

The Relationship between Personality, Cognitive Schemas,  
and Quality of Life in HIV Positive Gay Men.

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## **Overview**

Part I of this thesis, reviews research pertaining to quality of life and personality in HIV. Conceptual and methodological issues, which hinder research into quality of life and personality, are discussed. The review notes the lack of research into personality and HIV beyond prevention, and the need to investigate personality beyond neuroticism and extraversion. The review concludes that further replication of the reported associations between personality and quality of life in HIV is required. Studies that consider clinical directions and potential interventions are needed.

The empirical paper presents a cross-sectional, questionnaire, study looking at the relationships between personality, quality of life, and cognitive schemas, in HIV positive gay men. The study found that HIV is associated with poorer quality of life. Higher levels of neuroticism, and lower levels of extraversion, were found in the HIV positive group compared with the HIV negative group. Neuroticism and extraversion significantly predicted quality of life, and significant correlations were found between cognitive schemas and quality of life. Factor analyses of the Schema Questionnaire suggest problems with the measure. Results of the study are discussed with regard to future studies, and clinical implications.

The final part of the thesis is a reflective paper. It begins with a presentation of the processes leading to the conception of the research, and a discussion of clinical experiences that have informed and impacted on this process. An extended discussion of the strengths and weaknesses of the research is presented, followed by a consideration of the clinical and scientific implications of the

research. In the final sections of the paper, the author reflects on how the research has shaped her clinical understanding, and the methodological lessons learned.

Table of Contents:

Acknowledgments p. 1

**Part I:**

Quality Of Life, Personality, and HIV:

A Review Of The Literature	p. 2-65
Abstract	p. 3
1. Introduction	p. 4
2. Setting the scene: an overview of HIV	pp. 4-7
3. Quality of life	pp.7-24
3.1 <i>Definitions of quality of life</i>	pp. 7-8
3.2 <i>Quality of life and HIV</i>	pp. 8-24
4. Personality	pp. 24-35
4.1 <i>Personality and quality of life</i>	pp. 24-29
4.2 <i>Personality and HIV</i>	pp. 29-35
5. Personality and quality of life in PWHIV	pp.35-40
6. Future Directions	pp. 41-45
References	pp. 46-65

**Part II:**

The Relationship between Personality, Cognitive Schemas,

& Quality of Life in HIV Positive Gay Men. pp. 66-128

    Abstract pp. 67-68

    Introduction pp. 69-79

*The present study* pp. 77

*Hypotheses* p. 78-79

Method	pp. 80-86
<i>Participants</i>	pp. 80-81
<i>Ethics</i>	p. 81
<i>Procedures</i>	pp. 82-83
<i>Design</i>	p. 83
<i>Measures</i>	pp. 83-86
<i>Data Analysis</i>	p. 86
Results	pp. 87-106
<i>Participants' characteristics</i>	pp. 87-89
<i>Psychometric properties of measures used</i>	pp. 89-90
<i>Normality of measures</i>	p. 90
<i>Factor analysis of the SQ-SF</i>	pp. 90-96
<i>Group differences on QoL</i>	pp. 96-97
<i>Group differences on personality</i>	pp. 97-98
<i>Associations between Personality and QoL</i>	pp. 98-99
<i>Associations between Schemas and QoL</i>	pp.99-101
<i>Predicting QoL from Personality traits</i>	pp. 101-106
<i>Schemas mediating relationship between Personality and QoL</i>	p. 106
Discussion	pp. 107-117
<i>Conclusion</i>	p. 117-118
References	pp. 119-128

### **Part III:**

Critical appraisal	pp. 129-148
--------------------	-------------

1.	Introduction	p. 130
2.	How this research project developed	pp. 130-134
3.	Strengths and weaknesses of the research project	pp. 134-139
4.	Clinical and scientific implications	pp. 140-143
5.	How has the research affected my clinical understanding	pp. 143-144
6.	Lessons learned through the research project	pp. 144-146
	References	pp. 147-148

<b>Appendices</b>		pp. 149-166
Appendix I	Ethical approval letter	pp. 150-153
Appendix II	Information sheets and consent forms HIV positive participants	pp. 154-160
Appendix III	Information sheets and consent forms HIV negative participants	pp. 161-166

## Tables and Figures:

### **Part I.**

Figure 1. The model proposed by Burgess *et al.* (2000) p. 36

### **Part II.**

Table 1: Recruitment and response rates. p.87

Table 2: Demographic information of comparison and  
HIV positive groups p. 88

Table 3: Internal reliability coefficients p. 89

Table 4: Factors of the SQ-SF pp. 92-94

Table 5: Group differences on QoL domains p. 97

Table 6: Correlations between NEO personality  
scales and QoL domains p. 98

Table 7: Correlations between Schema and QoL domains p. 100

Table 8: Hierarchical regression analysis for NEO  
personality traits predicting physical QoL p. 103

Table 9: Hierarchical regression analysis for NEO  
personality traits predicting psychological QoL p. 105



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**Part I:**

**Quality Of Life, Personality, and HIV:**

**A review of the literature**

- **Abstract**

This review is concerned with the literature pertaining to personality and quality of life in HIV positive individuals. Studies of personality and quality of life are reviewed, and methodological and conceptual issues considered. Poor quality of life has been demonstrated in individuals infected with HIV. Both physical and psychological processes have been implicated as significant to quality of life of people infected with HIV. Few studies have examined the role of personality in quality of life, and most studies have focused on risk behaviour and rates of personality disorders. Neuroticism and extraversion have been demonstrated to be associated with quality of life in people infected with HIV; however, the roles of other personality traits have been largely neglected. Further replication of the reported relationships between personality traits and quality of life are needed. Studies that consider clinical directions and potential interventions are required.

## ▪ 1. Introduction

This review is concerned with personality and quality of life in HIV positive individuals. Consideration is given first to the scale of the HIV problem, and how it manifests clinically. I then discuss the various definitions of quality of life that have been used, and review studies of quality of life in people with HIV (PWHIV). The relationship between personality and quality of life is then considered, followed by an examination of the impact of personality on risk of contracting HIV and the ability to cope with the infection. In the final section an evaluation of research looking at quality of life and personality in PWHIV is undertaken, followed by some consideration of what published research has demonstrated and possible directions that research in this area might undertake.

## ▪ 2. Setting the scene: An overview of HIV

Awareness of acquired immunodeficiency disease began with a brief report in 1981 describing a rare strain of pneumonia, and other unusual opportunistic infections, in five gay men in Los Angeles (MMWR, 1981). The extent of the epidemic and its possible health and social implications became apparent with increasing case reports of similar immune deficiency syndromes reported in other parts of the US among gay men, intravenous drug users, haemophiliacs, recipients of blood transfusions, exposed infants, female and male sexual partners of infected individuals, and others. These syndromes were eventually linked to a virus named Human Immunodeficiency Virus or HIV (Coffin *et al.*, 1986). Despite dramatic advances in virology and clinical management, as well as a clear understanding of how the virus is transmitted, HIV infection has developed into a worldwide pandemic. Since AIDS was first described in 1981,

there have been more than 20 million deaths worldwide. There are now approximately 38 million people in the world (range 34.6-42.3 million) who live with HIV (UNAIDS 2004).

Untreated HIV disease is chronic and progressive. Depletion of CD4 lymphocytes, a subset of white blood cells responsible for coordinating and regulating immune responses (Gallo, 1988), is the hallmark of HIV infection. This depletion predicts an individuals' risk for infection with opportunistic pathogens such as pneumocystis carinii pneumonia and other illnesses normally prevented by a healthy immune system (Fahey *et al.*, 1990). Primary HIV infection, often marked by an influenza-like acute viral syndrome, is followed by a period of clinical latency, typically lasting several years, during which CD4 cell turnover leads to progressive immune dysfunction and eventually death. The time between initial infection and the development of AIDS is, on average, ten years, in the absence of medication (Bacchetti & Moss, 1989). Given the long course of HIV, infected individuals have the potential to pass the infection to others.

The primary route of the spread of HIV infection worldwide is through sexual exposure. In the United States and Europe, HIV infection through homosexual contact remains significant, and there is some evidence of increasing incidence among young gay men and ethnic minorities (Holmberg, 1996). Globally, in areas of the highest HIV prevalence, unprotected heterosexual intercourse is the primary mode of transmissions, accounting for approximately 70% of the overall

sexual transmission (Gayle, 2000). In Western Europe and in the United States, young gay men remain heavily affected.

The advent of new pharmacological treatments for HIV and AIDS, in the past five to ten years, known as combination therapies, have increased life expectancy and improved the health of those infected with the disease who have access to such medications. The introduction of protease inhibitors (PI's) in the mid-1990's revolutionised the treatment of HIV (Hammer *et al.*, 1997). Effective combination antiretroviral therapy (e.g. HAART) became the standard of care in the United States and Western Europe. In these regions a sharp decline in morbidity and mortality associated with HIV infection was noted (Palella *et al.*, 1998). The use of these drugs in developed countries has shifted the parameters of HIV/AIDS from an acute and usually fatal disease, to a more chronic long-term disease (Antoni & Schneiderman, 1998).

Potent pharmacological treatment of HIV is not however without complications. The long-term medication toxicity has been found to be a problem in individuals who are now living longer, healthier lives with HIV. In cases where CD4 count and clinical assessment indicate a low risk of imminent disease progression, the potential adverse effects of immediate treatment would be expected to outweigh any benefit (Dybul, Fauci, Bartlett, Kaplan, & Pau, 2002). Other HIV-infected individuals may have psychosocial barriers to medication adherence that preclude effective HAART (High Active Antiretroviral Therapies), at least in the short term, until these issues are addressed. A patient's incomplete adherence to medication regime can rapidly lead to lasting resistance against available

antiretrovirals. It is imperative to address issues that are likely to impair a patient's adherence to medication before starting pharmacological treatment. The realisation that pharmacological treatment is not without its costs, together with the shift of HIV to a chronic condition, has prompted researchers and medical professionals to consider lifestyle and individual factors that pertain to quality of life.

- **3. Quality of Life**

- **3.1 Definitions of Quality of Life**

Quality of life has become a firmly established goal in medical care (Editorial, Lancet 1995). This is especially true for chronic conditions for which a cure is unlikely (Smith, Avis, & Assmann, 1999). To fully understand the impact of a disease, traditional measures of psychopathology need to be complemented with Quality Of Life (QoL) measures that encompass key indicators such as satisfaction and enjoyment of life (WHOQOL Group, 1998a). However, research continues to be hampered by a lack of clarity regarding precisely what is meant by *quality of life* (e.g. Lerner & Levine, 1994; Mor & Guadagnoli, 1988). Investigators often use the constructs "*quality of life*" and "*health status*" interchangeably (McDowell & Newell, 1996; Spitzer, 1987). This is further complicated by references to "*health-related quality of life*" as used in medical settings, and "*subjective well-being*" and "*life satisfaction*" originating from sociological studies of healthy general populations (Smith *et al.*, 1999). Health-related quality of life refers to how well a person functions and to his or her perceptions of well-being in the physical, mental, and social domains of life (Coons, Rao, Keininger, & Hays, 2000).

Assessing health-related quality of life is important for documenting the burden of chronic disease, tracking changes over time, and assessing the effects of treatments (Hays *et al.*, 2000). There is a growing recognition that health status and quality of life are separate constructs, with the latter reflecting more psychological processes (Smith *et al.*, 1999). According to the World Health Organisation Quality of Life Group, QoL measures that go beyond symptom assessment and functional status evaluation are most appropriate for use in the context of HIV where social, environmental, and spiritual issues are considerable (Skevington & O'Connell, 2003). This is reflected in more contemporary measures of quality of life, which incorporate indicators of emotional well-being, coping styles, and social support (e.g. WHOQOL-100, QOLI). Although currently there is no unanimously accepted definition of QoL, researchers increasingly adopt a broader conceptualisation of the construct, systematically aiming to study individuals' evaluation of all domains that may impact on their sense of QoL, e.g. psychological, environmental and physical domains.

### ○ 3.2 Quality of Life and HIV

As discussed above, the shift in parameters of HIV from an acute and ultimately fatal disease to a more chronic long-term condition means that for people living with HIV (PWHIV) quality of life issues have become more significant. Increased lengths of survival, and improved health have highlighted the relevance of quality of life issues to the management of PWHIV. Improvements in the physical health of PWHIV have in some cases failed to produce concomitant changes in their quality of life as initially predicted, and have



introduced new uncertainties and issues. Research indicates that PWHIV often face stigmatising, prejudicial and discriminatory events, which can, in turn, be both demoralising and life altering (D'Augelli, 1989). Professional careers, living arrangements, financial solvency, and the ability to mix in certain social and professional circles, may all be threatened by the HIV status (Herek, 1999). In addition, individuals with HIV often face difficult decisions regarding informing past sexual partners, family members, and friends among others. Thus, HIV represents a complex condition spanning emotional and physical domains, which are further interactive.

In a qualitative study conducted by Brashers *et al.* (1999), participants raised the issue of quality of life. Participants expressed concerns over the side effects of medication, susceptibility to opportunistic infections, and living with a chronic disease, which can impede “normal” life. One of the challenges of living with HIV infection is the latency of disease progression. Fluctuating health and uncertainty are therefore common among people living with HIV. Mishel (1997) has described the way a lack of event congruence can increase uncertainty in chronic illness. Physical well-being and emotional well-being thus appear to be closely linked, as well as having independent effects on global measures of well-being.

Physical well-being, whether assessed in the form of CD4 cell counts, HIV viral load, or HIV-symptom severity, is a reliable predictor of many clinical outcomes in HIV-infected persons including psychological functioning, and quality of life (Weinfurt, Willke, Glick, Freimuth, & Schulman, 2000). Bing *et al.* (2000)

examined whether simply being HIV-infected is enough to decrease the QoL, or whether the onset of symptoms or immunological dysfunction is needed before QoL is adversely affected. The researchers administered the Medical Outcomes Short-Form Health Survey (SF-36) to 2,295 gay men enrolled in the Multicentre AIDS Cohort Study (MACS) in the USA. HIV positive men who were asymptomatic were found to have similar perceived mental health, but worse perceived physical health than HIV negative men. HIV positive men who were symptomatic were found to have both poorer perceived mental and physical health compared to HIV negative men. Merely being HIV positive was not found to adversely affect mental and physical health equally. The study also found that having one HIV-related symptom was sufficient to significantly decrease all of the health-related quality of life scores.

HIV symptoms have not been found to have a cumulative effect on well-being. Bing *et al.* (2000) found that participants with more than one HIV-related symptom had significantly higher scores of emotional well-being and the mental composite score (comprising scores on the SF36 mental health factor and CES-D depression scale) than those with only one HIV-related symptom. The reason for poorer well-being scores among the less symptomatic participants compared to those with more symptoms is unclear. Bing *et al.* (2000) speculate that the heightened sense of anxiety and depression often observed among mildly symptomatic people might reflect the emotional response to confronting worsening health status for the first time. The authors suggest that individual differences and psychological processes may also account for the other patterns they have observed.

Similar findings have been attained in other studies. In the USA, Hays *et al.* (2000) compared quality of life of 2, 864 PWHIV to quality of life of people with other chronic conditions, and people from the general population. This study also used the SF-36. Physical functioning was comparable in asymptomatic HIV positive individual and in the general population. However, physical functioning was much worse for symptomatic HIV positive individuals. Participants who had medical symptoms and were diagnosed with AIDS had worse physical functioning than those with other chronic conditions (e.g. epilepsy, localised prostate cancer, diabetes). Emotional well-being was comparable among participants with HIV (i.e. both symptomatic and asymptomatic). However, emotional well-being in participants with HIV was significantly worse than the emotional well-being both in the general population and participants with other chronic conditions. This study confirms that both physical and emotional well-being are adversely affected in PWHIV, and that these effects are more pronounced in PWHIV than in people with other chronic medical conditions.

A number of methodological limitations potentially limit the usefulness of the results presented by Hays *et al.* (2000) and Bing *et al.* (2000). The data used for the Bing *et al.* (2000) study was collected in 1994, and therefore does not reflect the impact of recent changes in treatment of HIV. Secondly, their sample is comprised primarily of White, well-educated, older, gay and bisexual men, and hence the results may not be generalisable to a randomly selected gay and bisexual male population, or heterosexuals. A related criticism, which applies to most research within this domain, is that most published studies are based on

North American and European cohorts, which limits the applicability to people in other regions. Thirdly, the results reported by Hays *et al.* (2000) are based on cross-sectional analyses, and causality can therefore not be inferred. Furthermore, the authors were unable to adjust the results in the comparison groups (e.g. depression, cancer), and the possibility that the differences may reflect factors other than those studied cannot be excluded. Nevertheless, the studies outlined above suggest that emotional and physical well-being may be compromised by HIV infection, and the impact of HIV, on both physical and psychological domains, may be greater than the impact of other medical conditions on quality of life.

Research exploring the interaction between physical and psychological well-being has shown that poor physical well-being can affect the QoL of HIV-infected persons in direct and indirect ways (Heckman, 2003). In the former, poor physical well-being can increase pain, fear of death, and anxiety about later disease progression. In turn, depression and anxiety can affect the body's functioning further compromising the individual's immunity. Indirectly, physical illness can disrupt existing social networks, hinder the establishment of new relationships (Kalichman, 1998), and can limit the buffering effect social support can have on coping in HIV positive individuals. Moreover, drug treatments for HIV and for the associated opportunistic infections, which are taken both for acute infections and for prophylaxis, potentially have a wide range of side effects, which can make patients, who are otherwise well, feel physically ill. In addition to the distress of having a chronic and terminal illness, people infected with HIV have been shown to have high rates of stressful life events and

traumas, such as previous sexual and physical abuse and multiple bereavements (e.g. Simoni & Ng, 2000).

To date, studies of quality of life of PWHIV have been limited by their focus on health-related quality of life and the outcomes of medical treatments (e.g. Sherbourne *et al.* 2002). The psychological components of quality of life, which tap the subjective experience of living with an illness and satisfaction with life, have been inadequately appreciated. Studies that have examined psychological factors impacting on quality of life of PWHIV have focused on emotional states (e.g. Revicki & Swartz, 1997; Zander, Jager, Palitzsch, Poppinger, Steinbuchel, & Bullinger, 1993). Other psychological factors that have been studied vis-à-vis quality of life in PWHIV include psychiatric disorders, stress, and buffering resources like social support. Some of the studies, which have attempted to investigate the relationship between psychological factors and quality of life in PWHIV, are reviewed below.

In a prospective study by Leserman *et al.* (1999), eighty-two HIV-infected asymptomatic gay men were followed up at six-month intervals for 5.5 years. The participants were recruited through the Coping in Health and Illness Project (CHIP) in the USA, which is a longitudinal study of the effects of stress on HIV progression. None of the participants were being prescribed protease inhibitors. Semi-structured interviews were used to measure depression and life events. Social support was assessed using the Sarason Brief Social Support Questionnaire (Sarason, Shearin, Pierce, & Sarason, 1987). The study looked at depression, life events, and social support, hypothesising that higher scores of

depression, more stressful life events, and less social support, would put men at risk for more rapid HIV disease progression to AIDS. This study was amongst the first prospective studies to provide evidence that the cumulative experience of stressful events and difficulties and social support may have a measurable impact on disease progression in HIV-infected men. The effects of stressful life events on disease progression were measured in terms of T4 lymphocyte counts, which indicate the capacity of the immune system to fight infections.

The study demonstrated that for every 4-point increase in cumulative average stressful life events, equivalent to one severe stressor or two moderate stressors, the risk of AIDS was doubled. For each one-point decrease in cumulative average social support, the risk of AIDS increased almost three fold. Although depressive symptoms were related to increased risk of AIDS, only stress and social support remained significant in the model when the three psychological variables were considered together.

In a subsequent study, Leserman *et al.* (2002) reported that for every increase in cumulative average stress, equivalent to one severe stressor, the risk of developing AIDS clinical condition was almost tripled. Kaplan-Meier survival analysis estimates, derived from the data, demonstrated a faster trajectory to an AIDS diagnosis in participants whose stressful life events scores above the median, compared with those below the median. For those above the median in terms of stress, the AIDS progression rate at the end of eight years was 74%, versus 40% for those below the median. The rate of progression to a clinical AIDS condition, at the end of eight years, for those above the median in stress

was 46%, while for those below the median in stress it was 26%. This suggests that psychological processes, such as stress, have a significant impact on the rate of HIV progression, and thereby morbidity and mortality.

The CHIP study has a number of limitations. First, a relatively small non-representative sample of gay men makes generalising the results problematic. Secondly, most of the subjects progressed before widespread use of HAART, and hence the results may be less applicable to current cohorts of HIV-infected people. In addition, the study's results are limited by the lack of a measure of disease progression, and the inability to infer direction of causality in the relationship between the psychological variables and disease progression. It is debateable whether psychological states such as depression contribute to disease progression, or whether the psychological states are a result of the disease. Moreover, the study failed to consider personality factors and other mechanisms, such as coping, that may underpin psychological states such as depression, and the person's ability to seek or benefit from social support.

The CHIP results, nevertheless, show that there is some important association between the progression in HIV and psychological well-being. In addition, the hypothesis that stressful events can hasten progression of HIV infection has been supported by other studies. In a retrospective study by Kimerling *et al.* (1999), 62% of the 67 asymptomatic HIV-infected African American women studied were found to have experienced a traumatic event during their lifetime. Traumatic exposure was in turn associated with greater decreases in physical indicators of disease progression, specifically CD4/CD8 ratio, which is an

indicator of immune suppression, highly correlated with HIV infection. However, the results of this study need to be considered with reference to the limitations posed by the methodological design. The study focused on African women, and hence generalising these results to other populations with HIV is problematic. The study adopted a retrospective design in so far as trauma was experienced prior to the study and possibly prior to infection with HIV. Moreover, participants had experienced acute trauma, which in itself may have affected the body's functioning, thus the effect of trauma may have exacerbated the effect of stress on HIV. However, Kemeny and Dean (1995) reported that the stress of bereavement, prior to their study (e.g. having a close friend or a lover who died of AIDS), was associated with more rapid decline in CD4 counts during a 3 to 4-year follow up. In a follow-up study, Bower, Kemeny, Taylor, and Fahey (1998) found that participants who found meaning in their bereavement had a less rapid decline in CD4 levels, and lower rates of mortality due to AIDS.

Research suggests that bereavement remains a significant effect on HIV disease progression when matching participants are compared. Kemeny *et al.* (1995) found that HIV-infected homosexual men, who were recently bereaved, showed increased risk of disease progression (indicated by increased serum neopterin- an immune activation marker associated with increased risk of AIDS), compared with a matched group of non-bereaved individuals. Evidence has been mounting to suggest that chronic stress, and dysfunctional coping, may affect the immune system, and hence explain some of the variation in HIV disease progression between different individuals and cohorts. A common weakness to most of the



studies outlined above is the cross-sectional, retrospective design. Moreover, correlation or association cannot be used to conclude causation, nor the direction of the effects. Most of the studies cannot readily verify that stress affects progression of HIV disease. The one study that did look prospectively at the effects of stress of bereavement on HIV, by Kemeny and Dean (1995), found that although bereavement was associated with rapid decline in CD4/CD8 ratios, bereavement did not predict progression to AIDS or mortality rate. This suggests that although stress does impact on HIV progression, the effect is rather complex and may be mediated by other factors.

The role of cortisol, a hormone associated with high stress levels, has been examined in relation to progression of HIV. Leserman (2003) has commented that understanding the effects of stress, coping, and cortisol, in HIV disease progression may spawn the development of new psychosocial and medical interventions. As discussed above, the effect of stress on physical well-being is well documented. Research has further demonstrated a link between passive coping strategies (e.g. denial) and HIV disease progression. Using the CHIP data described above, Leserman *et al.* (2000) showed faster disease progression to AIDS during 7.5 years among those scoring high on the denial sub-scale. Cox regression analyses from this study showed that for each 1-point increase in cumulative average denial (4-point scale), the risk of AIDS doubled after controlling for other psychosocial variables (e.g. stressful life events, social support), baseline demographics, disease status variables, and health behaviours.

A longitudinal study looking at coping and disease progression found that HIV-infected homosexual men scoring above the median on passive coping compared with below the median, had lower CD4/CD8 ratios and lower lymphocyte proliferative response to PHA (phytohemagglutinin), indicative of disease progression, at three weeks and one year, after testing positive for HIV (Antoni, Goldstein, & Ironson, 1995). Similarly, Ironson *et al.* (1994), and Solano *et al.* (1993), have also demonstrated that denial was associated with faster progression into symptomatic HIV disease. Mulder, Antoni, Duivenviirden, Kauffmann, and Goodkin (1995) have shown that active confrontational coping at baseline (indicated by seeking support, problem-solving, and less denial) was associated with a lower probability of symptomatic disease progression over a one-year period. In another study, by Cole *et al.* (1996), HIV-infected men who concealed their sexual orientation from others (argued by the authors to be indicative of denial) demonstrated faster disease progression.

Researches have considered cognitive explanatory styles as potential psychological factors impacting on QoL. Research on explanatory style has found that individuals with a more optimistic style have better health, for example fewer illnesses and physician contacts (Lin & Peterson, 1990; Peterson, 1988), better immune functioning (Kamen-Siegel, Rodin, Seligman, & Dwyer, 1991), better health over the life span (Peterson, Seligman, & Vaillant, 1988), and reduced mortality. Dispositional optimism has similarly been related to fewer health complaints (Scheier & Carver, 1985), and recovery from ill health such as coronary bypass surgery (e.g. Scheier *et al.*, 1989). People with greater optimism are also more likely to engage in health promoting behaviours, such as

exercise and treatment adherence, and less likely to engage in unhealthy behaviours such as smoking and recreational drug use (Scheier & Carver, 1992). These findings suggest that cognitive styles may impact on QoL by either predisposing to, or protecting from, illness, and by influencing the way people manage illness. However, the findings with respect to HIV and cognitive styles have been incongruous with the findings cited above.

In a recent two-year prospective study, Tomaskowsky, Lumley, Markowitz, and Frank (2001) demonstrated that optimistic explanatory style was associated with decreases in CD4 counts in HIV-infected men. Similar detrimental effects of optimistic styles on CD4 counts have also been found in other studies. For example in a 3-month prospective study of healthy women, Cohen, Mermelstein, Kamarck, and Hobermann (1999), found that dispositional optimism was associated with better immune functioning after acute stress, but worse immune function under chronic status. In another prospective study, Isaacovitz and Seligman (2002) found that optimistic explanatory style predicted increased depression in response to negative life events in elderly adults. Tomaskowsky *et al.* (2001) have speculated that the negative impact of optimism on immune function in PWHIV may reflect the chronic stress and prospect of a shortened lifespan associated with HIV infection. They further suggested that optimistic explanatory style might be maladaptive and related to denial in HIV-infected individuals.

By way of contrast to these results, Reed, Kemeny, and Taylor (1999) found that initially asymptomatic homosexual men with more negative or pessimistic HIV-

related health expectations had a greater chance of developing HIV-related symptoms, three years later, if they had lost a friend or a partner to HIV. The authors argued that the combination of AIDS-related bereavement and pessimistic attitude might indicate an underlying dysphoria that could contribute to poor health outcome and poor QoL. Reed, Kemeny, Taylor, and Visscher (1999) also found that pessimistic health expectations were positively related to avoidance and self-blame among the bereaved. These results are further corroborated by a study by Segerstrom, Taylor, Kemeny, Reed, and Visscher (1996), which demonstrated that negative causal attributions were associated with more rapid CD4 decline during 18-months follow up. The findings about coping are therefore somewhat contradictory, although there does seem to be some evidence that denial has a detrimental effect on health status, and therefore poorer quality of life, in HIV-infected individuals.

In an attempt to explore social support processes in HIV-infected individuals, Derlega, Winstead, Oldfield, and Barbee (2003), used the Sensitive Interaction Systems Theory (SIST) (Barbee, Cunningham, & Winstead, 1993; Barbee & Cunningham, 1995) to examine the means by which individuals with HIV seek and receive social support. The study compared social support in relationships with peers versus parents, and the association between different kinds of support receiving behaviours and depressive symptoms. The study recruited 125 participants, 75 men and 50 women, from HIV/AIDS service organisations and a hospital outpatient clinic in the USA. Questionnaires were used to assess support-seeking, support-receiving, and depression symptoms. In addition, participants were asked to provide some demographic information, and to

identify the person, if anyone, they would confide in about HIV infection. Participants reported using more Ask behaviours (a direct form of support seeking) with a friend and an intimate partner than with parents. They also reported receiving more Approach (Solve/Solace) forms of support from a friend and an intimate partner than from parents, and less Avoidance (Escape/Dismiss) from a close friend than from parents. As a support-seeking behaviour, Ask was most likely to be associated with Approach forms of support providing from all types of relationship partners. Avoidance from parents, an intimate partner, or a friend, was positively associated with depressive symptoms. This study highlights the different support experiences PWHIV may have within different relationships. Specifically, the study's results suggest that PWHIV may have more difficulty seeking support from parents (an involuntary relationship) than from peers (a voluntary relationship), and the support from parents may be less helpful. Importantly, the findings suggest that not all forms of support are experienced as helpful, and that not all support-seeking behaviours are effective at eliciting the type of support the person may find beneficial.

The authors of the study caution that the behaviours identified by SIST as support-seeking behaviours may not be intended to seek support, but may instead reflect what the person ("support seeker") feels at that moment. Burgess *et al.* (2000) argue that although mood states are informative, they represent constituents, rather than determinants, of quality of life, which renders them poor explanatory factors. Caution is needed when attributing cause to behaviour, as one cannot rule out the possibility that communication is related to long-standing dispositional tendencies. The results, nevertheless, highlight the importance of

supportive relationships to PWHIV, and the need to consider dynamic processes that mediate social support, such as relationship functioning. A recent qualitative study, by Bor, du Pleiss, and Russell (2004), exploring patterns of HIV disclosure and social support, found that many gay men do not regard their primary biological family as their primary social support system. Friends and partners were frequently identified as the primary caregivers. The emotional responses of both caregiver and the infected individual at disclosure were found to be reciprocal, and linked to the subsequent supportive relationship. Previous experiences within relationships may also affect a person's expectations of, and behaviours in, relationships.

In an attempt to provide a theoretical model for studying quality of life in PWHIV, Heckman (2003) proposed the Chronic Illness Quality of Life (CIQOL) model for explaining life satisfaction in people living with HIV. The CIQOL model theorises that life satisfaction in persons living with a chronic illness, such as HIV disease, is a function of health-related discrimination, barriers to health care and social services, physical well-being, social support and coping. Empirical evaluation of the model found that the CIQOL model provided excellent fit to study data. Heckman (2003) evaluated the CIQOL model using data from 275 persons living with HIV disease. The participants were recruited using a postal self-administered assessment, and the sample consisted of 221 men, 53 women, and one transgendered person. The assessment tool consisted of Satisfaction with Life Scales (Diener, Emmons, Larsen & Griffins, 1985), AIDS-related discrimination scale (Heckman *et al.*, 1998), the Barriers to Care Scale (Heckman *et al.*, 1998), the Physical Well-being subscale of the Functional

Assessment of HIV quality of life instrument (Cella, McCain, Peterman, Mo, & Wolen, 1996), Provision of Social Relations Scale (Turner, Frankel, & Levin, 1983), and the Coping with HIV/AIDS Scale (Boberg *et al.*, 1995).

Women reported less life satisfaction and confronted more barriers to health care and social services than men. White participants reported higher perceptions of AIDS-related discrimination than non-White participants. The study has several limitations. The sample was not random, geographically limited, and restricted to persons affiliated with local AIDS service organisations. The study's response rate of 46% is rather low, although typical of anonymous postal surveys, which precludes follow up. It is not possible to ascertain the extent of differences between respondents and non-respondents, who may have differed in terms of the psychosocial factors studied. Furthermore, the study failed to collect parameters of clinical health (such as CD4 counts or viral loads), which are likely to impact on quality of life. Finally, the cross-sectional design of the study means that bi-directionality cannot be ruled out. It is possible that greater life support produces greater life satisfaction; however the reverse may also be true.

Although the CIQOL model highlights five psychosocial factors on which AIDS mental health interventions can focus, the model fails to specify the precise content and nature of such interventions. The authors of the study suggested that future research should examine how factors such as cognitive appraisal of life stressors, comorbid physical and mental health conditions, cognitive functioning, dispositional factors, and personality traits. The role of personality and dispositional factors on quality of life has been long acknowledged. The studies

discussed below will illustrate the current perspectives on the relationship between personality traits and quality of life.

- **Personality**

- **4.1 Personality and Quality of Life**

Personality is defined by the emotional and behavioural characteristics, or traits, that constitute stable and predictable ways that an individual relates to, perceives, and thinks about, the environment and the self (Hutton, Glenn & Treisman, 2001). Individuals vary in the degree to which they possess a given trait, and in the way it influences their behaviour. Traits are not positive or negative; they may be adaptive in one setting and maladaptive in another. When a trait is present at a level that exceeds the level found in most of society, and when the trait is so rigid and maladaptive that it causes subjective distress or functional impairment, the individual can be diagnosed as personality disordered (DSM-IV, APA, 1994). Trait personality theories depict individuals along various dimensions of personality including extraversion-introversion and stability-instability (e.g. Costa & Widiger, 1994; Eysenck, 1990; Lucas, 2000).

The dimension of extraversion-introversion refers to the individual's basic tendency to respond to stimuli with either excitation or inhibition. Individuals who are extraverted are: 1) present-oriented; 2) feeling-directed; and 3) reward-seeking. Their chief focus is their immediate and emotional experience. Feelings dominate thoughts, and the primary motivation is immediate gratification or relief from discomfort. Extraverts are sociable, crave excitement, take risks, and



act impulsively. They tend to be carefree, inconsistent, and optimistic. By contrast, introverted individuals are: 1) future and past-oriented; 2) cognition-directed; and 3) consequence avoidant. Logic and function are seen to dominate over feelings. Introverts are motivated by appraisal of past experience and avoidance of future adverse consequences. They will avoid engaging in a pleasurable activity if it imposes a threat. Introverted individuals are quiet, dislike excitement, and distrust the impulse of the moment. They tend to be orderly, reliable, and rather pessimistic. The second personality dimension, stability-instability, or neuroticism, defines the degree of emotionality or lability. The emotions of stable individuals are aroused slowly and minimally, and return quickly to baseline. By contrast, unstable individuals have intense emotions, and act upon them in impulsive, and at times, irrational ways.

The well-documented association between Type A personality and heart disease perhaps best illustrates early studies of the potential influence of personality on health. There has since been a vast amount of evidence published suggesting that individuals who are mentally well-adjusted, socially stable, and well-integrated into their communities, are at a significantly lower risk for disease and premature mortality, than those who are more unstable, impulsive, isolated, and alienated (e.g. Cohen & Williamson, 1991; Friedman, 1990; 1991; 1992; Kielcot-Glaser, Glaser, Cacioppo, & Malarkey, 1998). Early work by Costa and McCrae (1980) showed that happiness was associated with greater extraversion and lower neuroticism. There is somewhat less agreement regarding what additional dimensions of personality to extraversion-introversion and stability-instability are needed to provide a comprehensive model. Eysenck (1990) suggests one additional dimension of psychoticism (people scoring high on this dimension are

aggressive, egocentric, impulsive and antisocial, whereas low scorers are empathic and able to control their impulses). McCrae and Costa (1989) propose openness-to-experience, agreeableness, and conscientiousness, which together with extraversion and neuroticism make up the “Big 5”. The Big 5 is now the most widely accepted and used model of personality, focusing on individual personality traits measures along the five dimensions named above. McCrae and Costa (1991) have suggested that agreeableness and conscientiousness should facilitate more positive experiences, in social and achievement situations respectively, which in turn increase subjective well-being. High neuroticism and low extraversion were found to be associated with emotion focused coping strategies that were generally judged as being ineffective by participants and related to lower levels of life satisfaction.

The findings reported by McCrae and Costa, have since been corroborated by Deneve and Cooper (1998). Neuroticism and extraversion were found to be the strongest Big-5 predictors of happiness, and neuroticism and conscientiousness were found to be the strongest Big 5 predictors of life satisfaction. In a subsequent study by Hayes and Joseph (2003), 111 participants completed a battery of measures including the NEO Five Factor Inventory (Costa & McCrae, 1992), the Oxford Happiness Inventory, (Argyle, Martin, & Crossland, 1989), the Depression-Happiness Scale (Joseph & Lewis, 1998), and the Satisfaction with Life Scale (Diener *et al.*, 1985). The authors of this study found that personality is an important correlate of subjective well-being, accounting for between 32 and 56% of variance in subjective well-being scores. Regression analysis further showed that although extraversion and neuroticism best predicted scores on

Oxford Happiness Inventory, it was neuroticism and conscientiousness that best predicted scores on the Satisfaction with Life Scale.

The authors also noted, however, that the operational definition of subjective well-being used, determined the strength of association between individual personality factors and subjective well-being. The results of this study indicate that various personality factors impact on both happiness and satisfaction with life, both of which are considered to be components of global quality of life. The findings also suggest that the operational definition of subjective well-being affects the strength of association found between personality factor and quality of life, stressing the importance of adopting a broad definition of QoL, or well-being, when researching its association with personality.

Increasingly, researchers acknowledge that many methodological and conceptual complexities thwart the investigation of causal pathways that underlie the associations between psychological factors and health. Friedman (2000) has argued that researchers have failed to consider the complexity of the association between personality and health, as many people have multiple psychosocial risk factors for interdependent health outcomes. Friedman (2000) employed a life-span data set to explore how childhood personality related to health-related growth and development (*dynamisms*), patterns of reactions and health behaviours (*mechanisms*), and movements toward and away from suitable environments (*tropisms*). The data analysed span 7-decades of information collected through the Terman Life Cycle Study. This data allowed a close

examination of the long-term effects of personality traits measured in childhood on health and illness in adulthood.

Research, such as data from the Terman Life Cycle Study (Friedman, 2000), suggests that a conscientious, dependable personality, in stable psychosocial environment, is a key predictor of health in adulthood, and may be a central underlying causal factor. Friedman (2000) argues that this is not because there exists a disease-prone personality, with direct link to ill health, but rather because certain people end up having unhealthy habits and behaviours, unbalanced socioemotional and psychophysiological style, and environments, that are not conducive to good health. Friedman suggests that a comprehensive personality model can only be achieved through the close examination of processes such as dynamisms, mechanisms, and dynamisms, which may illustrate the true nature of the relationship between personality and health.

A recent paper, by Wrosch and Scheier (2003), has addressed some of the issues that have impeded research into the relationship between personality and quality of life. The authors argue that personality factors can impact on the way in which people approach life circumstances, or on the kinds of outcomes people receive, which are in turn argued to impact favourably, or unfavourably, on QoL. For example, a conscientious person may overcome unexpected obstacles more easily than a person who is less motivated to achieve important life tasks. According to Wrosch and Scheier (2003), a conscientious person may be more successful in establishing objective indicators of quality of life (such as wealth, or a successful career), and may therefore report high levels of subjective well-

being. The authors further argue that broad definitions of both personality (as a predictor) and QoL (as outcome) are needed, as personality tends to affect many domains. A domain-specific QoL measure may underestimate or overlook the extent of the impact of personality on quality of life.

Wrosch and Scheier (2003) further suggest that personality factors be treated as part of the theoretical model underpinning investigation, rather than as nuisance variables that need to be controlled for. Given that personality may be a distal, as well as a causal factor, affecting the predictor and the outcome, controlling for personality factors means that researchers may remove variance that may be partly responsible for the QoL. The authors maintain that examining personality factors in this way will allow researchers to distinguish between important background variables (such as personality), as well as the mediating processes (e.g. coping), that affect people's quality of life. Thus, the studies summarised here, indicate the personality factors are important factors that may affect quality of life. Investigations that adopt broader approaches to both quality of life and personality may be most valuable in extending our understanding of the relationship between personality and quality of life. In the next section the research examining personality in PWHIV will be reviewed.

#### ○ 4.2 Personality and HIV

Professionals working in the field of HIV have long acknowledged the impact of personality in risk behaviour. Reflecting on their own clinical experience, in the John Hopkins AIDS Service (JAHS), Hutton, Glenn, and Treisman (2001) have argued that people with certain temperaments are more prone to engage in HIV -

risk behaviour. The authors have estimated that about 60% of their patients present with unstable extraverted temperament associated with unpredictable and inconsistent behaviour. Moreover, the authors have noted that regardless of these individuals' intellectual ability, or understanding of HIV, unstable extraverts engage in behaviour associated with a high risk of HIV infection. These individuals are motivated to pursue pleasurable experiences, however risky, and eliminate low moods. In reality, unstable extraverts rarely plan things ahead (and are therefore less likely to carry condoms), and are also less likely to accept the decrease of pleasure associated with the use of condoms. Unstable extraverts are also more vulnerable to substance abuse, which in turn add to risk behaviour and deferment of pleasure.

The second most common personality type observed by Hutton, Glenn, and Treisman (2001) are stable extraverts who like unstable extraverts are present-oriented and pleasure seeking, however have less intense emotions. Stable extraverts are vulnerable to risk taking behaviour because their emotion "flatness" may render them over optimistic or confident, to believe that they will become HIV-infected. Introverted personalities are argued, by the authors, to be the least common in their HIV population. They argue that introverts focus on the future and consequences, and that their preference for cognition over emotion renders them less vulnerable to risk behaviours compared with extraverts. They speculate that risk behaviour in unstable introverts may be motivated by an attempt to escape pain or distress (rather than pleasure seeking), or due to an external locus of control. Finally, the authors argue that stable introverts are

likely to have become infected through blood transfusions, or needle stick injury, rather than risk behaviour.

The observations of Hutton, Glenn, and Treisman (2001) are supported by empirical investigation. For example, using the Eysenck Personality Questionnaire, Trobst, Wiggins, Costa, Herbst, McCrae & Masters (2000), found that high extraversion is associated with sexual promiscuity, desire for sexual novelty, and multiple sex partners. Sher, Bartholow, and Wood (2000) found extraversion to be associated with substance misuse. Similarly, emotional instability has been found to related to unsafe sex practices (e.g. Fontaine, 1994; McCown, 1993) as well as substance abuse (McCormick, Dowd, Quirk, & Zegarra, 1998).

Another line of inquiry, within research examining personality and HIV, has examined the prevalence of personality disorders among HIV-infected people. Personality disorders represent extremes of normal personality characteristics and are disabling conditions. In general, these studies suggest that individuals demonstrating personality traits associated with character pathology (e.g. neuroticism and impulsivity) tend to express attitudes and behaviours commonly associated with risk-taking behaviours and poor health-maintaining habits (Ball, Tennen, Ploking, Kranzler, & Rounsaville, 1997). Individuals who display such traits are also more vulnerable to depression and psychological distress, greater social conflict, and poorer overall functioning (Johnson, Williams, Rabkin, Goetz, & Remien, 1995). Some of these studies will be summarised below.

Prevalence rates of personality disorders among people with HIV, or those at risk of HIV-infection, significantly exceed rates found in the general population. Johnson *et al.* (1995) studied the prevalence of personality disorders among 162 HIV-positive and HIV-negative homosexual men. Lifetime and current histories of DSM-III-R axis I disorders, anxiety, depression, hopelessness and adaptive functioning were assessed. Nineteen percent of participants (both the HIV-positive and HIV-negative) found to have personality disorders. The HIV-positive participants with personality disorders reported higher levels of psychiatric symptoms and poorer functioning than all participants without personality disorders, and they were over six times as likely as the HIV-negative participants without personality disorders to have current axis I disorders. The authors suggest that as many as one third of individuals living with HIV/AIDS, in Western countries, may meet the criteria for a personality disorder and may have concurrent Axis I disorders, with a mood disorder being the most commonly diagnosed Axis I disorder in this population. The rate of individuals living with HIV/AIDS who meet the criteria for a personality disorder is in stark contrast to the estimated 13% in the general adult population (Casey & Tyrer, 1986).

Perkins, Davidson, Leserman, Liao, and Evans (1994) obtained similar findings in their study of 98 asymptomatic HIV-positive and 71 HIV-negative homosexual men. Similar proportions of HIV-positive and HIV-negative participants reported a lifetime (29% and 45% respectively), an initial current (8% and 3%), and a 6-month follow-up (9% and 11%), history of major depressive disorder. Anxiety disorders were less common with similar



proportions of HIV-positive and HIV-negative participants reporting a lifetime, initial current, and a 6-months follow-up history of anxiety disorders. There were no differences in severity of mood disorders between HIV-positive and negative participants. The authors noted that a part history of depression placed both HIV-negative and HIV-positive homosexual men at risk for major depression.

In another study, Jacobsberg, Frances, and Perry (1999) looked at personality disorders among adults at risk for AIDS, therefore allowing exploration of premorbid personality traits and HIV. The Personality Disorder Examination (a diagnostic interview for DSM III-R) was administered to 260 volunteers for HIV testing and counselling. Thirty-seven percent of the subjects, who subsequently tested HIV-positive, and 20% of those who tested HIV-negative, were found to have a DSM-III-R axis diagnosis on the Personality Disorder Examination. Thirty percent of the HIV-positive subjects who knew their HIV status prior to testing were found to have a DSM-III-R axis diagnosis. This study presents some evidence for an association between certain personality characteristics and HIV risk, while the authors stress the importance of adequately assessing the occurrence of personality disorder in people at risk of HIV infection. The consistency of axis II diagnoses, before and after HIV diagnoses, suggests that the personality disorder construct is a stable, life long entity, not changed even by important life events such as a diagnosis of a life-threatening disease.

Research has further indicated that Antisocial Personality Disorder (ASPD) is the most common diagnosis, and is a risk factor for HIV infection (Hutton, Glenn &

Treisman, 2001). Individuals with personality disorder, particularly ASPD, have high rates of substance abuse, and are more likely to inject drugs and share needles, compared with those without an Axis II diagnosis (Brooner 1993; Dinwiddie, Cottler, Compton, & Abdallah, 1996). In another study, a half of 416 drug abusers, in two New York methadone programmes, met criteria for a diagnosis of ASPD (Kleinman *et al.*, 1994). ASPD individuals are also more likely to have higher numbers of lifetime sexual partners, to engage in unprotected anal intercourse, and contract sexually transmitted diseases compared with individuals without ASPD (Ramrakha, Caspi, Dickson, Moffitt, & Paul, 2000).

Caution is needed when interpreting results obtained by the studies discussed above, because only the Jacobsberg *et al.*'s (1999) study measured personality traits ahead of HIV diagnosis. It is difficult to ascertain the nature and direction of the interaction between personality traits, HIV, and quality of life, given that the distress caused by a positive HIV diagnosis can bias personality assessment. One cannot readily determine whether personality traits predated the HIV infection and perhaps increased the likelihood of infection, or whether the infection led to the personality changes. Given that research has demonstrated the deleterious effects of HIV on the brain, personality changes due to infection cannot be ruled out. It is also worth noting that the findings, reviewed above, have been derived from Western cohorts in developed countries, and hence may be less valid for explaining risk in Sub-Saharan Africa or South-East Asia.

Studies such as those discussed above, nonetheless, suggest that personality traits, such as neuroticism, are related to higher psychological distress in

individuals living with HIV/AIDS. Furthermore, the findings that certain personality traits may increase the likelihood of risky behaviour, may explain why traditional approaches in risk reduction counselling have been found to be ineffective (e.g. Kalichman, Heckman, & Kelly, 1996; Trobst *et al.*, 2000). This finding also suggests that a clearer understanding of the impact personality on health behaviours can pave the way for more effective interventions.

#### ▪ 5 Quality of Life and Personality in PWHIV

Few studies have assessed the relationship between personality factors and quality of life in HIV/AIDS. In one such study, Burgess, Carretero, Elkington, Pasqual-Masettin, Lobacaro, and Catalan (2000), proposed a model mapping the relationship between health status, neuroticism, quality of life, and mediating factors. Importantly, the model differentiates between psychological and physical quality of life. Referring to previous research findings, the model proposed by the study hypothesises that psychological and physical quality of life are non-causal covariates. As demonstrated by Fig 1, the model also hypothesises that neuroticism affects psychological quality of life, whereas health status affect physical quality of life. The model is useful in that it aims to address the association between physical and psychological quality of life, and also in the way it incorporates the effects of health status (an objective indicator of quality of life), and neuroticism (a stable personality trait)

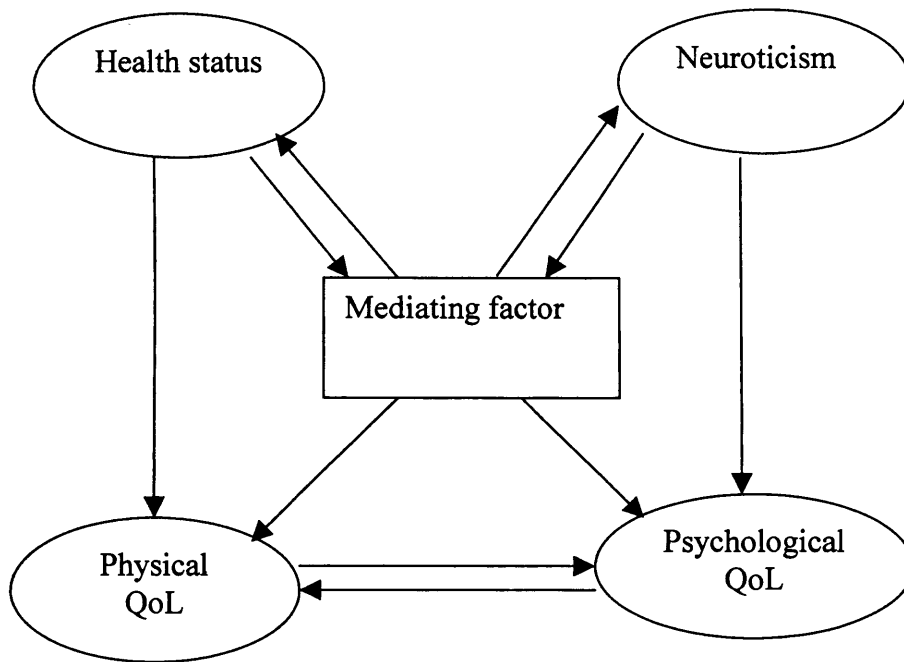


Fig 1: The model proposed by Burgess *et al.* (2000) showing the hypothesised relationships between health status, neuroticism, quality of life and mediating factors.

Burgess *et al.* (2000) set out to explore how neuroticism and health status influence health-related QoL, and how these relationships are affected by mediating influences such as coping style, social support, and other personality factors. A total of 249 HIV positive participants were recruited from three samples; gay/bisexual men from the UK, injecting drug users from the UK, and injecting drug users from Italy. All participants completed questionnaires evaluating quality of life (MOS-HIV) (Wu *et al.*, 1997), personality (EPQ-R) (Eysenck & Eysenck, 1991), coping style (S-COPE) (Carretero, Burgess, Soler, & Catalan, 1996), and social support (Interpersonal Support Evaluation List) (Cohen *et al.*, 1985).

Findings of the study demonstrated a modest association between health status and physical, but not psychological, aspects of quality of life. Neuroticism was

strongly associated with psychological QoL, but only weakly with physical QoL. These patterns did not differ across the three samples. Mediating factors such as coping style, social support, and other personality variables had only a weak influence on the role of neuroticism. Active coping, denial and disengagement, and social support, each played a small, but significant, role in mediating between neuroticism and psychological QoL. In terms of interventions, the results suggest that psychological QoL can be enhanced by encouraging active coping and social support, and by reducing denial and disengagement, however, within the context of this study's findings such benefits are likely to be small. The authors concluded that neuroticism had a significant effect on health-related quality of life, independently of health status. They further argued that neuroticism may bias self-reported QoL, and should be considered as a potentially serious nuisance factor. The findings of this study indicate that personality, and specifically neuroticism, has an important effect on quality of life in HIV, and that this effect outweighs the effects of other psychological factors such as coping styles.

The study is limited by several factors. One limitation is the sample size of 279 participants, which the authors recognise to be relatively small for the type of analysis undertaken. Furthermore, the model assumes that neuroticism scale (measured on the EPQ-R) provides a good measure of the underlying traits, and that this trait is unchanging over time. It is possible, although not likely, that the scale simply measures current mental state, which would undermine the usefulness of neuroticism as an explanatory construct. However, research has also demonstrated that neuroticism does show good stability over time between

adolescence to middle years (e.g. Costa and McCrae, 1994), which suggests that neuroticism may not be a measure of current mental state. In addition Kline (1993) summarises research supporting the validity of the EPQ-R.

Several other factors related to the model proposed by Burgess *et al.* (2000) are also debatable. For example, the study focused on neuroticism alone, yet McCrae and Costa (1991) have suggested that agreeableness and conscientiousness may also be related to subjective well-being (or psychological QoL). Although the model accounted well for psychological QoL, it fared less well with physical QoL, accounting for a smaller proportion of the variance ( $R^2= 0.34$ ). Health status was measured by CD4 count and disease stage obtained from medical notes. A better measure of health status might have been obtained through a checklist of symptoms or conditions. It is plausible that in everyday life, PWHIV understand their health in terms of symptoms they are experiencing, and these may not be necessarily related to CD4 or disease progression. For example, Bing *et al.* (2000) found that PWHIV experiencing one symptom displayed lower scores on QoL than did PWHIV with more than one symptom. It follows that the process by which PWHIV evaluate their physical well-being is complex one, and that a better understanding of the interplay between physical and psychological well-being will be achieved by a more comprehensive measurement of physical well-being.

Another study, by Penedo *et al.* (2003), examined personality, quality of life and Highly Active Antiretroviral Treatment (HAART) adherence. The study considered the relationship between personality traits, quality of life, and

HAART adherence among 116 men and women living with HIV. Participants were screened for personality disorders, mood disorders, substance use, anxiety and adjustment disorders related to HIV. Participants who met the inclusion criteria, were assessed using the NEO-PI-R (Revised NEO Personality Inventory) (Costa & McCrae, 1992), the HIV/AIDS-Targeted Quality of Life Instrument (HAT-QoL) (Holmes & Shea, 1997) and the Adherence to Combination Therapy Guide (ACTG) (Chesney *et al.*, 2000) self report questionnaire.

This study found that higher neuroticism was associated with poorer overall quality of life and HIV specific domains (e.g. medication mastery, and HIV mastery), which is consistent with previous studies (e.g. Burgess *et al.* 2000). Individuals who displayed personality traits associated with vulnerability to depression, anxiety, and fearfulness, reported poorer overall quality of life, and HIV-specific quality of life. This study was also among the first to demonstrate that more adaptive dispositional traits, such as assertiveness and trust, may contribute to the extent to which individuals are able to manage multiple demands associated with living with HIV/AIDS. Moreover, the study demonstrated that QoL, as determined by overall functioning (e.g. physical activity, job-related activity, and social activity), as well as HIV medication worries, is related to the extent to which individual adhere to HAART. Further analyses indicated that factors, such as older age and better functioning, accounted for adherence better than medication worries, underscoring the importance of perceived overall functioning. Personality traits were not found to be directly related to medication adherence; however this may have been because those participants who met the criteria for personality disorders were excluded.

Several limitations need to be considered with regard to these findings. First, the sample consisted primarily of Black, Hispanic and non-Hispanic White participants, in the USA, motivated to participate in a research study. This precludes generalising these findings to other HIV positive populations (for example substance abusers, individuals with severe psychiatric histories, as well as those from resource poor countries). These populations may be exposed to different stressors, which may relate to personality, quality of life, and HAART adherence in different ways. Furthermore, the cross-sectional design of the study precludes any causal inferences from the findings.

As reviewed above in the section “Personality and Quality of Life”, personality is an important mediator of quality of life in a range of medical conditions. Early investigations into the role of personality in HIV focused on risk behaviours. Such studies have specifically indicated that certain personality traits, such as extraversion and low conscientiousness, are associated with more risky behaviour, in relation to infection with HIV. However, the role of personality in the management of HIV has largely been neglected. The two studies, which have specifically explored the relationship between personality and quality of life in PWHIV, have indicated a significant association between personality and quality of life. However, research is needed to replicate and elaborate on the available studies. More importantly, there remains a critical gap in relation to interventions, and the ways in which findings can be used to design, enhance and deliver better interventions for PWHIV.



## ▪ 6 Future directions

Evidence, from the studies reviewed above, suggests that emotional and physical well-being may be compromised by HIV infection, and that this effect is greater than in other medical conditions (Hays *et al.*, 2000). Studies which have investigated the nature of the relationship between psychological and physical well-being in PWHIV have indicated that psychological and physical well-being have an independent, as well as an interactive, impact on global measures of well-being (e.g. Heckman, 2003). Stress and coping have been repeatedly implicated as important psychological factors affecting well-being. This has led researchers to consider individual differences and the ways in which personality may affect quality of life.

It has been suggested that agreeableness and conscientiousness should facilitate more positive experiences in social and in achievement situations (McCrae & Costa, 1986). Deneve and Cooper (1998) demonstrated that neuroticism and extraversion are the strongest Big 5 predictors of happiness, and that neuroticism and conscientiousness are the strongest Big 5 predictors of life satisfaction. Other studies have corroborated these findings, with neuroticism and conscientiousness consistently found to be correlates of quality of life. Nevertheless, the paths through which personality impacts on quality of life and the nature of the relationship between personality and well-being remain poorly understood. For example, it is not clear whether personality impacts on QoL by mediating the ways that people cope and manage challenges or stresses in their life, or whether people with certain personality traits are more likely to find themselves in certain situations that can compromise QoL. There remain a number of methodological

and theoretical problems that also obscure our understanding of the association between personality and QoL that need addressing in order for the findings to be integrated into clinical practice. Some of these issues are considered below.

Although quality of life has been identified as an important objective in healthcare, there is no one accepted definition of quality of life. There appear to be nearly as many definitions of QoL as there are studies of the concept, and different measures of quality of life comprise different sub-facets. Some researchers refer to health-related quality of life; others talk about subjective well-being. This debate surrounding the concept of quality of life is likely to reflect the diversity of professional backgrounds of the researchers, as well as the issues in which they have a particular interest. However, it is increasingly acknowledged that QoL spans both physical and psychological domains, and more recent measures of QoL assess both these domains. Nevertheless, evaluation and consolidation of findings from previous studies is often difficult. There is a need for further studies that assess QoL in a comprehensive and systematic manner. Similar problems pertain to the study of personality traits and QoL.

The big 5-factor personality theory arguably represents a general consensus as to the structure of normal personality (Costa & McCrae, 1992a; Digman, 1990; 1994; 1996). Most recent research that examines the association between personality traits and QoL has been guided by this theory. However, studies have used different measures of personality. As with quality of life, the disparity of measures makes comparison and consolidation of findings difficult. Analyses are

likely to be affected by the properties of the measures, and ultimately the factors that have been entered into the analysis. Despite the variation in measures studies have often reached similar conclusions. Neuroticism has been associated with poorer quality of life, and traits such as conscientiousness have been associated with better quality of life. This in turn suggests that the measures despite their differences are assessing similar concepts. However, the precise nature of the relationship between personality and QoL is still unclear. There exists some uncertainty as to what it is about neuroticism that may affect quality of life. A closer examination of facets of neuroticism may illuminate our understanding of the association between personality and quality of life.

Neuroticism is a higher order factor comprising facets of proneness to anxiety, hostility, depression, self-consciousness, impulsiveness, and vulnerability (Costa & McCrae, 1992b). Research that has examined neuroticism and QoL has failed to examine the contribution of the individual facets of neuroticism. Although all facets of neuroticism are related, it is plausible that they impact on QoL in different ways. As outlined above, researchers have debated whether personality renders people vulnerable to disease, or whether personality makes people more likely to find themselves in unhealthy situations (Friedman, 2000). For example, being hostile may impede one's ability to express distress or access support. Similarly, depression may affect QoL through withdrawal and low mood. Impulsiveness, on the other hand, may affect QoL by predisposing a vulnerable individual to act in a ways that places them at risk for life-compromising outcomes. Furthermore, personality may mediate the ways in which people interpret or cope with illness. Thus neuroticism may be conceptualised as an

umbrella construct for various personality traits that influence QoL through various pathways, some direct some indirect.

The case for studying individual facets of neuroticism is further strengthened by the current conceptualisation of personality traits as dimensional, rather than categorical, constructs. Rather than looking at the presence or absence of particular higher order personality factors, it may be more productive to assess people's personalities along dimensions of specific traits. A better understanding of individual facets of personality traits, such as neuroticism, may hold the key to better clinical interventions. Some failure of previous attempts at health promotion in the field of HIV may be attributable to an imprecise appreciation of the ways in which personality traits exert an influence on behaviours associated with QoL. Different approaches are appropriate for anxiety, hostility and impulsiveness, despite them all being facets of neuroticism. Moreover, there also remains a need to understand the pathways through which the personality traits mediate QoL. One way of elucidating the relationship between personality traits and QoL may be to look at core cognitions that operate on emotional and behavioural levels.

#### ▪ **Conclusion**

This literature review has demonstrated that personality traits impact on quality of life in several ways. However the exact pathways, especially as they related to HIV-infected individuals, remain poorly understood. With the advent of advanced pharmacological treatments HIV has become a chronic health condition. As the parameters of HIV have changed so QoL issues have come to

the fore of HIV management. The recognition of the side effects, and the adherence challenges to medication, also indicate the need to examine psychological factors, such as personality and quality and life. There is a paucity of systematic investigations into the influence of personality on QoL of HIV positive individuals. Research continues to be hampered by a lack of clarity about what quality of life means. Many studies rely on measures that are either overly psychologically or physically focused and hence may fail to encapsulate the extensive nature of QoL. Preliminary findings of quality of life issues in PWHIV need replicating, and a systematic approach to assess psychological, physical, environmental and social domains of quality of life is warranted.

Within the domain of personality, research has tended to focus on maladaptive traits, psychopathology, and deficits. Increasingly, with the emergence of “positive psychology”, researchers are turning to more adaptive constructs and their impact on health and illness. Personality disorders have been shown to be more common among individuals living with HIV. However, there have been only a few studies that have aimed to identify traits, which are positively associated with QoL. Moreover, health care professionals working within the field of HIV are largely ill equipped to deal with individuals with HIV who also have maladaptive personality traits. Personality not only impacts on the infected individual’s quality of life, but also on the way they manage their illness and health. Studies that examine specifically clinical directions and potential interventions are needed.

## References

- American Psychiatric Association. (1987). *Diagnostic and Statistical Manual of Mental Disorders* (3<sup>rd</sup> ed.) Revised. Washington, American Psychiatric Association, 1987.
- American Psychiatric Association (1994) *Diagnostic and Statistical Manual of Mental Disorders*. (4<sup>th</sup> ed.). Washington, DC.
- Antoni, M.H., Goldstein, D., Ironson, G., LaPerriere, A., Fletcher, M.A, & Schneiderman, N. (1995). Coping responses to HIV-1 serostatus notification predict concurrent and prospective immunologic status. *Clinical Psychology and Psychotherapy*, 2, 234-248.
- Antoni, M.H, Schneiderman, N., (1998) HIV & AIDS. In Bellack, A.S. Hersen, M. (Eds) *Comprehensive Clinical Psychology*, (pp 237-275). New York Elsevier, 1998, 237-75.
- Argyle, M., Martin, M., & Crossland, J. (1989). Happiness as a function of personality and social encounters. In J.P. Forgas & J.M. Innes (Eds) *Recent advances in social psychology: An international Perspective* (pp. 189-203). North-Holland: Elseiver.
- Bacchetti, P., & Moss, A.R., (1989) Incubation period of AIDS in San Francisco. *Nature*, 338:251-253

Ball, S.A., Tennen, H., Poling, J.C., Kranzler, H.R., & Rounsaville, B.J. (1997). Personality, temperament, and character dimensions and the DSM-IV personality disorders in substance abusers. *Journal of Abnormal Psychology, 106*, 545-553.

Barbee, A.P., Cunningham, M.R., Winstead, B.A., Derlega, V., Gulley, M.R., Yankeelov, P.A., & Duren, P.B. (1993). The effects of gender role expectations on the social support process. *Journal of Social issues, 49*, 175-190.

Barbee, A.P., & Cunningham, M.R. (1995). An experimental approach to social support communications. Interactive coping in close relationships. In B.R., Burleson, (Ed) *Communication yearbook:18*, (pp381-413). Thousand Oaks: CA: Sage.

Bing, E.G., Hays R.D., Jacobson L.P., Chen B., Gange S.J., Kass N.E., & Chmiel J.S. (2000) health-related quality of life among people with HIV disease: Results from the Multicentre AIDS Cohort Study. *Quality of Life Research, 9*, 55-63.

Boberg, E.W., Gustafson, D.H., Hawkins, R.P., Chan, C.L., Bricker, E., Pingree, S., & Berhe, H. (1995). Development, acceptance and use patterns of computer –based education and social support system for people living with HIV/AIDS infection. *Computers in Human Behaviour, 11*, 289-311.

- Bor, R., du Pleiss, P., & Russell, M. (2004). The impact of disclosure of HIV on the index patient's self-defined family. *Journal of Family Therapy, 26*, 167-192.
- Bower, J.E., Kemeny, M.E., Taylor S.E., & Fahey, J.L. (1998) cognitive processing, discovery of meaning, CD4 decline, and AIDS-related mortality among bereaved HIV-seropositive men. *Journal of Consulting and Clinical Psychology, 66*, 979-986.
- Brashers, D.E., Neidig, J.L., Cardillo, L.W., Dobbs, L.K., Russell, J.A., & Haas, S.M. (1999) 'In an important way, I did die': uncertainty and revival in persons living with HIV or AIDS. *AIDS Care, 11*, 201-219.
- Broner, R.K., Greenfield, L., Schmidt, C.W., & Bigelow, G.E. (1993). Antisocial personality disorder and HIV infection among intravenous drug abusers. *American Journal of Psychiatry, 150*, 53-58.
- Burgess, A.P., Carretero, M., Elkington, A., Pasqual-Marsettin, E., Lobacaro, C., & Catalan J. (2000) The role of personality, coping style and social support in health related quality of life in HIV infection. *Quality of Life Research, 9*, 423-37.
- Casey, P.R., & Tyrer, P.J., (1986) Personality, functioning and symptomatology. *Journal of Psychiatric Research, 20*, 363-374.



- Carretero, M.D., Burgess, A.P., Soler, P., & Catalan, J. (1996). Reliability and validity of an HIV-specific health-required quality of life (QoL) measure for use with injecting drug-users. *AIDS, 10*, 1699-1705.
- Cella, D.F, McCain, N.L., Peterman, A.H., Mo, F., & Wolen, D. (1996). Development and validation of the Functional Assessment of Human Immunodeficiency Virus Infection (FAHI) quality of life instrument. *Quality of Life Research, 9*, 423-437.
- Chesney, MA., Ickovics, J.R., Chambers, D.B., Gifford, A.L., Neidig, J., Zwickl., B., & Wu, A.W.(2000). Self-reported adherence to antiretroviral medications among participants in HIV clinical trials: the ACCTG Adherence Instruments. *AIDS Care, 12*, 255-266.
- Coffin, J., Haase, A., Lew, J.A., Montagnier, L., Oroszlan, S., Teich, N., Temin, H., Toyoshima, K, Varmus, H., Vogt, P., and Weiss, R., (1986) Human Immunodeficiency Viruses. *Science, 232*, 697.
- Cohen, S., Mermelstein, R., Kamarck, T., & Hobermann, H.N.(1985). Measuring the functional components of social support. In Sarason I., & Sarason, B. (Eds) *Social Support: Theory, Research and Applications* (pp73-94). The Hague: Martinus Nijhoff.
- Cohen, S., & Williamson, G.M. (1991). Stress and infectious disease in humans. *Psychological Bulletin, 109*, 5-24.

Cole, S.W., Kemeny, M.E., Taylor, S.E., Visscher, B.R., & Fahey, J.L. (1996). Accelerated course of human immunodeficiency virus infection in gay men who conceal their homosexual identity. *Psychosomatic Medicine*, 58, 219-231.

Coons, S. J., Rao, S., Keininger, D.L, and Hays, R.D. (2000) A comparative review of generic quality-of-life instruments. *Pharmacoeconomics*, 17, 13-35.

Costa, P. T., Jr., & McCrae, R. R.(1980). Influence of extraversion and neuroticism on subjective well-being: happy and unhappy people. *Journal of Personality and Social Psychology*, 38, 668-678.

Costa, P.T., Jr., & McCrae, R.R. (1992a). The five-factor model of personality and its relevance to personality disorders. *Journal of Personality Disorders*, 6, 343-359.

Costa, P.T., Jr., & McCrae, R.R. (1992b). *Revised NEO Personality Inventory (NEO-PI-R) and NEO Five-Factor Inventory (NEO-FFI)*. *Professional Manual*. Odessa FL. Psychological Assessment Resources.

Costa, P.T. and McCrae (1994) Set like plaster? Evidence for the stability of adult personality. In T.F. Heatherton and J.L. Weinberger (Eds.) *Can*

*Personality Change* (pp. 21-40). Washington DC, American Psychological Association

Costa, P.T. Jr., & Widigier, T.A. (1994a). Introduction: Personality disorders and the five-factor model of personality. In P.T. Costa Jr., & T.A. Widiger (Eds.) *Personality disorders and the five-factor model of personality* (pp.1-10). Washington, DC: American Psychological Society.

Costa, P.T. Jr., & Widigier, T.A. (1994b). *Personality disorders and the five-factor model of personality*. Washington, DC: American Psychological Society.

D'Augelli, A. R. (1989) Lesbians' and gay men's experiences of discrimination and harassment in a university community. *American Journal of Community Psychology*, 17, 317-321.

DeNeve, K.M., & Cooper, H.(1998) The happy personality: a meta-analysis of 137 personality traits and subjective well-being. *Psychological Bulletin*, 124, 197-229.

Derlega, V.J., Winstead, B.A., Oldfield, E.C., & Barbee A.P., (2003) Close relationships and social support in coping with HIV: A test of Sensitive Interactions Systems Theory. *AIDS and Behaviour*, 7, 119-129.

- Diener, E., Emmons, R.A., Larsen, R.J., & Griffin, S. (1985). The Satisfaction with Life Scale. *Journal of Personality Assessment*, 49, 71-75.
- Digman, J.M. (1990). Personality structure: Emergence of the five-factor model. *Annual Review of Psychology*, 41, 417-440.
- Digman, J.M. (1994). Historical antecedents of the five-factor model. In P.T. Costa Jr., & T.A. Widiger, (Eds.) *Personality disorders and the five-factor model of personality* (pp. 1-20) Washington., DC: American Psychological Association.
- Digman, J.M. (1996). The curious history of the five-factor model. In J.S.,Wiggins (Ed.) , *The five-factor model of personality: Theoretical perspectives* (pp1-20). New York: Guilford.
- Dinwiddie, S.H., Cottler, L., Compton, W., Abdallah, A.B. (1996). Psychopathology and HIV risk behaviours among injection drug users in and out of treatment. *Drug & Alcohol Dependency*, 43, 1-11.
- Dybul, M., Fauci, A.S., Bartlett, J.G., Kaplan, J.E., Pau, A.K., (2002) Panel on Clinical Practices for Treatment of HIV. *Annals of Internal Medicine*, 137,381-433.
- Eysenck, H.J., & Eysenck, S.B.G. (1991). *Manual of the Eysenck Personality Scales*. London: Hodder, Stoughton.

- Fahey, J.L., Taylor, J.M., Detels, R., Hofman, B., Melmed, R., Nishanian, P., & Giorgi, J. (1990) The prognostic value of cellular and serologic markers in infection with human immunodeficiency virus type-1. *New England Journal of Medicine*, 322, 166-72.
- Fontaine, K. (1994). Personality correlates of sexual risk-taking among men. *Personality and Individual Differences*, 17, 693-694.
- Friedman, H.S. (2000). Long-term relations to personality and health: Dynamisms, Mechanisms, Tropisms. *Journal of Personality*, 68, 1089-1107.
- Friedman, H.S. (Ed.). (1990). *Personality and Disease*. New York: Wiley.
- Friedman, H.S. (1991). *Self-healing personality: Why some people achieve health and others succumb to illness*. New York: Henry Holt.
- Friedman, H.S. (Ed.). (1992). *Hostility, coping and health*. Washington, DC: American Psychological Association.
- Gallo, R.C. (1988) "AIDS in 1988". *Scientific American*, (10/88), 259, 41.
- Gayle, H. (2000) An overview of the global HIV/AIDS epidemic, with a focus on the United States. *AIDS*, 14, 8-17.

Hammer, M.F., Spurdle, A.B., Karafet, T., Bonner, M.R., Wood, E.T., Novelletto, A., Malaspina, P., Mitchell, R.J., Horai, S., Jenkins, T., Zegura, S.L. (1997) The geographic distribution of human Y chromosome variation. *Genetics*, 145, 787-805.

Hayes, N., & Joseph, S. (2003). Big 5 correlates of three measures of subjective well-being. *Personality and Individual Differences*, 35, 723-727.

Hays, R.D., Cunningham, W.E., Sherbourne C.D., Wilson I.B., Wu, A.W., Cleary P.D., McCaffrey D.F., Fleishman J.A., Crystal S., Collins, R., Eggan, F., Shapiro, M.F., & Bozzette, S.A. (2000). Health related quality of life in patients with Human Immunodeficiency Virus Infection in the United States: Results from the HIV and Cost Services Utilization Study. *The American Journal of Medicine*, 108, 714-722.

Heckman, T.G., Somlai, A.M., Otto-Salaj, I., Peters, J., Walker, J., Galdabini, C.A., & Kelly, J.A. (1998). Barriers to care among persons living with HIV/AIDS in urban and rural areas. *AIDS Care*, 10, 365-375.

Heckman, T.G., (2003) The Chronic Illness Quality of Life (CIQOL) Model: Explaining life satisfaction in people living with HIV disease. *Health Psychology*, 22, 140-147.

- Herek, G.M., Gillis, J.R., & Cogan, J.C. (1999). Psychological sequelae of hate-crime victimization among lesbian, gay, and bisexual adults. *Journal of Consulting & Clinical Psychology, 67*, 945-951.
- Holmberg, S.D. (1996) The estimated prevalence and incidence of HIV in 96 large metropolitan areas. *American Journal of Public Health, 86*, 642-654.
- Holmes, W.C., & Shea, J.A. (1997). Performance of a new, HIV/AIDS-targeted quality of life (HAT-QoL) instrument in asymptomatic seropositive individuals. *Quality of Life Research, 6*, 561-71.
- Hutton, H.E., Glenn, J., & Treisman, G.J., (2001). Understanding the role of personality in HIV risk behaviors: Implications for prevention and treatment. Retrieved July 7, 2004, from the *World Wide Web*, [http://www.hopkins-aids.edu/publications/report/nov01\\_2.html](http://www.hopkins-aids.edu/publications/report/nov01_2.html).
- Ironson, G., Friedman, A., Klimas N., Antoni, M.H., Fletcher, M.A. LaPerriere, A., Simoneau, J., & Schneiderman, N. (1994). Distress, denial, and low adherence to behavioral interventions predict faster disease progression in gay men infected with human immunodeficiency virus. *International Journal of Behavioral Medicine, 1*, 90-105.

Isaacowitz, D.M., & Seligman M.E.P. (2002). Is pessimistic a risk factor for depressive mood among community dwelling older adults. *Behaviour Research and Therapy*, 39, 255-272.

Jacobsberg, L., Frances, A., & Perry, S. (1995). Axis II diagnoses among volunteers for HIV testing and counseling. *American Journal of Psychiatry*, 152, 1222-1224.

Joseph, S., & Lewis, C.A. (1998). The Depression- Happiness Scale: Reliability and validity of a bipolar self-report scale. *Journal of Clinical Psychology*, 54, 537-544.

Johnson, J.G., Williams, J.B.W., Rabkin, J.G., Goetz, R.R., & Remien, R.H. (1995) Axis I Psychiatric symptoms associated with HIV infection and personality disorders, *American Journal of Psychiatry*, 152, 551-4.

Kalichman, S.C., Heckman, T., & Kelly, J.A.(1996). Sensation seeking as an explanation for the association between substance use and HIV-related risky sexual behaviour. *Archives of Sexual Behaviour*, 25, 141-154.

Kalichman, S.C. (1998). *Understanding AIDS*. Washington DC: American Psychological Society.



- Kamen-Siegel, L., Rodin, J., Seligman, M.E.P., & Dwyer, J. (1991). Explanatory style and cell-mediated immunity in elderly men and women. *Health Psychology, 10*, 229-235.
- Kemeny, M.E., & Dean, L. (1995). Effects of AIDS-related bereavement on HIV progression among New York City gay men. *AIDS Education and Prevention, 7*, 36-47.
- Kemeny, M.E., Weiner, H., Duran, R., Taylor, S.E., Visscher, B., & Fahey, J.L. (1995). Immune system changes after the death of a partner in HIV-positive gay men. *Psychosomatic Medicine, 57*, 547-554.
- Kiecolt-Glaser, J. K., Glaser, R., Cacioppo, J. T., & Malarkey, W. B. (1998). Marital stress: Immunologic, neuroendocrine, and autonomic correlates. *Annals of the New York Academy of Sciences, 840*, 649-655.
- Kimerling, R., Calhoun, K.S., Forehand, R., Armistead, L., Morse, E., Morse, P., Clark, R., & Clark, L. (1999) Traumatic stress in HIV-infected women. *AIDS Education and Prevention, 11*, 321-330.
- Kleinman, P.H., Millman, R.B., Robinson, H., Lesser, M., Hsu, C., Engelhart, P., & Finkelstein, I. (1994). Lifetime needle sharing: a predictive analysis. *Journal of Substance Abuse & Treatment, 11*, 449-455.
- Kline, P. (1993). *The handbook of psychological testing*. London: Routledge.

Lancet (Editorial), (1995) Quality of life and clinical trials. *Lancet*, 346, 1-2.

Lerner, D.J., & Levine, S. (1994) Health related quality of life: Origins, gaps and directions. In: Albrecht, G.L, and Fitzpatrick, R. (Eds) (1994) *Advances In Medical Sociology: Quality of Life in Health Care* (pp. 41-62). Greenwich, CT: JAI Press.

Leserman, J.(2003). The effects of stressful live events, coping and cortisol on HIV infection. *CNS Spectrums*, 8, 25-30.

Leserman, J., Jackson, E.D., Petitto, J.M., Golden, R.N., Silva, S.G., Perkins, D.O., Cai, J., Folds, J.D., & Evans, D.L. (1999). Progression to AIDS: The effects of stress, depressive symptoms, and social support. *Psychosomatic Medicine*, 61, 397-406.

Leserman, J., Petitto, J.M., Golden, R.N., Bradley N. Gaynes, B.N., Gu, H., Perkins, D.O., Silva, S.G., Folds, J.D., & Evans, D.L. (2000). The impact of stressful life events, depression, social support, coping, and cortisol on progression to AIDS. *American Journal of Psychiatry*, 152, 1221-1228.

Leserman, J., Petitto, J.M., Gu, H., Gaynes, B.N., Barroso, J., Golden, R.N., Perkins, D.O., Folds, J.D., & Evans, D.L. (2002) Progression to AIDS, a clinical AIDS condition and mortality: psychosocial and physiological predictors. *Psychological Medicine*, 32, 1059-1073.

Lin, E.H., & Peterson C.,(1990) Pessimistic explanatory style and response to illness. *Behaviour Research and Therapy*, 28, 243-248.

Lucas, R.E., Diener,E., Grob, A., Suh, E.M., & Shao,L.(2000). Cross-cultural evidence for the fundamental features of extraversion. *Journal of Personality and Social Psychology*, 79, 452-468.

McCormick, R.A., Dowd E.T., Quirk, S., & Zegarra, J,A. (1998). The relationship of neo-pi performance to coping styles, patterns of use, and triggers for use among substance abusers. *Addictive Behaviours*, 23, 497-507.

McCown, W. (1993). Personality factors predicting failure to practice safer sex by HIV positive males. *Personality and Individual Differences*, 14, 613-615.

McCrae, R.R., & Costa, Jr., P.T. (1986).Personality, coping and coping effectiveness in an adult sample. *Journal of Personality*, 54, 385-405.

McCrae, R.R., & Costa, Jr., P.T. (1989). The structure of interpersonal traits: Wiggins's circumplex and the five-factor model. *Journal of Personality and Social Psychology*, 56, 586-595.

- McCrae, R.R., & Costa, Jr., P.T. (1991). Adding Liebe and Arbeit: The full five-factor model and well-being. *Personality and Social Psychology Bulletin*, *17*, 227-232.
- McDowell, I., & Newll, C. (1996) *Measuring Health: A guide to Rating Scales and Questionnaires*. (2<sup>nd</sup> edition). New York: Oxford University Press.
- Mishel, M.H. (1997). Uncertainty in acute illness. *Annual Review of Nursing Research*, *15*, 57-80.
- MMWR (1981). Pneumocystis Pneumonia- Los Angeles. *Morbidity and Mortality Weekly Report*, *30*, 250-252.
- Mor, V., and Guadagnoli, E. (1988). Quality of life measurement: A psychometric tower of Babel. *Journal of Clinical Epidemiology*, *41*, 1043-1053.
- Mulder, C.L., Antoni, M.H., Duivenviirden, H.J., Kauffmann, R.H., & Goodkin, K. (1995). Active confrontational coping predicts decreased clinical progression over a one-year period in HIV-infected homosexual men. *Journal of Psychosomatic Research*, *39*, 957-965.
- Palella, F.J., Delaney, K.M., Moorman, A.C., Loveless, M.O., Fuhrer, J., Satten, G.A., Aschman, D.J., Holmberg, S.D.(1998) Declining morbidity and mortality among patients with advanced human immunodeficiency virus

- infection. HIV Outpatient Study Investigators. *New England Journal of Medicine*, 338, 853-60.
- Penedo, F.J., Gonzales, J.S., Dahn, J.R., Antoni, M., Malow, R., Costa, P. and Schneiderman, N., (2003) Personality, Quality of Life, and HAART adherence among men and women living with HIV/AIDS. *Journal of Psychosomatic Research*, 54, 271-278.
- Perkins, D.O., Davidson, E.J., Leserman, J., Liao, D., Evans, D.L., (1994) Personality disorders in patients infected with HIV: a controlled study with implications for clinical care. *American Journal of Psychiatry*, 150, 298-9.
- Peterson, C. (1988). Explanatory style and response to illness. *Behaviour Research and Therapy*, 12, 119-132.
- Peterson, C., Seligman, M.E.P., & Vaillant, G. (1988). Pessimistic explanatory style is a risk for physical illness: a thirty-year longitudinal study. *Journal of Personality and Social psychology*, 55, 237-265.
- Ramrakha, S., Caspi, A., Dickson, N., Moffitt T.E, & Paul, C. (2000). Psychiatric disorders and risky sexual behaviour in young adulthood: cross-sectional study in birth cohort. *British Medical Journal*, 321, 263-266.

Reed, G.M., Kemeny, M.E., Taylor, S.E., & Visscher, B.R. (1999). Negative HIV-specific expectancies and AIDS-related bereavement predictors of symptoms onset in asymptomatic HIV-positive gay men. *Health Psychology, 18*, 354-363.

Revicki D, Swartz C. (1997) Quality of life outcomes of saquinavir, zalcitabine and combination saquinavir-zalcitabine therapy for advanced HIV-infection. *Conference for Retroviruses Opportunistic Infections*, (abstract no 266). Retrieved March 8, 2004, from the *World Wide Web*, <http://www.clinicaltrials.gov/ct/show/NCT00002333?order=2>.

Sarason, B.R., Shearin, E.N., Pierce, G.R., & Sarason, I.G. (1987). Interrelations of social support measures : Theoretical and practical implications. *Journal of Personality and Social Psychology, 52*, 813-832.

Scheier, M.F., & Carver, C.C. (1992) Effects of optimism on psychological and physical well-being: theoretical overview and empirical update. *Cognitive Therapy and Research, 16*, 201-228.

Scheier, M.F., Matthews, K., Owens, J.F., Magovern, G.J., Lefebvre, R.C., Abbott R.A., & Carver, C.S. (1989). Dispositional optimism and recovery from coronary artery bypass surgery: the beneficial effects on physical and psychological well-being. *Journal of Personality and Social Psychology, 57*, 1024-1040.

Segerstrom S.C., Taylor, S.E., Kemeny, M.E., Reed, G.M., & Visscher, B.R.(1996) Causal attributions predict rate of immune decline in HIV-seropositive gay men. *Health Psychology, 13*, 299-307.

Sher, K.J., Bartholow, B.D., & Wood, M.D. (2000). Personality and substance use disorders: A prospective study. *Journal of Consulting & Clinical Psychology, 68*, 818-829.

Sherbourne, C.D., Hays, R.D., Fleishman, J.A., Vitiello, B., Magruder, K.M., Bing, E.G., McCaffrey, D., Burnam, A., Longshore, D., Eggan, F., Bozzette, S.A., & Shapiro, M.F. (2000). Impact of psychiatric conditions on health-related quality of life in persons living with HIV infection. *American Journal of Psychiatry, 157*, 248-254.

Simoni, J.M. & Ng, M.T. (2000). Trauma, coping, and depression among women with HIV/AIDS in New York City. *AIDS Care, 12*, 567-580.

Skevington, S.M., & O'Connell, K.A. (2003). Measuring quality of life in HIV and AIDS: A review of the recent literature. *Psychology & Health, 18*,331-350.

Smith, K.W., Avis, N.E., and Assmann, S.A. (1999) Distinguishing between quality of life and health status in quality of life research: A meta-analysis. *Quality of Life Research, 8*, 447-459.

Solano, L., Costa, M., Salvati, S., Coda R., Aiuti, F., Mezzaroma, I., & Bertini, M. (1993). Psychological factors and clinical evolution in HIV-1 infection: A longitudinal study. *Journal of Psychosomatic Research*, 37, 39-51.

Spitzer, W. (1987). Advances in health assessment conference discussion panel. *Journal of Chronic Diseases*, 40, 187-189.

Tomakowsky, J., Lumely, M.A., Markowitz, N., & Frank C. (2001). Optimistic explanatory style and dispositional optimism in HIV-infected men. *Journal of Psychosomatic Research*, 51, 577-587.

Trobst, K.K., Wiggins, J.S., Costa, Jr. P.T., Herbst, J.H., McCrae R.R., & Masters, III H.L. (2000). Personality psychology and problem behaviours: HIV risk and the five-factor model. *Journal of Personality*, 68, 1233-1252.

Turner, R.J., Frankel, B.G., & Levin, D.M. (1983) Social support: Conceptualization, measurement, and implications for mental health. *Research in Community and Mental Health*, 3, 67-111.

UNAIDS, (2004) *UNAIDS 2004 Report on the global AIDS epidemic*. Retrieved from the World Wide Web, 18<sup>th</sup> December 2004, <http://www.unaids.org/bangkok2004/report.html>.



- Weinfurt, K.P., Willke, R.J., Glick, H.A., Freimuth, W.W., & Schulman, K.A. (2000) Relationship between CD4 count, viral burden, and quality of life over time in HIV-1-infected patients. *Medical Care*, 38, 404-410.
- Wrosch, C., & Scheier, M.F. (2003). Personality and quality of life: The importance of optimism and goal adjustment. *Quality of Life Research*, 12, 59-72.
- Wu, A.W., Revicki, D.A., Jacobsen, D., & Malitz, F.E. (1997). Evidence for the reliability, validity and usefulness of the Medical Outcomes Study HIV Health Survey (MOS-HIV). *Quality of Life Research*, 6, 481-493.
- Zander, K., Jager, H., Palitzsch, M., Poppinger, J.V., Steinbuchel, N., & Bullinger, M. (1993). *Health-related quality of life (HRQL) in HIV disease: Influences of symptom load, functioning, mood and coping styles*. IX International Conference in AIDS, Berlin, June 1993. Cited in Burgess *et al.* (2000) op cit.

## Part II

# The Relationship between Personality, Cognitive Schemas, and Quality of Life in HIV Positive Gay Men.

▪ **Abstract**

Objective: This study set out to explore the relationship between personality, cognitive schemas, and quality of life in HIV positive gay men.

Method: The study adopted a cross-sectional questionnaire design comparing a sample of HIV positive gay men, with a sample of HIV negative gay men. Both samples were recruited from the Royal Free Hampstead NHS Trust HIV outpatient clinic and completed the questionnaire comprising the DASS21 (Lovibond & Lovibond, 1995), WHOQOL-BREF (WHOQOL Group, 1998a), NEO-FFI (Costa & McCrae, 1992), and the Schema Questionnaire (Young, 1994).

Findings: Significantly higher reported quality of life scores in HIV negative participants was found when compared with the HIV positive participants. Higher levels of neuroticism and lower levels of extraversion were found among the HIV positive participants compared with the HIV negative participants. Neuroticism was found significantly predict physical and psychological quality of life. Extraversion significantly predicted psychological quality of life. The following schemas correlated with all four domains of quality of life: “failure”, “insufficient self control”, “abandonment”, “mistrust/abuse”, “self sacrifice”, “dependency”, “shame/defectiveness”, and “vulnerability to harm”. However, factor analysis of the Schema Questionnaire suggested problems with this measure.

Conclusion: HIV positive status was associated with poorer quality of life. Different levels of neuroticism and extraversion were found in HIV positive compared with HIV negative gay men, and these personality dimensions significantly predicted

quality of life. Results of the study are discussed with regard to quality of life and clinical interventions. Factor analysis of the Schema Questionnaire did not yield the same factor structure reported by Young (1998), and Welburn, Coristine, Dagg, Pontefact, and Jordan (2002).

## ▪ Introduction

There is no cure currently available for HIV, a disease characterised by a progressive depletion of CD4 T-Lymphocytes, a subset of white blood cells responsible for coordinating and regulating immune responses (Gallo, 1988). Untreated, this condition eventually leads to impairment of immunologic function, leaving the infected person susceptible to opportunistic infections, such as pneumocystis carinii pneumonia and other illnesses, normally prevented by a healthy immune system (Fahey *et al.*, 1990). The advent of new pharmacological treatments, such as Highly Active Antiretroviral Therapy (HAART), for HIV and AIDS in the past five years, has increased life expectancy and improved the health of those infected with the disease where they have access to such treatments. The use of these drugs in developed countries has shifted the parameters of HIV/AIDS from an acute and usually fatal disease, to a chronic, long-term disease (Antoni *et al.*, 1998). Despite significant advances in virology and clinical management of the condition, HIV infection continues to be spread through certain risk behaviours mostly associated with unprotected sex, and is pandemic with an estimated 38 million people living with HIV infection worldwide (UNAIDS, 2004).

There is a growing recognition, among researchers and healthcare professionals, that improvements in the physical health of people with HIV (PWHIV) have, in some cases, failed to produce concomitant changes in their quality of life as initially predicted, and has introduced new uncertainties and issues. Research indicates the PWHIV often face stigma, prejudice, and discrimination, which can, in turn, be both demoralising and life altering (D'Augelli, 1989). Professional careers, living

arrangements, financial solvency, and the ability to maintain social and professional relationships, may all be threatened by the HIV status (Herek, 1999). Potent pharmacological treatments of HIV, designed to delay the onset of clinical symptoms of disease, are not without their complications. Toxicity has been found to be a challenge in people who now live longer lives with HIV and are on long-term medication. Pharmacological therapy for HIV has been associated with additional medical complications, such as liver disease, high cholesterol, renal disease, and lipodystrophy (Highleyman, 2000). The shift of HIV from an acute to a chronic disease has made the study of quality of life more relevant and urgent among this patient group.

Quality of life (QoL) has become a firmly established goal in medical care (Editorial, Lancet, 1995). This is especially the case for chronic conditions for which a cure is unlikely (Smith, Avis, & Assmann, 1999). However, research into QoL continues to be hampered by a lack of clarity regarding precisely what is meant by *quality of life* (e.g. Lerner & Levine, 1994; Mor & Guadagnoli, 1988). Investigators often use the constructs “*quality of life*” and “*health status*” interchangeably (McDowell & Newell, 1996; Spitzer, 1987). This ambiguity is further complicated by references to “*health related quality of life*” as used in medical settings, and “*subjective well-being*” and “*life satisfaction*” originating from sociological studies of healthy general populations (Smith *et al.*, 1999). To fully understand the impact of a disease, traditional measures of psychopathology need to be complemented with quality of life measures that encompass key indicators such as satisfaction and enjoyment of life (WHOQOL Group, 1998a). There is a growing recognition that health status and quality of life are separate constructs, with the latter measuring more psychological

processes (Smith *et al.*, 1999). According to the World Health Organisation Quality of Life Group (WHOQOL Group), QoL measures that extend beyond symptom assessment and functional status evaluation are most appropriate for use in the context of HIV where social, environmental, and spiritual issues are prominent (Skevington & O'Connell, 2003). This is reflected in more contemporary measures of QoL that incorporate indicators of emotional well-being, coping styles, spirituality, and social support (e.g. WHOQOL-100, QOLI).

Physical well-being, whether assessed in the form of CD4 cell counts, HIV viral load, or HIV-symptom severity, is a reliable predictor of clinical outcome in HIV infected persons, including psychological functioning and QoL (Weinfurt, Willke, Glick, Freimuth, & Schulman, 2000). Hays *et al.* (2000) found significant morbidity associated with HIV disease in adults. They found both emotional and physical well-being to be impaired in PWHIV, compared to people with other chronic conditions (such as epilepsy and diabetes). Moreover, health-related QoL varied according to disease progression. Similar findings were reported by Bing *et al.* (2000) who found that people infected with HIV had worse perceived mental and physical health, compared to HIV negative men. Asymptomatic HIV infected men (as measured in CD4 counts), had lower scores on emotional well-being, than HIV infected men who had multiple symptoms of disease. Research which has investigated the relationship between psychological and physical well-being in PWHIV has suggested that psychological and physical well-being have an independent, as well as interactive, impact on global measures of well-being (e.g. Heckman 2003).

To date, studies of quality of life in PWHIV have been limited by their focus on health-related QoL, and the outcomes of medical treatments (Skevington & O'Connell, 2003). The psychological components of QoL may have been inadequately appreciated. Studies that have examined psychological factors have focused on emotional states (e.g. Revicki & Swartz, 1997; Zander, Jager, Palitzsch *et al.*, 1993); psychiatric disorders (e.g. Johnson, Williams, Rabkin, Goetz, & Remien, 1995); stress, and buffering resources such as social support (e.g. Friedland, Renwick, & McColl, 1996). In a longitudinal study, Leserman *et al.* (1999) demonstrated the cumulative experience of stressful life events and social support on disease progression in HIV infected men. For every 4-point increase in cumulative stressful life events, the risk of AIDS was doubled. In a follow-up study Leserman *et al.* (2002) demonstrated the progression rate to AIDS at the end of 8 years was 40% for infected individuals whose stress score were below the median, compared with 74% for those with stress score above the median. Similar findings have been found in studies that examined the detrimental effect of bereavement on HIV disease progression (e.g. Kemeny *et al.*, 1995).

A sizeable amount of research examining the relationship between personality and health has been published. Costa and McCrae (1980), the pioneers of the Five-Factor Model of personality, also known as the "Big 5", and Deneve and Cooper (1989), have demonstrated that the strongest predictors of happiness are neuroticism and extraversion. Neuroticism and conscientiousness have also been found to be the strongest Big 5 predictors of life satisfaction. The role of personality in secondary prevention efforts in HIV/AIDS has received limited attention in the literature. However, the study of personality in PWHIV is warranted by several inferences



made by previous research. Studies conducted in Western societies, which have examined personality in PWHIV, show a higher prevalence of DSM-IV axis I and II disorders among individuals living with AIDS (e.g. Perkins, Davidson, Leserman, Liao, & Evans, 1994). As many as one third of individuals living with HIV/AIDS may meet the criteria for a personality disorder, and may have concurrent Axis I disorders, with a mood disorder being the most commonly diagnosed Axis I disorder in this population (Johnson *et al.*, 1995). This rate of individuals living with HIV/AIDS who meet the criteria for a personality disorder is in stark contrast to the estimated 13% in the general adult population (Casey & Tyrer, 1986). These studies suggest that individuals found to have personality traits associated with character pathology, such as neuroticism and impulsivity, tend to express attitudes and exhibit behaviours commonly associated with risk behaviour and poor health habits (Ball, Tennen, Poling, Kranzler, & Rounsaville, 1997). Individuals with such traits are also more vulnerable to depression and psychological distress, greater social conflict, and poorer overall functioning (Johnson *et al.*, 1995). These variables that are associated with neuroticism are likely to be associated with quality of life.

A number of studies looking at QoL in PWHIV have demonstrated significant relationships associations between the personality traits of extraversion and neuroticism and QoL. In one recent study carried out by Burgess *et al.* (2000), the role of personality in QoL among individuals living with HIV/AIDS was examined. Findings indicated that neuroticism - a personality factor characterised by a high proneness to depression, anxiety, anger, and low self-confidence - was associated with poor health-related QoL. The authors concluded that neuroticism had a significant effect on health-related QoL, independently of health status. The findings

of this study suggest that personality traits, and specifically neuroticism, have an important effect on QoL. Furthermore, the effect of neuroticism outweighed the effects of other psychological factors, such as coping styles, which historically have been argued to be intrinsic to QoL (Burgess *et al.*, 2000). In another study, Penedo *et al.* (2003) found higher neuroticism was associated with poorer overall QoL, and HIV specific domains (e.g. medication mastery). This study was among the first to show that more adaptive dispositional traits, such as assertiveness and trust, may contribute to the extent to which individuals are able to manage multiple demands associated with living with HIV/AIDS.

Researchers increasingly acknowledge that many methodological and conceptual complexities thwart investigation of causal pathways that underlie the associations between personality and health. Friedman (2000) has argued against the notion of a “*disease prone personality*”, and has suggested that multiple psychosocial factors interact rendering people prone to developing certain habits or behaviours that are less conducive to good health. Wrosch and Scheier (2003) have argued that certain personality factors can impact on the way people approach life circumstances, or on the kind of outcomes people received, which are in turn argued to impact favourably, or unfavourably, on QoL.

Although research has highlighted the effect that personality factors can have on QoL, the paths through which personality impacts on QoL remain poorly understood. For example, there is some uncertainty as to what it is about neuroticism that may affect QoL. Some failure of previous attempts at health promotion in the field of HIV may be attributable to an imprecise appreciation of the ways in which

personality traits exert an influence on behaviours associated with QoL. Given the higher rates of maladaptive personality styles in PWHIV, and the significant association between traits such as neuroticism and QoL, studies that explore the relationship between personality and QoL and which consider the factors that may mediate this relationship are warranted. Such investigations may serve to inform healthcare provision, and thereby improve the QoL of people living with HIV. One method to elucidate the relationship between personality traits and QoL may be to examine the core schemas that operate on emotional and behavioural levels. Cognitive theorists have proposed models that describe the ways in which core cognitions can affect the way individuals think, feel and behave.

Cognitive therapy for personality disorder (Beck & Freeman, 1990) is a schema-centred psychotherapy based on an information-processing model of psychopathology. According to this theory individuals operate as scientists, such that hypotheses made about the world using personal constructs, or schemas, are used to interpret and predict events (involving self and others). Schemas are deep, unconscious, cognitive structures seated in long-term memory that give meaning to events, and operate on a number of psychological levels, affecting motivation, behaviour, affect, attention and memory. Maladaptive schemas can produce analogous cognitive errors or distortions, which bias interpretations thereby serving to confirm the schemas. Young (1990) has argued that personality pathology arises from the formation and maintenance of Early Maladaptive Schemas (EMS). These schemas are defined as pervasive cognitive themes developed in childhood, which affect self-perception and impact on interpersonal relationships. Schemas become self-perpetuating on a cognitive and behavioural level. Young (1990) has proposed a

classification system of common schemas that are presumed to underlie an individual's psychopathology, and has developed a questionnaire measure of these common schemas. The Young's Schema Questionnaire measures 15 maladaptive schemas including "emotional deprivation", "abandonment", "mistrust/abuse", "social alienation", and "enmeshment" (Young, 1998). Individuals with EMS's are likely to have interpersonal problems. Young's model may serve to elucidate the relationship between personality factors, such as neuroticism and QoL in PWHIV by clarifying the kind of themes that are pertinent to PWHIV.

The broad aim of this study is to improve understanding of the impact of personality on QoL. This understanding may help to improve medical and psychological interventions for PWHIV, particularly those with personality traits that render them more vulnerable to poorer QoL, or those whose personalities may impede them from benefiting from psychological support. Although altering personality characteristics appears to be an unreasonable objective given the stability of personality over the life span (Costa & McCrae, 1994), some amelioration may be possible via psychopharmacological (for example Knutson *et al.*, 1998) and psychotherapeutic interventions (e.g. Beck & Freeman, 1990). Interventions that target cognitive schemas may provide a throughway for interventions designed to take into account enduring individual differences. Successful control of challenging personality styles may require a range of interventions, each tailored to the basic tendencies of the individual. Krueger, Caspi, and Moffit (2000) argue that one important result of such an approach might be the development of classes of interventions organised not by the nature of the problems, but by the underlying dispositions of the people who suffer from them.

- The present study

Past research has demonstrated that personality traits impact on quality of life in several ways. However, the exact pathways, especially as they related to HIV infected, individuals remain poorly understood. This study has been designed to examine the relationship between QoL, personality, and cognitive schemas in HIV infected gay men. Previous studies examining personality and QoL have identified broad personality dimensions associated with poorer QoL. This study aimed to focus on those aspects of personality, and specifically neuroticism and extraversion, which have been shown to be associated with poor QoL. This is important because many healthcare professionals have difficulty understanding why individuals fail to adopt behaviours that would enhance their QoL. A greater understanding of the relationship between personality and QoL may help clinicians empathise with their patients. In order to explore potential clinical interventions, this study used Young's Schema Questionnaire to map out the core cognitive schemas, associated with personality traits and QoL. The study's design advances that of previous studies in that a comparison group was recruited in order to explore whether the personality and QoL patterns hypothesised are unique to HIV positive gay men, or whether these are trends that are generally more common in gay men.

- Hypotheses

**Hypotheses pertaining to differences between HIV positive and HIV negative groups**

Hypothesis 1. QoL in HIV positive versus HIV negative gay men:

Chronic medical conditions are associated with poor QoL. Therefore, it is hypothesised that the HIV positive gay group will have poorer QoL than the HIV negative gay group.

Hypothesis 2. Personality in HIV positive versus negative gay men.

Prior research reviewed above has found higher rates of personality problems in HIV positive participants compared with HIV negative participants. Thus, it is hypothesised that the HIV positive participants will have higher levels of neuroticism and lower levels of extraversion compared with the HIV negative participants.

**Hypotheses pertaining to analyses on HIV positive group only.**

Hypothesis 3. Associations between personality traits and QoL.

It is hypothesised that higher neuroticism and lower extraversion scores will be associated with lower scores on QoL measure. Higher levels of conscientiousness and agreeableness are hypothesised to be associated with higher QoL.

Hypothesis 4. Associations between QoL and schemas

A negative association is hypothesised between QoL and schemas, such that higher levels of maladaptive schemas are expected to be associated with lower levels of QoL.

Hypothesis 5. Personality predicting QoL

It is hypothesised that neuroticism and extraversion will be significant predictors of QoL independently of indicators of physical health and SES. Openness-to experience, agreeableness and conscientiousness are not expected to be significant predictors of QoL.

Hypothesis 6. Cognitive schemas and QoL.

It is hypothesised that lower scores on QoL will be associated with Young's Early Maladaptive Schemas. It is further hypothesised that cognitive schemas will mediate the relationship between personality traits and QoL. Specifically, early schemas pertaining to Young's (2003) domains of "disconnection and rejection" and "impaired autonomy and performance" will be associated with neuroticism and extraversion and predictive of QoL.

- **Method**

- Participants

Two samples were used in this study. Both groups comprised gay men in order to avoid potential confounding factors, such as sexual orientation and gender. The samples were recruited from the same medical clinic in an effort to ensure that the comparison group was as comparable as possible to the HIV positive group in terms of socio-demographic characteristics. Most participants were White (92%, 130), which represents the ethnic distribution of this clinic's patients. The HIV positive sample consisted of 140 participants recruited from the HIV Outpatient Clinic at the Royal Free Hampstead NHS Trust, London, between August 2004 and January 2005. All of the participants in this sample defined themselves as gay men. The HIV negative comparison sample comprised 85 gay men recruited from the HIV antibody-testing clinic held in the same HIV clinic at the Royal Free Hampstead NHS Trust. Participants with difficulties with the English language were excluded from both samples, due to lack of resources for translators and associated biases.

Power analyses were conducted at the planning stage of the study to estimate the number of participants. There have there have been few studies which have examined this hypothesised relationship. A recent study by Penedo *et al.* (2003) which examined the relationship between quality of life, personality and medication (HAART) adherence in an HIV positive population, found moderate associations (ranging 0.25-0.5) between personality traits and QoL in this population. Given the close relationship between schemas and personality psychopathology (Young, 1990), a mean correlation of 0.25 has been used to conduct a power analysis for this proposed study. In order to have 80% power to detect a correlation of 0.25 at  $\alpha$



=0.05, a sample size of 123 was indicated. As previous studies have not recruited a comparison group, the researcher aimed to recruit an equal sample for the comparison, with the acknowledgment of difficulties inherent in postal surveys and response rates.

- Ethics

Ethics approval was obtained from Camden & Islington Community Health Services Local Research Ethics Committee in May 2004 (REC reference no:04/Q0511/25). The project was also registered and approved by the Royal Free Hampstead NHS Trust R&D office in June 2004 (ID: 6782). UCL Data Protection covered the project (ref: Z6364106, section 19 Research: Social Research).

Research was carried out with the utmost sensitivity and respect for all participants. Care was taken to ensure that participants consented with a full understanding of the project and their involvement. All participants were informed that their decision to take part would in no way affect the service they receive at the clinic. The researcher provided contact details so that participants to use should they wished to discuss any issues raised by the questionnaire. Additionally, contact details of external sources of support were provided to all participants.

- Procedures

Participants for the HIV positive group were approached when they attended routine medical appointments at the HIV Clinic, Royal Free Hampstead NHS trust. They were informed about the study and what their involvement entailed. They were provided with an information sheet and invited to ask any questions they may have had, both when they were first approached to take part and at any later stage. Participants who expressed an interest in taking part signed a consent form, and were given the questionnaire to complete. On completion, the questionnaire was returned to the researcher.

Participants for the HIV negative group were recruited from the HIV-testing clinic at the Royal Free Hampstead NHS trust. The researcher approached gay men who came for testing immediately after they received a negative diagnosis. They were informed of the study and what their involvement entailed, and were provided with information sheets and opportunity to ask questions. If they agreed to take part in the study, they signed a consent sheet and provided a phone number that the researcher could contact them on. All negative participants were contacted a week after their negative diagnosis. The researcher contacted the potential participant and enquired whether they were still agreeable to take part. If verbal consent was given a questionnaire pack with a stamped addressed envelope was mailed to the participant to send back to the researcher on completion.

Questionnaires completed and returned by participants in the negative comparison group were anonymous. With their consent, questionnaires returned by the HIV

positive participants were marked with their hospital number, so that the researcher could obtain further details of their health status, such as their CD4 counts (a measure of their immune system functioning). (Samples of the information sheets and consent forms are contained in appendix 2.). All participants were provided with the researcher's contact details should they wish to discuss the questionnaire, or any other issues, at another time.

- Design

The study adopted a cross-sectional, between-groups design focusing on gay men. Participants from both samples completed a questionnaire pack comprising four separate measures (see below).

- Measures.

*Sociodemographic and HIV-related measures*

Date of birth, sexual orientation, years of formal education, employment status, and yearly income were requested on the front page of the self-report questionnaire. HIV positive participants were also asked to report whether they were currently taking antiretroviral medication, and to provide their hospital number, which was later used to obtain their recent CD4 counts as proxy for disease progression.

*Assessment of Mood*

The Depression Anxiety Stress Scales (DASS21) (Lovibond & Lovibond 1995) is a 21-item self-report measure of anxiety, depression and stress. The measure has been shown to effectively discriminate the constructs of depression, anxiety, and stress, and has been developed using non-clinical populations in order to capture the dimensional nature of these constructs. Each item asks to what extent a statement has

applied to the participant over the past week. Each item is rated on a 4- point Likert scale, ranging from *did not apply to me at all* to *applied to me very much, or most of the time*. DASS-21 has been shown to have good to excellent internal consistency. Antony, Bieling, Enns, & Swinson (1998) reported Cronbach's alpha coefficients of 0.87 for the anxiety subscale, 0.94 for the depression subscale, and 0.91 for the stress subscale. British normative data is available, which allowed the examination of levels of depression, anxiety, and stress, at data analysis.

### *Assessment of Personality*

The NEO –FFI (Costa & McCrae, 1992) is a 60-item version of the NEO-PI-R. It is a measure of the Five Factor Model of personality and yields scores on the following domains: Neuroticism, Extraversion, Openness-to-experience, Agreeableness, and Conscientiousness. Each item is rated on a five-point Likert scale ranging from *strongly disagrees* to *strongly agree*. The NEO has been extensively used in research, and has excellent psychometric properties (Scandell, 2000). Estimates for the internal consistency of the subscales for this inventory have ranged from 0.68 for agreeableness, to 0.86 for neuroticism (Costa & McCrae, 1992).

### *Assessment of Quality of Life*

The WHOQOL-BREF is a short form of the WHOQOL-100 questionnaire. The WHOQOL-100 questionnaire was developed through an international collaboration of 15 culturally diverse centres, and is therefore designed to be applicable cross-culturally. The WHOQOL-BREF has been developed to provide a short form of quality of life assessment that looks at 4 domain level profiles (namely: physical health, psychological health, social relationships, and environment). The

questionnaire contains a total of 26 items. Items are rated on a 5-point Likert interval scale, where 1 indicates low, negative perceptions, and 5 indicates high, positive perceptions.

The WHOQOL instrument has been validated successfully in the HIV positive population. Fang, Hsinug, Yu, Chen, & Wang (2002) found internal consistency scores ranging from 0.74 to 0.85 across the domains in HIV infected individuals. The test–retest reliability ranged from 0.64 to 0.79 across domains at average four weeks interval. Factor analysis yielded four factors consistent with the domains of the instrument. The scores on all four domains correlated with self-evaluated health status and happiness, and correlated negatively with number and severity of symptoms. A recent study by Hsuing, Fang, Chang, Chen & Wang (2005) concluded that the WHOQOL-BREF was a useful instrument for the HIV positive population and the instrument compared favourably against the well-established SF-36 (Ware & Sherbourne, 1992).

#### *Examination of Cognitive Schemas*

The Schema Questionnaire Short-Form was used to explore the schemas that may be associated with maladaptive traits and QoL. The Schema Questionnaire was developed by Young and Brown (1994) to measure early maladaptive schemas (EMS). Schema Questionnaire Short-Form (SQ-SF) (Young, 1998) is a 75-item questionnaire designed to assess 15 early maladaptive cognitive schemas. Each of the 75 items of the SQ-SF is rated on a 6-point scale, ranging from *completely untrue of me* to *describes me perfectly*. Higher scores indicate a greater presence of that maladaptive schema for the respondent. Welburn, Coristine, Dagg, Pontefract and

Jordan (2002) have tested the psychometric properties the Schema Questionnaire-Short form. Their factor analysis supported the 15 schema subscales proposed by Young (1998), and the 15 subscales demonstrated good internal consistencies (ranging from 0.76-.093). Their study examined the relationship between psychiatric symptoms and the Schema Questionnaire, and their results provided support for the construct validity of the Schema Questionnaire.

- Data Analysis

In the first part of the results section, descriptive and frequency statistics of the two groups are presented and compared. This includes age, income, education and employment. This is followed by tests of the psychometric properties of the measures used in the study, and also includes factor analyses of the Schema Questionnaire. The next section deals with hypotheses 1 and 2. Here, t-tests were used to compare the means of the HIV positive and HIV negative groups on the QoL domains, and the NEO-FFI traits.

The remaining analyses were performed on data from the HIV positive sample only. Hypothesis 3 is tested through correlation tests of the associations between the NEO personality traits and the WHOQOL-BREF domains. Hypothesis 4 is tested through correlation tests of the associations between Young's schemas and the WHOQOL-BREF. To correct for Type I error due to multiple comparisons, only results significant at  $p \leq .01$  are reported. Finally, multiple regression analyses predicting psychological and physical QoL from the personality traits, testing hypothesis 5, are presented. Hypothesis 6 was not tested due to the poor psychometric properties of the Schema Questionnaire in the current sample.

- **Results**

- Participants' characteristics:

A total of 225 participants were recruited for the study (see Table 1). Eighty-five participants were recruited from the HIV testing clinic for the comparison group, and 140 were recruited from the HIV outpatients' clinic for the HIV positive group. Of the eighty-five participants recruited to the comparison group, forty-eight participants returned their questionnaires, representing a response rate of 57%. One hundred and thirty two participants from the HIV clinic returned questionnaires (response rate 94%).

Table 1: Recruitment and response rates.

Group	No. Recruited	No. Questionnaires returned	Response rate
HIV positive group	140	132	94%
Comparison group	85	48	57%
Total	225	180	

All participants described their sexual orientation as gay. Mean CD4 counts for HIV positive group was 547.7 (range 5-1207, SD=254). The mean age for all of the participants was 38.7 years (range 18-63 years of age, SD=8.9). The mean age for the HIV positive group was 39.8 years (range 20-63 years of age, SD=8.8). The mean age for the comparison group was 35.5 years (range 18-56 years of age, SD=8.6). To test for differences in age between the comparison and HIV groups independent samples t-test were conducted. The results showed that the HIV positive group were significantly older than the comparison group [ $t(177)=-2.94, p=0.004$ ]; however the difference was less than 1 standard deviation unit.

Demographic characteristics of the two groups are presented in Table 2. The majority of participants in both the comparison group and the HIV positive group had attained education at university/college level (Comparison group 83%, HIV group 64%); this difference was not significant [ $\chi^2 (4) = 7.74, p=.113$ ]. Sixty percent of the comparison group (59.9%) and 81.2% of the comparison group were in employment. The mean income for the group was £32,012.04 (range £3,792-32,012.04, SD=25,492.79). Independent sample t-test on the income of the two groups indicated that the comparison group earned significantly more than HIV positive group [ $t (151) = 2.6, p=.01$ ].

Table 2: Demographic information of comparison and HIV positive groups

	HIV negative Comparison group	HIV positive group
Age *	Mean: 35.5 Median: 35 [Range: 18-56]	Mean: 39.8 Median: 38 [Range: 20-63]
Income *	Mean: £40,600 Median: £31,000 [Range: £5200-40600]	Mean: £28,762 Median: £22,000 [Range: £3792-120000]
Educational level	83% University/college	64% University/college
Employment	60% employment	81% employment

\* Denotes significant difference between the two groups

In terms of mood state, the HIV positive group scored significantly higher on all three sub-scales of the DASS-21, depression, anxiety, and stress [( $t (95.7) = -2.52, p$



= .013;  $t(97.6) = -2.47$ ,  $p = .014$ ;  $t(95.7) = -2.52$ ,  $p = .013$ , respectively]. However, the overall DASS scores of both groups fell within the normal range (Lovibond & Lovibond, 1995) (0-78<sup>th</sup> percentile). The mean score for the comparison group was within the 45<sup>th</sup> percentile, and the mean for the HIV positive group was within the 60-65<sup>th</sup> percentiles.

○ Psychometric properties of measures used:

The internal consistency reliabilities (Cronbach's  $\alpha$ ) of the psychometric measures were calculated for all measured used. The Cronbach's alpha coefficients are presented in Table 3.

Table 3: Internal reliability coefficients

Sub-scale	Cronbach's $\alpha$
<u>DASS</u>	
Anxiety	.845
Depression	.931
Stress	.901
<u>WHO-QoL</u>	
Physical health	.852
Psychological Health	.867
Social relationships	.67
Environment	.837
<u>NEO</u>	
Neuroticism	.866
Extraversion	.819
Openness-to-experience	.703
Agreeableness	.677
Conscientiousness	.839

Alpha coefficients for the DASS mood measure ranged between 0.85-0.9 suggesting good to moderate internal consistency for each of the three subscales (anxiety, depression, and stress). For the four scales of the WHOQOL-QOL, Cronbach's alpha

coefficients ranged between 0.7-0.87, indicating good consistency reliability. For the NEO-form S, Cronbach's alpha coefficients ranged between of 0.7-0.87.

For the SQ-SF- Schema questionnaire Cronbach's alpha coefficients for fourteen of the fifteen schemas were in the range of 0.71-0.93. However, "subjugation of needs" schema yielded a very low alpha of 0.27. The items for this schema were deemed to be unreliable and were excluded from subsequent analysis. A recent study by Cecero, Nelson and Gillie (2004), which examined the construct validity of Young's schemas, also found weaker internal consistency reliability for the same schema.

- Normality of measures

Tests were conducted on all variables to verify whether they were normally distributed, and for the possibility of skewness and kurtosis. All of the variables were normally distributed, indicating that parametric tests were appropriate for analysis.

- Factor analysis of the SQ-SF

In order to explore the psychometric properties of the Schema Questionnaire and in a bid to reduce the factors in the questionnaire, the Schema Questionnaire was factor analysed. An exploratory factor analysis was conducted using the principal components method. A varimax rotation was used for interpretability of results (Stevens, 1986), which included the entire sample of 180 participants. Although this was less than the suggested minimum of five individuals per variable, Gorusch (1983) suggests that a smaller sample size of less problematic when sample size is greater than 100 and the number of expected variables per factor is low. Using the Kaiser criterion (retention of components with eigenvalues greater than one; Stevens, 1986) 17 factors were retained. Based on the principal components methods, a 17-

factor solution converged in 12 iterations accounting for 77.8% of the variance. The resulting factor structure including eigenvalues, percent of variance accounted for each factor, and significant factors loadings are reported in Table 4 below.

Table 4: 16 factors of the SQ-SF (n=180)

Factor	Schema According to Young's theoretical model	Factor loading
<u>Factor 1</u>	(eigenvalue =23.1; % variance =30.8)	
Item 38	Vulnerability to harm	.767
Item 39		.748
Item 37		.732
Item 36		.721
Item 50	Subjugation of needs	.479
Item 19	Social alienation	.466
Item 14	Mistrust/Abuse	.423
Item 13		.409
Item 35	Dependency	.456
<u>Factor 2</u>	(eigenvalue =4.92; %variance =6.6)	
Item 30	Emotional deprivation	.838
Item 29		.806
Item 28		.781
Item 27		.668
Item 26		.616
Item 21	Defectiveness/ shame	.469
Item 23		.452
<u>Factor 3</u>	(eigenvalue =3.8; %variance =5.5)	.835
Item 8	Abandonment	.827
Item 7		.721
Item 9		.712
Item 6		.666
Item 10		
Item 14 (Also loaded on factor 1&15)	Mistrust/ abuse	.409
<u>Factor 4</u>	(eigenvalue =3.58; %variance =4.7)	.883
Item 57	Emotional inhibition	.781
Item 58		.741
Item 59		.705
Item 56		.497
Item 60		
Item 22	Defectiveness/ shame	.406
Item 71	Insufficient self-control	.418

<u>Factor 5</u>	(eigenvalue =3.14; %variance =4.2)	
Item 1	Emotional deprivation	.799
Item 4		.798
Item 3		.746
Item 5		.745
Item 2		.721
<u>Factor 6</u>	(eigenvalue =2.8; %variance =3.7)	.828
Item 62	Unrelenting standards	.778
Item 61		.773
Item 64		.760
Item 65		.740
Item 63		
<u>Factor 7</u>	(eigenvalue =2.4; %variance =3.5)	.681
Item 17	Social alienation	.628
Item 16		.617
Item 18		.602
Item20		.549
Item 19		
Item 25	Defectiveness/ shame	.505
<u>Factor 8</u>	(eigenvalue =2.1; %variance =2.8)	
Item 54	Self-sacrifice	.812
Item 51		.742
Item 52		.723
Item 55		.722
Item 53		.718
<u>Factor 9</u>	(eigenvalue =1.8 %variance =2.5)	.825
Item 44	Enmeshment	.779
Item 42		.773
Item 41		.585
Item45		.534
Item 43		
Item 46	Subjugation of needs	.583
<u>Factor 10</u>	(eigenvalue =1.7; %variance =2.4)	
Item 15	Mistrust/ abuse	.651
Item 11		.600
Item 14		.564
(also loaded on factor 1 & 3)		.525
Item 13		
(Also loaded on factor 1)		
Item 12		.506
Item 66	Entitlement	.512

<u>Factor 11</u>	(eigenvalue =1.5; %variance =2.1)	
Item 69	Entitlement	.861
Item 70		.736
Item 67		.704
Item 68		.676
<u>Factor 12</u>		
Item 48	(eigenvalue =1.5; %variance =1.9)	.724
Item 49		.639
Item 47		.509
Item 31	Dependency	.417
<u>Factor 13</u>	(eigenvalue =1.34; %variance =1.8)	.771
Item 33	Dependency	.760
Item 34		.567
Item 35		
<u>Factor 14</u>	eigenvalue =1.26; %variance =1.7)	.704
Item 74	Insufficient self-control	.626
Item 75		.409
Item 73		
<u>Factor 15</u>	(eigenvalue =1.1; %variance =1.5)	
Item 72	Insufficient self-control	.675
Item 73		.505
(Also on factor 14)		.490
Item 71 (Also loaded on factor 4 )		
<u>Factor 16</u>	(eigenvalue =1.02; %variance =1.4)	
Item24	Defectiveness / Shame	.876
<u>Factor 17</u>	(eigenvalue =1.02; %variance =1.4)	
Item 45	Enmeshment	.730
(Also loaded on factor 9)		
Item 32	Dependency	.400

Table 4 demonstrates that the factor analysis yielded 17 factors. The structure was not totally consistent with the original scoring of the instrument, and psychometric properties previously reported of 15 factors each representing a separate schema (Wellburn, Coristine, Dagg, Pontefract & Jordan, 2002; Cecero, Nelson & Gillie, 2004). Item 14 loaded on factor 1 (.423) and factor 3 (.409), as well as factor 10 (.564). Based on question content and factor loading, this item fits best on factor 10. Item 13 loaded on both factor 1 (.409) and factor 10 (.525), this item fits best on factor 10. Item 71 loaded on both factor 4 (.418) and factor 15 (.490), and fits best on factor 15. Item 45 loaded on both factor 9 (.585) and factor 17 (.730). Based on the loading this item fits better with factor 13, although in terms of content it fits better in factor 9, which also included the other items pertaining to this schema. The number of items comprising each factor varied, with factor 15 and 16 consisting of a single item each. The overall structure of the factor analysis reported here was somewhat at odds with the structure predicted by Young's theory of 15 factors. Factors 5, 6, and 8 are consistent with Young's model with all items loading onto the correct factors. Factors 3, 4, 7, 9, and 10 are reasonably consistent with Young's model with all five of the items pertaining to the specific schema loading on the same factor. However, each of these factors included an additional item, which pertains to a different schema. Factor 1 comprised 9 items; the highest loading items pertain to four of the five "vulnerability to harm" schema, and the remaining items pertaining to four different schemas. Factors 11 and 15 were also quite consistent with the model, with only one item failing to load on each of these factors. Similarly, factors 13 and 14 are easily identifiable as Young's "dependency" schema and "insufficient self control" schema respectively, however are comprised of only 3 items.

In a bid to further reduce the number of subscales in the questionnaire, a second factor analysis was conducted. The second analysis was guided by the scree plot, which indicated 4 factors. A principal component analysis with varimax rotation was conducted. Four factors were specified and the rotation converged in 12 iterations, accounting for 45.7% of the variance. The structure was marred by unequal number of items per factor; with the first factor consisting of 37 items, factor 2 of 29 items, factor 3 consisting of 12 items, and factor 4 of 6 items. Moreover, most of the items loading on factors 2,3 and 4 also loaded on factor 1, and some items loaded on 3 factors (e.g. item 19). The resulting factor structure was not made clearer by exploration of the item content. Factor 1 consisted of items corresponding to 9 schemas (“shame”, “emotional deprivation”, “social alienation”, “emotional inhibition”, “mistrust/abuse”, “failure”, “abandonment”, “insufficient self control”, and “dependency”). This factor appears to reflect global emotional dysregulation, or general emotional maladjustment. Factor 2 consisted of items corresponding to 7 schemas (“dependency”, “vulnerability to harm”, “enmeshment”, “mistrust/abuse”, “failure”, “abandonment” and “insufficient self control”). Factor 3 consisted of items pertaining to 3 schemas (“unrelenting standards”, “entitlement”, and “self sacrifice”). Factor 4 consisted of items relating to 2 schemas (“unrelenting standards” and “self sacrifice”). Thus, the factor analysis did not produce a manageable reduced structure of the questionnaire.

- Hypothesis 1: Group differences on QoL

In order to explore whether the comparison group differed from the HIV positive group on QoL, independent t-tests were conducted on all four QoL domains measured by the WHOQOL measure. HIV and comparison groups significantly



differed on all four domains of QoL (see Table 5). As hypothesised the comparison group scored, on average, higher on all four domains.

Table 5: Group differences on QoL domains

QoL Domain	df	t-value	t-sig.
Physical health	118.2	5.5	.001
Psychological health	100.2	3.16	.002
Social relationships	104	3.23	.001
Environment	113.3	2.4	.019

○ Hypothesis 2: Group differences on personality:

Independent t-tests were conducted comparing scores on the five personality traits measured by the NEO (neuroticism, extraversion, openness-to-experience, agreeableness, and conscientiousness) in order to explore possible differences in personality traits between the comparison and the HIV positive groups. As expected, the HIV positive group had significantly higher scores on neuroticism [ $t(178)=2.75$ ,  $p=.007$ ], and lower scores on extraversion [ $t(171)=2.3$ ,  $p=.021$ ]. However this latter finding did not attain the .01 significance level. No significant differences on openness-to-experience, agreeableness, and conscientiousness were found.

To investigate whether the effects of neuroticism and extraversion was the same across both groups, or whether there was an interaction effect of group and the two personality dimensions, regression analyses were conducted with interaction terms constructed for group X neuroticism, and group X extraversion, predicting physical and psychological QoL. The regression analysis predicting physical quality of life

indicated that neuroticism significantly predicted physical QoL [ $t = .9708$ ,  $p < .01$ ], with no significant interaction between group and neuroticism [ $t = .035$ ,  $p = .972$ ]. Similar results were found for extraversion with extraversion significantly predicting physical QoL [ $t = 2.308$ ,  $p = .022$ ], with no significant interaction of group and extraversion [ $t = .066$ ,  $p = .947$ ]. Neuroticism was also a significant predictor of psychological QoL [ $t = 2.82$ ,  $p = .005$ ]. Extraversion did not significantly predict psychological QoL [ $t = 1.65$ ,  $p = .101$ ]. No interactions were found for group and the two personality traits in predicting psychological QoL.

○ Hypothesis 3: Associations between Personality and QoL:

Pearson zero-order correlations were calculated to assess the extent to which personality factors were related to quality of life in the HIV positive participants.

These correlations are presented below in Table 6.

Table 6: Correlations between NEO personality scales and QoL domains

	Neuroticism	Extraversion	Agreeableness	Conscientiousness	Openness to experience
Physical health QoL	-.558**	.388**	.254**	.293**	.033
Psychological health QoL	-.706**	.587**	.239**	.420**	.078
Social relationships QoL	-4.53**	.422**	.326**	.236**	.149
Environment QoL	-5.24**	.350**	.281**	.380**	.093

\*\*  $p < .01$

As hypothesised, neuroticism scores were significantly associated with all QoL domains. Higher scores on neuroticism were significantly associated with poorer

physical health, psychological health, social relationships, and environment QoL. A high negative correlation was noted between neuroticism and psychological health QoL. By contrast, higher scores on extraversion, agreeableness, and conscientiousness dimensions were significantly associated with higher scores on physical health, psychological health, social relationships, and environments QoL. No significant relationships were found between the openness-to-experience dimension and physical health, psychological health and environment QoL. However, this dimension of openness-to-experience did have a modest, yet significant, association with the social relationships subscale of QoL.

○ Hypothesis 4. Associations between Young's Schemas and QoL:

Pearson zero-order correlations were calculated to assess the extent to which schemas (scored in accordance with Young's model) were related to QoL. These correlations are presented below in Table 7.

Table 7: Correlations between Schema and QoL domains

Schema	Physical QoL	Psychological QoL	Social relationships QoL	Environment QoL
Failure	-.295**	-.435 **	-.329**	-.347**
Control	-.352**	.553**	.407**	-.342**
Abandonment	-.296**	-.447**	-.347**	-.327**
Mistrust/Abuse	-.421**	-.511**	-.391**	-.384**
Emotional deprivation	-.130	-.365**	-.412**	-.217
Self sacrifice	-.234**	-.189	-.284**	-.181
Social alienation	-.270**	-.509**	-.438**	-.281**
Emotional Inhibition	-.211	-.406**	.406**	-.211
Dependency	-.303**	-.447**	-.374**	-.358**
Shame/ defectiveness	-.270**	-.424**	-.378**	-.265**
Vulnerability	-.477**	-.580**	-.468**	-.494**

\*\* Correlations significant at  $p \leq .01$

As hypothesised, some of the schemas were significantly associated with all QoL domains. Eleven of the fourteen schemas analysed (“subjugation of needs” schema was not investigated due to poor reliability, see above) were significantly associated with QoL. Higher scores on all of the schemas were significantly associated with lower scores on all 4 subscales of QoL, with the exception of the “insufficient self control” schema which was positively associated with psychological health and social relationships QoL, and “emotional inhibition” schema which was positively associated with social relationships QoL. All of the correlations were highly significant ( $p \leq .01$ ), with the exception of the correlations between “emotional deprivation” schema and environment QoL, “self sacrifice” schema and environment QoL, and “emotional inhibition” schema and physical and environment QoL. The large number of correlations between the schemas and the QoL domains indicates that only p-values smaller than .01 should be considered significant to reduce the risk of Type I error. No significant relationship was noted between “emotional deprivation” schema and physical health QoL, and no relationships were noted between “enmeshment”, “entitlement” and “unrelenting standards” schemas and any of the QoL sub-scales. The implications of these results will be considered in the discussion section of this paper.

○ Hypothesis 5: Predicting Quality of Life from Personality traits:

In order to investigate the predictive value of personality traits for QoL, hierarchical regression analyses were conducted entering neuroticism in the first block, neuroticism and extraversion in the second block, with openness-to-experience added in the third block, agreeableness in the fourth block, and conscientiousness in the fifth block, and physical quality of life as the dependent variable (see Table 8). As

hypothesised, neuroticism was found to be a significant predictor of physical quality of life, [ $F(1,136)=85, p <.001$ ]. Neuroticism accounted for 34% of the variability in physical QoL (adjusted R square = .34). After controlling for neuroticism none of the remaining four personality traits were found to be significant predictors of physical QoL (see Table 8). The overall regression was significant, however, the  $\beta$  values were not significant, suggesting that extraversion, openness-to-experience, agreeableness, and conscientiousness did not account for any additional variability in physical QoL (adjusted R square = 33% in the final block). Thus neuroticism was found to affect physical QoL independently of extraversion, openness-to-experience, agreeableness, and conscientiousness.

Table 8: Hierarchical regression analysis for NEO personality traits predicting physical QoL

Variable	$\beta$	<i>t</i> value	<i>p</i>	$\Delta R^2$	F	Sig <i>F</i>
<b>Step 1</b>						
Neuroticism	-.587	-.921	<.001	.534	85	<.001
<b>Step 2</b>						
Neuroticism	-.5.49	-6.91	<.001			
Extraversion	.064	.805	.422	.003	42.7	<.001
<b>Step 3</b>						
Neuroticism	-.546	-6.85	<.001			
Extraversion	.071	.871	.385			
Openness-to-Experience	-.028	-.432	.666		28.4	<.001
<b>Step4</b>						
Neuroticism	-.526	-6.35	<.001			
Extraversion	.066	.817	.415			
Openness-to-Experience	-.035	-5.36	.593			
agreeableness	.894	.894	.373		21.5	<.001
<b>Step5</b>						
Neuroticism	-.532	-.608	<.001			
Extraversion	0.68	0.832	.406			
Openness-to-Experience	-.037	-.557	.579			
Agreeableness	.066	.915	.362			
Conscientiousness	-.016	-2.10	.834		17.1	<.001

A second analysis was conducted following the same procedure but with psychological QoL as the dependent variable (see Table 9). In the first step, neuroticism prevailed as a significant predictor [ $F(1,136)=185.6, p < .001$ ], accounting for 53% of the variability in psychological QoL. In the second step, extraversion was also found to be a significant predictor of psychological QoL after controlling for neuroticism [ $F(2,136)=107.9, p < .001$ ]. The model with both neuroticism and extraversion accounted for 57% (adjusted R square = .57) of the variability in psychological QoL, suggesting that extraversion has a significant effect on psychological QoL beyond that which is predicted by neuroticism. In the subsequent steps of the regression, neuroticism and extraversion remained significant predictors of psychological QoL; however, the remaining personality traits (openness-to-experience, agreeableness, and conscientiousness) were not found to be significant predictors of psychological QoL. As the table demonstrates, the overall regression was significant however, the  $\beta$  were not significant suggesting that openness-to-experience, agreeableness, and conscientiousness do not have independent effects on psychological QoL.



Table 9: Hierarchical regression analysis for NEO personality traits predicting psychological QoL

Variable	$\beta$	<i>t</i> value	p	$\Delta R^2$	F	Sig <i>F</i>
Step 1						
Neuroticism	-.731	-.13.6	<.001	.534	185.6	<.001
Step 2						
Neuroticism	-.5.84	-9.1	<.001			
Extraversion	.246	.3.83	<.001	.039	107.9	<.001
Step 3						
Neuroticism	-.585	-6.85	<.001			
Extraversion	.244	.871	.385			
Openness-to-Experience	.007	-.432	.900		71.5	<.001
Step4						
Neuroticism	-.593	-8.82	<.001			
Extraversion	.246	3.73	.415			
Openness-to-Experience	-.010	.180	.593			
agreeableness	-.026	.894	-.458		53.4	<.001
Step5						
Neuroticism	-.568	-8.03	<.001			
Extraversion	.238	3.59	<.001			
Openness-to-Experience	.017	.324	.746			
Agreeableness	-0.43	-.739	.461			
Conscientiousness	.071	1.13	.262		43.1	<.001

Further regression analyses were conducted including CD4 counts and income to determine whether personality was significantly predictive of QoL above and beyond physical health (as indicated by CD4 counts), and SES (as indicated by income). After controlling for CD4 and income, neuroticism and extraversion prevailed as the only predictive factors of psychological QoL [ $F(7, 90) = 18, p < .001$ ]. Adding the personality traits increased the proportion of variance in psychological QoL from 5.8% to 55%. The same analysis was conducted with physical QoL as the dependent variable. CD4 levels and income were, again, not found to be predictive of physical QoL. Neuroticism was found to be predictive of physical QoL after controlling for income and CD4 [ $F(7,90)=6.59, p < .001$ ], with the variability in physical QoL accounted for rising from 9% to 29% when the personality traits were added.

- Hypothesis 6: Cognitive schemas mediating the relationship between personality and QoL

This hypothesis was not tested because the Young's Schema Questionnaire was found to have inadequate psychometric qualities in this study (see factor analysis in beginning of results section)

- **Discussion**

This study set out to examine the relationship between personality traits, quality of life, and cognitive schemas in HIV positive gay men. It was argued that a better understanding of the impact of personality on QoL might be achieved by an examination of the cognitive schemas associated with the personality traits. Higher levels of maladaptive personality traits and lower levels of QoL were expected in HIV positive gay men compared with HIV negative gay men. It was further hypothesised that higher neuroticism and lower extraversion will be associated with lower QoL independently of indicators of physical health and SES. Schemas were hypothesised to mediate the relationship between personality traits and QoL. Specifically, early schemas pertaining to Young's (2003) early developmental domains of "disconnection and rejection" and "impaired autonomy and performance" will be associated with neuroticism and extraversion and predictive of QoL.

The HIV negative comparison group reported superior quality of life to the HIV positive group as hypothesised. The HIV positive group had significantly lower scores on all four quality of life domains measured, including physical and psychological QoL, social relationships, and environment. The comparison HIV negative group also differed from the HIV positive group in terms of personality traits. Significantly higher levels of neuroticism were found in the HIV positive group compared to the HIV negative group. As hypothesised, the HIV positive group were found to have lower levels of extraversion compared to the HIV negative group. No significant differences on the other personality traits, namely, openness-to-

experience, agreeableness, and conscientiousness were found. Exploration of the effects of neuroticism and extraversion in the two groups indicated that the personality traits operated in the same way in both groups. There was no interaction of personality traits and group suggesting that neuroticism and extraversion affected the HIV positive and negative participants in the same way.

As expected, an association between quality of life and personality traits, in the HIV positive group, was found. Significant correlations between neuroticism and all QoL domains were found, with a particularly strong negative correlation between neuroticism and psychological health indicating that higher levels of neuroticism were associated with lower QoL. Higher neuroticism was also associated with poorer reported physical health, social relationships, and environment QoL. Similar findings have been reported by Burgess *et al.* (2000) and by Penedo *et al.* (2003) who also looked at personality and QoL in people infected with HIV. The study also examined the impact of adaptive personality traits, such as agreeableness and conscientiousness of QoL.

Costa and McCrae (1980) have argued that agreeableness and conscientiousness may be related to subjective well-being (or psychological QoL). The results of this study demonstrated that high scores on extraversion, agreeableness, and openness-to-experience, considered to be adaptive personality traits, were associated with higher scores on physical health, psychological health, social relationships, and environment QoL. The positive association between adaptive personality traits such as extraversion and QoL is likely to reflect an outward orientation to seeking help and support. People who are extravert may be more likely to seek and make use of

support by others. This in turn may buffer stress and isolation. Similarly, people who are conscientious may be more able to manage their medication regimens that would result in better health, and therefore improved QoL. Conscientiousness may also be associated with a greater sense of mastery and therefore better mood and perceived QoL. In terms of the effect of less adaptive personality traits, research suggests that the effect of neuroticism on quality of life is complex and operates on several levels. It has been demonstrated that individuals found to have personality characterised by high levels of neuroticism tend to express attitudes and behaviours associated with risk behaviours and poor health habits (e.g. Ball *et al.*, 1997). It therefore follows that people who have a neurotic predisposition may be more vulnerable to becoming infected, becoming depressed and anxious, and also more likely to engage in behaviours associated with poorer health, all of which in turn compromise a person's health, their ability to cope with their illness, and their sense of well-being.

This study hypothesised that personality traits would predict quality of life. Neuroticism was found to be a significant predictor of physical QoL, accounting for 34% of the variance. After controlling for neuroticism none of the other personality dimensions prevailed as significant predictors of physical QoL. Neuroticism was also found to be a significant predictor of psychological QoL accounting for 53% of the variance. Extraversion was also found to be a significant predictor after controlling for neuroticism (adjusted R square increasing to 57%). Moreover, these effects were found to be significant after controlling for CD4 counts and SES, which were not found to be predictive of QoL. This suggests that physical indicators of health (such as CD4 count) may not be effective predictors of QoL. In turn this fits with previous findings demonstrating that the perception of health may be more significant to QoL

than physical indicators of health (e.g. Bing *et al.*, 2000; Burgess *et al.*, 2000). This underscores the importance of considering psychological processes when examining QoL. This has implications for the manner in which QoL is defined and measured in research. As discussed in the introduction section, research into QoL is hampered by an absence of a universally accepted definition of quality of life. Studies that do not measure psychological factors may fail to assess QoL effectively.

Exploration of the relationship between Young's cognitive schemas and QoL yielded significant correlations between eleven of the fourteen schemas and QoL. Higher scores on schemas were associated with poorer QoL, with the exception of "insufficient self control" schema that was positively associated with psychological health and social relationships, and "emotional inhibition" schema that was positively associated with social relationships. No relationships were found between "emotional deprivation" and physical QoL, "enmeshment", "entitlement", and "unrelenting standards" and any of the QoL domains. Eight of the eleven schemas that correlated with QoL reflected schemas associated with Young's domains of "abandonment/ instability" and "impaired autonomy and performance", the earliest and most significant domains, hypothesised, in this study, to be related to neuroticism. Hypothesis 6, which predicted that schemas would mediate the relationship between personality and QoL, was not tested in this study. This was because of unsuccessful attempts to factor analyse the schema questionnaire.

The problematic structure of the Schema Questionnaire meant that it was not possible to analyse the predictive value of schemas. Conducting multiple regression analyses using all of the schemas would have meant elevated Type I error.

Nevertheless, the correlations reported between the schemas and personality traits do suggest that schemas may be useful in conceptualising difficulties associated with certain personality traits. Examination of the resulting factors and their items in the factor analysis indicated that the Schema Questionnaire may be helpful measure of emotional dysregulation and negative beliefs, rather than specific cognitive schemas. The Schema Questionnaire may be helpful within clinical settings. However, the results reported here query the usefulness of the Schema Questionnaire within research settings as a broad indicator of the scope of negative beliefs that an individual holds. In the absence of other clinically oriented measures, Young's Schema Questionnaire was the questionnaire of choice for the purposes of this study.

This study was among the few studies to have examined the relationships between QoL and personality in HIV positive gay men. It aimed to overcome some of the problems that have limited previous studies by addressing the following issues. Uniquely, this study recruited a comparison group in order to explore whether the relationship between personality and QoL, demonstrated by previous studies, are identifiable to HIV positive individuals, or rather reflective of trends among gay men. The results suggested that QoL varied across the HIV positive and HIV negative groups. However, no interaction was found between group and personality suggesting that personality dynamics may have analogous effect across HIV positive and HIV negative gay men. This suggests that although personality processes are comparable across groups, HIV positive gay men may be distinguishable from their HIV negative counterparts in terms of levels of neuroticism and extraversion. Due to the small size of the comparison group, it was not able to conduct regression analyses to determine how and to what extent HIV status and personality predict QoL

independently of each other. The preliminary findings suggest that comparison groups may hold the key to a clearer understanding of personality and QoL relationships within HIV positive populations.

A number of issues need to be considered with regards to the comparison group recruited for this study. The HIV negative group were recruited through an HIV-testing service. It is plausible that gay men who attend testing facilities may not be representative of all gay men living in London. It can be argued that individuals coming for HIV- testing reflect an “at risk” group. On the other hand, it may also be argued that these people came for testing because they are health-conscious. It is likely that findings presented here may not be as applicable to all gay men who live in London, and future research need to recruit larger and more varied sample of gay men for comparison purposes. The HIV negative group were all recruited immediately after they received a negative diagnosis, and the questionnaire was sent to participants a week later. This was done to ensure that all men recruited for the HIV negative group were certain of their status at the time of questionnaire completion. However, it is worth noting that some of the men may have needed a repeat test (because they presented for a test less than three months since their last risk), therefore, it is possible that some of these men may have subsequently tested positive. The comparison group used in this study represents an attempt to provide some context for the interpretation of personality and QoL results. Future studies should aim to recruit larger, and more varied sample of HIV negative participants. Similarly, it may also be useful to compare associations between personality and QoL in PWHIV to people living other with chronic illnesses



This study aimed to systematically explore quality of life. It has become increasingly accepted that QoL spans more than physical or health-related quality of life. The WHOQOL measure used here assessed four domains of QoL, which allowed closer examination and comparison of the impact of HIV on the various aspects of QoL. This measure has been validated for HIV populations, and also across cultures. However, like other self-report measure of QoL, the WHOQOL-BREF is not without its limitations. All self-report measures are open to certain biases, which may be only partly reduced by anonymity of respondents. Furthermore, self-reported measures reduce complexity by asking participants to select their responses from a limited number of possibilities. Research using self-report QoL measures has indicated that QoL is a subjective and complex phenomenon. It can be argued that self-reported measures, such as the WHOQOL-BREF, despite their efforts to incorporate both objective and subjective indicators, may not be able to reflect the entire complexity of the QoL or well-being construct.

Qualitative research where participants are invited to talk about their QoL and what they view as central to this, may give rise to different results to those reported in this study. It is possible that some people who complete the questionnaires view themselves as having good QoL, despite scoring low on QoL measures. Such people may have other factors in their lives, which affect their rating of QoL, which are not captured by the measure. Employing self-report questionnaires reflects a “trade off” between qualitative and quantitative research, and questionnaires are often used to maximise data collection under time and resource limitations.

A number of psychosocial factors need to be considered with regards to the generalisability of the findings reported here. The study reported here represents a narrow focus on HIV positive gay men living in London. Experiences of HIV positive gay men are likely to vary from those of other populations living with HIV. For example, the life of a gay man living in London is likely to differ greatly from that of a heterosexual woman living with HIV in Africa. Issues such as access to medical care, religion, social status, are a few amongst multiple factors that can differentiate the lives of African women with HIV from the participants in the current study. It can be argued that personality factors may be less relevant to people living with HIV in Africa, or to other heterosexual or underprivileged populations. It is worth noting, however, that some studies of psychosocial factors indicate some commonalities across populations. For example, studies investigating the effect of life events and specifically bereavement have demonstrated a faster trajectory to AIDS morbidity and mortality in both HIV positive gay men and African women. This suggests that some psychosocial factors may be relevant across HIV populations, whereas others may be of lesser explanatory power. Until findings such as those demonstrated here, are replicated with different populations, one should be cautious in generalising to other HIV infected populations. Given the prevalence of HIV disease in Africa, studies looking at QoL and related psychosocial factors, are warranted in such populations. Within Western societies, there remains a need to replicate such findings with heterosexual, female, and ethnically diverse populations.

The debate as to whether personality traits predate HIV infection and therefore whether personality predisposes vulnerable individuals to HIV through risky behaviour, or poor QoL, is only partially answered by this study. Neuroticism and

extraversion were found to independently predict QoL, however one cannot infer whether these traits are causal, or alternatively a result of HIV or poorer QoL. It is possible that higher neuroticism and lower extraversion occur as a result of HIV infection (see Costa & McCrae, 1994). It is known that HIV can affect the brain, and therefore it is possible that personality patterns observed in HIV positive people have been caused by cerebral atrophy or other central nervous system damage by HIV. Equally, it is also plausible that having poorer QoL renders people more vulnerable to becoming introverted, and therefore having poorer emotional adjustment. However, given the stability of personality traits, such as neuroticism, it seems more likely that personality traits predate infection and therefore, that HIV infection exaggerates maladaptive predispositions such as neuroticism.

Additional factors that may affect quality of life in HIV positive individuals, and were not measured in this study, need to be considered. The study looked at CD4 counts as proxy for disease progression, which has been used by previous investigations. However, research has demonstrated that QoL is affected by perception of health as well as by physical indicators of health (Bing *et al.*, 2000). It follows that perhaps a measure of symptoms, such as a symptoms checklist, could have supplemented the CD4 counts to provide a more elaborate picture of disease progression. This was not feasible within the framework of this study for the following reasons. The study relied on volunteers' good will for participation, and the number of items within the questionnaire was therefore kept to a minimum. More importantly, the same questionnaire pack was used for the HIV positive and negative participants, to eliminate exogenous influences, and therefore adding the symptom checklist was not feasible within this framework. Some information about generic

health and symptoms was covered by the WHOQOL measure. Future studies may benefit from exploring additional health indicators, particularly those which are specific to HIV infection.

Other methodological limitations of this study include the size of the comparison group, which precluded regression analyses with this group. The HIV positive group size was sufficiently large as indicated by early power analyses described in the method section of this paper. Future studies should indicate whether the differences between the HIV positive and negative group are primarily due to personality or HIV status. Similarly, the study employed correlation and regression analyses to explore the research questions. Specifically, a large number of correlations between personality and schemas are presented in the results section, which may be associated with elevations in Type I error. A stringent p-value, of  $p \leq .01$ , was adopted in an effort to minimise Type I error.

The broad aim of the study was to explore utility of clinical interventions with people who have certain personality traits that may affect their QoL. Although the study did not manage to explore the utility of schema-based therapy, the results of the study, especially the substantial impact of neuroticism on QoL, indicate some important inferences for therapy. Miller (1991) has studied the psychotherapeutic utility of the five-factor model of personality. He argues that a therapist, who wishes to plan treatment effectively, needs to assess a client's level of neuroticism in order to interpret and formulate the presenting problem. For example, an HIV positive individual, who presents with depressive and somatic complaints, who scores high on neuroticism, should be treated differently from an HIV positive individual scoring

low on neuroticism. In the latter case, the problem may be a reaction to a severe stressor of recent onset. In the former case, however, the depressive and somatic symptoms may interlock with long standing patterns of dysphoria and distress. With regards to QoL, it is likely that PWHIV with high neuroticism may continue to express difficulties and low QoL, which may be best addressed by work on their long standing and global responses. Miller's (1991) work demonstrates how the assessment of personality at the onset of therapy, can enhance the effectiveness of treatment. Better QoL for PWHIV who have high neurotic tendencies may be achieved by psychological work focusing on global, or generic difficulties, such as anxiety management, mood regulation and coping strategies. Whereas, a narrower focus may fail to produce long-term improvements. Given the stability of personality traits, objectives for therapy, need to be suitably realistic.

- Conclusion

This study provides further evidence to an increasingly growing body of research demonstrating a link between personality traits and quality of life. Neuroticism and extraversion were shown to be important predictors of QoL. Importantly, this study demonstrated that personality traits could have a positive, as well a negative, impact on QoL. The associations between schemas and QoL presented in this study further suggest that cognitive interventions may be appropriate in people whose personality renders them vulnerable to poorer QoL. However, the psychometric problems encountered with the Schema questionnaire indicate that alternative measures of core schemas, central to personality, may need to be considered. Alternatively the psychometric properties of the questionnaire may need to be addressed. Replication and further research is needed, both within HIV positive populations, and also within

other chronic illness populations. Although interventions that aim to change personality are likely to be unsuitable, interventions aimed at helping people understand the way in which their personality impacts on their responses to stress, emotional responses, and ability to make use of support and other resources may serve to increase QoL in an increasing population living with uncertainty, stress, and compromised health.

## References

- Antoni, M.H., Goldstein, D., Ironson, G., LaPerriere, A., Fletcher, M.A., & Schneiderman, N. (1995). Coping responses to HIV-1 serostatus notification predict concurrent and prospective immunologic status. *Clinical Psychology and Psychotherapy*, 2, 234-248.
- Antony, M.M., Bieling, P.J., Cox, B.J., Enns, M.W., & Swinson R.P. (1998). Psychometric properties of the 42-item and 21-item versions of the Depression Anxiety Stress Scales in clinical groups and a community sample. *Psychological Assessment*, 10, 176-181.
- Ball, S.A., Tennen, H., Poling, J.C., Kranzler, H.R., & Rounsaville, B.J. (1997). Personality, temperament, and character dimensions and the DSM-IV personality disorders in substance abusers. *Journal of Abnormal Psychology*, 106, 545-553.
- Beck, A.T. & Freeman. A. (1990). *Cognitive therapy of personality disorder*. New York: Guilford Press.
- Bing, E.G., Hays R.D., Jacobson L.P., Chen B., Gange S.J., Kass N.E., & Chmiel J.S. (2000) health-related quality of life among people with HIV disease: Results from the Multicentre AIDS Cohort Study. *Quality of Life Research*, 9, 55-63.

Burgess, A.P., Carretero, M., Elkington, A., Pasqual-Marsettin, E., Lobacaro, C., & Catalan J. (2000) The role of personality, coping style and social support in health related quality of life in HIV infection. *Quality of Life Research*, 9, 423-37.

Casey, P.R., & Tyrer, P.J., (1986) Personality, functioning and symptomatology. *Journal of Psychiatric Research*, 20, 363-374.

Cecero, J.J., Nelson, J.D., & Gillie, J.M.(2004). Tools and tenets of Schema Therapy: Toward the construct validity of the Early Maladaptive Schema Questionnaire-Research version (EMSQ-R). *Clinical Psychology and Psychotherapy*, 11, 344-3257.

Chesney, MA., Ickovics, J.R., Chambers, D.B., Gifford, A.L., Neidig, J., Zwickl., B., & Wu, A.W.(2000). Self-reported adherence to antiretroviral medications among participants in HIV clinical trials: the ACCTG Adherence Instruments. *AIDS Care*, 12, 255-266.

Costa, P. T., Jr., & McCrae, R. R.(1980). Influence of extraversion and neuroticism on subjective well-being: happy and unhappy people. *Journal of Personality and Social Psychology*, 38, 668-678.

Costa, P.T., Jr., & McCrae, R.R. (1990). Personality disorders and the five-factor model of personality. *Journal of Personality Disorders*, 4, 362-371.



Costa, P.T., Jr., & McCrae, R.R. (1992). *Revised NEO Personality Inventory (NEO-PI-R) and NEO Five-Factor Inventory (NEO-FFI). Professional Manual.* Odessa FL. Psychological Assessment Resources.

Costa, P.T. and McCrae (1994) Set like plaster? Evidence for the stability of adult personality. In T.F. Heatherton and J.L. Weinberger (Eds.) *Can Personality Change* (pp. 21-40). Washington DC, American Psychological Association.

Cronbach, L.J. (1951). Coefficient alpha and the internal structure of tests. *Psychometrika*, 16, 297-334.

D'Augelli, A. R. (1989) Lesbians' and gay men's experiences of discrimination and harassment in a university community. *American Journal of Community Psychology*, 17, 317-321.

DeNeve, K.M., & Cooper, H.(1998) The happy personality: a meta-analysis of 137 personality traits and subjective well-being. *Psychological Bulletin*, 124, 197-229.

Fahey, J.L., Taylor, J.M., Detels, R., Hofman, B., Melmed, R., Nishanian, P., & Giorgi, J. (1990) The prognostic value of cellular and serologic markers in infection with human immunodeficiency virus type-1. *New England Journal of Medicine*, 322, 166-72.

- Fang, C.T., Hsuing, P.C., Yu, C.F., Chen, M.Y., & Wang, J.D. (2002). Validation of the World Health Organisation Quality of Life instrument in patients with HIV infection. *Quality of Life Research, 11*, 753-762.
- Friedland, J., Renwick, R., & McColl, M. (1996). Coping and social support as determinants of quality of life in HIV/AIDS. *AIDS Care, 8*, 15-31.
- Friedman, H.S. (2000). Long-term relations to personality and health: Dynamisms, Mechanisms, Tropisms. *Journal of Personality, 68*, 1089-1107.
- Gallo, R.C. (1988) "AIDS in 1988". *Scientific American* (10/88), 259, 41.
- Gorusch, R. L. (1983). *Factor analysis*. Hillsdale, NJ: Erlbaum.
- Hays, R.D., Cunningham, W.E., Sherbourne C.D., Wilson I.B., Wu, A.W., Cleary P.D., McCaffrey D.F., Fleishman J.A., Crystal S., Collins, R., Eggen, F., Shapiro, M.F., & Bozzette, S.A. (2000). Health related quality of life in patients with Human Immunodeficiency Virus Infection in the United States: Results from the HIV and Cost Services Utilization Study. *The American Journal of Medicine, 108*, 714-722.
- Heckman, T.G., (2003) The Chronic Illness Quality of Life (CIQOL) Model: Explaining life satisfaction in people living with HIV disease. *Health Psychology, 22*, 140-147.
- Herek, G.M., (1999) AIDS and stigma, *American Behavioural Scientist, 42*, 1103-1116.

Highleyman L. Adverse Effects Associated with Antiretroviral Therapy. BETA, Spring, 2000. Retrieved March, 10, 2003, from the *World Wide Web*, <http://hiv.net/link.php?id=18>

Hsuing, P.C., Fang, C.T., Chang, Y.Y., Chen, M.Y., & Wang, J.D. (2005). Comparison of the WHOQOL-BREF and the SF-36 in patients with HIV infection. *Quality of Life Research*, 14, 141-150.

Hutton, H.E., Glenn, J., & Treisman, G.J., (2001). Understanding the role of personality in HIV risk behaviors: Implications for prevention and treatment. Retrieved July 7, 2004, from the *World Wide Web*, [http://www.hopkins-aids.edu/publications/report/nov01\\_2.html](http://www.hopkins-aids.edu/publications/report/nov01_2.html).

Johnson, J.G., Williams, J.B.W., Rabkin, J.G., Goetz, R.R., & Remien, R.H. (1995) Axis I Psychiatric symptoms associated with HIV infection and personality disorders, *American Journal of Psychiatry*, 152, 551-4.

Kemeny, M.E., & Dean, L. (1995). Effects of AIDS-related bereavement on HIV progression among New York City gay men. *AIDS Education and Prevention*, 7, 36-47.

Kemeny, M.E., Weiner, H., Duran, R., Taylor, S.E., Visscher, B., & Fahey, J.L. (1995). Immune system changes after the death of a partner in HIV-positive gay men. *Psychosomatic Medicine*, 57, 547-554.

Kline, P. (1993). *The handbook of psychological testing*. London: Routledge.

Knutson, B., Wolkowitz, O.M., Cole, S.W., Cha, T., Moore, E.A., Johnson, R.C., Terpstra, J., Turner, R.A., & Reus, V. (1998). Selective alteration of personality and social behaviour by serotonergic intervention. *American journal of Psychiatry*, *155*, 373-379.

Krueger, R.F., Caspi, A., & Moffitt, T.E. (2000). Epidemiological personology: the unifying role of personality in population-based research on problem behaviours. *Journal of Personality*, *68*, 967-998.

Lancet (Editorial), (1995) Quality of life and clinical trials. *Lancet*, *346*, 1-2.

Lerner, D.J., & Levine, S. (1994) Health related quality of life: Origins, gaps and directions. In: Albrecht, G.L, and Fitzpatrick, R. (Eds) (1994) *Advances In Medical Sociology: Quality of Life in Health Care* (pp.41-62). Greenwich, CT: JAI Press.

Leserman, J., Jackson, E.D., Petitto, J.M., Golden, R.N., Silva, S.G., Perkins, D.O., Cai, J., Folds, J.D., & Evans, D.L. (1999). Progression to AIDS: The effects of stress, depressive symptoms, and social support. *Psychosomatic Medicine*, *61*, 397-406.

Lovibond, S.H., & Lovibond, P.F., (1995) *Manuals for the Depression Anxiety Stress Scales*. Sydney: Psychology Foundation

McDowell, I., & Newll, C. (1996) *Measuring Health: A guide to Rating Scales and Questionnaires*. (2<sup>nd</sup> edition). New York: Oxford University Press.

- Miller, T.R. (1991). The psychotherapeutic utility of the five-factor model of personality: a clinician's experience. *Journal of Personality Assessment*, 57, 415-433.
- Mor, V., and Guadagnoli, E. (1988). Quality of life measurement: A psychometric tower of Babel. *Journal of Clinical Epidemiology*, 41, 1043-1053.
- Penedo, F.J., Gonzales, J.S., Dahn, J.R., Antoni, M., Malow, R., Costa, P. and Schneiderman, N., (2003) Personality, Quality of Life, and HAART adherence among men and women living with HIV/AIDS. *Journal of Psychosomatic Research*, 54, 271-278.
- Perkins, D.O., Davidson, E.J., Leserman, J., Liao, D., Evans, D.L., (1994) Personality disorders in patients infected with HIV: a controlled study with implications for clinical care. *American Journal of Psychiatry*, 150, 298-9.
- Revicki D, Swartz C. (1997) Quality of life outcomes of saquinavir, zalcitabine and combination saquinavir-zalcitabine therapy for advanced HIV-infection. *Conference for Retroviruses Opportunistic Infections* (abstract no 266). Retrieved March 8, 2004, from the *World Wide Web*, <http://www.clinicaltrials.gov/ct/show/NCT00002333?order=2>.
- Scandell, D.J. (2000). Development and initial validation of validity scales for the NEO-Five Factor Inventory. *Personality and Individual Differences*, 29, 1153-1162.

Skevington, S.M., & O'Connell, K.A. (2003). Measuring quality of life in HIV and AIDS: A review of the recent literature. *Psychology & Health, 18*,331-350.

Smith, K.W., Avis, N.E., and Assmann, S.A. (1999) Distinguishing between quality of life and health status in quality of life research: A meta-analysis. *Quality of Life Research, 8*, 447-459.

Spitzer, W. (1987). Advances in health assessment conference discussion panel. *Journal of Chronic Diseases, 40*, 187-189.

Stevens, J. P. (1986). *Applied multivariate statistics for the social sciences*. Hillsdale, NJ: Erlbaum.

UNAIDS, (2004) *UNAIDS 2004 Report on the global AIDS epidemic*. Retrieved from the World Wide Web, 18<sup>th</sup> December 2004, <http://www.unaids.org/bangkok2004/report.html>.

Ware, J.E. & Sherbourne, C.D. (1992). The MOS 36-Item short-form health survey (SF-36). *Medical Care, 30*, 473-483.

Welburn, K., Coristine, M., Dagg, P., Pontefact, A., & Jordan, S. (2002). The Schema Questionnaire- Short Form: Factor analysis and relationship between schemas and symptoms. *Cognitive Therapy and Research, 26*, 519-530.

Weinfurt, K.P., Willke, R.J., Glick, H.A., Freimuth, W.W., & Schulman, K.A.

(2000) Relationship between CD4 count, viral burden, and quality of life over time in HIV-1-infected patients. *Medical Care*, 38, 404-410.

WHOQOL Group (1998a). The World Health Organisation Quality of Life

Assessment (WHOQOL): Development and general psychometric properties.

*Social Science and Medicine*, 46, 1569-1585.

WHOQOL Group (1998b). Development of the World Health Organisation

WHOQOL-BREF Quality of Life Assessment. *Psychological Medicine*, 28,

551-558

WHOQOL-HIV Group (2003) Preliminary development of the World Health

Organisation's Quality of Life HIV instrument (WHOQOL-HIV) analysis of

pilot version. *Social Science & Medicine*, 57, 1259-75.

Wrosch, C., & Scheier, M.F. (2003). Personality and quality of life: The importance

of optimism and goal adjustment. *Quality of Life Research*, 12, 59-72.

Young, J.E., (1990) *Cognitive therapy for personality disorders: a schema focused*

*approach*. Sarasota, FL, Professional Resource Press.

Young, J.E. (1994) *Young Schema Questionnaire Short Form*. New York: Cognitive

Therapy Centre.

Young, J.E. & Brown, G. (1994). Young Schema Questionnaire. In J.E. Young (Ed.), *Cognitive therapy for personality disorders: A schema-focused approach*. (Rev. ed., pp. 63-76). Sarasota, FL: Professional Resource Exchange.

Young, J.E. (1998). Young Schema Questionnaire Short Form (1<sup>st</sup> ed.). New York: Cognitive Therapy Centre.

Young J.E., Klosko, J.S., & Weishar, M.E. (2003). *Schema Therapy: A practitioner's Guide*. New York , The Guilford Press.

Zander, K., Jager, H., Palitzsch, M., Poppinger, J.V., Steinbuchel, N., & Bullinger, M. (1993). *Health- related quality of life (HRQL) in HIV disease: Influences of symptom load, functioning, mood and coping styles*. IX International Conference in AIDS, Berlin, June 1993. Cited in Burgess *et al.* (2000) op cit.



**Part III:**  
**Critical Appraisal**

## ▪ 1. Introduction

In this paper I will reflect on the research process. The first section discusses how the research idea developed, starting with a brief overview of HIV, the implications of this type of research, and the objectives of the research. Clinical experiences of working with this population will also be discussed. I will then expand on the strengths and weaknesses of the study, considered in the discussion section of the empirical paper. The clinical and scientific implications of the study will then be considered, followed by a reflection of how the research has affected my understanding of personality and quality of life in HIV. Finally, the lessons learned through the research process will be discussed.

## ▪ 2. How this research project developed

HIV continues to represent a challenging condition for both sufferers and healthcare professionals, in spite of waning interest in HIV prevention. Enormous developments have been made since HIV was first recognised; pharmacological treatments have changed the parameters of HIV. Increasingly people with HIV live longer, making quality of life issues more pertinent. Having worked with HIV infected individuals I have been struck by the way these people cope and manage their condition in very different ways, drawing on numerous different resources. Whereas some individuals infected with HIV seem to adapt to their diagnosis by adopting a healthy lifestyle, or looking at positive changes to their lives since the infection, others seem to remain highly distressed and seem to struggle daily with their lives. Although it seems plausible that external influences such as time, social factors, and life circumstances, change the way people respond to their HIV positive status, individual differences in the way individuals react to having HIV seem to implicate deep-rooted personality characteristics. The relationship between personality and other health conditions

have been well documented. Within the field of HIV, personality factors have been studied vis-à-vis risk behaviours, and concurrent psychiatric conditions. For example, research has demonstrated a higher incidence of personality disorders among HIV positive individuals, compared with the general population. The idea for this particular research project grew out my reading of paper concerned with personality and HIV, and more recent studies that have linked personality and QoL in HIV positive individuals.

At an early stage of the research I considered the implications of examining personality in an HIV positive population. One of the considerations that helped me focus the research subject was what the utility of the findings might be, and also the scientific, theoretical, and political issues. Specifically, I was aware that some papers have presented data on higher rates of personality disorders in HIV positive gay men (e.g. Jacobsberg, Frances & Perry, 1995), and that this is politically laden. I was concerned that measuring personality in gay men might lead to the suggestion that gay men, or HIV positive men, are personality disordered. It was only in December 1974 that the American Psychiatric Association (APA, 1974) removed homosexuality from its list of psychiatric diagnoses. I wanted to avoid designing a study that might reinforce old prejudices. The decision to examine normal personality traits seemed more appropriate. The goal of this study was never to *highlight rates of psychiatric disorders in HIV or gay population*. Rather, it was recognised that a better understanding of the specific personality traits associated with quality of life was a more useful objective. The focus on specific personality traits, rather than psychiatric disorders, fits well with psychological models of personality along dimensions (e.g. Livesley, 2001) rather than dichotomies. In

developing this project I became more aware of how measures of personality traits may reflect amplification of traits by circumstances introduced by HIV infection.

I was fortunate to have the opportunity to work with an HIV positive population for a year whilst I was conducting my research. This was an invaluable opportunity, which has shaped my understanding of working with an HIV positive population, but more importantly, has allowed me to experience what it is like to work with HIV positive individuals whose personalities may impact on their QoL. It is a humbling experience to watch the way people can learn to accept and manage a chronic condition, such as HIV, which has huge social, as well as medical, implications. Health psychology literature has discussed the process of adjustment to a diagnosis, however, HIV differs from other diagnoses, such as diabetes or cancer, in the way it is understood and viewed by society. People infected with HIV often feel that they are held responsible for their infection, and the fact that HIV is most commonly sexually transmitted further contributes to the blaming and negative attitudes people with HIV can encounter. The way people cope with an HIV positive diagnosis, their ability to share their status with others and cope with sequelae of disclosure, such as rejection, is shaped by their experiences, their beliefs, and personalities. It is likely that people who have a neurotic predisposition will become very distressed about their diagnosis, and may also anticipate negative events to follow. In turn, this will impact on their emotional and behavioural responses to the diagnosis, and will also impact on the way they manage their condition, and hence their quality of life.

Within the HIV psychology service I worked in, referrals for depression and anxiety were very common. Individuals referred for these reasons would often present as highly distressed, and rather hopeless. Although this may sound no different to

depressed individuals encountered within general adult mental health services, there are important differences. Principally, HIV infection is incurable; hence any clinical work needs to formulate the mental health condition within the framework of this long-term, life-threatening, and stigmatising condition. Individuals with certain personality traits, such as neuroticism, may be less able to deal with the stresses introduced by their positive status, which is unchangeable. Similarly, extravert individuals may have more positive expectations of other people, and may be more able to seek and make use of support. I have worked with people whose history of distress suggests a neurotic predisposition, and they often describe low mood, hopelessness, and distrust of others. They often express an expectation of being rejected and hurt, and feel highly distressed when their prophecies come true. In turn, this makes daily life difficult to cope with, and carries important implications for interpersonal relationships, which further impacts on levels of distress, isolation, and their beliefs.

Working with HIV infected individuals, who also have maladaptive personality styles, can be a challenging process, characterised by fluctuating moods and variable attitudes towards therapy. I have experienced highly distressed clients who vary from suicidal to manic, and from keen to dismissive. However, always there is something about the way these clients present, which provokes a therapeutic concern, and empathy for the way their personalities seem fundamental to the issues they present with. The challenge, in my experience, is coping with these clients' changeability, keeping focused on the underlying causes, not becoming distracted by the numerous issues they may present with, and most importantly helping them recognise the way their personalities can determine their experiences, mood, and relationships. Within such therapeutic interactions, it is easy to feel as overwhelmed as these clients, and

there remains a need for therapies that can guide psychologists working with people who present with both mental health and medical needs.

▪ **3. Strengths and weaknesses of the research project**

In developing this project I noted that all previous research on quality of life and personality in HIV has failed to include a comparison group. This, I reasoned, means that one cannot know whether findings reported are unique to HIV positive people. This study recruited a comparison group, which provided a context in which the results, regarding personality and quality of life of HIV positive gay men, could be interpreted.

The results of the current study suggest that personality traits are significant to the quality of life of HIV positive gay men. Higher levels of neuroticism and lower levels of extraversion were found amongst the HIV positive group compared with the HIV negative group. There were no interaction effects between group and personality traits suggesting that the personality traits operated on QoL in the same way in the two groups. The comparison group was not sufficiently large to run regression analyses to determine whether the effects of neuroticism and extraversion on quality of life are equal in the HIV positive and HIV negative groups. However, it may have been the case that the effects of these personality traits on QoL were more pronounced in the HIV positive group. The fact that personality traits significantly predicted QoL, whereas physical indicators of ill health did not, suggests that personality traits are more important determinants of QoL than stage of HIV disease progression. This finding supports result demonstrated by Burgess *et al.* (2000), and stresses the significance of personality traits. Finding that personality traits, and specifically neuroticism, predict QoL in HIV positive gay men, independently of

health status, suggests that medical care may not be sufficient in increasing their perception of QoL. An individual infected with HIV, who demonstrates neurotic tendencies, may continue to perceive poorer QoL regardless of test results, such as CD4 counts, and treatments offered by medical teams. Crucially, a person's perception of their health status can override objective indicators of health and treatment options. The mechanisms by which this may occur will be further discussed later in the "clinical and scientific section" of this paper.

This study aimed to build on previous research by adopting a broad view of both personality and QoL. The effects of all of the "Big 5" personality traits on QoL were investigated. This was in view of recent findings demonstrating that personality traits can have adaptive, as well as deteriorative, impact on QoL. This study also adopted a systematic view of QoL, selecting the WHOQOL measure that encompasses four domains of QoL. Many previous studies have focused either on health-related or psychological QoL, or have used measures that have not been designed or validated for HIV populations or other cultural populations. Results indicated that neuroticism and extraversion have different effects on physical and psychological QoL. Neuroticism was found to be predictive of physical and psychological QoL, however, it had a larger effect on psychological QoL. Extraversion, on the other hand, was only found to be predictive of psychological QoL, and although it did predict psychological QoL independently of neuroticism, it had a smaller effect. The other personality traits were not found to be predictive of QoL, although it is possible that these personality traits have smaller effect sizes, and that there was not sufficient power in this study to uncover these effects.

Finally, this study sought to explore if specific schemas were associated with poor quality of life in HIV positive individuals, as this would have implications for cognitive therapy with this population. As discussed in the literature review, personality traits are fairly stable across the life span, and maladaptive personality traits such as neuroticism have a complex impact on individuals' lives. Personality traits operate on many levels, including behavioural, emotional, and interpersonal levels. People with personality disorders can be inflexible and difficult to engage in therapy. Given that HIV is a chronic medical condition associated with compromised health, uncertain life span, stress, and specific demands such as regular healthcare appointments and complex medication regimens, understanding the intricate relationship between personality and QoL could help to provide better services for HIV positive individuals. Engaging people with HIV in healthcare services is imperative, not just for their well-being, but potentially also for the protection of others from infection. Thus far, studies have been successful at identifying higher rates of maladaptive personality traits associated with QoL and ill health. However, although informative on a theoretical level, these findings not provide indication of what can be done to address such issues in people living with HIV.

The merits of schema therapy were examined in this thesis for several reasons. First, schema therapy has been designed to target core cognitions, which affect the way people, interpret events, respond, behave and relate to others. Secondly, schema therapy is a branch of cognitive therapy that has been used extensively in the domain of personality change. Schema therapy also lends itself to research in that the questionnaire can provide insight into early maladaptive experiences and schemas, without a clinical interview. Identification of core schemas associated with personality traits and QoL, could have allowed a deeper understanding of the



principal issues affecting people with HIV. Neuroticism is a broad construct, and it was hypothesised that schemas may help to elucidate what it is about neuroticism that has deteriorative impact on QoL.

Unfortunately, problems encountered with the schema questionnaire meant that I was unable to identify the specific schemas associated with neuroticism and extraversion and QoL. However, the findings did seem to indicate that there were significant associations between schemas and personality traits, and schemas and QoL. Moreover, the results of the factor analysis presented an interesting phenomenon of research, namely unexpected findings, and the significance of such findings. Admittedly, some disappointment or frustration can occur when a measure fails to perform as expected. However, in this case, the problems encountered with the Schema Questionnaire, provided a valuable lesson about the unpredictable nature of research, limitations of measures, and the scientific and theoretical implications such findings raise. For example, one factor analysis of the Schema Questionnaire I carried out (see empirical paper, pp. 87-92) suggests that most items of this questionnaire measure emotional dysregulation, or psychological distress, rather than core schemas. It may be hypothesised that the majority of items in the Schema Questionnaire are reflecting neuroticism, rather than a measure of core schemas. This has further implications for the utility of the Schema Questionnaire within the research field. It is worth noting that the Schema Questionnaire was developed with reference to clinical experience, rather than research driven. Research papers reviewed have supported the structure presented by Young (e.g. Welburn, Coristine, Dagg, Pontefact, & Jordan, 2002), however this study did not replicate these findings.

On reflection, the choice of the Schema Questionnaire presented some difficulties from the onset. Mixed findings regarding the reliability and validity of the Schema Questionnaire have been reported. However, this measure is rather unique in its exploring core schemas in a self-report questionnaire. From a clinical and theoretical stance schema therapy is also an interesting approach to conceptualising and understanding cognitions, and guiding clinical work. With these issues in mind the Schema Questionnaire seemed to be an appropriate choice of measure for the purposes of this study.

Several limitations need to be considered with regard to the current research. First, the study adopted a cross-sectional design focussing on gay men. The samples comprised of largely White and well-educated men, which limits the generalisability of the findings to other HIV populations. Nevertheless, previous studies have found complementary findings with other populations (Penedo *et al.*, 2003), which suggest that the findings may be comparable across HIV positive populations. Moreover, the decision to adopt a cross-sectional design needed be weighed against the impact of exogenous factors, such as sexual orientation and gender, associated with a more heterogeneous sample. The advantages of the cross-sectional design were deemed to outweigh the advantages offered by the mixed group design. The comparison group was also helpful in providing a context and a gauge against which the results for the HIV positive group could be considered.

Like many other studies within this field, conclusions of this investigation are based on correlation and regression analyses. Such analyses are no guarantee for causation, and their limitation need to be recognised. Predictions made by regression analyses are subject to the factors entered into the analysis, hence other factors, which have

not been studied, may be more predictive. However, it is argued that causation is not a necessary prerequisite for treatment, and by understanding the association between personality and QoL one can aim to devise appropriate interventions. Other limitations related to statistics include Type I error and power. Efforts were made to minimise Type I error by, where possible, only testing hypotheses made ad hoc. This was not possible with the Schema Questionnaire, as no previous studies have looked at Schemas and QoL. Given that the Schema Questionnaire comprises 15 factors, which were not amenable to reduction by factor analysis, many correlations were run to investigate the associations between schemas and the four domains of QoL. Stringent p-values were used to interpret significant correlations within this analysis to minimise the chances of Type I error. However, there always exists the possibility that some findings occurred by chance. Further replication is needed in order to confirm these findings.

Efforts were made to recruit large samples, and the size of the HIV positive sample exceeded the size determined by the power analysis. The recruitment of the HIV negative sample was more difficult. This group was recruited from the HIV-testing clinic. For ethical reasons, this sample was asked to sign a consent form during a face-to-face interaction, yet data collection was done via postal survey. As is often the case with postal surveys, the response rate was lower than it was for the HIV positive group, who completed the survey on the same day they consented. Replication of these findings with larger samples, both HIV positive and negative, is required. Importantly, it is possible that not finding conscientiousness to be a significant predictor of QoL, as some studies demonstrated, was due to smaller effect sizes which require more power for detection.

#### ▪ 4. **Clinical and scientific implications**

Quality of life represents an important goal for healthcare provision. Within the field of HIV clinicians and researchers are increasingly recognising the importance of quality of life, particularly with developments in pharmacology that allow HIV people to live longer lives. Research that examines the relationship between personality and HIV has focused mainly on prevention, and only recently have researchers started to explore the effect of personality beyond risk taking. The results of this study add to an accumulating body of evidence demonstrating a robust relationship between personality and quality of life. In particular, the results indicating that neuroticism accounts for a third of the variance in physical QoL, and over half the variance in psychological QoL, demonstrate the magnitude of the effect of personality on QoL. This suggests that personality is central to QoL, and interventions aimed at improving QoL must take personality factors under consideration. Limited success of previous health promotion efforts may be explained by the omission of personality factors in their planning. People who have a neurotic predisposition may need a different approach to people who are extravert and naturally orientate towards others for support and help.

From the research presented in the literature review paper in this volume one may be able to hypothesise about the actual mechanisms by which neuroticism and extraversion can affect QoL. Previous research has demonstrated the ways in which personality can affect someone's likelihood of becoming infected (e.g. Hutton, Glenn & Treisman, 2001). Some of these findings may be applied to elucidate the relationship between personality and QoL. To illustrate, the extraversion-introversion dimension refers to an individual's tendency to respond to stimuli with either excitation or inhibition. Typically, extraverts are more present-oriented, feeling-

directed, and reward seeking. Characteristically extraverts are also optimistic. Although having such attributes can contribute to people becoming infected through impulsive behaviour, such attributes may have a positive effect on how such people perceive their QoL. Extraverts may be more able to focus on the present, avoid ruminating about their past, and their optimistic tendency may allow them to accept their condition more easily than introverted individuals. Introverted individuals may be more likely to focus on their past and future, and therefore more likely to perceive the losses incurred through their infection. Their pessimistic style may also render them more likely to feel depressed and hopeless. Furthermore, introverted individuals may be less likely to turn to others, and thereby miss out on the beneficial effect of social support which extraverts may be more efficient at obtaining.

As research demonstrated (e.g. Derlega, Winstead, Oldfield & Barbee, 2003) not all support seeking behaviours are equally effective, and not all support behaviours offered are experienced as equally helpful. Specifically, directly asking for support seeking found to be more effective way of eliciting support, and was less likely to elicit avoidance behaviour from others. Importantly, depressive symptoms were associated with less direct forms of support seeking and more avoidance behaviour from people approached for support. Extraverts are, thus, more likely to seek support, but also more likely to elicit the most helpful support behaviour from others. This may account for the finding that extraversion is associated with psychological, and not physical, QoL. Social support and optimistic style may be more helpful in helping someone's psychological QoL. However, such tendencies may more relevant to psychological QoL, rather than physical QoL. Neuroticism, on the other hand, is associated with both physical and psychological QoL, and this may be because the effects of neuroticism operate on both mental and physical levels.

The neuroticism, or stability-instability-dimension, refers to someone emotionality or lability. People who have a neurotic predisposition are more vulnerable to depression and anxiety. They are more likely to experience intense emotions, and act impulsively, and at time irrationally. Depression, anxiety, and stress symptoms have been associated with ill health. As demonstrated in the literature review, the hormone cortisol has been studied vis-à-vis coping and stress in PWHIV (e.g. Leserevan, 2003). It is plausible that people who exhibit neurotic tendencies are more vulnerable to immune suppression and therefore poorer health. However, given that the physical indicators measured in this study were found to have a significant effect on QoL, it seems that the effect of neuroticism may be more complex. It seems likely that neuroticism, and the associated predisposition to anxiety and depressive, can be associated with a greater tendency to appraise situations and events in a more negative way, as theorised by cognitive models of psychopathology. Similarly, such individuals may be more likely to scan for possible threats to their health, focus on any symptoms, and therefore appraise any symptoms in a catastrophic way. The intensity of their emotions, and their impulsive behaviours, may also dispose them behave in ways that can further compromise their health.

Finding that personality accounts for so much variability in QoL presents some challenges to healthcare providers. One may reflect on data on the stability of personality across the life span (Costa & McCrae, 1994) and its influences on the feasibility of designing interventions that aim to change personality. Moreover, it may not be for healthcare professionals who are the forefront of providing services for HIV positive people, mainly nurses and doctors, to provide such interventions. To

try to change someone's personality is an unrealistic goal for healthcare providers and psychologists alike. However, interventions aimed at helping people manage certain personality traits that may interfere with their quality of life are feasible.

Cognitive therapy can be used to help people understand their own personality patterns, and the way in which these may affect the way they think, feel, and behave. Pharmacological therapies may also be helpful in managing depression and anxiety symptoms that are synonymous with neuroticism. Adopting a positive psychology stance, encouraging people to use their adaptive traits may also be important. For example people who are naturally extravert may be helped to identify additional sources of support. Healthcare providers, who have the challenging role of engaging people in ongoing treatment, or managing their demands, may also benefit from having a better understanding of people's personality types and the associated behaviours. Having this understanding may help workers, who may feel exasperated by patients, to have more empathy for these individuals, which may in turn lead to better interactions.

▪ **5. How has the research affected my clinical understanding**

Over the course of the research process my understanding of the relationship between personality and QoL, and issues pertinent to HIV positive individuals, deepened. The results of the study suggest that the relationship between personality and QoL in this population is a complex one, and that there remain many research opportunities to further investigate and clarify this intricate relationship. I found that my understanding of, and empathy towards, people with neurotic predispositions, has also grown. Working with people with deep neurotic predispositions can be overwhelming and frustrating at times. Dealing with recurring anxiety and depressive

cycles can be exhausting for a clinician. However, when one understands the extent to which neuroticism impacts on an individual's life, its pervasive nature, and the challenge it presents to that individual, the experience of working with such people changes. To an extent, one can imagine how difficult it must be for people who have a neurotic predisposition to become HIV infected. In some ways, becoming infected must be their worst fears come true. Their cognitive styles make it hard to deal with the challenges presented by HIV infection, and one can speculate that they invoke the same overwhelming feeling in others they may reach out. Altogether, the experience of living day-to-day with the infection and their depressive and anxious symptoms may be a constant struggle. Having this understanding in my mind, when working with such individuals, helped me as a psychologist to formulate, and also engage these people in therapy. At the same time, this has also shaped the way I set objectives for therapy. Although one can aim to make a significant change to axis I disorders, such as acute depression or anxiety. It was also recognised that these people's personalities may predispose them to future bouts of depression or anxiety. The service, within which I was working, does not specialise in therapy aimed at personality change. Moreover, a collaborative relationship is necessary for such therapeutic work, which is not always feasible with clients. Thus, therapeutic work with such clients, can aim to alleviate the symptoms, by helping people understand the way their cognitive styles affect how they feel. Longer term, and specialised, therapy may be more appropriate for individuals with extreme personality and interpersonal difficulties.

#### ▪ 6. **Lessons learned through the research process**

The process of this research project has afforded several lessons in methodology and research. First, it was recognised that the selection of measures for research even



when involving a consideration of psychometric properties, does not offer a guarantee that the measure would perform in the same way in another sample. The Schema Questionnaire was found to have a very different structure to that reported by its author and other researchers. Testing the reliability of the measures at the early stage of analysis proved important. The factor analysis of the measure revealed important findings about the questionnaire and its limitation within this project. Similarly, it was recognised that choosing a measure that yields many sub-scores, rather than an overall score, can complicate analysis. The Schema Questionnaire is designed to provide 15 sub-scores, rather than an overall score. The WHOQOL measure does not yield an overall score of QoL but rather scores on four dimensions of QoL. Importantly, one needs to consider the hypotheses carefully when selecting measures. Having multiple scores means having multiple variables, requiring multiple analyses, which increases the risk of Type I error. In this study, I was faced with the decision of either sticking to the hypotheses as made, or running many analyses using the 15 schemas. There was no logical or statistical basis for the latter, and as no previous studies have been published to guide more specific hypotheses, further analysis was abandoned. Perhaps, with hindsight a different measure to the Schema Questionnaire would have been easier to use. However, as discussed earlier, the Schema Questionnaire is unique, and the researcher was particularly interested in the Schema approach.

Recruitment is often an obstacle in research. Although the recruitment of the HIV positive group was not complicated, recruitment of HIV negative individuals proved more difficult. The recruitment for ethical reasons involved postal surveys, which have modest response rates. This means almost twice as many people were recruited,

as questionnaires returned. This required more time and resources, both of which were limited within the allowances made by this project's time and resource frame. Recruitment of a comparison, or control, group is often more complicated which may account for the paucity of studies in this field recruiting such groups.

Both recruitment and measures related issues represent a bigger issue of unpredictability of research, and the challenges this presents. Each research project brings with it new challenges and obstacles which need to be addressed. Although care should be taken to consider such issues at the planning stage, some issues, such as unexpected findings, cannot be anticipated. It is imperative that one continues to persist with the original plans for data analysis, and interpret unexpected findings thoughtfully.

## References

- American Psychiatric Association. (1974). Position statement on homosexuality and civil rights. *American Journal of Psychiatry*, 131,497.
- Burgess, A.P., Carretero, M., Elkington, A., Pasqual-Marsettin, E., Lobacaro, C., & Catalan J. (2000) The role of personality, coping style and social support in health related quality of life in HIV infection. *Quality of Life Research*, 9, 423-37.
- Costa, P.T. and McCrae (1994) Set like plaster? Evidence for the stability of adult personality. In T.F. Heatherton and J.L. Weinberger (Eds.) *Can Personality Change*. Washington DC, American Psychological Association
- Derlega, V.J., Winstead, B.A., Oldfield, E.C., & Barbee A.P., (2003). Close relationships and social support in coping with HIV: A test of Sensitive Interactions Systems Theory. *AIDS and Behaviour*, 7, 119-129.
- Hutton, H.E., Glenn, J., & Treisman, G.J., (2001). Understanding the role of personality in HIV risk behaviors: Implications for prevention and treatment. Retrieved July 7, 2004, from the *World Wide Web*, [http://www.hopkins-aids.edu/publications/report/nov01\\_2.html](http://www.hopkins-aids.edu/publications/report/nov01_2.html).

Jacobsberg, L., Frances, A., & Perry, S. (1995). Axis II diagnoses among volunteers for HIV testing and counseling. *American Journal of Psychiatry*, *152*, 1222-1224.

Leserman, J.(2003). The effects of stressful live events, coping and cortisol on HIV infection. *CNS Spectrums*, *8*, 25-30.

Livesley, J.,(Ed.) (2001) *Handbook of Personality Disorders: Theory, Research, and Treatment*. New York: Guilford Press.

Penedo, F.J., Gonzales, J.S., Dahn, J.R., Antoni, M., Malow, R., Costa, P. and Schneiderman, N., (2003) Personality, Quality of Life, and HAART adherence among men and women living with HIV/AIDS. *Journal of Psychosomatic Research*, *54*, 271-278.

Welburn, K., Coristine, M., Dagg, P., Pontefact, A., & Jordan, S. (2002). The Schema Questionnaire- Short Form: Factor analysis and relationship between schemas and symptoms. *Cognitive Therapy and Research*, *26*, 519-530.

## Appendices

## Appendix I

### Ethical approval



Camden and Islington Community Health Services Local Research Ethics Committee

28<sup>th</sup> May 2004

Miss Irit Levy  
Sub-Department of Clinical Health Psychology

Dear Irit Levy,

***Full title of study: The relationship between personality, cognitive schemas and quality of life of HIV positive gay men.***

***REC reference no: 04/Q0511/25***

***Protocol number: 2***

The Research Ethics Committee reviewed the above application at the meeting held on 24<sup>th</sup> May 2004.

#### **Ethical opinion**

The Committee was pleased to see that their previous concerns had been addressed so thoroughly and that sources of support will be made available to any participants that become distressed.

The members of the Committee present gave a favourable ethical opinion to the above research on the basis described in the application form, protocol and supporting documentation.

The favourable opinion applies to the following research site:

Site: Ian Charleson Day Centre, Royal Free Hospital  
Principal Investigator: Irit Levy

#### **Conditions of approval**

The favourable opinion is given provided that you comply with the conditions set out in the attached document. You are advised to study the conditions carefully.

#### **Approved documents**

The documents reviewed and approved at the meeting were:

Documents Type: Application Form

Version: 2

Document Date: 30/04/2004

Date Received: 30/04/2004

SOPs version 1.0 dated February 2004

SL6 Favourable opinion at first review



Documents Type: Covering Letter  
Version: 1  
Document Date: 25/04/2004  
Date Received: 30/04/2004

Documents Type: Applicant CV  
Version: 1  
Document Date: 30/04/2004  
Date Received: 30/04/2004

Documents Type: Supervisor CV  
Version: 1  
Document Date: 30/04/2004  
Date Received: 30/04/2004

Documents Type: Peer Review  
Version: 1  
Document Date: 09/04/2004  
Date Received: 30/04/2004

Documents Type: Data Protection Registration  
Version:  
Document Date: 10/04/2004  
Date Received: 30/04/2004

Documents Type: Participant Information Sheet  
Version: 2  
Document Date: 30/04/2004  
Date Received: 30/04/2004

Documents Type: Questionnaire  
Version: 1  
Document Date: 30/04/2004  
Date Received: 30/04/2004

Documents Type: Protocol  
Version: 2  
Document Date: 30/04/2004  
Date Received: 30/04/2004

### **Management approval**

The study may not commence until final management approval has been confirmed by the organisation hosting the research.

### **Membership of the Committee**

The members of the Ethics Committee who were present at the meeting are listed on the attached sheet.

### **Notification of other bodies**

We shall notify the North Central London Research Consortium and the Royal Free R&D department that the study has a favourable ethical opinion.

SOPs version 1.0 dated February 2004  
SL6 Favourable opinion at first review





## Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees (July 2001) and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

<b>REC reference number: 04/Q0511/25</b>	<b>Please quote this number on all correspondence</b>
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Yours sincerely,

**Chair**

Enclosures List of names and professions of members who were present at the meeting/  
those who submitted written comments

Standard approval conditions

## Appendix II

Information sheets and Consent Form

HIV Positive Participants

## ***DEPARTMENT OF HIV MEDICINE***

### **Personality, beliefs and quality of life of gay men**

You are invited to take part in a research study. Before you decide, it is important for you to understand why the research is being carried out and what it will involve. Please take time to read the following information carefully and discuss it with others if you wish. Ask us if there is anything that is not clear or about which you would like more information. Take time to decide whether or not you wish to take part. Thank you for reading this!

#### **The purpose of this study:**

The aim of this study is to learn more about how personality affects people's quality of life or sense of well-being. Research suggests how people's personality can affect their sense of well-being either in a positive or negative way. For example people who are very outgoing may find it easier to get support from other people or agencies. In this study we are looking to identify the personality types and beliefs that may affect people's quality of life. We believe that having a clearer understanding of the way people's personalities and beliefs affect their well-being can help us and other healthcare professionals improve the care of patients.

#### **Why have I been chosen?**

This study focuses on gay men, and compares two groups of people; HIV positive individuals with a group of HIV negative individual. We are approaching you today to take part in the study because you have been diagnosed as HIV positive. We will be recruiting a total of 250 individuals into this study.

#### **Do I have to take part?**

We are relying on people's goodwill for this research to be successful. Please take a moment to think about whether you can help us. If you decide to take part you will be given this information sheet to keep and be asked to sign a consent form. If you decide

to take part you are still free to withdraw at any time and without giving a reason. If you decide not to take part, or wish to withdraw at any stage, this will in no way affect your care.

information&consent\_positive\_version2

### **What will happen if you take part?**

If you decide to take part, you will be asked to complete a questionnaire. Most people prefer to complete the questionnaire here at the clinic whilst they are waiting for their appointment. The questionnaire is a multiple-choice type and it will take approximately 25 minutes to complete. The number of questions may look daunting but most people find they are quite quick to complete once they get into the swing of things. You will not need to come back on another occasion, or take part in any other tasks. You will be offered the opportunity to meet the researchers should there be any issues you would like to discuss either later on today, or on another occasion. Most people find the questionnaire easy to complete, however occasionally a question, or an issue, in the questionnaire, may upset someone. Should you become upset by anything in the questionnaire, or have any questions please contact the researcher. All such contact will be confidential, and information will not be passed on to the hospital team. The contact details for the researcher are also written at the end of this sheet for you to contact directly, if and when you would like to.

### **Will my taking part in the study be kept confidential?**

You are not required to put your name anywhere on your sheet or to identify yourself, however it is useful for us to know something about everyone taking part in the research. For example, we may ask you about your age and employment status. You will notice there will be a numerical code on your sheet this will allow us to keep each of your questionnaires together. We will ask you to give your hospital number so with your permission we can access your latest CD4 count and viral load. You can be assured that there will be no way that your participation can be traced back to you individually.

### **What if something goes wrong?**

If you are harmed by taking part in this research project, there are no special compensation arrangements. If you are harmed due to someone's negligence, then you may have grounds for a legal action but you may have to pay for it. Regardless of this, if you wish to complain, or have any concerns about any aspect of the way you have been approached or treated during the course of this study, the normal National Health Service complaints mechanisms should be available to you.

### **What will happen to the results of the study?**

The results of the study will be analysed and submitted as a Doctoral research thesis to UCL. The study may be published in a scientific journal in the future. We will contact all participants who expressed an interest at the time and provide feedback about the research.

**Who has reviewed the study?**

This study was reviewed by Camden & Islington Community Health Services Local Research Ethics Committee.

**Further information**

If you have any questions, or issues you would like to discuss with the researcher; whether about the questionnaire or any other related issues, please contact:

**Irit Levy,**

In completion of the project, a short research report will be produced. Please put your name and address below if you would like a copy sent to you.

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## Some useful sources of support

Please find below some contact details of organisations you could contact for support, guidance or information.

### Lighthouse West London

Web: [www.tht.org.uk](http://www.tht.org.uk)

Best time to telephone: normal office hours

Lighthouse is a charity providing services to people with HIV and AIDS. Some services are only open to people living in particular areas and other services are open to everyone. Contact the number above for details of which services are currently available.

**Eastern Aids Support Triangle.** EAST is an Independent voluntary agency with charitable status, set up in 1991 by a small group committed to easing the problems experienced by people who are HIV positive. We support people who are HIV positive and living with AIDS including families, partners, friends, carers and anyone who has concerns about HIV/AIDS.

**Admin (Telephone and Fax):** The office is usually open between 9am and 4pm, Monday to Friday. If the office should be unoccupied there is an answering machine service. Calls are replied to immediately on our return.

**E-mail:** [www.aidsmeds.com](http://www.aidsmeds.com) is dedicated to providing people living with HIV the necessary information they need to make empowered treatment decisions. The founder and writers of this web site are all living with HIV, and we know first hand the challenges of learning how to fight this virus. By offering complete, but not complicated, up-to-date info, AIDSmeds.com seeks to help those that are both new and old to this challenge, and to remain a powerful resource for years to come.  
[www.aidsmeds.com](http://www.aidsmeds.com)

### The Samaritans

The Samaritans provides confidential emotional support, 24 hours a day for people who are experiencing feelings of distress or despair, including those, which may lead to suicide. You don't have to be suicidal to call us. We are here for you if you're worried about something, feel upset or confused, or you just want to talk to someone.

**Telephone:** in the UK and Northern Ireland

**Email:**

Track your nearest branch at: [http://www.samaritans.org/talk/local\\_branch.shtm](http://www.samaritans.org/talk/local_branch.shtm)

**If you would like to discuss anything with the researcher, whether about the study or any issues the survey has raised with you please contact Irit on . Anything discussed with Irit will be confidential and will not be disclosed to the Royal Free Hospital medical team.**

Personality, beliefs and quality of life

**Researcher: Irit Levy**

**Consent form**

**1. I confirm that I have read and understand the information sheet dated May 2004 version 2, for the above study and have had the opportunity to ask questions. Please initial .....**

**2. I understand that my participation is voluntary and that I am free to withdraw at the any time without giving my reason, without my medical care or legal rights being affected. Please initial .....**

**3. I understand that by providing my hospital number/ my name, sections of my medical notes (specifically my CD4 count/ my HIV status) may be looked at responsibly by the researcher, and give my permission for the researcher to have this access.**

**Please initial .....**

**4. I agree to take part in the above study:**

**Yes**

**No**

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hospital number

.....  
date

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signature

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name of person taking consent  
(if different to researcher)

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date

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signature

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Researcher

.....  
date

.....  
signature



## Appendix III

Information sheets and Consent Form

HIV Negative Participants

**DEPARTMENT OF HIV MEDICINE**

**Personality, beliefs and quality of life of gay men**

You are invited to take part in a research study. Before you decide, it is important for you to understand why the research is being carried out and what it will involve. Please take time to read the following information carefully and discuss it with others if you wish. Ask us if there is anything that is not clear or about which you would like more information. Take time to decide whether or not you wish to take part. Thank you for reading this!

**The purpose of this study:**

The aim of this study is to learn more about how personality affects people's quality of life or sense of well-being. Research suggests how people's personality can affect their sense of well-being either in a positive or negative way. For example people who are very outgoing may find it easier to get support from other people or agencies. In this study we are looking to identify the personality types and beliefs that may affect people's quality of life. We believe that having a clearer understanding of the way people's personalities and beliefs affect their well-being can help us and other healthcare professionals improve the care of patients.

**Why have I been chosen?**

This study focuses on gay men, and compares two groups of people; HIV positive individuals with a group of HIV negative individuals. We are approaching you today to take part in the study because you have specifically come to be tested for HIV today. We will be recruiting a total of 250 individuals into this study.

**Do I have to take part?**

We are relying on people's goodwill for this research to be successful. Please take a moment to think about whether you can help us. If you decide to take part you will be given this information sheet to keep and be asked to sign a consent form. If you decide to take part you are still free to withdraw at any time and without giving a reason.

If you decide not to take part, or wish to withdraw at any stage, this will in no way affect your care.

### **What will happen if you take part?**

If you decide to take part, we will ask if you agree to the researcher contacting you by phone in about a week's time. If you agree to be contacted by telephone, the researcher will call you on the phone number you provided (we can arrange a specific time to call you at your convenience), and check if you still agree to take part. If you are agreeable, a questionnaire pack will be sent to you, together with a SAE for its return. The questionnaire is a multiple-choice type and it will take approximately 25 minutes to complete. The number of questions may look daunting but most people find they are quite quick to complete once they get into the swing of things. Most people find the questionnaire easy to complete, however occasionally a question, or an issue, in the questionnaire, may upset someone. Should you become upset by anything in the questionnaire, or have any questions please contact the researcher. All such contact will be confidential, and information will not be passed on to the hospital team. The contact details for the researcher are also written at the end of this sheet for you to contact directly, if and when you would like to.

### **Will my taking part in the study be kept confidential?**

You are not required to put your name anywhere on your sheet or to identify yourself, however it is useful for us to know something about everyone taking part in the research. For example, we may ask you about your age and employment status. You will notice there will be a numerical code on your sheet this will allow us to keep each of your questionnaires together. If you have come to be tested today, we may check your test results to ensure that you are HIV negative. You can be assured that there will be no way that your participation can be traced back to you individually.

### **What if something goes wrong?**

If you are harmed by taking part in this research project, there are no special compensation arrangements. If you are harmed due to someone's negligence, then you may have grounds for a legal action but you may have to pay for it. Regardless of this, if you wish to complain, or have any concerns about any aspect of the way you have been approached or treated during the course of this study, the normal National Health Service complaints mechanisms should be available to you.

**What will happen to the results of the study?**

The results of the study will be analysed and submitted as a Doctoral research thesis to UCL. The study may be published in a scientific journal in the future. We will contact all participants who expressed an interest at the time and provide feedback about the research.

**Who has reviewed the study?**

This study was reviewed by Camden & Islington Community Health Services Local Research Ethics Committee.

**Further information**

If you have any questions, or issues you would like to discuss with the researcher; whether about the questionnaire or any other related issues, please contact:

**Irit Levy,**

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Lighthouse is a charity providing services to people with HIV and AIDS. Some services are only open to people living in particular areas and other services are open to everyone. Contact the number above for details of which services are currently available.

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**Admin** (Telephone and Fax): . The office is usually open between 9am and 4pm, Monday to Friday. If the office should be unoccupied there is an answering machine service. Calls are replied to immediately on our return.

E-mail:

**AIDSmeds.com** is dedicated to providing people living with HIV the necessary information they need to make empowered treatment decisions. The founder and writers of this web site are all living with HIV, and we know first hand the challenges of learning how to fight this virus. By offering complete, but not complicated, up-to-date info, AIDSmeds.com seeks to help those that are both new and old to this challenge, and to remain a powerful resource for years to come. [www.aidsmeds.com](http://www.aidsmeds.com)

### The Samaritans

The Samaritans provides confidential emotional support, 24 hours a day for people who are experiencing feelings of distress or despair, including those, which may lead to suicide. You don't have to be suicidal to call us. We are here for you if you're worried about something, feel upset or confused, or you just want to talk to someone.

Telephone: in the UK and Northern Ireland

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If you would like to discuss anything with the researcher, whether about the study or any issues the survey has raised with you please contact Irit on . Anything discussed with Irit will be confidential and will not be disclosed to the Royal Free Hospital medical team.

**Personality, beliefs and quality of life in gay men**

**Researcher: Irit Levy**

**Consent form**

**4. I confirm that I have read and understand the information sheet dated May 2004 version 2, for the above study and have had the opportunity to ask questions. Please initial .....**

**5. I understand that my participation is voluntary and that I am free to withdraw at the any time without giving my reason, without my medical care or legal rights being affected. Please initial .....**

**6. I understand that my test results may be looked at responsibly by the researcher to verify my HIV status, and give my permission for the researcher to have this access. Please initial .....**

**4. I agree to take part in the above study: Yes**

**No**

.....  
hospital number

.....  
date

.....  
signature

.....  
name of person taking consent  
(if different to researcher)

.....  
date

.....  
signature

.....  
Researcher

.....  
date

.....  
signature