HIV Discordant Couples
An Exploratory Study
Insights from South Africa, Tanzania and the Ukraine
Laetitia Rispel, Carol Metcalf, Kevin Moody and Allanise Cloete
This is a summary of the findings of an exploratory study on coping strategies and life choices of couples in South Africa, Tanzania and the Ukraine living in long-term serodiscordant relationships (that is, couples in which one partner is HIV-positive and the other partner HIV-negative) undertaken by the Global Network of People Living with HIV (GNP+), and funded by World Health Organization (WHO). GNP+ worked collaboratively with South African researchers at the Centre for Health Policy at the University of the Witwatersrand and the Human Sciences Research Council (HSRC) to gather information on serodiscordant couples, with the aim of learning more about the strategies and choices used by serodiscordant couples to sustain their relationships, make sexual and reproductive choices, maintain their health, and avoid HIV transmission.

*Introduction*

Why was the study done? Globally, HIV prevention and treatment programmes tend to focus on individuals with the majority of HIV prevention programmes directed at HIV-negative individuals. In recent years, an increasing number of “positive prevention” programmes have been established that target HIV-positive individuals. Many of these programmes focus narrowly on identifying HIV-positive individuals by means of HIV testing; preventing HIV transmission from HIV-positive individuals to HIV-negative individuals; and promoting safe sex between HIV-positive individuals based on the premise that infection with additional HIV strains may place further strain on the immune system and hasten disease progression. Increasingly “positive prevention” programmes have developed a more holistic focus on “positive living”, with a shift towards healthy lifestyles, continuing to work and to participate in social and recreational activities, adherence to medication, good nutrition and on promoting and sustaining the health of HIV-positive individuals and their partners, irrespective of the partners’ HIV status.

In countries with a high HIV prevalence in the general population – such as many countries in sub-Saharan Africa – serodiscordant relationships are common. Improvements in the effectiveness and availability of HIV treatment in recent years - which enables HIV-positive individuals to lead longer, healthier lives - has also led to an increase in the number of HIV discordant couples in the region. The increasing lifespan of people living with HIV has also led to a shift in focus from preparing for death to viewing HIV as a chronic disease.

To date, research on HIV discordance has tended to be dominated by biomedical studies on the epidemiology of serodiscordance and factors related to HIV transmission; biological factors that affect the risk of becoming infected; and use of new or experimental prevention technologies, such as male circumcision, antiretroviral therapy (ART), pre-exposure prophylaxis (PrEP) post-exposure prophylaxis (PEP), herpes simplex virus type 2 (HSV-2) suppression, microbicides, and HIV vaccines. There has been relatively little psycho-social research done on being in an HIV discordant relationship. Information on the strategies used by serodiscordant couples to sustain their relationships, make sexual and reproductive choices, maintain their health, and avoid HIV transmission is limited. It is important to address these knowledge gaps in order to develop programmes to help serodiscordant couples make informed sexual and reproductive choices, and maintain healthy, mutually-supportive relationships. GNP+ is interested in developing holistic prevention programmes for serodiscordant couples in long-term relationships in view of the general lack of “positive prevention” programmes for couples; the unique challenges faced by individuals in serodiscordant relationships; and the support that partners are able to provide to one another to promote their mutual health.
Where and when was the study done?
The study was done in 2008 in three countries: South Africa (Johannesburg and Cape Town), Tanzania (Dar es Salaam) and the Ukraine (Kiev and Rivne).

How was the study done?
Ethics permission was obtained from independent research ethics committees in each of the three countries prior to conducting the study. In each country, the researchers aimed to recruit 10 to 20 serodiscordant couples who had been in a relationship for a minimum of one year. In South Africa, couples were recruited through health care providers and civil society organisations. In Tanzania, couples were recruited through the African Medical and Research Foundation (AMREF). In the Ukraine, couples were recruited through the All Ukrainian Network of People Living with HIV. Each participant completed a brief self-administered questionnaire. In addition, an in-depth semi-structured interview was conducted with each individual, and a couple interview was conducted with both partners together. These 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.

Who participated in the study?
Fifty-one couples were recruited: 26 from South Africa, 10 from Tanzania, and 15 from the Ukraine. The 51 couples included 48 heterosexual couples, one lesbian couple and two gay couples. Participants’ age ranged from 20 to 54 years (average: 34 years). Couples had been in their current relationship for an average of 6 years. Eight-three percent 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, 12% South Africa; 0/20, 0% Tanzania; 4/30, 13% Ukraine). When HIV status was taken into account, only 14% of HIV-positive individuals self-rated their health as poor. Thirty-seven of the HIV-positive participants (73%) were on ART (South Africa: 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. Of the HIV-positive participants, 52% had been tested and knew their status before the start of the relationship. Of the HIV-negative participants, 20% had been tested and knew their status before the start of the relationship. Once in a discordant relationship, the HIV-negative partner tended to be tested for HIV more frequently, with 51% reporting that they had been tested for HIV in the past six months.
*Main findings*

“I do have love for children and I still want to have one, but I am scared to infect my partner … that’s the only challenge that I have.”
(HIV-positive woman, Couple 3, South Africa)

“No plans to have children, and we use condoms always. I fear that the child might get infected, so I decided to remain with the existing child. I also fear to get infected during the process of sexual intercourse” (HIV-negative man, Couple 7, Tanzania)

“There is a gynaecologist in our city AIDS centre and we went to get a consultation from her, but she didn’t give us any relevant advice. We have friends who have a healthy child. We talked to them. We learnt how they prepared for the birth of a baby, what tests they took before that. That’s how we made our decision.” (HIV-positive man, Ukraine)

**Intimacy, Sexual and Reproductive Choices**

Sixty-two of the 102 participants (61%) had children, 25% 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%). Fifty-one percent of the African couples expressed a desire to have children, including those who already had children (see Table 1). 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. Among some couples, the desire for children was in direct conflict with the desire for the HIV-negative partner to remain uninfected.

The majority of participants in South Africa and Tanzania said that their discordant status had affected intimacy in their relationship (see Table 2). They attributed this to practising safer sex, fear of infecting the HIV-negative partner, and condom use.

<table>
<thead>
<tr>
<th>Table 1: Participants’ Desire for Children According to their Parental Status, South Africa and Tanzania</th>
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<tbody>
<tr>
<td>Desire for Children</td>
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<tr>
<td>Did not want an (additional) child or children</td>
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<tr>
<td>Wanted an (additional) child or children</td>
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<tr>
<td>Pregnant</td>
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<th>Table 2: Intimacy and Sexual Relations</th>
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<tbody>
<tr>
<td>Experience or practice</td>
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<tr>
<td>Experienced tension because of discordant status*</td>
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<tr>
<td>Intimacy affected by discordant status*</td>
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<tr>
<td>Sexual relationship with one partner only for longer than 6 months**</td>
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<tr>
<td>Always practise safe sex (e.g. consistent condom use)*</td>
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*Information obtained from qualitative interviews, not available for Ukraine. **Self-administered questionnaire
Disclosure and Discrimination

Disclosure of HIV status 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 serodiscordant status to some people (family, friends, colleagues, or support groups). This varied by HIV status, with 81% of HIV-positive participants compared to 75% of HIV-negative participants having disclosed that they were in a discordant relationship. Although the majority of individuals interviewed in South Africa and Tanzania had disclosed to one or more people, very few were living openly as serodiscordant couples. (Information on disclosure and discrimination was not available for the Ukraine because interview findings were collated before being translated into English).

The fear of stigma and discrimination was the overwhelming reason for non-disclosure. In Tanzania, the majority of participants (60%) had experienced discrimination because of their HIV status or because of being in a discordant relationship, compared to 21% of respondents in South Africa. In these two 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 in all countries reported that there was a shortage of information, education, communication (IEC) materials and support services for HIV-discordant couples, with less than half (45%) participating in a support group in the past year (SA=25%; Tanzania=75%; Ukraine=57%).

“My parents were not very happy and it took them a while before their attitudes began to change. So the difficult part was my parents. They felt being fearful, saying it’s too big of a risk; my mom had nightmares about what could happen… What we ended up doing was having conversations about facts and over time they developed respect for our relationship… It was quite a powerful thing and my partner was able to talk to my parents about issues.” (HIV-negative gay man, Couple 24, South Africa)

“I have not shared with anybody about being discordant, only with partner.” (HIV-positive man, Couple 2, Tanzania)

“When I need medical assistance I try to apply to the AIDS centre. If they don’t have a medical specialist I need, I go to the polyclinic but don’t inform them about my positive status. I feel better that way.” (HIV-positive woman, Ukraine)
Support Services

HIV-positive members of the couples were more likely to participate in support groups or to have received HIV-prevention counselling, compared to their HIV-negative partners (see Table 3). Sources of psycho-social support included various combinations of health care providers, family, friends, support groups, and faith-based leaders. Few of the couples were involved jointly in advocacy activities, and often the HIV-positive partner tended to be more active in activities ranging from participation in a rally or protest event to doing HIV-related voluntary work.

Table 3: Support Group Participation and Receipt of HIV Counselling by HIV Status

<table>
<thead>
<tr>
<th></th>
<th>HIV-positive participants (number, %)</th>
<th>HIV-negative participants (number, %)</th>
<th>All participants (number, %)</th>
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<tbody>
<tr>
<td></td>
<td>(n = 51)</td>
<td>(n = 51)</td>
<td>(N = 102)</td>
</tr>
<tr>
<td>Support group participation</td>
<td>29 (58%)</td>
<td>16 (31%)</td>
<td>45 (45%)</td>
</tr>
<tr>
<td>HIV-prevention counselling</td>
<td>43 (84%)</td>
<td>33 (66%)</td>
<td>76 (75%)</td>
</tr>
<tr>
<td>Risk-reduction counselling</td>
<td>43 (84%)</td>
<td>36 (71%)</td>
<td>79 (77%)</td>
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</table>

“I never relied on people; I never had religion; I have become Catholic through my male partner, and I slowly understand spirituality and life; drawing strengths from it.” (HIV-positive woman, Couple 5, South Africa)

“The positive partner is attending group therapy at AMREF, but the negative partner does not like to attend the sessions because they fear being labelled that she is positive.” (Couple 6, Tanzania)

“Support for me is first of all knowledge and understanding of my problem. When I’m often sick, his support is very important to ... understanding that I physically cannot handle some situations or I just want to take some rest when something has to be done. In other words, support and understanding of this kind is very important for me. Sympathy, support, warm words, hugs – all these are very important. First of all I draw support from the relationship with a man I love.” (HIV-positive woman, Ukraine)
*Recommendations*

**Recommendation 1**
Put serodiscordance on the HIV and AIDS policy and research agenda

We recommend that addressing the needs of couples as well as individuals form an integral part of the global and national response to the HIV epidemic; that information on HIV serodiscordance be collected as part of routine surveillance; and that further research be done to assess the effectiveness of interventions that aim to promote the health and wellbeing of couples.

**Recommendation 2**
Develop holistic and comprehensive HIV programmes for couples

We recommend that policies and programmes for serodiscordant couples be developed to promote the health of both partners, and to provide support in addressing the challenges of being in a serodiscordant partnership. Such programmes should include: appropriate HIV prevention strategies, health education and information on healthy living within the context of serodiscordant relationships, and HIV counselling and testing services directed at couples. The findings also underscore the need for capacity building among health care professionals, including those working at the primary care level, to orientate them to the needs of couples as well as 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 the 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 serodiscordant relationship. This should be provided in a supportive and non-discriminatory environment.

**Recommendation 4**
Involve discordant couples in the HIV response

The involvement of people living with HIV is widely recognised as key to successful implementation of policies and programmes and to the AIDS response. One of the key suggestions from participants was the involvement of serodiscordant 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 be placed in national plans and programmes to deal 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.

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