

Condemned, invisible and isolated

Stigma and support for people living with HIV in Khartoum

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Introduction

In 2001, and again in 2006, the UN committed to increasing the availability worldwide of HIV treatment, care, and support, with the concrete ambition of providing HIV treatment to everybody who needs it by 2010. However, the majority of people in developing countries do not know their HIV status, and do not access treatment even when it is freely available. Many refuse testing through fear – fear of HIV, and fear of the stigma surrounding not only those who test positive, but the act of seeking a test. Without widespread knowledge of HIV status, and without interventions to address stigma and the difficulties of living with HIV, the UN goals will never be met, and access to HIV prevention, treatment, care and support will remain the preserve of a small minority.

Nonetheless, stigma often seriously undermines many efforts to deal with HIV. While countries such as Senegal, Thailand and Uganda have all shown that open discussion of HIV can help to turn the epidemic around, the associations made between HIV and sex, drug use and other behaviours and practices deemed ‘immoral’ often leads to a reluctance amongst authorities – state, secular and religious – to address HIV in an open and non-judgemental way.

In February 2008, the HIV unit at Christian Aid, in collaboration with The Sudan National AIDS Programme (SNAP) and colleagues working on HIV in Khartoum, undertook a study to: 1: explore areas of concern for people with HIV; 2: identify issues of stigma, prejudice, and barriers to promoting better practices in treatment, care and support; 3: investigate; and social, economic and medical impacts of being HIV-positive in Khartoum.

Stigma is the most significant single barrier to effective work against HIV. The effects of being stigmatised as a result of HIV infection or association can be devastating. Too complex to list exhaustively, they include social rejection by friends, family and colleagues, and the psychological damage that comes with it, particularly at a vulnerable time after diagnosis, when empathy and respect are sorely needed; job loss or restriction of professional opportunities; a reluctance to seek health services, usually for fear of discovery, endangering health still further; a reluctance to be tested for HIV; and the sheer, grinding exhaustion of having to put up with the ignorance and discrimination of others.

In Sudan, and particularly in Khartoum, there is an urgent need for an action plan to address issues of stigma and discrimination. A number of simple interventions would start to make this possible: the widespread promotion of workplace HIV policies, public anti-stigma campaigns and the dissemination of accurate and comprehensive information; scaling up non-stigmatising, home-based care for people with HIV and their families.

Overview of the epidemic in Sudan

Sudan has the largest HIV epidemic in the Middle East and north African region, with unsafe sex between men and women the main driver. The adult HIV prevalence rate is estimated to be 1.6 per cent [0.8–2.7 per cent] in 2005³ and the estimation of the total number of people with HIV in Sudan is approximately 300,000–350,000.⁴ Sudan is in the early stages of a generalised HIV epidemic which has an almost exclusively heterosexual transmission pattern, but with indications of higher infection rates in the South than in the North. The results of sentinel surveillance conducted on a limited scale in 2004 and 2005 by SNAP reported prevalence rates of 0.95 per cent among pregnant women, 1.9 per cent among symptomatic sexually transmitted-disease (STD) patients, and 2.3 per cent among TB patients. Higher prevalence has been reported among the most-at-risk populations such as sex workers (4.4 per cent) and men-who-have-sex-with-men (9 per cent); as well as among clients attending the voluntary counselling and testing services (5–15 per cent).⁵

Despite the large number of people with HIV in Sudan, most do not know that they are infected, as uptake of testing is low and it is estimated that only 1.5 per cent of people with advanced HIV infection receive antiretroviral therapy.

Methods behind this report

This report is based on the results of an academic research initiative exploring the concerns of people living with HIV (PLHIV) in Khartoum. Using qualitative research approaches, including focus groups and in-depth interviews with PLHIV and service providers (including nurses, doctors and counsellors), the research was conducted in Arabic and attempts to quantify, to some extent, the social, economic and medical impact of being HIV-positive in Khartoum. Following focus group discussions with PLHIV, research was designed to focus on four key areas: stigmatisation within families, community, workplace and the health facility; the impact of stigma, psychosocial and economic; issues surrounding HIV care and treatment; and issues around HIV and AIDS policies and programmes.

Interviews were also carried out with the Khartoum representative and the sector coordinator of SNAP, four faith leaders, three representatives of civil society organisations, and four international NGOs working on HIV issues. Information published by SNAP, the Sudanese Ministry of Health, international NGOs and local organisations was also reviewed.

Sample studied

Thirty-eight PLHIV volunteered to participate in the interviews, 25 of whom were solicited through a Sudanese PLHIV care association and the remainder through their contacts.

Demographic data on gender, age, educational level, employment status and HIV-related data, including year of diagnosis and method of transmission, were collected via a standard form given to each participant prior to being interviewed. (See Annex 2 for graphs illustrating this.)

The sample included 21 males and 17 females, ranging from 21 to 52 years of age. Twenty-two per cent of the PLHIV in this sample were younger than 29, and 78 per cent were over 30. According to the Sudanese National Survey (2002) 85 per cent⁶ of PLHIV in the country are between 15 and 39. However, no participants under the age of 21 responded to the invitation to take part in the research. This may be related to issues of disclosure, vulnerability, and lack of community participation.

The majority of the people in the sample are receiving antiretroviral therapy (ART) funded by the Global Fund. Four were not receiving treatment: three of them because ART was not yet medically indicated, and one who had stopped treatment because of drug complications.

Though it was mentioned in the form given prior to being interviewed, it was not the intention of the research to pose the

question concerning method of transmission during the interview. Nevertheless, many interviewees wished to discuss how they became infected with HIV.

Limitations

Geographical limitations

All interviews took place in Khartoum. The majority stated that they came from Khartoum, and ten participants reported changing their place of residence because of their HIV status. As a result, the findings of this research relate particularly to Khartoum, where participants have been able to get health services since the time of diagnosis.

Sample limitations

Members of staff working with 15 service providers in Khartoum were interviewed, in order to obtain deeper understanding of the services provided for PLHIV and the experiences of health workers working in health facilities providing care for PLHIV. The majority of people were interviewed in their workplace, including voluntary counselling and testing (VCT) and counselling centres located in five different hospitals across Khartoum. One service provider was recruited from a church community self-help group. A formal letter was issued by the Ministry of Health, through SNAP, to facilitate interviews with service providers, including nurses, doctors and counsellors. Difficulty was encountered recruiting pharmacists despite rigorous efforts to engage them.

‘All of them [all of the family] are not accepting... They are not yet aware of the disease... they believe it can be transmitted by other ways... I mean by meetings... talking... and things like that... I don’t live with them anymore...’

PLHIV30, male, age 43

Stigma, discrimination, prejudice and HIV



Stigma, discrimination and prejudice reflect social disapproval and unfair treatment of an individual or group as a result of differences, such as in social group identity, race, sex, faith.⁷

Since the first diagnosis of AIDS in 1981, PLHIV have experienced a variety of forms of stigmatisation and discrimination, usually because of the moralistic association of HIV with behaviour – sexual and otherwise – considered undesirable or socially unacceptable, as well as with the potentially fatal consequences of the disease (now avoidable through treatment, but not always so). Stigmatisation and discrimination create hostile and intimidating environments. In Sudan, many people appear to retain outmoded concepts relating to HIV, in particular its mode of transmission, and these misconceptions lead to a blaming culture that attributes a sense of shame and disgrace to people with HIV. The majority of interviewees for this report had experienced direct stigmatisation and discrimination in a variety of settings, within families and local communities, from neighbours, in the workplace, and even while accessing health facilities. As a result, most interviewees suffered from constant anxiety, isolation and fear of discrimination.

The negative effects of such stigma impact not only on those infected, but also on society as a whole, causing people, particularly those within vulnerable groups, to be reluctant to undertake voluntary tests. In Sudan, this is creating and increasing an invisible population with HIV who are unable or unwilling to access treatment and care.

Forms of stigma

Stigma within families

A sense of social belonging, based on family and community ties, is a very strongly apparent characteristic of Sudanese culture, and the opinions, judgements, and attitudes of kin and social peers are exceptionally important.

When someone falls ill, families are usually the first and the main caregivers, providing care and moral and financial support for PLHIV. Family members with HIV seek support and acceptance, and look for compassion and empathy, from their families first.

'I told my family about the result, and that I'm HIV-positive... they treated me very well... They took care of me... they stood by my side and sympathised with me... there is no

problem.'

PLHIV18, female, age 48

Sadly, however, not all families respond positively. People with HIV often first encounter stigma and prejudice at home. More than two-thirds of PLHIV interviewed for this report have been discriminated against, stigmatised, condemned and isolated by close family members. Families frequently turn their backs on those diagnosed with HIV, as one participant describes:

'I'm stigmatised... I'm invisible now... my family abandoned me and left me here alone... I really... really don't know what to do... really... what crime I did? No body come and visit... they forgot I exist... My brothers always blame me... and they believe I'm bad... They said I've disgraced the entire family.'

PLHIV38, male, age 37

Wrong perceptions about HIV transmission and the fear of becoming infected increase the segregation, rejection and harassments which led many of the people interviewed in this study to cut off completely any contact with their families:

'All of them [all of the family] are not accepting... They are not yet aware of the disease... they believe it can be transmitted by other ways... I mean by meetings... talking... and things like that... I don't live with them anymore...'

PLHIV30, male, age 43

'My family knew that I have AIDS... their treatment is harsh... I left my family... there treatment is no good... speaking was limited... there was segregation regarding food and dishes... segregation with my glass of water... and laundry. When I do the washing, I wash alone... they look at me and think: this guy is ill... I left them'

PLHIV13, male, age 44

Self-stigma

Lack of knowledge and accurate information about HIV and its methods of transmission are not only of concern to families. Interviewees reported increased fear and apprehension of infecting family members at the early stages of discovering their HIV-positive status, and as a result many decided to seclude themselves from their siblings – and, in some cases, their children:

'At the beginning my attitude was of a person who has no feelings for life... at the start I isolated myself... Isolated myself from my children, they didn't understand why their mother doesn't want to touch them... I also isolated myself from the society. My brothers and sisters used to come, and they wanted to talk to me... sit and eat with me... I refused... I didn't want to... I didn't know at the time about the routes of transmission... I was scared to infect them.'

PLHIV25, female, age 37

Alongside that of becoming a 'financial burden', other shared concerns of interviewees – which in some cases forced them to change their place of residence – included the fear of becoming a 'social burden', and of disclosure in the community and its impact on their family. This was mainly a concern of many of our male participants:

'I don't have brothers... I have five sisters and my father is very old... I used to sit and eat... My family was OK... but psychologically I was not content... they feed me and they look at me sitting like that... So, I insisted to live in Khartoum... they want me and they want to help me... I told them I don't want money or anything... My problem is psychological. I can't say what's inside me. I don't want to cost them more than what they can afford.'

PLHIV14, male, age 36

'My sisters are engaged and I don't know if my brothers-in-law know about my status... I didn't visit my family for a long time... only through telephones... I don't have any relation with my brothers-in-law... and I prefer not to make any [contact] with them... They are not annoying themselves... but I'm annoyed by my [HIV-positive] status... I don't want it to affect their relation to my sisters or the family... so, I decided to remote myself [sic] from them.'

PLHIV1, male, age 37

The negative responses of and rejection by the families of PLHIV was supported and reinforced by 'faulty' religious and cultural beliefs about HIV. These beliefs have imposed moral judgements and assumptions on PLHIV by relating HIV to adultery, infidelity and 'immorality', as well as assuming that PLHIV are potentially dangerous – either because they could infect others, or because they set a poor 'moral' example. In addition, a lack of factual understanding – for example, about

the difference between HIV and AIDS – resulted in an inevitable association of PLHIV with illness and death:

'My brother-in-law told my family about my [HIV-positive] situation... now, nobody enters my house anymore... my brothers and my father, everybody. They don't visit me... we only talk through the phone... He [brother-in-law] told my family that I'm immoral... that my morals are bad... because AIDS [is] only transmitted through sexual intercourse and things like that... Well, all of them cut me off... they don't talk to me anymore... my sister too... and my cousin doesn't come to visit me because he thinks that PLHIV are harmful and they will infect us. He thinks that they are detrimental, will revenge... I wish they just understand the situation... '

PLHIV7, male, age 31

Stigma within families can also lead to serious negative behaviour towards people with HIV. Such behaviour includes abuse, isolation, and in more extreme instances such actions as denial of inheritance rights – as one participant explained:

'My relationship with my family is difficult; my brothers confiscated my ID, and denied my inheritance right... for them someone like me does not deserve to inherit... the illness has changed my life.'

PLHIV13, male, age 44

Whether because they know someone who has already been harassed, or through witnessing discrimination against and intolerance of PLHIV, or for fear of shocking and disgracing their families, some interviewees had chosen to conceal their HIV status from their families. Although this removed the burden of living under the pressure of stigma, it has a negative emotional impact, too – such PLHIV often feel alone, unsupported and hopeless. In some cases, interviewees had even considered suicide:

'I was very ill... my father said to me: "If your disease was AIDS, I will humiliate you!"... I'm infected, of course, I'm infected... but I can't tell him... I feel very guilty... and despair... I once tried to kill myself.'

PLHIV27, male, age 31

Stigma within the community

Evidence of lack of sympathy and resentment against PLHIV from different aspects of the community – friends and neighbours, in the workplace, and in faith-based groups – was reported consistently by participants. Social exclusion, condemnation and blame characterise the lives of PLHIV in Sudan, where HIV is seen as closely linked to ‘unwanted’ social groups. It seems more common in Khartoum to consider PLHIV as people with ‘bad morals’, rather than people with an illness.

The local community (neighbours and friends)

PLHIV and their families face isolation, insults and shaming; they are verbally abused, secluded from social events, and barred from rented accommodation. In some cases, their children are even refused schooling. In one example, a woman with HIV married to an HIV-negative husband, with eight healthy children, reported how she and her family suffered from continuous abuse from the surrounding community:

‘I appeared with my husband and kids in the newspaper. The very next day our landlord kicked us out to the street. My husband was sacked from his job... and my kids were denied school... the problem start growing... more and more problems appeared... and then I thought to myself, I will not stop talking, I will not infect anyone. I will go to the media.’

PLHIV25, female, age 37

Myths, misconceptions and irrational fear characterise much about attitudes towards HIV in Khartoum:

‘I once went to a wedding... when I sat down to eat with them from the same tray, people gazed at me... and then everybody left their hands up and some said: “We don’t want to eat with you...” I left the wedding, for fear to cause more embarrassment.’

PLHIV25, female, age 37

The Sudanese community is often not willing to talk about HIV, either through denial that it actually exists in Sudan, or because of the culture of secrecy that surrounds sex. Because of the unfortunate and incorrect moral judgements that surround it, people look at HIV as a problem of others, for others to deal with. As a result, when PLHIV try to use informal conversations or meetings to raise awareness in their communities and combat stigma, they are often shut out – even some cases suffering

physical abuse. This creates a lack of collective responsibility for challenging stigma. One male participant outlined several incidents in which PLHIV were subjected to violence or criticism whilst participating in awareness campaigns:

‘Neighbours... If they find out they will disgrace us! Once, some people went to a neighbourhood to raise awareness... the residents of the neighbourhood beat them up... they said to them: “Why are you bringing up such topics!?” [An implication of disgrace]... and before that one lady participated in an awareness lecture in a school... then the very next day they wrote in the local newspaper: “Why is she ruining our school’s reputation?”’

PLHIV1, male, age 37

Stigma and faith-based groups

Despite their potential to play a key role in breaking down stigmatising attitudes, faith-based groups in Khartoum are sometimes guilty of doing exactly the opposite. Several interviewees observed that much of the prejudice PLHIV encounter in Khartoum is instigated by faith groups or faith leaders who are homophobic and judgemental in their treatment of HIV. There was a sense among many participants that faith leaders, both Christian and Muslim, tend to associate HIV and AIDS with sin, promiscuity, immorality and adultery. Most felt that faith leaders were using HIV and AIDS as a hook for preaching against perceived moral corruption in the society, through condemning the disease as a ‘punishment from God’:

‘Faith leaders are using AIDS to combat adultery, and all religions refute adultery. So, to fight this thing they took on AIDS. They used it to scare girls... and parents... they thought when they scare people like this they will reduce adultery. Therefore, [adultery] is the idea on how [AIDS] become spread... and they don’t talk nicely about PLHIV. I remember I heard a recorded religious speech; he was talking about someone with AIDS that: “He was captured by the disease because he had a lover. So, when he became ill and in deathbed, his mother kept asking him to say Allah... but instead he kept saying his lover’s name till he was gone.” Well – that was a very long story. And I cried... No, not because it’s true... but because it’s fabricated to manipulate people that a patient with AIDS will not go to heaven... and they will die poorly.’

PLHIV14, male, age 36

A number of participants' accounts distinguished between the different approaches of leaders of different faiths, with many considering that Muslim leaders could be less tolerant to PLHIV than Christian leaders. Nevertheless, a large number of participants emphasised independently the opinion that if faith leaders from either religion were given sufficient knowledge about HIV and AIDS, they would then play a leading role in eradicating stigma around PLHIV, doing things such as disseminating information on protective measures like condom use. As one participant explained:

'Faith leaders have substantial role here... because our problem here, as Sudanese, many of us are illiterate... the problem lies in the untrained and uneducated human resources... you know, those whom you can't address with a scientific message... you can with a religious one, through mosques' and churches' messages. Faith leaders represent an important segment, and they can have a very good influence on people, especially on the issue of stigma.'

PLHIV1, male, age 37

However, the promotion of contraception and safe-sex principles may encounter resistance and rejection from faith leaders, who do not encourage condom use, considering it encourages sexual behaviour among young people. This can hinder the efforts of PLHIV to combat HIV, in some cases rendering them impossible.

'Faith leaders believe that AIDS is transmitted through sex only... and it only affects the homosexuals and those who work in sex. Even when we [PLHIV] talk about condom use to protect people and sex workers... they [faith leaders] do the opposite. And they say "This talk about condoms gives the chance for people to have sex anywhere anytime... therefore it is forbidden."'

PLHIV8, male, age 27

There is a need in Khartoum for consistent HIV training programmes and resources for faith leaders, and for awareness campaigns that encourage them to disseminate accurate information and positive messages about HIV and people with HIV.

'The unfortunate thing is that [faith leaders] say they work on HIV and AIDS but they say what they don't do... no

implementation in reality. I didn't see any of them do real work. Many NGOs spend money on faith leaders but without effective work. I mean when [a] faith leader is trained, they should sit with us, solve our problems... they have connections in the government and Al-Zakat committee, they can help HIV patients, but unfortunately I believe only one per cent of them did actual work. Even [a] speech about AIDS in the service comes only once a year on the AIDS international day... well, those who were trained are few, and in Sudan there are thousands of faith leaders... in just one area there are six to seven mosques. So, those who are not trained they usually ruin our reputation.'

PLHIV24, male, age 38

Sudanese faith leaders have recently endorsed a faith leaders' training curriculum and 'guidebook' to support PLHIV, which is based on tolerant faith messages intended to create more compassionate, stigma-free religious messages towards and about PLHIV. However, many of the interviewees, both PLHIV and faith leaders, did not know about this guidebook, and were doubtful of its potential to change the situation for PLHIV without intensive advocacy and widespread promotion.

'I don't think [a] faith leaders' guidebook will help... I don't know it exists actually. We were not part of the making process. But anyway, I hope it doesn't end as an "ink on paper" and [they] actually use it to train faith leaders on how to deal with HIV-positive people and stop stigmatising them... which I myself doubt will happen in the near future. I'm afraid they do the launch ceremony and go to hotel declaring this and that but without actually introducing it to the mass public in the mosques and churches it will not be useful.'

PLHIV38, male, age 37

Stigma in the workplace

Most interviewees had experienced various forms of stigma and discrimination in the workplace. These included loss of their jobs, harassment, being the subject of malicious gossip, and loss and denial of professional opportunities, such as being unable to find a job, or to get promoted.

Staff and employers in Khartoum have a high level of apprehension and concern about HIV. This may be due to

misconceptions about modes of HIV transmission, fear of contracting HIV at work, and a consequent fear of death; and it has resulted in discriminatory actions against PLHIV, such as firing, in some cases without notice. A 39-year-old secretary:

'I used to work in the university as the Dean[']s secretary. I used to issue transcripts along with the registrar... then I fell sick, and I stayed in the hospital a while, getting paid, till I

Church community and condom use – from an interview with a Christian faith leader

'Religious speeches in the church [are] usually empty of HIV/AIDS topic or about its danger. The reason for that is because the Church and government only started talking openly about HIV in the last two years. The government may be more open about HIV, and the Church only takes care of those infected through meetings and workshops. [We should] help people infected in order not to lose hope in life, through treating them as decent human beings. Through this guidebook we will be able to help them, but we need to study this guidebook first and see if it goes along with our Christian faith.

'We will not encourage condom use at all; therefore we need to make sure that its content goes along with the Christian faith... we want to reduce stigmatisation through this guidebook. It is not only faith leaders who are stigmatised...

it exists in any person. There is a fear [of] this person who's infected.

'Faith leaders should be the first ones to be trained to give hope to people. Those infected are an inseparable part of us. We shouldn't leave them, we should accept them, and bring them back to the society as a positive section, to live in the society – bearing in mind, though, the danger of their disease.

But if they want to get married we advise them... sometimes it's better to stop marriage if the other partner doesn't know, because it is not right. And sometimes it is difficult to accept to do the marriage, even if they both know their status, because it is forbidden to use condoms.'

Adultery and HIV – from an interview with a Muslim faith leader

'When we raise awareness in the mosque, we talk about

the seven sins. One of them is adultery. We alert people about the resentment of adultery by people, the community and all the prophets, and that they forbid adultery. And then we connect it to AIDS. It is one of the methods that transmit infectious diseases which end by death, and then they go to hell... the loss of now and after.

'We talk about facilitating marriages. When AIDS came first to Sudan [we] were utterly shocked by those infected and we didn't have any actual role. But through NGOs that made the concept clear, we saw our role as a humane one... So, we think of protection as the following:

1. To avoid adultery.
2. To increase the spirit and level of faith among young people and families to protect from AIDS.
3. Facilitate marriage and not to complicate the dowry and the procedure.
4. Condoms should be the doctor's responsibility. We do the spiritual teachings

and the technical part is the doctor's responsibility.

'There was stigma among faith leaders, but now it is changing... Religious institution[s] spread some thoughts about well-treatment of those infected. The person infected is a member of the society... there is not a Qu'ranic phrase that states revenge or retaliation [towards] someone who got infected with a serious illness... they should have mercy on them: "we are all sinners, but the best ones are those who sought after forgiveness!" And the punishment issues should be left to God. There is no person responsible to punish another.'

became healthy and went back to work. Then co-workers started gossiping that I "had certain infections," and they knew the truth that I'm carrying AIDS virus... and suddenly, while I was sitting by my computer, they gave me a letter, a "resignation letter"... "We discharge you from work"... I tried to appeal... in vain. They completely refused... they didn't tell me why... They were supposed to make a medical committee to investigate if I'm capable to work. They are still refusing. Now I work as a volunteer. I want to work, but I don't know where.'

PLHIV2, female, age 39

The demands of coping with treatment and the physical impact of being HIV-positive forced some participants to make the choice to leave work – a decision hastened by fear of discrimination and stigma. Such fear also presents others with the choice between leaving work and keeping their HIV status a secret. One female participant gave the reasons for which her husband made the choice to leave his job, though he was not forced to:

'He said "Everybody knows I'm infected..." Well, because of the disease you isolate yourself from the society, and sometimes the society isolates you. My husband does not have a desire to work or be seen at work. I guess he stigmatised himself.'

PLHIV11, female, age 28

Few participants have managed to hold on to their jobs (which were mostly in the private sector or the health sector). Some reported positive reaction and understanding from their bosses or co-workers, but others felt their status had created a discriminatory environment around them: for example, a highly trained 38-year-old nurse reported changes in her responsibilities and treatment from colleagues when they found out about her positive status.

'I'm suspended... they don't let me inject a needle because I'm HIV-positive. At the beginning I assumed they were afraid of me... that when I inject a needle it might drop and infect you. I didn't accept the situation. They transferred me to the reception area... I only circulate prescriptions – they told me that they worried about me to get ill, I mean opportunistic illnesses... but they don't even allow me to examine an HIV-positive patient. You have encountered any

people [HIV-positive] working in the medical field... nobody deprive[s] them from working in the medical field... I'm talking about myself here... I feel deprived. If you ask me to do a glucose drip, I will. Normal, I know the protective measures! They didn't sack me from work, but I'm not happy for being suspended... They didn't leave work in the ward. I want to stay there. I feel I'm discriminated against... our uniform is white, yet I sit downstairs [in the reception area] with logistics girls, they wear blue... I'm the only one wearing white and this is not my place.'

PLHIV15, female, age 38

Interviewees also reported gaps in the laws protecting their legal rights to employment. This was a particular concern of PLHIV who were dismissed and forced to leave highly paid jobs, either within state departments or abroad. Indeed, a number of participants were not only dismissed and even imprisoned as a result of their HIV status, but also were denied their rights and possessions in the country where they worked. One participant was detained for 17 days in a neighbouring country without charge. He had all his possessions confiscated, and was left without legal help:

'I was [working] in Jeddah, Saudi Arabia. We renew our work permit every two years; this includes a routine health check. I've been residing there since 1996. I decided to go on a holiday with my family in 2004. I went with my family to the airport, the guard said to me: "Let them travel and come along with me," then he took me to the airport's detention room, I was detained from 5.30 that afternoon till 1.30 after midnight. Then a policeman came and tied my hands to a chain and transferred me to a prison called Breeman. I was detained in an isolated room for 17 days without any charges. The guards didn't tell me anything. I was then deported, taken from the prison to the airplane restrained with handcuffs. I arrived in Sudan with nothing but my passport. I called my brother to pick me up from the airport. At that point, I still didn't have any idea about my situation and that I have AIDS. So, my brother told me that anyone who's HIV-positive or has hepatitis is usually deported. Therefore, I did the test and after seven days I discovered that I'm HIV-positive. I lost my work, my house, my car, my possessions and all my rights. I went to the foreigners' department here to solve my problem and get my rights back... they took my passport for two months and nothing

happened. The city council in Saudi Arabia took everything and threw them away. Everything is gone now, and I started from the scratch again.'

PLHIV7, male, age 41

Stigma in the media

Most participants had little time for recent Khartoum media reports and messages related to HIV, which they perceived to have done nothing but damage to their image. Media in Sudan, and sometimes even HIV advocacy bodies, have a tendency to use incorrect, fear-inducing messages including derogatory words or phrases such as 'AIDS victims' and 'the great danger'. This only results in the spread of panic and hysteria among the public about HIV, worsening stigmatisation of PLHIV.

The messages imply that immediate death or moral judgement awaits those infected or affected with HIV. An example was described by a 40-year old participant who expressed extreme anger and concern as a result of the language used in the media:

'I blame the media for our situation. It is not enough that I have to live with incurable disease, but also I have to be reminded that I'm a walking dead. I'm so annoyed by how the media talks about HIV/AIDS... when I flick through newspaper I see black bold coloured word "THE GREAT DANGER" or "Be aware of AIDS: the plague of the century." What do you think this will do to people? They will become even more scared and look at us as walking dead.'

PLHIV38, male, age 37

Moreover, media tends to be selective about what to publish or use in their efforts to combat HIV. In many cases, the information used in media campaigns, though to some extent factual, can be harmful and stigmatising when frequently used:

'Even SNAP uses this information that "Ninety-seven per cent of HIV/AIDS cases were infected through sexual intercourse..." They don't mention other forms of transmission, they only choose this one to educate the public. OK, sex is one of the routes to get infected but it is not the only one... [But] they have to stress on one thing: sex. This has increased stigma, I think.'

PLHIV38, male, age 37

Another example of a similar problem is to be found in the

posters and brochures in the headquarters of some NGOs, the Sudan National AIDS Control Programme headquarters, VCT centres, and – surprisingly – the Sudan National PLHIV care association. Though this material is, obviously, intended to educate people about HIV, it contributes obliquely to stereotyping PLHIV – and mainly young PLHIV – or their behaviour, using sensational images and linking certain conduct with HIV infection.

'With purity and marriage you will avoid AIDS!'

A poster by SNAP

'You might be the next victim, know your enemy and do not let ignorance kill you – AIDS.'

A poster by Rufaidaha, a local NGO

Service providers were also concerned about the quality of information given by the media, and the extent to which media indirectly deliver some pieces of information and veil others (such as the availability of treatment for HIV and the fact that PLHIV on medication can live normally). One service provider who was interviewed blamed the media for 'lacking' and 'misleading' information about HIV:

'Media messages are causing stigma... patients in the first session, they come here with preconceived ideas about the disease: that... if infected [they] will die... the only detail they know is that it's immunodeficiency... but [the] fact that if you become infected you can live is lacking... all patients believe HIV/AIDS is an extremely dangerous disease [that] has no treatment and that eventually [they] will die... so it takes really a long while to explain to them that they, in fact, will live. For example, yesterday I was with an HIV-positive patient [but] her husband still refuses to test. He is afraid of having a psychological shock. When she came at first, she was convinced and did the test, but her husband still not. What we hear about the disease is huge, that it's the "plague of the century," it is linked to bad moral behaviours, and it only infects certain groups in the society.'

SP9, female, age not available

Some participants believe that SNAP-led state media is in part to blame for inadvertently creating an atmosphere of shame around PLHIV in Khartoum, and that SNAP is itself being discriminatory in choosing to promote certain information while

dismissing other important and stigma-free facts. However, they also believe that this damage could be undone, should state media allow PLHIV to speak up, get involved, participate in the making of media messages, and take leading roles in advocacy campaigns:

'We have people here [who] are willing to appear on the media... but the state media does not give us a chance to appear [frequently]... they do one programme this year and then you wait till next year for another one... there is no follow-up. We did appear in the media satellite, abroad ones, not the state one. We want to appear in the state media to break the barriers stigma created, but we were not given the chance yet.'

PLHIV3, male, age 29

But there are some encouraging developments. More recent advocacy materials seem to demonstrate improvements in the wording of some messages, making them more empathetic to PLHIV. One example is a poster recently published by SNAP that encourages people to be friends with and support PLHIV. SNAP seems to have acknowledged this problem to an extent: a 'media messages' training resource is currently being designed, and will be introduced to media personnel to address issues of stigma in media messages.

Stigma and discrimination in healthcare

Stigma in non-HIV medical care

An alarming finding of this report was the fact that 53 per cent of PLHIV interviewed had experienced HIV-related discrimination by healthcare professionals, predominantly while receiving non-HIV-related medical care. Very few participants (13 per cent) reported having had no problems while seeking healthcare. Such problems were experienced repeatedly, in dental surgeries, clinics or hospitals, resulting from the stigmatising behaviour of surgeons, gynaecologists and nurses. PLHIV were withheld treatment or services in health facilities, left unattended by hospital staff, denied access to health facilities after disclosing their status, and – in some cases – were subjected to public disclosure, humiliation and unnecessary infection-prevention measures while undergoing treatment. Partly because of fear of such discrimination and being withheld access to healthcare facilities, 34 per cent of PLHIV decided to conceal their HIV

status while seeking medical care.

In general, women were more exposed to stigma and discrimination than men, particularly during childbirth. An example was given by a young woman in labour, who was refused access to the delivery room and made to give birth in the quarantine ward (a high risk-contagious area):

'I gave birth to my daughter in the seventh month of pregnancy. I went to the hospital with my husband and my sister... my husband told the staff that I'm HIV-positive... They immediately refused me and deprived me of the delivery room. I gave birth in a place called the quarantine... I delivered there because I'm living with HIV... One doctor finally attended... and he came wearing 12 gloves... I gave birth to a little baby [who] weighed 1kg. I wasn't given care. He just helped me with the delivery and left. I decided to leave the hospital immediately the very next day, because I had an open wound, and beside me, a tetanus patient. I was worried and left immediately! Even my daughter was not put in the incubator, although she was premature. She was deprived of care because I'm living with this disease. Her father searched the hospital for an incubator and was willing to pay for it. They refused and said 'we don't have any', although there were empty ones. I was terribly sad. My husband was conscious... I could have not told them and gave birth normally but we wanted them to be aware and careful... yet they refused.'

PLHIV5, female, age 24

In many cases, not only were PLHIV refused or denied medical treatment, but their close family members were also subject to the same treatment, even those who were not infected. This was particularly the case for the children of PLHIV.

'My daughter was six months old and she was ill. They gave me a file with my HIV status disclosed in order to stay with her in the hospital. She was given intravenous drips in her hand every six hours. I went to the bathroom when my little daughter took the IV drips off her hand... I was alarmed, she was very ill, I screamed to get the nurses [to] put a new one again... they all refused... although she is not infected they didn't want to do it. I didn't know what to do... I tried with everybody, and then decided to talk to the hospital manager, and he made one of the nurses to come forward and do the job.'

PLHIV5, female, age 24

Another patient had to face a doctor, who not only refused to treat her husband, but also removed the couple from his clinic:

'Once my husband broke his limb... so we went to the social services executive and she took us to an orthopaedist... he was having his lunch and he received and he was OK. Then when she told him that my husband was HIV-positive... he spat in our faces and kicked us out of his clinic. And told the social services lady: "As long as you are dealing with such people, don't you ever come back here again," and he also kicked her out! Such treatment puts you off [going to the hospital].'

PLHIV6, female, age 36

Many PLHIV experienced anxiety, sadness, uneasiness and lack of confidence while seeking non-HIV-related medical care. In such negative environments, openness appeared not to pay off, and many expressed regrets at having disclosed their status and attempted honesty in order to protect medical staff.

'I went to the orthodontist, I had a bad tooth. When he started filling my tooth I told him I'm HIV-positive... I told him that for him to take care. Then he said: "take your money and leave..." You see, you shouldn't disclose your status, you should keep your mouth shut... when they find out you are infected, they just refuse to treat you.'

PLHIV16, male, age 41

Such stigmatising attitudes are dangerous for all concerned. Many PLHIV have taken the decision to conceal their status when seeking medical care, as a result of having heard similar stories of PLHIV being discriminated against, denied adequate care, or refused services such as intravenous therapy and aid during childbirth.

'Anyone living [with HIV] goes to the dentist's, are kicked out... then they will go to another one and will not tell them, and s/he will treat them normally and this means that the one coming next will be infected... I, myself, when I go to the clinical laboratories... I don't tell them that I'm infected... because they will say: "Get out," and dismiss me. They are afraid, of course, so I prefer not to tell them. Although I didn't encounter stigma myself [in the health facility]... my friends have faced many situations.'

PLHIV21, male, age 52

Some medical staff, including doctors, nurses, and surgeons, expressed fear of contracting HIV because of lack of knowledge of transmission methods and lack of adequate HIV training. As one service provider commented:

'Service providers, in general, have [a] huge amount of stigma themselves... they have little information about the disease and its methods of transmission... This is why they treat PLHIV with a bit of carefulness or a lot of caution, which causes stigma and so [PLHIV] don't receive appropriate service. There are lots of problems... even with knowledge itself... although the disease has been here for a while now and it still here... it is not taught in the universities. I didn't know anything about the disease [until] I was trained through attending workshops.'

SP15, male, age not available

Misinformation was not the only factor contributing to stigma and discrimination at health facilities. Many service providers expressed concern about the scale of protection and health safety measures and standards that were inadequate. One service provider observed that many doctors would be happy to treat an HIV patient if the hospital guaranteed some level of protection while on duty:

'Doctors here in our hospital didn't refuse to treat PLHIV... but the surgeons have a problem with that... they see the hospital is not providing protection for them... they believe that they should [dress] and prepare [themselves] in a special manner. Well, the surgeon wants to protect her/him self... but other specialists they just don't accept AIDS patients. They don't work on [HIV patients] because they want to be protected by the hospital, asking for special [sterilised] outfits and special gloves... but these are not provided in the operation room. We did send one HIV patient, and they refused to undertake the surgery, they said: "Who will protect us ... or compensate us if we get infected?"'

SP11, female, age not given

According to many interviewees, health and safety measures were only implemented in a number of hospitals after being requested by the patient. There did not seem to be a general health and safety protocol which was known and routinely followed by medical and health personnel or management to adopt best practice 'universal precautions'. Many PLHIV

mentioned that they had had to remind health attendants to be careful and apply safety measures, and consequently were left without attendance after disclosing their status:

'I had a cut in my hand, so I went to the emergency... they were supposed to seal the wound, but I told the doctor to wear gloves... and he asked me: "why?" I told him I'm HIV-positive... he said: "are you sure?" Then he said to me, "wait here, I'll be back shortly"... he left me bleeding and never came back... he refused to treat me. I bandaged myself and left.'

PLHIV8, male, age 27

Health and safety measures – universal precautions – should be taken, regardless of the patient's condition. However many PLHIV reported that medical personnel only adopted full precautions with HIV-positive cases – something backed up by a number of service providers.

'One of our PLHIV patients wanted to go to the dentist, so I went with him and the dentist said to me, "He should pay money." I asked him why? [The service should be for free]. He replied: "Because in his case we will have to bring new equipments and throw them away." I told him: "You know this guy is infected, but do you know if those you are treating everyday are or are not infected? So, I can't trust you anymore!" Then my HIV patient felt offended and went to see another doctor.'

SP9, female, age not given

Implementing safety measures solely for PLHIV that are not generally perceived as routine procedure could under certain circumstances amount to involuntary disclosure, or at least stigma-inducing behaviour.

'Wearing gloves... doctors here in Sudan don't usually wear gloves. It is perceived that if the doctor wears gloves it means that there is something really, really wrong.'

SP8, female, age not given

Stigma in the HIV clinic

After facing problems getting medical care elsewhere, many interviewees living with HIV showed increased levels of contentment about being able to use the HIV clinic. Indeed, most of them expressed feelings of trust and comfort seeking

care at the HIV clinic, and came to depend on counsellors for help and moral support.

'AIDS patients can't bear [the] hospital mood... and... prefer not to tell that they are AIDS patients... It is better like this. We do have in our association a volunteer doctor, or we go to the HIV clinic doctor. And if there is a medical problem not in his domain, they refer us to the hospital. Doctors there refuse to deal with us... I prefer not to go to the non-HIV medical clinic unless necessary... and most often I prefer to go to the HIV clinic to avoid stigmatised doctors and nurses.'

PLHIV3, female, age 36

There were a few problems, however, related to stigma reported by a small number of participants at the VCT centres. It is worth noting that participants drew a distinction between doctors at the HIV clinic and counsellors. Most thought that counsellors were far less stigmatised and had more experience dealing with PLHIV than doctors. (For more information on this, see also the section on quality of care.)

'There are doctors at the counselling section... when a patient went to the doctor... the doctor didn't speak to him or shake hands with him... The doctor carried a paper in front of her mouth... The doctor was scared of him... she didn't accept him... she covered her mouth... I felt that this person is new here... So, I went to the counsellors and told them what's just happened... I asked them: "Why are they [the clinic doctors] like that?" The counsellors replied: "Well – she is new here and she does not know... she is here under training... she is new."

PLHIV4, male, age 38

Despite the good feedback participants generally gave about counsellors, describing them as supportive and informative, a few had encountered problems with them, mainly on issues related to marriage and having children. Some participants reported that a few counsellors showed reservations about PLHIV getting married or having children, and there were a number of reported breaches of client confidentiality. An example was given by a 32-year-old female living with HIV:

'The counsellor kept telling me "Don't marry that guy... he had a previous relationship and she was pregnant and he denied it..." he should not say things like that... these are

people's secrets... counsellors should not interfere. He said to me: "Don't get married." He added: "You might have a relationship and then it fails." I replied: "Well – I might be in a relationship that will succeed... this gives me hope in life."

PLHIV23, female, age 32

'I wanted to kill myself... drink something... or burn myself. I lost hope in life... because the patient's situation is difficult... his health is finished... my family don't treat me well... our relation has changed... My brother does not treat me well... he keeps yelling at me and beat[s] me all the time... he beats me and say[s]: "You married this guy and brought the disease and scandal to the family... you did this and that".'

PLHIV17, female, age 32

The impact of stigma



Psychosocial impact

Many PLHIV interviewees reported having had various psychological problems since their HIV diagnoses. These included lack of confidence, anxieties, guilt, shame, fear, social and emotional withdrawal, reduced self-esteem and depression. The psychological despair that PLHIV experience is mainly caused by negative responses from families, friends and communities. Many PLHIV reported facing similar psychological problems while trying to tackle stigma at work, dealing with pressures from families and friends, making informed health decisions, coping with illness, feeling weak, and being denied legal rights and support.

'I feel extreme anxieties, especially recently... sometimes I feel depressed... my depression is due to my situation as a person living with HIV... and because we live with HIV we can't demand our legal rights, particularly in case of job loss... I guess if I was not living with HIV I would have gone back to work... I know it's my right to go back to work... this is what makes me feel depressed: knowing that the road is closed in front of me.'

PLHIV1, male, age 37

A number of PLHIV – mainly younger participants and women – were self-stigmatising to the point where they considered suicide as a result of familial and social pressure and lack of knowledge about HIV. These were issues compounded by ignorance. Many PLHIV thought that HIV was untreatable and could only result in death – and that there was no point in waiting.

'When neighbours knew [that I was HIV-positive]... they started gossiping, [saying] that this guy got the disease through immoral ways... and inhuman ways... they stopped visiting... even my friends stopped talking to me... and when they see me in the street they change their way... So, [I] became psychologically worse... and I thought of suicide... I wanted to kill myself.'

PLHIV8, male, age 27

Receiving psychological support at the voluntary counselling and testing (VCT) centre is not sufficient to boost PLHIV confidence on its own. There is also a need for psychosocial support from families and communities. Many participants who

thought of suicide were dissuaded by counsellors, but still felt socially unaccepted, and as a result left their homes or changed their places of residence.

'The counsellor calmed me down... I wanted to kill myself in order not to ruin my family's reputation... but then I decided to talk about it and face it... My family, however, [were] still not accepting, they still believe that I'm a bad person... so I left home... When I'm at home I experience psychological pressure... I decided to live in the [PLHIV care association] instead.'

PLHIV8, male, age 27

In other cases, fear of discrimination and stigmatisation resulted in PLHIV moving from rural areas to urban areas, where they are less known. Such a strategy is risky, though, and can result in further alienation, self-stigmatisation, reluctance to disclose their status in a new environment (especially where previous experiences of disclosure have been negative), and reluctance to seek adequate health services.

Services and facilities for PLHIV do exist in Khartoum, though, and many participants have accepted their HIV status over time. Emotional adjustment – as described by most PLHIV who were interviewed – was achieved through counselling, training, and – most importantly – the discovery and use of free-of-charge treatment. This emotional adjustment was identified by most participants as 'positive living'. Many PLHIV in this research have shown hope and optimism about surviving HIV by overcoming social barriers and stigma, through training and participation in Sudan's awareness movement.

Gender, HIV and stigma

Women participants in the interviews displayed a greater tendency to emotional vulnerability, dependence on others, and self-stigmatisation. Many female participants reported anxiety, as a result of fear of disclosure, and uncertainties about the future – something especially concerning for those with children.

Women, as well as being more vulnerable than men to infection with HIV, are harder hit by the social and economic consequences of being HIV-positive, because they tend to be in positions of lesser power. In particular, because of the greater vulnerability of women to various forms of abuse –

including physical – HIV puts them at greater risk. For example, one interviewee reported violence at the hands of her brother on disclosure.

'I wanted to kill myself... drink something... or burn myself. I lost hope in life... because the patient's situation is difficult... his health is finished... my family don't treat me well... our relation[ship] has changed... My brother does not treat me well... he keeps yelling at me and beat[s] me all the time... he beats me and say[s]: "You married this guy and brought the disease and scandal to the family... you did this and that."

PLHIV17, female, age 32

Although not asked in the interviews, most married female PLHIV volunteered the information that they were infected through their husbands – in an apparent attempt to avoid expected blame or moral judgement. Many described themselves as 'victims'.

Furthermore, many married male participants expressed continuous feelings of guilt and responsibility for infecting their wives. In several cases, this had resulted in complete transformation of the relationship, with the men becoming more respectful to their wives for tolerating them, accepting the new situation, and eventually remaining in the marriage.

'In Sudan the society is reluctant to the thought that my wife is working and I'm not. I myself not ashamed of that, my wife have been spending on the family for a long time now... Well, before becoming infected I used to be against her working... But as a result of this unusual condition that we've been through, we should then change!'

PLHIV1, male, age 37

Acceptance and tolerance for many married female participants was not a choice, but more of a coping mechanism and safety net against social norms that indirectly tolerate and justify men's behaviour. For these women, remaining in the marriage, despite being infected by unfaithful spouses, could move social blame away from them and on to their husbands.

Men in this study were less likely to receive the same amount of blame as women for being HIV-positive, because while Sudanese society might justify and indirectly accept men having extramarital or pre-marital sex, it would not tolerate women doing so. A great difference in accepted gender roles

and responsibilities means that women experience greater social pressure as a result of being HIV-positive.

'For [HIV-positive] women, the society is convinced that they had different partners... there is more pressure on women, the society finds justification for men that they had different relations and so on... They justify it for men more than women... Women are usually scared to know the result... and they always consider the possibility [they were infected by] their husband... but if the husband is negative and the wife is positive, this is where we face a problem... he become[s] doubtful... we hope with awareness these things will change.'

SP11, female, age not given

Economic impact

Although HIV treatment is freely available to all in Sudan, being unemployed was of particular concern to all interviewees, as it affects their ability to respond to other needs, such as access to treatment, whether HIV-related (eg, opportunistic infections, access to health facilities) or non-HIV-related (eg, transportation, availability of adequate nutrition).

'I'm in a good health now... and I'm capable of living with the virus but the general situation is difficult... I mean I can work but there is not work... no one is willing to employ me because of the virus... I suffer, how am I going to provide for the daily requirements... treatment, transportation, and food expenses... this is now a problem caused by living with this virus.'

PLHIV16, male, age 41

Unemployment and other related problems mean that many PLHIV in this study have no sustainable source of income, and are therefore unable to meet basic daily requirements, or to get the services they need to cope with their treatment. Because their infection prevents them from earning a living, forces resignation or limits career options, a number of participants working abroad had to leave their country of employment and return to Sudan jobless – a situation that suggests a gap in the existing policies that protect the human rights of PLHIV.

'The state and politicians don't sympathise with us, there is a

huge inadequacy... those who were sacked from their jobs were not given their rights back... they don't give us a way or an opportunity to work...'

PLHIV10, female, age 34

Voluntary testing

Fear of discrimination and stigma may discourage people from disclosing information, including results of HIV tests. A more widespread culture of shame indirectly reduces voluntary testing, which may result in an invisible HIV-positive population who do not get the treatment or adequate information they need, increasing the risk of them inadvertently transmitting HIV to their sexual partners. Stigma can cause some voluntary testing programmes to fail.

'There is some improvement [in the media messages] now... but still we need more awareness [that the number of] people who come to undertake the voluntary test is really low... they are afraid of stigma.'

SP11, female, age not given

'A while ago we had expired ARTs... doctors allowed us to take it... no problem... as they said it can be effective up till six months after the expiry date... I started on ARTs with the expired ones... I didn't care... I wanted my health to be better... my only concern was health.'

PLHIV2, female, age 39

HIV care and treatment



In Sudan, HIV testing and counselling services are provided through VCT centres based in healthcare facilities (hospitals, primary healthcare centres and family planning clinics) most of which are in the north of Sudan. A few VCT centres have been established elsewhere, in venues such as universities and youth centres. There are around 56 VCT centres in north Sudan, half of which are in Khartoum.

As described by participants, antiretroviral therapy (ART) – both first- and second-line regimens – is prescribed on a monthly basis by doctors in the VCT centres and obtained from the pharmacies that are also based in these centres. HIV services, including VCT, ART and care for people both infected and affected by HIV, are provided free of charge in the public sector in Sudan. Provision of these services is coordinated through the Sudan National AIDS Control Programme and funded by the Global Fund for AIDS, TB and Malaria.⁸

All participants in this research were registered in the five VCT centres visited: Bashaier, Omdurman, Police, Military and Bahri hospitals. Thirty-four of the PLHIV interviewed were on ART; only four were not, either because their immune systems had not reached the advanced stages of HIV infection (three cases), or because they had stopped treatment abruptly as a result of complications and drug resistance (one case).

Treatment literacy, or the lack thereof, can have an effect not only on treatment adherence (and consequently effectiveness), but also on perceptions of health, and consequently on morbidity. Two of the interviewees not on ART expressed concern about their overall health, worried by the fact that they were not receiving treatment while they observed HIV-positive friends taking ART. One participant felt that by not receiving medication, he was not 'equipped' with the necessary 'weapons' to fight the virus in his blood.

'My health, in general, makes me wonder is the CD4 cell count really high? When I'm with my best friend sitting down watching TV, he has an alarm to remind him to take the pill, when he goes to take it... this particularly makes me feel, I mean his routine taking the pill in front of me, I feel that this medicine is doing something to HIV... I don't have this. At the end it's a battle in our blood between the virus and us. We are supposed to have weapons and I believe that this treatment is one of these weapons. And when my friend takes the treatment I don't feel that I'm doing anything to [fight] this virus.'

PLHIV1, male, age 37

PLHIV receiving no ART have sought other kinds of treatment, such as traditional medicine and participation in sport, to make them feel better about their overall health. The act of simply doing something about HIV can have a greatly beneficial effect on the perceived health of the patient.

'I use other elements [as weapons]... positive living kind of things, such as good dieting, sport and things like that... sometimes I take traditional medicine, under pressure from my wife, nothing I had was not logical anyway... she had something that I used. I felt its strong and immediate effect.'

PLHIV1, male, age 37

While most participants reported high levels of satisfaction with treatment supplies, key findings of this research suggested that issues of medical logistics were hindering the HIV response in Sudan. Issues included:

- problems and uncertainties with supplies of HIV monitoring tests (CD4 cell count and PCR tests)
- problems with procurement of drugs for opportunistic infections
- difficulties accessing information
- ART side effects
- high staff turnover, particularly with HIV clinic doctors.

HIV treatment and side effects

Interviewees reported no problems with ART supplies. A number of participants, however, expressed concerns about treatment side effects, and there was an incident in 2004 where there was a surplus of expired ART and a lack of in-date medication, and for a period PLHIV received ART that had exceeded their expiry date as a temporary solution to the supply problem. Doctors and pharmacists convinced the PLHIV (rightly) that it was reasonable to take these drugs for a period after the expiry date, and patients agreed on the basis that it is better to receive drugs than not to receive them at all (this is an issue of some wider concern, as this is accepted practice in Sudan and other settings, but – depending on the drug in question and storage facilities available – is not always advisable). This situation occurred prior to the Global Fund programme for ART provision.

'A while ago we had expired ARTs... doctors allowed us to take it... no problem... as they said it can be effective up till

six months after the expiry date... I started on ARTs with the expired ones... I didn't care... I wanted my health to be better... my only concern was health.'

PLHIV2, female, age 39

The importance of treatment literacy was, however, underlined by the fact participants received conflicting information on the safe period for drug consumption after the expiry date. In addition, some reported suffering from side effects that they attributed to using the expired drugs, despite the fact that there is no scientific reason why increased levels of adverse effects would be seen with recently expired ART, but misunderstandings about the safety and efficacy of using recently expired drugs could result in a greater level of perceived side effects.

'We used it because we are allowed for two months after the expiry date... so I used it for one month and when we went back we found the same [expired] drug. They said: "It can be used maybe after three months," [past the expiry date] so when we used again we suffered from side effects, diarrhoea, weight loss... Most people who used it were very sick... but then a new drug arrived.'

PLHIV4, male, age 38

Adverse effects associated with ART are a serious concern, however, and were a general concern, not one reported solely in relation to receiving expired ART. Many participants reported different adverse effects, including numbness, headaches, kidney problems, dehydration, stomach ulcers, and diabetes. A few changed their treatment, and others sought medication to treat the side effects. One participant continued to suffer side effects, despite changing his HIV medication dose, and expressed concern about the clarity of information given to him regarding their impact on his health.

'Currently I suffer from HIV medication. I have numbness... there is no clarity in the information given... they gave me vitamins and changed my medication dose... I'm on Trimon40, [then] I'm back to Trimon30... However, the side effects are still the same... there is numbness in my feet and I can't walk barefoot. I explained my situation to the doctor... sometimes he gives me vitamins... then he gives me medicine for numbness... I don't understand.'

PLHIV7, male, age 41

HIV-monitoring tests

HIV-monitoring tests are used to establish treatment regimes and analyse the patients' prognoses. In Sudan, they are of two types: CD4 cell count tests and PCR tests. A CD4 cell count test measures the number of T-cells (a type of immune system cell) per cubic millimetre of blood; a PCR test indicates a patient's viral load – the amount of HIV virus in a given volume of blood.

Shortages, disruptions and problems in HIV-monitoring tests (CD4 cell count and PCR) were a key concern of PLHIV in this research.

Problems identified in a number of accounts included:

- frequently disrupted availability of a CD4 cell count machine
- availability of only two CD4 cell count machines in public sector health facilities in Khartoum
- shortages in CD4 reagents/kits
- unreliability of CD4 test results.

Despite being under treatment, many PLHIV felt vulnerable and uncertain about their overall health. Many were anxious, tired and depressed as a result of not being able to undertake HIV-monitoring tests at what they thought to be the correct allocated intervals (monitoring guidelines in Sudan suggest ideally every six months, although in some circumstances it is acceptable to monitor a patient on ART without using CD4 or viral load measurements. Clinical monitoring (eg, weight and general health indicators) can be adequate. However it is important to explain to someone receiving ART how their treatment will be monitored so that they are not unduly concerned if they do not receive six-monthly CD4 measurements.

'It is supposed to be every six months... hospitals are bad... I mean when you call them they tell you "The machines are broken"... what are you supposed to do? You feel high-spirited and then at the same time it goes down... you go there for a hope... it is like going upstairs and someone is pushing you down... your attitude becomes bad... this is [a] problem for many patients.'

PLHIV13, male, age 44

Service providers also reported problems in decision-making about assessing patients' overall health and treatment

procurement because of lack or failure of HIV-monitoring tests. In these instances they were obliged to base decisions on less reliable indicators, including general health markers such as body weight.

'This is our problem here in Khartoum. We only have two CD4 machines, one in Omdurman hospital and the other Bashaier hospital. Every patient goes to do CD4 test[s] depending on their residence proximity... They face problems that the machine is broken... So, the alternative that we give is assessing overall general health... weight measure... weight gain means that they are responding very well to the treatment.'

SP9, female, age not given

This issue is exacerbated by patients' lack of understanding of the role of ART-monitoring tests, as well as the pressure imposed on testing machines by a very large number of patients testing in one or two laboratories in the public sector. As a result, many patients resort to the private sector on the assumption that they will be able to get a more 'trustworthy' test; or they fail to perform any test at all.

'All Sudan's [HIV-monitoring tests are] in one or two labs every six months... sometimes CD4 test is not convincing... they give a very disappointing result... for example your immunity is 20 while at the same time when you go outside [private labs] and make a test with your money ... you will find a huge difference between the result written in the hospital... I don't trust CD4 tests... I don't do CD4 cell count test... I live like this and it's enough.'

PLHIV24, male, age 38

For those who cannot afford to get private-sector testing, some PLHIV thought that assessing their overall health can be down entirely to guesswork.

'Every six months, when I go for the test, I find the machine out of order... I did not perform a CD4 test for one year now... every time I go for a check the machine is broken... I know that my immunity is good... When I feel that I'm good then my immunity is excellent... it's guesswork. I can't afford to test CD4 outside [in private labs].'

PLHIV3, male, age 29

Quality of care

Provision of high-quality care is an important element in enhancing satisfaction and incentives among people with HIV, and among service providers.

According to the accounts of many of the interviewees, the quality of care provided – including access to HIV-related information, availability of specialised and trained staff, patient confidentiality and proficiency of services and advice – were of concern. Many reported dissatisfaction at high staff turnover in the health sector and burnout in HIV clinics, mainly on the part of doctors. They also expressed their concern at the lack of specialised and well-trained HIV-doctors in HIV clinics and counselling centres.

'One month you go to HIV clinic you find one [doctor]... the next you find another one... and sometimes this doctor has attitude towards the person [patient]... you go to them, they don't understand you... and you can't talk clearly about things. I'm not comfortable.'

PLHIV37, female, age 34

Sudanese doctors are assigned to HIV clinics as part of their national service. According to the interviewees they usually stay two to six months, then leave. Although they have the choice to stay and settle in the HIV field, many decide not to, because they are not motivated to do so, receive insufficient training, and are not given opportunities to develop their skills. According to the interviewees, hospitals had no clear recruitment policy to appoint specialised HIV doctors, and facilities tend to rely on trainee doctors, who have no choice but to work there, to staff their HIV clinics.

'Doctors come one month and then leave... This is a huge problem... when the patient come[s] to take his/her medication... you know they [are] used to someone... then they come to me complaining: "When I find a new doctor, I had to go over my situation again and from the beginning... this is so exhausting"... I think these doctors have no interest in the field [of HIV] work... they work here to finish their national service, and then leave... [doctors in the HIV clinics] change every three to four months... they don't chose to work here...'

SP4, female, age not given

Doctors with inadequate training and experience can create a burden on other service providers, particularly counsellors, who are more experienced and better-trained.

'And the problem [with new doctors] is [the lack of an] AIDS training scheme... when [doctors] have a question they rely on counsellors or the manager of the unit... it is not the pressure... I mean this doctor, when I as a "patient" ask them [a question] and they don't know [the answer], it knocks my confidence down... when you are with the doctors and ask them a question and they tell you to wait a minute to consult another doctor... This will knock your confidence down... Right! You will have doubts about their knowledge and you will think they prescribe the wrong medication to you...'

SP4, female, age not given

A number of participants reported that doctors had made many mistakes, including writing wrong prescriptions for ART.

'Every time they bring new students... trainees to train on us... they change a lot, and sometimes they don't write the right prescription... and they don't ask you anything! Even if you suffer from a weight loss... they don't ask about the reasons... There is great neglect... I judge them that they are not well trained from the prescription and their treatment... once they gave a medication and I was convinced it was not the right one... I had severe diarrhoea... they prescribed a medicine for numbness instead. I was convinced then they are not qualified.'

PLHIV8, male, age 27

As a result of staff turnover and perceived lack of competence, many PLHIV lost trust and confidence in doctors, and felt embarrassed at repeatedly having to explain their medical histories to new ones.

'Continuous change, continuous... it is not a healthy phenomenon. We lose confidence when we go to the clinic and find a new one... Continuous doctors' turnovers is not good... it is better to build a relationship with the doctor, she or he knows your disease history, you become friends with them and this lift your spirit up... but when you face a new one... you feel embarrassed and you can't build a relation[ship] with them again.'

PLHIV21, male, age 52

In addition, PLHIV reported that doctors did little to inform them, and that they had to access most of their information on HIV issues like opportunistic infections and mother-to-child transmission by chance, through training via local NGOs, and from the experiences of other PLHIV.

'Doctors tell us about ART only... but about opportunistic illnesses... I didn't hear anything about them till today in the workshop... and I've been now one year infected, and I always go to the clinic... but [I] never heard of it... Well, I guess it is useful to know to be careful... in the clinic they ask, do you suffer for anything... fever... diarrhoea... but [they] never told us anything.'

PLHIV22, female, age 27

Service providers also reported dissatisfaction with the quality of care provided, particularly for children infected or affected by HIV. Highlighted issues included: lack of child-friendly care units in the VCT centres, lack of drugs for opportunistic infections, and lack of a balanced diets.

'Counselling for children is not existent. Only prevention measures and we usually directed [counselling] to parents. There is only one specialised unit for children in Omdurman hospital. There are, of course, VCT centres in the states [outside Khartoum], but for children only in Omdurman [in Khartoum]. In this hospital we have 129 children [infected and affected by HIV and AIDS]. Many of them were orphaned. They lack [a] family's affection and care.'

SP14, female, age not given

To expand the capacity and quality of care for people infected and affected by HIV, it is imperative that the needs of service providers should be met and fulfilled, as well as those of patients. Many service providers, particularly counsellors, have received training in HIV counselling, but many expressed other needs that should be met to ensure good quality and performance. These included the need for updated information, better provision of supplies and infrastructure, supervision on performance, professional support, and encouragements.

'We as counsellors are human beings... there [is] supposed to be, at least, supervision... for example: in Kenya they are supervised... SNAP provides medicine and that's it!... The level of stress I have... they have just trained us in 2000 [eight

years ago], and since then we didn't have any meeting with them... we just write monthly reports... We face problems, and the only one [who] understands them is a counsellor like me... they can give support if we have a monthly session where we can talk [and exchange experiences].'

SP9, female, age not given

‘Many people ask: “Where are the people living with HIV?” They think that PLHIV are the owners of AIDS. Our priority is how to find support for PLHIV... in order not to be homeless... [to] allow them to live positively... [to] provide moral support for them to come out from their appalling psychological and economic situation... To become normal humans who can live positively with [a] decent life... to be able to participate in a campaign combating HIV.’

PLHIV 21, male, age 52

HIV policies and programmes

PLHIV interviewees tended to have strong opinions on the level of awareness, extent of acceptance and HIV stigma, and shortcomings of the awareness (IEC) campaigns provided by the state and NGOs. They also highlighted a lack of political commitment to counteracting stigmatising behaviours in wider society. They expressed concern about conflict between the priorities of state HIV-awareness programmes and those of NGOs operating in the field, and the actual needs of PLHIV. While state and NGO policies and programmes do focus on including PLHIV in awareness and advocacy campaigns, many participants do not believe that advocacy is their main priority. PLHIV reported gaps in the policies and programmes addressing their immediate needs.

'Many people, when they hear the word HIV... they ask: "Where are the people living with HIV?" They think that PLHIV are the owners of AIDS issue... but never... At least here in the PLHIV care association... its main problem is how to provide PLHIV with decent life... As to AIDS problem, we participate in prevention... AIDS is not our main priority as PLHIV... Our priority is how to find support for PLHIV... in order not to be homeless... [to] allow them to live positively... [to] provide moral support, provide ways for them to come out from their appalling psychological, economic, and social situation... In order for them to become a normal human... a human being who can live positively with [a] decent life... to be able then to participate in [a campaign combating HIV and AIDS].'

PLHIV 21, male, age 52

The Sudanese government is not the only source of financial resources for programmes on HIV and related services in Sudan. Government spending is most closely focused on awareness and advocacy campaigns, and limited resources are available. Those that are available are largely dependent on external funding from the Global Fund, UN agencies and international NGOs. Indeed, HIV, despite being declared a domestic epidemic by the Sudanese president, Omar Hassan El-Bashir, in 2003, is not yet a priority programme. Government budgeting plans allocate only 3.8 per cent of total expenditure on health to HIV and AIDS programmes.

In addition, the capacity of HIV-related health services is limited, because of the impact of high-burden communicable diseases that are given greater priority (such as TB and malaria), high staff turnover, and inadequate human resources capacity.

Programmes targeting service providers lack a standardised action plan, training follow up, and psychosocial support.

PLHIV care associations, though they are excellent and obvious potential partners with government in any organised attempt to improve the lives of PLHIV and combat HIV, are usually bypassed by donors, because of gaps and weaknesses in their financial management, reporting, proposal-writing, and organisational capacities. As well as funding, a great deal of skills improvement is needed for the HIV response in Sudan, both at the level of such organisations and throughout the government and public sector response to HIV.

‘There are lots of problems facing PLHIV, of course these problems vary... the state should do something from above to combat stigma... but the issue is, in fact, moving in reverse... the base is understanding the situation or is willing to understand but we can’t reach the political high point... for example, in Uganda it is a top-down approach.’

PLHIV 21, male, age 52

Conclusions and recommendations

1. Policies to address stigma and discrimination

This study has revealed that HIV stigma and discrimination in Khartoum is ubiquitous – making the lives of people with HIV difficult, and obstructing effective HIV prevention and care programmes. There is, therefore, an urgent need for government policies and practices to address stigma and discrimination in Sudan, and protect the rights of people with HIV. Strategies which recognise HIV as a public health issue, rather than a moral one, require not only government support, but the strong engagement of a range of non-government stakeholders, particularly people with HIV.

Recommendations

- 1.1 SNAP, in conjunction with partner organisations, should undertake a comprehensive review of health and policies from other sectors that have a direct and/or indirect impact on HIV and the lives of people with HIV, to include the views of people with HIV, and address their needs fully and equitably.
- 1.2 SNAP, in collaboration with UNDP and the Federal Ministry of Justice, should ensure that the draft HIV policy HIV prevention and protection of the rights of infected persons⁹, which includes the views of people with HIV and addresses stigma and discrimination issues effectively, is approved and ratified by the National Assembly.
- 1.3 Following ratification, SNAP should ensure that the HIV prevention and protection of the rights of infected persons policy is disseminated throughout the public, private and non-governmental sectors, and monitor its implementation. Dissemination could be achieved through workshops for doctors and other health professionals, training for relevant NGOs and community groups, and interaction and review between people with HIV and government.

2. Healthcare worker training

This study has identified a need to build skills and provide communication training for medical service providers, in order to update standards for the provision of good-quality, HIV-related medical and counselling services, and to ensure that people with HIV are treated with dignity and not discriminated against in medical settings.

Recommendation

- 2.1 SNAP, in conjunction with the Federal Ministry of Health and other agencies involved in providing general healthcare training and review of hospitals, health polices, health protocols, such as WHO should support a healthcare-worker HIV training programme, which would include elements such as:
 - Improved technical HIV training for healthcare staff in clinics, hospital and dental surgeries, in both the public and private sectors.
 - Increased access to up-to-date information for HIV service providers (including safe monitoring treatment of adverse effects of ART, provision of prevention of mother-to-child transmission services and services for children and young people with HIV).
 - Communication and HIV-counselling training, with ongoing training, mentoring and support, with input from the experience of people with HIV.
 - Regular follow-up/mentoring of service providers should be undertaken including appraisal of their HIV knowledge and assessment of their communication/counselling skills, as well the opportunity to share experiences with other service providers.
 - Improved safe practices at the health facility, through provision of 'universal precautions'/safe practices training.

3. Addressing the needs of people with HIV more effectively

This study has demonstrated that many people with HIV in Sudan have poor social and emotional support, leading to hardship and distress and lack of ability to share their status with families, friends and community members.

Recommendation

- 3.1 A systematic approach should be developed (lead by SNAP, the Federal Ministry of Health, Federal Ministry of Social Affairs and supported by other strategic non-governmental and UN partners) to develop expanded comprehensive psychosocial support for people with HIV. This could include home-based care that provides counselling, accurate information and skills to people with HIV and their families.

4. Promotion of workplace policies

This study revealed that many people with HIV in Khartoum have been discriminated against in their workplaces or have unfairly lost employment. The absence of policies and programmes addressing HIV in the workplace allows stigma and discrimination against people with HIV to perpetuate. By developing and promoting HIV workplace programmes, stigma can be reduced and a positive working environment created for people with HIV. Support to develop and adopt HIV workplace policies should be prioritised both in the public and private sectors.

Recommendations

- 4.1 Christian Aid should work with its partner organisation to develop and implement workplace programmes. This work should be developed with input from the Sudan Network of People with HIV, who can provide practical examples of how HIV has affected their ability to work.
- 4.2 SNAP should work with the Ministry of Labour, supported by ILO, to develop laws to promote inclusion of and prohibit discrimination against people with HIV in the workplace, disseminated by implementing training workshops, and launching an advocacy campaign led by SNAP, with collaboration from agencies such as Christian Aid and the Sudan Network of People with HIV.

5. Promotion of stigma-free media messages

Although many recent HIV prevention messages developed by SNAP, in collaboration with other UN agencies (UNDP, UNICEF), challenge stigma and discrimination, the media in Sudan does not always present accurate information on HIV, and portrays people with HIV negatively. Dissemination of accurate and comprehensive HIV information is essential in reducing stigma. Broadcasters and media professionals have a responsibility to provide accurate comprehensive information on HIV. SNAP and UNDP have made initial steps to train media on responsible HIV reporting, but further work is required to roll out and monitor this work.

Recommendations

- 5.1 SNAP should continue and develop the media- and HIV-programme training for media personnel and NGOs working in the field to develop creative media messages

that are non-stigmatising, and do not further discriminate against people with HIV in Sudan. Christian Aid should work with the Sudan People with HIV Care Network to support its partner organisations to develop similarly appropriate non-stigmatising HIV messages.

- 5.2 A code of conduct for HIV reporting in the media should be developed by the Federal Ministry of Information and Culture, which has responsibility for the media with input from SNAP and the Association of people with HIV.
- 5.3 A media-monitoring system or committee (composed of media personnel) should be developed to screen and give consultation for media bodies or NGOs on stigma free messages.

6. Involving faith leaders

Faith leaders (both Muslim and Christian) are important in influencing opinions in Sudan and could have a key role in challenging stigma and discrimination and promoting inclusion of people with HIV. There should be a continuing effort to engage faith leaders in this work through training and the dissemination of a faith leaders' guidebook to a wide range of faith-based groups. It is vital that people with HIV work together with faith leaders to ensure that messages are inclusive and do not perpetuate stigma.

Recommendations

- 6.1 NGOs, SNAP and the Federal Ministry of Guidance and Endowment should continue prioritising working with faith leaders (both Muslim and Christian) on HIV and engage with the Religious Council (of which SCC is a member) to address HIV-related stigma and discrimination.
 - 6.2 The Federal Ministry of Guidance and Endowment with the support of SNAP and the Ministry of Higher Education should develop a training programme on 'stigma-free faith messages' for students in the Religious Affairs and Studies university departments. This programme should engage people with HIV.
- #### 7. Coordination and partnerships to reduce stigma
- Partnerships should be strengthened between the Sudan National AIDS Programme (SNAP), SAN (Sudan AIDS Network), civil society, and PLHIV associations, allowing SNAP to play a key effective and acceptable role in challenging stigma and discrimination effectively.

This can be done through strengthening the role of the Sudan Network of People Living with HIV, developing an e-forum that connects NGOs and civil societies or develop a tasking force through electing SNAP representatives, civil society representatives, NGOs representatives, and PLHIV care association representatives who meet regularly to report, update and follow up programmes. This will enable newer and less experienced organisations to learn and present their needs to SNAP and other organisations, and also create an opportunity for effective partnerships.

8. Funding for PLHA groups

Many people with HIV in Khartoum find it hard to survive because of the lack of employment opportunities and ill health. The PLHA group's impact and influence is also compromised because of lack of funding.

Recommendations

- 8.1 SNAP could work with other stakeholders to identify ways of improving financial support to PLHA groups and for people with HIV. This could include a wide range of options lobbying for direct support from the Global Fund to improve the skills of PLHIV self-help groups, through initiatives such as savings and loans groups, insurance schemes and income-generating interventions.
- 8.2 SNAP, UN agencies and other international NGOs could work directly with PLHA groups to identify their organisational, managerial and technical needs. This could include developing a wide range of organisational, managerial and technical training for PLHA groups such as management skills, reporting, organisational skills and proposal writing.

9. Future research

There remains a lack of information about HIV in Sudan. This study focused only on people with HIV and service providers in Khartoum, and cannot therefore be generalised to the rest of Sudan.

Recommendations

- 9.1 Comprehensive Sudan study should be undertaken. This research could be replicated in other parts of Sudan to investigate stigma and discrimination associated with HIV and issues for people with HIV in Sudan. This

research could be led by SNAP and sponsored by UN agencies (UNFPA, UNAIDS, and UNDP).

- 9.2 Detailed research should be undertaken to address the particular needs and concerns of women with HIV, including such issues as gender-based violence and gender-related stigma, and how best to address these. This could be led by SNAP, the Gender centre, and funded by United Nations Development Fund for Women (UNIFEM).
- 9.3 A detailed analysis involving other vulnerable populations, particularly young people and risk groups, should also be undertaken, to determine VCT coverage, capacity and finances and provide a clearer understanding of their needs. This could be led by SNAP, involving youth societies such as Sudanese Coalition on Youth & HIV/AIDS and sponsored by UNICEF (UNICEF has a youth programme).
- 9.4.1 Children affected by HIV. A national survey should be undertaken by UNICEF, led by SNAP in collaboration with the Federal Ministry of Social Affairs, mapping current prevalence of children living with HIV or orphaned because of HIV and their basic needs.

Endnotes

1 Declaration of Commitment on HIV/AIDS, United Nations General Assembly Special Session on HIV/AIDS, UN, June 2001.

www.un.org/ga/aids/coverage/FinalDeclarationHIVAIDS.html

2 High-level meeting on AIDS, 31 May-2 June 2006-2007, United Nations, New York.

3 Epidemic update regional summary, Middle East and north Africa fact sheet. UNAIDS, http://data.unaids.org/pub/FactSheet/2008/epi07_fs_regionalsummary_mena_en.pdf

4 www.who.int/GlobalAtlas/predefinedReports/EFS2006/EFS_PDFs/EFS2006_SD.pdf

5 http://data.unaids.org/pub/Report/2008/north_sudan_2008_country_progress_report_en.pdf

6 Sudan National Health Survey 2002.

7 *Cambridge Learner's Dictionary*, Cambridge University Press, 2001.

8 Sudan National AIDS Programme.

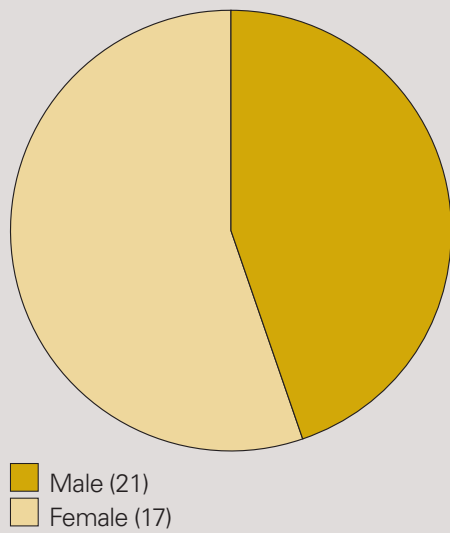
9 The progress of the Sudan's government's draft act on *HIV prevention and protection of the rights of infected persons*, United Nations General Assembly Special Session on HIV/AIDS, UNGASS report 2006-2007, UNAIDS, 2008.

Annex 1: Topics discussed with PLHIV in in-depth interviews and focus group meetings

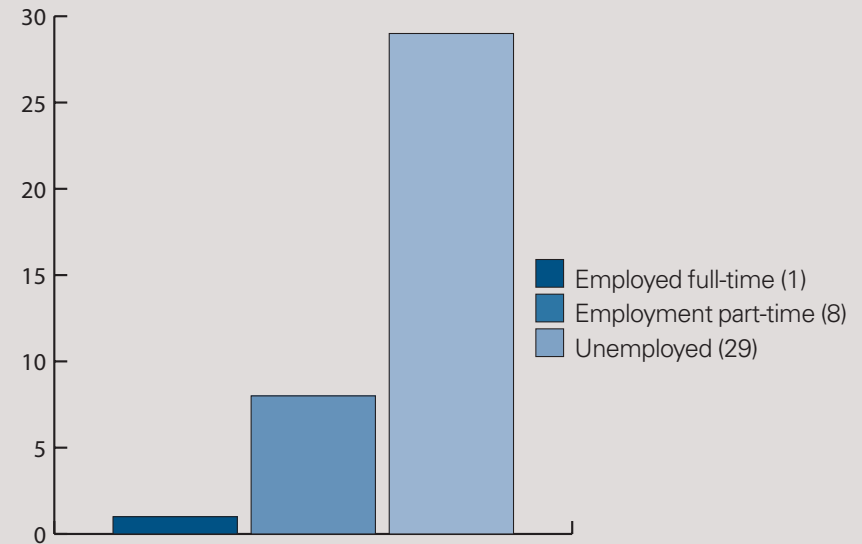
- **HIV history:** year of diagnosis, how they found out about status, overall health since diagnosis including treatment history.
- **The aftermath of HIV diagnosis** (immediate and gradual) regarding awareness, acceptance, and subsequent experience as PLHIV.
- **Attitudes,** perceptions and knowledge about HIV, including HIV prevention, care and support, provision of VCT and HIV advocacy before and after infection.
- **Access to information** on HIV, treatment, side effects, and opportunistic infections and illnesses.
- **Access to health services:** experience at HIV clinics, experience at non-HIV clinics, experience accessing HIV treatment and nutrition, treatment routine, availability of monitoring tests (CD4 cell count test), experience accessing preventive treatment of opportunistic infections including TB, experience of referrals to other health facilities and complementary services, and experience (if any) of home-based care.
- **Social impact:** disclosure of status to the family, family response and support, community support (neighbours, workplace, religious/spiritual institutions), real or feared discrimination, stigma, trepidation, anxiety, inaction or mis-action due to ignorance, perceived religious, political and social beliefs about HIV that could be misleading, and the relationships between gender and HIV.
- **Economic impact:** economic dependency, existence/non-existence of financial support while seeking care and treatment, drugs pricing, HIV impact on employment opportunities, workplace support and other indirect financial impacts of HIV-positive status on PLHIV lives (rent, food purchase, education, etc).
- **Legal support:** existing laws and protection of PLHIV against discrimination in wider society, at home and in the workplace; HIV and human rights.
- **Community participation:** community-based organisations and non-governmental organisation support activities and contact with PLHIV, involvement of PLHIV in awareness activities, PLHIV interactions with each other, and experience and availability of CBO and NGO service.

Annex 2: PLHIV interviewee graphs

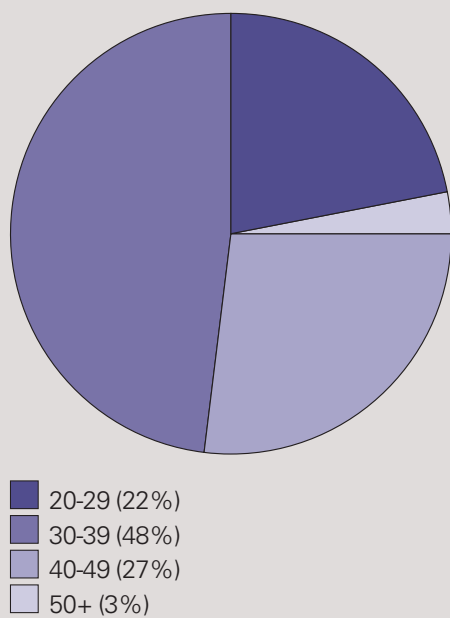
Graph 1: Gender dispersion



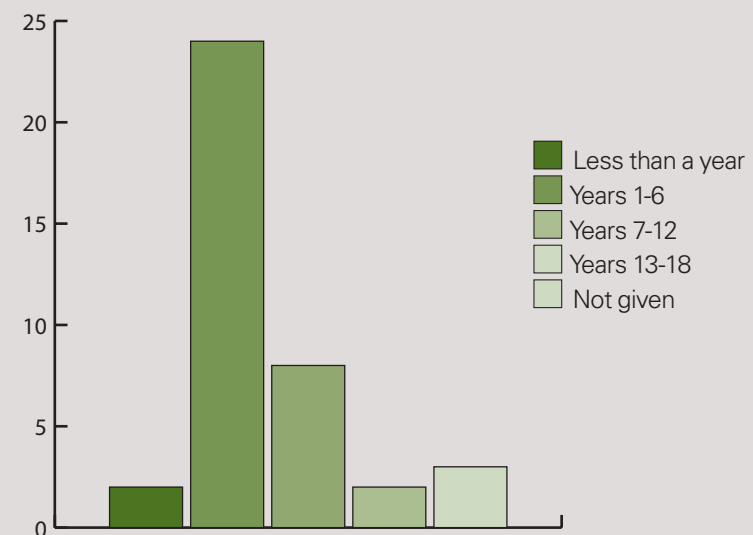
Graph 3: Employment status



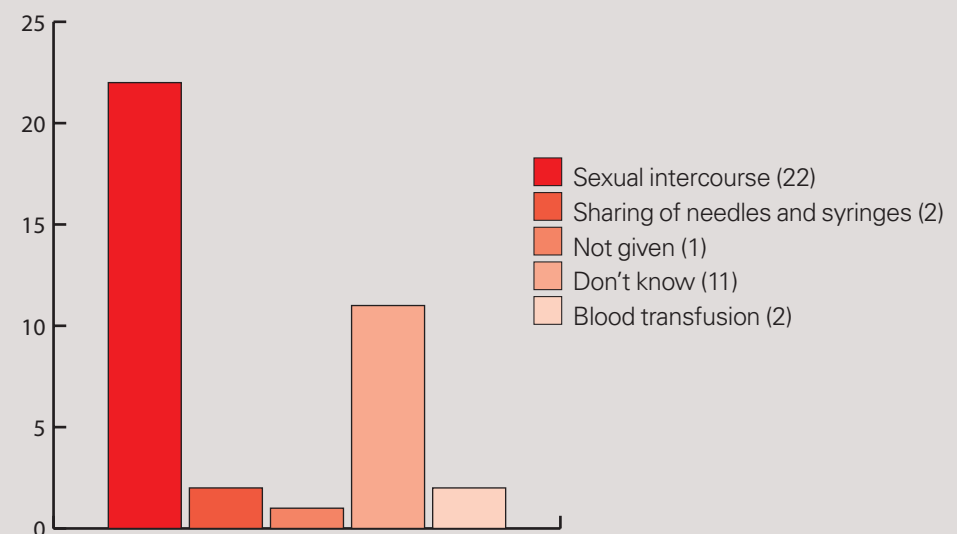
Graph 2: Participants' age group



Graph 4: Time since year of diagnosis



Graph 5: Method of transmission



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The Catholic Church Archdiocese of Khartoum: Ms Agnes Wasuk Sarafino (HIV programme coordinator).
Christian Aid Khartoum office: Mr Zuhair Sulieman

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2. Editorial

We would like to thank Neville Rigby, Mark Nunn and Jane Lewis.

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Christian Aid is a UK-based non-governmental organisation with more than 60 years of development experience. Established in 1945 as an agency of the churches in the UK and Ireland, Christian Aid works wherever the need is greatest, irrespective of religion.

Christian Aid works to achieve the eradication of poverty by supporting 574 partners in 56 countries. Christian Aid has made HIV a corporate priority. We focus on challenging stigma and discrimination; promoting hope and empowerment for people living with and affected by HIV; supporting communication; the learning and sharing of good practice; and continuing to work for the eradication of poverty and inequality, especially gender inequality. Christian Aid currently works with and supports 136 community-based partner organisations working on HIV programmes in more than 35 countries in sub-Saharan Africa, Asia, Latin America, the Caribbean, Eastern Europe and central Asia.

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'I wanted to kill myself... drink something... or burn myself. I lost hope in life... because the patient's situation is difficult... his health is finished... my family don't treat me well... our relation has changed... My brother does not treat me well... he keeps yelling at me and beat[s] me all the time... he beats me and say[s]: "You married this guy and brought the disease and scandal to the family... you did this and that".'

PLHIV17, female, age 32

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