>3. Abandonment</td>
</tr>
<tr>
<td></td>
<td></td>
<td>4. Physical and emotional abuse</td>
</tr>
<tr>
<td></td>
<td></td>
<td>5. Stigma &amp; Discrimination</td>
</tr>
<tr>
<td></td>
<td></td>
<td>6. Disruption of family relationships</td>
</tr>
<tr>
<td>114 Did you share your HIV status results with anyone</td>
<td>1. Yes</td>
<td>2. No</td>
</tr>
<tr>
<td></td>
<td></td>
<td>CHK</td>
</tr>
<tr>
<td>115 With whom did you share?</td>
<td>1. Partner</td>
<td>2. Parents</td>
</tr>
<tr>
<td></td>
<td>3. family</td>
<td>4. Neighbors</td>
</tr>
<tr>
<td></td>
<td>5. Employer</td>
<td>6. Friends</td>
</tr>
<tr>
<td></td>
<td>7. religious leaders</td>
<td>8. Other……………Specify</td>
</tr>
<tr>
<td>116 Who did you tell first?</td>
<td>1. Partner</td>
<td>2. Parents</td>
</tr>
<tr>
<td></td>
<td>3. family</td>
<td>4. Neighbors</td>
</tr>
<tr>
<td></td>
<td>5. Employer</td>
<td>6. Friends</td>
</tr>
<tr>
<td></td>
<td>7. religious leaders</td>
<td>8. Other……………Specify</td>
</tr>
<tr>
<td>117</td>
<td>Please share with me the reasons for sharing your HIV status with your partner?</td>
<td></td>
</tr>
<tr>
<td>-----</td>
<td>-----------------------------------------------------------------------------</td>
<td></td>
</tr>
<tr>
<td></td>
<td>1. Increased partner support</td>
<td></td>
</tr>
<tr>
<td></td>
<td>2. Improved access to necessary medical treatment and care HIV risk reduction</td>
<td></td>
</tr>
<tr>
<td></td>
<td>3. Increased opportunities to plan for the future</td>
<td></td>
</tr>
<tr>
<td></td>
<td>4. Wanted advice from them</td>
<td></td>
</tr>
<tr>
<td></td>
<td>5. They knew you that you got tested</td>
<td></td>
</tr>
<tr>
<td></td>
<td>6. They knew you were sick and had been asking about it.</td>
<td></td>
</tr>
<tr>
<td></td>
<td>7. Had tested together</td>
<td></td>
</tr>
<tr>
<td></td>
<td>8. Person is a sex partner and you thought you should tell them so they would get tested</td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>118</th>
<th>Was it difficult to disclose to your partner?</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>1. yes</td>
</tr>
<tr>
<td></td>
<td>2. No</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>119</th>
<th>Looking back do you regret you told them?</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>1. Yes</td>
</tr>
<tr>
<td></td>
<td>2. No</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>120</th>
<th>Why didn’t you share your HIV status with your sexual partner?</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>1. Partner would be shattered</td>
</tr>
<tr>
<td></td>
<td>2. Fear of neglect and isolation</td>
</tr>
<tr>
<td></td>
<td>3. Fear of verbal abuse</td>
</tr>
<tr>
<td></td>
<td>4. Fear of physical abuse</td>
</tr>
<tr>
<td></td>
<td>5. Fear of death</td>
</tr>
<tr>
<td></td>
<td>6. No care and support</td>
</tr>
<tr>
<td></td>
<td>7. Be kicked out</td>
</tr>
<tr>
<td></td>
<td>8. People would think am promiscuous</td>
</tr>
<tr>
<td></td>
<td>9. Other................................................................</td>
</tr>
</tbody>
</table>
KNOWLEDGE AND BARRIERS TO HIV STATUS DISCLOSURE

Focus Group Discussion Guide

1. What is your understanding of HIV status disclosure?

2. What are the barriers to HIV status disclosure to sexual partners?

3. How can clients be helped to overcome barriers to HIV Status disclosure to sexual partners?

4. Why should one disclose their HIV status to their sexual partner?

5. What challenges did you meet when disclosing your HIV Status?

6. What helped you or eased the process of HIV Status disclosure to your sexual partner?

7. What do you recommend should be done to increase HIV status disclosure to sexual partners?
Consent form (To be signed by respondents prior to data collection) 

Good morning/afternoon, my name is …………………………….. working with Makerere University Walter Reed Project (MUWRP). MUWRP is a non for profit organisation that provides treatment, care and support services through the government health centres in Kayunga and Mukono Districts. We are conducting an assessment to establish knowledge, skills and barriers to HIV status disclosure to sexual partners among HIV positive persons. Feel free to speak your mind and any information you provide will be handled confidentially. Your participation is voluntary and will not expose you to any risks. This activity will take a maximum of 1 hour of your time.

Before consenting to the evaluation, please read the following important information:

1. Purpose: The purpose of this study is to increase HIV status disclosure to sexual partners with the ultimate aim of reducing HIV transmission.

2. Benefits: By participating in this study, you will be contributing to the improvement of the lives of HIV positive people, by providing information that would ultimately ease HIV status disclosure to sexual partners. Disclosure will help an individual get the necessary support for care, treatment and reduce the transmission of HIV.

3. Risks: This study may cause you minimal anxiety and fatigue. You will be involved in this activity for a minimum of 60 minutes.

4. Confidentiality: All information collected from you will be kept confidential and you will not be identified by name in any reports or publications that may arise from this study.

5. Rights to refuse or withdraw: You may refuse to participate in this activity or withdraw your consent at any one time and your withdrawal will not affect your ability to continue attending the clinic. Your withdrawal will not be discussed or lead to any punishments.

6. Whom to contact: In case of you have any questions or problems, you can contact the investigator:

Solome Mukwaya on 0772-572991

For any questions regarding ethical conduct of this activity, you may contact: Prof Wabwire-Mangen, Higher Degree, Research and Ethics Committee Makerere University School of Public Health on Telephone: 0414 543872, 0772 732206

Certificate of Consent

I have understood the purpose of this study and agreed to the mentioned terms and conditions. I voluntarily accept to participate in this study.

Unique identifier………………………………………..

Signature…………………………………………………

OR

Thumbprint…………………………………………
APPENDIX 4: Guideline for HIV status Disclosure to Sexual Partners

A GUIDE FOR HIV STATUS DISCLOSURE TO SEXUAL PARTNERS ATTENDING HEALTH CENTERS IN KAYUNGA DISTRICT: DISCLOSING HIV STATUS TO SEXUAL PARTNERS FOR REDUCTION IN HIV TRANSMISSION

By: Solome Mukwaya (MakSPH-CDC Fellow)

Reviewed by: Mark Breda (MUWR PEPFAR Manager) , Fred Magala (MUWR PEPFAR coordinator) , Josephine Nassali (Nurse), Moses Isabirye (counselor)
**Background**

The average rate of HIV status disclosure to sexual partners is 49% and 79% in developing countries and developed countries respectively (WHO, 2004). Ironically, HIV incidence in the developing world is higher than in the developed world while disclosure is lower which is worrying for HIV prevention interventions. Evidence suggests that HIV status disclosure can prevent HIV transmission. A study in south Africa examined HIV serostatus disclosure and its relationship to risky sexual behaviours and established that those who did not disclose were more likely not to use condoms and to have multiple sexual partners. Another study established that having multiple partners and non-use of condom at last sex were significantly associated with non-disclosure of HIV serostatus.

**Intervention**

Based on the above background, Interventions to promote HIV status disclosure to sexual partners for purposes of reduction in transmission are important. This guide is to be used amongst a small group (20-25) people living with HIV with the aim that the content will be shared with peoples based on the diffusion of innovations theory.

**Key learning outcomes**

- Understanding HIV Status disclosure to sexual partners
- Increased partner discussion on disclosure
- Increased will to disclose
- Partner disclosure
SESSION ONE

Understanding HIV Status Disclosure to sexual Partner

Introduction

- It’s important to disclose HIV status
  - Who do you disclose to?
  - Why? (Discussion with participants)
  - Wrap up with people usually disclosed to
    - Parents
    - In-laws
    - Brothers
    - Sisters
    - Sexual Partners (Past, present and future)

- Priority should however be given to sexual partners
  - Who is a sexual Partner?
    - Any one you have had, are having, and plan to have sexual relations with.
  - Why disclose to sexual partners? (Discussion with Participants)
  - Wrap up with reasons for disclosure to sexual partners

You do not have to tell everyone that you are HIV+. For HIV prevention, care and treatment, disclose to anyone you have had sex with, are having sex with or plan to have sex with.

- Sexual intercourse is the main way though which HIV is transmitted
- Majorly to prevent HIV transmission through sexual intercourse
  - By promoting testing and counseling to all sexual partners and their networks
  - Promoting risk reduction practices such as partner testing and condom use
  - Prevent reinfection
  - Establish and maintain sero-discordance
    - What is Sero-discordance? (Discussion with participants)

- Disclosure Options
  - Self disclosure is when an individual discloses their HIV status to their sexual partner
Assisted disclosure is when one is assisted to disclose their HIV status to their sexual partner. For example, one could request the health worker to help them disclose to their partner.

- **NB: Shared confidentiality**
  Disclosure is usually on the understanding that people will not tell others, unless they have been given permission.

- **Introduce topics for the subsequent weeks i.e. barriers, benefits, and skills.**

**CONCLUSION:** Emphasize the need for everyone to share the acquired information with fellow PLHIV’s attending the clinic at the clinic days and at treatment club meetings, as well as all their peers at different fora.
SESSION 2:
Benefits and Barriers of Disclosure to sexual Partners

2.0 Benefits of HIV status Disclosure to Sexual Partners

Activity 1: Testimonies, Storytelling (From Participants)

True Story 1:

Nabitalo (not true names) is a 40 year old woman attending the Kojja Health Center; she accidentally found out that she was HIV positive when she went for antenatal. Though she was planning to use a traditional birth attendant (TBA) at delivery, she always visited the health center once or twice during her pregnancy. This was going to be her fourth pregnancy. On being tested for HIV, she was found to be positive; she contemplated not telling her husband and just going on to deliver at the TBA. After some counseling she was convinced to disclose her status to her husband. He was initially furious and apportioning blame. After a few days, he decided to take a test and was found to be HIV negative. He together with his wife where advised on how to reduce risk of transmission to both the baby and the negative partner. As time went on, he became more supportive and even ensured that nabitalo got the care and treatment she needed.

Wrap Up with list of benefits

• Disclosure can help you accept your status and reduce the stress of coping on your own.
• Disclosure can help you access the medical services, care and support that you need (for both you and your partner).
• Disclosure can help you protect yourself and others from infection and reinfection.
• Disclosure of HIV status to sexual partners can help you and loved ones plan for the future.
• Disclosure of HIV status to sexual partners promotes PMTCT

Question and Answer

• Anyone can ask questions
• Anyone can make a special request

CONCLUSION: Emphasize the need for everyone to share the acquired information with fellow PLHIVs attending the clinic at the clinic days and at treatment club meetings
2.1 Barriers to HIV Status Disclosure to sexual Partners

- **What are the barriers to HIV status disclosure to sexual Partners? (Q &A)**
  - (Participatory: each individual shows actions to imitate barriers, while others say out the barrier)
  - For each barrier, Explain together with the participants how it can be overcome
  - Testimony on an individual’s experience on how barriers where overcome

**Wrap Up of barriers**

**It’s important to understand the practicalities of HIV status disclosure:** It is hard to speculate the reaction of one’s sexual partner but one can come up with strategies to cope with the unpleasant reaction.

- Some people worry about losing their partner after disclosure. This is a possibility but a risk worth taking.

- Fear of violence and physical abuse- this can be overcome by disclosing in the presence of a close family member or friend or in the presence of a counselor/ health worker.

- You may fear accusations of infidelity. This is common among couples and sex partners. It is good to be as honest as possible and clear

- You may not want to upset family members. This is understandable, but your spouse or partner has a right to know so they can get tested and start treatment as soon as possible if required. The longer you keep it from them the smaller their chance of hindering replication of the virus and the sicker they will get.

- You may worry about losing financial and emotional support from your partner. By no measure is losing your partner's support as important as losing your partner altogether if you do not give them the chance to get tested.

- Someone can contact ex-partners for you. You could contact a family member that you were close to.

- Some people fail to disclose because they are not in a permanent relationship with their sexual partners- However as long as one is having sexual relations with someone else, they are putting themselves and the other person at risk, it is therefore important to disclose for risk reduction.

- The experience of rejection. People who have their HIV status may feel that people are constantly judging them. They need to be prepared for this and be ready to make full use of the support that is available.

- *Lack of support:* partners may not give the support the person needs and they will have to deal with everything on their own.

**CONCLUSION:** Emphasize the need for everyone to share the acquired information with fellow PLHIVs attending the clinic at the clinic days and at treatment club meetings
SESSION 3
DISCLOSURE SKILLS

First ask the questions

Why, when, How, where (3 W’s and 1 H)

Preparing for Disclosure
Disclosure means telling someone that you are HIV+. Sharing your HIV status can help with the stresses of living with HIV. But who to tell and how to tell can be complicated and difficult decisions.

There is no one best way to tell someone, just as there is no sure way to know how they will react to your news or whom they may choose to tell. To prepare, it may help to ask yourself a few questions:

- What is the benefit of disclosing to my sexual partner?
- How much am I ready to share or are they ready to hear?
- How will disclosing my HIV status affect me and how will it affect my partner?
- Where is the most comfortable place for me to disclose?

Steps in disclosing HIV status to sexual Partners

- Find out as much as possible about HIV. Learn as much as you can about HIV and what it means to be HIV positive so you can more confidently and explicitly explain it to someone who may not know as much. Your uncertainty could instill worry or fear in another person.

- Decide when and where you will tell them. It is recommended to do so in person in a calm environment when you are both not focusing on anything else. There is no right time to disclose your HIV status, even to a sex partner or date. You may wonder whether to tell them on a first date, second date, right before sex, after sex, or not at all - there is no right time. But as long as there is going to be sexual intercourse you are obliged to disclose your HIV status and not knowingly put the other person at risk of becoming infected.

- Before disclosing, use risk reduction strategies e.g. abstinence, condom use or Avoidance of any sexual contact.

- Think things through. Make sure it is what you want to do and plan how you are going to go about it.

- Identify sources of support, such as relatives close to partner and self. Seek further counseling to support and help you to accept yourself positively.
• Be prepared for a shocked and even hostile reaction. This often happens, but with time your partner should learn to accept your HIV status.

• Once you decide to disclose, it may be easier to start with discussions on HIV to prevent shock.

• Consider that your sexual partners need to protect self and others.

• When you have decided to disclose your HIV status to your sexual partners, think about their emotions and their level of knowledge about HIV and AIDS. This will help you decide what they need to know and how to tell them so it is less traumatic for both of you.

• It is important to be strong enough to allow others to express their feelings and concerns after your disclosure.

How to Ease HIV Status Disclosure

• Test together

• Come up with a plan with the health worker to help disclose on your behalf

• Discuss HIV and disclosure with sexual partner to determine how best to disclose to partner

ACTIVITY: Role Play

Different scenarios for disclosure are given and participant selected to act out the roles and use the acquired skills to show how disclosure would be done.

1. Group critiques

2. Share challenges of each scenario and how to deal with them

CONCLUSION: Emphasize the need for everyone to share the acquired information with fellow PLHIVs attending the clinic at the clinic days and at treatment club meetings
SESSION 4
WRAP UP/ CONCLUSION

This session will be a recap of all the previous sessions. Participants will be asked to:

- Mention the most enlightening session
- The areas in which they need further education and counseling
- Participants will be asked to wrap up the entire module

CONCLUSION: Emphasize the need for everyone to share the acquired information with fellow PLHIVs attending the clinic at the clinic days and at treatment club meetings