Chapter from the book *Current Perspectives in HIV Infection*
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1. Introduction

HIV/AIDS is probably the most challenging and pressing health issue of our time. Current estimates show that over 40 million people are now living with HIV. Despite the availability of antiretroviral therapy, the provision of this treatment continues to pose a big challenge for various reasons. Globally, of the 6 million people requiring treatment, only 8% receive it – with considerable geographical inequity. High income countries vs. low income countries. Despite understanding the risk factors for HIV infection, the incidence of new HIV cases has not reduced at an acceptable rate. An unprecedented number of people still have no access to treatment and continue to die from HIV related problems. This has brought about devastating social and economic consequences at country level, family level and at personal level. A considerable number of individuals suffer from mental disorders resulting from being HIV infected. Independently, mental disorders make a substantial independent contribution to the burden of disease worldwide. The recognition of mental disorders as a major contributor to the global burden of disease has led to an increase in the demand for the inclusion of mental health services in primary health care as well as in community-based health surveys in order to improve screening, diagnosis and treatment of mental distress. It is estimated that, neuropsychiatric conditions account for up to 15% of all disability-adjusted life-years, and up to 30% of those attributable to non-communicable diseases. Neuropsychiatric disorders also account for 1.2 million deaths every year. These figures are most likely underestimated as official statistics especially in low and middle income countries are scanty and unreliable. In sub-Saharan Africa, it has been reported that 20–30% of primary health care centre attendees present with depressive symptoms as the first or secondary reason for seeking medical care. A study conducted in Tanzania revealed a 41.6% prevalence of de-
pressive symptoms among primary health care patients while a similar study in Uganda reported a 20–30% prevalence of psychological disorders and depression among health care seekers. These research findings have also shown heightened risk for common mental disorders among the women i.e. a female to male ratio of 1.5–2.0. Other determinants have been found to include low socioeconomic position indicated by poor access to resources, unemployment and low educational attainment. It has also been shown to be higher among those with poor socio-support networks such as the unmarried, widowed and divorced. Mental disorders interact with many other health conditions, communicable and non-communicable. They commonly affect individuals with medical conditions and have been associated with adverse impacts on several measures of morbidity and mortality. Depressed patients have been shown to have worse physical, social and overall health than other patients. Of particular interest to this chapter is the interaction between HIV and mental distress

2. HIV and mental distress

Early stages of HIV epidemic

In the early stages of the HIV epidemic, the individuals who were affected did not know that their behaviour predisposed them to a potentially fatal disease. The epidemic also mushroomed at the time of a liberal and tolerant culture and dis-inhibited sexual restraint. Hence multiple sexual partners spread the epidemic in communities where these behaviours were more rampant. Intravenous drug use also contributed to the early spread of the epidemic. In the low and middle income countries, factors surrounding poor socio-economic position (poor education and low income) and inability to negotiate for condom use due to the disparity between the male and female gender have emerged as stronger predictors. Several early and recent epidemiologic studies elucidated these risk factors and more concerted effort was placed on public education directed at prevention. Other more recent innovations directed at rolling-back HIV infection have included massive male circumcision campaigns, innovation directed at the girl child to reduce early teenage pregnancies and early marriages and the introduction of Highly Active Anti-Retroviral Therapy (HAART). Recently efforts have been directed at the role mental distress plays in determining acquisition of HIV infection, initial individual’s reaction and post-infection adaptation. Further poor mental health has been associated with subsequent development of AIDS.

Mental distress

Mental distress in the context of this book chapter refers to a term used by users of mental health services as well as some mental health practitioners in describing a wide array of experiences of a patient's life that commonly manifest as somatic symptoms and held to be out of the ordinary, distressing, troubling or confusing for the patient, without actually being ill in the medical sense. Chipimo and Fylkesnes identified some of the common causes of mental distress in a study conducted among primary health care centers in Zambia. (Table 1)
<table>
<thead>
<tr>
<th>Category of factor</th>
<th>Frequency</th>
<th>Symptoms/comments</th>
</tr>
</thead>
<tbody>
<tr>
<td>Worries about money</td>
<td>51</td>
<td>Concerns about rent, day-to-day living, school fees</td>
</tr>
<tr>
<td>Problems of the mind</td>
<td>47</td>
<td>Recurrent headaches, sleeplessness, unhappiness, trouble thinking, loss of appetite, night mares</td>
</tr>
<tr>
<td>Unknown cause of symptoms</td>
<td>32</td>
<td>Most common among informants not acknowledging symptoms as an illness or as mental distress, suggested witchcraft</td>
</tr>
<tr>
<td>Relationship with spouse and family members</td>
<td>26</td>
<td>Commonest among women, included crying more than usual, unhappiness, headaches, sleeplessness.</td>
</tr>
<tr>
<td>Ill health</td>
<td>24</td>
<td>Sleeplessness, daily life suffering, inability to play useful role in life, tiredness</td>
</tr>
<tr>
<td>Low self-esteem</td>
<td>16</td>
<td>Worthlessness, loss of interest, unhappiness, crying more than usual, difficulty enjoying daily activities, experience of stigma</td>
</tr>
<tr>
<td>Recent life events</td>
<td>6</td>
<td>Bereavement, divorces, newly diagnosed with chronic disease including HIV. Included symptoms of restlessness, sleeplessness, trouble thinking, headache, unhappiness</td>
</tr>
</tbody>
</table>

Table 1. Factors associated with Mental Distress as identified by the informants (Chipimo & Fylkesnes, 2011)

The term mental distress is seen by users of mental health services as less stigmatizing as it fits better with the social model of disability, since everyone experiences mental distress at one time or the other. The other synonym is psychological distress. The term is also often preferred as they feel it better captures the uniqueness and personal nature of their experiences. Mental distress is often thought of as being a concept with a wider scope than the regularly used traditional term, mental illness. The later being a specific set of symptoms medically defined in psychiatry, for example: Mania, schizophrenia, anxiety disorders, depression etc. Difficult life situations such as: poor social-support structures, bereavement, stress, poor sleep, drug and alcohol abuse can induce mental distress. These inducers could be temporary and resolve without further medical intervention. However individuals who have protracted episodes and endure such symptoms longer are more likely to be diagnosed with mental illness. This definition is not without controversy and often these terms are used interchangeably.

Double tragedy

Mental distress has been recognised as a crucial factor to some individual’s ability to modify their behaviour to prevent HIV infection. With effective treatment options now available, care for HIV has become more dynamic and has transformed the HIV squeal from terminal care to chronic care. This further complicates the scenario as mental disorders have further been recognised as severely complicating treatment. These factors work in tandem with HIV causing direct damage on the brain, creating turmoil in the lives of the infected and further exacerbates mental disorders. Further the mental disorders reduce the individual’s ability to effectively change behaviour thus increasing the risk of infection and morbidity. Published
literature showing that individuals with pre-existing mental disorders are at increased risk for contracting HIV/AIDS has been largely indirect. However consistent reports from several countries have suggested that individuals with mental disorders have a higher sero-prevalence for HIV/AIDS and that mental distress generally precedes HIV infection. This is valid given that significant risk of HIV transmission exists within an individual’s network. Frequencies of 30-60% behavioural risk factors that have been identified among individuals with mental distress include: high rates of unprotected sexual contact, poor adherence to condom use and injection-drug abuse. In a study conducted among gay men with depressive symptoms, use of alcohol and drugs before sex were identified as independent predictors for sero-conversion. In a systematic review comparing an HIV sero-positive group and HIV sero-negative control group, the prevalence of depression in the sero-positive group was two times higher than in the sero-negative (OR 2.0, 95% CI 1.3-3.0).

3. Aetiology of HIV related mental distress

HIV related mental distress can occur in multiple phases in which premorbid psychological and social adjustment issues play a vital role. Additionally other social factors such as household income, culture, religion and family circumstances also influence and can alter an individual’s reaction to a diagnosis of HIV and subsequent adaptation to living with the diagnosis. The same factors have also been shown to influence and pose high risk of being infected with HIV. Put together all these factors singly or severally affect the clinical presentation and management of HIV patients. It is as such imperative that these factors are addressed and assessed in both the Voluntary-Counselling-and-Testing (VCT) and in the pre-HAART assessment. A self-perpetuating cycle (figure 1) of increasing morbidity appears to occur between HIV and mental distress; HIV infection leads to development of mental distress and/or pre-existing mental distress predispose to HIV infection. In their study, Chipimo and Fylkesnes (2009) showed that HIV infection has both a direct and indirect effects on genesis of mental distress.

Direct effect

HIV infection has been known to affect all other organ systems in the human body and is said to have replaced syphilis as the “great imitator” in the central nervous system (CNS) and almost any psychiatric or neurological presentation is possible. The CNS is the second most commonly affected organ in patients with AIDS. HIV can cause direct organic brain tissue damage thus leading to the development of mental disorders (Psychotic and non-psychotic). Virtually any mental disorder is possible. Among the most notable are depression and anxiety, personality disorders and dementia. The mechanisms explaining the development of these mental disorders are largely poorly understood but the presence of HIV-1-binding sites in the brain (chemokine receptors) allows HIV-1 to infect macrophages and microglia. It is however thought that it does not affect neurons, although neurons are injured and die by apoptosis. The pathway to neuronal injury is thought to be through release of macrophage, microglial and astrocyte toxins alongside the contribution of direct injury on
the neurons by viral proteins. These toxins overstimulate neurons, resulting in the formation of free radicals and excitotoxicity, similar to other neurodegenerative diseases.

Many HIV related opportunistic infections may involve the brain and lead to mental disorders. The four most frequent conditions are toxoplasmosis, progressive multifocal leukoencephalopathy (PML), cryptococcosis and cytomegalovirus infection. Although the incidence of these infections among patients with AIDS has decreased in the past years as a consequence of the introduction of highly active antiretroviral therapy (HAART), they remain a major cause of morbidity and mortality in this patient group. However, highly active antiretroviral drugs themselves such as, Zidovudine, Didanosine and Effervirenz have been associated with development of manic episodes.

**Indirect effect**  
Chipimo and Fylkesnes (2009) studied the relationship between HIV and mental distress in a population with high prevalence of HIV infection and low awareness of own HIV sero-status. In this study structural equation modeling (SEM) was used to establish the relationship between HIV infection and mental distress using maximum likelihood ratio as the method of estimation. The model indicated that underlying factors such as residence (rural or urban), level of education, marital status and age were inter-correlated as determinants for mental distress. Further Mental distress was found to be directly related to self-perceived risk and worry about being HIV infected, HIVsero-status and self-rated health. Further indirect inter-relationships were also found between self-rated...
health, self-perceived risk and worry about being HIV infected, and the underlying factors, namely age, residence, socio-economic position and education. Therefore self-rated health and self-perceived risk and worry about being HIV infected appear to be important mediators between underlying factors and mental distress. They are also important mediators between HIV status and mental distress. The results suggest that HIV infection has a substantial effect on mental distress both directly and indirectly. This effect was mediated through self-perceptions of health status, found to capture changes in health perceptions related to HIV, and self-perceived risk and worry of actually being HIV infected.

4. Prevalence of HIV related mental distress

Prevalence studies conducted world over have shown that when compared to the general population, mental disorders where considerably higher among the HIV infected individuals. However most of these studies have been conducted in the high income countries where the disease burden is relatively low and confined to selected groups for example Injection drug users and Homosexuals. Similar data in sub-Saharan Africa, where the HIV epidemic has its worse impact is limited. Therefore, given that mental disorders manifest in the majority of HIV infected individuals over the course of the illness, a simple assumption would then be that the prevalence reported in published studies represent an underestimate of the actual prevalence. A meta-analytic study identified 13 studies on mental disorders and HIV infection in low and middle income countries. The prevalence of mental disorders varied widely among these studies. Most of the studies done in Africa with HIV positive participants have shown differing but high percentages of mental distress, for example, Orange free state, South Africa 40%, rural Ethiopia 14% and Botswana 28%. In a study done in Zambia, Chipimo and Fylkesnes (2009) found a 13% prevalence of mental distress within the general population with a 2.0 higher odds ratio among the HIV infected. In Uganda, Musisi et. al. (2006) showed a 42% prevalence of depression among HIV infected individuals while in another study, Musisi & Kinyanda reported a prevalence of 41% among HIV infected adolescents.

5. Presentation of HIV related mental distress

Diagnosis of mental disorders in HIV infection is a relatively rarely made diagnosis in sub-Saharan Africa. Studies have reported that physicians tend to be oblivious to psychological problems in HIV in the presence of a physical ailment. Further, the clinical presentation of mental distress in HIV infection presents a diagnostic challenge. This is often because the clinical Indictors of mental disorders are often masked by the symptoms of HIV infection. It is also a challenge for health care providers to distinguish between mental distress and grief. This calls for careful history taking that probes for previous history of mental disorders in
the patient, suicide attempts, family history of mental illness, poor social support structures and a history of recent adverse events (deaths in family, physical violence, divorce, stigma).

**Symptoms**

Several studies have shown that mental distress often presents as somatisation. In a population based survey, Chipimo and Fylkesnes (2009) reported that the most frequently reported symptoms among the HIV infected were:

1. difficulty enjoying life,
2. feeling that their daily life was suffering,
3. poor sleep
4. low energy levels.

Among patients attending Primary Health Care, the most commonly reported symptoms observed by Chipimo and Fylkesnes (2010) were:

1. feelings of unhappiness,
2. loss of interest,
3. inability to enjoy daily life,
4. poor sleep
5. frequent headaches

Women reported these symptoms more than men in both studies. Musisi and Akena (2009) reported similar battery of symptoms and further added that, an otherwise asymptomatic HIV infected individual presenting with symptoms of fatigue and insomnia should be assessed for severe depression. These and other more pathognomonic symptoms put together allow clinicians to make a diagnosis of a full blown psychiatric disorder. The recognised HIV related psychiatric disorders are:

1. Anxiety disorders and depression
2. Psychotic disorder (Primary or secondary)
3. HIV-related Mania
4. HIV-related Dementia
5. HIV-related Delirium
6. Drug abuse ie. Substance and Alcohol abuse

**6. Impact of HIV related mental distress on course and prognosis**

There is a general lack of reported/published follow-up studies on HIV related mental distress. However left untreated mental distress has an effect on the cell mediated immunity,
where it causes impairments in T-cell mediated functions, reduced natural-killer cell counts and cytotoxicity. Depression in particular, has reproducibly been associated with decreased numbers and altered functioning of natural killer lymphocytes. It can also lead to an increase in activated CD8 T lymphocytes and viral load. By so doing mental distress can predict the onset and progression of both physical and social disability in HIV infection. Further, Co-morbid mental distress can delay health seeking hence reducing the likelihood of diagnosis and so can affect treatment and outcome in HIV infection. They may also adversely affect adherence to medication and activities to prevent disease and promote health.

7. Management

Mental disorders episodes are known to cluster around specific times in the course of the illness, such as, the period of diagnosis of HIV, period when the infected individual starts declining in health or the period in the early stages of HIV dementia. However, an episode of mental distress can occur at any point in the course of the illness. In the early stages social support alone can suffice alongside psychotherapy. However, in the later stages anti-depressants such as Imipramine or Amitriptyline can be used. Selective serotonin re-uptake inhibitors such as Fluoxetine may also be prescribed.

However the mainstay of management should fall around the time of diagnosis with adequate pre and post testing counseling surrounding the HIV test. The HIV counseling process should also be optimized to conditions that allow for higher acceptability of the counseling process. A Clinical trial study conducted in Zambia showed higher acceptability for Home-based-Voluntary-Counseling and testing as opposed to facility based counseling. Such innovative means of facilitating the counseling process will by induction lead to better acceptance of the HIV sero-status thus preventing subsequent maladjustment disorders. This has been shown in literature to reduce the risk of suicide at the initial diagnosis. Additionally follow-up counseling at every stage in the disease process emphasizing safer sex should be promoted alongside care giver support. This support should especially be extended to the most vulnerable; the women, children, orphans and those of low socio-economic position in society.

8. Conclusion

Mental disorders are common place in HIV infection and potentiate the course, progression and prognosis of the HIV disease process. The direct and indirect impact of HIV on the infected individual has conversely also been associated with mental distress episodes. Mental disorder and HIV/AIDS also have a lot of socio-demographic factors in common that have been attributed to each of their development. Therefore, a combination of these two disease entities leads to devastating morbidity and mortality, especially in the most affected communities. This thus emphasizes the need for prompt screening, diagnosis and treatment of mental distress in HIV infection.
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References


