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UNRESTRICTED

**HIV POSITIVE BLACK AFRICAN WOMEN:
ATTITUDES TO HIV, DISCLOSURE AND
PSYCHOLOGICAL WELL-BEING**

**A thesis submitted in partial fulfilment of the requirements of the
Open University for the degree of Doctor of Clinical Psychology**

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This work has not previously been accepted in substance for any degree and is not being concurrently submitted in candidature for any degree.

Signed *Munee* (Candidate)

Date *14-7-99*

STATEMENT 1

This thesis is the result of my own investigations, except where otherwise stated. Other sources are acknowledged by footnotes giving explicit references. A bibliography is appended.

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Date *16-7-99*

Signed *J. S. Holt* (Supervisor)

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Many thanks go to the doctors in my life : Dr Sue Holttum and Dr Fiona Hirst. You have been great in your own separate ways and for that, I am grateful.

Fi how will I ever repay you for that fateful night? You were brilliant.

Sue I was going to mention the !***!, but thought better of it in the end. I think I will just let the matter rest.

As if I need to say it, much love to the daddy for always managing to upstage the dissertation in his own special way, mummy for the comments “ *why don't they let you give it in on another day*”, “*you can't read for the rest of your life, what about marriage and children*” and Wally Junior, my friend and soul mate.

Finally, a huge thank you to all those individuals who took part in the study.

Joseph

Abstract

Objective: Using a sample of 56 HIV positive black African women, the study sought to explore the attitudes a HIV positive individual held towards persons with HIV and what the same individuals perceived the attitudes of their community to be towards individuals with HIV. The study also examined issues surrounding disclosure of HIV status and determined levels of psychological well being and health related quality of life.

Design: A one group, cross sectional design, was used.

Methods: Seven questionnaires were completed by the sample. In addition a small sub sample was interviewed about the factors affecting disclosure.

Results: Respondents reported moderately liberal attitudes towards persons with HIV but perceived the community attitudes to be less liberal than their own. They had higher levels of HIV related mental distress, lower levels of support and poorer health related quality of life in comparison to other HIV samples. A mixture of social and psychological factors predicted mental health related quality of life and HIV distress. Disclosure decisions were considered to be affected by a range of factors including stigma management and the need to achieve psychological well being.

Conclusions and implications: The results were discussed in terms of previous research. Implications for HIV positive African women were considered, with particular reference to the need for more cross culturally appropriate research.

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1. INTRODUCTION

It is estimated that over eighty per cent (20.5 million) of the world's entire population of people living with AIDS live within the Sub-Saharan African regions (Ssanyu-Sseruma, 1998a). In the United Kingdom HIV/AIDS constitutes a significant problem among Sub Saharan African communities, with the largest numbers of individuals from these communities with HIV/AIDS reported to live in the London area.

Black Africans living with HIV in London represent a unique social group. Many are immigrants to the country, with a significant proportion being classified as either refugees or asylum seekers (Ssanyu-Sseruma, 1998a). Trauma, represented by civil war, torture, rape and murder of relatives has been experienced by many (Health Education Authority, 1992). As part of a visible ethnic group they will likely also be subject to the social problems associated with being a member of an ethnic minority. Issues therefore relating to poverty, unemployment and racism may constitute significant areas of concern for these groups. In addition, leaving behind family members in their country of origin can mean a loss of normal sources of social support. The loss of normal support mechanisms means that the issue of disclosure of HIV status is viewed as a salient problem for many professionals working with Black African HIV positive individuals (Campbell, 1998). Frequently, individuals have not informed anyone of their diagnosis, apart from their health care services. As a group dominated by isolated single mothers, non-disclosure limits support from wider networks (Campbell, 1998). This raises clinical concern as previous research indicates women with young children without close confidantes, display an elevated risk of developing a depressive episode (Brown and Harris, 1978).

The following review aims to present a detailed overview of some of the different psychosocial issues experienced by individuals with HIV/AIDS, particularly women. The review begins with an exploration of the stigma which surrounds HIV/AIDS and

the negative effects it can have on individuals. The close relationship between stigma and negative attitudes is highlighted, with an inter-group perspective being applied to explain the negative attitudes that exist towards individuals with HIV/AIDS.

The issue of disclosure of HIV status is discussed in terms of the positive effects it can bring and the barriers that exist in disclosing one's HIV status. The author presents details on the different patterns of disclosure to family and friends and addresses the relationship between support, stigma and disclosure. The next section presents a review of the literature on coping and social support in chronic illness and HIV/AIDS. It is subsequently followed by a brief review of the data on health related quality of life.

The final section provides an overview of the statistics regarding the increasing numbers of women with HIV/AIDS, and highlights the relative neglect of female issues within HIV/AIDS research. The aims and rationale of the current research are then presented followed by the research questions.

1.1. THE NATURE OF HIV/AIDS

Acquired Immune Deficiency Syndrome (AIDS), is a constellation of symptoms that are a product of a deficiency in the human body's immune system. It is the result of an infectious disease thought to be caused by the Human Immunodeficiency Virus (HIV), which functions by systemically destroying the capability of the body to fend off diseases and infections through attacking the immune system. Individuals who have been screened via a blood test and found to be positive for antibodies to HIV, but are yet to exhibit any signs of AIDS, are often referred to as being HIV positive or HIV seropositive (Hubley, 1995). Thus, although they appear healthy and do not show any signs of AIDS they do, nevertheless, carry the virus and are capable of transmitting it to others.

Two different strains of HIV are known to exist: HIV-1 and HIV-2, but there are also various subtypes. Current statistics indicate that most individuals are affected by HIV-1, which is reported to have a faster disease progression, i.e. individuals move faster from having HIV to developing AIDS. HIV-2 is predominately associated with regions within West Africa and is known to have a slower disease progression compared to HIV-1. (Terrence Higgins Trust, 1998).

The most common transmission route for HIV is via unprotected sexual intercourse (both vaginal and anal) between two individuals, when one person is HIV positive. Other well known transmission routes for HIV are those which involve the direct entry of HIV into the blood stream. For example, individuals who have had blood transfusions which have been contaminated with HIV, or through intravenous drug use, where needles have been shared with HIV positive individuals (Hubley, 1995).

Although there is no cure for HIV/AIDS, there are various classes of drugs which treat any secondary manifestations and slow the progression of the disease by lowering the level of HIV in the blood. The drug treatments work by destroying the ability of HIV to reproduce (Terrence Higgins Trust, 1998). Individuals normally receive a combination of different drugs and need to follow complicated treatment regimes.

There is a great deal of uncertainty which accompanies a diagnosis of HIV. Unlike many other terminal and chronic illnesses, a positive result for HIV will not be delivered with a fixed prognosis. For many, HIV will follow a fluctuating course which gives rise to periods of good health followed by periods of illness and declining health (Chidwick and Borrill, 1996). Unlike in previous years, before the developments in drug treatments, it is no longer universally agreed that all HIV positive individuals, at some stage during their illness, will eventually develop the severe symptomology which was in the past classified as AIDS. The continuous advances being made in developing effective drug therapies combined with the research into psychosocial

factors that affect disease progression and identifying effective psychosocial interventions, contribute to the extending the length of incubation time between an individual becoming HIV positive and the subsequent development of AIDS (Chidwick and Borrill, 1996).

1.2. HIV STUDIES

The majority of studies which examine the psychosocial impact of HIV/AIDS have been conducted on white middle class gay or bisexual men. Furthermore, their sample size has generally been small, with an emphasis upon employing a qualitative methodology. Consequently, the applicability of their results to other HIV-infected groups such as women and ethnic minorities is limited. This situation is reflected in the studies presented in the current review. The author will specifically highlight studies in which female or ethnic minority samples have been used. However, the research which has used HIV positive ethnic minorities or females in their samples, has primarily originated from America. These findings must be interpreted within the context that the primary mode of HIV transmission amongst ethnic minorities in the USA is via intravenous drug use, which differs significantly to the heterosexual contact that predominates in African countries and recent immigrants to the UK.

1.3. STIGMA

1.3.1. Definitions of stigma

According to Goffman (1963) stigma is best understood as an individual attribute which is either deeply *discrediting* or *discreditable*. The former refers to one that is open for the public to see or have been told about. In contrast, the latter is one which remains un-apparent to the public. Goffman (1963) argues that stigmatised individuals are felt to hold certain characteristics that are deemed undesirable, because they have

failed to fulfil normative expectations. Stigma comprises three related concepts that require careful consideration in any stigmatising situation. First, *associative stigma*, also known as courtesy stigma, is experienced by caregivers or associates of those who are stigmatised. The second concept is *internalised stigma* which refers to circumstances where stigmatised individuals accepted their devalued worth (Jones, Farina, Hastorf, Markus, Miller & Scott, 1984). This process can occur in the absence of overt mistreatment and often leads to a lowered sense of self worth and esteem. The final concept is one of *stigma management*. This involves developing an awareness of the possible negative reaction of others and the methods for reducing these effects (Jones et al., 1984; Page, 1984).

1.3.2. Stigma and HIV/AIDS

Herek and Glunt (1988) argued that individuals with HIV are subject to a particular kind of stigma and thus, coined the term *AIDS related stigma*. AIDS related stigma appeared to differ from the stigma affecting other types of illnesses and social problems, due to a deeper level of discrimination and prejudice experienced by those infected by HIV/AIDS. Results from a meta analysis of twenty one studies concluded that HIV related stigma exceeded the stigma generated from other illness (Crawford, 1996). Ethnic differences have been found in levels of stigma. Thus, stigma associated with HIV within ethnic groups is reported to be significantly higher than the levels recorded in white populations (Diaz, 1993; Mays and Cochran, 1987).

The stigma attached to HIV/AIDS is generated from two distinct sources. First, there is the early association of HIV/AIDS with pre-existing stigmatised disadvantaged groups which were disproportionately affected by the illness. For example, gay men and ethnic minorities (Conrad, 1990; Corea, 1992; Weitz, 1991). Second, the stigma originated from the fact that the virus could be sexually transmitted and appeared to be self inflicted (De Jong, 1980; Jones et al., 1984).

1.3.3. Effects of stigma

Two distinct types of stigma are often referred to in HIV/AIDS. Enacted stigma refers to the sanctions that are experienced by those with HIV/AIDS on an individual or group basis. Felt stigma concerns the shame and oppressive fear of enacted stigma (Green, 1995). The evidence clearly suggests that irrespective of the type of stigma endured by the individual, both will have grave consequences for an individual's rights, freedom, self identity and quality of social interactions (Jaccoby, 1994). There is strong evidence confirming the existence of internalised stigma amongst individuals with HIV/AIDS (Green, 1995). Stigma also seems to affect the ordinary development of relationships (French, 1984). In attempts to avoid the stigma and the subsequent negative feelings, affected individuals invariably withdraw from social situations (Crandall and Coleman, 1992).

The social isolation accompanying HIV/AIDS stigma has been argued to be exacerbated for women (Semple, Patterson, Temoshok, McCutcahn, Straits-Troster, Chandler & Grant, 1993), particularly those from ethnic minorities (Bourdieu, 1986). HIV/AIDS stigma for women appears to be present at a number of societal levels. There is the general stigma which has associated HIV with acts of sexual deviance and promiscuity (Conrad, 1986). HIV positivity suggests that women as embodiments of all that is good and pure, have departed from socially respected behaviour (Lawless, Kippax and Crawford, 1996). Additionally, HIV positive women are subsequently perceived as potential sources of infection to a wider population and future generations (Gillman, 1988; Strebel, 1995).

In conclusion, evidence from stigma and HIV research suggests that HIV positive women, particularly those from ethnic minorities may be adversely affected by their illness. The research suggests that they are more likely to experience a damaged self identity, low self worth and social isolation.

1.4. ATTITUDES TOWARDS HIV/AIDS

An understanding of the attitudes prevalent in society towards those affected with HIV/AIDS is essential in order to achieve a complete understanding of the stigma (Bruce and Reid, 1998).

Evidence indicates that compared to individuals with cancer or contagious illnesses such as hepatitis, people are more reluctant to interact with people with AIDS (Sheehan, Lennon & McDevitt, 1991). Research findings suggest that negative attitudes towards individuals with HIV/AIDS are widespread amongst the public (Borcher & Rickbaugh, 1995; O'Hare, Williams and Ezoviski, 1996) with similar results being replicated in a number of different studies across the globe (Ralston, Dow & Rothwell, 1992; Porter, 1993).

However, many of the major studies which have explored the nature of public attitudes towards HIV positive people, have been characterised by an almost exclusive use of university undergraduate samples, using vignettes. The student population is relatively homogenous with regard to age and ethnicity. This has implications for generalisations to other groups outside of a student population. In much of the HIV/AIDS attitude research, many researchers have also failed to acknowledge the distinction between reported attitudes and actual behaviour. Finally, there has been minimal work examining quantifiably, the attitudes towards HIV from persons who are HIV positive themselves. Thus, while the literature is dominated with studies of students, limited knowledge exists on the actual attitudes of a sufferer and their perception of others' attitudes.

1.4.1. African attitudes towards HIV/AIDS

An understanding of the attitudes of African people towards HIV/AIDS is important given the proportions of African people affected by the illness. In many African countries, attitudes towards HIV/AIDS are thought to be negative from a young age.

Results from a survey of school children (mean age 16.3 years) in Kenya indicated that over sixty per cent felt that persons with HIV were at fault for having contracted the disease (Pattulo, Malonza, Kimani, Muthee, Otieno, Odhiambo, Moses and Plummer, 1994). Similar attitudes were obtained from a survey of health care workers in a large teaching hospital, of which the majority reported that they would not want to be placed in a situation where they had to interact closely or treat patients with HIV/AIDS (Adelekan, Jolayemi, Ndom, Adegboye, Babatunde, Tunde-Ayimode Yusiff & Makanjuola, 1995). However, no information was available on non respondents, who may have differed significantly from the sample and may not have had concerns about working with HIV positive persons. The attitudes towards HIV positive women are reported to be particularly negative from the wider African community, due to beliefs of being sexually indiscriminate and culpable for the spread of the virus (Campbell & Kelly, 1995; Ssanyu-Sseruma, 1998b).

From the foregoing, a large body of research suggests negative attitudes to HIV are widespread. However, some evidence counters this (Brook, 1988; Weilings and Wadsworth, 1990). This may imply that the problem of negative attitudes is overstated. Alternatively, there could be a disproportionate effect on stigmatised individuals from a minority who do react negatively. In addition, 'felt stigma' may be as important or more so than 'enacted stigma'.

1.4.2. Attitudes of HIV positive individuals

A significant predictor of felt stigma could be a HIV positive individual's understanding of societal attitudes. However, studies explicitly exploring the perceived attitudes of others, have rarely been considered within social psychology (Button, Grant, Hannah & Ross, 1993). To date, the author is aware of only one study which has attempted to explore the area of perceived societal attitudes within an HIV positive sample (Green, 1995). The study indicated strong evidence of felt stigma among persons with HIV. The sample perceived societal attitudes to be significantly less

liberal than their own and much more illiberal than the public reported their own attitudes to be. The study however, was based upon a sample of 42 white Scottish men and women. Therefore, the applicability of findings to non white HIV infected groups, who may already have existing stigmas due to being a member of an ethnic group, is restricted. Many authors have argued that it is essential to determine the information individuals have on the attitudes of others, as it can affect their readiness to be influenced by them (Aronson, Turner and Carlsmith, 1963).

1.4.3. Origins of negative attitudes

The research exploring the attitudes towards persons with disabilities including HIV, is still in its infancy and has yet to be successfully assimilated into mainstream social psychology. The present research employs an inter-group attitudes perspective.

1.4.3.1 Inter-group attitudes - a multi-component model

Inter-group attitudes have been referred to as the favourable or unfavourable global evaluations of social groups, based upon different sources of information. According to the multi-component model, negative attitudes towards particular groups comprise the independent and non equivalent contribution of affective and cognitive components. The affective component refers to the specific emotions or feelings an individual may have towards group members, including anxiety or fear. The cognitive component refers to the beliefs about group members, which may include stereotypical or symbolic beliefs. Finally, attributions regarding the extent of individual control and culpability over the onset of their disability also forms an integral part of the cognitive component. Pullium (1993) reported that attributions about perceived controllability had a significant affect on the subsequent reactions to HIV positive people.

1.5. DISCLOSING HIV

A major consequence of HIV stigma and the negative attitudes it generates towards its sufferers, has been the reluctance of HIV positive persons to disclose their status. The next section will explore the issue of disclosure.

1.5.1 Theory of disclosure

Self-disclosure encompasses issues such as the different types of information and feelings individuals disclose to others, the effect on psychological functioning following disclosure and its relationship with psychological problems (Derlega & Berg, 1987). In the current study, self-disclosure will be explored with specific reference to informing another person about one's HIV status. The general conclusion from disclosure literature suggests that an individual's psychological well being is facilitated via the discussion of negative feelings (Jourard, 1971).

1.5.2. The positive effects of disclosing HIV status

HIV disclosure is known to play an important role in helping individuals cope with their HIV status (Holt, Court, Vedhara, Nott, Holmes & Snow, 1998). Amongst gay men, HIV disclosure may strengthen interpersonal relationships and as a consequence, present the opportunity to receive emotional and financial support (Hays, McKusick, Pollack, Hillard, Hoff and Coates, 1993). This seems to act as an effective buffer to the effects of anxiety and stress that may accompany the illness (Cohen, 1988; Siegel and Krauss, 1991).

1.5.3. The barriers to disclosure

Different factors have been identified as making the act of informing another person of one's HIV status difficult. The desire to protect the emotional state of the infected individual and of significant others, are two of the most frequently reported reasons for non-disclosure amongst persons with HIV. The fear of disrupting relationships and being rejected are also cited frequently (Hays et al., 1993; Green, 1995). HIV/AIDS

related stigma and the irrationality concerning its contraction, combined with an apprehension of discrimination, are recognised by many researchers as decreasing the likelihood of an individual disclosing their status to friends, family and health care professionals (Sterling, Antoni, Fletcher, Margulies and Schneiderman, 1994).

It is often argued that non-disclosure may limit an individual's access to support and services which are crucial in the successful management of a long term illness (Cohen, 1988; Kulik and Mahler, 1989). However, when the illness is associated with significant levels of stigma such as HIV/AIDS, non-disclosure may help to reduce the chances of the individual experiencing negative consequences in social, personal and relationship domains (Mason, Marks, Simioni, Ruiz and Richardson, 1995). Dealing with the issue of informing another person of one's HIV status and at what stage, remains a potent stressor for many individuals irrespective of whether they choose to reveal their HIV status (Mcgain and Gramling, 1992).

1.5.4. PATTERNS AND LEVELS OF DISCLOSURE

1.5.4.1 Disclosing to partners, friends and family

Statistics indicate that men and women with HIV/AIDS, are more likely to disclose to primary lovers and spouses, rather than to non primary partners for example, occasional partners (Norman, Kennedy and Parish, 1998). Furthermore, HIV positive men and women are more likely to disclose their status to friends than to family members (Hays et al., 1993; Stempel, Moulton and Moss, 1995). Of the family members which are disclosed to, female members are the preferred choice for both gay men (Hays et al., 1993; Stempel et al., 1995) and non gay women (Simoni, Mason, Marks, Riz, Reed & Richardson, 1995).

1.5.4. 2. Ethnic differences in disclosure

Ethnic differences have been identified in disclosure levels. The results suggest ethnic groups in America such as African Americans and Latinos, are less likely to disclose their status to friends and families (Simoni, Mason, Marks, Ruiz, Reed and Richardson, 1995). Higher rates of non-disclosure of HIV status in ethnic minority groups have been attributed to the cultural values that exist in many non white groups. These are generally characterised by the idea of sparing the emotional distress of loved ones and avoiding the stigma of AIDS (Simoni, Mason & Marks, 1997). The shame and fear that a family may experience following the disclosure of HIV/AIDS, is reported to account for the lower rates of HIV disclosure amongst black and Latino ethnic groups in the USA (Kaminsky, Kurtines, Hervis, Blaney, Millon & Szapocznik, 1990). Keefe and Padila (1989) argue that for many ethnic minorities, immigration difficulties and social disadvantage encourage non-disclosure as a method of avoiding further discrimination and stigma. Individuals from minority groups live in a society where they may already be stigmatised because of their race. Non-disclosure of their HIV/AIDS status, therefore, may be their chosen method of avoiding another reason for being stigmatised and marginalised by the majority society (Madiros, 1984).

From the evidence, it appears that a vicious cycle exists between fear, stigma and non-disclosure, particularly within ethnic minority groups. The prospect of being faced with HIV/AIDS stigma and the possibility of discrimination, may ensure that disclosure does not occur. While non-disclosure may mean that an individual is less likely to become the target of stigma, it does mean, however, that any support and assistance specifically needed with regard to their illness, is unlikely to be offered. To receive social support per se is not dependant upon disclosure of one's HIV/AIDS status. However, to receive the type of support that is related to HIV/AIDS concerns is dependant upon disclosure, for which the individual must assess their need for gaining support against a strong risk of feeling stigmatised and discriminated.

1.5.5. Criticism of disclosure research

In comparison to males, there is a relative lack of information regarding the issues of disclosure amongst HIV positive women, particularly 'women of colour'. The findings detailing the pattern and reasons underpinning disclosure and non-disclosure have been largely based on white gay cohorts and are not easily generalisable to HIV positive women. There are significant differences in the context of their lives and social networks. Many HIV positive women are also mothers with concerns about protecting their children from HIV stigma (Moneyham, Seals, Demi, Sowell, Cohen and Guillory, 1996; Chung and Magraw, 1992) and who experience difficulties in discussing HIV related issues with their children (Nagler, Adnopoz and Forsyth, 1995). The decision to disclose, therefore, represents a complex burden for the HIV positive mother (Hacki, Somali, Kelly and Kalichaman, 1997).

The first half of this review has focused on stigma, its relationship to disclosure and the negative effect it exerts on an individual's psychological well being. The next section will focus upon coping and social support as mediating factors of psychological distress experienced by HIV positive individuals.

1.6. COPING

1.6.1. Coping and chronic illness

Most theoretical explanations of the role of coping in chronic illness have drawn upon the transactional approach to stress and coping provided by Lazarus and Folkman (1984) or the more recent extended model offered by Maes, Leventhal and De Ridder (1996). Coping incorporates thought processes and active responses and can refer to either specific methods or the general styles used by individuals. Coping strategies are generally divided between those defined as problem focused and those defined as emotion focused. The former refers to acts by the individual to alter the source of

stress, while the latter is concerned with the regulation of stressful emotions. Examples of emotion focused coping strategies include wishful thinking, (Felton and Revenson, 1984). In chronic illnesses such techniques are known to be most effective in circumstances in which minimal or no control exists over the course of the illness (Taylor and Aspinwall, 1993). In contrast, attempts to learn more about one's illness and treatments are examples of problem focused coping (Fleishman and Fogel, 1994; Longo, Spross and Locke, 1990). In general, a consistent relationship exists between emotion focused coping and higher levels of psychological distress including anxiety and poor adjustment (White, Richter and Fry, 1992; Vitalino, Mauro, Russo & Becker, 1987).

1.6.2. Coping strategies and HIV/AIDS

Unlike other chronic illnesses, in HIV the coping process appears to be complicated by the discrimination and stigmatisation of the illness (Holt et al., 1998). Nevertheless, the coping styles employed by individuals with HIV/AIDS appear to resemble those used by individuals living with other types of chronic illnesses (Folkman, Chesney, Pollack, Coates, 1993).

It can be argued that the findings from many of the coping studies in HIV research have unfortunately generated a rather restricted understanding of HIV positive individuals coping with chronic and stigmatising illnesses. Most of the studies have been criticised over their use of small samples of gay men (e.g. of sample sizes: 24, 29) and use of very diverse coping measures, that have generally been developed for the specific use of their sample. This practice ensures difficulties in comparisons across studies. Similar to the general coping literature, HIV coping studies have been cross sectional and correlational in design and therefore lacking in any conclusive proof of a cause and effect relationship between reported coping style and subsequent psychological functioning.

1.6.3 Coping and HIV positive women

The coping research which has favoured the use of a white gay male population has neglected the frequently highlighted fact that the main groups of women affected with HIV are those from minority groups, who are characterised by being mothers and members of socially and economically disadvantaged groups. Their role as mothers and carers invariably demands the constant coping with and balancing of different needs of self and others e.g. children and partner. Therefore, HIV positive women are considered to be susceptible to HIV related stressors and ill equipped to deal with the conditions of their illness, because of a depletion in the socio-economic resources that can facilitate effective coping (Moneyham, Hennessy, Sowell, Demi, Seals and Mizuno, 1998). The generalisability of mainstream HIV coping literature to HIV positive women and other demographic groups is limited.

Notwithstanding the significant gender imbalance in the literature, a few studies have examined coping in HIV positive women. In one study of 264 HIV positive women who were predominately African American, active coping was associated with lower levels of emotional distress (Moneyham et al., 1998). The authors argued that individuals were protected from psychological distress via active coping strategies, which included seeking social support. However the study was cross sectional, so it could be argued that women who were less distressed were more likely to use active coping than the reverse. The same study also reported a non significant relationship between avoidance coping and emotional distress (Moneyham et al., 1998). Thus, it is possible that avoidance may not work in a protective fashion, but does not do any harm either, with regard to levels of emotional distress. It appears therefore, that contrary to many of the existing studies with male cohorts, emotional distress does not necessarily have to be a negative consequence of emotion focused coping strategies. The authors of this study can be commended for their inclusion of a large, ethnic minority HIV positive female sample. However, it was noted by the authors that the validity of the coping measures used, which were specifically designed for the study,

needed to be explored with further psychometric evaluation. This is a relevant criticism of many HIV coping research measures. From the author's own reports many of the instruments employed were limited by psychometric weaknesses including low internal consistencies and poor construct validity (Stone, Kennedy-Moore, Newman, Greenberg & Neale, 1992).

In summary, coping style may play a role in the adjustment and management of HIV. The coping research is equivocal and has suggested a positive relationship between problem focused styles of coping and psychological well being. Evidence also indicates that emotion focused coping is not always associated with psychological distress. However, most studies have been based upon small select samples of white gay men and/or have used cross sectional designs. Therefore, the need to redress the gender and ethnic imbalance is essential, particularly given women's occupancy of different social roles and the demands these can have on their psychological and physical functioning.

1.7. SOCIAL SUPPORT

1.7.1. Defining social support

In the following discussion on social support with individuals with HIV/AIDS, it must be noted that most of the studies in this area are characterised by the variability in the definitions and conceptual frameworks applied to social support. For the purposes of this study, social support will be understood as a catch all term used to refer to the range of services received through the social contacts an individual has with others (Lesserman, Perkins and Evans, 1992).

1.7.2 Social support and illness

Social relationships are an important component in the process of coping with chronic diseases (Cohen, 1988). A large amount of evidence exists suggesting a relationship

between psychological well being and social support (Cohen and Wills, 1985; Turner, 1981; Weinberger, Tierney, Booher & Hiner, 1990). However, the precise direction of the relationship has yet to be proved conclusively, given the correlational design of most studies. Nevertheless, strong support has been received for the idea that the benefits of social support are provided by protecting individuals during times of high stress, otherwise known as the 'buffering' hypothesis (Cohen and Willis, 1985).

1.7.3. HIV/AIDS social support and stigma

There are HIV specific factors that can leave HIV positive individuals in need of social support and in a position of losing existing support (Crandall and Coleman, 1992).

These include the uncertainty and unpredictability associated with treatment and their effects on sexual and reproductive health (Weitz, 1989; Donlou, Wolcott, Gottlieb & Landverk, 1985; Catalan, 1990). The combination of such factors, in addition to the stigma of HIV, may threaten and destroy the social support offered by loved ones and friends, which existed prior to an individual's disclosure of HIV (Altman, 1986).

Using a variety of self report support measures in individuals with HIV/AIDS, the presence of social support has been consistently related to decreased episodes of mood disturbance (Dew, Ragni & Nimorwiwicz, 1990; Namir, Alumbaugh & Fawzy, 1989), lower levels of emotional distress (Kalichman, Sikkema and Somlai, 1996) and improved levels of self esteem (Donlou et al., 1985). However, many conclusions from studies about the beneficial effects of social support have been based upon cross sectional designs, with no control samples. Failing to employ a control group of HIV negative participants can make the attempts of isolating the effects of HIV and stigma very difficult. Although the conclusions of many studies profess to the propitious effects of social support on functioning, their correlational designs do give rise to alternative suggestions, albeit less publicised. It is possible, therefore, that it is precisely because an individual is in good psychological health that they are able to shape the levels and pattern of social support to their own requirement and

satisfaction. Equally, individuals who are experiencing emotional distress may be less likely to provide valid or accurate representations of their support network.

In conclusion, the evidence suggests a relationship exists between social support and the mental health functioning of individuals with HIV/AIDS. The precise nature of this relationship has yet to be clarified. The author notes that similar to other areas, the samples of HIV persons studied in relation to issues of social support have been almost exclusively white, homosexual/bisexual middle class men. The imbalance is clearly recognised as being problematic given the qualitative differences which exist between the social networks found in gay and non gay communities (Kurdeck, 1988). Thus, applying results to other HIV positive groups including black and ethnic minority groups and women, who may be facing multiple disadvantages with different social roles, is problematic.

1.7.4 An interaction of coping and social support

Many researchers regard coping and social support as powerful resources that can be used effectively together to mediate against the stressors of HIV/AIDS. Furthermore, coping and social support seem to be two of the most important factors that help to explain differences in quality of life following a diagnosis of HIV (Felton and Revenson, 1984).

1.8. QUALITY OF LIFE

1.8.1. Defining quality of life

Minimal uniformity exists amongst researchers with regard to what exactly constitutes quality of life or how to measure it. For the purpose of this study, quality of life refers to levels of existence that transcend basic subsistence and survival. It is those aspects of life that are assumed to make life enjoyable and worthwhile.

In chronic illnesses, many factors have been identified as influencing quality of life for sufferers including social factors, quality of family and social relationships, financial concerns and self esteem (Aronson, 1988; Berardo and Berardo, 1992; Smith, 1993). For many individuals, poorer quality of life has been associated with unpleasant and debilitating treatments including chemotherapy (Litchman, Taylor and Wood, 1987).

1.8.2. HIV/AIDS and quality of life

The stressors that accompany HIV are known to affect an individual's ability to maintain good levels of psychological and physical health and will, consequently, affect their quality of life.

Based primarily on the results of homosexual male populations, the evidence suggests that generally social and psychological factors and more specifically, 'role functioning', physical symptoms and psychological well being are important predictors of quality of life (Burgess, Catalan, Dayer, Hawkins & Gazzard, 1993; Lubek and Fries, 1992; Watchel, Piette, Mor, Stein, Fleishman & Carpenter, 1992; Cunningham, Bozzette, Hays, Kanouse and Shapiro, 1995). In addition, emotional types of social support and problem focused coping are known to share a positive relationship with quality of life (Friedland, Renwick & McColl, 1996). However, Nussbaum and Sen (1993) argue that the factors influencing quality of life in HIV positive women differ from those affecting HIV positive men. Furthermore, significantly lower levels of health related quality of life have been found in women with HIV/AIDS compared to men with HIV/AIDS (Watchel et al., 1992).

1.8.3. Women with HIV/AIDS and quality of life

Quality of life in women with HIV will probably be influenced by a complex interaction between physical, psychological and family factors (Rabkin, Remein, Katoff and Williams, 1993). There is a view that women, due to their occupancy of different social

roles, are prevented from accessing the health services which could ultimately contribute to the improvement of their quality of life (Gentry, 1993). The data suggest that women who are in full time employment exhibit better levels of quality of life than those who are unemployed. Employment appeared to provide assets which buffered the effects of stress associated with HIV infection and in doing so, helped to preserve levels of quality of life (Sowell, Seals, Moneyham, Cohen and Brake, 1997). In the UK, being a single parent or a recent immigrant to the country were important predictors of poorer mental quality of life (Lamping, Dooley, Murcott & Renton, 1996). Based on such evidence, there is a general argument that women's roles as wives, carers and mothers can take their toll and are hard to maintain in the presence of an illness (Rabkin et al., 1993). The different roles that women occupy means that it is essential to have a measure of quality of life that includes items on role functioning such as the SF-36 (Ware and Sherbourne, 1992).

1.9. BLACK AFRICAN WOMEN AND HIV

For a large majority of women, the stress of living with HIV is complicated by their roles of mother and partner and the burden of caring. Women with HIV are known to experience frequent episodes of low self worth and self esteem and some evidence suggests that this is precipitated by disruptions in their role due to physical problems, which subsequently prevent them from performing childcare duties and domestic tasks (Lea, 1994).

It was only in the last decade that any substantial attention from researchers has been paid towards the concerns and issues of women affected with HIV/AIDS. In circumstances where research has been conducted on females, there has been a tendency to focus on high profile marginalised groups with whom HIV has historically been associated for example, drug users and sex workers (Hankins, 1995; Plant, 1990; Scrambler and Graham Smith, 1992). Strebel (1995) argues that in such studies, these

groups have not been explored in terms of their own special needs and experiences. Instead, they have been studied because they were perceived as a source of infection and risk for the general population and non stigmatised groups. Furthermore, the experiences of women have been overshadowed by an over emphasis on issues of reproduction and a narrow focus on the concerns of the unborn or new-born (Hankins, 1995).

Stevens (1995) argues that it is essential that more information is collated on the needs and experiences of women with HIV/AIDS. The urgency of gathering these data is highlighted by the disturbing figures indicating women, particularly impoverished women and 'women of colour', are disproportionately affected by the virus and constitute the fastest growing demographic group with HIV (Chin, 1990; Keenlyside, Johnson and Mabey, 1993; Quinn, 1993; Ybarra, 1991).

1.10. AIMS AND RATIONALE OF CURRENT STUDY

The research discussed in the review suggests that HIV stigma and negative attitudes in society towards HIV positive persons, can have a negative effect upon the psychological well being and self identity of the HIV positive individual. The adverse consequences of HIV stigma may be compounded by being a member of an ethnic minority. For many individuals, HIV stigma will act as a deterrent to disclosing their HIV status. However, the accessing of appropriate services and the ability to cope and secure social support in response to HIV related stressors, is closely related to and at times dependant upon disclosure. Furthermore, coping and social support may play significant roles in achieving quality of life in HIV positive individuals. The data examining the psychosocial impact of HIV has suffered due to most studies being based upon white male gay cohorts. Sufficient information is noticeably absent for black HIV positive women in the UK. While the results of existing studies will to a

certain extent, remain relevant to women with HIV (Lamping et al., 1996), the specific issues which relate to a female ethnic minority position in society are largely missing. The purpose of this study therefore, was to redress some of the gaps in the HIV research by examining the nature of attitudes towards people with HIV in a sample of HIV positive black African women. Furthermore, the study explored whether a relationship existed between the participants attitudes towards HIV and their disclosure decisions and examined in relation to these factors, the quality of life of participants.

The study specifically examined what the group perceived the attitudes of their community to be towards persons with HIV. This was necessary given the studies suggesting that community attitudes occupy a central role in disclosure decisions of HIV positive persons (Moneyham et al., 1996). The data reviewed clearly indicate that living with HIV is associated with significant stressors. Therefore, the study explored the impact of HIV on this group and examined their health related quality of life, coping styles, and social support levels.

In view of the burden of care often faced by HIV positive women in roles as mothers, partners and patients and the evidence suggesting that women's occupancy of these different roles may contribute to poor quality of life, the study explored the relationship between their role limitation and methods of coping. Furthermore, given the situation where HIV positive women may be reluctant to disclose because of a wish to protect their children, the study examined relationships between disclosure and role functioning.

1.11. RESEARCH QUESTIONS

A) Quantitative

1. The first set of questions was exploratory, bearing in mind the relatively few published studies on black HIV positive women in the UK and looked at the sample's :

1. Demographic details
2. Own attitudes towards people who are HIV positive
3. Perceived attitudes of community towards HIV positive people
4. Comparison of participants own attitudes to those ascribed to the community
- 5a. Levels of HIV related mental health distress
- 5b. Levels of HIV concern
- 5c. Levels of HIV concern compared to other social concerns
6. Levels of disclosure and individuals disclosed to
7. Levels and types of social support.
8. Adopted coping styles.
9. Levels of mental and physical health related quality of life and specifically, levels of role limitation due to emotional problems and levels of role limitation due to physical problems

2) The second set of questions looked at the relationship between attitudes, disclosure, coping, social support, HIV distress and quality of life. The questions were:

- a) What is the relationship between attitudes and disclosure?
- b) What is the relationship between disclosure and role limitation?
- c) What is the relationship between coping styles and role limitation?
- d) What is the relationship between coping styles and HIV distress?
- e) What is the relationship between social support and HIV distress?

3) Of several factors implicated by previous research, which are the significant predictors of HIV distress, mental health and physical health related quality of life?

B) Qualitative

What are the issues affecting disclosure decisions in a small sub sample of black African women? In particular:

1. What factors make disclosure more likely ?
2. What factors make disclosure less likely?

2. METHODOLOGY

2.1 DESIGN

A one group, cross sectional design, using a combination of exploratory quantitative, correlational and qualitative approaches was employed.

The study consisted of two parts; a questionnaire section and a semi-structured interview with those who were interviewed.

2.2 PARTICIPANTS

2.2.1. General details of participants

Fifty six black African women with HIV were recruited. Fifty two were drawn from a variety of independent voluntary support groups in London, specifically designed for individuals infected with and affected by HIV/AIDS. In addition, four women were recruited from a hospital outpatient clinic for individuals with HIV/AIDS and an NHS funded psychology service for individuals with HIV/AIDS. Participants received £5.00 for their expenses.

2.2.2. Inclusion criteria

Women were accepted as participants in the study having met the following selection criteria:

1. Defined themselves as being of black African heritage.
2. Aged eighteen years and over.
3. Identified self as HIV seropositive and not having an AIDS defining illness.

Fifty six women completed the questionnaires. All completed questionnaires were used. Of these, seven women also agreed to be interviewed.

2.2.3. Refusal rates

The sample was self selected. The author was unable to determine the level of refusal because of the method of recruiting participants. As most participants were recruited indirectly, the author was unaware of how many people attended a support group and received information on the study and subsequently chose not to take part. Similarly, the author had no data on the numbers of participants who did not fit the criteria and therefore, did not take part or the numbers of participants who were judged to be physically or emotionally unwell by support group workers and therefore unable to take part in the study.

2.3. MEASURES

2.3.1 Demographic data (appendix 1)

The researcher designed a brief questionnaire, with the aim of gathering demographic data on all the variables believed likely to affect the dependant variables studied. The questionnaire included items on participants': age, ethnicity and date HIV diagnosis was received. The women were asked for their ¹CD4 count, ²viral load and medication, all of which are commonly well known by HIV positive individuals. Relationship and family status was asked for, as was employment, year of arrival into the United Kingdom and disclosure (from a list of nine categories i.e. those people to whom the participant had disclosed their HIV status). Finally, they were asked to rate their level of concern about HIV and level of concern regarding HIV in comparison to other areas for example, racism, immigration and housing difficulties.

¹CD4 count is a measure which reflects the ability of the immune system to combat any disease.

² Viral Load is a biomedical measure which provides a direct measure of units of the HIV virus in an individual's blood system. Used separately or more commonly in combination, the Viral Load and CD4 count provides one with a measure of the severity of the HIV/AIDS disease. CD4 count and Viral load are standard demographic measures within HIV/AIDS research.

2.3.2. HIV concern

Rating of HIV concern and HIV concern in relation to other issues (Appendix 1)

A Likert type scale anchored 0-10 was used to rate levels of HIV concern, where zero denoted *no concern*, and ten, the *highest level of concern*.

A list of seven concerns : financial, immigration, employment, housing, racism, relationship, and family difficulties were listed. Using the value they had assigned to their HIV concern, participants used the (0-10) ten Likert scale to note down their level of concern about these areas in comparison to their concern over HIV.

2.3.3. Health related quality of life

The Medical outcomes Study Short Form Health Survey (SF-36) (Ware and Sherbourne, 1992). (Appendix 2)

The SF-36 is a self report, short form measure of quality of life in chronic illness. Generally regarded as a generic indicator of health status, the SF-36 taps into areas known to be adversely affected by illness. The SF-36 was designed to be used in a variety of settings including both research and clinical work and broad population surveys. In addition to persons with HIV/AIDS, it has been widely used with a variety of patient groups including individuals with strokes, heart attacks, asthma and arthritis (Lyons, Lo and Littlepage, 1994) .

The SF- 36 generates eight dimension scores in three areas; functional status; well being and overall evaluation of health. It also yields two physical and mental component summary scores, which are reported to account for more than eighty per

cent of the variance of the eight subscales (Simon, Revicki, Grothaus & Vonkorrk, 1998).

The subscales from the SF-36 are :

Functional status

1. Physical functioning (10 items) the extent to which physical activities are limited by health.
2. Social functioning (2 items) the level of interference in social activities from emotional and physical problems.
3. Role limitations due to physical problems (4 items) the level to which physical problems interfere with daily activities.
4. Role limitations due to emotional problems (3 items) the level to which emotional problems interfere with daily activities.

Well being

5. Mental health (5 items): general mental health
6. Energy/ Vitality (4 items) energy levels
7. Pain (2 items) the intensity of pain and the effects exerted on normal activities

Overall evaluation

8. General health perception (5 items) evaluation of health

There is one un-scaled item that questions respondents on the change in their health over the preceding twelve months. All the scales are coded. Individuals finally achieve

a score on a scale anchored between 0 and 100. On all scales, higher scores indicate a better health status.

Extensive evidence exists documenting the psychometric properties of the measure (Ware & Sherbourne, 1992). Good criterion validity of the SF-36 against the longer form has been reported (Jenkinson, Layte, Wright and Coulter, 1994). Similarly, results from studies assessing convergent and discriminant validity have been good (Brazier, Harper, Jones, O’Cathain, Thomas, Usherwood and Westlake, 1992; McHorney, Ware and Raczek, 1993; Jenkinson, Coulter and Wright, 1993). There is a wide body of literature lending support to the reliability and construct validity of the measure in HIV/AIDS populations (Wu, Hays, Kelly, Maitz & Bozzette, 1997).

Extensive data published in both the UK and the USA attest to the internal reliability of the scale. Estimates of internal reliability have been reported for general population groups. High correlations have been reported for items within dimensions (Brazier et al., 1992). In one study the alpha coefficients for the inter-item correlation ranged from .73 for social functioning to .96 for role limitation (physical and emotional) and energy and vitality (Brazier et al., 1992). In a separate study the alpha coefficients ranged from .76 for social functioning to .90 for physical functioning (Jenkinson et al., 1993).

Different socio- demographic groups and individuals with differing disease severity have been examined for properties of internal reliability. For individuals with psychiatric and complicated medical disease, the reliability coefficients have ranged from .65 on the general health scale to .94 for the physical functioning scale among various patient groups (McHorney, Ware and Lu, 1994).

2.3.4. HIV impact

The HIV Impact Scale for Women (Gendron, Hankins, Lamping, Lapointe & Tran 1996). (Appendix 3)

The HIVIS-W is a 34 item disease-specific measure. It was designed to gather data on the psychological distress that women living with HIV are generally felt to encounter. The HIVIS-W was a development of a generic HIV disease specific measure which explored the distress associated with problems frequently experienced by individuals living with HIV. The generic measure was compiled using data from interviews, an exhaustive review of the literature on HIV infection and mental health and expert opinion (Lamping and Sewitch, 1990). The HIVIS-W was based upon data gathered from 161 HIV positive women. The reported evidence indicates that where the HIVIS-W is used in conjunction with either standardised scales of mood or health-related quality of life, more comprehensive assessments of the mental health needs of HIV positive women living with HIV are obtained.

The five main scales of the HIVIS-W are :

1. Interpersonal concerns
2. Intrapersonal concerns
3. Health related concerns
4. Practical concerns
5. Future outlook.

Individuals are required to read through a list of problems and answer how much they had been affected by such problems over the last month. Their responses are chosen from a Likert type scale which includes : not at all (1), a little bit (2), moderately (3), a lot (4) and extremely (5). The HIVIS-W produces a total psychological distress score

based upon the un-weighted average of individual responses from all the questions. Higher scores suggest higher degrees of psychological distress.

The evidence reporting on the internal consistency of the HIVIS-W is good (alpha 0.91). Similar figures are reported across different populations. Thus, for Caribbean or African women, intravenous and non intravenous drug users and Caucasian women, the alpha coefficients ranged from .88 to .92 (Gendron et al., 1996).

Concurrent validity of the HIVIS-W with the SF-36 attests to a greater sensitivity to psychosocial or mental dimensions of health rather than physical dimensions.

Therefore, its correlations with the mental component summary scores of the SF-36 were much stronger at -.70, compared to the physical component summary score -0.26. The correlations are negative, indicating that better quality of life is associated with being less affected by HIV related problems.

2.3.5. Attitudes to individuals with HIV

Attitudes and perceived attitudes to HIV (Green, 1995). (Appendix 4 & 5)

Attitudes towards individuals with HIV were assessed with this 15 item questionnaire. The measure was developed from data gathered from extensive in-depth interviews with men and women living with HIV. These interviews derived substantial data on individual instances of enacted stigma and behavioural restriction due to feelings of stigma. The data gave rise to the three domains of the questionnaire :

1. Ideas about what people with HIV are like.
2. Victim blaming : whether to blame the individual with HIV for their virus.

3. Treatment from society :whether constraints or limitations should be applied to their behaviour.

The attitude questionnaire yields a summary score which has a range of (-30) to (+30), where a positive score depicts a 'liberal attitude' and a negative score depicts an 'illiberal attitude'. Individuals must read through a set of statements and circle the extent to which they agree or disagree with each statement. Individuals can choose from strongly disagree, disagree, agree and strongly agree. An example of a statement concerned with constraints and limitations is '*people with HIV should not have a child*'.

Internal consistency was good ($\alpha = 0.82$). Results from factor analysis attest to high levels of inter-relatedness of all items in the questionnaire and indicated that no single domain of the questionnaire operated independently (Green, 1995).

In order to obtain the attitudes a participant perceived others as holding, participants were required to complete the questionnaire twice. On the second occasion, participants were asked to suppress their own responses and provide those they considered a typical member of their community would provide.

2.3.6. Social support

Interpersonal Support Evaluation List (ISEL) (Cohen, Mermelstein, Kamarck and Hoberman, 1985). (Appendix 6).

This is a 40 item questionnaire requiring respondents to read through a list of statements focusing upon the perceived availability of potential social resources. Respondents have to tick whether each statement is probably true or false. The

questionnaire is divided into four separate sub-scales, which are reported to be reflective of the different functions of social support reported in the literature. These functions have been argued to shield people from the pathogenic effects of stress (Cohen & McKay, 1985). The questionnaire produces an overall measure of functional support. Higher scores on the measure indicate higher levels of support.

The scales of the ISEL are:

1. Tangible : assesses the perceived availability of material aid.
2. Appraisal : assesses the perceived availability of someone to talk to about your problems.
3. Self esteem : assesses the perceived availability of a positive comparison when comparing one's self with others.
4. Belonging : assesses the perceived availability of people one can do things with.

The figures quoted from tests of concurrent validity indicate moderate correlations with existing measures of social support. Correlations of 0.30 to 0.46 have been quoted (Moos and Moos, 1981; Mermelstein, Lichtenstein and McIntyre, 1983). The alpha coefficients for the internal reliability for the scales range from (.88 to .90). Ranges reported by these authors for individual subscales are generally good : appraisal (.70 to .82), self esteem (.62 to .73) belonging (.73 to .78) and tangible support (.73 to .81).

With regard to short interval (2 days) test -retest reliability properties of the entire scale, correlations were good .87. The correlations for the individual scales were good to moderate : tangible .78, self esteem .74, belonging .67 and appraisal .84.

2.3.7. Coping

Shortened Ways of Coping Questionnaire-Revised (SWC-R) (Hatton and Emerson, 1994). (Appendix 7).

The SWC is an adaptation of the Ways Of Coping Questionnaire -Revised (WCQ-R) (Folkman and Lazarus, 1988). The original measure is a well established 66 item questionnaire designed to tap into a wide range of behavioural and emotional strategies used to cope with stressful encounters. It was derived from Lazarus and Folkman's (1984) cognitive phenomenological theory of stress and coping. In the original measure, eight scales were present. The WCQ-R has been used in a variety of population groups including psychiatric outpatients and parents of children with Downs Syndrome (Sloper & Turner, 1994).

The SWC-R is a fourteen item measure and therefore, easier and quicker to administer than the WCQ. Individuals were expected to evaluate the extent to which they used coping responses using a four point likert scale which consisted of : does not apply or not used 0, used somewhat (1), used quite a bit (2) and used a great deal (3). The SWC-R yields two separate subscales:

Practical coping : directly coping with a stressful situation with the aim of changing it e.g. 'I make a plan and follow it'.

Wishful thinking : attempts to change emotions generated about the stressful situation rather than the actual stressful situation itself. e.g. 'I have fantasies or wishes about how things might turn out'.

The SWC-R was developed on direct care staff working in learning disabilities services. Higher scores on practical coping subscales are known to be negatively

associated with maladaptive outcomes including distress (Knussen, Sloper, Cunningham and Turner, 1992; Sloper and Turner, 1991) and depression (Vitaliana, Russo, Carr, Maiuro and Becker, 1985). In contrast, results demonstrate that wishful thinking is positively associated with distress (Knussen et al., 1992; Sloper and Turner, 1991) and depression and anxiety (Vitaliana et al., 1985).

Internal reliabilities of both scales were similar to those reported from previous studies: .76 (range across samples from different services 0.70 - 0.80) for practical coping and .65 (range across samples from different services 0.52 - 0.82) for wishful thinking (Hatton, Emerson, Robertson, Henderson and Cooper, 1995).

To date there is no available data on the SWC-R for HIV populations. However, the original questionnaire was validated on various groups and the short form is a subset of the original items. The decision to choose the short form over the long version was reached following evidence of the length of time it would have taken to complete all the questionnaires. The SWC-R was chosen due to its ability to yield sensitive data on coping styles, as the original form does, as well as being easy and quick to administer.

2.4. SEMISTRUCTURED INTERVIEW SCHEDULE

2.4.1 Developing the interview schedule (Appendix 8)

The semi structured interview schedule was developed with the aim of addressing two research questions concerning disclosure decisions. To maximise the participants' opportunity to provide their own thoughts and beliefs in response to questions, the questions were intentionally open ended, although specific prompts were used if necessary. In light of participants' well documented concerns over confidentiality and secrecy regarding their HIV status, it was decided the interviews would be recorded by hand rather than audio taped. Recording participants' responses verbatim was also

considered an appropriate method for facilitating a relaxed environment and limiting the intrusiveness of the study. At the end of the interview, participants were given the opportunity to hear exactly what the researcher had written down.

2.4.2 Piloting the interview schedule

The significant difficulties experienced by the researcher in her recruitment of women with HIV, meant that the schedule was not piloted amongst HIV positive African women. This reduced the risk of loss of pilot participants from what was likely to be a small sample. The schedule however, was closely scrutinised by an expert in qualitative design and a psychologist working in the area of HIV/AIDS. Minor changes were made to the wording of sample questions.

2.4.3 Outline of the interview schedule

The interview schedule consisted of two questions. Participants were questioned on the factors they considered would make an HIV positive African woman more likely and less likely to inform another person of their HIV status.

2.5. PROCEDURE AND ETHICAL CONSIDERATIONS

Different strategies were adopted with the aim of addressing the numerous ethical issues involved in researching a known 'stigmatised group' in which secrecy and confidentiality around their status were fundamental issues. Thus, involvement in the study was strictly on a voluntary basis and informed consent was sought from all participants. The confidentiality and anonymity of all data collected was assured for each participant. All participating individuals received information on relevant support services specifically catering for the needs of this population (see appendix 9).

Information was given to all participants and their services where applicable, on the month during which the study results would be made available. All participants were provided with information on where to receive a copy of the results.

The research design was set up in accordance with research guidelines laid out in the British Psychological Society's Ethical Principles and Guidelines (1998) and the Division of Clinical Psychology Professional Practice Guidelines (1995). Permission to conduct the study was sought and granted from the South Thames (Salomons) Ethics panel (Appendix 10) and a hospital trust ethical committee (Appendix 11).

2.5.1 Briefing and debriefing procedures

Two information sheets were produced which differed slightly on the wording depending on the context in which the participant was being recruited (i.e. either a support group or outpatient clinic).

The information sheet (Appendix 13) had details on :

- a. The rationale for the research and why the area of study was important.
- b. The voluntary nature of their involvement in the study and what it would entail if they agreed to take part.
- c. What would happen to information collected, including anonymity and confidentiality issues.
- d. Contact details for the researcher.
- e. The timing of feedback of results.

Information sheets were distributed via the researcher, support group leaders and a specialist liaison nurse working with African women. They were also left in reception areas at the outpatient clinic and published in support group newsletters. Each individual, other than the researcher who distributed information sheets, had been thoroughly briefed on the nature of the research so they could respond appropriately to any questions put to them from prospective participants. After completing the questionnaire, questionnaire/being interviewed, participants were given the opportunity to discuss issues raised and were provided with information on HIV support services.

2.5.2. Consent

The researcher devised her own consent form (Appendix 12). After reading the information sheet for a second time in the researcher's presence and having had a chance to ask further questions, participants completed the consent form which was counter signed by the researcher.

2.5.3. Recruitment Procedure

The researcher approached the directors, group leaders and specialist workers of different support groups, specifically set up for or known to have significant proportions of African individuals with HIV/AIDS using their service. A number of face to face and telephone meetings were held with these individuals to explain the research and its procedure. The research proposal was requested by all parties .

For some support groups, once provisional agreement for the study to commence had been granted, the research idea alongside information sheets and adverts were discussed by prospective participants at a support meeting, sometimes with the researcher present and sometimes without according to the group's wishes. A subsequent decision was then reached as to whether any individual wanted to be involved in the study. (see appendix 14 for advert).

With regard to other support groups, following provisional approval and interest from service users, adverts and information sheets were distributed to members or published in monthly newsletters. The articles also provided individuals with advance warning on which day the researcher was due to visit their service. For those individuals recruited from services with no existing support group, individual meetings were set up in a chosen venue of their choice, typically their home, following the individual's having contacted the researcher indicating a willingness to take part.

Participants from the outpatient clinic and psychological HIV/AIDS psychology service were alerted to the study by the professional involved in their care. At the clinic, only individuals previously identified by the specialist African liaison nurse as willing to be involved in the study were approached by the researcher.

2.5.4. Completion of questionnaires

This was done in every case with the researcher present, so that any issues raised by completing the questionnaires could be discussed and information given on sources of support if necessary. The average time taken to complete the questionnaires was thirty minutes. The interview lasted approximately twenty minutes.

2.5.5. Contact with services to recruit participants

The author was aware long before ethical approval was sought, that she would encounter significant difficulties in the recruitment of participants. Over the course of ten months, the author made contact with thirty different organisations, often speaking to two different persons within the same organisation. The bulk of participants were recruited from six support services, with five other services providing approximately two participants each.. The failure to recruit participants from the majority of services was due to various reasons being cited (see appendix 15 for a sample of reasons provided).

2.6. DATA MANAGEMENT

2.6.1. Quantitative data

After completion, all the questionnaires and consent forms were filed in a secure place. Following the semi structured interview, transcripts were re-written to ensure clarity of the responses. All quantitative data were coded and entered into an SPSS file.

The quantitative data were analysed by using SPSS 7.5 for windows software and statistics package (Norusis, 1997). First, descriptive analyses were undertaken for all the socio-demographic, attitudes, HIV distress, social support, coping and quality of life measures. Second, significant differences between the means of several variables and those reported from other studies were examined using one sample t tests. Third, two tailed bivariate correlational analysis using Pearson's product moment correlation coefficient and where appropriate Spearman's rho, were conducted on different variables and socio-demographic data. Paired t tests were used for comparison between different aspects of the same measure. Finally, hierarchical regression was undertaken with the aim of identifying the variables which were the strongest predictors of health related quality of life and levels of HIV distress in this sample of black African women.

2.6.2. Analysis of interviews

Content analysis was used to code the data from the interviews to answer the two research questions on disclosure decisions.

The transcripts were re-read on a number of occasions with the aim of the researcher becoming familiar with the text and marking down any thoughts. A highlighter pen was used to distinguish the text that was considered relevant to the two research questions. The text was written down on pieces of card. This process was repeated several times with different pieces of text being grouped and re-grouped into different categories. These categories eventually formed overall themes which were checked against the data. Inter-rater reliability was obtained with the use of an independent rater. The rater coded the text independently, using the author's codes and their definitions. Cohen's Kappa coefficient of agreement was then computed.

3. RESULTS

To assess the quality of the data gathered, preliminary analyses were conducted. The reliability of all the scales was assessed using the Cronbach's alpha statistic.

Results from Kolmogorov-Smirnov tests attested to the criterion of normality being met for the distribution of most variables. For two out of the eight domains of the SF-36 quality of life measure: role limitation due to physical problems and role limitation due to emotional problems, it was necessary to undertake data transformation to reduce the skew, although this was not entirely successful. In response to statistical advice, it was decided that in overall analysis of the SF-36 composite scores (which draws on scores from all of its eight domains), the two scales would be included in the parametric tests. The decision was reached in light of evidence indicating that the statistical procedures to be used are known to be robust enough to withstand minor violations of the conditions required for parametric statistics. Further, evidence suggests that it is specifically the normality assumption that can be violated with minor effects (Howell, 1987). Non-parametric statistics were used for those variables in which the criteria had not been met for parametric tests and/or data were categorical. Significance levels for all statistical tests was set at 0.05.

The investigation of all the data are described in detail in appendix 16.

The results are presented in three sections :Section one presents descriptive analyses for the entire sample in response to research question 1. Where applicable data are compared with data from other studies. Section two presents data on research question 2. Spearman's rank and Pearson's product moment correlation coefficient were used, depending on the quality of the data. Section three includes data from hierarchical regression analyses, for which the two health related quality of life summary scales and the HIVIS-W were used as dependent variables, this addresses research question

3. The final section presents the qualitative data which explored participants' understanding of the factors they considered would affect disclosure decisions.

SECTION 1

3.1.1. The demographic details of the sample

The 56 participants ranged in age from 25 to 61 years, with an average age of thirty five years. Women originated from thirteen different countries, with most participants coming from Uganda (51.1%). Approximately 96% of participants identified themselves as being black African while two participants identified themselves as being black African and West Indian. Seventy eight percent of the women had been resident in the United Kingdom for more than five years, while just over 20% had come to England within the last five years.

Nearly two thirds of the women defined themselves as single (62.5%), with 17.9% being married and 10.8% reporting they had a partner that was not living with them. Approximately 84% of women reported having children and of these 76.6% had children who lived at home with them. Most of the women had one child (47.2%), with 27.8 % having two children and 16.7 % having three children. The largest group of children were aged between six and ten (39.3%). Twenty five percent of the children were below the age of five, 14.3% were between the ages of eleven to sixteen and 16.1% were over the age of sixteen. The majority of participants were unemployed (78.6%), with 14.3% working part time and 7.1% working full time .

The year in which participants received their diagnosis ranged from 1986 to 1999, with the average being in 1994 (s.d 3.24). The majority of women were on medication (69.6%). Approximately 20% of the women reported T4 cell counts below 200 (low immunity levels) with 50% having counts between 201 and 500 (mild immunity level)

and 10.7% having counts above 500 (moderate-normal level). Approximately twenty percent of the data on T4 cell counts were missing. (See appendix 17 for medical and demographic characteristics).

3.1.2. What are the attitudes of the sample towards people with HIV?

The overall summary scores for the women was +17.44 (range 1-30; s.d.7.40) indicating that participants held liberal attitudes towards people with HIV. This was from a total possible range of -30 to +30. The mean scores for each item are shown in Table 1, where the range is from -2 to + 2. A negative score indicates an illiberal attitude, while a positive score represents a liberal attitude. As a whole, the women had liberal attitudes towards people with HIV, having scored all items positive. Attitudes were particularly liberal with regard to cognitive aspects of HIV (i.e. what people with HIV are like, no. 1-6).

There were marked liberal attitudes for aspects of victim blaming (no. 7-10) and the attitudes varied somewhat across those aspects relating to the treatment from society towards those with HIV (no. 11-15). Although a higher proportion of participants felt that HIV prisoners should not be segregated, and it was safe to work with children, fewer felt that those with HIV should have children. Further, many of the participants felt that all persons with HIV should expect some restrictions on their freedom.

3.1.3. What do the sample perceive the attitudes of the community to be towards people with HIV?

The participants identified more negative attitudes in their community towards persons with HIV, with just over a third of their responses recorded as being illiberal. With the exception of one, all of the illiberal attitudes were related to how persons with HIV should be treated by society. Thus, it was felt that the community believed that the needs of HIV persons should not be given top priority and that they should expect restrictions on their freedom. The community were regarded as being in support of the

idea of segregating HIV prisoners. Participants believed the community felt that all HIV persons had something to feel guilty about and that they should not have children or be able to work with them. The attitude summary score for what participants considered the attitudes of the community to be was 2.35(s.d. 12.49; range -21.00 to +30.00). (See Table 1 for the mean scores for each item).

3.1.4. A comparison of participants' attitudes and those they ascribed to the community.

A significant difference existed between the attitudes participants' reported for themselves and those they considered the community held towards persons with HIV, with the sample reporting more liberal attitudes $t = -7.01$ ($df = 49$; $p < .001$; paired t test). No significant differences were found in the sample's attitudes towards persons with HIV and a sample of Scottish men and women with HIV (Green, 1995) ($t = 0.43$; $df = 51$, $p = 0.69$; one sample t test). However, significant differences were found between the two culturally different samples with regard to the attitudes they perceived their community to have. Participants rated the attitudes of their community as being more liberal than those reported by the 42 white Scottish men and women with HIV ($t = 3.55$; $df = 51$; $p = 0.00$; one sample t test).

TABLE 1: The mean values for the attitude statements about people with HIV

Individual items are scored between -2 and +2 . A negative score indicates a more illiberal attitude and a positive score a more liberal attitude.

No.	Attitude statement	What participants believe	What participants believe the community thinks
1	People with HIV are dirty	1.35	0.31
2	People with HIV are as intelligent as anybody else	1.30	0.11
3	People with HIV are not to be trusted	1.48	0.29
4	Being HIV positive says nothing about who you are	0.9	0.05
5	People with HIV are no different from anybody else	0.68	0
6	You can't tell by looking if someone has HIV	1.12	0.38
7	Nobody deserves to be HIV	1.32	0.59
8	People with HIV should be ashamed of themselves	1.68	0
9	People with HIV have nothing to feel guilty about	0.79	-0.29
10	Most people become HIV positive by being weak willed and foolish	1.33	0.09
11	Needs of people should be given top priority	0.91	-0.5
12	Prisoners with HIV should be segregated	1.16	-0.15
13	It is safe for people with HIV to work with children	1.07	-0.57
14	People with HIV must expect some restriction on their freedom	0.86	-0.27
15	People with HIV should not have a child	0.96	-0.16

3.1.5a. What are their levels of HIV related mental health distress ?

The HIVIS-W scores range between 1 to 5, where higher scores indicate higher levels of distress. The average HIVIS-W reported by participants was 2.86 (s.d 0.85). This reflected a moderate to high level of HIV distress. The mean scores for separate items of the HIVIS-W showed that women were most concerned by *financial difficulties* (mean 3.63); *feeling helpless* (3.39), *feeling uncertain about the future* (3.50), *not being able to realise life goals* (3.35), *physical pain* (3.24) and *feeling depressed* (3.33). The lowest scores were achieved on items of *drug and alcohol use* (mean

1.22), *thoughts about suicide* (mean 1.88), *how and where to get honest up to date information about HIV* (mean 2.15), *not knowing where to go for help* (mean 2.32), *feeling guilty* (mean 2.32) and *rejection by caregivers* (mean 2.36). (Full details in appendix 18 for mean scores of all individual HIVIS-W items).

Comparison with other populations

One sample t tests showed that compared to a sample of positive women living in Montreal (Gendron et al., 1996), HIV related distress as measured by the HIVIS-W was significantly higher for black African women ($t = 4.95$, $df = 47$, $p < .001$). A similar result was found in a comparison conducted between the current sample and a mixed sample of African and European women living in London (Lamping et al., 1996) ($t = 3.20$; $df 47$, $p = 0.002$).

3.1.5b. What are their levels of HIV concern ?

HIV was considered a high concern for many participants, with 53.6% ($n = 30$; median 10) giving HIV a maximum rating of 10, on the concern list. Approximately 30% of participants gave ratings of five or below for their level of HIV concern.

3.1.5c. How does the level of HIV concern compare to other social concerns?

Using Wilcoxon signed ranks tests, examination of levels of HIV concern in comparison to *financial concerns*, revealed no significant differences ($z = -1.58$, $p = 0.11$). Significantly higher levels of HIV concern were reported when compared to *employment difficulties* ($z = -2.16$, $p = 0.03$), *immigration difficulties* ($z = -3.31$, $p < .001$), *housing difficulties* ($z = -2.62$, $p = 0.01$), *relationship difficulties* ($z = -2.70$, $p = 0.01$), *family difficulties* ($z = -3.18$, $p = p < .001$) and *racism* ($z = -3.87$, $p < .001$). Medians for each concern in appendix 19.

3.1.6. What are their levels of disclosure and individuals disclosed to

From the nine possible targets, 8.9% (n = 5) of participants had not ticked any of the targets, while 21.4% (n = 12) ticked one target, 21.4% (n = 12) ticked two targets, 19.6% (n = 11) ticked three targets and 28.5% (n = 16) ticked four or more of the targets. See Table 7 for percentages of participants reporting disclosure to the nine targets. In descending order, disclosure rates for a participant's friend, partner and sister were higher than other targets. The lowest rates were recorded for grandparents.

TABLE 2 : Women's disclosure to different targets

TARGET	PERCENT	NUMBER OF PARTICIPANTS
Friend	62.5	35
Partner	55.4	31
Sister	53.6	30
Brother	34	17
Cousin	26.8	15
Mother	21.4	12
Aunt or Uncle	15	14
Father	12.5	7
Grandparents	1.8	1

3.1.7. What are their levels and types of perceived social support?

As a sample, participants considered themselves to be moderately supported (mean = 23.00 s.d. 8.84). No significant differences were found between the different levels of support, with the notable exception of appraisal and belonging. Thus, participants rated their levels of appraisal support to be significantly higher than their levels of belonging support ($t = 2.12$, d.f. 52; $p = 0.04$; paired t test). (See Table 3 for means of all support types).

Table 3 : The mean levels of participants overall support and of the different types.

SUPPORT TYPE	MEAN(STANDARD DEVIATION)
Overall support.	23.00(8.84)
Tangible	5.70(3.03)
Self esteem	5.69(2.25)
Belonging	5.38(2.69)
Appraisal	6.09(2.44)

Significantly lower levels of support were found in the sample of black African women when compared to US population norms (Cohen et al., 1985) ($t = -7.794$, $df = 50$, $p = <.001$; one sample t test). To enable comparisons to be made with a sample of HIV persons, it was necessary to collapse the self esteem and belonging support scales to form an *emotional* support scale. Using sample t tests, when compared to a sample of HIV positive men and women living in Canada (Friedland et al., 1996), the sample of black African women had significantly lower levels of support across each domain : tangible ($t = -4.27$, $df = 52$, $p = <.001$); appraisal ($t = -2.12$, $df = 53$; $p = 0.03$) and emotional ($t = -4.07$, $df = 52$, $p = <.001$).

3.1.8. What are their adopted coping styles ?

Two methods of scoring the Ways of Coping questionnaire have been reported in its manual. Raw scores refer to the coping effort and relative scores describe the proportion of effort of one type of coping style relative to the total effort.

The average level of practical coping (raw score) used by participants was 19.09 (s.d. 4.94 ; range = 7-28). The average level of wishful thinking (raw score) was 18.40 (s.d. 4.60, range 7-28). No significant differences existed between the two coping styles used by participants ($t = 0.75$, $df = 52$, $p = 0.46$; paired t test).

3.1.9a & 3.1.9b. What are their levels of mental and physical health related quality of life and specifically, their levels of role limitation due to emotional and physical problems?

The Mental Component Summary score (MCS) for participants was 36.56 (s.d. 9.38) and the Physical Component Summary score (PCS) was 34.09 (s.d. 11.44). There were no significant differences between the two summary component scores ($t = 1.31$; $df = 48$, $p = 0.19$; paired t test).

The scores on the role limitation due to physical problems was (38.18; s.d. 40.21) and on the role limitation due to emotional problems was (33.95; s.d. 38.56). These were the lowest scores of all the SF-36 eight domains. Higher scores were obtained for physical functioning (62.55; s.d. 28.06), mental health (52.07; 18.54) and pain (52.78; s.d. 29.68) scales.

In Table 4 participants' summary component scores and the means of the eight domains are presented alongside :-

- a) Norms for HIV positive women living in London and Montreal.
- b) General population norms for women in the United Kingdom aged 35 - 39
- c) Norms for women with a variety of chronic illnesses

Examination of the physical and mental summary scores via one sample t test revealed significantly lower physical component summary scores when compared to a sample of European and African positive women from London (Lamping et al., 1996) ($t = -2.79$, $df = 48$, $p = 0.01$) and a mixed ethnic sample of positive women living in Montreal (Gendron, et al., 1996) ($t = -5.57$, $df = 48$; $p < .001$). No significant differences were obtained in the mental component scores for both studies: Montreal ($t = -.10$; $df = 48$; $p = 0.32$), London ($t = -1.68$; $df = 48$; $p = 0.10$).

Comparisons with UK female population norms (Jenkinson, Layte, Wright & Coulter, 1996) revealed significantly lower physical component scores for the current sample ($t = -9.18$, $df = 48$, $p < .001$) and mental component scores ($t = -9.24$, $df = 48$, $p < .001$).

When compared to the norms of other individuals with chronic illness, the sample had significantly lower mental component summary scores ($t = -6.98$, $df = 48$, $p < .001$) and physical component summary scores ($t = -5.98$, $df = 48$, $p < .001$).

Using one sample t tests, an examination of the sample's scores on the eight domains showed significantly lower scores on all domains when compared to UK female (aged 35-39) population norms: physical functioning ($t = -7.12$, $df = 52$, $p < .001$), social functioning ($t = -15.67$, $df = 54$, $p < .001$), mental health ($t = -7.54$, $df = 53$, $p < .001$), energy vitality ($t = -5.313$, $df = 55$, $p < .001$), pain ($t = -6.96$, $df = 55$, $p < .001$), general health perception ($t = -13.11$, $df = 55$, $p < .001$).

Table 4 : SF-36 Mental and Physical Component Summary scores of the sample compared with other studies and illness groups.

Summary scores	Current sample	UK norms (Jenkinson et al 1996)	UK norms for people with chronic illnesses*	London sample (Lamping et al, 1996)	Canadian sample (Gendron et al 1996)
MCS	36.56 (9.38)	48.94 (10.46)	45.91(11.45)	38.81 (10.93)	37.9 (14.1)
PCS	34.09 (11.44)	49.1 (10.31)	43.86(11.98)	38.65 (10.97)	43.2 (12.9)

MCS -Mental component summary score

PCS - Physical component summary score

* Jenkinson et al, 1996

Table 5 : SF-36 domain scores of the sample compared with national norms and a London study.

SF-36 domain	Current sample	UK norms aged 35-39	London sample (Lamping et al., 1996)
Physical functioning	62.55(s.d. 28.06)	90 (s.d. 15.6)	56.86 (s.d. 30.48)
Role limitation-emotional	33.95(s.d. 38.58)	79.2 (s.d. 34.6)	40 (s.d. 43.74)
Role limitation-physical	38.18(s.d. 40.21)	83.7 (s.d. 32.2)	39.58 (s.d. 41.24)
Social functioning	41.01(s.d. 21.58)	86.6 (s.d. 20.7)	52.5 (s.d. 28.91)
Pain	52.78(s.d. 29.68)	80.4 (s.d.21.2)	49.3 (s.d. 29.95)
Mental health	52.07(s.d.18.54)	71.1 (s.d.17.8)	55.8 (s.d. 19.80)
Energy-Vitality	44.46(s.d.19.49)	58.3 (s.d.19.6)	42.08 (s.d. 23.06)
General health perception	43.48(s.d.17.78)	75.3 (s.d.19.5)	48.23 (s.d. 24.16)

SECTION TWO

3.2a)What is the relationship between attitudes and disclosure levels ?

A significant negative relationship existed between the attitudes a participant ascribed to members of their community and the numbers of individuals they had disclosed to. The result indicated that the more individuals a participant had disclosed to, the more negative they ascribed the attitudes of their community to be ($\rho = - .38$; $p = 0.00$). No significant relationship existed between participants own attitudes and levels of disclosure ($\rho = .22$; $p = 0.12$)

3.2b) What is the relationship between role limitation and disclosure ?

A significant negative relationship was found between the numbers of individuals a participant had disclosed to and role limitation due to physical problems ($\rho = -.36$; $p = 0.01$) and role limitation due to emotional problems ($\rho = -.279$; $p = 0.04$). The results suggested that the fewer persons a participant had disclosed to, the better role functioning they had.

3.2c) What is the relationship between role limitation and coping styles?

A significant positive relationship existed between practical coping and role limitation due to physical problems ($\rho = 0.39$; $p = 0.00$) and role limitation due to emotional problems ($\rho = 0.35$; $p = 0.01$). Results indicated that better role functioning was associated with higher levels of practical coping. No significant relationship existed between wishful thinking and role limitation due to physical problems ($\rho = 0.06$; $p = 0.67$) and role limitation due to emotional problems ($\rho = 0.04$ $p = 0.76$).

3.2d) What is the relationship between HIV distress and coping styles ?

Significant relationships were found between HIV distress and practical coping ($r = 0.32$; $p = 0.03$) and wishful thinking ($r = 0.42$; $p = 0.00$). The result suggests that the more HIV distress reported by a participant, the more practical coping and wishful thinking coping styles are employed.

3.2e) What is the relationship between social support and HIV distress?

A significant relationship was found between levels of social support and reported levels of HIV distress ($r = - .483$; $p = 0.00$). The relationship suggested that the more HIV distress reported by a participant the less support an individual perceived themselves to have.

SECTION THREE

Hierarchical regression analyses were conducted with the SF-36 physical and mental component summary scores serving as dependant variables (indicating physical and mental health related quality of life). The HIVIS-W (HIV distress) was also used as a dependant variable as it can be seen as a further measure of a mental health related quality of life (Lamping et al., 1996).

The sample size of 56, although not as large as one would like, was sufficient to provide responses to research questions concerning the predictors of mental and physical quality of life and HIV distress. In view of the sample size, the variables in the regression model were kept to a maximum of six to keep the amount of shrinkage small. This is assuming an R square of 13 to 26% which is a medium to large effect size. The table in Clark-Carter (1997) specifies a sample size between thirty and forty to give 80% statistical power. To reduce the number of different variables, coping raw scores were replaced with relative scores. This allowed the author to place only one of the coping styles into the regression model. The relative practical coping score is the complement of the relative wishful thinking coping score.

With a similar rationale, the author created a new variable referred to as *social risk*. Social risk was defined as the year in which a participant had arrived in the UK and the year in which they had received their HIV diagnosis. This was achieved by the use of the formula (arrival year -60) + (diagnosis year -80). Both factors have been found to be related to well being (Lamping et al., 1996) and may be inferred to have an additive effect. Year was expressed by a two digit number not a four digit as in 1980.

Inclusion of each of the variables was based upon theoretical evidence and data from the bivariate correlational analyses. To maximise available data, missing data were deleted in a pairwise fashion. Prior to regression, the correlations between independent variables were examined for collinearity. No substantial evidence of it was found (see appendix 20 for correlations).

3.3a :HIVIS-W:

In this regression model using HIVIS-W as the dependant variable, wishful thinking (relative score), overall levels of support and social risk were entered first, in recognition of their relationship to psychological distress. This was followed by

whether a participant was in employment, had children and whether they had disclosed their HIV status. In this model, disclosure, employment and children were coded dichotomously (0 = not disclosed, 1 have disclosed; 0 = no children, 1 = children, 0 = not employed, 1 = employed).

In the regression analysis reported in Table 6, the first step accounted for 47% of the variance, while the second step did not add further variance. Social risk, low social support and a wishful thinking coping style made a significant contribution to HIV distress ($F(3, 44) = 14.235, p < .01$). However, only two variables were responsible for this relationship: social risk ($t = 4.801, \beta = .54, p < 0.01$) and social support ($t = -3.168, \beta = -.36, p < 0.01$), as wishful thinking did not reach significance ($t = 1.88, \beta = .213, p = 0.07$). Employment, children and whether persons disclosed, did not add to the variance in HIV distress.

Table 6: Summary of hierarchical regression analyses predicting HIV distress

Predictor variables : social risk, wishful thinking social support , employment, children, and disclosure

Predictor	Step	R(2)	Adjusted R	F	df	Sig.
Social risk**	1	.51	.47	14.235	3, 44	<.001
Social support**						
Wishful thinking						
Employ	2	.55	.48	7.736	6, 44	<.001
Disclosure						
Children						

* * $p < 0.01$

This result suggested that the length of time since immigration and HIV diagnosis and level of social support predicted 47% of variance in HIV distress, with lower HIV distress for those who were not recently diagnosed and /or lived in the UK for longer

and who had higher levels of support. Regressional diagnostics are given in appendix 21 .

3.3b : Mental health component summary score (MCS)

In the second regression model using the mental health component score as the dependant variable, wishful thinking (relative score), overall levels of support and social risk were entered first. Whether a participant was in employment, age and CD4 count was entered next, in recognition of their reported relationship with quality of life.

In the regression analysis reported in Table 7, the first step accounted for 34% of the variance. When the second step was added, an additional 7% was accounted for. Low social risk, higher levels of social support and a practical coping style made a significant contribution to a better mental health component summary score ($F (3, 38) = 7.44, p = 0.01$). Two variables were responsible for the relationship: social support ($t = 2.46, \beta = .34, p = 0.01$) and wishful thinking ($t = -3.14, \beta = -.43; p < 0.01$), as social risk was not significant: ($t = -1.77, \beta = -.24, p = 0.08$). The combination of employment, age and CD4 count also predicted an additional small amount of the (MCS) ($F (6, 38) = 5.46, p = 0.00$). CD4 count was the only significant predictor variable from step two, suggesting that a lower count predicted (MCS) ($t = -2.54, \beta = -.36, p = 0.02$). This result suggested that higher levels of social support and more practical coping relative to wishful thinking and a lower CD4 count predicted 41% of the variance in the MCS. Regressional diagnostics are given in appendix 22.

Table 7: Summary of hierarchical regression analyses predicting mental health component summary score

Predictor variables : Wishful thinking, social support , social risk, employment, age and CD4 count

Predictor	Step	R(2)	Adjusted R	F	df	Sig.
Wishful thinking** Social support* Social risk	1	0.39	0.34	7.44	3,38	0.00
Employ Age CD4 count*	2	0.51	0.41	5.46	6,38	0.00

* p<0.05, * * p<0.01

3.3c : Physical health component summary score (PCS)

In the regression analyses using the physical health component summary score as the dependant variable, medication, employment and wishful thinking were entered first and accounted for only 14% of the variance (F (3, 38) = 3.08, p = 0.04). When age, CD4 count and social risk were added, only four percent was added to the total variance accounted for (F (6, 38) = 2.46, p = 0.05). As a group, the full set of predictor variables accounted for only 19% of the variance in physical health component summary score. It was only medicine which made a significant contribution (t = 2.07, beta = .32, p = 0.05). Regressional diagnostics are given in appendix 23.

Table 8 : Summary of hierarchical regression analyses predicting physical health component summary score

Predictor variables : Medicine, employment, wishful thinking, age, CD4 count and social risk

Predictor	Step	R(2)	Adjusted R	F	df	Sig.
Wishful thinking Employment Medicine*	1	0.21	0.14	3.08	3,38	0.40
Social risk Age CD4 count	2	0.32	0.19	2.46	6,38	0.05

* $p < 0.05$

SECTION FOUR

In the extracts, pseudonyms have been used to maintain confidentiality.

Reliability

There was a 95% agreement for the categories drawn. The kappa coefficients were 0.94 and 0.95 for question one and two respectively.

Question 1

3.4a) What are the factors which make an HIV positive black African woman more likely to inform another person of her HIV status?

The themes which arose from participants responses to this question are shown in Table 9

Table 9 : Summary of the themes arising from participants responses to the factors that would make a black African woman more likely to disclose.

Themes	Number of persons (n = 7)
Qualities of the persons being disclosed to	5
Immigration difficulties	5
To achieve psychological well being	4
The type of relationship shared with the persons being disclosed to	4
Family influences	4
The progression of one's illness	2
The age of the person	2
When you have reached an understanding in your self	2
When in need of specific help and assistance	2
Miscellaneous: finding a support group	1

* Quotes given below are for the most common themes, see appendix 24 for the remaining quotes.

1. The qualities of the person being disclosed to (n = 5).

There were particular qualities that were looked for in a person that could be disclosed to.

“You want to tell someone who will listen to you fairly and not automatically judge you. They must be fair, not just to you but to others they hear about on the television or somewhere. ”. Ella

2. Immigration difficulties (n= 5)

Although disclosure was not an immediate action, the general message from five responses was that if disclosure could go some way in ensuring their right of stay in the UK, then they would mention their HIV status. The high cost and limited availability of medicines in their country of origin would influence their decision towards mentioning their illness.

“ I would disclose only if I was really scared, some people say it would really help..... If I had to go back to my country there is no money for treatments, so it would make me think about saying something”. Lauren

3. To achieve psychological well being (n = 4)

There was a need to correct the emotional imbalance caused by non-disclosure.

“when you are feeling very sad and depressed about things, not just your sickness”

Misty

4. The type of relationship shared with the person being disclosed to. (n = 4)

The nature of the relationship the participants shared with the person being disclosed to made a significant contribution to their decision to disclose

“If I am going to have a relationship with that person, it is a must that I have to tell them because it is their life, their safety” Lauren

5) Family influences (n = 4)

Disclosure to family members was likely to occur in a bid to avoid the negative message which non-disclosure would convey. It was also felt that family members could be entrusted with the information.

“Keeping everything inside of you, means that you don't trust your family” Lauren

Question 2

3.4b)What are the factors which make an HIV positive black African woman less likely to inform another person of their HIV status?

The themes from this question are shown are shown in Table 10

Table 10 : Summary of the themes arising from participants responses to the factors that would make a HIV positive black African woman less likely to disclose.

Themes	Number of persons (n= 7)
Fear of a negative reaction	7
Stopping rumours	6
Negative attitudes towards persons with HIV	6
Protection of family from shame and worry	6
Negative thoughts about women with HIV	5
Previous negative reaction -experiences	4
Lack of understanding about HIV-self and other	3
Stigma associated with the illness	3
Confidentiality	2
No purpose or point to the disclosure	2
Development of illness	2
Miscellaneous	5

*** Quotes given below are for the most common themes, see appendix 25 for the remaining quotes.**

1) Fear of a negative reaction (n = 7)

There would be less likelihood of informing another person of one's HIV status due to strong fear of receiving a negative reaction.

“ You are less likely to tell others if you feel you will be discriminated against”.Ella

2) Stopping rumours (n = 6)

Being forced to put a stop to rumours by disclosing ones HIV status, was not considered an appropriate option by six of the women.

“I wouldn't say anything because of any talking I wouldn't care I am the one who is important, that is what they teach you here so unless it was right for me nothing would influence me to say anything ”. Betty

3) Negative attitudes towards persons with HIV (n = 6)

Less than positive attitudes towards any persons with HIV were considered a good enough reason not to disclose.

“ I won't expose myself to those type of peopleTelling someone about your HIV changes the whole situation and people's attitudes towards you. They may even start to feel sorry for you, being sympathetic towards you, because you are dying, in fact they already see you as being dead ”. Isabelle

4) Protection of family from shame and worry (n= 6)

The need to spare family members the pain and discomfort of knowing they are unwell was important for many women, particularly for their children.

“ if they thought it was HIV they would expect my daughter to die, it would only be a matter of time before she died..... It would affect her getting married, oh yes people would be afraid of her. My illness would stop my daughter and sister getting married, people think because Lauren got it then her daughter has got it”.

Lauren

5) Negative thoughts about women with HIV (n = 5)

The thoughts about women with HIV were heavily centred around been seen as being sexually indiscriminate.

“ They wouldn't even know how I got it but they would treat me in a way that meant I had got it because I was sleeping around with many people. This is what the community is like and it doesn't matter if my husband passed it to me, they would always believe I gave it to my husband and therefore I am the reason that he died. It will always be the women who will be blamed ”. Sophia

6) Previous negative experience (n = 4)

The personal experience or knowledge of another persons negative experience of disclosing often precluded or delayed disclosure to other persons.

“ When you go to groups it does make you more reluctant when you hear stories, it does make you think twice about telling others when you have heard such bad and sad stories”. Ella

7) Lack of understanding about HIV self and other (n = 3)

Disclosure was less likely when there was anticipated lack of understanding within the person being disclosed or when the person was not yet at a stage when they understood their illness

A lack of understanding in others :

'you may not tell your family out of fear that they would not understand' Ella

4. DISCUSSION

The results from the current study contribute to existing HIV/AIDS literature by detailing the different social and psychological aspects of the HIV experience amongst a sample of black African women. The discussion will consider each research question in turn before addressing the methodological limitations of the study and proposing recommendations for future research and services.

4.1. Descriptive statistics

4.1.1. The demographic details of the sample

Consistent with previous research and the pattern of HIV infection nationally, the majority of the sample originated from Uganda. The picture that emerged from the demographic data indicated an economically and socially impoverished group of women, of whom approximately 80% were classified as being unemployed. The majority of women were in their mid-thirties and single parents of young children.

If the presence of a partner was adopted as a valid index of support, one could conclude that the present sample represented a group characterised by their lack of support and their dual roles as caregivers and patients living with a chronic illness.

The majority of women were on medication programmes, of whom over 50% were on a triple combination. It could be hypothesised that for many women, finding the time and energy to provide appropriate care for young children, in addition to adhering to the requirements of their treatment programme may be a significant stressor. This would be further complicated if any of their children were also HIV positive.

4.1.2. The sample's own attitudes towards people with HIV

The findings from the current study could be said to provide evidence of internalised HIV stigma amongst the sample. The total sum of their attitudes towards persons with HIV fell within the moderately liberal range. Although there were no negative

(illiberal) scores recorded for any of the sample's responses, the results could indicate societal beliefs about the differentness of persons with HIV may have been internalised by the sample to some extent and negatively interfered with how they perceived themselves.

The attitude scores from the sample were consistent with the scores obtained from a white Scottish sample of HIV positive men and women (Green, 1995). The results are interesting given the evidence suggesting ethnic differences in the attitudes of non HIV sufferers to HIV. Higher levels of negative attitudes towards HIV have been recorded in non white groups (Elliott, Parida and Gruer, 1992). The current findings however, could provide evidence indicating a similarity amongst HIV positive individuals from diverse ethnic groups, towards HIV. The similarity between their attitudes, leads one to believe that the common variable shared between the two groups creates a group consciousness (Gurin, Miller & Gurin, 1980) which gives rise to its own perspective of the world.

4.1.3. Perception of the attitudes of the community towards people with HIV
& 4.1.4. Comparison of participants attitudes and those they ascribed to the community.

Consistent with previous research (Green, 1995), the attitudes the sample assigned to the community were significantly less liberal than their own, although, the mean still fell within the liberal range. These findings appear at odds with previous reports documenting that HIV persons considered the views of the public to be illiberal (Green, 1995). The failure to obtain a larger difference between the sample's own attitudes and those they assigned to the community may be due to the sampling methods used. Thus, the majority of participants were recruited via support groups and may have had more liberal views with regard to their assessment of community attitudes, compared to individuals who chose not to take part in the study or were not accessing statutory or voluntary services. It is also possible that attitudes towards HIV

may have changed in the last four years and therefore, individuals may perceive there to be less stigma amongst their own community.

4.1.5.a Levels of HIV related mental health distress

The levels of HIV distress amongst the sample fell within the moderate to high range. and was significantly higher than those reported amongst mixed ethnic HIV positive women in previous studies from Canada, (Gendron et al, 1996) and London (Lamping et al., 1996). The higher rates of distress found in the current sample in comparison to HIV positive women from London (Lamping et al., 1996) could be due to differences in the ethnic composition between the two samples. Thus, in the Lamping et al. (1996) sample, 42% were classified as white with 53% classified as black African. The significant differences in the ethnic composition ultimately has implications in terms of issues such as employment, relationship status and immigration and may explain the variability in the distress levels recorded.

In the current sample, financial difficulties were a significant contributor to current distress. The feeling of being unable to realise one's goals, feeling uncertain about the future, and feeling depressed, were also scored highly by the participants. The strong feeling of uncertainty about the future possibly reflects the unknown path of HIV, in which an individual can survive for many years relatively symptom free, and at some point develop an AIDS defining illness. The evidence indicates that the majority of African women in the United Kingdom tend to receive their HIV diagnosis after they have presented to ante natal services (Ssanyu Ssseruma, 1998a). Therefore, any plans they may have held about careers and family following immigration, may have significantly altered after receiving their diagnosis. The high levels of self reported depression could be interpreted as a response to the loss of opportunity and frustration over their situations.

4.1.5b & 4.1.5c Levels of HIV concern and concern over social problems

HIV was rated as a high concern for the majority of the sample. No significant differences were recorded between levels of HIV concern and concern generated by financial difficulties. In combination, the results indicate that for many women, while the prospect of living with HIV is a significant concern, the day to day realities of providing food, clothing and other material items for themselves and their children with limited resources, is equally a concern. This is perhaps not surprising since 84% were unemployed.

4.1.6. Levels of disclosure and individuals disclosed to

The pattern of disclosure amongst the current sample corresponded with patterns reported in the literature for HIV positive women (Simoni et al., 1995). Higher rates of disclosure were recorded for friends, followed by partners and then family members. The family member with the highest disclosure rate was the participant's sister, with the lowest rate reported for grandparents, aunts and uncles. With the majority of participants reporting disclosure to four or more targets, there was only a small proportion of participants (five) who had not disclosed to any of the targets. Given the large percentage of the sample who had disclosed to their friends, it could be argued that friends represent a significant source of support for HIV positive black African women.

4.1.7. Levels and types of social support

There were moderate levels of perceived social support reported by the sample. As a group, they reported significantly lower levels of support, when compared to a group of men and women with HIV living in Canada (Friedland et al., 1996). This suggests there are factors other than the reported negative effect of HIV stigma on support networks of individuals with HIV (Crandall and Coleman, 1992). The immigrant status of the present sample, in addition to the HIV diagnosis may present additional difficulties for women in their process of developing social relationships. This

correlates with other studies suggesting that the levels and pattern of social support may significantly differ for individuals with and without psychological difficulties (Schonfeld, 1991).

4.1.8. Adopted coping styles

High levels of wishful thinking and practical coping were reported by the sample in response to stressful situations. No significant difference was found between the two styles. The current findings differed with previous data reporting that individuals with lower incomes, ethnic minorities, and women with HIV/AIDS, are more likely to endorse emotion focused styles of coping than problem focused (Billings and Moos, 1981; Fleishman and Fogel, 1994). Therefore, the range of problems women may have experienced including financial and immigration difficulties, may have demanded a combination of problem and emotion focused coping styles.

4.1.9a. Levels of health related quality of life

The results indicated low levels of physical and mental health related quality of life amongst the current sample. The levels fell significantly below UK norms for women with a chronic illness. There were lower levels of physical quality of life in the current sample when compared to levels in a London sample of African and European women (Lamping et al., 1996). and a mixed ethnic group of HIV positive women in Canada (Gendron et al., 1996). Given the demographic details of the sample, the current findings appear consistent with previous data documenting that poorer levels of quality of life in HIV positive women are associated with unemployment (Sowell et al, 1997) or being a single parent and a recent immigrant to the UK (Lamping et al, 1996) and financial difficulties (Smith, 1993). Approximately 70% of the sample were on medication. However, levels of physical health related quality of life were poor. This finding may be interpreted in the context of evidence suggesting that poorer physical quality of life can be associated with unpleasant and debilitating treatments (Litchman,

et al.,1987). There is growing evidence detailing the side effects of antiretroviral drugs, and the negative impact on physical functioning (Treatment News,:1998).

4.1.9b. Levels of role limitation due to emotional problems and physical problems

The lowest score on the individual domains of the SF-36 were achieved on the role limitation due to physical and emotional problems scales. There is a tendency for women to assess their worth by their capacity to provide care for others (Lea, 1994). Therefore, it is possible that women in their different roles of mother, friend and caregiver, judged themselves to be under performing in their various duties according to subjectively set standards. It could be argued that being a single mother of young children, who characteristically require a lot of energy to care for and may also be HIV positive, in addition to being a patient with a chronic illness, a friend or a partner, had taken its toll on their physical and mental health functioning.

4.2 Correlations

4.2a. The relationship between disclosure and attitudes

There was no evidence to suggest a relationship between a participants' own attitudes towards people with HIV and their levels of disclosure. However, a significant negative relationship was found between disclosure levels and the attitudes participants assigned to a member of the community. The relationship indicated that the more individuals a participant had disclosed to, the more negative the attitude they ascribed to a community member. It could be argued that with each disclosure a participant has made, the more opportunity this allowed them to experience negative reactions and HIV stigma. Therefore, the sample's ratings of community attitudes may be based upon first hand experience of negative attitudes. Equally, HIV positive individuals may have experienced breaches of confidentiality or accidental disclosure (unplanned). Therefore, they may not have been able to control the choice of confidants in the same

way, or have the option of choosing the people with liberal attitudes to disclose to. If these interpretations are valid, it is encouraging that despite their awareness of the negative attitudes of their community, it has not prevented participants from disclosing, which could have an adverse effect on other areas such as social support. However, it is also possible that participants already had an awareness of the prevalent negative attitudes from the community towards HIV and its sufferers. Therefore, their high levels of disclosure was intentionally done with the aim of dispelling the stigma that surrounds HIV and women. This interpretation would be consistent with the work of many AIDS activists who advocate disclosure of HIV status, as a method of attempting to deconstruct the stigma of the illness (Woltski, Rietmeijer, Goldbaum and Wilson, 1998).

4.2b. The relationship between disclosure and role limitation

The results indicated that the fewer persons a participant had informed of their HIV status, the less limitation they experienced in their roles.

The results could suggest that individuals who were functioning well may not have felt the need to inform others of their situation. This finding fits in with the ideas generated from the qualitative findings, indicating that disclosure was not an indiscriminate act. Thus, if participants considered themselves to be coping and were not restricted in any of their activities for example, taking their child to school, they may have felt that there was no reason to inform someone else of their status because the benefits of doing so were unclear. It is also possible that the lower levels of disclosure ensure that women are allowed to get on with their everyday activities, without the fear of discrimination .

4.2c. The relationship between coping styles and role limitation

Practical coping (problem focused coping) was significantly associated with role limitation due to physical and emotional problems. A non significant relationship was

recorded between wishful thinking (emotion focused coping) and role limitation due to physical or emotional problems. The nature of these relationships suggested that participants experienced less limitation in their roles when higher levels of practical coping styles were employed.

In explanation of the failure to obtain a significant result between wishful thinking and role limitation due to emotional or physical problems, it could be hypothesised that, although wishful thinking does not adversely affect an individual's role functioning in the context of emotional or physical problems, it does not improve it either.

Consequently, wishful thinking may share a neutral relationship with role limitation due to emotional problems or physical problems, while practical coping is what is specifically required to achieve better levels of functioning. This would support the work of Moneyham et al. (1998).

4.2d. The relationship between coping styles and HIV distress

Significant positive relationships were reported between HIV distress and practical coping and wishful thinking styles of coping. It could be argued that higher levels of HIV distress require a flexibility in the styles of coping. Thus, wishful thinking may have been used to manage the parts of HIV distress that were not amenable to practical styles of coping. Given that the feeling of not being able to realise one goals was a significant component of HIV distress, wishful thinking therefore, may have been adopted as an effective method of managing the feelings generated from these issues. Practical coping may have been used to obtain information about HIV and medical treatments, which would be consistent with the evidence showing that lack of information over HIV and available treatments was not a significant component of HIV distress.

4.2e. The relationship between social support and HIV distress

The results yielded a significant result between levels of social support and HIV distress. The pattern of results suggested that perceived levels of social support were lower for those individuals reporting higher levels of HIV distress. This indicates that during those times of need and distress, participants felt that their social support diminished. Thus, the more difficulty they experienced, the fewer people they felt were on hand to provide them with help. This would be consistent with evidence that support for individuals can sometimes suffer under the strain and stress of HIV (Turner, Hays, Coates & 1993).

4.3 The predictors of HIVIS-W and mental and physical component summary scores

The current findings provide an initial contribution to the understanding of various social and psychological factors that may influence HIV distress and quality of life in HIV positive black African women.

4.3a. HIV distress (HIVIS-W)

Social risk and social support proved to be the most significant predictors of HIV related mental health distress. Women who were more recent immigrants to the UK and/or recently received their HIV diagnosis and women with lower levels of social support were at risk for greater HIV related mental health distress. It is possible, that the stress of receiving a diagnosis of HIV would be severely compounded by difficulties associated with being a refugee or asylum seeker, particularly if one is not sure how long one will be allowed to remain in the country. One of the significant components of the sample's HIV distress was financial difficulties. Naturally being a recent immigrant to the UK precludes one from supplementing financial benefits via paid work. Furthermore, if individuals have arrived in the UK having left their family

behind, their levels of support following their arrival would be low and may exacerbate feelings of isolation, which could compound the original distress from being diagnosed HIV positive. The current predictors of HIV distress differed to those reported in the Lamping et al.(1996) study. In that study, being older, a woman who is either a single parent or recent immigrant to the UK and a woman with a diagnosis of AIDS were significant predictors. The difference suggests that a range of social, psychological and medical factors can contribute to HIV distress, but probably also reflects the difference in samples noted earlier.

4.3b. Mental component summary score

The mental component summary score was best predicted by lower levels of wishful thinking relative to practical coping, higher levels of social support, lower CD4 counts, not being a recent immigrant to the UK or having recently received one's HIV diagnosis. Inconsistent with previous research (Sowell et al., 1997) employment and age were not significant predictors. Primarily, the idea that a lower CD4 count would contribute to mental health related quality of life may seem rather inconsistent with existing research and incongruous with common sense explanations. However, it could be argued that lower CD4 counts increase the likelihood that participants seek or come into contact with different voluntary and support services. As discussed in a previous section, the role of social support in facilitating psychological functioning in chronic illness, is well documented. The suggestion that higher levels of practical coping contributes to mental health quality of life, is consistent with research indicating a relationship between problem focused coping and psychological adjustment in chronic illness (Moneyham et al., 1998). Finally, not being a recent immigrant to the UK or recently diagnosed with HIV, could mean that women are not having to cope with the immediate trauma of arriving in a country (e.g issues of residency and language and cultural difficulties) and difficulty with accommodation, whilst managing the distress of their HIV diagnosis.

4.3c. Physical component summary score

The predictors entered into the model for physical quality of life accounted for only 19% of the variance. Medicine (i.e. taking antiretroviral drugs) was the only significant predictor out of CD4 count, social risk, employment and wishful thinking. The failure of age to be a significant predictor of physical health quality of life was inconsistent with existing literature (Watchel et al., 1992). This particular finding may be due to the fact that the majority of participants fell into a relatively narrow age range and the variability on age was less than in some other studies.

The author attributes some of discrepancies between findings of this study and other studies to the characteristics of the sample. Thus, some variables in the regression model did not have much variance. For example, most participants had disclosed rather than had not, and most participants were unemployed. Ideally you would aim to obtain a sample in which there was greater variance and therefore, the characteristics of the sample would be improved. The lack of variability in the sample would have affected the ability to model the relationship between variables using multiple regression.

4.4. Qualitative findings

The responses from the small sub-sample who were interviewed regarding the factors which make disclosure more or less likely, strongly pointed towards the existence of an evaluative process that involved careful analysis of the potential risks and benefits of disclosure and non disclosure.

4.4a. The factors that make HIV positive black African women more likely to disclose?

It must be noted that the author was struck during the interviews, by the visible difficulty most participants experienced when asked to think about the factors that

would make disclosure more likely. There was a greater use of interview prompts during this question. Nevertheless, the different themes generated from the sample's responses appeared consistent with previous research documenting the factors felt to influence HIV disclosure amongst an ethnically diverse sample of women (Simoni, et al., 1995). The planning that went into disclosure decisions precluded disclosure from ever being a worry free act.

It was suggested that the need to achieve psychological well being was an important factor influencing disclosure decisions and perhaps supports arguments from Goffman (1963), that attempts at concealing one's stigma can be exhausting. For many women, disclosure may provide them with freedom in their relationships to concentrate on other issues related to HIV instead of spending time attempting to avoid detection. Psychological well being could be the outcome of disclosure, enabling the individual to request and receive specific forms of help which would be consistent with the work of Coates and Winston (1987).

Disclosure was more likely where there were specific services that could be received such as material and emotional support and improved immigration status. The idea of disclosing in order to improve one's immigration status was inconsistent with the work of Mason et al. (1995), who attributed lower levels of disclosure amongst ethnic minorities in America to a fear of deportation. The current results could be due to differences in the samples and their reasons for entering the country. Thus, evidence has shown that the majority of black African woman arriving in the UK, are classified as refugees or asylum seekers (Ssanyu Sseruma, 1998a). Thus, returning to their countries of origin could have implications for their safety. Fleeing one's country due to persecution is significantly different from fleeing due to economic reasons, which was the case for participants in Mason et al. (1995) study. Furthermore, returning to countries of origin for many women could signal the end of their access to medical treatments they were receiving in the UK, due to a limited availability and expense.

Equally, it is possible that some women may have intentionally come to the UK to access medical help for their HIV.

4.4b. The factors that make HIV positive black African women less likely to disclose

The factors offered by participants were consistent with previous qualitative studies of HIV positive women (Moneyham et al., 1996; Chung and Magraw, 1992) and were largely related to stigma management. The results from stigma management suggest that individuals have a strong awareness of the possible negative reactions of others and thus, managing their stigma via disclosure is a way of limiting those effects. The fear of negative reactions for many women could be based on their own previous negative disclosure experiences. However, it is possible that their own fear could be a reflection of their past prejudices towards HIV positive people.

Concerns over associative stigma were also related to factors that would make HIV disclosure less likely. Individuals chose not to disclose due to a need to limit the adverse consequences to significant others, particularly their own children and family members in their country of origin. From the data, one could argue that the strong need to protect others from the stigma and discrimination of HIV, was a price willing to be paid by many women. This was so, even if the consequences meant having to withstand the stressors of HIV alone or with limited support. Although sparing the emotions of loved ones could be understood as a very selfless act from the HIV positive black women, it may also be an adaptive strategy designed to preserve their own psychological functioning.

4.5. Methodological Limitations

The study has a number of methodological limitations, which suggest that caution must be applied in interpretation of the current findings.

The cross sectional design of the study prevented causal inferences being made with regard to the dependant variables in the regression analyses. As with most research within HIV positive populations, there was a failure in the present study to employ a HIV negative control group. The absence of a control group precludes definitive conclusions being drawn, determining whether the current findings were specific to black African women with HIV. However, the likelihood of obtaining a control group that was appropriately matched on all variables would be difficult. Nevertheless, it was possible to compare findings with a norm sample and with other studies that used different HIV samples.

The convenience sampling employed within the study meant that participants were primarily recruited from HIV/AIDS support services and therefore, represent only a portion of the HIV positive black African women in London. Naturally, there are women who do not attend support groups or receive assistance from statutory sexual health services. Consequently, participation in the study is restricted to women who were in contact with such services and were willing to share their feelings and experiences. Whether the inclusion of non respondents would have significantly altered the current findings is difficult to assess. Similarly, the study is limited by its use of only seven participants to explore factors affecting disclosure. There is a possibility that individuals who may have had the most concern about issues of disclosure may not have been willing to participate. Consequently, the generalisability of the findings are limited. It must be acknowledged that until the precise population of HIV persons is known, convenience sampling of small known populations continues to be a well adopted strategy amongst HIV researchers.

There were clear limitations attached to the use of the standardised questionnaires with women from non western countries. For example, the SF-36 has been validated and translated across a number of European languages. For four of the domains of the SF-36, the alpha coefficient were low. To date however, there are no standardised

instruments available for exploring health related quality of life amongst ethnic Africans. There is also the possibility that such measures may overlook the important areas relevant to specific patient groups. For example, the SF-36 excluded important aspects such as intimacy and sexual functioning, which is an integral part of quality of life and may also hold particular significance for individuals with a sexually transmitted disease. A significant criticism often levelled at the SF-36, concerns the data on which their UK population norms have been computed. The UK norms are based on data gathered from Oxford and surrounding regions. How representative these areas are of other areas in the UK is questionable. This may account for some of the difference between the current sample's quality of life and norms based on the Oxford sample. To date however, apart from the Oxford data there are no other large scale studies that have used the measure sufficiently from which national norms can be determined.

The data gathered on participants coping styles was significantly limited by the fact that only two coping styles were examined. Attempts to keep the duration of the study to a minimum, precluded the use of the full sixty-six item Ways of Coping questionnaire (Folkman & Lazarus, 1984). However, the full questionnaire would have generated a more extensive list of coping styles used by participants and detected any significant differences which existed between the various coping styles.

With regard to the attitude measures used, the possibility that results may have been influenced by the presence of a uniqueness bias must be acknowledged (Goethals, Messick & Allison, 1991). The bias originates out of social comparison theory and the tendency to perceive oneself as nicer than peers or at least no worse. Thus, an individual with liberal views would attribute illiberal views to others to feel unique. This theoretical understanding could provide the explanation for the difference between the sample's own attitudes and those they assigned to the community. Similarly, a common criticism applied to most studies employing attitude measurement, is the implicit assumption that reported attitudes are accurate representations of what

the respondent is thinking or synonymous with their private beliefs. Furthermore, reported attitudes do not accurately predict behaviours (Fishbein, 1967). It is possible that participants are not reporting what they truly believe and may be influenced by a social desirability bias. Nevertheless, trends can be inferred by reported attitudes (Green, 1995).

4.6. Recommendations for future research and service implications

4.6.1 Parenthood and HIV

There are a number of implications arising from the current findings, which will be important to providers of statutory and voluntary HIV/AIDS services. The women in the sample were multiply disadvantaged. Parallel to their HIV status, there were high levels of unemployment and single parenthood. Financial difficulties were felt to be a major concern. There could be significant numbers of single parents who in addition to coping with their own deteriorating health, are providing care for one or more ill children. According to Melvin and Sherr (1993) difficulties may arise in their effective parenting, as a result of the physical and emotional consequences associated with HIV. Consequently the mental health and social needs of children living with HIV positive mothers must be noted. The cumulative effect of HIV stigma and the burden of providing care for children and family who could also be infected, can result in shorter survival periods (Lea, 1994).

4.6.2 Social support

As a group, the evidence suggested that they perceived themselves to have low levels of support, which is concerning given the fact that these were mainly women in contact with support services. The beneficial effects of social support in coping with a chronic illness has been documented. The current findings highlight the importance of examining the perceived and actual support network of HIV positive black African

women. Identification of the particular components of support which are important and contribute to well being is required. Furthermore, research which examines the psychosocial and cultural factors that may influence the availability, quality and utilisation of social resources amongst black African women with HIV is essential.

Given the importance of social support in the management of a chronic illness, clinicians share an important task in helping black African women to develop and utilise existing supportive social networks. HIV positive black African women need to be specifically targeted for formal social support given the stigma of their illness and the isolation that their race and immigration status may generate. Interventions that enable African women to identify and seek out realistic sources of support and to think constructively over what can realistically be expected from the social contact could be beneficial .

4.6.3 Coping

In response to the limitations of the coping questionnaire, future studies could focus on incorporating a larger pool of coping behaviours to be studied using a longitudinal design. This would allow for conclusions to be drawn about what groups of disease related coping are associated with what stage of illness and the outcomes they generate. The benefits of practical coping were implicated in both types of role functioning. Therefore, providing training in coping skills may enhance outcomes in this crucial area for women. Training women in a variety of coping styles may ensure that flexibility can be used in response to different stressors that may arise over the course of their illness. However, the evaluation of such training could provide important evidence as to its effectiveness.

4.6.4 HIV Stigma

In the absence of a cure, HIV will continue to remain a significant problem for many positive individuals. Therefore, significant work is needed in tackling the stigma and its

interaction with areas such as race and gender. Without such a shift, the interactions may work to produce an underclass of women suffering with a chronic but terminal illness. Given the demographic details of the sample, it is essential that research is undertaken in which attempts are made to explore the impact of multiple stigmas on black African women, who may be contending simultaneously with racism and sexism.

For individuals who are feeling stigmatised, services to facilitate stigma management could be offered as part of HIV/AIDS clinical psychology services. With multidisciplinary input, individuals may be assisted in developing alternative discourses about their position as women with HIV. Parallel to individual programmes, psychologists can play a central role in deconstructing the stigma of HIV, by actively confronting the negative images of HIV persons in the media.

4.6.5 Disclosure

HIV positive women could benefit from the provision of supportive programmes that can openly address the different barriers that exist to disclosure to friends, partners and family members. The emphasis of programmes should be to assist those who want to disclose, to do so, without sustaining damage to their self worth and identity. Future research should attempt to investigate personal barriers to disclosure on a much larger scale. It would also be useful to examine the experiences of women for whom disclosure is no longer an issue, maybe due to a deliberate decision to disclose. Thus, determining the consequences on different aspects of their lives, when their time is no longer spent on stigma management would be important.

4.6.6 Attitudes towards HIV

Future use of the same methodology employed in the current study, must assess the attitudes of the wider African community towards HIV and make comparisons between perceived attitudes from participants and actual attitudes from the community. The evidence collected may lead to a realisation by HIV positive black African women,

that the negative attitudes about them may not exist or be as pervasive as they imagined. This would significantly affect levels of felt stigma. Alternatively, where their perception of the community attitudes proved to be correct representations, work reducing HIV stigma within African communities may be necessary.

4.6.7 Quality of life

The current findings provide clinicians with clear indicators of areas where work may be targeted to improve levels of quality of life amongst HIV positive black African women. The extension of the HIV buddy system and wider development and sufficient funding of support groups may be useful methods for managing the isolation generated from a lack of support, particularly for the newly diagnosed or recently arrived immigrants. This is particularly pertinent with the current removal of funds from many HIV support services. Assessment of quality of life in HIV positive black African women is important given their demographic details and could be done more frequently with the aim of providing a subjective evaluation of the general impact of the disease, its treatments and social concerns. Clearly, additional data are required to isolate the variables that can facilitate psychological functioning and limit the difficulties of HIV being a stigmatised chronic illness.

4.6.8. Research in to black HIV positive African women

The difficulty experienced by the author and others in participant recruitment will have implications for the viability of future research projects. However, to fully appreciate the experience of HIV in black African women, studies must be conducted in which they are compared to control groups of HIV negative persons from the same sub population, for example women with sickle cell disease. It is also important that results of studies are fed back to participants and services.

5.CONCLUSION

The present work largely supports and adds to previous research on HIV positive women, with evidence of poorer quality of life, greater HIV distress and poorer social support. In addition, results pointed towards evidence of felt stigma and fears about discrimination following disclosure.

There must be an end to the assumption that extrapolation of the results gathered from studies of gay men is sufficient to develop clinically appropriate psychotherapeutic services for HIV positive women (Cotton, 1990; Minkoff, 1991). It is clear that more needs to be done to redress the bias in gender specific knowledge of HIV experiences and to obtain a greater understanding of the impact of HIV within the female black African population living in the UK. It is only then that culturally appropriate services can be delivered to women who may have already experienced significant trauma in their country of origin (Campbell, 1997).

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APPENDICES

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- Appendix 19** Median scores of HIV concern in comparison to other social concerns

Appendix 20. Correlations between independent variables used in hierarchical regression

Appendix 21. Regressional diagnostics for HIVIS-W.

Appendix 22. Regressional diagnostics for Mental component summary score

Appendix 23. Regressional diagnostics for Physical component summary score

Appendix 24. Quotes illustrating themes from participants responses to qualitative question 1

Appendix 25. Quotes illustrating themes from participants responses to qualitative question 2

APPENDIX 1

Demographic Sheet

1. What is your age? _____

2. How would you describe your ethnic origin _____

3. If you were born outside of the United Kingdom, please can you state your:
country of origin.....

the year in which you came to England.....

4. How would you describe your relationship status :

Single

Married.....

Cohabiting.....

Partner who does not live with you.....

Divorced.....

Separated.....

5. Do you have any children ?

YES..... NO.....

6. Do your children live at home with you ?

YES..... NO.....

If yes, then please state how many, and list their ages

7. Are you :

employed in a full time job.....

employed in a part time job.....

not currently in employment.....

APPENDIX 1

8. What year did you receive your HIV diagnosis ?.....

9. Are you currently on any medication for your HIV?

YES..... NO.....

If YES, please circle the kind of combination

1 2 3

10. What was your most recent CD4 count?

11. What was your most recent viral load reading?

12. Please tick any of the persons below who you have disclosed your HIV seropositivity to :

- partner.....
- friend.....
- mother.....
- father.....
- sister.....
- brother.....
- cousin.....
- grandparents.....
- aunt or uncle.....

13. Using a scale of 0 to 10, where 0 indicates no concern, and 10 denotes a high level of concern, please rate how much of a concern your HIV status is to you.

0. 1. 2. 3. 4. 5. 6. 7. 8. 9. 10 please circle

Using the same scale of 0 to 10, please allocate a figure which best describes your level of concern in the following areas, when compared to the figure you gave to indicate your concern about your HIV status.

- a. Financial difficulties _____
- b. Housing difficulties _____
- c. Employment difficulties _____
- d. Immigration difficulties _____
- e. Racism _____
- f. Relationship difficulties _____
- g. Family difficulties _____
- h. other, please state _____

SF-36 HEALTH SURVEY

INSTRUCTIONS: This survey asks for your views about your health. This information will help keep track of how you feel and how well you are able to do your usual activities.

Answer every question by marking the answer as indicated. If you are unsure about how to answer a question, please give the best answer you can.

1. In general, would you say your health is:

(circle one)

- Excellent 1
Very good 2
Good 3
Fair 4
Poor 5

2. Compared to one year ago, how would you rate your health in general now?

(circle one)

- Much better now than one year ago 1
Somewhat better now than one year ago 2
About the same as one year ago 3
Somewhat worse now than one year ago 4
Much worse now than one year ago 5

APPENDIX 2

3. The following questions are about activities you might do during a typical day. Does your health now limit you in these activities? If so, how much?

(circle one number on each line)

| <u>ACTIVITIES</u> | Yes,
Limited
A Lot | Yes,
Limited
A Little | No, Not
Limited
At All |
|--|--------------------------|-----------------------------|------------------------------|
| a. Vigorous activities, such as running, lifting heavy objects, participating in strenuous sports | 1 | 2 | 3 |
| b. Moderate activities, such as moving a table, pushing a vacuum cleaner, bowling, or playing golf | 1 | 2 | 3 |
| c. Lifting or carrying groceries | 1 | 2 | 3 |
| d. Climbing several flights of stairs | 1 | 2 | 3 |
| e. Climbing one flight of stairs | 1 | 2 | 3 |
| f. Bending, kneeling, or stooping | 1 | 2 | 3 |
| g. Walking more than a mile | 1 | 2 | 3 |
| h. Walking half a mile | 1 | 2 | 3 |
| i. Walking one hundred yards | 1 | 2 | 3 |
| j. Bathing or dressing yourself | 1 | 2 | 3 |

4. During the past 4 weeks, have you had any of the following problems with your work or other regular daily activities as a result of your physical health?

(circle one number on each line)

| | YES | NO |
|---|-----|----|
| a. Cut down on the amount of time you spent on work or other activities | 1 | 2 |
| b. Accomplished less than you would like | 1 | 2 |
| c. Were limited in the kind of work or other activities | 1 | 2 |
| d. Had difficulty performing the work or other activities (for example, it took extra effort) | 1 | 2 |

Appendix 2

5. During the past 4 weeks, have you had any of the following problems with your work or other regular daily activities as a result of any emotional problems (such as feeling depressed or anxious)?

(circle one number on each line)

| | YES | NO |
|---|-----|----|
| a. Cut down on the amount of time you spent on work or other activities | 1 | 2 |
| b. Accomplished less than you would like | 1 | 2 |
| c. Didn't do work or other activities as carefully as usual | 1 | 2 |

6. During the past 4 weeks, to what extent has your physical health or emotional problems interfered with your normal social activities with family, friends, neighbours, or groups?

(circle one)

- Not at all 1
- Slightly 2
- Moderately 3
- Quite a bit 4
- Extremely 5

7. How much bodily pain have you had during the past 4 weeks?

(circle one)

- None 1
- Very mild 2
- Mild 3
- Moderate 4
- Severe 5
- Very severe 6

APPENDIX 2

8. During the past 4 weeks, how much did pain interfere with your normal work (including both work outside the home and housework)?

(circle one)

- Not at all 1
- A little bit 2
- Moderately 3
- Quite a bit 4
- Extremely 5

9. These questions are about how you feel and how things have been with you during the past 4 weeks. For each question, please give the one answer that comes closest to the way you have been feeling. How much of the time during the past 4 weeks -

(circle one number on each line)

| | All of the Time | Most of the Time | A Good Bit of the Time | Some of the Time | A Little of the Time | None of the Time |
|--|-----------------|------------------|------------------------|------------------|----------------------|------------------|
| a. Did you feel full of life? | 1 | 2 | 3 | 4 | 5 | 6 |
| b. Have you been a very nervous person? | 1 | 2 | 3 | 4 | 5 | 6 |
| c. Have you felt so down in the dumps that nothing could cheer you up? | 1 | 2 | 3 | 4 | 5 | 6 |
| d. Have you felt calm and peaceful? | 1 | 2 | 3 | 4 | 5 | 6 |
| e. Did you have a lot of energy? | 1 | 2 | 3 | 4 | 5 | 6 |
| f. Have you felt downhearted and low? | 1 | 2 | 3 | 4 | 5 | 6 |
| g. Did you feel worn out? | 1 | 2 | 3 | 4 | 5 | 6 |
| h. Have you been a happy person? | 1 | 2 | 3 | 4 | 5 | 6 |
| i. Did you feel tired? | 1 | 2 | 3 | 4 | 5 | 6 |

Appendix 2

10. During the past 4 weeks, how much of the time has your physical health or emotional problems interfered with your social activities (like visiting with friends, relatives, etc.)?

(circle one)

- All of the time 1
- Most of the time 2
- Some of the time 3
- A little of the time 4
- None of the time 5

11. How TRUE or FALSE is each of the following statements for you?

(circle one number on each line)

| | Definitely True | Mostly True | Don't Know | Mostly False | Definitely False |
|--|-----------------|-------------|------------|--------------|------------------|
| a. I seem to get ill more easily than other people | 1 | 2 | 3 | 4 | 5 |
| b. I am as healthy as anybody I know | 1 | 2 | 3 | 4 | 5 |
| c. I expect my health to get worse | 1 | 2 | 3 | 4 | 5 |
| d. My health is excellent | 1 | 2 | 3 | 4 | 5 |

Appendix 3.

SECTION 4 : IMPACT OF HIV (HIVIS-W)

21. In this section, I will go through a list of problems that you, like many others living with HIV, may be facing. For each of these problems, I would like you to tell me how much you have been bothered by this problem during the past month (the last four weeks).

How much have you been bothered
by this problem during the past month?

| | not at
all | a little
bit | moder-
ately | a
lot | extremely |
|---|---------------|-----------------|-----------------|----------|-----------|
| a. Not knowing where to go for help | 1 | 2 | 3 | 4 | 5 |
| b. Fear of infecting other people | 1 | 2 | 3 | 4 | 5 |
| c. Being discriminated against | 1 | 2 | 3 | 4 | 5 |
| d. Feeling helpless | 1 | 2 | 3 | 4 | 5 |
| e. Feeling angry or frustrated at
the health care system | 1 | 2 | 3 | 4 | 5 |
| f. Rejection by others close to you
(eg. family or friends) | 1 | 2 | 3 | 4 | 5 |
| g. How and where to get honest, up-to-date
information about HIV | 1 | 2 | 3 | 4 | 5 |
| h. Feeling isolated | 1 | 2 | 3 | 4 | 5 |
| i. Problems in your sex life | 1 | 2 | 3 | 4 | 5 |
| j. Financial difficulties | 1 | 2 | 3 | 4 | 5 |
| k. Feeling angry | 1 | 2 | 3 | 4 | 5 |
| l. Getting sick or sicker | 1 | 2 | 3 | 4 | 5 |
| m. Feeling guilty | 1 | 2 | 3 | 4 | 5 |
| n. Drug/alcohol use | 1 | 2 | 3 | 4 | 5 |

APPENDIX 3

How much have you been bothered by this problem during the past month?

| | not at all | a little bit | moderately | a lot | extremely |
|---|------------|--------------|------------|-------|-----------|
| o. Fear of dying | 1 | 2 | 3 | 4 | 5 |
| p. Feeling depressed | 1 | 2 | 3 | 4 | 5 |
| r. Being less able to provide care for others | 1 | 2 | 3 | 4 | 5 |
| s. What to say and to whom | 1 | 2 | 3 | 4 | 5 |
| t. Housing problems | 1 | 2 | 3 | 4 | 5 |
| u. Concern about not being able to care for yourself | 1 | 2 | 3 | 4 | 5 |
| v. Legal problems | 1 | 2 | 3 | 4 | 5 |
| w. Planning for your future care (living will, life support, power of attorney) | 1 | 2 | 3 | 4 | 5 |
| x. Feeling uncertain about the future | 1 | 2 | 3 | 4 | 5 |
| y. Concern about confidentiality | 1 | 2 | 3 | 4 | 5 |
| z. Rejection by caregivers | 1 | 2 | 3 | 4 | 5 |
| aa. Physical pain | 1 | 2 | 3 | 4 | 5 |
| bb. Feeling less physically attractive | 1 | 2 | 3 | 4 | 5 |
| cc. Feeling lonely | 1 | 2 | 3 | 4 | 5 |
| dd. Feeling less in control of your life | 1 | 2 | 3 | 4 | 5 |
| ee. Thoughts about suicide | 1 | 2 | 3 | 4 | 5 |
| ff. Feeling anxious | 1 | 2 | 3 | 4 | 5 |

Appendix 3 :

**How much have you been bothered
by this problem during the past month?**

| | not at
all | a little
bit | moder-
ately | a
lot | extremely |
|--|---------------|-----------------|-----------------|----------|-----------|
| gg. Fear about loss of your mental abilities | 1 | 2 | 3 | 4 | 5 |
| hh. Not being able to realize life goals
(eg. establishing intimate relationships,
completing your education, attaining
career goals) | 1 | 2 | 3 | 4 | 5 |
| ii. Loss of self-esteem | 1 | 2 | 3 | 4 | 5 |

Overall, how do you feel about your life?

22. Are you:

- Very dissatisfied 1
- Somewhat dissatisfied 2
- Somewhat satisfied 3
- Very satisfied 4
- No opinion 9

23. Are you:

- Very unhappy 1
- Somewhat unhappy 2
- Somewhat happy 3
- Very happy 4
- No opinion 9

Appendix 4

Below is a list of statements about people with HIV. Can you look at these statements and say how much you agree or disagree with each one by ringing the answer which most nearly represents what you think.

| | | | | |
|---|-------------------|----------|-------|----------------|
| People with HIV are no different from anybody else | strongly disagree | disagree | agree | strongly agree |
| People with HIV are dirty | strongly disagree | disagree | agree | strongly agree |
| People with HIV are as intelligent as anybody else | strongly disagree | disagree | agree | strongly agree |
| Most people become HIV positive by being weak-willed or foolish | strongly disagree | disagree | agree | strongly agree |
| Nobody deserves to be HIV-positive | strongly disagree | disagree | agree | strongly agree |
| It is safe for people with HIV to work with children | strongly disagree | disagree | agree | strongly agree |
| People with HIV are not to be trusted | strongly disagree | disagree | agree | strongly agree |
| People with HIV have nothing to feel guilty about | strongly disagree | disagree | agree | strongly agree |
| People with HIV should not have a child | strongly disagree | disagree | agree | strongly agree |
| Needs of people with HIV should be given top priority | strongly disagree | disagree | agree | strongly agree |
| People with HIV must expect some restrictions on their freedom | strongly disagree | disagree | agree | strongly agree |
| Prisoners with HIV should be segregated | strongly disagree | disagree | agree | strongly agree |
| You can't tell by looking if someone has HIV | strongly disagree | disagree | agree | strongly agree |
| People with HIV should be ashamed of themselves | strongly disagree | disagree | agree | strongly agree |
| Being HIV positive says nothing about who you are | strongly disagree | disagree | agree | strongly agree |

Appendix 5

Now I want you to imagine that you are a typical member of the public. Show how much you think Mr or Mrs Average would agree or disagree with each statement by ringing the appropriate answer.

| | | | | |
|---|-------------------|----------|-------|----------------|
| People with HIV are no different from anybody else | strongly disagree | disagree | agree | strongly agree |
| People with HIV are dirty | strongly disagree | disagree | agree | strongly agree |
| People with HIV are as intelligent as anybody else | strongly disagree | disagree | agree | strongly agree |
| Most people become HIV positive by being weak-willed or foolish | strongly disagree | disagree | agree | strongly agree |
| Nobody deserves to be HIV-positive | strongly disagree | disagree | agree | strongly agree |
| It is safe for people with HIV to work with children | strongly disagree | disagree | agree | strongly agree |
| People with HIV are not to be trusted | strongly disagree | disagree | agree | strongly agree |
| People with HIV have nothing to feel guilty about | strongly disagree | disagree | agree | strongly agree |
| People with HIV should not have a child | strongly disagree | disagree | agree | strongly agree |
| Needs of people with HIV should be given top priority | strongly disagree | disagree | agree | strongly agree |
| People with HIV must expect some restrictions on their freedom | strongly disagree | disagree | agree | strongly agree |
| Prisoners with HIV should be segregated | strongly disagree | disagree | agree | strongly agree |
| You can't tell by looking if someone has HIV | strongly disagree | disagree | agree | strongly agree |
| People with HIV should be ashamed of themselves | strongly disagree | disagree | agree | strongly agree |
| Being HIV positive says nothing about who you are | strongly disagree | disagree | agree | strongly agree |

Appendix 6.

INTERPERSONAL SUPPORT EVALUATION LIST

This scale is made up of a list of statements each of which may or may not be true about you. For each statement I would like you to circle probably TRUE if the statement is true about you or probably FALSE if the statement is not true about you.

You may find that many of the statements are neither clearly true nor clearly false. In these cases, try to decide quickly whether probably TRUE (T) or probably FALSE (F) is the most descriptive of you. Although some questions will be difficult to answer, it is important that you pick one alternative for each statement.

Please read each item quickly but carefully before responding. Remember that this is not a test and there are no right or wrong answers.

- | | | |
|---|---|--|
| T | F | There is at least one person I know whose advice I really trust. |
| T | F | There is someone I could turn to for advice about changing my job or finding a new one. |
| T | F | In general, people don't have much confidence in me. |
| T | F | If I decide on a Friday afternoon that I would like to go to a movie that evening, I could find someone to go with. |
| T | F | If for some reason I were put in prison, there is someone I could call who would bail me out. |
| T | F | There is someone who I feel comfortable going to for advice about sexual problems. |
| T | F | If I needed a ride to the airport very early in the morning, I would have a hard time finding anyone to take me. |
| T | F | If I wanted to have lunch with someone, I could easily find someone to join me. |
| T | F | I am able to do things as well as other as most other people. |
| T | F | There is someone I can turn to for advice about handling hassles over household responsibilities. |
| T | F | If I had to post an important letter at the post office by 5.00 and couldn't make it, there is someone who could do it for me. |
| T | F | I feel that I am on the fringe in my circle of friends. |
| T | F | I have someone who takes pride in my accomplishments. |
| T | F | Most people I know don't enjoy the same things I do. |
| T | F | If I got stranded 10 miles out of town, there is someone I could call to come get me. |
| T | F | There is really no one I can trust to give me good financial advice. |
| T | F | No one I know would throw a birthday party for me. |
| T | F | There is no one I could call on If I needed to borrow a car for a few hours. |
| T | F | I regularly meet or talk with members of my family or friends. |

APPENDIX 6

- | | | |
|---|---|--|
| T | F | I think my friends think I am not very good at helping them solve problems. |
| T | F | If I wanted to go out of town (e.g to the coast) for the day I would have a hard time finding someone to go with me. |
| T | F | If I needed a quick emergency loan of £100, there is someone I could get it from. |
| T | F | There is very few people I trust to help solve my problems. |
| T | F | I have a hard time keeping pace with my friends. |
| T | F | If a family crisis arose few of my friends would be able to give me good advice about handling it. |
| T | F | If I were sick there would be almost no one I could find to help me with my daily chores. |
| T | F | When I feel lonely, there are several people I could call and talk to. |
| T | F | I am closer to my friends than most other people. |
| T | F | I feel there is no one with whom I can share my most private worries and fears. |
| T | F | I don't often get invited to do things with others. |
| T | F | If I needed some help in moving to a new home, I would have a hard time finding someone to help me. |
| T | F | There are several different people with whom I enjoy spending time. |
| T | F | There is really no one I can trust to give me objective feedback about how I am handling my problems. |
| T | F | If I were sick and needed someone to drive me to the doctor, I would have trouble finding someone. |
| T | F | Most people I know think highly of me. |
| T | F | If I had to go out of town for a few weeks, someone I know would look after my home (the plants, pets garden etc.). |
| T | F | When I need suggestions for how to deal with a personal problems I know there is someone I can turn to. |
| T | F | Most of my friends are more interesting than I am. |
| T | F | I am more satisfied with my life than most people are with theirs. |
| T | F | Most of my friends are more successful at making changes in their lives than I am. |

INSTRUCTIONS

To respond to the statements in this questionnaire, you must have a specific stressful situation in mind. Take a few minutes to think about the most stressful situation that you have experienced in the past week.

By "stressful" I mean a situation that was difficult or troubling for you, either because you felt distressed about what happened, or because you had to use considerable effort to deal with the situation. The situation may have involved your family, your job, your friends or something else important to you. Before responding to the statements, think about the details of this stressful situation, such as where it happened, who was involved, how you acted and why it was important to you. While you may still be involved in the situation, or it could have already happened, it should be the most stressful situation that you experienced during the week.

As you respond to each of the statements, please keep this stressful situation in mind. Read each statement carefully and indicate, by circling 0, 1, 2, or 3, to what extent you used it in the situation.

Key:

0 = Does not apply or not used
2 = Used quite a bit.

1 = Used somewhat
3 = Used a great deal.

Please try to respond to every question

Appendix 7

| | Not used | Used somewhat | Used quite a bit | Used a great deal |
|---|--------------------------|--------------------------|--------------------------|--------------------------|
| I daydream or imagine a better time or place than the one I am in | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| I draw on my past experiences | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| I think up a couple of different solutions to problems | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| I wish that I could change how I feel | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| I try to come out of experiences better than when I went in | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| I wish I could change what has happened | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| I try to analyse the situation in order to understand it better | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| I usually know what has to be done, so I keep up my efforts to make things work | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| I take it out on other people | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| I avoid being with people in general | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| I have fantasies or wishes about how things might turn out | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| I stand my ground and fight for what I want | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| I wish that the situation would go away or somehow be over with | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| I make a plan of action and follow it | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |

SEMI-STRUCTURED INTERVIEW SCHEDULE

TO BE READ OUT TO EVERY PARTICIPANT BEFORE THE INTERVIEW BEGINS

I would like to thank you for agreeing to take part in this study. There is one thing I would like to look at in this interview.

- ◆ *The sort of things you see as being important for HIV positive black African women when they are deciding about telling others or not telling others about being HIV positive.*

I would like you to read again the consent form you were given before you completed the questionnaires earlier. I would also like you to ask me any questions you have about the research before I ask you to formally give your consent to this interview.

ALLOW TIME FOR PARTICIPANT TO READ CONSENT FORM

I would like to remind you that you can withdraw from this interview at any stage and this will not affect any services you are receiving now or at a future date.

*The results will be compiled and presented to the HIV/AIDS service at the XXXXXX.
There will also be a research report which can be requested from XXXXXXXX hospital
tel. after August 1999.*

Were there any questions ?

Complete consent form

APPENDIX 8

Participant No.

THE INTERVIEW

Record the interview questions and responses by hand

Record interview date :

Record the time interview began :.....

Note: Headings in square brackets are to guide interviewer, not to be said to the participant.

QUESTION 1: DISCLOSURE

[What factors do you feel affect disclosure decisions HIV+ black African women living in London i.e. factors more likely or less likely to influence disclosure?]

a. Can you tell me what factors you feel, make a HIV positive black African woman living in London, more likely to inform another person of their status ?

Areas to cover if not mentioned spontaneously:

1. Timing of finding out status
2. Relationship shared with other person

APPENDIX 8

3. Personal attributes of the persons being disclosed to :

4. Precipitant reason:

5. How far developed their illness is.

Sample question: To what extent would it make a difference how far developed the illness is ?

Follow up question if needed : Could you say a bit more about why that would /wouldn't make a difference.

b. Can you tell me what factors you feel, make it less likely that a HIV positive black African woman living in London, will inform another person of their status?

1. Stigma in society around HIV

2. Unsure of what their reaction would be

3. Concerns about negative consequences

4. Uncertainty about immigration status.

5. Prior awareness of negative attitudes towards HIV

APPENDIX 8

DEBRIEFING

TO BE READ OUT AFTER BOTH QUESTIONS HAVE BEEN ANSWERED:

Thank you for taking part in this interview. The results from the entire study will help me to achieve some understanding of the various factors that may affect disclosure decisions of African women with HIV. I am particularly interested in what role is played by their own attitudes to their illness and what they perceive the attitudes of their community to be. The research will look at whether any relationship exists between African women's disclosure decisions, and their methods of coping, levels of social support and their health related quality of life

Before we end, I would like to read to you the comments you made which I have recorded. I would like you to tell me if any of the statements I have made are incorrect.

a. Can you tell me whether I have made an accurate representation of the information you have provided me with. (Read verbatim your own notes; record their comments)

b. What, if any, sections would you prefer I altered?

c. Were there any sections you would prefer I left out when this research is finally written up?

Remind all participants that : No individual persons will be identifiable in the report, but if you feel at all concerned or weary about any sections I am happy to take them out.

d. Are there any additional pieces of information, you would like to be included?

APPENDIX 8

Were there any issues which were not raised in this interview, which you would like to discuss now.

At the end of the interview remind participant of the list of organisations and support groups printed in the information pack, if they wish to discuss any issues raised from the interview.

A summary of the study's findings will be available in the August 1999. If you would like to receive a copy then please let me know.

Record the time interview ended :.....

**LIST OF SELF-HELP ORGANISATIONS AND SUPPORT GROUPS FOR
INDIVIDUALS AFFECTED WITH HIV/AIDS**

- 1. Africare - provides advocacy and respite services for children and families in the African community Tel: 0171 226 2130.**
- 2. Africa Advocacy Project - Provides peer advocacy, support and immigration advice for people from African Countries. Tel : 0171 691 0234.**
- 3. Blackliners - Care and support for people who are of African, Caribbean or Asian descent Tel : 0171 738 5274.**
- 4. Black HIV/AIDS South East London (BHASEL)
Tel : 0181 694 6638.**
- 5. Body and Soul - A centre for women and their families. Tel : 0171 833 4929
0181 675 5821-evenings.**
- 6. Body Positive - Provides support and advice to those living with HIV and their families, carers and friends. Tel : 0800 616 212.**
- 7. International Community of Women living with HIV and AIDS (ICW).
Tel : 0171 704 0606.**
- 8. National AIDS Helpline - 24 hour helpline offering advice on HIV/AIDS.
Tel : 0800 567 123.**
- 9. Network of Self Help HIV and AIDS Groups. Tel : 0171 250 1540.**
- 10. Positive Partners/Positively Children - Support for children, women, and men affected. Tel : 0171 738 7399.**
- 11. Positively Women - Counselling and support services for women. Tel 0171 713 0222.**
- 12. Terrence Higgins Trust - Helpline open everyday 12-10PM. Provides advice on HIV/AIDS. Tel : 0171 242 1010.**
- 13. The Positive Place Women's Group - An afternoon for women living with HIV and their children. Tel : 0181 694 9988.**

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SALOMONS
CENTRE

Appendix 10

Ms J Onwumere

2nd October 1998

Dear Juliana,

Re: Ethics Approval – A study of the role of one's attitudes and the perceived attitudes of society to being HIV seropositive on disclosure decisions, and the relationship to health related quality of life, coping styles and levels of social support in Black African women living in London.

Thank you for sending the above proposal for Ethics Approval. The Panel has considered your application and Provisional Approval is given. For Full Approval we would want you to take the following points taken into account:

1. It should be made clear what will happen to the tapes when they have finished being transcribed and what will happen with the transcripts after completion of the study.
2. It should be clarified how the participants will be informed about the tape recording of the interview as it did not appear on the information sheet.
3. Appendix 15 did not contain an indicative list of questions and these are obviously important in considering the ethical issues raised by the study. The panel would like to see an indicative list of questions or an outline of what will be asked.

It was hoped that these conditions would be relatively easy to meet and providing you met these the Panel foresaw no problems granting full approval.

The Panel also ask that you consider a number of issues:

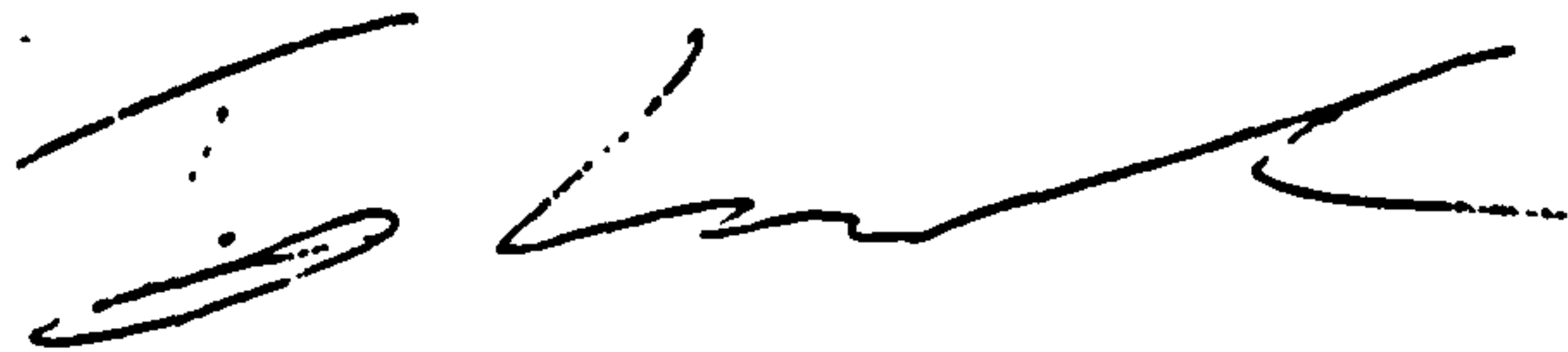
1. Appendix 3 – this Questionnaire did not have the title that it was given in the test. It is often helpful to check.

Appendix 10

2. As much care as possible should be taken to ensure that an easily accessible service is offered by the list of organisations that participants are given to contact in the event of difficulties.

We look forward to seeing the results and hope you enjoy the research.

Yours sincerely,



Professor Tony Lavender
Chair of Ethics Panel

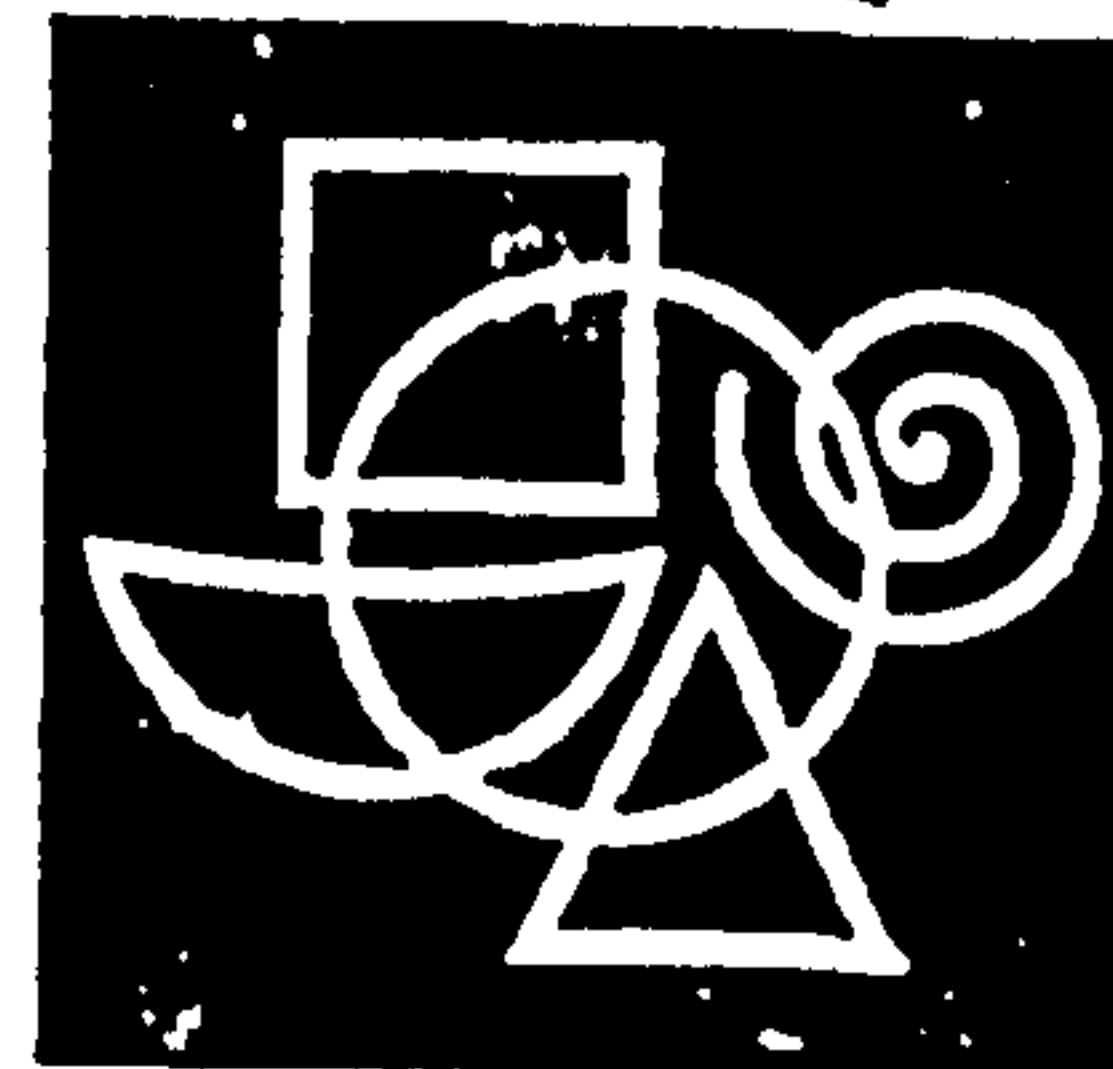
c.c. Caroline Hogg
Viv Martin

Appendix 10

Salomons Centre
David Salomons Estate
Broomhill Road, Southborough
TUNBRIDGE WELLS
Kent TN3 0TG

Telephone: 01892 515152
Facsimile: 01892 539102

Our Ref: LT/075
Direct Fax: 01892 518446
E-mail: l.thompson@salomons.org.uk



SALOMONS
CENTRE

Ms J Onwumere

21st October 1998

Dear Juliana.

Re: Ethics Approval – A study of the role of one's attitudes and the perceived attitudes of society to being HIV seropositive on disclosure decisions, and the relationship to health related quality of life, coping styles and levels of social support in Black African women living in London.

Thank you for your letter dated 9th October. The Panel note that you have given very good and careful consideration of all the points raised in our letter dated 2nd October 1998 and is pleased to provide full ethical approval for your research project.

We look forward to seeing the results and hope you enjoy the research.

Yours sincerely,

Professor Tony Lavender
Chair of Ethics Panel

c.c. Caroline Hogg
Viv Martin

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Appendix 10



Ms J Onwumere

01 March 1999

Direct line 01892 507665

Direct fax 01892 507660

E-mail t.lavender@salomons.org.uk

Our Ref LT/075

Dear Juliana,

Re: Ethics Approval – A study of the role of one's attitudes and the perceived attitudes of society to being HIV seropositive on disclosure decisions, and the relationship to health related quality of life, coping styles and levels of social support in Black African women living in London.

Thank you for your letter dated 17 February 1999 with enclosures. The Panel note that you have given very good and careful consideration of all the points raised in our letter dated 2 October 1998 and is pleased to provide full ethical approval for your research project.

The panel noted you intended to destroy the data before you knew whether you had passed the dissertation and it maybe advisable not to destroy until December, in the unlikely event of you needing to access the data post submission.

We wish you well with the project and would be extremely interested to see the results.

Yours sincerely,

Professor Tony Lavender
Chair of Ethics Panel

c.c. Caroline Hogg
Nigel Armstrong



Appendix 10

Ms J Onwumere

7 July 1999

Direct line 01892 507665

Direct fax 01892 507660

E-mail t.lavender@salomons.org.uk

Our Ref LT/075

Dear Juliana,

Re: Ethics Approval – A study of the role of one's attitudes and the perceived attitudes of society to being HIV seropositive on disclosure decisions, and the relationship to health related quality of life, coping styles and levels of social support in Black African women living in London.

Thank you for your letter dated 28th June 1999. The panel note the contents of your letter and grant Chair's Approval for this modification to your original methodology.

We wish you well with the project and would be extremely interested to see the results.

Yours sincerely,

**Professor Tony Lavender
Chair of Ethics Panel**

Appendix 11

HOSPITAL TRUST

RESEARCH ETHICS COMMITTEE

12 February 1999

Juliana Onwumere
Psychologist

Dear Ms Onwumere

EC99/012 A study of the role on one's attitudes and the perceived attitudes of society to being HIV seropositive on disclosure decisions, and the relationship to health related quality of life, coping styles and levels of social support in Black African women living in London

Thank you for your correspondence dated 18.2.99 and for submitting a revised consent form and addressing the queries raised by the Research Ethics Committee. This is satisfactory and I am happy for the study to commence.

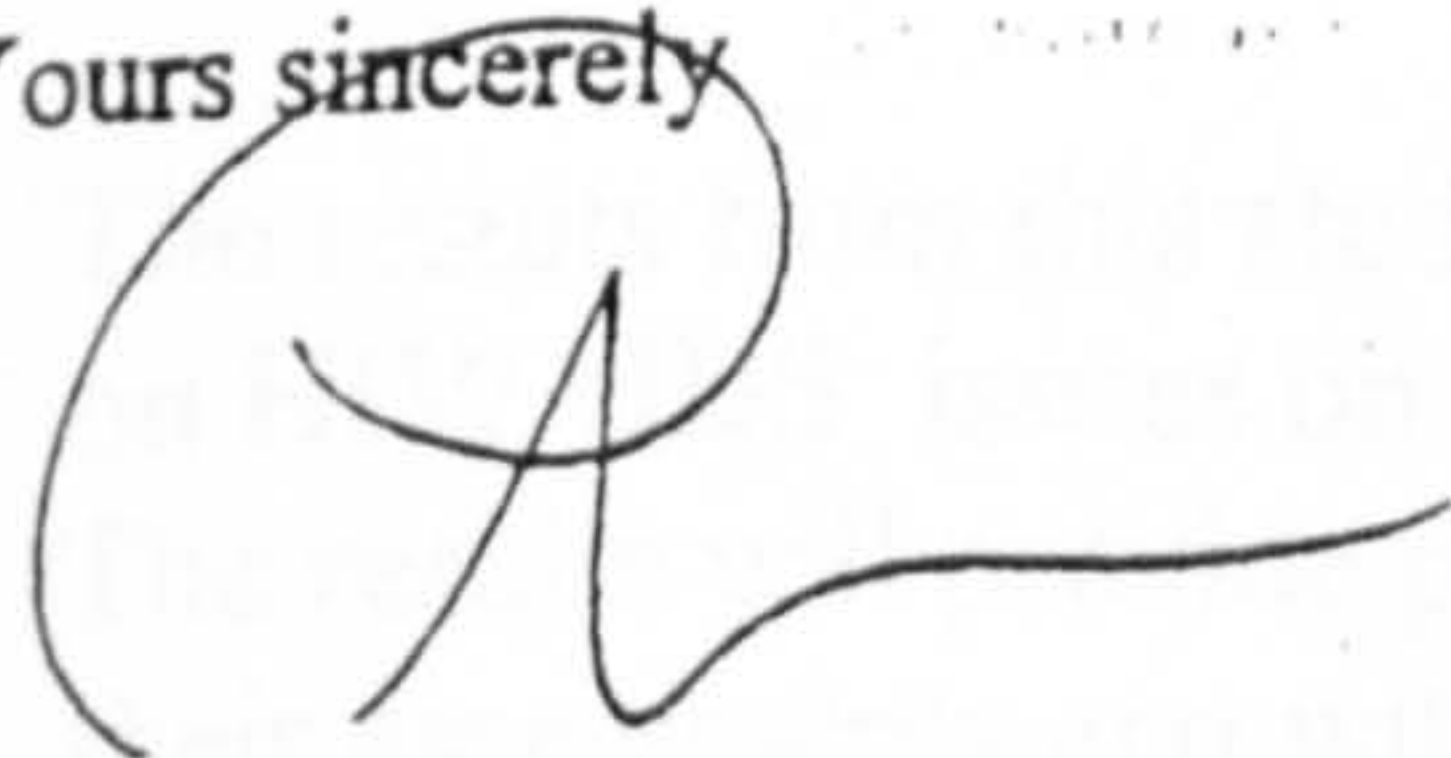
Please note that this project carries a reference number, noted above, which must be quoted in any future correspondence.

The project number and the principal investigator must be clearly stated on the consent form. If approval is given to named investigators only, these names must also be stated on the form.

In the case of research on patients, a copy of the consent form must be placed in the patient's medical records, together with a note of the date of commencement of his/her participation in the research. A label must appear on the outside cover of the records when the patient is

The investigators must adhere to the published Guidelines of the Committee and provide the Chairman with annual progress reports and an end of study report. The research should start within 12 months of the date of approval.

Yours sincerely



Chairman,
Research Ethics Committee

INFORMATION SHEETS FOR PROSPECTIVE PARTICIPANTS

TITLE OF STUDY

A study of the role of one's attitudes and the perceived attitudes of society to being HIV seropositive on disclosure decisions, and the relationship to health related quality of life, coping styles and levels of social support in Black African women living in London.

OUTLINE OF THE RESEARCH

Informing another person of one's HIV status remains a constant stressor for many individuals with HIV, irrespective of whether they choose to disclose their HIV status. This research will be an exploration of an individual's own attitude to their illness and what they think the attitudes of their community are to being HIV seropositive. The research intends to explore how these attitudes may affect a person's decision to disclose their HIV status and how this may affect their coping methods and the social support they receive.

Globally women form an important group within the HIV/AIDS population. The unique responsibilities which accompany their gender role such as parenting and caring must be managed alongside the numerous stressors associated with being HIV seropositive. I have chosen to focus my research on Black women of African origin because although they are a significant group living with HIV/AIDS in London they are an under researched group.

WHAT WILL I HAVE TO DO IF I DECIDE TO TAKE PART IN THE STUDY?

The study involves two parts. The first part will require you to complete six relatively short questionnaires, each taking approximately 5 to 10 minutes each to complete.

The second part of the study will involve a short interview. The interview questions will enquire about what factors you feel may affect an individual's decision to disclose.

So I can accurately report on the content of the interview, I will write down your responses to the questions. If you agree to be interviewed you do not need to reveal any personal details about yourself or your own disclosure decisions.

THE IMPORTANCE OF THIS STUDY

The results from this study will make a vital contribution to the small body of literature on HIV/AIDS issues on women from Black African communities living in London. The results will provide professionals with useful information on how best to conduct their assessments and will increase their understanding and awareness of the needs of African women living with HIV in London, ultimately tailoring their services to meet their specific needs.

Appendix 12

DO I HAVE TO TAKE PART IN THIS STUDY?

The answer to this question is NO. Your participation is entirely voluntary.

WHAT HAPPENS TO THE INFORMATION COLLECTED IN THE STUDY?

THIS IS A STRICTLY ANONYMOUS AND CONFIDENTIAL STUDY.

All the information you provide in the questionnaires will be anonymous. Therefore, neither I or anyone else will know who has answered the questionnaires as none of the questionnaires require you to write down your name, address or any other information which may lead to you being identified.

The information gathered from the interview will be confidential, which means no individual apart from myself and two research supervisors, will have access to the written record of the interview and your identity will be kept completely private. Although I may use short quotes to illustrate points when the study is written up, it will not be possible for anyone to be identified from these.

All returned questionnaires alongside the written notes from the interview will be destroyed in December 1999, following the completion of the study.

Feedback on the results from this study will be made available from August 1999 to your support group.

If you would like to take part in this study or would like to discuss your possible participation, please contact me on 0171-407 2000.

If participating in this study raises some personal concerns which you feel you would like to discuss with someone further outside of your own support group, you may like to contact one of the organisations listed on the attached sheet.

May I take this opportunity to thank you for taking the time to read this information sheet.

**Juliana Onwumere
Psychologist**

" Appendix 13

CONSENT FORM FOR PARTICIPATION IN RESEARCH

A study of the role of one's attitudes and the perceived attitudes of society to being HIV seropositive on disclosure decisions, and the relationship to health related quality of life, coping styles and levels of social support in Black African women living in London.

I

hereby give my consent to take part in the above study, the rationale and nature of which have been explained to me. Any questions I have wanted to ask have been answered to my satisfaction. I fully understand that I may withdraw from the study at any stage without giving a reason for doing so and withdrawal will not affect any care or services I receive.

SIGNED (Participant) DATE

SIGNED (Psychologist) DATE

ATTITUDES, DISCLOSURE AND YOU

My name is Juliana Onwumere and I am a Psychologist. I am conducting some research with xxxxxxxxxx a Clinical Psychologist working at xxxxxxxxxx, which is a psychological service for individuals with HIV /AIDS.

The research is concerned with women of African origin who are HIV seropositive. It will explore your attitudes to being HIV seropositive and your decisions regarding who to tell. It will also look at the impact of the illness on your lives, your adopted coping methods and patterns and sources of social support.

If you are a Black woman of African origin with HIV or know of one who may be interested in taking part in this study would you please contact your support group leader to receive an information sheet, which will provide you with further details about the study.

Alternatively, you can contact me on xxxxxxxxxxxxxx, if you would like to discuss the study further.

Thank you for your time and support.

Juliana Onwumere
Psychologist

APPENDIX 15

A sample of the different reasons cited for the non recruitment of participants from services

- *"We haven't got a policy on recruitment of women ...the idea will need to go to an executive board meeting which is being held in April 1999"*
- *"There are lots of drug trials happening at the moment and they are paying a lot more money".*
- *"We don't know if funding for the group will be granted.....so I don't want to commit ourselves....can you call me after April 1999"*
- *"We are just about to conduct our own internal questionnaire and I do not want the women to be confused"*
- *"There has been no response to the adverts, I don't really want to force the issue"*
- *"There is some similar research going on at moment by another agency and they are paying £ 10.00"*
- *"It would be impossible to fit the research into our programme of events.....you would need to wait until March/April to see if we can fit you into the programme for summer 1999"*
- *"I have got so many things going on now, I couldn't cope with anything else.....maybe some other time.....I don't know when".*
- *" I am about to leave my post so I will pass on everything to the person taking over my job, but I don't know whether anything will happen for a long while because they will need time to settle into their post and get to the client group, so I don't think anything will happen for sometime, I'm sorry because I know you have a timetable your are working towards".*
- *" I liked the idea of the research but we decided we would like to change a few things before the project goes ahead.....we would like to take out three of the questionnaires and put in a focus group instead, because that has worked best in the past".*
- *"I know that none of the members would be interested....the incentive is not enough They have been over researched ...they are sick of being researched and never seeing the results....they don't want to be and don't need to be researched anymore".*
- *"The persons I had identified for you have become unwell and are in hospital, there is a lot of flu going around.....I'll try and get in touch when they get better"*

APPENDIX 16 :

Internal reliability and one sample Kolmogorov-Smirnov tests for questionnaire measures used

SF-36

INTERNAL RELIABILITY (CRONBACH'S ALPHAS STATISTIC) FOR EIGHT DIMENSIONS OF THE SF-36

| | Physical functioning | Role functioning | Role emotional | Social functioning |
|-------|----------------------|------------------|----------------|--------------------|
| n | 53 | 55 | 54 | 55 |
| alpha | 0.92 | 0.84 | 0.74 | 0.5 |

| | Mental health | Pain | General Health Functioning | Energy Vitality |
|-------|---------------|------|----------------------------|-----------------|
| n | 54 | 56 | 56 | 56 |
| alpha | 0.68 | 0.83 | 0.56 | 0.61 |

ONE SAMPLE KOLMOGOROV-SMIRNOV TEST FOR EIGHT SF-36 DOMAINS & THE MENTAL AND PHYSICAL HEALTH COMPONENT SUMMARY SCORES

| | PF | P | MH | SF | EV | GHP | RE | RP |
|----------------------|-------|------|------|------|------|------|------|------|
| n | 53 | 56 | 54 | 55 | 56 | 56 | 54 | 55 |
| Kolmogorov-smirnov z | 0.873 | 0.95 | 0.69 | 1.1 | 0.7 | 0.84 | 1.87 | 1.97 |
| Sig. | 0.43 | 0.33 | 0.72 | 0.18 | 0.71 | 0.48 | 0 | 0 |

| | Mental component summary score | Physical component summary score |
|----------------------|--------------------------------|----------------------------------|
| n | 49 | 49 |
| Kolmogorov-Smirnov Z | 0.65 | 0.5 |
| Sign. | 0.79 | 0.96 |

APPENDIX 16 :

Interpersonal support evaluation list

INTERNAL RELIABILITY (CRONBACH'S ALPHAS STATISTIC) FOR INTERPERSONAL SUPPORT EVALUATION LIST

| | Appraisal | Belonging | Tangible | Self esteem |
|-------|-----------|-----------|----------|-------------|
| n | 54 | 55 | 53 | 54 |
| alpha | 0.7 | 0.62 | 0.81 | 0.59 |

ONE SAMPLE KOLMOGOROV-SMIRNOV TEST FOR INTERPERSONAL SUPPORT EVALUATION LIST

| | Total support |
|----------------------|---------------|
| n | 51 |
| Kolmogorov-Smirnov z | 0.63 |
| sig. | 0.82 |

APPENDIX 16 :*Attitudes questionnaire***INTERNAL RELIABILITY (CRONBACH'S ALPHAS STATISTIC) FOR ATTITUDE QUESTIONNAIRE**

| | Participants own attitude towards people with HIV | Participants perception of community attitudes towards people with HIV |
|--------------|--|---|
| n | 52 | 52 |
| alpha | 0.72 | 0.88 |

ONE SAMPLE KOLMOGOROV-SMIRNOV TEST FOR ATTITUDE QUESTIONNAIRE

| | Participants own attitudes towards people with HIV | Participants perception of community attitudes towards people with HIV |
|-----------------------------|---|---|
| N | 52 | 52 |
| Kolmogorov-Smirnov z | 0.588 | 0.842 |
| sig. | 0.88 | 0.477 |

APPENDIX 16 :

HIVIS-W

INTERNAL RELIABILITY (CRONBACH'S ALPHAS STATISTIC) FOR HIVIS-W

| | HIVIS-W |
|-------|----------------|
| n | 48 |
| alpha | 0.94 |

ONE SAMPLE KOLMOGOROV-SMIRNOV TEST FOR HIVIS-W

| | HIVIS-W |
|----------------------|----------------|
| n | 48 |
| Kolmogorov-Smirnov z | 0.74 |
| Sign. | 0.65 |

APPENDIX 16 :*Shortened ways of coping -revised***INTERNAL RELIABILITY (CRONBACH'S ALPHAS STATISTIC) FOR SHORTENED WAYS OF COPING -REVEISED QUESTIONNAIRE**

| | Wishful thinking | Practical coping |
|---------|-------------------------|-------------------------|
| N | 53 | 56 |
| Alpha's | 0.74 | 0.73 |

ONE SAMPLE KOLMOGOROV-SMIRNOV TEST FOR SHORTENED WAYS OF COPING-REVEISED

| | Wishful thinking | Practical coping |
|----------------------|-------------------------|-------------------------|
| N | 53 | 56 |
| Kolmogorov-Smirnov Z | 0.1 | 1.17 |
| Sign. | 0.28 | 0.13 |

APPENDIX 17 : Medical and demographic details of the sample

Demographic characteristics of study participants (N= 56)

AGE (years)

| | |
|-----------|--------------|
| Mean (SD) | 35.45 (7.54) |
| Range | 25-61 |
| 25-29 | 11 (19.6%) |
| 30-34 | 16 (28.6%) |
| 35-39 | 16 (28.6%) |
| 40-44 | 7 (12.5%) |
| >45 | 6 (10.7%) |

Ethnicity

| | |
|-------------------|-------------|
| Black African | 54 (96.4 %) |
| Black West Indian | 2 (3.6 %) |

Country of origin

| | | | |
|----------|-------------|----------|----------|
| Uganda | 29 (51.8 %) | Zambia | 1 (1.8%) |
| Zimbabwe | 10 (17.9%) | Kenya | 3 (5.4%) |
| Angola | 1 (1.8%) | Burundi | 1 (1.8%) |
| Rwanda | 2 (3.6 %) | Jamaica | 1 (1.8%) |
| Tanzania | 1 (1.8 %) | Cameroon | 1 (1.8%) |
| Ghana | 1 (1.8%) | Ethiopia | 1 (1.8%) |
| England | 4 (7.1%) | | |

Years in the United Kingdom

| | |
|------------------------------------|------------|
| Resident for > 5 years | 44 (78.6%) |
| Arrived within the last five years | 12 (21.4%) |

Relationship status

| | |
|-----------------------------|------------|
| Single | 35 (62.5%) |
| Married | 10 (17.9%) |
| Cohabiting | 1 (1.8%) |
| Partner not living with you | 6 (10.7%) |
| Divorced | 1 (1.8%) |
| Separated | 1 (1.8%) |
| Widow | 2 (3.6%) |

APPENDIX 17 : Medical and demographic details of the sample

Employment status

| | |
|-------------------|------------|
| Working full time | 4 (7.1%) |
| Working part time | 8 (14.3%) |
| Unemployed | 44 (78.6%) |

Children

| | |
|------------------------------------|------------|
| Women who had children | 47 (83.9%) |
| Women whose children lived at home | 36 (76.5%) |

Numbers of children who lived at home

| | |
|----------------|------------|
| One child | 17 (47.2%) |
| Two children | 10 (27.8%) |
| Three children | 6 (16.7%) |
| Four children | 2 (5.6%) |
| Five children | 1 (2.7%) |

Age distribution of children living at home

| | |
|-----------|------------|
| < 5 years | 14 (25%) |
| 6-10 | 22 (39.3%) |
| 11-16 | 8 (14.3%) |
| >16 | 9 (16.1%) |

MEDICAL CHARACTERISTICS OF PARTICIPANTS

Year in which they received their diagnosis

Mean (SD) 1994. (3 years and 3 months)
 Range 1986-1999

Medication

Currently on medication 39 (69.6%)

Combination of medicines

:Two types 7 (12.5%)
 Three types 29 (51.8%)
 >Three plus 3 (5.4%)

T4 cell count

Mean (SD) 356.09 (198.55)
 Range 50-950
 Low immunity levels (< 200) 11 (19.6%)
 Mild immunity level (201-500) 28 (50%)
 Moderate-normal level (>500) 6 (10.7%)
 Missing 11 (19.6%)

Viral load

Mean (SD) 22 28289.23 (58653.43)
 Range 370-275000
 undetectable range 19 (33.9%)
 missing 15 (26.8%)

Appendix 18 : Mean scores of all individual HIVIS-W items

| HIVIS-W ITEM | MEAN (SD) |
|--|------------------|
| Not knowing where to go for help | 2.32 (1.40) |
| Fear of infecting other people | 2.70 (1.73) |
| Being discriminated against | 3.04 (1.50) |
| Feeling helpless | 3.39 (1.49) |
| Felling angry or frustrated at the health care system | 2.79 (1.34) |
| Rejection by others close to you(e.g family of friends) | 2.69 (1.67) |
| How and where to get honest, up to date information about HIV | 2.15 (1.41) |
| Feeling isolated | 2.95 (1.48) |
| Problems in your sex life | 3.16 (1.70) |
| Finanical difficulties | 3.63 (1.39) |
| Feeling angry | 2.96 (1.45) |
| Getting sick or sicker | 2.98 (1.46) |
| Feeling guilty | 2.32 (1.51) |
| Drugs/alcohol use | 1.22 (0.85) |
| Fear of dying | 2.98 (1.62) |
| Feeling depressed | 3.33 (1.25) |
| Being less able to provide care for others | 2.89 (1.40) |
| What to say and to whom | 2.84 (1.50) |
| Housing problems | 2.94 (1.75) |
| Concern about not being able to care for yourself | 3.02 (1.50) |
| Legal problems | 2.48 (1.63) |
| Planning for your future care(e.g living will, life support,
power of attorney | 3.26 (1.57) |
| Feeling uncertain about the future | 3.50 (1.40) |
| Concern about confidentiality | 2.95 (1.51) |
| Rejection by caregivers | 2.36 (1.52) |
| Physical pain | 3.24 (1.40) |
| Feeling less physically attractive | 2.93 (1.35) |
| Feeling lonely | 2.93 (1.40) |
| Feeling less in control of your life | 3.11 (1.49) |
| Thoughts about suicide | 1.88 (1.39) |
| Feeling anxious | 3.05 (1.37) |
| Fear about loss of mental abilities | 2.79 (1.52) |
| Not being able to realise life goals (e.g establishing intimate
relationships, completing your education, attaining career goals) | 3.35 (1.53) |
| Loss of self esteem | 2.80 (1.37) |

APPENDIX 19: HIV CONCERN

Median scores of HIV concern in comparison to other difficulties

| N | CONCERN | MEDIAN | RANGE |
|----------|---------------------------|---------------|--------------|
| 56 | HIV CONCERN | 10 | 0-10 |
| 40 | Finance | 9 | 0-10 |
| 37 | Housing | 7 | 0-10 |
| 36 | Work | 8 | 0-10 |
| 38 | Immigration | 7 | 0-10 |
| 36 | Racism | 5.5 | 0-10 |
| 37 | Relationship difficulties | 8 | 0-10 |
| 39 | family difficulties | 5 | 0-10 |

Correlations

Appendix 20 Correlations between independent and dependant variables used in regression analyses

Correlations

| | | MEDICINE | EMPLOY | WT | AGE | COUNT4 | SRISK |
|------------------------|----------|----------|--------|---------|---------|--------|---------|
| Pearson
Correlation | MEDICINE | 1.000 | .034 | -.058 | -.013 | .244 | -.174 |
| | EMPLOY | .034 | 1.000 | -.059 | .173 | .082 | -.094 |
| | WT | -.058 | -.059 | 1.000 | .089 | -.329* | -.170 |
| | AGE | -.013 | .173 | .089 | 1.000 | -.158 | -.449** |
| | COUNT4 | .244 | .082 | -.329* | -.158 | 1.000 | -.190 |
| | SRISK | -.174 | -.094 | -.170 | -.449** | -.190 | 1.000 |
| | TSUPPORT | .309* | .190 | -.159 | .134 | .005 | -.153 |
| | NDISCLOS | -.202 | .011 | .126 | -.032 | -.115 | .181 |
| | CHILDREN | -.289* | .008 | .009 | -.098 | -.092 | .188 |
| | PHYSUM | .299* | -.162 | -.306* | .082 | .188 | .169 |
| | MENTSUM | .214 | .154 | -.441** | .011 | -.047 | -.220 |
| | TOTALHIV | -.140 | -.026 | .177 | -.258 | -.075 | .560** |
| Sig.
(2-tailed) | MEDICINE | . | .805 | .678 | .922 | .106 | .216 |
| | EMPLOY | .805 | . | .674 | .203 | .593 | .507 |
| | WT | .678 | .674 | . | .525 | .034 | .242 |
| | AGE | .922 | .203 | .525 | . | .300 | .001 |
| | COUNT4 | .106 | .593 | .034 | .300 | . | .227 |
| | SRISK | .216 | .507 | .242 | .001 | .227 | . |
| | TSUPPORT | .027 | .182 | .282 | .348 | .974 | .300 |
| | NDISCLOS | .136 | .936 | .367 | .817 | .453 | .199 |
| | CHILDREN | .031 | .951 | .947 | .473 | .548 | .182 |
| | PHYSUM | .037 | .265 | .036 | .574 | .251 | .267 |
| | MENTSUM | .140 | .290 | .002 | .942 | .775 | .147 |
| | TOTALHIV | .341 | .859 | .233 | .077 | .654 | .000 |
| N | MEDICINE | 56 | 56 | 53 | 56 | 45 | 52 |
| | EMPLOY | 56 | 56 | 53 | 56 | 45 | 52 |
| | WT | 53 | 53 | 53 | 53 | 42 | 49 |
| | AGE | 56 | 56 | 53 | 56 | 45 | 52 |
| | COUNT4 | 45 | 45 | 42 | 45 | 45 | 42 |
| | SRISK | 52 | 52 | 49 | 52 | 42 | 52 |
| | TSUPPORT | 51 | 51 | 48 | 51 | 41 | 48 |
| | NDISCLOS | 56 | 56 | 53 | 56 | 45 | 52 |
| | CHILDREN | 56 | 56 | 53 | 56 | 45 | 52 |
| | PHYSUM | 49 | 49 | 47 | 49 | 39 | 45 |
| | MENTSUM | 49 | 49 | 47 | 49 | 39 | 45 |
| | TOTALHIV | 48 | 48 | 47 | 48 | 38 | 45 |

Appendix 20

Correlations

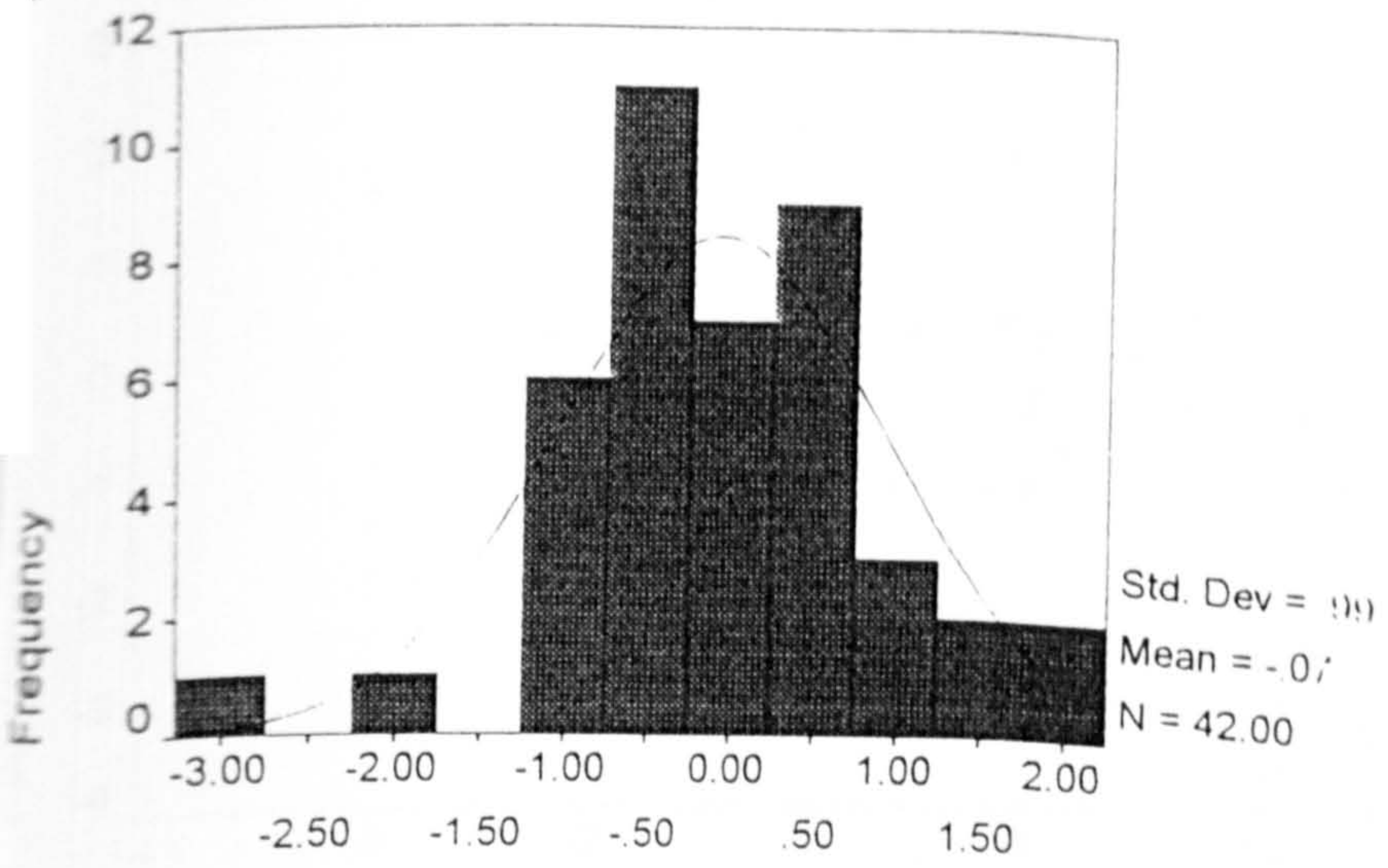
| | | TSUPPORT | NDISCLOS | CHILDREN | PHYSUM | MENTSUM | TOTALHIV |
|------------------------|----------|----------|----------|----------|--------|---------|----------|
| Pearson
Correlation | MEDICINE | .309* | -.202 | -.289* | .299* | .214 | -.140 |
| | EMPLOY | .190 | .011 | .008 | -.162 | .154 | -.026 |
| | WT | -.159 | .126 | .009 | -.306* | -.441** | .177 |
| | AGE | .134 | -.032 | -.098 | .082 | .011 | -.258 |
| | COUNT4 | .005 | -.115 | -.092 | .188 | -.047 | -.075 |
| | SRISK | -.153 | .181 | .188 | .169 | -.220 | .560** |
| | TSUPPORT | 1.000 | -.083 | .117 | .265 | .440** | -.473** |
| | NDISCLOS | -.083 | 1.000 | -.033 | -.059 | -.228 | .136 |
| | CHILDREN | .117 | -.033 | 1.000 | .053 | -.057 | -.096 |
| | PHYSUM | .265 | -.059 | .053 | 1.000 | .213 | -.167 |
| | MENTSUM | .440** | -.228 | -.057 | .213 | 1.000 | -.244 |
| | TOTALHIV | -.473** | .136 | -.096 | -.167 | -.244 | 1.000 |
| Sig.
(2-tailed) | MEDICINE | .027 | .136 | .031 | .037 | .140 | .341 |
| | EMPLOY | .182 | .936 | .951 | .265 | .290 | .859 |
| | WT | .282 | .367 | .947 | .036 | .002 | .233 |
| | AGE | .348 | .817 | .473 | .574 | .942 | .077 |
| | COUNT4 | .974 | .453 | .548 | .251 | .775 | .654 |
| | SRISK | .300 | .199 | .182 | .267 | .147 | .000 |
| | TSUPPORT | . | .563 | .412 | .078 | .003 | .001 |
| | NDISCLOS | .563 | . | .806 | .686 | .115 | .357 |
| | CHILDREN | .412 | .806 | . | .720 | .699 | .515 |
| | PHYSUM | .078 | .686 | .720 | . | .142 | .280 |
| | MENTSUM | .003 | .115 | .699 | .142 | . | .110 |
| | TOTALHIV | .001 | .357 | .515 | .280 | .110 | . |
| N | MEDICINE | 51 | 56 | 56 | 49 | 49 | 48 |
| | EMPLOY | 51 | 56 | 56 | 49 | 49 | 48 |
| | WT | 48 | 53 | 53 | 47 | 47 | 47 |
| | AGE | 51 | 56 | 56 | 49 | 49 | 48 |
| | COUNT4 | 41 | 45 | 45 | 39 | 39 | 38 |
| | SRISK | 48 | 52 | 52 | 45 | 45 | 45 |
| | TSUPPORT | 51 | 51 | 51 | 45 | 45 | 46 |
| | NDISCLOS | 51 | 56 | 56 | 49 | 49 | 48 |
| | CHILDREN | 51 | 56 | 56 | 49 | 49 | 48 |
| | PHYSUM | 45 | 49 | 49 | 49 | 49 | 44 |
| | MENTSUM | 45 | 49 | 49 | 49 | 49 | 44 |
| | TOTALHIV | 46 | 48 | 48 | 44 | 44 | 48 |

*. Correlation is significant at the 0.05 level (2-tailed).

** . Correlation is significant at the 0.01 level (2-tailed).

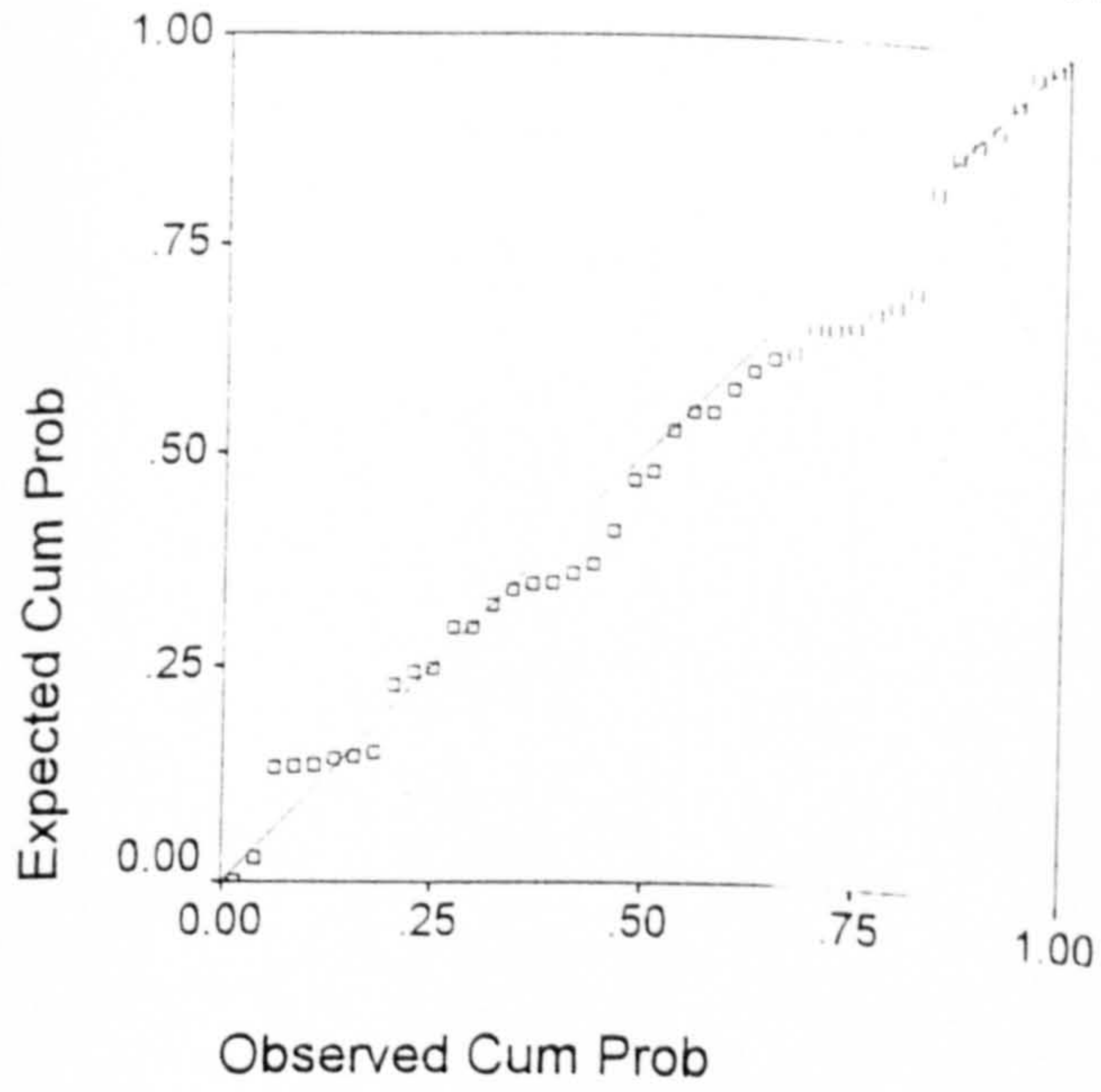
Histogram

Dependent Variable: TOTALHIV



Regression Standardized Residual

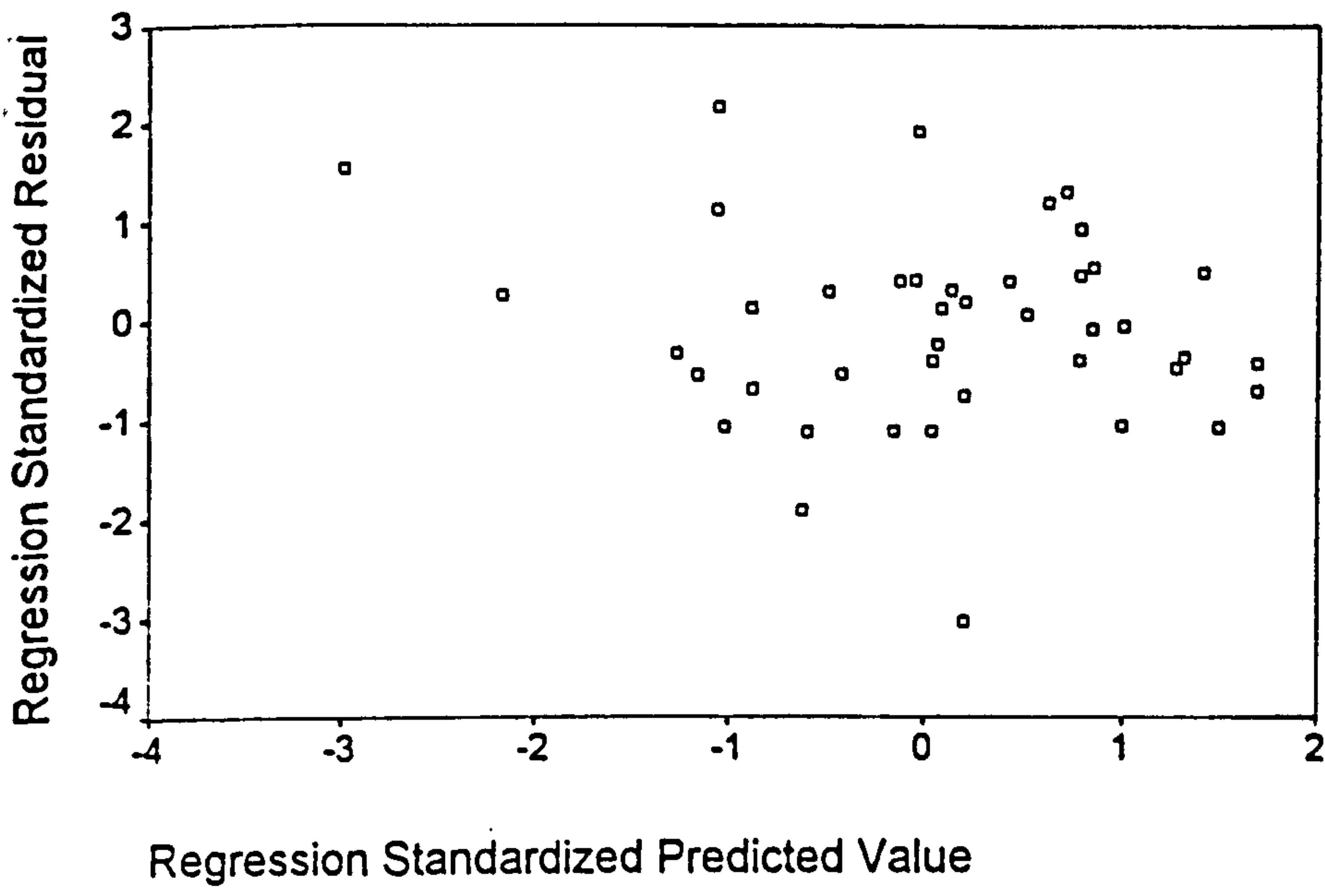
Normal P-P Plot of Regression Standardized Residuals
Dependent Variable: TOTALHIV



Scatterplot

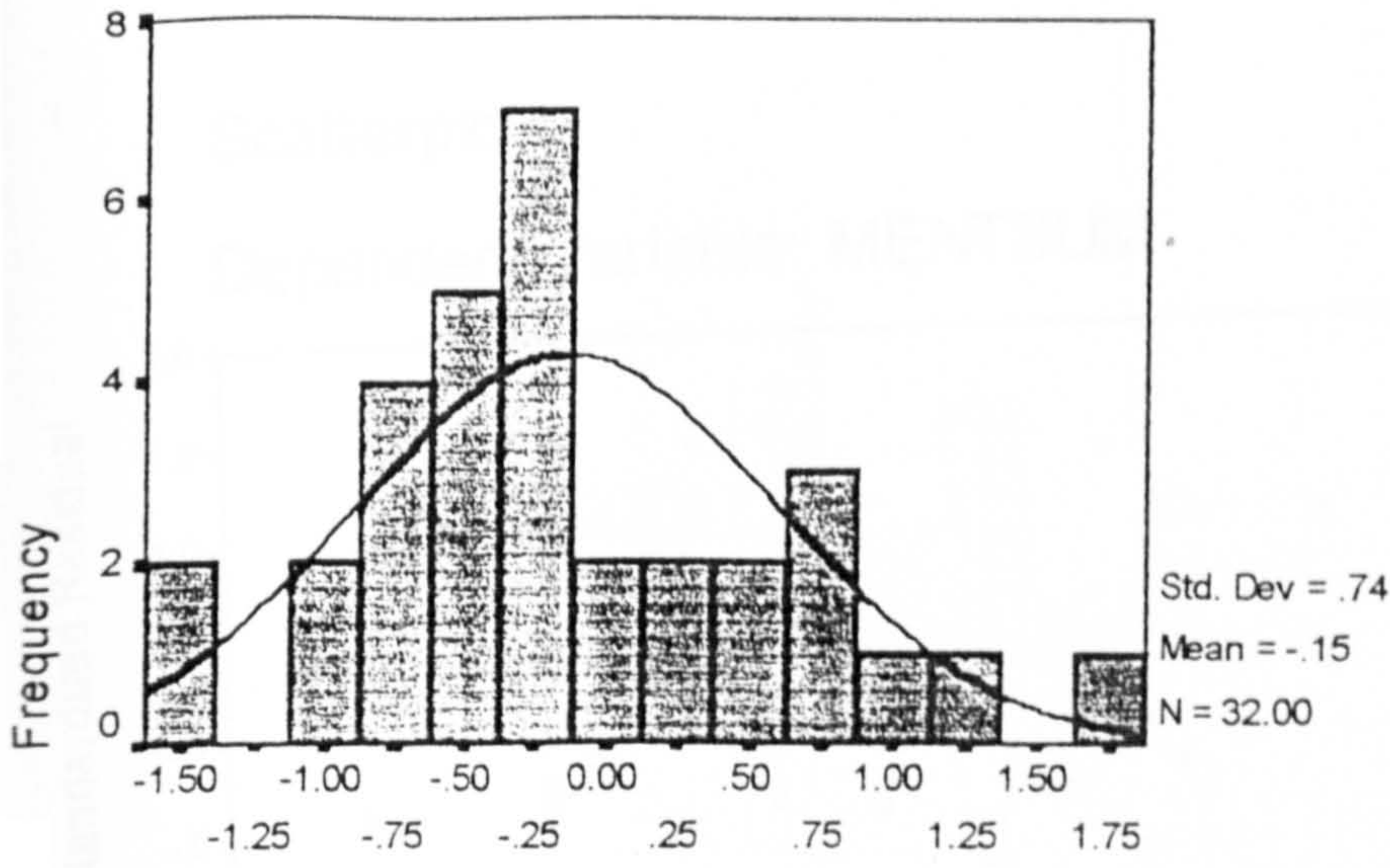
Appendix 21

Dependent Variable: TOTALHIV



Histogram

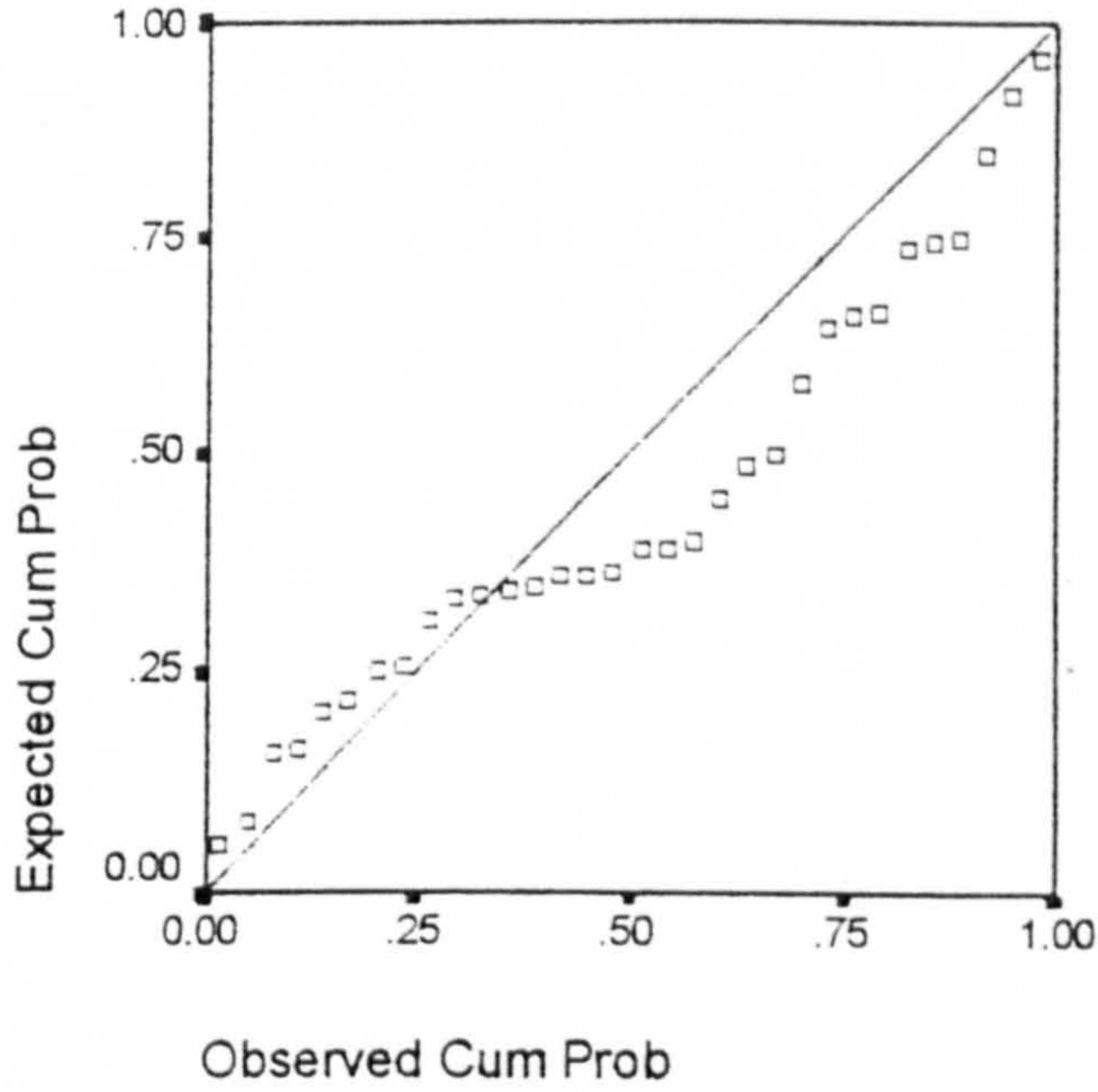
Dependent Variable: MENTSUM



Regression Standardized Residual

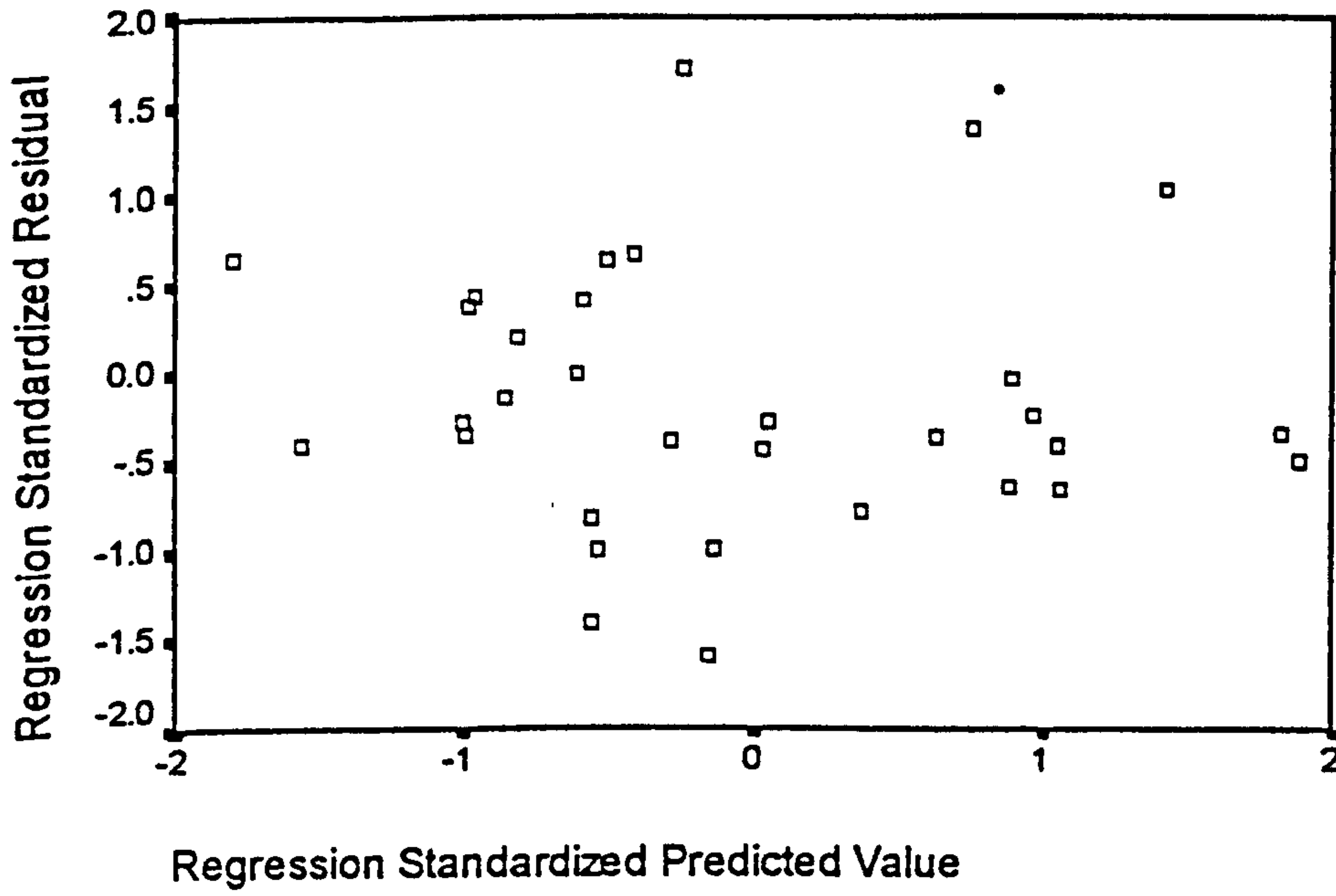
Normal P-P Plot of Regression Standardized Residual

Dependent Variable: MENTSUM



Scatterplot

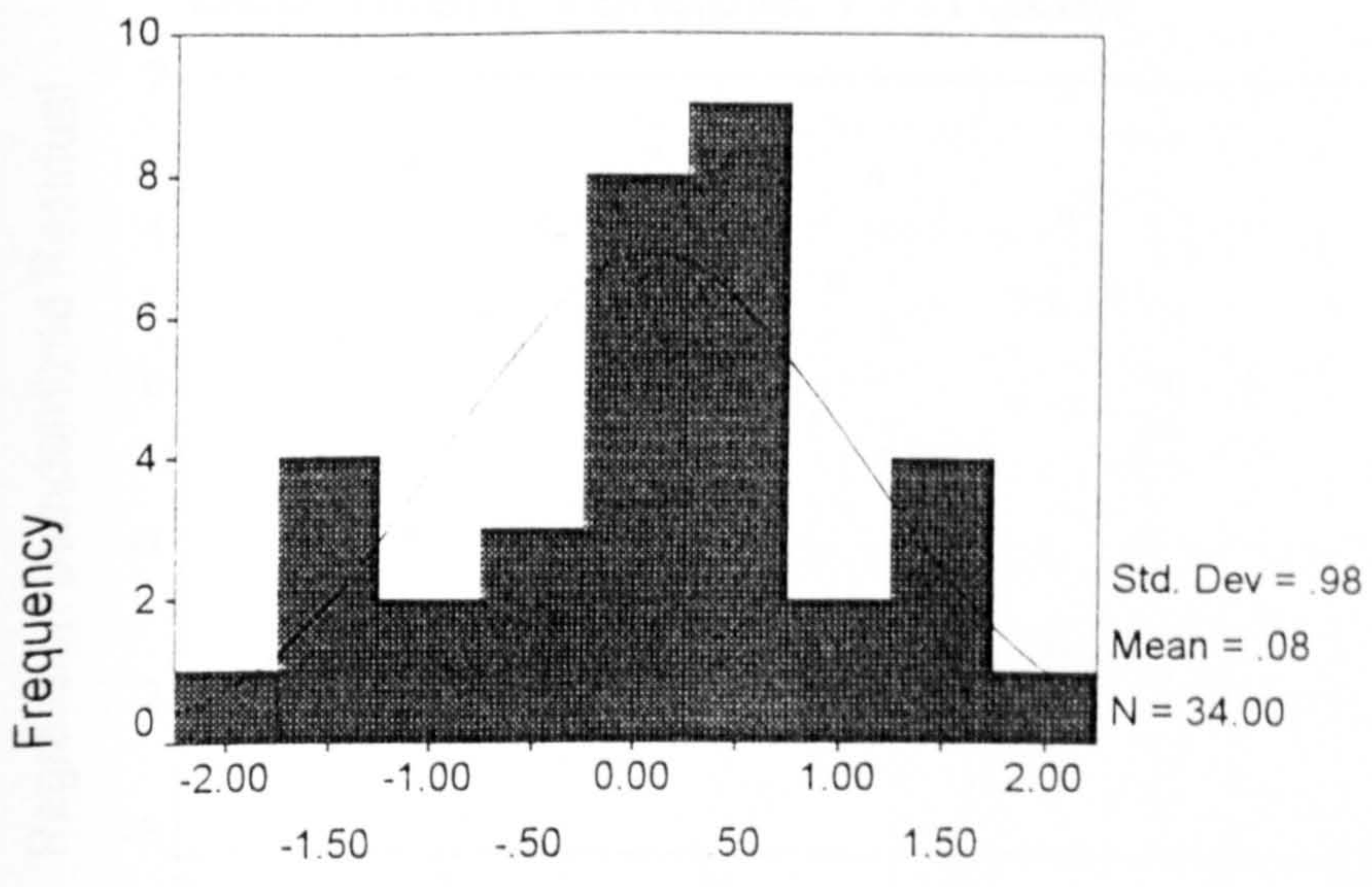
Dependent Variable: MENTSUM



Regression

Histogram

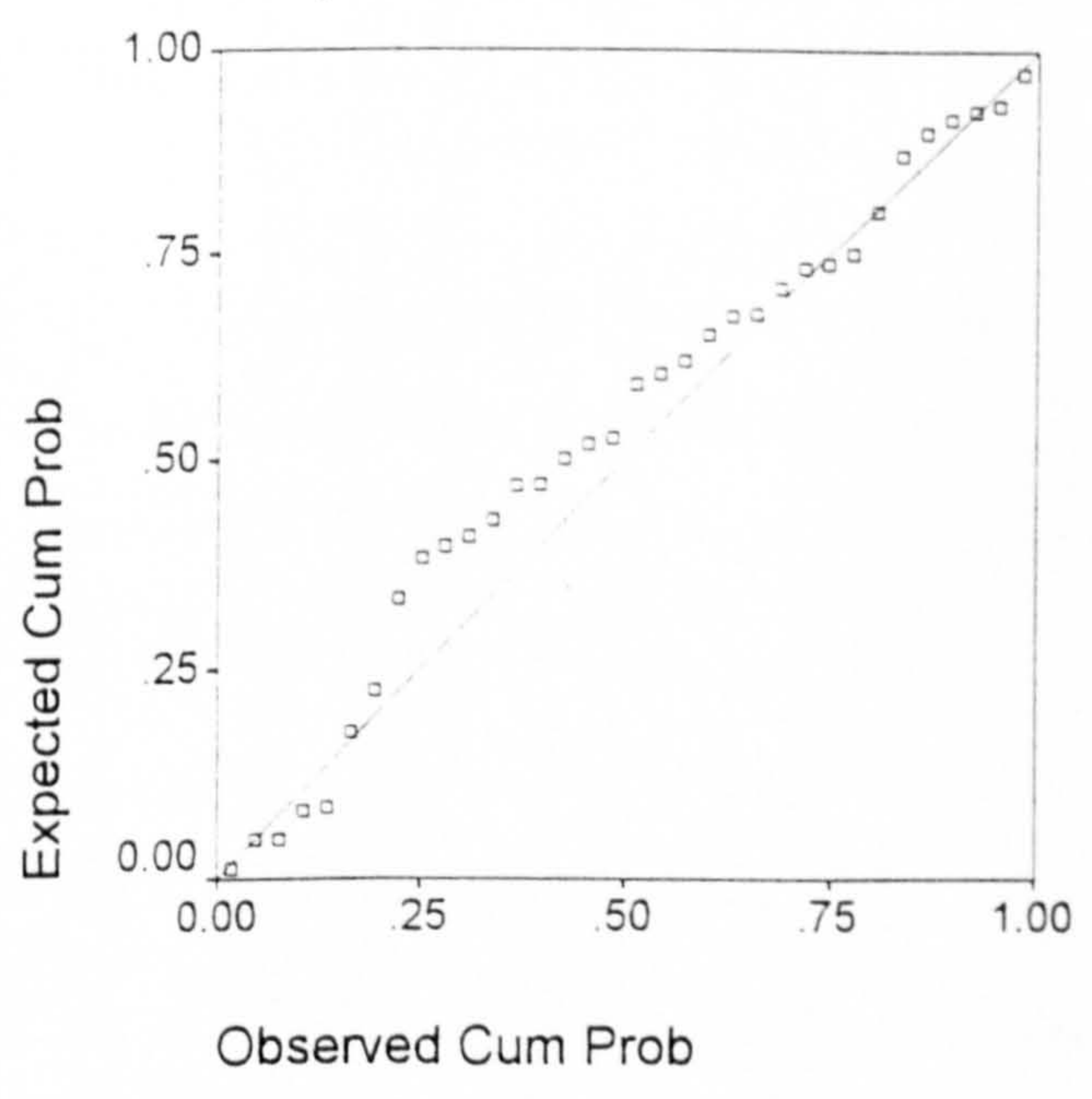
Dependent Variable: PHYSUM



Regression Standardized Residual

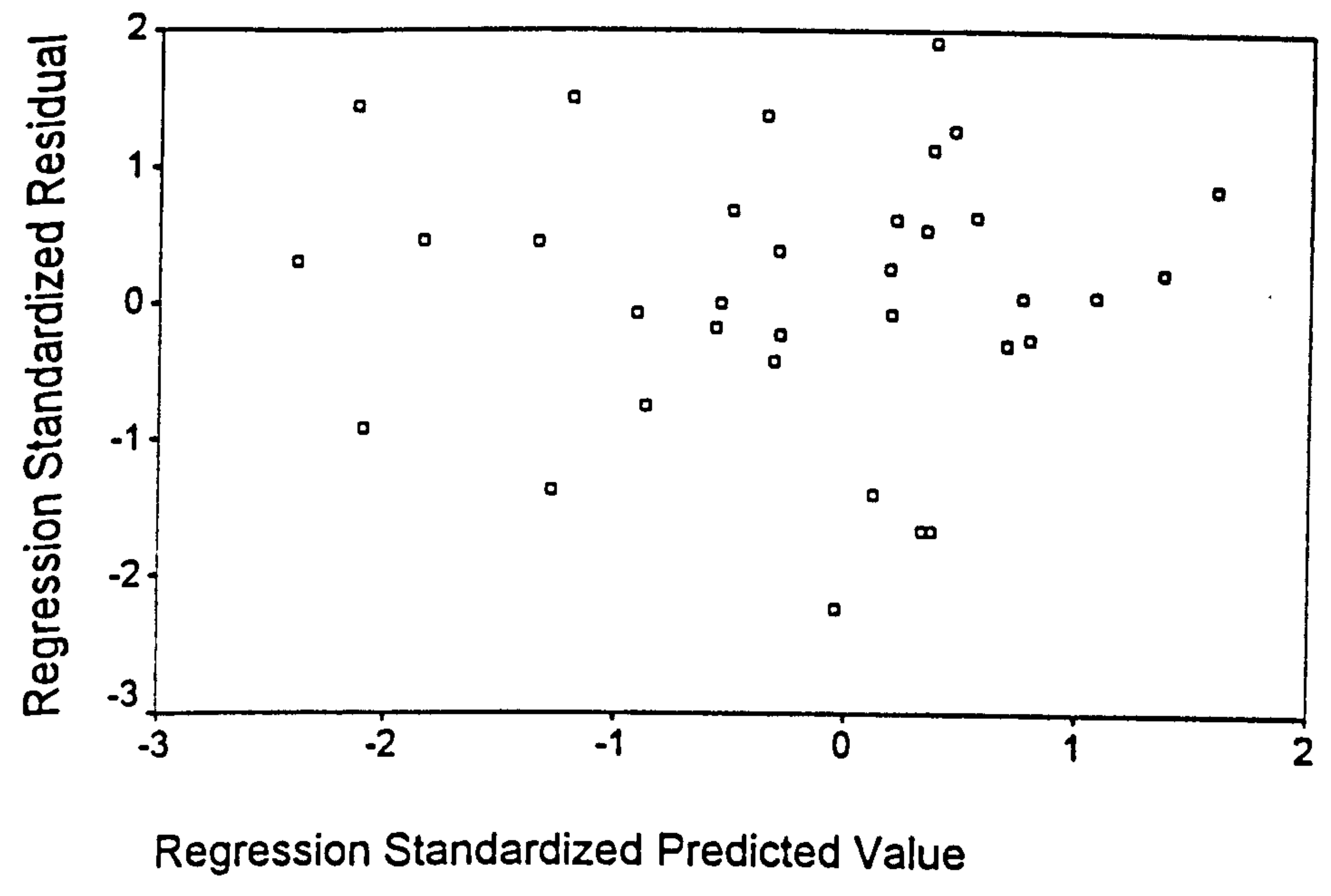
Normal P-P Plot of Regression Sta

Dependent Variable: PHYSUM



Scatterplot

Dependent Variable: PHYSUM



APPENDIX 24

Further quotes illustrating different themes from participants responses to qualitative question 1 : What are the factors which make an HIV positive black African woman more likely to inform another persons of her HIV status.

The progression of one's illness (n= 2).

There was a feeling that once the illness had progressed, disclosure was a preferable option. It was also seen as a likely option in the early stages.

“ You may be more likely to say something if you were really ill and you knew you might be going, if your family was near you might tell them but you might not its not certain.....It is nice if you talk about it, all you think is you are going to die, you don't think of the next minute, you don't know how to cross the road and get to the other side” Lauren

The age of the person being disclosed to (n = 2)

Deciding on the right age at which to disclose to children appeared to be difficult for two participants. One said that the older the child then the more likely the disclosure, although in reality it was felt that there would never be a correct age or time.

“telling your children depends on their age, telling them is a very personal thing.....There will never be an all right time, I think about it a lot with my own daughter It is not a simple fact of saying when they get older I will tell them, I have two older ones and I still haven't told them. There is no right time it will just depend on how you feel at the time”. Isabelle

APPENDIX 24

When you have reached an understanding about HIV in yourself. (n= 2)

Coming to terms with the prospect of a terminal illness that invariably requires adjustment in all areas of one's life must be achieved or at least understood by the sufferer before they are in a position to discuss it, with others.

"Only once I had got used to the idea myself would I even think about telling my partner or anyone. They would be confused if I told them about my illness, when I didn't know much about it myself" Misty

When in need of specific help (n= 2)

It was felt that disclosure would be prompted by a need to receive help and services from another person and without disclosure it may be refused.

"Because they want help, I need help from that person especially when I am sick at night. If I have told them I won't need to explain what my illness is when I am ill and need their help. If I call them when I am in hospital and they know my status, it is easier to know if they would help me, you can't just hope they would help me" Lauren

Miscellaneous

A response from one participant was not appropriately placed into any of the existing themes. Their attendance at a support group was heralded as the important factor in ensuring disclosure.

"Coming to a drop in centre like this one. Before I came here I was so lonely and isolated until I found this group. They, the group changed my life forever. Before I was so scared of anyone finding out about my status about my illness and people knowing. Coming to the group made me start to feel strong in being able to tell others". Betty

APPENDIX 25

Further quotes illustrating different themes from participants responses to qualitative question 2 : What are the factors which make an HIV positive black African woman less likely to inform another person of her HIV status.

Stigma associated with the illness (n = 3)

Three participants felt that the stigma of the illness would definitely make them less likely to tell someone about their diagnosis. Fear of contagion contributed to the stigma. Consequences of the stigma were such that HIV was sometimes compared to cancer, which was felt to draw more favourable responses.

“Some times you feel ashamed, guilty for having it and you keep on asking yourself why me? why not the other person ?why don't I get something else?, Something else like cancer leukaemia, people won't treat those with cancer and leukaemia like they treat those with HIV. They think HIV is a dirty thing and no one wants it” Lauren

Confidentiality (n= 2)

The prospect of having their diagnosis purposefully or inadvertently shared with others they had not intended it to be shared with precludes disclosure.

“If I tell them tomorrow he will leave me and tell the whole world and tell everyone about me being sickyou are scared to tell others because you feel they will tell everyone else, you have no confidence in yourself and think that there is no confidentiality around. ” Lauren.

No purpose or point to the disclosure (n= 2)

The decision not to disclose was because there was no real reason to. They were not in distress and there was not an unwritten code that said they should do.

APPENDIX 25

“You can’t tell everyone why should I tell everyone? I don’t owe anybody.....Just because I am ill does not mean I have an obligation to inform anyone..... some people who are not important to you, so even if you are ill you don’t tell them anything at all.....” Isabelle

Development of illness (n= 2)

The likelihood of disclosure was felt to diminish as the effects of the illness became worse.

“I wouldn’t feel the need to tell someone about my illness if I were getting ill, the exact opposite in fact. It is the people who are healthy who actually come out with it and not those who are sick. When you are ill, you are more likely to say nothing and keep quiet within the Ugandan community. Ella

Miscellaneous (n= 5)

Examples of some of the comments that did not fit neatly into existing theories are presented below. There were comments relating to the need to restrict the actual amounts of information given when disclosing.

“If you tell some people there are some people who would want to know everything about it, its depressing I don’t want to tell them everything about it or how I got it, that brings me back to day one and I don’t want to go there.” Lauren