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Disclosure of HIV results among discordant couples in Rakai, - Uganda: A facilitated couple counselling approach

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Abstract

Disclosure of HIV seropositive results among HIV-discordant couples in sub-Saharan Africa is generally low. We describe a facilitated couple counselling approach to enhance disclosure among HIV-discordant couples.

Using unique identifiers, 293 HIV-discordant couples were identified through retrospective linkage of married or cohabiting consenting adults individually enrolled into a cohort study and into two randomized trials of male circumcision in Rakai, Uganda. HIV discordant couples and a random sample of HIV-infected concordant and HIV-negative concordant couples (to mask HIV status) were invited to sensitization meetings to discuss the benefits of disclosure and couple counselling. HIV-infected partners were subsequently contacted to encourage HIV disclosure to their HIV uninfected partners. If the index positive partner agreed, the counsellor facilitated the disclosure of HIV results, and provided ongoing support. The proportion of disclosure was determined.

81% of HIV-positive partners in discordant relationships disclosed their status to their HIV-uninfected partners in the presence of the counsellor. The rates of disclosure were 81.3% in male HIV-positive and 80.2% in female HIV-positive discordant couples. Disclosure did not vary by age, education or occupation.

In summary, disclosure of HIV-positive results in discordant couples using facilitated couple counselling approach is high, but requires a stepwise process of sensitization and agreement by the infected partner.

Keywords

HIV disclosure; Facilitated couple counselling; Discordant couples

Background

Couple HIV-discordance in sub-Saharan Africa is high; with prevalence rates ranging from 3% to 20 % in the general population to over 60% among HIV infected married or cohabiting individuals (Carpenter, L.M., *et al*, 1999; De Walque, D., 2006; Guthrie B.L, De Bruyn G. & Farquhar, C., 2007; Lurie, M.N., *et al*, 2003; McKenna, S.L., *et al*, 1997; Tanzania Government

and ORC Macro., 2005). HIV transmission among discordant couples is substantial, ranging from 5.0 to 16.7 per 100 person years (Gray, R.H., *et al*, 2000; Gray, R.H., *et al* 2001; Hira, S. K., *et al*, 1997; Hugonnet, S. *et al*, 2002; Quinn, T.C., *et al*, 2000; Senkoro, P.K., *et al*, 2000; Serwadda, D., *et al*, 1995), which is 5 to 17 times higher than incidence among HIV concordant negative couples. Thus, couple HIV discordance considerably contributes to the HIV epidemic and represents an unmet HIV prevention need in sub-Saharan Africa. However, less than 10% of HIV sero-positive individuals know their partners' status and only about 20% of HIV discordant couples know that they are living in a discordant relationship in East Africa (Tanzania Government and ORC Macro., 2005; Bunnell, R., *et al*, 2008). The lack of knowledge of partner HIV status poses an increased risk of HIV transmission to the uninfected partners (Carpenter, L.M., *et al*, 1999; Serwadda, D., *et al*, 1995) and may lead to unprotected sex if the HIV infected partner incorrectly assumes that their sexual partners are also HIV infected. HIV infected individuals may have difficulty disclosing their HIV sero-status to their sexual partners (Sullivan, M.K., 2005) or they may disclose incorrect HIV results to their HIV uninfected partners for fear of blame, violence and marital dissolution.

HIV disclosure to sexual partners is an important HIV prevention strategy (Medley, A., *et al*, 2004; UNAIDS, 2000), and is associated with a reduced risk of HIV transmission by 18% to 41% (Pinkerton, D.S., & Galley, L.C., 2007) and increased use of condoms from 4% to 57% (Allen, S., *et al*, 1992). Appropriate counselling approaches to facilitate HIV positive persons in discordant relationships to disclose their status to their HIV-uninfected partners is thus central to HIV prevention in couples. We describe a stepwise strategy to promote disclosure of HIV-positive results among discordant couples using a facilitated couple counselling approach in Rakai district, Uganda.

Participants & Methods

Eligible couples were identified from three studies conducted by the Rakai Health Sciences Programme: (1) the Rakai Community Cohort Study (RCCS); a prospective population-based surveillance study, which obtains annual data from approximately 14,000 men and women aged 15–49, resident in Rakai communities. (2) A randomized trial of male circumcision for HIV/STD prevention which enrolled 5000 uncircumcised HIV-negative men who accepted voluntary HIV counselling and testing (VCT); and (3) a randomized trial of male circumcision which enrolled 997 HIV-positive men. Female partners of men enrolled in the circumcision trials were invited to enrol into a parallel study.

Participants were informed of procedures, benefits and risks of the study in which they were enrolled, and provided written informed consent for interviews and blood sample collection. All individuals were provided with health education on HIV prevention and safe sex practices, were offered condoms and individual and couples VCT free of charge. The studies were approved by the Science and Ethics Committee of the Uganda Virus Research Institute (Entebbe, Uganda), the Committee for Human Research at Johns Hopkins University, Bloomberg School of Public Health (Baltimore, MD, USA), and the Western Institutional Review Board (Olympia, WA, USA), and the Uganda National Council of Science and Technology, the body that oversees all medical research in Uganda.

Interviews and blood collection were conducted in private by same sex interviewers to obtain socio-demographic, health and behavioural data. For participants who were currently married or cohabiting, we requested information on their partners and retrospectively linked them to identify HIV concordantly positive or negative and HIV-discordant couples. Couples were invited to attend couple meetings at the counsellor's office in their respective communities. The invitation letters were sent to all 293 HIV-discordant couples identified, as well as randomly selected concordant HIV-infected ($n = 22$) and uninfected couples ($n = 22$) in the

same communities. The concordant couples were included to mask the discordant couples' HIV status and avoid breach of confidentiality. Attendance was extremely high, with 100% being represented by at least one partner and reasons for the other partner not present in the meeting were given by the attending partner and include: away business/official duties, away burial and away hospital among others. The attending partner assured the authors of his/her commitment to inform the absentee partner about the details of the meeting.

During the sensitization meetings, the following issues/topics were discussed: HIV sero-discordance, the benefits of HIV disclosure and couple counselling and partner communication (see table 1 for detailed outline). Couples were also informed of the availability of free HIV care and antiretroviral therapy offered by the Rakai Health Sciences Programme with funding from the United States President's Emergency Plan for AIDS Relief (PEPFAR). After the couples' meetings, participants were followed up either at home or at the counsellor's office to facilitate HIV disclosure and couple counselling. For the HIV-discordant couples, the counsellor first met with the HIV- positive partner and, subject to his/her agreement, the counsellor met with the HIV-negative partner and then scheduled a meeting with the couple where both partners disclosed their results to one another in the presence of the counsellor. If one of the partners refused to share their HIV result, a record of non-disclosure was recorded.

After disclosure (for couples that accepted), the counsellor conducted a 45–60 minute couple counselling session to help the couple understand the implications of each other's HIV status and map out new strategies for the future. The counsellor provided the couple with free condoms and encouraged them to collect more condoms from the Rakai Health Sciences Programme condom distribution outlet sites in the community in case they needed more supplies. Every HIV-infected individual who accepted disclosure and facilitated couple counselling was referred to the HIV clinic for on-going counselling and clinical management (CD4 screening, treatment for opportunistic infections and initiation of antiretroviral therapy if eligible) and their HIV-negative partners were counselled and provided with repeat HIV testing as appropriate (see figure 1 for detailed profile).

Also, after the disclosure and couple counselling session, the idea of forming an HIV self-help sero-discordant couple group in the community was suggested to the couple. If the couple agreed, a letter of invitation was handed to them detailing the agenda, date, time and venue of the self-help sero-discordant couple group meeting. There are currently ten such groups in the Rakai Health Sciences Programme communities and membership is open to new qualifying couples in the Rakai Health Sciences Programme cohort. Every group is led by two counsellors who facilitate group sessions as planned. Counsellors were sufficiently trained in group psychotherapy skills. The groups meet every six months to discuss, review and evaluate coping strategies and devise new plans. Each group developed its own contract (verbal ground rules) with the counsellors and during the sessions, individuals freely share experiences among themselves and discuss disputes and challenges that arise in their day-to-day living and the counsellors provide group leadership, direction and support (see table 2 for detailed outline). After every group session, counsellors make a follow-up of every member individually and as a couple either at home or at the counsellor's office to discuss their feelings about the group and also as a follow-up on couple relational issues and provide additional support as needed.

In this analysis, we determined HIV disclosure by gender of the infected partner, age, education, occupation, and condom use. Tests of statistical significance included chi square test and Fisher's exact test and analyses were done using STATA™ version 8.2.

Results

The study population comprised 293 HIV-discordant couples, among whom the male partner was HIV-infected in 192 (65.5%) and the female partner was HIV-infected in 101 couples (34.5%). Overall, 237 HIV-infected persons (80.9%) disclosed their HIV positive results and accepted facilitated couple counselling (Table 3). Disclosure was similar irrespective of the sex of the HIV infected partner (male HIV-positive couples 81.3%, female HIV-positive couples 80.2%) (Table 3). Disclosure did not differ significantly by age, education or occupation of the HIV infected partners (Table 3). Though not statistically significant, over all disclosure was higher among couples where the HIV-infected partner reported prior discussion of condom compared to no condom discussion (83.7% versus 76.5%, $p=0.13$). With regard to use of condoms, over all disclosure was significantly higher where the HIV-infected partner reported use of condoms compared to non condom use (87.2% versus 76.8%, $p=0.03$). Disclosure was also marginally significantly higher among couples in which the male partner was HIV-positive and reported having discussed use of condoms, compared to couples where the male partner was HIV infected but reported no condom discussion (85.3% versus 75.0%, $p=0.07$). Similarly, disclosure rates were significantly higher in couples in which the male partner was HIV-positive and reported prior use of condoms (90.1% disclosed) compared to couples who reported no prior use of condoms (75.3%, $p=0.01$) (Table 3).

Discussion

We found that our (facilitated couple counselling) approach to disclosure among HIV-discordant couples resulted in high rates (80.9%), irrespective of the sex of the HIV-infected partner (81.3% in male HIV-positive versus 80.2% in female HIV-positive discordant couples) (Table 3). Prior studies reported lower average HIV-disclosure rates of 49% in sub-Saharan Africa (World Health Organization, 2003) and these studies were based on self-reported disclosure by the HIV-positive partners which are subject to social desirability bias. In this study, disclosure was directly observed by the counsellor and thus, reducing on instances of social desirability biases. Also, prior studies suggested lower disclosure rates among HIV-infected women than men (Maman, S. *et al*, 2001; Maman, S. *et al* 2003; Mayfield, A., *et al*, 2008; Semrau, K., *et al*, 2005), contrary to our findings in which disclosure did not differ by gender of the HIV-infected partner. This possibly might be due to the fact that our disclosure intervention was a stepwise process involving prior sensitization couple meetings in which we registered a high degree of attendance of 100% being represented by at least one partner in addition to emphasizing the importance of disclosure and couple counselling in these sensitization meetings. Also, the availability of free HIV care and antiretroviral therapy offered by the Rakai Health Sciences Programme could have enhanced the disclosure proportions.

Disclosure was also marginally significantly higher among couples in which the male partner was the HIV-infected and reported prior discussion of condoms and significantly higher where the male partner was the HIV-infected and reported use of condoms. These results are similar to findings from previous studies (Allen S. *et al*, 1992; Crepaz, N., & Marks, G., 2003; Semrau, K., *et al*, 2005) suggesting that interpersonal communication on safe sex may facilitate disclosure. Also, it is possible that gender-associated power imbalances within couple relationships may contribute to greater rates of disclosure where male partners are the HIV sero-positive compared to where female partners are the HIV infected.

It is difficult to generalize our findings to the usual VCT programmatic settings in which most clients coming for couples counselling are self-selected because they have already agreed to disclosure prior to attending the service. It is possible that because individuals in this study were research participants, they may be more motivated to disclose their HIV test results. However, the stepwise process of sensitization meetings, agreement by the infected partner

and subsequent disclosure may be applicable to HIV longitudinal studies where married or cohabiting respondents are enrolled as individuals, in national HIV sero-surveys and in the roll-out of male circumcision for HIV prevention programmes where married or cohabiting individuals are part of the target group.

In summary, we found that high rates of disclosure of HIV results among HIV-discordant couples can be achieved using a phased approach of sensitization meetings, individual-level counselling to gain agreement from the HIV-infected partner and ultimately open disclosure of results by the couple.

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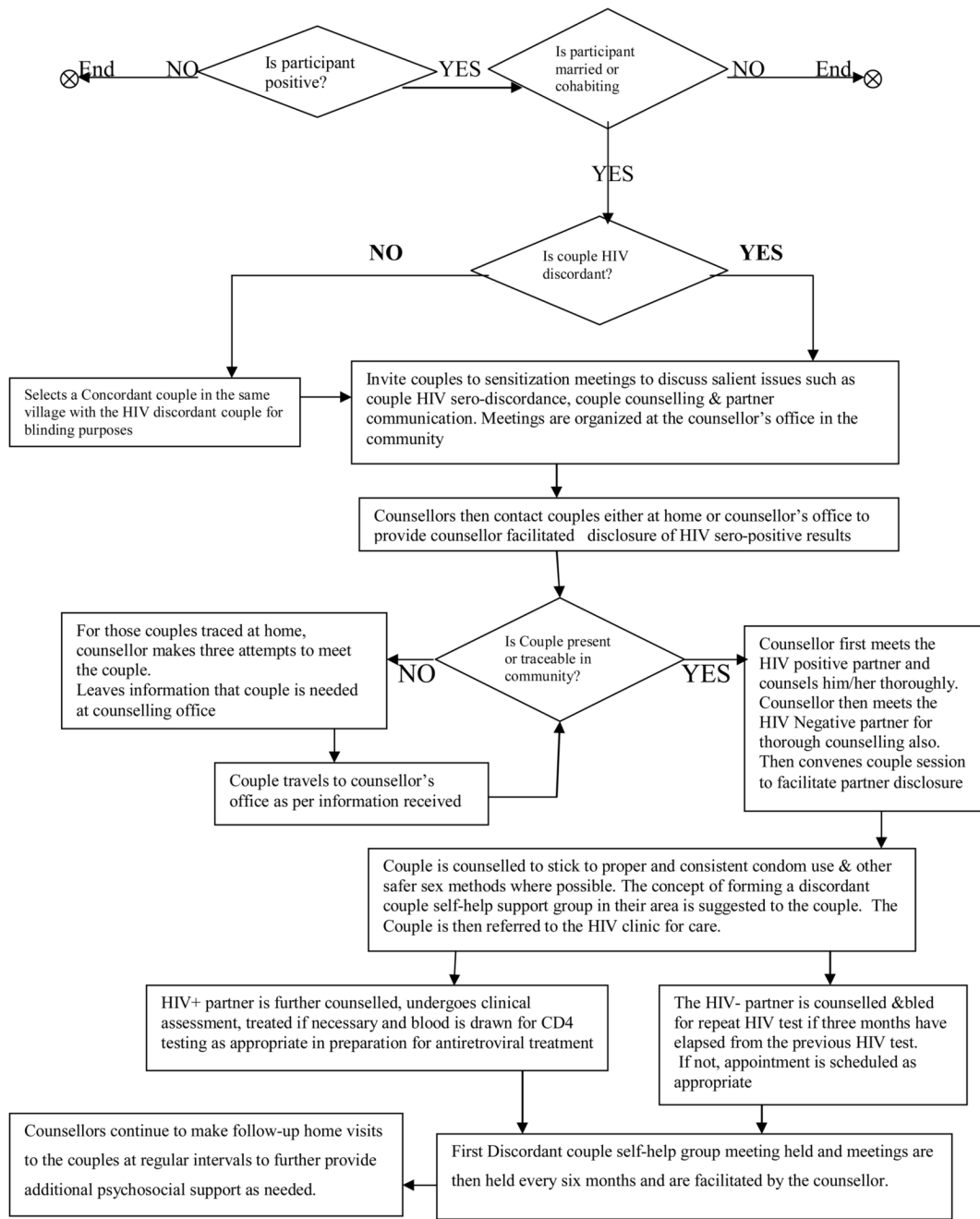


Figure 1. Profile of activities during facilitated couple counselling and HIV sero-status disclosure among concordant & discordant couples and related services provided.

Table 1

Sample session Plan for HIV Discordant & Concordant Couples’ Sensitization Outline

Subject: Couple Sensitization Session for HIV Discordant & Concordant Couples	Lead Counsellor:
Date:	
Time:	Co-Lead Counsellor:
Participants are engaged in:	
<ul style="list-style-type: none"> • Cooperative learning • Small group discussion • Brain storming • Experience sharing • Active listening • Asking and answering questions 	
Pre-Session: (Time: 20 – 30 minutes)	
<p>The Counsellors warmly welcomes participants into the Hall, provides them with seats and begins by introducing him/her self and other Rakai Program staff if available</p> <p>Counsellor proceeds on by requesting participants to introduce their neighbours (Via pre-determined format)</p> <p>Counsellor solicits for ground rules and expectations from participants</p> <p>Counsellor displays the chart with the session objectives of the session</p>	

Objective	Duration	Content	Teaching Method	Teaching Aids/materials	Participants/Learners activity	Evaluation Method
Willing participants share individual experiences with regard to VCT	30 min	Participants share the individual experiences regarding VCT and the lessons learned from this endeavour. The facilitator moderates the exercise	Experience sharing/story telling		Active Listening	Asks questions
Mention at least 4 benefits of couple HIV counselling & testing	20 min	<ol style="list-style-type: none"> 1 Individuals are not burdened with the need to disclose results and persuade partners to be tested 2 Offers safe environment for couples to discuss risk concerns and issues 3 Partners hear information and messages together – enhancing the likelihood of a shared understanding 4 Receive appropriate and timely interventions to reduce MTCT including antiretroviral treatment/prophylaxis and Infant-feeding counselling and support 	Small Group discussion	Flip Chart	-Asking Questions -Answering Questions -Brainstorming	Ask a participant to summarize all points presented.

Objective	Duration	Content	Teaching Method	Teaching Aids/materials	Participants/Learners activity	Evaluation Method
		<p>5 Facilitates the communication and cooperation required for risk reduction e.g consistent condom use, mutual faithfulness, HIV retesting etc</p> <p>6 Opportunity to mitigate tension and avert blame</p>				
	20 min	BREAK- BREAK –BREAK- BREAK- BREAK- BREAK- BREAK –BREAK- BREAK- BREAK				
Explain the cardinal elements of effective communication among couples	20 min	<p>Good communication is the first step in problem solving and in relation building:</p> <ol style="list-style-type: none"> 1 Partners must be eager to express themselves honestly 2 They must warmly receive each other's communication 3 The thoughts or emotions of the speaker must represent the actual words that come out of the speakers mouth 4 The listener must understand or interpret accurately what is said or heard 	Small group discussion then counsellor corrects myths	Flip Chart	Asking Questions Answering Questions -Brainstorming	Asks questions
List at least 8 reasons why spouses fail to communicate effectively	25 min	<ol style="list-style-type: none"> 1 One of the partners doesn't have a personal need to: (a) share experiences or feelings, (b) discuss the relationship, or (c) doesn't understand importance of verbally expressing to partner feelings of love, appreciation, or praise. 2 Talks, but doesn't make sure that partner is listening 3 Speaker mumbles, is ambiguous or vague; listener misinterprets or mind-reads 4 Doesn't reveal himself because he fears he'll be vulnerable 5 Doesn't communicate because he believes that talking would be futile 6 Doesn't communicate because he doesn't respect his partner's opinion 7 Doesn't share decisions because of a desire to control 	Small group discussion then counsellor corrects myths & misconceptions in the groups	Flip Chart	Asking Questions Answering Questions -Brainstorming	Asks questions

Objective	Duration	Content	Teaching Method	Teaching Aids/materials	Participants/Learners activity	Evaluation Method
Outline at least five benefits of effective communication in couples	15 min	<p>8 Couple does not communicate because of incompatible schedules and lack of time together</p> <p>9 Communicates in an offensive manner</p> <p>10 Lying or withholding vital information.</p> <p>11 Does not communicate because s/he believes that partner is not interested.</p> <p>12 Excellent communication from speaker but listener does not care.</p> <p>1. Good communicators avoid misunderstandings, unacceptable behaviours, fights and separation 2. Good communicators can disagree, yet agree respectfully and when and how to talk, and when and how to listen. 4. Good communicators resolve problems through discussion and constructive arguing. 5. Good communication promotes sharing, companionship, and bonding 6. Good communicators engage in frank discussions that reveal each person's needs/desires/agenda and develop a clear understanding of how to fulfill each other's expectations</p>	Small group discussion then counsellor corrects myths and misconceptions	Flip Chart	Asking Questions Answering Questions -Brainstorming	Asks questions
Describe the salient issues regarding Couple HIV discordance	30 min	<p>a. Factors contributing to HIV transmission Risks</p> <ol style="list-style-type: none"> 1) Presence of Sexually transmitted infections <ul style="list-style-type: none"> • Lesions/ Sores/ Ulcers 3) Increased frequency of sexual intercourse <ul style="list-style-type: none"> • Less sex often means fewer chances of transmission • Dry sex and traumatic sex. 4) Absence of male circumcision <p>b. Other issues</p>	Small group discussions then counsellor corrects myths and misconceptions	Flip Chart	Asking Questions Answering Questions -Brainstorming	Asks questions

Objective	Duration	Content	Teaching Method	Teaching Aids/materials	Participants/Learners activity	Evaluation Method
Rapping up the session	10 min	<ul style="list-style-type: none"> • Mutual masturbation is said to cause no risk. • Continued exposure will lead to HIV infection in the currently HIV negative partner. • Discordance is not a sure sign of infidelity <p>Couples can remain discordant for lifetime if risk reduction practices are absolutely implemented in the couple. HIV negative females in discordance are often threatened especially when male partner refuses to use condoms</p> <p>c. Common misperceptions about discordance</p> <ul style="list-style-type: none"> • The window period does not absolutely explain discordance • The uninfected partner is not immune to HIV • Faith can not protect one from becoming infected and a curse cannot cause one to become infected • The characteristics of a woman's vagina or a man's penis are not an explanation for HIV discordance 				
		Counselor appoints one or two participants to summarize the whole session. Then counsellor appreciates all participants for their presence and active participation		-		Summative evaluation

Table 2

Establishing Discordant Couple Self-help Groups in Rakai, Uganda.

Rationale
<ul style="list-style-type: none"> • To reduce myths and misinformation about the realities of couple HIV discordance, mitigate associated stigma and discrimination, and consequently improve self esteem and coping strategies among discordant couples.
Objectives
<ul style="list-style-type: none"> • To provide opportunity for fellowship and peer support. • To provide opportunity for the negative partners to get information on risk reduction and address questions on couple HIV discordance. • To provide forum where discordant couples can share experiences and challenges • To help discordant couples develop ability to communicate accurate empathic understanding skills in marriage and family.
Anticipated Benefits
<ul style="list-style-type: none"> • Experiences will be shared with other members of the community and belonging will be cultivated. • Group cohesiveness & Universality (all clients share the same problem and this is both supportive and therapeutic) • Feedback will be shared among client's themselves. • Destructive criticism is unlikely • The feelings of powerlessness which many people experience when they are sick/infected will be overcome as a result of the therapeutic effects of group membership • Will allow clients to act as both clients and therapists • Corrective emotional experiences (Clients who have been defensive and guarded will be encouraged to share their feelings with others and in doing so will become more self-confident and self-accepting) • Imitative Behaviours (Clients will also learn from one another through observations and modelling and new ideas and attitudes will be explored and nurtured through group interaction.)
Requirements for Becoming a Member
<ul style="list-style-type: none"> • Discordant the last time they received their HIV results and know the status of one another • Willing to continue participating in couple meetings regularly or as convened • Willing to share with peers issues regarding HIV disclosure/discordance challenges and coping strategies • Willing to respect Human rights and Human dignity of their partners • Willing to provide support to either partner as necessary • Willing to explore and implement realistic and concrete risk reduction steps/strategies • Willing to keep and maintain confidentiality of all issues discussed in the group and abide by the restrictions of shared confidentiality
Counsellor/Group Leader roles
Beginning sessions
<ul style="list-style-type: none"> • Helping members get acquainted • Setting a positive tone • Clarifying the purpose of the group • Explaining the leader's role • Explaining how the group sessions will be conducted • Helping members verbalize expectations • Checking out the comfort levels of the members • Explaining group rules including the group contract • Focusing on the content • Addressing questions

Subsequent sessions
• Assessing the benefits
• Assessing members' interest and commitment
• Assessing each member's participation
• Assessing members' level of trust and group cohesion
• Assessing how much to focus on the content or process

Table 3

Characteristics of the HIV infected persons among discordant couples

Characteristics	All Couples Combined		M+F-		M-F+	
	Disclosed (%)	P	Disclosed (%)	P	Disclosed (%)	P
Over all	237/293 (80.9)		156/192 (81.3)		81/101 (80.2)	
Age						
15-34	145/184 (78.8)		478/99 (78.8)		67/85 (78.8)	
35-49	92/109 (84.4)	0.24	78/93 (83.9)	0.37	14/16 (87.8)	0.42
Education						
Primary or Lower	196/240 (81.7)		128/157 (81.5)		68/83 (81.9)	
Post primary	41/53 (77.4)	0.47	28/35 (80.0)	0.83	12/18 (72.2)	0.15
Occupation						
Agriculture	140/177 (80.9)		86/106 (81.1)		54/71 (76.1)	
Skilled/Other	96/116 (82.8)	0.44	70/86 (81.4)	0.96	26/30 (86.7)	0.23
Ever discussed Condom with this Partner? (N=293)						
Yes	149/178 (83.7)		99/116 (85.3)		50/62 (80.6)	
No	88/115 (76.5)	0.13	57/76 (75.0)	0.07	31/39 (79.5)	0.89
Ever Used Condom with this Partner? (N=263)						
Yes	109/125 (87.2)		73/81 (90.1)		36/44 (81.8)	
No	106/138 (76.8)	0.03	67/89 (75.3)	0.01	39/49 (79.6)	0.79