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ABSTRACT

Objective: **To describe the perceptions of key stakeholders regarding the counselling needs of HIV sero-discordant couples as part of preparation for a clinical trial involving HIV sero-discordant couples.**

Design: **Qualitative study using key informant and couple interviews.**

Setting: **Moi Teaching and Referral Hospital (MTRH).**

Subjects: **A purposive sample of nine key informants and 31 couple interviews totaling 71 participants. The couple interviews consisted of HIV untested, HIV concordant (positive and negative) and discordant couples.**

Results: **Seventy one individuals participated in nine key informant and 31 couple interviews. The responses identified the following as key issues in counselling HIV discordant couples: The need for education on the meaning of HIV sero-discordancy including potential sources of infection; assistance in disclosing HIV test results to one's partner; discussion of the stigma surrounding formula feeding. Overall, the participants supported safer sexual practices in discordant partnerships.**

Conclusions: **Psychosocial support of HIV sero-discordant couples should include messages about the meaning, mechanisms and implications of sero-discordancy. Culturally appropriate HIV-disclosure and safer sex messages are also needed to support these partnerships.**

INTRODUCTION

HIV sero-discordancy within stable sexual partnerships is a phenomenon that is poorly understood by the lay community and even by some HIV counsellors. Many individuals assume that if one partner in a sexual relationship is HIV infected that the other partner is also infected (1). However recent data from sub-Saharan Africa have documented that sero-discordancy is quite common. Among couples tested for HIV in Rwanda and South Africa approximately 75% were found to be concordant negative while the remaining 25% were equally distributed as discordant and concordant positive (2-5). The prevalence of partner discordance ranges between 20–35% in studies of individuals seeking HIV care (6-8). These couples provide a significant opportunity to impact HIV transmission rates since in the absence of prevention intervention, 17% of HIV negative partners will seroconvert within 12 months compared to only 6% when safer sexual practices are adopted (2,4,9,10). Currently the only

viable prevention options for a discordant couple are either abstinence or condom use. However, both of these approaches require disclosure of HIV sero-status between partners which is often fraught with difficulty (2,4). In fact, disclosure of HIV status does not occur in a substantial proportion of partnerships. In one study 24% of HIV-infected individuals had not disclosed their status to a known HIV-negative partner and 41% had not disclosed to a partner with an unknown sero-status (11). Knowledge of partner status, particularly negative sero-status has been associated with an increased likelihood of condom use in discordant partnerships. Hence disclosure should be encouraged as part of transmission prevention (12,13). However, many barriers to disclosure have been identified and include fear of rejection and abandonment, as well as physical and emotional abuse (14-16).

The data on community and individual expectations with regard to sexual behaviour and social / community support of discordant couples in Kenya is scarce. As Kenyan society is highly integrated and socio-cultural expectations significantly impact individual behaviours, we chose to undertake this study to identify community stakeholder perceptions of appropriate sexual behaviours, counselling services and other support services for HIV discordant couples in western Kenya.

MATERIALS AND METHODS

Design: This cross-sectional study used key informant and couple interviews to identify perceived counselling and support needs for HIV discordant couples living in the community. The formative study was a component of the partners in prevention study (PIPS), a clinical trial designed to evaluate the use of acyclovir in preventing HIV transmission from HIV and herpes simplex type-2 (HSV-2) co-infected individuals to their HIV uninfected partners. The clinical trial demanded development of innovative approaches to identifying, enrolling and retaining the discordant couples in the clinical trial over a 24 month period. The formative study was approved by the Institutional Research and Ethics Committee of the Moi University School of Medicine as well as the Indiana University and Purdue University at Indianapolis (IUPUI) and Clarian Institutional Review Board and was carried out between April and August 2004.

Study population: Participants for this study were recruited from Eldoret town and its environs within the Uasin Gishu District. Eldoret has a population of approximately 450,000 people and is located 300 kilometres west of Nairobi, Kenya. Both Moi Teaching and Referral Hospital and Moi University School of Medicine are located in Eldoret and jointly offer voluntary counselling and testing (VCT), prevention of mother-to-child transmission (PMTCT) and HIV clinical services including anti-retrovirals free of charge. The Ministry of Health, at the time of the formative study, also provided VCT services at ten other health centres within the district.

To assess the attitudes and beliefs about HIV discordancy held by the local community, key informants were selected from community leaders (local government administrators), health care workers and health programme managers. A purposive sample of opinion leaders from each of these various categories were selected for participation in the study.

To assess general community and potential client attitudes and beliefs about HIV-discordancy we interviewed a purposive sample of stable couples from each of three categories: never HIV-tested, concordant HIV status and discordant HIV status. In polygamous relationships, only one wife was permitted to participate in the interviews. Concordant and discordant couples were identified through the index partner during a visit to either a participating MCT centre or HIV clinic. Untested dyads were recruited by posting flyers inviting their participation at the Moi Teaching and Referral Hospital. Concordant and discordant dyads were only interviewed if partners were aware of each other's sero-status. Participating couples were not required to be sexually active with each other. At the time of initial contact the research assistant provided an explanation of the study and invited the potential participant to bring their partner for an interview at the place and time of their convenience. All participants were adults over 18 years old and provided written informed consent prior to initiation of the interview.

Data collection: Each data collection team consisted of a moderator and a research assistant. Detailed notes and audio-taping of the interviews was the responsibility of the research assistant while the moderator was responsible for guiding the interview.

The interviews were structured using an interviewer guide in English or Swahili as per the interviewee's preference. Appropriate translation and back translation procedures were used in developing the Swahili interview guide. The interview guide was designed, *a priori,* to explore two concepts: (i) the perceived counselling needs of discordant couples and (ii) the perceived ideals for sexual behaviour and partner relations after HIV sero-discordancy has been identified.

The couple interviews were conducted sequentially with the individuals within the couple to avoid gender dominance in communication. When issues that required clarification as a couple were identified, the partners were brought together after the individual interviews in order to clarify these unresolved issues. Limited personal information was collected to create a relaxed interview environment for the participants.

Data analysis: Audio-tapes were transcribed into Word 2000 by an individual fluent in both Swahili and English. After transcription, interview team members compared each audio-tape to its respective transcript for accuracy. Swahili transcripts were translated into English by an individual fluent in both languages prior to analysis and reviewed by team members for translation accuracy. Analysis of the manuscripts was undertaken by two behavioural scientists with extensive experience in qualitative research. Standard content analysis was used to identify emerging themes as well as representative quotations. Views from the various participant categories were used for triangulation purposes to derive consensus.

RESULTS

Seventy one interviews were conducted with nine local opinion leaders and thirty one couples (Table 1). Three thematic areas were explored, namely; perceived counselling needs of discordant couples; previous experience with counselling and perceived appropriate sexual behaviour among discordant couples. A summary of the consensus opinions and selected representative quotes are presented.

Perceptions on the meaning and mechanisms of HIV sero-discordancy: Under this theme, the key construct discussed was the meaning and mechanisms for HIV sero-discordance. Several perceptions emerged. First perception was that stable couples are likely to have the same HIV serostatus. Some illustrative quotes for this perception were:

Table 1

Type and number of respondents

Strategy	Category of participants	No.
Key informant interviews	A senior official of the HIV clinical programme in Eldoret	1
	A senior VCT official	1
	District administrative officers	2
	A senior administrative official at district headquarters	1
	A senior public health official in Uasin Gishu district	1
	A clinical officer, Mosoriot Health Centre	1
	Traditional birth attendants, Uasin Gishu district	2
	Total	9
Couple interviews	Untested couples	10
	Concordant positive couples	7
	Concordant negative couples	3
	Discordant couples	11
	Total	31 couples = 62 individuals

> "I think this is a new phenomenon we thought ... if the husband is positive then the wife must be positive" Key informant interview — opinion leader.
> "I expected that even my results would come out that I have the virus. Because I already knew that if people have had sexual intercourse, then in that situation, they must be found that way. I thought they were just lying to me." Couple interview —Negative partner of a discordant couple.

We found that within discordant relationships the HIV uninfected partners had frequently been tested multiple times. Some of the repeat testing was recommended by clinicians to exclude the window period phenomenon. However, other testing was an effort by the couple or the negative partner to confirm their negative results.

The second perception was that if stable partners were discordant, then non-sexual transmission mechanisms explained the infection in the positive partner. A representative quote for this perception was:

> "... for the years that we have stayed together, I don't go out and she does not go out either.... You know the women who deliver [babies] in the villages.... I think [that] is where she got infected..., because we have stayed [together] for two, three years. We were not using condoms and yet I am negative and she is positive. Now it didn't get to us through sexual intercourse." Male partner in a discordant couple interview.

The third perception identified was that disclosure facilitates prevention of transmission. However, disclosure is challenging and men and women may handle it differently. Illustrative quotes included:

> "Personally, I think it [disclosure] is good. He will want protection. This one [the one who discloses] does not want to transmit but the one who wants to transmit it [HIV] does not say it" Key informant interview – opinion leader.

> "I was nervous; I didn't tell my husband for a long time .... A very very long time ... almost five years. Couple interview — female HIV positive
> "The woman may look at the children in the family... But the man may say no let me start another family" Key informant interview — opinion leader.

The fourth perception was that stigma impairs disclosure and is a barrier to use of formula feeding for babies of HIV positive mothers in discordant and concordant couples. Some illustrative quotes are presented:

> "I just went [from the counselling session], thinking I'm pregnant, and that baby is not going to breastfeed. If am asked [why I am not breast feeding], people would laugh at me [if they knew the reason]." Couple interview-HIV positive woman.
> "Now I started thinking ... what will neighbours think of me or us? That now the mother has given birth and is not breastfeeding the baby. Now there I started having thoughts [worrying], not sleeping well." Couple interview — HIV negative man.

The fifth perception was that children of an HIV positive woman in a discordant partnership can be disinherited if the sero-discordant state is considered a proxy for marital infidelity. A representative quote is presented:

> "It [a mother being HIV- infected] can also lead to children being disowned by the negative partner, if it is a man. The husband can easily say that all those children are not mine because I am negative and you are positive." Couple Interview — female partner.
> This perception was also consistent with the view that there could be gender differences in handling disclosure of HIV status.

Perceptions on previous experience with HIV counselling: Under this theme we explored the views on previous experience with HIV counselling and its benefits for discordant couples. The first perception was that counselling has a positive impact on the couples but not for all. Some illustrative quotes are presented below:

> "Well, after that testing, I felt that it is not good to move around [have sex outside the partnership] anyhow.... because you can't know the status of the lady. So I also felt that it is not good to use [intoxicating] drugs as the husband, because when you use drugs, you can be tempted maybe to befriend other women…… And I felt that with the wife it is good at least to use the condoms. It is wise and it really protects." Male partner -discordant couple interview.
>
> "Things changed so much [after counselling and testing]. There is no love any more and there's a lot of grief with no happiness. When he wrongs me he does not want to apologise. When we have a misunderstanding he won't even answer me. He says that he does not love me." Female HIV positive partner — couple interview.

The second perception under this theme was that support group meetings gives solace for the HIV infected partners. This is illustrated by the following quote:

> "When I go for a [support group] meeting ... I attended it and while we were learning I saw that I am not alone. Now there I became happy". HIV positive partner- couple interview.

Perceptions on socially appropriate sexual behaviour for discordant couples: Several perceptions emerged under the theme of sexual behaviour of discordant couples. The dominant perception was that it was impractical to prohibit sex among young HIV sero-discordant couples even though there were contrary views. Illustrative quotes are presented below:

> "I think it [sex] should continue ... People marry at your age [interviewer's age *25* years], young and active. And then if you are telling this guy now "stop this", you are telling the one who is HIV positive to go out... you can still continue [to have sex] but with protection... What I don't know is the . . .percentage of effectiveness of a condom used over a long period of time with an HIV positive person.". Couple and key informant interviews.
>
> "It [sex] should not be encouraged. Sometimes, they are not going to use these things [condoms], they are going to say, maybe this thing [condom] is disturbing [uncomfortable or difficult to use], and this is not the best. They are going to do it [have sex] without a condom and when they come to realise, they have already infected each other." Couple interviews — Concordant negative.

Some views on efforts to prevent sexual contact between discordant couples were extreme. In the process of continuing sexual activity, the negative one will be infected.., we can help by giving medicine to reduce the urge of the man ... he won't feel the urge but his life will continue". Key informant interview- opinion leader.

DISCUSSION

Developing an understanding of sero-discordancy was identified as a major counselling and educational need by this study. We identified misconceptions about the accuracy of the HIV tests especially where there is a sero-discordant test result in a stable partnership. These findings are consistent with a study from Uganda which also reported widespread misconceptions about sero-discordant status among stable partners (1). Clearly, there is a significant need for community-wide education about HIV testing and sero-discordancy as well as the need to enhance counselling services on this issue.

In previous studies, the risk of emotional or physical abuse and possibility of rejection have been identified as significant barriers to disclosure of the HIV status by the positive partner (14-16). None of our participants had experienced or expressed concern about physical violence as an issue with disclosure. However, as noted above, one of our respondents had experienced emotional abuse after disclosure. A new issue recognised in this study was the concern that children of sero-positive women would be rejected by their sero-negative father because of the concern that sero-discordance implied marital infidelity and as such the children could have been conceived outside the partnership. The participants' views on the gender difference in reactions to disclosure are consistent with the cultural norms in a patriarchal society. As such, we feel that a counselling programme addressing

the needs of sero-discordant couples in addition to providing education about sero-discordancy must help couples specifically work through issues of perceived or actual infidelity. Also, messages and support for disclosure of sero-status must be tailored to the gender of the individual disclosing.

Stigma related to formula feeding (avoidance of breastfeeding), as part of prevention of mother to child transmission of HIV was found to be a significant issue for both the HIV positive concordant and discordant couples interviewed. This contributed to a lack of self confidence in the ability to adopt formula feeding in an environment where breastfeeding is considered the norm. As this issue was of concern to both sero-negative and sero-positive partners within the relationship, it appears to be part of the shared stigma phenomenon which has previously been reported by others (17). Shared stigma affects both partners equally regardless of their individual sero-status and is both internally directed (self stigma) and also comes from outside the partnership. As such, there is an intense, shared desire to avoid disclosure to individuals outside of the partnership. Given that formula feeding is considered in this community as an indication of an HIV diagnosis, it is not surprising that this issue is of great concern to our HIV infected couples. This issue brings up a new and very complex issue of disclosure to the community at large which must be addressed when counselling both sero-discordant and concordant positive couples.

Participants generally appeared supportive of continued sexual activity within a sero-discordant partnership however there was consensus about the need to adopt safer sexual practices. This finding was contrary to our pre-study assumption that the community would discourage continued sexual activity within a sero-discordant partnership. In fact, the general view was that continued sexual activity was critical, not only to preserving the partnership, but, also to protecting the community by preventing the spread of infection outside of the union. The idea of couples staying together was supported by HIV-negative partners within sero-discordant relationships who generally expressed the intention of staying in the relationship in order to look after their ill spouse. Our findings are consistent with those of a study from the Democratic Republic of Congo that reported separation of couples to be infrequent after disclosure of sero-discordance (9). Though support for partnership preservation by the community provides a positive environment for the discordant couple, this attitude emphasizes the need for extensive education on safer sexual practices which will likely need to be re-emphasised at consistent intervals in order to prevent transmission of HIV within the partnership. Regarding which safer sexual practices are consistent with community opinion, it appears that reduction of sexual activity within a relationship is considered an acceptable option. Though this will reduce transmission risk and has been used as a component of behavioural interventions directed at HIV prevention, other options are necessary in order to further decrease the risk of transmission (18-21). Condom use is considered the most effective method of preventing HIV transmission after abstinence, however there appears to be some doubt within the community about the long term effectiveness of condoms. As such, it is clear that education about condom effectiveness and use should be integrated into the post-testing counselling, education and support offered to HIV impacted couples. In the future, vaginal microbicides and pre-exposure prophylaxis with antiretroviral drugs may provide an alternative method for transmission prevention within such discordant partnerships, if ongoing and planned clinical trials prove efficacious (22,23). In addition, specialised peer support groups appear to be an acceptable framework for the emotional support of HIV discordant couples especially for the index partner and may be used as a venue in which to encourage safer sexual practices.

As with many qualitative, interview-based studies a limitation of this study is the small sample size. The views expressed by the interviewees may not fully encompass the range of opinions on this issues that exist in western Kenya. In addition, because we were unable to interview individuals from marriages or partnerships which had dissolved over the issues surrounding HIV discordancy, we may have obtained a more positive view of the ability of discordant couples to stay together than is actually present in this society. Inclusion of such individuals would have enriched our data to make our results more representative of discordant couples in general. Also, because all our tested couples had disclosed their HIV test results to each other, our conclusions may not reflect the views of those who have chosen not to disclose. We did

not explore views on how HIV discordant couples should respond to any unmet reproductive health intentions, specifically, having children. Such unmet needs, especially in an environment where having children has high premium, may strongly influence both expected and actual sexual behaviour.

In conclusion, counselling and education of HIV sero-discordant couples must include information about sero-discordancy and the HIV window period without over-emphasizing this as a potential reason for discordancy. Consideration should be given to the development of tools and methods for disclosing HIV-status to the community at large with particular emphasis on the needs of HIV infected pregnant women who choose to formula feed in order to prevent HIV transmission. Because there was general consensus among respondents that sexual relations should continue within a discordant partnership, there is a need to develop culturally appropriate safer sex messages and materials targeted toward this population. HIV infected individuals who may or may not be in a sero-discordant partnership need assistance in disclosing their HIV status to their partner. Our findings suggest that such messages and materials should be gender specific.

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