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# Social context of disclosing HIV test results in Tanzania

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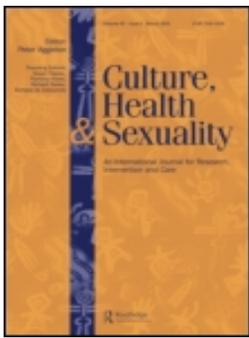
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## Social context of disclosing HIV test results in Tanzania

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This study sought to understand how individuals reveal their HIV test results to others and the ways in which social relations affect the disclosure process. The data were collected through open-ended interviews administered in Swahili to informants who had just been tested for HIV and to those who were living with HIV in Dar es Salaam and Iringa regions. Analysis shows that social relations influence the decisions individuals make about disclosure. Most people preferred to reveal their HIV status to close family members. Most also mentioned the fear of being rejected and discriminated against as major reasons for not disclosing their test results to others.

**Keywords:** Africa; HIV/AIDS; HIV prevention; disclosure

### Introduction

The HIV epidemic escalated rapidly for two decades and now has been levelling off in some countries in Africa. In Tanzania, HIV infection spread rapidly before reaching a plateau, affecting people from all walks of life and decimating the most productive segment of the population. According to the Tanzania HIV/AIDS Indicator Survey carried out in 2007 by the National Bureau of Statistics (Tanzania Commission for AIDS 2008), 6% of Tanzanian adults aged 15–49 were infected with HIV (UNAIDS gives 5.6% for 2009). Findings by the survey included lower life expectancy, an increased dependency ratio, reduced productivity, increasing poverty, rising infant and child mortality and a growing number of orphans (TACAIDS, ZAC, NBS, OCGS, and Macro International 2008). Among the 21 regions of the country, the highest levels of HIV infection were found in the regions of Iringa (16%) followed by Dar es Salaam (9%) and Mbeya (9%) (TACAIDS, ZAC, NBS, OCGS, and Macro International 2008).

Increasing public use of voluntary counselling and testing (VCT) services has been a key mechanism for the prevention of HIV transmission. The ANGAZA network of VCT centres set up by the African Medical and Research Foundation (AMREF) has greatly expanded the number of VCT centres around the country in the past few years. The Tanzanian government, AMREF and other donors now provide more than 500 sites in the country where a person can obtain an HIV test along with counselling. The Ministry of Health and Social Welfare has introduced provider initiated HIV testing and counselling (PICT) and is also considering introducing routine testing in some health care facilities.

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There are basically five different forms of HIV counselling and testing found in Tanzania today. The first and most common is client initiated VCT, which takes place in most cases in stand-alone sites like the ones under ANGAZA that are run by AMREF. Then there are counselling and testing services that seek to prevent the transmission of HIV from mother to child through the testing of pregnant women in antenatal clinics. A more recent type of testing is known as PICT, an approach used in ordinary health care facilities where the health service provider can encourage a patient to take an HIV test if he has symptoms suggestive of HIV or AIDS. Then there is HIV testing carried out for medical research and surveillance purposes. Finally, in some contexts, HIV screening is mandatory.

### **Objectives**

The overall objective of this study was to understand peoples' experiences of revealing their HIV test results to others, to discover the patterns of disclosure (whether or not, to whom, how it was done, after how long) and to examine the role of social relations in facilitating disclosure. A better understanding of factors that facilitate disclosure of HIV test results can be useful to programmes that aim to promote it. We were particularly interested in the following questions: What are the factors that compel a person to take an HIV test? What factors affect the disclosure of HIV test results to others? Are those factors primarily individual characteristics that push an individual toward disclosure? To what extent are those factors aspects of the social relations maintained by individuals? Under what circumstances do people get tested? How do they decide to disclose or not disclose the test results to others? To whom do they disclose? How do they disclose? How long a time after the HIV test? How do those who receive the information react? What is the impact of disclosure on the infected person?

### **Issues in the study of disclosure**

The significance of this study stems from evidence that the disclosure of HIV test results is critical to HIV prevention, maintaining good health and continuing social relations, as supported by a variety of studies (see Nsabagasani and Yoder 2006). Disclosure is critical to HIV prevention for many reasons. First, disclosure to others allows the person to garner support for any preventive actions they may want to undertake. Individuals who keep HIV testing and results to themselves are on their own to protect themselves against HIV infection. Second, for those who test positive, disclosure to a spouse or regular partner is essential to prevent HIV transmission. Third, without disclosure, a person cannot easily access available social or medical services. While disclosure of test results does not guarantee access to social or medical services, without disclosure access to services is more difficult.

Disclosure may also help break the stigma surrounding the disease and have a positive effect on antiretroviral adherence (Skogmar et al. 2006). Disclosing one's HIV status may, however, also confer risks to the individual, particularly for women, as negative social effects such as rejection, discrimination and violence may follow (Gielen et al. 1997; Rothenberg and Paskey 1995). Parsons and his team have identified both negative and positive consequences of disclosing one's serostatus to sexual partners. Negative consequences include stigma, rejection by sexual partners and others, loss of intimacy and threats to personal wellbeing (Parsons et al. 2004; Paxton 2002). Positive benefits include increased social support and intimacy with partners, and a reaffirmation of one's sense of self (Parsons et al. 2004; Paxton 2002).

### *Disclosure as a social process*

The process of disclosure has been found to be quite complex to describe, measure and evaluate. Disclosure may be voluntary or involuntary, direct or indirect, full or not at all. Most studies have examined disclosure that is voluntary and direct, that is, situations in which an individual voluntarily tells someone else directly of his or her serostatus (Nsabagasani and Yoder 2006). Disclosing HIV test results is not an easy action; it is a complex and difficult personal matter that entails communication about a potentially life threatening, stigmatized and transmissible infection. These decisions sometimes change with time, an individual's experiences with HIV/AIDS, and they depend on the state of health of the individual.

Viewed in this light, disclosure is a social process that occurs over time with certain people and not others. As Cusick and Rhodes (1999) have pointed out, 'Disclosure is therefore best envisioned as a social process which is 'situated' within particular social relationships and contexts' (4). Thus the process may involve revelations to some people along with active concealment from others, including people known to gossip, those who will blame the individual or who may react violently (Nsabagasani and Yoder 2006). Therefore, in order to properly understand disclosure, we must consider the time elapsed since testing, the social relationship of the respondent to the persons told, the manner in which disclosure occurred and the identity of the people from whom the respondent wants to conceal the results.

### *Disclosure and social relationships*

Although studies have shown that disclosure is a process that occurs over time and that may involve family, friends and other relationships, describing and measuring the effect of social relations on disclosure and vice versa continues to challenge researchers. The important questions asked are: (1) How do social relations influence the process of disclosure? (2) How does disclosure itself affect social relationships? (3) How does disclosure affect sexual relationships? (4) How is it embedded in care relations?

Regarding the first question, many studies have shown that decisions to take an HIV test are often not made individually. Several different factors lead a person to make such a decision. In many cases, the social context within which one lives and the kind of social relations that one maintains facilitates taking an HIV test. People may discuss the decision to take an HIV test with people who are very close to them. Once tested, most HIV-positive or negative persons disclose their status to some but not all of their partners, friends and family. Disclosure or non-disclosure (including perceptions of benefits and costs) are linked with the type of close relationships that people have with significant others (Derlega et al. 2004).

Disclosure to significant others can help increase support for HIV-positive persons. Disclosure can also lead to support that facilitates initiation of, and adherence to, HIV treatment and medications (Klitzman et al. 2004; Stirrat et al. 2006). According to some studies, disclosure generally becomes easier the longer someone has been living with HIV, as she/he becomes more comfortable with their status. Disclosure to sexual partners is more likely in longer-term, romantic relationships than in casual relationships like one night stands, anonymous partners, group scenes etc. (Duru et al. 2006).

The relationship between disclosure, sexual risk behaviours and potential transmission of HIV varies widely. While on the one hand Parsons and his team (2003) argue that increased disclosure is indeed associated with a reduction in sexual risk behaviour, on the other hand Crepaz and Marks (2003) have shown that disclosure does not always alter risk

taking behaviours since, according to them, even with disclosure, unsafe sex sometimes occurs. Furthermore, some people engage in safer sex behaviours even without discussion of HIV status (Klitzman et al. 2007).

Disclosing an HIV-positive status sometimes does result in rejection, discrimination or violence. In some cases, disclosing to some persons can be more of a burden than a benefit. A study by Medley and Garcia-Moreno (2004) noted that barriers to disclosure identified by women included fear of accusations of infidelity, abandonment, discrimination and violence. Other studies have found that friends were disclosed to most often and perceived as more supportive than family members, and mothers and sisters were disclosed to more often than fathers and brothers, since they were perceived as more supportive (Kalichman et al. 2003).

A disclosure study carried out in Dar es Salaam by Antelman and colleagues (2001) assumes that the nature of social relations – evaluated through an examination of household composition and friendship networks, daily activities and a discussion of social ties and obligations – will affect an individual's ability to reveal test results. The methodological challenge in evaluating this assumption lies in the way in which evidence about social relations is collected and the ways evidence is assessed.

What we learn from the various studies of disclosure reviewed above is that a better understanding of the factors that facilitate disclosure could be useful for programmes that aim to promote it. Yet very little is known about the factors related to disclosure of HIV test results or the factors enabling individuals to discuss their results with others. Achieving a better understanding, however, presents many methodological challenges. Longitudinal studies are the most effective, provided they allow respondents to relate the circumstances surrounding their acts of disclosure, but they are time consuming and expensive.

## **Methods**

Several methodological challenges related to both sampling and data collection had to be addressed. First was how to obtain information about individuals' social relations, which inform decision making about their health. Second was how to ethically identify individuals who have used VCT services, given the importance of confidentiality and anonymity. And, third, how could we identify individuals who have been tested some months earlier and arrange an interview with them? In other words, what entry points were we to use?

The attention paid to social relations derived from the assumptions made by the study team. First, we assumed that the nature of social relations, evaluated through an examination of household composition and friendship networks, would affect their ability to reveal their HIV test results. Since each person has their own network of social relations, it was considered important to take into account their relationships as well as their individual characteristics when thinking about the potential for disclosure. The methodological challenge in evaluating this assumption lies in the way in which evidence about social relations is collected and how evidence is assessed.

This study used two methods to identify eligible respondents. First, the study contacted clients of testing facilities after they had completed their HIV testing and counselling and asked if they would be willing to discuss their experience and if they would agree to a second conversation a few weeks later in their home. In this way individuals were free to refuse and those who were willing talked to our research assistants after signing an informed consent form. This approach helped us to get our research subjects, which we

categorized as 'new cases'. Second, we visited associations of people living with HIV/AIDS and post-test clubs in order to recruit research subjects who had been living with HIV for some time and who may have already disclosed their HIV test results to others.

### *Data collection sites*

The study was carried out in Dar es Salaam and Iringa municipalities, the former representing urban residents and the latter semi-rural and semi-urban residents. In addition, at the time of research (2007), Dar es Salaam and Iringa ranked third and second, respectively, in terms of regional HIV prevalence. Eight VCT centres were identified (five in Dar es Salaam and three in Iringa) and were included in this study. The VCT centres included were those with the highest number of clients in both areas. Only one post-test club (SHIDEPHA+ in Iringa) was included in the study. In most cases, the interviews were conducted in VCT sites run and managed by Wamata, Angaza, PASADA and Masana Hospital. We also included one routine testing site located at Temeke District Hospital. All sites offered rapid HIV testing services.

We obtained 30 clean transcribed first and second interviews in Dar es Salaam: 10 males and 20 females. Most respondents were between the ages of 20 and 39. Of the 30 respondents, 11 (37%) were married, 9 (30%) were single and 7 (23%) were separated or divorced, 10 respondents (5 men and 5 women) lived with their spouses.

In Iringa, the study was carried out in three different sites: Iringa regional hospital, Alamano Health Centre, and Angaza (AMREF) VCT centre. In addition, interviews with people living with HIV/AIDS were conducted at the post-test club SHIDEPHA+. A total of 103 interviews were conducted in Iringa, 40 with individuals who had just received their HIV test results, 60 with people living with HIV/AIDS and 3 with counsellors. Since some individuals did not return for a second interview, and others dropped out, we ended up with 27 first and second interviews that were suitable for analysis. Of the respondents, 19 were married, 4 were divorced or separated and only 3 were single. For both sites, there were a total of 57 research subjects whose interviews were finally used for analysis and for writing the report.

We also interviewed a number of individuals in positions of authority and who were likely to be knowledgeable about HIV/AIDS, to discuss their experiences in talking to people about disclosure of HIV test results. The data collection in the field was carried out by nine research assistants who were already knowledgeable about HIV/AIDS and who had experience in working on similar research projects.

### *Data collection methods*

The instruments or conversation guides developed were loosely structured and open-ended so that the interviews would follow normal styles of conversation more than a question and answer sequence. Three conversation guides were developed to direct discussions with the three groups of respondents.

#### *Conversation guideline for respondents who had just taken an HIV test (new cases)*

This guideline was divided into two parts. The first interview, which took place at the VCT facility after the respondent had taken an HIV test, focused on social and demographic characteristics of the respondent. The second interview took place four to eight weeks later and the venue was either the home of the respondent or a neutral place. This interview

guideline focused on their overall impression of the VCT services, their views about pre- and post-test counselling, their experiences in talking to others about their HIV test results, activities engaged in to conceal their test results and how the people reacted who were told about their HIV status.

#### *Conversation guideline for people living with HIV/AIDS*

This conversation guide followed much of the guide used for recent testers. Another section focused more in-depth on the extended period of time living with HIV infection: the process of revealing their situation to others over time, particularly to a sexual partner; for those taking antiretrovirals, we asked about their experience of taking medication and the effect it had on their health. Finally, we invited them to talk about their participation in the activities of groups for people living with HIV/AIDS, the process of becoming a member, their activities, the advantage of membership and activities in the community to prevent HIV transmission.

#### *Conversation guideline for health workers, particularly VCT counsellors*

The conversation guide for counsellors encouraged them to talk about the reasons clients come for testing, the different kinds of clients they serve, the advice they give to those who test positive and those who test negative and the referral they give to those who are HIV-positive.

Data collection also included observations of interactions at health care facilities and households, a study of records and reports of client consultations at testing facilities and participation in meetings among VCT clients and members of people living with HIV/AIDS organizations. These observations proved valuable in establishing the context of interactions related to HIV/AIDS. Respondents were asked to sign an informed consent form as proof that they were participating in the study voluntarily. Prior to the collection of data in the field, the research protocol was submitted to and cleared by two ethical review boards.<sup>1</sup> We also secured research permits from regional authorities of Dar es Salaam and Iringa.

#### *Data processing and analysis*

Data analysis of the recorded interviews consisted of the following steps. First, the interviews were transcribed verbatim in Swahili. Second, the transcriptions were translated into English and typed in Microsoft Word. We then prepared a framework of analysis that had specific themes of particular importance for the study and summarised each interview according to this framework. Guided by these themes, we then prepared a profile of one or two pages for each respondent to provide an overview of their individual situation. We described and classified the respondents' different types of social relations in order to see how the types connected to disclosure practices.

We expected to find four types of respondents classified by their pattern of disclosure: (1) those who learned their HIV test results but told no one about them, (2) those who told only their sexual partner(s) and no one else (either spouse or a significant other), (3) those who told only an authority figure such as a doctor, a nurse, a counsellor or a pastor and, finally, (4) those who told family members and a few friends. Our overall goal was to understand the social interaction through which individuals keep information about HIV testing to themselves or shared it with someone else.

## Findings and discussion

The findings show how HIV testing and disclosure are social processes that need to be contextualised in order to be understood. We examine how the respondents decided to take an HIV test, the people they consulted before testing and their general experience of testing. We also examine the problems and challenges of HIV testing. Since we interviewed only individuals who had tested positive for HIV, the majority of individuals explained that they sought HIV testing because of health problems: they had been sick for some time or their spouse had passed away without a known cause of death.

### *Seeking an HIV test*

Respondents who had just taken an HIV test and those who had lived with HIV for some time were asked what had motivated them to get tested for HIV. Several reasons were mentioned. Poor health was the main reason given by both groups of respondents in deciding to test for HIV: 68% of people living with HIV/AIDS and 60% percent of new cases, respectively. The data also shows that 25% of people living with HIV/AIDS and 30% of new cases sought an HIV test not because they were in poor health, but because they just wanted to know their serostatus.

Many respondents who stated that they tested because of poor health mentioned different symptoms of chronic illness that compelled them to take an HIV test. The three main symptoms mentioned by people living with HIV/AIDS were fever (33%), cough associated with TB (26%) and abdominal pain (13%). The same symptoms ranked high for both men and women. Among new cases, the three main symptoms mentioned were fever (35%), chest pain (16%) and coughing (16%). Other symptoms mentioned by both people living with HIV/AIDS and new cases were mumps, headache, herpes zoster, diarrhoea, STIs, TB, swollen legs and rashes.

Some of the respondents stated other reasons compelling them to test for HIV, like simply being interested in knowing their serostatus. The response below from a male respondent named Asakwe, aged 47 years, illustrates the reasons mentioned by such respondents:<sup>2</sup>

At first, I had one wife, and when she died she bore a child, I married a second one. . . . The second one was constantly ill, suffering from diarrhoea. In the end I began to wonder . . . why was she ill frequently?! It became necessary that we both go to the hospital for further examination, and when we did; we were both found to be HIV-positive.

Analysis of our findings shows that other reasons respondents gave for testing ranged from having multiple sexual partners or suspecting their spouses or sexual partners of having multiple partners, to concern about unsafe blood transfusion. Some had spouses or sexual partners who had tested positive for HIV or had been advised to test by a doctor. Although most of these people were in good health, they felt compelled to take an HIV test because of concerns about what had happened to their sexual partners.

### *Social relations and getting tested*

Although our findings show that some people decided to take an HIV test without consulting others, some discussed the decision with family or friends. For example, about 26% of new cases reported that they had discussed it with their spouses; overall, most people discussed testing with a family member. Some respondents felt comfortable discussing their interest in taking an HIV test with people whom they thought shared a similar situation or fate.

In the course of these discussions relatives or friends provided a range of advice, including the importance of knowing one's serostatus. According to respondents, particularly women, some of the people with whom they had discussed their health problems had apparently advised them to take an HIV test and also accompanied them to a VCT facility.

### *Social relations and disclosure*

Disclosure of HIV status has been linked to acceptance of the HIV-positive diagnosis. In most cases some time will elapse from the time of testing to the time of sharing the outcome with other people. Several studies have shown that people who are sick are more likely to disclose their HIV status than people who are asymptomatic (Meursing 1999).

The interviews reveal that the social context of individuals and the nature of their social relations often facilitated testing for HIV. Respondents discussed the decision to take an HIV test and their result with some people and not others, for various reasons. The strength of social ties to family friends and acquaintances influenced disclosure patterns. In addition, the kinds of marital ties (single, married, separated or divorced) and sexual partnerships (monogamous, multiple, concurrent) that individuals maintained greatly affected disclosure. People generally discussed HIV tests and revealed the results to people with whom they shared a high level of trust. These are mainly relatives such as parents (especially a mother), a brother, sister, uncle, aunt and sometimes close friends. The findings reveal a close overlap between people with whom respondents discussed taking an HIV test and those to whom they disclosed their results.

If we consider only the identity of the persons to whom respondents told their HIV test results at a particular time, without taking into account the passage of time, we find that many respondents disclosed their results to their spouses (42%). Men were more likely to disclose test results to their spouses than women (55 versus 34%). Approximately 1 in 10 respondents disclosed to their mothers (12%), about 18% to sisters and about 19% to brothers. While there was no significant difference between men and women in terms of disclosing to sisters, more men than women tended to disclose to their brothers. Very close family members were the most likely to be involved in both decisions of getting tested and sharing of test results.

The findings obtained from new case respondents interviewed some four to eight weeks after testing were somewhat different from the responses of those who had been living with the virus for some time. In this latter group, more men disclosed to their spouses than women to their spouses (57 and 22%, respectively). About one third of the respondents disclosed to their mothers, but there was a slight difference by sex: 37% of women spoke to their mother, compared to 30% of men. The findings reveal a gender dimension in the patterns of disclosure in the longer as well as shorter term. More than half of the female respondents (56%) disclosed their test results to their sisters and only 11% to their brothers. On the other hand, about 33% of male respondents disclosed their results to their brothers and 24% to their sisters. Overall, about 32% of the respondents disclosed their results to their children. Female respondents were more likely to do so than males (44 versus 21%). Most respondents disclosed their results to a family member. Apart from blood relatives, married couples were inclined to discuss their results with their spouses, brothers and sisters-in-law, followed by uncles, aunts and friends.

Generally, respondents did not find it easy to discuss and disclose their results to fathers. This finding may reflect the fact that in Tanzanian society in general, children find it easier to discuss personal issues concerning their health with their mothers than with their fathers.

It also reflects the traditional position and role of women in Tanzanian society, where women act as caregivers in situations of health and sickness. Our findings show that women too were more likely to disclose their test results to their female relatives like mothers, aunts and sisters. The response below from a 46-year-old married man named Jonathan illustrates the motives and expectations for disclosing test results to specific persons:

I told my wife the same day that I got my test results because she supports and nurses me. Not telling her would have hurt her, but I told my brother after two days. He was surprised and asked where I got the disease from.

A 30-year-old married woman named Nesia, from Iringa, responded by saying:

I told my mother and my sister the same day of getting my test results. My young sister who is also positive accompanied me to the hospital where I had to take a test. I told them because they are the ones who care for me. You know, I have to eat well. I don't like my neighbours to know that I am positive; they will just point fingers at me and won't give me any help.

Since disclosure is a process that occurs over time, often over a long period, it may be useful to examine disclosure in terms of time elapsed since testing positive. Given its complexity, we anticipated finding differences in how, when and where disclosure occurred. The time elapsed is important, particularly for those who test positive, because they need to take measures to protect their sexual partner(s) from HIV infection and to bolster their own health. Table 1 provides a summary of the time that people living with HIV/AIDS took before disclosing their HIV test results to their significant others.

Table 1 shows that more than a quarter of the people living with HIV/AIDS disclosed their test results to others within a period of one month, about 18% disclosed between a period of one to six months, 5% between six months to one year and 4% after more than one year. Only 1 out of 32 respondents had not disclosed to anyone after more than one year had passed. Not all people who disclosed did so directly after learning their test results. Some time elapsed before any disclosure. Unfortunately, our study did not assess whether sexual activity continued between the time of discovering HIV status and the time of disclosing to the partner and, if so, whether condoms were used.

Further analysis of the data shows that an individual's social group, the social interactions in which they participate and the type of reaction and support they anticipate from others upon disclosure influence how different individuals decide to share the results of HIV tests with others. Marital status played an important role in individuals' decisions about the person with whom they discussed the decision to take an HIV test and also to whom results were disclosed.

Table 1. People living with HIV/AIDS by sex and time duration of disclosure.

Time from HIV testing to first disclosure	Sex				Total	
	Male		Female		N	%
	N	%	N	%		
Less than one month	7	24.3	9	33.3	16	28.1
One month to six months	4	13.3	6	22.2	10	17.5
Six month to twelve months	1	3.3	2	7.4	3	5.3
More than one year	2	6.7	0	0.0	2	3.5
No disclosure	1	3.3	0	0.0	1	1.8
Did not remember	15	50.0	10	37.0	25	43.9
Total	30	100.0	27	100.0	57	100.0

Women were much less likely to reveal the test results to their spouses than men: the majority of married men (55%) revealed their results to their wives, though only 34% of women disclosed their results to their husbands. Women tended to have someone else with whom they shared information about testing and results. For instance, most women had someone to accompany them when they went to take an HIV test, usually a close female relative such as a sister and/or mother.

Because of gender inequality in Tanzania, disclosure of HIV test results by a woman to a husband can potentially harm or destroy a relationship. Women have to think hard before disclosing their HIV-positive status to their husbands. Some are beaten, accused of infidelity or of bringing death into the family. Some are simply divorced and sent away. When asked about the reaction of her husband after revealing her results to him, Mwanahawa, a 30-year-old woman from Dar es Salaam, confirmed such a situation in the following way:

My husband was furious and blamed me of infidelity and he planned to call a meeting of relatives to tell them that I had brought a disease in the family.

Due to this fear of violence, some (though not all) female respondents indicated that they were reluctant to disclose their results to their husbands first. The understandable fears expressed by women stand in marked contrast to the situation of married men, who tend to disclose their test results to their wives first. The major reason given by men for disclosing to their spouse is the support they expected they will receive – especially when their health began to deteriorate.

One respondent, a 37-year-old married man called Hamisi, elaborated on his motives for disclosing the results of his HIV test to specific persons by saying:

I told my wife because she is my first aide. She is able to work and earn money. I told my brother as well, because he wanted to know what disturbs me, and he is very helpful. Moreover, there are some of my friends who know my status and they support us... other relatives know my status although they are not helpful.

The statement above shows the patterns and reasons for disclosing HIV results to specific persons, as opposed to just anyone. In addition to their spouse, men preferred to discuss and disclose their results to a close male relative, especially a brother, uncle or friend. One man even disclosed to his ten-cell leader, an important local political figure. If someone reports to a ten-cell leader, unless it is a close friend or relative the individual is seeking government support (particularly financial), which is distributed by such leaders at the community level. This could come in the form of tax exemptions, school fee waivers and help for their family to financially assist orphaned children.

We also noted from the 11 young and unmarried youth (3 young men and 8 young women) that the patterns of disclosure among this group differed from those who were married or divorced. Four individuals (two men and two women) disclosed their results to their mothers, two girls disclosed to their boyfriends and one young man disclosed to his girlfriend. In addition, one woman and one man also disclosed to their friends. One woman disclosed to a church leader in addition to her relatives. One young man did not disclose to his girlfriend because, he said, he feared that she might commit suicide. Three young women did not disclose to anybody at all due to their fear of being discriminated against. One 17-year-old girl disclosed neither to her relatives nor to her boyfriend because she was uncertain about their reaction. More probing into this revealed that the girls who did not disclose their positive results to their sexual partners felt that since they had been faithful in their relationships they therefore were not to blame for their HIV-positive status. In brief, very few single people disclose their results to their sexual partners.

One situation in which respondents actually felt comfortable disclosing their HIV results is to a friend or relative who is also HIV-positive. They feel at ease disclosing their test results to these people because they are in the same situation; they share a common fate and experience similar feelings and thus respondents believe that such people are very unlikely to stigmatize or discriminate against them.

Both women and men prefer disclosing their results to female relatives. A 29-year-old divorced woman from Iringa, named Amelye, had a sexual partner but chose not to share her results with him. Instead she shared her results with her mother and sister. She explained her reasoning in the following manner:

I told my sister and mother. They understood and promised to help me. I am divorced; otherwise, I could have told my husband. . . I don't want my neighbours to know because they will start talking to other people. I did not want to inform my sexual partner because he will be angry and might harm me. I know for sure that he will say that I have not been honest in our relationship.

Another respondent, a 40-year-old divorced man called Sitapakwe, elaborated on his experience of disclosure in the following way:

I told my sister first. I disclosed to her because she is a loving sister. I told my young sister as well because she has the same problem. . . . The advantage of disclosing to them is the moral and material support that they give me. They know my problem and I feel more close to them and it is easier for me to communicate with them.

These two examples simply confirm the fact that most people in this study preferred to disclose to their close relatives like mothers and siblings. They also confirm the earlier argument that good relationships and anticipated social and psychological support are among the prime factors that shape the dynamics of the disclosure process, particularly in terms of how and when to disclose and to whom.

## **Conclusion**

These results demonstrate how the process of disclosing HIV test results takes place in two regions of Tanzania. It is evident that the decision to disclose or conceal one's serostatus remains an intensely personal one. While there are many challenges involved in disclosing serostatus in Tanzania, disclosure rates are high.

Both men and women tend to evaluate keenly their relationships when deciding whether or not to disclose. Disclosure to some and not to others was determined by the nature and quality of the relationships. Most of the respondents who disclosed their test results did so to their spouse or blood relatives, most likely to a female. Most respondents disclosed to their family members because of their close and mutual relationship, as well as the social support they expected to gain. Married men disclosed their test results to their spouses. The majority of unmarried people disclosed the results to their parents and relatives, but not to their sexual partners.

These differences by sex can be attributed to the gender inequality that exists in Tanzania. Since men are powerful, they can disclose their HIV-positive status to their spouse without fear of rejection or violence. On the other hand, women are vulnerable to accusations of infidelity if they test positive and are blamed for bringing a deadly disease into the family. At the same time, it is the women who shoulder the responsibility of taking care of the sick and providing for all the necessary services they need at home. Therefore, people feel obliged to disclose their HIV-positive status to women because they anticipate support and care from them once they fall ill. What we learn here is that people do balance the benefits as well as the costs to themselves and their significant others when making decisions whether or not to disclose their HIV-positive test results.

The findings of this study help us to understand the social relations that surround and influence not only processes of counselling and testing for HIV, but also how people go about informing others of HIV test results. More specifically, this study reminds us that it is important to understand that individuals live in a social context that influences the way they perceive risk, the way they make decisions to take or not to take an HIV test and, finally, whether to disclose their test results to others. Understanding this reality can encourage counsellors to understand the individual circumstances of their clients and make sure that their counselling fits their needs.

With respect to future intervention, most of the unmarried respondents who were sexually active did not disclose their HIV results to their sexual partners. This presents a challenge for counsellors to persuade individuals to share their test results and engage in 'safe sex'. It is important therefore for all counselling interventions that promote disclosure to understand the social context of their clients as well as what the clients perceive as the possible consequences of disclosure. In counselling women, it is particularly important to address inequalities in power between men and women.

There is a need, too, to develop an efficient referral system so that clients who take an HIV test in facilities that do not offer care and treatment services can have access to such services for medical and social support. At the same time, efforts should be made to expand care and treatment services in VCT facilities. Finally, links should be created between clients and local support services so that continuous advice is available at community or household level to assist clients on how to communicate with their friends or families about their situation.

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1. The Institutional Review Board of Macro International in Calverton, Maryland, and the National Institute of Medical Research in Tanzania.
2. Respondents have been given pseudonyms to protect anonymity.

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## Résumé

Cette étude avait pour objectif d'examiner comment les personnes révèlent le résultat positif de leur test de dépistage du VIH aux autres, et en quoi les relations sociales influencent ce processus du dévoilement de la séropositivité au VIH. Les données ont été collectées au cours d'entretiens ouverts conduits en swahili avec des participant(e)s qui venaient d'être diagnostiqué(e)s séropositives pour le VIH, et d'autres qui vivaient avec le VIH à Dar-es-Salaam et dans les régions d'Iringa. L'analyse montre que les relations sociales ont une influence sur les décisions prises par les personnes en ce qui concerne le dévoilement de la séropositivité au VIH. La plupart de ces personnes préféraient révéler leur séropositivité au VIH à des membres de leur famille qui leur étaient proches. Elles ont également évoqué la peur d'être rejetées et de subir des discriminations comme motivations principales du non dévoilement aux autres du résultat de leur test de dépistage.

## **Resumen**

El objetivo de este estudio es comprender cómo las personas revelan a otros los resultados de sus pruebas de detección del VIH y cómo afectan las relaciones sociales en este proceso de divulgación. Se recogieron datos a través de entrevistas abiertas llevadas a cabo en swahili con informantes que acababan de hacerse la prueba del VIH y con personas seropositivas en las regiones de Dar es Salaam e Iringa. Los análisis indican que las relaciones sociales influyen en la decisión de cada persona de revelar su estado. La mayoría de las personas preferían revelar su condición de seropositivo a familiares cercanos. La mayoría de los participantes también mencionaron que uno de los principales motivos de no revelar a otras personas los resultados de las pruebas era su temor a ser rechazados y discriminados.