

# **The vicious circularity of mental health effects of HIV/AIDS: Symptom and cause of poor responses to the epidemic<sup>1</sup>**

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## **Abstract**

In this paper we consider the possibility that psychosocial effects of the HIV/AIDS epidemic may have acted to sustain and entrench the epidemic. After reviewing the evidence for an association between HIV/AIDS and psychological dysfunction in the form of breakdown of coping responses to the point of psychiatric disorder, we suggest that it is not inevitable that this should have happened. We argue that these effects are partially created and certainly sustained by the manner in which the epidemic has been responded to. Reviewing findings from our previous research on mental health effects of HIV/AIDS and analysing interviews conducted with HIV positive respondents, we describe psychological responses to HIV infection and their possible epidemiological consequences. We argue that these have acted with vicious circularity, undermining responses to the epidemic and compounding the predisposing psychosocial vectors of HIV infection. In closing we suggest that particular intervention strategies need to be much more carefully thought through and we make some recommendations regarding the need to respond to the mental health dimensions of HIV/AIDS.

**Key words:** Mental health; HIV/AIDS; epidemiology; South Africa; well-being; psychosocial support.

## **Introduction**

HIV/AIDS is by now widely recognised by developing country governments, international funders and the scientific community, as an obstacle to socio-economic advancement in sub-Saharan Africa and a major humanitarian crisis.

There has been a massive commitment of new funds to the development of a comprehensive response to HIV/AIDS, by governments of affected countries and the international community. Advances have been made in understanding the virology and epidemiology of HIV. Treatments are becoming more effective and more affordable, and most countries have or are instituting national antiretroviral treatment programmes (ART). National strategies and the development of governmental and

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civil society structures for responding to HIV/AIDS have been established. Populations in areas heavily affected by HIV/AIDS have time and again been shown to be aware of the threat of HIV infection and of how to avoid it.

There have been some encouraging outcomes of these developments. Rates of infection are declining in some countries, and HIV infection levels in many high risk populations appear to have reached a plateau. ART is proving effective in curbing mortality of those infected, although many country programmes are rolling out very slowly on the back of massive skills deficits in the health field, poor health services and formidable infrastructure challenges.

In some respects it comes as no surprise that successful responses to HIV/AIDS have been slow to develop and were initially less than hoped for. This is especially true in countries where there are multiple social and health challenges, weak or conflicted governments and poor infrastructure, and where the majority of citizens are poorly educated, poverty-stricken and hungry. Yet there are exceptions such as South Africa, Swaziland and Botswana, which cause us to look deeper at why responses have been slow to develop or at least initially ineffective.

There have been numerous attempts to understand this. Much effort has been focused on understanding the conditions under which HIV has thrived, and why some countries or localities have been worse affected. It has been thought that by better understanding the drivers of country-level epidemics we may improve our ways of responding to them. Migrancy, urbanisation, impoverished living conditions, gender inequality and domination, cultural practices, income inequality, and patterns of sexual mixing attending all of these, are some of the many social epidemiological vectors associated with high prevalence.

In general, success in responding to HIV/AIDS epidemics has been hard won. Researchers have responded by digging ever deeper into socio-economic and context-specific vectors to identify apparent missing links in understanding the spread of HIV, but with diminishing returns. Others have focused on understanding the ingredients of success where this is in evidence, with early successes in Uganda having created the hope that with the right intervention approach the drivers of HIV infection might be rolled-back.

In this paper we cross between epidemiology and response analysis. We consider the possible influence on the epidemic of a complex set of psychosocial factors which are a by-product of how HIV/AIDS responses have been conceived and managed.

After outlining the extent of the HIV/AIDS epidemic in South Africa and its impacts, we focus on mental health dimensions of the epidemic. We begin by providing evidence for a mental health epidemic which has accompanied and is related to the HIV/AIDS epidemic. We suggest that for the most part, mental health sequelae of HIV infection are a symptom of the manner in which the epidemic has been responded to, rather than an inevitable psychiatric effect of the viral infection.

We suggest that these mental health outcomes are not only symptoms of the ways of responding to the epidemic, but in a viciously circular way have entrenched and exacerbated it. They have undermined the effectiveness of the very strategies which have shown positive responses to the epidemic, and have compounded the predisposing psychosocial conditions or vectors of HIV infection.

## **HIV/AIDS in South Africa**

South Africa is in the grip of a ‘generalised’ epidemic, no longer confined to specific high risk groups of population.

In 2006, HIV seroprevalence in public sector antenatal clinic attendees (DOH, 2007) was 28.6%. This means that more than one in four pregnant women in 2006 was HIV-positive. One in nine (11.4%) South Africans over the age of two years were estimated to be HIV positive at the end of 2007<sup>3</sup>. Although fewer than 3 in 100 South Africans aged 10-14 years are infected with HIV, at current infection rates more than 20% will be infected by the time they turn 25 years old.

The total number of new HIV infections in 2007 is estimated at 512,931 which translates to 1,405 new infections every day. The ASSA Model predicts 38,510 babies infected at or before birth in 2007, and 25,705 babies infected through mother’s milk. This amounts to a total of 64,215 HIV positive infants in 2007, or 176 new HIV positive babies a day.

AIDS deaths were estimated at 360,689 in 2007 (988 per day) and the accumulated number of AIDS deaths to mid-2007 is 2,168,836. Life expectancy at birth has fallen from 56.7 years in 2000 to 50.6 years in 2007.

By the end of 2007 there was an estimated 1.2 million maternal orphans (children under 18 years old who have lost a mother or both parents) due to AIDS. This amounts to about 14% (1 in 7) of children between the age of 2 and 18 becoming maternal orphans.

A total of 537,803 people in South Africa in mid-2007 were in need of antiretroviral therapy but were not receiving it, and a further 4,589,436 were HIV positive but in the pre-AIDS phase of illness progression, and will be needing ART in future.

About one in six public school educators were HIV positive in 2005 (Shisana et al. (eds.), 2005) and a similar situation prevails in the health sector (Shisana et al., 2004), undermining the society’s capacities to respond to the epidemic.

This situation prevails despite the existence, over the past 20 years, of both the information and the technology to prevent most new infections. Since 2004 the public health system in South Africa has been committed to the provision of antiretroviral therapy, and if comprehensively done this would prevent the majority of current AIDS deaths.

### **Mental health correlates of HIV infection**

Studies of the mental health status of people infected with HIV have consistently found higher prevalence of mental health problems than is found in general community or clinic samples (Catalan, 1999; Cournos & Forstein, 2000; Green & Smith, 2004). Reasons for the higher prevalence of mental health problems in HIV

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<sup>3</sup> Unless otherwise stated, data presented in this section is extracted from the Actuarial Society of South Africa’s ASSA2003 modelling instrument released in 2005 and updated in 2006. Data sources used to build the instrument include annual large-scale antenatal surveys conducted by the Department of Health as well as data from independent nationally representative HIVseroprevalence studies. ASSA is considered the most inclusive and reliable source of estimates relating to a range of HIV/AIDS prevalence and impact indicators in South Africa.

infected populations include: premorbid mental conditions which predispose people to infection, the effects of the virus on the central nervous system, the psychological impacts of living with HIV/AIDS, side-effects of medication, and results of social stigma and discrimination (Freeman et al 2005). Whilst there have been some advances in understanding the mental health sequelae of HIV infection and the mental health support needs of those with HIV/AIDS, until recently there has been very little research conducted in developing country contexts, where HIV/AIDS is most prevalent. We know relatively little about the levels of mental health problems amongst HIV positive populations in those countries most affected by the epidemic.

A study conducted by the authors (Freeman et al., n.d.) describes the prevalence of mental disorder in people living with HIV/AIDS in South Africa in a sample of 900 HIV positive people, using a cross-culturally validated diagnostic instrument and a structured socio-demographic and health information questionnaire. We found a prevalence of one or more diagnosable mental disorders in 43.7% of respondents, which is significantly higher than the prevalence of mental disorder in the South African population. A general population stress and health study conducted at about the same time (Williams DR et al., 2007) provides a standard of comparison, with 16.5% reported as having a diagnosable mental disorder.

In our survey of HIV positive people, depression was the most common disorder (40%, including 11.1% with major and 29.9% with mild depression), followed by alcohol abuse disorder (12.4%). By comparison, in the general population (Williams DR et al., 2007) major depressive disorder was found in 4.9% of the population and alcohol abuse disorder was found in 4.5% of the population. This confirms in a South African context what has already been shown in countries which have more localised or concentrated epidemics; that HIV infection is associated with much higher levels of mental disorder, especially depression and alcohol abuse.

Presence of (any) mental disorder was significantly associated with the clinical stage of progression of HIV/AIDS. In other words, progression leads to greater levels of mental disorder and most significantly depression, from stage one (39.8%) to stage four (full-blown AIDS) at 68.8%. It is notable that 18% of the sample were on ART, and this did not prove to alter the likelihood of mental disorder.

Males were more likely than females to experience a mental disorder. This is a reflection of higher levels of alcohol abuse amongst the male population, as in all other categories of mental disorder there was no significant gender difference.

Unemployed people were more likely to experience any mental disorder and have particular susceptibility to depression and alcohol abuse compared to their employed counterparts. It should be noted that poverty and HIV prevalence are related in South Africa, and that poverty and mental health disorders are also related (Hargreaves, 2002; Shisana et al., 2005; Patel & Kleinman, 2003). It may be the case that an elevated prevalence of mental disorders amongst HIV positive people is a consequence of poverty rather than HIV specifically. However, given that other mental health prevalence studies have found much lower rates than this HIV focused study, it is likely that poverty and HIV/AIDS exacerbate each other and in combination impact on mental health, leading to levels of mental disorder higher than are expected for other very poor people or those who have HIV but are not poor. This vicious circle may be further exacerbated by the possibility that poor mental health can be both a risk factor for poverty and HIV/AIDS as well as a consequence of both

of them. High unemployment, HIV/AIDS and mental health are likely intertwined in a complex relationship of mutual causality.

Those with children were more likely to experience mental disorder, but having children is not related to the presence of any particular disorder. It seems likely that problems associated with caring for children and worries about what will happen to the children with disease progression and possibly death of parents, results in raised mental disorder. Furthermore, the financial burden of caring for children and associated stress may lead to higher levels of disorder.

The origin of HIV infection was shown to be associated with both depression and alcohol use. Respondents who said they did not know how they were infected were more likely to suffer from depression than those who knew – no matter how they were infected. On the other hand a diagnosis of alcohol abuse was often associated with having been infected by a casual partner.

The pathway through which the person discovered their HIV positive status was related to alcohol abuse only. Respondents who fell ill and were tested as part of a medical investigation were more likely to have an alcohol abuse disorder than those who discovered their status by other means, such as voluntary counselling and HIV testing or testing for insurance purposes.

Given that the stage of progression of HIV/AIDS is an independent predictor of mental disorder we cannot eliminate biomedical reasons for mental disorders. However, the significance of the other independent predictors points to the need for a psychosocial as well as neurological understanding of the findings. To study the influence of psychosocial factors further we identified associations between the presence of mental disorder in people with HIV and a range of independent variables, defined as psychosocial supports. The results are reported in Freeman et al. (2007).

Eighty seven percent of interviewees had received some pre-test counselling and 78% post-test counselling. The vast majority found the pre-test counselling to be either very helpful (71.7%) or somewhat helpful (13.4%), while 78.1% found the post-test counselling to be very helpful and 10.7% found it to be somewhat helpful in coping with their positive diagnosis. Fifty one percent of people were counselled by a lay person and 38% by a nurse. The remainder were counselled by a doctor (5.3%), a social worker (2.4%) or a psychologist (0.4%). Thirty five percent of people saw the counsellor only once, when they were given their results, while 39% saw the counsellor 2-3 times, 11% of people 4-10 times and 14.4% saw a counsellor more than 10 times. Interestingly, no significant differences were found between people diagnosed with a mental disorder in terms of whether they had counselling (pre- or post-test), who they had seen for counselling nor how many sessions they had with the counsellor. There were also no significant differences in mental disorder between those that found the counselling to be helpful and those that did not. Whether someone had pre- and post-test counselling was not related to mental disorder; nor were the number of sessions of counselling, the professional status of the counsellor and the perceived helpfulness of counselling. So the actual event of counselling at the time of discovering HIV positive status was not independently associated with mental disorder. It is thus likely that the events that transpired after finding out their HIV status had the greater influence on development of mental disorder.

Half the interviewees joined a support group for people with HIV after receiving their positive diagnosis. Of these 43% were still part of such a group at the time of the

interview. Eighty seven percent felt that the group had been very helpful and 5.2% somewhat helpful in coping with being HIV positive. People who had been part of a support group were significantly less likely to have a diagnosis of mental disorder than those that had never been part of a group. However, the number of times a person attended a group or whether they were still in the group at the time of the interview were not significantly correlated with mental disorder. It seems that knowledge of available support gained through having attended support groups at some point, makes some difference, rather than the actual effects of ongoing attendance of a group.

The majority of respondents had informed one or more people outside of the clinic that they were HIV positive (85%) and 44.5% reported that they were fully open about their status. Although most of those who disclosed their HIV status found the experience helpful, there was a significant positive association between the presence of a mental disorder and having disclosed HIV positive status. This is interesting and important, as it suggests that disclosure and openness does not necessarily buffer against development of psychological problems although, by the accounts of respondents, disclosure provides emotional support, but was not really helpful at the level of informational support.

Eighty percent of people were in a relationship/married at the time of hearing their HIV status and 72.6% informed their partner of their positive status. Of these 40% felt that it has made the relationship stronger, 17% reported that it made the relationship difficult but they were still together, 14% said it made no difference and in 27% of cases the marriage/relationship broke up.

Twenty three percent of interviewees said that they had been discriminated against or had had negative reactions due to their positive status. This correlated strongly with the presence of mental disorders amongst the interviewees. The discrimination mainly took the form of being blamed for the infection and name calling by members of the community and family. Twelve percent of respondents said that they had been isolated as a result of their positive status. This too correlated significantly with the existence of a mental disorder.

Fifty nine percent of respondents said that they were very religious, 19% were somewhat religious, 12.7% a little and 9.2% were not religious. Religious status had no significant correlation with a diagnosis of mental disorder. However, seventy percent said that their faith had been very helpful in helping them to cope with their status, 15% found it to be somewhat helpful, 8.4% said it helped a little, 4.4% found religion no help at all and 2.3% said that religion had made things worse for them.

More than half of the respondents (57%) had had someone close to them die of AIDS. Those that had had a close person die from AIDS were significantly more likely to have a mental disorder than those that did not. Seven percent had had a child die, 20.5% a friend, 1.6% a parent, 10.3% a partner, 12.2% another relative and 18% a sibling. Twenty six percent of respondents had experienced other major losses due to non-AIDS related deaths in the year prior to the interview. This included deaths of children, spouses, parents, siblings and friends. Deaths due to other causes did not correlate with the presence of a mental disorder.

### **Psychological responses to discovering HIV status**

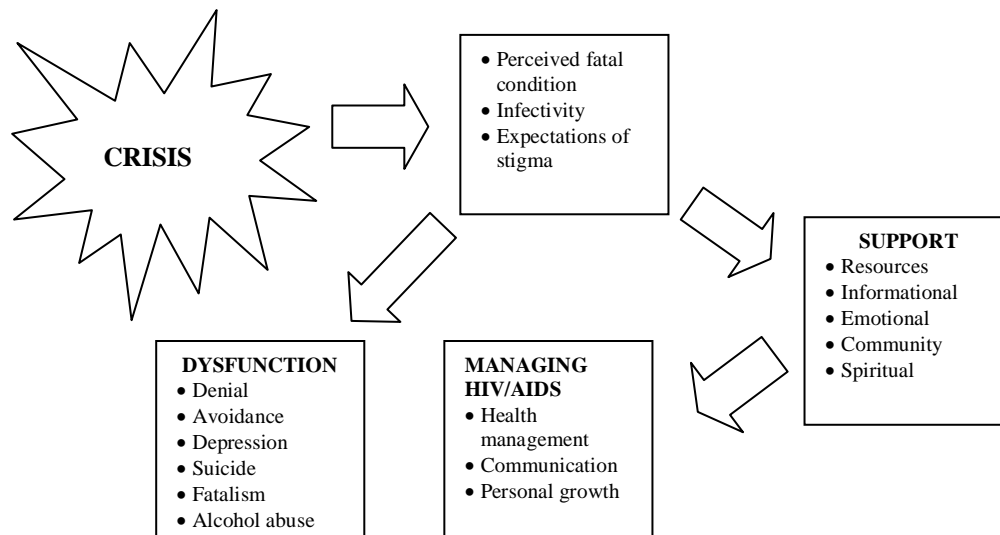
To gain further understanding of how the determinants of mental health correlate with HIV infection we now discuss hitherto unpublished work which documented the experiences of 19 persons diagnosed HIV positive. These respondents were interviewed in order to better understand the results of the survey discussed above and to make sense of them in the context of South African HIV/AIDS response. In particular the individuals' experiences were analysed in an attempt to understand their reactions to discovering their HIV status and the factors that influenced their changing experiences thereafter.

The results show a remarkable range of ways in which people interpreted and responded to their HIV positive diagnosis, contingent on their preexisting ways of coping with adversity and on the degree and quality of support within their immediate social environment. The ways in which the meaning of, and response to, the diagnosis took shape, was a product of the ways in which each individual had previously learned to engage with adversity and the convergence of this with their perceptions of what being HIV positive means. But as importantly, sequences of responses were shaped by perceptions relating to the consequences of HIV/AIDS and perceptions related to the responses of others to whom they had disclosed this HIV positive status.

However, our concern here is not so much to distinguish what leads people to differ in responses to HIV, but rather to explore the commonalities of response. We are interested in how the environment in which they struggle to discover positive responses, shapes their experiences. We are then interested in discovering whether the consequences of these 'common' responses may have epidemiological significance.

Focusing on the personal experience of being HIV positive we have considered the ways in which the outcomes of an HIV positive diagnosis are shaped. It is apparent that the initial discovery of HIV positive status tends to be met with a sense of shock, and often even disbelief. How long this period lasts, its severity and whether an individual is able to pass through it, depends on various factors both internal and external to the person. For example how one comes to know one's status, prior psychological state and seeing the effects of HIV/AIDS on others. But whatever the starting point the mediating influence of various supports available makes a significant difference. The flow chart summarises how opportunities for support and assistance profoundly influence how people react and eventually adapt to their diagnosis (Figure 1).

## **Figure 1**



The initial reality of being HIV positive corresponds to what Ezzy (2000) calls a polyphanous reality. It is oriented to multiple fragments of understanding about what it might mean to be HIV positive, rather than to a coherent framework for understanding or responding to HIV.

The truncation of the promise of a future and feelings of alienation from others unsurprisingly tended to lead the respondents to a sense of despair and hopelessness. At the point of first hearing about their positive status respondents tended to be consumed by thoughts about death and dying, and attuned to the negative ways in which they imagined others reacted to their status. A number of respondents contemplated suicide and engaged in self-destructive behaviours. One respondent described her experiences in the months following discovery of her HIV positive status thus: “I told myself that I was going to die... 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, I was dying anyway but I couldn’t commit suicide: alcohol would do it for me”.

In response to the constructions of meaning of being HIV positive which they had prior to learning of their status, many felt intense disappointment, a sense of having lost all hope for the future. Some respondents felt so depressed or angry that they engaged in destructive and fatalistic behaviours such as abusing alcohol and knowingly engaging in unsafe sex.

To a large extent the meaning of HIV/AIDS was often not based on experience of the responses of others or experience of the effects of HIV/AIDS, but on the prevailing image of HIV/AIDS as a death sentence and the expectation of experiencing stigma and isolation during a slow and inexorable process of deterioration and disease. This is not surprising given what is known about the effects of media depictions of HIV/AIDS in South Africa (Connelly & Macleod, 2003). This is also unsurprising given the lack of treatment options for most in South Africa at the time and to this day, where only about one in three of those needing ART are receiving it.

For some respondents the equivalence of HIV/AIDS and death was transformed as they realised that the continuity of their lives had not been permanently disrupted, that they could manage their condition and that rejection was not inevitable. Such transformation was largely a consequence of the availability of various support



mechanisms. For others though, the same “recovery” did not take place. Those who coped best managed to piece together ways of engaging with the reality of being HIV positive. They discovered for themselves how to survive the damning social image of the condition and the perceived fatalism of its consequences.

The process of adapting to one’s HIV positive status does not appear to follow discernible stages or time frames. Some respondents were able to rapidly adapt by either adopting or constructing meaningful ways of engaging with their HIV positive status. This however sometimes provided only temporary solace, and the process of finding a meaningful relation to their HIV status was an ongoing challenge. Three main domains of meaning, each associated with an external reality, were identified: having a chronic and possibly fatal medical condition; being infective to others; and the realities of preconceptions of others and society about what it means to be HIV positive.

Each domain has consequences which almost any HIV positive person needs to orient to. Having a chronic and likely fatal condition means a possibly shortened life and hence radical challenges to current goals in all areas of life. It has implications for relationships, it implies illness and the need for care, it has financial implications and so on. The fact of being infective to others implies the need to consider at least selective disclosure, a limitation in possible future relationships, a changed relationship to child bearing and need for use of protective measures during sex. The fact that others (be they intimate friends and family, or strangers) have preconceptions about the meaning of being HIV positive, often leads the HIV positive person to project such preconceptions onto his/her own identity - at least at the level of how they see themselves in the context of relationships with others. This is sometimes termed ‘self-stigma’.

The way in which respondents progressed in engaging with knowledge of their status and coping with this knowledge in their own thoughts, feelings and actions, depended in part on their own individual predispositions, but it was also significantly mediated by external factors. While some respondents felt that open disclosure was a precondition to self-acceptance and living a positive life, others felt that it would lead to further pain and hurt and assessed the risk to be too high. In reality the disclosure experience was predominantly positive, though for a few, initial experiences of negative reactions seemed to vindicate a “non-disclosure” position. Nonetheless most who chose not to disclose felt isolated and continued their psychological battle not only to deal with the magnitude of their situation but of whether or not to disclose.

The same could be said of all of the challenges faced. Progress was hard won, and required the seizure of small opportunities to work through the difficulties faced. These included issues related to having a serious medical condition, being infective to others and the realities of how others and the society in general perceive HIV positive people. These challenges all involve encountering and having to overcome specific externalities, and involve considerable adjustment and courage. Many do not confront these realities and have few personal or external skills and opportunities for achieving this. They experienced anxiety, depression, alcohol abuse, hopelessness and self-destructiveness.

They also posed an epidemiological risk

## **Epidemiological consequences**

It is evident from the above that the experience of being HIV positive is a complex process and positive outcomes are not assured. The process towards a positive outcome requires social support, or at least perceived social support, and acceptance as well as qualities of resilience and confidence. We have suggested above that such social support is not assured. Psychological adjustment and mental health are hard-won and the halting processes involved, and the failures have epidemiological significance.

### ***Treatment compliance***

Baingana et al. (2005) review research which shows that psychological, psychosocial and psychiatric factors play a significant role in how well people comply with antiretroviral treatment (ART). Interestingly factors such as age, education, employment, religious support and perceived quality of life are not specifically correlated with adherence to ART, but adaptive coping ability and level of depression are. Depressed subjects with poor support adhere to ART only about half as frequently as non-depressed subjects with good social support (Gordillo et al., 1999).

“Because of the strong correlation between mental health disorders and noncompliance with treatments, addressing mental disorders within the HIV epidemic is critical for preventing drug-resistance.” (Baingana et al., 2005, p.16). It is of utmost importance that strong measures be taken to secure compliance with HIV treatment regimens once these have started, to avoid an equivalent risk of the development of particularly virulent and non-treatable forms of the virus, such as has been the case in the development of multiple drug resistant-tuberculosis (MDR-TB).

The South African national treatment (DOH, 2004) guidelines recommend that untreated active depression or alcohol abuse should be considered as contraindications in assessing eligibility for ART. Mental stability, sobriety and emotional robustness are necessary to endure the first few months of treatment in particular, where treatment side-effects tend to be experienced. Any kind of psychological instability threatens ART adherence at the 95% level needed to prevent resistance. We have reported above on the high levels of mental disorder, and in particular depression and alcohol abuse, in HIV positive people in South Africa. Short of excluding them, ART services in the country have a major challenge in managing the mental health of their clients. This problem has yet to be confronted and could have a significant epidemiological consequence if not addressed.

### ***HIV infection risk***

One of the core psychological issues facing participants was the realisation that they are HIV infective. This was not always an immediate realisation, but when it inevitably dawned it had significant consequences leading to, for example, the risk of termination of relationships, unlikelihood of forming new relationships and a permanent change in sexual practices. “I revealed my result certificate and she saw that I was positive and ended the relationship on the grounds of my status and expressed that she loved me but could not continue with me, as I was HIV positive. I was hurt.” (study participant)

In the words of another respondent in our qualitative study: “Then I did not use condoms or anything of that nature. I just engaged in sex without using a condom, ‘flesh to flesh’... The thought of spreading the infection never came to my mind.”

Others may not deny the obvious fact that they are infective but avoid communicating it to their partners. It must be appreciated that the mental state of people who have recently discovered their HIV status is fractured, chaotic and often lacking in the resolve to raise and discuss the consequences of what it means to be infective. As one respondent reported, “Everything happened very fast. I was really scared, this was weighing heavily on my mind and I couldn't confront him about it.... We stayed this way for about a year.” She subsequently attempted suicide and separated from her partner, but never confronted him with the fact that she was HIV positive.

It must be appreciated that beyond people knowing their HIV status, there is a great and largely unaddressed challenge, in assisting people to constructively engage in safe sex practices. The once-off nature of HIV counselling and testing does little to manage the complexities of prevention, especially since it is done in the immediate context of people learning of their HIV status for the first time.

This situation plays out also in the context of mother-to-child HIV transmission, giving rise to tens of thousands of infants becoming HIV infected either during the birthing process or through breastfeeding practices.

The epidemiological consequences are obvious and much more thought must be given to how to support HIV positive people through the process of learning their status, such that prevention outcomes are likely to ensue. Unless voluntary counselling and testing procedures are optimised in the interests of prevention, current efforts to promote the population knowing their HIV status will come to little, and may have negative consequences for the epidemic.

Amongst the respondents, the experiences of feeling stigmatised, whether imagined or based on actual responses of others, created an aversion to being open about their HIV status, and this effect of stigma thus also has epidemiological consequences.

A further infection risk issue is posed by the possibility that people with patterns of alcohol abuse may be at higher risk for HIV/AIDS infection as a result of impaired judgment. One might speculate about the risks of other mental disorders, but we have little evidence at hand about HIV sexual risk behaviour related to mental disorders. This is an area worth investigating.

## **Recommendations**

We now outline what we believe are priority actions that need to be taken to address the mental health dimensions of HIV/AIDS. These, we believe, would help to curtail the epidemiological risks described above, as well as improve the health, quality of life and psychological adjustment of HIV positive people.

### ***Re-categorising HIV/AIDS***

For many years HIV/AIDS was spoken about in the media, in communication campaigns, and in popular discourse, as a death sentence. It is now a treatable condition with HIV positive people able to live happy and productive lives.

HIV/AIDS needs to be redefined as a chronic, serious illness condition, which is preventable and treatable.

It appears that much of the mental health mayhem that infuses the experience of learning about one's HIV positive status is a product of the aura of AIDS, which has been 'exceptionalised' amongst other chronic and serious health conditions.

HIV/AIDS is shrouded in secrecy and whilst concerns about confidentiality relating to the condition may be justified given the realities of stigma surrounding the condition, they also feed it.

We believe that if routine (provider initiated) HIV testing were introduced as a part of medical services it would pose some risks in the current environment. Evidence for this is the emotional turmoil of those who discover their HIV positive status. Yet if routinisation were gradually introduced in an environment which brands HIV/AIDS as a manageable condition, the fear and stigma would reduce correspondingly.

### ***Expanded counselling and support***

HIV/AIDS impact mitigation is usually separated as a programme area from HIV/AIDS prevention. Yet by diminishing the mental health impacts on HIV positive people, disclosure and discussion of HIV status, and hence prevention purposes, can be better served.

Currently HIV testing and counselling services are hopelessly inadequate for supporting people through the emotional turmoil of discovering their HIV status. Once-off post-test counselling, sometimes lasting as little as 20 minutes (Magongo et al., 2002) is clearly inadequate and it is of critical importance, even at an epidemiological level, that attention be paid to extending services. This needs to include emotional support, informational support and instrumental support, in other words, practical assistance (cf. Kalichman, Sikkema & Somlai, 1996). Currently South Africa supplies cash support to HIV positive people in the form of a disability grant. While this may provide some relief at a financial level, there has been little justification for this as a response strategy aimed at supporting health adjustment to living with HIV and preventing infection.

A portion of the significant resources currently deployed in this programme would be much more usefully deployed in an expanded programme of counselling and support. There is ample international evidence to support the value of investing in support programmes (Kalichman et al., 1996).

Key issues that need to be addressed in developing programmes of post-HIV testing support are: disclosure of status; dealing with stigma; support in solving relationship problems; prevention as a concern of HIV positive people; and meeting of information needs relating to management of the disease condition.

### ***Mental health integrated into treatment and support programmes***

Improving the mental health of HIV positive people is likely to lead to reduced possibilities of them infecting others, greater involvement in building awareness of the HIV epidemic, reduced morbidity because of access to health and support services, and greater ART compliance. It is also likely to lead to a greater reduction in stigma, thus leading to a reduction in fear about knowing and communicating HIV positive status, which also has prevention value.

Mental health services need to become a central part of comprehensive HIV/AIDS support, care and treatment programmes. Mental health interventions have not been systematically integrated into HIV/AIDS care and treatment programmes in most

developing countries, including South Africa (WHO, 2005; Baingana et al., 2005; Freeman et al., 2005). Important reasons for this include a lack of resources for effective interventions, poor identification of mental disorders, stigma, and a low prioritisation of mental health in health services generally. Critically, planners of HIV/AIDS programmes in developing countries appear unaware of HIV-AIDS/mental health co-morbidity and of the possibilities of improving physical and mental health through mental health treatment.

## **Conclusion**

Evidence has been presented that severity of stress and mental disorders experienced by HIV positive people is not surprising given the way in which the epidemic has been managed. There has been a fundamental failure within society to create a positive environment for responding to HIV, and poor mental health in HIV positive people is a consequence of this. Furthermore, mental health concerns have barely featured in HIV/AIDS response strategies, except as an addendum to be concerned about when all other business is taken care of. Addressing mental health issues is often regarded as a desirable, but not essential or necessary, element of HIV/AIDS intervention programmes. We have presented evidence that there are strong mental health correlates of HIV infection, and that there are significant epidemiological risks if we continue to overlook these in responding to the epidemic.

## References

- Baingana, F., Thomas, R., & Comblain, C. (2005). *HIV/AIDS and Mental Health*. World Bank.
- Catalan, J. (1999). *Mental health and HIV infection. Psychological and psychiatric Aspects*. London: UCL Press.
- Connelly, M. & Macleod, C. (2003). Waging war: Discourses of HIV/AIDS in South African media. *African Journal of AIDS Research*, 2(1), 63-73.
- Cournos, F., & Forstein, M. (eds.) (2000). *What mental health practitioners need to know about HIV and AIDS*. San Francisco: Jossey-Bass.
- DOH (2004). *National Antiretroviral Treatment Guidelines*. Pretoria: National Department of Health.
- DOH (2007). *National HIV and syphilis antenatal seroprevalence survey in South Africa - 2007*. Pretoria: Department of Health.
- Ezzy, D. (2000). Illness narratives: time, hope and HIV. *Social Science and Medicine* 50(5), 605-617.
- Freeman, M., Nkomo, N., Kafaar, Z. & Kelly, K. (2007). Factors associated with prevalence of mental disorder in people living with HIV/AIDS in South Africa. *AIDS Care*, 19(10), 1201-1209.
- Freeman, M., Nkomo, N., Kafaar, Z. & Kelly, K. (n.d.). Mental disorder in people living with HIV/AIDS in South Africa. Under review, *South African Journal of Psychology*.
- Freeman, M.C., Patel, V., Collins, P.Y., & Bertolote, J.M. (2005). Integrating mental health in global initiatives for HIV/AIDS. *Br J Psychiatry*, 187, 1–2.
- Gordillo, V., del Amo, J., Soriano, V. & Gonzalez-Lahoz, J. (1999). Sociodemographic and Psychological Variables Influencing Adherence to Antiretroviral Therapy. *AIDS*, 13, 1763-1769.
- Green, G., & Smith, R. (2004). The psychosocial and healthcare needs of HIV positive people in the United Kingdom: a review. *HIV Med*, 5 (1), 5–46.
- Hargreaves, J.R. (2002). Socio-economic status and risk of HIV infection in an urban population of Kenya. *Trop Med Int Health*, 7, 793–802.
- Kalichman, S.C., Sikkema, K.J., & Somlai, A. (1996). People living with HIV infection who attend and do not attend support groups: a pilot study of needs, characteristics and experiences. *AIDS Care*, 8 (5), 589-599.
- Magongo, B., Magwaza, S., Mathambo, V. & Makhanya, N. (2002). *National Report on the Assessment of the Public Sector's Voluntary Counselling and Testing Programme*. Durban: Health Systems Trust.
- Patel, V., & Kleinman, A. (2003). Poverty and common mental disorders in developing countries. *Bulletin of the World Health Organisation*, 81(8), 609–615.
- Shisana O., Hall E., Maluleke R., Chauveau J. & Schwabe, C. (2004). HIV/AIDS prevalence among South African health workers. *South African Medical Journal* 94(10), 846-850.

Shisana O., Peltzer K., Zungu-Dirwayi N. & Louw J. (eds.) (2005) *The health of our educators: A focus on HIV/AIDS in South African public schools, 2004/5 survey*. Cape Town, HSRC Press.

Shisana, O., Rehle, T., Simbayi, L.C., Parker, W., Zuma, K., Bhana, A., Connolly, C., Jooste, S., & Pillay, V. (2005). *South African National HIV Prevalence, HIV Incidence, Behaviour and Communications Survey, 2005*. Cape Town: HSRC Press.

Williams D.R., Herman A., Stein D.J., Heeringa S.G., Jackson P.B., Moomal H. & Kessler R.C. (2007). 12-Month Mental Disorders in South Africa: Prevalence, Service Use and Demographic Correlates in the Population-Based South African Stress and Health Study. *Psychological Medicine* (Oct), 1-10.

World Health Organisation (2005). *Mental Health and HIV/AIDS. Organisation and Systems Support for Mental Health Interventions in Anti-retroviral (ARV) Therapy programmes*. Johannesburg.

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