

Volume 1

The Role of Shame
In
Human Immunodeficiency Virus (HIV) Disclosure

Eleanor Murray

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University College London

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ABSTRACT

Given the increased prevalence of the Human Immunodeficiency Virus (HIV) in the United Kingdom, it is important to examine variables associated with HIV positive individuals' disclosure of their HIV status. This cross-sectional study used both quantitative and qualitative methods to examine the role of shame and other variables in disclosure of HIV-positive status. Sixty-six participants were recruited from HIV out-patient clinics and drop-in centres of voluntary sector HIV services. All participants completed the Experience of Shame Scale as well as standard measures of anxiety and depression.

Highest reported rates of HIV disclosure were to partner(s), followed by disclosure to friends, then family members. Higher levels of characterological shame were associated with increased HIV disclosure to friends, but not to partner(s) or family. Behavioural and bodily shame were not associated with HIV disclosure. The main reason reported for HIV disclosure was a perceived 'Duty to inform', 'Protecting the other person from distress' was the most commonly cited reason for not disclosing their HIV status. In the quantitative study, shame was not reported as a reason for disclosure or non-disclosure.

Increased time since HIV diagnosis was associated with increased disclosure to family and friends. Men made more HIV disclosures than women to friends. Black participants and participants who had English as a second language made fewer disclosures.

Focus groups and semi-structured interviews revealed that some important others in participants' lives were reported to perceive HIV as a shameful illness and for some participants shame was given as a reason for non-disclosure. Some, but not all, participants spoke about being ashamed about not having disclosed their HIV status. Participants reported both self-focussed and other-focussed reasons for disclosing or not disclosing their HIV status. The qualitative study's findings provide additional evidence for the idea that HIV-positive individuals primarily disclose to access support. The focus group and interview participants' main reported reasons for non-disclosure were protecting others from emotional distress, and avoidance of negative consequences for the self, including fear of rejection, discrimination and stigma. These findings support the consequence theory of HIV disclosure.

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CHAPTER 1: INTRODUCTION

Since 1981 when it was identified in the United States (US) (Centres for Disease Control, 1981), Acquired Immunity Deficiency Syndrome (AIDS) has become a worldwide epidemic. This has resulted in significant attention being devoted to reducing the spread of the Human Immunodeficiency Virus (HIV), which is the cause of AIDS. The National Strategy for Sexual Health and HIV (Department of Health 2001), outlines that one of the mechanisms that may help reduce the spread is early disclosure of HIV-positive status by infected parties to significant others. Many factors contributing to disclosure rates have been researched including gender, ethnicity and cultural values, time since diagnosis, and the degree of presentation of symptoms. However, until recently, studies have not focussed on the extent to which psychological variables, such as shame, influence HIV disclosure.

The first part of this chapter outlines the psychological and medical issues surrounding HIV/AIDS, including the consequences to HIV-positive individuals of disclosing or not disclosing to important others. A brief summary of the theoretical approaches to understanding HIV disclosure is provided, followed by a review of the existing HIV disclosure literature. Previous studies have suggested that shame is associated with having HIV/AIDS and also plays a part in non-disclosure of HIV status. The concept of shame is examined and a brief review of the research on shame and disclosure is presented. Finally, the rationale and research questions addressed in the present study are outlined.

1.1. Psychological and Medical Issues Surrounding HIV/AIDS

1.1.1. Human Immunodeficiency Virus

When someone becomes infected with HIV, the virus begins to attack their immune system - the body's natural defence against illness. HIV gradually impairs and destroys cells of the body's immune system (CD4 Lymphocyte cells), progressively destroying the body's ability to fight illnesses, infections, diseases, tumours and certain cancers. This failure in the immune system is called "immunodeficiency".

The normal CD4 count for a healthy individual is between 500-1200 cells. Following initial infection with HIV there is generally a period of good health, where individuals experience no symptoms (HIV asymptomatic), characterised by stable laboratory values such as high CD4 count and low viral load. Individuals are described as being HIV symptomatic when they begin to experience symptoms reflective of CD4 cell destruction. When the immune system is impaired to the point where CD4 cell count drops below 200, individuals are at high risk from life threatening illnesses (opportunistic infections). This clinical situation is known as AIDS - the final stage of HIV infection (Centre for Disease Control, 1993).

The stages of HIV infection are becoming more difficult to identify as more treatment advances are made and as more is learned about the illness. Prior to the introduction of combination therapies, the typical course of HIV was continuous and progressive, with 70% to 80% developing AIDS six to eight years after primary infection. Combination therapies were introduced in 1996 and were designed to prevent HIV replication through multiple methods – addressing the ability of HIV to

rapidly mutate when only one type of medication is used. Following this, the focus of HIV treatment has shifted from delaying to halting disease progression. Assessment of disease progression has also changed from a focus on the presence of opportunistic infections to on-going assessment of both CD4 count and viral load, with the aim of treatment to reduce viral load to undetectable levels and increase CD4 count to within normal limits.

Introduction of Combination Therapies has led to a degree of control over HIV illness symptoms for many HIV-positive individuals. This has subsequently led to HIV-positive individuals remaining well, retaining physical appearances and living longer. This progression has subsequently led to re-definition of HIV/AIDS from a terminal to a chronic, but manageable, illness (McReynolds, 1998).

Individuals living with HIV/AIDS may subsequently continue to be sexually active, or engage in other high-risk behaviours, thus increasing the chances of infecting others. Subsequently the importance and focus towards HIV disclosure has risen in the efforts to suppress the continuing advances of this infection.

1.1.2. Prevalence of HIV Infection within the UK

According to the Health Protection Agency (HPA, 2004), over a ten year period between 1993 and 2003, the number of new episodes of HIV infection reported in the United Kingdom (UK) has continued to rise from 2,627 through to 5,047, representing a 92% increase in HIV infections. Taking a shorter time frame, there has been a 20% increase in new HIV infections in the last year, with 4207 new cases reported in 2002 and 5047 cases reported in 2003.

The highest rates of new infection in the UK in 2003 were found in heterosexuals (55%), followed by men who have sex with men (28%) and injecting drug users (1.5%). According to the HPA the proportion of women diagnosed HIV-positive continues to rise, with women accounting for 445 of all new diagnoses in 2003. 83% of newly diagnosed individuals in 2003 reported being infected by heterosexual partners, who had also been infected through heterosexual intercourse. Furthermore, of these individuals 80% were probably infected in Africa, and 8.5% infected abroad in other countries.

Looking at regional variations, the HPA reports that the HIV epidemic in the UK remains concentrated in London, and the South East, with these regions accounting for 59% of new diagnoses in 2002 and 57% in 2003, with absolute numbers diagnosed in London, continuing to increase each year. The HPA has also highlighted that the highest rise in HIV infections in the UK has occurred in the last three years.

The HPA concludes that the recent rises in HIV infection are related to a general deterioration in sexual health practices and increasing rates of other sexually transmitted illnesses which increases susceptibility to HIV infection. They also note a recent increase in individuals coming forward to be tested for HIV.

From the trends described above, it is clear that the transmission of new HIV infections continues to be a major public health issue in the UK, as rates of new infections continue to grow each year. Heterosexuals, homosexual men and individuals of African origin appear to be most at risk. The risk of infection

continues to be proportionately higher for individuals from these groups living in London.

There is an assumption that HIV disclosure will promote safer sex and reduce HIV transmission rates (Haltkitis, 2000; Kegeles, Catania & Coates, 1998; Marks, Richardson & Maldonado, 1991; Marks, Burris & Peterman, 1999). The National Strategy for Sexual Health and HIV (Department of Health 2001) endorses this, and aims to reduce the number of newly acquired HIV infections in the UK in a variety of ways. This includes making sure services for individuals living with HIV help them deal confidently around issues of disclosure, condom use and safer sex.

1.1.3. Disclosure and HIV Transmission

The importance of disclosure to HIV prevention remains a controversial subject. Currently little evidence exists that HIV disclosure reduces either the amount of unprotected sexual intercourse between individuals of different HIV status or the overall prevalence of HIV infection (King-Spooner, 1999; Summerside & Davis, 2001; de Rosa & Marks, 1998) as cited in the recent Health Development Agency Review Briefing Paper on HIV Prevention (King-Spooner, 1999; Summerside & Davis, 2001; de Rosa & Marks, 1998, all cited in Ellis et al., 2003). However, disclosure of one's HIV status to sexual partners is believed to play an important role in the prevention of new HIV infections, because it informs others of the potential risk of transmission. Still, it is well documented that some HIV-positive individuals do not disclose their HIV status to all of their sexual partners. Kalichman (2000) reports that one in three HIV-positive individuals continues to practise HIV transmission behaviours, including having unprotected sex. Should a sexual partner

unknowingly become infected, he or she in turn may unwittingly go on to infect others. Thus, disclosure is an important component of HIV prevention, because knowing whether a potential sex-partner is HIV-positive may help individuals to make informed decisions and choices regarding their sexual behaviours, such as whether to have sex with a person and whether to use condoms (Rhodes & Cusick, 2000).

Research has shown that HIV disclosure is a major stressor regardless of whether individuals go on to actually disclose their HIV status (McCain & Gramling, 1992). In addition to the stresses inherent in having a chronic and life-threatening illness, HIV-positive individuals may also face potential social and psychological challenges based on their own, other people's and society's reactions to the illness. Reactions to HIV infection are influenced in part by cultural norms and stereotypes and standards about "cultural correctness" of various kinds of sexual behaviours, along with attitudes about drug use that are associated with the transmission of HIV (Pryor & Reeder, 1993; Shilts, 2000).

Research has found that there are a number of potential social and psychological dangers associated with disclosing HIV status. HIV-positive individuals frequently believe that disclosing to their HIV status to sexual partners, friends, family and the wider communities they live in, will be catastrophic and may lead to rejection or abandonment (Green & Sobo, 2000; Marks, Richardson, Ruiz & Maldonado, 1992). These potential social and psychological harms may not only be located in consequences to the HIV-positive individual following disclosure, but may also influence how the HIV-positive individual thinks and feels about themselves.

1.2. HIV Disclosure Theories

HIV disclosure indicates whether an individual has revealed their diagnosis of HIV/AIDS to partner(s), family, friends or significant others in their lives (Chin & Krossen, 1999; Simoni et al., 1995).

1.2.1. Disease Progression Theory of HIV Disclosure

The most commonly held theory of HIV disclosure contends that disease progression triggers disclosure (Babcock, 1998; Hays et al., 1993; Kalichman, 1995). According to this theory, HIV-positive individuals disclose their HIV status as they become ill because when HIV progresses to AIDS they can no longer keep it secret (Babcock, 1998; Kalichman, 1995). States of ill health and the emergence of AIDS related illness can often lead to hospitalisation, which may require explanation. In addition, if death is imminent or HIV-positive individuals perceive that they will need additional support and assistance to manage their illness, they may disclose as a means of accessing emotional and practical support (Holt et al., 1998).

The relationship between disease progression and disclosure has been substantiated in numerous studies using various indexes of disease progression (Hays et al., 1993; Marks, Bundek et al., 1992; Marks, Richardson et al., 1992; Mason, Marks, Simoni, Ruiz, & Richardson, 1995). For example, Marks, Bundek, and colleagues (1992) reported that, in a study of Hispanic men, as overall symptom severity increased, disclosure to others increased. This trend remained consistent for both overt and less overt symptoms as well as various targets of disclosure such as parents and siblings. Using a sample of symptomatic and asymptomatic men, Hays and colleagues (1993) found asymptomatic men were less likely to disclose their HIV status to family and

friends than symptomatic men. Furthermore, disease severity and time since testing for HIV have both been shown to be positively related to disclosure (Mason et al., 1995).

Mansergh, Marks and Simoni (1995) used both time since diagnosis and symptomatology, to investigate the relationship between disease progression and disclosure and found significant differences. That is, rates of HIV disclosure were found to be higher among symptomatic than asymptomatic men and disclosure increased with time since HIV diagnosis. These differences were significant for disclosure to parents, siblings, and friends. These results provide compelling evidence for the disease progression theory.

However, studies of disease progression and disclosure of HIV status to sexual partners, have failed to show this same relationship (Mansergh et al., 1995). For example, Perry and colleagues (1994) did not find a relationship between severity of physical symptoms and disclosure to sexual partners.

However, a critique of this theory is that, with the introduction of combination therapies, HIV-positive individuals who are accessing these treatments are not exhibiting a standard pattern of declining health that was initially associated with a HIV diagnosis. In the light of these changes, disease progression may no longer be a component of the disclosure process.

1.2.2. Consequence Theory of HIV Disclosure

An alternative theory proposes that HIV disclosure occurs after careful deliberation of the perceived and actual positive and negative consequences associated with disclosing one's HIV status.

The consequence theory of HIV disclosure (Serovich, 2001) suggests that the relationship between disease progression and HIV disclosure, is mediated by the consequences HIV-positive individuals anticipate will result from HIV disclosure. Serovich suggests that as HIV illness progresses, stressors accumulate which result in the need to evaluate the consequences of disclosure, and that HIV-positive individuals are likely to disclose their HIV status to significant others in their lives when the rewards of disclosing outweigh the associated costs.

The consequence theory of HIV disclosure employs the core assumptions of social exchange theory. Social exchange theorists maintain that individuals avoid costly relationships and interactions and seek rewarding ones to maximize the profits in their relationships and behaviours (Thibaut & Kelley, 1959). More specifically, when individuals are faced with numerous choices they tend to make those which provide the most rewards with the least associated costs. Rewards are "pleasures, satisfactions, and gratifications the person enjoys" (Thibaut & Kelley, 1959, p.12) and include social, physical, psychological or emotional dividends that satisfy or please. Costs are things of value relinquished in preference for an alternative reward that is of equal or greater value or something that would be punishing or distasteful and would otherwise be avoided.

Support for this consequence theory has begun to emerge from recent work by Derlega and colleagues (e.g., Derlega, Metts, Petronio & Margulis, 1993; Derlega, Lovejoy, & Winstead, 1998) whose research studies have found evidence to support the idea that HIV-positive individuals contemplate the need for privacy, and that they weigh up the risks and benefits involved in disclosing and not disclosing their HIV status. They concluded that HIV-positive individuals disclose to those who pose little risk and avoid disclosing to those who could harm them.

Support for the consequences theory of HIV disclosure was well supported in a sample of HIV-positive homosexual men (Serovich, 2001), which found evidence that rewards and costs of disclosure to family and friends were assessed before disclosure occurred. This theory, however, was found not to be predictive of HIV disclosure to sexual partners.

When reviewing the HIV disclosure literature, it seems clear that HIV disclosure is a difficult task to undertake, but that many HIV-positive individuals are able to disclose to at least one important other in their lives.

1.2.3. Benefits of HIV Disclosure

There is relatively little research available on predictors of HIV disclosure. However, when reviewing the existing HIV disclosure literature, it is clear that there is growing evidence to support that HIV disclosure has major physical and psychological benefits, as well as social benefits.

Social Support and Acceptance

Research has explored the impact of HIV disclosure and non-disclosure on relationships and social support, including obtaining practical assistance with home-related chores, health and childcare as well as support to adhere to medical regimes. Evidence exists that lack of HIV disclosure, may decrease opportunities to access social support from important others in the HIV-positive person's life. Social support has been shown to be an important factor in coping and recovery from chronic physical illnesses (Cohen & Willis, 1985; Cohen, 1988). Consistent with these ideas, studies have found that disclosure of HIV status can lead to important social support which can counteract the negative effects of the stress of having HIV (Hays et al., 1993). Demi et al., (1997) also provide evidence in support of the view that HIV-positive individuals, who do not disclose their HIV status, restrict their access to emotional and practical support that may be necessary to increase their ability to effectively cope with their diagnosis. Furthermore, homosexual men with HIV who are part of strong social networks have shown higher levels of psychological well-being, and lower rates of anxiety and depression, than those who are not (Hays et al., 1993).

There is growing evidence across HIV populations that HIV-positive discloses more frequently to partners and friends than family members. Hays et al. (1993) report that HIV-positive individuals prefer to access support from partners and friends rather than 'burden' their families with their HIV status. Other studies of HIV-disclosure patterns also highlight that HIV-disclosure is a selective process in where partners and friends tend to be more frequently disclosed to than family

members (Marks et al., 1992; Mason et al., 1995; Petrak, Doyle, Smith, Skinner & Hedge, 2001; Simoni, et al., 1995).

Gaining Access to Medical Treatments and Therapies

Research also suggests that HIV disclosure to health care providers, grants HIV-positive individuals access to medical treatments such as combination therapies which extend life expectancy. Conversely, if HIV-positive individuals choose not to disclose their HIV status, the process of keeping the diagnosis secret can interfere with accessing medical assessment, care and treatments, which may have direct effects on disease progression, leading to a significant decline in physical health (Cole, Kemeny, Taylor, Visscher, & Fahey, 1996; Holt et al., 1998). Although disclosure to health professionals is especially important, recent research findings suggest that this is not an easy thing to do. Several studies have shown that not all HIV-positive individuals have been able to disclose their HIV status to health professionals or dentists (Barnes, Gerbert, McMaster & Greenblatt, 1996; King 1989; Perry et al., 1993; Robinson, Zacherzewska, Maini, Williamson & Croucher, 1994; Yeddia, Barr & Berry, 1993).

Psychological Well-Being

Gaining an HIV-positive diagnosis exposes individuals to affective changes and varying degrees of emotional distress (Nott & Vedhara, 1999). There is some evidence to suggest that HIV positive individuals are more prone to experiencing high levels of anxiety and depression (Hays et al., 1993). In addition, it has been shown that emotional distress and tension adversely influence HIV disease progression (Herbert & Cohen, 1993) and that keeping one's HIV status secret from

significant others causes physical and psychological tension (Stein et al., 1998; Mansergh et al., 1995; Hays et al., 1993). Mansergh and colleagues (1995) claimed that non-disclosure of an HIV diagnosis heightens levels of anxiety and stress experienced, while Caulfield Cary and Mason (1994) suggest that lower rates of HIV-disclosure to employers are also associated with increased levels of anxiety and stress. Studies have also shown that when HIV status is not disclosed, HIV positive individuals can feel anxious, isolated and depressed (Van Dervanter, Thacker, Bass & Arnold, 1999). Timewell (1992) also states that secrecy and non-disclosure of HIV status is associated with psychological isolation and depression. Moneyham et al. (1996) provide further evidence for HIV non-disclosure being linked to depression. They found that HIV-positive women who had not disclosed that they were HIV-positive were at greater risk of becoming depressed. Disclosure of HIV status has also been shown to be related to improvements in psychological well-being. Consistent with this idea, Hays et al. (1993) longitudinal study of gay men's patterns of HIV disclosure, provides evidence that disclosure of HIV status to individuals who respond well to the disclosure, is linked with reduced levels of anxiety and depression experienced immediately and 1 year following disclosure. Kalichman and Nachimson (1999) in a community study of HIV positive men and women, also report that HIV disclosure leads to reduced rates of emotional distress, anxiety, depression and increased quality of life in comparison to individuals who had not disclosed. Evidence also exists that HIV-positive women who choose to disclose their HIV status with a confidant or a partner experience significantly lower levels of emotional distress than those who choose to keep their HIV diagnosis a secret (Armistead, Morse, Forehand, Morse & Clark, 1999; Smith et al., 1996). Hence it appears that levels of psychological distress and HIV disease progression

experienced may be influenced by HIV-positive individuals decisions to disclosure or keep secret their HIV status. More specifically, we may hypothesise that lower rates of increased HIV disclosure in the current study will be associated with increased levels of anxiety and depression.

Health Benefits from Disclosure

Two theoretical approaches have emerged in an effort to develop a better understanding of possible relationships that exist between disclosure and non-disclosure of emotionally traumatic experiences and health. These are the “non-expression approach” and the “expression-approach”. According to the “non-expression approach”, people who inhibit their emotions are more prone to disease than individuals who are emotionally expressive (Alexander, 1952; Freud, 1917/1957; Gross & Levenson, 1997; Scheff, 1979).

However, more directly relevant to the present study is the recent research which has focussed on the “expression approach”, exploring the beneficial health effects of disclosing emotionally personal experiences. Pennebaker and Beall (1986) initially speculated that there was a connection between inhibition of emotions and physical and psychological health.

According to Pennebaker’s inhibition theory (e.g., Pennebaker, 1989; Pennebaker & Hoover, 1986), keeping emotionally traumatic experiences secret involves inhibiting or holding back one’s thoughts, feelings and behaviours associated with the non-shared emotion. Pennebaker suggests that this inhibition of felt emotions requires physiological work, in the form of increased physiological activity and autonomic

nervous system arousal, as evidenced via increased skin conductance and heart rates (Pennebaker, Hughes & O' Heeron, 1987). If active inhibition of emotion occurs over long periods of time, it is argued that this will place more stress upon the body and increase the probability of disease and illness occurring (Pennebaker, 1989, 1997). Pennebaker's inhibition-confrontation model (Pennebaker, 1982; Pennebaker & Beall, 1986) goes onto explain why beneficial effects occur following disclosure of emotional experiences. According to this model, active confrontation of traumatic emotional experiences activates cognitive processing and gives insight into the meaning of these experiences, helping individuals to develop a sense of mastery and control over the traumas experiences (Pennebaker, 1989, 1990). Decreased trauma specific ruminations and inhibition of these then occur and it is presumed that their reduction brings about psychological and physical health benefits.

In order to test the validity of his inhibition-confrontation theory, Pennebaker developed a specific paradigm, which involved participants writing about various personal experiences. This writing task typically consists of writing openly for around twenty minutes on three consecutive days about a trauma or an emotionally stressful experience. In the control condition, participants write about superficial topics, such as their plans for the day.

More recently, a number of empirical studies have explored the value of writing and talking about emotional experiences. Variations exist in the method of inducing writings but all studies have the common goal to test the power of disinhibition (e.g., Pennebaker & Susman, 1988; Smyth, 1998).

Evidence for the inhibition model and stress-related illness has come from a variety of sources. Empirical studies have consistently found that not disclosing emotionally traumatic experiences is correlated with a variety of health problems among college students and adult samples (Pennebaker & Susman, 1988). In addition, a meta-analytic review of thirteen intervention studies in which healthy adults wrote about their thoughts and feelings about stressful and traumatic experiences, provides support for the idea that disclosure is associated with improvements in physical and psychological well-being in comparison to controls (Smyth, 1998).

Most pertinent to the current study is the research by Cole et al. (1996), which indicates that homosexual men who conceal their homosexual status are more likely to suffer from a major illnesses such as cancer if they are HIV-negative, and to die more quickly from AIDS if they are HIV-positive, than men who are more open about their homosexuality. Also, emotional inhibition, of which non-disclosure is an exemplar, has been shown to have adverse effects on immune functioning, including lower T-cell counts and antibody response (Pennebaker, Keicolt-Glaser & Glaser, 1988; Petrie, Booth & Pennebaker, 1998).

Although the evidence for the model is largely supportive, several limitations in empirical studies have been noted. A brief overview of the limitations of this disclosure paradigm are presented.

Smyth (1998) in his meta-analysis noted that all thirteen intervention studies reviewed differed in the type and gender of samples used, the nature of instructions priming emotional disclosure, the setting within which the expressive writing task took place, and the duration of the writing task. Of note, most previous research in

this area has involved healthy participants and whether inhibition and disclosure are associated with disease outcomes in healthy samples.

In addition, the choice of topic to be disclosed may also have influenced results obtained. For example, writing about starting college influenced grades more than writing about traumatic experiences for first year college students (Pennebaker, 1997a). There is also some evidence that some types of traumatic experiences may benefit from being disclosed more than others. Stroebe, Stroebe, Schut, Zech, and van den Bout (2002) failed to find benefits of emotional disclosure through writing for bereaved adults.

A further limitation noted across empirical experiments is the use of differential definitions of the constructs studied. Emotional non-expression has been conceptualised either as a deficit in emotional processing (Taylor, Bagby & Parker, 1997), or as a conscious attempt to suppress thoughts and feelings, due to fear of social repercussions (Pennebaker, 1989). Similarly, emotional expression has been defined as a spontaneous venting of negative emotions (Berkowitz, 1982) or as a cognitive process involving verbalisation and communication of inner emotional states (Pennebaker, 1993; Pennebaker and Francis, 1996).

Finally, disclosing as part of an experimental disclosure study may be quite different from the way in which, individuals normally socially exchange personal information or talk to important others in their lives about emotionally traumatic experiences. In the context of a disclosure study, participants are not seeking or receiving emotional support, and are not receiving concrete feedback from the listener. In that way, disclosure studies are not related to true interactions in that there is no two-way

interaction possible. Consequently, writing and talking about traumatic experiences in laboratory settings are not comparable with individuals' real-life experiences of disclosing personal information.

1.2.4. Costs of HIV Disclosure

Rejection, Abandonment and Isolation

Negative emotional consequences have been documented to be linked with HIV disclosure. These have included rejection, abandonment, and isolation (Lovejoy, 1990; Stulberg & Buckingham, 1988; Zuckerman & Gordon, 1988.) Other consequences external to the HIV-positive individual include fear expressed by others and bigotry.

Gender and Risk of Threat and Violence

For HIV-positive individuals, gender and risk of sexual threat and threat of or actual physical abuse also appear to be linked to HIV disclosure decisions. Although research in this area has typically contrasted populations of gay men with heterosexual men and women, evidence exists that men are more likely to disclose their HIV-positive status than women (Buckingham & Rehm, 1987; Simoni et al., 2000). Simoni et al. (2000) suggest that this gender difference in HIV-disclosure exists because: "It is probable that the expected costs of HIV-disclosure such as abandonment and violence counter the more usual tendencies for women to reveal intimate information" (P. 148). van der Straten et al. (1998) in their HIV-disclosure study provide evidence that a male's partner's knowledge of a woman's HIV-positive diagnosis is associated with coercion to have sex or anger and violence towards HIV-

positive women who deny sexual intercourse. This fear of violence has also been described in many studies by HIV-positive women as another potential cost of disclosing and as a reason for not disclosing a HIV-positive diagnosis (Armistead et al., 1999; Brown, Melchior, Rebak, & Huba, 1994; Gielen, O'Campo, Faden, & Eke, 1997; Kimerling, Armistead, & Forehand, 1999; Rothenberg & Paskey, 1995, van der Straten et al., 1998). Only one study has found no association between HIV disclosure and physical abuse directed at women (Vlahov et al., 1998).

Stressors within the Family Network

Costs in terms of stressors within the individual's family network, such as denial, anger, guilt, and uncertainty have also been reported to be associated with HIV disclosure (Frierson, Lippman, & Johnson, 1987; Herek & Glunt, 1988; Macklin, 1988). Bor, Miller & Goldman (1992), on reflection of their family-systems work with HIV positive individuals in the UK, propose that keeping a HIV diagnosis a secret, may be a solution for many HIV positive individuals, as doing so may reduce opportunities of being shunned and reduce the possibility of social alliances and support networks being weakened or destroyed.

Cultural Factors

Studies outside of the UK suggest that cultural factors in the form of ethnicity, and whether HIV-positive individuals have English as their second language, can further exacerbate the difficult task of disclosing an HIV positive diagnosis. A number of studies have suggested that ethnic minority groups disclose their HIV status less so than European Americans. For example, Mason et al. (1997) found that African-American men, independent of sexual orientation, were less likely to disclose their

HIV status to partners, friends and family than European American men. Other studies reporting lower rates of HIV-disclosure in African Americans and Latino's in comparison to European Americans include (Armistead et al., 1997; Mason et al., 1995; Simoni et al., 1997). While Stein et al.(1998) found that European Americans and Latino's disclosed more to partners than African Americans. Marks et al. (1992) & Simoni et al. (1995) also provide evidence that having English as a second language influences HIV disclosure patterns. In both these studies Spanish speaking Latino men and women living in the United States were less likely to disclose their HIV-positive status to significant others than English speaking Latino's and White European Americans.

Disclosure of Personal Information and Loss of Privacy

Information about HIV diagnosis and status is perceived as private or secret information and revealing it can be associated with feelings of vulnerability and loss of control. The strength of relationship between an individual and an important other in their life influences the decision to disclose and the extent of control the important other is given over this sensitive information. Petronio (2002) describes how disclosure of private information is regulated by rules that determine who is a target of disclosure and when, and how much they are told.

Concealment, Disclosure and Shame

Despite the possible advantages of disclosing one's HIV status, when reviewing the literature on HIV disclosure, it is clear that discussing HIV status is not easy and that the decision to hide or reveal one's HIV status is a complex decision, perceived to involve risk. Silver, Wortman & Grafton (1990) noted that individuals who experience negative life events often have the best chance of adjustment by revealing their secret, but they also "risk alienating their social network" (pp. 401). Harber & Pennebaker (1992) also talk about the dilemma of whether or not to disclose personal information as a "cruel paradox" (pp. 360). Often individuals long to share a trauma or a secret with another, yet fear being rejected or alienated by the listener. The concept of a cruel paradox may be especially salient with regards to HIV disclosure (Hays et al., 1993). Consistent with this idea, Limandri (1989), found that HIV-positive individuals with other sexually transmitted illnesses were confronted with a need to tell or conceal. According to Limandri, the contradictory nature of HIV disclosure is due to the fact that the HIV is a stigmatising condition, and that the stigma attached to being HIV-positive generates feelings of shame and the wish to conceal or hide. However, those HIV-positive individuals who experience feelings of shame also often need to confide in others and seek help. In the present study, it is hypothesised that holding the secret of being HIV-positive would be emotionally traumatic for some individuals and would involve experiences of shame, and attempts to inhibit this self-conscious emotion would be associated with reduced HIV disclosure.

1.3. Shame Theories

In order to understand the possible role of shame in HIV diagnosis, and HIV disclosure and non-disclosure, one must first have a thorough understanding of the nature of shame. As summarised by Gilbert (1998) numerous theories of shame have been proposed from various theoretical perspectives.

1.3.1. Psychoanalytic Viewpoints

Historically, shame was first conceptualised from psychoanalytic viewpoints beginning with Freud (1909/1955, 1917/1957, 1924/1961). However, Freud devoted far more attention to the pathological implications of guilt, whereas shame held only a marginal place in his theory as it was subsumed under the umbrella of guilt (Gilbert, Phel & Allan 1994; Tangney, Wagner & Gramzow, 1992). More recently, shame has assumed a more prominent role in psychoanalytic theory, with the introduction of H.B. Lewis's theoretical account of different roles of shame and guilt in psychopathology (Lewis, 1971).

Central to H.B. Lewis's theory is the belief that shame is a state of devaluation that involves self-consciousness and self-imagery. H.B. Lewis's theory suggests that shame arises out of, and in part is caused by, loss of approval from a significant other, which leads to thoughts about self-devaluation which, in turn lead the individual to experience feelings of shame.

1.3.2. Affect Theory

In contrast to H.B. Lewis's (1971) theoretical model of shame, Sylvan Tomkins's Affect theory (1987), which has been elaborated on by both Nathanson (1994) and

Kaufman (1996), is based upon the central idea that shame is one of nine innate human emotions that are elicited as a natural consequence of specific actions (Tomkins, 1987). Tomkins's theory of shame uses the idea of an automatic elicitor, one that does not require thought to activate the experience of shame. Tomkins's automatic eliciting event is any event that inhibits interest and enjoyment:

“Shame is an innate auxiliary affect and a specific inhibitor of continuing interest and enjoyment. The innate activator of shame is the incomplete reduction of interest or joy” (Tomkins, 1963, p.123). Tomkins (1987) viewed affects such as shame as central to motivation development. However, Tomkins's theory does not consider shame from the point of view of violating social norms.

1.3.3. Affect-Cognitive Perspectives

Affect-cognitive perspectives of shame have been developed by theorists such as Lewis (1992), and they view the emotion of shame as arising from self-evaluation in which the self does not meet the self's own standards. From this perspective, shame can be defined as an intense negative emotion that stems from an individual experiencing failure in relation to meeting their personal or other people's standards, feeling responsible for that failure, and believing that this failure represents a defective self (Lewis, 1995). Lewis, in discussing shame states that shame does not exist at birth, but rather develops over time and that through interpersonal relationships with others in the first three years of life, the capacity for conscious awareness of the self develops. Lewis, proposes that it is only when this objective self consciousness is by specific cognitions about 1) standards, rules, and goals; 2) one's own behaviour with regards to these standards; and 3) oneself that shame can

occur. Lewis argues that it is the evaluation of standards and secondary cognitive evaluative processes that serve as a stimulus for self-conscious emotions. Lewis's model suggests that standards more central to the definition of the self are more likely to lead to shame. What constitutes a more central or peripheral standard is defined by the individual as well as by partners, friends, family, and the wider cultural communities and societies in which they live. Lewis suggests that shame is elicited as a consequence of a failure of an evaluation relative to the standards, when the individual makes a global evaluation of the self as opposed to specific aspects of the self.

1.3.4. Psychobiological Perspectives

In addition to psychoanalytic perspectives, affect theory and cognitive affect theories of shame, recently shame has been studied by psychobiologists and evolutionary theorists, who are exploring such questions as whether shame's psychobiological mechanisms are of relatively recent origin or whether shame is an older evolutionary mechanism (Gilbert & McGuire, 1998). Gilbert (1998) further suggested that shame could be examined not only in terms of emotions, cognitions and beliefs about the self and behaviours, but also in terms of evolved mechanisms and interpersonal relationships. Gilbert suggests that shame is related to the evolved need for social attractiveness. The evolutionary root of shame is in a self-focussed, social threat system related to competitive behaviour and the need to prove oneself as acceptable/desirable to others (Gilbert, 1989; 1997). Gilbert relates shame to the competitive dynamics of life, and links shame with social standing and personal reputations (Gilbert, 1997). Gilbert (1989, 1997) suggests that humans track their social attractiveness to others by calculating their social attention holding power

(SAHP). SAHP is seen to mediate shame, and can be positive (attracting positive attention/interest from others, stimulate positive feelings in others, with low risk of criticism or ostracism), or negative (attracting negative attention, stimulate negative feelings in others such as contempt, anger, or fear with a high risk of criticism or ostracism). SAHP can also be internal or external. Internal SAHP is related to our own attention to the self (things about the self we attend to but do not like). External SAHP is related to closely monitoring what is seen as attractive (useful) to the self and others, while Internal SAHP is related to feelings of personal pride or shame. Individuals are highly motivated to avoid negative SAHP and obtain positive SAHP.

Although shame requires a symbolic sense of self (Lewis, 1992), from an evolutionary perspective, it is seen to also be regulated by social threats and automatic defences to protect the self from threats posed by others (Gilbert, 1997). Indeed, there is now evidence that shame acts as an inner warning signal, alerting the individual to impending threat to the self and rejection by the surrounding environment, with a triggering of automatic defences especially the desire to escape (flight), submissive behaviour (Keltner & Harker, 1998), anger (Tangney et al., 1996), and concealment (MacDonald & Morley, 2001). Shame is explained as involving feeling looked down upon or inferior in the eyes of others, that results in the self feeling impaired, profoundly helpless and powerless (Gilbert, Phel & Allan, 1994; Tangney et al., 1996). Gilbert (1992) considers shame to have an evolutionary protective role, suggesting that as a transient signal state, shame alerts the individual to impending threat to the self and rejection by the surrounding environment. Gilbert suggests that even brief intense feelings of shame can be functional, such as when

intense feelings of shame result in submissive and appeasing behaviour, which might help people to survive in abusive situations (e.g., Gilbert & McGuire, 1998).

1.3.5. Tripartite Conceptualisation of Shame

In contrast to the above conceptualisations of shame, Andrews (1998) suggests that an individual may be ashamed of independent parts of themselves only, such as their character, behaviour or body, rather than globally evaluating the self as shameful and no good. Andrews' conceptualisation of shame is based on Janoff-Bulman's influential distinction that negative judgements can be directed at one's behaviour and one's character (Janoff-Bulman, 1979). Andrews and colleagues constructed the Experience of Shame Scale (ESS: Andrews, Qian & Valentine, 2002). In contrast to other shame measures, in which scores are based on global self-descriptions (ISS: Cook, 1988, 1989, 1993; OAS: Goss, Gilbert & Allan, 1994), in the ESS respondents are asked direct questions about whether they have felt ashamed about particular aspects of themselves (body, character and behaviours). Thus the ESS does not rest on the assumption that shame prone individuals will have generalised shame, but rather that there might be particular aspects of themselves about which they experience feelings of shame. The underlying assumption is that an individual may report feelings of shame about one or more aspects of themselves, but does not necessarily feel ashamed of all aspects of themselves.

1.4. Empirical Studies

1.4.1. *Empirical Studies of Shame and Disclosure*

Anticipated Shame and Emotional Disclosure

Recent research has suggested that shame may play a role in the non-disclosure of negative emotional experiences generally. There has been a considerable body of research in recent years which has demonstrated that people benefit from disclosing disturbing experiences to others (e.g., Pennebaker & Beall, 1986; Pennebaker, 1993). Explanations of this phenomenon have concentrated on two intrapsychic factors. First, it is assumed that undisclosed emotions require inhibition which is effortful and therefore costly to the individual (e.g., Traue, 1995). Secondly, the benefits are thought to reflect the extent to which disclosure facilitates the assimilation of the disturbing experience (e.g., Pennebaker & Francis, 1996).

This process of cognitive assimilation has also been invoked to explain the mechanism of emotional change in psychotherapy (Stiles, Meshot, Anderson & Sloan, 1990). However, as Kelly & McKillop (1996) have pointed out, so far there has been little attempt to map out the social dimensions and implications of disclosure, perhaps because much of the literature to date has involved written disclosure that takes place when the participant is alone (e.g., Pennebaker & Beall, 1986). Kelly and McKillop (1996) make the point that disclosure does not usually take place in a social vacuum and that the qualities of the recipient of the disclosure are unavoidably central in evaluating the benefits of disclosure. Kelly & McKillop (1996) survey a range of studies which suggest that in a great many instances recipients of disclosures may react in ways that are damaging to the discloser. For

instance, they cite research that suggests that people who have experienced traumas are likely to receive unsatisfactory responses when they relate their experiences to others; and they point out that because people construct their identities with interactions with others, in such cases disclosure could lead to the construction of a negative identity. This more social perspective on disclosure implies that social emotions such as shame may influence disclosure and non-disclosure.

Work by Finkenauer and her colleagues (Finkenauer & Rime, 1996; Finkenauer, Rime & Lerot, 1996, both cited in Macdonald, 1998), suggests that social emotions of shame and guilt do indeed play an important role in the inhibition of emotional experiences that are not socially shared. Finkenauer and Rime (1996) aimed to examine factors which might underlie the non-disclosure of the 10% or less of emotions which, according to the literature on social sharing (Rime et al., 1991; Rime et al., 1996, both cited in Macdonald, 1998), are not disclosed to others. They asked participants to recall an important emotional episode that they had never told anyone and one which they and shared with another person. They found that emotional secrecy was not associated with the degree to which secret episodes elicited shame, guilt, and perceptions of responsibility. On the basis of these results, the authors proposed a social model of secrecy, in which non-disclosure of emotional experiences was hypothesised to result largely from the projected personal and interpersonal consequences of the disclosure.

Finkenauer et al. (1996), (Finkenauer et al., 1996, cited in Macdonald, 1998), explored this idea in a study in which participants were interviewed following an induction, in which they were asked to imagine either an important negative event that they would have kept secret or one they would have shared. Results indicated

that compared with the shared emotional experience the secret one was associated with the perception of social threat. Furthermore, in the sharing condition the anticipation of sharing the secret elicited significantly more shame, guilt, embarrassment, and unease in participants the first time they shared their emotional event. In these studies, non-disclosure was associated with shame evoked by anticipation of disclosure.

In Macdonald et al.'s (1997) diary study, (Macdonald et al., 1997, cited in Macdonald 1998) participants who had not disclosed an emotion were asked the question, "did the thought of telling anybody make you feel any shame?" Results indicated that a very high proportion, 91% (10 of 11 undisclosed episodes), of the responses to this question were positive when the emotion itself was shame. However, 73% (8 of 11) of the instances of undisclosed hatred, 67% (12 of 18) of instances of undisclosed guilt, and 55 (6 of 11) of the instances of undisclosed disgust were also accompanied by feelings of shame. This suggests that anticipatory shame may have played a part in over half of the undisclosed instances of guilt, hatred and disgust. Participants were also asked questions in the follow-up interviews about why they had chosen not to disclose. Qualitative data for these interviews are consistent with Finkenauer's social model of secrecy. Thus, references to shame and embarrassment about the experience, such as "I felt ashamed of the way I felt", were accompanied by many references to how the participants imagined disclosure of their emotions would have on negative interpersonal consequences (Macdonald et al., 1997, p.13).

These studies illustrate that shame associated with perceived interpersonal consequences of an action is associated with the inhibition of this action (in this case

the disclosure of emotional experiences). This idea is highly congruent with both Goffman's (1959, 1963) analysis of dealing with destructive personal information and Tomkins's (1963) model of shame acting "at a distance" in order to pre-empt higher intensity experiences of shame. These studies also supplement the existing literature on the dynamics of disclosing negative emotional experiences, by emphasising the role perceived interpersonal consequences of disclosure, including shame costs and benefits, play in disclosure decisions. It has been suggested that the increased cognitive organisation and narrative coherence that has been associated with beneficial disclosure (Pennebaker, 1990; Pennebaker & Francis, 1996), may also be related to the degree to which the participants become able to disclose their experiences. H.B. Lewis, (1987), suggests, that if individuals disclosure does justice both to the actual events experienced and to the survival of their identity, then shame or guilt may not be experienced.

1.4.2. Relationship between Shame, HIV Diagnosis and HIV Disclosure

There is a body of evidence indicating that cognitive and emotional experiences of shame and stigma, are crucial in influencing individual and interpersonal responses in coping with receiving a diagnosis of a sexually transmitted disease (e.g., Fortenberry et al., 2002, Dixon-Woods et al., 2001).

Recent research has linked shame with HIV in a variety of ways. Fortenberry et al. (2002) reported that shame can be a significant barrier to accessing diagnostic and treatment services for HIV. Shame has also been found to be associated with the source of HIV infection in women from ethnic minorities, especially where transmission is thought to have occurred through sexual behaviours (Wyatt and Chin,

1999). Shame can also affect identity and how individuals perceive themselves. Serovich and Mosack, (2003) found that HIV-positive homosexual males in the United States, who had not disclosed their HIV status, were most likely to endorse the statement “I felt ashamed about being HIV-positive”.

1.4.3. Other Studies Measuring Levels of Shame

None of the above studies that explore the possible relationship between shame and HIV disclosure, appear to have been informed by existing shame theories or have used a common shame measure, for example, the Test of Self-Conscious Affect (TOSCA: Tangney, Wagner & Gramzow, 1989), the Internalised Shame Scale (ISS: Cook, 1988, 1989,1993) or the Experience of Shame Scale (ESS: Andrews, Qian & Valintine, 2002). In these studies the level of shame experienced has been explored through qualitative, semi-structured interviews (Chin & Kroesen, 1999), by asking participants to rate the intensity of their emotions on a 4-point scale (Cunningham, Tschan, Gurvey, Fortenberry & Ellen, 2002), or by asking participants to complete a ‘reasons for HIV non-disclosure’ scale, adapted from Derlega et al. (1997), that included one shame item (Serovich and Mosack, 2003).

As indicated above, a review of the existing literature has revealed no studies that attempted to empirically investigate whether an association exists between shame and HIV status and/or HIV disclosure. However, a number of studies have investigated associations between shame and various psychopathologies using standard measures of shame. Topics addressed included symptoms of depression (e.g., Allan, Gilbert & Goss, 1994; Tangney et al., 1992), anxiety (Tangney et al., 1992), social anxiety (Gilbert, 1998), bulimia (Andrews, 1997), eating disorders

(Swan & Andrews, 2003) and post-traumatic stress disorders at intervals after experiences of crime (Andrews, Brewin, Rose & Kirk, 2000). Gilbert and Gerlsma (1999) report a number of further studies that provide evidence for associations between shame and a number of other psychopathologies, including personality disorders and suicide.

1.5. Limitations of Shame Theories and Measures

1.5.1. Definitional Issues

Given the numerous theories and diverse perspectives, there is not a widely accepted definition of shame. There has also been a longstanding debate about the differences between, and the extent to which it is possible to differentiate shame, and the related emotions of guilt, embarrassment, humiliation, and self-esteem.

Shame and Guilt

There is general agreement that shame and guilt are distinct constructs that differ along affective, cognitive, and behavioural dimensions. Several theorists however, have not distinguished explicitly between shame and guilt. Because shame and guilt share a number of features, they are often confused with each other and their terms are frequently used interchangeably. Tomkins (1984) and Kaufman (1996), whose work follows Tomkins's, maintain that guilt is a variant of shame, rather than a discrete emotion. Specifically, Tomkins asserts that shame and guilt arise from a common biological basis, but are differentiated on the basis of their cognitive distinctions. In addition, some authors have reported holding the belief that the distinction between shame and guilt is irrelevant, particularly for clinical populations

(e.g., Cook, 1996). According to Lewis (1971), shame and guilt can co-occur and, in fact, one may mask the other. Lewis describes how the affective aspect of the shame experience may be by-passed, for example, experienced as a wordless jolt or shock, and followed by guilty ideation about the self from the perspective of the other. As a result, by-passed shame, it is argued, could be indistinguishable from guilt. Shame may also become absorbed or submerged by or fused with guilt (Erikson, 1963). Tantom (1998) also considers that guilt and shame are alike, apart from guilt not being associated with hiding. Lewis (1971) suggests that the main way in which guilt and shame differ is that while guilt can only occur as a result of one's behaviour, shame can occur as a result of one's character, body or behaviour.

More recently, evolutionary psychologists, including Gilbert (1989; 1997), have also proposed that shame and guilt are in fact two distinct concepts. Gilbert suggests that the root of shame is self-focused, and derives from assessing our behaviour in situations of threat and is related to protecting the self and the need to prove ourselves acceptable and/or desirable to others (Gilbert, 1989; 2002). Guilt however, is considered to be evolved from a care-giving and avoiding doing harm to others. (Gilbert, 1998). Guilt in contrast, is considered to be a highly adaptive evolved psychological mechanism, which, unlike shame, is rooted in empathy and promotes action to take responsibility to try and relieve the other's discomfort. Guilt unlike shame serves to maintain social ties and relationships.

Shame and Embarrassment

Evidence exists that shame and embarrassment are distinct constructs. Shame is linked with moral violations, whereas embarrassment is linked with violations of

conventions. Embarrassment is seen as the impulse to hide and conceal without the justified self-blame associated with shame (Tangney, 1996; Tantam, 1998).

Shame and Humiliation

Although many researchers (e.g., H. B. Lewis, 1987; Nathanson, 1994) have tended to bracket shame and humiliation together, there are important differences between them. In humiliation, people perceive others to find fault with them that they themselves do not feel is justified, and could be challenged (Tantam, 1998). In shame, the negative judgement by self or others is accepted as just and no reversal of the negative judgement seems possible.

Shame and Self-Esteem

In the self-esteem literature, definitions and descriptions of self-esteem seem increasingly close to concepts of shame-proneness. Some authors view shame-proneness (rooted in various early experiences) as the source of low or poor self-esteem (Jacoby, 1994). However, Tangney (1996) argued that shame experiences should not be confused with pre-existing factors such as low self-esteem, which can be a precursor of shame. Leary, Tambor, Terdal, & Down's (1995) sociometer theory argues that self-esteem is indexed by a social monitor that is sensitive to social interactions, especially ones standing in relationship to others. Self-esteem, in their view, monitors social interactions and sets the person in a state of mind to be vigilant to certain kinds of social threat. Low self-esteem primes submissive behaviour and displays, and is a damage limitation state of mind. Hence low self-esteem could increase sensitivity to many social emotions such as shame. Self-esteem can also be experienced separately from shame.

It has been highlighted that individuals can feel shame about personal shortcomings in the absence of specific events or interpersonal relationships (Andrews, 1995). Andrews' conceptualisation of shame (Andrews, 1998) and the Experience of Shame Scale (ESS: Andrews et al., 2002) proposed that individuals can experience distinguishable feelings of shame about different aspects of themselves (character, body and behaviours), as opposed to experiencing generalised shame about the whole self.

1.5.2. Limitations of Shame Measures

Different Conceptualisations of 'High Shame' Individuals

Not only are there different theoretical approaches to shame, but it also can be conceptualized and studied in terms of its components and mechanisms (Tangney, 1996). It can be examined in terms of emotion (e.g., as a primary affect in its own right, as an auxiliary emotion, or as a composite of other emotions such as fear, anger or self-disgust, cognitions and beliefs about the self (e.g., that one is and/or seen by others to be inferior, flawed, inadequate, etc.), behaviours and actions (e.g., such as running away, hiding or concealing, or attacking others to cover one's shame), evolved mechanisms (e.g., the expression of shame seems to use similar bio-behavioural systems to those of animals expressing submissive behaviour), and interpersonal dynamic interrelationships (shamed and shamer; Fossum & Mason, 1986; Harper & Hoopes, 1990). Shame can also be used to describe phenomena at many different levels including internal self-experiences, relational episodes, and cultural practices for maintaining honour and prestige.

Limitations of Shame Questionnaires

Emphasis on aspects of shame in scales representing global shame varies considerably. One problem with the use of global self-evaluations as measures of shame is that they tend to be highly correlated with self-esteem (Cook, 1993) and thus lack specificity.

According to Cook, who designed the Internal Shame Scale measure (ISS; Cook, 1988, 1989, 1993), the development of the ISS was informed by theoretical conceptions of shame by authors such as G. Kaufman, H.B. Lewis, and S. Tomkins. The ISS comprises 24 items (with 6 additional filler items from the Rosenberg Self-Esteem scale), nearly half involving global negative self-esteem or global self-criticism (cited in Tangney, 1996, p.745).

In terms of their specificity to shame, many of the items of the Internal Shame Scale (ISS) may have more theoretical than empirical support. The ISS has been criticised by Tangney (1996) on the grounds that it has more to do with self-esteem than shame and that these are two distinct constructs.

Authors of shame measures also differ in their conceptualizations of the characteristics of high shame individuals (Andrews, 1998). In perhaps, the best known and most widely used shame scale, contained in the Test of Self-Conscious Affect (TOSCA: Tangney, Wagner, & Gramzow, 1989), respondents are presented with brief hypothetical scenarios involving social and moral transgressions followed by four common reactions (including shame and guilt as defined by the researchers). They rate how likely they are to react in each of the ways described. In line with

Tangney and colleagues' conceptualization of shame as a negative evaluation involving the entire self (Tangney, Burggraf, & Wagner, 1995), the majority of the shame responses are attributions to internal and stable causes. As such, many of the items appear to reflect generalised or global reactions to the scenarios, for example, responses of feeling 'inadequate' or 'incompetent'.

Generalised Shame versus Specific Areas of Shame

According to Andrews (1998) the main questionnaire measures used to identify high levels of shame, the TOSCA and the ISS, both have associated limitations. The main limitation of the TOSCA, is that it asks participants to rate anticipated feelings of shame associated with hypothetical scenarios evaluating personal behaviour. In light of the evidence that a propensity to feel shame about personal characteristics is, to some extent, independent of the propensity to experience feelings of shame in response to personal behaviours (Andrews & Hunter, 1997), it appears that the TOSCA fails to assess other components of shame.

The Internalised Shame Scale (ISS: Cook, 1988) is the most commonly used measure of global shame. Global shame measures conceptualise high shame individuals as frequently or continuously experiencing generalised feelings of global shame. In the ISS, respondents are asked to rate self-referent statements about experiences of shame in order to indicate the frequency and extent of shame felt.

Do Measures Directly Reflect Shame?

Like the TOSCA, the ISS also does not focus exclusively on shame related behaviours. It has also been suggested that global, negative self-referent

questionnaires, such as the ISS, tend to be more reflective of negative mood states, than shame (Andrews & Brown, 1993). It has been shown that the ISS is correlated with different measures of depression (Allen et al., 1994). The ISS has also been criticised on the basis that it appears to contain more items measuring self-esteem than shame.

1.5.3. Limitations of Cross-Sectional Shame Studies

Apart from recent studies conducted by Andrews and her colleagues that have looked at the predictive role of shame in various psychopathologies (Andrews, 1995; Andrews 1997; Andrews et al., 2000; Andrews et al., 2002), the majority of other studies carried out have been cross-sectional in nature. While cross-sectional studies provide some indication of whether shame is linked with certain psychopathologies, they do not indicate whether shame is an antecedent, concomitant or consequence of the particular psychopathology studied.

In summary, while the TOSCA does not give an adequate measure of shame excluding guilt and feelings of inadequacy, the ISS mainly reflects global negative mood states and self esteem, the ESS fortunately measures the following components of shame: characterological, behavioural and bodily shame. Due to the ways in which HIV is transmitted and the physical and psychological consequences that can arise from being HIV positive, it was felt to be important to include assessments of shame related to behaviour, the body and non-physical personal characteristics. For these reasons, the ESS was considered the best available measure to use in the present study.

1.6. Chapter Summary and Rationale for Study

The rate of new HIV infections continues to increase in the UK. The introduction of combination therapies has altered the parameters of the disease and the majority of HIV-positive individuals are living longer, healthier lives than previously anticipated. Heterosexual men and women of African origin and White homosexual men are the two main at risk groups within London and the UK (Health Protection Agency 2004). The National Sexual Health and HIV Strategy (Department of Health 2001) suggests that successful disclosure of HIV status to significant others in HIV-positive individuals lives will reduce HIV transmission rates. The benefits and difficulties associated with HIV disclosure have been identified. However, little is known about psychological variables associated with the HIV disclosure process. The issue of shame has emerged in several studies as a barrier to disclosure of information about sexually transmitted diseases including HIV. It is proposed that anticipated and/or actual shame cognitions may therefore account for individual differences in HIV disclosure activity.

The first part of this study is quantitative in nature and aims to determine whether the experience of feeling shame (characterological, behavioural and bodily shame) is associated with HIV disclosure.

The relevance of HIV related factors (months since diagnosis, CD4 cell count, and overt physical health symptoms), cultural demographics (gender, ethnicity, and language spoken), and emotional factors (anxiety and depression) have also been highlighted in the literature as being associated with HIV disclosure. These may have independent effects on subtypes of shame and HIV disclosure. The first study

will seek to establish the presence of any independent effects. The hypotheses are as follows:

1. Lower rates of HIV disclosure will be associated with increased levels of shame (Characterological, behavioural, bodily, shame)
2. Higher rates of HIV disclosure will be associated with increased severity of HIV illness indicators.
3. Higher rates of HIV disclosure will be associated with increased length of time since HIV diagnosis.
4. Lower rates of HIV disclosure will be associated with increased levels of psychological distress (Anxiety and Depression).
5. Lower rates of HIV disclosure will be associated with the following demographics: being female, Black/Mixed ethnicity and English as a second language.
6. People with HIV infection will have made more disclosures to partners and close friends than to family members.

The second part of this study is qualitative in nature and aims to elaborate our understanding of the experiences of HIV disclosure and non-disclosure through the use of Interpretative Phenomenological Analysis (IPA: Smith, 1996). The aim of this part of the study is to provide a rich and detailed picture of HIV disclosure and non-disclosure as experienced by HIV-positive individuals, from different cultural backgrounds living in the UK.

CHAPTER 2: A Quantitative Study of the Determinants of HIV Disclosure

2.1. Methods

2.1.1. Overview and Design

The study aimed to explore the relationship between experiences of feeling shame (characterological, behavioural and bodily shame) with levels of disclosure of HIV status to self-identified important others. The research design was cross-sectional. The selection of independent and dependent variables corresponds to the research aims and hypotheses as outlined in the introduction. The main independent variables were the experience of shame subscales (characterological, behavioural and bodily shame). The dependent variables were HIV disclosure to all targets in the sample, to partners, family and friends. Furthermore, the study attempted to ascertain the contribution of anxiety and depression, measured using the HADS, to HIV disclosure rates.

2.1.2. Setting

The study took place in an HIV outpatient clinic and HIV voluntary sector agencies in North London. Patients attend the outpatient clinic for medical consultations, blood tests and collection of their medication. Social support from fellow patients, information and advice can be accessed via the voluntary sector HIV drop-in centres in the district.

2.1.3. HIV Clinic Characteristics

The HIV clinic and voluntary sector HIV drop-in centres participating in the current study were chosen because they were identified as being located in an area with a diverse multi-ethnic community and a high prevalence of HIV. Individuals attending these services were more heterogeneous in terms of gender, sexual orientation and ethnicity than might have been the case at central London HIV clinics and services where attendees tend to be White, homosexual men.

2.1.4. Sample

Sample Size Requirements

A target sample size was estimated on the basis of statistical power analysis using Cohen's tables (Cohen 1992). These showed that assuming a medium effect size of .30, the sample size required was estimated at 85.

Recruitment

In the current study, the inclusion criteria, other than being an attendee at the HIV out-patient clinic were 1) aged between 18 and 65 years, and 2) competency in the English language. (This was assessed informally by the researcher when participants were initially approached to take part in the study). A total of 13 potential participants who had English as their second language declined to take part in the study, giving the explanation that they did not consider their English skills were good enough to complete the questionnaire and did not wish assistance to do so.

A total of 300 HIV-positive individuals attending the HIV outpatient clinic were approached by the researcher and asked to participate in the study. Of those 67 (18 White men, 21 Black men, 28 Black women), (45%) declined to take part. The most frequent reasons given were insufficient command of the English language to complete the questionnaires or simply lack of interest in the study. 15 sets of questionnaires were returned partially completed and therefore not used (3 White men, 7 Black men, 5 Black women). 148 questionnaires were not returned.

Twenty five of the above sets of questionnaires were distributed to clinic attendees attending drop-in centres for HIV-positive people in the borough. Stamped addressed envelopes were provided so that completed questionnaires could be returned to the researcher. Of those sets of questionnaires seven were returned, however, five of these questionnaires had extensive missing data and therefore were not included in the sample. As a result, a final sample of 70 participants was obtained.

Participants

Approximately half of the sample was male. The mean age of participants was 39 (range 21-65). Just over one third of the sample described their ethnicity as White/White British. Black Africans made up just under half of the sample. In light of the local census data showing the borough from which data was collected to be a culturally diverse district, the sample collected reflected adequately the population from which participants were recruited.

2.1.5. Ethics

Ethical approval for this study was granted by Barnet, Enfield and Haringey LREC (Appendix 1a) and permission was gained from the local hospital HIV outpatients clinic and various HIV voluntary organisations in the area to recruit participants from their premises. Once informed consent had been obtained from the HIV outpatients clinic and voluntary organisations, a letter and information sheet about the aims of the study was forwarded to service managers who ensured these were displayed on notice boards within their premises.

2.1.6. Procedure

Following arrival at the clinic reception potential participants were approached and those that confirmed that they were attending for HIV-related treatments were subsequently introduced to the researcher by the clinic receptionist. If they indicated an interest in participating, the nature of the research was explained and they were given the study information sheet to read (Appendix 3). Participants were then given the questionnaire pack (Appendices 5-5H) to complete whilst waiting for appointments. Participants, especially those waiting to see their doctor, were given the option of completing the questionnaires in a room off the main waiting area to maximize privacy. Participants were encouraged to ask questions about the research and to ask for clarification of questions they were unclear about or uncertain of. Participants were informed that the researcher would meet with them in private should they have any worries or concerns raised by the study. The information sheet also included contact details for the researcher and a qualified clinical psychologist who specialised in working with HIV-positive individuals. Questionnaires were self-administered and anonymous. They were either handed back to the researcher or

alternatively, if the participants had no time to fully complete them, or wished to complete them in their own time they were asked to return them in the stamped-addressed envelope provided.

The recruitment procedure at local HIV voluntary organisations was somewhat different. The study was introduced to the service attendees as a group, via an informal discussion about the nature and purpose of the research. Following this, the information sheets were distributed to all potential participants, the content of the information sheet and the limits of confidentiality were outlined and explained and participants were invited to ask questions about the study. Service users were asked in person by the researcher if they would be willing to take part in the study, and if they consented, were given a questionnaire pack to complete. Participants were made aware that the researcher would remain behind at the end of the groups to privately discuss any issues that had been raised following completion of the questionnaires. For those who opted to take the questionnaires away and complete it in their own time, the contact details of the researcher and clinical psychologist were highlighted on the information sheet. The majority of individuals, twenty participants, agreeing to take part in the study opted to take the questionnaires away with them and return them to the researcher by stamped addressed envelope in due course.

2.1.7. Measures

Participants were asked to complete the following set of questionnaires in the order presented below.

Demographic Details

All participants were asked to complete a set of demographic questions. The demographics form (Appendix 5A) asked about the participant's gender, age, ethnicity, sexuality, relationship status, current living circumstance, educational level, employment status and number of dependents (children). In addition, as participants were recruited from a multi-ethnic population, they were also asked to report whether English was their first language.

HIV Illness Indicators

All participants were asked to provide the date of their HIV/AIDS diagnosis and details of their most recent CD4 and viral load results in order to determine stage of illness. In addition, participants were asked to list any combination therapies currently taken and record any medication side effects experienced. (See Appendix 4). Assessment of HIV health status was measured by self-report of CD4 count and viral load. This method was adopted because assessment of disease progression has changed from an emphasis on the presence of opportunistic infections to CD4 count and viral load testing. (See Appendix 5B).

Severity of Physical Symptoms

All participants filled in the severity of HIV physical symptoms scale used by Marks et al. (1992) which assesses the overt level of physical symptoms or signs of HIV/AIDS related illness experienced (see Appendix 5C). Participants were asked to rate the severity of 18 physical signs of HIV/AIDS related illness experienced in the last month on a 4-point scale ranging from (1) = no problem to (4) = severe

problem. Perceptions of changes in their physical appearance since receiving an HIV-positive diagnosis were also assessed. All participants were asked to rate the extent of this perceived change on a 4-point scale by circling the one of the following four statements: (1) = Improved, (2) = Not changed, (3) = A little worse, (4) = Much worse.

HIV Disclosure Diagram and Index (Petрак, Doyle, Smith, Skinner & Hedge, 2001)

In the present study HIV disclosure/non-disclosure is defined as participants indicating whether or not they have revealed their diagnosis of HIV/AIDS to family, friends, partner(s) or significant others in their lives (Chin & Kroesen, 1999; Simoni, et al., 1995).

Rates of HIV disclosure and reasons for HIV disclosure and non-disclosure was assessed by asking participants to complete the HIV disclosure index and supplementary questions devised by Petрак et al. (2001) (See Appendices 5D & 5E). Respondents were asked to identify up to 10 'most important people in your life at the moment' and were asked to provide the initial or first name for each person and indicate their relationship to them. Following this, participants were then asked to indicate if they had disclosed their HIV status to these self-identified significant others and to record their main reason(s) for disclosing or not disclosing, and to list the HIV status of their identified significant others if known.

An overall disclosure rate was calculated for each respondent as the percentage of targets to whom the respondent disclosed their HIV status to out of the total number of 'important others' identified. Rates of disclosure to partner(s), friends and family

were also calculated for each respondent as the percentage of individuals to whom that respondent disclosed their HIV status out of the total number of 'important others' identified for each group. 'Important others' were excluded from the disclosure analysis if they were already aware of the respondents' HIV status because of their involvement in their HIV care (e.g., health and social care professionals, voluntary sector group attendees) or were not informed about respondent's HIV status due to young age. 'Important others' who were identified by participants as pre-school children were excluded from the analysis.

Content Analysis for Reasons for Disclosure

Reasons for disclosure and non-disclosure of HIV status to 'important others' were reviewed and categorized to identify themes that emerged from participants responses to the open-ended questions asked. The following seven thematic categories for disclosure and eight categories for non-disclosure were derived from a review of the literature and previous research regarding HIV disclosure rates. (Derlega & Winstead 2001; Hays et al., 1993; Petrak et al., 2001).

Table 1: Description of thematic categories

Themes	Description
Reasons for disclosure	
1. Catharsis or Self Expression	Self-expression or catharsis as an attribution for disclosure emphasises the opportunity to release or express pent-up feelings. Individuals who find out that they are HIV-positive may have strong feelings that they need to share with another
2. Seeking Help	HIV-positive individuals may attribute the decision to disclose to a tangible need for help. For instance, they may have a need for medical advice & treatment, but seeking practical or emotional help may also be cited as a reason for disclosing to important others
3. Duty to Inform	Individuals may tell someone out of a sense of loyalty to partners, parents or other family members. Another facet of the duty to inform as a reason for disclosure derives from a desire to have an honest relationship with another person. Others focus on the duty to tell to help prepare another person for what might happen in the future or to protect the other from gossip or disease. The duty to inform also appears in the context of health concerns in starting or maintaining a sexual relationship
4. Ethical and Educative Purposes	HIV-positive persons may disclose to relatives, friends, or an intimate partner in order to educate them about HIV and AIDS is frequently mentioned as a reason for disclosure about the diagnosis
5. Breach of Confidentiality and Becoming Unwell	Respondents indicated that having their HIV status revealed was not their choice and/or emerged in the context of illness
6. Emotionally Close and Supportive Relationship	This perception is based on perceptions of trust, love, and affection for the other person, as well as the belief that the other person can provide emotional support
7. Similar Background & Experiences	HIV-positive individuals may decide to disclose this fact to someone because they share a common background with that person or they have had similar experiences

Themes	Description
Reasons for non-disclosure	
1. Shame Related Reasons for Non-disclosure	Some HIV-positive persons may feel morally tainted or personally stigmatized by the diagnosis. They may conceal the information because they feel ashamed or personally at fault for having contracted HIV
2. Privacy & Protection	Individuals who decide not to tell someone about the diagnosis may attribute their decision to right to privacy. The assertion of a right to privacy may derive from a claim to ownership over the information about the self and worries about confidentiality
3. Fear of Rejection or Being Misunderstood	Concerns about being misunderstood, discriminated against, ridiculed, or rejected were frequently cited as an attribution for not disclosing the HIV diagnosis
4. Protect the Other Person from Distress	The desire or need to protect others as an attribution for non-disclosure
5. Physical Distance	Some respondents indicated that they did not disclose their HIV status due to friends or family living abroad/far away or being uncontactable
6. Superficial Relationship	Decision not to disclose because they did not feel close to a particular person or they were not emotionally close enough to the person to feel disclosing was worthwhile
7. Communication & Timing Difficulties	Individual has not found a way to tell identified other of their HIV status or does not feel it is the right time to disclose for a number of reasons
8. No Reason or Benefit from Disclosing	No specific reason given for non-disclosure or perception that individual would not benefit from knowing this information at present. For example if they are perceived not at risk of contracting HIV therefore no need to disclose HIV status to them

In order to assess the inter-rater reliability (IR) for the reasons given for HIV disclosure and non-disclosure, the percentage of agreement between two independent reviewers was calculated by dividing the number of agreements for each theme by

the total number of agreements and disagreements. According to Miles and Huberman (1994) agreement of 70% and above indicates acceptable levels of agreement.

The Experience of Shame Scale
(ESS: Andrews, Qian & Valentine, 2002; Appendix 5F)

All participants completed the Experience of Shame Scale, a questionnaire based on a previous interview measure used by Andrews and Hunter, (1997). The 25 item questionnaire assesses recent feelings of shame ("over the past year") covering four areas of characterological shame, three areas of behavioural shame and one area of bodily shame. Each of these eight areas was assessed in terms of experiential, cognitive and behavioural components of shame. In addition, bodily shame had an additional item assessing avoidance of mirrors. The Experience of Shame Scale has been shown to have good validity, internal reliability and test-retest reliability of the total scale and the three sub-scales (Andrews et al., 2001; Andrews et al., 2002). Moreover, factor analyses have confirmed the existence of the three separate subscales (Andrews et al., 2002). In the current study the Cronbach alpha coefficients were .93 and .92, .91 and .81 for the total Experience of Shame Scale Score and the characterological, behavioural and bodily shame subscales respectively.

The Hospital Anxiety & Depression Scale
(HADS: Zigmond & Snaith, 1983; Appendix 5G)

The Hospital Anxiety and Depression (HADS) scale was designed to ensure measurement of depression and anxiety was not contaminated by symptoms

primarily attributable to physical illness. The HADS scale was selected to measure anxiety and depression for this reason.

The HADS scale consists of 14 items of which seven assess anxiety and seven assess depression. Each item is a statement that the participant must rate in terms of frequency of their experience in the past week. Items are rated on a 4-point scale according to severity. A score of zero means the absence of a symptom and a score of three signifies the maximum intensity of a symptom. Scores on the HADS subscales can range from 0 to 21. Scores between 11 and 21 indicate clinical levels of anxiety or depression. Scores between 8 and 10 denote probable levels of clinical anxiety or depression and scores below seven are in the normal range.

A recent review paper exploring the validity of the HADS (Bjelland, Dahl, Haug, & Neckelmann, 2002) showed that most factor analyses demonstrated a two-factor solution in good accordance with the HADS subscales for Anxiety (HADS-A) and Depression (HADS-D), respectively. The correlations between the two subscales varied from .40 to .74 (mean .56). Cronbach's alpha for HADS-A varied from .68 to .93 (mean .83) and for HADS-D from .67 to .90 (mean .82). In most studies an optimal balance between sensitivity and specificity was achieved when caseness was defined by a score of 8 or above on both HADS-A and HADS-D. The sensitivity and specificity for both HADS-A and HADS-D of approximately 0.80 were very similar to the sensitivity and specificity achieved by the General Health Questionnaire (GHQ-12; Goldberg & Williams, 1988). Correlations between HADS and other commonly used anxiety and depression questionnaires were in the range .49 to .83. In conclusion, the HADS was found to perform well in assessing the symptom

severity and caseness of anxiety disorders and depression in both somatic, psychiatric and primary care patients and in the general population.

However, identifying anxiety and depression in HIV-positive populations is complicated due to the symptom overlap between HIV manifestations and somatic symptoms of anxiety and depression. (e.g., Savard,, Laberge, Gauthier, Ivers & Bergeron, 1998). It is therefore crucial to use measures that validly and reliably assess these psychological states in HIV-infected patients.

Savard et al. (1998) assessed the psychometric properties of the HADS, when used with HIV-positive individuals. Because the study was conducted among French Canadian individuals, the quality of the translation was first subjectively and empirically assessed. Then, the psychometric properties of the HADS were evaluated in 162 HIV-positive patients, who, in addition to the HADS, also completed the Beck Depression Inventory (BDI-II; Beck, Steer & Brown, 1996) and the State-Trait Anxiety Inventory (STAI; Spielberger 1983). The French Canadian version of the HADS was found to be subjectively and empirically equivalent to the original English version. Moreover, results of this study demonstrated a bifactorial structure with factors corresponding to the HADS anxiety and depression subscales, an excellent internal consistency and test-retest reliability, a very good convergent validity, and acceptable discriminant validity. Strikingly, in contrast to the BDI, HADS scores were found to be unconfounded by the presence of HIV symptomatology. These findings suggest that the HADS is reliable and valid when assessing anxiety and depression in HIV-positive patients. In the current study the Cronbach alpha coefficients for both the HAD-A and HAD-D was .82.

2.1.8. Data Analysis

Once data were collected, participants' responses were coded and transformed into variable data and input to SPSS v.11. Total scores and subscale scores were calculated manually in two cases to check the accuracy of the computer assisted computations. Chi-square tests and independent samples t-tests were used to explore the effects of demographic variables, anxiety, depression and shame variables on HIV disclosure rates (HIV disclosure to all targets in the sample, partner(s), family, and friends), while logistic regressions were employed to examine the effects of significant demographic, HIV illness variables and the Experience of Shame on the above four HIV disclosure variables.

2.2. Results

Following preliminary analyses to assess the normality of the data, the demographic characteristics of the final sample are presented. Descriptive data for all variables in the study are then presented. Section two describes analyses aimed to identify psychological variables that might discriminate between HIV disclosure rates. The final section presents the analyses employed to test each of the hypotheses.

2.2.1. Preliminary Analysis

Prior to statistical analyses, the data were cleaned by checking all variables for outliers and missing data. In order to determine whether parametric or non-parametric statistical analysis could be carried out, the degree of fit with the normal distribution was assessed by examining histograms, levels of skewness, and kurtosis,

and the results of the Komogorow-Smirnov (K-S) test for each continuous dependent variable.

Outliers

Using a cut-off point of more than three standard deviations from the mean, all variables were checked for statistical outliers. One outlier was identified in the depression subscale of the Hospital Anxiety and Depression Scale ($z = 3.00$). Following standard procedures, this outlier was replaced by the highest score on that particular variable plus one ($16+1$), a procedure commonly used to avoid excluding values that can affect the statistical power of the analyses conducted (Tabachnick & Fidell, 1996).

Missing Data and Final Sample

There were no missing items from the demographic or independent variables. Missing data from the number of self identified important others, in the HIV disclosure diagram and HIV disclosure index, were coded as such. Four participants did not identify any important others to whom they would consider disclosing. Disclosure data for these participants are therefore missing, resulting in the data for these four participants being excluded from all further analysis. Thus the number of participants for this variable and the four dependent variables (HIV-disclosure rates to all targets, partner(s), family and friends) was therefore reduced from 70 to 66.

Test of Shape of Distribution Scores

When dependent variables were continuous, the distribution of scores was checked for normality by visual inspection and statistical analyses. The shape of the

distribution was assessed by looking at histograms, level of skewness, kurtosis and Kolmogorov-Smirnov Statistic tests for each variable. Any variables with associated K-S probability <0.01 were deemed to be significantly different from the normal distribution. This would generally mean that non-parametric tests would be carried out on such variables, unless various transformations (including reflecting and squaring the values) improved the fit with the normal distribution. The HIV disclosure variables presented highly skewed distributions with large numbers of participants having either reported 100% or 0%; HIV disclosure rates. It was therefore decided to dichotomise all the HIV disclosure variables into participants who had disclosed or had not disclosed their HIV-positive status.

Demographic Characteristics of the Final Sample

The demographic characteristics of the whole sample were given in Table 2. However, as a result of a minority of participants not identifying any important others in their lives that they had considered disclosing their HIV status to, four cases were excluded from the sample due to having missing data, reducing the total number of participants from 70 to 66.

The demographic characteristics of the final sample are presented in Table 2. The final sample of 66 HIV-positive individuals consisted of a roughly even male - female split, with 35 men (53%) and 31 women (47%). It contained a broad range of ethnicities, which was representative of the borough. However due to low numbers in each category, for the purpose of statistical analyses, participants were grouped into two ethnic categories: White and Black/Mixed race. The sample consisted of mainly Black/ Mixed race participants (58%). The majority of these participants

were of Black African ethnic origin (49%), (3%) reported their ethnic origin as Black Caribbean and (6%) reported that they were Mixed race. Just under half of the sample were of White British ethnic origin (42%). The sample was also diverse in terms of sexual orientation. Just over half the sample (59%) were heterosexual and just under half (41%) were homosexual/bisexual. The majority (55%) were employed and (89%) had educational qualifications at O-level or above.

Table 2: Demographic details of the final sample (n= 66)

Variable	N (%)
Gender	
Male	35 (53%)
Female	31 (47%)
Age	
20-29	9 (14%)
30-39	32 (48%)
40-49	17 (26%)
50-59	5 (8%)
60-65	3 (5%)
Ethnicity	
White	28 (42%)
Black/Mixed	38 (58%)
1st Language	
English	43 (65%)
Other	23 (35%)
Sexual Orientation	
Heterosexual	39 (59%)
Homosexual/Bisexual	27 (41%)
Relationship Status	
Single	30 (45%)
Not Single	36 (55%)
Living Arrangements	
Alone	26 (39%)
With Other(s)	40 (61%)
Number of children	
0	28 (42%)
1	17 (26%)
2	12 (18%)
3 or more	9 (14%)
Education	
No Formal Qualifications	7 (11%)
O=Levels/GCSEs	19 (29%)
A-Levels	8 (12%)
Diploma	14 (21%)
Degree	11 (17%)
Higher Degree	7 (11%)
Employment	
Employed	36 (55%)
Unemployed	30 (45%)

2.2.2. Descriptive Statistics

HIV Illness Indicators

The mean length of time since testing positive for HIV infection was 61 months (range 3 -201 months). Twenty six percent had an AIDS diagnosis, and the mean length of time since this diagnosis was 48 months (range 7-80 months). The CD4 data (Table 3) suggests that most participants were not currently at an advanced stage of HIV disease progression, as indicated by the modal CD4 count in the 201-500 range and the modal viral load being “undetectable.”

Table 3: Participants' CD4 count and viral load details

Variable	N (%)
CD4 Count	
<50	14 (21%)
51-200	12(18%)
201-500	24 (36%)
501+	16 (24%)
Viral Load	
Undetectable	41 (62%)
51-1000	13 (20%)
1001, 10,000	4 (6%)
10, 001-50,000	3 (5%)
50,001 -100,000	2 (3%)
100,000+	3 (5%)

2.2.3. Information Regarding Participants' Combination Therapies

Forty-six participants (70%) were taking Combination Therapies, and of these 24 (36%) reported side effects. The mean number of combination therapies taken by participants was three (see Table 4).

Table 4: Use of combination therapies

Variable	N (%)
Combination Therapies Taken	
Yes	46 (70%)
No	20 (30%)
Side Effects	
Yes	24 (36%)
No	42 (64%)
Common Side Effects	
Weight loss	8 (32%)
Lipodystrophy	5 (20%)
Nausea	6 (24%)
Drowsiness	3 (12%)
Skin Problems	3 (12%)
Diarrhoea	2 (8%)
Headache	2 (8%)
Karpoisis Sarcoma	1 (4%)
Lethargy	1 (4%)
Mood Problems	1 (4%)
Neuropathy	1 (4%)
Other Infections	1 (4%)
Weight gain	1 (4%)
Appearance changes since HIV diagnosis	
Not changed	22 (33%)
Improved	13 (20%)
A little worse	23 (35%)
Much worse	8 (12%)

The three most commonly reported side effects from taking combination therapies were: 1) Weight Loss; 2) Lipodystrophy (HIV lipodystrophy syndrome (LDS), consists of unusual changes in the distribution of body fat and can occur as a result of taking highly active antiretroviral therapy (HAART); 3) Nausea. Twenty five participants (35%) reported that they felt their physical appearance had become “a little worse” following their HIV-positive diagnosis.

2.2.4. Independent Variables

Table 5 below shows mean scores for each of the independent variables.

Table 5: Descriptive statistics for independent variables (n=66)

Variable	Mean (s.d.)	Possible Range	
		Min	Max
Experience of Shame Scale			
ESS Total Score	53.09 (16.11)	(25-100)	
Characterological Shame	22.93 (8.85)	(12-48)	
Behavioural Shame	21.83 (7.54)	(9-36)	
Bodily Shame	8.32 (3.51)	(4-16)	
Hospital Anxiety & Depression Scale			
Anxiety	9.39 (4.32)	(0-21)	
Depression	7.19 (4.17)	(0-21)	

Shame

The mean total score for the Experience of Shame Scale (ESS) score was 53.09. Mean scores for the ESS subscales were highest for Characterological and Behavioural Shame and lowest for Bodily Shame.

Anxiety and Depression

The mean anxiety and depression scores for the sample were 9.39 and 7.19 respectively. Participants' self reported levels of anxiety and depression scale on the HADS were also categorised according to specified ranges (Zigmond and Snaith, 1983). Using this criteria, twenty nine (44%) of the total sample scored above the cut off score (11) used to determine probable caseness for clinical anxiety. Fourteen participants (21%) scored above the lower cut off score (8) that is used to identify borderline cases and twenty three participants (35%) scores fell within the normal range. Regarding depression, Ten (15%) participants scored above the cut off (11) indicating probable caseness for depression, twenty one (32%) scored above the lower cut-off suggesting borderline cases and thirty three (50%) scored within the

normal range. Anxiety was more commonly encountered in participants than depression.

2.2.5. Rates of HIV Disclosure

The mean number of 'important others' identified by participants was 7 (SD = 2.79). Disclosure was measured by four variables: disclosure to all targets, disclosure to partner(s), disclosure to family, disclosure to friends. The frequencies of the four HIV disclosure rates as dichotomised variables are located in Table 6.

Table 6: Frequencies and percentages of HIV disclosure rates as dichotomised variables

Target Group	Disclosed N (%)	Not Disclosed N (%)	Not Applicable N (%)
Any Target	58 (88%)	8 (12%)	0 (0%)
Partner(s)	34 (52%)	7 (11%)	25 (38%)
Family	38 (58%)	24 (36%)	4 (6%)
Friends	34 (52%)	16 (24%)	16 (24%)

Participants may have disclosed their HIV status to one or more important other in one or all of the above target groups.

The mean overall rate of HIV disclosures made by the sample overall, expressed as a percentage, to all identified 'important others' was 58% (SD= 38.74). Of the 66 participants, eight (12%) had not disclosed their HIV status to any target, while 58/66 (88%) had disclosed their HIV status to at least one target. In terms of disclosure to partner(s), the mean HIV disclosure rate to partner(s), was 80% (SD= 38.46). Of the number of participants who had indicated partner(s) as 'important', 7/41 (17%)

persons had not disclosed their HIV status to partner(s), while 34/41 (83%) had disclosed their HIV status to all identified partner(s). The mean HIV disclosure rate to family member(s) expressed as a percentage was, 49% (SD=47.79). Of the number of participants who had indicated family member(s) as targets, 24/62 (39%) had not disclosed their HIV status to any family members, while 38/62 (61%) had disclosed to all family members. Finally, the mean rate of HIV disclosure to friends, was 63% (SD= 45.83). 16/50 (32%) persons had not disclosed their HIV status to any friends, while 34/50 (68%) had disclosed to all friends identified.

From Table 7 it can be seen that where partner(s) are deemed important others to participants, HIV disclosure rates are consistently high across the sample (78%). With regards to family member(s) who are identified as important others, disclosure rates are relatively lower with approximately one in two identified family member(s) being disclosed to (47%). HIV disclosure rates within the group friends lies between that for partner(s) and family member(s) with a disclosure rate of approximately two in three (67%) in the current sample.

Table 7: Disclosure of HIV infection to targets

Target Group	Identified ‘important others’ N	Disclosure to identified ‘important others’ N (%)
All Targets	483	265 (55%)
Partner(s)	46	36 (78%)
Family	288	136 (47%)
Friends	139	93 (67%)

2.2.6. Exploring Variables associated with HIV Disclosure

Associations between Demographic, HIV Illness Variables & HIV-Disclosure

Before proceeding to test the main hypotheses of the study, analyses were carried out to determine possible effects of demographic variables and HIV illness variables on HIV disclosure rates. These analyses were important in guiding decisions regarding the need to control for the effects of demographic, HIV illness and shame variables in all subsequent analyses.

Associations between the following demographic variables were explored: Age, relationship status, living arrangements, number of children, education and employment status.

The relationship between age and HIV disclosure was investigated using independent samples t-tests (Table 8). There was no significant difference in age for participants who disclosed or did not disclose their HIV status to self identified important others in the sample overall and to partner(s), family and friends.

Table 8: Independent sample t-tests - means and standard deviations of age for participants who disclosed and did not disclose their HIV status

Target Group	Disclosed HIV Status Mean (SD)	Not Disclosed HIV Status Mean (SD)	t (df)	p
All Targets (N = 66)	39.46 (9.83)	35.13 (6.40)	-1.209 (64)	2.31
Partner(s) (N = 41)	38.29 (9.26)	35.43 (6.43)	-.777 (39)	.442
Family (N = 62)	40.50(8.79)	36.71 (10.79)	-1.514 (60)	.135
Friends (N = 50)	40.97 (9.89)	37.19 (7.03)	-1.373 (48)	.176

In order to examine the effects of participants demographic details have on HIV disclosure, a series of Chi-square tests were conducted (Table 9). Due to small numbers within sub-categories the data for relationship status, living arrangements, number of children, education and employment status were formed into dichotomous categorical variables.

Table 9: Associations between participant's demographics and HIV disclosure

Variable	All Targets		Partner(s)		Family		Friends	
	$\chi^2(1)$	p	$\chi^2(1)$	p	$\chi^2(1)$	p	$\chi^2(1)$	p
Relationship Status	1.067	.452	2.153	.15	.492	.483	2.407	.121
Living Arrangements	.790	.464	.290	1.00	.918	.338	.633	.426
Number of Children	6.708	.017*	.806	.438	.000	1.000	.885	.347
Education	1.080	.347	.433	1.000	1.984	.162	.737	.650
Employment	1.067	.452	.855	.421	.304	.581	.428	.513

*A Bonferroni Correction was applied for multiple comparisons. Significance testing indicated that a p value of less than .00085 is required for significance.

After controlling for type one errors, the results of the Chi-square tests indicated that there was no significant relationships between participants' demographic details and their HIV disclosure rates to all targets in the sample, to partner(s), family and friends.

In addition, a series of chi-square tests were conducted to explore the effects of HIV illness variables on HIV disclosure (Table 10).

Table 10: Associations between HIV illness variables & HIV disclosure

Variable	All Targets		Partner(s)		Family		Friends	
	$\chi^2(1)$	p	$\chi^2(1)$	p	$\chi^2(1)$	p	$\chi^2(1)$	p
AIDS Diagnosis	.837	.669	1.183	.399	.633	.426	.280	.746
Combination Medications	4.468	.049*	8.553	.010*	5.496	.019*	.123	1.000
Physical Side Effects	.005	1.000	.143	1.000	.307	.580	.027	.870
Appearance Changes	.076	1.000	.119	1.000	1.984	.232	.737	.650
CD4 Count	.028	1.000	.234	1.000	.042	.838	2.393	.122
Viral Load	2.345	.242	5.218	.035*	.000	1.000	.027	.870

* A Bonferroni Correction was applied for multiple comparisons. Significance testing indicated that a p value of less than .00208 is required for significance.

The results of the chi-square test indicated that after controlling for type one errors, having an AIDS diagnosis, taking combination therapy medications, medication side effects, appearance changes following HIV diagnosis, CD4 counts and viral load were also not significantly associated with HIV disclosure to all targets in the sample, to partner(s), family and friends. It is worth noting however, that taking combination therapy medications almost reached significance.

The relationship between time in months since HIV diagnosis and HIV disclosure to all targets in the sample, to partner(s), family and friends, was investigated using independent samples t-tests (Table 11).

Table 11: Independent sample t-tests comparing means and standard deviations of months since HIV diagnosis for disclosure and non- disclosure of HIV status

Target Group	Disclosed HIV Status Mean (SD)	Not Disclosed HIV Status Mean (SD)	t (df)	p
All Targets (N = 66)	66.24 (54.49)	26.75 (23.24)	-3.625 (20.21)	.002
Partner(s) (N = 41)	66.65 (58.33)	36.57 (41.95)	-1.29 (39)	.204
Family (N = 62)	76.92 (57.11)	37.41 (37.27)	-3.29 (60)	.002
Friends (N = 50)	81.76 (58.01)	41.56 (39.99)	-2.500 (48)	.016

Table 11 indicates that time in months since HIV diagnosis was significantly associated with HIV disclosure rates to all targets in the sample, and HIV disclosure to family and friends. HIV-positive individuals made more disclosures to all targets in the sample, to family and friends the longer the time in months since receiving their HIV diagnosis was. Length of time since HIV diagnosis however, was not significantly associated with HIV disclosure to partner(s).

The relationship between the severity of overt HIV symptoms experienced and HIV disclosure was also investigated by using independent samples t-tests. The results obtained in Table 12 shows that no significant relationships were found between overt HIV symptoms experienced and HIV disclosure to all targets, to partner(s), family and friends.

Table 12: Independent sample t-tests comparing means and standard deviations of overt HIV symptoms experienced for disclosure and non- disclosure of HIV status

Target Group	Disclosed HIV Status Mean (SD)	Not Disclosed HIV Status Mean (SD)	t (df)	p
All Targets (N = 66)	1.66 (.64)	1.98 (.67)	1.29 (64)	.200
Partner(s) (N = 41)	1.62 (.66)	1.89 (.81)	.948 (39)	.349
Family (N = 62)	1.81 (.69)	1.50 (.59)	-1.82 (60)	.075
Friends (N = 50)	1.82 (.73)	1.54 (.59)	-1.37 (48)	.176

2.2.7. Test of Hypotheses

Association between Gender and HIV Disclosure Rates

To examine the hypothesis that females would have made fewer disclosures about their HIV-positive status to self identified important others in their lives than males, a series of chi-square tests were conducted (See Table 13).

There were no significant differences between males and females regarding disclosure of HIV status to all targets, to partner(s), and family. The results of chi-square tests however, indicated a significant difference between males and females and HIV disclosure to friends ($\chi^2(1) = 5.391, p = .020$), indicating that 17.2% of males in comparison to 52.4% of females had not disclosed their HIV status to identified friends and that 82.8% of males in comparison to 47.6% of females had disclosed their HIV status to identified important friends.

Association between Cultural Factors and HIV Disclosure Rates

As a test of the hypothesis that Black participants would have made fewer disclosures than White participants a series of chi-square tests were conducted (Table 13). The results indicated that this prediction did not hold for levels of disclosure to partner(s) and family member(s). However the tests showed that there were significant differences between Black and White participants with regards to disclosing their HIV status overall in the sample ($\chi^2(1) = 6.708$, $p = .017$) and to friends, ($\chi^2(1) = 6.434$, $p = .011$).

21.1% of Black/Mixed participants in comparison to zero percent of White participants had not disclosed their HIV status to any of their self identified important others. 33.4% of Black/Mixed participants had disclosed to their identified important others, while 100% of White participants had disclosed. 50% of Black/Mixed participants in comparison to 12.5% of White participants had not disclosed their HIV-positive status to important friends. 50% of Black/Mixed participants in comparison to 87.5% of White participants had disclosed their HIV status to self identified important friends.

A series of chi-square tests were also carried out to explore the prediction that participants with English as their first language would have made significantly more disclosures about their HIV status to important others in their lives than those who did not have English as their first language (Table 13).

The results of these tests showed that significant differences in levels of HIV disclosure overall, ($\chi^2(1) = 6.464$, $p = .018$) and to friends, ($\chi^2(1) = 6.752$, $p = .009$)

were found between participants whose first language was English and those who did not. 26.1% of participants who did not have English as their first language had not disclosed their HIV status in comparison to 4.7% of participants whose first language was English. 73.9% of participants who did not have English as their first language had disclosed their HIV status, while 93.5% of participants who had English as their first language had disclosed. With regards to disclosure of HIV status to friends, 18.2 % of participants with English as their first language had not disclosed to friends while 58.8% who did not have English as their first language had not disclosed to this group of important others in their lives. 81.8% participants with English as their first language had disclosed their HIV status to friends while, 41.2% of participants who did not have English as their first language had disclosed to their friends. However, significant differences were not found in terms of HIV disclosure to partner(s) or family members for those with and without English as their first language.

Table 13: Chi-square tests - Demographic variables

Variable	All Targets		Partner(s)		Family		Friends	
	$\chi^2(1)$	p	$\chi^2(1)$	p	$\chi^2(1)$	p	$\chi^2(1)$	p
Gender	.034	1.000	.041	1.000	.021	.886	5.391	.474
Ethnicity	.005	.017*	3.006	.112	1.053	.305	6.434	.011*
English 1st Language	6.464	.018*	1.105	.361	2.644	.104	6.752	.009*

Associations between psychological distress and HIV disclosure rates

In order to examine whether participants who disclosed their HIV status had significantly different scores on the variables measuring psychological distress

(anxiety and depression) from participants who did not disclose their HIV status overall, to partner(s), family and friends, a series of independent t-tests were conducted (Table 14 and Table 15).

Table 14: Independent sample t-tests comparing means and standard deviations of anxiety scores for participants who disclosed and did not disclose their HIV status

Variable	Disclosed HIV Status Mean (SD) (n)	Not Disclosed HIV Status Mean (SD) (n)	t (df)	p
All Targets	9.21 (4.42)	10.75 (3.53)	.945 (64)	.348
Partner(s)	9.26 (4.69)	8.43 (3.41)	-.446 (39)	.658
Family	9.61 (3.79)	8.63 (5.17)	-.860 (60)	.393
Friends	9.44 (3.54)	8.63 (5.52)	-.541 (21)	.594

Table 15: Independent sample t-tests comparing means and standard deviations of depression scores for participants who disclosed and did not disclose their HIV status

Variable	Disclosed HIV Status Mean (SD) (n)	Not Disclosed HIV Status Mean (SD) (n)	t (df)	p
All Targets	7.00 (4.42)	8.63 (3.50)	1.035 (64)	.305
Partner(s)	6.38 (3.84)	6.00 (3.42)	-.244 (39)	.809
Family	7.45 (4.19)	6.54 (4.13)	-.833 (60)	.408
Friends	7.26 (4.36)	6.81 (4.65)	-.335 (48)	.739

It was predicted that there would be an increase in HIV disclosure, (disclosure in sample, to partner(s), family and friends), associated with increased levels of anxiety and depression as measured by the HADS. These predictions did not hold. There were no significant differences in anxiety and depression for those participants who had disclosed their HIV status to all targets, to partner(s), family and friends and those participants who had not disclosed their HIV status to these groups of self identified important others in their lives.

2.2.8. Research Hypotheses - Predictors of HIV Disclosure

The main hypothesis is that HIV disclosure rates, to all targets, to partner(s), family and friends can be predicted by all of the shame constructs. It is hypothesised that low rates of HIV disclosure will be associated with increased levels of shame, characterological, behavioural and bodily shame, as measured by the Experience of Shame Scale (Andrews et al., 2002).

A series of independent t-tests were also conducted to explore the role of shame in HIV disclosure to all targets, to partner(s), family and friends (16 to Table 19).

Table 16: Independent sample t-tests comparing means and standard deviations of Experience of Shame Scale scores for participants who disclosed and did not disclose their HIV status

Target Group	Disclosed HIV Status Mean (SD)	Not Disclosed HIV Status Mean (SD)	t (df)	p
All Targets	52.16 (16.31)	59.88 (13.56)	.128 (64)	.206
Partner(s)	52.29 (13.98)	56.29 (11.80)	.703 (39)	.486
Family	53.42 (18.18)	52.42 (13.33)	-.250 (59)	.803
Friends	52.24 (17.09)	50.88 (11.32)	-.334 (42)	.740

Table 17: Independent sample t-tests comparing means and standard deviations of Experience of Shame Scale Characterological Shame Subscale scores for participants who disclosed and did not disclose their HIV status

Target Group	Disclosed HIV Status Mean (SD)	Not Disclosed HIV Status Mean (SD)	t (df)	P
All Targets	22.59 (8.84)	25.50 (9.06)	.871 (64)	.387
Partner(s)	22.85(9.00)	23.29 (8.86)	.116 (39)	.908
Family	24.24 (9.19)	20.75 (8.47)	-1.500 (60)	.139
Friends	24.18 (8.79)	18.63 (6.47)	-2.250 (48)	.029

Table 18: Independent sample t-tests comparing means and standard deviations of Experience of Shame Scale Behavioural Shame Subscale scores for participants who disclosed and did not disclose their HIV status

Target Group	Disclosed HIV Status Mean (SD)	Not Disclosed HIV Status Mean (SD)	t (df)	P
All Targets	21.19 (7.66)	26.50 (4.75)	1.904 (64)	.061
Partner(s)	21.00 (6.07)	25.57 (5.32)	1.849 (39)	.072
Family	20.66 (8.11)	23.79 (6.35)	1.605 (60)	.114
Friends	20.00 (7.87)	23.63 (6.78)	1.584 (48)	.120

Table 19: Independent sample t-tests comparing means and standard deviations of Experience of Shame Scale Bodily Shame Subscale scores for participants who disclosed and did not disclose their HIV status

Target Group	Disclosed HIV Status Mean (SD)	Not Disclosed HIV Status Mean (SD)	t (df)	P
All Targets	8.38 (3.60)	7.88 (2.95)	-.379 (64)	.706
Partner(s)	8.44 (3.42)	7.43 (2.76)	-.733 (39)	.468
Family	8.53 (4.09)	7.88 (2.71)	-.754 (60)	.454
Friends	8.63 (3.22)	8.06 (3.52)	.545 (48)	.588

Intercorrelations between the shame variables are shown in Table 20. Variables include ESS total scale, ESS characterological, behavioural and bodily shame subscales.

Table 20: Intercorrelations between Experience of Shame Scale subscales

Shame Scale	2	3	4
1. ESS Total Scale Score	.901**	.811**	.575**
2. ESS Characterological Shame	--	.537**	.461**
3. ESS Behavioural Shame		--	.222
4. ESS Bodily Shame			--

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

* . Correlation is significant at the 0.01 level (1-tailed)

On examination of the correlations between the shame variables it was found that the three subscales of the ESS were highly inter-correlated with the ESS Total Scale

Score (see Table 20). These highly inter-correlated shame constructs have important implications with regards to future analyses and collinearity (Tabchnick & Fidell, 2001).

2.2.9. Predictors of HIV Disclosure to All Targets and Partner(s)

The very small number of participants who had not disclosed to any identified targets (N = 8) and to partner(s) (N = 7), precluded any meaningful multivariate statistics to be undertaken.

2.2.10. Predictors of HIV Disclosure to Family

Due to only one demographic variable, months since HIV diagnosis, being significantly associated with HIV disclosure to family, no further meaningful multivariate statistics could be carried out to explore factors influencing HIV disclosure to family members.

2.2.11. Predictors of HIV Disclosure to Friends

In order to address the extent of overlap between associations found between demographic, HIV illness variables, characterological shame and HIV disclosure to friends, a hierarchical logistic regression analysis was conducted with HIV disclosure to friends as a dichotomous dependent variable. In the first step, gender, months since HIV diagnosis, ethnicity and English as 1st language were entered as predictors and in the second step the shame construct, characterological shame was included in the model (see Table 21).

Table 21: Logistic Regression Summary Predicting HIV disclosure rates from shame variables statistics for HIV disclosure to friends (n=50)

Logistic regression test statistics					
Predictor Variable	B - value	Odds ratio	Wald	χ^2	p - value ^d
Model I	--	--	--	19.850 ^a	.001
Months since HIV diagnosis	.016	1.017	3.241		.072
Gender	1.528	4.609	3.482		.062
Ethnicity	-.574	.563	.415		.519
English as 1st Language	-1.781	.168	4.679		.031
Model II				28.354 ^b	.000
Months since HIV diagnosis	.015	1.015	2.424		.119
Gender	1.779	5.924	3.548		.060
Ethnicity	-1.364	.256	1.556		.212
English as 1st language	-2.062	.127	4.244		.039
Characterological Shame	.187	1.206	5.500		.019
Change (Model II- Model I)	--	--	--	8.505 ^c	.004

^a d.f. = 4; ^b d.f.= 5; ^c d.f.=1 ^d All p-values for independent effects are based on the difference in χ^2 between the full model and a model with the IV in question dropped (evaluated 1 d.f). Tests based on the Wald statistic are known to be inaccurate, especially when B-values/odds ratios are large (Tabachnick & Fidell, 1996)

The significance of the independent contribution of characterological shame after controlling for gender, months since HIV diagnosis and ethnicity and English as 1st language was assessed by the difference in χ^2 between the two models (Tabachnik & Fidell, 1996). The χ^2 statistics of the two models and the B-values, odds ratios and associated significance levels are presented in Table 21.

From Table 21 it can be seen that the change in the χ^2 between model I and model II was highly significant (p = .004), suggesting that characterological shame plays a substantial role in HIV-positive individuals' decisions to disclose or not disclose

their HIV status to friends. Using a probability cut-off of .50 as a classification rule, model II correctly classified 78% of cases as either HIV disclosers or non-disclosers.

Examination of the effects of individual variables suggested that greater levels of characterological shame were significant independent predictors of HIV disclosure to friends. Over and above statistical significance. Odds ratios reflect the change in the ratio of the probability of HIV disclosure to non-disclosure to friends following a one unit change in the independent variable. More specifically, a unit increase in characterological shame is associated with increased odds of HIV disclosure to friends for this sample.

Overall, the results of the logistic regression analyses suggested that characterological shame factors are linked with HIV disclosure to friends when demographic and HIV illness variables were controlled for. Preliminary analyses indicated that characterological, behavioural and bodily shame factors were not found to be linked to HIV disclosure to all targets, partner(s) and family members and that behavioural and bodily shame were not associated to HIV disclosure to friends.

2.2.12. Reasons for HIV Disclosure and Non-Disclosure

Of the participants, 57 of 66 (86%) provided a variety of reasons for and against disclosure (see Table 22 to Table 28). 19 participants gave more than one reason for disclosing. Four themes emerged from the responses given by participants who had been able to disclose their HIV status to identified, significant others (see Table 22).

Table 22: Reasons given for disclosure of HIV status

Thematic category (IR: Inter-rater reliability)	n	Percentage (%)
Duty to inform (IR:100%)	43	75
Emotionally close & supportive relationship (IR: 90%)	22	39
Breach of confidentiality & becoming unwell (IR: 100%)	10	18
Similar background & experiences (IR: 100%)	6	11

The main theme identified was ‘Duty to inform’. 75% of respondents perceived that they had a personal obligation and responsibility to disclose their HIV status, particularly to partner(s), close family members and close friends. The second most commonly cited reason was ‘Emotionally close and supportive relationship. (39%), ‘Breach of confidentiality & becoming unwell’ was the next most common reason given for disclosing. 18% of respondents indicated that having their HIV status revealed was not their choice and/or emerged in the context of illness. Finally, the fourth theme reported was ‘Similar background & experiences’. 11% of respondents indicated that their reason for disclosing was knowing the other person was HIV seropositive and had or was dealing and coping with similar experiences.

Table 23: Reasons given for disclosure of HIV status - Thematic categories

Duty to inform (IR:100%)	43	75
<p>“Because I felt that they needed to know”</p> <p>“Needed to know the reality and face the challenges”</p> <p>“Because I thought it was wise for X to get checked since they are my partner”</p> <p>“X had to know”</p> <p>“I wanted X to know my status”</p>		
Emotionally close relationship (IR:90%)	22	39
<p>“Because we are friends and we confide in each other.”</p> <p>“I am close to X”, “very close family member”</p> <p>“X is my best friend and loves me for who I am, whatever the circumstances”</p> <p>“Supportive and loving relationship”</p> <p>“Because I feel safe to talk with X”</p> <p>“Very good friend and I can trust them”</p>		
Breach of confidentiality & becoming unwell (IR:100%)	10	18
<p>“My child (Adult child) is HIV, I had no choice”</p> <p>“ They found out when I was rushed into hospital with PCP”</p> <p>“They found out because I was seriously ill and in hospital”</p> <p>“X saw me getting ill, I needed to explain”</p> <p>“It got difficult explaining hospital visits”</p> <p>“Doctor told my partner”</p>		
Similar background & experiences (IR:100%)	6	11
<p>“X had experience of having another positive friend”</p> <p>“X is also infected”</p> <p>“To share problems affecting us”</p>		

Table 24: Reasons given for non-disclosure of HIV status - Thematic categories

Thematic category (IR: Inter-rater reliability)	n	Percentage (%)
Protecting other person from distress (IR:100%)	18	32
No reason or benefit from disclosing (IR: 100%)	12	21
Fear of rejection or being misunderstood (IR: 100%)	10	18
Physical distance (IR: 100%)	7	12

Protecting others

‘Protecting the other person from distress’ (IR = 100%): 18/57 (32%) was the most commonly cited reason for respondents being unable to disclose their HIV status to self identified important others.

Table 25: Reasons given for non-disclosure of HIV status - Thematic category: Protecting others (IR:100%)

“Because she would be distraught”
“I don’t want to worry her/him/them”
“old and infirm, don’t want to worry X”
“Disabled, don’t want to worry X”
“Not to hurt them”
“ X suffers from X. Disclosing to them would be like committing suicide”
“X will be too worried as to what is going to happen to me”
“Emotionally weak person”
“X would collapse and die”
“What for would only worry X”.
“Suffers from X physical condition. I love her to death.
“Disclosing this information could break her down”
“Because I do not want X to think that I am going to die”
“X suffers from X medical condition. Lost most of their children in genocide in Rwanda, so I find it unwise to add more injuries to X”.

No Reason or benefit from disclosing

The perception that there was ‘No reason or benefit from disclosing’ (IR = 100%): 12/57 (21%) was the second most common reason given by respondents for not disclosing their HIV status at the present time. This group included those respondents who perceived their ‘identified important others’ were not at risk of contracting HIV therefore they did not need to disclose HIV status to them.

Table 26: Reasons given for non-disclosure of HIV status - Thematic category: No reason or benefit from disclosing (IR:100%)

“They are not at risk, no need to tell”
“I just feel that they do not need to know”
“I do not feel that they need to know about it”
“No need to tell”

Fear of rejection and being misunderstood

‘Fear of rejection and being misunderstood’ (IR = 100%): 10/57 (18%) of respondents indicated that concern over how others would react due to stigma associated with HIV or protecting themselves from others reactions was a reason for not disclosing.

Table 27: Reasons given for non-disclosure of HIV status - Thematic category: Fear of rejection or being misunderstood

“My niece is very religious. Her religion would talk against gay people and anything like that. Scared how she would react towards me if she knew”
“Too scared to tell. scared of rejection”
“Afraid of rejection”
“Afraid, as I don’t know how my family will react”
“I am afraid to tell them. I’m afraid how they will react”
“Afraid they won’t handle it well and they will not want to know me”
“They would not relate to HIV. They would not understand”
“Our discussions about people with HIV makes me see that family won’t accept me if they know”

Physical distance

'Physical distance' (IR = 100%): 7/57 (12%) of respondents indicated that they did not disclose their HIV status due to friends and family living abroad.

Table 28: Reasons given for non-disclosure of HIV status - Thematic category: Physical distance (IR:100%)

"Waiting for the right time, or when in close contact.

"He lives abroad. I want to do it personally"

"Not disclosed to my relatives because they live in Africa"

"Wife is back home, I only knew about it when I got here (UK), so it is very difficult to call her & convey the message"

CHAPTER 3: Qualitative Study of HIV Disclosure Experiences

3.1. Overview

To date there is limited understanding of the specific role psychological variables may play in HIV disclosure, or the role that psychological variables may have on HIV disclosure among HIV positive individuals from different ethnic and cultural backgrounds living in the UK. By combining both quantitative and qualitative approaches, this study aimed to elicit original descriptive and analytical information. The qualitative part of the study aims to further explore HIV positive individuals experiences of HIV disclosure with the aim of clarifying if psychological variables such as shame, anxiety or depression have influenced HIV disclosure experiences or if other variables are highlighted as being more prominently associated with HIV disclosure.

3.2. Study Design

A qualitative method of inquiry was used for this part of the study. It has been argued that qualitative methods are especially useful for exploratory research where little is known about the phenomenon of interest. Qualitative studies have also been highlighted as a useful complement to quantitative studies and can be used to elucidate or further explore quantitative findings (Barker, Pistrang & Elliot, 2002).

Focus groups were used as the primary source of data collection. Krueger (1994) defined focus groups as “carefully planned discussions, designed to obtain perceptions on a defined area of interest in a permissive and non-threatening environment” (p.6). These groups consist of interactive group discussions, with an

investigator acting as a facilitator, to optimise exchanges between members of the group and to prompt group members to expand on ideas, clarify points and develop insights which may not originally have seemed of major importance to individual members of the group (Kitzinger, 1994). What differentiates focus groups from other methods of qualitative data collection is primarily the presence of group interaction in response to research questions. In addition, the participants selected tend to have certain characteristics in common that relate to the topic of the focus group discussion. Thus gathering information in this way taps into a collective experience and the analysis of the participants' responses can provide important clues and insights into the area under investigation (Krueger, 1994).

3.3. Ethics

Ethical approval for this study was granted by Barnet, Enfield and Haringey LREC (Appendix 1b).

3.4. Participants

Multiple groups, typically composed of 6-10 people who are similar to each other, are needed to detect patterns and trends across groups (Krueger, 1994). The present study aimed to conduct three groups with 6-8 HIV-positive individuals from different cultural backgrounds in each group.

Participants recruited to complete the study's questionnaires were also asked whether they would take part in focus group discussions regarding their experiences of HIV disclosure and non-disclosure. Among the 66 participants who agreed to complete the questionnaires, 12 Black African females, 10 Black African males and 5 White

males agreed to take part in a focus group discussion. Dates and times for three focus groups were organised and potential participants were given study information sheets and details of where and when the groups would take place.

9 Black African women attended focus group 1 (FG1), participants in this group ranged in age from 25 to 55 years of age (mean age: 37 years). 8 Black African males attended focus group 2 (FG2). The age range of the participants who attended (FG2) was 30 to 40 years of age (mean age: 39 years). However, none of the White males who had been approached to attend focus group 3 (FG3) attended. In order to obtain qualitative data on HIV-positive White males experiences of HIV disclosure it was decided to approach five White males, who regularly attended the local HIV outpatients clinic where the questionnaire study had been undertaken, and ask them to take part in a semi-structured interview about their experiences of HIV disclosure. Five HIV-positive males were approached and completed a semi-structured interview about their experiences of HIV disclosure. The age range of the White males who were interviewed was 26 to 67 years of age (mean age: 44 years). Summary demographic details for attendees of the focus groups and the demographic details and HIV illness variables of the White males who were interviewed are given in Tables 29 to 31 respectively.

Table 29: Demographic details of focus group 1 (n= 9)

Variable	N (%)
Gender	
Female	9 (100%)
Ethnicity	
Black/Mixed	9(100%)
1st Language	
English	3 (33%)
Other	6 (67%)
Sexual Orientation	
Heterosexual	9 (100%)
Relationship Status	
Single	9 (100%)
Not Single	0 (0%)
Living Arrangements	
Alone	5(56%)
With Other(s)	4(44%)
Number of children	
0	2 (22%)
1	4 (44%)
2	0 (0%)
3 or more	3 (33%)
Education	
No Formal Qualifications	4 (44%)
O=Levels/GCSEs	5 (56%)
A-Levels	0 (0%)
Diploma	0 (0%)
Degree	0 (0%)
Higher Degree	0 (0%)
Employment	
Employed	2 (78%)
Unemployed	7 (22%)

Table 30: Demographic details of focus group 2 (n= 8)

Variable	N (%)
Gender	
Male	8 (100%)
Ethnicity	
Black/Mixed	8(100%)
1st Language	
English	4(50%)
Other	4 (50%)
Sexual Orientation	
Heterosexual	7 (88%)
Bisexual	1 (12%)
Relationship Status	
Single	4 (50%)
Not Single	4 (50%)
Living Arrangements	
Alone	4(50%)
With Other(s)	4(50%)
Number of children	
0	1 (12%)
1	4 (40%)
2	2 (24%)
3 or more	1 (12%)
Education	
No Formal Qualifications	1 (12%)
O=Levels/GCSEs	1 (12%)
A-Levels	0 (0%)
Diploma	0 (0%)
Degree	0 (0%)
Higher Degree	0 (0%)
Employment	
Employed	4 (50%)
Unemployed	4 (50%)

Table 31: Demographic details of participants - semi-structured interviews (n=5)

Variable	N (%)
Gender	
Male	5(100%)
Ethnicity	
White/White British	5(100%)
1st Language	
English	5(100%)
Other	0 (0%)
Sexual Orientation	
Homosexual	5(100%)
Relationship Status	
Single	1 (20%)
Not Single	4 (80%)
Living Arrangements	
Alone	2(40%)
With Other(s)	3(60%)
Number of children	
0	3 (60%)
1	0 (0%)
2	2 (40%)
3 or more	0 (0%)
Education	
No Formal Qualifications	1 (20%)
O=Levels/GCSEs	1 (20%)
A-Levels	0 (0%)
Diploma	0 (0%)
Degree	0 (0%)
Higher Degree	0 (0%)
Employment	
Employed	4 (80%)
Unemployed	1(20%)

Table 32: Focus group and Interview participants' CD4 count and viral load details

Focus Group 1	N9 (%)
CD4 Count	
<50	1 (11%)
51-200	0(18%)
201-500	5 (56%)
501+	2 (22%)
Unknown	1 (11%)
Viral Load	
Undetectable	5 (56%)
51-1000	0 (0%)
1001, 10,000	0 (0%)
10, 001-50,000	0 (0%)
50,001 -100,000	0 (0%)
100,000+	1 (11%)
Unknown	2 (22%)
Focus Group 2	N 8(%)
CD4 Count	
<50	1(12%)
51-200	2(25%)
201-500	4 (50%)
501+	0(0%)
Unknown	1(12%)
Viral Load	
Undetectable	5 (63%)
51-1000	0 (0%)
1001, 10,000	0(0%)
10, 001-50,000	2 (25%)
50,001 -100,000	0 (0%)
100,000+	0 (0%)
Unknown	1 (12%)
Semi-Structured Interviews	N 5(%)
CD4 Count	
<50	0 (0%)
51-200	1(20%)
201-500	2(40%)
501+	1(20%)
Unknown	1(20%)
Viral Load	
Undetectable	3 (60%)
51-1000	0 (0%)
1001, 10,000	0 (0%)
10, 001-50,000	0 (0%)
50,001 -100,000	0 (0%)
100,000+	0(0%)
Unknown	2 (40%)

3.5. Materials

The content of the focus group/interview questions was generated from the review of the literature and previous research regarding HIV disclosure among different ethnic and cultural groups and from consultation with clinicians such as psychologists, doctors and nurses working with HIV-positive individuals.

Once an initial set of questions and a moderator's guide for facilitating the focus group was compiled, the focus group format was field-tested by having experts familiar with the study area review the logical and sequential flow of the questions and the ability of the probes to elicit the information desired, a process recommended by Kreuger (1994). The focus group interview schedule was then piloted with one group, reviewed and amendments were made following this. In this way it was possible to ensure that questions were appropriately phrased in terms of clarity, precision and brevity. (See Appendix 12 for the focus group/interview schedule).

3.6. Procedures

In order to ensure that the participants were comfortable taking part in the focus groups/interviews, and felt able to talk freely about their experiences of HIV disclosure and non-disclosure, the researcher visited the centres from which they were recruited prior to the groups and interviews taking place, to introduce herself to them and familiarise them with the aims and procedures of the study. All participants were provided with a copy of the study information sheet (See Appendices 6 & 8) and consent forms (Appendices 7 & 9) to read prior to their consent to take part being obtained.

The focus groups lasted approximately one hour and the interviews lasted between thirty and forty five minutes. Both were conducted by the researcher, who acted as the facilitator. The facilitator's role was to ask the open-ended questions as planned, probe for additional comments and monitor the group discussion /interviews. The facilitator also made brief notes of participants' responses. Additional summary notes were also made immediately after the focus groups and interviews had ended, regarding the main themes that emerged and the general atmosphere and emotional quality of participant's responses. The focus groups and interviews were audio-taped following the instructions outlined in the recording procedures (See Appendix 10). They were then transcribed verbatim, with all identifying details excluded in order to ensure confidentiality, in preparation for later data analysis.

3.7. Data Analysis

Careful attention was paid to participants' language and meaning rather than the linguistic features of their speech, such as repetitions or pauses, during the transcription process. A sample section of two transcripts can be found in Appendix 13. The transcripts were then analysed using Interpretative Phenomenological Analysis (IPA: Smith, Jarman, & Osborn, 1999; Willig, 2001), a method of analysis that has been widely used in health psychology research (Shaw, 2001).

IPA works with texts generated by participants, most commonly with transcripts of semi-structured interviews (see Smith, 1995). It takes an idiographic approach, engaging in detailed and exhaustive analysis of each individual transcript before integrating these at a later stage into an overarching thematic representation that reflects the experience of all participants. IPA involves the identification, clustering

and integration of themes in individual transcripts in an ongoing and cyclical process. The analysis continues until the themes from all transcripts are fully integrated into an overarching thematic representation of all participants experiences in the form of themes and sub themes (Smith et al., 1999; Willig, 2001). This section details each step of the IPA analysis as it was conducted in this study. Examples illustrating each of the steps are provided in the appendices.

The first step of the analysis aimed to identify in each individual transcript the main ideas, concerns and experiences expressed by that particular group or participant. This involved reading and re-reading each individual transcript, following the guidance of Smith et al. (1999) to note down in the margin ‘anything that strikes you as interesting or significant about what the respondent is saying’ (p. 220). These notes comprised the participant’s own words, and no attempts to thematically summarise or group these were made at this initial stage of the analysis. An example of this stage of the analysis is shown in Appendix 14.

The second step of the analysis involved organising the notes made for each individual transcript, and considering how they related to each other. This process aimed to identify possible connections between the ideas and experiences identified in step 1, and to begin to group these into tentative themes and sub-themes. This was done for each focus group and individual interview transcript and is illustrated in Appendix 15.

Once steps 1 and 2 had been carried out with each transcript, a cross-case analysis was undertaken with the aim of integrating the themes and sub-themes identified for each transcript into an overarching structure that represented the experience of all

participants. This process began by writing out the identified themes from each transcript and tentatively grouping together those that appeared to express similar ideas. Some of the themes from across the transcripts clearly expressed a common idea and were easy to cluster together into a 'master theme.' Other themes were less readily grouped together and required careful thought about how they might be related, requiring a return to the transcripts from which they had emerged to re-examine the participant's meaning. During this process certain themes were identified that were shared by a number of individual transcripts, and these were also grouped together on the basis of shared meanings. Some themes were wholly subsumed into new master themes, or their sub-themes divided between emerging master themes that appeared to more closely relate to their individual meanings. This stage of analysis was thus cyclical and moved between emerging themes and the verbatim transcripts, ensuring that the themes identified were grounded in the data from which they were derived.

During this cross-case analysis a small number of themes that were identified in only one or two of the participant's transcripts and which did not appear to be related to any other identified themes were dropped from the analysis. The remaining list of themes thus constituted a 'master list' that reflected the experience of the group of participants as a whole, and consisted of the 'major themes which seem[ed] to capture more strongly the respondents' concerns on this particular topic' (Smith et al., 1999, p. 223). This master list of themes and sub-themes is presented in Table 33.

Finally, the final stage of IPA required a complete set of quotations for each master theme and sub-theme to be gathered. This was done by returning to the transcripts

and re-analysing them using the themes and sub-themes identified in the master themes (See Appendix 16). These quotations were then listed in full in a final master table of themes and quotations, which provided the basis for the account given in the results section of this chapter.

3.8. Credibility Checks

While IPA recognises that an individual's experience cannot be directly accessed but can only be mediated through the researcher's own interpretation of the data, the credibility of the analysis can be enhanced by the engagement of more than one researcher with the text (Elliott, Fischer, & Rennie, 1999).

In this case, a second researcher with extensive experience of IPA and specialising in working with HIV-positive individuals read a selection of the transcripts and examined them for emerging themes. These were then cross-checked with the themes originally identified, and suggestions made about where the analysis could be extended. The second researcher then examined the completed list of themes for each individual transcript and later the master list of themes, each time suggesting points where the analysis might be improved in terms of its comprehensiveness or clarity. She also checked the final master list of themes to ensure that it was internally coherent and meaningful, and that the themes identified reflected the original transcript data. Feedback from this researcher was incorporated at each stage into the cyclical process of analysis.

3.9. Results

3.9.1. Background Information

Nine Black African females and 8 Black African males living with HIV /AIDS took part in two separate same sex focus group discussions about their experiences of HIV disclosure. However, due to confidentiality concerns it was not possible to conduct a focus group with White male participants as intended, so semi-structured interviews using the focus group questionnaire schedule were conducted individually with five White males instead.

3.9.2. Qualitative Data

The analysis of the focus groups and interviews identified a total of 5 themes and 31 sub-themes and are shown in Table 33 below.

Participants' accounts have been quoted to provide examples of the themes and sub-themes identified. Verbatim reports are recorded in quotation marks or in separate italicised paragraphs. In the excerpts from these transcripts, a convention of FG1 and FG2 is used to indicate whether the participants are from focus group one (FG1), comprising of HIV-positive Black African females or from focus group two (FG2), comprising of HIV-positive Black African males. Individual interviews were carried out with five White HIV-positive males, who are identified as WM1 to WM5.

Table 33: HIV disclosure and non-disclosure qualitative themes and sub-themes

Themes	Sub-themes
Reasons for Disclosure	Moral Obligation
	Relief
	Needing Support
	Sick Can't Wait
	Educating Others
	Similar Others
	Trust
Reasons for not Disclosing	Down to the Individual
	Protecting Self
	Protection of Others
	Fear & Lack of Confidence
	This is My Business-Confidentiality
	Going Back - Fear of Deportation and Death
The Process of Disclosing	Hard to Tell
	The Right place, the Right Time, the Right People
	I Just Say it Straight
	Cook My Story
	Leaked by Someone Else
	They Gathered What was Wrong
	The One who Passed the Message
HIV-positive individuals own reactions to disclosing not disclosing	Shame
	Guilt
	Regret
Other peoples reactions to HIV disclosure	Denial
	Shocked/Upset
	It's a Shameful Illness
	It's a Stigma
	Discrimination
	Treated like a Leper
	They Reject You
Supportive	

3.10. Reasons for Disclosing

Moral Obligation - Many participants felt that they had a responsibility or obligation to disclose their HIV status to important others in their lives. Many indicated they had disclosed their HIV status out of a sense of duty and felt that others “needed to be aware” or had a “right to know”. Some talked about having to disclose because of a sense of duty and obligation to family members. ‘My children have to know

because they are my children. My mum is my mother. My brother is my brother. That's that'. (FG1). For a number of participants, this sense of duty also extended to friends. One participant described how 'I had no option where my family and friends were concerned. 'You had to tell them, there was no option' (WM4). Some but not all participants talked about feeling that their partner(s) 'needed to know' or 'needed to be aware' of their HIV status. One participant felt very strongly that if you were HIV-positive and '... you have a partner, then you have a moral obligation to tell' the partner (WM5). Finally one participant described how he had felt obliged to inform his friends and co-workers of his HIV status to ensure their safety wouldn't be compromised should he be in a situation where he required their help following an accident:

If friends are in your company and something happens they need to know. I expect... if I fell off, fell over and started bleeding like mad and my friends are around me I'd expect them, I'd have to tell them, so they knew, just in case they had a cut or... I couldn't face that. So simple, they have to know. It is a bit like if I have an accident, I immediately tell anyone around me. I have done that. Some of my colleagues at work didn't know for several years and I only came out to a few of them when I had a major accident in work and was pouring with blood. And at that time, I just done it. It was the first thing that I came out with. Be careful, get gloves, go to the first aid kit, I'm HIV-positive, so make sure that mmm. That's how it has been. WM4

Relief – Mostly women and some men talked about how keeping the secret of being HIV-positive status created a psychological burden and how "Sometimes it's too much to keep it yourself" and that "Telling can be a relief" (FG1).

I tell her, I don't care Mother. It was too much. Too much on my mind, too much. So, I just said, so you know what, this one, this, I have this one (HIV), that's why I can't be concentrating. FG1

Women reported feeling they were carrying less of a burden following disclosure of their HIV status:

For me it was like I had to tell everybody I'm positive and to be free.
FG1

Needing Support – Mainly Black African females and White males indicated that they had ‘Told for support’. They described disclosing their HIV status with the idea that it could be beneficial and that by doing so they would gain practical and emotional support from those they told. Partner(s), friends and family were all identified as being expected to play a central role in providing practical and emotional support:

He (partner) would probably need to be giving that support to me. WM1

I said my friend, I told you as a friend, I need help from you. I want you to help me. FG1

The importance of family support for HIV-positive individuals was also highlighted and discussed:

They (HIV positive individuals) need support in other respects from their family until they get to a certain age or certain standing so that they can actually stand by themselves. People still need support of their families in certain cultures. WM4

Black African men also highlighted disclosing to gain “support and advice from medical people”. FG2

Sick Can't Wait - Some of the Black African females and the White males interviewed reported that becoming seriously unwell, being hospitalised and fear of death and dying had led or forced them to disclose their HIV status:

I came down with full-blown AIDS. So in a way I had no option where my family and close friends were concerned [had to tell them]. WM4

I had to do it because I was quite ill.

WM2

I was seeing, I would be dying I'm going to die soon (that's why I disclosed). FG1

Educating Others – Some participants talked about trying to educate others about HIV through disclosing their HIV status. They suggested that ‘It is only when you share these things [your HIV status] that you create the awareness and sensitise others (FG2). Some people mentioned using the disclosure of their HIV status as an educational way to talk and highlight to others the seriousness of the illness and to provide an opportunity for both parties to talk about safety issues:

You should be trying to avoid the disease that I have just got. So my thinking was you know that you should know half the information I'm telling you anyway. And if you didn't you are a much more ignorant person than I thought you were. WM4

Some people also described disclosing their HIV status as a way to fight against the ignorance surrounding HIV. It was highlighted that ‘There is a general lack of awareness. People not even having the basic knowledge about HIV or how it spreads or whatever.’ (FG2). Finally, others wished to explain from their own experience what the reality of being HIV-positive is:

First you have to let them know before you disclose that a person can live with it for many years. It doesn't mean if you have it like people used to think before, that it is the end of you. You are just a normal human being who can do things, just like the rest. So if they get to know about all these things, when they discover that you have it, they will just treat you like the rest of them, I know it. He's going to live with us. It doesn't mean he is going to die or whatever. FG2

Similar Others - Black African participants in particular reported feeling that they had felt more comfortable to disclose their HIV status to those who were also HIV-positive. They also described indirectly disclosing their HIV status by attending support services for other HIV-positive individuals. Many talked openly about how

they found it easier to talk to individuals who share the same problems, and that they preferred being with similar others who were able to understand and emphasise with the difficulties they faced as HIV-positive individuals. Many participants shared the views that 'You've all got the same thing and all got the same problems' and Even if you are telling them your problems, you don't feel shy. It's easier because they are like you [HIV-positive]' (FG1). Many also highlighted that it was a relief to meet similar others in a setting where there was no need to disclose their HIV status or explain themselves:

I have never told anyone; just I meet people who have the same condition as me. FG1

Trusting People to Tell - All participants reported a belief that without trust you can't disclose and reported that HIV disclosures were made to people who they deemed to be close and believed could be trusted. The belief behind this being that only when you can ensure protection for one's self, can you disclose your HIV status. Common ideas reported were 'You have to know someone first. You have to know the person first' and 'Make sure you trust the person' before you can disclose. The idea of absolute trust was also a recurrent theme. People talked about disclosing to others they 'trust completely' or 'trust one hundred percent'

You know your family or your boyfriend or your friends and even your sister. You actually know which sister to tell and which not to tell. FG1

If you have known people for a long time, you have enough confidence to tell them your inner most fears as opposed to meeting a stranger on the street and having to disclose or tell people you work with. FG2

In Summary, this section has described how HIV-positive individuals reported disclosing their HIV status due to a strong sense of moral obligation to do so and/or

because keeping their HIV positive status a secret was a psychological burden. Many disclosed in order to access support. When symptoms became more noticeable or they were seriously ill and required hospitalisation, some participants described a process of being prompted or forced to disclose their HIV status. For some, the reason they disclosed was because they trusted the person they told or knew that the target was similar to them in some way or also HIV-positive and having to deal with similar issues. A another reason cited for disclosing was as a means of educating other people about the HIV virus, with the hope that it would reduce the shame and stigma attached to the illness.

3.11. Reasons for Not Disclosing

Down to the Individual – All participants reflected on an individual's choices to disclose or not disclose their HIV status to others. Participants unanimously acknowledged that 'HIV disclosure is person specific' that 'not everybody can tell' and 'not everyone should tell.' Participants also talked about how disclosing is 'different for different individuals'. Both Black African Women and White males pointed out respectively that:

For some people it might be the right decision not to tell their family. WM5

and

Not everyone should tell their family or friends or that everyone should tell their friends. FG2

Protecting Self - In talking about reasons for not disclosing HIV status, participants also described how the certainty and uncertainty of how others would react to

learning about their HIV status significantly influenced whether or not they disclosed. Many participants mentioned that 'You have to take care of yourself first' and that they commonly don't tell as they have made a decision to 'protect' themselves. Participants described how when faced with anticipated fear of rejection, stigmatisation, ostracism, discrimination and hostility non-disclosure of HIV status was seen as a form of self protection.

Yes, don't come and spread it in here. They'll (family) sack you. So it is better that you keep it by yourself. FG1

People openly acknowledge that if they felt that by disclosing their HIV status that they were '...going to be made to feel uncomfortable or ashamed or rejected' then they would not. Others indicated that 'If you know they can cause you a problem then you won't go there (you won't disclose). For others it was the fear of the unknown and the potential repercussions of disclosing that led them not to reveal their HIV status:

It's in my mind if I do tell them how are they going to react. So, I just keep it to myself. WM3

For two of the White males, discussion about reasons for non-disclosure brought up very real worries about losing their jobs, pensions and homes. One person explained how he felt that if he disclosed his HIV status he'd have:

A cat in hell's chance of getting a mortgage because of the disease WM2

Others talked about the potential added strains being HIV-positive puts on relationships and because deep down nobody really knows what others are thinking about it or how they are going to react many participants 'decided that it (disclosing)

could cause more problems than it was worth'. The idea that disclosing is about taking a 'chance' or 'risk' or could in some way be counterproductive, was also expressed. Participants who held this belief indicated they thought that it was best not to disclose:

There's no percentage in telling anybody. Why tell? They are not going to make my life any better. WM5

Protection of Others - Worry about others ability to cope with the knowledge of a HIV diagnosis leads to non-disclosure as a form of protecting others from psychological, emotional and physical distress. All participants expressed a belief that their choice not to disclose their HIV status was a form of protecting others from the psychological and emotional distress that maybe associated with them revealing their HIV diagnosis. Many participants weighed up the potential impact disclosing may have on those they wished to tell. Worry about others' ability to cope with knowledge of their HIV status and fears were reported that 'they just couldn't handle it'.

I thought no, I'm not going to tell them (Adult children), this may affect them. FG2

Mum will die. She will collapse. FG2

She's not strong, so I don't know what will happen to her if I tell her. That's why I keep quiet. FG2

Fear & Lack of Confidence – Mainly Black African females reported that when things are stacked against you, you have no legal status, you have AIDS and you don't feel good about yourself or life, you don't have the confidence to disclose your HIV status to others. In comparison, having legal status to remain in the UK

stability, security, hope and confidence means you are more likely to disclose your HIV status:

I think what brings people not to disclose is they lack confidence. Now suppose you are here, you are in asylum, you have no money, you are having problems, I don't think you can come out and start saying I'm HIV-positive. Those people who are confident, those who are rich, if you have something you can be proud of, then you can come out and say I am positive. So what are you saying, cause if I have a definite, if I have a house or I have a family I'll feel happy, I'll feel confident and then I'll be able to tell people I'm HIV-positive because I know I can feed myself, I can go to work, I can do everything as a normal person, that's why I can come out and say that I am HIV-positive...// You are sure of yourself. FG2

Black African participants, especially the women, compared and contrasted their personal circumstances and were very forthcoming in stressing the belief that a number of women present or that they knew had been able to disclose their HIV status because 'She doesn't have the same problems' because she has her stay in the UK. However, for some women having their legal status to remain did not appear to make a difference and they talked about how this alone would not give them the confidence to disclose:

Even if I get my status or whatever, I don't think I can just go straight to my family (Yeah, yes) and tell them that I am HIV-positive. FG1

One White male also highlighted how security, hope & confidence may positively influence HIV disclosure:

It is probably better if you didn't [disclose] until you know you are secure in yourself, secure in your job, secure in everything, so that you could stand there by yourself against them. WM4

This is My Business - A number of the White males interviewed reported that their decisions to not disclose their HIV status were based around the belief that by

keeping their HIV status confidential they were able to feel protected and in control of personal information about themselves and their HIV status. Participants talked about their HIV status being something 'personal' that they liked to keep to themselves. Describing their HIV status as 'not the type of thing they want to tell people'. Some people talked about not disclosing to ensure their privacy and expressed worries that if they told one person, they may not be able to control who else may find out:

But, I wouldn't [disclose], that's as far as it goes. This is my business, this is my problem, and I don't want people talking behind my back or whatever. WM2

Going Back – Finally, Black African participants were very open about the role that uncertainty, fear of deportation and death played in non-disclosure of their HIV status. For many Black African participants, living in the UK represents access to medical support and treatments which provide a chance for a longer and better life. They talked openly about their fears of being deported back to Africa and concerns about the lack of medical treatments available for HIV in Africa. Many people also expressed anxiety concerning the varying types of suffering that this could mean:

You've got medicine here and I'm HIV. Then I tell you. Then you tell me go back to your own country. FG1

Still, the Home Office here write and say with your HIV status, you have to go back to your home. Think how you feel. You are already diagnosed here and you are treated like an asylum seeker. FG1

There is a gap with regards to people who are over here whose stay over here is a bit shaky. They have overstayed and they can't really come forward to get medication because they are afraid they are going to end up being deported. They are going to be very many people in the community who are hiding. They will still be spreading the virus. FG2

Participants explained that in Africa that financial resources are limited and that the limited medication that is available is very expensive meaning that if they were to go back to Africa it would mean you ‘Don't have money to sustain yourself’

The whole world now say there is medication in (Africa) and it's rated to be best there is in the world but on the ground there is nothing. If you are actually there, there is nothing on the ground. FG2

People also talked about how the health implications of limited medication and linked this with their concerns about death and dying:

But if someone who has been here [UK] and knows that whole drill and goes back home they won't feel any motivation because they know I can't just take one drug. I need my viral load tested, I need my liver tested, I need my, I need this. I need that. FG2

3.12. Process of Disclosing

Independent of participants' gender, sexuality and cultural backgrounds, similar themes emerged in relation to the process of disclosing their HIV status to others.

Hard to Tell – Once the decision had been made to inform others of their HIV status both male and female participants reported experiencing a variety of difficulties related to making the actual disclosure including breaking the ice, saying the unsayable and the difficult experience of being in the room with the person to whom the disclosure is being made.

No you can't go straight (To tell family). FG1

I can't begin to tell some people I see, I have the thing (HIV). FG2

All participants talked about disclosing their HIV status as something which was 'difficult' or 'hard' to tell others. For some it was something that they could not contemplate doing. These participants talked about how you 'can't speak' or 'daren't say' that you are HIV-positive. Participants also reported not only that it was generally hard to disclose their HIV status but that it was difficult regardless of whom they wished to disclose to, or their own gender, sexuality or cultural background. Both Black African and White males thought that it would be just as difficult for females and males to disclose their HIV status.

The Right Place, the Right Time, the Right People – Many participants, both men and women talked about the process of controlling who is told or not told about their HIV status and where and when disclosures should take place to ensure protection of themselves. One theme which ran across all participants was that you should be very selective in who you tell:

You have got to know who you are disclosing to and why. FG2

It depends on whatever situation, whether you can tell. FG2

I Just Say It Straight – some participants were able to disclose their HIV status in a matter-of-fact way. Both males and females talked about the benefits of being 'open', 'straight' and 'honest' with others about their HIV status. Many participants described using a direct approach to disclosing their HIV status to family, friends, work colleagues and, for some, the wider communities in which they lived:

I just say it straight, that I was HIV-positive - So we could talk about it. FG2

I just explained to him. I just let him sit down and I explain to him. FG1

I stood up in church, I said look I am HIV-positive. FG1

I've shared it with all my friends, most of my relatives & the community of life. FG2

It's best to come straight and be honest. FG2

I sat down with my direct manager and my manager above and told them what the exact situation was. WM4

Cook My Story – Where as other participants explained that disclosing their HIV status was not something that was 'cut and dried' suggesting that it was not a straightforward process. They described a pattern of initially pretending that they did not have HIV but some other medical condition or other troubles that were affecting them. Following this many people reported 'skirting' around the issue of their HIV status, not denying it, but not confirming it. People described this as having 'told the truth up to a certain point' or 'cooking' their story. Some also reported disclosing their HIV status using less direct communication. Some participants talked about how 'you can raise the issue, but not referring to yourself' in order to gauge and test others reactions before disclosing one's own HIV status:

I said I have problems, school fees, health problems, money problems, don't worry. FG1

I have had some medical conditions which have been related to HIV, which could have been acquired without being HIV-positive – I have been focusing on talking about those. WM1

People know I come to hospital. I come to hospital because I have arthritis, I've got gout, I've got liver problems, I have acid problems. I tell people this, but I don't admit to the big H (Being HIV positive). WM5

Leaked by Someone Else - All participants talked about having experienced their privacy and confidentiality breached following disclosure of their HIV status to

others. The Black African participants in particular stressed that this 'leakage' or 'spreading' of their HIV status had occurred by other HIV-positive individuals and health and HIV service providers, people they would not have anticipated to act in this way:

Listen, sometimes even us positive people we talk about a person as they are positive. FG2

How dare you? I confide in you as my cousin. I confide in you, you know, because I broke down. I started crying and I said to her this is the issue. Little did I know, she went just outside and picked up the phone and she called straight with her mobile, straight to [Name of African Country], she told them she's dying...//. FG1

I said my friend, I told you as a friend, I need help from you, I want you to help me. Now that you have given it out. Now what can I do. She said no I have not. But, there were at least two people have said that your friend like this, like this, she told me. FG1

You say to the person you are with, that person is positive even though you yourself are positive. FG1

In our communities there is a lot of talking and one thing leads to another. Even people you trusted do not hold back. FG2

Like we are here [at HIV support group], you say something and the next five minutes the person who is there to provide whatever service you want is going out and spreading it everywhere. FG2

Doctor didn't tell me - but told my niece because she was a nurse. FG1

Once you tell, the information gets to one and it gets to all of them. Information gets out; it spreads like wild fire. WM4

They Gathered What was Wrong - Although a minor theme, both men and women talked about knowing that other people 'suspected' or had gathered that they were HIV-positive:

The children back home were chastised about HIV. So this girl knew, said then Mummy must be sick if Daddy has told me that he is dying of AIDS. Then Mummy must be what, but she also swallowed it. And to cut the story short, when I got here..., Of course when I when I fell sick it was when I came here (UK). And then one day I told her that I was HIV-positive and she told me, Yeah, Mummy all along I've know, that was why I pushed you to come here. That was after 10 years. FG1

One White male talked about how his mother may in the back of her mind know, but she never really discloses it or asks him directly if he is HIV-positive:

My mum is a nurse and every time I'm coming to the hospital, she wants to know what's been going on, what the Dr has said what treatment I'm getting, what's this, what's that. WM1

and

My mum is always asking, she says are you sure that you are telling me everything. Are you sure that you are telling me everything that the doctors are telling you? WM1

Indirect Disclosure (The One Who Passed the Message) - Some participants both males and females explained how they did not directly tell everyone they disclosed to, preferring in some instances to get a trusted family member or health professional to 'tell them the facts as clearly as you can':

So she (counsellor) she was the one who passed the message to my children. FG1

I told this one person and she had to tell everybody else. So I told and I didn't have to go through who I am going to tell because someone else did it for me. FG1

I can let others know and then in the process other members of the family or community will try and find a way to let these people know. FG2

Even my mother made a decision to tell some of my other relatives - because I was not going to come into contact with them. They were going to wonder where I was, what I was up to. WM4

This section has highlighted how many participants described the process of HIV disclosure itself as a hard thing to do. Although some participants had not disclosed their HIV status, those that had appeared to have gone through a process of either initially telling lies, skirting around the issue, cooking their story and putting others to a test before going making a decision to disclose or not disclose. Where participants were more confident in themselves and they perceived others reactions would be accepting or supportive, HIV disclosure was communicated in a straight forward matter of fact style.

3.13. HIV-positive Individuals' Reactions to Disclosing and Not Disclosing

Participants reported varying experiences associated with HIV disclosure and non-disclosure. Both males and females experienced feelings of shame and guilt for not disclosing their HIV status, although these experiences were not universal. A minority theme associated with disclosure of HIV status for one White male was regret.

Shame - Some participants said that they 'felt ashamed' of their HIV status and for not disclosing this to others. One woman talked about how she "saw HIV on my face" (FG1) and could only attend the HIV clinic if she protected her identity in some way 'I could come when I'm covered' (FG1). Other participants also talked about how feelings of shame lead to them feeling that they couldn't face people. Some people also described how others think that HIV is a 'shameful illness' but that they themselves were not ashamed of being HIV-positive.

I felt ashamed.

FG2

People definitely think it's a shameful illness. WM2

They expect you to feel ashamed and that adds stigma to it. WM2

I couldn't face people. FG2

Guilt - Both males and females reported feeling guilty with regards to not disclosing their HIV status. One woman described experiencing this:

When somebody looks to me like that I feel guilty. I thought she's going to confront me. FG1

You can feel guilty that you haven't told. FG2

Guilty – for keeping it to myself. FG2

Some participants on the other hand reported a low incidence of negative feelings about not disclosing their HIV status. For these participants there appeared to be a personal characteristic which they possessed that meant that they did not tend to experience guilt per se and therefore did not experience an association between choosing not to reveal their HIV status and guilt:

I am one of those people who don't suffer guilt at all. FG2

I don't feel bad about it (not disclosing) at all. FG2

Regret - A minor theme reported by one of the White males interviewed was regret. For this participant there seemed to be an association between disclosing his HIV status and feelings of regret and a wish that he could change the way in which he revealed his HIV status:

I regretted having told that person [female friend] in those circumstances. I would have rather not just have blurted it out when I was drunk and I would rather had more..., I was quite newly diagnosed at the time and I would rather have had more sort of time to decide who I was going to tell and who and I'm not going to tell and the circumstances that I'm going to tell people in. WMI

This section highlights the varying emotional responses experienced by HIV-positive individuals in relation to non-disclosure and disclosure of their HIV status to others. Experiences of shame, guilt and regret appear to vary from one HIV-positive individual to another.

3.14. Other People's Reactions to HIV Disclosure

Denial –In talking about how other people reacted to telling them about their HIV status, both males and females reported how some people failed to accept or rejected their HIV-positive status as being true. Men tended to talk in general terms of their HIV status not being 'believed' or accepted. Women however, talked mainly about friends not being able to believe them when they disclosed their HIV status to them. Some women also mentioned that because they themselves did not outwardly look unwell that friends had accused them of lying when they disclosed:

My friend she say I'm lying. She told me that the way I look you lie. You lie, you cannot be that way. I said look I am [HIV-positive]. FG1

One woman talked about how her husband had denied that either she or he could be HIV-positive even though their child had been diagnosed as having HIV. She reported perceiving his denial as a form of self-protection from blame:

So he is lying to say he is okay. He doesn't want to accept the truth that he has given me that sickness [HIV]. FG1

Finally one woman described how when she attended a public event as a ‘positive speaker’, to share with members of the public how she herself has a positive attitude and outlook to living with an HIV-positive diagnosis, that even then her HIV status was questioned:

I went as a positive speaker and they didn't believe it. They said that they have paid you to tell us. I told them they haven't paid me, I'm HIV. They doesn't want to believe me if I am. [HIV-positive]. FG1

Another Black African positive speaker, in the men's focus group, described how in some cultures denial of the existence of HIV is universal and highlighted once more how it is thought to be a shameful and stigmatising illness:

It depends on cultures. There are some cultures where they do not believe HIV/AIDS exists. I normally go out and do outreach work with a lot of people out there, many cultural groups. A week ago I was out somewhere and what they say is if you are a true Muslim, you cannot catch HIV. And if they see you with a condom, they would say you are immoral and that's why you have this thing (HIV). It's hard really to convince some of them to understand. So it depends on whatever situation whether you can tell. FG2

Shocked/Upset – Many individuals who were informed of the discloser's HIV-positive status reacted by being shocked and or upset. Mostly male participants reported that those that they had informed about their HIV status had been ‘a little bit shocked’ or experienced ‘emotional upset’ by this news. Participants talked about how these initial reactions were often followed by acceptance:

They cried and cried until they had to accept it. FG1

It's A Shameful Illness – A strong theme emerged across participants that others they had told about their HIV status reacted in a socially disapproving manner, suggesting that the discloser had done something which was deemed as wrong, indecent and

dirty which had resulted in them contracting HIV. Both males and females openly discussed how 'People definitely think it's a shameful illness'.

Women described how after disclosing that others both here in the UK and Africa made the assumption that she had become infected by having multiple sex partners and that they were made to feel like a 'prostitute':

They think that you have messed about or what, what? FG1

Back in Africa it's seen as a shame...// They think...//They think you are messing about. FG1

They also reported how they were frequently made to feel tainted in some way once their HIV status was known:

They look down upon you. You are rotten, you are dirty, You are what? You are poisonous. FG1

You should know that if I tell that person I'm going to live the rest of my life in condemnation, because they will make me feel condemned. They will make me feel, oh that I am rotten. You feel outcast. FG1

These feelings of shame for some appeared to then become associated with the process of HIV disclosure itself and was given as a reason for not disclosing. Telling that you are HIV-positive for some had become 'A big shame' and that by disclosing one's HIV status this meant that 'You are adding more shame. You are becoming more shameful because HIV is like a shameful disease'.

Black African males talked about how for HIV-positive males disclosing in their culture HIV was often associated with being 'a criminal' or drug use' and that this

lead to some families and partners to ‘abandon you because of the stigma and shame’ associated with the illness. White males on the other hand described how, in the UK, HIV is still a ‘taboo’ and for White males how HIV is ‘...still associated with sex, it’s still associated with homosexuality, it’s still associated with drug use.’

It’s a Stigma – Another strong theme participants reported being associated with HIV disclosure was stigma. Participants across groups described those they had disclosed to as marking them out as being HIV-positive to others and being accused of contracting HIV through socially disapproved behaviours.

A common theme reported by participants was that there is stigma associated with HIV and how having an HIV diagnosis has ‘got a dirty stigma stuck to it’. It was suggested that ‘If you could change the name of it’ people’s reactions to HIV-positive individuals may be different. Common reactions encountered following HIV disclosure included the following scenarios ‘When you tell someone you have HIV. They, they point and whisper or that ‘when you are walking on the street, they start pointing and looking at you. One White male also talked about how his family received the news of his HIV status as something which marked him out as different from others, like he now had ‘A big badge on the front of his lapel “He’s got HIV.” ’

It was also highlighted that, even although HIV is much more common in Africa that ‘There was still a stigma among the African people with HIV/AIDS’ and that this stigma was associated with ignorance of the disease.’

Discrimination - All participants described having experiencing extremely negative reactions to disclosing their HIV status. They reported experiencing physical and verbal hostility, bigotry and ignorance about HIV and how it is contracted:

Some participants pointed out that ‘people can still be hostile over it [telling them you are HIV-positive] reporting others ‘had had a go at me’ or that they had experienced ‘verbal abuse’ One participant even described how their ‘Doctor was a little bit hostile [at time of diagnosis]’. Participants also described how ‘You fear to go out in public. By going out you end up going through hell’ by doing so. In addition to individuals, institutions such as people’s employers and religious and medical centres were reported to discriminate against HIV-positive Individuals as the following excerpts show:

I want to get a better job, but I can't. If I put it on the form, they won't process my application. FG2

If you have an education, you can't always get a job because you are discriminated against because of your HIV status. FG2

Churches punish you for that (standing up and saying you are HIV-positive). FG1

A lady's file in the hospital was marked with a red marker and they knew what the sign meant. FG2

Many participants reported feeling that ‘There is a lot of ignorance about HIV.’ Male participants tended to stress the belief that the general public don’t realise how many different types of people HIV affects. As one participant stated:

It affects everybody, no matter what colour or what your background. WM2

I just think that the public think that people who have HIV are either drug users, gay or from Africa. WM1

Heterosexuals still haven't realised completely that they are the highest infected and so on. WM4

Black males in particular talked at length about how the media were both ignorant and discriminatory about HIV/AIDS and those who are HIV-positive:

One thing I wanted to say about the press and the way it's portrayed HIV is, from what I've seen in advertisements etc it's all seemed aimed at gay men and Black people. Well again as well and Africa it's been the hot spot for AIDS etc, which is totally wrong really. I'm aware it's spreading in London like wild fire and basically I would say, I would like the press to be being more proportionate in its wording etc. FG2

Finally, both Black and White males talked about bigotry and narrow mindedness still being around in others minds of HIV-positive individuals. One participant also indicated that 'some cultures are small minded unless you play by their rules'.

With straight men it comes back down to sex when you are talking about HIV/AIDS. That slight uncomfortableness that my straight friends may have with me being gay tends to come to the forefront when I tell them [about my HIV status]. This [disclosing] brought back what I do in bed. They make assumptions about how I caught it. They didn't ask if I had a blood transfusion, didn't ask if I was a haemophiliac, didn't ask, all this kind of stuff, they didn't ask. They just assumed. They made an assumption. Women friends-ask "how did you catch it?" Male straight friends would think it is purely gay sex and that's it. WM4

Treated Like a Leper - After disclosing their HIV status participants across the groups talked about the experience of being treated like 'a leper'. They reported those they had told holding a belief that HIV is contagious and directly and indirectly expressing fear that they may be at risk of becoming infected by the discloser:

They don't want even to touch you. (even if they too are positive). FG1

You are thinking about people who are negative here. Even if you tell someone and they support you, but still inside of them they are scared of you. If you scratch yourself - and they see blood, they still don't support you.
FG1

Friends who are telling a different story when disclosed to their families [Negative reactions].when disclosed to their families they have to cook their own food, don't use what is theirs, have their own cup, they don't use the shower or the bath, they don't use the toilet. They have to disinfect it.
FG1

For instance they may change their cups, change their bedding, they might not want you to touch certain things and they may not treat you friendly.
FG2

Some people think because if you are sick and that person who is HIV-positive is sharing dishes whatever, you may catch it.
FG2

Nobody want to be near her [HIV-positive women in maternity ward]. Because some people even think that it is airborne. That you can get it just by sharing a room, whatever.
FG2

People start thinking oh, unclean, keep away and things like that.
WM1

My neighbours talk about it. I'm sure that they don't actually know. But I'm sure that they wouldn't even drink a drop of water in the house if they thought or knew. They'd definitely would think that it's that contagious.
WM3

They are still thinking back in the days - The contagious part. The contagious part - that's what's stuck - don't think that will ever go.
WM3

They Reject You – All participants reported being rejected by family, friends, intimate partners, work and other HIV-positive individuals they had confided their HIV status to. HIV-positive individuals talked openly about being rejected in some way. Many talked of being ‘abandoned’ and ‘disowned’ others talked about being ‘sent to Coventry’, ‘scorned’ and ‘ostracised’. Partner(s), family, friends and even other HIV-positive individuals were pin-pointed as having reacted to disclosers in this way:

Negative reaction from the people that tell you. So this is the reaction she got from her ex-boyfriend. FG1

I was thrown out it was really terrifying. FG1

West Africa is very, very different / difficult. In West Africa, if you go and tell your family you've got AIDS, even your Grand mum even drive out of the family house. FG1

Even some families you disclose like now and then they abandon you because of the stigma and shame and even some partners. You tell somebody now and for them the only option now would be running away from you. FG2

He [male friend] had enough trouble accepting that [when I came out as gay], so I didn't think it was a particularly good idea to say hey by the way [I'm HIV-positive.] WM2

But you know what, when you see someone you know is HIV-positive and say hello. The person doesn't hear it. FG1

I said to her [College Tutor] and now the way she is treating me. She wants to take me off the course. You have so many thing in your head, you can't continue this course. FG1

Supportive – Finally, all participants who had disclosed their HIV status described experiencing a positive and supportive reaction from some of the individuals they had disclosed to. Participants talked about receiving practical, emotional and social support from partner(s), family and friends. All participants also mentioned receiving practical and emotional support from HIV professionals in addition to medical advice and support. Black African participants also highlighted the important role other HIV-positive individuals who were 'Positive Speakers' played in providing them with support and hope for the future. All participants highlighted gaining support to remember to take their HIV medication:

They keep on reminding me to take my medication. FG1

They have all reacted in the same way, they have all been there to support me and I am lucky in that way because if I do have problems or I do feel down, mmm, I can ring with out thinking Oh God, he's on the phone again whinging. I know I'm not going to get that reaction from them. So I've just been lucky I suppose, I have got good friends to support me. WM2

Like when I came out of hospital, my mum is a housekeeper, so she came and did my cleaning and my ironing and stuff like that, and my brother came round and did my DIY stuff in the house that I needed to do on my house, and my sister was just there to gossiping and to give me moral support kind of thing. They all had their things that they did and the same with my friends. Even friends would help me get in and out of the bath, stuff like. I wouldn't want my brother to do that anyway. Each of my friends and my family did different things for me during that time. WM4

Positive response and co-operation from specific medical people. Nurses, Dr's. They encourage you, they counsel you. This is where I get most of my support and advice from medical people. FG2

Because I had people come to see me who were positive speakers come to see me and they helped me a lot. They said you can be strong when I was in hospital. FG1

3.15. Summary of Results

The results obtained from the IPA analysis of the focus groups and interviews are consistent with those obtained from the analysis of individuals' written questionnaire responses. The themes of reasons for HIV disclosure and non-disclosure emerge from both sources of data and although there are similarities in the sub-themes, the focus groups and interviews provided a number of additional sub-themes relating to individuals' experiences of HIV disclosure.

Additional reasons for disclosure of HIV status that emerged from the focus groups/interviews were that for many participants disclosing their HIV status was seen as a relief from having to withhold this information. Some participants also talked about disclosing their HIV status in order to educate others about the true facts

of HIV or as a way of educating them to reduce future potential risk of transmission in general.

Evidence that reasons for HIV non-disclosure are 1) specific to the HIV positive individual concerned and associated with 2) lack of confidence and fears about 3) others' reactions to the disclosure and 4) confidentiality were found across groups. In addition, Black African participants reported experiencing fears of 5) being deported following disclosure of their HIV status which could ultimately result in suffering and death due to shortages of medical treatments in Africa.

An additional three themes and accompanying sub-themes emerged from analysis of the focus groups and interviews: 1) The process of disclosing; 2) HIV-positive individuals' own reactions to not disclosing and 3) Other peoples' reactions to HIV disclosure.

Participants in the focus groups and interviews consistently talked about the difficulties of disclosing their HIV status, even though most had managed to do this. Participants had individual experiences of how they prepared to and disclosed their HIV status to important others in their lives. Common sub-themes that arose were participants telling others in a matter-of-a-fact way of their HIV status versus, initially lying and covering up their HIV status until they felt confident to disclose. Many participants also described how others in their lives gathered what was wrong. For some their HIV status was leaked by another person they had confided in and, for a minority, important others they knew disclosed their HIV status on their behalf or without their permission.

HIV positive Individuals' reactions to disclosing/not-disclosing their HIV status showed that participants who reported having not disclosed their HIV status at times experienced feelings of shame and guilt. A minority theme that emerged was that one White male reported regretting having disclosed his HIV status even though he experienced no negative repercussions.

Common reported reactions were that some significant others in the participants' lives had either denied or been shocked and upset following disclosure of the participants' HIV status. Participants across groups described how others made it clear that they thought HIV was a shameful or stigmatising illness. Many participants talked about being mistreated, discriminated against, or rejected in some way by some of the people to whom they had disclosed. Many participants however, described how disclosing had resulted in very supportive reactions from many important others in their lives.

CHAPTER 4: Discussion

4.1. Overview

The present study attempted to explore psychological variables that may influence disclosure of HIV-positive status in individuals living with HIV or AIDS. Governmental health directives and clinical research in the field of sexual health and HIV disclosure highlight the possible public health, physical, and psycho-social benefits of disclosing one's HIV status to important others. However, at the same time the research findings also acknowledge and highlight that HIV disclosure is not always easy to achieve. Some of the costs and benefits of HIV disclosure for HIV-positive individuals have been identified by both quantitative and qualitative research studies, predominately with homosexual men living in the United States. To date there has been limited research carried out with mixed samples of individuals living in the UK with HIV/AIDS.

The main aim of the study was to explore whether shame influenced HIV disclosure using The Experience of Shame Scale (Andrews et al., 2002) as a theory-based framework. In accordance with Andrew's tripartite theory of shame, it was hypothesised that low rates of HIV disclosure can be predicted by HIV-positive individuals holding perceptions of high levels of shame about distinct component parts of themselves, their character, behaviour or body. The present study also aimed to explore other possible psychological variables (such as anxiety and depression). Focus groups and individual interviews were also used to explore shame and other possible health, psychological and social-cultural factors that may influence HIV disclosure and non-disclosure.

4.2. Overview of the Main Findings of the Quantitative Study

HIV disclosure was examined towards four distinct targets. Each of these measures was assessing a different aspect of HIV disclosure, namely, HIV disclosure to all targets, to partner(s), family and friends. A large percentage of HIV-positive individuals had been able to disclose their HIV-positive status to some important others in their lives. High to moderate levels of HIV disclosure to partner(s), friends and family were found. In terms of disclosure to partner(s), of the participants identifying targets in the group partner(s) as important, just over three quarters had disclosed their HIV status to all identified partner(s), while just under one fifth had not disclosed their HIV status to any identified partner(s). Of the number of participants who had indicated family members as 'important', just over one third had disclosed their HIV status to all family members, while two fifths had not disclosed to any family members. Finally, of those participants who had indicated friends as 'important', just over half had disclosed to all friends identified, while one third had not disclosed their HIV status to any friends.

Since the present study recruited from an ethnically and culturally diverse population of HIV-positive individuals living in the UK, a wide range of demographic and cultural data were collected and effects on HIV disclosure were explored.

Irrespective of all other demographic variables, gender was found to be linked with HIV disclosure. Gender was associated with HIV disclosure to friends, as hypothesised, with females in comparison to males having made fewer disclosures about their HIV status to friends. However, contrary to the initial hypotheses, no

significant differences were found between females and males in terms of HIV disclosure to partner(s) and family members.

Since half of the sample was Black, this permitted the exploration of possible differences between different cultural groups in terms of patterns of HIV disclosure. Cultural considerations appear to be important for the present sample in relation to decisions around whether to disclose or not to disclose their HIV status in general and in particular to friends. Ethnicity (White/Black-Mixed) and English as first language were significantly associated with HIV disclosure to all targets, and to friends. As hypothesised, Black and Mixed race participants made fewer disclosures about their HIV status to all targets and friends in comparison to White participants. Participants whose first language was not English had also made fewer disclosures about their HIV status to all targets and friends.

In addition to demographic and cultural variables, a wide range of HIV illness data was collected regarding individual HIV illness status, including current symptomatology, treatment and therapy regimes. Time in months since diagnosis was significantly associated with HIV disclosure. HIV-positive individuals made more disclosures to all targets, family and friends the longer the time in months since receiving their HIV diagnosis. Having an AIDS diagnosis, taking combination therapy medications, medication side effects, appearance changes following HIV diagnosis, CD4 counts and viral load were all found not to be associated with HIV disclosure to all targets, partner(s), family and friends.

In terms of assessing the relationship between psychological distress and HIV disclosure, contra lower rates of HIV disclosures. Both anxiety and depression were not significantly associated with HIV disclosure in the present study.

In terms of the predictive power of shame, use of the Experience of Shame Scale (Andrews et al., 2002), made it possible to identify possible sources of shame experienced by individuals living with HIV/AIDS and associated with HIV disclosure. Logistic regression analyses indicated that characterological shame made significant independent contribution to the prediction of HIV disclosure to friends after controlling for gender, months since HIV diagnosis, ethnicity and English as a first language. Greater levels of characterological shame were significant independent predictors of HIV disclosure to friends.

The thematic analysis of participants' written responses about reasons for disclosure to important others in their lives is consistent with the Consequence theory of HIV disclosure, Serovich (2001). HIV-positive individuals in the current study appeared to weigh up the costs and benefits of disclosing and reported disclosing more when the benefits were perceived to outweigh the costs. The main reasons cited for disclosing HIV status were a duty to inform others and to access support from those to whom they felt emotionally close. A small number reported that their HIV status had been disclosed via a breach of confidentiality or when they had become very unwell and could no longer hide it. Finally, some individuals had been able to tell because they had shared their HIV status with people similar to them in terms of background or because they were going through a similar experience (of being HIV-positive). Protecting others, no reason or benefit for disclosing, fear of rejection, and

physical distance emerged as the main reasons why participants had not disclosed their HIV status.

4.3. Interpretation of the Main Quantitative Findings

4.3.1. Patterns of HIV Disclosure

HIV disclosure rates to important others were highest for partner(s), lower for friends, and lowest for family members. These results are consistent with patterns of HIV disclosure found in a recent UK study by Petrak et al., (2001) and despite different methodologies and populations studied, three previous studies conducted in the United States (Mansergh et al., 1995, Mason et al., 1995; Simoni et al., 1995).

Given the large percentage of participants who had disclosed to partner(s) and friends and the moderate levels of disclosure to family, it could be argued that for this sample of HIV-positive individuals the potential benefits of disclosing their HIV status to important others in their lives is recognised. These findings also support the idea that the strength of relationship that individuals have with each other influences to whom disclosures are made (Petronio, 2002). Non-disclosure of one's HIV status to partner(s), in comparison to friends and family, is likely to have different implications and consequences for that relationship. Partner(s) of HIV-positive individuals run a more substantial risk of being exposed to, and becoming infected by, the illness. Non-disclosure of HIV status therefore could not only affect the relationship with the partner, but also the health of the partner. Unless the HIV/AIDS is acknowledged, strategies for reducing risk of infection cannot be fully discussed or implemented. On the basis of this information, it might be expected that a large number of HIV-positive individuals disclose their HIV status to their

partner(s) and important others in their lives through a sense of duty and obligation. This was confirmed by the quantitative study in which duty to inform others of one's HIV status was the main reason cited for HIV disclosure. In addition, the main theme that emerged from the focus group study for HIV disclosure was the belief that participants had a moral obligation to tell others about their HIV-positive status. A consistent belief held by participants was that partners and important friends and family 'needed to know' or 'had a right to know' that the participant was HIV-positive.

Analysis of the reasons for HIV disclosure revealed findings similar to those found in earlier studies (Simoni et al., 1995; Petrak et al., 2001). A main theme cited by participants for disclosing HIV status was to access emotional and practical support from important others that would be needed at various times following their HIV diagnosis. Many participants in both parts of this study talked about disclosing because they needed support. The patterns of HIV disclosure found are also consistent with the idea that HIV-positive individuals prefer to access support from partners and friends rather than 'burden' their families with knowledge of their HIV status (Hays et al., 1993).

Another possible explanation for participants' moderate to high levels of HIV disclosure may be as a result of positive reactions received from those to whom they have disclosed. It is possible that changes in attitudes relating to HIV/AIDS may explain the HIV disclosure rates obtained in the present study. Kalichman (1998) has highlighted that, as knowledge about HIV/AIDS has increased, there are less negative attitudes towards individuals living with HIV/AIDS. It is possible that

HIV-positive individuals experiencing less negative reactions than expected following disclosure may be more likely to make further disclosures.

In contrast, participants were aware of ongoing negative attitudes relating to being HIV-positive and reported that they disclosed their own HIV status intentionally with the aim of dispelling the shame and myths that surround HIV while educating important others in their lives about the illness. This interpretation would be consistent with the work of many HIV/AIDS activists who advocate HIV disclosure as a means of deconstructing the shame and stigma that surround the illness (Paxton, 2002; Wolitski, Rietmeijer, Goldbaum & Wilson, 1998), and the theme of Educating Others identified as a reason for disclosing in the qualitative component of the current research.

4.3.2. Demographic Differences

It appears that, for this population of HIV-positive individuals, the gender of the discloser plays an important part in influencing whether to disclose one's HIV status. Gender (male/female) was found to be significantly associated with HIV disclosure. Specifically, it was found that females were less likely than males to have disclosed their HIV status to friends. A review of the general self-disclosure literature (Dindia, 2002) suggests that females make more self-disclosures in comparison to males. Unlike previous studies that have concentrated primarily on populations of homosexual men (Hays et al., 1993, Marks et al., 1992 & Perry, Moffat, Ashman, Fishman, & Jacobsberg, 1990, Simoni et al., 1995), the present study sample consisted of females, homosexual males and heterosexual males. Few mixed-sample studies having been carried out in this area, and previous research has typically

contrasted populations of homosexual males with populations of heterosexual males and females. Differences in the populations studied and methodological differences therefore make it difficult to make comparisons with the current findings. Consequently, reasons for gender differences in rates of HIV disclosure still remain unclear and further studies are required.

However, we may speculate that issues around control and the cost and benefits of disclosing one's HIV status to friends may have had an effect upon females disclosing their HIV status. The findings of the qualitative component of this study indicate that females reported not disclosing their HIV status to friends because of fears and concerns about their diagnosis being kept private and breaches of confidentiality occurring where their diagnosis is shared with others in their social networks and communities without their permission. It may also be possible that females chose not to disclose their HIV status to friends, in an attempt not to overload or burden their existing support networks of friends who themselves may also be HIV positive and sick or dying.

Time in months since HIV diagnosis

The current findings support the idea that HIV disclosure to friends and family members, but not to partner(s), increases in relation to the length of time since HIV diagnosis. The findings bear similarities to previous studies (Holt et al., 1998; Mansergh et al., 1995; Petrak et al., 2001) in which HIV disclosure rates to important others increased as length of time since HIV diagnosis increased.

One possible reason why disclosure to partners was not associated with length of time since diagnosis is that the average length of time since receiving an HIV-positive diagnosis was 61 months (range 3-201 months) and that, for those participants with partners, a feeling of obligation or sense of duty may have resulted in disclosure occurring shortly after diagnosis. Also, as previously indicated, HIV-positive individuals disclose to partners first for support, rather than 'burden' friends and family (Hays et al., 1993).

In line with the findings of these previous studies, participants' reports from the focus groups and interviews confirmed that many of them did not initially feel ready or strong enough to inform others, or face others' reactions. Some participants reported fears that potential targets for disclosure would associate the discloser's HIV status with perceived shameful activities such as sleeping around, prostitution, or being homosexual. Protecting the self from discrimination, stigma, along with fear of rejection and removal of practical and emotional support emerged as frequent themes amongst the reasons why participants did not disclose their HIV status initially. Protecting important others from unnecessary distress, fear of discrimination, associated shame and stigma, especially for family members were also given as reasons for not disclosing to family and friends in the initial time period following HIV diagnosis. Participants also reported that disclosing their HIV status in a planned and controlled way, to trusted, important others, had resulted in fewer negative reactions than they had expected.

Ethnicity and Culture

Cultural considerations appeared to be important for the present sample in relation to decisions about whether to disclose or conceal their HIV status in general, and in particular to friends. Ethnicity and English as a first language were significantly associated with HIV disclosure to all targets, and to friends. Black and Mixed race participants made fewer disclosures about their HIV status to all targets and friends in comparison to White participants. Participants whose first language was not English had also made fewer disclosures about their HIV status to all targets and to friends.

These findings have some similarities with previous studies carried out in the United States which have suggested that European Americans are more likely to disclose their HIV status than ethnic minority groups. For example, lower rates of HIV disclosure have been reported in Latinos and African Americans in comparison to European Americans (Armistead, Klein, Forehand, & Wierson, 1997; Mason et al., 1995, Mason, Simoni, Marks, Johnson, & Richardson, 1997; Simoni, Mason & Marks, 1997), while Stein et al., (1998) reported European Americans and Latinos disclosed more to partners than African Americans.

The importance of community as sources of support within African cultures is emphasised in the literature (McGrath, Ankrah, Schumann, Nkumbi & Lubega, 1993). The qualitative component of the current study provides support for the idea that HIV continues to be a highly taboo topic within many African communities. Both male and female Black African participants talked about the shame and stigma African communities can still attach to HIV both in Africa and the UK. It is possible

that HIV-positive Black Africans are less likely to disclose their HIV status in general and to friends as means of shame and stigma management. In addition, a strong awareness of possible negative reactions within specific cultural groups may limit HIV disclosure as an adaptive strategy, with non-disclosure being a more favourable means of protecting the self and preserving social, emotional and practical support networks as well as the discloser's own psychological well-being.

4.3.3. *Psychological Distress*

In contradiction to the hypotheses that low levels of HIV disclosure would be associated with high levels of psychological distress, both anxiety and depression were not linked with HIV disclosure in the present study. One possible explanation for lack of associations is that levels of psychological distress experienced played less of an influencing role, in comparison to other variables, on HIV disclosure for the population studied. It is possible that the need to evaluate the costs and benefits of disclosure is more of an influence than the emotional states they are experiencing. The current study suggests social and cultural variables play a more central part in influencing and predicting HIV disclosure than the levels of anxiety and depression experienced by HIV-positive individuals.

4.3.4. *Shame*

Logistic regression analyses indicated that after controlling for gender, months since HIV diagnosis, ethnicity and English as first language, greater levels of characterological shame were found to be significant independent predictors of increased HIV disclosure to friends, but not to partners or family members. This finding lends support to the theoretical assertion made by Macdonald (1998) that

shame influences an individual's capacity to speak about personal issues, but not in the way anticipated. Macdonald suggests that increased levels of shame would inhibit disclosure, but the reverse was seen in the current study. Support was found for the idea that HIV-positive individuals experience shame and that increased levels of shame, in particular an increased level of characterological shame is linked with increased rather than decreased HIV disclosures to friends.

Characterological shame in the ESS assesses three areas about which participants' may feel ashamed: 1) personal habits, 2) manners with other people and 3) the sort of person the respondent is. It is therefore possible that increased scores of characterological shame may be due to participants' thoughts about their HIV status and themselves as HIV-positive. However, it may also be due to shame about other personal characteristics, which might be independent of their HIV status. It is possible that the burden of shame experienced by having shameful thoughts about one's self and one's HIV status may be too much to bear and leads to disclosure of HIV status within the context of trusted relationships with friends. It is also possible that HIV-positive individuals disclose their HIV status to friends with the aim of looking to them for support to minimise and challenge perceived feelings of characterological shame they may be experiencing. It could be argued that the sharing of their HIV status with trusted friends initiates a process where shameful thoughts about their character can begin to be challenged, diluted and dispelled, enabling the HIV-positive individual to recognise that the perceived shame does not dictate their personal value or worth. Schneider (1977) highlights how entering into relationships where shame is exposed may for some lead to a connection being formed between the discloser and the person disclosed to. Schneider goes on to say

that by being seen and being accepted, one is set free and can experience a sense of relief. The current results could suggest that HIV-positive individuals who were experiencing high levels of characterological shame may have felt the need to inform their friends of their HIV status for a variety of emotional and therapeutic reasons. (Klitzman, 1999; Limandri, 1989) suggested that HIV disclosure may be a form of “venting”, a “desperate need to tell someone”. Holt et al. (1998) also highlighted how many HIV-positive individuals experience a sense of relief associated with telling others about their HIV status, allowing them to begin coping with being HIV-positive and this in turn facilitating self-acceptance.

The current results could also be explained in line with the ideas put forward by Goffman (1963) and more recently Pennebaker (1993), that attempts to conceal difficult or traumatic experiences can be psychologically exhausting. Evidence exists that distressing personal experiences generate significant amounts of emotional tension and as this tension mounts, the desire to disclose one’s thoughts and feelings about these events increases (Pennebaker, 1989; Stiles, 1987). If an individual chooses to disclose this personal information rather than keep it secret, they often experience the sense of relief from emotional tension or catharsis (Stiles, 1987). In order to receive this cathartic effect, however, individuals must completely self-disclose about distressing experiences and not merely relate trivial details (Kowaski, 1999, Pennebaker, 1997, 1988). It is therefore possible that by fully disclosing the details of one’s HIV status to friends, HIV-positive individuals may trigger the level of disinhibition necessary to release the emotional stress, in this case characterological shame, they are experiencing in relation to their HIV-positive

status. Psychological well-being for the discloser could therefore be the outcome of HIV disclosure to friends.

4.3.5. Reasons for HIV Disclosure and Non-Disclosure

Analysis of the reasons for disclosure and non-disclosure cited by participants in the quantitative study revealed findings similar to those found in earlier studies. In line with Simoni et al. (1995), study participants reported both self and other-focussed reasons for disclosing. The two main reasons given for HIV disclosure in the quantitative component of this study were 'Duty to inform others' (Other-focussed reason) and 'Emotionally close and supportive relationship' (self-focussed reason). A recent study by Petrak et al. (2001) indicated that one of the main reasons HIV-positive individuals living in the UK disclose their HIV status to important others in their lives, is a means of accessing emotional and practical support. The current findings provide additional support for this idea. Disclosing to important others to access emotional support was the second most cited reason given by HIV participants for disclosing their HIV status.

In line with previous studies (Petrak et al., 2001) reasons for non-disclosure reported by participants in the current study were protecting others from emotional and psychological distress, and negative consequences for the self, including fear of rejection from others.

4.4. Discussion of the Results of the Qualitative Study

As outlined earlier, focus groups and semi-structured interviews were used to explore participants' views and beliefs regarding HIV disclosure and non-disclosure.

As Krueger (1988) argues by using qualitative methods, the researcher gains an understanding of the topic under study by attending to the participant's discussion rather than by testing or confirming hypothesis or theory. In line with Krueger's argument, the purpose of the focus groups and interviews in the present study was to explore and gain an understanding of HIV-positive participants' experiences of HIV disclosure and non-disclosure.

Interpretative Phenomenological Analysis (IPA: Smith et al., 1999) of participants responses to the questions of the focus group interviews and individual interviews revealed a number of themes pertinent to HIV-positive individuals' experiences of HIV disclosure and non-disclosure.

4.4.1. Experiences of HIV Disclosure

In terms of reasons for disclosure of HIV status, the majority of participants' regardless of gender, sexual orientation or ethnicity reported the theme of 'Moral obligation' as an important factor in their decisions to disclose their HIV status to partner(s), family and friends. That is, participants across focus groups and interviews shared the belief that HIV/AIDS is a serious illness with psychological, relational and health implications for important others that makes it important to inform them of their HIV status. It was acknowledged by many participants that they needed to disclose to important others so that these individuals would be prepared if the HIV-positive person's health deteriorated. Some participants felt the need to inform others in case they ever found themselves in a situation, such as a workplace accident involving loss of blood, where the important other may potentially be at risk of contracting the HIV virus. In line with the findings of Greene and Faulkner

(2002), some participants also talked about feeling obliged to disclose their HIV status because this is what they perceived was expected of them. Telling lies and keeping secrets was something that many participants said they did not do with specific important others in their lives. So, for many participants, HIV disclosure through moral obligation appeared to be linked with reducing worries and concerns about risks to others and reducing negative feelings about one's self associated with keeping their HIV status secret. It may also be possible that for some participants the sense of obligation and perceived social responsibility to disclose their HIV status reported was influenced by experiencing feelings of guilt. In line with Gilbert's, (1998) description of guilt as an adaptive social mechanism, rooted in empathy, participants reported experiencing a need to forewarn and disclose to important others in their lives at a time where these others were not at risk and therefore would be prepared to protect themselves should situations of risk arise in the future. Protection of the self and fear of other people's reactions, breaches of confidentiality and, for Black African participants in particular, fear of deportation and dying were the main reasons identified for HIV non-disclosure. Participants explained that the uncertainty and fear associated with not knowing how others would react to their disclosure, in itself, stopped them from disclosing their HIV status. Participants described how when faced with anticipated fear of rejection, stigmatisation, ostracism, discrimination and hostility, HIV non-disclosure was seen as a form of self-protection. Participants explained that even though HIV is widespread in their communities, having an HIV diagnosis can still be shameful and stigmatising resulting in discrimination, bigotry, rejection and, at worse, hostility and physical violence. As a consequence, they keep their HIV status secret even from some important others in their lives. Similar findings have been found in earlier studies

(e.g., Petrak et al., 2001) and clinical populations of HIV positive individuals in the UK (e.g. Bor et al., 1992). The current findings therefore provide further support for the idea that anticipated shame, stigma, discrimination and rejection may discourage HIV-positive individuals from disclosing their HIV status.

In addition to fear of negative reactions from others, Black participants reported issues relating to their residential status that made them lack confidence to disclose their HIV status. Those participants who had unclear residential status highlighted the “double-bind” that disclosing their HIV status may create for them. Whilst disclosing may lead to access to medical support and treatments, which would stabilise their HIV infection, there was uncertainty about whether disclosing their HIV status might lead them to have their applications to remain in the UK revoked by the Home Office. Black participants talked openly about how fears of being deported back to Africa, where there is restricted access to medical treatments, could result in additional suffering and ultimately death.

Recently, the media in the UK has focussed upon the issue of HIV and migration, with many stories appearing in the press (The Guardian, 30 & 31 December 2003; The Times, 15 & 31 May 2004) about the burden that migrants with HIV have placed on the National Health Service. Stories about “treatment tourism”, suggesting that people are coming to the UK purely to access free HIV treatments, has led the UK government to introduce the Asylum and Immigration (Treatment of Claimants etc.) Bill (Department of Health, 2003) which makes it more difficult for HIV-positive migrants to obtain leave to remain within the UK. General concerns regarding these changes have been highlighted within a briefing paper on the Asylum and Immigration Bill 2003, produced by the Refugee Council (2004). More specific

concerns relating to HIV and implications for disclosure in HIV-positive migrants in the process of applying for “Leave-to-Remain” in the UK are outlined in a recent briefing paper (Treatment Access Rights for People Recently Arrived in the UK) published by the Terrence Higgins Trust (2002).

Another important theme that emerged as a reason for not disclosing was protection of others. The majority of participants reported that they wished to protect important others from emotional and psychological distress and, in some cases, stigmatisation, shame and other possible negative consequences that could result from being linked to an HIV-positive individual. Participants talked about weighing up how important others would cope or bear the burden of knowing their HIV status. They talked about protecting others they felt could not manage or handle knowing about their HIV status. This finding was also reported in a number of previous studies exploring reasons for HIV non-disclosure (e.g., Armistead, et al., 1997; Derlega, et al., 1998; Diaz, 1998; Greene & Faulkner, 2002; Hayes, et al., 1993; Klitzman, 1999; Mason et al., 1995; Petrak et al., 2001; Winstead et al., 2002). These findings suggest consideration of important others’ ability to handle and deal with knowing about the discloser’s HIV status is an important factor in disclosure decisions.

4.4.2. The Process of Disclosing

Issues of control strongly prevailed in participants’ accounts of their actual experiences of disclosing their HIV status to partner(s), friends and family. All participants talked about how it was hard to tell others about their HIV status, while a minority were able to “just say it straight” and tell others in a “matter of fact” manner. The majority talked about disclosing in stages. This finding is similar to

that reported by Greene and Faulkner in their 2002 study. They explained how participants maintained control over how much information was told, when it was told, and to whom it was told. In line with this, participants in the present study reported initially disclosing that their health wasn't very good, or "cooking" their stories by revealing significant health problems, without necessarily linking these to HIV. For many, this was accompanied by hinting that they may have a weakened immune system and testing the reactions of others about HIV, with the intention of disclosing fully when they felt confident about targets' likely reactions. They would then plan to find the right time and place to make a full disclosure.

These findings support the idea put forward by Yep, Reece & Negron (2003) that HIV-positive individuals prefer pre-planned and deliberate disclosures as this ensures greater control of this sensitive information. Disclosure is often a gradual process, starting with implicit messages which become more explicit as reactions are perceived to be more favourable.

4.4.3. Reactions to HIV Disclosure

The effects of not disclosing one's HIV status commonly led participants to report experiences of feeling shame and guilt.

A small number of participants talked about how feelings of shame made them feel that they could not face people or disclose their HIV status. This contrasts with the results of the quantitative part of this study where high levels of characterological shame were associated with increased disclosure to friends. Therefore, it appears that shame's role in HIV disclosure varies from individual to individual and that, to

gain a better understanding of the role of shame on HIV disclosure, further quantitative research with a larger sample is required to explore the predictive role of shame in HIV disclosure experiences.

Two main themes emerged when participants were asked to report others' reaction to disclosure. All participants perceived that some targets considered HIV as a shameful and/or stigmatising illness. They also reported experiencing supportive reactions from the majority of targets to whom they had disclosed. Participants talked about the emotional and practical support that they had gained as a result of disclosure, but also of being abandoned or "treated like a leper" by others.

Although the above discussion points concerning HIV disclosure indicate that similarities may exist between HIV-positive individuals from different cultural and ethnic backgrounds, these findings need to be interpreted with caution. Although individuals from a specific community group may share a range of experiences and beliefs about HIV disclosure, individual diversity may also be present.

Therefore, although the main findings of the qualitative study have provided useful insights regarding HIV-positive individuals' experiences of HIV disclosure they are far from conclusive. These findings need to be further substantiated by additional research before firm conclusions can be drawn.

4.5. Strengths and Limitations

The current study extended previous research on HIV disclosure by being the first, as far as the author is aware, to 1) explore the role of shame in HIV disclosure using a

standard measure of shame, and 2) use a sample consisting of different cultural groups living with HIV in the UK and, 3) use a mixed research methodology using both quantitative and qualitative perspectives. However, several limitations deserve mention.

4.5.1. Sample Bias

There are a number of characteristics of the sample which may limit the ability to generalise the current findings. Firstly, because of the low number of participants who had not disclosed their HIV status to identified partner(s), family and friends, the present findings therefore represent a somewhat limited picture of HIV disclosure experiences, since the majority of participants had managed to disclose their HIV status. In addition, participants in the present study were not at an advanced stage of HIV disease progression, as indicated by the modal CD4 count of 201-500 and the modal viral load being undetectable. Thirdly, many HIV-positive individuals did not wish to talk about their HIV status and were reluctant to participate in HIV-related research studies. This was reflected in the return rate (45 %) obtained for the quantitative component of the present study and recruitment difficulties encountered when trying to recruit White/European participants to the qualitative component of the study. Finally, because data is not available for those HIV-positive individuals who chose not to participate in this study, it is not possible to determine the extent to which the participants of this study are representative of HIV-positive individuals living within the UK. The above sample biases make it difficult to generalise the present findings to the general population of HIV-positive individuals currently living in the UK. However, the proportions of HIV positive individuals from different ethnic backgrounds participating in the current research were

representational to the numbers of known HIV positive individuals for these ethnic groups reported in the latest Communicable Diseases Surveillance Centre Reports for the Primary Care Trusts, in which the research was undertaken (CDSC, Health Protection Agency, August 2003).

4.5.2. Sampling Method

The convenience sampling method employed within the study meant that participants were primarily recruited from statutory HIV services in North London and therefore represents only a portion of HIV-positive individuals in London and the UK. Inevitably, there are those who do not access services and consequently, participation in the study was restricted to those who were in contact with services and willing to share their experiences. Whether the inclusion of non-respondents would have significantly altered the current findings is difficult to assess. There is a possibility that individuals who may have been concerned about issues of disclosure or experiencing significant levels of shame may have declined to participate. Consequently, the ability to generalise from the findings of the current study is limited. However, it must be acknowledged that until the precise population of HIV-positive individuals is known, convenience sampling of small, known populations will continue to be the most well-adapted and frequently-used strategy amongst HIV researchers.

4.5.3. Statistical Power & Sample Size

The power analysis showed that to detect a medium effect size of .30, the quantitative component of the study would require a sample size of 85 participants (Cohen 1992). However, due to recruitment and data collection difficulties, the final

sample size obtained in the present study was 66. The lack of significant results regarding predictors of HIV disclosure is most likely due to the small sample size. A larger sample may have facilitated further analyses and have provided the necessary power to detect more statistically significant results with greater generalisability. In addition, some variables in the regression analysis did not have much variance. For example, most participants had disclosed to partners, rather than not. This lack of variability would have affected the ability to model relationships between variables using regression analysis and would have affected and limited the results that could be obtained. Ideally, a sample in which there was greater variance would improve the characteristics of the sample. Thus, additional research evidence is needed to substantiate the present findings before firm conclusions can be made regarding the role of shame and other psychological and cultural factors in HIV disclosure. Although the current sample was recruited from an ethnically and culturally diverse population, and is therefore more representative of individuals living with HIV in the UK at this time, the small numbers within each subgroup means that the results cannot be generalised to the adult HIV population in the UK as whole.

4.5.4. Design

As the design used in the quantitative component of the study was cross-sectional, it only acknowledged the presence and levels of various constructs. It did not address cause and effect, in particular, whether shame is an antecedent, concomitant and/or consequence of HIV diagnosis or HIV disclosure. A longitudinal study would be necessary to explore this further.

4.5.5. Measures

As this was the first time that the ESS was used with a HIV-positive population, this section will highlight the possible limitations of using this scale. Cronbach's alpha inter-item correlations on the relatively newly established ESS showed adequate internal consistency in the ESS in line with levels found in previous studies by Andrews and colleagues (e.g., Andrews et al., 2002). However, by not extending the ESS to specifically assess shame in relation to HIV and HIV-disclosure, it was not possible to determine whether the increase in characterological shame was mainly due to issues around their HIV status, or some other personal characteristics which were independent of their HIV status.

The qualitative part of the study aimed to conduct a number of focus groups representative of the sample recruited for the quantitative element. However, focus groups have limitations. On reflection, it is questionable how appropriate focus groups were for eliciting information about different groups of HIV disclosure experiences. Although focus groups were conducted with Black African females and males, it was not possible to recruit White/European participants. As a result, separate one-to-one interviews were conducted with five White males.

Although there are reports indicating the benefits of using focus groups to explore sensitive topics (Krueger & Casey 2000), including sexually transmitted diseases (O'Brien, 1993), the author's experience raised a number of questions regarding the appropriateness of group based methodologies in exploring HIV disclosure experiences in different communities. Previous research in the HIV field has discussed the challenges of ethnic-minority recruitment in HIV/AIDS related

research. El- Sadr and Capps (1992) highlighted that African communities' historical mistrust of clinical trials frequently leads to small numbers of this ethnic group taking part in HIV research studies. In contrast, the author found it particularly difficult to recruit White males to take part in the qualitative focus groups. All potential participants who were approached indicated that they were unlikely to attend a focus group discussion for fear that their confidentiality would unwittingly be broken by meeting with peers who they may know socially, but to whom they have chosen not to disclose their HIV status. These participants expressed a preference for one-to-one communication with the researcher.

It appears that for these White/European males participating in a focus group would seem too daunting an experience, where control, confidentiality and trust issues around the disclosure of their HIV status may have influenced them not to take part. In addition, local clinical psychology services in the area of sexual health have experienced difficulties in recruiting White male participants to attend a psycho-education group to discuss living positively with HIV, substantiating how difficult it is to recruit from this group of service users. Therefore future research studies that wish to use focus groups with HIV-positive populations need to be aware of the above difficulties and the importance of participant confidentiality in order to ensure successful recruitment occurs.

Another limitation of focus groups is that while offering the opportunity to learn a large amount about a topic of interest in a limited period of time, the fact that the moderator facilitates the discussion makes it an unnatural setting. Group discussion is initiated and managed by the researcher. Compared with individual interviewing, there is less opportunity to follow up new leads or skip unwanted discussion, as it is

often important to retain some form of structure to prevent the discussion from becoming too chaotic.

Individual interviews also have their limitations. While they can provide an in-depth understanding of a person's views and experience, they are unable to observe interaction on a topic. Focus groups enable the observation of the interaction between group members, providing direct evidence of similarities and differences in participant's opinions and experiences, and identifying areas in which there is agreement and disagreement between members. Focus groups can also be used to compare different groups or communities experiences of the same topic or concept.

As Morgan and Krueger (1993) note, the comparisons that participants make among each other's experiences and opinions are a valuable source of information into complex behaviours and the motivations underlying these. But this too produces a corresponding limitation for focus groups, because the focus group itself may influence the nature of the data it produces. The question of how interacting in a group influences what each individual will contribute to the group discussion is a classic issue in social psychology (e.g., Janis, 1982). The concerns for focus groups include both a tendency towards conformity, in which some participants withhold experiences and opinions that they might say in private, and a tendency towards polarization, in which some participants express more extreme views in a group than in private (Sussman, Burton, Dent, Stacy & Flay 1991).

4.5.6. Methods of Analysis

Qualitative data were analysed using Interpretative Phenomenological Analysis (IPA; Smith et al., 1999) which is concerned with experiences and meanings. It looks at phenomena from the point of view of those who experience them. However, IPA is not without its limitations, and neither was the application of this approach in the qualitative part of this study.

The fact that this study used questionnaires, focus groups and individual interviews meant that data was obtained from multiple sources. Participation in the focus group discussions and individual interviews occurred following participation in the questionnaire study. Consequently, the qualitative data on HIV disclosure experiences obtained from the focus groups and interviews were not completely independent from the data obtained from the questionnaire.

Inevitably, the analysis of the focus groups and individual interviews could not have been totally uninfluenced by the prior analysis of the questionnaire data. The benefits of having a mixed methodology, with participants having both a quantitative and qualitative mode of expression, bore the cost of not having two completely independent analyses, despite efforts to make the analyses as transparent as possible.

In line with suggested guidelines for good practice in qualitative research (e.g., Elliot et al., 1999), IPA also recognises that the thematic outcome of the analysis represents both the participants' accounts and the researcher's interpretative framework. Therefore the analysis and findings of this study may have been influenced by my own pre-existing beliefs as well as the literature which informed the study. My

previous work with HIV-positive individuals guided my interest in HIV disclosure. Many of the individuals with whom I worked seemed to experience feelings of shame, and the existing literature provided little theoretical guidance about how experiences of shame may influence HIV disclosure. My work as a health professional, conducting research with HIV-positive individuals about HIV disclosure is likely to have influenced both their perceptions of me and my perceptions of them. First, participants may have made assumptions about my position as a colleague of health professionals involved in their care. This may have influenced their responses to the questions asked, for example, participants may have been selective or misleading regarding the information provided (e.g., saying they had disclosed their HIV status to many important others) in order to maintain a positive relationship with service providers. Second, my emotional responses to the distressing nature of some of the experiences discussed in the focus groups and individual interviews may have influenced my interpretations of the difficulties experienced by HIV-positive individuals regarding disclosure of their HIV status.

In order to monitor how my own subjectivity may have influenced the interpretations I made during the analysis, I carried out several credibility checks. First, I kept detailed notes about each group/interview in which I recorded my clinical observations as well as emotional responses. These were used to record the initial thoughts I had about each focus group and interview, and were later examined for strong emotional reactions that could have influenced the analysis of each transcript. Second, as suggested by Elliot et al. (1999), the themes extracted from each transcript were ordered into a coherent structure to resonate with the reader. To achieve this, participants' own words were used as much as possible to label and

describe the themes, rather than using psychological terminology to label each category. Third, the themes were also combined into an overall framework in an attempt to illustrate the connections between the themes that emerged. Fourth, once the analysis was completed, credibility checks of the themes and overall framework were carried out. This involved two supervisors auditing the data and commenting on the results. The comments made by both supervisors were used to refine the thematic account and the overall framework that described the HIV disclosure experiences reported. These checks aimed to ensure the themes were a good reflection of HIV-positive individuals' accounts and helped increase the validity of the findings. Fourth, descriptive data about each focus group and interview participant has been presented to allow the reader to make judgements about the trustworthiness of the findings presented. Fifth, excerpts of the focus group and interview transcripts have been provided to allow transparency of how interpretations were made at each stage of the qualitative analysis. Finally, the process of explicitly describing how concepts were linked together into themes and sub-themes and providing specific detailed examples of each of these has been used to illustrate the authors understanding and interpretation of the data obtained.

Credibility checks were also implemented (Elliot et al., 1999). Firstly a second analyst, with extensive experience of working in the area of HIV and using IPA, independently analysed participants' transcripts. However, whilst this does improve the reliability of the interpretations, it does not address the validity, since both researchers could have held similar biases and preconceptions. Secondly, the 'triangulation' of multiple data sources was sought. The data set consisted of participants' perspectives of HIV disclosure in the form of both quantitative and

qualitative data, as the aim of the study was to examine the differences as well as the similarities between HIV-positive individuals, from different ethnic backgrounds, experiences of HIV disclosure. Finally, although the results of the focus groups and interviews have not been validated with the participants (testimonial validity, Stiles, 1999), they will be sent a summary of the findings.

4.6. Future Research

4.6.1. Validity and Generalisability

It would be highly desirable to replicate this study with a larger number of HIV-positive individuals. In particular, it would be desirable to target individuals from the same backgrounds as participants in the current study in an attempt to replicate and validate these findings. It is important that future investigations allow sufficient time and resources to recruit an adequate sample size.

Another aim of future research would be to test the generalisability of the findings obtained, to see whether they hold for other groups of HIV-positive individuals from different ethnic and cultural backgrounds, at different stages of HIV illness progression, living in different geographical areas of the UK. Only through the future use of the current methodology within the wider community of HIV-positive individuals in the UK will it be possible to generate more conclusive knowledge about the generalisability of these findings.

It would also be useful to undertake future research in this area which would provide a full and accurate picture of the relationships between disclosers and the targets to whom they had disclosed. Although it might be methodologically difficult to

implement, it would be useful to carry out a complementary study exploring targets experiences of the disclosure process. This would provide information of HIV disclosure from the target's perspective and could help further understand barriers to HIV disclosure.

Although this study provides a useful starting point, a deeper understanding of HIV non-disclosure would be a useful area for further exploration. An extension of the present study would be to examine in more detail experiences of HIV positive individuals for whom disclosure of HIV status continues to be an issue. Future use of the current methodology with HIV positive individuals experiencing disclosure difficulties may generate more knowledge about this. Although the current study indicates that recruitment of participants may be difficult, the benefits of conducting such research are likely to outweigh the associated recruitment difficulties that may be encountered.

4.6.2. Research Designs

Some HIV-positive individuals who took part in this study reported that their views of themselves and their HIV status had changed significantly over time since receiving their initial diagnosis. In previous interview studies by Andrews and colleagues, participants' experiences of current shame and shame they had felt at another time in their lives were assessed (Andrews, 1995; Andrews & Hunter, 1997). A longitudinal study, or a series of follow-up studies, would help develop an understanding of any changes that occur over time in HIV-positive individuals experiences of shame and what if any other things influences HIV disclosure and non-disclosure to important others in their lives. For instance a replication of the

current study at point of HIV diagnosis, one month post diagnosis and then at six monthly or yearly intervals may further highlight the role shame and other variables play in HIV disclosure decisions over time and at different stages of HIV illness. Such information could be used by health professionals to assess and determine appropriate therapeutic interventions for HIV-positive individuals.

A number of Black African participants who took part in the present study reported that they had become 'positive speakers', actively making the decision to think positively about living with HIV. Positive speakers freely disclose their HIV status to others in order to provide support for other HIV-positive individuals and to educate the wider society about HIV with the hope of reducing shame, stigma, and discrimination associated with being HIV-positive. Further research could compare positive speakers' experiences of shame and HIV disclosure with a matched sample of HIV-positive individuals who are not positive speakers. Information about similarities and differences in their experiences may have important clinical implications, and could help confirm whether shame is a core issue of being HIV-positive.

4.6.3. Measures

Extension of the ESS

The findings of the current study highlight that it would be useful to extend the ESS to include an additional subscale which assesses shame in relation to being HIV-positive. This subscale would be developed in line with the existing ESS subscales and would include an experiential item (e.g., "Have you felt ashamed of being HIV-positive?"), a cognitive item (e.g., "Have you worried about what other

people think of your HIV status?") and a behavioural item (e.g., "Have you tried to hide or conceal your HIV status from others?"). Extension of the scale in this way would help differentiate between HIV-specific shame, characterological shame, bodily shame and behavioural shame as predictors of HIV disclosure.

4.7. Clinical Implications

4.7.1. Attitudes and Education

The current findings provide clinicians and politicians with indicators of areas where work may be targeted to improve HIV disclosure at both local and national levels. Reports from both the quantitative and qualitative components of this study highlighted that many individuals had not disclosed their HIV status because of perceived fears of society's continuing ignorance, lack of knowledge and understanding of the transmission mechanisms and health risks associated with HIV. Other respondents reported having experienced negative reactions and breaches of their confidentiality by family, friends, and health professionals following a disclosure. At a local level, clinical psychologists could be involved in developing surveys to determine current attitudes and beliefs about HIV/AIDS and identify where unjustified, negative perceptions and misunderstandings continue to exist in the local community. They could then join with the health promotion, public health and voluntary sector HIV services to deliver education and training programs designed to deconstruct negative images and beliefs, and positively emphasise HIV as a non-shameful, chronic illness.

4.7.2. Supporting HIV Disclosure

The results of the quantitative and qualitative parts of the study indicated that one of the main reasons reported for disclosing HIV status was to access support from important others in the participants' lives. The need to fully consider the costs and benefits of disclosure was also highlighted. HIV health professionals could help individuals examine important others' knowledge, attitudes and beliefs regarding HIV so that likely reactions to disclosure could be gauged. This would assist the HIV-positive individual to maximise positive consequences such as accessing support while minimising negative consequences such as rejection. It would also help HIV-positive individuals to make informed decisions about the most appropriate time and way in which to disclose their HIV status to important others.

4.7.3. Support for Targets of HIV Disclosure

Following HIV disclosure to an important other, that person inherits responsibilities for maintaining the confidentiality of the information that has been shared. They may also experience emotional and psychological distress associated with supporting and caring for someone with HIV (Hedge, 1999). This is confirmed by reports of reactions to disclosure made by participants in the current study. These important others will benefit from therapeutic support and advice in a similar way to the discloser. Consequently, clinical psychologists should offer important others support services such as individual or joint therapy sessions, support groups, and education about HIV/AIDS. It would also be beneficial to discuss the costs and benefits of disclosing an individual's HIV status to third parties and, through role play, provide practical opportunities for the important other to learn how disclosure might be managed.

4.7.4. Use of Positive Speakers

One of the themes that emerged from the focus groups was that HIV-positive individuals felt it was easier to disclose to 'similar others' who were also HIV-positive and faced similar challenges. This suggests that it would be beneficial to use 'positive speakers', individuals who have made a decision to publicly disclose their HIV status, to support and encourage further HIV disclosures. The benefits and positive consequences of disclosing may appear more plausible, as the 'positive speaker' will be able to provide first-hand accounts of actual disclosure experiences. The use of peer educators is recognised at a policy and strategy level in planning sexual health services in the UK, especially with reducing sexual risk taking and increasing safer sex practices (Kelly, 1994; Pinkerton et al., 1998, both cited in Ellis et al. 2003). A service implication is that it may be beneficial for clinical psychologists to provide training and consultation to 'positive speakers' within the UK to support them in helping improve local and national rates of HIV-disclosure. In qualitative interviews with HIV positive speakers in Africa and the Asia-Pacific regions Paxton (2002) found that the majority reported disclosing their HIV status to be extremely rewarding. The strongest of all the themes obtained in Paxton's (2002) study was that positive speakers reported no regrets about disclosing their HIV status publicly. Almost all participants indicated that the psychological release of being liberated from the burden of keeping their HIV status secret, along with increased feelings of self esteem linked to reducing stigma around HIV in their communities, far out weighed any disadvantages they had encountered as a result of disclosing. Fenton (2001), (Fenton, 2001, cited in Ellis et al., 2003), recommends that both researchers and professionals should establish partnerships with HIV affected communities in order to reduce stigma associated with clinical research and

therapeutic interventions. Individuals living with HIV acting as positive speakers could therefore be trained to follow a manualised approach to assisting other HIV positive individuals to disclose their HIV status. Serovich (2000) has outlined a series of steps that a range of professionals, including support leaders and volunteer workers can take when helping HIV positive individuals disclose to others in their support network. The first step in this process is to help HIV positive individuals decide if they wish to disclose to anyone in their social support networks. Next HIV positive individuals are asked to identify if their relationship with potential targets is strong enough to withstand disclosure of their HIV status. Following this individuals assess the possible costs and benefits of disclosing. The penultimate step in this process is to help the HIV positive individual to identify why it is important to disclose to identified targets and then finally, to identify if potential targets should be 1) told now, 2) told later or 3) whether the discloser should wait and see. If the themes of the current qualitative study were to be replicated, they could be used to extend Serovich's (2000) framework for disclosure by generating a number of "real life scenarios" that could be used to introduce role play exercises, coping strategies and therapeutic interventions in a further attempt to maximise the positive outcomes associated with HIV disclosure and minimise the associated stresses inherent to keeping secrets such as having an undisclosed HIV diagnosis.

4.7.5. Use of Systemic Interventions

HIV and HIV disclosure have been reported to affect social networks and relationships (Bor et al., 1992; Miller, Goldman, & Bor, 1994). As the main reasons for non-disclosure cited in this and previous studies have emphasised fears in relation to the loss of and protection of important relationships, it is suggested that HIV

positive individuals may also benefit from Systemic counselling approaches when thinking about HIV disclosure. A systemic approach recognises that problems can present between patients, family and other important others following the onset of illness, such as HIV. Systemic approaches have been used clinically to help individuals living with HIV, to think about adjustment difficulties they are experiencing within the wider context of family and other social relationships (Miller et al., 1994). The use of hypothetical future-orientated questions such as, “How do you think disclosing your HIV status would affect your relationship with your (partner, friends, family)?”, may facilitate HIV positive individuals to think about and make decisions about the costs and benefits of disclosing their HIV status to important others in their lives. Within the context, of systematic therapy, problems relating to secrecy and disclosure could also be used to work upon fostering more open communication of issues which otherwise may be difficult to face. Disclosure of HIV status, when thought about in the wider context of social relationships can be discussed in terms of openness, protection, loyalty, boundaries and obligations and help HIV positive individuals find the most appropriate times and ways to disclose their HIV status ways without destroying or weakening their existing support networks.

4.8. Conclusion

This study extends the existing literature by exploring the relationship between shame and HIV disclosure by using a standardised measure of shame. A culturally diverse group of HIV-positive individuals completed the Experience of Shame Scale (ESS; Andrews et al., 2002) and standard, self-report measures of anxiety and depression. Participants reported low levels of characterological, behavioural and

bodily shame. High rates of HIV disclosure to partners, and moderate levels of HIV disclosure to friends and family members were reported. When cultural, demographic and HIV illness variables were controlled, characterological shame was identified as a predictor of HIV disclosure to friends. High levels of characterological shame were predictive of increased HIV-disclosure to friends. . However, this finding only just reached significance and therefore should be interpreted with caution. None of the ESS shame subscales or other variables investigated were found to be associated with, or predictive of, HIV disclosure to partners or family members. Focus groups and individual interviews were carried out to provide more detailed information about HIV disclosure experiences. The main themes that emerged through Interpretative Phenomenological Analysis (IPA) of the data were that moral obligation (duty to inform), relief and accessing support where the main reasons for disclosure. Protection of others and protecting self were the two main reasons for non-disclosure. A clinical implication arising from the work is the potential benefit of using 'positive speakers' to improve rates of HIV-disclosure. This study also highlights the need to support important others who are the targets of disclosures as well as the HIV-positive individuals making the disclosures. Other clinical implications are discussed. A number of suggestions for future research are presented, including replication with a larger sample size, investigation of other populations of HIV-positive individuals to test generalisability, and extension of the Experience of Shame Scale to incorporate an HIV-specific subscale to provide a more detailed understanding of the role of shame in HIV-disclosure.

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APPENDICES

**Appendix 1A: Ethical Permission Letter from Barnet, Enfield & Haringey
NHS Primary Care Trust – Quantitative Study**

North Central London



Health Authority

Victory House
170 Tottenham Court Road
London
W1P 0HA

Tel: 020 7756 2500
Fax: 020 7756 2502

Chair
Chief Executive

Marcia Saunders
Christine Outram

5 August 2002

Miss E Murray
Trainee Clinical Psychologist
39 Central Street
Clerkenwell
London EC1V 8AB

Dear Miss Murray

43/02 – The role of shame in HIV disclosure decision making processes.

Acting under delegated authority I write to inform you that the final amendments to questionnaires and revised questionnaire pack have been received and the view of the LREC is that they present no apparent additional ethical issues therefore additional approval is not required.

Please quote LREC number 43/02 on any future correspondence.

With best wishes.

Yours sincerely

Christine Hamilton
LREC Co-ordinator, Barnet Enfield & Haringey
North Central London Health Authority

**Appendix 1B: Ethical Permission Letter from Barnet, Enfield & Haringey
NHS Primary Care Trust – Qualitative Study**



Barnet, Enfield & Haringey Local Research Ethics Committee

Holbrook House,
Cockfosters Road,
Barnet EN4 0DR.
Herts.

Tel: 020 8272 5699

Fax: 020 8272 5691

Email: alison.okane@enfield.nhs.uk

1st December 2003

Ms. E. Murray,
1st Floor Sexual Health Centre,
St. Ann's Hospital,
St. Ann's Road
London N15 3TH.

Dear Ms. Murray,

03/131: Psychological factors associated with HIV Disclosure

Acting under delegated authority I write to inform you that the LREC reviewed your application on 25th November 2003. The documents reviewed were as follows:

- LREC application form
- Covering letter on headed paper
- Research protocol
- Flow diagram
- CV of E. Shaw and E. Murray
- External peer review
- Interview schedule
- Recruitment flyer
- Letter of invitation to research participants
- Information sheet
- Consent form
- Follow up recruitment letter

The members of the committee present agreed that there is no objection on ethical grounds to the proposed study. I am therefore happy to give you the favourable opinion of the Local Research Ethics Committee.

Please note that this opinion alone does not entitle you to begin research

The Barnet, Enfield & Haringey LREC considers the ethics of proposed research projects and provides advice to NHS bodies under the auspices of which the research is intended to take place. **It is the NHS body, which has the responsibility to decide whether or not the project should go ahead**, taking into account the ethical advice of the LREC. Where these procedures take place on NHS premises or using NHS patients, the researcher must obtain the agreement of local NHS management who will need to be assured that the researcher holds an appropriate NHS contract and that indemnity issues have been adequately addressed.

The following conditions apply to this project

- The LREC will require a copy of the final report on completion of the project and require details of the progress of the project periodically (i.e. annually for longer projects)
- The committee must receive immediate notification of any adverse or unforeseen circumstances arising out of the project.
- If data is to be stored on a computer in such a way as to make it possible to identify individuals,

then the project must be registered under the Data Act 1998. Please consult your department data protection officer for advice.

- Failure to adhere to these conditions set out above will result in the invalidation of this letter of no objection.

I confirm that LRECs are fully compliant with the International Committee on Harmonisation/Good Clinical Practice (ICH) guidelines as they relate to the responsibilities, composition, function operations and records of an Independent Ethics Committee/Independent Review Board.

Please forward any additional information/amendments regarding your study to the LREC Co-ordinator at the above address.

Your application has been given a unique reference number 03/131, please use it on all correspondence with the LREC.

Yours sincerely



Alison O'Kane
LREC Co-ordinator
Barnet, Enfield & Haringey

Appendix 2: Procedure Protocol

Individuals Experiences of HIV Disclosure

Protocol and list of materials

1. Introduction
 1. Explanation of study: aims and procedures
 2. Information sheet
 3. Informed Consent form
2. Questionnaires
 1. Demographic Information
 2. Stage of illness
 3. HIV Illness symptoms
 4. Self Disclosure
 5. HIV Disclosure Diagram
 6. HIV Disclosure Index
 7. Experience of Shame Scale
 8. Hospital Anxiety and Depression Scale
3. Focus group / Individual Interviews (to be recorded)
 1. Introduction: aims and procedure
 2. Information sheet
 3. Consent forms
 4. Procedure for recording focus groups/interviews
 5. Questions for Focus groups/interviews
4. De-briefing

Appendix 3: Study Information Sheet – Questionnaire Study

**HIV Disclosure Research
Participants Information Sheet
(Please Detach & Keep)**

The aims of the research

We are currently conducting research into the experiences of individuals who have disclosed, or thought about disclosing their HIV-positive status to others in their lives. We know that disclosing HIV status is not always easy, and we are hoping that this study will enable us to understand the factors that make it difficult to inform others of ones HIV-positive status.

How the information will be used.

The information collected will be used to find better ways to support positive individuals who are thinking about disclosing their positive status. By helping us you will be helping others in similar positions to you. It will also be used as part of a doctorate research thesis. If you are interested, you can find out about the outcomes of the study - every participant can get a summary of the results of the research sent to them if they want. A copy will also be available at the reception at T1 ward.

What we would like you to do

We would therefore invite you to take part in this study, which involves completing a series of questionnaires which should take between 30 – 40 minutes to complete in total. The number of questions may look daunting, but most people find they are quite quick to complete once they get into the swing of them. The questionnaires ask you about your experiences, feelings and views about disclosing your HIV status to significant others. A few of the questions are of a personal nature but the information requested will be very useful to us. If you feel the need to talk about anything arising from the questionnaires please feel free to contact either Liz Shaw or Eleanor Murray (contact details below).

Confidentiality

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

Indemnity

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

All research proposals using human participants are reviewed by an ethics committee before they can proceed. This study was reviewed by Barnet, Enfield and Haringey Health Authority Research Ethics Committee.

If you have any further questions about the study do not hesitate to ask the researcher that has approached you with this information sheet, or contact any of the people involved in the research listed below.

People and organisations involved in the research

Liz Shaw
Clinical Psychologist
1st Floor Sexual Health Centre
St Ann's Hospital
St Ann's Road
N15 3TH

Tel: 0208 442 6464

Eleanor Murray
Clinical Psychologist in Training
Sub Department of Clinical Health Psychology
University College London
Gower Street
WC1E 6BT

Tel: 0790 594 3654

If you would like to help us with this study, please complete and sign the consent form attached to this page

Thank you for your time

Liz Shaw
(Chartered Clinical Psychologist)

Eleanor Murray
(Trainee Clinical Psychologist)

Appendix 4: Informed Consent Form – Questionnaire Study

CONFIDENTIAL

CONSENT FORM FOR PARTICIPANTS

Centre Number:
Study Number:

Patient Information number for this trial:

Title of Project: INDIVIDUALS EXPERIENCES OF HIV DISCLOSURE

Name of Researcher: ELEANOR MURRAY, MA Hons Tel: 0790 594 3654

LIZ SHAW, BSc, MSc Tel: 0208 442 6464

Please initial box

1.	I confirm that I have read and understand the information sheet dated.....	
2.	I understand that my participation is voluntary and that I am free to withdraw at any time without my medical care or legal rights being affected.	
3.	I am willing to allow access to my medical records but understand that strict confidentiality will be maintained. The purpose of this is to check that the study is being carried out correctly.	
4.	I agree to take part in the above study	

Name of Patient (block capitals) Date Signature

I have explained the nature, demands and foreseeable risks of the above research to the subject.

Name of Person (block capitals) Date Signature

Appendix 5: Instructions - Questionnaire Study

<p style="text-align: center;">HIV Disclosure Your Views General Instructions</p>

Thank you for agreeing to take part in our study. The aim of the study is to find out what HIV-positive individuals views are about disclosing their HIV status to others. It is only with your help that we can find out how to support HIV-positive individuals who are considering disclosing.

Please read each question carefully. There are no right or wrong answers. Try to answer every question without missing anything out. If you can't answer a question or are not sure about something, ask the researcher to explain it to you.

When you have finished the questionnaire please put it in the envelope provided and either place it in the marked box in the clinic, or give it to the researcher. If you have been given a stamped addressed envelope please return the questionnaire as soon as possible.

Thank you very much for your help with this research.

If you would like to be sent a summary of the results of this research, please fill in your name and address below, tear off the slip and hand it in at reception or give it to the researcher.

✂

Name:

Address:

Appendix 5A: Study Questionnaires – Demographic Sheet

Some Questions About You

If you have children, please indicate how many:

.....

7. Language

Is English your first language? Yes No

8. Education

Please List any educational qualifications gained (tick as many as apply)

No formal educational qualifications O-levels/GCSEs or equivalent A-levels or equivalent

Diploma or equivalent Degree Masters Degree or Higher

9. Employment

At the moment are you unemployed? Yes No

At the moment are you involved in any of the following (tick as apply):

Part time work Full time work Contract/temporary work Work placement

Work related training (e.g., computer course) Further education (full time) Further education (part time) Voluntary work

Set up own business Other (please specify)

If NOT WORKING, please give month and year if possible when last worked and brief details:

Month	Year	Details
.....

Appendix 5B: Study Questionnaires – HIV Illness Indicators

Appendix 5C: Study Questionnaires – Severity of HIV Physical Symptoms

Some Questions About Physical Symptoms Experienced

People who are HIV-positive can experience a variety of physical symptoms. Have you experienced any of the following symptoms in the last 30 days? Please use the scale below to rate how much of a problem these symptoms have been for you.

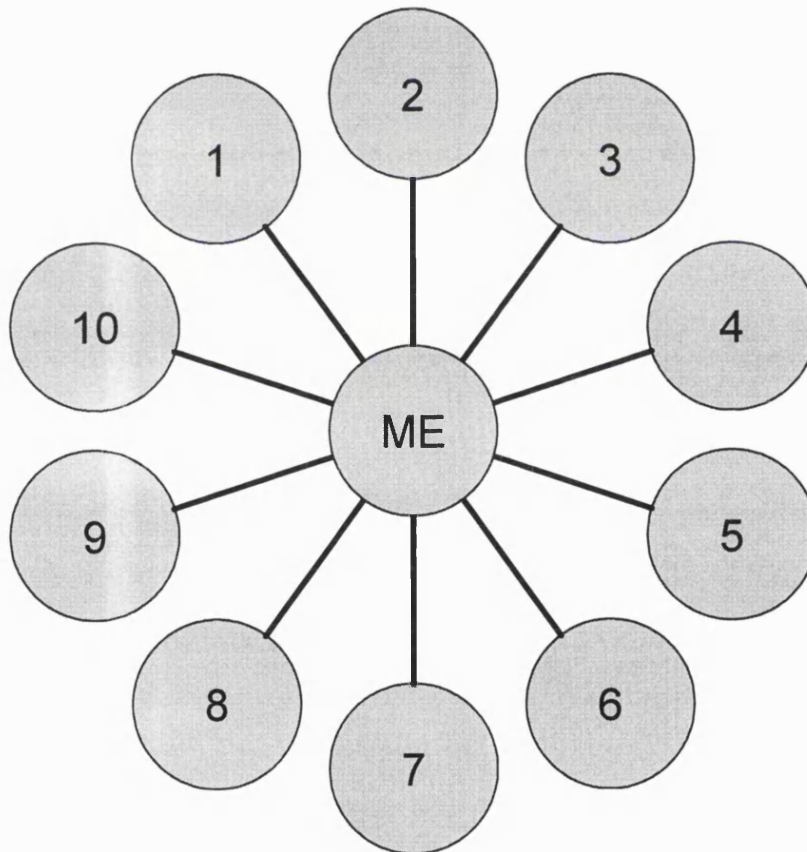
1 = No Problem	2 = Minor Problem	3 = Mild Problem	4 = Moderate Problem	5 = SevereProblem
1. Weight loss	1	2	3	4 5
2. Swollen glands	1	2	3	4 5
3. Dry cough	1	2	3	4 5
4. Skin rashes	1	2	3	4 5
5. Purple skin spots	1	2	3	4 5
6. Fever	1	2	3	4 5
7. Night sweats	1	2	3	4 5
8. Lack of energy	1	2	3	4 5
9. Diarrhoea	1	2	3	4 5
10. Stomach problems	1	2	3	4 5
11. Bloody Stools	1	2	3	4 5
12. Chest congestion	1	2	3	4 5
13. Shortness of breath	1	2	3	4 5
14. Spots on tongue	1	2	3	4 5
15. Headache	1	2	3	4 5
16. Difficulty remembering things	1	2	3	4 5
17. Difficulty walking	1	2	3	4 5
18. Difficulty concentrating	1	2	3	4 5

Appendix 5D: Study Questionnaires – HIV Disclosure Diagram

Who Are the Ten Most Important People in Your Life?

Please List the Ten Most Important People in Your Life and Their Relationship to You on the Diagram Below

Write the name of the most important person in your life and their relationship to you next to circle 1. (E.g., Ann, Mother). Then write then name of the next most important person and their relationship to you next to circle 2. Continue until you have listed the ten most important people in your life.



Appendix 5E: Study Questionnaires – HIV Disclosure Index

About the Ten Most Important People in Your Life

For each significant person you have listed above please indicate if **you** have disclosed your HIV status to him or her and complete the questions that follow.

Initials or First Name	Does the Person Know You are HIV-positive?	What is The Main Reason for Telling / Not Telling?	HIV status of this person?
1.	Yes <input type="checkbox"/> No <input type="checkbox"/>		+ve <input type="checkbox"/> -ve <input type="checkbox"/> Don't Know <input type="checkbox"/>
2.	Yes <input type="checkbox"/> No <input type="checkbox"/>		+ve <input type="checkbox"/> -ve <input type="checkbox"/> Don't Know <input type="checkbox"/>
3.	Yes <input type="checkbox"/> No <input type="checkbox"/>		+ve <input type="checkbox"/> -ve <input type="checkbox"/> Don't Know <input type="checkbox"/>
4.	Yes <input type="checkbox"/> No <input type="checkbox"/>		+ve <input type="checkbox"/> -ve <input type="checkbox"/> Don't Know <input type="checkbox"/>
5.	Yes <input type="checkbox"/> No <input type="checkbox"/>		+ve <input type="checkbox"/> -ve <input type="checkbox"/> Don't Know <input type="checkbox"/>
6.	Yes <input type="checkbox"/> No <input type="checkbox"/>		+ve <input type="checkbox"/> -ve <input type="checkbox"/> Don't Know <input type="checkbox"/>
7.	Yes <input type="checkbox"/> No <input type="checkbox"/>		+ve <input type="checkbox"/> -ve <input type="checkbox"/> Don't Know <input type="checkbox"/>
8.	Yes <input type="checkbox"/> No <input type="checkbox"/>		+ve <input type="checkbox"/> -ve <input type="checkbox"/> Don't Know <input type="checkbox"/>
9.	Yes <input type="checkbox"/> No <input type="checkbox"/>		+ve <input type="checkbox"/> -ve <input type="checkbox"/> Don't Know <input type="checkbox"/>
10.	Yes <input type="checkbox"/> No <input type="checkbox"/>		+ve <input type="checkbox"/> -ve <input type="checkbox"/> Don't Know <input type="checkbox"/>

Appendix 5F: Study Questionnaires – Experience of Shame Scale

Your Thoughts About How You See Yourself

These questions are about your feelings about yourself and the way you look at any time in the past year. There are no 'right' or 'wrong' answers. Using the scale below please circle the response for each item which applies to you.

	0 = Not At All	1 = A Little	2 = Moderately	3 = Very Much
1. Have you felt ashamed of any of your personal habits?	0	1	2	3
2. Have you worried about what other people think of any of your personal habits?	0	1	2	3
3. Have you tried to cover up or conceal any of your personal habits?	0	1	2	3
4. Have you felt ashamed of your manner with others?	0	1	2	3
5. Have you worried about what other people think of your manner with others?	0	1	2	3
6. Have you avoided people because of your manner?	0	1	2	3
7. Have you felt ashamed of the sort of person you are?	0	1	2	3
8. Have you worried about what other people think of the sort of person you are?	0	1	2	3
9. Have you tried to conceal from others the sort of person you are?	0	1	2	3
10. Have you felt ashamed of your ability to do things?	0	1	2	3
11. Have you worried about what other people think of your ability to do things?	0	1	2	3
12. Have you avoided people because of your inability to do things?	0	1	2	3
13. Do you feel ashamed when you do something wrong?	0	1	2	3
14. Have you worried about what other people think of you when you do something wrong?	0	1	2	3
15. Have you tried to cover up or conceal things you felt ashamed of having done?	0	1	2	3
16. Have you felt ashamed when you said something stupid?	0	1	2	3
17. Have you worried about what other people think of you when you said something stupid?	0	1	2	3
18. Have you avoided contact with anyone who knew you said something stupid?	0	1	2	3
19. Have you felt ashamed when you failed at something which is important to you?	0	1	2	3
20. Have you worried about what other people think of you when you fail?	0	1	2	3
21. Have you avoided people who have seen you fail?	0	1	2	3
22. Have you felt ashamed of your body or any part of it?	0	1	2	3
23. Have you worried about what other people think about your appearance?	0	1	2	3
24. Have you avoided looking at yourself in the mirror?	0	1	2	3
25. Have you wanted to hide or conceal your body or any part of it?	0	1	2	3

Appendix 5G: Study Questionnaires - Hospital Anxiety & Depression Scale

Some Questions About How You Feel At the Moment

Read each item below and tick ✓ the reply which comes closest to how you have been feeling in the past week.

Don't take too long over your replies; your immediate reaction to each item will probably be more accurate than a long, thought-out response.

1. I feel tense or "wound up"

- Most of the time
- A lot of the time
- From time to time, occasionally
- Not at all

2. I still enjoy the things I used to enjoy

- Definitely as much
- Not quite so much
- Only a little
- Hardly at all

3. I get a sort of frightened feeling as if something awful is about to happen

- Very definitely and quite badly
- Yes, but not too badly
- A little, but it doesn't worry me
- Not at all

4. I can laugh and see the funny side of things

- As much as I always could
- Not quite so much now
- Definitely not so much now
- Not at all

5. Worrying thoughts go through my mind

- A great deal of the time
- A lot of the time
- No too often
- Very little

6. I feel Cheerful

- Never
- Not often
- Sometimes
- Most of the time

7. I can sit at ease and feel relaxed

- Definitely
- Usually
- Not often
- Not at all

8. I feel as if I am slowed down

- Nearly all the time
- Very often
- Sometimes
- Not at all

9. I get a sort of frightened feeling like "butterflies" in the stomach:

- Not at all
- Occasionally
- Quite often
- Very often

10. I have lost interest in my appearance

- Definitely
- I don't take as much care as I should
- I may not take quite as much care
- I take just as much care as ever

11. I feel restless as if I have to be on the move

- Very much indeed
- Quite a lot
- Not very much
- Not at all

12. I look forward with enjoyment to things

- As much as I ever did
- Rather less than I used to
- Definitely less than I used to
- Hardly at all

13. I get sudden feelings of panic

- Very often indeed
- Quite often
- Not very often
- Not at all

14. I can enjoy a good book or radio or television programme

- Often
- Sometimes
- Not often
- Very seldom

Appendix 5H: Study Questionnaires – Final Thoughts

Some Final Thoughts?

Are there any other comments or concerns about your decisions to or not to disclose your HIV status that you would like to tell us about?

Please Continue on a separate sheet if necessary.

Thank-you for answering the questions in this booklet. We hope that hearing your views will help us deliver better services for HIV-positive individuals.

- **Please check that you have completed all the questions.**
- **Once you have completed the questionnaires, please put it in the envelope and place it in the marked box in the clinic.**

Local HIV Support Services – In formation Sheet

If you would like additional advice or support around disclosing your HIV status, or would like to talk more about your experiences of HIV disclosure, you may wish to contact one of the service providers listed below:

HIV & Sexual Health Psychology & Counselling Services	020 8442 4646
HIV liaison nurse/counsellor	020 8874 544
Antenatal HIV counsellor	020 8874 547
Blackliners	020 7272 9271
UMOJA/AWWG (African Women's Welfare Group)	020 8374 0145
IVO (Inovative Vision Organisation)	020 8365 0349
The Terrence Higgins Trust	020 7242 1010
Positively Women	020 7713 0222
Body & Soul	020 8272 5500

Appendix 6: Information Sheet – Focus Groups

Individuals' Experience of HIV Disclosure Focus Group/Participant Information Sheet

The aims of the research

We are currently studying the experiences of individuals', who have disclosed, or thought about disclosing, their HIV-positive status to others in their lives. We know that disclosing HIV status is not always easy, and we are hoping that this study will enable us to understand the factors that make it easier or more difficult to inform others of one's HIV-positive status.

How the information will be used

The information collected will allow us to begin to develop an idea of the kind of difficulties people who are HIV-positive are faced with. This will be used to improve services. By helping us you will benefit others in similar positions to you who are thinking about disclosing their HIV-positive status. The information obtained will also be used as part of a doctoral research thesis and may be published in professional journals. If you are interested, you can find out about the outcomes of the study - every participant can get a summary of the results of the research sent to them if they want. A copy will also be available at the reception at T1 outpatients.

What would be expected if you agree to take part?

We believe that a good way of hearing about your views and experiences is to invite you to an informal group discussion. If you agree to take part, you would be expected to take part in a discussion with around 8 other people who are also living with HIV. The group discussion will take about one and a half hours. The discussion will be tape recorded to guarantee accuracy but your identity will not be revealed on the tape and any subsequent research report. Refreshments will be provided as a thank you for your participation in the study.

Confidentiality

All conversations will be anonymous. All information discussed will be treated confidentially and processed collectively without names. The tape recording of the group will be erased immediately after transcribing. This means that it will not be possible for anyone to identify who has taken part in the discussions. All research proposals using human participants are reviewed by an ethics committee before they can proceed. This study was reviewed by Barnet, Enfield and Haringey Health Authority Research Ethics Committee.

Indemnity

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

If you would like to help us with this study and are willing to take part in one of the discussion groups, please complete the form attached to this page or telephone Eleanor Murray on the number given below. If you decide to take part in a group discussion, you may withdraw from the study at any time without having to give a reason and without affecting your treatment in any way.

If you have any further questions about the study do not hesitate to contact the researchers, at the addresses and phone numbers listed below.

People and organisations involved in the research.

Eleanor Murray
Trainee Clinical Psychologist
Sub Department of Clinical Health Psychology
University College London
Gower Street
London
WC1E 6BT
Tel: 0208442 6464

Liz Shaw
Clinical Psychologist
1st Floor Sexual Health Centre
St Ann's Hospital
St Ann's Road
London
N15 3TH
Tel: 0208 442 6464

Thank you for your time

Eleanor Murray
(Trainee Clinical Psychologist)

Liz Shaw
(Chartered Clinical Psychologist)

Appendix 7: Informed Consent Form - Focus Groups

CONFIDENTIAL

CONSENT FORM FOR PARTICIPANTS (FOCUS GROUPS)

Centre Number:

Study Number:

Patient Information number for this group:

Title of Project: INDIVIDUALS' EXPERIENCES OF HIV DISCLOSURE

Name of Researcher: ELEANOR MURRAY, MA Hons Tel: 0208 442 6464
LIZ SHAW, BSc, MSc Tel: 0208 442 6464

Please initial box

1.	I confirm that I have read and understand the information sheet dated.....	
2.	I understand that my participation is voluntary and that I am free to withdraw at any time without my medical care or legal rights being affected.	
3.	I am willing to allow access to my medical records but understand that strict confidentiality will be maintained. The purpose of this is to check that the study is being carried out correctly.	
4.	I agree to take part in the above study	

The group discussion will last for about one and a half hours. It will be recorded on audiotape but erased immediately after the details are transcribed to ensure confidentiality. Please tick one of the statements below to indicate whether you would like to participate in the group discussion.

- I do NOT wish to discuss my experiences of telling important others about my HIV status in a group discussion.
- I would be happy to join a group discussion and discuss my experiences of telling important others about my HIV status.

 Name of Patient (block capitals) Date Signature

I have explained the nature, demands and foreseeable risks of the above research to the subject.

 Name of Person (block capitals) Date Signature

Appendix 8: Information Sheet - Interviews

Individuals' Experience of HIV Disclosure Interview Participant Information Sheet

The aims of the research

We are currently studying the experiences of individuals', who have disclosed, or thought about disclosing, their HIV-positive status to others in their lives. We know that disclosing HIV status is not always easy, and we are hoping that this study will enable us to understand the factors that make it easier or more difficult to inform others of one's HIV-positive status.

How the information will be used

The information collected will allow us to begin to develop an idea of the kind of difficulties people who are HIV-positive are faced with. This will be used to improve services. By helping us you will benefit others in similar positions to you who are thinking about disclosing their HIV-positive status. The information obtained will also be used as part of a doctoral research thesis and may be published in professional journals. If you are interested, you can find out about the outcomes of the study - every participant can get a summary of the results of the research sent to them if they want. A copy will also be available at the reception at T1 outpatients.

What would be expected if you agree to take part?

We believe that a good way of hearing about your views and experiences is to invite you to take part in a short interview. If you agree to take part, you would be expected to take part in a short discussion which will take about 30 minutes. The discussion will be tape recorded to guarantee accuracy but your identity will not be revealed on the tape and any subsequent research report. Refreshments will be provided as a thank you for your participation in the study.

Confidentiality~

All conversations will be anonymous. All information discussed will be treated confidentially and processed collectively without names. The tape recording of the interview will be erased immediately after transcribing. This means that it will not be possible for anyone to identify who has taken part in the discussions. All research proposals using human participants are reviewed by an ethics committee before they can proceed. This study was reviewed by Barnet, Enfield and Haringey Health Authority Research Ethics Committee.

Indemnity

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

If you would like to help us with this study and are willing to take part in an interview, please complete the form attached to this page or telephone Eleanor Murray on the number given below. If you decide to take part in this research, you may withdraw from the study at any time without having to give a reason and without affecting your treatment in any way.

If you have any further questions about the study do not hesitate to contact the researchers, at the addresses and phone numbers listed below.

People and organisations involved in the research.

Eleanor Murray
Trainee Clinical Psychologist
Sub Department of Clinical Health Psychology
University College London
Gower Street
London
WC1E 6BT
Tel: 0208442 6464

Liz Shaw
Clinical Psychologist
1st Floor Sexual Health Centre
St Ann's Hospital
St Ann's Road
London
N15 3TH
Tel: 0208 442 6464

Thank you for your time

Eleanor Murray
(Trainee Clinical Psychologist)

Liz Shaw
(Chartered Clinical Psychologist)

Appendix 9: Informed Consent Form - Interviews

CONFIDENTIAL

CONSENT FORM FOR PARTICIPANTS (INTERVIEWS)

Centre Number:

Study Number:

Patient Information number for interview:

Title of Project: INDIVIDUALS' EXPERIENCES OF HIV DISCLOSURE

Name of Researcher: ELEANOR MURRAY, MA Hons Tel: 0208 442 6464
LIZ SHAW, BSc, MSc Tel: 0208 442 6464

Please initial box

1.	I confirm that I have read and understand the information sheet dated.....	
2.	I understand that my participation is voluntary and that I am free to withdraw at any time without my medical care or legal rights being affected.	
3.	I am willing to allow access to my medical records but understand that strict confidentiality will be maintained. The purpose of this is to check that the study is being carried out correctly.	
4.	I agree to take part in the above study	

The interview will last about 30 minutes. It will be recorded on audiotape but erased immediately after the details are transcribed to ensure confidentiality. Please tick one of the statements below to indicate whether you would like to participate in this study.

I do NOT wish to discuss my experiences of telling important others about my HIV status in an interview.

I would be happy to be interviewed and discuss my experiences of telling important others about my HIV status.

Name of Patient (block capitals) Date Signature

I have explained the nature, demands and foreseeable risks of the above research to the subject.

Name of Person (block capitals) Date Signature

Appendix 10: Focus Group/Interviews Recording Procedures

PROCEDURE FOR RECORDING FOCUS GROUPS/INTERVIEWS

Needed before hand

1. Equipment: Sony portable minidisk recorder(s), voltage adapter, stereo-microphone(s), or boundary microphone, blank minidisks, headphones.
2. Documents: information sheets, informed consent forms, focus group record forms, recording procedure.

Setting up the Equipment

1. Place the minidisk recorder where it can be operated easily. The microphone should ideally be placed within a metre of participants, and positioned so that the (the facilitator is predominantly on one stereo channel and the participants on the other.)
2. Set the recording level to manual, with a level at about 90% of maximum. Switch on the microphone. (The battery needs regular checking.)
3. Put a verbal header on track 1 of the disc (and then listen back to it as an equipment test): "This recording is focus group (1) on (date). The facilitator is (name)."
4. The focus group discussion will be recorded on track 2 onwards. The facilitator will press the pause button.

Introducing the Focus Group/Interview

1. Give information forms to potential participants. When the person has had time to read it, introduce yourself, ask if they've read the information sheet, if they have any questions and if they want to participate.
2. If they say yes, give them the informed consent form to sign (and countersign it yourself afterwards).

Appendix 11: Focus Group/Interviews Facilitator's Guide

HIV DISCLOSURE

FOCUS GROUP/INTERVIEWS FACILITATOR'S GUIDE

Explanation/reason for group

I am here today because I want to hear about your experiences of telling others about your HIV-positive status. I am interested in understanding more about what things may have influenced your decision to disclose or not disclose your HIV status to important others in your lives.

Hi, good morning/evening and welcome.

Thanks for taking the time to join this discussion group on experiences of HIV disclosure. My name is Eleanor Murray, and I am a trainee clinical psychologist based at University College London. I am carrying out my Doctoral Dissertation research on HIV-positive individual's experiences of disclosing their HIV status to important others in their lives. The aim of this research is to gain information from service users to help us improve the local counselling and support services provided for HIV-positive individuals thinking about telling others in their lives about their HIV status. You have been asked along today because we want to hear about and to learn from your experiences.

I'm tape recording the discussion because I don't want to miss any of your comments. No names will be included in any reports. Your comments are confidential. I am just as interested in your experiences about difficulties telling others about your HIV-positive status as well as times when it was okay to tell. Hearing about what things made it okay to tell and what things made it difficult to tell are both helpful.

There are no right and wrong answers to the questions I'll ask. You may have different points of view, that's okay. Please feel free to share your point of view even if it differs from what others have said. If you want to follow up on something that someone has said, you want to agree, disagree, or give an example, feel free to do that. Don't feel like you have to respond to me all the time. Feel free to have a conversation with one another about the questions asked. I am here to ask questions, listen, and make sure everyone has a chance to share. I'm interested in hearing from all of you. So if you are talking a lot, I may ask you to give others a chance. And if you aren't saying much, I may call on you. I just want to make sure I hear from all of you.

Participation in the discussion is completely voluntary and no one needs to answer any of the questions asked. You are free to take a break or leave at any time if you feel uncomfortable. You do not need to offer an explanation if you choose to stop taking part in the group.

Some of the topics we will be discussing today can be very sensitive and personal. I am aware that some of you may know each other and for others this may be the first time that you have met. I don't want you to say anything that you may regret later. And we don't want you to feel stressed by this discussion. In order that everyone feels comfortable to take part in today's discussion, I'd like to spend five minutes with you all, before we begin, to think about ground rules for the group that will ensure that no-one discloses too much personal or identifying information about themselves or others. Also, if I sense that the discussion is getting too stressful or personal, I'll have us take a little break, relax for a minute, and then start up again at a level where everyone feels comfortable.

Finally, my desire to hear from you is not nearly as important as your comfort. For this reason, should anyone feel at all uncomfortable or stressed at any point, they should take a break from the group discussion. My first priority is to make sure that participants take care of themselves and each other, and that they should not under any circumstances subject themselves to stress in an effort to help me.

Appendix 12: Focus Group/Interview Schedule

**SEMI-STRUCTURED INTERVIEW GUIDE: EXPERIENCES OF HIV
DISCLOSURE**

1. I wonder if I could start by asking what your general experience has been about telling others that you are HIV-positive?

2. Who have you told that you are HIV-positive?

Probe: Have you disclosed to:~ Partner(s); Mother; Father; Friends; Siblings / Extended Family

Probe: Who was the first person you disclosed to?:~ Partner(s); Mother; Father; Friends; Siblings / Extended Family

Probe: Why did you tell?

3. Now let's talk about your experiences of telling important others about your HIV-positive status. What things helped you tell about your HIV-positive status?

4. What was people's reaction(s) been to hearing about your HIV status?

Probe: How have you felt about their reactions?

5. What difference has telling made to you? What would you say the benefits of telling important others about your HIV status are?

6. What for you, if anything, were the negative consequences of disclosing your HIV status?

7. Let's talk about the difficulties of disclosing. Are there important others in your life that you thought about telling that you are HIV-positive, but decided not to? I wonder what your experiences are of this? Why did you decide not to tell them?

Probe: ~ Partner(s); Mother; Father; Friends; Siblings / Extended Family; Children

8. What things made it difficult to tell others about your HIV status?

Probes:

Protecting other person from distress

No reason or benefit from disclosing

Fear of Rejection or being misunderstood

Physical distance

Previous bad experiences of disclosing HIV status

9. **How did you feel about not revealing your HIV status?**
10. **In your experience are there any advantages to not telling others that you are HIV-positive?**
11. **In your experience are there any disadvantages to not telling others that you are HIV-positive?**
12. **Have your feelings about telling others changed over time? How so?**
13. **People living with HIV often experience thoughts and feelings about themselves and how others see & think about them which can make it difficult to tell others about their HIV-positive status. Does that fit in anyway with you?**

Probes:

Re thoughts & feelings about self image, character, behaviour and body

Re thoughts & feelings of shame

Has having HIV changed the way you think about or see yourself?

Do you think other people look at you or see you differently because of your HIV status?

14. **What would be helpful in supporting HIV-positive individuals' to disclose their HIV status to important others in their lives?**

Probes:

~ Peer support groups

~ More access to counselling & therapy services

~ More information about the benefits of disclosing

~ More information about success stories

~ More information about how disclosure can be hard but is achievable

15. **The purpose of our discussion was to explore your experiences of telling others about your HIV status and to think about reasons why this may be okay or difficult to do. Have we missed anything? Is there anything that we should have talked about but didn't?**

Local HIV Support Services – In formation Sheet

If you would like additional advice or support around disclosing your HIV status, or would like to talk more about your experiences of HIV disclosure, you may wish to contact one of the service providers listed below:

HIV & Sexual Health Psychology & Counselling Services	020 8442 4646
HIV liaison nurse/counsellor	020 8874 544
Antenatal HIV counsellor	020 8874 547
Blackliners	020 7272 9271
UMOJA/AWWG (African Women's Welfare Group)	020 8374 0145
IVO (Inovative Vision Organisation)	020 8365 0349
The Terrence Higgins Trust	020 7242 1010
Positively Women	020 7713 0222
Body & Soul	020 8272 5500

Appendix 13: Sample Sections of Transcripts from Focus Groups and Interviews

Focus Group 1 – Black African Women

EM: [Introduces interview.] I just wanted to start by asking what your general experiences have been about telling other people in your lives that you are HIV-positive.

P8: Umm?

EM: I just wanted to ask what your experiences have been when you have told other people your HIV status?

P4 Which People?

EM: Disclosing your status to other people. Who have you told? //

P4: A friend, family, anyone//

P8: Boyfriend?

P3: Myself I have never told anyone, just I met people who have the same condition as me, so I already know what I have.

P1 I told my friend and she say I'm lying. She told me that the way you look you lie. You lie, you cannot be that way. I said, look I am. She said no, up 'til know she has said no, it can't be. Then I tell her to forget about it. Since then I have never told anyone except my sisters and brothers who know me.

EM: When you say your sisters and brothers who know you...//

P1: These ones, I mean the ones in the same status as me.

EM: Right. So you, you talk about what it's like to have Alzheimer's and how other people //

P4: That's right, yes. It affects people in a different way, you know, different ways ...yes. Loss of memory, you know. My memory's not too good.

EM: Yeah. And that's why you go to the group.

P4: That's right, yes.

EM: What about for other people, what's it been like...//

P: Mm-hmm. Yes.

P: Yeah, me. When my husband died, of course there were those who suspected. And eh, back home in Uganda, when I was there even the doctor did not want to tell me. He knew what was happening, but he didn't tell me. He kept it to himself.

EM: The doctor kept it to himself that your husband was positive?//

P: Yes, that he had AIDS. That he was sick. After that I went to have some tests because my husband requested me on his death bed, that I should go and take test, which I did. And then to cut the story short, I also turned out to be positive, which effected me so much. I had a niece who was a nurse, simply because she was a nurse this doctor told her. She said to me if your husband is sick then you are also sick. I said oh well, but I must not feel. But it effected me so much, it hit me so hard. But, then when I was still looking after children, they were so young. Should I tell these children? How would it effect them?

EM: How old were your children at that time?

P: Mm-hm, The youngest was five and a half. You see in Africa my husband was a sodium, he had other children from other women. they were big, because. They were 16, 17 years upwards. Then, mmm, of course I thought No, I'm not going to tell them, this may effect them. Little did I know that my husband had disclosed it to one of my daughters. He liked this girl so much and this girl was going to do her o-levels. 2 months to her sitting her o-level. He told her, but said, please never, never tell your brothers or sisters. So this girl also swallowed it.

EM: What about you, did you...//

P: No me myself I didn't., I didn't tell. Myself I didn't. But of course back home our president was moving from county to county, sub-county to county chastising, so children were aware in the schools. This awareness meant she knew. So they knew. The children back home were chastised about HIV. So this girl knew, said then Mummy must be sick if Daddy has told me that he is dying of AIDS. Then Mummy must be what, but she also swallowed it. And to cut the story short, when I got here..., Of course when I when I fell sick it was when I came here (UK). And then one day I told her that I was HIV-positive and she told me, Yeah, Mummy all along I've know, that was why I pushed you to come here. That was after 10 years. I was just trying to educate them. Waiting the time eh, that I knew that anything would happen to me. She told me Mummy I knew. One day afterwards I told all of them. But they are very, very hopeful. My children, the youngest is eighteen now, They all know. They are very, very helpful. They keep on reminding me about taking my medication "Mummy, have you taken your medication, don't forget, blah, blah, blah. Yeah, they are all very, very supportive.

EM: So what's it like going to the group – what's it like being in the group?

P4: Oh, I like it very much. 'Cos you feel, well after all there's other people in the same boat as you are... [3 second silence]. Um, I clam up when I'm talking.

EM: What about for other people? Has anyone else been able to tell?

P: When I came (to UK) in 2000, I found out when through having my son, and husband and he said to me I just be patient, because if we do the test three or twice, we find out I'm negative. And when it is just the same. I just rang him again and explained to him. He say's no. I said to him okay take my son and when we do the test if he is not. After that when I phone again, he says to me they are all fine. For him he doesn't want to tell me the truth that he has given me that sickness. So he is lying to say that he is okay. So for me he thinks..., so he doesn't believe me if I am.

Focus Group 2 – Black African Men

P4: I guess, it's like we were saying earlier it's different for different individuals.

P6: Uhhu, sure.

P4 Yeah.

EM: You wanted to say something?

P2: Yeah, trying to clarify what he was trying to put forward. For my shares, I'm just like him. I've shared with all my friends, most of the relatives and the community of life because, what I do now is to speak openly. Because it is only when you share these things that you create the awareness and sensitize others and you feel really relieved.

P6: Yeah.

P2: Because if I tell right now, tomorrow if I meet you, you're not going to tell someone, "oh do you see that man there he is living with HIV or whatever". Because I will have already told you. So, but one thing is when it comes to disclosing you have got to know who you are disclosing to and why and you should think about what may come off it. Like at work, because there is a general lack of awareness, people not even having the basic knowledge about having HIV or how it spreads or whatever. So when you go out and tell just anyone at place of work, the only thing an employer would think is the days you are going to be off because of days of sickness or somebody may even think that you will infect others. Because some people think because if you are sick and that person who is HIV-positive is sharing dishes whatever, you may catch it. So there (at work) you have to be a bit cautious. But if it is a place where people are aware about HIV is, it is very easy to let everyone know.

EM: So it's about picking who you choose to tell?

P2: To tell yes.

EM: And something about their knowledge of HIV is also important?

P2: Yes.

EM: Are there other important factors about people, that makes you decide who to tell. What about family and friends helped you to tell them?

P4: I suppose, if you have known people for a long time, you have enough confidence to tell them your most inner most fears as opposed to meeting a stranger on the street and having to disclose or tell people that you work with. I've stayed in full-time work, but I have never really told them because I'm not sure how they will take it and I still need the job so.

EM: So you have been able to keep working and decided that's not someone who needs to know.

P: That's right.

EM: And that's worked out okay for you? What about other people?

P4: That's right, yes.

EM: What about for other people, what's it been like...//

P2: I think in the process, if we are family and then I feel that out of everyone there may be others who may not receive what I am trying to put across, I can let others know and then in the process other members of the family or the community will in a way try and find a way to let those people know, but it takes time. First you have to let them know before you disclose that a person can live with it for many years. It doesn't mean if you have it like people used to think before, that it is the end of you. You are just normal human being who can do things, just like the rest. So if they get to know about all these things, when they discover that you have it, they will just treat you like the rest of them, I know it. He's going to live with us. It doesn't mean he is going to die or whatever. So it is better if you know a section is not cannot receive. Even some families you disclose like now and then they abandon you because of the stigma and shame and even some partners. You tell somebody now and for them the only option now would be running away from you.

Interview - White Male 1

WM1: People expect you to feel ashamed. Yeah they do. They expect you to feel ashamed and that adds stigma to it.

EM: Do you think people think it is a shameful illness?

WM1: Yes, people definitely think it is a shameful illness. The people in work thing that I have got L and I'm on treatment for that and that is perfectly acceptable to them, they think oh bless him. If I went in and tell everyone I've got HIV the reaction would be completely different, I know it would. Mmm, so it's very difficult who you disclose to. I mean my partner has had huge problems with his family. Some have accepted it, others have disowned him, basically. Which doesn't help. I mean, you do need support.

EM: Other than the work situation, have there been other negative things that have happened as a result of you telling anyone about your HIV status?

WM1: No.

EM: So that's quite a positive experience you've had. I was just thinking as well, you said it was difficult to tell like your Mum and family and things was that about your HIV status...//

WM1: I was thinking about them really, because. You see before I was diagnosed, I was ill for about 8 weeks, really ill, and people were so worried because I kept on coming back and forwards for tests nobody really knew what was going on. So when I told them they did get upset and in a funny sort of way they were relieved as well. And, there is a lot of ignorance about HIV and I'm probably the same as

everybody else, it doesn't cross your mind. It was a relief for me and for them as well, especially my mother. My mother just turned around and she said, you know I am really sorry, but I sort of guessed. Mmm. She said now we know what it is, we can move on. You know and have the treatment when you need it and we'll take it from there. I think it has helped them as well. I think it has helped them the fact that I'm a different person to, well in a matter of three weeks I've completely, I'm healthy.

EM: It sounds like telling has helped you access emotional and medical support. Have there been other things that you have been able to access because you have been able to tell.

WM1: I just think that it's not for everybody, but for me personally, I wanted these people to know. You know, I care about them and I didn't like lying to them. It was better to tell these people the truth. Because I know them so well and I have known them so long, I wasn't expecting anything else other than support from them.

EM: How did you feel once you had been able to let them know what was going on?

WM1: Mmm, relieved. You know relieved that the lies could stop and we could actually talk about the disease itself. Everybody said is there anything we can do. We'll no, just be there. There is so much ignorance surrounding it. I think that the mental problems it fetches are probably worse than having it. The added strains it does put on..., especially on relationships.

**Appendix 14: Interpretative Phenomenological Analysis (Stage 1): Initial
Notes in the Margin**

Extract from Focus Group 1 – Black African Women

Extract from Transcript	Margin Notes
<p>P8: To support my school work. That's why I tell her. P: Yeah to support. P1: And now she is treating you, discrimination, stigma. P8: Stigma too. P9: In the end, I return, I tell her if it is because I tell you this one that's why you want to take me off? 'Cause if she says to me if you bring your work, I will see if it's okay you will go to level 2 And last week she has told me: Oh you are copying from somebody. No, if I was copying from somebody, I couldn't hand my work before people. It's because I'm doing my work myself, that's why I bring my work late. And she said, I'm sorry I didn't know that but, I'll talk to you later. But she didn't give me any form yet for the level 2 for me to enrol. You see! P3: Yeah, sometimes you have to know someone first. You have to know the person first. P8: No (Shouts) If she continues I will go to the headteacher too...// P1: Okay Listen, listen. P2: is to find who the right person to disclose to is P8: Yes, that's the thing P2: and to find a right time to disclose...// P8: And do you know, I did...// P2: and if you find you are discriminated you have to go to these organisations at least for support...// P8: Yes. P2:... because at that time you are vulnerable, you can't talk to...// P8: Because I did. When I spoke to her, she said oh, don't worry and she start telling me the best thing with the work and I said that she is good, you know. And she says you've got so many problems so you can't. I says to her believe me I can do it, it's only because I have a lot of problems. But now because I am concentrating I can do it. P2: Some people think we need sympathy from them, which we don't need at all...// P: Ah maybe she can do that. Maybe, yeah. P2: We need some need their understanding not their sympathy. It's the only problem that comes, that they think you need them to sympathise with you, but it's not the case. For her she wanted the other one to know she was going through something, but she didn't understand her problem. P8: Me what I think is that you need to disclose to the people who are close to you. P, P1, P5: Yes, it is true. P8: But if it is boyfriend, you just meet – I can't tell you...// P: Even a friend you are very close to...// P: Yes, it's true...// P: You can't tell P: It is very difficult to tell</p>	<p>To support my school work. That's why I tell her. To support now she is treating you, discrimination stigma you have to know someone first You have to know the person first Find who the right person to disclose to is Find a right time to disclose If you find you are discriminated you have to go to these organisations for support...// because at that time [time of disclosure] you are vulnerable, you Some people think we need sympathy from them, which we don't need at all...// We need their understanding not their sympathy. Wanted other to know she was going through something [person she disclosed to] But she didn't understand her problem. You need to disclose to the people who are close to you. But if it is boyfriend, you just meet – I can't tell you...// Even a friend you are very close to...// You can't tell It is very difficult to tell</p>

**Appendix 15: Interpretative Phenomenological Analysis (Stage 2): Analysis
of Themes Within Interviews**

Themes initially identified with Focus Group 1 – Black African Women

1 Reasons for Disclosing / Not Disclosing

- 1.1 It is a Support – HIV positive individuals disclose with the idea of unburdening themselves and gaining practical and emotional support from those they tell

Told for support

To support my school work. That's why I tell her

Wanted other to know she was going through something [person she disclosed to]

You want a friend to help you out

I said my friend, I told you as a friend, I need help from you, I want you to help me

The reason why (I disclose) it is a support

- 1.2 Telling can be a Relief - Disclosing can remove a psychological burden from the discloser

Telling can be a relief

When everybody knew it helped me because I could be myself. It helped me to be normal, because they all knew

For me it was like I had to tell everybody I'm positive and to be free

I spill it (that I'm HIV positive) Because, I was scared myself

Sometimes it's too much to keep it yourself

1.3 One's in the Same Status as Me – You chose to tell only those who are HIV positive or you disclose your HIV status only by attending HIV support services

Myself I have never told anyone just I meet people who have the same condition as me

I have never told anyone except my sisters and brothers who know me - one's in the same status as me

These people [HIV positive Individuals] know who their friends are

She (newly diagnosed woman) needs somebody to talk to. (needs to talk to someone in the same situation)

It's good just to have friends who are positive

Not to try and tell to saying to someone who is negative. We are all positive, we are all dying together

Even if you are telling them your problems, you don't feel shy. It's easier because they are like you

1.4 How Would it Affect Them? – Protection of others from psychological, emotional and physical distress

Should I tell these children? How would it effect them?

I thought No, I'm not going to tell them (children), this may effect them

I was just trying to educate them. Waiting the time eh, that anything would happen to me

Mum will die. She will collapse. She's not strong, so I don't know what will happen to her if I tell her. - That's why I keep quiet

You were thinking of him? So we are still looking for the way to tell the children

Children too young to tell

1.5 You Have Your Stay! – Having legal status to remain in the UK stability, hope & a positive outlook means you are more likely to disclose

Mmm. That's you whom I thought I'd feel comfortable, (disclosing to) if, because...//

You have nothing to think about as much (that's why you can disclose). For you, you have your stay (that's why you can disclose)

Because everybody is different. Everybody is different

How long have you been here (UK)? (10 ½ years now?). That's why! (that's why she's more comfortable disclosing)

Even if I get my status or whatever, I don't think I can just go straight to my family

(Yeah, yes) and tell them that I am HIV positive

She doesn't have the same problems. You don't have the same problems

People are different. Yes, you are different from me

1.6 Sick Can't Wait – Being ill forces you to disclose

Sick can't wait (The sick can't wait to talk)

I was seeing, I would be dying, I'm going to die soon. (that's why I disclosed) have to tell him. I said I am going to die soon

You will die before, you will die before you tell

1.7 I've Made a Decision to Protect Myself - Non-disclosure as a form of Self Protection

Protect yourself. Don't tell to protect yourself

Ruining your future. [Disclosing ruins your future]

Better to keep to yourself

Sometimes it's too much...//

I told you my uncle, he told me no don't tell our people...//

I decided not to tell anyone. Even if I have my stay, even if I have a house. I just decided not to tell

Yes, don't come and spread it in here. They'll sack you. So it is better that you keep it by yourself. (Better to keep it to yourself) as Long as you are healthy

Take care of yourself. You have to take care of yourself first

It's not that I want to say that I don't care whether they know, but that I've made a decision for myself to protect myself, so that I won't have suicidal thoughts

1.8 Trusting People to Tell - Protecting the self - Without trust you can't disclose

I don't trust anyone to tell

You have to know someone first

You have to know the person first

You need to disclose to the people who are close to you

Even a friend you are very close to...//

You can't tell

My children have to know because they are my children. My mum, is my mother. My brother is my brother. That's that

There's my brother, He's young, so know he keep the secret

It depends on the person

You know your family or your boyfriend or your friends and even your sister. You actually know which sister to tell and which not to tell, you know

1.9 Being in That Status - When things are stacked against you, no legal status, you have AIDS and you don't feel positive about yourself or life, you can't disclose.

So I don't think... You can't get the guts to come out and say I'm positive when you are in that status

You were just having HIV, look normal nobody can detect. But if you have scars or what you have AIDS, I don't think you can come up and say oh, I'm HIV or AIDS

You have to be some one, you have to somewhere, someone to come out and say that you are positive

If I had AIDS, I don't think that I could come out and say that I am HIV

Because I was like that I couldn't tell anyone. Even working in the clinic. I saw HIV on my face. I could come when I'm covered, I was fine...//

If everything is turning towards negative, no I don't think how you can come out and have that confidence to come out and say that you are HIV positive

2 Other People's Reactions to the Disclosure

2.1 They are all very Supportive

They are all very supportive

Three ladies came to me and said we like you, you are very brave

They keep on reminding me to take my medication

Ex-boyfriend took it real well

They are very very hopeful. They all know. They are very very helpful

Since I told them they have been very supportive

Whoever is going to stick around will stick around. Whoever is going to go is going to go. When you know the people, who are real to you, if you tell them

Whoever is going to stick around can stick around

They were surprised. But then when I told them that.

She also swallowed it (secret of knowing Mummy has HIV)

They [family/in-laws] were talking bad about AIDS before I disclosed

So this girl also swallowed it

My family have all stuck around, because they all just realise that I am still the same person

[Son Reads about HIV] Now he's accepted. He doesn't worry

2.2 Denial - They Don't Believe You - Actual and Unwanted reactions of others
to disclosure

They [friends] don't believe you

So he is lying to say he is okay. He doesn't want to accept the truth that he has given me that sickness

If you could see me you won't believe it. (If you saw me, you wouldn't believe it that I have HIV). That is life.

It's not easy because, if you tell them (friends)...If you tell them, straight away they think you are lying

My friend she says I'm lying. She told me that the way I look you lie. You lie, you cannot be that way. I said look I am

He say's no. he doesn't want to tell me the truth that he has given me that sickness

I went too as a positive speaker and they didn't believe it. They said that they have paid you to tell us. I told them they haven't paid me, I'm HIV

He doesn't want to believe me if I am. (HIV positive)

2.3 Rejection – They Reject You -Unwanted reactions to disclosure, including
anticipated and actual reactions

They reject you

You can get a negative reaction

I was thrown out it was really terrifying

But she didn't understand her problem

They don't want even to touch you. (Even if they too are HIV positive)

Now she is treating you, discrimination

Stigma

*But you know what, when you see someone you know is HIV positive and say hello.
The person doesn't hear it*

*At first I understand that maybe they would throw me out of the house but it was not
the case [expectations]*

Teacher lacks awareness

They don't understand (About HIV & transmission of HIV)

Don't want people who are positive to come

Even those who I think have accepted it, haven't accepted it

People under look you as being...

They cried and cried until they had to accept it

I it is because I tell her that's why she do that (she ask me to leave the course)

Negative reaction from the people that tell you

So this is the reaction she got from her ex-boyfriend (negative reaction)

Children don't want to share because Mother is HIV positive

*Ex boy friend. He takes the HIV leaflet. When he read, he say I'm losing weight,
look, look. I want to die now*

*People were actually not comfortable with me being normal. As people knew they
expected me to act in a certain way or feeling I a certain way or be sick in a certain
way because of the diagnosis*

That is the problem – she disclose

You are thinking about people who are negative here. Even if you tell someone and they support you, but still inside of them they are scared of you

West Africa is very very different/difficult. In West Africa, if you go and tell your family you've got AIDS, even your Grand mum even drive out of the family house

If you scratch yourself - and they see blood, they still don't support you

I said to her and now the way she is treating me. She wants to take me off the course. You have so many things in your head, you can't continue this course. So many friends have told me that they have gone through a rough time

I don't like to stay with the people. [in case they confront me] I decided, I resign from work

Some people think we need sympathy from them, which we don't need at all...// We need their understanding not their sympathy

Friends who are telling a different story when disclosed to their families [Negative reactions].when disclosed to their families they have to cook their own food, don't use what is theirs, have their own cup, they don't use the shower or the bath, they don't use the toilet. They have to disinfect it

At first he was angry with me. What, And when he look at himself in five minutes, when he look at himself and he say "I'm losing weight now". You gave me this sickness. Ah you see, I'm losing weight. You give me the sickness. Why you not tell me? That's why I tell you to use a condom

3 The Process Of Disclosing / Not Disclosing

3.1 I Just Say It Straight-The process of how one's HIV status is disclosed

I just say it straight, that I was HIV positive - So we could talk about it

Sometimes it's okay (to tell friends). It's better to know...//

I started to arrange to tell everyone

No it's not better. You just tell them (disclose)...//

And when it just the same. I just explained to him. I just let him sit down and I explain to him

3.2 So I Told My Brother All My Story - The process of disclosing

So I told my brother all my story

I just told her (sister) it was easy to tell her

I tell my younger brother

Me I've told. My mum knows

Yeah. I've told my two sisters and my in-laws I'm living with

I've told two sisters and my in-laws

One day afterwards I told all of them But if it is a boyfriend you just meet - I can't tell you...//

All my family they don't know

I stood up in church, I said look I am HIV positive

3.3 At That Time You Are Vulnerable - How the discloser feels emotionally and psychologically at the time of disclosing

Because at that time [time of disclosure] you are vulnerable.

Until that day (when I disclosed my HIV status) I was feeling guilty towards my children

I spill it because scared myself. I just let him sit down and I explain it to him.

I confide in you, you know, because I broke down. I started crying have this problem but they don't have anybody to share it with

3.4 It is Very Difficult to Tell - The process of disclosing – what makes it difficult to disclose.

It's difficult to tell

It's not easy to tell (friends)

You can't tell friends

No you can't go straight (To tell family)

You can't do that (go straight and tell family)

There is nobody whom I can tell

So it is hard to tell

It is very hard. {To disclose}

Yeah, not everybody can tell. It's not easy

I can't begin to tell some people I see, I have the thing.

Sometimes you don't tell... //[Friends]

It's not easy to tell [friends]

Disclosing HIV it's (Makes large spitting out noise)

3.5 I Have to Cook My Story - Protecting the self and others.

I have to cook my story

I said I have problems, school, fees, health problems, money, don't worry

People keep on asking me are you sick or are you okay? I say I'm okay.

4 Control - Issues of Control

4.1 The One Who Leaked the Thing

The one who leaked the thing

There is a difference here I want to make. Listen sometimes even us positive people we talk about a person as they are positive

Some family you tell them today, they will go and tell people [back home in Africa] - You don't tell someone in the village

They [friends] just spread it, spread it

How dare you? I confide in you as my cousin

[After disclosing] – But, the thing just scattered like thaaaaaaaat

Even in Africa everybody knows.

I told one relative initially, you know. Like soon after.

I was diagnosed, I was comfortable telling one person and that one person took it to the whole family

Now you have given it out. Now what can I do?

You can't tell [friends] because I know her behaviour – she always talk.

Please, please, please don't tell my parents.

(I don't tell) - I don't want people to reveal this thing to my children.

I was careless and they were inquisitive, they got it from my will

I told my friend first. But my friend was not trusted and started telling people

I told this one person and she had to tell everybody else. So I told and I didn't have to go through who I am going to tell because someone else did it for me. She phoned up and said she's dying, we're going to be looking for money to send her back home

Like that friend of mine, we are working together she's taken to suggesting because I am in hospital, that I've got HIV

No [I haven't disclosed], but time to time it will come out

[HIV positive individual admits disclosing other HIV positive status to others] and then you say you are a friend!

Little did I know that my husband had disclosed it [to one of my daughters]

You say to the person you are with, that person is positive even though you yourself are positive

In Uganda, even the doctor did not want to tell. He knew what was happening, but he didn't tell me. He kept it to himself. Doctor didn't tell me – but told my niece because she was a nurse

4.2 The Right Place, the Right Time, the Right People

Wait for the right place, the right time, the right people

If it doesn't feel right don't disclose

You have to know someone before you tell them

If you have to disclose wait for the right time and when you can disclose to your relatives and friends. Like some of us did.

Find who the right person to disclose to is

Find the right time to disclose

Disclosure is person specific

I don't know who to see & tell first

But I think on that one you can't really sort of come to appoint where you help someone make them ultimate decision because they know either their husbands or family members, their friends or their boyfriends or girlfriends to know exactly if they can tell the person or not

It's him [brother] and me who only know which is very good

Counsellor comes in private – talk in privacy

I am the loved one in the family. I doesn't have to lose this, so I told my brother not to tell

It's easy to tell somebody on the phone

I don't have to tell her

I don't have to disclose what I am, because I am HIV positive

There is one time when I left my safe. When they got it [my will]. So I had to be honest with them

4.3 They Gathered What Was Wrong

They gathered what was wrong

For me it wasn't a secret that my husband had died of AIDS. Everybody knew - because I have some counselling in the Kampala. The children back home [Uganda] were chastised about HIV so they were aware and so they knew. Awareness meant she knew. So they knew

I believe if that someone find out, they find out, there's nothing you can do

People keep on asking me are you sick or are you okay? I say I'm okay

Of course there were those who suspected

Daddy has told me that he is dying of AIDS. Then Mummy must be. [Dying of AIDS too]. One day it old her that I was HIV positive and she told me, yeah, Mummy all along I've known

4.4 She Was The One who Passed the Message

So she (counsellor) she was the one who passed the message to my children

Then I tell her to forget about it

Brother never told anybody, of the family members

He told her, but said, please never, never tell your brothers or sisters

5 Shame

5.1 Shame

[Uganda], when you tell someone you have HIV. They, they point and whisper. A big shame to me (telling that you are HIV positive) They think that you have messed about or what, what?

Back in Africa it's seen as a shame...// They think...// They think you are messing about

You are adding more shame. You are becoming more shameful because HIV is like a shameful disease

Like a prostitute

When they (friends) find out that you are HIV, they just scorn you

Churches punish you for that (standing up and saying you are HIV positive)

Some of them feel difficult (to tell), as they look down upon you. You are rotten, you are dirty. You are what, you are Poisonous.

You should know that if I tell that person I'm going to live the rest of my life in condemnation, because they will make me feel condemned. They will make me feel, oh that I am rotten, you feel outcast

Yeah, But if I have no food, I have no family, I'm in asylum, there is no way I can come out and say I'm positive, because people will be adding on that shame

Shame and stigma about it

The stigma back home

They don't want even to touch you. (even if they too are positive)

6 People's own reactions to their diagnosis

6.1 It Hit Me So Hard

It hit me so hard I said oh, I must not feel

I was really terrified

You fear to go out in public. When somebody looks to me like I feel guilty. I thought she's going to confront me.

When you go out sometimes you feel bad

I already know what I am saying: some of us are still in denial

I jumped high and low and it really effected me but after I settled I say I have to do something

But you end up by going out you end up going through hell

Sometimes when you think about it. You will upset yourself

Sometimes when I think about the message like when I shared it with (my teacher) I start thinking and I can't be concentrating [when studying]

I found out when through having my son. My husband said to me I just be patient, because if we do the test three or twice, we find out I'm negative

My husband requested I have the test on his deathbed

I also turned out to be positive which affected me so much

Too much on my mind (thinking about HIV) can't concentrate

But people are hurting – need to talk

People [HIV positive individuals] they know they are stranded

I tell her, I don't care Mother. It was too much. Too much on my mind, too much. So, I just said, so you know what, this one, this, I have this one, that's why I can't be concentrating.

6.2 Deciding To Be Positive

You can decide to be positive yourself

She herself may be positive

It would be so nice to actually join hands in agreeing not to talk about negative stuff

You can choose not to be depressed

Trying to encourage people you can live and be strong and you can be like this you can't talk something opposite

I'm just saying that in general it is good if we can speak of things that will lift our spirits up more

You choose to look.... You choose to look that way

For some of us we are positive speakers. But, you know what brings you that confidence is like you are looking nice, looking well, it's not that you are having AIDS

I'm at a point where now. Where if I am living life, I might as well live life and fulfil what I'm living for now and spend it with my child. I have a child, I have a life, I have energy. I they and live it in the best possible way. If I have the energy, I have everything.

7 Organisational Support

7.1 Organisations Give You Back up - HIV organisations support you

The organisations give you back up

I don't really think that any outside help may do much because you know your own conviction

I don't think much outside help would help them make the ultimate decision. (Who to disclose to)

HIV organisations, they say what you do take care of yourself, no sex, no alcohol...//

In-laws work with one of the HIV organisations. Advises and supports me on every issue around HIV/AIDS

If you find that you are discriminated, you have to go to these organisations for support...//

7.2 Group Is To Support - Way this particular group is supportive

Group is to support you not to feel like that [wanting to kills elf because HIV positive]

If I come here and I want someone to lift me up

But, time to time when you come to these groups they give you confidence and when you go back home things they can be come to be positive

It's good to come to be together with everybody and other women get to talk

Yeah it's our favourite day

Another thing, it's good to have space to say what we feels

But when you come back you feel like you want to talk about it

7.3 Positive Speakers Help Me a Lot - The role of positive speakers

Because I had people come to see me who were positive speakers come to see me and they helped me a lot. They said you can be strong when I was in hospital

That's why I was saying, whoever that advisor be. They would be able to make you feel confident to go out there and they should also be able to help you deal with things and you don't know what kind of reactions there are going to be.

I guess if an advisor could come in the form of a counsellor, if they could sort of help you to deal with the people's reactions. Because you might be thinking I'm confident and then when you tell them their reactions can make you feel worse than you felt before. For instance they may change their cups, change their bedding, they might not want you to touch certain things and they may not treat you friendly

Preparing us for their [people disclosed to] reactions

We just need confidence from maybe bringing in some advisors. I don't know

For me I think it's better if a positive speaker be our leader or something like that

I think if you are a positive speaker, I mean, you have to start living and talking positively. Who can you encourage if you sometimes, if you are sometimes not positive yourself

The positive speaker lives positively as well. Because you can't come to be a positive speaker if you someone says you are going to live and then one minute all hope is gone

Yes, we just need confidence, confidence {to disclose}

I think they can be inviting some advisors on disclosure to come and advise us on how to go about this all [HIV disclosure]

8 Confidence

8.1 Lacking or Having Confidence - The role of confidence & lack of confidence on disclosure decisions

I think what brings people not to disclose is they lack confidence

Confidence, Energy & Confidence

Because I had mastered that feeling, I had mastered that feeling, I felt confident.

After I mastered that I was soooo confident

Look at me I do something

I think what brings people not to disclose is they lack confidence. Now suppose you are here you are in asylum, you have no money, you are having problems, I don't think you can come out and start saying I'm HIV positive. Those people who are confident, those who are rich, if you have something you can be proud of, then you can come out and say I am positive. So what are you saying, cause if I have a definite, if I have a house or I have a family I'll feel happy, I'll feel confident and

then I'll be able to tell people I'm HIV positive because I know I can feed myself, I can go to work, I can do everything as a normal person, that's why I can come out and say that I am HIV positive...//

I have become oblivious to what people say, even if someone is trying to treat me like I'm disgusting whatever, I don't see it, why, because I made a decision not to try and not to look for that and to try not to notice it. Because I am sort of oblivious to what people say or think or do. I don't see how people treat me

You are sure of yourself

By the time you have AIDS you lack confidence

9 Going Back

9.1 Going Back - The role of uncertainty and fear on disclosure

Think how you feel. You are already diagnosed here and you are treated like an asylum seeker. You've got medicine here and I'm HIV. Then I tell you. Then you tell me go back to your own country, there is medicine, which is a lie...//

In Uganda there are no machines even to do detecting. Checking your CD4 and whatever. Those who have money to come here. They would rather leave us (to die)

The moment they take us back to Uganda we are going to take some drugs and die.

They take our bodies here. We are dying of HIV but they will not leave us to bring up our kids

I think it's more traumatising for people who have come here and been diagnosed here where they knew about having your liver tested and your CD4 count. Because all the time you think about it, and no food

You know, without education, imagine they can actually live more positively than someone who has been here and has gone back because they don't know

They are telling us to go back. That is the burning point

We are ready to start our good life here and they want to take us back to Africa

I'm alright now and they tell you go back to Africa

And you HIV, you have that knowledge in head and you have to go back. You'd be dying...// So because they are motivated by the fact that they think that that one pill will work. But if someone who has been here and knows that whole drill and goes back home they won't feel any motivation because they know I can't one drug. I need my viral load tested

Instead of taking me back I kill my twins then kill myself. You should just poison them after you poison yourself. It is easier. (to kill yourself than go back to Africa)

Wait (Loudly) And then you can take that medication maybe for two weeks and then you don't have money or resource there and then you start building what...//

Group: Resistance (Lots of voices)

That is Uganda we are talking about. The sodiums, themselves are dying of AIDS like rats every day. The majority of us we don't have status to stay- they are telling us to go back

If you go back home, you are going to suffer more before you die and these people – immigration they can leave us alone because we are sick