

**\* Full report**

# **HIV Discordant Couples**

## **An Exploratory Study**

**Insights from South Africa, Tanzania and the Ukraine**

**Laetitia Rispel, Carol Metcalf, Kevin Moody and Allanise Cloete**





**Exploring Coping Strategies and Life Choices  
made by HIV Discordant Couples  
in Long-Term Relationships  
Insights from South Africa, Tanzania and the Ukraine**

**Laetitia Rispel, Carol Metcalf, Kevin Moody and Allanise Cloete**

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## ACRONYMS AND ABBREVIATIONS

<b>ABC</b>	Abstinence, <b>B</b> e faithful, use <b>C</b> ondoms
<b>AIDS</b>	Acquired immune deficiency syndrome
<b>AMREF</b>	African Medical and Research Foundation
<b>ART</b>	Antiretroviral therapy
<b>ARVs</b>	Antiretrovirals
<b>AVAC</b>	AIDS Vaccine Advocacy Coalition
<b>CHP</b>	Centre for Health Policy
<b>GIPA</b>	Greater involvement of people living with HIV
<b>GNP+</b>	Global Network of People Living with HIV
<b>HAART</b>	Highly active antiretroviral therapy
<b>HIV</b>	Human immunodeficiency virus
<b>HPV</b>	Human papillomavirus
<b>HSRC</b>	Human Sciences Research Council
<b>HSV-2</b>	Herpes simplex virus, type 2
<b>IAVI</b>	International AIDS Vaccine Initiative
<b>IDU</b>	Injecting drug user
<b>IEC</b>	Information, education, communication
<b>IVF</b>	In-vitro fertilisation
<b>GCM</b>	Global Campaign for Microbicides
<b>MCP</b>	Multiple concurrent partners
<b>MSM</b>	Men who have sex with men
<b>NGOs</b>	Non-governmental organisations
<b>PrEP</b>	Pre-exposure prophylaxis
<b>PLHIV</b>	People living with HIV
<b>PMTCT</b>	Prevention of mother-to-child transmission
<b>PEP</b>	Post-exposure prophylaxis
<b>SA</b>	South Africa
<b>STI</b>	Sexually Transmitted Infections
<b>USA</b>	United States of America
<b>VCT</b>	Voluntary Counselling and Testing
<b>WHO</b>	World Health Organization

# EXECUTIVE SUMMARY

## Introduction

This document reports on 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 – in which one partner is HIV-positive and the other HIV-negative. The primary motivation for doing the study was to inform prevention programmes and global advocacy efforts of GNP+ to promote the health of people living with HIV. The study was conducted by GNP+, in collaboration with the Centre for Health Policy at the University of the Witwatersrand in Johannesburg, South Africa, and the Human Sciences Research Council (HSRC) in Cape Town, South Africa.

## Background

Globally, HIV prevention and treatment programmes tend to focus on individuals with most HIV prevention programmes directed at HIV-negative individuals. In recent years, an increasing number of ‘positive prevention’<sup>1</sup> programmes have been established that target HIV-positive individuals. Many of the early ‘positive prevention’ programmes focused 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’ – i.e. 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 generalised HIV epidemics, 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 enable HIV-positive individuals to lead

longer, healthier lives – have also led to an increase in the number of HIV discordant couples.

Research on HIV discordance has been dominated by biomedical studies focused on the epidemiology of serodiscordance and factors related to HIV transmission; factors associated with resistance to becoming infected; and use of new or experimental prevention technologies as a means of reducing HIV transmission, including 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 research done on the psychosocial aspects of 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 discordant couples make informed sexual and reproductive choices, and maintain healthy, mutually-supportive relationships.

In view of the general lack of 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, the Global Network of People Living with HIV (GNP+) is interested in developing holistic prevention programmes for people living with HIV.

## Purpose and methods

The purpose of this study was to gather preliminary information about the coping strategies and choices made in the context of long-term HIV discordant relationships, in order to support advocacy efforts and to inform policy and programmes catering to people living with HIV and their HIV-negative partners. The specific objectives of the study were to assess among serodiscordant couples in long-term relationships:

- Choices about child-bearing and child-rearing choices;
- Choices and strategies regarding safer sex practices;

- The effect of antiretroviral therapy (ART) on strategies used and choices made; and,
- Psycho-social support and HIV prevention needs and preferences.

The study was limited to serodiscordant couples who had been in a sexual relationship for at least a year, and in which both partners had been aware of the other partner's HIV status for at least a year. Both opposite-sex (heterosexual) and same-sex (homosexual) couples were eligible to participate. Exclusion criteria included: couples who were in a recently-established relationship; people who had recently been diagnosed with HIV; and people living with HIV who had only disclosed their HIV status to their partner recently (or who had not disclosed). Participants were required to have one primary partner but were not required to be monogamous. Ethics approval was obtained through a local research ethics committee in each country prior to conducting the study in that country. HIV discordant couples were recruited through health care providers and civil society organisations after ethics approval had been obtained. After obtaining individual written informed consent from both partners in the couple, brief self-administered questionnaires and in-depth semi-structured individual and couple interviews were used to gain an understanding of: the health history of each partner, including wellness management, use of ART and other medications, and use of traditional or folk remedies; disclosure of HIV status to others outside the relationship from the perspective of both the HIV-positive and HIV-negative partner; HIV prevention strategies, including safer sex practices; dealing with the emotional impact of being in a serodiscordant relationship and its effect on intimacy and sexual relations; reproductive history and reproductive choices, including whether the couple had children and/or planned to have children; experiences of stigma and discrimination; planning for the future; and history of participation in HIV-related programmes, support groups and research. Because the focus of the study was on coping strategies and choices made by serodiscordant couples in long-term relationships, HIV testing and disclosure-related issues between partners were not explored in any depth. The quantitative information from the self-administered questionnaires was analysed using Stata Version 10. Interview transcripts from South Africa and Tanzania – were analyzed to identify themes; interview data from the Ukraine was not included as only a summary was available.

## Results

A total of 51 couples were recruited: 26 in South Africa; 10 in Tanzania and 15 in the Ukraine. Forty-eight of the 51 couples were in heterosexual relationships, and three of the couples – all located in South Africa – were in same-sex relationships (two gay male couples and one lesbian couple). Participants were aged from 20 to 54 years, with an average age of 34 years. Seventy-three percent (74/102) of participants were employed. Sixty-seven percent (34/51) of the HIV-positive participants were employed compared to 78% (40/51) of the HIV-negative participants.

Participating couples had been in their relationship for an average of six years. Just over half (27/51; 53%) of the HIV-positive participants were women. The majority of HIV-positive participants in the two African countries were women (23/36, 64%), while in the Ukraine the majority of HIV-positive partners were men (11/15, 73%).

Couples' experiences of being in an HIV discordant relationship were summarised under three major themes: (1) Support, care and concern for the health of the HIV-positive partner; (2) the notion of normality, with HIV as an underlying theme; and (3) tensions inherent in being in a serodiscordant relationship.

All participants were asked to rate their own *health* as poor, good, very good or excellent. Only ten out of 100 participants (10%) rated their health as poor (6/50, 12% South Africa; 0/20, 0% Tanzania; 4/30, 13% Ukraine), and only 14% of the HIV-positive participants rated their health as poor. The majority of HIV-positive participants (37/51, 73%) were taking ART (South Africa: 21/26, 81%; Tanzania: 6/10, 60%; Ukraine: 10/15, 67%). The average number of years on medication was three years, with a range of 2 weeks to 9 years.

With regard to *fertility and reproductive matters*, the majority of participants (61/102; 61%) had children (South Africa: 32/52, 63%; Tanzania: 16/20, 80%; Ukraine: 14/30, 47%), either from the current relationship or previous relationships. Twenty-nine percent of participants had children from previous relationships, and 18 of the 51 couples (35%) had children from their current relationship. Regardless of HIV status, approximately half the participants (49%) in the two African countries expressed a desire to have a child or children. Individuals without children were more likely to desire children (74%) than those who already had one or more children (36%). In general, conflict or tension in relationships related to four main issues: fear of infecting the HIV-negative partner; perceived infidelity; the 'safer sex imperative' (consistent condom use); and strained relations at the time of first disclosure.

The majority of individuals in South Africa and Tanzania said that their serodiscordant status had affected *their relationship*, particularly with respect to sexual relations. Changes in sexual relations included loss of spontaneity; decreases in the frequency of sexual intercourse or libido; and avoiding certain sexual acts, such as oral sex. Condom use was the main method used to practice *safer sex*, although some participants reported inconsistent condom use. When asked about the challenges/difficulties of practising safer sex in a serodiscordant relationship, the majority of couples indicated that condom use requires some adaptation in the beginning, that good communication is important, but that over time it becomes routine. The difficulties of consistent condom use mentioned by couples are the fear of infecting the negative partner, some reluctance on the part of male partners to use condoms, and the desire to have children. *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 serodiscordant couple status to some people (family, friends, colleagues or support groups), with 81% of HIV-positive participants and 75% of HIV-negative participants having disclosed that they were in a serodiscordant relationship. However, very few were *living openly* as serodiscordant couples. The qualitative interviews revealed the complexity of 'selective disclosure' – i.e. individuals and couples appear to make conscious choices regarding the person(s) to whom they disclose. The fear of stigma and discrimination was the main reason for non-disclosure. In Tanzania, the sixty percent (12/20) of participants reported experiencing *discrimination*, compared to 21% (8/39) of participants in South Africa. In these two countries, forty-three percent (13/30) of HIV-positive participants in these two countries reported having experience discrimination compared to 24% (7/29) of the HIV-negative participants. In the Ukraine, there were repeated reports of discrimination from health care professionals.

With regards to *couple communication on HIV and AIDS*, the majority of couples in South Africa and Tanzania (22/36, 61%) indicated that they talk about HIV like any other condition, and that it does not over-shadow their lives. In the Ukraine, those couples who were aware of their discordant status when they met each other, said that they discuss HIV and AIDS more at the beginning of the relationship, as the negative partner got to know about HIV, the disease and the need for condom use. Couples where one of the partners got infected during the current relationship, reportedly avoid talking about HIV and discordance as much as possible.

The couple interviews also explored the kinds of *concerns that the partners talk about with regards to the future*. Common concerns included having biological children; preventing HIV transmission to the HIV-negative partner; addressing immediate needs; the future health and survival of the HIV-positive partner; and future investments to take care of the surviving partner and/or children.

HIV-positive members of the couple were more likely to participate in support groups or to have received HIV prevention counselling, compared to HIV-negative members of the couple. Sources of 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 and AIDS voluntary work. A key limitation of the study was that discordant couples were recruited largely through attending medical doctors and non-governmental organisations (NGOs) that provide services to HIV-positive individuals and discordant couples. Thus, participating couples all had some degree of access to health care or social services, and are likely to have had better access and greater use of services and programmes than a typical discordant couple in each of the three study countries. The couples who participated in the study agreed to be contacted and interviewed, and may have differed in important respects from those who could not be contacted or who refused to participate. Another limitation is that the study was conducted in only three countries on two continents, and thus may not reflect the experiences or perspectives of discordant couples in other parts of the world.

Despite these limitations, we believe that the information obtained provides useful insights into and rich perspectives on the issues faced by discordant couples, and that our study findings have important implications for policy and health services and programmes.

## Recommendations

Our recommendations are premised on the critical role of governments in managing national responses to HIV epidemics, and take into account the findings from this study and the perspectives of couples interviewed, jointly and individually, on additional information or support needed for dealing with the challenges of discordance. The following five recommendations should be integrated into a holistic framework that recognises the complexity of HIV discordant relationships, while implementing creative strategies to meet the prevention, treatment and psychosocial needs of serodiscordant couples:

### **Recommendation 1**

#### **Put serodiscordance on the HIV and AIDS policy and research agenda**

HIV discordance should form an integral part of the global and national response to HIV epidemic management; its contribution to HIV transmission should be acknowledged; and the prevalence of discordance should be monitored as part of routine surveillance. National policy guidelines on strategies for managing HIV discordance should also be developed.

Research on HIV prevention technologies (see [Appendix](#)) should consider the needs of couples in long-term relationships, including the desire of many couples to have children conceived through natural methods with both partners as biological parents. Priority should be given to research to measure the effectiveness of ART as a means of preventing HIV transmission and guidelines and recommendations should be developed on the use of ART for prevention purposes. Research and development of potentially useful new prevention technologies, including PrEP, microbicides, and vaccines should continue. Further research is needed into the psychosocial, reproductive and sexual health, and social service needs of serodiscordant couples in diverse geographical settings and serodiscordant couples in same-sex relationships. Importantly, there are few research or policy efforts that focus on sexual health and services beyond having children. Strategies for addressing stigma and discrimination associated with being a partner in a serodiscordant relationship need further research. In addition, research is needed to analyse why leadership action to address the prejudice and stigma is wanting, and to determine some of the key drivers of and constraints to change in policies and attitudes.

Operational research is also needed on developing integrated prevention and care models that meet the needs of couples in diverse settings, but with particular focus on improving access to HIV programmes in resource constraint settings.

### **Recommendation 2**

#### **Develop holistic and comprehensive HIV programmes for couples**

Policies and programmes should be developed for discordant couples that promote the health of both partners and provide support in addressing the challenges of being in a discordant relationship. These should include appropriate HIV prevention strategies, health education and information on healthy living in the context of discordant relationships, and counselling and testing services that cater for couples. The findings also underscore 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, as distinct from individuals. Appropriate clinical guidelines – located within a 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**

Develop explicit policies that recognise the sexual and reproductive rights and choices of HIV-positive individuals and discordant couples, and provide reproductive health services that cater for HIV-positive individuals. These services should include counselling and medical interventions that advance safe reproductive options for discordant couples. Couples also need ongoing information and counselling on safer sex and sexual health within a discordant relationship in a supportive and non-discriminatory environment. Guidelines and information on safer sex and reproductive options should be regularly updated as new findings emerge from research, particularly research on prevention technologies including ART, PrEP and microbicides (see [Appendix](#)).

### **Recommendation 4**

#### **Involve discordant couples in the HIV response**

The involvement of people living with HIV, also known as ‘greater involvement of people living with HIV (GIPA)’, is widely recognised as key to successful implementation of policies and programmes and to the HIV 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**

National AIDS plans and programmes should place greater emphasis on dealing with issues of stigma and discrimination. Addressing stigma and discrimination requires a supportive policy, programme and resource environment.

# INTRODUCTION

This document reports on 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 discordant relationships. The primary motivation for doing the study was to inform prevention programmes and global advocacy efforts of GNP+ to promote the health of people living with HIV. The study was conducted by GNP+, in collaboration with the Centre for Health Policy at the University of the Witwatersrand in Johannesburg, South Africa; and the Human Sciences Research Council (HSRC) in Cape Town and Pretoria, South Africa.

**Section 1** provides a background on the need for this research; **Section 2** provides a brief summary of literature on HIV discordance; **Section 3** describes the approach to and methods used for the exploratory study; **Section 4** summarises the main themes and results of the study; and **Section 5** integrates the information from the different components, highlights the key messages and lessons learnt, and concludes with the main recommendations arising from the study.

# 1 BACKGROUND

Globally, HIV prevention and treatment programmes tend to focus on individuals. Initially most HIV prevention programmes were directed at HIV-negative individuals. In recent years, an increasing number of ‘positive prevention’ programmes have been established that target HIV-positive individuals. Until recently, ‘positive prevention’ programmes tended to 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 safer sex between HIV-positive individuals based on the premise that infection with additional HIV strains may have an adverse effect on disease progression.

Increasingly ‘positive prevention’ programmes are developing a more holistic focus on ‘positive living’ – i.e. healthy lifestyles, continuing to work and to participate in social and recreational activities, adherence to medication, good nutrition, etc. – and on promoting and sustaining the health of HIV-positive individuals and their partners, irrespective of the partners’ HIV status. In the broader sense, ‘positive prevention’ also includes actions that assist people living with HIV to protect their general health; enjoy human rights, have fulfilling sexual relationships and community life; and access to sexual and reproductive health services. The term recognises the leadership role of people living with HIV in advocacy and policy change.

Despite this increasingly holistic focus, ‘positive prevention’ programmes that cater to couples in which one or both partners are living with HIV are still rare. It is important to develop ‘positive prevention’ programmes that cater for couples as well as individuals because a large portion of people living with HIV (varying by setting) are in long-term relationships. Also, as social support from a partner can be a very important source of health and well-being, ‘positive prevention’ programmes could be strengthened by recognising the importance of primary partners as an asset.

In countries with generalised HIV epidemics, 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 enable HIV-positive individuals to lead longer, healthier lives – have also led to an increase in the number of HIV discordant couples.

Research on HIV discordance has tended to be dominated by biomedical studies on the epidemiology of discordance and factors related to HIV transmission; factors associated with resistance to becoming infected; and use of new or experimental prevention technologies as a means of reducing HIV transmission, including 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 research done on the psychosocial aspects of being in an HIV discordant relationship; information on the strategies used by HIV discordant 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 discordant couples make informed sexual and reproductive choices, and maintain healthy, mutually-supportive relationships.

In view of the general lack of ‘positive prevention’ programmes for couples, the unique challenges faced by individuals in discordant relationships, and the support that partners are able to provide to one another to promote their mutual health, the Global Network of People Living with HIV (GNP+) is interested in developing holistic prevention programmes for people living with HIV, including programmes for serodiscordant couples in long-term relationships.

## 2 LITERATURE REVIEW

### 2.1 Introduction

In order to inform the exploratory research study, we searched for published abstracts and papers related to HIV discordance. A search was conducted on PubMed, searching titles and abstracts for combinations of the following terms: HIV; serodiscordant couples; discordant couples; coping strategies; sexual behaviour; child-bearing; child-rearing; psycho-social support; 'positive prevention'; risk factors; wellness management; HIV prevention; fertility; reproductive choices; stigma; discrimination; social services; and health programmes. The literature review was neither systematic nor exhaustive. Additional papers published while the study was in progress were added to the literature review.

Sub-Saharan Africa continues to have the largest number of people living with HIV, many of whom are in HIV discordant relationships. Recent studies suggest that a large proportion of new HIV infections in countries with mature epidemics occur within discordant partnerships, making discordance a major contributor to the spread of HIV in Africa.<sup>2</sup> It is therefore not surprising that much of the research identified in our literature review had been conducted in sub-Saharan African countries.

From the literature reviewed, we identified the following major themes:

- Epidemiology and biomedical aspects of HIV discordance;
- Psycho-social aspects of HIV discordance;
- Reproductive health and child-bearing issues;
- Interventions to reduce HIV transmission; and
- Health, social services and human rights.

Although these themes overlap, we have summarised the literature according to these themes.

### 2.2 Epidemiology and biomedical aspects of HIV discordance

The prevalence of HIV discordance among married and cohabitating couples in Sub-Saharan Africa is high,<sup>3</sup> ranging from 3-20% in the general population<sup>4,5,6</sup> to

20-35% in couples in which one partner seeks care for HIV-related conditions.<sup>7,8,9</sup> However, with the exception of participants tested for HIV in a research context, most individuals living in resource-poor countries are unaware of their own and their partners' HIV status.<sup>10</sup> Recently-published research found a high prevalence of HIV-1 discordance among couples in 12 communities in Eastern and Southern Africa participating in a multi-site clinical trial, with some regional differences (Figure 1).<sup>11</sup> Evidence suggests that HIV-negative partners in discordant relationships are at high risk of HIV infection. A 2007 review of studies of HIV discordant couples summarised HIV incidence rates, and biological and behavioural risk factors for HIV transmission.<sup>2</sup> Estimates of HIV incidence rates among HIV-negative partners in discordant relationships have ranged from 1.2% to 19.0% per year, with the risk of HIV-1 transmission per coital act being nearly 12-fold higher during the first two and a half months of infection than during the subsequent period of established infection.<sup>2</sup> Early studies on HIV incidence rates among discordant couples were generally small, with limitations, but reported overall HIV incidence rates of 8.3% per year.<sup>12</sup> More recent studies have shown that HIV-negative partners in discordant relationships may have HIV incidence rates of 10-20% per year, approximately 10- to 100-fold higher than relationships where both partners are HIV-negative.<sup>13,14</sup> A one-year prospective study of HIV transmission in HIV discordant couples in Pune, India found an HIV incidence rate among HIV-negative partners of 1.2% per year, which is much lower than HIV incidence rates reported among discordant couples in Africa.<sup>15</sup> The authors concluded that higher rates of condom use, lower rates of STIs and higher CD4 counts among the Indian HIV serodiscordant couples might account for the lower rates.<sup>14</sup>

Biological factors that may influence HIV transmission rates in discordant partnerships may include sex, pregnancy, co-infection with other STIs, male circumcision, and virologic, genetic and immunologic factors.<sup>2</sup>

Behavioural factors that may influence HIV transmission rates include condom use, sexual practices, frequency of

intercourse, relationship duration, multiple concurrent partners (MCP), and partnership dynamics.<sup>2</sup> HIV incidence rates among HIV-negative partners in serodiscordant relationships are high even when couples are aware of their HIV discordant status and have access to condoms and voluntary counselling and testing (VCT) services.<sup>16</sup> Pregnancy in serodiscordant couples is common.<sup>17,18,19</sup> It has been speculated that the desire for children may partially explain the persistently high HIV incidence among HIV discordant couples in Africa and elsewhere.<sup>17,20</sup> High HIV incidence could also be explained by the poor quality of many voluntary counselling and testing (VCT) sessions, and more specifically counsellors' inability to explain HIV discordance.<sup>16</sup> A United States study that followed discordant couples for 10 years, found that STIs were also a risk factor for HIV seroconversion.<sup>21</sup> An intervention trial for heterosexual serodiscordant couples in California, found that over two-thirds of participants reported unprotected sex with their partner in the previous 6 months.<sup>22</sup> Viral load testing and awareness of PEP had no effect on condom use. In the California study, HIV-positive participants who were taking protease inhibitors – an ARV – were 2.4 times less likely to report unprotected sex than those not taking protease inhibitors, and 33% of HIV-positive and 40% of HIV-negative participants acknowledged decreased concern about HIV transmission in the light of new HIV treatments.<sup>22</sup> In comparison with their HIV-positive partners, HIV-negative individuals were significantly more likely to acknowledge increased risk-taking and decreased HIV transmission concerns.<sup>22</sup>

### 2.3 Psychosocial aspects of HIV discordance

Factors that have been shown to influence risk behaviour in HIV discordant partnerships include psychological stress, poor emotional adaptation, excessive use of alcohol and drugs and (among female partners) a perceived lack of freedom to discuss safer sex.<sup>14</sup>

A 1998 New Jersey study found a marked decline in reported sexual activity and an increase in condom use in the first few months after couples learned of their HIV discordant status.<sup>23</sup> However, at the 6-month follow-up, the proportion who abstained from sex declined from 33% to 21%, the proportion who practised unsafe sex increased from 15% to 26%, and the proportion of couples who used condoms consistently remained constant, being 53% at follow-up compared to 51% in the month preceding enrolment.<sup>23</sup> Another US study that examined behaviours associated with HIV transmission in non-regular (casual) and regular (steady) serodiscordant relationships, found higher rates of both unprotected and protected sex with regular partners than with non-regular partners.<sup>24</sup> The study also found that there was a substantial risk of HIV transmission even when partners were aware that one partner was HIV positive.<sup>24</sup>

A qualitative study conducted in Uganda explored HIV discordant couples' challenges of, and strategies for, living in a serodiscordant relationship.<sup>16</sup> Reported challenges included disclosure, limited knowledge of HIV discordance, feelings of isolation, and strained relationships following disclosure of HIV-positive status to their partners.<sup>16</sup> Sexual relations posed the most formidable challenge for HIV

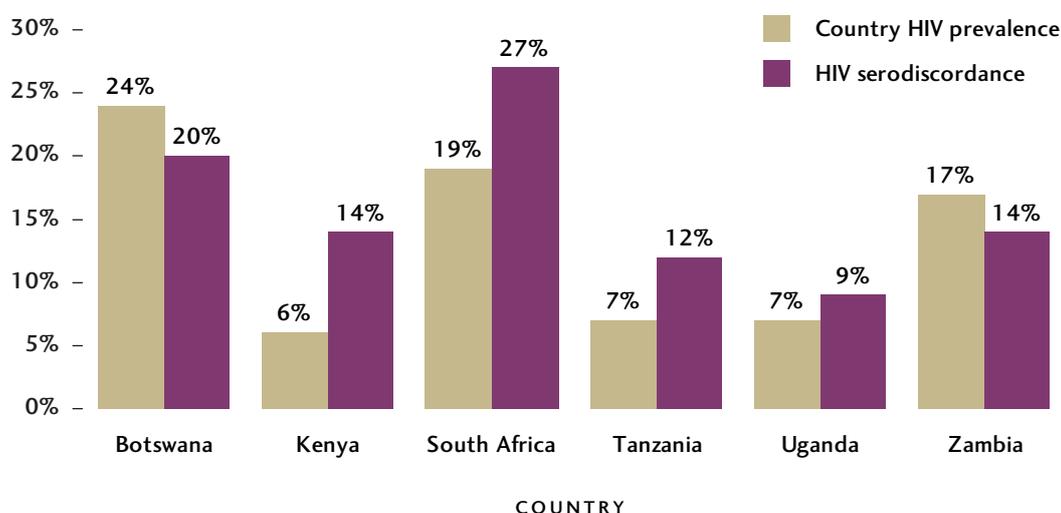


FIGURE 1: PREVALENCE OF HIV DISCORDANCE AMONG COUPLES SCREENED FOR A MULTI-SITE HIV PREVENTION TRIAL AT EASTERN AND SOUTHERN AFRICA SITES (Source: Lingappa et al, 2008)

discordant couples, particularly for women, regardless of their status.<sup>16</sup> Coping and prevention strategies used by couples included consistent condom use, termination of the relationship, and abstinence.<sup>16</sup>

A case series study conducted in the US, found that fear of HIV transmission, coping with the uncertainty of potential illness, shifts in emotional intimacy, and reproductive dilemmas were the most commonly-experienced emotional issues for serodiscordant couples.<sup>25</sup>

A small study of gay men found that HIV disease progression and finding out about serodiscordance sometimes destabilised long-term relationships, particularly with regard to physical and emotional intimacy.<sup>26</sup> Initial findings from the Straightpoz study of heterosexual couples in Australia, which included some HIV discordant couples, found that non-disclosure to partners, discretion and silence constituted “*the nitty-gritty of participants’ everyday living with HIV*”.<sup>27</sup>

#### 2.4 Reproductive health and child-bearing issues

Research on reproductive health and child-bearing has tended to focus on heterosexual discordant relationships, particularly on minimising the risk of HIV infection to the HIV-negative partner and to any offspring.<sup>28,29,30,31</sup>

In recent years, with the increasing availability of prevention of mother-to-child transmission (PMTCT) programmes, vertical transmission from HIV-positive mothers to their babies has declined substantially.<sup>32</sup> Most of the research focusing on reproductive issues of HIV discordant couples has been biomedical, notably the provision of reproductive assistance (such as sperm washing or artificial insemination) to reduce the risks of HIV transmission from HIV-positive men to HIV-negative women partners, while fulfilling the desire for children.<sup>33,34,35</sup>

Proponents of reproductive assistance for heterosexual couples have argued on the basis of human rights of all, including the rights of HIV-positive people.<sup>36,37</sup> Nevertheless, providing reproductive assistance to HIV discordant couples remains controversial, and is not frequently addressed by health care providers. A Zimbabwean study on the impact of HIV and AIDS on women’s sexual and reproductive lives, found that women did not disclose their status to health workers because of health worker prejudices that HIV-positive women should not be sexually active or have children.<sup>38</sup> An Indian study found that provider counselling played a key role in HIV-positive women’s decisions about child-bearing.<sup>39</sup> An ancillary study conducted among discordant couples in association with the Swiss HIV Cohort Study, found that 47% of study participants thought that health

care providers would not sufficiently address personal issues such as relationships, sexuality and the desire for children.<sup>40</sup> A Brazilian study found that there was reluctance on the part of health workers to discuss the desire for parenthood with HIV-positive men.<sup>41</sup>

#### 2.5 Interventions to reduce HIV transmission

Evaluations of VCT programmes have demonstrated an increase in condom use in serodiscordant couples in the short term following discovery and disclosure of an individual’s HIV-positive status.<sup>16,20</sup> A three-country VCT efficacy study that examined the incidence of positive and negative life events seven months after recruitment, found that serodiscordant couples in which the woman was HIV-positive were most likely to report the break-up of a marriage and the break-up of a sexual relationship.<sup>42</sup> A group-based couples’ intervention in India, Thailand and Uganda focused on communication, problem-solving and negotiation skills to increase condom use in serodiscordant couples.<sup>43</sup> The participants reported increased comfort in discussing sex and condom use with their partners after the intervention.<sup>43</sup> At the three-month follow-up, 90% of the participants reported having been able to use the skills from the intervention with their partners.<sup>43</sup> In Rwanda, a counselling and testing programme for HIV discordant and concordant couples implemented as part of a longitudinal study, reviewed the effects of the programme on men.<sup>44</sup> Counselling and testing was associated with a high level of condom use, reduced rates of sexual coercion by male partners, and relatively low seroconversion rates in the HIV-negative partners in discordant relationships.<sup>44</sup>

Biomedical prevention interventions may also have a major effect on HIV transmission. Male circumcision has been shown to reduce female-to-male HIV transmission by about 60%,<sup>45,46,47</sup> and there is some evidence that male circumcision may also prevent male-to-female transmission.<sup>48</sup> However, the recent Rakai circumcision trial showed that male circumcision does not protect female partners of HIV-positive men against acquiring HIV infection.<sup>49</sup> Post-exposure prophylaxis (PEP) is widely used to prevent HIV infection following occupational exposure or sexual assault, but is generally not suitable for use among discordant couples except for occasional use following accidental sexual exposure.

The use of ART to prevent sexual transmission of HIV has been explored in recent years<sup>50</sup> and remains controversial, having both proponents and opponents.<sup>37,51,52,53,54</sup> There is currently limited information on the magnitude of reduction in HIV transmission brought about as a result of using ART. A recent study of heterosexual couples

found that the sexual partners of HIV-positive people on ART had a low risk of acquiring HIV, especially if the HIV-positive partner had a low viral load.<sup>55</sup> A number of other potential prevention technologies including microbicides, pre-exposure prophylaxis (PrEP), and vaccines are the subject of large-scale ongoing research (see [Appendix](#)), but have not yet been shown to be efficacious and are not available other than to clinical trial participants (although PrEP may be purchased on the black market in some countries).

## 2.6 Providing inclusive health and social services for people living with HIV

There have been calls to pay increased attention to providing prevention programmes for couples<sup>5,22,56</sup> in view of the high prevalence of HIV discordance in many countries. Although there is a lack of consensus about the benefits of couples counselling and HIV testing, it has been hypothesized that scaling-up couples counselling and testing programmes has the potential to reduce heterosexual HIV transmission by up to 80%.<sup>46</sup> Client-initiated individual counselling and testing remains the prevailing HIV testing paradigm in Africa, despite evidence of advantages of couples' counselling and testing, and providing support for HIV discordant couples.<sup>57,58</sup> It is often difficult for HIV-positive women to get appropriate information or support from family planning clinics or maternity units.<sup>39</sup> Services for HIV-positive men and for serodiscordant couples are not readily available in many countries. There have been calls for greater efforts to ensure that health services address the needs of HIV-positive men as well as women.<sup>59</sup> There are few research or policy efforts that focus on sexual health and services beyond having children. The role of health systems in providing integrated services, in improving access to, and quality of care, has also received scant attention.<sup>57</sup> In recent years, there has been increasing attention paid to the rights of people living with HIV.<sup>57,60</sup> A rights-based approach to prevention, treatment and care was a major theme of the XVII International AIDS Conference, held in Mexico in 2008.<sup>61</sup> It has been argued that the recognition of rights is an essential step towards strengthening and expanding appropriate health care and support services for people living with HIV.<sup>56</sup>

### SUMMARY

- There is a high prevalence of HIV discordance among couples in sub-Saharan Africa.
- Research efforts in serodiscordance have tended to focus on clinical and biomedical aspects of HIV transmission in couples. Some new and possible future HIV prevention technologies may provide potential benefits to HIV discordant couples.
- Little is known about the psychosocial, reproductive and sexual health, and social service needs of serodiscordant couples
- Although HIV-related stigma and discrimination is an important barrier to positive living, social pressure on HIV-negative and HIV-positive people to engage in HIV-concordant relationships has received scant attention.
- Little is known about the coping strategies and life choices made in the context of long-term discordant relationships

# 3 APPROACH AND METHODS

## 3.1 Purpose and objectives of the study

The purpose of this exploratory study was to gather preliminary information about the coping strategies and choices made in the context of long-term HIV discordant relationships, in order to support advocacy efforts and to inform policy and programmes for HIV-positive persons and their HIV-negative partners. The specific objectives of the study were to assess among serodiscordant couples in long-term relationships:

- Child-bearing and child-rearing choices;
- Sexual behaviour and choices, and strategies regarding safer sex practices;
- Influence of ART on strategies used and choices made; and
- Psycho-social support and HIV prevention needs and preferences.

## 3.2 Overview of study areas

The study was conducted in South Africa (Johannesburg and Cape Town), Tanzania (Dar es Salaam) and Ukraine (Kiev, Rivne and Ivano-Frankovsk). Table 1 shows a few selected indicators for these three countries.<sup>62,63</sup> However we wish to emphasize that this was an exploratory study and there was no intention of drawing inferences about individuals' countries or making comparisons between countries.

Although inclusion of couples in African countries was the top priority in view of the disproportionate burden of HIV infection and high prevalence of serodiscordance on the African continent, the choice of study countries was determined largely by practical considerations, i.e. the location of the researchers; a means of recruiting serodiscordant couples within a short time period; and access to an appropriate in-country research ethics committee (or an equivalent entity) to provide ethics approval for the research.

As this was an exploratory study and as GNP+ serves people living with HIV globally, we initially hoped to include a few couples from a number of other countries with varying HIV epidemics. Efforts to include additional

countries did not materialise due to a lack of a simple, efficient and inexpensive means of recruiting discordant couples; access to an appropriate in-country research ethics committee; availability of qualified people fluent in local languages and English to conduct interviews; and a lack of budget for translation services.

Although we initially planned to include only 3 to 10 couples per country and about 25 couples in total, the availability of discordant couples and people qualified to conduct interviews in the three study countries led us to increase the sample size in these countries. The final sample size of 51 couples was more than double the planned sample size.

## 3.3 Study participants

The eligibility criteria were:

- Couples who had been in a sexual relationship for at least one year;
- One partner HIV-positive and the other HIV-negative (based on self-report);
- HIV-positive partner had disclosed his/her status to the partner at least one year previously;
- Both partners aged 18 years or older; and
- Both partners willing to provide voluntary informed consent.

Both opposite-sex (heterosexual) and same-sex (homosexual) couples were eligible to participate. In line with the purpose of the study, couples who were in a recently-established relationship; people who had only recently found out that they were HIV-positive; and people living with HIV who had only disclosed their HIV status to their partner recently (or who had not disclosed) were not eligible to participate.

Partners making up the couple were not required to be monogamous, living together or to have formalised their relationship through marriage or a civil union. No HIV testing or documentation was used to confirm the HIV status of either the HIV-positive or the HIV-negative partner.

### 3.4 Ethics and recruitment

In each country, ethics approval was obtained from an appropriate local research ethics committee before the start of participant recruitment. HIV-serodiscordant couples who met the study criteria were purposively recruited through health care providers and civil society organisations in South Africa, Tanzania, and the Ukraine. Potential participants were approached by a person who was already aware of the couple's serodiscordant status; this was done to protect privacy and respect confidentiality of the individuals' HIV status. Researchers contacted potential participants after they had given permission to be contacted.

Individual written voluntary informed consent was obtained from both members of the couple and the interviews only proceeded if both members agreed to participate in the study. The consent forms and interview guides were developed in English, and translated into appropriate local languages for each country.

In South Africa, 26 serodiscordant couples were recruited into the study through health care providers and civil society organisations. An additional nine South African serodiscordant couples were identified but were not included in the study, either because they could not be contacted or because one or both partners refused to participate. In Tanzania, 10 couples were recruited through the African Medical and Research Foundation (AMREF) as part of its project on *“Improving couple and individual counselling methods to increase disclosure of HIV status*

*among serodiscordant couples in Dar es Salaam”*. All couples approached agreed to be interviewed. In the Ukraine, 15 couples were recruited through the All-Ukrainian Network of People Living with HIV/AIDS.

### 3.5 Measurement

After obtaining informed consent from both partners in the couple, face-to-face interviews were conducted. Couples were interviewed by trained interviewers, working individually or in pairs, in the couple's home or at a suitable, convenient venue. Participants were interviewed in the language of their choice. The interviews with each couple took between two to three hours.

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; influence of ART on choices made; and perceived psycho-social support needs.

Topics in the interviews included the following:

- History and duration of the relationship;
- HIV-testing history of each partner;
- Health history of each partner, including wellness management, use of ART and other remedies, including ‘traditional’ medicines;
- Disclosure of HIV status and issues related to other family members and friends from the perspective of both the HIV-positive and HIV-negative partner;

TABLE 1: KEY HUMAN DEVELOPMENT INDICATORS FOR SOUTH AFRICA, TANZANIA AND UKRAINE

Indicator	South Africa	Tanzania	Ukraine
2005 Population (in millions)*	47.9	38.5	46.9
Gross Domestic Product per capita (US\$)*	11,110	744	6,848
Human development index*	0.674	0.467	0.788
Adult literacy rate (per cent)*	82.4	69.4	99.4
Life expectancy at birth*	50.8	51.0	67.7
HIV prevalence in persons aged 15 to 49 years (per cent [95% CI])†	18.1 [15.4–20.9]	6.2 [5.8–6.6]	1.6 [1.2–2.0]
Estimated number of people living with HIV†	5.7 million	1.4 million	440,000
Estimated number of women aged 15 years and above living with HIV†	3.2 million	760,000	190,000
Deaths due to AIDS†	350,000	96,000	19,000
Public health expenditure as a per cent of GDP*	3.5	1.7	3.7
Private health expenditure as a per cent of GDP*	5.1	2.3	2.8

Sources: \*UNDP 2007/2008; †UNAIDS country fact sheets

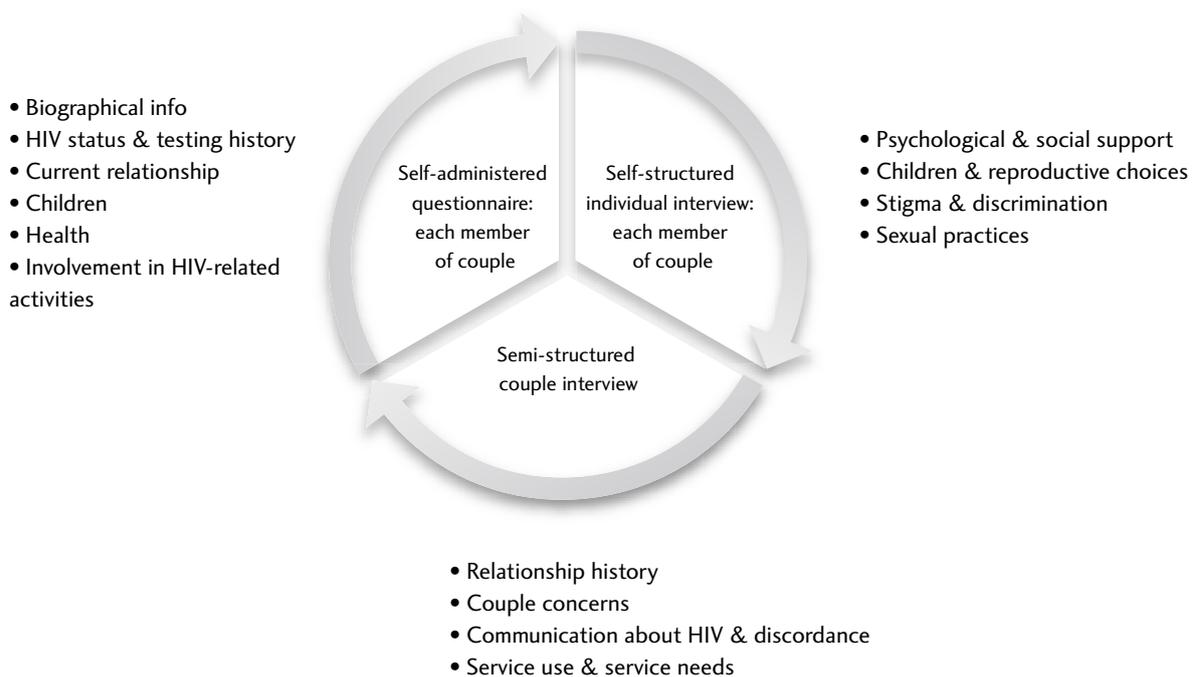


FIGURE 2: OVERALL APPROACH TO THE STUDY

- HIV prevention strategies and history of attempts to maintain safer sex practices;
- Dealing with the emotional and sexual impact of serodiscordance on the relationship;
- Fertility and reproductive choices, including whether the couple has children, and whether they plan to have children;
- Experiences of stigma and discrimination, including rejection of the HIV-positive partner by current or former partners, experiences of domestic violence, and social pressure faced by both partners to have only HIV concordant partnerships;
- Planning for the future of children and the surviving partner;
- History of participation in HIV prevention programmes, including 'positive prevention' programmes;
- Resources, services providers, and programmes that have been helpful to addressing the challenges of discordant partnerships; and
- Suggestions for assistance, services and programmes for discordant partners.

### 3.6 Data analysis

Data analysis differed between the Ukraine and South Africa and Tanzania, due to logistical difficulties with translating all the Ukrainian qualitative interviews into

English. Only a summary of the Ukrainian qualitative interviews is available.

In South African and Tanzania, the self-administered questionnaires were coded, using a standard coding sheet and analysed using Stata Version 10. The following aspects from the individual and couple qualitative interviews were coded and analysed using Stata:

- Relationship in terms of health/wellness management;
- Current children and desire to have children;
- Experience of conflict or tension in relationship;
- Whether serodiscordant relationship affects the intimacy between partners;
- Whether the couple practices safer sex;
- Disclosure to others outside the partnership;
- Experiences of stigma and discrimination;
- Couple communication about HIV and AIDS; and
- Sources of social support.

The interviews were transcribed verbatim and analysed using thematic content analysis. The steps consisted of: open coding using the participants' own words and phrases and without preconceived notions or classification; examining language used by each partner or couple; categorising the information from all the interviews and finally theoretical coding in which open codes and categories were compared to generate an analytic schema and to interpret the findings.

## 4 RESULTS

*“There are lots of discordant couples, but they are not visible. The system does not allow for relationships, for disclosure and options” (HIV-positive woman, South Africa)*

*“More education should be given to the community. That will help them to understand the problem [of HIV discordance] and how to cope with it” (HIV-negative man, Tanzania)*

The main themes and results are presented as follows:

- Couple demographics;
- Experience of being in a HIV discordant relationship;
- Perceptions of health and well-being, and wellness management;
- Sexual and reproductive health and reproductive choices;
- Intimacy and sexual relations;
- Disclosure of HIV status;
- Experiences of stigma and discrimination;
- Communication and concerns of serodiscordant couples;
- Sources of support and services; and
- Participation in HIV and AIDS activities.

### 4.1 Couple demographics

A total of 51 couples were recruited: 26 in South Africa; 10 in Tanzania and 15 in the Ukraine. The vast majority of the couples were in heterosexual relationships, with only three homosexual couples, all of whom were located in South Africa (two gay couples and one lesbian couple). The mean age of all participants was 34 years, with a range of 20 to 54. The Ukrainian participants were slightly younger with a mean age of 29 years (range 20 to 39), compared to a mean age of 35 years of South African participants and 37 years of Tanzanian participants. Seventy-three percent (74/102) of participants were in employment, with 67% of HIV-positive participants in employment, compared to 78% of HIV-negative individuals; a non-statistically significant difference. The nature of employment of individuals varied greatly, from low-skilled occupations such as cleaning and driving, to highly-skilled occupations such as senior civil servants, managers and lawyers.

The majority of couples (83%) lived together (South Africa: 19/26, 73%; Tanzania: 10/10, 100%; Ukraine: 13/15, 87%), and 58% had formalised their relationship either through marriage or a civil union (South Africa: 14/26, 54%; Tanzania: 5/10, 50%; Ukraine: 11/15, 73%). The mean length of the current relationship was 6 years, with a range of 1 to 29 years. Just over half (27/51, 53%) of the HIV-positive participants were women, with the number rising to 64% if the Ukraine is excluded.

Just over one-third (36%) of participants had had an HIV test *before* they became involved in the relationship with their current partner (South Africa: 20/52; Tanzania 6/20; Ukraine: 10/29). However, 26 of 50 HIV-positive participants (52%), compared to 10 of 50 HIV-negative participants (20%) had had an HIV test *before* they became involved in the relationship with their current partner; this difference is statistically significant ( $p=0.002$ ).

### 4.2 Experience of being in an HIV discordant relationship

The qualitative interviews with each individual partner and the couple explored the couples' perspectives of their relationship as an HIV discordant couple and in what ways the serodiscordant relationship differed from previous or other relationships. Three major themes came out of the analysis: Support, care and concern for the health of the HIV-positive partner; the notion of normality, with HIV as a subliminal theme; and tensions inherent in an HIV discordant relationship. These themes overlap, but are highlighted separately, with quotes from the interviews.

#### SUPPORT, CARE AND CONCERN FOR THE HEALTH OF THE HIV-POSITIVE PARTNER

*“We are both very happy with the relationship. We are different in that we are using a condom in the relationship. When the positive partner is sick, the negative partner supports him.” (Couple 3, Tanzania)*

*“Our relationship is not different from other couple’s relationships. My partner who is HIV-negative helps a lot towards my well-being as he often reminds me of the time for taking medication, and clinic visit dates.” (Couple 10, South Africa)*

*“We are very supportive and helpful towards each other. The HIV-negative partner usually supports the infected partner to take her immune boosters, vitamin tablets, and anti-hypertensive medication. Also encouraging her to eat healthy and to exercise.” (Couple 12, South Africa)*

*“When my husband was very sick, I used to assist him with washing himself, eating, and encouraging him to take his TB medication. I also massaged his body and motivated him that having HIV is not the end of the world; he will become better as it is with other conditions.” (Couple 18, South Africa)*

#### THE NOTION OF NORMALITY, WITH HIV AS A SUBLIMINAL THEME

*“We live a normal life, like any other married couple.” (Couple 1, South Africa)*

*“I would say it is a normal relationship. I fought a battle with my family, I explained to my parents. My parents are protective, and they are worried that we will default... so they keep a watchful eye. We still battle to be together. But I believe what won’t kill us, will make us stronger.” (HIV-negative man, Couple 4, South Africa)*

*“It got normal after a year. I still find it surprising that someone could say ‘I love you’. It struck me that HIV is here. I believe in love and life; HIV is just one obstacle to overcome, I feel blessed.” (HIV-positive woman, Couple 4, South Africa)*

*“...I don’t see much difference. Difficulties in relationships happen, but that’s the same as in any family.” (HIV-positive man, Ukraine)*

*“I don’t want to give it [HIV] a permanent agenda status. We respect one another. In the relationship, HIV is not the biggest issue..... except when it comes to taking medication and the constant check-ups of my [negative] partner.” (HIV-positive woman, Couple 5, South Africa)*

*“There is no difference in our relationship as a serodiscordant couple, as compared to that of ‘so called’ normal couples. I am very concerned about my partner’s health and well-being. I motivate and advise her positively.” (HIV-positive man, Couple 11, South Africa)*

*“[We are] very supportive and loving towards each other. We believe our relationship is normal like that of other couples.” (Couple 21, South Africa)*

#### TENSIONS INHERENT IN HIV DISCORDANT RELATIONSHIPS

Many couples experienced tensions related to practising safer sex:

*“Discordant couple needs to use a condom all the time when they have sex, the negative partners do not use a condom most of the time. Discordant couples can face stigma and discrimination; negative partners do not face stigma and discrimination.” (Couple 1, Tanzania)*

*“There is a big difference between us and other negative couples. Negative couples have no concerns, but we have many concerns. Some of the concerns are: having sex, and keeping sex alive, medical appointments, stigma and discrimination by relatives and friends, recurrent illness which takes more time and reduces time to look for food, diminishing our future vision. Discordant couples are aware of keeping each other safe, without infecting each other with HIV. They have to use condoms always, which is different from the couple with a negative status.” (Couple 7, Tanzania)*

*“Our relationship is similar to non-discordant relationships except that we practice safe sex. We discuss sex with each other and use condoms consistently. Our relationship is generally healthy with open discussion, and we are concerned about maintaining each other’s health.” (Couple 23, South Africa)*

Some couples identified issues regarding HIV disclosure, stigma and discrimination as a source of tension in their relationship:

*“My mother once said that she knows about our misfortune (respondent’s wife is HIV-positive) but we never talked about it after that. My brother probably guesses too, but we don’t discuss these issues with him either.” (HIV-negative man, Ukraine)*

#### 4.3 Perception of health and wellbeing, and wellness management

All participants were asked to rate their health as poor, good, very good or excellent. Ten of the 100 participants (10%) who answered this question, rated their health as poor (South Africa: 6/50, 12%; Tanzania: 0/20, 0%; Ukraine: 4/30, 13%). Of the HIV-positive participants, only 14% rated their health as poor.

Twenty-four of the 47 (51%) HIV-negative participants who gave an HIV-testing history reported that they had been tested for HIV in the previous six months, while 12 of the 47 (26%) had been tested more than a year previously.

The majority of HIV-positive participants (37/51, 73%) were taking ART (South Africa: 21/26, 81%; Tanzania: 6/10, 60%; Ukraine 10/15, 67%). Those taking ART had been taking it for a mean of three years, ranging from 2 weeks to 9 years. Very few HIV-positive participants reported using traditional medicines (South Africa: 2/26, 8%; Tanzania 1/10, 10%; Ukraine 0/15, 0%), but 9 of 51 (18%) reported using herbal remedies or food supplements.

With regards to injection drug use (IDU), 16 of 95 (17%) of participants, all from the Ukraine, reported having injected drugs at some time in their lives; only three participants reported that they had injected drugs in the past year. None of the participants reported ever sharing needles with their current partner.

The couple interview explored the relationship in terms of health and wellness management, and the extent to which the HIV-negative partner took an active interest in the well-being of the HIV-positive partner. In South Africa, the majority of couples indicated active participation of the HIV-negative partner in the health of the HIV-positive partner.

*“My wife who is HIV-negative, used not to be involved in the administration of medication and the children assisted. But of late she assists by reminding me if I have forgotten.”* (Couple 1, South Africa)

*“I have to nag about medication. She tends to be mean when she is ill. It was more difficult in the beginning. I felt that if she ate correctly, side effects can't be so bad.”* (HIV-negative man, Couple 5, South Africa)

*“I had difficulties in the beginning, with many side effects. I changed the medication recently, and I take it regularly. I felt that he did not understand the issues about medication and the side effects.”* (HIV-positive woman, Couple 5, South Africa)

*“The condition has actually strengthened our relationship, as I sometimes even go to queue for my partner at the clinic. I even buy her immune boosters in a juice form, and antioxidants like procynadin and others. I encourage her to take her vitamin tablets.”* (HIV-negative man, Couple 12, South Africa).

One couple interview in South Africa revealed that the HIV-negative male partner became verbally abusive when drunk. He admitted that he swore at his female partner.

*“My partner supports me fully when he is sober, but he has a habit of insulting me when he has taken one too many, especially over the weekend.”* (HIV-positive woman, Couple 22, South Africa)

In Tanzania, all the couples reported active participation by both partners in the well-being of one another, as illustrated by the following:

*“The negative partner is involved in the well-being of her partner by supporting him in all aspects of life like adhering to the medication. The positive partner is also involved in the well-being of his partner by protecting her from being infected with HIV.”* (Couple 2, Tanzania)

*“The HIV-negative partner is the bread-winner; she is doing small business to make sure they are getting food. She reminds the positive partner on how to take ARVs at the right time.”* (Couple 8, Tanzania)

*“The negative partner usually gets involved in different activities relating to HIV/AIDS. He also has a role of reminding the partner to use ARVs effectively. The positive partner insists that her partner be aware about HIV/AIDS, on how he can be infected.”* (Couple 10, Tanzania)

The qualitative interviews conducted in the Ukraine found that HIV-positive participants generally received an extra level of care about their health from HIV-negative partners. This care was reflected in reminders to take medications, including ART and attempts to improve their diet.

#### 4.4 Fertility and reproductive choices

The majority of participants (62/102; 61%) had children (South Africa: 32/52, 63%; Tanzania: 16/20, 80%; Ukraine: 14/30, 47%). Twenty-nine percent of participants had children from previous relationships. Eighteen of the 51 couples (35%) had children from their current relationship. Table 2 shows individual participants' desire for children among the South African and Tanzanian participants; this information was not available for the Ukrainian participants. Almost one in two participants (49%) expressed a desire to have a child or children. When analysed by HIV status, while 47% of HIV-positive participants expressed a desire to have a child or additional children, individuals without children were more likely to desire children (74%) than those who already had one or more children (36%). The individual interviews explored separately with each member of the couple decisions or plans to have children. Responses revealed a complex set of issues, which are categorised below.

TABLE 2: PARTICIPANTS' DESIRE FOR CHILDREN BY PARENTAL STATUS, SOUTH AFRICA AND TANZANIA

Desire for Children	Participants with Children (n = 44)	Participants without Children (n = 23)	All Participants (n = 67)
Did not want (additional) child / children	26 (59%)	6 (26%)	32 (48%)
Wanted (additional) child / children	16 (36%)	17 (74%)	33 (49%)
Pregnant	2 (5%)	0	2 (3%)

### THE DESIRE FOR CHILDREN, BLAME AND FEAR OF INFECTION

This category includes expressed wishes or “the need” to have children, which was at times mixed with issues of blame and the fear of infecting the HIV-negative partner.

*“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)

*“The HIV status has affected the relationship with my partner. Sometimes the partner blames me for being HIV-positive. I plan to have a child in future, but for now use a condom’* (HIV-positive woman, Couple 1, Tanzania)

*“The issue of condom use affects the relationship with my partner. I am negative, and I need to have a child, so I feel that using a condom can hinder us from getting a child. We plan to have a child in future, but we use a condom for now – sometimes we use a condom, and sometimes we don’t use it. When I use a condom I get abdominal pain.”* (HIV-negative man, Couple 1, Tanzania)

*“We will definitely have one or two children in future, when my wife feels better and we have information that will assist us to have children without me or the children being infected”* (HIV-negative man, Couple 8, South Africa)

*“Would love to have children in future. We were a bit reluctant to have children because my partner was scared that he may infect me.”* (HIV-negative woman, Couple 17, South Africa)

*“We want children, but my wife’s HIV status makes it difficult to have sex without protection.”* (HIV-negative man, Couple 22, South Africa)

*“There are no plans to have children; we are using a female condom to prevent pregnancy. We fear to infect a new child if we decide to have a child.”* (HIV-positive woman, Couple 7, Tanzania)

*“We have 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 one existing child. I also fear to get infected during the process of sexual intercourse.”* (HIV-negative man, Couple 7, Tanzania)

### THE CENTRALITY OF MEDICAL ADVICE AND DECISIONS ON CHILD-BEARING

This category includes expressed wishes, plans or desires for children, but as influenced by the advice of the attending physician. In the Ukraine, the issue of family planning or reproductive advice was quite pressing, especially for young couples under 35. Participants living in Kiev reported having better opportunities for reproductive health and medical support, such as availability of doctors who have experience of work with serodiscordant couples and better medical services. Couples living in Rivne and towns in the Ivano-Frankivsk region of the Ukraine reported that there was a lack of qualified medical staff that could provide expert advice on this issue. Several of these participants reported that they had obtained information from serodiscordant couples who already had children:

*“We know a family who already had a baby. We asked them what tests should be taken and what doctors to go to.”* (HIV-negative woman, Rivne, Ukraine)

*“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, Rivne, Ukraine)

In both South Africa and Tanzania, the role of the attending physician came through repeatedly.

*“Children...yes, in the near future and as advised by our medical doctor.”* (Couple 18, South Africa)

*“Yes, we intend to have children in the near future with the advice of our attending physician.” (HIV-positive woman, Couple 22, South Africa)*

*“Although we need to get children, we need to seek advice from doctors.” (HIV-negative woman, Couple 8, Tanzania)*

#### CONFRONTING DIFFERENT WISHES

This category includes expressed *differences* in wishes to have children between the partners in a couple, shown by the quotes below.

*“Babies: I do not want children because of my HIV-positive status. He does not want to talk about it. I am not sure if he knows about masturbation (if we go for the IVF [in-vitro fertilisation] route) and the embarrassment and shame. I still feel shame and embarrassment, I don’t want shame and embarrassment for him, and that’s why it is not discussed. Yes, we use condoms consistently. I am not sure about children. The only reason I consider them is because he has done a lot for me.....he is one of the first people to show unconditional support, despite my status. I would feel guilty and selfish for not wanting kids.” (HIV-positive woman, Couple 5, South Africa)*

*“Children are an issue... we plan to have children, and maybe she will fall pregnant before the wedding.” (HIV-negative man, Couple 5, South Africa)*

*“The discordant status affects the relationship, because I have children and the negative partner does not have children. Sometimes the negative partner does not want to use a condom, but I encourage her to use a condom. I do not have children with the current partner.” (HIV-positive man, Couple 5, Tanzania)*

*“The issue of condom use affects the relationship with my partner. He has enough knowledge of HIV/AIDS, but sometimes refuses to use a condom. I plan to have children in future.” (HIV-negative woman, Couple 5, Tanzania)*

*“I discuss children often in therapy. I want a child that is biologically related and I am still grappling with the issue.” (HIV-positive gay man, Couple 23, South Africa)*

*“I don’t have current plans; I am not interested.” (HIV-negative gay man, Couple 23, South Africa)*

#### CONSIDERING ADOPTION OR SAVING FOR IVF

*“We are thinking of adopting a little boy, when we are financially settled.” (HIV-positive lesbian woman, South Africa)*

*“We do not have any children and we use condoms consistently. We plan to go for IVF once we have enough money.” (HIV-positive woman, Couple 4, South Africa)*

*“The hospital has advised us that the best way to do it is through IVF. It costs money and we are saving now. It would be great if there was an organisation to support couples who wish to have IVF.” (HIV-negative man, Couple 4, South Africa)*

#### NO PLANS OR WISHES TO HAVE CHILDREN

*“Fears, lack of trust, I felt betrayed. We are not going to have a child together. We have agreed that now we have to forget about children at all as we have to use condoms all the way.” (HIV-negative woman, Couple 6, South Africa)*

*“We are not planning to have children, as we tried and failed. Fortunately, we have children from our previous relationships with other people.” (HIV-negative man, Couple 9, South Africa)*

*“I would have to think and be very careful before going into that one. It has come up before and I feel that if we were to have a child...what happens if or when my partner dies? I would have to be responsible and support this child. How would I cope with that? For now – no I don’t think so.” (HIV-negative gay man, Couple 24, South Africa)*

*“There is no plan of getting children.” (HIV-negative man, Couple 10, Tanzania)*

#### MAYBE CHILDREN IN FUTURE

*“I am not planning to have children yet, maybe at a later stage.” (HIV-negative woman, Couple 7, South Africa)*

*“I had a miscarriage in 1997. I would like to have children in future. [We are] exploring the possibility of in-vitro fertilisation.” (HIV-positive woman, Couple 8, South Africa)*

*“We are planning to have children in the near future, but are currently practising safe sex.” (HIV-negative man, Couple 12, South Africa)*

## 4.5 Intimacy and sexual relations

Table 3 provides a summary of whether the individuals in the couples reported tension or conflict as a result of their HIV discordant status, whether physical or emotional intimacy had been affected by the HIV discordant status, the term that best describes their sexual relationship and whether they practise safer sex – defined as steps taken (e.g. consistent condom use) to prevent the transmission of HIV or other sexually-transmitted infections between partner(s).

The interviews with each partner and with the couple explored whether and how the serodiscordant status had affected the intimacy between, and sex life of, the partners, steps taken to practice safer sex, and the difficulties (if any) of practising safer sex.

intercourse or decreased libido; and avoiding certain sexual acts such as oral sex:

*“In terms of making love, some things have changed. Oral sex and not having it any more.” (HIV-positive woman, Couple 3, South Africa)*

*“Sex is no longer spontaneous, as one must first think of practising safe sex and be careful that my partner does not infect me.” (HIV-negative woman, Couple 7, South Africa)*

*“The decrease in sexual practise has been one of the major effects. The sexual practice has decreased from six times per month to two times per month. Using a condom has been a challenge as the partner does not find enough satisfaction.” (HIV-negative man, Couple 7, Tanzania)*

TABLE 3: INTIMACY AND SEXUAL RELATIONS

Variable	South Africa (%)	Tanzania (%)	Ukraine (%)	Total (%)
Experience of tension because of serodiscordant status*	14/48 (29%)	10/20 (50%)	N/A	24/68 (35%)
Intimacy affected by serodiscordant status*	26/47 (55%)	14/19 (74%)	N/A	40/66 (61%)
Sexual relationship with only one partner at least 6 months <sup>#</sup>	43/51 (84%)	15/20 (75%)	28/30 (93%)	86/101 (82%)
Always practise safer sex (e.g. consistent condom use*)	37/48 (77%)	12/20 (60%)	N/A	49/68 (72%)

\* Information obtained from qualitative interviews, not available for Ukraine

<sup>#</sup> Information obtained from self-administered questionnaires

In South Africa, the majority of individuals (34/48, 71%) did not report tension as a result of the serodiscordant status, but half (10/20) the participants in Tanzania reported tension related to their discordant HIV status. Conflict or tension was related to four issues: fear of infecting the HIV-negative partner; lack of trust (perceived infidelity, multiple sexual partners, etc.); the “safer sex imperative” (consistent condom use); and strained relations at the time of first disclosure.

The majority of individuals in South Africa and Tanzania said that the serodiscordant status had affected the intimacy in their sexual relationships due to changes in sexual practices; fear of infecting the HIV-negative partner; and condom use. Changes in sexual practices included a loss of spontaneity; decreases in frequency of sexual

*“My sex drive when it comes to my wife has diminished, because of safety measures.” (HIV-negative man, Couple 22, South Africa)*

Fear of infecting the HIV-negative partner was a major concern:

*“It has limited our relationship in some ways e.g. not brushing teeth for fear of bleeding gums. If the condom is not there, no sex....I am hyper-conscious of protecting him.” (HIV-positive woman, Couple 5, South Africa)*

*“In the beginning, my partner was afraid to have sex... [My] partner was not clear where I got the virus.” (HIV-positive woman, Couple 7, Tanzania)*

Condom use was seen to have a negative effect on sexual intimacy:

*"The issue of condom use affects the relationship."* (HIV-negative man, Couple 1, Tanzania)

*"By using a condom, you affect one's sex life."* (HIV-positive man, Couple 5, Tanzania)

*"[I noticed that] He lost appetite in sex. Using condoms after so many years together is painful, but we had to."* (HIV-negative woman, Couple 6, South Africa)

*"The fact that we must use condoms every time we have sex is not appealing to me."* (HIV-negative man, Couple 15, South Africa)

*"We always quarrel with my partner, because he sometimes wants to have sex with me without a condom."* (HIV-positive woman, Couple 15, South Africa)

Most participants used condoms as a means of practising safer sex, although some reported inconsistent condom use:

*"We practised safer sex from the first time, but now we don't practise safer sex because we sometimes use a condom, and sometimes don't. [We believe that] if you prepare each other well before sex you cannot get HIV."* (Couple 5, Tanzania)

*"We frequently use condoms, though this is not consistent. We also practise [non-]penetrative sex."* (Couple 14, South Africa)

*"With using condoms, there are questions of trust and fidelity e.g. Are we cheating on one another?"* (HIV-negative man, Couple 16, South Africa)

One HIV-negative participant reported using sex workers as a 'safer sex practice,' while his partner vacillated in her response between consistent condom use and his refusal to use condoms.

*"Rather than establishing secret relationships outside marriage, I normally use sex workers, because there is no way we can have sex without a condom. A sex worker is a stranger to me."* (HIV-negative man, Couple 22, South Africa)

In the Ukraine, the majority of couples interviewed reported using condoms, but several participants acknowledged practising unsafe sex:

*"We do have unprotected sex occasionally when we are drunk. I know that I can get infected. But I have HIV tests often. I try to take the test monthly."* (HIV-negative woman, Ivano-Frankivsk, Ukraine)

Participants reported that it was usually the HIV-positive partners who initiated condom use during sexual intercourse, although the majority of HIV-negative partners reported that they understood the need for consistent condom use:

*"We understand all risks and that it's probably more dangerous for me than my partner."* (HIV-negative woman, Rivne, Ukraine)

When asked about the challenges and difficulties experienced in practising safer sex in their serodiscordant relationship, the majority of couples reported that condom use had required some adaptation in the beginning, that good communication is important, but that over time it had become routine. As one South African couple noted:

*"For the first time it's easy as we have compromised and we understand each other and we focus on the future. The positive partner should be honest, considerate, understanding and respect the negative partner."* (Couple 26, South Africa)

Difficulties mentioned by couples included a fear of infecting the HIV-negative partner, some reluctance on the part of male partners to use condoms, and balancing the desire to have children with safer sex practices.

#### 4.6 Disclosure of HIV status

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 serodiscordant couple status to some people (family, friends, colleagues or support groups). Of HIV-positive participants, 81% had disclosed their serodiscordant status to someone, compared to 75% of the HIV-negative participants.

The fear of stigma and discrimination was the overwhelming reason for non-disclosure:

*"We made a decision with my partner to keep her HIV-positive status to ourselves because of the stigma and discrimination attached to the condition."* (HIV-negative man, Couple 10, South Africa)

*"We did not feel comfortable to share my status with family or friends due to the stigma attached to the condition." (HIV-positive woman, Couple 10, South Africa)*

*"I have decided with my partner not to disclose my status as my mother is hypertensive and is easily disturbed by minor issues. Additionally, I do not want to disclose my status to my two brothers and sister as they all abuse alcohol, and after their drinking spree, they will abuse me verbally as always." (HIV-positive woman, Couple 13, South Africa)*

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

Couple 2 from Tanzania said that the reasons for not disclosing their serodiscordant were that they thought that family members did not have knowledge of HIV and HIV discordant couples. They also feared stigma and discrimination. They lived in a rented house, and that they might be evicted from their house and become isolated and labelled if people found out about the HIV-positive partner's HIV status. Another Tanzanian couple said that they did not want to disclose to their family members and friends because the family members did not have enough knowledge of HIV discordant couples, and the couple feared being stigmatised. The HIV-positive partner said that he did not want to disclose yet because he was still healthy. He planned to disclose later when he became sick and bed-ridden.

In the Ukraine, participants reported that people in serodiscordant relationships generally try not to make their status public. In some cases closest relatives, such as parents were informed.

*"Practically no one in my family knows about my problem. Only close friends and my partner, the person I live with, know. I don't hide it (the status) but I don't think one should yell about it." (HIV-positive woman, Kiev, Ukraine)*

Although the majority of individuals interviewed in South Africa and Tanzania had disclosed to someone in addition to their partner, very few were living openly as a HIV discordant couple:

*"It is different when one is living openly. People shy away from probing and there is no need to be funny." (HIV-positive woman, Couple 4, South Africa)*

*"I was comfortable talking to my family and friends, because I know they care about me. Experiences I had was when I had to explain my situation to them about my love for this girl. I told them I fell in love with her soul, and I did what it takes*

*and I will still do to take care of me and her. I was actually safe because I knew her status and she knew mine, so we know we have to protect ourselves and get tested." (HIV-negative man, Couple 4, South Africa)*

*"I decided to share due to fear of AIDS-related illness. I also wanted to be a role-model, so that anyone who is infected can be open and go for treatment, rather than going to traditional healers." (HIV-positive woman, Couple 7, Tanzania)*

*"We came out on a local educational TV series about our HIV discordant status. Most if not all of the people that we are close with know about [our] HIV discordance. We discuss our discordant couple status with everybody and anybody." (HIV-positive man, Couple 23, South Africa)*

The interviews also revealed the complexity of "selective disclosure", i.e. individuals and couples appear to make conscious choices regarding the person(s) to whom they disclose:

*"Not many people know that we are in a discordant relationship. My mother knows. She finds it comforting that my partner is negative." (HIV-positive woman, Couple 5, South Africa)*

*"It was easy for me to tell at work. I work in the organisation working with both HIV-positive and HIV-negative people. We met at work." (HIV-negative woman, Ivano-Frankivsk, Ukraine)*

*"I shared with a group of people living with HIV and AIDS because they share the common objective and receive counselling support from the group. I also shared with this group of people because I get emotional support." (HIV-positive man, Couple 5, Tanzania)*

*"[We have] not yet disclosed to family members, friends and co-workers, but we have discussed the issue with our pastor so that he can motivate us regarding this challenge we are facing." (Couple 18, South Africa)*

Many individuals and couples talked about family and community members' limited knowledge or understanding of HIV discordance and having to deal with a 'positive by association' perception following disclosure:

*"I told my family that I am living in discordant relationship, even though relatives did not believe that I am negative, while my partner is positive. My friends are making me scared of staying with a positive partner. They are asking questions every day." (HIV-negative woman, Couple 3, Tanzania)*

*"I experienced shock and disbelief from family and friends. Most could not understand the fact that I am negative and my wife is HIV-positive."* (HIV-negative man, Couple 14, South Africa)

*"The family does not agree. Friends think I am also HIV-positive as my wife."* (HIV-negative man, couple 10, Tanzania)

Another issue is dealing with the perceptions or pressures from the HIV-negative partner's family members or friends.

*"My family don't have any problem about the situation, but my partner's family had problems at first. But we made them to understand – like give them a lot of information in terms of HIV and AIDS and we are still doing it [having sex]."* (HIV-positive woman, Couple 3, South Africa)

*"I am open and I used to tell people about our status. There is conflict in the family about why I am staying with an HIV-positive partner."* (HIV-negative man, Couple 6, Tanzania)

*"I disclosed to my best friend, and my mom. My brother and sister were totally against the relationship. My friend wanted to find out if I am certain of starting a relationship with a partner who is HIV-positive, and if I understand the implications and consequences of being in such a relationship. My mom advised that if I really love this gentleman I should take precautions and practise safe sex. She was not against the relationship."* (HIV-negative woman, Couple 17, South Africa)

*"The family knows that I am in a discordant relationship. My parents told me to escape, but I came back to my husband."* (HIV-negative woman, Couple 8, Tanzania)

*"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)

#### **4.7 Experiences of stigma and discrimination**

Participants were asked whether they have ever been discriminated against because of their or their current partners' HIV status. The majority of participants in Tanzania (12/20, 60%) had experienced discrimination,

compared to 21% in South Africa (8/39). Forty-three percent (13/30) of the HIV-positive participants, compared to 24% (7/29) of the HIV-negative participants had experienced some form of discrimination.

*"I was discriminated against by my previous partner... I was also rejected by my friends I was living with. I used to have separate eating utensils."* (HIV-positive woman, Couple 2, South Africa)

*"Yes, sometimes friends blame me saying: Why are you living with an HIV-positive woman? You are still young, you can get another woman."* (HIV-negative man, Couple 1, Tanzania)

*"[Discrimination occurs] in a more subtle way. For example there are rumours that my partner wants attention, and that's why he is having a relationship with an HIV-positive woman. My partner got calls from his ex-girl friends who are questioning his choices."* (HIV-positive woman, Couple 4, South Africa)

*"I was rejected by all insurance companies for applying for life insurance. I do working with various companies and many of them insurance companies, I thought I could go through certain channels via the connection that I have but I was still shut out. Obviously I took them to task and went as far as exposing it landing-up on the front page of newspapers...but the insurance companies never passed a policy yet."* (HIV-positive man, Couple 24, South Africa)

*"There is no direct discrimination, but there is hidden discrimination."* (HIV-positive man, Couple 3, Tanzania)

*"The stigma exists in the family. The family labels us and calls us stigmatizing names. My wife's relatives are the most stigmatizing family members especially during festivals like marriage, etc. We are stigmatised when eating and drinking, and given names like walking corpse."* (HIV-negative man, Couple 7, Tanzania)

In the Ukraine, discrimination from health-care professionals was reported to be a problem.

*"I needed serious surgery on my jaw. When I applied to medical professionals (surgeons) informing them about my positive status, I was refused on the basis of all kinds of made-up reasons."* (HIV-positive man, Rivne, Ukraine)

*"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 clinic but I don't inform them about my positive status. I feel better that way."* (HIV-positive woman, Kiev, Ukraine)

Many countries have policies barring entry of travellers who are HIV positive. One HIV-positive woman interviewed in the Ukraine reported that she had been refused a United States travel visa because she was HIV-positive. Another woman in the Ukraine reported having difficulty in securing a car loan because she worked for an HIV service organisation.

*“There was such a moment when I was buying a car. I was paying a rather good pre-payment – 25% of total cost and when I presented an income statement – it was okay, I have a decent salary – it had the name of my employer. I received a phone call from the bank asking a lot of questions about the organisation I work for. I think it was connected with that, and because of that I was asked to present a number of additional documents they didn’t mention before, and find a guarantor, although with such big pre-payment the guarantor is not required.”* (HIV-positive woman, Kiev, Ukraine)

#### 4.8 Communication and concerns of discordant couples

The interviews also addressed the extent to which the couples communicated about HIV and their serodiscordant status, and whether being serodiscordant over-shadowed their lives. The majority of couples in the two African countries (22/36, 61%) reported that they talked about HIV like any other condition, and that it did not overshadow their lives.

*“It (HIV) is there...It is part of the relationship. He has helped me to move on, and I get tremendous support. I don’t wake up thinking about HIV, it has become a routine. He has lessened the load.”* (HIV-positive woman, Couple 4, South Africa)

*“We communicate about HIV and AIDS, but not always. During leisure times and recreational times, we share information about HIV/AIDS. In the beginning HIV over-shadowed our lives, but as time went by and access to information was available, we found some light to move on, and cope with life.”* (Couple 7, Tanzania)

TABLE 4: COUPLES’ CONCERNS ABOUT THE FUTURE, SOUTH AFRICA AND TANZANIA

CONCERN	ILLUSTRATIVE QUOTES
Biological children	<p><i>“My partner is the most precious thing to me. We have a big fight about babies, and I would like to have babies. I feel she is playing delaying tactics; not having the baby.”</i> (HIV-negative man, Couple 5, South Africa)</p> <p><i>“Our biggest concern is that we will not have biological children, and maybe the [positive] partner will die early before the negative partner.”</i> (Couple 26, South Africa)</p> <p><i>“The future plan is to get children.”</i> (Couple 6, Tanzania)</p>
Preventing HIV transmission to the HIV-negative partner	<p><i>“I am always concerned about his next test result (every 6 months). I am more anxious.”</i> (HIV-positive woman, Couple 4, South Africa)</p> <p><i>“We both decided to use a condom to avoid transmitting HIV [to the negative partner], and also to avoid pregnancy.”</i> (Couple 9, Tanzania)</p>
Addressing immediate needs	<p><i>“Better accommodation – a house with better bathroom facilities and [more] space.”</i> (Couple 2, South Africa)</p> <p><i>“We would like to get married, and bring-up our children in good home, and get employed. Invest money for our child’s schooling education. Would like to study further so that we can earn better salaries. We would like to see our child grow up, before we can have other children.”</i> (Couple 19, South Africa)</p> <p><i>“I am struggling with income-generating activities that will help to maintain a balanced diet for my partner.”</i> (HIV-negative man, Couple 6, Tanzania)</p>
Potential illness and limited life-expectancy of the HIV-positive partner	<p><i>“One of the future plans is not to have children anymore, for the survival of my partner to help her and make her comfortable and to feel supported.”</i> (HIV-negative man, Couple 4, Tanzania)</p> <p><i>“Medication failure – What happens if my medication stops working? What if my partner becomes positive? What if I become sick? If I get sick with AIDS, will my partner stick by me? We have a friend whose partner abandoned him.”</i> (HIV-positive man, Couple 23, South Africa)</p>
Future investments to take care of surviving partner and/or children	<p><i>“We are in the process of planning for retirement and life insurance policy. Have a funeral policy with Old Mutual.”</i> (Couple 6, South Africa)</p> <p><i>“We discuss issues pertaining to retirement annuity funds, life insurance, policies and burial funds, including educational policies for the children.”</i> (Couple 7, South Africa)</p>

**TABLE 5: SUPPORT GROUP PARTICIPATION AND RECEIPT OF HIV COUNSELLING BY COUNTRY**

Variable	South Africa (number, %) (n = 52)	Tanzania (number, %) (n = 20)	Ukraine (number, %) (n = 30)	All participants (number, %) (N = 102)
Support group participation	13 (25%)	15 (75%)	17 (57%)	45 (45%)
HIV prevention counselling	41 (80%)	17 (85%)	18 (60%)	76 (75%)
Risk-reduction counselling	43 (83%)	16 (80%)	20 (67%)	79 (77%)

**TABLE 6: SUPPORT GROUP PARTICIPATION AND RECEIPT OF HIV COUNSELLING BY HIV STATUS**

Variable	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%)

However, 13/36 (36%) of the African couples reported that discussions related to HIV overshadowed their lives.

*“We always talk about HIV and AIDS because we are both involved in HIV and AIDS field, but our plans of having children are slim that’s the only reason that made us to talk about sex and HIV.”* (Couple 3, South Africa)

*“Most of the time, we communicate about HIV and AIDS, normally we like to share on how we can get a child.”* (Couple 5, Tanzania)

*“We frequently communicate about test results (e.g. CD4, viral load). We talk to other people about safe sex. We participate in a research study every three months. We talk about moving and access to medication; what to do if medication fails; talk about safe sex.”* (Couple 23, South Africa)

In the Ukraine, those couples were aware of their serodiscordant status when they had first met each other, said that they had discussed HIV and AIDS more at the beginning of their relationship, as the negative partner got to know about HIV, the disease and the need for condom use. Couples in which one of the partners first discovered that they were infected after being married avoided talking about HIV and serodiscordance as far as possible.

Couple interviews also explored the kinds of concerns that the partners talked about with regard to the future. These concerns are summarised in Table 4.

#### 4.9 Sources of support and services

The self-administered questionnaire asked each member of the couple about: support group participation; whether they had had counselling to prevent HIV; and whether they had risk-reduction counselling, i.e. counselling on how to lower the risk of transmitting or contracting HIV. The recall period was the previous year. The results are shown by country in Table 5, and by HIV status in Table 6.

The individual interviews explored the sources of support received for being in an HIV discordant relationship, and the couple interviews asked about useful services and couple support in terms of health maintenance, emotional or material support. Sources of support included various combinations of health care providers, family, friends, support groups, and the pastor or priest:

*“We have a circle of close friends [who provide] support to each other, [participate in] church activities, and family as well.”* (HIV-negative man, Couple 5, South Africa)

TABLE 7: PARTICIPANTS' PARTICIPATION IN HIV- AND AIDS-RELATED ACTIVITIES IN THE PREVIOUS YEAR

Variable	South Africa (number, %) (n = 52)	Tanzania (number, %) (n = 20)	Ukraine (number, %) (n = 30)	All participants (number, %) (N = 102)
Participation in an organisation providing services for people affected by HIV or AIDS	14 (27%)	17 (85%)	16 (60%)	49 (48%)
Participation in an advocacy organisation that campaigns for better services for people affected by HIV or AIDS	15 (29%)	14 (70%)	5 (17%)	34 (33%)
Participation in HIV or AIDS volunteer work	11 (21%)	14 (70%)	15 (50%)	40 (39%)
Participation in a rally, march or protest	4 (8%)	5 (25%)	12 (40%)	21 (21%)
Participation in an educational event on HIV or AIDS	23 (44%)	16 (80%)	12 (40%)	51 (50%)
Participation in a workshop on HIV or AIDS	14 (27%)	16 (80%)	16 (53%)	46 (45%)

*"I have no sources of support except that of my partner, with words of encouragement and motivation to take my medication as prescribed, and a positive mental attitude. I also receive support through counselling at the hospital."* (HIV-positive woman, Couple 11, South Africa)

*"I receive support from the groups like post-test clubs and discordant groups."* (HIV-positive woman, Couple 1, Tanzania)

*"Psychological support from the discordant group and counselling centres at AMREF, and from other organizations that provide psychological support and material support."* (HIV-negative man, Couple 9, Tanzania)

In the Ukraine, the majority of participants said that their partners were their main source of support:

*"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, Kiev, Ukraine)

Other sources of support in the Ukraine were colleagues and support groups. Very few participants mentioned health care providers as the *only* source of support (South Africa: 8/47, 17%; Tanzania 1/20, 5%). Couple counselling was the most useful service mentioned to deal with the challenges of being in a serodiscordant

relationship. Tanzanian couples also mentioned the usefulness of meetings for HIV discordant couples and post-test clubs for psychological support and obtaining information on serodiscordance.

*"First time, it was not easy because I was taking myself as a dirty person, but I went for couple counselling, so it helped me a lot."* (HIV-positive woman, Couple 3, South Africa)

*"I received knowledge received on how to prevent myself from getting new infections, and also to protect my husband from being infected with HIV."* (HIV-positive woman, Couple 6, Tanzania)

In South Africa, hospital services were mentioned as providing health support, including information and advice on medication side effects and providing counselling.

*"In the beginning when my husband had health problems, problems such as skin problems and lactic acidosis, we used to call the sister at the hospital and she would counsel us over the phone and explain to us how to handle the challenges or side effects of the ARVs."* (HIV-negative woman, Couple 1, South Africa)

*"We receive counselling at the hospital."* (Couple 21, South Africa)

In Tanzania, post-test clubs and support groups were mentioned consistently as a source of emotional and therapeutic support. Non-governmental organisations were a source of material support such as food and school supplies for children.

Some individuals draw strength from their religion:

*“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)

*“Our main source of support is our pastor from the church.”* (Couple 18, South Africa)

#### **4.10 Participation in HIV and AIDS-related activities**

Couple interviews also explored joint participation in advocacy activities. Table 7 shows participants' participation in HIV and AIDS advocacy activities. Few of the couples were jointly involved in advocacy activities. HIV-positive partners tended to be more active:

*“I attend different events and provide testimonials to the public. My husband attends the discordant group meetings and post-test clubs only.”* (HIV-positive woman, Couple 1, Tanzania)

*“We do, we are both members of the Treatment Action Campaign. It gives us a lot of support and information.”* (Couple 3, South Africa)

*“We are involved in AIDS advocacy work, and are free to talk or do any activity publicly.”* (Couple 6, Tanzania)

*“As soon as I heard that I was HIV-positive, I started advocating, doing television campaigns, media-radio. I've spoke to more than 450,000 people over a period of 9 years, including children, and it makes me see and experience other realities and also being able to take that back to corporations and politicians in drawing up policies.”* (HIV-positive man, Couple 24, South Africa)

Time constraints and non-disclosure were cited as the major reasons for non-involvement.

*“No. Because of our other commitments and scarcity of free time. We will probably play a major role in advocacy work with our website.”* (Couple 7, South Africa)

*“We are not involved due to work commitments. We are eager to join a support group of HIV discordant couples or HIV infected and affected couples so that we can share our experiences and probably learn lessons from others.”* (Couple 11, South Africa)

*“I am attending group therapy at AMREF, but my wife does not like to attend the sessions because she fears that she will be labelled as being HIV positive.”* (HIV-positive man, Couple 6, Tanzania)

## SUMMARY

- A total of 51 couples were interviewed from South Africa (26 couples), Tanzania (10 couples) and the Ukraine (15 couples), with rich insights obtained.
- Couples' experiences of being in an HIV discordant relationships fell into three broad categories: support, care and concern for the health of the HIV-positive partner; the notion of normality, with HIV as a subliminal theme; and tensions inherent in an HIV discordant relationship.
- 73% of HIV-positive participants were on ART. The majority of participants rated their health as good, very good, or excellent.
- Almost half the HIV-negative partners had last been tested for HIV more than 6 months previously.
- The majority of couples indicated active participation by the HIV-negative partner in the health and wellness management of the HIV-positive partner.
- Just over half (51%) the couples expressed a desire to have a child or children; 47% of HIV-positive participants expressed a desire to have a child or additional children, without infecting their partners.
- Tension was not a major issue highlighted by couples. When experienced, tension related to four issues: fear of infecting the HIV-negative partner; lack of trust (perceived infidelity, multiple sexual partners, etc.); the 'safer sex imperative' (consistent condom use); and strained relations at the time of first disclosure.
- 61% of participants indicated that intimacy had been affected by their serodiscordant relationship, with the overwhelming issue related to changes in sexual relationships, including changes in sexual relations, fear of infecting the negative partner, condom use, and the desire for children.
- 82% of participants reported that they had been monogamous for at least 6 months, and 72% of the South African and Tanzanian participants reported that they always practised safer sex. Difficulties relating to practicing safer sex included a fear of infecting the HIV-negative partner, reluctance on the part of male partners to use condoms, and the desire to have children.
- 73% of South African participants and 90% of Tanzanian participants had disclosed their HIV discordant couple status selectively to some people, with non-disclosure related to fear of stigma and discrimination.
- 60% of the Tanzanian participants reported having experienced some form of discrimination, compared to 21% of South African participants.
- The majority of couples in South Africa and Tanzania (61%) reported that they talked about HIV but that it did not dominate their lives.
- Couples' concerns about the future related to: having biological children; preventing HIV transmission to the HIV-negative partner; addressing immediate material or other needs; coping with potential illness or survival of the HIV-positive partner; and ensuring future investments to take care of the surviving partner and/or children.
- HIV-positive partners were more likely to participate in support groups or to have received HIV prevention counselling, compared to HIV-negative partners.
- Sources of support included health care providers, family, friends, support groups, and religious leaders.
- Few couples were jointly involved in advocacy activities. HIV-positive partners tended to be more active in activities such as participating in rallies, marches or protests and to doing HIV and AIDS-related volunteering.

# 5 DISCUSSION AND RECOMMENDATIONS

## 5.1 Introduction

Perhaps not unexpectedly, HIV runs as a thread throughout the experiences of couples in serodiscordant relationships, whether in the care and concern for the health of the HIV-positive partner, couples stressing the 'normality' of their relationship, or, in some instances, the overt and subtle tensions inherent in an HIV discordant relationship.

This section discusses key aspects of the findings, as they relate to the recommendations.

## 5.2 Health and wellbeing

A key concern of couples was the future well-being and life expectancy of the HIV-positive partner. Almost three-quarters (73%) of the HIV-positive participants were taking ART, but there was no explicit evidence that the use of ART had made them less concerned about HIV transmission or less conscientious in practising safer sex, i.e. condom use. In general, couples seemed to have found a balance in taking care of one another, and the majority of couples indicated active participation by the HIV-negative partner in the health and wellness management of the HIV-positive partner. Very few participants – including HIV-positive individuals – self-rated their health as poor. Of note is that almost one in two (49%) of the HIV-negative partners had been tested more than 6 months ago. There is currently a lack of guidelines on repeat HIV testing of the HIV-negative partners in serodiscordant relationships.

Existing strategic plans on HIV and AIDS in all three countries fall short of addressing the issue of HIV discordant couples, evidenced by a review of the national reports on monitoring progress towards the UNGASS Declaration on HIV/AIDS submitted by the governments of South Africa, Tanzania and the Ukraine.<sup>64,65,66</sup> Not a single mention is made in any of the three country reports of serodiscordance and its contribution to HIV transmission. There are currently no policy guidelines on strategies for managing HIV discordance.

Overall, 75% of participants reported that they had received HIV prevention counselling, with a higher proportion HIV-positive participants (84%) than HIV-negative participants (66%) reporting that they had received prevention counselling. As participants had contact with and access to health services, these findings suggest that there are missed opportunities for HIV prevention and risk-reduction counselling among serodiscordant couples.

Sources of support include various combinations of health care providers, family, friends, support groups, and faith-based leaders. Overall, 45% of all study participants have participated in support groups, with Tanzania the highest at 75%, followed by Ukraine at 57%, and a low 25% in South Africa. HIV-positive members of the couple are more likely to participate in support groups (58%), compared to 31% of HIV-negative members, and this difference was statistically significant. Participation in support groups have been shown to assist HIV-positive individuals to deal with stigma and isolation, provides emotional support, improves HIV knowledge and promotes positive living.<sup>67,68</sup>

## 5.3 Sexual health, sexuality and reproductive choices

Almost one in two African participants (49%) expressed a desire to have a child or children, while 47% of HIV-positive participants in South Africa and Tanzania expressed a desire to have a child or additional children. Individuals without children in these two countries were more likely to desire children (74%) than those who already had one or more children (36%). Balancing the desire to have children with the risk of HIV transmission is a theme that emerged throughout the individual and couple interviews, a finding supported by other studies.<sup>69</sup> Participants from the Ukraine indicated lack of trust in the ability of health care professionals to understand the issues and to provide appropriate advice, and sometimes depended on their peers to give them information on reproductive options. A study, conducted in Cape Town, South Africa, to investigate HIV-positive individuals' reproductive intentions and influencing factors found that both HIV-positive women and men had reproductive

desires, but that most HIV-positive women had not discussed their reproductive desires and intentions with health care providers in HIV care or general health services because of anticipated negative reactions.<sup>70</sup> The minority who had expressed their intentions experienced an unsupportive counselling environment, not conducive to open discussion on reproductive issues.<sup>68</sup>

Having biological children, while avoiding HIV transmission to the HIV-negative partner, was found to be a major concern among serodiscordant couples. The findings from this study suggest greater attention needs to be paid in national strategic plans to the provision of sexual and reproductive health services in a supportive and non-discriminatory environment, with careful attention being paid to the concerns of discordant couples.

However sexual health goes beyond reproduction. In this study, 61% of the African participants indicated that intimacy had been affected by the HIV discordant relationship, with the overwhelming issue related to: changes in sexual relations; fear of infecting the negative partner; and condom use. The majority of couples indicated safer sexual practices: 82% said that they have sex with one partner only for longer than 6 months, and 72% of the African participants said that they always practise safer sex, but there are difficulties. These difficulties relate to the fear of infecting the negative partner, some reluctance on the part of male partners to use condoms, and again the desire to have children.

#### 5.4 Disclosure, stigma and discrimination

HIV remains one of the most stigmatised conditions throughout the world. The XVII International AIDS Conference in Mexico in 2008 was “a watershed moment that established reducing stigma and discrimination as fundamental priorities in working towards universal access to HIV prevention, treatment, care and support”.<sup>59</sup> In this study, the majority of South African (73%) and Tanzanian (90%) participants had disclosed their serodiscordant couple status, but only selectively. The reasons for non-disclosure related to fear of stigma and discrimination, evidenced by the moving testimonies from various participants. In the Ukraine, participants preferred to keep their HIV status to themselves, and not make it a topic for discussion. Fear of stigma and discrimination was not unfounded: 60% of Tanzanian participants and 21% of South African participants had experienced some form of discrimination. In the Ukraine, some HIV-positive participants reported overt discrimination by health care professionals. Increasingly, there are calls for ensuring that stigma and discrimination reduction are national and international funding, policy and programme priorities.<sup>59</sup>

To this end, the *People Living with HIV Stigma Index*<sup>71</sup> has been developed to provide a tool to measure and detect changing trends in relation to stigma and discrimination experienced by people living with HIV.

#### 5.5 Strengths and Limitations

Strengths of the study included the use of mixed quantitative and qualitative methods; and conducting both couple interviews and separate interviews with both partners, thus allowing complexities and contradictions of HIV discordant relationships to be explored. In addition, this study addresses a gap in knowledge and understanding because it focused on psychosocial issues while most research among discordant couples has focussed on clinical and/or biomedical aspects of HIV transmission in couples. This study makes an important contribution to knowledge on serodiscordant couples in long-term relationships, the issues they face and strategies that they use to sustain their relationships, maintain their health, make sexual and reproductive choices, and prevent HIV transmission.

This study was conducted in only three countries on two continents, and thus may not reflect the experiences or perspectives of discordant couples in other parts of the world. The sample of 51 couples (which was more than double the sample size of 25 couples originally planned) does not and could not reflect the diversity of epidemics and health systems, and also may not adequately reflect the experience of same-sex couples as only three same-sex couples were included. However, as the bulk of the burden of HIV is in Sub-Saharan Africa, and the most common mode of transmission globally is through heterosexual sex, having the majority of the sample (33/51, 65%) being heterosexual African couples can also be viewed as a strength.

Study participants should also not be viewed as representative of serodiscordant couples in the three study countries. Participants were recruited largely through health care providers and non-governmental organisations (NGOs) that provide services to HIV-positive individuals and serodiscordant couples. Thus, participating couples all had some degree of access to health care or social services, and are likely to have had better access and greater use of services and programmes than a typical HIV discordant couple in each of the three study countries. The couples who participated in the study agreed to be contacted and interviewed, and may thus have differed in important respects from those who could not be contacted or who refused to participate. The study depended entirely on self-reported information on a sensitive topic and of behaviours that may be subject

to socially desirable responses and to response biases. In addition, the behaviours of couples who agreed to participate might be different to that of other known serodiscordant couples. Despite these study limitations, we believe that our study findings have important policy and/or health service implications. Despite these limitations, we believe that the study provides useful insights into the issues faced by serodiscordant couples, and has important implications for policy and health services and programmes.

## 5.6 Recommendations

The following five recommendations are premised on the critical role of governments in managing the overall national response to the HIV epidemic, and take into account the findings from this study and the perspectives of couples interviewed, jointly and individually, on additional information or support needed for dealing with the challenges of discordance. The recommendations should 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, thereby contributing to turning the tide against the HIV epidemic.

Our five recommendations are:

- Put HIV discordance on the HIV and AIDS research and policy agenda
- Develop holistic and comprehensive HIV programmes for couples.
- Ensure the provision of sexual and reproductive health services in a supportive and non-discriminatory environment
- Involve serodiscordant couples in the HIV response
- Address stigma and discrimination

### Recommendation 1

#### Put serodiscordance on the HIV and AIDS research and policy agenda

Recent studies, conducted in a number of African countries with generalised HIV epidemics, have shown that a substantial number of couples in long-term sexual partnerships have discordant HIV status.<sup>2,3,11</sup> To date, the issue of HIV discordance has not featured in national strategic plans in any of the three study countries.<sup>62,63,64</sup> As several participants noted in their recommendations for additional support or information:

*“Acknowledge the existence of discordant couples. Try and normalise the situation around HIV.”* (HIV-negative man, couple 5, South Africa)

*“Information should be made available. People need to be well informed about issues of discordance. The population in general needs to be well informed regarding HIV and AIDS.”* (HIV-negative man, couple 16, South Africa)

*“People should know and be aware about discordant couples. Also, once you know your HIV status you should disclose to your partner.”* (HIV-positive woman, Couple 4, Tanzania).

Hence, we recommend that HIV discordance should form an integral part of the global and national responses to HIV epidemic management; its contribution to HIV transmission should be acknowledged; and the prevalence of serodiscordance should be monitored as part of routine surveillance. National policy guidelines on strategies for managing HIV discordance should be developed. Such policies should ensure that the rights of people living with HIV are respected and should provide support in making informed choices regarding their health and measures taken to prevent HIV infection, and should provide options for couples who desire children

Research on HIV prevention technologies (see [Appendix](#)) should consider the needs of HIV discordant couples in long-term relationships, including the desire of many couples to have children conceived through natural methods with both partners as biological parents. Research measuring the effectiveness of ART as a means of preventing HIV transmission, and on developing guidelines and recommendations on the use of ART for prevention purposes should be prioritised. Research and development of potentially useful new prevention technologies, including PrEP, microbicides, and vaccines should continue. Further research is needed into the psychosocial, reproductive and sexual health or social service needs of HIV discordant couples in diverse geographical settings, including an exploration of the needs of couples in same sex relationships. Importantly, there are few research or policy efforts that focus on sexual health and services beyond having children. Although HIV-related stigma is an important barrier to epidemic management, couples’ experiences of stigma and discrimination and potential pressures to be in concordant relationships needs further research. In addition, research is needed to analyse why leadership action to address the prejudice and stigma is wanting, and to determine some of the key drivers of and constraints to change.

Operational research is also needed to develop integrated prevention and care models that meet the needs of couples in diverse settings, with a particular focus on improving access to HIV programmes in resource constraint settings.

### **Recommendation 2**

#### **Develop holistic and comprehensive HIV programmes for couples**

In a few countries, HIV counselling and testing services engage with couples have been established to help overcome some of the difficulties associated with disclosure, and with HIV prevention in the context of an ongoing relationship. However, counselling, prevention and support services that focus on couples, rather than individuals, are currently not widely available and tend to be small-scale pilot projects. There is, thus, an urgent need to develop policies and programmes for HIV discordant couples in order promote the health of both partners, and to provide support in addressing the challenges of being in a discordant partnership.

Current HIV prevention strategies – including the abstinence, be faithful, and use condoms (ABC) approach – are largely ineffective in the context of serodiscordant partnerships because abstinence is usually not a realistic option and being faithful does not prevent exposure to HIV. This study has shown that consistent condom use among couples in long-term sexual relationships is difficult to maintain.

In general, couples expressed a desire for information on healthy living, within the context of HIV discordant relationships, as can be seen from their recommendations below:

*“Special training for discordant couples and skills of disclosure. VCT centres to encourage couples to undergo VCT services together.” (Couple 2, Tanzania)*

*“What is lacking in SA [South Africa] is assistance to live positively. There must be an organisation that supports discordant relationships, so that one goes in with open eyes. There must be a support structure, it should be government. We need to know about options and support one another. Give opportunities in terms of access to information and health care as a couple. For example, if the condom breaks, what will happen?” (Couple 4, South Africa)*

*“Training that will help us [HIV discordant couples] to accept [and will provide] coping mechanisms. Also training that will make us competent so that we can educate others.” (Couple 4, Tanzania)*

*“More information about discordant couples, to show people it is possible. Much more friendly testing for the other couples.” (HIV-negative man, Couple 9, South Africa)*

*“We would like to have more information on how to live as a discordant couple. Advice on healthy lifestyle such as nutrition, exercise and health in general. Information on facts and developments in the field of HIV and AIDS” (Couple 18, South Africa)*

*“I think what is necessary is that there should be widespread knowledge that there is support. I got told at a dinner party by my then partner that he was HIV-positive... not really a good setting to be told that kind of information. I did not have time to think it through. I think it is very important to have support at that time and support that is non-judgmental, confidential ... and counselling. (HIV-negative man, Couple 24, South Africa)*

The findings also underscore 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 just 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 safer reproductive options for HIV discordant couples. It has been suggested that health care professionals should adopt a non-judgemental and culturally sensitive approach, take into account couples' perspectives and assist couples to make informed reproductive decisions.<sup>32,36,57,58</sup>

Our recommendations are best expressed through the individual and joint views of the couples.

*“We would like to have more information about the sperm wash as we would like to have more children.” (Couple 3, South Africa)*

*“We have questions about what will happen if the condom breaks. It is anxiety provoking, even though her viral load is undetectable. Our relationship is very special.” (HIV-negative man, Couple 4, South Africa)*

*“Information on how my wife can fall pregnant again without putting her life in jeopardy.” (HIV-negative man, Couple 15, South Africa)*

*“More information on having children who will not be HIV infected, and without infecting my husband.” (HIV-positive woman, Couple 8, South Africa)*

Couples also need ongoing information and counselling on safer sex, including the correct and consistent use of condoms, the benefits of male circumcision, lower-risk sexual practices as alternatives to penetrative sex, and sexual health advice appropriate for a serodiscordant relationship, 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 is the involvement of HIV discordant couples in the HIV response broadly, and, specifically, the need for support groups.

*“I would want to belong, I like to talk about my fears and insecurities; I would like to be in a circle to talk and to help others.” (HIV-positive woman, Couple 5, South Africa)*

*“We would like information on support groups. There is no information on serodiscordant couples, which discourages other couples to come out as serodiscordant couples because most people think that it is not possible to have a relationship with an HIV-positive partner.” (Couple 9, South Africa)*

*“They need more education about discordant couples, because it is a new thing in our society so it needs more effort or empower the community to be aware. By using trained discordant couples it will be easier to educate the society rather than other people.” (Couple 10, Tanzania)*

*“It is important that there should be more involvement of discordant couples in educating community members though this all depends on one’s interest in being empowered with HIV and AIDS knowledge, and also educating other people. We also need to know the realities of transmitting HIV, when the male partner is negative.” (Couple 14, South Africa)*

#### **Recommendation 5**

##### **Address stigma and discrimination**

As one of the participants said: *“There is still too much stigma attached to being HIV-positive.”* We recommend that greater emphasis should be placed in national plans and programmes on dealing with issues of stigma and discrimination. A Tanzanian couple recommended the need to develop a programme to support HIV discordant couples to fight stigma and discrimination and achieve greater acceptance by the community. Another Tanzanian couple noted that the community should understand that HIV-positive people have human rights, and that these rights should be respected. Fighting stigma and discrimination, however, cannot be separated from the need for a supportive policy, programme and resource environment.



# APPENDIX

## TECHNOLOGIES FOR PREVENTING HIV TRANSMISSION

HIV TRANSMISSION PREVENTION TECHNOLOGIES OF KNOWN EFFICACY					
TECHNOLOGY	EFFICACY* AT PREVENTING HIV TRANSMISSION	EFFECTIVENESS* AT PREVENTING HIV TRANSMISSION	ACCEPTABILITY	AVAILABILITY	COMMENTS
Condoms	Estimated to be > 90% (but has not been measured by means of clinical trials)	Variable. Only effective if used consistently and correctly.	Low–moderate	Readily available in most settings, but may not be available 'in the heat of the moment.' Cost limits availability in some settings.	The mainstay method of preventing HIV and STI transmission. Most other prevention technologies are intended to supplement, rather than replace, condom use.
Treatment of bacterial STIs	Varying efficacy in different clinical trials that used different treatment regimens and approaches to drug administration (prophylactic or therapeutic). <sup>72,73,74</sup> No effect on preventing HIV infection in some trials.	Varies with different STIs and in different populations.	Generally moderate to high. In some cultures traditional beliefs (e.g. associating STIs with bewitchment rather than infection) may limit acceptability.	Reasonably available in most settings. May not be readily available in some rural settings and areas where primary health care services are not readily available.	Prompt treatment of symptomatic STIs recommended, including syndromic management in settings where diagnostic services are not readily available. No known benefit for taking antibiotics to prevent STIs.
Male circumcision <sup>75</sup>	About 60% for preventing female-to-male HIV transmission. <sup>45,46,47</sup> Conflicting evidence on effect of male circumcision on risk of male-to-female transmission. <sup>48,49</sup> No evidence that male circumcision reduces risk of HIV transmission through anal sex.	Assumed to be similar to efficacy once penile wound has healed.	Varies – Influenced by cultural & religious beliefs.	Variable.	Has the advantage of being a 'once off' intervention that does not require ongoing adherence. Not a 'magic bullet' – Only effective if used to supplement, rather than replace, other forms of prevention (e.g. consistent condom use). Efficacy at preventing male-to-female HIV transmission; HIV transmission through insertive anal sex and long-term efficacy at preventing female-to-male transmission; are the subject of ongoing research.
Post-exposure prophylaxis (PEP)	High, if initiated within hours of exposure, with efficacy waning rapidly the longer the delay.	High.	Generally high among health workers with needlestick injuries and sexual assault victims. Likely to also be acceptable to people with accidental high-risk sexual exposure.	Variable.	Needs to be commenced within 48 hours of exposure to HIV, preferably as soon as possible. PEP has side effects, so only suitable for use in occasional situations of accidental exposure.

\* Efficacy refers to how well the technology works in experimental conditions of optimal use. Effectiveness refers to how well the technology works in 'real world' conditions of normal use.

NEW TECHNOLOGIES UNDER INVESTIGATION FOR PREVENTING HIV TRANSMISSION

TECHNOLOGY	EFFICACY* AT PREVENTING HIV TRANSMISSION	EFFECTIVENESS* AT PREVENTING HIV TRANSMISSION	ACCEPTABILITY	AVAILABILITY	COMMENTS
Treatment (ART) as prevention <sup>75</sup>	A recent study found that heterosexual partners of HIV-positive people on ART, especially those with a low viral load, have a low risk of acquiring HIV from their sexual partners. <sup>51</sup>	Assumed to be high.	High for prevention if HIV-positive person is taking ART anyway.	Variable.	Measuring efficacy of ART at preventing HIV transmission should be a high priority for further research. Potentially useful for serodiscordant couples who wish to conceive children without the use of artificial reproductive technologies. (ART is already being used for this purpose by some couples, though largely without the endorsement by health care professionals).
Pre-exposure prophylaxis (PrEP) <sup>75</sup>	Unknown. <sup>76</sup> Results of first efficacy trial expected to be released in late 2009 or early 2010.	Not applicable.	Not applicable.	Generally only available to trial participants, although purchase of PrEP on the black market has been reported in some countries.	Some drugs are used topically (e.g. inserted into the vagina) so the distinction between PrEP and microbicides (see below) is becoming blurred. If found to be efficacious, PrEP could potentially be used by serodiscordant couples who wish to conceive children without the use of artificial reproductive technologies.
Herpes simplex virus 2 (HSV-2) suppression <sup>75</sup>	Initial trials have had mixed results. <sup>77,78,79</sup> The Partners in Prevention HSV-2/HIV-1 Transmission Trial (Partners Study) of acyclovir among > 3,000 discordant couples is ongoing. <sup>80</sup>	Not applicable.	Not applicable.	Not applicable.	HSV-2 plays an important role in HIV transmission and acquisition. <sup>81</sup> Trials of HSV-2 suppression therapy ongoing. No HSV-2 vaccine has been developed yet, but (hypothetically) a HSV-2 vaccine might be useful at preventing HIV transmission in serodiscordant partnerships.
Human papillomavirus (HPV) vaccine	Unknown.	Not applicable.	Not applicable.	Variable.	Safety of administering HPV vaccines to HIV-positive individuals still being evaluated. <sup>82</sup> Potential role of HPV vaccines in reducing the risk of HIV acquisition in HIV-negative individuals has not yet been assessed.
Microbicides <sup>75,85</sup>	Several candidate microbicides have not shown a protective effect in clinical trials and some (e.g. nonoxynol-9) have been shown to be increase risk of acquiring HIV infection. Some promising microbicides are in the advanced stages of efficacy trials.	Not applicable.	Variable, depending partly on the form in which it is delivered.	No microbicide available yet.	Potentially useful, especially for people whose male partners refuse to use condoms, although should not replace condom use. If found to be efficacious, non-spermicidal microbicides could potentially be used by serodiscordant couples wishing to conceive children without the use of artificial reproductive technologies.
HIV vaccines (preventive) <sup>75,84,85</sup>	No efficacious vaccine discovered yet. May need to develop different vaccines for different HIV subtypes.	Not applicable.	Not applicable.	No vaccine available yet. No prospect of a preventive vaccine becoming available in the next 5 years.	Vaccines have the advantage of not requiring ongoing adherence. If a safe and efficacious vaccine were to become available, this could have a marked impact on the global HIV epidemic, and would be especially beneficial to serodiscordant couples.
HIV vaccines (therapeutic) <sup>75,84,85</sup>	No efficacious vaccine discovered yet. May need to develop different vaccines for different HIV subtypes.	Not applicable.	Not applicable.	No vaccine available yet. No prospect of a therapeutic vaccine becoming available in the next 5 years.	Vaccines have the advantage of not requiring ongoing adherence. A therapeutic vaccine would delay or arrest the progress of HIV infection among people who are already HIV-positive and could potentially reduce the need for ART. If a safe and efficacious therapeutic vaccine were to become available this would be a very useful 'positive prevention' intervention.

\* Efficacy refers to how well the technology works in experimental conditions of optimal use. Effectiveness refers to how well the technology works in 'real world' conditions of normal use.

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- 1 'Positive prevention' is placed in quotation marks throughout the report because in April 2009, after this study was concluded, GNP+ and UNAIDS co-organised an International Technical Consultation on 'Positive Prevention' where it was replaced by the term 'Positive Health, Dignity and Prevention'. See [www.gnpplus.net](http://www.gnpplus.net)
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