

**Psychosocial factors associated with vocational activity and quality of life in people living with human immunodeficiency virus (HIV) infection**

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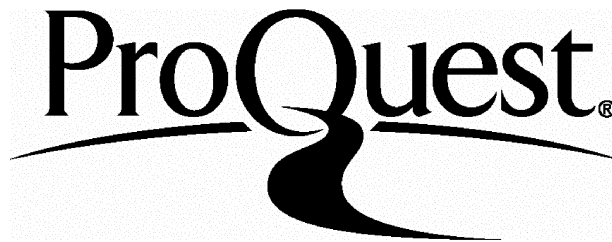
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## **Abstract.**

The number of people infected with HIV in the United Kingdom continues to grow. The introduction of new antiviral combination therapies for HIV infection has shifted the parameters of the disease from a usually fatal condition to a more chronic long-term disease. Many people taking combination therapies have experienced improved physical health and the halting of disease progression while others who have not been able to take them continue to experience symptoms associated with a progressive and debilitating disease.

HIV infection is associated with a range of adverse psychological and social outcomes. It is known that there are increased rates of unemployment among HIV positive individuals. Despite this knowledge relatively little attention has been paid to identifying the barriers people with HIV infection face to gaining or maintaining employment. Furthermore psychological variables that may mediate the impact of HIV on employment have not yet been identified. In the few studies specifically examining the difficulties faced by people with HIV in relation to work lack of confidence has repeatedly emerged as an important issue. Self-efficacy refers to people's beliefs in their abilities to perform behaviours necessary to deal with prospective situations and represents an individual's level of confidence in their capacity to exercise control over their behaviour and social environment. It has been shown to predict behaviour in a variety of areas. Therefore self-efficacy may help explain individual differences in vocational activity. This study attempted to determine whether self-efficacy was associated with vocational activity in people

living with HIV.

There is growing recognition that to fully capture the impact of a disease traditional measures of psychopathology should be supplemented with quality of life measures that assess the degree to which goals and needs have been fulfilled in areas of life regarded as important. Work is a significant component of quality of life. Self-efficacy may influence vocational activity and thereby contribute to quality of life. HIV can impact upon other valued areas of life and self-efficacy may contribute to quality of life beyond work. This research attempted to determine the association between self-efficacy and quality of life and establish the specific contribution of vocational activity to quality of life in people living with HIV.

In this cross-sectional study sixty five participants were recruited from Genito-Urinary Medicine Clinics and voluntary sector HIV services using non-random sampling methods. The main independent variables were self-efficacy (vocational specific and general), personality, and coping. The dependent variables were vocational activity and quality of life. Data on anxiety and depression was also collected. Participants completed questionnaire measures of relevant constructs.

Overall there was a high level of psychological morbidity. Over half the sample reached caseness for anxiety and one quarter reached caseness for depression. Furthermore over half the sample were classified as low or very low on quality of life. This means they fell between the first and twentieth percentiles that distinguish clinical from non-clinical samples. Only a small proportion of participants were engaged in paid employment.



Higher levels of vocational self-efficacy and lower levels of depression were associated with higher degrees of vocational activity. Logistic regression failed to show independent effects for either vocational self-efficacy or depression but together they were powerful predictors of vocational activity, suggesting that the two constructs may be related. Although higher levels of general self-efficacy was associated with better quality of life, general self-efficacy failed to demonstrate independent effects in linear regression analyses. On both conceptual and empirical grounds general self-efficacy did not appear to be a unitary construct but a poor relation of problem-focused coping. Only neuroticism and problem focused coping were independent predictors of quality of life. The presence of paid employment was associated with greater quality of life highlighting the psychological costs associated with unemployment in people with HIV infection.

The clinical implications of these findings were discussed. It was proposed that psychological interventions for people living with HIV needed to be designed within a quality of life framework. Interventions were likely to fall into two broad categories - those that assist people return to work and thereby improve quality of life, and those that improve quality of life through other strategies when return to work is not feasible.

## **Chapter One: Introduction.**

The Acquired Immune Deficiency Syndrome (AIDS) was first identified in 1981 when a handful of patients in several large US cities presented with unusual opportunistic infections and evidence of immune system failure (Centres for Disease Control, 1981). Since that time Human Immunodeficiency Virus (HIV) has become the most serious disease epidemic of modern times and it is the subject of intense epidemiological, virological, biomedical and psychological research. Since 1984 there have been 43,026 reported cases of HIV infection and 13,782 reported deaths from AIDS in the United Kingdom (PHLS AIDS & STD Centre, 2001a). It is currently estimated that there are 30,000 people infected with HIV in the United Kingdom of which one third are undiagnosed (PHLS AIDS & STD Centre, 2001a). By September 2000 there were over 3500 new reported cases of HIV, the largest increase ever recorded in the United Kingdom (PHLS AIDS & STD Centre, 2001a). This generated concern in the medical profession that HIV was becoming a “forgotten disease” (Dobson, 2000).

The costs of HIV disease world-wide have been enormous impacting upon individual's physical and psychological well-being, their relationships with others and their communities. Direct costs such as expenditure on medical treatments are more apparent and therefore easier to measure and in the United Kingdom the Department of Health currently spends £372 million per year on HIV care (Department of Health, 2000). The indirect costs of HIV are far greater and much harder to identify. There is the loss of usually young members of society to

premature disability and death and increased psychological morbidity and decreased productivity for those infected, as well for their partners, friends and family members who provide care. It is not possible to calculate the indirect cost of HIV disease but in financial terms it has been estimated in the United States alone to be over \$23 billion (Farnham, 1994).

This introduction will be divided into six sections. In section one the nature and course of human immunodeficiency virus (HIV) infection, developments in medical treatment and current psychological issues will be outlined. This will provide the reader with the context to the areas under investigation: self-efficacy and its relationship to vocational activity and quality of life. For the purpose of this research project vocational activity is defined as “any activity that might reasonably increase the likelihood of employment as well as work itself.” This definition was adopted because previous studies have focused only on the impact of HIV infection on full-time employment. This is unlikely to reflect the diversity of “work” patterns in people affected by HIV. In section two what is known about the impact of HIV on vocational activity will be explored. The gaps in the literature that formed the impetus for the research project will be identified. In section three the potential value of self-efficacy in explaining individual differences in vocational activity will be outlined. In section four the importance of quality of life and the way self-efficacy and vocational activity may relate to it will then be considered. In section five the relevance of personality to the proposed research will be discussed. Section six will contain a statement of research aims and hypotheses that flow from the preceding discussion.

## **Section One: Medical and psychological aspects of HIV infection.**

### **1.0 Understanding HIV and AIDS.**

HIV is a virus belonging to the retrovirus family and is transmitted via bodily fluids such as blood and semen. The HIV virus invades cells that bear the necessary viral receptor site on their surfaces. This is the CD4 antigen and is found on the surfaces of the CD4 or helper T-lymphocytes white blood cells that are at the core of the body's immune system. CD4 cells act to switch on the immune system when the body is exposed to infectious agents. Gradually the body's CD4 cells are invaded and destroyed by the virus leading to low CD4 counts and opportunistic infections that may prove fatal. The infections are termed opportunistic because they take advantage of immune system failure and would not usually be seen in people with healthy immune systems.

At the time of primary infection some people develop a flu like illness known as HIV conversion syndrome although generally infection goes unnoticed even in the presence of conversion syndrome. People will remain fit and healthy and experience no symptoms (termed HIV asymptomatic) for a period of time until they begin to experience symptoms reflecting CD4 count destruction. At this point individuals are described as being HIV symptomatic. CD4 count destruction continues resulting in the emergence of serious opportunistic infections. AIDS is the end stage consequence of HIV infection and is diagnosed either when CD4 count has fallen

below 200 regardless of symptoms, or when CD4 count is between 500 and 200 and an AIDS defining opportunistic infection is present (Centre for Disease Control, 1993). These criteria however are primarily for reporting purposes. Clinical practice in the United Kingdom is based on HIV disease as a continuum with stages of infection that range between primary, asymptomatic, symptomatic and advanced (Easterbrook, 1999).

### **1.1 The course of HIV infection.**

Prior to the introduction of highly active antiretroviral therapy (HAART) (also known as combination or triple therapies), the typical course of HIV disease was continuous and progressive with 70% to 80% developing AIDS six to eight years after primary infection. There was however variation within this established pattern. Approximately 10% to 15% of people infected progressed to AIDS within two to three years and they were categorised as “rapid progressors.” In less than 5% of individuals CD4 counts remained within normal limits and immune system function was unimpaired for between fifteen and twenty years and these were termed “long-term survivors”. A very small proportion of people have also showed increased survivability from the typical course whilst showing evidence of extensive CD4 destruction yet remained stable and free of opportunistic infections for extended periods of time (Pantaleo & Fauci, 1996). The sources of this variability remain unclear although psychosocial factors have been identified that are associated with long-term survival (Ironson, Solomon, Cruess, Barroso & Stivers, 1995).

Discoveries of very rapid rates of virus production and clearance from the body and

of CD4 cell infection and turnover suggested that virus-producing cells had a short life span (Ho et al., 1995). This also meant the majority of virus particles circulating at any given time were the result of new or recent virus replication. Thus it was thought possible to restore adequate immune functioning even in the late stages of HIV infection. In 1996 combination therapies (CTs) were introduced designed to prevent virus replication in a number of different ways given the ability of HIV to rapidly mutate when only one medication was used. The focus of treatment shifted from delaying to halting disease progression. Prior to CTs the only anti-viral treatment available was AZT (Zidovudine) and the ineffectiveness of AZT in the long term was attributed to the virus's ability to mutate thus rendering the drug's mode of action useless (Matsushita, 2000). Assessment of disease progression has changed from a focus on the presence of opportunistic infections to on-going assessment of both CD4 count and viral load with the aim of treatment to reduce viral load to undetectable levels and increase CD4 count within normal limits.

In many HIV infected persons who have been able to take CTs, viral load has been reduced to undetectable levels and CD4 counts have returned to normal or near normal levels. The survival prospects for newly diagnosed individuals and people who have remained asymptomatic are dramatically different from those who lived with the disease prior to the introduction of CTs. In 1996 there were 1386 deaths from AIDS while in 2000 there were 254 deaths, an 80% reduction (PHLS AIDS & STD Centre, 2001a). There is evidence that improved treatments have renewed treatment optimism in those infected with HIV. Remien, Wagner, Carbolla-Diequez & Dolezal (1998) found 47% of their sample comprising 62 gay couples agreed with the statement "reducing viral load also reduces the risk of HIV transmission." Also

21% agreed with the statement “new treatments will soon be able to reverse HIV infection and eliminate the virus from the body.”

People who were previously diagnosed with AIDS and had only months to live have also experienced improved physical health and the removal of their AIDS diagnosis. The scale of recovery in people with AIDS is unprecedented and not seen before in any other fatal illness. It has been referred to as the “Lazarus Syndrome” (King, 1997), named after the biblical character, Lazarus, who was brought back from the dead after four days in his tomb. Others have defined the experience of people who believed they were dying from HIV infection but who came to believe they would live as “revival” (Brashers et al., 1999).

The use of these new drugs have shifted the parameters of HIV and AIDS from a usually fatal illness to a more chronic long-term disease (McReynolds, 1998). The implications are that people currently living with HIV will form a heterogeneous group. They will vary by the length of time infected and hence experience of life-threatening opportunistic infections. CTs are associated with numerous side effects and there are detailed and strict directives on their ingestion. Some people have not been able to take them and so will continue to experience symptoms associated with a progressive disease, while others who can take them will remain physically well.

It is not known for how long CTs will remain effective and there are already reports of multiple drug resistant strains of HIV developing (Loder, 2000). Furthermore there is growing recognition that improvements in physical health experienced by some people with HIV and the apparent halting of disease progression in others

brought about by CTs, has not changed the lives of people with HIV as initially contemplated.

Previous research established that the risk of developing psychiatric disorders, particularly depression and anxiety was higher in people with HIV than in the general population (e.g. Atkinson, Grant, Kennedy et al., 1988). There is no indication that improved treatments and prolonged survival have reduced these rates. Catalan, Meadows and Douzenis (2000) conducted an audit of referrals to the Psychological Medicine Unit at the Chelsea and Westminster Hospital. They found that compared to 1995 when CTs were not available referrals for depression and anxiety disorders have increased. Tacconelli (2000) compared rates of anxiety and depression in a 1999 GUM clinic cohort with a 1993 cohort and found no significant differences in rates. Furthermore recent studies suggest that there are new uncertainties in relation to HIV positive individuals in addition to those documented by previous research. These will now be considered.

## **1.2 Uncertainty and HIV.**

The concept of “uncertainty” has been studied extensively in relation to chronic illness and it is proposed it is a theme that pervades HIV infection. Mishel (1997) defines uncertainty as the inability to determine the meaning of illness-related events. Mishel (1997) argues that people with chronic illnesses experience uncertainty due to ambiguous symptom patterns, complex systems of care, insufficient information about diagnosis and unpredictable disease progression and prognosis. People with



HIV are likely to experience all of these. Sources of uncertainty change as an individual's disease progresses.

Even before individuals receive a test result for HIV, there is often uncertainty about the likelihood of a positive test result. Sometimes people may not seek testing indicative of a situation where uncertainty is preferred because testing while reducing uncertainty can also eliminate hope. When people receive a positive HIV test result it has been identified that a substantial source of uncertainty is the origin and length of infection (Gaskins & Brown, 1992). People often aim to establish when their infection may have occurred so they can identify the source. However, the source of infection usually remains uncertain because for many people primary infection is insidious and they may have engaged in HIV risk behaviours for many years. When individuals receive a positive test result there is uncertainty about who to disclose this information to. This uncertainty constantly reappears as individuals attempt to adjust to their HIV diagnosis.

During the period after diagnosis, the vast majority of individuals will feel well and experience no symptoms of HIV infection for between six and eight years. During this time the disease is characterised as "a time when the disease is asymptomatic, concealable, and presumably the least overtly disruptive in general; however it may still be covertly disruptive in terms of internal feelings of anxiety and distress" (Alonzo & Reynolds 1995, p. 308). However a number of features of the disease during this period serve to heighten uncertainty. HIV infection is likely to be the first major experience of illness for most of those infected because of their relative youth and so they will lack "event familiarity" (c.f. Mishel, 1997). Frequent

appointments with doctors, and regular testing of blood to ascertain immune status, combined with attempting to understand subjects such as virology and immunology will be confusing and unfamiliar for many infected with HIV.

The evidence discussed below will indicate that in addition to the established areas of uncertainty for people living with HIV outlined above, new sources have emerged as improved health and increased prospects of survival have taken hold.

Brashers et al. (1999) used focus group methodology to identify the sources of uncertainty in people with HIV who had experienced revival. Participants were recruited using purposeful sampling and twenty one people were identified as most likely to have undergone revival on the basis of either having CD4 counts of less than 200 or counts that had fallen below 200 but had risen above 200. They identified through content analysis of transcripts revival as a major source of uncertainty. One respondent was quoted as saying “The weirdest thing to me now is that I am experiencing stress, because now it looks like I’m going to be living for a long time. You know, I’d said good-bye and I felt free from all these responsibilities that had to do with my career and so on... So, with me its almost as though the stress had really ended when I got really sick because I reached this, kind of coming to terms - I don’t think that I felt an enormous amount of emotional stress for a while. But, now it has started back up again, when I’ve gotten more healthy. And that’s the most perverse thing in the world...” (Brashers et al., 1999, p. 205.)

There was also uncertainty related to feeling optimistic about the future given that the long-term efficacy of CTs was unknown. Some felt their recovery was tenuous

and were fearful of being hopeful only for their hopes to be dashed. One participant was quoted as saying “The things we are not certain about are ultimately what this drug or drug combination is going to do to us a year from now - we are the test” (Brashers et al., 1999, p. 206). Other concerns raised that appeared to dampen optimism were the development of viral resistance to CTs and the safety of the drugs including their side effects.

Sowell, Phillips and Grier (1998) attempted to explore the psychosocial changes accompanying a positive response to CTs using in-depth interviews with eleven men. Participants were eleven men who were diagnosed with AIDS, whose CD4 counts were  $<200/\text{mm}^3$ , and who had a positive response to treatment as indicated by substantially decreased viral load, increased CD4 count and decrease in experienced symptoms. Open-ended questions were used in the interviews and verbatim transcripts were analysed to identify themes from the data.

They reported a number of themes to emerge from the data. CTs were regarded as a reprieve and it appeared that while welcoming the improvements in physical health they were also experiencing a range of conflicting emotions such as anxiety, optimism and uncertainty. In one way participants felt they had a second chance at life, but this was countenanced by uncertainty about the length of time improvement would last. Another theme to emerge focused on changed roles and relationships and suggested that becoming ill with HIV impacted upon the dynamics of participants relationships with important others, family and the wider community. Improvements in physical health now meant that the dynamics of their current relationships would change once more and they would have to face the stress and emotional turmoil that

had become familiar to them during this process. Sowell et al. (1998) highlight the case of one participant who having lived with a HIV positive partner for several years, re-examined the relationship and decided to end it because the basis for the relationship as he perceived it had changed i.e. they were both no longer sick.

Uncertainty about disease progression has always predominated the period after diagnosis. Weitz (1989) for example noted uncertainty in people with AIDS stemmed from not knowing how much longer they would live and concerns about whether they would be able to die with dignity. However with the introduction of CTs sources of uncertainty appear to stem from questions about living rather than dying. Many people had to put their aspirations for the future on hold due to illness caused by HIV infection. Some people are now experiencing improvements in their health and starting to think about what they want from life and what gives their lives meaning. This may include thinking about starting or returning to work.

## **Section two: HIV and vocational activity.**

### **2.0 Impact of HIV on vocational activity.**

HIV disease primarily affects people aged between 25 and 44 years. According to Super, Savickas & Super (1996) young adulthood is a period when people are thinking about and experimenting with career options and then go on to develop and consolidate their career choice. HIV infection therefore has enormous potential to disrupt these activities as well as to interfere with the processes of finding and maintaining employment. For most people work provides a focus for personality organisation (Super et al., 1996) helping to provide meaning and purpose to people's lives. It is an important source of self-worth, self-esteem, stability, role fulfilment, goal achievement, self-identity, social support and financial independence (Simon, 1997).

According to Thoits (1995) the impact of acute or chronic stressors depend on whether the role identity affected is central to self-conception. Stress events are more likely to be psychologically harmful if they disrupt a valued aspect of the self. Furthermore in order to compensate for a loss to a valued role identity and protect self-esteem individuals cope by reducing the amount of importance they attach to the disrupted role for self-worth. For those who have already experienced an identity threatening event, a lack of alternative roles upon which they can attach importance is a vulnerability factor for psychological distress (Thoits, 1995). Brashers et al.'s (1999) study highlighted this phenomenon where participants had made health care the focus of their lives since becoming HIV positive. Indeed people with HIV face

multiple challenges to their sense of self through the gradual erosion and loss of valued roles. It is suggested that the absence of employment in the lives of people with HIV influences psychological distress through the absence of the rewarding features of work and limiting the roles that provide sources of self-conception and meaning.

Given the range of needs work helps to meet it is not surprising that unemployment can have profound psychological costs. For example, Warr (1984) reported that the proportion of unemployed people who scored above the cut off for psychiatric caseness on the General Health Questionnaire was 60% compared with 20% among employed groups. Lyketsos et al. (1995) found unemployed HIV-infected persons were more likely to reach caseness indicating the need for psychological intervention than were employed HIV infected people. Although one of the major losses an HIV infected person may experience is job loss relatively little is known about the ways HIV affects employment.

In a prospective study Kass et al. (1994) examined the natural progression of HIV infection in 5000 gay and bisexual men in the United States. On entry into the study they were classified into four mutually exclusive categories: HIV negative, asymptomatic HIV positive, symptomatic HIV positive and having AIDS. The majority of the cohort was white and had a degree. During the seventh year of the study information on employment status defined as either employed full time or not employed full time and whether their job status had changed for any HIV related reason was collected between two visits six months apart. Data was collected from 60% of the original cohort. Over a six-month period 26% of HIV positive

individuals were no longer employed full-time compared to 7% of HIV negative individuals. They found that being HIV positive regardless of disease stage increased the likelihood of not being in full-time employment. Furthermore disease progression was associated with loss of full-time employment, and participants with AIDS were the least likely to be in full-time employment followed by symptomatic and asymptomatic participants. While the use of only two categories of employment (full-time or not in full-time work) does not reflect the probable range of work patterns in people with HIV, it is clear that HIV infection is associated with loss of full-time employment status.

It is unclear what factors might account for individual differences in employment status among HIV infected people. Leigh et al. (1995) collected data on employment status and the number of work hours per week in a sample of gay men who were nearly all white and two thirds had a degree. Health status was classified as either HIV negative, HIV positive or having AIDS. Although HIV negative individuals were more likely to be working, 54% of participants with AIDS were also working. No significant differences were found in hours worked per week between people classified HIV negative, HIV positive or having AIDS although people with AIDS worked on average three hours less per week. This suggests that the impact of HIV may be on employment per se but it also points to substantial variation in vocational behaviour amongst HIV positive individuals and those diagnosed with AIDS.

The above findings need to be viewed in the context of several limitations of the Leigh et al. (1995) study. Data were collected at one time point so it is not possible to assess the impact of disease progression on employment and work hours of

participants was collected for only the previous week and so may not be representative of typical hours worked. Furthermore the non-random sample was predominately white, gay men who achieved higher levels of education than the general population.

Massagli et al. (1994) investigated demographic and jobs characteristics associated with loss of employment. Only 36% of respondents were working 16 months after receiving an AIDS diagnosis compared to 76% at the time of diagnosis. Those most likely to remain in employment at both diagnosis and follow-up were gay men, whites, college graduates, professional and clerical workers, and respondents with no prior history of injecting drug use. Furthermore, people with non-manual jobs rather than jobs requiring physical effort were in work much longer after receiving an AIDS diagnosis and this was not because employers were making allowances. These findings indicate that HIV disease has a direct impact on work and that socio-economic variables are additional barriers to maintaining employment in the context of living with a chronic disease. Nevertheless the finding that people with non-manual jobs remained in employment longer than manual workers without employer assistance suggest the involvement of other variables in maintaining vocational activity in spite of HIV infection.

## **2.1 “Revival” and vocational activity.**

The introduction of CTs has altered perceptions about what kind of life people living with HIV could have. In 1997 the UK Coalition for People Living with HIV/AIDS



started a “Back to Work” project funded by Glaxo Wellcome. This led to the setting up of the “Positive Futures Initiative” in 1998. This was a community-based program co-ordinated by seven major London voluntary sector HIV organisations. It was designed to promote access to education, training, and employment. They provided informal learning, computer skills training, volunteer placements, careers advice, employment legal advice and welfare benefits advice. The program remains in operation although it has been affected by the closure of one of its partner organisations, the FACTS (Foundation for AIDS Counselling) centre. This was indicative of the squeeze placed on public sector funding due to the rising costs of CTs. The funding crisis has made it difficult for the remaining organisations to operate due to the constant threat of closure.

Service developments such as the Positive Futures Initiative reflected the expectation that people with HIV who had experienced improvements in health could return to work. However, there is growing recognition of the difficulties faced by people undergoing revival in relation to employment and attempts have been made to elucidate the nature of these problems.

In the study described previously by Brashers et al. (1999) evidence emerged of the impact of revival on social roles and identities. The renewed experience of health necessitated a re-negotiation of roles and identities as people attempted to incorporate their new illness experience into their identities and social relationships. Many people with HIV had made end of life plans such as seeking disability allowance, planning funerals, and charging credit cards etc. Participants now reported pressures because of the perceived need to return to work and to get off

disability allowance yet were concerned that their health would be adversely affected by the stress of working. Difficulties appeared to arise for participants because of discordant experience. On the one hand the sick role was no longer felt to be valid because of improved physical health but on the other they were still threatened by a condition that was incurable and chronic. Thus they appeared to be stuck within an identity dilemma. They could return to work and achieve greater independence and self-sufficiency or remain in the sick role and make health care the focus of their lives.

There were also indications that improved physical health would influence interpersonal relationships within work. There was concern about re-stigmatisation if they re-entered the work force and how to handle issues related to illness disclosure and potential HIV-related discrimination. Many had not worked for between three and five years and participants felt explaining CV gaps would be difficult.

The study by Sowell et al. (1998) previously referred to also found similar findings to Barshers et al. (1998). It appeared that some participants were caught in a dilemma where they were interested in returning to work, but were concerned about the impact this would have on their health in terms of interfering with treatment compliance and the effects of job stress on their immune system. Other participants did not express this level of interest in returning to work and felt the symptoms they were experiencing and remaining immunocompromised precluded any serious move towards vocational activity. Some participants mentioned work was important to their self-esteem. There was also an expectation that gains in self-esteem from

returning to work would be offset by probably having to re-enter the work force at a much lower level. This was thought likely because of the extended time being out of the job market or not being able to cope with the demands of their previous occupation.

There were calls from participants that services for people with HIV restructure so that they were responsive to the changing needs of people who were experiencing physical health improvements. Reflecting how health care is organised in the United States concerns were expressed about the ability to afford their medication if they no longer were eligible for Medicaid. However, a more general concern was expressed about whether the gains from returning to work would be offset by loss of disability and health benefits and this dilemma has been expressed in British studies of people with HIV experiencing improvements in physical health (Anderson & Weatherburn, 1998).

In Britain Anderson & Weatherburn (1998) conducted in depth interviews with 40 people (25 participants were gay and 15 were African men and women) to ascertain the personal and social impact of taking CTs. In relation to work a wide range of issues emerged. There were uncertainties about the ability to cope with the perceived stresses of work, the financial implications of stopping benefits, the sustainability of improved health and side-effects and whether any employer would be interested in people with HIV. There was fear that work would interfere with treatment adherence and a lack of confidence about possessing the necessary skills and abilities for work. Anderson & Weatherburn also identified other factors that influenced vocational activity. These were employment history and current work

status, attitudes to work, experience of illness and CT treatment, opportunities for work and financial stability of daily life.

The aim of qualitative research is to explore and understand the nature of people's experiences from their own perspective as far as this is possible. Elliot, Fischer and Rennie (1999) have identified quality standards to assist in the evaluation of qualitative studies. The qualitative studies discussed above are exploratory in nature and can be commended in the way they bring to life the issues facing their participants. Attempting to understand the impact of CTs on people's lives, they cover a wide range of domains such as work, relationships, and health. All studies provide detailed information on participants to enable a judgement to be made about the wider relevance of the findings. Credibility checks on the data appeared to be performed only in the study by Brashers et al. (1999). In all three studies the perspective of the authors were not made explicit. This is regarded as important in qualitative research because one of its principles is that it is impossible to set aside one's own assumptions.

## **2.2 HIV and vocational activity: resume and further questions.**

Quantitative studies investigating the impact of HIV on employment are scarce. Another problem is that work has been defined in a narrow way with people categorised as either employed full-time or not employed full-time. Other work related concepts such as work satisfaction have not been explored. Samples have comprised mostly white, middle-class gay men. Nevertheless these studies have been valuable in suggesting the following:-

- \* HIV positive people are less likely to be in full-time employment than HIV negative individuals.
- \* Among HIV positive people, those with AIDS are the least likely to be in full time employment.
- \* Disease progression is associated with loss of employment status.
- \* Although HIV positive people are less likely to work, those who do work roughly the same hours as HIV negative individuals.
- \* There are factors in addition to HIV that influence vocational activity in those infected with the disease.

In the three qualitative studies discussed above that examined the experience of people on CTs, a number of issues arose in relation to work. These were:-

- \* Perceived costs and benefits to health of returning to work.
- \* Perceived costs and benefits to financial stability of returning to work.
- \* The ability to handle issues of HIV related discrimination and illness disclosure in the work place.
- \* The length of time out of work
- \* The lack of confidence in having the necessary skills and abilities to work (possibly related to the above).
- \* The ability to cope with the stresses of work.
- \* Impact of work on treatment adherence.

It is not possible to determine to what extent these issues arise across the whole

spectrum of HIV disease progression. Participants in the study by Sowell et al. (1998) were diagnosed with AIDS and in the study by Brashers et al. they were diagnosed with AIDS or had just recovered from it. The majority of participants in all studies white, gay men educated to graduate level so it is unclear whether the issues are similar for those from ethnic minorities. Furthermore, in all studies nearly all the participants were unemployed. Nevertheless it is known that a proportion of people infected with HIV do work and it is likely that people with HIV who are employed also face many of these issues such as taking treatments while at work and whether to disclose their illness. Therefore it is conceivable that there are individual differences in the ways people deal with these obstacles.

The importance of psychological factors in explaining individual differences in HIV and AIDS has been established in other contexts. Ironson et al. (1995) reviewed studies on the long-term survivors of AIDS (people who survive more than twice the median expected time of two years). They reported a constellation of psychological characteristics (active coping, social support, having a meaning or sense of purpose in life, and maintaining perspective and connectedness) were associated with long term survival. It is possible therefore that psychological characteristics may also account for variations in vocational activity in people with HIV. Many of the issues to emerge from participants in the qualitative studies concerned uncertainties or doubts about their abilities and confidence in number of work related domains in the context of HIV infection. It could be argued therefore that these issues relate to self-efficacy.

## **Section three: Self-efficacy.**

### **3.0 Self-efficacy theory.**

Self-efficacy theory originated from work on behavioural treatments of phobias. It was postulated that reductions in avoidant behaviour were a result of increases in people's perceptions of their abilities to cope with threats. Self-efficacy theory proposes that self-referent thinking is the core element affecting people's decisions to undertake activities. Bandura (1997a) defines self-efficacy as "people's beliefs in their capabilities to organise and execute the courses of action required to deal with prospective situations" (Bandura, 1997a, p. 160). It represents an individual's level of confidence in their ability to exercise control over their behaviour and social environment.

Perceived self-efficacy is regarded as a dynamic cognitive process that people perform rather than as a stable quality that individual's possess. When evaluating their abilities for action people assess the relationship between their perceived skills and the demands of the task. People are unlikely to execute behaviours necessary for a specific outcome if they doubt their capabilities to succeed. It has been established that self-efficacy beliefs are situation-specific and do not necessarily generalise from one domain of functioning to another (Forsyth & Carey, 1998).

An early objection to self-efficacy theory was that the association between self-efficacy and behaviour were a result of methodological artefact or merely a correlate

of successful action. However there is strong evidence that self-efficacy beliefs do operate as casual factors in human behaviour (Bandura, 1992). In the context of HIV the study of self-efficacy has been limited to its ability to predict adoption and maintenance of safer sex practices for HIV risk reduction. Within this domain it has been shown to be a significant predictor of safer sex behaviour (e.g. McKusick et al., 1990). Beliefs of self-efficacy have also been found to predict behaviour in other areas including vocational behaviour (Lent, Brown & Hackett, 1994), smoking cessation (Carey & Carey, 1993) and the self-management of chronic disease (Holman & Lorig, 1992). As the role of self-efficacy in vocational activity in people with HIV has yet to be elucidated the following discussion will suggest some of the ways the concept may apply to people with HIV and vocational activity.

### **3.1 Empirical studies of self-efficacy.**

Bandura, Reese and Adams (1982) manipulated self-efficacy in people with phobias either through mastery experiences or by modelling coping strategies. Perceived self-efficacy was raised from extremely low levels to low, moderate or high levels. Greater degrees of perceived self-efficacy were associated with higher levels of performance. Beliefs of self-efficacy have also been shown to exert an influence on performance when pre-existing ability level is controlled for. In a study by Collins (1982) children were selected at three levels of mathematical ability and were required to rate themselves on level of mathematical self-efficacy. They found that across all mathematical abilities, children with high self-efficacy solved more problems and persisted longer than those with low self-efficacy. The effect of perceived self-efficacy on performance was smallest for those with highest



mathematical ability. This suggests that the lower the level of ability, the greater the positive or negative impact of self-efficacy beliefs on functioning. This may mean that for people living with HIV the influence of self-efficacy beliefs on vocational activity will be greatest for those who have been out of work the longest.

Studies have illustrated the impact of self-efficacy beliefs on motivation. One study by Cervone (1989) altered beliefs of efficacy by making participants concentrate on task components that might help or hinder its solvability. Focusing on difficult parts of the task weakened self-efficacy beliefs while concentrating on achievable components increased self-efficacy and the length of time participants spent on solving a problem before they gave up. Difficulties in maintaining or returning to employment in people with HIV have been noted. Self-efficacy beliefs might therefore be expected to influence the amount of effort people spend on trying to solve them. Furthermore the obstacles people with HIV face will vary in degree. Thus the area of difficulty focused upon may moderate self-efficacy and determine level of motivation.

Beliefs of self-efficacy will affect various forms of cognitive activity associated with behaviour and therefore enhance or undermine performance. The setting of goals is influenced by self-appraisal of abilities and greater levels of perceived self-efficacy are associated with people setting higher goals for themselves and persevering with them for longer (e.g. Bandura & Wood, 1989). Furthermore since much behaviour is cognitively influenced self-efficacy beliefs will affect the kind of situations people envisage and whether these are anticipated as success or failures. Performance will be enhanced if success is anticipated or undermined if failure is expected. Studies

have found that constructing imaginal scenarios where people perform well improves subsequent performance and this effect is mediated by increased self-efficacy (Bandura, 1997b). On the basis of these findings it is plausible that there would be an association between vocational self-efficacy and vocational behaviour in people with HIV. The stronger the belief of self-efficacy, the higher the expectation that obstacles can be overcome and the greater the degree of vocational activity.

### **3.2 Self-efficacy and depression.**

Kavanagh (1992) has outlined the ways associations between self-efficacy and depression may be related. Low self-efficacy may worsen depressed mood particularly if it makes the opportunity for positive outcomes appear unlikely. It may also affect performance making aversive outcomes more likely and deepening depression. Depressed mood may directly reduce self-efficacy judgements and through impacting upon performance further lower self-efficacy and thereby mood. Studies have provided partial support for the above. Depressed people have been found to possess low levels of self-efficacy (e.g. Cane & Gotlib, 1985). In a study by Kavanagh and Bower 1985, depressed mood triggered experimentally was found to lower self-efficacy. In addition, when self-efficacy was reduced experimentally it was found to trigger depressed mood. Overall the association between self-efficacy and depression appears to be reciprocal where reduced self-efficacy can lead to depression and self-efficacy can be impaired by depression. Given the higher prevalence of depression in people with HIV it is likely that this would be associated with higher levels of impaired self-efficacy.

### **3.3 The relationship of self-efficacy to coping.**

It was noted that perceived self-efficacy is an appraisal of the level of performance in a given scenario. People who believe they can exercise control over events do not generate aversive cognitions and therefore do not experience anxiety while people who do not believe they can exercise control experience cognitions focused on threat and experience high levels of anxiety (Bandura, 1992). Therefore self-efficacy will have wider relevance to people's efforts at coping with difficult situations.

Coping is defined as the cognitive and behavioural strategies people apply in order to manage stressful situations. Different coping styles have been implicated in the onset of diseases ranging from ulcers to cancer and in subsequent adjustment and recovery (Auerbach, 1989). Coping has in the past been conceptualised as a trait possessing cross-situational consistency or as a process that is influenced largely by situational factors. However the transactional model of coping developed by Lazarus and Folkman (1984) has been extensively utilised in helping to understand coping with chronic illness including HIV infection. According to this theory a person defines an event as stressful when it is appraised as personally significant to their well being and as taxing or exceeding his or her personal resources.

This model divides coping strategies into emotion-focused and problem-focused strategies. The purpose of emotion-focused strategies is to control the emotional response to the stressful situation. This could be achieved through altering the meaning of the situation or through meeting friends. These tend to be utilised when people believe they can do nothing to change the stressor (Lazarus & Folkman,

1984). The function of problem-focused strategies is to reduce the demands of the stressful situation or expanding the resources to deal with it. Devising a new timetable for studying or learning new skills would be examples of problem-focused strategies. These are more likely to be employed when the stressor is perceived as controllable (Lazarus & Folkman, 1984).

The evidence indicates that each strategy can be potentially adaptive or maladaptive depending on the situation (Petrie & Moss-Morris, 1997). Some emotion-focused coping strategies produce gains across illnesses such as reframing the illness in a positive light. Problem-focused strategies have generally not been associated with favourable outcomes in chronic illness although obtaining information about the illness and planning are associated with improved outcomes. The use of avoidance in dealing with chronic illness is consistently associated with greater distress, poorer adjustment and worse outcome in chronic illness.

Bandura (1992) has proposed general self-efficacy as a personal resource or vulnerability factor that will influence how people cope with environmental challenge and threats. People who have confidence in their abilities to deal with a range of challenges and obstacles in life will be more likely to interpret difficulties as challenges rather than threats and thus a strong level of general self-efficacy will act as a buffer against stress. By contrast people with low general self-efficacy will respond to environmental challenges with self-doubt about ability to cope and experience psychological distress. In a study by Jerusalem & Schwarzer (1992) the role of general self-efficacy in stress appraisals were examined over time in response to academic tasks that involved graduations of challenge in sample of 210 adults

recruited through newspaper advertisements. They found general self-efficacy to be a strong predictor of subjective perceptions of performance following repeated failure on tasks. Those with high general self-efficacy were more likely to make positive appraisals of their performance, less likely to view challenges as threats, and experienced lower levels of distress compared to individuals with low general self-efficacy.

There is little other data examining the role of general self-efficacy in dealing with environmental challenges. Nevertheless the difficulties people living with HIV experience and the range of roles that HIV may disrupt suggests general self-efficacy may mediate the impact of HIV on individuals. In the context of this research it is proposed that both general self-efficacy and self-efficacy beliefs specific to vocational activity will play a part in explaining differences in the level of vocational activity.

### **3.4 Summary.**

A number of conclusions can be made in the light of the above discussion.

1. Self-efficacy beliefs are important determinants of motivation, affect, thought and behaviour. Therefore in relation to vocational activity and people with HIV beliefs of self-efficacy may influence:-

\* What people decide to do

\* The amount of energy devoted to a course of action

- \* The degree to which they will continue when faced with obstacles and failures
- \* Thought processes associated with a course of action which may assist or hinder the chosen course
- \* The level of depression and anxiety experienced in coping with difficult situations

2. Self-efficacy can be viewed as a personal resource factor and therefore one that plays an important role in coping with significant life events.

3. The protective function of general self-efficacy may be expected to influence quality of life of which work is regarded as an important component.

## **Section four: Quality of Life.**

### **4.0 Definitions of quality of life.**

The World Health Organisation defines health as “a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity” (World Health Organisation, 1948). There is growing recognition among those involved in providing health care that commonly utilised measures of psychological distress or symptoms such as the Beck Depression Scale (Beck, Ward, Mendelson, et al. 1961) or General Health Questionnaire (Goldberg, 1972) do not give a complete picture of an individual’s mental health status (e.g. Jenkins, 1992). It can not be assumed that people are content and happy merely because psychiatric symptoms are absent. Furthermore Ware (1986) recommends that to fully capture the impact of a disease or disorder traditional measures of psychopathology should be supplemented with quality of life measures that encompass key indicators such as satisfaction with and enjoyment of life.

A number of approaches have been adopted in the literature to defining health in terms that go beyond merely the absence of psychopathology. Some have adopted global conceptions of subjective well-being defined in terms of affect or cognition. Affective conceptualisations regard subjective well-being as either positive affect alone or as a dominance of positive affect over negative affect (e.g. Costa & McCrae, 1980). Cognitive formulations of subjective well-being refer to a process of cognitive judgements about whether one’s needs, goals and wishes have been met in reference to perceived normative standards (e.g. Michalos, 1985). Life satisfaction is

a result of the perceived discrepancy between a person's goals and their success in meeting them; the larger the discrepancy, the greater the dissatisfaction with life. There is growing agreement that the broader construct of subjective well-being or happiness is derived from cognitive, affective and evaluative components and that measures of subjective well-being must include all three.

Frisch (1994) equates life satisfaction with quality of life and adopts the view that quality of life is determined by an individual's overall subjective evaluation about the extent to which goals and needs have been fulfilled in areas of life regarded as important. The larger the gap between their goals and achievements, the lower their satisfaction will be. An individual's level of satisfaction in any life domain will depend upon the objective characteristics of the situation, how these are perceived, the perceived discrepancy between goals and achievements, and the degree of importance the person attaches to the area. It is proposed that these cognitive judgements produce the affective component of quality of life. The positive and negative affect accompanying quality of life is regarded as components of the higher-level construct of subjective well-being or happiness. Thus quality of life is seen as the end product of a process of cognitive judgements with synchronous affect leading to a global appraisal of subjective well being.

#### **4.1 HIV infection and quality of life.**

The shift in parameters of HIV from an acute and usually fatal disease to a more chronic long-term illness means that for people living with the disease quality of life issues will become more pervasive. There has been some recognition of the



importance of addressing quality of life issues in the literature because of increased survival times and improved physical health. However this has been limited to assessing health related quality of life (e.g. Sherbourne, Hays, Fleishman et al., 2000). As the term implies health related quality of life focuses on functioning in physical, mental and social domains of life and its primary purpose is to assess the outcome of medical treatments beyond purely biological parameters. It does not capture the wide range of domains that HIV has the potential to disrupt nor does it encompass the cognitive, affective and evaluative components of quality of life. HIV infection can have an independent effect on quality of life and people with HIV are also at an increased risk of developing other conditions such as depression (e.g. Catalan, 1999) that can also negatively impact upon quality of life. The studies discussed below illuminate some of the ways HIV can impact upon quality of life.

In the qualitative study previously discussed by Brashers et al. (1999) participants raised the issue of the impact of revival on quality of life. There were concerns about side effects, unforeseen opportunistic infections, and living with a chronic disease which all could be potential barriers to leading a “normal” life. One participant was reported as saying, “...the good news is you’re going to live. The bad news is you’re not going to enjoy the rest of life” (Brashers et al., 1999, p. 212). Mishel (1997) has outlined the way a lack of event congruence can increase uncertainty in chronic illness. 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. Not only will side effects have an impact on quality of life, but will increase uncertainty in attempting to ascertain the meaning of any symptom.

Neidig et al. (1996) analysed reported symptoms at the initial clinic visit of 972 adults attending a trial for experimental treatment for HIV infection. Although greater damage to immune function (as measured by CD4 count) was associated with more reported symptoms, the vast majority of those with healthy immune function also reported on average four symptoms. The most common reported symptom was headache with a third of patients with CD4 counts less than 200 reporting it as a current symptom. Thus, a given symptom may appear at any time during the course of HIV infection, but each time a symptom re-appears people must interpret it, attribute cause and decide on a course of action. This is by no means easy when it could be a side effect of medication, a result of stress, or a sign of opportunistic infection.

The above studies illustrate some of the ways HIV can impact upon quality of life but little is known about psychological variables that may mediate the impact of HIV on quality of life. Like other chronic illness, HIV can negatively impact upon the degree to which people believe they are able to exercise control over conditions that affect their lives. It is true that Bandura (1997b) advocates the use of situation specific measures but this refers to measurement strategy rather than theoretical assertion. There was recognition of the possibility of cross-situational generalisation in self-efficacy beliefs because of studies finding changes in self-efficacy and behaviour towards one phobic stimulus generalising to another (e.g. Williams, Kinney & Falbo, 1989).

Bandura (1992) states that a growing body of evidence suggests an optimistic sense

of personal efficacy is required for positive well being and achieving goals. He argues that the stresses, difficulties, setbacks and obstacles associated with modern life mean that in order to succeed, a strong sense of general self-efficacy is required to sustain motivation. Bandura points to the way many artists, novelists and scientists persevered in spite of repeated rejection and concludes that early rejection and disappointment is the rule rather than the exception in human activities. The adage "If at first you don't succeed, try and try again" may have stemmed from this common predicament. Thus general self-efficacy may mediate the extent to which HIV disrupts functioning in important life domains and the impact of HIV on quality of life. Frisch (1994) proposes that repeated failures to achieve goals in highly valued areas of life can lead to depression. He states low general self-efficacy partly leads to these failures and is further diminished by them.

Empirical investigations have also shed some light on the role of psychological factors and quality of life. Swindells, Mohr, Justis et al. (1999) attempted to identify factors associated with health related quality of life in 138 HIV positive individuals recruited from three outpatient clinics in the United States. They found age, gender, ethnicity, HIV risk factor, living alone and CD4 count to be unrelated to quality of life. Employment, satisfaction with social support, and problem-focused coping correlated with greater quality of life and emotion focused and avoidance coping was associated with poorer quality of life. Ramanaiah, Detwiler & Byravan (1997) examined the association between personality traits and life satisfaction in a non-HIV population (245 undergraduates) and found high life satisfaction to be significantly associated with higher levels of extroversion, agreeableness and conscientiousness and lower levels of neuroticism than low life satisfaction. The study suggests major

personality factors are important determinants of life satisfaction and this finding has been reported by others (e.g. Furnham & Brewin, 1990) (Personality is discussed below in section five).

The discussion until now may have given the impression that it is assumed that work is important for HIV positive individuals and those in work would have a better quality of life. The qualitative research presented earlier highlighted how some people with HIV chose to make health care the focus of their lives while work was no longer regarded as a priority. Whether the presence or absence of employment affects quality of life will be treated as an empirical question.

For most individuals vocational activity is an important component of quality of life. Self-efficacy may influence vocational activity and thereby contribute to quality of life. Furthermore the contribution of self-efficacy to quality of life may extend beyond vocational status because in theory it should influence whether behaviours necessary to achieve goals in other valued areas of life are undertaken.

## **Section five: The importance of personality factors to the research.**

There has been growing recognition of the importance of dispositional factors in susceptibility to illness and this had led to an increase in the appearance of health related personality constructs such as optimism, self-faith, locus of control and self-esteem. However there is also disagreement about the utility and validity of the plethora of constructs to emerge and concern that they have done so without reference to a broader framework of personality (Marshall, Wortman, Vickers, Kusulas & Hervig, 1994). Personality issues in HIV infection have received little coverage and when they have it is usually in the context of personality disorders. Individuals with personality disorders have been shown to be at an increased risk of acquiring HIV infection (Ellis, Collis & King, 1995) and developing psychiatric problems after acquiring HIV infection (Johnson, Williams, Goetz et al., 1996). There is even less known about the role of normal personality traits in susceptibility to psychiatric problems in people with HIV and their influence on coping with the difficulties associated with infection. Nevertheless knowledge that has been gained about characteristics associated with normal personality traits may prove useful in explaining individual differences in the way people respond to HIV infection.

While there are a number of models of personality two of the most widely employed are Eysenck's three factor model (e.g. Eysenck, 1990) and the five factor model (e.g. McCrae & Costa, 1989). Both models arose out of factor analytic work. Eysenck's model has the following dimensions: neuroticism (discussed below), extroversion

(discussed below) and psychoticism (people scoring high on this dimension are aggressive, egocentric, impulsive and antisocial whereas low scorers are empathic and able to control their impulses). The five factor model, sometimes known as the “Big Five” consists of the following dimensions: neuroticism, extroversion, openness-to-experience, agreeableness and conscientiousness. From the perspective of the five factor model Eysenck’s psychoticism factor is a combination of agreeableness and conscientiousness and might be considered a “super” factor (McCrae & Costa, 1985).

Neuroticism or the tendency to experience emotional distress is a major personality factor. People fall somewhere on a continuum between negative affectivity and emotional stability. Individuals who score high on neuroticism are more prone to experience a wide variety of negative emotions such as anxiety, sadness and guilt. In addition they are less effective in dealing with external stressors often becoming overwhelmed and feeling helpless. They are more likely to think unrealistically about things and self-image is poor. People who score low on neuroticism are resilient in the face of stress, less prone to experience negative emotions, more able to keep calm and stronger emotionally. Neuroticism is associated with an increased risk of a wide variety of psychiatric disorders. It has been positively associated with susceptibility to anxiety and depression (Eysenck & Eysenck, 1985) and in one longitudinal study the correlation between neuroticism and psychological distress seven years on was found to be 0.55 (Ormel & Wohlfarth, 1991).

While high neuroticism appears to some extent to be a vulnerability factor for psychological distress, high extraversion appears to offer some degree of protection

(e.g. Williams, 1990). There are interpersonal and temperamental components to extraversion. Interpersonally extraverts are warm and friendly, and enjoy contact with other people particularly the social stimulation of crowds of strangers. Temperamentally they are distinguished by a need for excitement, high levels of energy and activity, and cheerful optimism. People with low extraversion scores are introverts and tend to avoid crowds and have a serious outlook. This does not mean they will not have adequate social skills and neither is it the case that introverts are necessarily introspective or deep thinkers.

Personality factors have also been shown to influence coping strategies in response to stressors. McCrae & Costa (1986) examined the contribution of extroversion, neuroticism and openness-to-experience to coping strategies. High neuroticism and low extroversion was 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. High levels of neuroticism and low levels of extraversion have also been shown to be associated with lower levels of coping by Parkes (1986).

The above evidence suggests personality factors influence vulnerability to psychological distress and coping with stressors. People with HIV infection are at increased risk of developing psychological problems. Moreover the obstacles and difficulties people infected with HIV may face has been shown to be extensive and thus personality factors can be expected to influence attempts at coping with them. The issues that people with HIV face in relation to vocational activity have been highlighted. Personality factors may also account for individual differences in overcoming these. Moreover as outlined by Fishbein (2000) personality traits will

influence self-efficacy because as appraisals they are likely to be influenced by underlying knowledge, particularly of one's enduring characteristics.



## **Section Six: Research aims and hypotheses.**

The rate of new HIV infections continues to increase in the United Kingdom. The introduction of CTs has altered the parameters of the disease and HIV is increasingly thought of as a chronic condition. The difficulties associated with vocational activity and HIV infection have been identified. However little is known about psychological variables that mediate the impact of HIV on vocational activity. The issue of confidence emerged in several qualitative studies and it is proposed that self-efficacy may account for individual differences in vocational activity. Self-efficacy can be conceptualised in two ways: specific to the domain in question and as a general quality that influences action in a variety of domains. The research will determine whether vocational self-efficacy and general self-efficacy are associated with vocational activity.

Vocational activity is an important part of quality of life. Self-efficacy may influence vocational activity in people with HIV infection and thereby contribute to quality of life. Moreover HIV infection can impact upon other valued areas of life and self-efficacy may mediate its impact beyond vocational activity. The research will test for an association between general self-efficacy and quality of life. The specific contribution of vocational activity to quality of life will be ascertained.

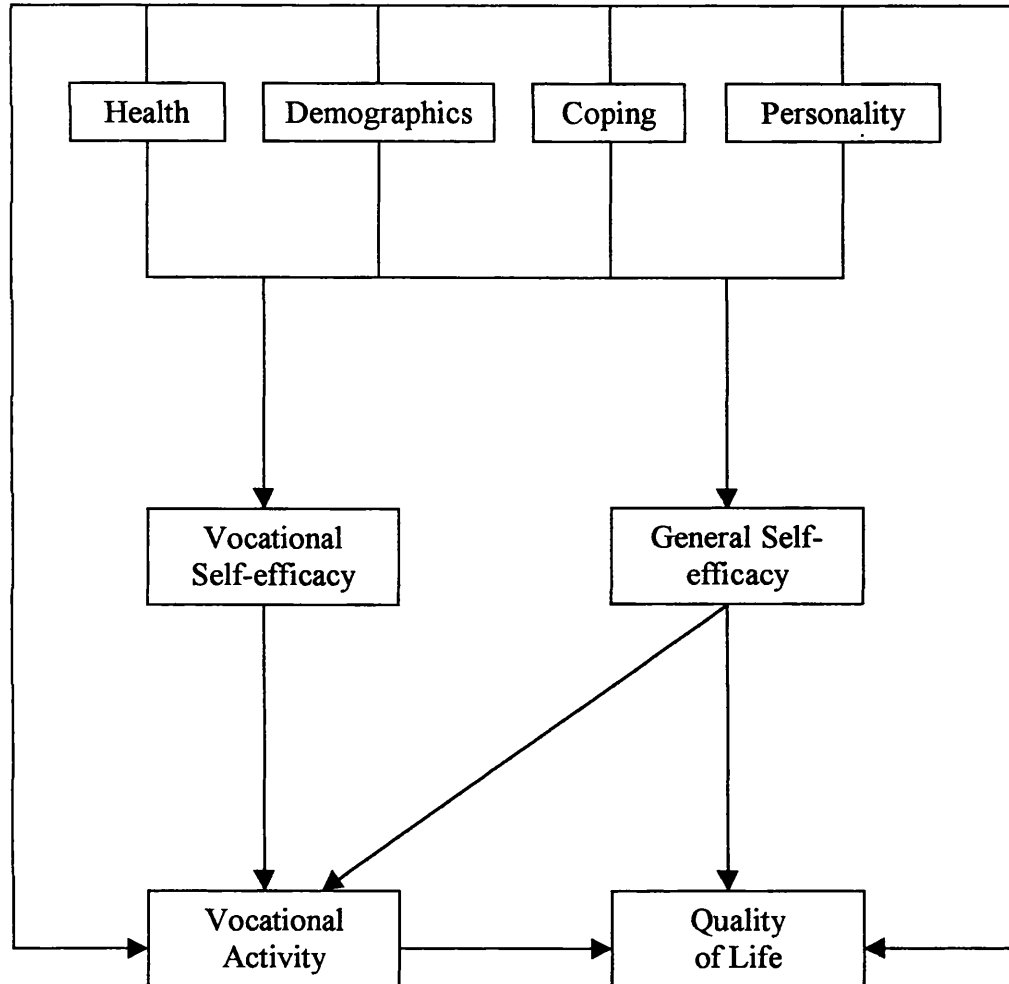
The relevance of HIV related factors, demographics, personality traits and coping to the research has been highlighted. These may have independent effects on vocational activity and quality of life as well as indirectly influence self-efficacy. The research will seek to establish the presence of any effects. Figure (1) is a

diagrammatic representation of how the study variables are hypothesised to interact with one another. The research hypotheses are as follows:

1. Higher levels of general self-efficacy and vocational self-efficacy will be associated with greater degrees of vocational activity in people with HIV infection.
2. Higher levels of general self-efficacy will be associated with greater quality of life in people with HIV infection.
3. Vocational activity will be associated with quality of life in people with HIV infection.

A further aim of the research project is to produce recommendations on the design of interventions to address vocational needs in people with HIV infection. Catalan (2000) refers to the changing needs of the HIV infected population but services in the NHS have been slow to respond to the evolving needs of this client group. Partly this is due to lack of knowledge about psychological variables that may influence vocational activity in people with HIV infection. The Positive Futures Initiative coordinated by the voluntary sector attempts to meet some needs but its implementation is not informed by psychological principles and is also largely unregulated. It is hoped that the research will contribute to knowledge in this area and therefore help people living with HIV achieve their goals in relation to vocational activity.

Figure 1. Hypothesised relationships between study variables.



Notes.

1. Health, demographics, personality, coping & general self-efficacy directly influence quality of life and vocational activity.
2. Health, demographics, coping and personality indirectly influence general and vocational self-efficacy.

## **Chapter Two: Methodology.**

### **Section One: Participants.**

#### **1.0 Source of participants.**

Individuals with HIV infection receive their medical care either through genito-urinary medicine clinics or designated HIV outpatient clinics and inpatient wards. In addition to the services provided by the NHS, voluntary sector organisations provide support and care to people infected with and affected by HIV infection. At the time of writing there were five voluntary sector organisations operating in London. These were The Globe Centre in East London, London Lighthouse in West London, UK Coalition of People Living with HIV/AIDS in south-east London, Terrance Higgins Trust in central London and Positively Women also situated in central London. NHS and voluntary sector services provide most HIV related care.

The voluntary sector HIV services were established in the early days of the HIV epidemic and provided hospice care as well as support and counselling. They were important because NHS services were poorly developed and there was prejudice and hostility towards people with HIV. Since that time the role of these organisations has changed due to advances in medical treatments. The Positive Futures Initiative described in the introduction reflects this change. Rather than providing care for the dying the focus of the support and advice offered has shifted to helping people with HIV access activities such as work.

All participants in this study were recruited either through HIV outpatient clinics or voluntary sector organisations. The sample consisted of 65 individuals who met the single entry criteria of being infected with HIV (detailed descriptive statistics of the sample are available in the results section). While a few participants were recruited from the London Lighthouse and UK Coalition, most were recruited from the HIV outpatient clinics at the North Middlesex Hospital and at St. Ann's Hospital, and from the Globe Centre in East London. The outpatient clinics are situated within Enfield and Haringey that has a diverse multi-ethnic community and a high prevalence of refugees. Thus people attending these clinics are more heterogeneous in terms of gender, sexual orientation and ethnicity than might be the case at central London clinics where attendees tend to be white, gay men. The Globe centre is also situated in area with an ethnically diverse community but people who attend the Globe tend to be white, gay men partly because the gay community established the organisation.

### **1.1 Sample size requirements.**

The required sample size was calculated so that the study would have sufficient power. Power is defined as the probability of rejecting the null hypothesis when it is false (and thus should be rejected) (Siegal & Castellan 1988). It is related to the probability of making a type II error i.e. failing to detect a difference when one exists. Power in fact is equal to 1 – the probability of a Type II error. Power varies as a function of sample size, effect size, measurement error and sampling distribution.

In order to arrive at a reasonable estimate of effect size previous studies examining self-efficacy in a variety of contexts can be used as a guide. These have shown self-efficacy to be a modest predictor of safer sex behaviour (Forsyth & Carey, 1998). Theoretical considerations also guide estimation of effect size. Self-efficacy is part of a broader cognitive-social theory of personality. Moreover the introduction highlighted other factors that could influence vocational activity. Thus for the purposes of this study two effect sizes were selected for correlational analyses. Based on an effect size for self-efficacy of 0.15 at 80% power with a 0.05 significance level, the sample size required is 51. An effect size of 0.2 would require a sample size of 37.

## **1.2. Recruitment of participants.**

Participants were recruited to the study in a number of ways. At the Globe Centre and North Middlesex Hospital posters were displayed in prominent locations (See appendix One) briefly explaining the purpose of the research project and what participants were required to do. The posters also informed participants that they could collect questionnaires from waiting areas and at reception. Return boxes were provided in prominent areas so people could return their completed questionnaires anonymously.

A non-randomised procedure of purposive and accidental sampling was also utilised. This involves selecting a clearly defined sample (purposive) i.e. HIV positive people, visiting sites where they attend, and recruiting participants who the researcher

happened to meet (accidental). This approach was adopted at the North Middlesex Hospital and at The Globe Centre.

The approach adopted for recruitment at St. Ann's HIV outpatient clinic was different because the HIV outpatients were seen alongside patients attending for other sexually transmitted diseases. Thus it was not felt appropriate to attempt to identify people in the waiting room who met the inclusion criterion. The Consultant GUM Physician held an HIV clinic every fortnight. He agreed to explain the nature of the research project to his HIV positive patients and ask if they would participate. If they agreed he gave them a questionnaire and a stamped addressed envelope in which to return it.

It is difficult to provide figures on refusal rates given that one method of recruitment was through advertisement. Some information however is available based on refusal rates when the researcher was approaching individuals. Fifteen percent of individuals approached in this way refused to take part. The main reason given was English not being their first language.

## **Section two: Design.**

The research design was cross-sectional in nature. The selection of independent and dependent variables corresponds to the research aims and hypotheses as outlined in the introduction. The study aimed to compare levels of vocational self-efficacy and general self-efficacy with degrees of vocational activity. The study also tested for an association between general self-efficacy and quality of life. Thus in these instances the independent variables were vocational self-efficacy and general self-efficacy and the dependent variables were vocational activity and quality of life. Furthermore the study attempted to ascertain the contribution of vocational activity to quality of life and in this instance vocational activity became the independent variable and quality of life remained a dependent variable.

The relevance of HIV related factors, demographics, personality traits and coping to the research was highlighted. These were also independent variables but their utilisation will be limited to establishing the presence of any effects on the above comparisons.



## **Section Three: Measures.**

A questionnaire pack was produced for each participant. At the front of the pack was a participant information sheet (A copy can be found in appendix one). The participant information sheet:

- \* Explained the purpose of the research project.
- \* Outlined what was required of participants.
- \* Stated that replies would be confidential and anonymous.
- \* Gave details of the personnel involved and how they could be contacted if the need arose.
- \* Provided a tear off slip so participants could receive a summary of the outcome of the research if they wished.

The questionnaire pack was divided into sections headed demographic information, vocational information and health information. These sections were followed by the pre-existing measures selected for use in the study. All study materials were typed to provide a clear presentation of study materials.

### **3.0 Demographic Information.**

Information was requested for age, gender, ethnicity, sexual orientation, first language, employment status and the first part of postcode.

### **3.1 Vocational Information.**

The following information was requested:

- \* Source of income.
- \* Income before testing positive for HIV and current income.
- \* Details of any educational qualifications
- \* Date (month and year) when last worked and brief details

### **3.2 HIV related Information.**

Assessment of HIV health status was measured by self-report of CD4 count and viral load. This method was adopted because assessment of disease progression has changed from an emphasis on the presence of opportunistic infections to CD4 count and viral load testing.

Some people with HIV have experienced improved physical health and the removal of their AIDS diagnosis as a result of CTs. The experience of people who believed they were dying from HIV but who have come to believe that they will live as been defined as “revival” (Brashers et al., 1999). Identifying people who had undergone revival presented a challenge. The study attempted to identify such people in two ways. First participants were asked if they had ever received an AIDS diagnosis and if so the date (month & year). Second participants were asked how much they believed their life expectancy would be reduced when they first tested positive for HIV and currently.

In addition to the above HIV related information details were requested on the following items:

- \* Date (month and year) of testing positive for HIV
- \* Use of CTs (number & details of any side effects)
- \* Use of complimentary therapies (number)

### **3.3 Vocational Activity.**

It was noted in the introduction that studies examining the impact of HIV on work are limited because work has been defined in a narrow way with people defined as either employed full-time or not employed full-time. Thus variation in work patterns amongst people with HIV could be ignored if employment activity were measured in this way. Thus the operational definition of vocational activity was “any activity that is likely to increase the chances of work as well as work itself.” Participants were asked if they were currently involved in any of the following:

- \* Part or full time work
- \* Contract/temporary work
- \* Work placement
- \* Work related training
- \* Part of full time education
- \* Voluntary work
- \* Running own business

Three questions were devised to ascertain participant's intentions about work. One question asked if they were considering work because of health improvements. Two questions asked if they were not considering work because of concerns about becoming ill or losing benefits respectively. It was noted that people with HIV face uncertainty in relation to their diagnosis. One question asked if participants were not considering work because they believed their lives were too uncertain. In all the above questions participants rated their level of agreement or disagreement.

### **3.4 Vocational Self-efficacy Scale.**

Forsyth & Carey (1998) examined the methodological features of research assessing the relationship between self-efficacy and safer sex behaviour. They identified a range of methodological weaknesses in the research and made recommendations for improving the reliability and validity of self-efficacy measurement in the light of these weaknesses. Their recommendations were as follows:

- \* Self-efficacy measures should assess beliefs, behaviours and circumstances.
- \* Self-efficacy measures should contain items that reflect people's beliefs about their capacities to perform behaviours within a particular area of functioning under circumstances that present graduations of challenge.
- \* Greater accuracy is afforded by contextual measures that identify a class of related behaviours within an area of functioning and describe typical circumstances in which behaviours occur.
- \* Brief measures may not take into account variations in situational demands.

- \* Attention must be given to conditions relevant to target population.
- \* Likert scaling with wide response intervals should be used.
- \* Items reflecting graduations of challenge reduce ceiling effects.
- \* Items should not assess knowledge.

These recommendations were adhered to as far as possible in the construction of the vocational self-efficacy scale. Items were required that reflected the range of obstacles and conditions faced by the target population in relation to the domain under consideration. The qualitative research literature discussed in the introduction identified the nature of the difficulties faced by people with HIV in relation to employment. These provided one source of potential items. Other research findings on the psychological aspects of HIV infection were also used as a potential source of items. Another source of potential items was the clinical experiences of a senior clinical psychologist working in HIV and the experiences of a vocational training manager at FACTS. Once no more items could be generated they were subject to a process of peer review (four clinical psychologists) where items not judged to reflect self-efficacy were eliminated.

The vocational self-efficacy scale used in the study consisted of 10 items that attempted to meet the methodological recommendations outlined above. All items reflected beliefs about the ability to work in the context of a range of different situations (e.g. feeling depressed, feeling unwell) that reflected graduations of difficulty (e.g. taking combination therapies, suffering side effects from taking combination therapies). A five-point Likert scale was used for each item with possible responses ranging from 1=not at all confident to 5=very confident. The

overall score indicated the strength of an individual's belief that they would be able to overcome the obstacles described. A copy of the scale is provided in appendix two.

### **3.5 Generalised Self-efficacy scale.**

General self-efficacy refers to an individual's general beliefs about their ability to respond to and control environmental challenges and demands. The Generalised Self-Efficacy Scale (GSES) (Jerusalem & Schwarzer, 1992) measures the strength of an individual's belief in their capacity to respond to difficult situations and to overcome associated obstacles or setbacks.

The GSES contains ten items and respondents are required to indicate the degree to which each statement applies to them. For each item individuals must select one of four possible responses that are coded numerically from 1 to 4. The choices range from "not at all true" (1) to "exactly true" (4). The scores for each item are summed and the total score indicates the degree of a person's generalised self-efficacy belief. The greater the score, the stronger their general belief of self-efficacy.

The psychometric evaluation of the GSES has been conducted with German samples. Reported reliability coefficients have ranged from 0.82 to 0.93. Validity has been examined by comparison with other measures. The GSES has been found to be positively associated with self-esteem ( $r = 0.52$ ), and optimism (0.49). A negative correlation was reported between the GSES and general anxiety ( $r = -0.54$ ).

### **3.6 Coping Inventory for Stressful Situations.**

The Coping Inventory for Stressful Situations (CISS) (Endler & Parker, 1990) was designed to assess coping strategies usually employed in dealing with stressful situations. It was employed in the study because of its known psychometric properties and because of the theoretical conceptualisation of coping underpinning it. The CISS measures three types of coping strategy that correspond closely to the coping styles outlined in the introduction. Emotion-focused coping strategies are described as emotional reactions that are self-orientated and aim to reduce stress. Task or problem-focused coping is described as purposeful and task-orientated strategies aimed at solving, cognitively restructuring or altering the problem. Avoidance-focused coping describes cognitive and behavioural strategies aimed at avoiding the stressful situation. There are two components to avoidance coping: distraction (using activities to distract oneself) and social diversion (using people to divert attention from stress).

The CISS consists of 48 items. Emotion-focused coping and problem-focused coping are each assessed by 16 items. Avoidance focused coping has two subscales: distraction (8 items) and social diversion (5 items). The remaining three items of the avoidance scale are not scored for these two subscales but are added to the distraction and social diversion scores to form the total score for avoidance-focused coping. Each item consists of a statement of a way of coping and participants are invited to rate the frequency of engaging in that activity when they encounter a difficult, upsetting or stressful situation. There is a 5 point frequency rating scale

with 1 = not at all, and 5 = very much. The range of scores for the three main coping scales is 16-80. For the distraction and social diversion subscales the range of scores is 8-40 and 5-25 respectively. For the three coping scales and two avoidance-focused subscales the higher the score, the greater the utilisation of the coping strategy.

Internal consistency of items for the task, emotion and avoidance coping scales were reported as .90, .90 and .81 respectively in males and .87, .89 and .82 respectively in females in a normative sample of North American adults (Endler & Parker, 1990). Test-retest reliabilities conducted six weeks apart in a sample of undergraduates for task, emotion and avoidance coping scales were reported as .73, .68 and .55 respectively (Endler & Parker, 1990). The validity of the CISS has been evaluated in different ways with populations in the United States. A correlation of .56 was reported between the emotion scale of the CISS and the Beck Depression Inventory and a correlation of -.43 found between the task scale of the CISS and the Beck Depression Inventory (Endler & Parker, 1990). A correlation of .66 was observed between the CISS emotion scale and the neuroticism scale of the Eysenck Personality Inventory (EPI). The CISS task scale was unrelated to the extroversion scale ( $r = -.15$ ) and neuroticism scale ( $r = -.16$ ) of the EPI (Endler & Parker, 1990).

### **3.7 Eysenck Personality Questionnaire Revised Short Scale.**

The Eysenck Personality Questionnaire Revised (EPQ-R) short scale (Eysenck & Eysenck, 1991) was used in the study to measure personality variables. This is a shortened version of the Eysenck Personality Questionnaire Revised (EPQ-R) that



contains several improvements from earlier Eysenck personality questionnaires. It measures three major dimensions of personality: neuroticism (emotional stability), extroversion-introversion and psychoticism (tough-mindedness). It also contains a Lie Scale that attempts to measure the tendency of participants to give socially desirable answers. The Lie Scale also appears to measure some type of stable personality trait indicating conformity. The EPQ-R short scale was selected because of its sound psychometric properties and to limit time demands on participants.

The EPQ-R short scale comprises 48 items. 12 items are allocated to measure extroversion (E), neuroticism (N), psychoticism (P), and to form the Lie Scale (L). Each item contains a statement and participants must give a yes or no response. One point is awarded for each answer given that is in the appropriate direction of the specific scale. For E, N, P, and L the range of scores is 0-12. The higher the score, the greater the degree a specific personality trait is present.

The validity of the EPQ-R has been confirmed by numerous factor analytic studies. Eysenck & Eysenck (1991) reported reliability coefficients for males of the EPQ-R short scale of 0.88 for E, 0.84 for N, 0.62 for P and 0.77 for L. In women reported reliability coefficients are slightly reduced at 0.84 for E, 0.80 for N, 0.61 for P and 0.73 for L. The very slight decreases in the reliability coefficients of the EPQ-R short scale compared to the EPQ-R suggest no significant loss in reliability by a reduction in the number of items.

### **3.8 Hospital Anxiety and Depression Scale.**

The Hospital Anxiety and Depression (HAD) scale (Zigmond & Snaith, 1983) was developed to measure depression and anxiety in surgical and medical outpatient settings. Traditional measures of depression included items about the presence of physical symptoms such as loss of appetite and sleep disturbance. These symptoms are often present in physical illness although the person may not be depressed. Thus the HAD scale was designed to ensure measurement of depression and anxiety was not contaminated by symptoms primarily attributable to physical illness. The HAD scale was selected to measure anxiety and depression for this reason.

The HAD scale consists of 14 items of which 7 assess anxiety and seven assess depression. Each item is a statement that the participant must rate in terms of frequency of their experience in the past week. Items are rated on a 4-point scale according to severity. A score of zero means the absence of a symptom and a score of three signifies the maximum intensity of a symptom. Scores on the HAD scale can range from 0 to 21. Scores between 11 and 21 indicate clinical levels of anxiety and depression. Scores between 8 and 10 denote probable levels of clinical anxiety and depression, and scores of 7 and below are normal. The HAD scale is a widely used instrument and has been shown to be reliable and valid (e.g. Zigmond & Snaith, 1983). Another advantage is that it is quick and easy to complete.

### **3.9 Quality of Life Inventory.**

The Quality of Life Inventory (QOLI) (Frisch, 1993) undertakes a comprehensive

assessment of life areas that contribute to quality of life. It is based on the assumption that a finite number of life domains contribute to overall life satisfaction and happiness. In addition for a life domain to be included in the QOLI it was required to be empirically associated with life satisfaction and happiness. There are 16 life domains included in the QOLI: health, self-esteem, goals and values, money, work, play, learning, creativity, helping, love, friends, children, relatives, home, neighbourhood and community.

Working definitions are provided for participants for each of the 16 areas of life covered by the QOLI. For each life domain participants are requested to rate its importance to their overall level of happiness. There are three responses available: not important, important and very important. Participants are then requested to rate their level of satisfaction with the area in question. They are six possible responses ranging from very dissatisfied to very satisfied. Overall they are 32 items in the QOLI. Sample items for work and friends are provided in appendix two. There is also a qualitative section that asks participants to elaborate upon their satisfaction ratings by listing any difficulties that interfere with their satisfaction with the life areas. This section was removed in order to keep completion time for participants within reasonable limits.

The QOLI produces weighted satisfaction ratings for each life domain. Weighted satisfaction ratings are calculated by multiplying the importance ratings (on a scale of 0 to 2) by the satisfaction ratings (on a scale of -3 to +3). Weighted satisfaction ratings range in value from -6 (extreme satisfaction) to +6 (extreme satisfaction). The QOLI produces an overall raw score. This is calculated by adding all the

weighted satisfaction ratings and dividing this number by the number of life areas rated as important or very important. The designated ranges in raw scores are used to categorise an individual on one of four quality of life classifications: high, average, low and very low. People whose scores fall within the range of 1.6 to 6.0 are classified as high or average. They are characterised as possessing important psychological attributes and showing very low levels of psychological distress. People who score between -6.0 and 1.5 are classified as low or very low. Such individuals are distinguished by lacking important psychological resources and exhibiting clinical levels of psychological distress. They are also likely to be at risk of developing mental health problems in the future.

Frisch (1994) evaluated the psychometric properties of the QOLI in a standardisation sample of 798 North American adults. Test-retest reliability of the QOLI was reported as 0.73 over a two-week test interval, and internal consistency reliability for weighted satisfaction ratings was 0.79. The correlation between weighted satisfaction ratings and the overall raw score was 0.99. Positive and significant correlations between the QOLI and other measures of life satisfaction were reported. Frisch (1994) reports that overall scores on the QOLI have some ability to predict mental health problems, particularly depression.

## **Section four: Procedure.**

### **4.1 Pre-data collection phase.**

Ethical approval for the study was obtained from the Enfield and Haringey Health Authority Ethics Committee by the research supervisor. A copy of the letter of approval for the study can be found in appendix three. In addition approval was obtained from the directors of the non-statutory HIV services used for participant recruitment in the study.

### **4.2 Pilot phase.**

The questionnaire package was tested with five service users at the FACTS centre to check for procedural difficulties. This was important because the questionnaire package was to be self-administered. The author sat with the volunteers as they read the questionnaire package. Several minor changes were made to the package following this process. One service user became visibly distressed whilst reading the health information section. He said it made him think about his partner who had recently died of an AIDS-related illness. It was decided to re-emphasise that participants could contact either the author or supervisor if they felt the need at the end of the questionnaire package. This had already been written on the participant information sheet. In addition personnel at the recruitment sites were informed of possible reactions following completion and that they could direct participants to research personnel if they were distressed. Other changes made were a brief explanation of each of the measures, and providing a definition of the word

“procrastinating” on item number five of the Coping Inventory for Stressful Situations. It was estimated that completion of the research package took between twenty and thirty minutes.

### **4.3 Data collection phase.**

When the study commenced recruitment was taking place at the Foundation for Aids Counselling and Support (FACTS) and at the HIV outpatient clinic at the North Middlesex Hospital. However one week into data collection FACTS closed without warning due to lack of funding amid an outcry among the local HIV positive community. Therefore the Globe Centre, London Lighthouse and UK Coalition were approached about recruitment taking place on their premises. London Lighthouse agreed but this site was abandoned after the person involved left without warning. The UK Coalition was approached and a meeting took place between the author and the director of the organisation. There was concern expressed by one manager about the research because it was felt to be “too western in orientation” and the inclusion of the Eysenck Personality Questionnaire was seen as pathologising. Attempts were made to address these concerns and although permission was eventually given for recruitment to take place, this site was also abandoned due to lack of response. The Globe centre was approached and the researcher met with the director of the organisation. He felt the research was important and gave permission for recruitment to take place. The author enjoyed considerable support with recruitment from this organisation.

As outlined in section one, there were several approaches to recruitment. To ensure

anonymity and because some recruitment was through self-selection, participants were not required to sign a written consent form. It was stated at the front of the questionnaire package that it was assumed that participants were happy to participate in the study and had contacted the researchers if anything was unclear. One of the purposes of the participant information sheet was to provide enough information about the study to make an informed decision about participation. It also provided contact details including a mobile telephone number if participants wanted any further information or were distressed. When recruitment was through non-randomised purposive sampling, the author approached individuals in waiting areas and provided them with an A4 sized copy of the poster advertising the study to read (A copy can be found in appendix one). The author then answered any questions and asked if they were happy to participate. On four occasions the author attended the Globe Centre and outlined the nature of the study to groups undertaking computer skills training courses. Questionnaires were left for them to collect at the end of their classes if they wished to participate.

#### **4.4 Post data collection phase.**

All data was transformed into variable data and inputted into SPSS v.10.0.5. Overall scores on measures was calculated manually in two cases to check the accuracy of computer assisted computations.

## **Chapter Three: Results.**

The results will be divided into three sections. Section one will provide descriptive data for all variables in the study. This will include assessment of the distribution of scores for continuous variables to check for normality. Section two will comment on the reliability of the vocational self-efficacy scale developed for use in the study. Section three will present the outcome of statistical analyses employed to test the research hypotheses.

A total of 71 questionnaires were returned. Six questionnaires were unusable leaving 65 that were included in the analyses. Although missing data was minimal in a few cases participants either failed to complete a measure or missed too many items of a measure invalidating their response. Therefore with some of the variables the number of cases was be slightly less than 65.

When variables were continuous, the distribution of scores was checked for normality by visual inspection and statistical analyses. For the purposes of statistical analyses a probability level of 0.01 was selected for judgements about normality i.e. the likelihood of the sample not being drawn from a normal population.



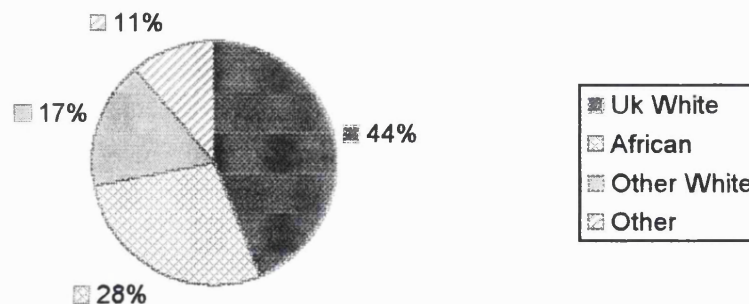
## Section One: Descriptive Analyses.

### Part 1: Demographic and HIV data.

#### 1.1 Demographic Characteristics.

Seventy five percent (n=49) of the sample were male. The mean age of the sample was 39 years (range 24-56). Twenty nine described their ethnicity as UK white, 18 as African, 11 as other white and the remaining 7 were made up of UK Black, Caribbean, Asian, and Latin American persons. Figure (2) illustrates the ethnic breakdown of the sample in percent. For 72% of the sample English was their first

Figure 2. Breakdown of participant's ethnicity in %



language. Fifty five percent of the sample described their sexual orientation as homosexual and 29% as heterosexual. Eight percent of the sample described themselves as bisexual. The remaining 8% did not disclose their sexual orientation.

Twenty six percent (n=17) were in paid employment compared to 74% (n=48) of the sample who were not. Sixty eight percent were in receipt of social security benefits while 6% received no income from either employment or social security benefits. Modal level of income before testing positive for HIV was £10000-14999, compared to current modal income of £0-4999. Fifteen percent of the sample had no formal educational qualifications, while 28% had “O” or “A” levels, and 57% had been educated to degree level.

## **1.2 HIV Data.**

Mean length of time since testing positive for HIV infection was 72 months (range 2-248 months). Forty three percent (n=28) had previously been diagnosed with AIDS and the mean length of time since an AIDS diagnosis was 38 months (range 1-99 months). In addition for those who were previously diagnosed with AIDS and were without paid employment, mean length of time without paid work was 44 months.

The data in tables (1) and (2) suggest that the majority of the sample were not currently at an advanced stage of HIV disease progression as indicated by the modal CD4 count of 201-500 and the modal viral load being undetectable.

Seventy seven percent (n=50) of the sample were taking CTs and of these 68% reported side effects. Thirty three percent (n=22) were receiving treatment with complimentary medicines. Only 20% of the sample currently felt their life would be cut short either “a lot” or “completely”. However, 81% rated that at the time of receiving an HIV positive diagnosis, they thought their life would be cut short either

“a lot” or “completely”.

Table 1. CD4 Count.

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CD4 Count	Frequency (n=64)	Percent
<50	3	5
51-200	22	34
201-500	25	39
501 +	11	17
Don't know	3	5

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Table 2. Viral Load

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Viral Load	Frequency (n=63)	Percent
Undetectable	28	44
51-1000	13	21
1001-10,000	4	6
10,001-50,000	2	6
50,001-100,000	2	3
100,000 +	5	8
Don't know	7	11

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## Part 2: Independent Variables.

### 2.1 General Self-efficacy.

Table (3) gives the mean, standard deviation and skewness for general self-efficacy. Schwarzer (1993) provided a mean generalised self-efficacy rating of 29.28 and SD of 4.6 based on a standardisation sample of 1660 German adults. The mean score for the sample was slightly lower than this at 26.44 with a slightly higher SD of 5.04. The distribution of scores and associated skewness were consistent with a normal distribution thus enabling parametric analyses to be employed for this variable where appropriate.

Table 3. Mean, std. deviation and skewness for generalised self-efficacy.

Variable (score range)	N	Mean	Std. Deviation	Skewness	Std. Error of skewness	Range
Generalised Self-efficacy (10-40)	64	26.44	5.04	-.537	.299	10-40

### 2.2 Personality Traits.

Table (4) gives means, standard deviations and skewness for the EPI subscales. Eysenck and Eysenck (1991) provide mean scores and SDs for the subscales of the EPQ-R based on a sample of 408 males and 494 females who were students, teachers

and unspecified others. These mean scores are shown in italics in table (4). Comparison of these means scores with the mean scores of the sample indicated similarity with the standardisation sample in terms of extraversion, psychoticism and the Lie Scale. The mean score of the sample for neuroticism was considerably higher than in the standardisation sample. This suggests a higher level of neuroticism in the sample than might be expected in the general population. Analysis of the score distribution did not reveal a significant departure from normality. Visual inspection of the distribution of neuroticism scores did however suggest it was negatively skewed and this was also the case with extraversion. Therefore for these two variables both parametric and non-parametric analyses were performed where appropriate and any substantially different results reported.

Table 4. Means, std. deviations and skewness for the EPQ-R Short Scale.

Variable (score range)	N	Mean	Std. Deviation	Skewness	Std. Error of skewness	Range
Extraversion (0-12)	63	7.31	3.65	-.457	.302	0-12
		<i>6.36</i>	<i>3.80</i>			
Lie Scale (0-12)	63	4.75	2.59	.077	.302	0-10
		<i>3.86</i>	<i>2.71</i>			
Neuroticism (0-12)	63	7.24	3.33	-.277	.302	0-12
		<i>4.95</i>	<i>3.44</i>			
Psychoticism (0-12)	63	2.95	1.90	.642	.302	0-8
		<i>3.08</i>	<i>2.20</i>			

### 2.3 Coping.

The CISS measures three types of coping strategy. Table (5) gives means, std. deviations, and skewness for the three major CISS subscales. Analysis of score distributions for the three coping strategies revealed these were normal. This was also established by visual inspection. The figures in italics in table (5) are the means and standard deviations provided by Endler and Parker (1990) based on a non-clinical sample of North American adults. There were lower levels of problem focused coping and higher levels of emotion focused and avoidance coping in the sample compared to the normative sample. Mean scores for the three coping styles in the sample were very similar to scores obtained in a sample of psychiatric inpatients by Endler and Parker (1990) of 55.63 for problem focused coping, 47.92 for emotion focused coping and 47.31 for avoidance coping.

Table 5. Means, std. deviations and skewness for CISS subscales.

Variable (score range)	N	Mean	Std. Deviation	Skewness	Std. Error of skewness	Range
Problem-focused coping (16-80)	63	55.24 <i>58.6</i>	11.72 <i>9.95</i>	.046	.302	32-78
Emotion focused coping (16-80)	63	46.02 <i>39</i>	12.92 <i>11.54</i>	.0235	.302	19-76
Avoidance coping (16-80)	63	46.03 <i>38.10</i>	10.93 <i>9.59</i>	-.054	.302	21-68

## 2.4 Anxiety and Depression.

Mean level of anxiety and depression was 9.74 and 6.75 respectively. Analysis of skewness revealed a normal distribution for these variables. Table (6) summarises these data for anxiety and depression.

Table 6. Means, std. deviations and skewness for HAD Scale.

Variable (score range)	N	Mean	Std. Deviation	Skewness	Std. Error of skewness	Range
Anxiety (0-21)	62	9.74	4.87	.283	.304	2-21
Depression (0-21)	62	6.75	4.75	.712	.304	0-20

Total scores on the HAD scale can be categorised according to specified ranges. This revealed that 42% of the sample scored above the cut off (11) used to determine probable caseness for clinical anxiety. Nineteen percent scored above the lower cut off (8) that is used to identify borderline cases and 39% fell within the normal range. In the matter of depression, 26% scored above the cut off (11) indicating probable caseness for clinical depression, 11% scored above the lower cut-off suggesting borderline cases and 63% scored within the normal range.

### Part 3: Dependent Variables.

#### 3.1 Vocational Activity.

Overall 26% (n=17) of the sample were in paid employment. Data were available that provides more detail on the type of vocational activities engaged in by participants. Table (7) provides a breakdown of vocational activity in terms of frequencies.

Table 7. Frequency of Vocational Activity

Type of Vocational Activity	Frequency
Full time work	7
Part time work	10
Work related training	16
Further education part time	14
Voluntary work	17

The data for vocational activity was transformed into one of three mutually exclusive categories for the purposes of future analyses. Table (8) provides figures for these categories and the inclusion criteria for each. The majority of the sample was involved in vocational activity that was unpaid and limited in terms of time commitment. Only a small number of people were not involved in any vocational activity.



Table (8). Proportions falling into different levels of vocational activity.

Category	Frequency	Percent
Paid (included if involved in either full or part time work)	17	26
Unpaid (included if involved in either education, voluntary work, or work related training)	34	52
None (included if not involved in paid or unpaid)	14	22

For those not engaged in paid employment, a series of questions attempted to identify participant’s intentions towards employment. Fifty two percent agreed with the statement that they were not considering employment because they were concerned about falling ill compared to 23% who disagreed. However forty six percent also agreed with the statement that they were considering employment because they felt a lot healthier compared to 31% who disagreed. Nineteen percent agreed with the statement that they were not considering employment because they were worried about losing benefits compared to 35% who disagreed.

A further question attempted to assess the extent that uncertainty was perceived as an obstacle to employment for those without paid work. Fifty six percent agreed with the statement that it would be difficult to work because their lives were too uncertain compared to 33% who disagreed.

### 3.2 Quality of Life.

The raw scores obtained from the Quality of Life Inventory (QOLI) (Frisch, 1994) are used to categorise individuals according to one of four quality of life classifications. The majority of participant's quality of life was classified as very low. The second and third most frequent category was average and high respectively. Low was the least frequent classification. Table (9) shows frequencies and percentages for quality of life. The low and very low classifications can be collapsed together as can the average and high classifications. Thus 56% of participants quality of life was classified as low.

Table 9. Quality of Life Classifications: Frequency and Percentage Data.

Quality of Life	Frequency	Percent
High	8	13
Average	19	31
Low	7	12
Very low	27	44

QOLI raw scores can also be treated as continuous scores. Table (10) provides the mean, standard deviation and skewness for the QOLI raw scores. The mean score was 1.22 and this is equivalent to a low quality of life classification. Moreover, Frisch (1994) reports a mean QOLI raw score of 2.6 based on a standardisation sample of 798 US adults of whom 30% were non-white. This emphasises the special nature of the population in terms of quality of life. Neither visual inspection of the distribution of raw scores or statistical analyses revealed a problem with normality.

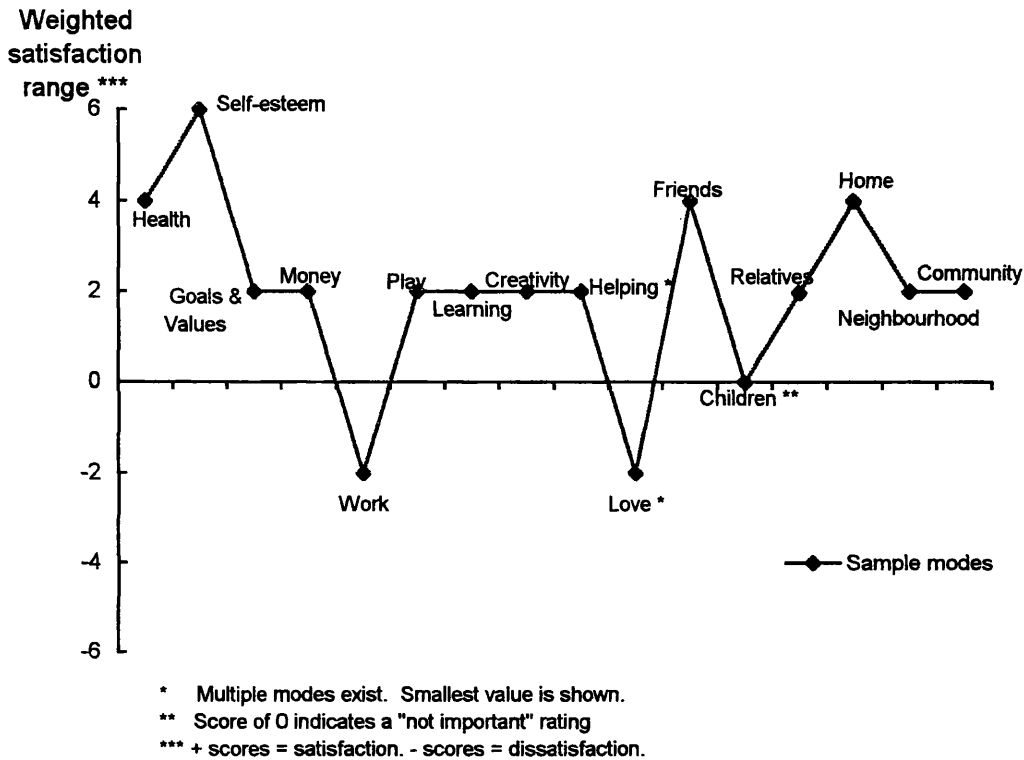
The raw scores cannot truly be regarded as continuous data however because scores falling within a specified range are used for classification purposes. Furthermore Frisch (1994) provides percentile equivalents for QOL raw scores and reports that the 20<sup>th</sup> percentile distinguishes clinical from non-clinical samples. Fifty six percent of the sample scored at or below the 20<sup>th</sup> percentile and therefore the distribution of scores can not be regarded as normal. Thus both parametric and non-parametric statistics were employed where appropriate and any substantially different results reported.

Table 10. Mean, standard deviation and skewness of QOLI raw scores.

Variable (score range)	N	Mean	Std. Deviation	Skewness	Std. Error of skewness	Range
Quality of Life (-6.0 - 5.9)	61	1.22	2.12	-.112	.306	-4.2 - 5.6

Weighted satisfaction scores (as described in the methods section above) combine both importance and satisfaction ratings indicating the contribution of a specific life domain to quality of life. These can be used to provide a quality of life “profile” for each individual. Figure (3) provides a quality of life profile for the entire sample using modal values. This indicates that self-esteem, health, friends and home provided the greatest sources of satisfaction with quality of life and that work and love were the greatest sources of dissatisfaction.

Figure 3. Quality of life sample profile



Weighted satisfaction scores range from -6 to 6. In view of this modal satisfaction ratings could be misleading because when multiple modes exist they may obscure the absolute levels of satisfaction and dissatisfaction. Thus table (11) gives percentage for weighted satisfaction and dissatisfaction for each life domain and the proportions that judged a life domain as not important thus giving a score of 0.

While the percentage figures in table (11) do not account for degrees of satisfaction and dissatisfaction with life areas, they give a slightly different picture than the modal weighted satisfaction scores. There are more people dissatisfied than satisfied with money. There are equal numbers satisfied and dissatisfied with work. The

number of people satisfied with love is slightly above those dissatisfied, but the modal weighted satisfaction score for love indicates dissatisfaction. For most life domains the proportion of people judging it as unimportant was low with the exception of children where 34% of the sample rated it as “not important”.

Table 11. Satisfaction and Dissatisfaction with Life Areas in %.

Life Domain	% Satisfied	% Dissatisfied	% not relevant
Health	62	38	-
Self-esteem	62	38	-
Goals and values	65.6	31.1	3.3
Money	41	44	15
Work	46	46	8
Play	67.2	31.2	1.6
Learning	73.8	24.5	1.6
Creativity	67	28	5
Helping	69	23	8
Love	47	43	10
Friends	78.4	18.3	3.3
Children	46	18	36
Relatives	72.1	16.4	11.5
Home	75	23.3	1.7
Neighbourhood	53.3	36.7	10
Community	65	30	5

Table (12) shows the proportion of people satisfied and dissatisfied with work across the three levels of vocational activity. It suggests satisfaction with the work quality of life domain increases with vocational activity and dissatisfaction decreases with greater vocational activity.

Table 12. Degrees of satisfaction across levels of vocational activity.

Vocational activity		% Satisfied	% Not satisfied
None	% within none	42%	58%
	<i>% within work satisfaction</i>	16%	24%
Unpaid	% within unpaid	41%	59%
	<i>% within work satisfaction</i>	40%	66%
Paid	% within paid	82%	18%
	<i>% within work satisfaction</i>	44%	10%

## **Descriptive Analyses Section summary.**

- UK Whites made up less than half the sample.
- Approximately one third of participants were heterosexual and one quarter were female.
- The average length of HIV infection was six years. Over one third of the sample had previously been diagnosed with AIDS.
- CD4 count and viral load data suggested the majority of participants were currently not at an advanced stage of HIV infection despite some participants having previously been diagnosed with AIDS.
- Over three-quarters of participants were taking CTs.
- Mean general self-efficacy was slightly lower compared to standardisation samples.
- There was a higher level of neuroticism compared to standardisation samples.
- Compared to standardisation samples there was more emotion and avoidance coping and less problem focused coping.
- Over one half of the sample were in the probable range for the screening measure for anxiety.
- One quarter of the sample were in the probable range for the depression screening measure.
- Three quarters of the sample were not in paid employment.
- The majority of the sample were dissatisfied with the absence of paid employment in their lives.
- Those not in paid employment appear to be caught in a dilemma between

wanting to work because of improved health but also not wanting to because of concerns about falling ill.

- Over half the sample was classified as “very low” or “low” on the quality of life instrument. This means that they fell below the 20<sup>th</sup> percentile which distinguishes clinical from non-clinical samples.
- Work and love were the largest sources of dissatisfaction with quality of life.



## Section two: Vocational Self-efficacy.

A vocational self-efficacy scale was constructed as outlined in the methods section above. Table (13) provides measures of central tendency and skewness. They indicate a slightly positively skewed distribution of scores. Statistical analysis of skewness however indicated the distribution of scores was normal. This was also confirmed by visual inspection of score distribution.

Table 13. Mean, std. deviation and skewness for vocational self-efficacy.

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Variable (score range)	N	Median	Mean	Std. Deviation	Skewness	Std. Error of skewness	Range
Vocational self-efficacy (10-50)	65	23	23.98	9.14	.705	.297	11-50

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Reliability analysis was performed on the scale. All ten items correlated significantly with each other ( $p = <0.05$ ). Furthermore the reliability coefficient (Cronbach's Alpha) was 0.90. The largest difference in mean scores between two items was 2.0 and 3.2. For one of these items, participants rated their level of confidence in their ability to take CTs while working and for the other they rated their confidence level in their ability to work while suffering side effects from CTs. The difference in mean scores between these two items suggests they did reflect circumstances that presented graduations of challenge (as recommended by Forsyth and Carey, 1998), but it appears all other items failed to do so. Thus it would appear that the vocational self-efficacy scale deflates true levels of vocational self-efficacy

due to ceiling effects. Nevertheless the items are representative of the obstacles identified in the literature.

There was evidence from the Pearson correlation coefficients obtained that the vocational self-efficacy scale was measuring a unitary construct. As expected vocational self-efficacy did not correlate significantly with generalised self-efficacy ( $r = 0.14$ ,  $p = .284$ ). Furthermore no significant correlations were observed between vocational self-efficacy and extraversion ( $r = 0.13$ ,  $p = .331$ ), neuroticism ( $r = -0.08$ ,  $p = .523$ ), psychoticism ( $r = 0.14$ ,  $p = .286$ ), problem-focused coping ( $r = 0.18$ ,  $p = .165$ ), emotion-focused coping ( $r = -0.20$ ,  $p = .114$ ) or avoidance coping ( $r = 0.15$ ,  $p = .250$ ).

### **Section three: Statistical analyses.**

Unless otherwise stated Spearman's rho was used for all correlational analyses reported in this section.

#### **Part One: Research hypotheses.**

Hypothesis One: Higher levels of general self-efficacy and vocational self-efficacy will be associated with greater degrees of vocational activity.

Vocational activity was categorised according to three levels: paid, unpaid and none as outlined previously. The mean level of vocational self-efficacy for the three groups was 29.1 for paid, 23.3 for unpaid and 19.5 for none. A one way analysis of variance revealed that there were significant differences in mean levels of vocational self-efficacy amongst the three groups ( $F(2,62) = 5.026, p = .009$ ). Post hoc comparisons (Bonferroni) indicated that only the paid and unpaid groups were significantly different from each other in mean vocational self-efficacy ( $p = .009$ ).

Both parametric and non-parametric correlations were also employed to test the hypothesis and there were no substantive differences in the results generated. The number of participants in paid employment was small however thereby skewing the sample. Therefore non-parametric correlations are reported here. There was a positive correlation between vocational self-efficacy and vocational activity ( $r = 0.37, p = .002$ ). There were negative correlations between depression and vocational

activity ( $r = -0.39$ ,  $p = .002$ ), and between emotion-focused coping and vocational activity ( $r = -0.33$ ,  $p = .009$ ). The association between general self-efficacy and vocational activity was not significant ( $r = 0.18$ ,  $p = .157$ ). Vocational activity was not significantly associated with extraversion ( $r = 0.05$ ,  $p = .719$ ), neuroticism ( $r = -0.11$ ,  $p = .412$ ), psychoticism ( $r = 0.02$ ,  $p = .879$ ), problem-focused coping ( $r = 0.03$ ,  $p = .805$ ), avoidance coping ( $r = 0.01$ ,  $p = .981$ ) nor anxiety ( $r = -0.22$ ,  $p = .088$ ).

A logistic regression was used to test for independent effects of vocational self-efficacy, depression and emotion-focused coping on vocational activity defined as the presence or absence of paid employment. Overall the regression was significant ( $\chi^2(2) = 15.9$ ,  $p = .001$ ). Emotion-focused coping failed to demonstrate an independent effect on vocational activity ( $B = -0.35$ ,  $p = .303$ ). Vocational self-efficacy showed the greatest independent effect on vocational activity ( $B = 0.71$ ,  $p = .061$ ) followed by depression. ( $B = -0.186$ ,  $p = .098$ ), although both were not significant at the 0.05 level. When emotion-focused coping was removed from the logistic regression the above findings for vocational self-efficacy and depression remained the same, indicating that they did not predict vocational activity independent of each other.

In summary, there was a strong positive relationship between vocational self-efficacy and vocational activity. General self-efficacy was not associated with vocational activity. Depression and emotion-focused coping both showed strong negative associations with vocational activity. Logistic regression revealed that only vocational self-efficacy and depression combined predicted vocational activity;

neither demonstrated independent effects on vocational activity.

**Hypothesis Two. Higher levels of general self-efficacy will be associated with greater quality of life.**

As over half the sample fell into the lowest category of quality of life, non-parametric analyses are reported here. All of the following results did not differ substantially when parametric analyses were employed.

General self-efficacy was positively associated with quality of life ( $r = 0.54, p. < .001$ ). There were also positive correlations between quality of life and vocational self-efficacy ( $r = 0.30, p. = .018$ ), extraversion ( $r = 0.39, p. = .002$ ), Lie Scale ( $r = 0.28, p. = .030$ ), and problem-focused coping ( $r = 0.49, p. < .001$ ). There were negative correlations between quality of life and anxiety ( $r = -0.54, p. < .001$ ), depression ( $r = -0.55, p. < .001$ ), neuroticism ( $r = -0.61, p. < .001$ ) and emotion-focused coping ( $r = -0.39, p. = .002$ ).

Linear regression analysis was employed to assess the independent effects of those variables found to have significant associations with quality of life. Raw quality of life scores were used as the dependent variable in this case. Overall the regression was significant ( $F(8,51) = 8.407, p. < .001$ ). Only neuroticism ( $t = -2.270, p. = .027$ ) and problem-focused coping ( $t = 2.184, p. = .034$ ) predicted quality of life independently. General self-efficacy, vocational self-efficacy, extraversion, anxiety, depression and emotion-focused coping all failed to show independent effects.

In summary, general self-efficacy was found to have a strong and positive association with quality of life. A range of variables however were also found to have significant positive and negative associations with quality of life. Linear regression and logistic regression analyses attempted to identify variables that were independent predictors of quality of life. These suggest that problem-focused coping, and neuroticism have independent effects on quality of life.

**Hypothesis 3: Vocational activity will be associated with quality of life.**

Vocational activity defined as the presence or absence of paid employment was associated with quality of life when categorised dichotomously as either low or average ( $\chi^2 = 3.993$ ,  $p = .046$ ). This effect disappeared however when vocational activity was categorised on three levels: paid, unpaid and none ( $\chi^2 = 4.181$ ,  $p = .124$ ). This pattern of results was also confirmed by correlational analyses using Spearman's rho. There was a significant and positive correlation between the presence or absence of paid employment and quality of life ( $r = 0.29$ ,  $p = .026$ ). This association disappeared when vocational activity categorised on three levels was tested for an association with quality of life ( $r = 0.20$ ,  $p = .122$ ). Parametric analyses did not produce a substantially different outcome to these results.

In summary, these results suggest that the presence or absence of paid employment makes the key difference to quality of life.

## **Part two: Supplementary analyses.**

### **2.1 The role of AIDS.**

The experience of receiving an AIDS diagnosis has been used by some authors (e.g. Brashers et al., 1999) to assist in the identification of people living with HIV who had undergone “revival”. This was defined as the experience of those who believed there were dying from HIV but who came to believe that they would live. Analyses were performed to assess if there were any group differences between those who had previously received a diagnosis of AIDS and those who had not. Only the use of avoidance coping was significantly different between the two groups ( $t = 2.273$ ,  $p = .027$ ). Those with a previous AIDS diagnosis used more avoidance coping. The groups did not differ significantly in vocational self-efficacy ( $t = -1.502$ ,  $p = .138$ ), general self-efficacy ( $t = -.746$ ,  $p = .459$ ), anxiety ( $t = -1.853$ ,  $p = .069$ ), depression ( $t = -.873$ ,  $p = .386$ ), problem-focused coping ( $t = .748$ ,  $p = .393$ ), emotion-focused coping ( $t = -.861$ ,  $p = .393$ ), extraversion ( $t = -.152$ ,  $p = .880$ ), neuroticism ( $t = -.806$ ,  $p = .423$ ), psychoticism ( $t = .033$ ,  $p = .974$ ) and the Lie Scale ( $t = -.636$ ,  $p = .974$ ).

### **2.2 Correlates of anxiety and depression.**

Statistical analyses of score distributions for variables tested for association in this sub-section and in sub-section 2.3 indicated normality. Therefore Pearson correlation coefficients are reported in both sub-sections. Visual inspection of neuroticism and extraversion scores did however suggest negative skewness. Non-parametric analyses were also performed therefore and no substantial differences

were found.

Significant negative correlations were found between general self-efficacy and anxiety ( $r = -0.29$ ,  $p = .021$ ) and depression ( $r = -0.36$ ,  $p = .005$ ). There was a significant negative association between vocational self-efficacy and depression ( $r = -0.26$ ,  $p = .045$ ), but not with anxiety ( $r = -0.21$ ,  $p = .104$ ). Extraversion was not associated with either anxiety ( $r = -0.17$ ,  $p = .188$ ) or depression ( $r = -0.20$ ,  $p = .122$ ). There were significant and positive associations between neuroticism and anxiety ( $r = 0.68$ ,  $p < .001$ ) and depression ( $r = 0.60$ ,  $p < .001$ ). Significant negative associations were found between problem-focused coping and anxiety ( $r = -0.30$ ,  $p = .020$ ) and depression ( $r = -0.41$ ,  $p = .001$ ). There were significant positive correlations between emotion-focused coping and anxiety ( $r = 0.64$ ,  $p < .001$ ) and depression ( $r = 0.57$ ,  $p < .001$ ).

A linear regression analysis was performed to test for independent effects of emotion-focused coping, problem-focused coping, neuroticism and general self-efficacy on anxiety. Overall the regression was significant ( $F(4, 56) = 17.814$ ,  $p < .001$ ). Neuroticism predicted anxiety scores independently ( $t = 3.540$ ,  $p = .001$ ) as did emotion-focused coping ( $t = 3.263$ ,  $p = .002$ ). Problem-focused coping failed to show independent effects ( $t = -1.365$ ,  $p = .178$ ) as did general self-efficacy ( $t = .244$ ,  $p = .808$ ).

Emotion-focused coping, problem-focused coping, neuroticism, general self-efficacy and vocational self-efficacy were tested for independent effects on depression. Overall the regression was significant ( $F(5, 55) = 11.341$ ,  $p < .001$ ). General self-



efficacy failed to demonstrate independent effects ( $t = .196, p = .845$ ) as did vocational self-efficacy ( $t = -.844, p = .402$ ). Neuroticism ( $t = 2.466, p = .017$ ), problem-focused coping ( $t = -2.528, p = .014$ ) and emotion-focused coping ( $t = 2.731, p = .008$ ) all showed independent effects.

In summary higher levels of general self-efficacy and problem-focused coping were associated with lower levels of anxiety and depression. Greater levels of neuroticism and emotion-focused coping were associated with higher levels of anxiety and depression. The outcome of regression analyses suggested general self-efficacy was redundant in predicting levels of anxiety and depression. Neuroticism and emotion-focused coping appeared to play a role in anxiety whereas neuroticism, problem-focused coping and emotion-focused coping were predictors of depression.

### 2.3 Associations among coping and personality variables.

Pearson correlation coefficients are reported in this sub-section. General self-efficacy was negatively associated with neuroticism ( $r = -0.48, p < .001$ ) and emotion-focused coping ( $r = -0.26, p = .040$ ). There were significant positive associations between general self-efficacy and extraversion ( $r = 0.43, p < .001$ ), problem-focused coping ( $r = 0.41, p = .001$ ) and avoidance coping ( $r = 0.32, p = .011$ ).

There was a significant and positive correlation between extraversion and avoidance coping ( $r = 0.43, p < .001$ ). Neuroticism and emotion-focused coping were positively associated ( $r = 0.61, p < .001$ ). A significant negative correlation was

found between neuroticism and problem-focused coping ( $r = -0.29$ ,  $p = .022$ ).

In summary, higher levels of general self-efficacy were associated with greater degrees of extraversion, problem-focused coping and avoidance coping. Greater levels of general self-efficacy were associated with lower degrees of emotion-focused coping and neuroticism. The greater the degree of neuroticism the higher the use of emotion-focused coping and the lower the level of problem-focused coping.

## **Chapter Four: Discussion.**

The discussion section will be divided into three sections. Section one will outline the strengths and weaknesses of the study. Section two will discuss the meanings of the results obtained in relation to the research hypotheses. Section three will consider the clinical implications of the findings.

### **Section One: The strengths and weaknesses of the research.**

This study attempted to identify psychological factors that might explain individual differences in vocational activity amongst people with HIV infection. Some of the obstacles to employment faced by people with HIV infection were identified by qualitative studies but little was known about individual differences in response to these obstacles. It was appropriate therefore for this research to be focused on hypothesis testing rather than further exploration. To the author's knowledge this was the first attempt to identify psychological factors that might predict vocational activity in people infected with HIV. The research also aimed to identify psychological factors associated with quality of life in people with HIV infection after the advent of CTs. Previous research conceptualised quality of life in a limited way using measures that were restricted to assessing the outcome of medical treatments beyond purely biological parameters. The quality of life measure used in this study considered a far greater range of life domains that contribute to quality of life. To the author's knowledge this was the first time it was used with HIV positive people.

The introduction of CTs and the halting of disease progression generated the perception that HIV was no longer a serious condition. The closure of the FACTs centre detailed in the methods section was indicative of the perception amongst some that people with HIV infection no longer required support beyond medical care. The research discussed in the introduction suggested that if anything, the psychological needs of people with HIV were greater now than they ever had been. Thus it was within this context that the research aimed to assess empirically the level of need amongst people with HIV infection.

The non-random method of sampling used in the study introduced bias. This was most evident in the low number of participants who were in paid employment. The use of the Globe Centre partly accounted for this because participants were involved in the Positive Futures Initiative that was designed for people who were considering returning to work. It was hoped that the use of genito-urinary medicine clinics might have increased the number of participants in paid work since it was plausible that HIV positive people regardless of employment status would be in contact with health services. The clinics were situated within Enfield and Haringey, an area of North London with high levels of economic and social deprivation, and this may have also accounted for the low number of participants who were in paid work. The use of a range of sampling locations did mean that data were collected on vocational activity that enabled a broader range of work patterns to be considered than merely the presence or absence of paid employment.

Nevertheless caution is warranted when considering the relationship between

vocational self-efficacy and vocational activity and between vocational activity and quality of life. Although the sample size requirements outlined in the methods section were met, the unequal numbers who were engaged in the various categories of vocational activity could have artificially increased the strength of the relationship observed.

In spite of the low number of participants in paid employment, the heterogeneous nature of the sample in terms of ethnicity and sexual orientation is more representative of the range of people infected by HIV at this stage of the epidemic. Previous studies were largely composed of white, gay men and thus the extent that findings could be generalised to other groups with HIV infection was unknown. The two largest ethnic groups in the study were UK White and African, and analyses revealed no significant differences between the two groups on measures of the independent or dependent variables. A concern was raised by one voluntary sector organisation was that the research might not be applicable to African people infected with HIV. The results however suggest this not the case. Furthermore, it was African participants who tended to express most interest to the author about the research and express the view that more services needed to be offered to help them return to work. It would seem therefore that the results would be relevant to people from diverse ethnic backgrounds although African people are more likely to face additional barriers to returning to work compared to their UK White counterparts, such as racial discrimination.

The use of CD4 counts and viral loads as objective markers of disease progression in this study could be criticised precisely because they were objective and did not take

into account subjective perceptions of illness. Furthermore the study did not assess the level of physical disability in participants which has been shown in some studies (e.g. Griffin, Rabkin, Remien & Williams, 1998) to have a greater impact on psychological adjustment than laboratory markers. One of the domains in the QOLI used in this study was health and participants rated its level of importance and their level of satisfaction with it. Perhaps it was this appraisal that is more important ultimately because it required people to weigh up the positive and negative aspects of their health status.

## **Section Two: Interpretation of findings.**

Before discussing the research hypotheses the meaning of descriptive data will first be considered. This will provide a context for the remainder of the discussion.

There was strong evidence from this study of the disabling impact of HIV infection. The level of anxiety in the sample was considerable with over half of the sample falling in the probable range for caseness. The level of depression while less was also high with a quarter falling in the probable caseness range. Moreover nearly half the sample was classified as very low on the quality of life instrument. Frisch (1994) states: "Respondents whose satisfaction with life is very low are likely to be extremely distressed; that is, they may be experiencing high levels of anxiety, depression or anger...They tend to be frustrated and unfulfilled in most areas of life without the compensation of feelings of fulfilment or gratification in other areas of life." (Frisch, 1994, p. 25). These findings emphasise the clinical nature of the sample.

The introduction outlined the effect of CTs in shifting the perception of HIV from a usually fatal illness to a more chronic long-term and manageable disease (McReynolds, 1998). This was accompanied by renewed treatment optimism and the perception that HIV was no longer a disabling condition (Day, 1997; Remien et al., 1998). The data for anxiety, depression and quality of life however provide no indication that improved treatments and prolonged survival have reduced psychological morbidity. A study by Tacconelli (2000) in a central London HIV clinic also found very similar rates of anxiety and depression. An audit by Catalan,

Meadows and Douzenis (2000) of referrals to another central London genito-urinary medicine clinic suggested that levels of psychological distress have actually increased since CTs were introduced. The contraction of HIV service provision in London that particularly affected community support services is concerning given the level of need revealed in this study.

The psychological difficulties associated with adjusting to what some have termed “revival” (Brashers et al., 1999) was outlined in the introduction. New sources of uncertainty emerged such as the length of time recovery would be maintained for those previously diagnosed with AIDS and having only months to live. While most of the sample were currently not at an advanced stage of HIV infection, that nearly half of the sample was previously diagnosed with AIDS attests to the existence of the “Lazarus Syndrome”. Furthermore it appeared that they were experiencing conflicting emotions in relation to their current health status. There was a large degree of optimism expressed about life expectancy yet for many who were not in paid employment, uncertainty was identified as an obstacle. Furthermore the screening instrument detected high levels of anxiety in the sample. These findings nest readily with the themes that emerged in the qualitative studies by Brashers et al. (1999) and Sowell et al. (1998). Participants experienced a range of conflicting emotions. There was optimism brought about by health gains but this also created uncertainty and anxiety over the stability of these gains. Uncertainty and anxiety were also generated by the process of re-constructing roles and relationships.

Interestingly, there was only a significant difference in avoidance coping between those who had received an AIDS diagnosis in the past and those who had not.



Avoidance coping has consistently been associated with faster disease progression in the literature (e.g. Ironson et al., 1995). One might have expected participants who were previously diagnosed with AIDS to have lower levels of self-efficacy or higher levels of anxiety but this was not the case.

The discussion above indicates that interpretation of the results for the research hypotheses will have to be made in the knowledge of high levels of psychological distress in the sample, and the difficulties associated with the removal of an AIDS diagnosis.

## **Part i) Self-efficacy and Vocational activity.**

Compared to the general population the rate of unemployment amongst the sample was much higher. Only twenty six percent of the sample was in some kind of paid employment. Furthermore disease progression was associated with loss of paid employment as the average length of time without paid work was only six months longer than the average length of time since a diagnosis of AIDS. Moreover there was evidence that acquiring HIV infection regardless of disease progression had a financial impact upon participants with a reduction in modal income from £10,000-£14,000 before testing positive, compared to a current modal income of between £0-£5,000. The experience of revival was manifest by the dilemma most people not in paid employment seemed to be facing. Most wanted to work because they felt their health had improved but at the same time, most were not considering work because they were concerned about becoming ill.

The study sought to examine the relationship between self-efficacy (vocational and general) and vocational activity. Higher degrees of vocational self-efficacy were associated with greater levels of vocational activity. Fourteen percent of the variance in vocational activity could be attributed to vocational self-efficacy. There was not a significant relationship between general self-efficacy and vocational activity. Theoretically general self-efficacy would not be expected to be associated with vocational activity because most theorists regard self-efficacy as being situation-specific. Some have made a convincing argument for the existence of general self-efficacy (e.g. Bandura, 1992) but there appear to be compelling theoretical and empirical reasons why general self-efficacy may be limited as an explanatory

construct. These will be discussed in due course.

It was also found that depression and emotion-focused coping were also significantly associated with vocational activity so that higher degrees of depression and emotion-focused coping were associated with lower levels of vocational activity. Logistic regression attempted to assess the independent effects of these three variables. Emotion-focused coping failed to show independent effects. In addition both vocational self-efficacy and depression failed to show significant independent effects at the 0.05 level of significance. Vocational self-efficacy was just on the cusp of significance at .061 and showed the greatest independent effect after depression. When the logistic regression was repeated without emotion-focused coping the outcome remained the same. The logistic regression indicated that vocational self-efficacy and depression together exerted a powerful effect on vocational activity but their predictive power was limited alone. Indeed there was a strong negative association between vocational self-efficacy and depression. This raises the question of the nature of the vocational self-efficacy scale used in the study and whether it was distinct from the cognitive manifestations of depression.

There were some problems with the vocational self-efficacy scale. No precise definition of work was provided so it is uncertain what participants were alluding to. Furthermore the scale did not pretend to assess comprehensively self-efficacy perceptions of the ability to perform the extensive range of other skills required in work. The very high alpha coefficient for the items on the vocational self-efficacy scale suggest that the circumstances outlined by the items did not reflect sufficiently gradations of challenge. A study by Simoni, Mason and Marks (1997) showed that

HIV positive gay men were more likely to disclose their HIV status to a gay or bisexual employer than a heterosexual employer. Disclosure of HIV status to an employer was included as an item but this was assessed crudely without considering the different situational demands of disclosure to employers of different sexual orientations. It is possible therefore that the scale measured perceived self-efficacy in the most difficult of circumstances and therefore underestimated the level of vocational self-efficacy in the sample.

The items were however derived from obstacles identified by participants in qualitative studies. It could also be therefore that the high inter-item correlations reflect the challenging nature of the obstacles faced by people with HIV face in relation to employment. Furthermore, the distribution of scores for vocational self-efficacy was normal and there were significant differences between groups in the mean level of perceived self-efficacy. A skewed distribution would be more likely if the scale included items that were so difficult that only a relative few could be expected to overcome them. It is clear that the analyses relating to the vocational self-efficacy scale must be interpreted with caution and that it would require further development. As an original scale however it possessed a high level of face validity and demonstrated some divergent validity by the absence of an association with general self-efficacy.

There are compelling theoretical reasons for the association between vocational self-efficacy and depression and their additive effect. Cognitive formulations of depression (e.g. Beck, Rush, Shaw & Emery, 1979) emphasise the primacy of cognition in regulating mood. Furthermore, a core part of the cognitive theory of

depression is the tendency for people to make distorted predictions about the future. Depressed people are more likely to make negative predictions about the future and this will include negative appraisals about their ability to succeed in valued areas of life. Perceived inefficacy to succeed at activities that are important for self-conception is likely to produce depression. The psychological cost of unemployment is well documented and this is illustrated by the strong negative relationship in this sample between depression and vocational activity. It is possible that a vicious circle operates where low vocational self-efficacy impacts upon vocational activity and generates depression that in turn further undermines individuals confidence in their ability to overcome potential obstacles. The high level of depression associated with HIV infection may attenuate this cycle.

The relationship between vocational self-efficacy, depression and vocational activity would appear to be reciprocal. It might also be the case that depression would influence the manner participants dealt with the dilemma of wanting to work but fearing the health consequences, and the way uncertainty was perceived. The clinical implications of these relationships will be explored in section three.

## **Part ii) General self-efficacy and Quality of Life.**

As discussed earlier for most participants in this study their quality of life was well below that of the general population and it is clear that HIV infection still has enormous potential to impact upon quality of life. This study tested for an association between general self-efficacy and quality of life. It was expected that higher levels of general self-efficacy would be associated with greater quality of life. There was a very strong relationship between general self-efficacy and quality of life suggesting that the higher the degree of general self-efficacy the better the quality of life. At one level there are compelling reasons why this might be the case.

In any quality of life domain, satisfaction implies a person having achieved their goals and this would require people possessing the requisite psychological attributes. General self-efficacy refers to people's beliefs in their ability to respond to difficult situations and to overcome obstacles or setbacks and would clearly be advantageous to individual's efforts to achieve what they want out of life with respect to any of the quality of life domains. However general self-efficacy would not be the only psychological attribute associated with quality of life. It might also include but not be limited to reasonable problem solving skills, being largely free from cognitive distortions such as catastrophising, accurate reality testing skills, the ability to formulate realistic targets and stick to them, and resilience in the face of setbacks. Indeed a number of other psychological factors were found to be associated with quality of life and it may be that the role of general self-efficacy in quality of life becomes redundant when other variables are considered. Nevertheless the association between general self-efficacy and quality of life draws attention to

psychological factors as important potential sources of individual differences in quality of life amongst those infected with HIV.

A surprise finding was the significant association between the Lie Scale of the Eysenck Personality Questionnaire and quality of life so that the higher the score on the Lie scale the better the quality of life. Eysenck and Eysenck (1991) included the Lie Scale to account for the tendency of some respondents to “fake good” or present themselves in a more favourable light. They also suggested that it might represent a separate personality dimension of social conformity. This finding could represent a spurious result indicative of the phenomenon that the more variables that are tested for an association, the greater the possibility that some will be found to be significantly related by chance. Alternatively the association might have resulted from respondents who scored in the high range for quality of life but who were trying to minimise their unhappiness, symptoms or problems and therefore fake good. The positive association between quality of life and vocational activity and the negative association between anxiety and depression, and quality of life makes this unlikely. Furthermore participants who were minimising the impact of a life domain would more likely rate a life area as unimportant rather than exaggerate their level of satisfaction. The meaning of the association between the Lie Scale and Quality of Life remains unclear but since quality of life was the only variable to correlate with the Lie Scale, the possibility of random error seems likely.

Higher levels of extraversion, problem-focused coping and vocational self-efficacy were all associated with greater degrees of quality of life. Higher levels of neuroticism, emotion-focused coping, depression and anxiety were all associated

with lower degrees of quality of life. General self-efficacy failed to demonstrate independent effects on quality of life. Only neuroticism and problem-focused coping predicted quality of life independently. Clearly the relationship of these psychological factors to quality of life is not straightforward and requires consideration.

It would be expected that lower degrees of quality of life would be associated with higher levels of depression and anxiety. Depression and anxiety would directly impact upon quality of life. Furthermore failure to achieve goals or meet one's own needs in valued areas of life would increase the likelihood of developing anxiety and depression. Dissatisfaction with close, intimate relationships given their protective value would increase vulnerability for depression. Dissatisfaction with money is likely to generate anxiety over issues such as paying household bills. Frisch (1994) refers to "dissatisfaction depression" which he posits is a distinct subtype of clinical depression arising in the context of repeated failures to meet personal goals in highly valued domains of life. These results support this contention. Another way depression and anxiety would relate to quality of life is that they would constitute obstacles to improving quality of life given their detrimental impact on the psychological attributes required for improving quality of life such as problem solving skills.

Neuroticism, problem-focused coping and emotion-focused coping were independent predictors of depression while neuroticism and emotion-focused coping were independent predictors of anxiety. When these results are considered with the findings that only neuroticism and problem-focused coping were independent



predictors of quality of life, it suggests that personality and coping variables have a more important role in influencing quality of life and the levels of psychological distress associated with it. These have important implications for strategies designed to improve quality of life and these will be discussed in section three. These findings also point to problems with general self-efficacy and these will now be considered.

The failure of general self-efficacy to show independent effects and its strong relationship with problem focused coping raises the possibility that general self-efficacy is not distinct from problem focused coping. Conceptually they appear to be somewhat similar. General self-efficacy refers to an individual's belief in their capacity to respond to difficult situations and to overcome obstacles. It is a task-orientated construct and thereby refers to the ability to execute behaviours necessary to deal with prospective situations. The items in the general self-efficacy reflect this, for example, "I can always manage to solve difficult problem if I try hard enough". Problem-focused coping encompasses purposeful task-orientated attempts to solve problems and there would appear to be considerable convergence between the two constructs. In addition the strong positive relationship between extraversion and general self-efficacy and strong negative relationship between neuroticism and general self-efficacy further raises the possibility that the general self-efficacy scale is tapping different aspects of these personality dimensions. Furthermore there are theoretical reasons that cast doubt on the value of general self-efficacy as an explanatory construct.

Cervone (1997) investigated experimentally the extent that self-efficacy beliefs generalise across situations. There was a considerable degree of both within group

and between group variability. This meant that on an attribute such as confidence, individual's level of perceived self-efficacy differed from one another but also varied across situations for each individual. Thus although one person may generally be more confident than another, their belief in their ability to be confident would be different depending on whether were leading a classroom discussion or talking to new people at a party. Therefore general self-efficacy ignores cross-situational variation in self-efficacy by assigning people a single score that supposedly represents a unitary dimension that is relatively fixed across individuals. Mischel (1999) distinguishes between "sign" and "sample" measurement strategies and the general self-efficacy scale is an example of the former; ignoring the possibility that even if two people rate themselves as highly confident, their behaviour may be substantially different depending on the context.

It might be the case that the problem with general self-efficacy is at the level of measurement rather than construct and that scales that sampled a given attribute in a variety of situations would have greater construct validity. However there is little evidence to support this view and a wealth of evidence that affirms the situational specific nature of self-efficacy beliefs. Furthermore there has been a plethora of supposedly unique constructs developed within health psychology such as self-mastery, generalised self-efficacy, and self-faith. Marshall et al. (1994) examined the association between the five-factor model of personality and a range of health-related constructs and found that most were related to certain aspects of extraversion and neuroticism. It would appear therefore that personality factors and coping styles possess greater explanatory power.

The results of this study suggest that personality factors and coping styles may be important determinants of quality of life among people with HIV infection. Similar results were obtained by Swindells et al. (1999) who found problem-focused coping to be associated with greater quality of life, and by Ramanaiah, Detwiler and Byravan (1997) who reported higher levels of neuroticism to be related to lower quality of life. Neuroticism is closely related to the extent that events are perceived as stressful. In response to a stressful life event, people who score high on neuroticism are more likely to experience a range of negative emotions, become overwhelmed, experience intrusive cognitions such as guilt, and engage in unhelpful ruminations about their behaviour (Costa, Somerfield & McCrae, 1996). All these tendencies would clearly make it more difficult for people to achieve their goals in any life area. Furthermore, such tendencies would increase vulnerability to develop anxiety and depression in response to adversity that would further impair quality of life, and efforts to improve it.

The role of coping in mediating the impact of HIV infection has been extensively studied. Although operational definitions of coping in studies of HIV infected people has varied, the findings have been generally consistent. These are that problem-focused coping strategies are associated with lower levels of psychological distress and better quality of life (e.g. Kalichman, Heckman, Kochman, et al. 2000) and emotion-focused strategies and avoidance coping are associated with higher levels of psychological distress and poorer quality of life (e.g. Schmitz & Crystal, 2000). There are caveats within this general pattern of findings however. There is evidence that the value of problem-focused or emotion-focused coping strategies partly depends on the stage of HIV infection and the perception of controllability.

Emotion-focused strategies may be more beneficial at the time of diagnosis where perceived controllability is low. Problem-focused strategies seem to be more adaptive after the initial stage of adjusting to the news of an HIV positive diagnosis and particularly when stresses are perceived as controllable (Reeves, Merriam, & Coutenay, 1999). The results of this study also suggest that problem-focused coping mediates the impact of HIV infection upon quality of life.

The way problem focused coping may do this is illustrated in a study by Suarez and Reese (2000). They found problem-focused coping was related to higher levels of alternative medicine used to help combat disease symptoms and combination therapy side effects. This in turn was associated with better quality of life. This study highlighted the mechanism through which problem-focused coping could have beneficial effects on quality of life because it increased the possibility of people seeking solutions to problems, and ultimately helping them minimise their impact. There is intuitive appeal to the differential effectiveness of problem-focused strategies over emotion-focused strategies in confronting the challenges posed by HIV infection. Trying to alter the emotional meaning of side effects from medication is unlikely to be as effective as active efforts to alter the situation. Furthermore an individual's quality of life refers to the degree that important goals have been fulfilled. Problem-focused coping will therefore assist people to meet their goals. It will also provide protection against events that could have a detrimental effect on quality of life.

These results point to the importance of personality and coping in mediating the impact of HIV infection upon quality of life. They also suggest targets for

intervention efforts aimed at improving quality of life. This will be considered in section three.

### **Part iii) The relationship between vocational activity and quality of life.**

The psychological benefits of employment and the psychological costs associated with unemployment have been documented by numerous authors (e.g. Simon, 1997; Warr 1984). Studies have found HIV infection to be associated with higher rates of unemployment than in the general population and disease progression to precede the loss of full time employment status (e.g. Kass et al., 1994). However the nature of the relationship between vocational activity and quality of life of people with HIV is less clear. This study aimed to assess the contribution of vocational activity to quality of life.

There was a significant relationship between quality of life and the presence or absence of paid employment. People who were engaging in paid employment had a significantly greater quality of life compared to those who were not in paid employment. Interestingly when quality of life was tested for an association with vocational activity categorised on three levels (paid, unpaid and none) the association became non-significant. This suggested that the effect of unpaid vocational activity, which included voluntary work, skills training and education, on quality of life was not as powerful as paid vocational activity. Further support for this interpretation was provided by data from the quality of life measure concerning the level of satisfaction with work. This indicated that the majority of those engaging in either no vocational activity or unpaid vocational activity were dissatisfied with this situation. Furthermore the level of dissatisfaction within these two groups was almost identical.

These results point to the importance of paid employment for maintaining a perception of a satisfactory quality of life for people living with HIV infection. Employment can be an important source of self-worth, role fulfilment, social support and financial independence and its absence can clearly have a negative impact upon quality of life. Thoits (1995) proposed that the impact of chronic stressors depend on the extent that it disrupts valued roles. Higher levels of psychological distress were associated with lower levels of vocational activity. These results suggest that HIV infection influenced levels of psychological distress by impacting upon a domain of life that most regarded as important. Therefore it would appear that paid employment serves a protective function against psychological distress amongst people with HIV infection.

In a qualitative study of people undergoing “revival” by Brashers et al. (1999), it was reported that some participants made a decision not to return to work, and instead make health the focus of their lives. It was suggested that this decision could have a positive impact on quality of life because expectations were congruent with reality. However the results of this study suggest that the absence of paid employment does reduce quality of life. Furthermore, most participants without paid employment were concerned that returning to work could make them ill. It would appear that decisions regarding employment are based on the perceived costs of returning to work in the context of a tenuous recovery. People manage uncertainty in a variety of ways and part of this includes an assessment of the risk of change (cf. Mishel, 1997). If people are in a situation perceived as unstable, the risk involved of any change is more likely to be perceived as negative. This has implications for programs designed to

assist people with HIV infection gain employment and these will be considered in section three.

The quality of life sample profile created using modal weighted satisfaction ratings indicated that in addition to work, love was equally the greatest source of dissatisfaction amongst the sample. Research attests to the protective nature of intimate relationships (e.g. Brown, Harris & Copeland, 1977). Thoits (1995) proposed that a lack of alternative roles that people can draw on for self-worth increase vulnerability towards psychological problems for those who have already experienced an identity threatening event. These results give rise to concern because they suggest HIV infection disrupts at least two major areas of life that provide multiple benefits for mental health.

It could be argued that the level of depressed mood contaminates the quality of life instrument and this would account for the strong negative association between depression and quality of life. The quality of life model devised by Frisch (1994) that was outlined in the introduction specifies components that contribute to a person's level of satisfaction with a particular life domain. One of these is concerned with the way the individual perceives and interprets the objective characteristics of the situation and another is the evaluation of whether their aspirations in a particular area are fulfilled. The cognitive biases and distortions that operate in depression have been well documented. The quality of life measure could reflect these biases and therefore produce findings that are tautological.

There are reasons however to doubt this proposal. The core of the quality of life

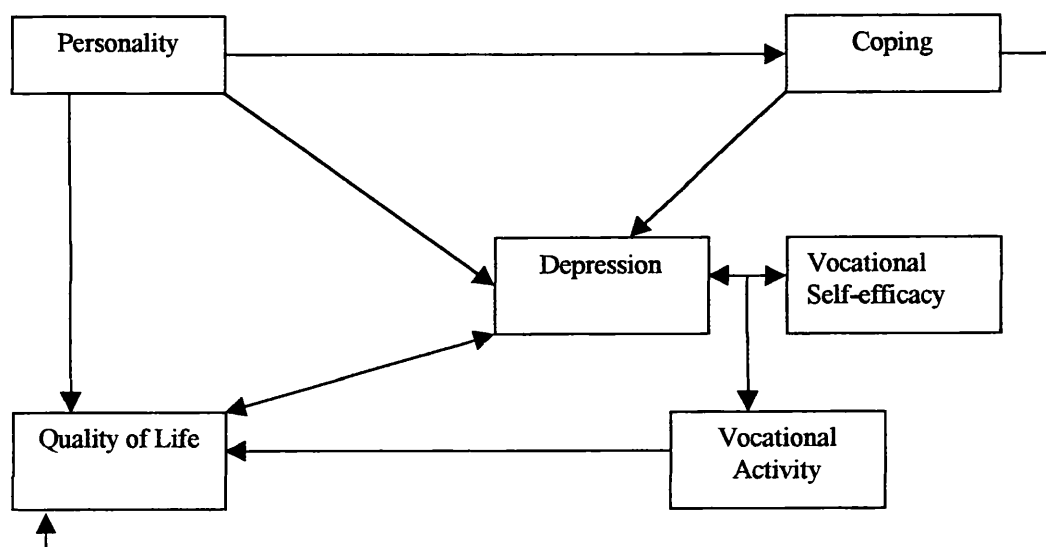


theory put forward by Frisch (1994) is that subjective appraisals are indeed fundamental in producing life dissatisfaction, and what he terms “dissatisfaction depression.” Essentially a poor quality of life means there is a discrepancy between a person’s needs and them being met. There is no doubt that depression itself can impact upon quality of life by interfering with the psychological attributes necessary to achieving one’s goals. However in this study the effect of a person's objective situation in relation to one life area i.e. vocational activity was shown to be associated with subjective well-being i.e. quality of life. It is improbable that this association would disappear if people were no longer depressed. Further evidence that depression is not a primary cause of poor quality of life but rather is a correlate was provided by the failure of depression to predict quality of life scores independently. Moreover, Frisch (1994) notes that some patients treated successfully for depression often describe feeling unhappy or discontent with life, long after their scores of depressive symptoms on the Beck Depression Inventory have fallen within the normal range. It would seem that interventions designed to reduce psychological distress in people with HIV might be more effective if they were focused on improving satisfaction with life domains that people find wanting, as opposed to treating the symptoms that arise in the context of life dissatisfaction. This will be considered further in section three.

### Section Three: The Clinical Implications of the findings.

Vocational self-efficacy and depression were strongly associated with vocational activity levels. Quality of life was in turn influenced by vocational activity levels. Personality and coping variables directly influenced quality of life and depression. Depression was not an independent predictor of quality of life, but appeared to be a correlate of low quality of life. Once depression was established it could impede efforts to improve quality of life. Depression did have an indirect effect on quality of life by its influence on vocational activity levels. In view of these findings the hypothesised relationship between study variables summarised by figure one in the introduction requires modification. Figure (4) illustrates the observed relationship between study variables and this could help inform interventions designed to assist people with HIV infection return to work, and improve quality of life.

Figure 4. Observed relationship between study variables.



The relationships between study variables outlined in figure (2) shares some similarities with the integrative model of behavioural change outlined by Fishbein (2000). In his model, personality traits and other individual difference variables have an indirect role in influencing efficacy beliefs and thereby behaviour. There are a number of variables in Fishbein's model that were not included in this study such as attitudes and norms but it provides a useful starting point for developing a model of vocational behaviour change. Further research would be needed to establish the applicability of Fishbein's model to vocational behaviour in HIV positive people and specify more precisely the interactions between the different factors.

It would appear that work is inextricably linked to quality of life in people with HIV infection. Returning to work may not be an option however for some people with HIV because of physical morbidity. It is proposed that interventions addressing vocation for HIV positive people would need to be delivered within a broader context of quality of life assessment and intervention. In this vein, interventions would fall broadly into two groups: those that assist people to return to work and thereby improve quality of life, and those that attempt to improve quality of life through other life domains for people whom work is not a possibility. A suitable psychological framework is required therefore to assist in making these judgements. Frisch (1994) developed Quality of Life Therapy based on his theory of quality of life that underpins the measurement instrument employed in the study. It would appear to have considerable utility for assessment and treatment planning for quality of life. Quality of Life Therapy utilises cognitive behavioural techniques but is distinct at the level of treatment strategy and in this respect it is similar to Interpersonal Psychotherapy.

The selection of treatment strategies depends on an assessment of the four components that are theorised to contribute to life satisfaction as previously outlined in the introduction. One component is relevant in cases where there is no possibility of a return to work for people with HIV. Quality of life theory proposes that satisfaction with a life area is weighted by its importance. The more important a life domain is to life satisfaction, the greater its influence on overall quality of life. The implication is that by increasing the importance of other life domains, the negative influence of one life domain on overall quality of life can be alleviated. Thoits (1995) highlighted the way individuals who have lost a valued role may be at increased risk of further distress if they do not have alternative roles they can attach importance to. This strategy attempts to reduce this risk by increasing the level of importance of other life domains. This might mean increasing the importance of “purpose in life” in people with HIV infection to their overall quality of life. Having a sense of purpose in life has been shown not to be restricted to vocational status (Frisch, 1994).

The other components would be pertinent to interventions that assist people with HIV return to work. The objective characteristics of a situation may be responsible for life dissatisfaction rather than the result of distorted thinking i.e. people will be dissatisfied with their unemployed status regardless of the positive thinking they apply to the situation. Thus interventions can be provided that help people with HIV make the changes they want in their lives. An individual’s perception of the area may not fit with the objective reality. Some people with HIV infection may perceive themselves to be inefficacious, particularly if they are depressed. This can be

corrected through cognitive restructuring and by raising self-efficacy. People evaluate their success at meeting their goals and standards and this contributes to life satisfaction. The identification of realistic goals and the steps necessary to achieve them would be an integral part of vocational interventions. An HIV positive individual with mild cognitive impairment who had not worked for several years would be inviting failure if his goal were to return to full time employment as an architect.

The above components indicate that self-efficacy and depression would be important targets for interventions assisting people to return to work. The results of this study also suggest that they are important determinants of vocational activity. The remainder of this section will explore ways self-efficacy could be raised and depression reduced. It will also discuss a number of caveats to which the results draw attention.

Any intervention that assists people with HIV infection return to work will be attempting to tackle problems that are complex. As the results of this study indicate, people are likely to have dual diagnoses of HIV infection and mental health problems. There are likely to be multiple barriers to returning to work and therefore it is imperative that intervention programs contain a package of measures to address the multiple needs of this population. Brooks and Klosinski (1999) recommend that interventions assisting people with HIV infection return to work must contain the following components:

\* Vocational assessment to identify realistic goals, provide career planning, and

identify services that will help reaching these goals.

- \* **Benefits Counselling.** The benefits system in the United Kingdom is complex and many people may have anxieties about the benefit implications of returning to work.
- \* **Employment Services** to build skills in the practical aspects of finding work and to identify potential employers who could accommodate flexible working patterns.
- \* **Advice on HIV disclosure in the work place and HIV related discrimination.**
- \* **Emotional support** provided through workshops and support groups.
- \* **An attempt to bring about systemic changes in local and national government organisations in respect to HIV infection.**

The complex psychological needs of HIV positive people are unlikely to be met by the provision of workshops or support groups. Proudford et al. (1997) conducted a cognitive-behavioural group intervention designed to assist long term unemployed people return to work. The content of the seven group sessions focused on teaching participants the cognitive model, identifying and challenging automatic thoughts and dysfunctional assumptions, goal setting and graded task-assignment, and the application of these skills to personal and work settings. At three month follow-up, 34% of the participants in the cognitive behavioural group had obtained full-time work compared to 13% in the control group program that emphasised building social supports. Both programs made a positive impact on psychological well-being. Although the participants did not suffer any mental or physical illness, the results demonstrate that interventions need to be model based and focused to be effective.

The level of complexity involved in assisting people with HIV infection returning to work will require sophisticated psychological approaches. The failure of vocational

self-efficacy and depression to exert independent effects on vocational activity indicate that it would be unwise to consider them separately and it makes clinical sense to target both when assisting people with HIV return to work.

Bandura (1997b) notes that beliefs of self-efficacy are influenced by mastery experiences, vicarious experiences, social persuasion and affective and physiological states, and can be strengthened from these sources. The most powerful is mastery because it provides the most compelling evidence of whether one can perform the required behaviours. Graded task assignment provides suitable mastery experiences because tasks can be accomplished in a relatively short time. People with HIV infection will therefore require the opportunity to return to vocational activity in a graded way. Although computer skills training is often provided to HIV positive people, it is unlikely to be sufficient to raise people's levels of self-efficacy if the graded assignments do not continue in a structured way. Furthermore appraisals of performance are likely to be influenced by the level of depressed mood. The incorporation of cognitive techniques to challenge distorted thinking would be required (Beck, Shaw, Rush & Emery, 1979).

Self-efficacy beliefs are also influenced by knowledge of one's enduring characteristics (Bandura, 1997b) or self-schema. A person with a uselessness schema will consistently generate low self-efficacy appraisals. This points to schemas as appropriate targets for intervention. There is a large body of research to support the existence of schematic processes; however, whether these structures can be changed is uncertain. Schema-focused therapy approaches have developed in recent years but there is yet no controlled outcome research to support its

effectiveness (Young, 1999). Absence of evidence does not of course mean absence of effect. Trait theories of personality are distinct from social-cognitive theories of personality from which self-efficacy theory is derived, but it is also uncertain whether personality traits can be altered.

To some extent the question of whether personality can be changed depends on the definition of personality that is adopted. If personality traits are regarded as basic tendencies or general potentials that the individual possesses then they may not be amenable to change. Costa and McCrae (1994) point out that longitudinal studies indicate considerable consistency over time of personality traits such as extraversion and neuroticism. There is an interaction however over the course of human development between these basic tendencies and external influences that produce characteristic adaptations. If personality were regarded as characteristic adaptations then it would appear to be changeable. Psychotherapy focuses on changing people's adaptations that are problematic such as repeated abusive relationships, or phobias and there is considerable evidence for its effectiveness (e.g. Roth and Fonagy, 1996). Bandura (1997b) views self-efficacy as a component of self-concept that is influenced by basic tendencies but also by repeated interactions with the environment. The relationship is reciprocal in his view so that different environmental interactions can change levels of self-efficacy within the general parameters of an individual's basic tendencies.

There is consensus that neuroticism is associated with less problem-focused coping and more avoidance and emotion-focused coping that are less effective (Costa, Sommerfield & McCrae, 1996). In this study problem-focused coping was an



independent predictor of quality of life. In addition coping strategies were independent predictors of levels of depression and anxiety. Although it may be very difficult to alter the nature of basic tendencies and their influence on coping processes, these results suggest that changing people's coping strategies could improve quality of life and reduce psychological distress.

There is clear evidence that interventions designed to improve coping abilities in people infected with HIV increase adaptive coping responses, reduce psychological distress and improve quality of life (e.g. Heckman et al., 2001; Lutegendorf, et al. 1998). Furthermore although problem-focused coping was not associated with vocational activity in this study, increasing the level of problem-focused coping would seem to be an obvious target for assisting people to return to work in view of the close relationship between work and quality of life. Teaching people ways to solve their own difficulties is another way of providing mastery experiences and ones that can generalise to other areas of their lives. There is consensus that schema-focused approaches require between eighteen months and two years to take effect (Young, 1999). Any interventions designed to assist people with HIV return to work or improve quality of life for those who cannot return to work are unlikely to be able to operate to this time scale. Coping strategies would appear to be indicated as targets for treatment because they seem amenable to change within likely time and resource constraints.

It was established that people with HIV infection experience a considerable degree of uncertainty in relation to their diagnosis. In this study uncertainty was the most frequent reason cited for not returning to work. Leahy (1999) proposes that there is a

particular relationship between uncertainty and depression that has important implications for people considering change. Leahy (1999) outlines the difference between a maximisation strategy of producing as many rewards as possible and a minimisation strategy of avoiding loss at all costs. People with depression may be committed to a minimisation strategy. Negative predictions about the future are a core element of depression and therefore action is perceived to be more likely than inaction to lead to regret. The old adage of “better the devil you know” reflects a strategy designed to avoid further losses.

Leahy (1997) proposes an investment model of decision making based on microeconomic theory and modern portfolio theory. He argues people consider their current assets, future ability to produce rewards and ability to diversify. All of these will be limited by HIV infection. Moreover, the depressed individual calculates risk-reward ratios and predicts they will lose more than they will gain. Greater certainty is therefore required before change is initiated. Uncertainty is equated with risk, whereas conceptually uncertainty is neutral concerning loss. It refers to the extent that people know what will definitely happen, but says nothing about the direction of change.

People with HIV infection who have experienced improved physical health and the removal of an AIDS diagnosis are likely to regard their recovery as tenuous. Many participants in this study were concerned that returning to work would make them ill. People with HIV who are depressed are likely to distort the probability of a negative outcome from change, and therefore uncertainty and risk become correlates of loss. Interventions will need to address this primarily by shifting the balance so that

successful outcomes are more likely. This could be achieved in a number of ways. Cognitive behavioural techniques can be used to challenge negativistic thinking, self-efficacy can be raised so that people believe they can perform the behaviours necessary for change, and environmental manipulations can be made, for example placing people with HIV friendly employers.

The above discussion indicates that interventions intended to assist HIV positive people return to work or improve quality of life for those unable to work must contain at least the following: a cognitive-behavioural element, procedures designed to increase self-efficacy, coping skills training, and strategies to counter the effect of uncertainty on motivation for change. Programs assisting people return to work will need to have multiple components as previously outlined. The Positive Futures Initiative organised by London based voluntary sector HIV organisations offers computer training, benefits and careers advice and its own work placement service, but it does not contain a psychological component. Both self-efficacy and depression were associated with vocational activity in this study. The implication is that intervention programs that do not make a systematic attempt to intervene at this level are likely to be of limited use.

It is unlikely that any single organisation would be able to provide all of the required components and therefore co-operation between statutory and voluntary sectors will be essential. This may not be straightforward however. The author found that amongst some voluntary sector organisations there was some hostility towards mental health professions. This is not without foundation; for example, a recent qualitative study of psychodynamic therapists showed that some mental health

practitioners continue to be influenced by theoretical notions of homosexuality as pathology (Phillips, Bartlett & King, 2001). It will be imperative however that there is a sharing of expertise if intervention programs are to be maximally effective.

## **Conclusions.**

The nature of the HIV epidemic has evolved since the first cases of AIDS was reported in 1981. This research was conducted in the context of a change in the nature of the disease from a fatal illness to a long-term chronic disease. Despite improved treatments and increased life expectancy this research indicated that the level of psychological need amongst people with HIV infection remains high. This research indicated that psychological factors account for some of the variance in vocational activity and quality of life. The implication is that by designing interventions that address these psychological factors people can be helped to improve the quality of their lives. Making adequate provision for the psychological needs of HIV positive people will require considerable resources to be allocated to statutory and voluntary sector support services. The introduction of CTs has caused a squeeze on the funding of these services and there have already been several casualties such as the Body Positive organisation and the FACTs centre. It is likely that increased funding will not be made available meaning that some people with HIV will not receive the psychological assistance they need.

The increased life expectancy of people living with HIV has re-directed attention towards quality of life issues. This research emphasises the importance of quality of life assessment and treatment over traditional assessment and treatment of symptoms of psychological distress. There are signs that the HIV epidemic is beginning to evolve once again. Figures released by the Public Health Laboratory in April 2001, show that one quarter of people newly diagnosed with HIV in the United Kingdom

are infected with strains of virus that are multiply resistant to CTs (PHLS AIDS & STD Centre, 2001b). This means that with CTs no longer effective, physical morbidity and mortality is likely to increase. The psychological needs of people infected with HIV is also likely to change once more perhaps becoming increasingly focused on issues around death and dying rather than living.

The emergence of new strains of HIV that are multiply drug resistant just over three years after their widespread introduction in the United Kingdom suggests the contraction of support services for HIV positive people was hasty and unwise. There is a generation of people infected with HIV and involved in providing HIV care that did not experience the severity of the epidemic when it first appeared in the 1980s. Thus increased physical morbidity and mortality is likely to be demoralising for all those involved with HIV infection. Adopting a quality of life framework to any change in the course of the epidemic will help ensure that the needs of people infected with HIV are met.

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## **Appendix One.**

Research Promotion Flyer.

Participant Information Sheet.

## **Future Options Research**

### **Are you living with HIV?**

### **Wondering about the future?**

Many people have had to put their aspirations for the future on hold due to illness caused by HIV infection. Some people are now experiencing improvements in their health and are thinking about what to do with their lives. For some this may include thinking about starting or returning to work, going to college or learning a new skill. We hope to find out what might make it easier or harder for people to engage in these activities.

This information is urgently needed and will help those involved in providing support to people with HIV such as the London Lighthouse and the National Health Service. It will also be useful to community based programs like the Positive Futures Initiative. The information will assist these organisations provide services that fit the needs of people using them. By helping us you will be helping others in similar positions to you.

### **Can you help us?**

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 feel you can spare 20 to 30 minutes of your time to fill out some questionnaires, then please pick up a pack from the waiting area or reception. The questionnaires mostly ask about things in your everyday life. The number of questions may look daunting but most people find they are quite quick to complete once they get into the swing of them. All the information you need to complete the questionnaires are in the pack.

### **Confidentiality.**

All replies that you give us will be confidential and anonymous. This means it will not be possible for anyone to trace who has filled out the questionnaires.



## **People and organisations involved in the research.**

Liz Shaw  
Clinical Psychologist  
Sexual Health Centre  
St. Ann's Hospital  
St. Ann's Road  
N15 3TH

Tel: 8442 6464

Robert Watson  
Clinical Psychologist in Training  
Sexual Health Centre  
St. Ann's Hospital  
St. Ann's Road  
N15 3TH

Tel: 8442 6464 or 07941-027765

Please feel free to contact any of the above people involved in the research if you have any questions or would like some help with completing the questionnaires.

## **Future Options Research**

### **Participant Information Sheet (Please detach & keep)**

#### **The aims of the research.**

Many people have had to put their aspirations for the future on hold due to illness caused by HIV infection. Some people are now experiencing improvements in their health and starting to think about what they want from life and what gives their lives meaning. For some this may include thinking about starting or returning to work, going to college or learning a new skill. We hope to find out some of the things that might make it easier and harder for people living with HIV to engage in these activities.

#### **How the information will be used.**

The information collected will help those involved in providing support to people with HIV such as the London Lighthouse and the National Health Service. It will also be useful to community based programs like the Positive Futures Initiative. The information will assist these organisations provide services that fit the needs of people using them. By helping us you will be helping others in similar positions to you. It will also be used as part of a doctorate research thesis. Every participant can get a summary of the results of the research sent to them if they want.

#### **What we would like you to do.**

There are a series of questionnaires which should take between 20 to 30 minutes to complete in total. The number of questions may look daunting but most people find they are quite quick to complete once they get into the swing of them. Most of the questionnaires ask about everyday things. A few questions are of a personal nature but the information requested will be very useful to us. If you feel the need to talk about anything arising from the questionnaires please feel free to contact either Liz Shaw or Robert Watson (contact details below).

#### **Confidentiality.**

All replies that you give us will be confidential and anonymous. This means it will not be possible for anyone to trace who has filled out the questionnaires.

**People and organisations involved in the research.**

**Liz Shaw**  
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Please feel free to contact any of the above people involved in the research if you have any questions or would like some help with completing the questionnaires.

## **Appendix Two.**

Quality of Life Inventory Sample Items.

Vocational Self-efficacy Scale.

## Quality of Life Inventory (Frisch, 1994) Sample Items.

Work means your career or how you spend most of your time. You may work at a job, at home taking care of your family or at school as a student. Work includes your duties on the job, the money you earn (if any), and the people you work with. If you are unemployed, retired or can't work, you can still answer these questions.

1. How important is work to your happiness?

Not important

Important

Extremely important

2. How satisfied are you with your work? (If you are not working, say how satisfied you are about not working).

Very  Somewhat  A little

DISSATISFIED

A little  Somewhat  Very

SATISFIED

Friends are people (not relatives) you know well and care about who have interests and opinions like yours. Friends have fun together, talk about personal problems, and help each other out. If you have no friends, you can still answer these questions.

1. How important are friends to your happiness?

Not important

Important

Extremely important

2. How satisfied are you with your friends? (If you have no friends, say how satisfied you are about having no friends).

Very  Somewhat  A little

DISSATISFIED

A little  Somewhat  Very

SATISFIED

## Vocational Self-efficacy scale.

Please read the following statements and tick whichever number applies. Still complete this question regardless of whether you are working or not.

I am confident I could work/continue to work even if:	Not at all confident	Slightly confident	Somewhat confident	Quite confident	Very Confident
It was stressful	1	2	3	4	5
I felt unwell	1	2	3	4	5
I was taking combination therapies	1	2	3	4	5
I was worried about my employer discriminating against me as a person living with HIV	1	2	3	4	5
I hadn't worked for several years	1	2	3	4	5
I felt depressed	1	2	3	4	5
I had to fit in clinic appointments	1	2	3	4	5
I had to tell my employer I was HIV positive	1	2	3	4	5
I felt anxious	1	2	3	4	5
I suffered side effects from taking combination therapies	1	2	3	4	5

## **Appendix Three.**

Ethical Approval.



*of*

*Chairman:* Peter Dixon  
*Chief Executive:* Christine Outram

23 August 1999

Ms Liz Shaw  
Clinical Psychologist  
Psychology Service  
Haringey Healthcare NHS Trust

Dear M Shaw

683 – Positive futures for people with HIV/AIDS

Acting under delegated Authority, I write to inform you that the amendment and clarification to the above study contained in your letter dated 19 August 1999 have been approved.

The committee looks forward to receiving a copy of your interim report in six months time or at the end of the study if this is sooner.

Yours sincerely

Dr Peter Sheridan  
Deputy Director of Public Health  
(on behalf of the LREC Chairman)

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