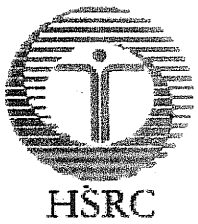
COPING PSYCHOLOGICALLY WITH BEING HIV SERO-POSITIVE: A STUDY OF LIVED EXPERIENCE, SUPPORTIVE AND AGGRAVATING FACTORS.



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CHAPTER 1

Introduction

HIV/AIDS has had unprecedented impacts in sub-Saharan Africa. Out of 40 million people estimated to be infected with HIV globally, 70% are found in the region (UNAIDS, 2003). Morbidity and mortality patterns have been dramatically transformed and development, the economy, human resources and education have all been detrimentally affected – and the worst is still to come *But what about the personal impacts? How is HIV affecting the internal lives of individuals and how does this impact on how they act on their world? What is helping people cope psychologically and what factors are making life more difficult for them to cope with?*

These are extremely important questions yet have received little attention in developing countries. The significance of these concerns can be reflected upon at three important levels. Firstly mental health is an integral part of health (as reflected in the WHO definition of health). In order to treat any health problem effectively (including mental health problems) one needs to identify the problem, understand it and intervene - based on good evidence of effectiveness. This includes mental health problems. In developing countries there is inadequate identification, understanding and intervention. Secondly, mental and physical health outcomes are closely intertwined. Poor mental health is likely to have an important bearing on disease progression (including HIV progression) and adherence (including adherence to anti-retroviral medication [ART]). Treating and preventing mental health problems is thus a critical holistic health intervention. Thirdly, people are both formed by the world they are born into and live in and are part of forming and changing it. Creating and transforming environments into productive and vibrant places requires productive and vibrant people to do it. Often people with mental disorders or in high states of stress or distress are poor actors and transformers of their personal and social environments. If anything, they are likely to allow the environment around them to get worse rather than better. Assisting people personally can thus become an important social, as well as personal, intervention.

Freeman (2004) has identified five "categories" of people whose mental health is likely to be detrimentally affected by HIV/AIDS. These are i) people unsure of their HIV status, ii) people living with HIV/AIDS, iii) families and caregivers of HIV-infected people, iv) people left behind following AIDS-related deaths (including children) and v) society as whole. While some research has been conducted on the mental health/HIV interface, especially in developed countries, the mental health impacts of HIV/AIDS in countries that have high HIV prevalence rates remains largely unknown. Research is needed in each of the above categories so that effective interventions can be implemented. However this research focuses only on the mental health and well being of people living with HIV/AIDS.

The research has two complementary components – one quantitative and the other qualitative. In the quantitative section the prevalence of mental disorders in 1000 people living with HIV/AIDS is assessed. Factors which help people to cope or make coping more difficult were assessed through a structured/semi-structured interview and statistically analyzed. Mental health risk factors for developing HIV/AIDS were analyzed.

In this component the "voices" of people infected with HIV/AIDS are heard. Through in-depth interviews the *lived experiences* of people is documented. Respondents talk about their feelings and behaviour since their diagnosis and, as in the quantitative interview, supportive and aggravating factors to coping are explored. However, unlike the quantitative interview, in this section subjects were encouraged to identify and explore various directions of their own choice. While the qualitative interviews stand as important results in their own right they were also utilised to structure the quantitative questionnaire.

Living with HIV/AIDS

There are a number of reasons why people living with HIV/AIDS may develop mental health disorders/problems. In a proportion of people, cognitive impairment and dementia arise due to viral infection of the brain. Psychosis in late stage AIDS occurs in some people. Depression, anxiety and substance abuse may occur due to the impact of the infection on the person's life. There are side effects of anti-retroviral therapy

which effects some individuals, and social difficulties and stigma make coping with HIV/AIDS extremely difficult for some people - leading to severe distress or even mental disorder. Moreover the "stage" of disease progression, as well as how long the person has been aware of their status, are likely to bare on mental health. There have been some changes in mental health in developed countries since the introduction of antiretroviral therapy, however this has not alleviated problems. As people with HIV live longer due to improvements in treatment, they often experience social and emotional problems resulting from symptomatic illnesses, stigmatisation and relationship problems (Kalichman et al., 1996; Walker, 2002).

Not everyone who is living with HIV/AIDS develops marked mental health problems. Clearly there are complex reasons for this. "Resiliency" factors, a person's biological make-up and previous life history are all important. Notwithstanding, an important question is "are there identifiable circumstances which protect people living with HIV/AIDS from developing mental health problems"?

Moreover, not all HIV/AIDS/mental health co-morbidity is uni-directional. While clearly some mental health problems identified in HIV positive individuals are a direct or indirect result of being infected, for some people mental disorder may have pre-existed HIV and may even have predisposed the individual to the infection.

PREVALENCE OF MENTAL DISORDER IN PEOPLE LIVING WITH HIV/AIDS

What proportion of people living with HIV or AIDS have mental health problems/disorders? What are these disorders and why do they arise?

In this section results from epidemiological and qualitative studies, rather than qualitative research, are documented.

Evidence from developed countries

The study of mental health and HIV/AIDS in developed countries can largely be divided in two distinct phases - "pre HAART" (Highly Active Anti-retroviral Treatment) and "post introduction of HAART". Reasons for this are firstly that the neuropsychiatric progression of HIV is fundamentally linked to treatment and secondly because peoples' psychological responses to living with HIV/AIDS are influenced by the availability of treatment and its sequelae. As a result, since the mid-to-late 1990s, rates of certain mental health problems have changed, content of the psychological issues faced by people living with HIV/AIDS has changed and treatment approaches have been adapted.

Five major disorders have dominated the literature on mental health and HIV/AIDS. These are mood disorder, anxiety disorder, neurocognitive disorders, substance abuse and severe mental illness.

Mood disorder

Depression is the most frequently psychiatric complication associated with HIV disease (APA Fact sheet, 2002), however prevalence has varied across studies depending on the instrument used, sample utilised (e.g. health care verses community based studies), stage of disease, criteria for defining depression, gender, socio-economic status of respondents, ART utilisation and so on. According to Halman (2001) depressed mood may reflect intrapsychic distress associated with living with HIV/AIDS with its uncertainties and stigma, may be associated with physiological changes directly associated with medical illness or may be a symptom of a major depressive episode. Major depression results from a coming together of a person's diathesis to developing depression and the psychosocial stressors they are facing (Halman 2001).

The following table summarises some important studies on mood disorder in developed countries.

Author	Year	Study Population	Sampling	Instruments	Prevalence Rate Mood Disorders			Rate In general Population
					Depression	MDD	Dysthymia	
Lipsitz, JD	1994	male (85 HIV-positive and 62 HIV-negative) and 76 female (39 HIV-positive and 37 HIV-negative) intravenous drug users, USA	Clinical population at HIV Centre	Structural Clinical Interview for DSM-III-R and measures of psychiatric symptom severity, global functioning, and stress	Current overall rate 26% HIV+ men 33% HIV- men (16%) HIV+ women 26% HIV- women 30%.			Greater than in the general community, but not greater than in other studies of intravenous drug users.
Perkins	1994	Asymptomatic, HIV+ (n=98 and HIV- (n=71) gay men	Community	Clinical, psychiatric and neuropsychological battery	Not reported	Current MDE 8% (HIV+) 3% (HIV-) 6mnth f/up 9%(HIV+) 3%(HIV-)	Not reported	Mood disorder high in HIV+ persons relative to gen population
Rabkin, J.G.	1997	112 HIV+ and 84 HIV- volunteers	Community	SCID Hamilton Rating Scale for Depression Beck Hopelessness Scale	Any Depressive D/O HIV+ 17% HIV- 15 %	MDE only HIV+ 3% HIV- 8 %	Dysthymia Only HIV+ 10% HIV-5 % MDE and Dysthymia HIV+ 0% HIV- 4%	
Johnson, JG	1999	187 intravenous male and female drug users, 82 HIV- and 105 HIV+	Clinical methadone clinics and medical centers (43 remained for study duration)	SCID DSMIII-R		1MDE 105 HIV+ 37% 82 HIV- 22% recurrent MDD 105 HIV+ 14% 82 HIV-5%		

Author	Year	Study Population	Sampling	Instruments	Prevalence Rate Mood Disorders			Rate In general Population
					Depression	MDD	Dysthymia	
Sherbourne	2000	HIV+ urban and rural men and women with at least one visit to medical provider (n=4042)	Clinical Representative multistage sampling (area, practitioners patients)from the HIV Cost and Services Utilization Study (n=2864 representing 231,400 HIV+ people)	WHO Composite International Diagnostic Interview, short form.		12 prevalence 36%	12 month prevalence 26%	Not reported
Alciati	2001	110 HIV+ men and women on HAART	Clinical Consecutive, Outpatient infectious diseases hospital unit (n=90)	Structured Clinical Interview for DSMIII-R Non-Patient Version (SCID-NP) Zung Self-Rating Depression Scale (ZSDS)	Current Depressive D/O 4.4% (SCID-NP) Adjustment D/O with depressed mood 2.2%(SCID-NP)	None	2.2%(SCID-NP)	13% Ballenger, et al, 1999) and 18.7% Balestrieri, 2004 in primary care patients

Author	Year	Study Population	Sampling	Instruments	Prevalence Rate Mood Disorders			Rate In general Population
					Depression	MDD	Dysthymia	
Bing	2001	HIV+ urban and rural men and women with at least one visit to medical provider (n=4042)	Clinical Representative multistage sampling (area, practitioners patients)of from the HIV Cost and Services Utilization Study (n=2864 representing 231,400 HIV+ people)	University of Michigan Composite International Diagnostic Interview (UM-CIDI), brief screener	12 month prevalence	12 month prevalence 36%	12 month prevalence 26.5%	Previous National estimates not available
Ciesla	2001	Data from10 published studies 1888-1998) on relationship between HIV infection and risk for depressive disorders	Clinical PyschInfo Medline and AIDSLINE literature search (HIV+ and HIV- , diagnostic interviews, ME and Dysthymia reported)	3 Meta-analytic techniques(vote counting, study size effects, probability levels) to aggregate and reanalyze data		(N=2596) Vote counting HIV+9.4% HIV- 5.2% (p<0.001) *study size effects* HIV+ 1.99 times more likely to have MDE than HIV-, significant *probability levels* Highly significant relationship between HIV status and MDE risk (p[z≥3.79],0.0001,)	(n=1,822) Vote counting HIV+ 4.2% HIV- 2% (p<0.001) *study size effects* HIV+ 0.28 times more likely to have MDE than HIV-, non significant *probability levels* Unclear if above relationship between HIV status and Dysthymia is significant	No national prevalence, reported rates in past 15 years from 0%-47.8%.
Morrison	2002	163 pre telephone screened HIV infected and un-infected women 18-70 years	Clinical Outpatient medical clinics and community (outreach presentations) HIV+(93)and HIV- (62) women (95% of screened)	Modified SCID fir DSM IV 17 item Hamilton Depression rating Scale.	Current NOS HIV+ 2.2% HIV- 0.0%	Current MDE HIV+ 19.4% HIV- 4.8% Life time prevalence HIV+ 47.3% HIV- 38.7%	Current HIV+ 4.3% HIV- 3.2%	Reported prevalence rates from 1.9% to 35% in clinical samples, and from 30%-60% in community samples

Changes in depression with ART.

Several studies suggest that HAART may be associated with a significant improvement in depressive symptomotology (Alciati 2001). In cross sectional studies Brechd et al (2001), Low Beer et al (2000) and Alciati et al (2001) all found a significant reduction in depression in patients with advanced HIV infection who were receiving HAART. In longitudinal studies, after two years Judd et al (2000), and Rabkin et al (2000) also found decreased depression (though the former expressed caution against drawing too many conclusions due to methodological problems). With longer life and hope for people living with HIV and their families, the despondency and depression of expectant death and later bereavement may be lifted (Rotherham-Borus, 2001). Kalichman, Graham, Webster and Austin (2002) found that people who were not on antiretroviral treatment had a greater level of depression and greater pessimistic attitudes than those on treatment

However, these reductions in depression rates should neither be seen as unequivocal, nor meaning that an HIV diagnosis is no longer "profoundly distressing" (Green and Smith, (2004). Catalan et al (2000) talk about "new and unforeseen difficulties" in the HAART era. At the point that HAART was introduced in developing countries many infected people went through crises of re-adjusting to an extended life expectancy. People had to re-think their futures and adapt to what was called a "second life" (Rabkin and Fernando,1997; Halman et al, 2002). Practical issues such as returning to work, giving up social benefits and planning for old age all surfaced and created problems for people. Reflecting on losses of friends and family members who had died of AIDS and "survivor guilt" surfaced. Uncertainties around the effectiveness of the new medication also led to psychological stressors for many.

In the "post introduction of HAART" period a number of additional issues have arisen for people, leading to varied levels mental health difficulties. In a review of patterns of disorders seen in a central London health centre pre and post HAART, Catalan et al (2000) found that though there was a notable decrease in the proportion of individuals referred for adjustment disorders and organic brain syndromes were seen less often, there was an *increase* in the proportion of people experiencing depressive disorders. These people often required antidepressant medication or psychotherapy. There was

also a steep increase in the numbers of people experiencing sexual dysfunction - often with psychological concomitants. Moreover they point to a number of psychological shifts that they have observed. For example, in the pre HAART people were dealing with issues of their short-term future, With the availability of anti-retrovirals they tend to focus on uncertainty around their futures and anxieties about forming future relationships, disclosure, demoralisation around side effects and so on (Catalan, 2000). As Catalan et al remark "faced with complex treatment regimes, with the risk of unpleasant side effects, and the possibility of treatment failure in spite of high levels of adherence, many will become demoralized and despondent about the new treatments." (p 338). Issues of having children and possibly infecting them, infecting partners, starting relationships knowing that their HIV status will need to be negotiated with the new partner, fear of rejection and sexual dysfunction all may make living an extended life with HIV extremely difficult.

In AIDS Weekly (2002), even in the HAART era, it was reported that more than 80% of HIV-positive patients reported symptoms of depression and anxiety. The report states further that although the psychiatric causes are many and include factors such as direct Central Nervous System (CNS) effects of HIV, CNS opportunistic infections and street drugs, the majority of physicians surveyed believed that HIV medications (antiretrovirals) are a leading cause of their patient's most common mental health problems (84%).

There is a further paradox with the introduction of HAART in that people who are depressed are less likely to adhere to their HIV treatment than people who are not depressed (Ingersoll, 2004; Ammassari et al, 2004). This is likely to lead to a cycle of further depression.

Suicide was found to be extremely high in early studies on mental health and HIV/AIDS. For example in the non-metropolitan areas of Louisiana, over a five year period, suicide rates of people with AIDS was 191 times higher than the general population (Mancoske and Wadsworth, 1995). Cote et al (in Halman 2002) reported suicide rates 7.4 times higher in men with AIDS. Marzuk et al (1997) found that in the early 1990s in New York positive HIV individuals had a two-fold higher risk of suicide than the general population. Twenty five percent of all black or Hispanic men

and 19% of black or Hispanic women who committed suicide were HIV positive. However, according to Mitchell (1999) there has been a decline in the prevalence of suicide and this appears likely to be directly linked with the introduction of HAART.

Suicidal ideation also appears to be much higher in people living with HIV/AIDS than the general population. Kalichman et al (2000) found that 37% of older infected individuals had thought of committed suicide in the week before they were interviewed, while Heckman et al (2002) found that 38% of rural people living with HIV in eight states in the US had thought about taking their life.

Mania

New onset manic episodes appear to be increased in people with HIV and, according to Catalan et al is the most common reason for psychiatric hospitalization (Catalan, 2000). The prevalence of mania in HIV has been estimated to be 1.4% (Lyketsos in Halman, 2002). Prevalence increases at more advanced stages of HIV. The reasons for acute manic episodes are multiple and include a primary bipolar disorder, a medication side effect, an HIV CNS effect, or can be a metabolic or CNS opportunistic condition associated with severe immunosuppression (Halman, 2002).

Anxiety disorders

People living with HIV/AIDS may experience numerous psychological stressors as a result of their illness. According to the American Psychiatric Association, feelings of anxiety are a normal and even healthy response to the diagnosis, onset or progression of HIV related illness (American Psychiatric Association, 2002b). However anxiety may reach clinical levels. The levels of distress amongst people with anxiety disorders may impair their overall functioning and capacity of adequate self care (Karasic and Dilley in McDaniel and Blalock, 2000).

The prevalence of anxiety disorders in HIV/AIDS patients in developed countries range from almost negligible to as high as 40% (McDaniel and Blalock, 2000). People

may experience symptoms of anxiety across the spectrum of anxiety disorders, though many of these disorders will occur no more frequently than the general population. However other anxiety disorders, including post-traumatic stress syndrome, can be prompted or exacerbated by the experience of HIV (American Psychiatric Association, 2002b).

Anxiety may be provoked by the unpredictability of the illness but also by certain "milestones" such as the initial diagnosis, first opportunistic infection, declining CD4 count or the onset or progression of an AIDS defining illness.

Neurocognitive disorders and delirium

Neurocognitive impairment related to HIV disease results from HIV in the brain as well as a host of indirect effects of host immune factors liberated in response to brain and systemic HIV infection (Halman, 2002). HIV enters the Central Nervous System (CNS) early during the course of infection and can be detected in the cerebrospinal fluid of over 90% of asymptomatic patients (Garcia et al in Ferrando, 2000). Up to 35 % of asymptomatic/mildly symptomatic and over 50% of symptomatic patients have neuropsychological test abnormalities (White et al in Ferrando, 2000) while 75% of AIDS patients have brain pathology at autopsy. According to the American Academy of Neurology there are two significant HIV related neurocognitive disorders, HIV dementia and minor-cognitive disorder. The risk of impairment is increased at each successive stage of HIV infection (CDC in Halman, 2002).

In some individuals dementia may be the earliest manifestation of HIV infection. Deficits of HIV dementia include impaired attention and concentration, psychomotor slowing, diminished visuospatial performance, poor complex reaction time, memory disturbance and personality or mood alterations such as apathy and irritability (Weiner and Lipton, 2002).

People with AIDS are also vulnerable to delirium. Delirium may be caused by a range of factors including metabolic abnormalities, sepsis, hypoxemia, anemia, CNS

infections and malignancies, almost all HIV related drugs, opiods and illicit substances as well as initial HIV infection (American Psychiatric Association, 2002c)

Since the introduction of HAART, the incidence of HIV dementia has decreased (Moore in Halman 2002) and HAART is in all likelihood the most effective strategy for treating HIV related brain disorders. Studies by Ferrando et al, Sacktor et al, Tozzi et al (all in Ferrando, 2000) and Cohen et al (2001) have all found that HAART has significantly reduced the course of HIV-associated cognitive disorders. Catalan reported a reduction of the incidence of dementia immediately after the introduction of HAART (Catalan, 2000) In one study (Cohen et al, 2001) it was found that neurocognitive improvements were greater for subjects treated for more than 18 months than for those who received HAART for 12 months or less.

Nonetheless while dementia only occurs in a small proportion of people on HAART, according to Cohen et al (2001) milder HIV associated cognitive and motor impairments are still common, often affecting functional autonomy and quality of life. Moreover, as Halman (2002) points out, while the incidence (new cases) of neurocognitive deficits have decreased, the prevalence of people living with HIV dementia has increased. Many people receiving HAART have experienced only partial improvements of brain functioning, possibly due to variable penetration of anti-retroviral medications to the brain (Ferrando, 2000) and require psychosocial interventions to sustain the benefits of HAART. A study by Dore et al in Australia (AIDS 2003) found that the proportion of AIDS patients with AIDS Dementia Complex increased from 5.2% to 6.8% from the pre HAART (1993-1995) to the HAART (1996-2000) periods

Substance abuse

In developing countries substance abuse, especially intravenous drug use, accounts for a significant proportion of people with HIV. In the USA in 1998 injecting drug use was the second highest HIV risk factor (Ferrando, 2000). In Spain as many as 64% of AIDS cases contracted the virus from use of intravenous drugs (Meteos and Lastra, 1996). It is therefore not surprising that there is a high co morbidity between

substance abuse disorders and HIV infection. In seroprevalence studies in inpatient populations, links between substance abuse and HIV status have been clearly demonstrated (McKinnon and Cournos, 1998).

Studies by O'Dowd et al and Worth and Halman (In Halman, 2002) showed that 42%-45% of ambulatory patients with HIV/AIDS referred for psychiatric evaluation had substance abuse related disorders. Rabkin et al (1997) reported high rates of depression and psychological distress amongst HIV/AIDS patients with substance related disorder.

Severe mental illness

In the US, twelve studies examining HIV seroprevalence among people with severe mental illness have found an infection rate of 7.8% at a time when the prevalence in the general population was only 0.4%, people with mental disorder were thus almost twenty times more likely to be infected (McKinnon and Rosner, 2000). It appears that lack of appreciation of risk, impaired social interactions and lower levels of assertiveness are major obstacles for people with severe mental illness. Psychosocial variables such as homelessness are also risk factors for development of HIV (Susser, 1997).

Onset of psychosis in HIV does occur although it is rare (Halman, 2002). It is probably related to HIV CNS infection, seizure disorder, adverse drug side effects or other CNS complications of HIV. Where this has been studied, 100% of patients had delusions and 90% hallucinations (Sewell et al in Halman, 2002).

Mental disorders of people living with HIV/AIDS in South Africa

To date there have been three quantitative studies (known to the authors) which have looked at mental disorder in people living with HIV/AIDS.

In 1999, Els and colleagues screened 100 HIV infected patients (57% female, 43% male) attending immunology clinics at Pelonomi and Universitas Hospitals in

Bloemfontien using the Mini Mental State examination (MMSE), the Mini International Neuropsychiatric Interview (MINI), the Hamilton Anxiety Scale and the Self-rating Anxiety scale (Els et al, 1999). In addition to prevalence they measured mental disorder relative to disease staging (measured by CD4 T cell count) and time from diagnosis. Psychiatric co-morbidity was identified in 58% of the patients. Thirty five percent had major depressive disorder and 6% bi-polar disorder. A considerable number also screened positive for anxiety disorders – 37% panic disorder; 9% agoraphobia; 15% social phobia, 10% specific phobia; 21% generalized anxiety disorder and 6% post-traumatic stress disorder.

The study found higher levels of depression amongst Stage 1 and Stage 2 patients compared with patients in Stage 3 of the disease. No explanation for this was offered. In addition, stage of disease was associated with dysthymic disorder, bipolar disorder, agoraphobia and social phobia with patients who had been diagnosed for a longer period being at increased risk.

Bganya, in an unpublished M.Med thesis, assessed 115 patients (80 female, 35 male) attending the Ga-Rankua Hospital HIV clinic using the Beck Depression Inventory (BDI) (Bganya, 1999). The interviews were conducted in either English or Tswana depending on the patient's preference. Patients with a score of 17 or more on the BDI were further evaluated using DSMIV/ICD IV criteria. Using WHO staging, 14.8% were in stage II, 20.9 in stage III and 64.3% in stage IV. None of the patients were taking anti-retroviral medication. Over 50% of patients scored above the BDI cut off, but after the clinical assessment 38% of patients were diagnosed as having major depression. Another 6.9% had adjustment disorder with depression and a further 5.2% had dysthymia. According to Bganya this is high compared with patients with other chronic medical diseases such as cancer and renal failure whom she reports as having depression rates in the 24-32% range. Bganya also reports that patients in Stage 4 of the disease showed higher levels of depression than patient's in other stages but it is unclear whether this is at statistically significant levels.

Olley and colleagues evaluated 149 (44 male, 105 female) patients attending an infectious diseases clinic at Tygerburg Hospital, Cape Town (Olley et al, 2003). Subjects were assessed using the MINI International Neuropsychiatric Interview

(MINI), the Carver Brief COPE and the Sheehan Disability Scale, the most frequent disorder diagnosed was major depression (34.9%), followed by dysthymic disorder (21.5%). Over 11% of females and 4.5% of males were at risk for suicide.

A number of anxiety disorders were diagnosed including post-traumatic stress disorder (19% female, 4.5% male), panic disorder (7.6% female, 6.8% male), social anxiety disorder (6.7% female, 6.8% male), and generalized anxiety disorder (6.7 female, 6.8% male). Especially amongst males alcohol problems were identified as a major factor for people living with HIV. Twenty three percent of males were diagnosed as alcohol dependent while 20% of males had alcohol abuse problems.

In addition to these three studies some research has been conducted in South Africa with regard to the prevalence of HIV amongst people with serious mental illness. Unlike findings in the USA, rates of infection have not been found to be higher than in the general population (De Villiers (2001), Singh (2000), von Brandis-Matini (2001). However such research needs to be repeated at regular intervals and in both community and hospital samples as the risk for spreading the virus amongst this population is high.

RISK AND PROTECTIVE FACTORS

Not everyone who is HIV positive has mental health problems, hence finding answers to two related questions may assist with prevention of mental disorder in HIV positive people. Firstly what are the risk factors for developing mental disorder and secondly what protective mechanisms can be utilized to reduce the incidence of mental disorder in people living with HIV/AIDS. In this research we are not looking so much at "internal" protective mechanisms (for example internalized coping behaviour patterns, locus of control etc) but rather external factors such as social support and whether counseling has been beneficial. Moreover the impacts of factors such as whether the person has disclosed their sero-positive status (and to whom) and their religiosity are explored.

Social Support

Social support appears to be crucial to the mental health of people living with HIV and has been identified as an important indicator of quality of life for people living with HIV (Heckman et al., 1997). This support may come from various sources such as family, friends, spouses or relationship partners, formal care-givers etc. (Johnston et al in Kalichman et al., 1996).

Linn et al. [in Kalichman et al (1996)] have identified three types of social support. *Emotional* - which is characterised by affection, moral support and encouragement; *informational* – which improves knowledge; and *instrumental support* - which involves practical assistance such financial and other kinds of tangible support. All three have been demonstrated to ameliorate psychological distress amongst people with chronic illnesses (Cohen, 1988; Green, 1993; Meyerowitz in Kalichman, 1996).

Serovich et al. (2001) have found a strong relationship between perceived support and mental health. Using a quantitative methodology to measure perceptions of social support from family and friends amongst HIV positive women, they found that perceived social support was more significant than the availability of actual support. Furthermore, compared with support from friends, support from family was correlated more strongly in terms of reduced depressive symptoms, anxiety, stress and loneliness. In another study, participants found that "seeking out family and friends" assisted their ability to cope with life (DeMatteo et al., 2002).

The relationship between emotional support and good health amongst people living with AIDS has been demonstrated in a number of studies (Zich & Temoshock in Friedland, Renwick, & McColl, 1996). Friedland et al (1996) also found a strong relationship between emotional support and quality of life in a sample of people living with HIV/AIDS, however even though respondents reported satisfaction with emotional support, they still wanted more.

Conversely, tangible social support negatively correlated with quality of life measures. The researchers discovered that the more tangible support that is required,

the greater the possibility that people living with HIV and AIDS view their health negatively. In turn their perception of quality of life is likely to be lower.

Support groups

In the case of HIV and AIDS, support groups are another crucial site for social support. Support groups come in different forms with regard to numbers of people, whether they are open or closed, whether they are time limited or continuous and so forth (Foster et al., 1994; Land & Harangody, 1990 in Kalichman et al., 1996). They may also be directed to specific target groups such as gender or staging of HIV (Kalichman et al., 1996). There is little evidence that one form of support group is more effective than another and, depending on the circumstances, different kinds of groups are appropriate.

Moreover there is little evidence to show that any particular theoretical model for support groups is preferable – though support groups are better than no treatment. In a study that compared a social support group modeled on supportive psychotherapy against a coping skills group based on cognitive behaviour therapy, Kelly et al. (1993) demonstrated that they both resulted in improved psychological adjustment when compared to a no treatment condition group. In addition Kalichman et al. (1996) compared 'attenders' and 'non-attenders' of support groups on measures of distress, coping and social connectedness and found that 'non-attenders' reported more distress, and utilised an avoidant coping strategy. They also manifested lower self-esteem, loneliness, and somatic depression versus 'attenders' .

Religiosity

Somlai et al. (1996) has found that people living with HIV/AIDS are more inclined to participate in religious activities than the general population. Other studies have found that spiritual or religious activities affect perceptions of well-being and adjustment amongst people living with HIV/AIDS (Carson et al, 1990; Kendall, 1994). People that live with HIV for a long time and manifest an ability to be resilient against stressful events also exhibit a healthy spiritual life (Carson et al., 1995).

According to Hall (1998) three spiritual themes have become apparent amongst people living with HIV and AIDS, namely: 'new spiritual meanings', 'incorporating illness into self-concept of spiritual being' and an understanding of life that is influenced by spirituality.

In an investigation of the relationship between quality of life and spirituality/religiosity through utilising scales that measure prayer, alternative practices, formal religions, spiritual beliefs and issues regarding divine justice, Somlai et al. (2000) found that prayer, 'strong beliefs in life after death', 'believing that a higher power cares for them', possibility for miracles, and belief that HIV is not punishment from God were very significant for people living with HIV and AIDS. Furthermore they found a relationship between spirituality and support from family. This relationship, in turn, increases the likelihood that the people concerned will demonstrate positive problem solving strategies and satisfaction with life.

Mathews et al. (1998) have found a significant relationship between religiosity and coping with a physical illness. Religion was found to provide an important source of social support, especially amongst individuals that are involved or engaged with spiritual activities (for example, church and prayer groups) (Mathews et al. in Somlai & Heckman, 2001). According to these writers the support that the churches provide is instrumental, informational, and emotional (for example financial assistance, spiritual support etc). Lazarus and Folkman (1984) have highlighted the importance of incorporating a spiritual component into quality of life improvement programs for people living with HIV.

Disclosure

Across a number of studies concerns regarding disclosure have been found to create difficulties in psychological adjustment after diagnosis of HIV (for example, DeMatteo et al., 2002; Walker, 2002; and Green & Smith, 2004). Fear of stigmatization and rejection are common reasons given for lack of disclosure (Walker, 2002; Green & Smith, 2004). In a study with HIV positive mothers, fear that their

children might be stigmatised in the community or by other family members was another reason given for non-disclosure (DeMatteo et al., 2002).

From research thus far it is not possible to assert that either disclosure or non-disclosure has a bearing (whether positive or negative) on psychological health. Clearly the *circumstances of disclosure* is most critical.

A number of studies have shown that complete lack of disclosure reduces opportunities to receive social support and could lead to social isolation (Bennet-Murphy et al., 1999; Green & Smith, 2004). The importance of receiving social support has already been discussed (See social support above). Moreover non-disclosure acts as a barrier against seeking psychological help (Bennet-Murphy et al., 1999). On the other hand if the response received to disclosure is extremely negative, psychological distress may result (Nyblade L et al 2003). Bennett-Murphy et al (1999) found that psychological adjustment of women infected or affected with HIV was unrelated to whether the person had disclosed, nor to the number of people respondents had disclosed to, however disclosure was related to high perceived stress and low efficacy in managing caregiving demands..

According to Bennet-Murphy et al (1999) partial disclosure within families could isolate family members; create fear and confusion, and may act against the development of trusting and satisfying relationships.

CHAPTER 2

STUDY DESIGN

Aims

The study explored the following main questions:

'What do people diagnosed HIV positive go through from a psychological perspective?'
'What helps them to cope?'
What makes coping with HIV/AIDS more difficult?

Methodology

Subjects

In-depth interviews were conducted in Gauteng and the Eastern Cape with 19 HIV sero-positive individuals. (A 20th interview was conducted but was later found to be unsuitable for analysis) Twelve (12) females and 7 males with average ages of 32 and 33 respectively formed the study population. Out of 19 respondents, 3 people were employed full time. The respondents were more or less evenly distributed in terms of marital status between being married, single and widowed.

Procedure and instrument

Respondents were individuals with known HIV sero-positive status attending public health services or were recruited by non-governmental organisations dealing with people living with HIV/AIDS in the two provinces. Those recruited through public health services were attending 'wellness clinics' or health services for opportunistic infections. The study was explained to groups of people waiting for treatment and

Chapter 3
RESULTS

EMOTIONAL/PSYCHOLOGICAL RESPONSES TO LIVING WITH HIV/AIDS

Respondents were interviewed regarding emotional/psychological responses to being HIV positive. Interviewees were asked to speak about periods prior to their HIV diagnosis, immediately after being diagnosed and a period (not time dependent) from the initial diagnosis[2].

Diagnosis of mental health problems prior to knowledge of HIV status

Few respondents reported serious mental health problems before they were diagnosed with HIV. Those that reported mental health problems were linked to identifiable stressors. One respondent for example had been raped twice in her childhood and had received no professional help until she became an adult. This manifested in maladaptive ways of coping. She was later diagnosed with depression and received counselling.

A second respondent was also diagnosed with depression and although she did not state where it stemmed from, she said that she knew what was behind her depressive mental state. A third respondent had attempted suicide even before she was diagnosed HIV positive and had suffered from depression. The respondent had had a 'difficult childhood', as well as a string of unsuccessful and abusive relationships.

Most respondents reported that at some points in their lives they had either felt depressed or stressed. Sources of stress include unemployment, financial difficulties

[2] There is clearly overlap in the latter two stages for many respondents and though reported on here as independent phases, it is clear from the discourse that there is an interweaving of periods.

subjects were randomly chosen from these groups. Informed consent was obtained before proceeding with the interview.

Interviews were conducted in the language of choice of the respondent. They were conducted either by a registered clinical psychologist or by masters level students under the supervision of a clinical psychologist. Tape recording of the interviews were made, translated and transcribed.

The aims and objectives of the study were discussed in detail with the interviewers prior to the interviews and the areas which needed to be covered by the interview were discussed with them. A set of questions to guide the interview were used as necessary by the interviewees. However, for the most part interviews were unstructured and interviewees were encouraged to move with the flow of the person in order to get as much in-depth information about their psychological state and ways of coping as is possible within a single interview.

The themes of the interview cover the period before diagnosis, the initial stage of living with HIV, as well as the ongoing experience of living with HIV.

The Atlas.ti programme was utilized for the analysis. This involved arranging the data into codes from which themes were identified.

and marital problems. For instance, one respondent reported that her husband's unfaithfulness led her to misuse alcohol and to multiple relationships. Unemployment is also another factor cited as a source of stress and frustration for a number of respondents. Most respondents have never been able to maintain employment or have a reliable source of income. In fact when the interviews were conducted only 3 people were employed.

For most respondents stressors linked to HIV came on top of their economic and existing relationship problems.

Finding out about HIV status

Most respondents had known about their status for at least a year and others had been diagnosed as early as 1992 and 1994. Two respondents were diagnosed in 2004.

The most common pattern for testing seems to have been illness (sometimes hospitalisation) or falling ill during pregnancy with recommendation for testing by a health professional. In one case the husband became ill and went for a test while in another case, the parents were alerted to the fact of their status through their child becoming ill, and when they were tested, they were diagnosed as HIV positive.

Reasons for testing included a sense of wanting to unravel whether a "mysterious disease" (HIV) was plaguing one and wanting to know if they are actually HIV positive as this is perceived to be better than being in the dark about one's status. One respondent went for a test after she was sexually assaulted.

Initial reactions

Even though there are differences between respondents in the manner and the time in which they found out about being HIV positive, generally for most people an HIV positive diagnosis came as a major 'shock', a 'blow' or something difficult to either 'believe or comprehend' initially. The next quotes are illustrative:

- "I had to come back on the Friday. I was really 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…" *(F, diagnosed 1998)*
- "When I first heard I did not believe it, I couldn't be positive. *(F, diagnosed 2001)*

For most interviewees the time just after diagnosis was an extremely difficult period. Some reported that it was a very lonely time, particularly for interviewees that struggled to disclose to significant people in their lives. This precipitated feelings of paranoia with some respondents describing periods when they thought or felt like other people around them could actually see that they are HIV positive - even though they had not disclosed to any person at that stage:

- "Respondent: Actually, psychologically it affects everything because when you walk in the street you think people do see that you are HIV positive. Being in the room watching 'TV' documentary on HIV/AIDS you think people around you know that you are HIV positive. So that thing affects you and it makes you not capable of doing the things you did before because you suspect that whomever you are with might find out that you are HIV positive and when they find out they might reject you. So by the time I was not telling my status to anyone" *(M, diagnosed in 2002)*
- "Respondent: I was feeling as if when I walk in the street all the people saw me; I wanted to be alone" *(F, diagnosed in 2000).*

Along with the concern that other people could actually see that they are HIV positive was a fear of rejection. As a result it became difficult for some respondents to be around other people. The mention of HIV/AIDS by other people, the media etc. was difficult to tolerate. It was a reminder to them that they were living with a virus that is terminal, especially amongst respondents that equated an HIV diagnosis with imminent death. Two respondents battled with the diagnosis:

- "R: I would change at the mention of HIV and AIDS. I would get up and leave if this subject was mentioned".
- "I: Has this always been the case, have you always felt as strong as you are feeling now? R: No, when I was first diagnosed I used not to be able to listen to talk about HIV/AIDS. I would turn off the TV or radio if the subject was brought up and would bury myself under my blankets".

At this stage, some respondents described how concerned they were about how other people would react to the news, particularly family and close associations. A number of respondents were concerned about acceptance:

- "I: Tell me what was going through your mind at this time. R: I was thinking that I could no longer have relationships and a partner; I didn't know how my family would feel when I told them, and my friends, what I would say to them…".
- "I was thinking of the stigma as it occurs from people around you, my family, relatives and the public comments. That depressed me a lot".

Some respondents mentioned how after diagnosis they reflected either on their future or what they could have done differently:

- "R: I was thinking mostly about my goals and where my life could have been; I had applied for admission at a college of education but had not been able to secure a place. I was thinking that if I had managed to go through perhaps I would have been spared this ordeal…was such a negative turn of events, more so in the light of what I could have been" *(F, diagnosed 1998)*

For other interviewees, the diagnosis propelled them to destructive and fatalistic behaviors. Even though this was not very common, there were some interviewees that became destructive as a result of the diagnosis. Examples include over indulging in alcohol or engaging in risky sex. The following quotes serve as examples of behaviours that reflect difficulties in coping with the diagnosis:

- "Respondent: Then I did not use condoms or anything of that nature. I just engaged in sex without using a condom 'nyama to nyama' (sex without protection). I was telling myself what am I scared of because I was already HIV positive. I convinced myself that I have the biggest disease in the world, which everybody is scared of. What am I caring for? If I met a person with a disease I told myself that I have a bigger disease than she has. The thought of spreading the infection never came to my mind because in a way I am going to die and that person is going to die. But I did not use condoms or things of that nature and that was then." *(M, diagnosed 2002)*
- Another example: "R: I had to face reality; I told myself that I was going to die. 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, I was dying anyway but I couldn't commit suicide, alcohol would do it for me" *(M, diagnosed 1992)*

Suicidal thoughts were also common at this stage, and one respondent reported having had a strong urge to do harm to others in retaliation, as he believed that other people were responsible for infecting him with the virus.

For some people thoughts about being positive became obsessional.

- I used to think about it all the time. I would go to sleep and on waking up would think 'God, am I still alive?' *(F, diagnosed 2002)*

Having seen how others dealt with their positive status seems to have a bearing on how people react to the diagnosis. One respondent reported being quick to accept the diagnosis and HIV status as they did not want to suffer the same fate as their sibling who had deteriorated fairly quickly as a result of not having accepted his status.

- "I saw with my own brother that depression kills and to deny I am HIV positive was going to lead me to death. It was better to face my condition because by denying I would not change anything.... *(F, diagnosed 2003)*

A few reported that they had suspected that they would test positive and it was thus easy for them to accept the results as the test had only been for purposes of confirmation.

Living with HIV/AIDS

Living with HIV/AIDS was been far easier for some people than for others. Following this section we will deal with what has helped people to cope. Here some of the difficulties which have been experienced are described.

Behavioural patterns: sleeping disturbances

A number of interviewees mentioned disturbances in their sleeping patterns. Some respondents mentioned difficulties falling asleep and others indicated that they overslept. Reasons for sleeping problems varied across different respondents. One respondent utilised sleeping as an avoidance mechanism:

- "When the subject came up I would switch off the radio and think that it's better to sleep, that I would wake up having forgotten about this whole thing, that I would leave my thoughts behind if I went to sleep".

Another respondent experienced difficulties with falling asleep because they were struggling with disclosure:

- "I: Can we talk about specific issues now, to do with how you personally experience living with HIV...Has this had any impact on your sleeping pattern? R: No, not at the moment. I sleep well, there's no change. I: Has this always been so, I mean, after you had been diagnosed with HIV. R: I couldn't sleep at first. I would toss and turn, thinking about what I would say to my family".

One person was afraid that they might not wake up:

- "Interviewer: It has depressed me at times because at night you certainly become afraid of sleeping because you might not wake up the following morning because by then you were informed about the results of being positive and be that I might sleep and sleep forever, so it was difficult".

One of the respondents that experienced a change in eating pattern said the following:

- "There was a lot of difference and change and I improved in many ways. I was a person that eats too much. Interviewer: You mean now that you are HIV positive? Respondent: Yes".

One respondent expressed the notion that they had no will to get up as they were 'going to be sick and bedridden anyway'. Another respondent reported that she could not cope with the task of looking after her baby and would often sit up all night and delegate the task to her mother:

- I did not wake up in the morning I slept because I saw no reason to wake up any way I am going to be bed ridden. I used to be always weak and now when I get weak I do not think I am hungry it is because I have got HIV/Aids and I am sick that is the reason why. And the more I reacted from that is the more I became weaker and weaker and loose weight and thought it is HIV/Aids. *(F, diagnosed 2002)*
- I always find that I am tired and feel like sleeping just like yesterday when I knocked off work I slept and did not want to wake. *(M, diagnosed 2002)*

Death and fear of dying

Some respondents, at times, viewed HIV as 'a death sentence':

- "The most prominent thought with me was that of dying...but what was uppermost in my mind was the thought of death..."

- "The most prominent thought with me was that of dying. . .'this thing is real, I really am going to die'. I really cursed that thing (the virus) when I first had it.

The reality of death became real for one respondent when another person that was HIV positive succumbed to the disease:

- '. . .or when a friend dies. Especially if it's someone I have been close to, someone who has been strong". Another interviewee described how they struggled to be alone and to sleep because 'what was uppermost in my mind was the thought of death'.

Though very few respondents cited being physically ill as a stressor in coping with HIV, thoughts of death and seeing other people in advanced stages of the disease have been difficult to cope with. Respondents reported that although they may appear to be going on with their everyday lives, there is a daily struggle to deal with what is going on. As one respondent puts it:

- I'm still struggling to cope; there is no 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. *(F, diagnosed 2003)*

One interviewee-raised concerns about dying young:

- "But now I want to say a person should at least die after reaching 60 years when he has done almost everything for his children not at a young age" He was concerned about what will happen to his family: "In my mind I always think about the years as they progress that if I die what will happen to my family and who will look after my children?" (*M*, diagnosed 2002)

However, one interviewee described how they dealt with the issue positively. For instance:

- "Yes, death.. I have told myself that I'm not going to be killed by HIV; I will die in whatever way I would have died anyway. I think that has helped be strong, even in the face of the death of close friends".

The realisation that dying is everyone's process and not exclusively for those infected with HIV is also said to help in coping with HIV.

Substance abuse

Substance abuse was not very common amongst interviewees, however clearly some people cope with their status by abusing alcohol. Even though some people recognised the maladaptive nature of it, drinking 'to blot out problems' was identified as a means of coping with being HIV positive.

- "Yes I went on drinking but not as heavily as I had done initially. I was now drinking occasionally but I would drink heavily when I did drink. Perhaps once a month but I would really go overboard". *(M, diagnosed 1992)*
- "I used to stress a lot and believed that alcohol would solve my problem, but it only added to my troubles. I would cry and expect people to take pity on me when I was drunk". *(M, diagnosed 1992)*

Upon diagnosis one person's physical state and drinking worsened:

- "I stopped looking after myself and kept drinking. My physical state deteriorated, I couldn't care less, I was dying anyway but I wouldn't commit suicide, alcohol would do it for me…" (*M*, diagnosed 1992)

Suicidality

There were some respondents that considered suicide.

- So I ended up telling my older sister because I was now overwhelmed by a sense of wanting to kill myself. *(F, diagnosed 2002)*
- It's mostly to do with my boyfriend, and when I think about the fact that I have nowhere else to go. That is when I think of taking an overdose of pills. I was feeling this way last week and I told my sister. It just gets too much for me sometimes. He was being abusive as usual. At these times every residual hurt surfaces, like the fact that my younger brother was stabbed to death in December. It all comes to the fore and threatens to engulf me, then I think about ending it all. *(F, diagnosed 2003)*

Suicidality or suicidal ideation came up with some of the respondents' pre and post diagnosis. One of the respondents' contemplated suicide before being HIV positive:

- "Interviewer: Before you were HIV positive did you ever contemplate committing suicide? Respondent: Yes I did think of committing suicide in 1982 and 1983…" *(F, diagnosed 2000)*

The same respondent contemplated suicide even after the diagnosis:

- "Interviewer: Earlier you said you thought of taking your own life. How serious was that? Respondent: There were stages that the thought was serious but I thought of my children and I accepted that I was HIV positive…" Another respondent also contemplated suicide after diagnosis: "Interviewer: You have talked about taking your own life life. Was that thought always

occupying your mind? Respondent: The thought was always in mind and I have already arrived near to the final decision but I changed my mind since I realised the responsibility to look after my children." *(F, diagnosed 2000*

Reasons behind this range from a sense of having failed significant others to feelings of outrage and self-pity. The feeling that one has been singled out, that this could and should have happened to others, coupled with lack of understanding around why this has happened at all are also strong contributors to the overall sense of the unfairness of having contracted the disease. Most have been able to contain and reverse these feelings, often as a result of the realisation that one has certain responsibilities to others, like for example, one's children:

- The thought was always in mind and I have already arrived near to the final decision but I changed my mind since I realized the responsibility to look after my children. *(M, diagnosed 2002)*

For some, the diagnosis cane as an additional stressor to already existing problems; a number of respondents reported that they had social or emotional problems even prior to being diagnosed with HIV and suicidal ideation has thus been a thread through their lives. One respondent reported having been informed about the HIV status of her partner long before they got married. He later developed symptoms, went for a test and later disclosed to her. She reported that the knowledge she had buried had put a lot of strain on her and she had on some occasions attempted suicide though she never openly admitted that he could really be positive, not even to her:

- I can't really say, everything happened very fast. I was really scared, this was weighing heavily on my mind and I couldn't confront him about it. He was well, and happy, and I ended up telling myself that it could not be true. We stayed this way for about a year. I ended up drinking battery acid... *(F, diagnosed 2002)*

For most other respondents, suicide was not an issue either pre or post diagnosis. However, some of the cases cited above reveal perhaps a propensity amongst some HIV positive individuals towards suicide.

Apportioning of blame

A few respondents raised the issue of blame; though in different ways. Blame was either turned inward or directed at another person. Blaming one's partner was more prevalent than self-blame as a number of (female) respondents reported that they harboured feelings of hostility towards their partners. In a number of circumstances respondents reported that they vented these feelings on their partners. Respondents described how they felt betrayed by those they trusted, with one respondent even regretting why they became involved in a relationship:

- "I was angry towards him because after I tested I took it that he infected me with the virus since I heard that he was in a extra-marital affair with a certain woman... I trusted him and showed him my results at the time and moved in with him. From that day if I should not have trusted him, that trust killed me now I am HIV positive" *(F, diagnosed 2000).*
- "There have been times...there are times when I would feel very angry. I used to get angry over the fact that I had been in a relationship; to me it was like if I'd never been in one I would have been safe...I used to hurl insults at my boyfriend even if I saw him in town and really vent my anger." *(F, diagnosed 1998)*

In the case of respondents that turned the blame inward, regrets accompanied this. Upon diagnosis one respondent felt that being HIV positive was a consequence of having lived recklessly:

- "I blamed myself in such a way that I saw myself on the wrong because as cheaters, men have a tendency that they will suffer the consequences..." *(M, diagnosed 2003).*

One respondent initially construed the diagnosis as 'punishment' from God.

Self blame was reflected in 'why me' questions, as the following quote illustrates:

- "I was blaming myself and asking questions such as why me, why should it be me? What have I done especially?" *(M, diagnosed 2002).*

The next section explores the issue of relationships in the context of HIV/AIDS. It represents an area that a number of respondents were battling with.

Relationship issues in the context of HIV/AIDS

The issue of relationships, particularly sexual relationships was a difficult and complex point for a number of respondents. It is an area that most interviewees were struggling to deal with. The difficulties were predominantly with establishing or maintaining sexual relationships, communication on HIV with partners and infidelity. A number of respondents expressed concerns about either establishing or maintaining sexual relationships:

- "I was worried about a lot of things. Women would they turn me away? Would they even consider being involved with me?" *(M, diagnosed 1992)*
- "The only thing I struggled with was the area of relationships. I found it hard to deal with it, I would be attracted to a woman and sometimes the feeling would be mutual but dealing with the next step was difficult. It's always a shock for the women and they tell their friends, you can see it in their eyes that they know" *(M, diagnosed 1992)*
- "I had a lot to lose, I would lose out on love because I still had feelings and wanted to be loved back. What woman would accept this thing? *(M, diagnosed 1992)*

Another fear associated with a positive status was finding a supportive partner who would not be adversely influenced by an HIV status. According to one respondent, she would rather remain with her current, physically abusive partner than leave him, as finding a partner who would accept her HIV status as readily as he does, would be

extremely difficult. (This is dubious though, as she also stated that he sometimes insists that she cannot be HIV positive because she is not showing the signs that a truly sick person should have). One respondent mentioned that HIV has changed the way he views sex and relationships:

- "For me sex and pleasure are no longer a goal, what I need most is care and happiness, to live and be loved, to care for and be cared for, sex is of no real consequence..." *(M, diagnosed 1992)*

Interviewees mentioned relationships that had failed or ended because of their HIV positive status:

- "I: Were there other areas of difficulty? R: Yes, in the area of relationships...I was open about my status and people would say that they 'could not go where the writing is on the wall' *(F, diagnosed 1998)*
- "I fell in love with a person who was HIV negative and I knew that I am positive, it came to me but gave me a good direction. Whereas that time I knew myself that I was HIV positive she went for tests and I told her she can go to test I am fine and came back with a certificate results showing that she was negative and demanded to see mine. Through honesty, 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...*(M, diagnosed 1992)*"

One respondent lost a partner because the partner refused to use a condom. Problems were also reported with partner attitudes to disclosure of HIV status. Men especially tend to refuse to accept that the HIV status of their partners could mean that they too are positive. Reactions range from complete denial of the fact to refusal to take a test, often citing the fact that they are not sick as an indication that they are not HIV positive. The following example illustrates this point:

- No, he won't hear of using condoms. He says he doesn't have AIDS but I don't know what he thinks of the AIDS that I do have. I'm sure in the end he wants

to accuse me of having infected him. I sometimes wish I had asked him to go the very day I went for the test... *(F, diagnosed 2003)*

Communication with partners over the HIV status varies, with some reporting that the subject is never broached while others are able to talk about it. The following opposing scenarios illustrate this point:

- We never spoke about it, we rarely ever spoke... it remained largely ignored though we both knew it was there. *(F, diagnosed 2002)*
- ...and I am always keeping busy and talk to my wife about HIV/Aids that helps me a lot. *(M, diagnosed 2002)*

A number of respondents reported having been coerced into having unprotected sex with their partners, even when they were fully aware of their HIV status. One person stated that she does not like to have unprotected sex but that her partner refuses to use a condom and beats her if she refuses to have sex with him. Another reason given for giving into demands to have sex is fear of losing the partner:

- I couldn't refuse to have sex with him because I didn't want him to leave me for others who would give him what he wanted. *(F, diagnosed 2002)*

Infidelity is also an issue that some respondents have had to deal with. For example, a respondent reported deterioration in their marriage right after they had both been diagnosed with HIV. The man had been tested first as he had been showing symptoms. Instead of adopting a healthy lifestyle as a result of the diagnosis as was expected by his wife, he went all out and had other relationships:

- At this time my marriage had hit an all time low and my now physically abusive husband had gone from sleeping out to actually spending holidays with other women and I had gone to live with my mother. *(F, diagnosed 2002)*

Finances

Lack of finance and employment was reported as a challenge that made living with HIV/AIDS more difficult. The following quotes illustrate this:

- "Perhaps there would be something bothering me, like for example when I don't have money for something I need. You know when you have money to do stuff everything becomes less burdensome. I get bothered when I don't have money, say if I need to buy boosters or something and they are too expensive or I just don't have the money for it…"
- "I noticed that my anger was caused by hunger and there is this saying I do not know if you know it that: 'an angry man is a hungry man' and 'a hungry man is an angry man'.

Other difficulties

There are other instances when the thought of living with HIV wears respondents down as the following examples illustrate:

- "Interviewer: Would you please share with me how you best describe, in your own language, how you feel inside being an HIV positive person? Respondent: I feel pain and hurt but I try to persevere because I am not going to be able to bear children and have a brighter future".
- "It is difficult because at other times when you are living with HIV you become tired and short tempered sometimes if people are talking to you. You have different feelings to those you had before and become constantly absent minded".
- "R: When sober the thought would come but I would tell myself not to worry about it, I would distract my self by watching TV or listening to the radio, I would read a book and fall asleep. I: In other words you could do other stuff and push it to the back of your mind. R: Yes, but it was a different case when I had been drinking. I would cry and the thought would sit with me, it weighs

me down. I could not cope with myself and with my thoughts. I would be drunk and would consider my solace in death".

These quotes capture moments of difficult times in the three people's lives despite living positively with the virus. Even when people have accepted their condition, for some people it is a challenge to stay optimistic all the time:

- "R: You don't stay positive all the time, sometimes you feel down and want to be by yourself..." These moments are brought on by other issues in people's lives, such as finances, relationships etc. Along side these issues, is the reality of the condition itself, particularly it's terminal nature: "I: What is happening with you at these times? R: Perhaps there would be something I need...you know when you have money to do stuff everything becomes less burdensome...I get bothered when I don't have money, say if I need to buy boosters or something and they are too expensive...or when a friend dies".

Feelings about living with HIV

Respondents expressed both negative and positive feelings about living with the disease, however most seemed to have accepted the fact that they are HIV positive. Nonetheless it must remembered that this is a group of people who have disclosed their status and have therefore had time to come to terms with certain issues around their positive status.

- A great deal of emphasis was put on knowing one's status – even if it is positive. Some respondents spoke about dealing with the uncertainty of not knowing ones status. Knowing meant that one could live in the "here and now" and allow one to live each moment to the fullest. This was also evident in the way respondents reported their attitudes to death and dying, including use of expressions like 'acknowledging it makes you feel fine', 'it is like any other disease', and 'everyone has to die ultimately'.

These responses point to the fact that respondents have found ways of assimilating the disease into the process of their lives. Some even expressed the fact that they think they may have contracted the disease for a reason, perhaps so that they can be in a position to help others in the same position. Yet despite the different explanations, as one respondent put it, there is the realisation that one may be fine for now, but this quite clearly will not last forever. Another respondents stated that she is fine as long as she keeps reminding herself that she has just been diagnosed and that there are still years ahead before she will succumb to the disease.

On the negative side, feelings of being unlucky and having been at the wrong place at the wrong time or 'as if they were cursed' were expressed. Being positive is described as 'not nice' and 'very hard':

- It is not nice... it's not nice because some things you think about, like the fact that you're going to die... *(F, diagnosed 2002)*

Variations of the incapacitating effect of HIV include descriptions of what the disease prevents respondents from enjoying, e.g. having a trusting, loving partner who will accept your HIV status; having a baby; living to be a grandparent and being the strong person other people in your life (children, parents) would like you to be, as well as maintaining a healthy and positive lifestyle.

Other negative aspects of the disease include the physical and mental effects that one has to contend with:

- My fear is about the fact that it changes you so much, it eats away at you until you're unrecognisable even to those who know you well. *(F, diagnosed 2003)*
- It is a painful disease in that what would ordinarily have been a minor ailment will be quite significant if you have HIV. *(F, diagnosed 2002)*

There are a range of specific thoughts and feelings described by respondents around being HIV positive. The following quote serves as an illustration:

- I felt like a victim for the first time I heard I was HIV positive and I felt I was dead already. I thought I was dead before getting sick. And all the things I heard people talking about I thought of killing myself. I felt awkward and it was very difficult even now I cannot describe it because I changed a lot they way I am feeling. I used to cry and I did not want to meet with other people. I thought if a person is close to me they will see I am HIV positive and I started to be so concerned about myself I just could not do anything because I thought I was just about to die. It was about the blame, I always blamed myself. *(F, diagnosed 2002)*

As one respondent explained, you do not get consumed with negativity, 'not all the time, but you don't really forget about it'. Although such negative thoughts are not all encompassing, it is to be expected that negative aspects of the disease will inevitably be brought to the fore and most respondents seem able to counter these with productive thoughts. However, the concession is that they are very hard to deal with:

- It has to do with the way people seem to be dying like flies, I've seen so many people getting emaciated and ... dying. Especially those I've been close to, I was thinking 'I'm also going to be like them'. I could picture them. But then I also realised that there were people like this friend of mine I was telling you about, who have lived with the virus for a long time and are still going strong. If and when I get sick... I'll cross that bridge when I get to it... I would think about those who had died of AIDS... and I would pray that God will at least allow me to see my son out of childhood. *(F, diagnosed 2003)*

Some respondents have described feelings of anger, frustration and aggression with accompanying thoughts of wanting to harm others; this seems rooted in the sense that 'others' are responsible for the HIV status or that life is unfair.

Others reported that they have quit harmful habits like smoking and drinking as they can adversely affect one's health status. Shifts in priorities have also been reported, with one respondent expressing more love and compassion for others generally and another noting how they now have more appreciation for the elderly as they can no

longer take it for granted that they will live to be that age. Some also note shifts to more responsible money-spending patterns:

- I'm different. I'm very touchy, I experience my family as different... like they have changed and do not love me anymore... those are thoughts that go through my mind. I now need to be cared for a lot, more than has been the case previously... *(F, diagnosed 2002)*

SUPPORTIVE AND AGGRAVATING FACTORS

Ideally supportive and aggravating factors would be in two separate sections. However, it is evident from this section that with a complex disease such as HIV/AIDS, and particularly the stigma which surrounds it, listing simple "pros" and "cons" to living a positive life are usually not possible. For example while disclosure had positive consequences for most respondents in this study this was not the case for all; most people who went for counseling benefited, but others found it a waste of time. Even the role of religion and the church was equivocal.

Disclosure

For many respondents talking about their HIV status was not a major problem. However, by virtue of the sampling procedure used in this study, all respondents had disclosed to at least some people and this no doubt biased the study to more openness than may be the case in a randomized sampling procedure.

Almost all the respondents agreed that it is not easy to disclose to close family, especially parents. Respondents were loath to face reactions of disappointment, rejection and anguish which they anticipated would ensue. Disclosure to children is also perceived to be as difficult. One female interviewee reported that her adolescent children have become disrespectful towards her since she disclosed her status to them.

Reasons for disclosing to particular people, as well as how long it took to disclose, varied across respondents. A number were able to disclose to partners or families within a day or two after having been diagnosed while others found this much more difficult. The main reason for disclosing was to garner support and empathy. This made the situation less threatening. One person reported having been overwhelmed by suicidal thoughts at the prospect of disclosing while another felt that she had no option as her partner, while under the influence of alcohol, had on several occasions loudly insulted her about the fact that she had been diagnosed with HIV:

- "I thought that denying it, or keeping it secret would kill me... and felt that I should look for things that would help me make peace with it". *(F, diagnosed 2001)*
- "You know it was eating me inside so why I kept quiet with this thing maybe if I can share this thing with somebody I will be ok". *(F, diagnosed 1999)*

Disclosure was mentioned by some respondents as a precondition for psychological adjustment and for living with a positive attitude - particularly after disclosing and family, friends and the community responded positively. A number of respondents valued an opportunity to disclose, especially to close family and friends. Disclosing to familiar persons had the effect of lifting a burden from the shoulders of the person living with the virus:

- "R: I have found that with each disclosure, you feel so much better. It becomes less of burden on you... if you keep it a secret; it becomes a problem when you see your friends talking and laughing, as your conscience will tell you that it's you they are laughing at. You always imagine that people are pointing at you and laughing behind your back. This is not the case when you can talk openly about it, you become free *(M, diagnosed 1992)*
- "R: For me the whole experience has been positive, I mean people have responded positively to me" *(F, diagnosed 2001)*
- "I introduced her to the family and she then told them that I was HIV positive...I'm proud to say that they accepted me. I was grateful for the fact

that my mother is a nurse as I feel that she accepted the news easily..." *(M, diagnosed 1992)*

- "Interviewer: Then if any what are the things that allow you cope better with being HIV positive? Respondent: Be open to talk about it". It also shows self-acceptance: "I strongly believe that disclosing is a sign of acceptance and adaptation".

Relief and a sense of strength and courage were reported to come about as a result of talking to others. Support from others, especially from family, tended to reduce the burden and to enable respondents to be strong and to cope better:

- You should always be free and not keep on hiding and talk and as long as you are not free and disclose you won't get any help and support. But if you tell other people you will get assistance. *(F, diagnosed 2003)*

Disclosure elicited diverse reactions from other people. Disbelief and empathy were reported to be common reactions to disclosure, especially if the person disclosing was still asymptomatic. Some respondents shared negative reactions resulting from disclosure. For instance, one respondent lost a friend due to being HIV positive and another one had a family member react negatively:

- "R: One bad thing that came out of this was that I lost some friends. There was one friend in particular whom I was very close with, I love him a lot, we grew up together but he's in Cape Town now. Once I told him about my status, he kept away from me. Even now he is very distant from me".
- "My grandmother had problems accepting it and this was a huge problem for me. She used to stay with us and when she heard, she would not even want me to go and buy her tobacco as I used to. It had previously been our secret and she had not wanted anyone to know about her habit. But when she heard, she would call my friend whom she had previously been adamant that he should not be told (about her habit). Even I tried to help her when cooking she would fend me off without actually coming out and saying because you are HIV positive" *(F, diagnosed 1998)*

Conversely, lack of disclosure was viewed as a hindrance to adjustment. It was seen as reducing the opportunity to receive support from other people. For one respondent lack of disclosure is akin to living a lie:

- "Yes. The problem is the questions you need to answer. Interviewer: You are not being able or is it difficult to answer those questions? Respondent: The problem is that it is not difficult but you won't be able to answer them because you have to lie. At some stage there are people who will see that you lie because today you tell this story and tomorrow is another story and when they meet they would relate your stories to one another and conclude that you lie. And by then within the following period you start loosing weight and then when you start loosing weight that is where the problem begins because you worry a lot about what they think about your weight loss. And you think a lot about not being able to live the following day".

Not disclosing also induced concern or worry over what other people think:

- "And what made it worse is TV. At some stage programs like 'Soul City' when you look at the treatment of people infected with the virus you begin to suspect that everyone around you see that you are HIV positive. So by then you are trying to distance yourself from TV and you shut yourself out and start thinking too much and that begin to affect you". Lack of disclosure may reflect a fear of rejection; the fear is imagined and anticipated (*M, diagnosed 2002).*

When disclosure leads to support from other people it makes living with the virus easier:

- "Respondent: Talking about my HIV status makes me strong because people encourage me. Sometimes people comments that HIV infected people are killed by heart failure due to thinking too much because they are always silent".

Generally, most people valued an opportunity to talk about their status, whether with a minister, colleague, a friend or a partner. For some people, it was much easier to disclose to some people than others:

- "Respondent: Other people you disclose to them and they will go and reveal your status all over the township. But another person who is infected I do not have a problem telling him" (*M, diagnosed 2004*)

One respondent had no difficulty sharing with one particular individual whom he is acquainted with; however, it was difficult for him to tell his family:

- "I met an older woman who was an AIDS activist in 1997 and it was only then that I decided to inform my family. I asked her to tell them on my behalf and we to see them together. I introduced her to the family and she told then told them that I was HIV positive" (*M, diagnosed 1992*)

A common thread amongst the respondents was that either they struggled at first to tell more than one person or they started with one person they trusted and then gradually developed the courage to tell others. This first person they told could be a minister, a cousin, a sister, or some other person that they were comfortable with. Someone that is unlikely to pass judgment; someone that will offer empathy and support was seen as critical:

- "When I first disclosed I first told my sister who is suffering from 'sugar diabetic'.. then we sat down and disclosed to my mother... (*M, diagnosed 2002*)"
- "Yes I have two brothers who were building my moral support after I disclosed first to my sister and then to them" (*F, diagnosed 2003*)

Acceptance

The theme of acceptance includes self-acceptance and being accepted by other people - in the interviews this included families, friends, churches and communities. Generally acceptance was viewed not only as a precondition for adjustment after being diagnosed HIV positive, but also as a way of living harmoniously with the condition. For example:

- "Being HIV positive should be no different from being negative, you are not in pain or anything, it's just that you have been told that you are positive... it is up to you how you go on from there" *(F, diagnosed 1998)*.
- "I said before acceptance is the biggest thing. Once you start to accept that you are living with HIV and by then I did not just accept and forget but I also disclosed to people and researched a lot of information around HIV/AIDS" *(F, diagnosed 2001)*.
- "I only think about it when somebody mentions it, like 'HIV and AIDS, oh yes, that's my friend'. It's only then that I think that 'by the way, I have this thing'. Otherwise I never even think about it. You forget about it because it's unlike a headache that's there, you can't feel it".
- "To me the only remedy, the way I see it, is myself..."
- "For me living with HIV is just like any other disease, it is not something that is bothering my mind".

A sign of acceptance is the extent to which a person thinks the condition has resulted to a positive difference in their life. For example:

- "I also take it that being HIV positive is the start of life because it has helped me to manage my life such as being used to saving money and to be cautious about my life. Because long ago I was drinking alcohol and I stopped because of my HIV status since I realized that I would worsen my health condition. And that being HIV positive also taught me to love and care for other people" *(F, diagnosed 2000)*

On the other hand, lack of acceptance impedes psychological adjustment:

- "I was really frustrated. I felt ugly; I felt that I now had HIV. Anyone could see it. It was painful and I had to sit in the dark because it got worse if I was in direct sunlight...I hated the fact that you could see just from looking at me that I really had AIDS" *(F, diagnosed 1998)*

One respondent reported having had a very difficult time accepting that she was positive, as she had been dealing with the death of her mother when she was diagnosed.

Social acceptance (family, friends, community and significant others) was valued by a majority of respondents. The view amongst the interviewees is that this type of acceptance facilitates their own self-acceptance and it is a useful coping mechanism. If it is not present or there is no acceptance it could hinder adjustment and coping:

- "If they swear at you and throw insults at you because of your status, it makes it that much more difficult for you to accept yourself" *(M, diagnosed 1992)*
- "Well, firstly, when I disclosed to my family and they accepted me, I became strong because of their attitude. I also told some of my friends and they were fine with it",
- "Respondent: Presently if people disclose their status, families start to prejudice them by separating cup of tea, plate and chair. But for me that has never happened. At home each plate belongs to everybody and that thing kept me going that people are and my friends are coming around to support me and that encouraged me",

Some respondents cited the lack of social acceptance as a major stressor. In some cases, this was created by partners that refused to accept the possibility that they were themselves HIV positive. Denial often manifested in unreasonable demands being placed, especially on females, by their partners. One respondent related how her boyfriend would not accept that he could be HIV positive after she had been

diagnosed with HIV. He insisted on having unprotected sex with her and demanded that she have a child with him:

- When I thought that I have met with someone to start a family with him and you discover you are HIV positive you are not supposed to have children. And then that person is so much punishing he says if you do not want to have children with him, he will go and have them somewhere else. I was in a tight situation it was hard for me. I wanted to have children and family of myself but at the same time I was not supposed to. He already had two children from two different women and they both died I did not know and discovered after my child died. So it was hard because he was blackmailing me by saying that if I did not want to have children with him he would go out and make children with other women and would not blame him if he did not have time to spend with me. That was quite hard as well you do not know what to do and end up doing something you regret. *(F, diagnosed 2002)*

The church and the community was another important source of strength and acceptance. For one respondent this was her only support system. There was no acceptance and support at her home.

- "But through the support that I got from my pastor and the people or congregation at the 'Seventh Adventist Church' I really became strong until today that I manage speak and share about my status" *(F, diagnosed 2000)*.
- "R: You always think that people will react negatively, that they do not like you. I had a similar experience when I disclosed at my church, people kept going to my house to support me".
- "R: For me the whole experience has been positive, I mean people have responded positively to me. Even at a community level, I've never encountered negative stuff. People will come and discuss their problems and problems they have with families".
- "Respondent: What gave me hope is to see people coming out or opening up as a community talking to ourselves about this epidemic. That gives me hope that people are now getting used to the idea that they are HIV positive and as I

mentioned that I give health talks around local schools...And that also keeps me going and the community coming around to disclose and accepting that there is HIV disease which our sisters, brothers and cousins are living with".

Social Support

Social support is closely linked with social acceptance. Social support can be categorised into three areas: emotional/moral, material and informational support. However, these are clear overlaps between them.

Emotional/moral support was cited as critical by most respondents, though who provided, or who they wanted to provide the support, varied significantly.

Family members and friends provided much of the emotional/moral support received, however the church and the community were highly significant for some people. Family support was seen as especially important as family members are usually the first. Further disclose is often dependent on how family members reacted:

- "Respondent: My family provides me with support especially my mother makes me all the time to stay strong".
- "Respondent: I do not think the times that are there now is just understanding and support that I have now including my partner. So they can take any load off my shoulders which I cannot deal with on my own"
- "Sometimes when I feel tired to go out my friends will come to me and say that I am starting to isolate myself..."

A sense of others caring about you and how you feel, coupled with a show of love (verbal and physical) was seen as very important by some respondents. One respondent felt that any show of affection makes a significant difference:

- "Oh yea, love. People living with the virus like to see that they are accepted, loved and are given a chance to give love in return. I: How do you see when you are loved? What kinds of things are we talking about here? R: I mean

things like hugging, simple things like that make you feel really good. The little things…we look out for them, they're very important to us. I: Yes…ja I hear what you say, but I'm thinking that it's not the way that people do…in the way they generally relate to each other. If I started doing that kind of thing with you, am I not saying I see you as different to other people, that the HIV is setting you apart from others now…or is that something you accept, that you're HIV positive and that others should also acknowledge that fact with a hug, so to speak. R: No, I don't think I mind. It's rare to get a hug and I always feel good whenever a hug comes my way. To me it's a show of love. I: In what context perhaps? In what situation would you expect somebody to hug you? R: Maybe you have just given a talk in some event; it's nice when people come to hug you afterwards. It makes you feel accepted, appreciated. I: So, yes, a positive show of acceptance…" *(F, diagnosed 1998).*

Examples of material/physical support included some respondents receiving tangible assistance from people that were close to them. The next quote is an example of both material and moral support:

- "Respondent: Yes I have two brothers who were building my moral support after I disclosed first to my sister and then to them. Sometimes they buy me food parcels and fruits…" *(M, diagnosed 2003)*

Information support include cases or examples where close people provided respondents with information to improve their well being, live positively and to manage the virus effectively. This type of support was cited from various sources, such as siblings, relatives, support groups or even post test counseling:

- "Respondent: I get support from my sister. When I first disclosed I first told my sister who is suffering from 'sugar diabetic'…So I was so much surprised that she so well informed about HIV/AIDS…She responded that HIV/AIDS is a disease like any other disease…When I disclosed to her she ended up counseling me and saying that HIV is not the end of the world, you can live long if you take care of yourself. And if you have a girlfriend use a condom

and stick to one relationship you can prolong your life...my sister informed me about the whole dynamics of HIV/AIDS..." *(M, diagnosed 2002)*

- "My sister shared other things with me like providing me with pamphlets on HIV/AIDS information. Time and again I would find information on HIV/AIDS nutrition and positive living on my dressing table left by my sister and I would read it" *(M, diagnosed 2002)*

When support is missing, this becomes a barrier to effective coping. For instance, an interviewee reported that she had no support at all when she had lost her child - her partner was in fact blaming her for the child's death. Lack of support from family is also reported to be as much a problem as lack of partner support.

Support groups

Support groups also seem to play a very central role in helping to live with the disease as this provides a space wherein one can express fears and concerns and allows for exchange of information for better management.

Living with HIV is also made better by a sense of goodwill inspired by some service providers and a sense of belonging that comes from being with others in similar circumstances:

- I think it's mixing with other people at the Centre that has helped. I've dealt with a lot on my own, I had a lot of strange things on my body that I didn't understand.... all I knew was it was because of the AIDS. But at the Centre you share information, you understand stuff and are able to get a grip on things. It has really been an enlightening experience for me. *(F, diagnosed 2002)*

One respondent stated that it is especially uplifting to be part of a healthy-looking, assertive and successful group:

- When I went to the support group just looking at all the other people that were around me not even one you could tell were HIV positive, you could not tell they were confident and some of them were successful and working. Just like other normal people they gave me confidence to be as normal as they are. I just learned to live with it, it does not change anything in me all I had to do is to be confident. I have got nothing to lose and it is not going to change anything, it is just one of those things. *(F, diagnosed 2002)*

Counseling

Most people who had received counseling reported that it has played a vital role in facilitating acceptance. An important element of the counseling process was referral to support structures that respondents would not have otherwise known about. One respondent stated that counseling helped root the experience in reality - where otherwise they might have gone into denial. Another respondent reported that their initial experience of counseling was bad, in the sense that she was not at all ready to accept the diagnosis. She only recalled the shock and the negative associations whatever was said to her had at the time. However, she was later able to use the counseling effectively and felt much better as a result.

For most people pre and post test counseling was useful or helpful as a first step in the process of accepting their status and living a healthy and positive lifestyle. It helped some view HIV positively:

- "Yes it helped me because I was advised that I should not give up and always follow counseling instructions".
- "It helped me to accept that I am HIV positive, attend to things that I want to do and do them".
- It even taught me to like counseling and with that I have changed, I now care for other people and give other people advice on what thinking you are cursed and being negative have shown me, the advantages and disadvantages of the wrong belief system. *(F, diagnosed 2002)*

Counseling and support groups are also often cited as elements that lend to positivity as they enable people to address problems in concrete ways, which in turn has a major bearing on how one begins to accept the diagnosis and to adjust socially and emotionally.

However, some interviewees were either not satisfied or they felt that it was not helpful.

- "Respondent: To be honest it did not help me" (*F, diagnosed 2001*)
- "I can't say the post was effective though because I was too nervous, after I had been given my diagnosis I couldn't listen. I felt drained and was too tired to listen" (*M, diagnosed 1992*).

Activism

A number of respondents found that being involved in HIV related activities has enhanced psychological functioning, and has made them feel good about themselves:

- " People would come to me and I would help them and see how this had a positive effect on them then I would ask myself 'what if I'd gone drinking as I had planned to, how would that person have been helped"

It elicits a sense of purpose and some meaning to an experience that may potentially be negative:

- "I felt good about myself and because I was living what I was teaching, the whole thing fed on itself. I was doing good for others, which in turn was doing good for me".
- "I always encourage people and in the process become self encouraged"
- "Interviewer: If any, what were and what are the things that you believe have allowed you to mentally cope better with being HIV positive? What are the sources that you draw your strength from? Respondent: I do not sit around not

doing anything and I enjoy helping other people living with HIV, participate and contribute in community work". (*F, diagnosed 2000*)

Sharing the experience with others has, to the surprise of most respondents, proved uplifting and very helpful. In some cases this involved encouraging other people to live healthy and positive lifestyles. It also included imparting useful information that will help other HIV positive individuals adjust and live positively.

A number of people felt a sense of achievement in being "at the centre of things" and actually feeling that they were doing something that is of benefit to others less empowered than themselves. This was said to enable one to step out of the realm of self-pity and take others in. This had positive outcomes in rebutting oppressive feelings associated with a positive HIV status.

Respondents also described various secondary benefits from being part of an HIV/AIDS activist group, For example development of presentation skills and English language proficiency. It gave others the opportunity participate in workshops that have improved their ability to speak in public and to be open about their status to other people.

Religiosity

Religion was important to a number of respondents. Some respondents drew solace, comfort and strength from religion. These respondents looked to religion for coping or meaning to their experience:

- "Spiritual support has also helped me be where I am today; I get my Minister to pray for me when I feel burdened, and that makes me feel better". (*F, diagnosed 1998*)
- "Respondent: Religion has helped me a lot because I became 'born again' in 1997. I grew up in a 'Catholic Church'. I married at the 'Swiss Mission' at first then I became a 'Muslim' for two years and in 1997 until now I became a 'born again Christian'. That helped me a lot since I started to see that what happens to me was the result of God's purpose at me to change and become

born again and know Him because I only knew that there is God but could not communicate with Him" *(F, diagnosed 2000)*

- "There is a paragraph in the bible which I like to refer to which goes: 'What should you grab if your house was burning?' And I can answer the paragraph and say my bible and my faith carrying me everyday... the reason that I breathe with God in my life I can survive everywhere. That means I was strengthened by those words when I started to feel sick and I believed that God wanted to show himself up so we can see that he is alive" *(M, diagnosed 2004)*

Christian beliefs, and in some cases traditional ancestral belief systems seem to be favoured by most, with a number of respondents expressing a sense of having overcome through these:

- I am a staunch believer in healing brought about the traditional way but where have you ever heard of a traditional healer burying another? We need priests for this purpose. The two are just not mutually exclusive. I used to be very sick and anyone could see that I had AIDS but I asked God to be there for me. I am now in good health. *(F, diagnosed 2002)*

Much emphasis is placed on being right with God and being buried by the church.

- I might go to church feeling stressed but once I get into the swing of things the problem just melts away. I go there with the problem of the HIV and with the problem of whatever it is that is stressing me at the moment. I get soothed just by being in church, the priest might add on to the good feeling if we get to speak. He encourages me to pray, and to be thankful to God for every minute of my life. I have complete faith in God. *(F, diagnosed 2002)*
- Now ... with the HIV thing, I said to myself ... if God loved me ... and I know that God loves me ... I will spend the rest of my life praying that he will helped me survive with my children, my mother ... and I will stay the rest of my life ... in his house. *(F, diagnosed 2004)*

Prayer and the belief that divine justice prevails were also central to keeping people strong. These were reported to help in understanding the context of the illness, that is, not seeing it as 'punishment' but as having religious meaning. .

The church was also viewed as an important source of social support:

- "Spiritual support has also helped me be where I am today; I get my Minister to pray for me when I feel burdened, and that makes me feel better" *(F, diagnosed 1998)*
- "I: And did you find that your minister was supportive? R: Yes, he also said he hoped this would be an example to others, that more people would come out instead of thinking they are bewitched. He felt I had done the right thing...everyone has gone out of their way to be supportive. They even use me in their youth education programs and other events at church" *(F, diagnosed 1998)*

However, even though most of the respondents were positive about the role of religion in their lives, two people expressed different views on the subject. One respondent described a difficult phase in his spiritual life:

- "I: Is there any stage where you blamed yourself, where you had regrets and wished you had done things differently? R: Yes, initially I blamed myself and regarded the whole thing as punishment from God. I: What did you attribute the punishment to? How did you explain that concept to yourself? R: To me it was like, I had done so much for God, I had done my dues, gone to church, done this and that, so why... I never thought that I could have HIV because I'm such a firmly church oriented person" *(M, diagnosed 1992)*

The person's faith in God was shaken to a point that he stopped going to church:

- "I: And did this perception affect your relationship with God, did you end up not going to church, losing your faith or was this not the case? R: Yes it did. I

did not go to church for three years and I'd never done this before. Usually if I miss church it's like there's something I haven't done. .but when I became positive I really felt bitter towards God. Not just a little" *(M, diagnosed 1992)*

Another view reflects a perceived lack of support from the church towards people living with HIV/AIDS:

- "Respondent: I would not say very much with religion because so far we are having difficulty with religious people to tell you the honest truth. Most of them are having difficulty accepting the epidemic. Last of last week I attended a funeral of a person who died because of HIV/AIDS...I asked the brother 'priest' if we were allowed to say whatever we wanted to say regarding the person and he answered that we are not. The brother told us we have to wait for him to consult with other family members first...On the following day he told us that we can say whatever we want but not mention the reason or cause of the deceased death which is HIV/AIDS" *(M, diagnosed 2002)*.

Additional aggravating factors

Other factors reported to adversely affect coping on a day-to-day basis included concern about family (including parents and offspring), difficulty in making decisions that affect the future (e.g. to buy a house or not to), and worrying not only about the fact that children have been infected with HIV, but what would happen to them once they died. One male interviewee who was diagnosed in 2002 was very worried about his children if he or his wife were to fall ill or pass way.

Overcoming barriers to coping

Respondents described different means they employ in trying to overcome difficulties. These include being completely focused on the positive and refraining from cluttering the mind with stress-invoking thoughts, simply learning to live with being positive and coping through better understanding.

One respondent talked about learning not to ground oneself in negative thoughts but rather to turn them around into a sense of purpose and determination to make the most of one's life. For example seeing others on their deathbed certainly triggered fear, but reframing these thoughts went a long way to making these thoughts more manageable:

- I do get frightened but then I counter this with the thought that it doesn't matter, I'll be getting a reprieve that way. I've also noticed that people get over a death quickly so my family should be able to deal with it. *(F, diagnosed 2003)*

Another respondent stated that accepting that the situation will not go away and learning to live with it is very helpful.

Some other ways reported to assist with coping were:

- "Respondent: Yes for a while. I told myself that HIV/AIDS is mostly theory as I understand it and should never be final stage"
- "R: It occurs, I'm comfortable with it, HIV is something I live with and I see no need to thwart the thought if it occurs. There's no running away from it, I'm comfortable thinking about it. I live with it but it is the lodger, we have to find a way of living together.. I always regard it as a challenger; it is up to you to decide how you live with it.."

Another view expressed by a respondent was coping through educating oneself about the subject.

- "Respondent: You know before you know your status you do not take time to go out to research and do whatever. So it was like HIV is the best weapon is there and I am dying. But once you start knowing exactly what is going on, going to do research in the libraries immediately you are diagnosed you will find that definitely it is like any other disease such as high blood or sugar diabetes and you will start living with it" *(F, diagnosed 2001)*

HEALTH ISSUES

Being HIV positive changed the lifestyles of a number of respondents. In the majority of the interviews people mentioned that HIV had pushed them to strive to lead healthier lifestyles:

- "Interviewer: Would you please share with me how you best describe, in your own language, how you feel inside being an HIV positive person? Respondent: I took it that being HIV positive is the beginning of life.. I also take it that being HIV positive is the start of life because it has helped me to manage my life such..Because long ago I was drinking alcohol and I stopped because of my HIV status since I realised that I would worsen my health"

However, the change was not always smooth because it requires adjustment, financially and psychologically:

- "As of now I do not have a problem I am coping very well. But the fact that it can make me change the lifestyle, there are quite a few things that I have to change in my life and other things are expensive for me because I am used to carry myself as I used to before being infected. But now that I have to make room for this HIV condition in my life most of the things have changed do you understand. That is the thing, which I can say, is there in my life. Otherwise other than that I have to put in nutrition and medication do you realize that is something that makes my life expensive".

The thought of becoming ill was a common theme in the interviews:

- "The other thing that makes it difficult living with HIV is the thought of getting sick, that one day one of us of the three infected in my family would one day get sick..."
- "Could you please tell me what are the things that you think make, or previously made, living with HIV more difficult for you? Respondent: Sometimes things, which made living with HIV difficult, is when children became sick....
- "Although there were so many things which after counseling you are told, one thing which nearly disturbed me it is the CD4 count story...my CD4 counts that are going down that there is something it was 134, it went down to 113, it went down to 11".
- "R: Yes! It was at the time when I had skin problems; I was involved in a trial in PE and had been told this would be one of the side effects. It was bad and I really could feel that I was HIV positive. It was painful, I had sores, but I did the best I could..."

Perception of health services and treatment

Amongst some respondents there was a feeling that health care providers were negative towards people living HIV and AIDS. The following quotes are illustrative:

- "The first thing is that health providers should wear protective gloves when giving treatment and that they should avoid commenting negatively about people living with HIV/AIDS…" *(M, diagnosed 2003)*
- "People with HIV/AIDS should not be treated with disregard, they are human beings also and I encourage the health service providers to treat (PWA's) with utmost care" *(F, diagnosed 2001)*
- "Like when I take my children to hospital for treatment, I take my child's medication or drugs along with me and health service providers do not have that confidential behaviour to call you on the side and talk to you about the status of your child" *(F, diagnosed 1994)*
- "Interviewer: Is there anything else that we have not spoken about about which you think people providing health services need to know about what you have gone through inside yourself and how this has affected your life? Respondent: I can say that some of them are not willing to help us and assist us…Though they try on the other things to give us support and care we need I think more should be done. They know that we need their services and need their care".

On the other hand some respondents expressed a sense of well being brought about through being treated in a caring and humane fashion by the health services.

The issue of the roll out of anti-retroviral treatment has provided some of the respondents renewed hope.

- "I: And how do you see the question of treatment…the fact that it's going to be made widely available? I'm interested in what it means for you personally. R: I think it's great; I'm excited about it because it will 'help a lot people to their feet'. It's really a good thing…that the advance of the virus will be slowed down. It's slow but there's hope. It has started in some provinces and it will get here also. ARV treatment is also a source of strength for some in that some respondents express the hope that they allow one to live a longer, healthier life, hopefully to the time when a cure can be found.

However, some of the enthusiasm expressed by respondents is tempered by real concerns as explicated by this respondent:

- "R: It doesn't really make a difference because, whether I am on treatment or not makes no difference to me. I am glad that people will get treatment as this will help them, people will live longer and there won't be so much dying. But there's the question of the CD4 count, which I think will be problematic. I mean, if your count is 200 and less you will get treatment but if it's over 200, say if it's 205, them you won't get it. I think it's a problem because even with the grant, it your count is high it can be withdrawn".

CHAPTER 4

Discussion

A diagnosis of sero-positive HIV is (almost) invariably psychologically life-changing. Whether the outcome is extremely poor ongoing mental health, adjustment to a new lifestyle, finding meaning and direction, or any other response, the impact is consistently significant. While denial and attempts to carry on life as usual are fairly common, the internal world of most people living with HIV/AIDS goes through often quite dramatic modifications and adjustments.

There are a number of stages/phases that people diagnosed HIV sero-positive tend to go through. These depend on factors such as stage of the disease, physical illness, when the person decides to disclose and to whom, levels of acceptance, responses from other people and so forth. However, from these interviews there are two important periods which we examine. The first is the "crisis" period after hearing of the diagnosis. For most people this crisis comes immediately on hearing that they are HIV positive, however for others there is first a period of denial or disbelief. Nonetheless some form of psychological crisis seems almost inevitable. How long this period lasts and its severity varies from person to person, depending on numerous internal and external factors.

The second period we refer to as "Living with HIV/AIDS". This is the period following the "crisis" and continues throughout the person's life. Clearly for most people (both sero-positive and negative) emotions change with time and across situations and various different emotional phases or stages would be expected within any person's life. However, for people living with HIV/AIDS it appears that the disease is an ongoing psychological presence and a highly significant force in shaping life decisions and emotions from the point of diagnosis onwards.

Mental health prior to knowledge of HIV status

Respondents were requested to discuss any mental health problems they may have had prior to being diagnosed positive to assess whether mental health problems may have preceded their positive HIV status. This was important for two main reasons. Firstly it was important not to ascribe any mental health condition which may have preceded HIV as possibly being an effect or impact of HIV. Secondly it was hypothesised as part of this study that poor mental health status may be a significant risk factor for becoming HIV positive. While this hypothesis will only be fully assessed by the quantitative part of the study, by asking about pre HIV mental health status, various pointers could be picked up.

While some respondents did indeed have mental health problems prior to being infected with HIV, within this small sample it would appear to be no higher than would be expected in the general population. However it appears from the interviews that people with a history of mental illness seem to have increased difficulty coping with being HIV positive. For example people with a prior propensity towards suicide or who had previously attempted suicide, appeared more likely to be propelled towards suicide as a result of being HIV sero-positive than people without a previous history.

The "crisis" period

Many respondents felt quite overwhelmed by their positive test. Questions of disclosure arose quickly for most people and, especially for those who did not disclose to anyone, many experienced intense loneliness. Anxieties around how other people would react was at the forefront of the thoughts of many people, but so too were thoughts of their own death and dying. A number of respondents felt suicidal and thought if they were going to die it should come sooner rather than later. Intense hurt and pain were felt by most people.

Some respondents felt so depressed or angry that they engaged in destructive and fatalistic behaviours such as abusing substances and engaging in unsafe sex. For some people this behaviour was nihilistic while for others it was vengeful.

Though most respondents had received some post-test counseling, and though a number of people said that this had been helpful, many interviewees were in too much of a state of shock to effectively take in the educational components of the counseling and perhaps even more importantly unable to make much use of the psychological support and insight offered. The fact that some individuals reported engaging in risky sexual behaviour more or less immediately on hearing their status suggests that the counseling was inadequate. Clearly some people's state of mind required much more assistance than was offered. Though some people may have rationally known that they could be passing on the virus, psychologically they either did not care or wanted to infect others.

However, even at this early stage of the knowledge of being sero-positive it appears that the type and quality of support available, levels of previous social isolation and subjective feelings of being judged by others seem to have mediated people's responses to the diagnosis.

Stigma and discrimination were extremely difficult for people to live with, however for some people imagined stigma appears to have been as psychologically destructive as real stigma.

Living with HIV

For some people the acute responses described above did not disappear but rather changed shape and form and set in as chronic problems. For example some people experienced ongoing problems with sleeping, with fear of death and dying, abused substances and felt suicidal. Depression was common. Some respondents continued to feel angry – especially with those they thought had infected them. On the other hand, some respondents continued to blame themselves. For some this self blame was

religious (i.e. being punished by G-d for bad behaviour) while for others the self-blame was for not conducting themselves differently.

Others though had come to accept their status – a few to the point where they had been able to come to terms with their lives in a far more profound way than prior to their infection. For most people though experiences fluctuated between feeling positive about life, to times when it was difficult to stay upbeat and positive. The view articulated by one respondent who spoke about putting on an accepting and contented face in public but suffering pain and hurt when on her own appears to reflect a somewhat common scenario. It was also expressed by at least one interviewer that certain respondents may have given answers that were more "socially acceptable" and that though most respondents were indeed coping, their lives were perhaps more difficult than they portrayed.

Apart from dealing with the diagnosis itself, some respondents faced challenges such as unemployment and financial difficulties which severely confounded their coping abilities. The other major issue which most people found extremely difficult to deal with and which caused a lot of stress was relationships. This included establishing and maintaining sexual relationships, communication around HIV with partners and infidelity. Some respondents had relationships breaking up because of HIV while others were too scared to talk about it because they feared that their relationships would break up. In conditions of poverty this was particularly problematic – especially for women. A number of women also reported abuse and many others feared it if they divulged their status to their partner.

For some respondents, the reality of living with HIV was made real during times of sickness and the deaths of other people known to them that were infected with HIV. At such times coping was particularly difficult.

Support and aggravating factors to coping

Social support (emotional, informational and instrumental), like the studies reported in the literature review in Chapter 1, was very important to respondents in this study. Many interviewees praised family members and friends who had stood by them,

helped them through difficult times and given them sustenance to go forward with life. However, obtaining social support implies disclosure and for some people this was extremely difficult. Certain respondents felt that open disclosure was a precondition to self-acceptance and being able to live a positive life, but for other people disclosure felt too difficult. For many people it is the anticipation of stigma (and hurt that it will cause other close people) rather than the stigma itself which prevented them from disclosing - and hence opening up to receiving support. Unfortunately however, it cannot be said that fear of disclosure is (always) a paranoid response as even in this sample some people had in fact been rejected as a result of their status. A number of people identified one or a few trusted people to disclose to and managed to receive support from them rather than being publicly open about their status.

Nonetheless some respondents were completely open about their status and had become community activists around HIV. They found that sharing their experiences with others had been uplifting and had helped them cope better - as much as it had helped those they were serving. Where people had found meaning through being HIV positive, it was usually because they had taken up the public struggle against HIV/AIDS and/or helped others who were living with HIV/AIDS.

Religion was a source of considerable emotional strength to many respondents. It appears that this strength was derived both from prayer/religious upliftment as well the social support provided by the church and its members. However the fact that some churches have not fully embraced people with HIV/AIDS had also meant additional stressors for people looking to religion/religious institutions for emotional and spiritual assistance but finding only stigma and rejection.

The positive role of support groups was highlighted by a number of respondents. They were seen to be important for emotional/moral support and as a source of information on HIV/AIDS. Their role in mitigating the psychological impacts of HIV/AIDS was seen to be important. Counseling was also seen by a number of respondents as having been vital in facilitating acceptance of themselves and their status. However counseling was not effective for everyone.

A number of interviewees reported that the anti-retroviral roll out programme has given them some hope for the future. They reported that the thought of receiving treatment uplifted their spirits. According to Rotherham-Borus (2001) with the prospect of a longer life and hope for people living with HIV and AIDS and their families, depression and hopelessness may be reduced.

Conclusion

The mental health of all people living with HIV/AIDS is effected. For some this results from physical impacts of the diseases itself while for others there are psychological reactions or responses to it. But not everyone responds in the same way; some people develop clear-cut diagnosable disorders while others become distressed for short or longer periods and to different degrees. Yet others overcome their initial negative reactions and, through their status, find meaning in their lives.

The experiences of most people in this study show significant emotional pain and suffering – made worse by stigma and discrimination. Though a number of people had accepted and come to terms with their status, being HIV sero-positive continued to have a significant impact on their lives, influencing relationships, employment and life-style.

Factors which helped people to cope or made things worse for their mental health cannot be listed into separable columns and recommendations made - largely because of the complexities involved with HIV/AIDS. Perhaps the best example of this is social support. It is very clear from both the international literature and this study that support from family and (to a slightly lesser extent) friends, is critically important to positive living with HIV/AIDS and better mental health. However a prerequisite to getting this support is disclosure. Unfortunately, while perhaps logical from the above argument, it is too simple to recommend that for better mental health people should therefore disclose their status. Even in this study there were examples of people being rejected due to their status - even by people quite close to them. The pain of this, and for many people anticipation of this, far outweighs the potential gains. One strategy to get support that appeared to be effective for most people in this study was to identify a

single person (or a few people) who, for one reason or another, would be likely to be sympathetic, and to begin a disclosure process slowly.

Another important, yet complex, example is religion. Many people in this study as well as in other research, have gained significant support and meaning through religion and religious structures. On the other hand though, some people became quite disillusioned with religious belief because they could not comprehend how a G-d could inflict such a disease on him/her and on the world. Moreover, certain churches stigmatised HIV/AIDS and instead of providing people with much needed support, tended to put more blame and additional stress on the individuals concerned.

With the above caution in mind, the results of this study do point to certain public services that could assist people's mental health. These include:-

- Stepping up the campaign against stigma and discrimination. This would, amongst other things, help infected people get the support (emotional, informational and instrumental) that they clearly need. Less social stigma and discrimination would also assist with the process of self-acceptance which appears crucial for better mental health and positive living.
- Support groups appear to be effective for a number of people. These need to be expanded. In particular, however, some people will require more psychotherapeutically oriented groups rather than more informationally/educationally oriented groups.
- Pre and post test counseling have benefits. However, for many people the timing and the lack of follow-up make this of limited value. Counseling services spaced a while after receiving a positive diagnosis, and which involve up to 10 sessions, would be extremely beneficial to a number of people.
- Greater exchange is needed with traditional and religious organisations to provide greater assistance to people living with HIV/AIDS - and particularly not to make things worse for infected individuals.
- Health personnel who mistreat people living with HIV/AIDS have no part in public health care. Appropriate action is needed, including training in basic counseling techniques, better understanding of HIV/AIDS and, where repeated transgressions have been made, disciplinary action should be taken.

- Many studies have shown mental health to improve with the introduction of anti-retroviral therapy. However a whole new set of mental health problems arise. Health workers in both general and mental health need to be trained in what to expect and how to deal with mental health problems in people taking ART (both medical and psychological).

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