Information leaflet, study on discordant couples, presented at the SA AIDS Conference, on 1 April, 15:30

An exploratory study of coping strategies and life choices made by HIV-discordant couples in long-term relationships

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Why the study?

The Global Network of People Living with HIV/AIDS (GNP+), a global advocacy organisation for people living with HIV (PLHIV), has embarked on a number of positive prevention initiatives targeting PLHIV and their partners. The term "positive prevention" encompasses a set of actions that help PLWHA protect their health, avoid other sexually transmitted infections (STIs), delay HIV/AIDS disease progression, and avoid passing HIV infection on to others or avoid re-infection.

One of the first GNP+ positive prevention initiatives was an exploratory study on long-term serodiscordant couples (one partner HIV-positive, the other partner HIV-negative), funded by the World Health Organisation (WHO). GNP+ worked collaboratively with South African researchers at the Centre for Health Policy at the University of the Witwatersrand in Johannesburg, the Human Sciences Research Council (HSRC) to gather information on discordant couples, with the aim of learning more about the strategies and choices made in the context of long-term discordant relationships.

The study was done because information on discordant couples and the strategies that they use to sustain their relationships make sexual and reproductive choices, maintain their health, and avoid HIV transmission, is extremely limited. It is important to address these gaps in knowledge in order to develop programmes to help discordant couples make informed sexual and reproductive choices, prevent HIV transmission, and to maintain healthy, mutually-supportive, long-term relationships.

Where was the study done?

The study was done in three countries: South Africa (Johannesburg and Cape Town), Tanzania (Dar es Salaam) and the Ukraine.

How was the study done?

Ethics permission was obtained prior to conducting the study in each of the three countries.

In South Africa, 26 serodiscordant couples who have been in a relationship for a minimum of one year were recruited through health care providers and civil society organisations. In Tanzania, 10 couples were recruited through the African Medical and Research Foundation (AMREF). In the Ukraine, 15 couples were recruited through the All Ukrainian Network for People Living with HIV.

Brief self-administered questionnaires and in-depth semi-structured individual and couple interviews were used to gain an understanding of: sexual behaviour and strategies to reduce the risk of HIV transmission; child-bearing and child-rearing decisions; effect of antiretroviral therapy (ART) on choices made; and perceived psycho-social support needs. The couples were interviewed in their home, or at a suitable, convenient venue. The set of interviews with each couple took around two hours.

What are the main study findings?

Fifty-one couples were recruited: 26 from South Africa, 10 from Tanzania, and 15 from the Ukraine. South African couples included one lesbian couple and two gay male couples. Participants' age ranged from 20 to 54 years (mean: 34 years). Couples had been in their current relationship for a mean of 6 years; 83% were cohabiting; and 58% had formalised their relationship through marriage or a marriage equivalent. Positive partners were predominantly female in South Africa and Tanzania, and predominantly male in the Ukraine.

All participants were asked to rate their *health* as poor, good, very good or excellent. Only 10/100 (10%) participants self-rated their health as poor (6/50 South Africa; 0/20 Tanzania; 4/30 Ukraine). When HIV status is taken into account, only 14% of HIV positive individuals self-rated their health as poor. Thirty-seven of 51 HIV-positive participants (73%) were on *antiretroviral treatment* (SA: 21/26, 81%; Tanzania: 6/10, 60%; Ukraine: 10/15, 67%). The mean number of years on medication was three years, with a range of 2 weeks to 9 years. The vast majority of couples indicated active participation by the HIV negative partner in the health of the HIV positive partner.

Only 36% of participants had been tested for HIV prior to the beginning of their relationship. HIV-positive participants were more likely to have been tested (52%) than those who were negative (20%). Of 47 HIV-negative participants, 24 (51%) had been tested for HIV in the past six months, but 12 (26%) had last been tested over a year previously. Of 51 HIV-positive participants, 37 (73%) were taking antiretroviral treatment (ART), and had been on treatment for between 2 weeks and 9 years (mean: 3 years).

Reproductive choices

Of the 102 participants, 62 (61%) had children, 29% from the current relationship, and 35 % from a previous relationship. Having children varied by country (Ukraine 14/30, 47%; South Africa 32/52, 63%; Tanzania 16/20, 80%). Of the African couples including those who already had children, 51% expressed a desire for children. Qualitative individual interviews revealed a complex set of issues related to a desire or an intention to have children, including fear of the HIV-negative partner becoming infected, reconciling conflicting desires of the two partners, the influential role of medical doctors, and availability and affordability of alternatives to natural conception. The desire for children sometimes conflicted with the desire for the HIV-negative partner to remain uninfected.

The majority of individuals in South Africa and Tanzania said that the discordant status has affected the *intimacy in their relationships*. The overwhelming issue related to changes in sexual relationships, with sub-themes of: changes in sexual relations fear of infecting the negative partner and condom use. A related issue was the desire for children.

Disclosure and discrimination

Disclosure was explored in individual interviews with each member of the couple, and in the joint interview with the couple. The majority of participants in South Africa (35/48, 73%) and Tanzania (18/20, 90%) had disclosed their discordant couple status to some people (family or friends or colleagues or support groups). If examined by HIV status, 81% of HIV-positive participants, compared to 75% of HIV-negative participants had disclosed that they are in a discordant relationship. The fear of stigma and discrimination was the overwhelming reason for non-disclosure. Although the majority of individuals interviewed in South Africa and Tanzania had disclosed, very few were *living openly* as discordant couples.

In Tanzania, the majority of participants (60%) had experienced *discrimination,* compared to 21% of respondents in South Africa. In these 2 countries combined, 43% of HIV-positive participants had experienced some form of discrimination compared to 24% of HIV-negative participants. In the Ukraine, participants reported discrimination from health care professionals. Participants reported that there was a shortage of information, education, communication (IEC) materials and support services for HIV-discordant couples, with less than half (45%) participation in a support group in the past year (SA=25%; Tanzania=75%; Ukraine=57%).

Support services

HIV positive members of the couple are more likely to participate in support groups or to have received HIV-prevention counselling, compared to HIV negative members of the couple (table 1). Sources of support include various combinations of health care providers, family, friends, support groups, and faith-based leaders. Few of the couples are involved jointly in advocacy activities, and often the HIV positive partner tends to be more active in activities ranging from participation in a rally or protest event to doing HIV and AIDS voluntary work.

Table 1: Support group participation and receipt of HIV counselling by HIV status

	HIV-positive participants (number, %) (n = 51)	**HIV-negative participants (number, %) (n = 51)**	**All participants (number, %) (N = 102)**
Support group participation	29 (58%)	16 (31%)	45 (45%)
HIV-prevention counselling	43 (84%)	33 (66%)	76 (75%)
Risk-reduction counselling	43 (84%)	36 (71%)	79 (77%)

What are the main recommendations from the study?

Recommendation 1: Put discordance on the HIV and AIDS policy and research agenda

Our first recommendation is that HIV discordance should form an integral part of the global and national response to HIV epidemic management; that its contribution to HIV transmission should be acknowledged; that evidence on discordance be collected as part

of routine surveillance systems; and that national policy guidelines on strategies for managing HIV discordance be developed.

Recommendation 2: Develop supportive programmes to improve couple access to, and coverage with, prevention, treatment and care services

We recommend that policies and programmes for discordant couples be developed to promote the health of both partners, and to provide support in addressing the challenges of being in a discordant partnership. These must include appropriate HIV prevention strategies, health education and information on healthy living, within the context of discordant relationships and counselling and testing services directed at couples. The findings also under-score the need for the education of health care professionals, including those working at the primary care level, to orientate them to the needs of couples, rather than individuals. Appropriate clinical guidelines, located within an overall human rights framework, should be developed for prevention, treatment, care and support services that are directed at couples.

Recommendation 3: Ensure the provision of sexual and reproductive health services in a supportive and non-discriminatory environment

The findings highlight the need for explicit HIV policies recognising sexual and reproductive rights and choice of individuals and couples. The findings also support the need for counselling and service interventions that advance safe reproductive options for HIV discordant couples. Couples also need ongoing information and counselling on safer sex, the use of condoms, the promotion of lower-risk sexual practices as alternatives to penetrative sex and sexual health advice within a discordant relationship in a supportive and non-discriminatory environment.

Recommendation 4: Involve discordant couples in the HIV response

The involvement of PLHIV is widely recognised as key to successful implementation of policies and programmes and to the AIDS response. One of the key suggestions from participants is the involvement of discordant couples in the HIV response, broadly, but specifically the need for support groups for discordant couples.

Recommendation 5: Address stigma and discrimination

We recommend that greater emphasis should be placed in national plans and programmes on dealing with issues of discrimination and stigma. Fighting discrimination and stigma, however, cannot be separated from the need for a supportive policy, programme and resource environment.
These five recommendations have to be integrated into a holistic framework that recognises the complexity of HIV discordant relationships, while implementing creative strategies to meet the prevention, treatment and psycho-social needs of HIV discordant couples.

Questions?

If you have any questions about the study or wish to obtain more information, contact :
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