

HIV/AIDS: A mental health perspective

Numerous studies exist in every area of life on HIV/AIDS. One neglected area however is its psychological and mental health impacts. **Nkululeko Nkomo** and **Melvyn Freeman** discuss a study which reveals the importance of this area in combating the affects of AIDS.



Public interest in how people living and affected by HIV/AIDS are personally coping with their lives is growing. Though there is still significant stigma surrounding the disease, recently in the media ordinary citizens with HIV/AIDS are beginning to communicate the personal affects of the epidemic. Even some well-known personalities are disclosing their status and writing accounts of their experiences, such as Judge Edwin Cameron in his *Witness to AIDS*; Khabzela who disclosed his status before his death and his personal struggle is recorded in Liz McGregor's *Khabzela: The life and times of a South African*, and Adam Levin in his *AIDS Safari*.

The *Sunday Times* is running a campaign called *Everyone Knows Someone* that encourages people to get tested for HIV and also aims to reduce the stigma. Every week it publishes stories of people living with, or caring for individuals with HIV/AIDS. Judging by the response, it clearly provides a

much needed platform for South Africans to share their experiences. Moreover leaders such as Nelson Mandela and Mangosuthu Buthelezi have spoken about the grief of losing children to the epidemic. Yet, despite all this, there is little research in developing countries on HIV/AIDS and mental health.

The impacts of HIV/AIDS are multifaceted. There is a growing body of information on its effects on different sectors of the South African economy and the labour market. It is at the household level, however, where its destabilising effects seem to be the greatest. There is evidence suggesting that HIV/AIDS is transforming the way families are structured and the way they function. It is at this level where both the economic and social consequences are felt most acutely. But what about the psychological and mental health impacts? Recent work done by the Human Sciences Research Council attempts to shed light on this important, yet often overlooked, area.

RESPONDING TO HIV STATUS

The study, which had two parts, was conducted before the concerted public sector roll-out of the anti-retroviral programme and few of the respondents were receiving ART at the time. For many people though ART is still not available. In any event, although ART is lifesaving for many people, it is not easy living with HIV/AIDS and many people still suffer from depression and other mental health problems. Part one sought to determine the personal experiences of being diagnosed HIV positive and subsequent adjustment and coping. This was done through in-depth interviews with 19 men and women in Gauteng and the Eastern Cape.

For a majority of the respondents, an HIV positive diagnosis was initially experienced with shock and disbelief. A woman who did not say when she was diagnosed said, "I was shocked because I had never considered HIV as a possible diagnosis in all the time I had been sick... I believed that HIV was an affliction of the promiscuous."

My soul mate gave me HIV



Then violence became our daily bread. We separated last year.

Michael tried a number of times to contact me. There were calls where he cried and asked for forgiveness.

Then one Sunday came an SMS saying he didn't care about me any more as we were both infected with the dreaded virus.

He is the only man I ever slept with without protection and I trusted him with my dear life.

I have had persistent flu and lost weight. Migraines last longer than normal.

How could I have been so blind? How will I apologise to my friend for stealing his man? How will I even begin to tell him that we are probably

Soon I have to go for a blood test to confirm what I already know. If only I could get the courage to face my demons.
— Name withheld

● **Everyone Knows**
Someone is a campaign to encourage people to know their HIV status. We publish the experiences (and, where the writer feels comfortable, photos) of people living with HIV or caring for loved ones with the virus. E-mail your story to Everyoneknows@sundaytimes.co.za or fax it to 011-280-5151

● **Psychologists Khumo Seopela and Kgamadi Kometsi** are offering HIV counselling free every Saturday morning in Rosebank, Johannesburg. Bookings are on a first-come, first-served basis. To book, fax 011-280-5151, or e-mail

friendship ceased to exist.

After two years, the relationship took a turn for the worse. Michael became a monster, controlling every movement that I made, the friends who came to visit us.

The "Sunday Times" is running a campaign to encourage people to get tested for HIV

The shock of hearing of their positive status was accompanied by varying degrees of distress, denial, anger, fear of rejection, as well as concerns about establishing new or maintaining existing romantic relationships. Two respondents reported feeling propelled to destructive and fatalistic behaviour soon after diagnosis.

One man said: "I stopped using condoms or anything of that nature. I just engaged in sex without using a condom 'nyama to nyama'. Nothing really scared me at that point because after all I am HIV positive... I convinced myself that I had the biggest disease in the world... why should I care?"

Another person diagnosed in 1992 explained, "I told myself that I was going to drink alcohol and die if I had to but I was too scared to hang myself or to shoot myself. Drinking was an easier option; I would drink myself to death. I stopped looking after myself and kept drinking. My physical state deteriorated, I couldn't care less."

However following the initial shock, most respondents were able to find ways of making sense of being HIV positive. Yet, for some the

experience of living with HIV/AIDS was characterized by serious difficulties. These included difficulties with adapting their lives, excessive alcohol misuse, changed sleeping and eating patterns, lack of acceptance of their status and an inability to find inner peace. They also experienced difficulties with establishing and maintaining intimate relationships, and a number felt suicidal.

One woman stated that, "I am still struggling to cope; there is no inner peace in me... I can say the right things to people, go through the motions... but when it's time to be by myself it's a different story. This thing just takes control whether you like it or not. You can't have a headache without fearing for the worst. You sit with the feeling that you might keel over and die anytime."

A man reported that, "It depresses me at times because at night you certainly become afraid of sleeping because you might not wake up the following morning."

Significantly, how well an individual adjusted was mediated or aggravated by factors such as the availability of social support (from family, friends, or just being a

member of a support group), disclosure of status, involvement in HIV/AIDS activism, imagined and actual stigma and discrimination, and finding meaning in being HIV positive. A woman diagnosed in 2001 said that: "Being HIV positive to me represents the beginning of a new life because it has helped me manage my life better. I am now able to manage my finances a lot better than I used to. I have also stopped drinking alcohol because of my HIV status since I realised that to continue consuming alcohol will worsen my health condition. Being HIV has also taught me to love and care for other people."

HIV/AIDS AND MENTAL DISORDERS

The second part of the study used the World Health Organisation Composite International Diagnostic Interview which assesses mental disorder and an especially designed interview to determine factors associated with mental disorder. This was conducted with a sample of 900 people living with HIV/AIDS in Gauteng, Kwa-Zulu Natal, Free State, Western Cape, and the Eastern Cape provinces.

Some previous studies in South Africa had been conducted to determine the coexistence of HIV/AIDS with a mental disorder but these studies had relied on very small clinic-based samples.

An overall rate of 43.7% of mental disorders was found in people living with HIV/AIDS. To put this into perspective, other studies of mental disorder in the general population in South Africa have found rates ranging from 8% to around 25%. Hence people living with HIV have significantly higher rates of mental disorder than is found in the general population.

Nearly one third (29.9%) of people in this study met the diagnostic criteria for a minor depressive disorder and 12.4% met the diagnostic criteria for an alcohol abuse disorder. Of interest is that no significant differences were found between men and women regarding depression related disorders. This is very unusual as women generally have between 1.5 and 2 times higher rates of depression than men. However, as found in other mental health studies, men had more alcohol related problems than women. It is difficult to say why men and women had equal rates of depression but it is possible that the HI virus itself attacks the central nervous system, causing raised levels of depression in both sexes.

Despite the reservations that some experts have about the quality and efficacy of pre- and post-test counselling for HIV/AIDS in South Africa, a significant majority of people said that they found counselling very helpful (71.7% of pre-test counselling and 78.1% of post-test counselling).

We were surprised to learn that most people had told someone outside the clinic of their HIV positive status. However, even though many said that they had disclosed and found it helpful to do so, the

results of our study showed that those that had disclosed their status were more likely to suffer from mental disorder than those who had not disclosed. It is likely that stigma and people's reactions to HIV make it emotionally very difficult once they disclose their status. Twenty three percent said that they had been discriminated against and this was very strongly associated with a diagnosis of a mental disorder.

As in the first part of the study, the second part also found that being a part of an activist/advocacy or support group for people living with HIV/AIDS was very helpful for psychological adjustment. For instance, 87% of people reported that being in a support group had been very helpful and 93% of those that are part of an activist organisation found that such activities were very helpful in coping with their HIV status.

WHAT DOES THIS MEAN?

Being diagnosed HIV positive is a significant life altering experience that elicits varying emotional responses for people. Close on half had a diagnosable mental health problem that warranted a specific mental health intervention.

Pre- and post-test counselling have some benefits. However, the length and lack of follow-up reduces the impact and benefit. Increasing the number of sessions and the intensity of counselling services could yield significant benefits for a number of people. This means that current skills levels among pre- and post-test counsellors have to be increased to conduct more in-depth psychological counselling.

Moreover, the expansion and establishment of more psychotherapeutically focused support groups would complement pre- and post-test counselling. Also, while not everyone can be an AIDS

activist, it appears that those who are a part of activities associated with HIV/AIDS activism benefit considerably from this involvement. Taking part in activities that helps prevent others becoming infected, or helps people get treatment, seems to give meaning to the lives of many people living with HIV.

Stigma and discrimination continue to present real challenges for many people living with HIV and AIDS. Understandably most media messages on HIV/AIDS focus on prevention and more recently on being tested and receiving treatment if HIV positive. However, there are few messages on care and support for people affected by the epidemic.

Scaling up efforts and messages around support for people living with HIV from both professional and lay sources such as counsellors as well as friends and family that also discourage stigma and discrimination, would go a long way towards helping infected people cope better with their lives. This is particularly important as treatment roll-out expands, as people experiencing mental health problems are poor adherers to medication.

We have shown that mental health problems such as depression are higher in people living with HIV/AIDS. Without attention to these mental health problems a significant number of people are unlikely to take their treatment in the manner that is needed for good health. Finally, complete alleviation of social stigma and discrimination would significantly assist with the process of mental health adjustment and acceptance necessary for positive living. LB

Nkululeko Nkomo is a doctoral intern at the HSRC and Melvyn Freeman was chief research specialist at the HSRC at the time of the research.