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A PORTFOLIO OF STUDY, PRACTICE AND RESEARCH

Submitted in partial fulfilment of the requirements for the degree

of Doctor of Clinical Psychology (D.Clin.Psych)

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SECTION A

INTRODUCTION TO THE PORTFOLIO

SECTION A: Introduction

Two main components of interest in psychology seem to run through my career development, reappearing at different stages and in different contexts. I am now in the position to define these components in terminology unavailable during my earlier career. The two components may be described as holistic and systemic. In other words, the individual who exists as an integrated mind and body and who exists within an integrated system. These interests are reflected in the clinical, research, teaching and managerial components of my career as well as in the different sections of this portfolio.

1. Academic Background

I acquired my first degree, a BA in Social Sciences in 1978, having majored in psychology and sociology. Throughout this degree I enjoyed the different focuses that these two subjects had, psychology on the individual, and sociology on society. Together they represented the individual within the social system. A pertinent part of my first degree was the psychophysiology teaching which interested me greatly and which probably represents the start of my interest in the mind-body interaction, long before I learned of the concept of the 'holistic approach'.

My first and Honours degrees in Psychology were followed by the Masters programme in Clinical Psychology. During my masters course I saw my first patients, which further stimulated my interest in the concept of the individual within the system. I realised that an overemphasis on the individual, in isolation, was not helpful in clinical practice as a large proportion of clinical presentations is generated or maintained by the social system it exists in. I also realised that the family could not only be considered in terms of the *damage* it caused the individual, as was taught in my first degree, but that the positive aspects such as the support of family had equal importance in the assessment and treatment of the individual. During this period of study, I developed my interest in looking at patients, both as individuals and also as part of a larger system social system. This was followed by a MSc degree in ‘Medical Psychology’ in England, which further shaped my thinking and future career path. This course gave me the opportunity to learn more about the theory of psychology and its relationship with health and illness. The MSc degree was followed by a trainee placement in clinical psychology in South Africa, this time in a general hospital, where I was able to apply my knowledge and extend my experience in health psychology by working in several medical settings such as oncology, kidney dialysis and paediatrics. My interest in health psychology and systemic psychology continued to be evident in my clinical, managerial and research work.

2. Research

My research interests developed mainly as a result of clinical work, growing from a desire to better understand clinical presentations and to test anecdotal experience. As a consequence my research interests can be described as clinically applied. One of my first research projects was undertaken during two years of national service in South Africa (1983/84). This research was on the effects of the trauma associated with upper and lower limb amputations in soldiers. These soldiers were in a special section of a military hospital. During family visits I observed the distress of family members. Trauma clearly also affected the family, with different but no fewer emotional repercussions than the practical consequences of being maimed. Unfortunately contact with the families was not allowed and my interest in the effect of trauma on the families of these victims of war could not be directly explored.

During 1989 I had my first professional contact as a clinician with people who were infected with the HIV virus. Since then I have almost exclusively worked in the field of HIV psychology and mental health. Over the years my interest in the impact of illness and potential illness and death on the family grew. It became increasingly apparent that the social support networks of people with HIV were varied and non-traditional and that the social and emotional support network of HIV infected people sometimes mainly consisted of partners and close friends. I had to reassess my concept of the family and was influenced by Robert Bor, who first introduced me to the concept of 'self-defined' family (Bor et al., 1990, 1992, 1994, 1998; Miller, Goldman and Bor, 1994). As a result one of my first research projects and publications in HIV was about the social support systems of HIV infected people (du Plessis et al., 1995).

3. Section B

The research described in Section B came about as a result of an increasing awareness that many aspects of living with HIV such as disclosure and social support had not been fully studied and that there was a need for more comprehensive and in-depth research. The first part of section B reviews the literature on HIV, social support and the paradigms of social support in health, with particularly reference to HIV and AIDS. From this review it became clear that the available HIV research had not accounted for social changes and the consequent redefining of the family in some communities. The inner city population of HIV infected people in London consists predominantly of gay men, intravenous drug users and sub-Saharan immigrants, all with non-traditional support systems. Two research projects are described in this portfolio. The first project focuses on patterns of HIV disclosure, the identification of social support networks or 'self-defined' family and how social support is experienced by men who attended an inner city HIV clinic in London. The second project focuses on HIV disclosure, social support and coping mechanisms from the perspective of the self-defined family. Finally I had the chance to talk to the family.

4. Section C

My first job as a clinical psychologist in England was in 1989 in the Adult Mental Health Department of Guy's Hospital, London. I was asked to do a feasibility study for a dedicated HIV psychology service. I had no career interest in HIV at the time but it provided me with the opportunity to do something in the field of health psychology. It became clear that such a service was needed and again I had the opportunity to work with people who had to deal with potential illness, but this time also with the wider system of people affected by HIV. The challenge of the development of this service lay in the combination of social, moral, legal, sexual and political issues associated with HIV and how it impacts uniquely on each individual and family. The development of this HIV mental health service from its inception in 1990 through to April 1999 is described in section C. A definition of an HIV psychology service is proposed along with the assessment of need for such a service. In addition the objectives, management and service models, operational standards, quality standards and data collection for the HIV mental health service are described.

5. Section D

Section D is an overview of the literature relating to the impact of HIV on Families. My interest in systems is again reflected in the subject matter of this review. This section critically reviews the content and methodology of research in HIV. Areas reviewed include the impact of HIV on individuals and families, social support and the response to illness and the impact of loss in the family. It only briefly examines the literature on HIV disclosure, as this is the topic of the research projects in Section B.

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SECTION B

RESEARCH

HIV DISCLOSURE AND SOCIAL SUPPORT: THE IMPACT OF HIV ON RELATIONSHIPS

SECTION B: HIV Disclosure and Social Support; the Impact of HIV on Relationships

CHAPTER 1: Literature Review

1.1 Introduction

The global epidemic of Human Immunodeficiency Virus (HIV) and Acquired Immune Deficiency Syndrome (AIDS) has continued to grow at a formidable rate over the past decade (WHO, 1998). Significantly however, whereas in the 1980's a positive HIV diagnosis signalled a progressive and fatal disease course, recent advances made in respect of both antiretroviral therapy and therapeutic regimens in developed countries have been such that many currently working in the field now view HIV as chronic and treatable, rather than a progressive and fatal disease. Provided that access to appropriate health care is available, and assuming that the patient is able to tolerate the therapeutic regime, HIV infection can now be managed for a seemingly indefinite period of time. Many infected people are now able to lead relatively normal lives with apparently good immune system functioning (Rabkin and Ferrando, 1997; Kalichman Ramachandran and Ostow, 1998; Schoub, 1999, Catz, Pequegnat and Stover, 1999).

In parallel with these advances in pharmacology, characterised by the shift in therapeutic emphasis towards illness management and infection control, many psychologists working in the HIV field have begun to look anew at the concept of social support for those affected. Of particular relevance is the potential mediating role of social support in areas such as treatment efficacy and disease course (Theorell, Blomkvist, Jonsson Schulman, Berntorp and Stigendal, 1995; Lesserman, Jackson, Petitto, Golden, Silva, Perkins, Cai, Folds, and Evans, 1999), patient quality of life (Swindells, Mohr, Justis, Berman, Squier, Wagener and Singh, 1999), compliance with medication regimens (Blumenfield, Milazzo and Wormser, 1990; Morse, Simon, Coburn, Hyslop, Greenspan and Balson, 1991), and patient adherence to medical appointment schedules (Catz, McClure, Jones and Brantley, 1999). Whilst much of this research can be thought of as a continuation of earlier work as to the role of social support in illness progress and outcome, there are also important reasons to speculate that the systems of social support operating for patients with HIV may in some respects be markedly different from those found elsewhere. These reasons include the unique way in which HIV can be transmitted between people, the social stigma and prejudice that has historically accompanied infection with HIV and the often alienation and ostracism often experienced by many of those most affected by HIV, such as intravenous drug users and gay men (Bennett, 1990; Crandall and Coleman, 1992). It has already been observed that whilst traditionally, biological family members provide practical, emotional and social support during a time of illness, this typical pattern of support is not necessarily available when the patient concerned is HIV infected (Bor and Elford, 1994).

In addition to the direct benefit that might be derived for HIV infected people from an improved understanding of their social support networks, a better knowledge of social support systems will concomitantly also be of significant value in understanding and meeting the needs of the individuals providing social and practical support. Although relatively little attention has been given to this side of the support equation, numerous researchers have nevertheless highlighted the fact that HIV *infects* individuals and simultaneously *affects* a whole network of significant relationships, especially those who provide the majority of the day-to-day social support (Bor, Miller, Goldman, 1993; Bor and Elford, 1994, 1998; Sherr, 1995; Levine-Perkell, 1996; Leask, Sabin, Miller, Stuhldreer, Jarrett and Johnson, 1998).

In order to gain a clearer understanding of how systems of social support operate for HIV infected patients, the present study undertook to explore the dynamics of such systems as they were found to be operating for attendees at a central London Hospital HIV clinic. The aim was to gain an insight into the nature of such support systems. Two separate, yet convergent investigations were conducted in order to achieve this. Firstly, an initial investigation explored specific characteristics of HIV patient disclosure patterns. The approach used has previously been reported (Bor and du Plessis, 1997) and offers a non-prescriptive entree into understanding *who* is identified by the HIV patient as a source of support. In addition, this approach offers a view of the HIV patient's perception of *strengths* in these various relationships. Secondly, acknowledging the reciprocal nature of the patient-supporter interaction, a further qualitative study was conducted. This second study aimed to improve the in-depth understanding of how those individuals that comprise an HIV infected patient's support nexus, perceive and understand their relationship with the HIV infected person. The outcome of these studies is likely to be relevant to an understanding of how HIV affects relationships and patterns of support. An improved understanding of how HIV affects social support systems enables HIV psychosocial service providers to provide better access to HIV services for all 'family' members. It also helps to identify the range of responses pertinent to the discovery of HIV in the 'family', for all concerned. Improved functioning of the family and social support system can in turn facilitate increased psychological well being for 'family' members and physical health for the HIV infected individual as a result of improved adherence to HIV medical treatment. The most salient findings of the two investigations will be drawn together and overall conclusions will be made in relation to both clinical practice and future research.

1.2 Review of HIV Literature

This section reviews HIV literature and studies and attempts to provide an overview of the history and aetiology of HIV and local and national HIV epidemiology. Furthermore it briefly describes the mechanisms of HIV infection, modes of transmission and HIV clinical symptoms and disease progression.

1.2.1 History and Aetiology of HIV

It is now almost two decades since AIDS as a distinct syndrome was first formally reported in the medical literature. In June 1981, a group of physicians practising in Los Angeles filed reports with the US Centers for Disease Control (CDC), describing a cluster of infections of a highly unusual form of pneumonia previously associated with immune system deficiency (Pneumocystis carinii pneumonia [PCP]). This had come to light in five young homosexual men who were unacquainted and with no medical history of immune suppression (CDC, 1981). A month later, there was a similar report from the CDC, this time concerning 26 homosexual men mainly from New York, all of whom had an unusual form of skin tumour known as Kaposi's sarcoma (KS). Notably, just as PCP had previously been found almost exclusively in patients with severe immune system suppression, KS had also been earlier linked to immunosuppression. These clinical cases were the first systematic medical reports of what soon became known as "acquired immunodeficiency syndrome" or AIDS. Subsequently, in 1982, clinical criteria were established for AIDS, facilitating more rigorous diagnosis and epidemiological monitoring (Schoub, 1999).

In 1983, a possible cause of AIDS was traced to a retrovirus which was both isolated (Barré-Sinoussi, 1983) and subsequently propagated in cell culture (Popovic, Sarngadharan, Read and Gallo, 1984). This virus later became known as the human immunodeficiency virus (HIV) or more specifically HIV-1, and has since been accepted as the cause of AIDS (Green, 1993; Barré-Sinoussi, 1996; National Aids Manual, NAM, 1999). In 1983, doctors in Belgium and France first became aware that African patients infected with HIV were generally without the two lifestyle risk factors that had up to then been characteristic of the disease in the West, namely, male homosexuality and intravenous drug use. Subsequent investigations revealed that there was a considerable amount of HIV infection among communities in African countries, particularly Rwanda and Zaire (Schoub, 1999). In 1984, a test for detecting HIV antibodies was developed, and this revealed that only a proportion of those with HIV had gone on to develop the AIDS related symptoms (NAM, 1999). In 1985, the first commercially produced HIV diagnostic tests were licensed by the Food and Drugs Administration in the USA (Schoub, 1999). In 1986, a second HIV virus (HIV-2) was identified and some researchers claim that there may be further strains of the virus (NAM, 1999).

1.2.2 Epidemiology

Following the initial reports in the USA, the number of AIDS cases diagnosed worldwide increased rapidly. By May 1985, over 100,000 cases of AIDS had been reported in the US alone and in other developed countries the pattern of growth was almost identical (Schoub, 1999). For example, in the United Kingdom (UK), whilst only 18 cases of AIDS were reported in 1982, the comparable figure had grown to 33 by the following year and then to 110 by 1985. In the mid 1980's, most HIV infected people died within two years of diagnosis. (Public Health Laboratory Service AIDS Centre (PHLS AIDS Centre), 1998) (See Appendix 1 and 2).

Epidemiological data for HIV infection reflect a similar picture. In global terms, the most recent HIV figures suggested that by the end of 1998, 33.4 million people were living with HIV and 13.9 million people had died as a result of HIV infection (UNAIDS/WHO, 1998). Significantly, the data also demonstrated that HIV is not distributed evenly throughout the world and that it is an epidemic that disproportionately affects developing countries. Currently, more than 95% of all HIV-infected people live in developing countries and a similar proportion of all AIDS related deaths have reportedly occurred in these countries (UNAIDS/WHO, 1998). Whereas the HIV epidemic has been described as being 'out of control' in many developed countries, by contrast, the rate of new HIV infection in North America and Western Europe has remained broadly stable since the mid-to-late 1980's (UNAIDS/WHO, 1998). In the United Kingdom, the number of reported HIV cases for the years between 1993 and 1998 have been 1598, 1775, 1573, 1857, 1381, 964 respectively. The numbers, particularly for recent years, are likely to be rated upwards as delayed reports are received (PHLS AIDS Centre, 1999) (See Appendices 3, 4 and 5). In the UK, HIV infection data demonstrate that this is a disease that at present predominantly affects young adults (See Appendices 6 and 7). This is not to say, however, that HIV does not also affect a significant number of children and the more elderly in our society (Nokes, 1996).

The two research studies reported on in this thesis drew participants from a population of HIV infected individuals, most of whom lived in South East London. The HIV figures from the health authority serving this part of London, Lambeth, Southwark and Lewisham Health Authority (LSL) indicate a diverse population with substantial numbers from minority groups such as homosexuals, intravenous drug users (IDU), haemophiliacs and people from diverse ethnic backgrounds (See Appendix 8 and 9). The epidemiological picture supported the need to investigate the self-defined families of this diverse population and its support mechanism.

The unique immunopatology and natural history of HIV has influenced the social impact HIV has had, and will now be discussed in more depth.

1.2.3 Mechanisms of HIV infection

Since its initial identification, HIV has been widely researched and the natural history of HIV infection is now better understood. It belongs to a family of viruses called retroviruses (Retroviridae). These viruses consist of two strands of ribonucleic acid (RNA) whilst outside the cell that will be parasitised. Once inside the cell the retroviral RNA genome is able to produce numerous analogues (the provirus) of the host cell's deoxyribonucleic acid (DNA). This process is called enzyme reverse transcriptase. The provirus then go on to multiply by becoming integrated in the DNA of the host cell itself (Barré-Sinoussi, 1996).

Retroviridae are further stratified, with HIV traditionally classified as belonging to the sub-group known as lentiviruses or slow-viruses. A lentivirus is characterised by the way it produces slow viral diseases, often affecting cells of the immune system and central nervous system. However, it is now known that whilst the overt clinical signs of HIV are slow to present, in other respects the HIV virus is very far from "slow" in its destructive course. In keeping with all primate lentiviruses, the main cellular receptor site for HIV is the CD4 protein (Weiss, 1993), which is a surface antigen found on numerous cells. In particular, the principle target of HIV are the CD4-bearing TH-lymphocyte cells (otherwise known as T-helper lymphocytes, T-4 lymphocytes, CD4 lymphocytes, or T4 cells), which play a crucial regulatory role in the human immune response system (Green, 1993).

On entering the body, the HIV virus is able to attach itself to the CD4 surface-marker of CD4 lymphocyte cells. The HIV virus is then able to inject its viral RNA core into the CD4 lymphocyte cells. The viral RNA then produces a DNA provirus through reverse transcriptase, and finally, multiplication of the HIV virus' DNA is achieved through an integration of the viral DNA into the chromosome of the host cell DNA itself (Green, 1993; Barré-Sinoussi, 1996). Crucially, once the viral DNA and the host cell DNA become integrated, the virus will continue to multiply, causing progressively more and more damage to the host's immune response system. This is the hallmark of HIV infection. In addition to the system damage, the HIV retrovirus also infects the central nervous system (CNS), which produces a wide range of clinical presentations. Whatever the individual presentation, without active intervention, an infected individual is likely to eventually succumb and die (Hoffman, 1994).

HIV attacks the very cells that multiply as an immune response to the HIV virus, by acting as a parasite. Because the HIV virus invaded and copied the cell, it also multiplies with the cell and eventually dominates and then overcomes it.

1.2.4 Modes of HIV Transmission

In infected individuals, HIV is present both in the blood and in the semen or vaginal fluid (NAM, 1999; Schoub, 1999). It can only be transmitted if these infected fluids are passed to another person's body (NAM, 1999). Correspondingly, the main HIV transmission routes are as follows: a) HIV can be transmitted across the body's mucous membrane during the act of unprotected vaginal or anal sex or b) HIV can be passed on through inoculation with infected blood. This form of transmission now mainly occurs via the sharing of drug injecting equipment, although in the past, prior to blood screening, it also occurred both through blood transfusion and through the use of other infected blood products such as Factor VIII treatment for haemophilia. On very rare occasions, transmission through this route has also occurred in occupational accidents such as needle-stick injuries or during medical procedures where sterile equipment had not been available. c) HIV can also be transmitted vertically, from an HIV infected mother to her baby during either the pregnancy, birth, or otherwise through breast-feeding. It is reported that the risk of transmission during pregnancy is between 10 and 15%. This figure may be higher if the mother has a high viral load or had developed AIDS (NAM, 1999). Table 1.1 provides a breakdown of the most probable HIV infection routes in respect of data concerning HIV infected cases in the UK to date.

Table 1.1: HIV Infected Cases in the UK by Exposure Category

Probable route of HIV infection:	HIV Infected	
	Number	Percentage
Sex between men*	22719	60.64%
Sex between men and women	7956	21.24%
IDU	3489	9.31%
Blood Factor	1354	3.61%
Blood/tissue transfer	271	0.72%
Mother to infant	546	1.46%
Other/undetermined	1131	3.02%
Total	37466	100%

#Includes 51 HIV infections first reported from Channel Islands or Isle of Man. *Includes reports of 568 individuals exposed to infection through sex with both men and women as well as through both sex and IDU

Source: Public Health Laboratory Service AIDS Centre - Communicable Disease Surveillance Centre, and Scottish Centre for Infection & Environmental Health. Unpublished AIDS/HIV Quarterly Surveillance Tables - UK data to end December 1998, No. 42, 98/4 Table A.

1.2.5 HIV Disease Progression and Clinical Symptoms

Although there has been some debate as to the most appropriate diagnostic categories for HIV disease progression, the main stages of the disease course can now be broadly summarised as follows: Initially there is a stage of acute HIV infection, followed by a latent stage. This is followed by a stage of progressive generalised lymphadenopathy (PGL), then the stage of AIDS-related complex (ARC), and finally AIDS itself (Schoub, 1999). These are described in detail below.

Shortly after the initial HIV infection, the acute clinical picture is one of a mild, flu-like illness, typically with fever and aching muscles. This phase usually lasts for just a few weeks, and is sometimes referred to as “seroconversion illness”. It is during this stage that the newly HIV infected individual develops HIV antibodies which would register as ‘HIV positive’ on the HIV antibody test. Throughout this time of acute infection, there are large amounts of HIV material present in the bloodstream and the probability of transmission to another during this period is high (Green, 1993). In response to the viral infection, the body's immune system becomes galvanised and begins to eliminate infected cells and distributing HIV. A proportion of the HIV infected cells however remain in the body and the virus now enters the second stage of the disease course.

The second stage of illness is termed the "silent" or latent stage of infection, and it typically lasts eight to fifteen years. However, whilst from a clinical point of view the HIV infected patient usually appears quite well throughout this period, it is now known that an extensive viral replication and turnover takes place (Ho, Neumann, Perelson, Chen, Leonard and Markowitz, 1995; Wei, Ghosh, Taylor et al., 1995). Wei et al. (1995) report that during this phase, 110 million virus particles are produced daily and destroyed, and simultaneously, the HIV virus destroys 5% (2000 million) CD4 lymphocytes. These need to be replaced by the body's immune defence system. Lipsky (1996) has recently questioned whether it might not be something of a misnomer to describe this stage as clinically 'latent'.

Although the body is able to maintain the onslaught of the HIV virus for a considerable period of time, eventually the immune system starts to become exhausted and a progressive destruction of the lymphoid tissue itself follows. From this point, the replenishment of CD4 lymphocytes fails to keep abreast of the viral destruction, which precipitates both a sharp increase in the quantity of the virus and a corresponding precipitous drop in the CD4 lymphocyte count. The first clinical manifestation of this watershed is a swelling of the lymph glands, especially in the head and neck region. It is this clinical presentation that is associated with the third stage of the HIV disease course or PGL. A swelling of the lymph nodes is however not specific to HIV infection and on its own would not represent a diagnostic criterion.

Following the PGL stage, many clinicians have identified a fourth discrete stage of disease progression being referred to as pre-AIDS or AIDS-related complex (ARC). This stage is characterised by three non-specific presentations of chronic pyrexia, weight loss and chronic diarrhoea, together with other AIDS non-specific opportunistic infections such as thrush. Though not specifically diagnostic of AIDS, this fourth penultimate stage of HIV disease designates an important stage in HIV infection (Schoub, 1999).

The last stage of the HIV disease course is AIDS itself. The clinical symptoms associated with this final stage can be categorised under two types according to their origin. Firstly there are the symptoms which arise as a result of direct HIV damage. These include more severe forms of the three core symptoms of ARC, including profound wasting. Secondly, there are symptoms arising as a result of direct HIV damage to various body organs, such as the gut, the central nervous system (CNS), and the kidneys. These symptoms present as an indirect consequence of the HIV induced immuno-suppression. The particular clinical picture depends on the type of opportunistic infections, the tumour types and the body location it affects.

1.2.6 Combination Therapy and Changing Treatment Protocols

Until recently, a diagnosis of HIV was synonymous with a disease progression that eventually led to certain death. Even as recently as the early 1990's, the antiretroviral drugs available only offered a limited respite before the HIV virus became resistant. Since then, advances in antiretroviral therapy have been dramatic, leading to a notable shift in treatment approach (Havlir and Lange, 1998). This shift emerged on the back of two almost simultaneous medical advances. Firstly, in 1995 there was the development of a measure for quantifying the degree of HIV viral load in the plasma which in conjunction with CD4 cell count greatly facilitated the monitoring of illness progression and the making of treatment decisions. Secondly, the other major breakthrough came with the approval of a new class of antiretroviral drugs, namely the protease inhibitors (Rabkin and Ferrando, 1997; Rabin and Chesney, 1999). Even more significantly, it was found that when protease inhibitors were used in conjunction with at least two other antiretroviral agents, most patients showed a dramatic reduction in their rate of viral replication, which both limits further proliferation of HIV and minimises the opportunity for further viral mutation to occur (Molla, et al., 1996; Nelson, 1996). Subsequently, "combination therapy", or HAART (highly active antiretroviral therapy) in which at least one protease inhibitor is administered in conjunction with two or more antiretroviral drugs, has since become the treatment of choice for HIV/AIDS. Subsequent clinical trials confirm that combination treatment has a dramatically beneficial impact on the morbidity and mortality previously associated with HIV/AIDS (Mouton, et al., 1997; Montaner, Hogg, Raboud, Harrigan and O'Shaughnessy, 1998; Hirschel and Opravil, 1999). Following these advances, the traditional monotherapy regime of administering a single antiretroviral drug such as

AZT in isolation, is now widely thought to be both ineffective and ill advised because of the likelihood of HIV resistance developing within months or even weeks (Rabin and Chesney, 1999).

HAART typically consists of two kinds of reverse transcriptase inhibitors (drugs such as zidovudine, AZT, and lamivudine, 3TC) used in conjunction with one kind of protease inhibitor (such as saquinavir or ritonavir). Reverse transcriptase inhibitors restrain the enzyme reverse transcriptase essential to HIV replication whilst protease inhibitors in contrast work by interfering with enzymes in order to disrupt the HIV replication cycle. In other words, HAART combination therapy interferes with the HIV virus at multiple stages in its life cycle, producing not only a decline in the amount of free virus in the blood, but also leads to a corresponding improvement in immune system function (Ho, 1996; Lipsky, 1996; Kalichman, Ramachandran and Ostow, 1998).

1.2.7 Adherence to Combination Therapy

In line with these HIV treatment changes, new challenges have arisen. These include the promotion of patient quality of life now that HIV has become more of a chronic condition and helping individuals establish and adhere to drug treatment have become an additional focus. This is of crucial importance because, as Treisman (1999) states: “the drugs don’t work if you don’t take them”. Combination therapy for HIV/AIDS is perhaps the most rigorous, demanding and unforgiving of any oral medication ever introduced (Rabkin and Chesney, 1999). For a start, the side effects of combination therapy are common and severe. They include not only nausea, vomiting, diarrhoea and fatigue, but also entail more lasting effects such as oral numbness, peripheral neuropathy and a metallic taste sensation (Baker, 1996; Deeks, Smith, Holodnly and Kahn, 1997). Combination therapy is not only prescribed to patients with severe medical conditions. It is often prescribed to patients in the absence of any current HIV or AIDS symptomatology. Another consideration is the short half-life of the currently available protease inhibitors that require patients to take the medication every 8 hours around the clock, either with a meal (e.g. saquinavir, ritonavir) or without a meal (e.g. indinavir). The drug taking is further complicated by an additional two or more antiviral drugs which also need to be taken on differing schedules and which brings the number of administrations up to 20 or more tablets each day (Kalichman, Ramachandran and Ostrow, 1998; Rabkin and Chesney, 1999). Finally, this basic core drug regimen might not be the end of it, for other medications are also often prescribed, either for symptomatic treatments or as a prophylactic, increasing the drug schedule even further (Rabkin and Chesney, 1999).

Failure to adhere to a drug regimen is also of critical significance for future treatment outcomes. Findings indicate that resistance to all protease inhibitors commences within a week of missed medication, with irregular use or with inadequate dosing (Condra et al., 1995; Jacobsen et al., 1996). Findings also suggest that the drug resistance that develop with one drug may additionally span several other protease inhibitors as well, and may even extend to those still under development (Kuritzkes, 1996; Hirsch, 1997). In summary, failure to adhere to a therapeutic regimen not only delays viral suppression during the unsuccessful trial but can also eliminate this entire category of drug treatment for any future use. Lastly it is also important to note that once a patient developed resistance, the drug-resistant strains of HIV can be transmitted to other people which in turn limits the treatment options for the newly infected person as well (Kalichman, Ramachandran and Ostrow, 1998; Rabkin and Chesney, 1999).

With the advances in the medical management of HIV infection, new challenges have emerged for the psychological care and social support of those infected with the HIV virus. In line with the frequent and multiple changes in HIV diagnosis, treatment and medicine, in a relatively short period of time - less than 20 years - this is yet another change that requires social and psychological adjustment. Although the medical advances are positive for most HIV infected and affected people, for some, the potential of a new lease of life have had a profound social and psychological impact. There have been many studies to date which indicate the importance and usefulness of social support as a construct in the treatment and management of health presentations, not least HIV (Green, 1993). One research route into areas such as treatment adherence and patient quality of life, is social support.

1.3 HIV Disclosure and Social Support

1.3.1 Definitions and Theoretical Considerations

Whilst the notion of social support has attracted wide research interest over the years, there is little consensus as to how it should be defined (Barrera, 1986; Green 1992) or how it should be measured (Green, 1992; Stewart, 1993). Vaux, Phillips, Holly, Thomson, Williams and Stewart (1986) maintain that social support is a "meta-construct" relating to many different aspects of social relationships, including, (a) the existence, type and quantity of interpersonal relationships, (b) the functional content of such relationships (emotional, psychological, informational) and (c) the perceived quality of the social support. Pearlin, Leiberman, Menaghan and Mullan (1981) argued that the term social support could potentially embrace all social relationships, even the most transitory and contractual. More recently, Leiberman (1986) suggested that the term social support was over-inclusive, and that it needed to be divided into a number of component parts if meaningful progress was to be made. In a somewhat similar vein, Barrera (1986) and Dunkel-Schetter and Bennett (1990) argued that more precise models and concepts should replace a global concept of social support. As detailed by Hutchison (1999), one definition of social support that has been quite widely accepted in the literature is that of House and Kahn (1985), which asserts that social support entails the realms of emotional, instrumental, informational and appraisal assistance. Lately, a fifth dimension, that of social integration, had been added to this list (Cutrona, 1990). Echoing this work, Laireiter and Baumann (1992) have suggested that a multidimensional taxonomy of social support is required, comprising of at least the five elements of social integration, network resources, supportive climate, received support and perception of support.

The lack of consensus regarding the definition and conceptualisation of social support is also reflected in how it should best be measured (Green, 1992, Green 1993; Stewart, 1993). Veiel (1990) suggests that there have almost been as many methodologies and instruments for collecting data regarding social support, as there have been actual theoretical and empirical discussions of the concept itself. More recently, Hutchison

(1999) clarified some of the issues that need to be addressed if consensus is to be achieved regarding the operationalisation of social support as a construct.

Notwithstanding these conceptual and theoretical hurdles, there have been many research findings to date which indicate just how important and useful social support is in mediating many aspects of the treatment and management of health presentation, not least in the field of HIV and AIDS (Green, 1993). These are discussed in the following sections.

1.3.2 Theoretical Paradigms of Social Support and Health

1.3.2.1 Social Support and Health

Although few studies have demonstrated a direct causal relationship between extent and quality of social support and physical health, there is nevertheless an accumulated body of both cross-sectional and longitudinal studies which suggest that various aspects of social support are positively associated with physical health and psychological well-being (Broadhead et al., 1983; Berkman, 1985; Cohen and Syme, 1985; Cohen and Wills, 1985; Cohen, 1988; House, Landis, and Umberson 1988; Sarason, Sarason and Pierce, 1990; Green, 1993, Vilhjalmsson, 1993). In an extensive literature review, De Boer, Ryckman, Pruyn and Van den Borne (1999) found that, of all the various psychosocial variables that related to cancer pathology, social support provided the strongest evidence of a link. Seven out of fifteen studies reviewed reported a positive correlation between high levels of social support and cancer relapse and survival. In a longitudinal study, Berkman, Leo-Summers and Horwitz (1992) found the presence of emotional support significantly correlated with a good prognosis following myocardial infarction. Conversely, there is a considerable body of research evidence documenting the negative effects of social isolation on prognosis for patients with coronary heart disease (Rubberman, Weinblatt, Goldberg and Chaudhary, 1984; Case, Moss, Case, McDermott and Eberly, 1992; Williams, Barefoot, Califf, Haney, Saunders, Pryor, Hlatky, Siegler and Mark, 1992; Shumaker and Czajkowski, 1994). In short, people who have had surgery seem to respond well to the provision of social support as it appears to promote or enhance physical recovery whereas the absence of social support seems to slow it down.

Other research evidence, allowing for stronger causal inferences, found that following exposure to a cold virus, those individuals with the greatest range of social ties were least likely to develop subsequent symptoms of a cold (Cohen, Doyle, Skoner, Rabin and Gwaltney, 1997). Some research demonstrates that for heart disease and surgery patients, higher levels of social support predict faster recovery rates (Fontana, Kerns, Rosenberg and Colonese, 1989; Kulik and Mahler, 1989; Berkman, 1995; Reifman, 1995). Several studies have also found that social network size is predictive of mortality in general, with those who have fewer social ties being most at risk (Berkman and Syme, 1979; House, Robbins and Metzner, 1982). In addition to these findings from general medicine, there is also a large body of empirical evidence to suggest that social support plays an important role in the aetiology and treatment of psychiatric disorders (Fokias and Tyler, 1995) and numerous studies that demonstrate that social support is linked to psychological well-being in general (Cohen and Syme, 1985; Cohen and Wills, 1985; Sandler and Barrera, 1984; Vilhjalmsson, 1993).

However, whilst evidence linking social support and a range of health indexes abound, the actual direction of causality between social resources, psychological well-being and physical health is poorly understood and remains a theoretical and methodological challenge (Madge and Marmot, 1987; Green, 1993). It is currently unclear as to whether good physical health facilitates psychological adaptation, which in turn attracts a wider network of social support, or, alternatively, whether good social support promotes better psychological health, which in turn promotes good physical health.

Researchers have endeavoured to gain better insight into the relationship between health and social support through a consideration of the processes by which social support might generate a greater sense of well-being and health. Two different theories have been posited, with empirical evidence in support of each. The first theory is known as the ‘Direct Effects’ or ‘Main Effects’ model of social support. This model proposes that social resources have a beneficial effect on health, irrespective of whether or not the individual is actually under stress. The terms ‘direct effects’ or ‘main effects’ stem from the research findings that support this model. These findings demonstrate the statistically significant effect of social support when no additional stress support is provided. There are several postulates of the ways in which a direct effects model works (Cohen and Wills, 1985; Wortman and Dunkel-Schetter, 1987). For example, it could be that individuals with high levels of social support have a greater sense of self-esteem and social belonging which leads to a positive outlook and is beneficial to health, independent of any stressful experiences. Alternatively, high levels of social support may also help to promote health through a positive influence on health-related behaviours such as keeping fit and anti-smoking or drinking behaviours (Wills, 1983; Broman, 1993). This theory requires acceptance of a biopsychosocial model of disease causality and acknowledgement that ‘illness’ is as much a social concept as a medical one.

The second theory of social support is referred to as the ‘Buffering Hypothesis’. In contrast, this theory contends that instead of operating in an independent manner, social support operates by protecting the individual from stressful situations which then staves off potentially damaging effects on health (Cohen and Wills, 1985). In this model, it is argued that individuals with strong social support are less likely to cognitively appraise any particular situation (such as moving home or changing job) as stressful. Instead, such a situation will be seen as an achievable challenge (Pierce, Frone, Russell, and Cooper, 1996). Additionally, it is suggested that on an occasion where a situation is appraised as being stressful, social support might provide a buffering effect. This buffer will be provided by producing supporting sources who might either suggest solutions to the stressor being faced, or help the individual to reinterpret the stressor as not that bad after all.

Whilst these theories and models of social support offer some insight, it remains to be seen whether these approaches offer the most useful terms of reference for research or debate on social support. As they stand, these models are still some way from offering us a comprehensive account of how the processes of social support actually operate.

1.3.2.2 Social Support and Physiological Reactivity

Other research in this area has focused more broadly on the issues of stress physiology and health, and consequently on how factors of social support might play a mediating role within these systems. This approach stems from the notion that stress can affect health either indirectly through its effects on behaviour or directly through the changes it brings about in the body's physiology, otherwise known as 'reactivity'. The main systems of stress reactivity are the cardiovascular system, the endocrine system, and the immune system (Manuck, 1994; Evan et al., 1994; Glaser et al., 1985).

Cardiovascular reactivity encompasses any physiological changes that occur in the heart, blood vessels and blood in response to stressors. Whilst at present there is no clear evidence of causality, it has for long been known that there is a strong correlation between chronically high cardiovascular reactivity and the presentations of both hypotension and cardiovascular disease (Manuck, 1994; Sherwood and Turner, 1995). In a similar way, endocrine reactivity, which affects the release of hormones such as catecholamines and corticosteroids (Evan et al., 1994), is also potentially harmful with damaging effects on the cardiovascular system (Sarafino, 1999). The other main system of stress reactivity is that of the immune system. High levels of stress can lead to a reduction in immune system efficiency (Glaser et al., 1985; Kiecolt-Glaser and Glaser, 1986) and endocrine reactivity is now also known to affect the immune system, with certain catecholamines and corticosteroids directly impairing immune system functioning (Jemmott and Locke, 1984; Schleifer, Scott, Stein and Keller, 1986). For example, increases in cortisol and epinephrine are associated with a reduction in the activity of both T-lymphocytes (including CD4 lymphocyte) and B-lymphocytes antigens. This decrease in lymphocyte activity appears to play an important role in the development and progression of a variety of infectious diseases as well as cancer (Kiecolt-Glaser and Glaser, 1995). In addition to stress and endocrine activity, several other factors also play a crucial role in the functioning of the immune system. For example, both increased pessimism and increased depression are reportedly related to impaired immune functioning (Biondi and Pancheri, 1995; Dunn, 1995; Leonard, 1995; Levy and Heiden, 1991).

There is a growing body of work postulating how social support is likely to be tied with these reactive processes. This has led to the development of the so-called ‘Social Support-reactivity Hypothesis’. This broadly asserts that social support enhances health prospects by preventing or attenuating at least some of the harmful physiological consequences of stress (Lepore, 1998). For example, some findings suggest that social support is correlated with endocrine production (Gore, 1978, Thomas, 1985; Kirschbaum, Klauer, Filipp and Hellhammer, 1995) and that those individuals who have higher levels of social support tend to exhibit relatively lower endocrine reactivity (Seeman and McEwen, 1996). Furthermore, it is reported that social support is correlated with immune functioning (Thomas, 1985; Theorell, Blomkvis, Jonsson, 1995) and that for stress induced immunological reactivity, the degree of change in immune cell activity is a function of the stressor’s intensity, duration and type (for example, interpersonal or non-social). In this regard, long-lasting, intense interpersonal events produce especially large immune system changes (Herbert and Cohen, 1993).

It has also been reported that an absence of social support leaves a person more vulnerable to the effects of adverse life events, and hence indirectly to the detriment of the immune system functioning (Kaplan, 1991). Several research findings also demonstrate that for people who are exposed to intense long-term stress, strong systems of social support positively correlate with both stronger immune system functioning and reduced immune system impairment (Esterling, Kiecolt-Glaser and Glaser, 1996; Kennedy, Kiecolt-Glaser and Glaser, 1990; Levy et al., 1990). The relationship between psychosocial process and physiological processes such as the nervous system, endocrine system and immunological system forms the basis of the paradigm known as psychoneuroimmunology (Ader and Cohen, 1985; Maier, Watkins and Fleshner, 1994; Dunn, 1995).

In summary, recent research into the construct of social support has attempted to determine to what extent, and by what route, social support might be related to various health and well-being outcomes. In addition, an increasing body of research has also attempted to elucidate the biological mechanisms that might underpin such mediation. In particular, the physiological mechanisms that seem to be implicated include the cardiovascular system, the neuroendocrine system and the immune system, crucial to the understanding of AIDS and HIV. This discussion now considers in more detail some of the empirical findings on social support and how it relates to HIV and AIDS.

1.3.3 Social Support in HIV and AIDS

Solomon (1987) hypothesised that stress and psychosocial factors might influence the replication of HIV and hence disease progression: "Psychoimmunology deals with psychological influences (experiences, stress, emotions, traits, coping) on immune function and on the onset and course of immunologically resisted diseases.. . It seems clear that AIDS is 'ideal' for study from a psychoneuroimmunologic frame of reference..." (Solomon, 1987, p. 629). Several studies have sought to explore this since and have produced results that are supportive to this notion. For example some findings indicate that men with greater distress at the time of HIV serostatus notification were more likely to have developed HIV-related symptoms at 2-year follow-up (Ironson et al., 1994). Similarly, other studies found that those patients who reported no serious life stress and few symptoms of depression had a lesser decline in the percentage of CD4 lymphocytes at a 6 month follow-up (Patterson et al., 1995). Kemeny and Dean (1995) found that the stress of bereavement prior to HIV diagnosis was associated with a more rapid decline in CD4 count over the following 3-4 years. Some studies have however found no such relationship. Perry, Fishman, Jacobsberg and Frances (1992) and Rabkin et al. (1991) found no evidence of a link between stress and CD4 lymphocyte count. This anomaly may however lie in the methods of measuring stress (Leserman, Jackson, Petitto, Golden, Silva, Perkins, Cai, Folds and Evans, 1999).

In respect of social support and HIV progression, the available empirical evidence is also limited. Theorell et al. (1995) found in a longitudinal study of 49 HIV-infected haemophilic men, that men with low availability of attachment and support went on to demonstrate a significantly more rapid deterioration in CD4 count over a subsequent five years. If such findings were replicated and found to be robust, it would have important implications for future clinical practise. In similar vein, Solano et al. (1993) found individuals with lower social support more likely to be HIV-symptomatic after 6 months than their counterparts with better support networks. Strong research evidence as to impact of stress and social support on HIV disease progression comes from a longitudinal study by Leserman et al. (1999). These researchers examined the effects of stress, depressive symptoms and social support on a cohort of 82 HIV-infected homosexual men, following the individuals up every six months over a five-and-a-half year period. It was found that a faster progression to AIDS significantly correlates with high levels of stress, low levels of social support and greater depressive symptoms. At 5 and a half years after HIV infection, the probability of developing AIDS was about 2-3 times higher for those who had higher stress and low social support in comparison to those with lower stress and high social support levels. These findings suggest that factors such as poor social support and stress play an important causative role in HIV disease progression and warrant further investigation.

1.3.3.1 Social Support and Psychological Adjustment

Several studies have investigated the nature of the relationship between social support and psychosocial adjustment in HIV patients. Wolcott, Namir, Fawzy, Gottlieb, Mitsuyasu (1986) studied 50 homosexual and bisexual men within 3 months of their first AIDS diagnosis, and found that the concerns about illness, attitudes towards homosexuality and social support satisfaction were all significantly correlated not only with each other, but also with both previously reported psychological distress and subjective measures of health. Zich and Temoshok (1987) found that in a sample of 103 AIDS and AIDS-related complex (ARC) patients, high social support was significantly negatively correlated with ratings both of hopelessness and depression.

In a study with 50 homosexual men with AIDS, Namir, Alumbaugh, Fawzy and Wolcott (1989) found that self-perception of poor physical health (such as number of symptoms) was negatively correlated to high social support, although significantly it was not the quantity but rather quality of support that was found to be crucial here. In a similar study Hays, Chauncey and Tobey (1990) found both quantitatively and qualitatively low levels of social support were significantly associated with high psychological distress in 25 homosexual men. In particular, the network characteristics most highly correlated with psychological well-being included: a) the degree to which a person with AIDS felt able to reciprocate support, b) the number of close relationships, c) the amount of emotional and informational support received, and d) the percentage of friends compared to relatives in the support network. In similar fashion, Blaney, Goodkin, Morgan, Feaster, Millon, Szapocznik and Eisdorfer (1991) found that low levels of social support in a group of 67 asymptomatic HIV positive homosexual men was significantly related to the degree of psychological distress experienced.

In a more recent study, Pakenham, Dadds and Terry (1994) examined both social support and coping strategy in a group of 96 HIV-infected homosexual men (44 asymptomatic, 51 symptomatic, 1 excluded). This research is of particular interest for not only was a control group of 33 seronegative participants introduced for comparison, but in addition, the researchers also monitored a range of other health parameters including a CD4 count for each person. Several findings from this study are of interest. Firstly, it was shown that though not differing significantly on many variables of social support, the comparison group did have a significantly greater proportion of close friends in their support network than was the case for either the symptomatic or the asymptomatic group. This finding is of interest because it suggests that whereas uninfected individuals might arrange their social networks to maximise contact with significant others, infected individuals seem not to do this to the same extent, either because they do not wish to, or because they do not have the resources to do this. Secondly, good adjustment to HIV was found to be significantly related both to good coping strategy and good social support. Even after stage of HIV illness had been factored out, good social support was still significantly related to low CD4 counts, high ratings on a psychological adjustment scale (*Psychological Adjustment to Illness Scale - Self-Report: PAIS-SR*), and low number of self-reported HIV symptoms.

In addition to cross-sectional research, longitudinal studies have found similar outcomes. Hays, Turner and Coates (1992) conducted a cross-sectional and longitudinal study of social support in 508 homosexual men from across the age range 25-54 years and found that satisfaction across each of three domains of social support (emotional, practical and informational) was inversely correlated with depression, both cross-sectionally and one year later. In other words, the more satisfied an individual was with each type of social support, the less depressed they reported to be. Other studies (Hays, Chauncey and Tobey, 1990) similarly found that satisfaction with informational support correlated strongly with psychological well-being, and that the degree of satisfaction with informational support is especially critical in buffering the stress associated with HIV symptoms (Hays et al., 1992).

In contrast to other illnesses where informational support or advice is often not perceived as helpful (Wortman and Lehman, 1985), this finding may reflect the uncertainty and ever changing knowledge base surrounding the HIV/AIDS illness. In line with the other research findings in this area, Leserman, Perkins and Evans (1992) found that for a group of 52 HIV infected asymptomatic homosexual men, subjects primarily coped with the threat of AIDS by seeking social support and that satisfaction with social support was related to more healthy coping strategies. Both replicating and extending these earlier findings, McClure, Catz, Prejean, Brantley and Jones (1996) found that for a sample of 120 HIV infected patients of low socio-economic status, it was perceived availability of social support that accounted for the greatest variance in depression ratings. In addition they found that a major life stress and HIV related symptomatology were also significantly associated with depression. Friedland, Renwick and McColl (1996) found that for a sample of 107 male HIV positive individuals the scores on a quality of life (QoL) inventory were positively correlated with self-reported ratings of emotional social support. Likewise, Swindells et al. (1999) studied 138 HIV infected patients and found that whilst QoL did not correlate with variables such as gender, marital status or education, it was significantly associated with social support, regardless of its source.

1.3.3.2 Social Support and Treatment Adherence

Another area in which social support has been found to be implicated in HIV/AIDS management concerns the area of adherence, both with medication regimens, and with general therapeutic regimens. It has been recognised that medication adherence is a problematic issue in virtually all presentations and treatment protocols, even where the regimen is simple and the patient is recognisably ill (Blackwell, 1973). As previously discussed, the issue of adherence is both problematic and at the same time crucial to treatment efficacy in HIV/AIDS, with "poor compliance .... the potential 'Achilles heel' to the entire effort of aggressive combination therapy as now recommended in the treatment of HIV" (Bartlett, 1995, p.1865). For example, of five studies of AZT (reviewed by Rabkin and Chesney, 1999), successful adherence (defined as more than 80% of doses taken) ranged from 42% using a time frame of 1 month (Singh et al., 1996) to 67% for a time frame of one week (Samet et al., 1992). Since compliance is associated with patient belief and perception about treatment efficacy, care must be taken not to extrapolate too much from these findings, but studies of adherence in the more recent and successful combination therapy regimes also give cause for concern. Hecht et al., (1998) investigated adherence to protease inhibitor regimes in 134 patients at an AIDS clinic in San Francisco and found that 22% of subjects reported missing 20% or more of their protease inhibitor doses over the 3 day period of the study. In a large American telephone survey of combination therapy, of 665 HIV infected patients 26% reported missed doses the day before and 43% reported missed doses in the previous week (Rabkin and Chesney, 1999). A CDC national American survey in 1997 found that of 294 patients interviewed about taking their medication, 67% said they always took it, 23% said they usually took it and 9% said they took it "sometimes, rarely or never" (Nakashima, 1998, cited in Rabkin and Chesney, 1999). Substantial non-adherence seems to pervade HIV treatment and the self-reporting nature of these studies may suggest rather conservative estimates of non-adherence. On the issue of conformity, Treisman (1999) anecdotally relayed how, after two years of pretence, when finally he asked a patient why they just hadn't earlier said that they were not taking their HIV medication, the patient had replied: "*Well, it seemed so important to you.*"

In addition to other factors such as the co-ocurrence of substance abuse, neuropsychiatric complications and socio-economic variables, there is also evidence to suggest that social support might play a significant role in the adherence process (Meichenbaum and Turk, 1987, & Besch, 1995, for reviews). In medicine, social isolation has been reported to be associated with lower treatment adherence (Hogue, 1979) and increased social support has been linked to better treatment adherence (Dunbar and Agras, 1980; Janis, 1983; Sweeney et al., 1984; Morisky, 1986; Tillotson and Smith, 1996). Specifically with regard to HIV and AIDS, Morse et al. (1991) found that of 40 HIV positive patients, the more compliant patients were significantly more likely to report a greater perceived level of support from a primary significant other. A recent longitudinal study by Swindells et al. (1999) found, amongst 138 HIV patients, that on 6-month follow-up, lower levels of satisfaction with social support was significantly associated with a decrease in quality of life. This reduced quality of life was then significantly associated with lower adherence with antiretroviral therapy. In a study of HIV infected women in a prison, it was found that acceptance and adherence to antiretroviral therapy was significantly correlated both with patient-physician relationship and interpersonal support from peers (Mostashari, Riley, Selwyn and Altice, 1998). Lastly, highlighting the inter-related nature of the many factors implicated in social support and adherence, social support has been found to be significantly associated with depression in patients with HIV (e.g. McClure et al., 1996), and likewise depression has been found to be predictive of treatment adherence in HIV patients (e.g. Singh et al., 1996). This resonates with the ideas put forward by Blumfield et al. (1990), who suggested that depression in AIDS patients might lead to hopelessness, and in turn, this might lead to reduced treatment adherence. Adherence in HIV treatment also covers areas such as attending medical appointments and again, appointment non-attendance has been found to be significantly associated with HIV patients' perceptions of insufficient social support (Catz, McClure, Jones and Brantley, 1999).

To summarise, it can clearly be argued that social support plays a significant role in many areas of HIV treatment and management. Many studies demonstrate a positive relationship between psychological well being and adherence to treatment. Research into the social support of HIV positive individuals and, in turn, the social support of their support systems, is a valid and fertile area for ongoing research and exploration. The implications of increased knowledge in this area are likely to improve the quality of life for people affected by HIV. Identifying the HIV social support configuration is instrumental in understanding the mechanisms of support in HIV.

1.3.3.3 Social Support: A Case for Redefining the Family

The first step in any assessment of social support adequacy begins with a consideration of the background characteristics and the targets of the social support system (Turner, Hays, and Coates, 1993). Social support structures have been found previously to vary according to numerous variables including: gender (Grove, 1975; Broadhead, Kaplan, Jones, Wagner, Shoenbach, Grimson, Heyden, Tibblin and Gehlbach, 1983), social class (Oakley and Rajan, 1991), household type (Bott, 1972; Wallman, 1984) and race (Wallman, 1984; Ostrow, Whitaker, Frasier, Cohen, Wan, Frank and Fisher (1991). Studies in HIV and AIDS also indicates that age might be an important variable of social support, with older patients being found to be in less satisfied with the levels of support that they received (Swindells et al., 1999). Furthermore, socio-economic status and higher general education have also both been found to be positively correlated with greater levels of social support (Turner, Hays and Coates, 1993).

Another variable that seems to mediate social support mechanisms is that of sexual orientation, and clearly this factor is of particular importance when it comes to HIV and AIDS. Kurdek (1988) for example argued that patterns of support for gay men may vary considerably from those found in heterosexual samples. In contrast to heterosexual couples, for gay couples it was friends rather than biological family members who were perceived as being the more supportive (Kurdek and Schmitt, 1987). In a similar vein, studies of gay men in North America have found that whilst participants reported quite good levels of support overall, there was also a tendency for gay men to be both more distant from their biological family members and to have fewer biological family members in their support networks (Donlou, Wolcott, Gottlieb, Landverk, 1985; Wolcott, Namir, Fawzy, Gottlieb, Mitsuyasu, 1986; Namir, Alumbaugh, Fawzy, Wolcott, 1989). Similarly, Hays et al., (1990) reported that for a sample of gay men, peers were identified as the most helpful sources of support, with family members being perceived to be the least helpful. Indeed, in the light of such arguments, Turner et al., (1993) have speculated that in respect of gay men, integration into the gay community may be of particular importance for social support maintenance. In a more recent study, Friedland et al., (1996) found that for a sample of 120 HIV patients, it was close friends, rather than family members, who in practise provided the bulk of social support.

It has been suggested that findings such as these are consistent with the idea that revealing gay sexual orientation often leads to a withdrawal of family support (Turner et al., 1993). However, lack of family support might also stem from reluctance on the part of gay men to disclose their sexual orientation to members of their family. Research shows that it is not uncommon for parents to only learn of their son's homosexuality after an AIDS diagnosis or once a serious HIV-related illness develops (Coppola and Zabarski, 1983; Quirk, 1989). Whereas with other chronic illnesses it seems to be the biological family who provide the social support when a family member becomes ill (Bulmer, 1987), such a trend cannot be generalised to HIV and AIDS (Bor and Elford, 1994; Irving, Bor, Catalan, 1995). In short, there is considerable empirical evidence to point to the fact that in HIV and AIDS it is frequently friends and peers of the patient who provide the most social support, rather than the biological family. It is this finding that has led to a call for a redefinition of 'the family' in respect of AIDS and HIV, and social support (Bor and du Plessis, 1997).

1.3.3.4 Social Support from the Care-giver Perspective

Social support is very much a two-way, reciprocal process. Whilst there have been several studies concerned with the impact of social support from the perspective of the ill recipient, there have been considerably fewer studies examining the nature of the experience from the perspective of the care-giver (McShane, Bumbalo, Patsdaughter, 1994). One study examined the distress experienced by volunteers and health professionals who were working with HIV patients (Raphael, Kelly, Dunne, and Greig, 1990). They found that 37% of participants showed indications of probable psychological morbidity and 14% severe psychological morbidity. Similar results were reported by Guinan, McCallum, Painter, Dykes and Gold (1991). They found that 37% of the HIV volunteer workers they studied could be classified as having some form of mental ill health, of which 24% showed signs indicative of a severe mental disorder. Irving et al., (1995), Church, Kocsis, and Green (1988) investigated the impact of the caring role on the partners of HIV patients, and found that carers were highly anxious. Irving et al., (1995), Kocsis, Church and Green (1991) studied the carers of gay men with AIDS or ARC and found that the majority of carers (70%) were involved in a gay relationship with the patient, and that levels of depression and anxiety were raised in the carers compared to controls. In another study, Irving, Bor and Catalan (1995) investigated the psychological state of 38 gay men, some themselves infected with HIV, who were the primary carers of a lover or partner with AIDS. It was found that the participants reported high levels of both global and AIDS-specific psychological stress, the levels of stress being of such a degree that the majority of the sample were probably suffering from significant psychiatric problems. Certainly, whilst the design of the Irving et al. (1995) paper precluded a definitive causal analysis, the results suggest that providing care and support for a lover or partner with AIDS may have an adverse effect on the carer's own psychological health.

Murphy, Bahr, Kelly, Bernstein and Morgan (1992) reported that in a needs-assessment questionnaire used with HIV infected people, the fifth highest need identified by participants was "wanting help concerning problems your family is having". Furthermore, this study also reported that some 32% of their sample reported that the family needs were not being met by the medical and health care facilities. In a more recent study McShane, Bumbalo and Patsdaughter (1994) assessed psychological health in both AIDS patients (PWA) and their families. They found that parents, siblings and PWA all reported higher levels of overall distress, and also scored higher on symptom dimensions and clinically discrete symptom indicators as compared to a normative control. These authors summarised their research as follows: "The findings of this study indicate that whether or not family members are involved in direct care-giving, psychological distress is a predominant experience for both parents and siblings... policy needs to be developed to refocus services toward family supplementation and support" (McShane et al., 1994, p. 59). It would appear that whilst there are at present several gaps in our understanding of the care-giver experience, what is clear is that such a role is often both stressful and debilitating. Though important, the caregiver role also appears to be largely overlooked by both HIV health-care agencies and researchers alike.

1.3.3.5 The Impact of Stigma on Social Support in HIV

In conjunction with the other areas so far reviewed, there is also the difficulty of stigma associated with AIDS and HIV (Herek and Glunt, 1988; Herek and Capitano, 1993). Stigma in HIV can be related to the history of early reports of it being a 'disease' found only amongst gay men and soon after amongst intravenous drug users. Newspaper reporting was particularly provocative at the time and newspapers referring to HIV as "the gay plague" were common in the middle of the 1980's. HIV has moved from an epidemic that was seen as life threatening and untreatable to an infection that can be controlled for indefinite periods by HIV combination drug therapy. Unfortunately the images left by the early reporting of HIV has left its impact and people who are HIV infected as well as their families still suffer the consequences of HIV stigma.

Stigma may inhibit some people infected by HIV to disclose their HIV status because of the associations with regard to sexual activities, sexual orientation and contagion. Failure to disclose HIV status may in turn limit opportunities for obtaining social support (Leask, Elford, Bor, Miller and Johnson, 1997). Disclosure of HIV diagnosis to family members may mean exposing loved ones to revelations of sexuality, infidelity or illicit drug use (Bor, Miller and Goldman, 1993). The perceived social unacceptability of an HIV diagnosis is reported to be one of the greatest concerns for people living with an HIV diagnosis (Miller, 1988; Longo, Spross and Locke, 1990). Indeed, it has been found that such concerns as these might lead to decreased socialisation, withdrawal and self-imposed familial estrangement (Longo, Spross and Locke, 1990). In summary, it would appear that just when HIV disclosure might be most important to help mobilise social support, concomitant fears of stigma and rejection may in some cases jeopardise, or at least postpone, crucial help-seeking behaviour.

1.3.4 HIV Disclosure Patterns

Patterns of disclosure of HIV status are the entrée to understanding how HIV infected individuals define their close family, as well as the strength of relationships and social support. There is an assumption that when a person decides to disclose his or her HIV status to other family members, everyone in the family is informed. Research suggests otherwise, and disclosure is often in stages and selective (Foley, Skurnick, Kennedy, et al., 1994; Holt, Court, Vedhara, Nott, Holmes & Snow, 1998; Leask et al., 1997). Individual family members may draw a boundary between the wider family and others outside this system by not disclosing the diagnosis to more distant relatives, friends, and close colleagues (Bettoli-Vaughan, Brown, Brown, & Baldwin, 1998). Researchers have investigated the effect of public disclosure, defined as sharing the diagnosis with the community through television or newspaper, on HIV infected children and their families (Wiener, Heilman, & Battles, 1998). Their findings suggest that this type of disclosure affected children negatively, with children perceiving themselves as having a lower sense of social self-competence, as well as low scholastic, physical, and global self-competence. These families also experienced less social support and more family conflict (Simoni, Mason & Marks, 1997).

There may also be secrets within the family unit: children are not told the diagnosis or elderly parents are protected from the news because of a belief that this would affect their health. Parents who are HIV infected face the dilemma of whether to inform their children. Disclosure was also more prevalent in Caucasian families and families where the father was more severely ill (Armistead, Klein, Forehand, & Wierson, 1997).

Among gay men, mothers and sisters are more commonly informed, suggesting that disclosure is linked to gender. Friends, lovers and partners are also more frequently informed (Simoni, Mason & Marks, 1997; Holt, Court, Vedhara, et al., 1998). Results of recent research point to a noticeable pattern of nondisclosure to fathers (Leask et al., 1997). Heterosexual women disclose their HIV status to their family of choice or partner more than to their biological family. Similarly, among HIV discordant couples, mothers and sisters are chosen more often than either HIV-negative partners or brothers and fathers (Foley et al., 1994). Reluctance to disclose to family members is associated with higher levels of education, possibly suggesting either greater levels of guilt and shame or a preference to cope on one's own.

The results of two studies in Africa give conflicting evidence. In one study, the majority of adults in an HIV positive cohort had disclosed their HIV status to at least one other family member (Kamenga, Ryder, Jinhu et al., 1991). In another study (Lie & Biswalo, 1996) fear of rejection and lack of understanding deterred most from disclosing to biological family members. Disclosure is seen as a major stressor in the HIV-infected individual's life. Discrimination and a disruption in their personal relationships often accompany disclosure (Holt, Court, Vedhara, et al., 1998). The decision to disclose is often influenced by an individual's perception of the social, psychological, and material consequences of informing others rather than the length of time since testing positive for HIV (Mason, Marks, Simoni, et al., 1995; Simoni, Mason & Marks, 1997). Disclosure seldom occurs immediately post-diagnosis, as the infected individual has to deal with their own feelings first before having to contend with other people's reactions (Holt et al., 1998). Of course, disclosure may be delayed until a specific event occurs, such as hospitalisation or a serious illness (Holt et al., 1998). Disclosure in the symptomatic phase is usually more prevalent as the HIV-infected individual reaches out for more support networks, and this is likely to increase as the severity of HIV illness increases and they can no longer ‘hide’ their HIV status.

Among gay men who had AIDS, the majority who had disclosed to their family found them to be supportive (Fisher et al., 1993). In a study of HIV positive women, most feared disclosure because of a fear of rejection, discrimination or violence. The majority of women received supportive and understanding responses following disclosure, but there were incidences where disclosure was accompanied by rejection, abandonment, verbal abuse and even physical abuse (Gielen et al., 1997). It is possible, therefore, that one deterrent to testing for HIV is the perception that the family may be unsupportive or even rejecting. Further research is needed to investigate the extent to which those at risk for HIV choose not to be tested for HIV antibodies because of poor family relationships or a fear that family members may be unsupportive. Furthermore, if HIV disclosure leads to less support for some individuals, it should not unconditionally be encouraged.

Researchers have found that a significant amount of men and women do not disclose their HIV status to sex partners (Kalichman & Nachimson, 1999) despite evidence that suggests that most relationships endure the crisis of disclosure (Leask et al., 1997). This should not be taken to imply that relationships are unperturbed by news of an HIV-diagnosis. Although the majority of relationships survived 18 months after disclosure, Kamenga et al. (1991) found that 11% of couples in an African cohort with HIV suffered acute social problems, including one partner’s suicide threats as well as threats of abandonment, eviction from the household or divorce. Among HIV-positive adults in the regional hospitals in the Arusha and Kilamanjari districts of Tanzania (Lie & Biswalo, 1996), two-thirds of married or cohabiting participants had not disclosed their HIV status to their partner. Although researchers have found that 76% of African American heterosexual men reported disclosure and regular condom use (Niccolai, Dorst, Myers & Kissinger, 1999), many HIV infected individuals choose to rather practice safe sex than disclosing their diagnosis to sex partners (Kalichman & Nachimson, 1999). However, 86% disclosed following repeated counselling at post-test and HIV clinics (De Rosa & Marks, 1998). Among those who chose to inform close family members, brothers, sisters, and mothers were most frequently told.

The decision to disclose seems to serve a function of either gaining support or an acceptance of illness. Disclosure to 'whom' and 'when' is usually well planned and most often takes place after the infected individual has made some adjustment to living with their HIV positive diagnosis. It has far reaching consequences for the infected individual as it usually results in considerable change to self-concept and in relationships with partners, friends and family (Holt et al., 1998). It can lead to either greater intimacy or increased distance in relationships, although these changes may themselves be transitory. After disclosure, some adults may initially abstain from sexual relationships. The infected partner often experiences their diagnosis as a loss of their sexuality and grieves for their previous experience of sex. Combined with the ever present threat of transmission, non-infected partners have to struggle harder to maintain sexual contact with the infected individual (Van der Straten, Vernon, Knight, Gomez & Padian, 1998). This is more often transient than permanent. Disclosure can also be used as a means of ending bad relationships or putting off an unwanted suitor (Adam and Sears, 1994).

Signs of advancing illness, such as weight loss or dermatological problems, may deny a person the choice of whether or not they choose to disclose news of their condition, which could undermine the infected person's independence and self-esteem (Holt, Court, Vedhara, et al., 1998). Patterns of disclosure are useful for understanding how people engage others in support. Nonetheless, secrecy or non-disclosure should not be taken to imply that others are not affected ("don't tell, don't know" is not always feasible). Secrets may regulate how people relate to one another and therefore have an impact on the family. We know little about what happens in families where disclosure never takes place and the legacy of loss is punctuated by mystery and assumptions surrounding the circumstances of death. Studies have also shown that non-disclosure has a detrimental effect on HIV-infected individuals. It was associated with more psychosis, somatic anxiety, hostility and phobic anxiety (Holt, et al., 1998; Kalichman & Nachimson, 1999). Nondisclosure in families increased the stresses and emotions that family members experience (VanDevanter, Thacker, Bass & Arnolds, 1999) and children who were uncertain of their father's illness experienced more anxiety and depressive symptoms (Steele, Tripp, Kotchick, Summers & Forehand, 1997). Research has also indicated that the secrecy surrounding the diagnosis of HIV threatened family stability and resulted in a lack of support (VanDevanter et al., 1999).

Parents of an HIV infected child face the dilemma of 'if,' 'how' and 'when' to tell their child of his or her HIV status. Most research into this problem has been conducted with families in which the child was infected through contaminated treatment for haemophilia (Tsiantis et al., 1990) or through blood transfusions. In most of these cases, there is a greater chance that only the child in the family has been infected. In cases where one parent's HIV infection has caused the child's infection, other issues need to be addressed. Parents often feel ill equipped to handle the questions that their children might ask about their diagnosis. Children will often want to know how they became infected which might lead to awkward questions about their parents' sexual or drug use history. They may also have questions about their own and their parents' mortality. Parents are sometimes afraid that their children might not be able to cope emotionally with the news or that they might not be able to keep it a secret (Lewis, Wesley & Haiken, 1996). The issue of disclosure to non-infected siblings in the family has been addressed in clinical practice (Bor, Miller, & Goldman, 1992), but has not been extensively researched. Findings suggest that disclosure does not affect the adjustment and adaptation of siblings (Bettoli-Vaughan, Brown, Brown, & Baldwin, 1998). When disclosure was considered in the family context, it was found that the parent-child relationship had a greater influence on child functioning than disclosure of an HIV diagnosis. A positive parent-child relationship was associated with lower levels of child depression and externalising problems (Armistead et al., 1997). Most issues are similar for natural and foster parents regarding issues of disclosure, support and preparation for the parent’s death. However, natural parents also have to consider the effects of their illness on the relationship with the child and guilt about loss or fostering. Foster parents may need to address reasons for fostering, the effect on their own children and family, and fear of transmission (Cohen, Malm, Nehring, & Harris, 1995). Natural parents could be very protective of their children and resist telling them or providing support from outside of the family for the child (Niebuhr, Hughes, & Pollard, 1993).

The stage at which parents choose to disclose the diagnosis to a child, and how they do this, is an important topic since it yields insights into family dynamics and how each member comes to terms with the diagnosis and illness. There is little in the way of research, however, into this important issue, and there is no way of comparing the different approaches to disclosure in families and the effect of this on individual and family development.

1.3.5 Overview of HIV and Social Support Literature and Rational for the Study

Following the review above it became more apparent that many aspects of living with HIV such as status disclosure and social support systems are not fully explored and a need for more comprehensive and in-depth research is required. This is particularly true for the inner city population from which participants were invited for this research. Southeast London has a mix of HIV positive African immigrants, intravenous drug users and gay men whom have largely moved away from their families of origin. On the whole they have non-traditional, non-biological, self-defined families, families that may function quite differently from the traditional families studied in most other HIV research to date. Too much research on HIV in families had not taken into account the social change and consequent redefining of the family. Current definitions focus on those people who provide ongoing support in place of, or in addition to, the biological family. The self-defined family may thus include close friends, carers, HIV professionals and so forth.

The importance of social support in many spheres of the HIV infected person's life is highlighted by the HIV literature. These include a diversity of spheres ranging from health indicators such as disease progression and treatment adherence to emotional functioning and psychological adjustment of both HIV infected people and the people that make up their social support structures.

Disclosure of HIV status plays a crucial part in social support. Appropriate social support that addresses the difficulties of living with HIV cannot be activated until disclosure of HIV status had taken place. Even so, the difficulties of coping with severe illness and unpleasant treatments, stigma and uncertainty, may put a severe strain on even the best functioning families and social support systems.

The potential for research on social support in HIV seems limitless. Therefore, for the purposes of this research, the study is limited to a particular cohort and certain aspects of social support. For the first part of the research, the focus is on HIV infected men who live in inner London and who attend an inner London HIV clinic. The focus is on patterns of HIV disclosure, identification of family and social support structures and experiences of social support. The second part of the research sets out to further explore social support structures, relationships and coping mechanisms utilised by *both* HIV infected people and those they identified as providing social support.

The two research studies are discussed in detail in the following two chapters. A final chapter is devoted to an overall discussion of all the research findings, drawing together the salient findings from both parts, highlighting the potential ramifications and suggesting possible implications for future lines of enquiry.

1.4 Research Framework

Both quantitative and qualitative research methods were used in this research. This section outlines the advantages of using both methods. Clinical psychologists and other specialists have traditionally seen qualitative and quantitative methods as operating from different, usually opposing, paradigms (Todd, 1998). Quantitative methods have been linked with positivism and claims of objectivity while qualitative methods have been linked with a more constructivist epistemology which points to ways in which knowledge is generated within systems of socially constituted meanings (Henwood and Pidgeon, 1995). Recently, a number of researchers have argued that this distinction is both unproductive and unnecessary (Hammersley, 1992; Miles and Huberman, 1994; Orford, 1995). Rossman and Wilson (1991) highlight some of the advantages of a mixed methodological approach. For example, the data collected may enable confirmation or corroboration of each other through triangulation. Qualitative data may enable the researcher to elaborate or develop quantitative data providing a richer detail. Different methods may be appropriate for different questions in the same study (Todd, 1998).

The combination of methods in these studies was used to address several questions. Firstly, no previous research of this kind had been conducted in South London and it was necessary to establish the demographic and health profile of participants in both studies. Additional objectives were to investigate the patterns of HIV disclosure and to explore possible correlations between different health indicators and correlations relating to satisfaction with support. Quantitative methods seemed appropriate to this task as it lends itself well to describing groups in terms of frequencies and relational findings. Secondly, the perceptions and experiences that families have of the HIV social support systems were explored using qualitative methods. Qualitative methods are useful for capturing the richness of participants' accounts and are considered suitable when doing research on individual processes, interpersonal relations and wider social processes (Charmaz, 1995).

CHAPTER 2: RESEARCH, PART 1

2.1 Aims of the Research

This study sets out to identify factors of living with HIV that may assist local HIV support services and other HIV organisations to maximise the provision of support to HIV infected and affected individuals. The particular focus is aspects of health, stress, HIV disclosure, family construction and social support as experienced by HIV positive individuals. Unlike other family HIV research, no assumptions are made about participants' support systems. Biological family members and partners are therefore only included as 'family' if so identified by the participant. The research is exploratory and as such no formal hypotheses were posited. Instead, a set of clearly defined aims were developed to increase our understanding of how this particular sample of HIV infected men experienced disclosure and social support. The aims are:

1) To identify who were identified by HIV individuals as their self-defined family or social support network
2) To identify to whom HIV disclosure was made and the possible consequent impact on relationships
3) To identify the sources of emotional stress resulting from an HIV diagnosis as perceived by the HIV infected individual
4) To investigate the nature and levels of satisfaction with social support.

2.2 Method, Part 1

2.2.1 Setting

An estimated 2140 HIV positive people live in Lambeth, Southwark and Lewisham, in South East London, England (Survey of prevalent diagnosed HIV infections, SOPHID, 1998). Of these, a large percentage is men, mostly gay, as illustrated by SOPHID figures between 1994 to 1998 (Table 1.2).

Table 1.2: HIV Positive Men Treated in the UK

	1994	**1995**	**1996**	**1997**	**1998**
Homosexual/Bisexual (all male)	784	1034	926	1165	1257
Heterosexual Male	59	117	142	156	234
Total Number of HIV Infected Men	835	1151	1068	1321	1491
Total Number HIV infected	1359	1604	1539	1863	2140
Percentage of the Total Number	61%	71%	69%	71%	70%

A sizeable number attend an HIV dedicated treatment clinic at St. Thomas' Hospital, London for their ongoing medical, psychological and social care. In addition to the medical treatment provided by Consultants and Registrars in Genito-Urinary Medicine, other medical specialties such as dermatology, gastro-intestinal medicine, ophthalmology and psychiatry regularly provide clinics. Other services at the clinic include Community Psychiatric Nursing, Social Work and Benefits Advice, Health Advising, Community Specialist Nursing and Clinical Psychology. The clinic sets out to provide wide a range of services to HIV patients and provides a good venue for consultation and collaboration. Research is encouraged but monitored by a research committee to prevent patients from being overwhelmed by too many projects at the same time. The first part of this study was conducted there during July and August 1997.

2.2.2 Design

The first study was a one-sample cross-sectional design with no control group due to its explorative nature. A poster describing the nature of the research and participation and an invitation to participate was displayed in the waiting area of the clinic (See Appendix 10). A total of 102 HIV positive individuals participated and the cohort consisted of 100 HIV positive men attending a London teaching hospital. Sample recruitment took place over a 6-week period during June and July 1997.

2.2.3 Instruments

All participants were interviewed using a semi-structured questionnaire (Appendix 11) as used in previous research (Leask et al., 1997). The questionnaire was not piloted as it has been extensively used in previous research on a comparable population. The questions focused on (a) demographic information, (b) health status information, (c) emotional stressors experienced in relation to HIV positive status, (d) self-defined family relationships and social support networks (e) nature of these relationships and (f) the quality of support expressed as *perceived* versus *ideal* support.

2.3 Data collected

2.3.1 Demographic Data

2.3.1.1 Age

Age was coded in categories of 9 intervals: The first interval was coded for people of 15 to 20 years, followed by 7 intervals of 10 years each and the last interval for people over 71 years of age. Patients under the age of 15 were not treated at this clinic.

2.3.1.2 Country of Birth

Country of birth was reported to establish the country of origin of participants. These countries were coded in the following 12 categories: England, Scotland, Wales, Ireland, North America, South America, Europe, Africa, Asia, Australia, Caribbean, Other.

2.3.1.3 Ethnic Origin

Participants were asked to indicate ethnicity and this (as recommended by the Department of Health), was recorded in the following categories: White, White other, Indian, Pakistani, East African Asian, Bangladeshi, Chinese (Hong Kong), Chinese Other, Vietnamese, African (excluding West Indies), Caribbean (including West Indies) and an Other category for Participants who did not describe themselves as falling within these categories.

2.3.1.4 Employment Status

Employment was coded for 3 dimensions:

a) Each participant was coded as employed, not employed or retired.

b) Each participant's employment position was coded for the following categories: Self employed, Manager/Supervisor, Employee, Apprentice or Student.

c) The reason for unemployment was coded in 3 categories, which included 'unemployment as a result of illness', 'retirement' or 'discrimination' because their employers were aware of their HIV status.

2.3.1.5 Living arrangements

The type of living arrangement was established to give an indication of socio-economic status at the time. These were coded as follows: 'rent from landlord', 'rent from a Housing Association', 'home owner', 'Squat', 'living with parents', 'Bed-and-breakfast accommodation', 'no fixed living arrangements' and 'other'.

2.3.1.6 Route of HIV infection

Participants were asked how they thought they became HIV infected. The information was coded in the following categories: 'sex with same sex partner', 'sex with opposite sex partner', 'sex with both men and women', 'through injecting drugs', 'through blood transfusion' or 'do not know'.

2.3.2 HIV Health Status

2.3.2.1 Self-reported HIV Health Symptoms

Patients were asked to describe their health in relation to 4 categories: (a) HIV positive but symptom free, (b) HIV positive with an HIV illness in the past, (c) HIV positive with HIV illness at present and (d) AIDS diagnosis with life threatening HIV medical condition at present.

2.3.2.2 CD4 Lymphocyte Counts

CD4 lymphocyte counts were recorded, as it is an indication of immune system functioning. The intervals for CD4 counts for this study reflect the intervals used by physicians to make decisions regarding HIV treatments. For example, any individual with a CD4 count of less than 50 would have a seriously compromised immune system and are very likely to have had an HIV related illness at the time blood was taken to do the CD4 lymphocyte count. An HIV infected individual with a CD4 count of less than 200 will be diagnosed as having AIDS according to WHO guidelines even in the absence of any HIV related illnesses. A CD4 lymphocyte count between 201 and 500 indicates a compromised immune system, which may be sufficient for most physicians to consider starting combination treatment. CD4 lymphocyte counts of around 750 are considered within the normal range, but lymphocyte counts may vary according to an individual's state of health at the time blood is taken to do the CD4 lymphocyte count. As such, individuals who were not infected with HIV may still have CD4 lymphocyte counts lower than 750 when their immune systems are combatting other illnesses.

Most non-infected people have a CD4 count that is considerably higher than 750 when they are fit and in good health. In short though, lower CD4 lymphocyte counts indicate a compromised immune system whereas higher category indicate normal immune functioning. It has to be pointed out that there is some variation in the use of CD4 lymphocyte counts by different physicians and researchers. The method as describe above is however most widely used in the UK. CD4 lymphocyte counts for this study were obtained from the participants' medical notes after the interview and recorded for 93 participants. For 7 of the participants, CD4 lymphocyte counts were not available. The lymphocyte counts were put into 5 categories, which reflects immune functioning. The intervals used for categorisation for this research are: (a) Lower than 50, (b) between 51 and 200, (c) between 201 and 500, (d) between 501 and 750 and (e) above 751.

2.3.3 HIV Related Emotional Stressors

Participants were asked to identify the most stressful aspects of life since being diagnosed HIV positive. These were coded into the following 8 categories based on findings by Leask et al. (1997): 'relationships', 'sex', 'uncertainty about the future', 'disclosure', 'secrets', 'unmanageable feelings', 'health problems' and 'other'.

2.3.4 Self-defined Family

An explanation was given to each participant about the definition of self-defined family and about the inclusion of biological family, extended family, partners and close, significant friends. Each participant was asked to identify up to 3 people in terms of this definition and the same questions were then asked for each of these. The information gathered about self-defined family consisted of information on: (a) basic demographics such as age and gender, (b) relationship to the participant, (c) disclosure of HIV status to the family member, reason for disclosing or not disclosing and if disclosure took place how it happened, (d) relationship changes since disclosure.

2.3.5 Quality of Support

Further data about the actual versus ideal support for each of the identified family members were collected using the seven point Lickert scale contained in the questionnaire. The degree of actual versus ideal level of trust, emotional support, practical support and availability of each family member was recorded.

2.4 Data Analysis

Data were coded and entered into a data file of the Statistical Package for the Social Sciences (SPSS-Windows) (Nile, 1983). The accuracy and consistency of the data was cross checked after entry on the SPSS database. The first step in the analysis was to gain an overview of the participants' characteristics. Descriptive data using frequency distributions and measures of central tendency and dispersion were calculated for some of the demographics, health indicators and stressors associated with HIV positive status. Further quantitative analysis included correlations between the various health indicators and correlations on the support data.

CHAPTER 3: RESULTS, PART 1

Descriptive data are reported to describe the characteristics of the sample of participants. Firstly, data such as age, ethnicity, occupational characteristics as well as data on the length of time since HIV diagnosis, route of HIV transmission, HIV symptomatology and the most stressful aspects of living with HIV since diagnosis will be reported. Secondly, characteristics of the people who provide primary support are reported. The characteristics include the nature of the relationship with the participant, HIV disclosure data and changes in relationships since HIV diagnosis. In addition to frequency distributions, trends within the sample will be highlighted. Where appropriate, tables summarise the data.

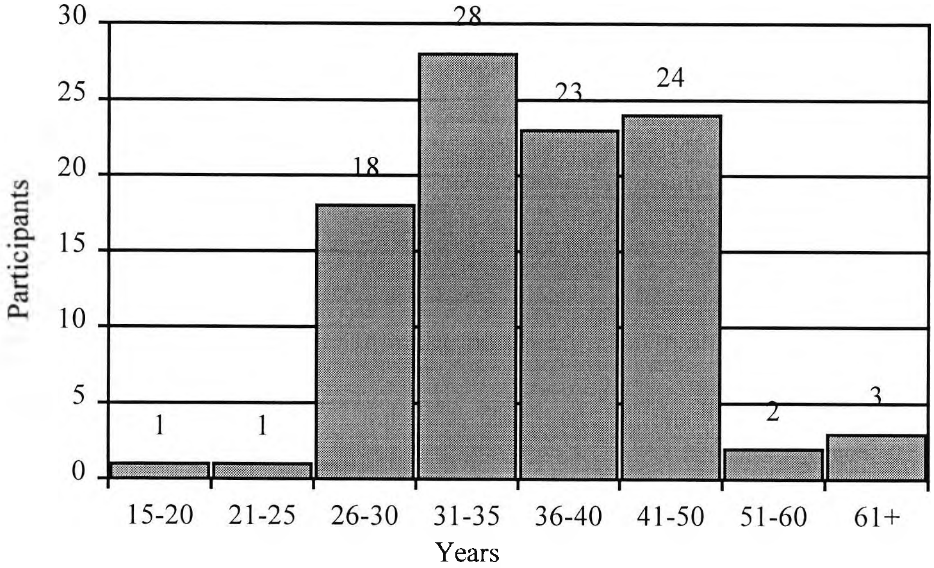
3.1 Participant Characteristics

Of the 102 participants, two were female. For statistical purposes, only the 100 men were included in the analysis of the data. The participants were predominantly white, gay men, born in the United Kingdom. Most of the participants stated that they believed that they contracted HIV between one and five years before the interview and were all at varying stages of HIV disease progression. The main characteristics are described below.

3.1.1 Age

The research sample comprised 100 male participants with an age range of between 17 and 68 years and with a mean age of 38 years. The age distribution is set out in Figure 1.1.

Figure 1.1: Age Distribution of Participants, Part 1



3.1.2 Country of Birth

Half (51) of the participants were from England and 19 from other parts of the United Kingdom. A further nine men were from the rest of Europe, 7 from Africa and 4 from North America. Two participants each were from South America, the Caribbean, Asia and Australia.

3.1.3 Ethnic Origin

The majority of participants described their ethnic origin as white (85), 5 as African (excluding West Indian), 3 as Caribbean (also including the West Indies) and one as Bangladeshi.

3.1.4 Employment Status

A large number (69) of participants were unemployed and 8 were officially retired. 57 of those who were unemployed indicated that it was as a direct result of their HIV sero-positive status. The specific reasons for unemployment that directly related to HIV positive status was HIV related illness (35), stress relating to living with HIV and having to attend to medical decisions (22). Another 3 participants reported that they were unemployed as a result of discrimination. 23 participants were in employment and 8 did not indicate whether they were employed or not.

3.1.5 Living arrangements

Participants lived in varied types of accommodation. 43 of the participants lived in privately arranged accommodation of which 25 lived in property they owned and 18 rented from a private landlord. Of the other 57, twenty-six lived in council flats, 17 in Housing Association accommodation, 12 with friends, one with his parents and one in 'Bed-and Breakfast' accommodation.

3.1.6 Route of HIV infection

Eighty-five of the participants reported contracting HIV as a result of having sexual intercourse with a same-sex partner. Five participants identified sex with the opposite sex as the route of HIV infection and 5 sex with partners of both sexes. Three participants associated their positive HIV status with intravenous drug use and 2 with blood transfusions.

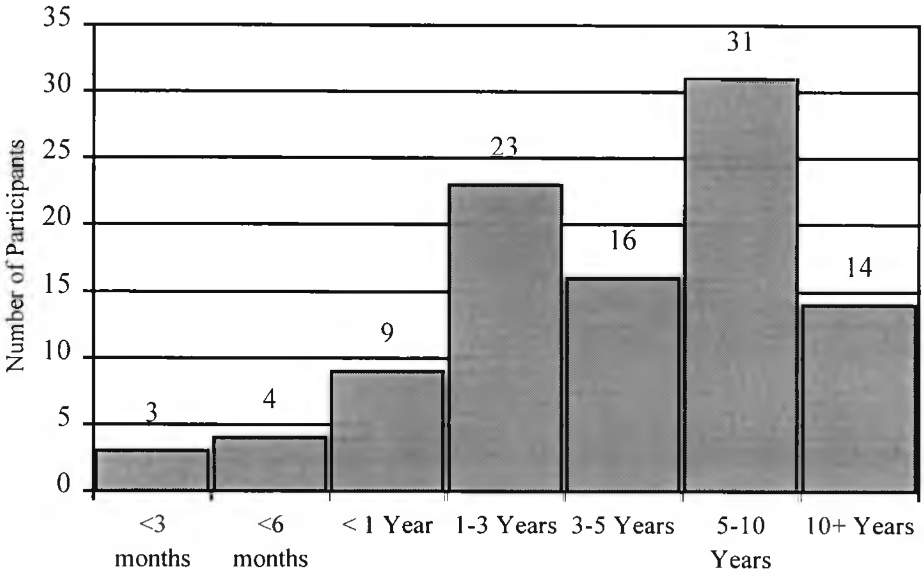
3.2. HIV Health Status

Time since first HIV positive diagnosis, self-reported HIV physical symptoms and CD4 lymphocyte counts were used as indicators of health status.

3.2.1 Time Since Testing HIV positive

The results indicate a large spread in the time that participants had been HIV positive. Some participants (3) had known about their HIV positive status for less than 3 months, some (4) for less than 6 months and some (9) for less than a year. Other participants first tested HIV positive many years before. 14 participants had been diagnosed HIV positive longer than 10 years before, one third (31) between 5 and 10 years before, 16 between 3 and 5 years before and 23 between 1 and 3 years before. (See Figure 1.2)

Figure 1.2: Time Since First HIV Diagnosis, Part 1



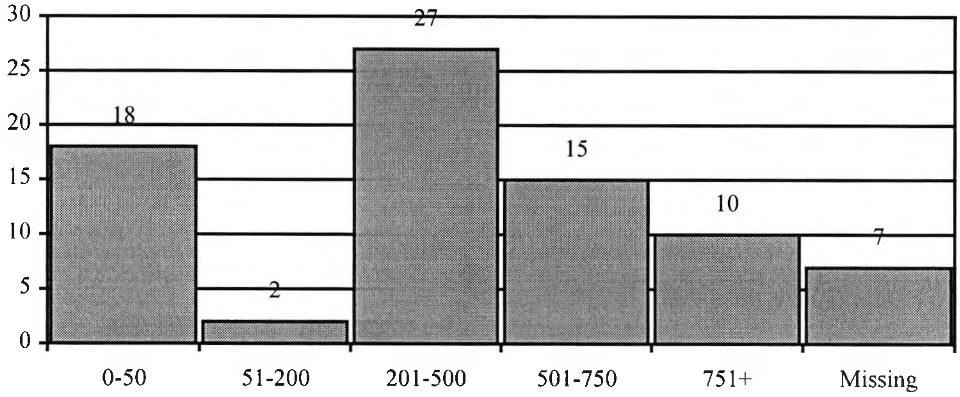
3.2.2 Self-reported HIV Health Indicators

Participants were asked to report on their physical symptoms of HIV. 39 reported to be HIV symptom free, 20 had HIV symptoms in the past requiring treatment and 25 had HIV defined symptoms at the time of the interview. Sixteen of the participants had an AIDS diagnosis at the time of the interview.

3.2.3 CD4 Lymphocyte Counts

CD4 lymphocyte counts were obtained for 93 participants. The total range of CD4 lymphocyte counts for this sample was between 0 and 951. CD4 lymphocyte counts of more than 751 were recorded for 10 participants, which indicate a healthy immune system, comparable to most in the population. CD4 lymphocyte counts of between 501 and 750 were recorded for 15 participants, indicating a moderately healthy immune system but less than the average count for the general population and counts of between 201 and 500 for 27 indicates a compromised immune system. Under the World Health Organisation classification all HIV positive people with CD4 lymphocyte counts of less than 200 can be diagnosed as having AIDS. 20 Participants fit this category with 2 who had a CD4 lymphocyte count of between 51 and 200 and 18 who had a count of less than 50. (See Figure 1.3)

Figure 1.3: CD4 Lymphocyte Counts by Number of Participants



3.2.4 Health Status Correlations

Correlations between the different HIV health indicators and between health indicators and some personal characteristics were investigated. The correlations are mostly predictable such as participants with a higher CD4 lymphocyte count would describe their health as worse, than those with a lower CD4 lymphocyte count. The following Pearson's correlations were found to be significant (2-tailed):

a) There was a positive correlation (r=.519; p>0.01) between low CD4 lymphocyte counts and participants reporting poor health.

b) There was a positive correlation (r=.347; p>0.01) between the length of time since first positive HIV diagnosis and low CD4 lymphocyte counts.

c) There was a positive correlation (r=.231; p>0.05) between length of time since first positive HIV diagnosis and description of poor health.

d) There was no correlation between age or ethnic origin and either CD4 lymphocyte counts or description of health.

3.3 Stressful Aspects of Living with HIV

Participants were asked to indicate what aspect of their life they experienced as being the *most* stressful since testing HIV sero-positive. Of the 100 interviewed, 93 responded to this question. Uncertainty about the future was most frequently cited as a stressor (35 participants). Other stressful aspects identified were more specifically about health (17), relationship difficulties (14), disclosure of HIV status to others (12), unmanageable feelings (6), keeping secrets about issues other than their HIV status (5) and sex (1). One participant each stated that their main fear was losing a job, people's reaction to their HIV diagnosis and payment for medication.

3.4. Self-defined Family

Asked to list and rank the three primary people to have provided emotional support since their HIV diagnosis, all 100 participants identified at least one person who was supportive. Ninety-four participants also ranked a second person and 87 a third person.

The data collected were categorised into 3 categories, one for each of the ranked people. The results for all three categories are summarised in Table 1.3.

Table 1.3: Participant's rankings of providers of emotional support

	Ranked first	Ranked Second	Ranked Third
	(n = 100)	(n = 94)	(n = 88)
Partner	39	4	1
Friend	34	47	40
Mother	16	14	9
Father	0	6	6
Sister	6	12	16
Brother	1	4	8
Extended Family	1	4	2
Colleague	1	0	1
Children	0	3	4
Other	2	0	1

3.4.1 Ranked First

Relationship partners were most frequently identified as a first-rank supporter (39). 34 participants ranked close friends first in terms of support and some biological family members (parents and siblings) were also identified as first ranked supporters. Mothers were ranked first by 16 participants and sisters by 6. One brother, cousin, colleague, nurse and priest each were identified as first-ranked amongst the remaining participants.

3.4.2 Ranked Second

Of the 94 participants that ranked a second person, 47 identified a close friend, 14 their mother, 12 a sister, 6 their father and 4 each their partner and brother as second most supportive. Another 4 identified members of their extended biological family and 3 indicated that their children fitted into this category. The 6 participants who did not put any one in this category reported that they did not have a second person they regarded as supportive.

3.4.3 Ranked Third

88 participants ranked a third supportive person. For this category 40 identified a close friend, 16 a sister, 9 their mother, 8 a brother, 6 their father and 4 their child as supportive. Of the rest of the 87 participants, 2 identified members of their extended biological family, one a colleague and one a partner. The remaining 13 participants (including the six who did not identify a second ranked person) reported not having a third person they regarded as supportive.

3.5 Characteristics of Self-defined Family

3.5.1. Gender

The family gender distribution in the three ranking categories was 60% male to 40% female for the first ranked person, 50% each for the second ranked person and 48% male to 52% female for the third ranked person.

3.5.2 Age

The age range for the self-defined family was between 15 and 61 years.

The mean age of the primary supporter was equal to that of the mean age of the individual with HIV.

3.5.3. Living Arrangements with Self-defined Family

Of 100 participants 41 indicated that they lived with the person they ranked first, 8 participants lived with the person they ranked second and 11 with the person they ranked third. 40 participants did not live with any of the people they identified as family.

3.6 Disclosure of HIV Status

A high proportion of participants had disclosed their HIV status to the people they identified as main supporters. 95% of the participants had disclosed their HIV status to their first ranked supporter, 84% (79/94) to their second rank supporter and 80% (70/88) to their third rank supporter.

3.6.1. Reasons for Disclosure/Non-disclosure of HIV Status

Participants reasons for disclosure were: (a) to be honest with the people who supported them, (b) to gain emotional support, (c) to receive additional support for reasons of ill health and (d) for no particular reason. 29 participants disclosed their HIV positive status to the first ranked person because they wanted to be honest, 18 disclosed for reasons of ill health and 17 because they needed emotional support. 31 reported that they had no particular reason for disclosing to the person they ranked first. The remaining five participants did not disclose their HIV status to the person they ranked first because two indicated that they did not want to worry the person, while two indicated that they feared rejection or a negative response, and one indicated that he did not want to create unnecessary stress. Similar reasons for disclosing and not disclosing were reported for the people ranked second and third. (See Table 1.4). In all three categories approximately one third did not have any particular reason for disclosing their HIV status.

Table 1.4: Reasons for Disclosure of HIV Status

	First ranked	Second ranked	Third ranked
Honesty	29 (31%)	18 (23%)	20 (28.5%)
Health reasons	18 (19%)	12 (15%)	21 (30%)
Need for emotional support	17 (18%)	25 (32%)	9 (13%)
No particular reason	31 (32%)	24 (30%)	20 (28.5%)
Total number responded	95	79	70

3.6.2. Perceived Changes in Relationships after HIV Disclosure

Participants were asked whether and how their relationships with the identified primary supporters had changed. Those who reported a change were also asked to identify the main component of change. Seventy two percent of participants who had disclosed their HIV status reported no major change in any of the three ranked relationships after disclosure. Of those who did report a change after disclosure, over 70% of participants in each category reported their relationship to be closer than before the disclosure. Only 1 (1%) participant reported a distancing in their relationship with the first ranked person and less than 8% with the second and third ranked person. Detailed results of the relationship changes are discussed in the sections below.

3.6.2.1 First Ranked

Twenty-six (26%) of the participants indicated some change in the relationship with the first ranked person. Of these 73% (19/26) perceived this person as emotionally closer than before disclosure while one participant perceived the relationship as more distant (with a friend). Four participants reported increased stress and concern in this relationship and 2 were unclear about the nature of the change (See Table 1.5).

Table 1.5: Changes in First Ranked Relationship.

Relationship	Number in category	Reported changes	Type of Change			
	(n=100)	(n=26)	Closer	More Distant	>Worry and concern	Uncertain
Partner	39	9 (23%)	6	0	2	1
Friend	34	8 (24%)	7	1	0	0
Mother	16	8 (50%)	5	0	2	1
Father	0	0	0	0	0	0
Sister	6	1 (17%)	1	0	0	0
Brother	1	0	0	0	0	0
Other Family	1	0	0	0	0	0
Colleague	1	0	0	0	0	0
Children	0	0	0	0	0	0
Other	2	0	0	0	0	0
TOTAL	100	26	19	1	4	2

3.6.2.2 Family Ranked Second

Twenty seven percent (25/94) of participants who identified a second rank relationship reported a change in the relationship after disclosing their HIV status. Of these, 18 (72%) reported that the relationship had become closer after disclosure whereas 2 reported more distance in the relationship. One participant reported increased stress and worry in the second ranked person and 4 participants reported feeling unclear about the reason for the change. One participant reported that the second ranked person "just did not want to talk about it (HIV)" and another participant reported that the person blamed them for being HIV sero-positive. Amongst the relationships that changed after disclosure, relationships with biological family members (mother, father, sister and brother) appear to be more likely to change after HIV disclosure. (See Table 1.6).

Table 1.6: Changes in Second Ranked Relationship

Relationship	Number in category	Reported changes	Type of Change			
	(n=94)	(n=25)	Closer	More distant	> Stress and worry	Uncertai
Partner	4	2 (50%)	1	0	0	1
Friend	47	7 (15%)	4	0	1	2
Mother	14	5 (36%)	4	1	0	0
Father	6	3 (50%)	2	0	0	1
Sister	12	6 (50%)	5	1	0	0
Brother	4	2 (50%)	2	0	0	0
Other Family	4	0	0	0	0	0
Colleague	0	--	--	--	--	--
Children	3	0	0	0	0	0
Other	0	--	--	--	--	--
TOTAL	94	25	18	2	1	4

3.6.2.3 Family Ranked Third

28% (25/88) of participants reported a change in their third ranked relationship after disclosing their HIV positive status of whom 76% (19/25) perceived the relationship as closer. Two participants reported that this relationship was emotionally more distant and the other 4 were unsure about the reason for the change in the relationship. (See Table 1.7)

Table 1.7: Changes in Third Ranked Relationship

Relationship	Number in category	Reported changes	Type of Change			
	(n=88)	(n=25)	Closer	More distant	> Stress and worry	Uncertain
Partner	1	1	0	0	0	1
Friend	40	8	6	1	0	1
Mother	9	1	1	0	0	0
Father	6	4	3	0	0	1
Sister	16	6	5	1	0	0
Brother	8	3	2	0	0	1
Other Family	2	0	0	0	0	0
Colleague	1	0	0	0	0	0
Children	4	1	1	0	0	0
Other	1	1	1	0	0	0
TOTAL	88	25	19	2	0	4

Overall, where changes in relationships were reported, disclosure of HIV sero-positive status was seen to bring relationships closer. The relationships that were reported as more distant were mainly with biological family members.

3.7 Social and Emotional Support

Participants were asked to rate (on a 7-point Lickert scale) the *actual* level of support followed by the *desired* level of support for each of the first, second and third ranked relationships. Four areas of self-reported support were categorised: (a) level of trust; (b) level of reliability; (c) level of practical help and (d) level of time spent with the person. Pearson's correlation coefficient was calculated and significant correlations were found between actual and desired levels of support for all four categories of self-reported support for all three ranked relationships (See Table 1.8).

Table 1.8: Actual versus Ideal Levels of Support

Levels of TRUST

	n	r	P
First ranked	100	.706	>.01
Second ranked	94	.547	>.01
Third ranked	88	.579	>.01

Levels of RELIABILTY

	n	r	P
First ranked	100	.499	>.01
Second ranked	94	.608	>.01
Third ranked	88	.515	>.01

Levels of PRACTICAL HELP

	n	r	P
First ranked	100	.542	>.01
Second ranked	94	.642	>.01
Third ranked	88	.553	>.01

Amount of TIME SPENT

	n	r	P
First ranked	100	.480	>.01
Second ranked	94	.607	>.01
Third ranked	88	.589	>.01

Overall participants reported that they received the support they desired from the relationships they valued.

5.8 Summary

The most significant findings of this study point to the high level of satisfaction that HIV positive men have with their social support. The results indicated that disclosure of HIV sero-positive status did not significantly change relationships, though where it did, there was a tendency towards increased emotional closeness. Gay men were more likely to choose a partner or friend as their primary support, as is reflected in the mean age that is equal in both participants and primary supporters. When considering biological family, there was a clear tendency for participants to choose their mother or sister. The most stressful aspect of life after an HIV sero-positive diagnosis was feelings of uncertainty. Overall, there were no correlation or trends evident between HIV health indicators (CD4 lymphocyte counts and self-reported health) and satisfaction with support. The following section aims to integrate and discuss the findings as it relates to the aims of the study.

4. DISCUSSION: PART 1

4.1 Overview

The majority of participants in this study were unemployed gay men, born in the United Kingdom, with an age range of between 17 and 68 years and a mean age of 38 years. The most stressful aspect of life since their HIV diagnosis was uncertainty about the present and future. The majority of participants tested HIV positive at least 1 year before the interview and about half had known their HIV positive status for more than 5 years. Most participants in this study had lived with the knowledge of their HIV status for many years. Many of the participants had therefore lived with HIV through many stages of personal adjustment to being HIV positive as well as through the many varied developments in HIV since the early 1980's. Predictably, the health of men in this study correlated with their immune system functioning. Those men who had been HIV positive for many years reported poor health more frequently than those who had recently been diagnosed and on objective measures of health, had a more compromised immune system (lower CD4 lymphocyte counts). The majority of participants had disclosed their HIV status to the person they identified as closest in their support system. Furthermore, a large majority of participants indicated a high level of satisfaction with their support as is evidenced in the strong correlation between *actual* and *ideal* levels of support. This discussion will now focus on the findings that specific relate to the aims of the study.

4.2 Self-defined family

The majority of participants identified either their partner or a close friend as the closest person in their support structure. These findings support research which found that HIV positive gay men depend on other gay men for social support and practical support during illness (Hart et al., 1990; McCann & Wadsworth, 1992) and that gay men more frequently disclose to friends, lovers and partners (Simoni et al., 1997; Holt et al., 1998). Close friends or mothers were mostly ranked as second closest and mothers or sisters third closest supporters in this cohort. Gender did not appear to be a strong consideration in obtaining social support because close friends were chosen for their emotional and social compatibility whereas biological family is a given. However, amongst the biological family identified as supportive in this study, there was a preference for women (mothers and sisters) which is consistent with the findings of Bulmer (1987) that HIV positive individuals expressed a preference for woman to provide psychological support. Woman may be preferred because fathers are perceived as less supportive than mothers, friends and sexual partners (Manserg et al., 1998). The similarity in age between participant and support system may be as a result of the majority of participants identifying friends or partners as their support system. However, it could also reflect a preference for HIV positive men to choose people from their own generation to be part of their support system. Several HIV organisations in London provide psychosocial support for HIV infected individuals. The choice of whom to identify as supportive may have been influenced by the support participants acquired from outside their personal social circle. Furthermore the men in this study predominantly identified as homosexual and this may have affected the choice of who they identified as their support structures.

4.3 HIV Disclosure and Changes in Relationships

Patterns of HIV disclosure further define social support systems and the relationships contained in these systems. This was illustrated in this study by the additional information about the relationships that participants had defined. Ninety five percent of the participants had disclosed their HIV status to the person they identified as the closest person in their support system. Many participants indicated that the choice of who to disclose their HIV status to was crucial. The patterns of disclosure in this research suggests that disclosure is selective as previously reported by Foley et al. (1994) and Holt et al. (1998).

Whereas close friends appear to be disclosed to more readily, most were reluctant to disclose to biological family to avoid unnecessary stress or worry. This highlights the notion that HIV disclosure has the potential to create stress for the biological family (Miller et al., 1994) and that family have the potential to be particularly helpful or especially harmful to gay men trying to cope with their HIV status (Turner et al., 1993). The reluctance of some people to disclose their HIV positive status to biological family may also be associated with the risk of ‘secrets’ such as homosexuality, infidelity or illicit drug use being disclosed, (Bor et al., 1993), Any of these disclosures can add to the potentially negative impact on an existing family support structure. In disclosing an HIV positive status, the individual is likely to choose someone who is perceived to be capable of bearing the burden of such knowledge. Close friends are more likely to be aware of lifestyles and 'secrets' and consequently more accessible for emotional support. In addition to the risk of 'secrets' and lifestyle, the perceived social unacceptability of an HIV positive status may add to the reluctance to disclose to a biological family member (Longo et al., 1990) and the perceived stress that HIV disclosure may create. The importance of choosing whom to disclose to and by implication selecting social support is clearly of great importance to HIV positive individuals. This may explain why some HIV infected individuals choose to re-define their social support system.

The fear that HIV disclosure might negatively affect close relationships is not upheld in this study. Only 5 participants indicated that any of the ranked relationship had become 'more distant' whereas the majority reported either increased emotional 'closeness' or no change in their significant relationships after HIV disclosure. These findings support those of Leask et al. (1997).

4.4 Emotional Stress Related to HIV Infection

An understanding of the links between stress, social support and health, in particular immune functioning, is pertinent to the study of HIV in the family. If stress affects health, and social support has an impact on stress (Gore, 1978; Thomas, 1985; Kirschbaum et al., 1995), by deduction, the quality of social support is likely to affect the quality of health and indeed the quality of life (Swindells, 1999). A considerable body of research has focused on the relationship between increased levels of stress and its impact on various areas of health such as the cardiovascular, endocrine and immune systems (Manuck, 1994; Sarafino, 1999; Evan et al., 1994; Kiecolt-Glaser et al., 1986, to name a few). Although only a few studies specifically focus on stress and HIV illness, most of these appear to have found a link with various types of stress and HIV-related health (Ironson et al., 1994; Patterson et al., 1995; Kemeny and Dean, 1995).

In this study a third of the participants reported that feelings of uncertainty about their future were the primary stressor since their HIV diagnosis. For most individuals the concerns about dying was perceived as less stressful than the uncertainty about the unpredictable course of HIV illness. Feelings of uncertainty may result from the constantly changing face of HIV. Over the past 20 years the perceptions, implications and treatment of HIV have changed constantly and at times drastically. As a consequence, HIV positive individuals have to go through the stress of adjusting their perceptions, expectations and planning accordingly. Interestingly, many participants in this study had not considered ‘who’ or ‘what’ might influence their needs for support. Identifying the available support systems and potential support services may alleviate feelings of uncertainty in the individual. Feelings of uncertainty may weaken the functioning of the HIV infected individual’s support system. Those affected by HIV, both HIV infected people and their support systems, appear to face more complex social adjustments than those dealing with other illnesses (Irving et al., 1995). Support services such as HIV counselling and mental health services should therefore be responsive to both HIV infected individuals and their support systems. HIV medical services could also alleviate stress through the clear dissemination of HIV treatment information to HIV patients. However, the rapid change in HIV treatments makes this a daunting task.

4.5 Satisfaction with Social Support

Previous research findings suggest the existence of a link between the presence of good social support and good psychosocial adjustments in HIV. Zich and Temoshok (1987) found that high levels of social support correlated with low levels of hopelessness and depression in HIV infected individuals, whilst Namir et al. (1989) found that HIV infected individuals who reported poor quality of support described their health as poor more consistently than those with good quality support. This cohort expressed a high level of satisfaction with various types of support. These results are encouraging as social support is related to psychological well-being and a lower incidence of physical illness (Turner, 1993). Social support in HIV *may* play an important role in promoting psychological adjustment to illness and having a positive effect on both immune function and 'survival' time (Irving, 1995). However, the extent to which psychological well-being mediates immune system functioning need to be examined further.

RESEARCH, Part 2

5.1 Aims of the Research

The first study explored the experiences of HIV positive men and their perceptions of their social support systems. Participants in the first study mainly reported positive outcomes in their relationships with self-defined family as well as with their social support after HIV disclosure. The second study sets out to further explore the relationships and the nature of social support in HIV, but with particular emphasis on the self-defined family members themselves. The importance of social support for HIV infected individuals has already been discussed. It is therefore important to ensure that HIV social support systems are improved and maintained. Research on families affected by HIV has hitherto concentrated on biological family or partners, and of these studies none have investigated the support system as perceived and experienced by the family member. The second study's unique approach is to invite family to report on the effect that HIV disclosure had on their own lives. This study was different from previous research on two counts: Firstly it invited HIV positive participants to identify the people they found most supportive themselves (self-defined family) and secondly, those identified were themselves invited to report on their perceptions of social support and functioning since HIV disclosure.

The second study utilised quantitative methods to investigate a sample of HIV positive participants and a combination of quantitative and qualitative methodologies to investigate their self-defined families. The aims of the study were to explore the following:

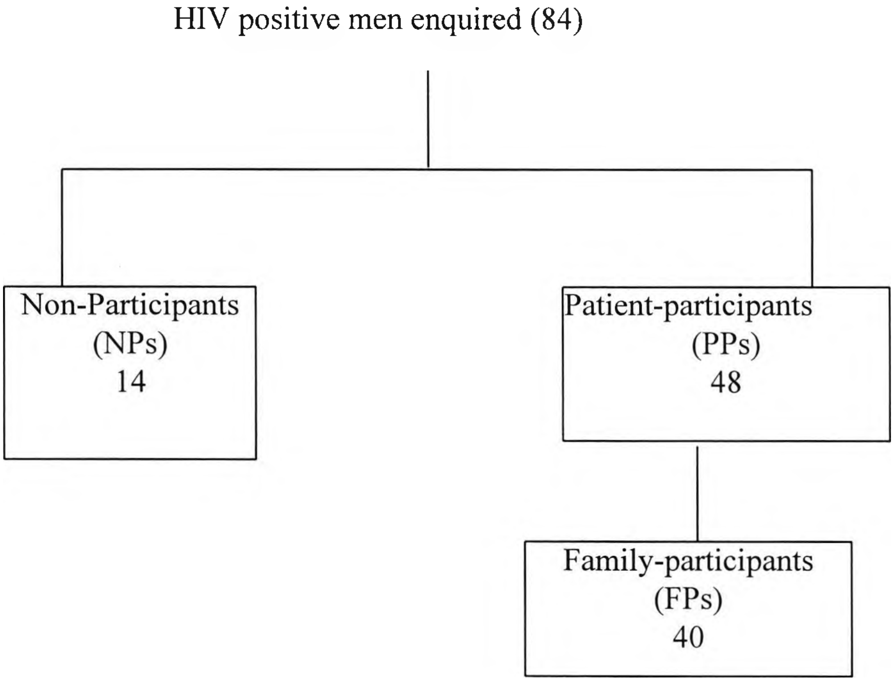
1. Who this cohort of HIV infected men identify as family
2. The circumstances of the HIV disclosure event as perceived by the family member
3. The consequences of HIV disclosure as perceived by family members
4. Social support issues for family after HIV disclosure
5. Self-defined family members' coping with HIV disclosure.

5.2 Method

5.2.1 Participants

Participants were recruited from the London clinic over a period of 10 weeks. An invitation poster (Appendix 12) describing the purpose of this study and participation was posted in the reception area of the clinic. All HIV positive men who attended the clinic were eligible. 84 men made enquiries about the research and 62 agreed to participate. Each participant was asked whether they would agree to a self-defined family member being interviewed. 14 of the 62 participants who agreed to be interviewed declined to have a family member interviewed and the results of this sub-group will be discussed separately. The remaining 48 participants agreed to a total of 117 family members being interviewed. These participants were asked to discuss the 'family interview' with the family members concerned and pass on an information pack. The information pack contained an invitation to the family member to participate in the research with instructions and a return slip (Appendix 13), consent form (Appendix 14) and an addressed, stamped envelope to return should they decide to participate. Of the 117 family members who were identified by patients, 55 returned reply slips and consent forms. These family members were then contacted by one of the 2 interviewers to arrange an interview and were again asked whether they were still prepared to be interviewed. 15 family members changed their minds at this stage and consequently 40 family members were interviewed. However, because several family members from the same patient-participant agreed to be interviewed, this resulted in the family members of only half (24/48; 50%) of the patient-participants' being interviewed. In total 102 participants were interviewed. There were three groups of participants, 2 patient groups (those agreeing to a self-defined family member being interviewed and those declining). For the purposes of this reporting, participants are distinguished throughout as follows: Patients who agreed to a family member being interviewed are referred to as PPs (Patient-participants) and patients who declined are referred to as NPs (Non-participants). The family members interviewed are referred to as FPs (Family-participants) (See Figure 1.4).

Figure 1.4: Diagram of Participants, Part 2



5.2.2 Method of Data collection

Interviews with all three groups were conducted using semi-structured questionnaires with open and closed questions. 2 questionnaires (Appendices 15 and 16) were used for the interviews with patients. The first part of both patient questionnaires was identical but the second parts differed depending on whether the patient agreed or not to have family members interviewed. The FPs were interviewed using the third questionnaire (Appendix 17). At the end of each family interview, FPs were invited to supply additional information that related to their relationship with the PP or their own coping mechanisms. In addition to the data from the interviews, patients agreed that information regarding their HIV health status could be collected from their medical notes.

5.2.2.1 Patient Interviews

Patients were interviewed by one of two interviewers in the HIV treatment clinic. Before any patient was interviewed, the 2 interviewers practised by interviewing each other whilst 2 additional members of staff observed the interviews. This was followed by discussions about the way questions should be asked and the amount and types of follow-up questions or comments acceptable for the qualitative section, to ensure a high level of consistency. The interview included (a) demographic information; (b) the person's HIV health status such as CD4 lymphocyte counts, viral load counts, medication and the period since first diagnosis; (c) information about their family relationships such as emotional closeness, concerns and changes in the relationship and (d) information about disclosure. The patients who chose not to have anyone interviewed were also asked what their concerns would be about family or friends being interviewed.

5.2.2.2 Family interviews

The family interviews were structured using the third questionnaire and were undertaken by the 2 trained interviewers. All interviews were audiotaped. The interview included (a) demographic information such as age, ethnicity, country of birth; (b) questions about the disclosure of the HIV status; (c) questions about the relationship with the HIV positive person interviewed; (d) questions about their own emotional support and (e) questions about 'coping' with HIV disclosure. Participants were encouraged to talk freely and to add information they perceived as relevant to the topic being discussed.

Interview transcripts were typed and identifying details were changed or omitted from the transcripts to ensure patient confidentiality.

5.3. Data Collected

5.3.1 Patient-participants

Demographic information was collected for each patient from both the patient groups in order to more fully describe the patients for this particular study and to establish any trends that may exist for the participant group.

5.3.1.1 Age

Age was coded in categories of 9 intervals: The first interval was for the 15 to 20 year age group, followed by 7 intervals of 10 years each and the last interval for people over 71 years of age.

5.3.1.2 Country of Birth

The population consists of many immigrants, of who some receive treatment in the HIV clinic participants attended. Participants were therefore asked what their country of birth was to establish the nationality mix of participants. Country of birth was divided and coded in the following 12 categories: England, Scotland, Wales, Ireland, North America, South America, Europe, Africa, Asia, Australia, Caribbean, Other.

5.3.1.3 Ethnic Origin

Participants were asked what they would regard as their ethnicity. Ethnicity was recorded for the following categories: White, White other, Indian, Pakistani, East African Asian, Bangladeshi, Chinese (Hong Kong), Chinese Other, Vietnamese, African (excluding West Indies), Caribbean (including West Indies) and an Other category for participants who did not describe themselves as falling within these categories. The categories are in line with the Department of Health recommendations.

5.3.1.4 Employment Status

Employment was coded for 3 dimensions:

a) Each participant was coded as employed, not employed or retired.

b) Each participant's employment position was coded for the following categories: self-employed, manager/supervisor, employee, apprentice or student.

c) The reason for no employment was coded in the following categories: sickness, discrimination or retirement.

5.3.1.5 Living Arrangements

The type of living arrangement was coded for: rent form landlord, rent from housing association, home owner, squat, live with parents, bed-and-breakfast accommodation, no fixed living arrangements and other.

5.3.1.6 Route of HIV Infection

Participants were asked how they became infected. The information was coded in the following categories: same-sex partner, sex with opposite sex partner, sex with both men and women, 'through injecting drugs', 'through blood transfusion' or 'do not know'.

5.3.1.7 Time Since First HIV Diagnosis

Participants were asked when they were first tested HIV positive. The data was categorised into 8 categories according to the time between first HIV positive diagnosis and the time of the interview, as follows:

Category 1:	Longer than 10 years
Category 2:	Between 5 years and 10 years
Category 3:	Between 3 years and 5 years
Category 4:	Between 1 year and 3 years
Category 5:	Between 6 and 12 months
Category 6:	Between 3 and 6 months
Category 7:	Between 1 and 3 months
Category 8:	Less than 1 month

5.3.1.8 HIV Treatments

The number of medications directly related to HIV that each participant was on at the time of the interview. This was coded into 9 categories. Code 1 related to patients who were on one medication, code 2 for those on 2 medications and so fourth up to code 7. Patient–participants on 8 or more HIV related medications were coded as 8 and those who were not taking any HIV related medication was coded as 9.

5.3.1.9 HIV Disclosure

Participants were asked whether they thought the relationship with the person who was being interviewed had changed since disclosure had taken place and whether the way the person behaved towards them had changed. These questions were both coded as ‘yes’ or ‘no’. Participants were also asked how each of these changed if they answered ‘yes’. In addition, participants were asked if other ‘secrets’ were disclosed at the time. This was also coded as ‘yes’ or ‘no’ and they were asked what it was if the answer was ‘yes’.

5.3.1.10 Impact of the Interview

Participants were asked whether they had any concern about (a) the effect of the interview on the person interviewed and (b) the effect it might have on their relationship with the person. Both these were coded as a ‘yes’ or ‘no’. In addition participants were asked what the concern was which was not coded but which was qualitatively analysed.

5.3.2 Family-participants

Demographic information such as age, country of birth, ethnic origin, and employment status was recorded for each FP. In addition, data such as the relationship to the PP, the FPs’ own HIV status and data regarding the disclosure of the PPs’ HIV disclosure was recorded. Additional data included the emotional responses to HIV disclosure, coping with the knowledge of the PPs' HIV status and data about various supportive relationships. Some of the questions in the family interviews were followed up with open-ended questions particularly those relating to the disclosure event, feelings about the HIV disclosure, coping strategies, changes in the relationship with the PP and the FP's own support structures. The answers to these questions produced a considerable amount of additional data. As the family interviews were recorded, transcripts were made of the interviews and analysed using 'Framework' (Richie and Spencer, 1994) (See Section 8 for data analysis).

Due to faulty recording equipment, 11 interviews of patients were either lost or spoilt to make the recordings incomprehensible. This left 29 fully comprehensible interviews to be qualitatively analysed. Fortunately the quantitative data was recorded by hand at the time of the interview. The quantitative data collected for FPs is discussed in the following section.

5.3.2.1. Age

Age was coded for each FP in 8 categories coded in the following intervals: 21 to 25 years, 26 to 30 years, 31 to 35 years, 36 to 40 years, 41 to 50 years, 51 to 60 years, 61 to 70 years and 71 years and older.

5.3.2.2 Country of Birth and Ethnic Origin

For country of birth, ethnic origin and employment status the same coding and categories were used as those for PPs as discussed in the corresponding sections.

5.3.2.3 Employment Status

Employment was coded for 2 dimensions:

a) Each FP was coded as employed, not employed or retired.

b) Each FP's employment position was coded for the following categories: self-employed, manager/supervisor, employee, apprentice or student.

5.3.2.4 Relationship with the Patient-participant

The relationship with the PP was coded in the following categories: male partner, female partner, mother, father, sister, brother or close friend.

5.3.2.5 Family-participants' HIV status

Each FP was asked whether they had an HIV test. They were further asked what their own HIV status was. HIV status was coded as positive, negative or do not know.

5.3.2.6 Disclosure of HIV status to Family-participants

A combination of 5 closed and open questions were asked about the HIV disclosure event. FPs were asked (a) whether they remembered the event (coded as 'yes' or 'no'); (b) whether they thought the disclosure was planned or not (coded as 'yes', 'no' or 'do not know' and (c) whether the FP suspected that the PP was HIV positive before the disclosure event. Some additional data about HIV disclosure is discussed in the qualitative result section.

5.3.2.7 Responses to HIV Disclosure

The FPs were asked what their first reaction was after HIV disclosure. The responses were coded as ‘shock’, ‘sadness’, ‘anger’, ‘surprise’, ‘not surprised’ and ‘other’, based on the range of reactions from the first study. The other category was included to allow for additional responses not anticipated and will also be reported. FPs were asked if their feelings about the disclosure had changed from the time of the disclosure event to the present time (coded ‘yes’ or ‘no’) and what might have changed their feelings if the answer was ‘yes’. A more general open question was also asked about how ‘things’ were at present.

5.3.2.8 Coping with Knowledge of HIV Status

Two open questions explored what (a) helped and (b) made it difficulty, to cope with the knowledge that the PP was HIV positive, for the FP.

5.3.2.9 Relationship with Patient-participant

A change in the relationship with the PP was recorded. If the FP indicated that it had changed, they were asked open questions about how the relationship had changed and what they thought brought about the change. They were further asked whether the way in which disclosure happened made a difference in how they reacted. FPs who felt that the relationship had not changed since disclosure were asked why it had not changed.

5.3.2.10 Social Support of Family-participants

FPs were asked whether they had anyone emotionally close who knew about the PP's HIV status, and if the answer was yes, who they were. The information was coded in terms of the following relationships: Male partner, female partner, mother, father, sister, brother, friend, close friend and other. Information about the disclosure to these individuals was also recorded. They were asked whether the PP's HIV status was ever discussed and whether talking about the HIV status helped. In addition information about who the FP received emotional support from was coded as Male partner, female partner, mother, father, sister, brother, friend, close friend and other.

5.3.2.11 Disclosure of 'Secrets' other than HIV

FPs were asked whether they became aware of other 'secrets' or information at the time that HIV disclosure was made. This information was recorded as well as the way in which this information affected the FP.

5.3.2.13 Qualitative Data

Qualitative data were collected in order to explore issues further and enhance understanding of more complex behaviours, needs, systems and cultures. The FP questionnaire contained open questions to enable the interviewer to collect qualitative data in addition to quantitative data. In addition to these open questions, the FPs were asked to add any additional information they deemed important relating to their relationship with the PP and their own coping mechanisms. For example the FP was asked to add any information they deemed important relating to their relationship with the PP, their own coping mechanisms and anything relating to their knowledge of the PPs HIV status.

More than one FP was interviewed for some of the PPs as a result of the pattern of acceptance by FP's to be interviewed. This resulted in 5 FP interviews for 2 of the PPs ('Alan' and 'John'). Pseudonyms have been allocated for each PP to ensure anonymity when phrases from the interviews are quoted in the reporting of results. Other identifying names such as the names of organisations have been substituted to further ensure anonymity (See Table 1.9).

Table 1.9: Pseudonyms for PPs, FP's Relationship to PP, and Status of Transcripts

Code/Number	Pseudonym (PP)	FP (Gender: m/f)	Transcript Status
001/1	Alan	Close Friend (f)	Spoilt*
001/2	Alan	Partner (m)	Successful
001/3	Alan	Mother	Successful
001/4	Alan	Employer (f)	Spoilt
001/5	Alan	Sister	Successful
003/1	Carl	Close Friend (m)	Successful
003/2	Carl	Close Friend (m)	Successful
005/1	Ben	Close Friend (m)	Successful
009/1	Ash	Mother	Spoilt
009/1	Ash	Nephew	Spoilt
012/1	Simon	Close Friend (f)	Successful
012/2	Simon	x-Partner (f)	Spoilt
014/1	Gene	Close Friend (m)	Successful
019/1	Frank	Close Friend (m)	Successful
019/2	Frank	Close Friend (m)	Successful
022/1	Mark	Close Friend (m)	Successful
023/1	Richard	Partner (m)	Spoilt
023/2	Richard	Close Friend (m)	Successful
026/1	Matt	Close friend (f)	Successful
027/1	Joe	Close Friend (m)	Spoilt
029/1	Damien	Mother	Successful
029/2	Damien	Partner (m)	Successful
032/1	Rob	Close Friend (m)	Successful
033/1	James	Sister	Spoilt
036/1	David	Close Friend (m)	Successful
040/1	Chris	Close Friend (m)	Successful
043/1	Steve	Partner (m)	Successful
045/1	Philip	Close Friend (m)	Successful
050/1	Cramer	Close Friend (m)	Spoilt
054/1	Michael	Partner (m)	Spoilt
057/1	John	Close Friend (m)	Spoilt
057/2	John	Close Friend (f)	Successful
057/3	John	Close Friend (m)	Successful
057/4	John	Close Friend (f)	Successful
057/5	John	Brother	Successful
058/1	Pete	Partner (m)	Successful
061/1	Jack	Close Friend (m)	Successful
061/2	Jack	Close Friend (m)	Successful
061/3	Jack	Mother	Successful
063/1	Philip	Close Friend (m)	Successful
40 participants			28% Spoilt

* Spoilt' transcripts refer to audio transcripts that were inaudible as a result of faulty equipment

5.4. Data Analysis

Quantitative data were coded and entered into a data file of the Statistical Package for the Social Sciences (SPSS-Windows) (Nile, 1983). The quantitative data for both PPs and FPs were included on the same data file to enable cross-referencing. The qualitative data for PPs were entered against each of the FPs that were interviewed for that particular PP. A separate data file was created for the data collected from the NPs. The accuracy and consistency of the data were cross-checked on SPSS for each of the data files. The first step in the analysis was to gain an overview of participants' demographic data. Descriptive data using frequency distributions and some measures of central tendency and dispersion were calculated for the demographics, health indicators and stressors associated with HIV positive status.

The qualitative data collected from FP interviews was analysed using a method based on 'Framework', a qualitative method developed in the context of applied qualitative research by Ritchie and Spencer (1994). The advantage of using 'Framework' is that it involves a systematic process of sifting, charting and sorting key issues and themes and therefore enables the analyst to sometimes jump ahead and at other times to return to reconsider and rework earlier ideas, because the analytical process had been documented throughout the process. Analysis was conducted according to procedures described by Ritchie and Spencer (1994) and involved a number of steps, which are outlined below:

1. Familiarisation: During this stage the analyst reads through transcripts, listing key ideas and recurrent themes and gaining an overview of the richness, depth

and diversity of the data. This involves repeated readings of the transcripts. Due to the volume of data gathered in this study, a selection of 5 transcripts were initially read during this step to establish emerging themes, as suggested by Ritchie and Spencer (1994).

2. Identifying a thematic framework: The second step was to identify the key issues, concepts and themes according to which the data can be examined and referenced, thereby setting up a thematic framework. (See appendix 18)

3. Indexing: This is the process whereby the thematic framework is applied to the data in the text. The framework was tested against all the transcripts and after some alterations, it was used to code or 'index' each transcript. Corresponding themes and issues lifted from the transcripts were then grouped together according to their thematic reference, theme and sub-theme. Verbatim examples of the identified themes were added under each heading during this step.

4. Charting: After applying the thematic framework to individual transcripts, data were lifted from their original context and rearranged according to the appropriate thematic reference. This process is called charting. Charts were devised using headings and sub-headings, which were drawn from the thematic framework and in consideration of the research aims.

5. Mapping and interpreting: When all the data had been sifted and charted according to core themes, comparisons were made between the individual's

responses across the various themes. The data set was mapped and interpreted as a whole with regards to the original aims and associations that had emerged from the analysis.

5.4.1 Reliability and Validity

A fellow clinical psychologist who had prior experience of qualitative research was asked to be a second coder. A method described by Miles and Huberman (1994) was used to address the issues of reliability and validity. The second coder was provided with a sample of 5 transcripts and a list of the codes and asked to code the transcripts according to the existing codes but also to add other codes that might seem relevant. Inter-coder reliability was calculated as follows:

$$\textit{Reliability} = \frac{\textit{number of agreements}}{\textit{Total number of agreements} + \textit{disagreements}}$$

Agreement between the coders was .78 which is within the limits of reliability. Miles and Huberman (1994) indicated that acceptable levels of inter-coder agreement is .70 and above. Internal reliability was established by coding the same transcripts a few days apart and using the same formula to calculate the intra-coder consistency. The intra-coder consistency was .86, which is above the point of .80, as suggested by Miles and Huberman (1994) for intra-coder reliability. Validity was addressed through periodic meetings with the other coder and supervision with a sociologist experienced in the ‘framework’ method of qualitative analysis. During these meetings extracts of transcripts were checked against themes and interpretations.

One of the disadvantages that should be considered in qualitative analysis is analytic bias. The include the ‘holistic fallacy’ which relate to “interpreting events as more patterned and concrete than they really are, lopping off the many loose ends of which social life is made” (Miles and Huberman, 1994, p.263). In order to address this bias, contradictory material is presented where relevant. Miles and Huberman (1994) also identify another bias, which they call ‘elite bias’. This term describes the risk of overweighing data from articulate participants and underweighing data from less articulate ones. The quantitative data of the second part of the research will now be discussed followed by the results of the analysis and interpretation of the qualitative data.

CHAPTER 6: Results, Part 2

The first part of this section reports on data collected for the PPs who agreed to have family members interviewed. In addition to PP characteristics, reporting includes information on the relationship with the family member interviewed and the possible concerns about the impact that the interview may have on the individual family member and on their relationship. In addition, information about the disclosure event and responses to the event is reported. In the second section, quantitative data about the FPs are reported and where appropriate further illustrated by examples from the FP transcripts. The third section reports on the qualitative data acquired from the second part of the FP interviews. The data for NPs is reported in the fourth section including concerns they had about such an interview. This also includes information about the relationship as perceived by the NPs.

6.1 Patient-participants

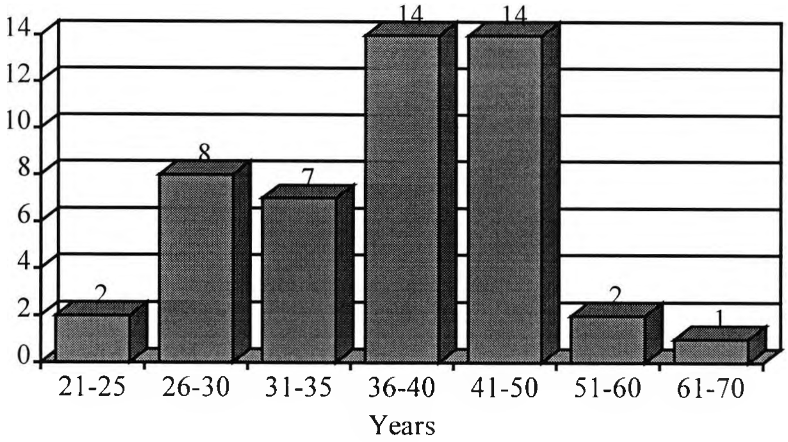
Forty-eight (77%) of the 62 participants interviewed agreed that family members could be interviewed. The data relating to these 48 participants is discussed in this section.

6.1.1 Patient-participant Characteristics

6.1.1.1Age

The age range for PPs was between 22 and 61, with a mean age of 38 (Standard deviation: 8.08). The age distribution is set out in Figure 1.5.

Figure 1.5: Age Distribution of Patient-participants



6.1.1.2 Country of birth

More than half (27/48; 56%) of the PPs were born in England, 3 in Scotland and 2 in Ireland. A further 8 (17%) were born in other parts of Europe, 5 (10%) in Africa and 1 each in North America, South America and Asia. There were no PPs from Australia or the Caribbean.

6.1.1.3 Ethnicity

The majority of PPs (42/48; 88%) described their ethnic origin as white. One each described their ethnic origin as East African Asian, African (excluding the West Indies) and White Other. Three of the PPs described themselves as European-Jew, Iraqi and Latin respectively.

6.1.1.4 Employment Status

A large number (33/48; 69%) of PPs were unemployed of which 3 were retired. Of the 30 unemployed PPs, 25 (76%) indicated that their unemployment was as a result of an HIV related illness. An additional 4 indicated that they believed that their unemployment was related to their HIV positive status and the remaining one reported that it was as a result of discrimination. This participant went on to describe how his fellow workers would not shake hands with him and how his telephone receiver was disinfected. 46 (98%) PPs reported on their present or last position in employment. 24 (50%) participants worked as employees whereas 11 (23%) were self-employed and 11 (23%) in managerial positions. There were 2 missing values in this category.

6.1.1.5 Living Arrangements

Twenty-four participants (50%) lived in Housing Association accommodation, 12 (25%) owned the house they lived in and 8 (17%) rented from a landlord. One participant was living with his parents, one with friends, one with a partner and another one in bed-and-breakfast accommodation.

6.1.1.6 Route of HIV Infection

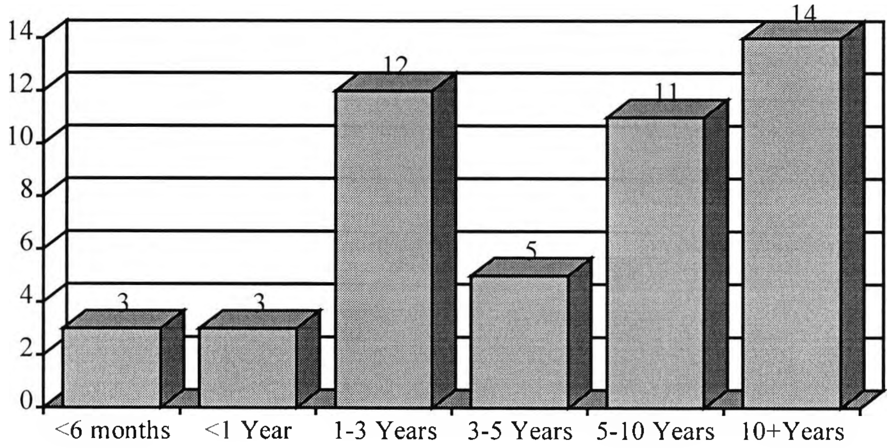
Thirty-nine (81%) of PPs reported contracting HIV as a result of sexual intercourse with same sex partners and 2 (4%) through sex with the opposite sex partner. A further 2 became infected through blood transfusions. 5 PPs did not say how they became infected.

6.1.2 Health Status Information

6.1.2.1 Time Since Testing HIV Positive

The results indicate a wide spread in the time since PPs were first diagnosed HIV sero-positive. 14 (29%) PPs tested positive more than 10 years before the interview, 11 (23%) between 5 and 10 years before, 5 (10%) between 3 and 5 years before and 12 (25%) between 1 and 3 years before. Another 3 (6%) PPs tested sero-positive less than 1 year and 3 (6%) less than 6 months before the interview (See figure 1.6).

Figure 1.6: Time Since First Diagnosis: Patient Participants



6.1.2.2 HIV Treatments

The number of HIV related medications an HIV positive person was taking at the time of the study could be considered an indication of their immune system status. As discussed previously, most HIV patients on HIV combination therapy take 3 medications in total. For those with existing HIV related illnesses, further medications may be prescribed. In addition many patients may take prophylactic medicines.

The data for PPs indicates that just under half (21/48; 44%) were taking 3 HIV-related medications at the time of the interview. A further 3 (6%) took only 2 HIV-related medications. Another 4 (8%) and 5 (10%) PPs were on 4 and 5 HIV-related medications respectively. Thirteen percent of the sample took more than 6 medications, which reportedly required them to take up to a total of 24 tablets 3 to 4 times a day. 9 (19%) PPs were not on HIV-related medication at the time of the interview, due to 3 reported reasons: a) their CD4 Lymphocyte counts and virus loads were within acceptable health parameters, b) individual choice despite immune-system compromise and c) a drug free period was medically indicated.

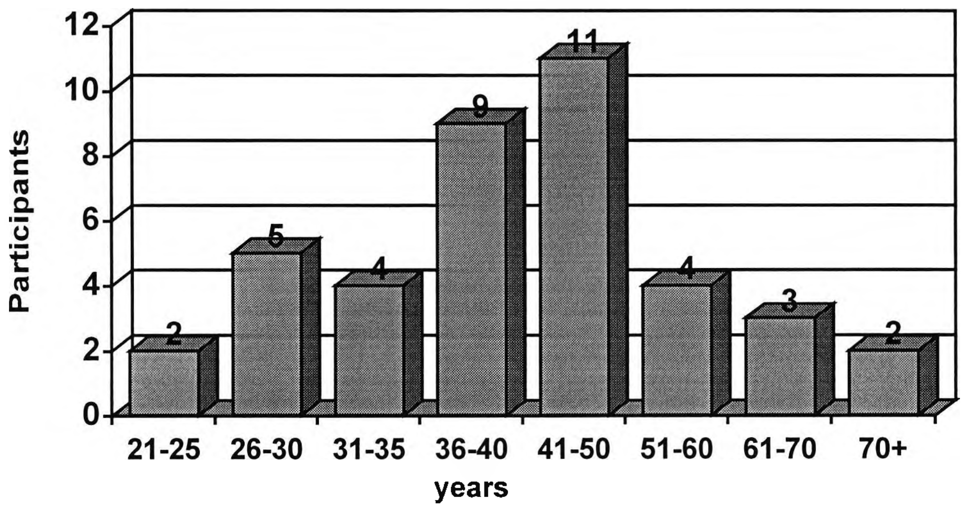
6.2. Family-participants

6.2.1 Family-participant Characteristics

6.2.1.1 Age

The age distribution for FPs resembled a more or less normal curve with most participants falling into the 41-50 year category (11/40; 28%). The second largest cluster was in the age category 36 to 40 years (9/40; 23%). (See Figure 1.7)

Figure 1.7: Age Distribution of Family-participants



6.2.1.2 Country of Birth

Mostly FPs were born in England. 29/40 (73%) of FPs reported their country of birth as England, 1 (3%) was born in Wales and 4 (10%) in Ireland. Another 4 (10%) was born in the rest of Europe and the remaining 2 in North America and Asia respectively.

6.2.1.3 Ethnic Origin

By far the majority (37/40; 93%) of FPs described their ethnicity as White with an additional one as 'white other'. One participant described himself as Caribbean and the remaining participant did not want to report on his ethnicity.

6.2.1.4 Employment Status

Thirty (75%) of the FPs were employed at the time of their interview of which 9/40 (23%) were self-employed, 6 (15%) were in a managerial or supervisory position and

15 (38%) were employees. The remaining FPs were either retired (6/40; 15%) or unemployed (2/40; 5%). There were 2 missing values for employment status.

6.2.1.5 Relationship to Patient-participant

A significant number (24/40; 60%) of FPs were close friends of the PP. A further 5 (13%) were male partners, 4 (10%) mothers, 2 (5%) brothers and 2 (5%) sisters. The remaining 3 described themselves respectively as an employer, an ex-boyfriend and an ex-girlfriend.

6.2.1.6 Family-participant HIV Status

Of the 40 FPs, 25 (62.5%) had at least one HIV test in the past. 5 of these (12.5%) reported receiving an HIV positive result and 15 (37.5%) a negative result. 18 FPs reported that they did not know their HIV status at the time and 2 did not answer the question.

6.2.2 Circumstances of HIV Disclosure Event

The disclosure of HIV status was remembered by 37 (92.5%) of the 40 FPs. Of these, 36 (97%) were told by the PP. One FP (2.5%) was told by her daughter. 2 (5%) FPs could not remember the disclosure event and there was 1 missing value for this variable. 17 (47%) of the 36 FPs who were disclosed to by the PP thought that the PP planned to tell them, 9 (25%) thought it happened spontaneously and 1 could not tell whether it was planned or not planned. 10 of the FPs reported that they could not remember well enough to report on this variable.

There were 15 of the 40 (38%) FPs who reported that they suspected that the PP was HIV positive prior the HIV disclosure event and 19 (48%) who did not suspect anything before the event. One FP experienced guilt because he knew about the PP's HIV diagnosis before he disclosed to them.

> ... *feeling quite guilty about knowing because he hadn't told me himself...I couldn't hold on to it ...knowing it and him not knowing that I knew...* (Guy's close friend)

6.2.3 Emotional Effects of HIV Disclosure

FPs' initial reactions to the HIV disclosure was varied: 13 (33%) of the 40 FPs described themselves as shocked by the disclosure, 7 (18%) described sadness and 4 (10%) were not surprised. A further 8 FPs went on to describe various additional reactions to the ones asked. These included: a) 'devastation'; b) fear; c) confusion because of a lack of HIV knowledge; d) disappointment because of the perceived shortened life expectancy; and e) disbelief. One FP described the HIV disclosure as a 'journey of disclosure' which he shared with the PP and which happened 'gradually' over time. None of the FPs described themselves as 'angry' at the time of the HIV disclosure. Below are some examples of the responses after HIV disclosure:

> *We were all upset at the time and by talking about it, it helped us to overcome the fear that Ben might die.* (Ben's male close friend)

> *Initially...at that time* (1993) *people really didn't know how long they might have to live and because at that time the various medical treatments available now weren't available then...it was sort of a different situation then.* (Philip's close male friend)

> *...You sort of worried about the health aspects...I worry about should you be doing all this; you should be looking after yourself.* (Matt's close female friend)

One FP reported that his fear of HIV interfered with his ability to cope and to give and receive support. The PP's acceptance of the illness and their fears were important in how the FP coped. Other people's fears can exacerbate a problem.

> *...I'm going through something and I'm kind of lost...also we compound each others fears or reinforcing...in a sense we probably both imbued this idea that HIV...is like the most terrible thing....* (Jack's close friend)

25/40 (63%) of the FPs reported that their feelings about the PP's HIV status had changed over time, mostly in a positive sense. Increased HIV knowledge and adjustment over time seemed to moderate the first reaction to the HIV disclosure. The following example illustrates the advantage of increased HIV knowledge:

> *So it's gradually getting rid of ignorance that has got rid of my fears and anxiety.* (Chris' close friend).

Increased stress during periods when the PP had an HIV related illness was reported, as that seemed to bring the reality of the HIV positive status to the fore. 9 (23%) FPs reported no change in their feelings since HIV disclosure and 6 did not respond.

In response to the question about a change in the relationship with the PP, half (20) of the FPs reported no change in their relationship and 19 (48%) reported a positive change and described the relationship as emotionally closer. Despite reporting to be emotionally closer, the changes were sometimes experienced as stressful and there were reports of difficulties in adjusting to the new roles that FPs had to adopt. For example, whereas before the relationship was more friendship based, it changed into a carer role after HIV disclosure. This also lead to changes of a practical nature. Day-to-day routine, hospital visits, procedures and medication played a role in this change. FPs reported that they had to be quite assertive at times to get what was required for the PP. These FPs show particular concern for the PPs' comfort and health.

> *...I tried to get him moved to somewhere with a bit more privacy...there was very little sensitivity...I didn't feel that I got very much of a hearing...people were blanking me...* (Gene's male partner)

> *...an awful lot of onus on me to...try and get him access to things that he needed...he wasn't being taken very seriously at first by the hospital.* (Gene's male partner)

> *I'm nearly always on him about appointments...if I notice things about his behaviour .... or if I notice anxiety...aware how certain things affect him...* (Pete's male partner)

Support to the PP is sometimes given out of a sense of duty or guilt.

> *...I thought he was going to die...I did feel in a way a little trapped and I didn't feel as though I could leave the house...I felt as though I was deserting him* ...(Richard's close friend).

FPs also reported that they became more passive in their supportive role during certain times. During these times they seem to feel that they have to be available for the PP but would not intrude unless asked for support.

> *...I'm just there in the background if he needs any help.* (Damien's mother)
>
> *I don't want to feel...like I'm prying...I'd hope that...Damien know that I'll be there for him if he needs me.* (male partner)

One FP was unsure how to relate to the PP.

> *...I don't know what to do, whether to leave him alone to cope with it...there is times when perhaps I'm not needed?* (Alan's mother)

One FP reported that whereas she expected her children to take care of her at her age, she now has to take care of her son and her own needs are not being taken into consideration.

> *...as you get older you think it would be nice if people would do little things for you...* (Alan's mother)

Alan's mother also found it difficult to communicate her concerns to her son, so she tended to 'withdraw a bit':

> *Because I don't want to add to his worries of course by, you know, showing him that I'm distressed.* (Alan's mother)

Changes in sexual relationships were also reported. For example, Steve's male partner reported that they had not had sex since Steve was diagnosed HIV positive 7 years earlier. He had kept this very much to himself and first talked about it during the interview. He reported that it actually helped to express his feelings during the interview and that he would try to seek support. (He was given advice regarding counselling by the interviewer)

6.2.4 Patient-participants' Experience of Support as perceived by Family-participants

Some FPs had a definite idea as to how they thought the PP perceived their level of support. Most thought that the PP perceived them as supportive. One FP indicated that he felt that the PP appreciated his commitment, but only after years and years of unconditional support.

> *...he probably knew that I would be supportive.* (Chris' close friend)

> *...I think I sort of have this inside me...if he is low he knows he can always come to me for a hug, he can always cry on my shoulder...* (Carl's close friend)

> *...he knows he's got a good support network and stuff.* (Matt's close female friend*)*

> *...he is slowly appreciative of the fact that I'm very supportive...made him realise the depth of my emotional commitment to him.* (Alan's male partner)

6.2.5 Family-participants Views on their Biological Family

One FP (Alan's mother) expressed concern for the biological family and reported that the PPs HIV disclosure and the effect the illness had on him had damaged family relationships. This affected her more than anything else did. She was particularly concerned about how her son's illness had influenced her daughter. Her tone indicated a sense of anger because of her son's (the PP's) attitude towards his sister. She expressed herself as follows in different parts of the interview:

> *I mean I do talk with* (daughter) *about it...*
>
> *...she looked up to him...it has been hard for her.... I mean she has enough to worry about..... that in fact is where the pain is for me... no longer has any patience with the type of lifestyle, which is meaningless to him...*
>
> *I mean he hates it, ... It's not his life at all. And he's not very good at hiding the fact that he thinks it's so awful...daughter very hurt as a result.*

Some FPs reported that the PP's extended family were not supportive and in some cases were not told about the PP's HIV status, probably fearful of a negative reaction. One FP mentioned that the PP was planning to tell his family, but this had not actually happened yet.

> *...I believe that he'd still not told any of his family...any support that he needs is going to have to come from here...if it ever comes to the crunch...then*

> *somehow we're going to have to smooth this over with his family.* (Carl's close friend)

> '*...he needed to tell family and he needed to work it out with his partner...* (Chris' close friend)

One FP (male partner) felt that because he was not part of the biological family he was treated as less important. They made him feel that had no right to be there.

> *...I was just utterly ignored, not a flicker of eye contact...I had no legitimacy as part of this person's life...* (Gene's male partner)

6.3 Family Participants' Social Support

6.3.1 Disclosure of HIV by Family Participants

A high proportion (32/40; 80%) of FPs made their own disclosure of the PPs HIV status to their own close friends. They also shared the information with their own partners, family and relatives. Only 1 FP did not disclose the information at all. The people who FPs disclosed to themselves are described in Table 1.10.

Table 1.10: To Whom Disclosure was made

Relative	Number told	Percentage
Male partner	10	25%
Female partner	1	2.5%
Mother	10	25%
Father	7	17.5%
Sister	3	7.5%
Brother	3	7.5%
Close friend	32	80%
Other people	11	27.5%

Percentages do not add up to 100% as most FPs told more than one person each

6.3.2 People Identified as Supportive to Family-participants

FPs were asked to identify the people who they found to be supportive regarding the HIV disclosure. 20 (50%) received their primary support from a close friend. Sharing with close friends who know about the PP's HIV status helps:

> *There's a sort of group of us and we all know about him and we're all quite good friends ...... So you don't feel that you're the only person who knows about it .... You're one of a group of people that is dealing with the situation.* (Carl's close friend)

One FP who is a close friend reported that he received most support from close friends who are also HIV positive:

> *Balancing each other up, really, I think..* (John's close friend)

8 (20%) FPs were mainly supported by male partners (2 husbands) and 1 each (2.5%) from a mother, daughter and a female partner. None reported receiving support from a father, sister or brother, although one FP reported surprise at the level of support both he and his male partner (the PP) received from his parents after disclosure, especially as he put it off for a long time:

> *I hadn't come out to my parents long before. ...... actually the whole thing has gone like a dream really with my parents; they're quite old and by no means liberal people, which is why I put off telling them for a long time. ...... there was one time when my mother said, "Is there anything we can do?" ...and I said you can meet him ... and I said that at a time when it was like, I effectively thought, I want you to meet before the funeral....... I was kind of apprehensive that they would fuss over cutlery and that kind of shit. And they weren't at all.*

> *And my mother kissed him and stuff and I was really very impressed because I'd thought, I'd decided beforehand that if there was any surreptitious disposal of cutlery or what have you that I wouldn't blame them for it, because I just think they had never come across the situation before and they're coping the best they can and it would just complicate things to be angry with them. So in fact it was a very nice surprise that they behaved impeccably.* (Gene's male partner)

Most participants found that talking to certain people were more helpful than to others. Husbands, daughters and friends were found to be most helpful, whereas mothers and the participants themselves were less helpful.

> *'Occasionally I speak to him...but we don't go into any further than that...I talk to my daughter-in-law...I feel I can sort of talk to her more than to my son...but the person I talk to most is my daughter.* (Jack's mother)

> *I would talk to my husband about my feelings about it and to my close friends because it would just be a very personal thing.....* (John's close female friend)

> *I mean I talk with her* (daughter) *about it...have a little moan at her now and again. Some very good friends...when I want to say things... I couldn't possibly talk to Alan* (PP) *about it. No way... harder and harder to talk to...he's not very forthcoming.* (Alan's mother)

> *I probably do to some degree with some of my friends not with my mum though.* (Guy's close friend)

Of those who indicated the 'other' category, 2 reported that their main support came from their psychologist. Another 2 reported that they gained support from the PP himself:

> .... *he is so brave and so positive.* (Damien's mother) and
>
> .... *his resilience has given me some hope*. (John's close friend)

Ben's told his close friend (the FP) that she could tell whomever she wanted as long as she lets him know whom she had told. She told her parents, boyfriend and some close friends because she did not want to:

> .... *be carrying a huge secret about. It was good to be able you know, to know that they knew.*

6.3.3 Mechanisms of Social Support

FPs reported that support is obtained mainly through a) talking to either PP or own supports and b) being informed about HIV and the PP's state of health. 30/40 (75%) of the FPs could talk about HIV with the people they identified as supportive and all reported that talking was helpful. Talking is obviously highly valued by FPs:

Alan's partner obtained support from his own friends who helped him to cope with Alan being HIV positive:

> *I often talk to friends and that's very important.*

Although she realises that some people may have a problem talking about HIV or understanding it, Carl's close friend thinks that talking about it does help:

> *....talking about it all the time so it becomes something that's in your life as opposed to something scary on the sidelines. Talking about the person's HIV status makes it more accessible, more everyday. He's very open and he talks about it all'. In fact it can be boring.* (Carl's close female friend)

FPs report that support are often obtained through talking openly, honestly and not having to hide too much:

> *The fact that my friends know and that I can talk.* (Alan's mother)

She can also talk to her daughter:

> *And I have a little moan at her now and again. I think it helps one sort things out for oneself and helps one get something out.... Instead of bottling it up.* (Alan's mother*)*

Talking is also used as a means of obtaining information about the PP's health and treatment. Some FPs expressed the need to ask questions of the PP and report that practical matters such as hospitalisation and medication are often discussed. Some reported their need to ask questions and not to ignore the problem.

> *I talked to my parents...talk specifically about his medication, about how he is and talk generally about the situation.* (Alan's partner).

> *We all talked and we asked loads more questions.* (Ben's close friend).

> *I talk about health practicalities but I wouldn't talk about feelings.* (Gene's male partner).

Talking also helped to relieve the 'burden' of knowing the PPs' HIV status. Carrying a secret around was reported to be a huge burden and made it more difficult to cope with feelings around the HIV. Talking helped with difficult emotions such as fear and anxiety and appears to relieve the pressure of knowing and dealing with the HIV situation.

> *He has been prepared to talk about it... told most of his friends...he sort of wanted to tell people which I think helped everyone...then everyone could sort of .... you could talk to other people about it.* (Matt's close friend)

> *I wouldn't have spoken to people... so I suppose it did help me to get that off my chest and it certainly helps me now as I said earlier to be able to talk positively about it.* (Carl's close friend)

> *I would never have anxiety again 'cause I know where to go for help and I could talk about it with him now.* (Chris' close friend)

For some FPs a large amount of communication revolved around the PPs' problems, which was a way of supporting him. This in turn helped FPs to feel needed and useful and lead to a sense of purpose, taking away feelings of helplessness and powerlessness.

> *... when something happens to you, you want to talk about it...talk around it so it makes him feel better... I know that he needed to talk about it... he shouldn't go along not talking about it to anybody.* (Carl's close friend)

> *At times when he's had a very bad time he has actually talked to me ... when you are in a life and death situation...it makes you talk about things that perhaps you don't talk about in other situations.* (Jack's close friend)

Conversely, some FPs saw no need to talk about the PPs HIV or health. There was a view amongst these FPs that there were no need to talk while the PP was in good health, motivated by the decision to appreciate the 'good' times and worrying about the bad times when it comes.

> *I don't think I would do it* (talking) *unless I felt that I needed to. I haven't felt that I needed to tell people that were close to me.* (Carl's close friend)

Talking could also be experienced as unhelpful. Some FPs wanted to avoid the subject altogether or balance it out with other things. They felt more able to cope if HIV was something that was interspersed with the rest of their lives instead of being the main focus.

> *I was fed up with him always banging on about it ... I just wanted to not hear about it for a while.* (Frank's close friend)
>
> *I mean not all the time, ... it has to be balanced by fun.* (Chris' close friend)

The quality of talking changed over time. Soon after HIV disclosure, many FPs found it more important to talk than later.

> *I was actually able to talk .... he told me I was allowed to talk to different people...that was just at the beginning now I don't need to.* (Richard's close friend).

> *When we first found out we talked about it all the time about what it would mean and everything. ...Then we talked a little bit more about it recently.* (David's close friend).

There seems to be some factors that made talking easier. Some FPs reported that it made coping easier if they knew that they could talk to other people. FPs who could not talk about HIV reported that it was a huge burden and responsibility.

> *He has been prepared to talk about it... told most of his friends...he sort of wanted to tell people which I think helped everyone...then everyone could sort of, you could talk to other people about it.* (Matt's female friend).

It was helpful for some FPs to talk to someone objective, someone who was not involved in the situation. The reasons for this were unclear, but it could be that they felt less guilty to express their own needs when it is not friends who are also concerned about the PPs, someone who was mainly concerned with the FP. Someone who is separate from the situation and who provided anonymity may feel safer to talk to especially for people who are discouraged to discuss the matter with anyone else.

> *A couple of friends that I speak to a lot... I could talk to people who are out of the situation.* (Damien's male partner)
>
> *...to talk about it ... with somebody I didn't know.* (Gene's male partner).
>
> *It is something that I've talked about a lot you know...I would feel like I need therapy in order to help me with it ...I do with my therapist.* (Guy's close friend)

Gene's partner reported that knowing someone who worked in HIV helped, to direct support:

> *We kind of knew our way around....* (Gene's partner)

Gene's partner was able to go for counselling almost immediately. Although the first counsellor *didn't work for me*, he was able to go to another counsellor who he described as *'hugely helpful'*

On the other hand, some interviewees found it more useful to talk to people whom understood the situation and who was involved in it.

> *...That was quite a big help as well, because she had known... Talking to people who understand help.* (Simon's close friend)

Chris' close friend felt that he was 'very ignorant' when he was first told. He did not know where to go for support or advice when Chris was first diagnosed in February 1994, but now:

> *I would never have anxiety now 'cause I know where to go for help and I could talk about it with him now* (Chris' close friend)

6.3.4 Level of Support

Initially HIV support systems were found to be inadequate to deal with the adjustment to HIV disclosure. The inadequacy was attributed to the support systems' lack of knowledge of FPs' needs and not to a lack of interest. Some continued to seek support despite disappointments and incompetence. It appears that some FPs came to rely more on their own skills and knowledge, in a positive way taking control of their situation and looking for their own answers instead of passively waiting for external support.

> *We had no counselling through any of this... and we had no, there were no support mechanisms at all...the doctor who gave us information sort of did his best, but he didn't know what he was doing.* (Alan's male partner)

> *I went for counselling at first I went to* (HIV Counselling Organisation), *which was lousy, or at least didn't work for me. But the one that did work...that particular service was excellent.* (Gene's close friend)

> *... had some counselling from the Health Advisor there. It wasn't very helpful...he came out of the room on his own after they'd disclosed it, but he asked then, he was going in to get some counselling afterwards and he asked then if I could come in and they didn't mind.* (David's close friend)

Some FPs reported that their need for support lessened as time went by. Some FPs also indicated that their need for support would be likely to change if the PP's became ill. These FPs seem to need an open door approach with non-intrusive support.

> *He himself tends to forget to tell me whereas at the beginning it was 'oh this, this at the clinic, I said this, they said that' ... and over the years its just become such a matter of routine.* (Carl's close friend)

> *I don't think of it that much really...but I don't really know what is happening at all at the moment because we don't talk that much.* (Simon's close friend)

> *If and when he becomes very ill again it might be completely different and I might be looking for this sort of support then, but as things are at the moment you know its okay I think.* (Chris'close friend)

FPs who did not know where to obtain support reported that this caused increased anxiety. Knowledge of support systems seems very important in coping with difficult situations.

> *So I knew where to access counselling...so I went for counselling immediately...* (Gene's male partner)

> *But then I didn't know quite who to ask...and I actually rang up some support organisation, various help lines and so on, who were very supportive...I would never have anxiety now cause' I know where to go for help and I could talk about it with him now.* (Chris' close friend)

6.3.5 Recognition of the Need for Support

There was recognition for the need for support but support is sometimes not available from those expected to provide it. Some FPs said that the support they needed came from people who understand the situation.

> *...getting involved in the response to HIV ...for me it's working* (in the HIV field*)...gives me a sense that I'm doing something about it rather than simply having it wash over my life...I mean my family is not very supportive. I find it very hard, that there's a real lack of support there ...and those people ...did that to show support for it, to show and interest in what I was doing...and my family didn't do that.* (Alan's male partner)

> *...to have a big support network of people who had been through the same thing and had the same condition and knew what it felt like was hugely important.* (Gene's male partner)

> *'I think perhaps it would be twice as supportive to be... to have contact with other people who are friends with other people who's got HIV I think that would probably been quite helpful.* (Guy's close friend)

One FP reported that he found it more difficult over time and needed more support to cope. A number of FPs indicated that although they did not need support when it was going well, they would need some kind of support if the subject's condition worsened or if he died.

> *...actually, it gets more difficult and I get more depressed and I get more confused...it gets harder and I don't know what support that I want, but I need more support...I think there are some people who think that somehow you get used to it and therefore you know what you're doing.... I think that it is completely the opposite and that it's far harder to cope now than it was ten years ago.* (Alan's male partner)

> *I was even more cautious when I thought things were going progressively downwards... because the trend is so good that if things were to change .. well then I would know that it was time perhaps to think about a ...difference of my attitude.* (Carl's close friend)

> *If he became really sick again because in the meantime I don't feel... I don't really need to talk to anyone about it as long as the status quo is maintained; I am quite accustomed to the situation.* (John's close friend)

6.3.6 Reasons for the Absence of Support

Some FPs did not attempt to gain support. The reasons were: a) they did not realise they needed support, b) they were unsure that it would help and c) they felt more comfortable with giving support than receiving it.

> *I had to get very low before I realised I felt I needed support...that I was struggling then...and I didn't always have to be strong for him...he was suffering and I was suffering, so acknowledge that and face...* (Alan's male partner)

> *I don't know what the solution is. I don't know whether or not me talking about it with people would make me feel easier – it might do, I don't know. Or, me talking about it with some professional person might make me feel easier about it, I don't know.* (Steve's male partner)

> *I don't think I really need to off-load... seem easier to cope with other peoples problems than my own...this sort of thing I take in my stride.* (Carl's close friend)

2 FPs indicated that they did not know where to get the support.

> *I went for counselling immediately and I went to one place that didn't work...* (Gene's male partner).

> *I didn't know quite who to ask.* (Chris' close friend).

One FP was discouraged by the PP to find support, as he wanted his HIV status kept secret.

> *... and I haven't been able to talk about that to anybody, including my friends.* (Steve's male partner)

Two FPs indicated that they felt they needed to support the PP because he needed them, rather than needing the support themselves.

> *...I'm probably his closest friend, so I knew that he would turn to me in times of need and he would be relying on me quite a lot...I am a little bit more fatherly towards him...he's got no close family. I think he probably looks up to me as, well, almost as a father figure...as someone to support him or give him support.* (Philip's close friend)

> *... he told me after it happened, it's not going to change anything and then I thought, hmmm, well you've been depressed a lot more than you were before and stuff like that. He still gets lots of depressions all the time but... I talk to him about it.* (Simon's close friend)

Some FPs felt that they had to cope on their own, so as not to add to the PP's problems. This resulted in denial of feelings and hiding emotions from the PP.

> *...he has found it very hard to cope with I think...I certainly am not going to give him added problems by complaining...he's got enough on his plate* and *...showing him that I'm distressed...I think it's best if I withdraw a bit....* (Alan's mother)

> *I think to begin with I felt I had to be the strength/strong one...I had to be his support...before I realised I felt that I needed support.* (Alan's male partner)

3 FPs reported that they experienced distress because they could not help more, either because the PP did not share problems with them or as a result of practical difficulties.

> *...the thing that I really felt upset about was that he'd had to sort of deal with on his own...I wished that he had told me sooner...so that I could have given him some sort of support or understanding about it.* (Jack's mother)

> *I think he doesn't want to worry me probably. I am sure that that's true and that doesn't help in a way.* (Alan's mother)

> *...there are limits.... the presence that I can have in his life at this point just because there are so many demands on me in my immediate family...I am there for him in all sorts of different ways but I can't be there for him full on all the time...* (John's close female friend)

6.4 Coping Mechanisms Utilised by Family-participants

FPs recognised that there were different ways for them to cope with the PP's HIV status. FPs reported varied ways of coping. Coping consisted of denial of the reality of the situation by never thinking of the implications of the PP's future illness or by occupying themselves with work or social activities and using humour and fun activities to reduce the intensity. Two FPs described how they stepped out of the situation to take a break from HIV.

> *...partly one has to cope in order to be of use to the person in question...on the purely practical level I have a job, which is quite demanding, and when I'm doing it I sort of forget about other things.* (Jack's mother)

> *I'm the sort of person that when things get difficult I just work and shut it out…you can't shut it out…I mean that's the way I've dealt with things.* (Damien's mother)

> *I bury, I shut the door virtually, I cope with that when it comes because that's gonna be a baddie.* (John's close female friend)

> *…we talked about it all the time…we talked about it in relation to the treatment and things like that…we wouldn't broach David of what's going to happen when he gets ill and when he dies. … No, we don't talk about that, I don't know why, but I don't want to think about it either…because it's for David to be able to talk about and…. in the open. It can't be something that's constantly put away…*(David's close friend)

> *I think it has to be balanced by fun…we giggle a lot and have a lot of fun together and that's important to have a balance…sometimes fun will be more important and sometimes talking seriously will be more important, it varies from time to time.* (Chris' close friend)

> *…right from the start we made a joke out of it…* (Frank's close friend).

6.4.1 Factors Influencing Coping

Several factors seem to influence the way that FPs coped with HIV affecting their lives, such as the PP's own level of coping, their own personalities and coping styles and the meaning that death had for them.

6.4.1.1. Patient-participant's Level of Coping

FPs indicated that they coped better if the PP could talk about their diagnosis and implications for the future.

> *...he's got a very positive attitude to everything...because of his attitude to the whole thing...he's not bitter or anything at all...he talks about everything...I've told a couple of friends.* (Simon's close friend)

> *...because he's very, very good at coping and he's very open and he talks about it all.* (Carl's close friend)

> *it wasn't as though the whole thing was a shock...I knew the kind of care that was on offer, it has helped me cope...it's his attitude that' been the best thing to cope...where he will talk honestly about death and future plans...his hugely positive attitude to life and sense of humour...he's not denying the illness, he's not denying it's possible effects either.* (Chris' close friend)

FPs found it difficult to cope with the PPs' suffering or imagined suffering as this made the HIV diagnosis more real and impossible not to deal with. Negative emotions of the PPs (like sadness and depression) also make it difficult to cope.

> *...he has coped remarkably and better than any can hope for anyone to cope in a way...I am so glad that he is in such a loving and stable relationship...It helps...to know that he is not lying in his flat kind of lonely and terrified without there being any persons who cared about him anywhere in the vicinity that would freak me out...* (John's close female friend)

> *...he is suffering ...that makes it difficult to cope, because they sort of like remind you that things could go down and the illness could get worse. That makes it difficult to cope, seeing him going through all these sort of minor complaints and his body not being really well and fit like it could be...* (David's close friend)

> *So that when he's in good shape...all is well and we chat and it's all right. But when he's down I find it quite difficult to know how to cope with it...because I say I don't know how to cope...I don't say I don't think I cope particularly well when he's really down.* (Alan's mother)

> *...because with me I already have another very close friend and I have sort of dealt with that...I suppose when you talk about it with him, you can see him welling up with tears and that's very difficult because he is very emotional and sometimes I am a bit as well. So it's kind of like I tend to get upset and that's a bit difficult.* (Richard's close friend)

When the PP were coping and their relationship with him went well, some FPs reported coping better themselves. One FP mentioned that the PP denied what was going on but that he (the FP) went along with it to help the PP to cope.

> *...you know part of how anyone cope is how the people around you cope and deal with things and the relationship and all that.* (Pete's male partner)

> *...when he felt he didn't want to know...that was his way of coping...people cope different ways and you just go along with it really. There are no rules and regulations about how people cope.* (Chris' close friend)

> *...the fact that he's...how he's been made it easier...able to share things openly with my wife makes a different...the fact that she understands and is not fazed by it either.* (John's brother).

The positive attitude of PPs made a considerable difference to FPs' own coping. FPs expressed admiration for PP who lived life to the full and refused to be defeated. Some saw it as an example of how to live life in spite of hardships. This helped particularly with coping when someone is dying.

> *...he's got a very positive attitude to everything...because of his attitude to the whole thing...he's not bitter or anything at all...he talks about everything...I've told a couple of friends.* (Simon's close friend)

> *...this is the man who knows what's going on and is doing his best to...live life to the full...one lives alongside that with him...'cause he's such a positive person...he was still giving to life.* (Chris' close friend).

> *In many ways he's...been a complete example because he's tried so hard...and he's got on with life despite everything and refused to be defeated...I have tremendous admiration for him.* and .... *Damien has been absolutely amazing and very, very brave. He kind of fought it, fought the difficulties.* (Damien's mother)

> *...he's very positive you see. I think his own temperaments help a lot because he doesn't focus on it all the time. I mean he focuses on the positive side to it ...responded very positively to this medication...that makes it a lot easier.* (Carl's close friend)

> *...he's a very strong person...a load of friends...he's just accepted...a lot of that being through his coping mechanism as being able to shut things out so well...and I've got to deal with this situation the best way I can.* (Frank's close friend)

6.4.1.2 Personality of Family-participants

FPs who had experience of people dying appeared to cope better with the implications of the PP's future illness. The FPs' who accepted death as part of life seem to deal better with the fear of the unknown and the insecurity of HIV.

> *I worry about should you be doing all this, you should be looking after yourself...but people deal with things in different ways...I think I'm quite good at coping with things, because I've had a lot to cope with. ... I think he relies on me a bit cause I do cope, you know.* (Richard's close friend)

> *...I recognise that death...one of the features of life...I think I was brought up with this because my mother was a young widow...if she needed to open up she would open up to me...I sort of have this inside me.* (Carl's close friend)

> *...from early childhood having always being involved with people having illness or people dying you know, I don't think that people being ill and dying is something that comes with...from the blue.* (Pete's male partner)

Some FPs indicated that feelings of impotence make it difficult to cope. One FP reported that feeling needed helped her to cope better.

> *...in terms of feelings...feeling guilty about needing any help about it so when I talk about it in therapy if I'm very upset I feel I shouldn't feel like this because it's not me...he's the one with all the need and...I should put my needs secondary.* (Guy's close friend)

> *...partly one has to cope in order to be of use to the person in question...on the purely practical level I have a job, which is quite demanding, and when I'm doing it I sort of forget about other things. ....the thing that's most difficult for me is the fact that I feel that I'm absolutely impotent, in the sense that I can't do anything to help to improve the situation...mothers...generally feel that they should be able to make them better.* (Jack's mother).

FPs self-perception and general attitude also contributed to adjusting and coping with HIV. FPs who saw themselves as strong and accepting coped better with the PP's illness. Some FPs also indicated that their positive way of looking at life helped them coped with most adverse conditions. The reason for this positive attitude differed in FPs. One FP indicated that she was able to feel positive because she does not generally see things as a catastrophe. Another FP was able to stay positive by focusing on what can be done instead of agonising about what could not. Yet another FP indicated that he was able to be positive because he wasn't directly involved and could thus see a solution to it.

> *I haven't needed any help particularly. I'm quite a strong person. It's just something else to deal with.* (Philip's close friend).

> *I can quite easily leave things behind and deal with the other things that's going on...to accept Ben is no problem...* (Ben's close friend)

> *I'm not so much thinking about that, I see it more positively in that he can be well and there are things you can do to sort of prevent the symptoms coming. I feel that since I have the information about it that it's less...of a burden.* (David's close friend)

> *I've always found it's much easier to be positive about other people than about myself...to some extent I can do something about those...I can't see my own solution...* (Carl's close friend)

One FP reported that it helped him to have a balance between seriousness and humour, and that he tried to infuse his relationship with the PP with both.

> *I think it has to be balanced by fun...we giggle a lot and have a lot of fun together and that's important to have a balance...sometimes fun will be more important and sometimes talking seriously will be more important, it varies from time to time..* (Chris' close friend).

FPs recognised that most people have different coping styles. Because it differs, everyone has to find the way that works best for him or her.

> *...and I've got to deal with this situation the best way I can.* (Frank's close friend*)*

> *...when he felt he didn't want to know...that was his way of coping...people cope in different ways and you just go along with it really. There is no rules and regulations about how people cope.* (Chris' close friend)

> *...I had a lot of people to talk about it wasn't huge...it was just, you know another thing that would happen to somebody. I wasn't going to have a future problem with it. I don't have a problem with the illness and I don't have a problem with people being gay, so it wasn't going to change me at all...it was something we dealt with...it wasn't a huge change at all.* (Carl's close friend)

One FP indicated that his ability to cope lessened as time went on because of the insecurity and unpredictability of HIV.

> *...it gets harder, it doesn't get easier as one,...it gets more difficult and I get more depressed and I get more confused...but I need more support...some people who think that somehow you get used to it and therefore you know what you're doing...and that it's far harder to cope now than it was than it was ten years ago...I think that's just the length of time...it's like Chinese Water torture or something, it's just get worse as it goes on and on...if somebody even put a dagger through your hand you know that would hurt for the first two years but if it carried on hurting then you would be, it sort of becomes, you know, it's there for fourteen years...it just gets worse and worse and doesn't stop. It's as if there's no end in sight except his death...the endlessness ends up being worse than the imminence of illness and death.* (Alan's male partner)

6.4.1.3 The Meaning of Death to Family-participants

FPs reported that thinking about the PP either dying or suffering makes coping harder. The future implications of the PP's HIV status makes it harder to cope.

> *...we talked about it all the time...we talked about it in relation to the treatment and things like that...we wouldn't broach the subject of what's going to happen when he gets ill and when he dies. No, we don't talk about that, I don't know why, but I don't want to think about it either...because it's not to be a subject that you're able to talk about and that's in the open. It can't be something that's constantly put away...it helps because you're just sort of bringing an awareness to it and your sort of dealing with it by finding out how the other person feels about the treatment or whatever...* (David's close friend)

> *...he is suffering ...that makes it difficult to cope, because they sort of like remind you that things could go down and the illness could get worse. That makes it difficult to cope, seeing him going through all these sort of minor complaints and his body not being really well and fit like it could be.* (David's close friend)

> *I think the only thing that would make it harder for me to cope with Ben is if he started to deteriorate because I didn't know Ben as a person to give up or as a person to be ill, or as a person to have any problems and then to see like a grown man deteriorate or to see a grown man cry, or to see a grown you know die for something that there should be a cure for that would be my biggest problem. You know the end result would be my biggest problem.* (Ben's close friend)

For some FPs it was important that PPs should have had a full and productive life. It seems especially the case if the PP is still very young, as if the thought that the person might be missing out on life is harder to cope with.

> *the fact that he was young and it seems a complete waste for somebody who is...he does a lot of voluntary work and all sorts of things...he's contributed an awful lot back into that kind of world.* (Frank's close friend)

> *...the obvious overwhelming reality of any...young person having to contemplate their death and not being able to think about their life in the same way.* (John's close female friend)

Coping was improved by the experience of death as reported by some FPs.

> *...from early childhood having always been involved with people having illness or people dying you know, I don't think that people being ill and dying is something that comes with...from the blue.* (Pete's male partner)

6.4.1.4 Level of Involvement with Patient-participant

Some FPs indicated that having some distance from the PPs' situation helped them cope better.

> *I'm not having to cope with the everyday situation...so you know that I don't actually have to confront the issue too much.* (Alan's sister).

> *...I feel in some ways that I've been able to step back a little bit.* (Jack's close friend)

FPs who were more involved and had more experience with HIV found it much harder because they had to confront the issue more often and intensely.

> '*...I've treated a lot of people with HIV related conditions...I think that's quite difficult...seeing what happened as a result...one has a bit more insight into the potential pain.* (John's brother)
>
> *...when it hits nearer home then you think more about it.* (Rob's close friend)

6.4.1.5 Ignorance and Insensitivity

FPs indicated that ignorance and insensitivity in other people hindered their ability to cope with the PP's illness. One FP indicated that the insensitive attitude of people around him affected his ability to cope adversely. Some FPs also indicated that their own ignorance and lack of knowledge made it more difficult to accept the subject and implications of the subject's illness.

> *And I even had people who have known an awful lot about HIV and are very well involved in the response to it, who erm, who say things like, "well yes it must be very hard to watch someone go through something like that."...and I'm not actually just watching someone go through something like that, you know, it is my life, my life has been completely upended by this...I'm not a viewer, I'm not a tourist, I'm not a member of the audience .... other peoples' ignorance, and I don't mean in terms of prejudice, but just in terms of ignorance....there become this barrier between certain people that you can't even, you can't begin to transcend.* (Alan's male partner)

...it's that irrational bit of all of us you know and that's there... (John's close female friend).

6.5 Non-participants

Fourteen participants decided not to have a family member interviewed. These participants were interviewed using a similarly structured questionnaire to those used for the PPs. NPs were interviewed in order to obtain information regarding the characteristics of this group and how it may differ from the PP group. More importantly the study aimed to establish what might deter NPs from allowing a family member being interviewed. The following data will be reported on the NPs: age, ethnicity, country of birth, occupation, length of time since first HIV diagnosis, route of HIV transmission, and HIV treatments. Data about NPs' views of the impact that an interview might have on family is reported along with NPs perceptions of relationship and or behaviour changes in their family since HIV disclosure.

6.5.1 Non-participant Characteristics

6.5.1.1 Age

Of the fourteen NPs 10 (71%) were between the ages of 31 and 40 years. The age range was between 27 and 64 years with a mean age of 39.5 years.

6.5.1.2 Country of Birth

Nine of the 14 (64%) NPs were from the United Kingdom and 3 (21%) from the rest of Europe. The remaining 2 were from Africa and the Caribbean respectively.

6.5.1.3 Ethnic Origin

12/14 (86%) of the NPs described their ethnic origin as white, 1 as East African Asian and one as Caribbean.

6.5.1.4 Employment Status

Half (7/14; 50%) of the NPs were unemployed, 6/14 (43%) were in employment and 1 retired. Participants were also asked what employment position they were in most of their working lives. The data indicates that 3/14 (21%) were self-employed, 2 (14%) described their position as managerial and 5 (36%) were employees. A further 2 NPs were students and 2 did not indicate their employment position. Of the 7 participants that were unemployed, 6 (86%) reported that it was as a direct result of being HIV sero-positive and HIV related illness. 1 participant was unemployed as a result of discrimination because of his sexual orientation (homosexual).

6.5.1.5 Living Arrangements

All the NPs made their own living arrangements. Five of the 14 NPs (36%) lived in their own home, 5 (36%) rented from a housing association and 3 rented from a landlord. The remaining participant lived with friends.

6.5.1.6 Route of HIV Infection

Ten of the 14 (71%) NPs reported contracting HIV through intercourse with same sex partners, one through intercourse with an opposite sex partner, 2 through injecting drugs and one was unsure of how he contracted HIV. Ten (71%) NPs were on between 3 and 4 medications at the time of the interview.

6.5.2 Concerns Regarding a Family Interview

One of the main reasons for interviewing participants who did not want any one interviewed was to establish the reasons and concerns about a close supportive person being interviewed. As this was an open question the responses were not coded but looked at qualitatively. A wide range of responses was reported. Half (7) of the NPs reported that there was nobody close that knew about their HIV positive status. One participant went on to say that he did not discuss HIV with close friends and that other friends are gay and they may use the information that he is HIV positive against him "when there is competition". Other reasons were to avoid putting pressure (1) on the relationship and not wanting to intrude (1). One NP was having trouble with his close friends and reported quite intricate dynamics. He felt that his friends were not supportive and reported that they were negative about his improving health, especially as his partner died from an HIV related illness. Another participant did not feel supported by his close friends and family because they see him as “tough and independent”. One participant felt supported but did not feel any of his close supporters could cope with an interview and discussion of his HIV status.

6.5.3 Changes in Relationships after Disclosure of HIV Status

NPs were asked whether they perceived changes in the relationships with people they had disclosed to, and secondly whether there were changes in the behaviour of people they disclosed to. Open questions were asked to explore how the relationships and behaviour changed.

Eight of the 14 (57%) NPs felt that their relationship with the individual they had disclosed to had changed. 8 of the 14 NPs also felt that the behaviour of the individuals they disclosed to had changed after HIV disclosure. An equal number (5/14; 36%) of participants reported that neither their relationships nor the behaviour towards them had changed since HIV disclosure. 1 person could not answer the question (felt unsure).

Amongst the positive relationship changes reported were increased honesty, open-mindedness, sympathy and becoming emotionally closer and feeling that family was more available. Amongst the negative relationship changes was an over-reaction by family to their HIV positive diagnosis and feeling more excluded. One participant was surprised that a relationship did not change after HIV disclosure as he expected rejection and subsequently re-evaluated the relationship, realising that is was “deeper”.

CHAPTER 7: Discussion, Part 2

7.1 Overview

This research supports the findings of other studies that HIV infected individuals choose mainly non-biologically related individuals such as close friends for their social support (Friedland et al., 1996; Bor et al., 1994 & 1997 and Irving et al., 1995). The HIV infected participants in this study are similar in demographic and HIV health characteristics to the participants in the first study. Despite the heterogeneity of the self-defined families in this study, some themes emerged that add considerably to the existing knowledge of the social support mechanisms and coping styles of self-defined families in HIV. To this end the broad aims of the study have been achieved in that a clearer understanding of patterns of HIV disclosure, social support and coping have been established.

As with the results of McShane et al. (1994), the present study found high levels of psychological distress amongst a considerable number of family members. As discussed previously, social support has an impact on both the psychological adjustment of HIV infected individuals (Temoshok, 1987; Hays et al., 1990; Chauncey et al., 1990; Blaney et al., 1991; Pakenham et al., 1994), and on their ability to maintain health through reduced stress, healthier immune system functioning and improved adherence to HIV treatment (Solomon, 1987; Ironson et al., 1994; Patterson et al., 1995; Theorell et al., 1995; Solano et al., 1993; Lesserman et al. 1999; Rabkin et al., 1999). The qualitative data provide in-depth information regarding the relationships, social support and coping-strategies of both HIV infected men and their self-defined families. The findings of this study also suggest that the provision of appropriate, personalised social support to both those infected and affected by HIV can enhance their psychological and physical well-being. The findings are now discussed in turn as they relate to the aims of the study.

7.2 Participant Characteristics

The majority of patient-participants were white, unemployed men between the ages of 26 and 50 years, born in the UK and living in accommodation they had organised themselves. The route of HIV infection for these men was mostly through sexual intercourse with other men. There was a wide spread in the time since first HIV diagnosis. 88% had tested HIV positive at least one year before the interview and approximately half of the patient-participants had tested HIV positive more than 5 years before. The data regarding HIV treatments suggest that 75% of the patient-participants were receiving HIV combination treatment at the time of the interview, which suggests that a high proportion of this group were either symptomatic and unwell or becoming so.

The fourteen participants who decided not to have a family member interviewed were similar in demographic and health characteristics to the participants who did agree to this. However their reported reasons for not having a family member interviewed were that half (7/14) were not able to identify a close supportive person while others reported complex relationships with intricate dynamics. Hays et al. (1990) reports that psychological well-being in gay men is associated with a social network of a substantial number of close relationships. The paucity of close relationships and social support as reported by some non-participants in this study may have a negative impact on both their psychological and physical health. Complex relationships were also reported for those who experienced a positive change in their relationship after HIV disclosure. Some non-participants give complicated relationships as a reason for social distance. These relationships are likely to become more complex after HIV disclosure as so many additional complex issues are associated with an HIV positive diagnosis. The concepts of stigma, illness, mortality, and sexuality that are associated with HIV are intricate subjects to deal with in relationships that are already strained. This may be a reason for non-participants avoiding an interview about HIV that might upset heir family. In the absence some of the basic mechanisms of maintaining relationships such as communication, caring and protection (Reibstein and Richards, 1992) prior to HIV disclosure, such disclosure may further complicate the relationship. This group of HIV infected people who either lack support or who have complex relationships may require more specific and dedicated attention from HIV support services to assist them in establishing and maintaining social support networks.

Self-defined family were mostly close friends and partners (29/40; 73%). This supports the findings of the first part of the research as well as the observations of Friedland et al. (1996) who also found HIV infected individuals mainly relied on close friends and partners. Kurdek (1988) argued that patterns of support for gay men might vary from those found in heterosexuals. The high percentage of gay men (39/48; 81%) in this research probably influenced those whom they identified as self-defined family in several ways. Firstly, gay men's sexuality often creates tension in their relationship with parents and other biological family which might lead to a withdrawal of family support (Turner et al., 1993). They consequently turn to close friends and partners for support. Secondly, many gay men move to London from other parts of the UK because of the accessibility and openness of the gay lifestyle that London affords. This puts a geographical distance between them and their biological family. Lastly, integration into the gay community, which is more exposed to and familiar with HIV, is particularly important for social support maintenance (Turner et al., 1993).

7.3 HIV Disclosure Event and Consequences of HIV Disclosure

The majority of family members were able to recall the HIV disclosure event and reported that the HIV infected individuals themselves had disclosed their HIV status to them. The HIV disclosure was perceived as planned by approximately half of the family members, whereas approximately a quarter thought the HIV disclosure happened spontaneously and unplanned. Many family members reported that they had not suspected that the HIV infected person was positive. A broad range of reactions was reported which reflects a variety of coping mechanisms utilised by family soon after disclosure. No firm assumptions can therefore be made about the support needs of family soon after disclosure. The clarity with which family members remembered the HIV disclosure event, often many years earlier, may indicate the extent of the impact of first learning that a loved-one is HIV positive and could potentially die.

As in the first study, approximately half of the family members interviewed reported that their relationship with the HIV infected person had not changed and the other half reported mostly positive changes, such as feeling emotionally closer. This is consistent with the anecdotal reports that the threat of a shortened life expectancy encourages both HIV positive individuals and family members to attend to ‘unfinished business’ in their relationships. The qualitative analysis enabled the researcher to understand the relationship between the HIV infected person and family members in greater depth because it revealed subtle aspects of the relationship changes that could not be established by a question and (forced) answer method. For example, family members explained that they became carers. The caring role mostly took the form of practical assistance, which is a more obvious way of supporting the HIV individual and may have addressed the feelings of helplessness that are often felt as the illness progresses. Many family members took the role changes in their stride and some enjoyed it, whereas others almost resented the change and fulfilled their caring role out of a sense of duty or guilt. These role changes may be a reflection of: 1) the nature of the relationship before the HIV disclosure, 2) changes in the needs of the HIV positive individual as a result of receiving a potentially terminal diagnosis and, 3) the personality of the family participants. More focussed investigations could now be done to explore these facets of relationships before and after HIV disclosure.

Family members had clear opinions of what they thought the HIV infected individuals’ support needs were. Since most of the family members interviewed reported that the HIV infected individual perceived them as supportive, then such individuals should be encouraged to communicate their specific support needs to family and other support systems. Family and supportive friends should in turn be encouraged to establish what support the HIV infected individual needs through discussion rather than providing the type of support that they *guess* might be needed. It may also be helpful to reassess the HIV infected individual's expectations for support from time to time.

7.4 Social Support for the Family

As with the HIV positive participants in this study and previous studies, half of the family members received their primary social support from a close friend or from their male partner (Holt et al., 1998). Results from both the first and second studies indicate that social support is primarily gained from non-biological family for both HIV infected and affected individuals and very few (2/40) family members received support from a biological family member. As with HIV infected individuals, family members are likely to consider similar issues when choosing social support. The stigma associated with HIV and homosexuality play a particularly important role when family members choose whom to gain support from, as they are usually aware of the prejudiced views their family may have. This could discourage family members from choosing their own biological families. Despite this, the two family members who said that biological family members were supportive were pleasantly surprised by the high level of support they received. This leads one to speculate that some HIV infected individuals are unnecessarily reluctant to gain support from their biological family for fear of rejection, though this fear may not always be substantiated. However it should be recognised that those family members who choose people from their biological family probably do so because they have an open and supportive relationship to start with.

Talking, and talking particularly about the impact of HIV on the person's life, featured prominently as a mechanism of support for family. Close friends were identified as most helpful to talk to, but there was considerable variety in people's preferences as to whom to talk to, when it helped, and whether talking was helpful or not. One may speculate that it is not the *type* of relationship that facilitates talking about a loved one's HIV status, but qualities such as openness and emotional closeness. In addition, knowing that a person is not prejudiced, particularly regarding HIV, would simplify the choice of whom to confide in. This is reflected in some family members' preference to talk to people that are working in the HIV field or who have knowledge of HIV. It may also explain why some family members reported that mutual support and conversations with the HIV infected individual were their main coping mechanisms. Opportunities to discuss and freely talk about HIV appeared to be helpful probably because sharing their concern relieved the burden of HIV and the burden of guilt. Gaining information about HIV and specifically the person's health status could be reassuring. This may explain why, in contrast with some other illnesses, discussion and information about HIV appear to be helpful to both family and HIV infected people (Wortman and Lehman, 1985). The range of preferences and utilisation of talking and discussion in the present study suggests that talking is a mechanism that is utilised in a personalised way and that its use cannot be generalised for all family members affected by HIV.

In the initial stages after HIV disclosure, family members reported that they were unaware of the dedicated HIV support services and that when they did attempt to access these, it was not always helpful. It is unclear whether this is as a result of inadequacies in these systems or whether it is associated with the state of mind of family members after HIV disclosure. The initial reaction to the HIV disclosure may make any help offered seem inadequate and superficial. Many family members continued to look for specific HIV support despite the fact that they initially found the support systems unhelpful. This indicates a strong need for specialist professional support for some of the family members interviewed. Dedicated HIV counselling and psychology services as well as volunteer support services should ensure that information about social support is widely advertised and that their services are clearly accessible for family, partners and friends. The present study identified the need of family members for support, which resonates with the findings of Murphy et al. (1992), who found that HIV infected people reported *help for their family* as a high priority. HIV support services therefore need to focus their services toward family supplementation and support (As McShane et al., 1994). Supporting the family would in turn support the HIV infected person. Past research concentrated on the degree of stress that carers of HIV infected people experience, but there is a paucity of studies on the coping mechanisms of carers (Irving et al., 1995; Kocsis et al., 1991). The findings of the present study suggest that some family members depended on their own coping skills and utilised pre-existing social support systems. Family members should be encouraged to utilise their own coping skills and social systems when appropriate.

There is some concern that family members who do not actively seek outside support may be most in need of social support, unless they obtain it from their own family and close friends. It might be that these people are the ones most in need of help because they may not be as proactive in accessing social support. The need for HIV support services to be active in facilitating accessibility for these family members is particularly important.

For some families the need for social support decreased as time passed after the HIV disclosure. This is likely to be associated with the knowledge of the HIV diagnosis being assimilated and the family continuing with their lives according to their previous routines. This links to the ability of family to adapt to the circumstances or alternatively to deny the situation. Some family members expected their need for social support to increase when the HIV infected individual became ill. HIV support services need to maintain an 'open door' approach for family members because the need for social support may arise at any time after HIV disclosure.

7.5 Coping with HIV for Self-defined Family

As with social support, family members identified a range of coping-styles and mechanisms. For some, coping with HIV is affected by the attitude of the HIV infected individual. If he was positive about coping with HIV, lived life to the full and refused to be defeated by the difficulties of living with HIV, family members found it easier to cope with the HIV situation themselves. Seeing the person live a full, productive and meaningful life was particularly important if he was still young. Family members interviewed expressed admiration for HIV infected people who continued their lives as before and took it as an inspiring example of how they might cope themselves. The thought of the individual missing out on life made it harder to cope with the HIV. There appears to be an interesting circularity in these findings: Family members coped better when the HIV infected person was coping well and in turn provided better support or felt less pressure as they felt less obliged to provide support. Conversely, for HIV infected individuals, reciprocal support to carers correlated highly with positive psychological well-being in a study by Hays et al. (1998).

The attitude and personality of family members themselves also affected coping with HIV. Those who perceived themselves as strong and accepting and with a positive outlook on life coped better with the HIV infected individuals' illness. A positive outlook was maintained through various strategies such as focusing on what can be done rather than agonising about what could not, avoiding direct involvement in the every day life of the HIV infected person and not turning the situation into a catastrophe. It seems that 'healthy' avoidance enabled family members to take a break from HIV and their responsibilities as a supporter. A positive outlook and good coping strategies appear to be associated with good adjustment to HIV in both family members and HIV infected individuals, as reported by Blaney et al. (1991). Family members appeared to be coping well by utilising existing mechanisms of coping, particularly those they had previously used during adverse circumstances.

Some family members found it difficult to maintain a positive attitude about HIV, particularly when the individual developed an HIV related illness. Suffering brought the real meaning of HIV closer to home and could not be avoided during times of illness. There was recognition that the HIV infected individuals' suffering might not be as bad as imagined and family members responded with a mixture of feelings from wanting to know more about the illness to not wanting any detail. During times of illness the need of family members to be informed about the illness should be assessed along with the wish of HIV patients to maintain their privacy. The fact that information about the HIV infected person's medical condition may help family members to cope should be known to staff and HIV patients to help them decide how, what and how much they should tell. Illness created feelings of helplessness in some. Conversely, 'feeling needed' helped some to cope better as they reported feeling less helpless. Involvement of family members in the care of HIV patients could also benefit the coping and consequent support of the whole social support system.

Family members who had a previous experience of a bereavement appeared to cope better with the implications of HIV, and family members who accepted death as part of life appear to cope better with the insecurities of HIV illness and death. HIV is inevitably linked to dying in people's minds and most people consider the implications of death after HIV disclosure. Many people may not reflect on their own meaning of death until they are personally confronted with it. HIV disclosure may be the first time this happens. However, people who had experienced bereavement in the past may have had an opportunity to develop their own personal philosophy or meaning of death. It is likely that these people will have a different starting point in terms of the meaning attached to death from those who had no previous experience of bereavement. Similarly some family members, who had an involvement with HIV through other friends or volunteer work before the HIV disclosure, reported that this helped them to cope, mainly through their knowledge and access to HIV social support services. Conversely, the ignorance of HIV and insensitivity of other people affected coping in family members. Ignorance about HIV is often expressed in terms of fear, prejudice and stigma. Both the ignorance of people in their support system and their own lack of knowledge appear to negatively affect family members' ability to cope with HIV. This parallels the findings that the social unacceptability of an HIV diagnosis was one of the greatest concerns for people living with an HIV diagnosis (Miller, 1988; Longo et al., 1990).

These research findings add considerably to the understanding and knowledge of the impact of HIV disclosure on HIV infected individuals, their relationships and particularly the impact on HIV on social support systems. The following section discusses some of the implications of these findings and its application for research and clinical service provision.

CHAPTER 8: Conclusions, Limitations and Recommendations

The outcomes of the present research provide confirmation of previous HIV disclosure research, but more importantly, add to the existing understanding of HIV disclosure through a new perspective, namely the reactions of the recipient of the disclosure. The participants in the present research are representative of the HIV male population in Southeast London, including the preponderance of gay males among HIV infected participants. The following conclusions relate to this part of the HIV population and their 'family'. Suggestions for further research and the limitations of the present research will be discussed.

8.1 Conclusions

The findings of the present study suggest a heterogeneous social support network for HIV infected people, which is largely representative of the 'real' world in terms of its range and diversity. Family members reported a wide range of responses, support networks and coping mechanisms, sometimes poles apart, but also with a continuum of responses that reflect human diversity.

Although the focus of the research is on HIV infected men and their self-defined family, the findings have wider implications. There are also obvious implications for HIV service providers and for research. The implications of the findings will now be discussed in turn for the HIV self-defined family and social support networks, the HIV infected individual, and HIV service providers.

8.1.1 Implications for the Social Support Network or Self-defined Family

Families appear to be affected by the same issues and developments that affect HIV infected individuals. The potential for terminal illness, the impact of medical advances, stigma, hopes and 'false' hopes and the need for constant adjustment affects both the supporter and the one being supported. The network of people affected is clearly larger than just the HIV infected person and their immediate support system. Some family members in the present study were supported by people who did not personally know the HIV infected person. The implications are that there are potentially a substantially larger number of people who provide secondary and tertiary support in the larger HIV support network. HIV may in turn affect these people even though they may not know anyone who is HIV infected themselves. This secondary and tertiary support system may need to be included in further studies of the social support systems of HIV infected people. HIV support services may need to consider the implications of this cascading larger support network and how to support it.

Family members in this study reported a need for social support, either continuous or intermittently. Some family members identified a need for social support immediately after HIV disclosure whereas others reported that they needed it later on or during particularly stressful times such as when the HIV infected individual was ill or being hospitalised. There was also a range of people from whom the family gained support. This included the HIV infected person himself, current support systems and independent HIV support systems. The lack of adequate social support for family clearly affects not only their ability to cope with HIV, but also impacts on the support they provide, their quality of life, psychological functioning, immune system functioning and physical health (Broadhead et al., 1983; Sarason et al., 1990; Green, 1993; Vilhjalmsson, 1993; Kiecoly-Glaser et al.,1986; Lepore, 1998; Seeman and McEwan, 1996; Theorell et al., 1995).

As with HIV infected individuals, family members also had difficulty in disclosing HIV to the people who usually supported them, probably as a result of the stigma that remains attached to HIV. In a similar pattern to those found in HIV infected individuals, family members identified sources of social support for HIV such as HIV counselling services, that were additional to the systems they routinely used for support, such as biological family members. When disclosing their HIV status, HIV infected individuals occasionally request their HIV status to remain confidential, which in effect cuts family off from their existing social support network. The resultant lack of support affects one of the main coping mechanisms identified in the present research, namely the opportunity to talk or discuss HIV and the impact it has on family. Applications of the knowledge gained in this study could make a significant change by strengthening the social support both directly to the HIV infected individual and indirectly through the family and social support system they identified.

8.1.2 Implications for HIV Service Providers

Most HIV providers of social, counselling and psychological support have recognised the need for social support for both HIV infected individuals and their support systems. However, hitherto the planning of support services for HIV *affected* people have been mainly in response to research on HIV infected individuals or anecdotal clinical observations. The present research findings could have positive outcomes for HIV service users as it enables service providers in their planning of services. The additional information gained from this research on HIV social support systems could assist existing and new HIV social support services to ensure access and equity in several ways. Firstly, the 'family' defined by HIV infected people in the present study were mostly non-biological and therefore HIV services need to widen their criteria to enable easy access for the extended social support network. In the promotion of HIV support services, the access criteria need to be clear and widely advertised. Secondly, the intermittent need for support identified by family requires a case management system that will allow people to remain part of the service with a 'non-active' status during the periods that they require less support, unlike conventional services where clients are discharged automatically after each treatment episode. Thirdly, the many types of support that the families identified require HIV support services to offer both a range of services and a high level of flexibility. Services need to be clear about which service they cannot provide and review their consultation, liaison and collaboration with associated HIV support services to facilitate seamless referrals. Lastly, services may need to review their routine assessments of family social support with their HIV infected clients. Such assessments should include discussions of the support needs of family and a 'normalisation' of these needs to ease feelings of responsibility and guilt in the HIV infected person. This is likely to facilitate the access to the service for family. These conclusions reflect the findings of McShane et al. (1994) about the refocussing of services towards family and social support.

8.1.3 Implications for HIV Infected People

Findings from this research can also be applied to the improvement of psychological care and social support for HIV infected individuals. Personalised support could be offered in accordance with the individual's needs, such as support when planning to disclose an HIV status. HIV infected people may find it comforting to know that they do not need to provide the only, or indeed any, support to the person they disclose to, but that other support systems may be in place. Furthermore, informing HIV infected clients about the alternative sources of social support that family members use, may relieve the burden of responsibility towards their family. It may further assist them in understanding the importance of family support systems and how good support for their family potentially improves their own support.

8.2 Limitations of the Research

It is both a strength and a limitation of this research that it focuses on one sub-group of HIV infected individuals, namely predominantly white HIV infected men and their families. Ideally a more representative sample in relation to gender, sexuality and ethnic background would have provided more representative findings. However, the scale of such research might have detracted from the depth of analysis that was possible in this study. Future research on more representative samples of the HIV infected population could be modified to take account of the limitations of this research. For example, the small number of woman and small representation of people from minority ethnic groups suggest that a different, more explicit method of recruitment is required if these groups are to be attracted as participants in HIV research. Volunteering for this type of research without directed invitations and specific explanations of the research did not produce a representative sample of the HIV population attending the HIV clinic. The invitation to participate was only in English, which may have excluded people who are not fluent in English but this facilitated the quality of the data that depended on fluency and accuracy of expression.

The method of selection of self-defined family had limitations too. Firstly, the patient-participants were asked to select the people closest and most supportive to them, without any restriction on the number of people they could select. As a consequence there were considerable differences in the number of family members identified. Although this represented the varying sizes of the participants' social support systems, the second level of self-selection by family negated this outcome.

Another example of a limitation in the family sampling is the possible lack of availability of type of family member for all patient participants. For example, participants who did not have a sibling or whose parents were deceased could not identify such a person as a family support and the findings of the spread of family members are therefore potentially flawed. This also applies to patient participants who had small social support systems compared to those with a large social support network. These factors resulted in a varied ratio of patient participants and family participants being interviewed. It is suggested that a refinement of the selection of family participants could lead to a closer representation of HIV social support systems. Future studies should ideally attempt to maximise the number of family participants who participate. However the reasons for non-participation by family members in this study are unclear and leave us to speculate as to what supportive or contradictory data the family participants produced in the present study.

8.3 Recommendations for Future Directions in Research

Further family and social support research to study HIV infected women, HIV infected heterosexual men and HIV infected people from a more varied ethnic background is clearly indicated. The explorative, qualitative and open-ended nature of this research has identified the issues in HIV that require further investigation such as the social support systems of other HIV infected groups. Research that focuses on specific issues in HIV support and coping with HIV in family, which has now been identified, would increase the understanding of HIV support needs in the larger system of support.

Research design may include control groups such as heterosexual men, woman and gay men who are not HIV infected to establish if any of the HIV social support data of the present research pertains to people who are not HIV infected. The influence of earlier experiences of stigma on the choice of social support system, such as that of gay men, could further contribute to our understanding of the support systems that HIV infected gay men utilise. For example, would another stigmatised label such as HIV sensitise gay men more, or does previous exposure to stigma facilitate the development of appropriate defences and alternative social support systems. If, as a consequence of previous exposure to stigma, the person has an appropriate support system in place, it may make the adjustment of these gay men smoother. This may be reflected in the choice of close gay friends for support by patient participants in this study. Further research could explore these variants and may further add to our knowledge of the extended HIV social support system.

Both this research and previous studies reported on the importance of high quality social support for HIV infected people because of its impact on the quality of physical and psychological health. The nature and quality of the relationships that provide the most important social support should be more closely investigated. For example, how do self-defined family come to be the support and what are the mechanisms that will reduce stress and increase the utilisation of available social and emotional support?

We are now clearer about the nature of the cascading social impact of HIV and how those who are not directly involved but nevertheless affected by HIV, themselves cope. The similar patterns of social support that emerged from this study for both family and HIV infected person are likely to operate for the larger system of social support and could be a subject for future research. We have a clearer understanding of whom HIV infected people disclose to, whom they identify as support and considerably more about how social support systems operate for HIV infected people and their primary support.

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SECTION C

CASE STUDY

STARTING AND DEVELOPING AN HIV MENTAL HEALTH SERVICE IN SOUTH LONDON

CHAPTER 9: Starting and Developing an HIV Mental Health Service in South London

9.1 Introduction

The public response to the HIV epidemic has been particularly emotional and traumatic since the early 1980's. The lack of knowledge about the disease and the most visible groups it infected, created stigma and strong reactions, which only added to the burden of uncertainty, and trauma of what was a new disease. It was therefore not surprising that emotional and psychological difficulties were integral to the presentation of HIV. The need for specialised counselling services, dedicated to people with HIV, was apparent from early on (Bor et al., 1988). As with other medical conditions, such as cancer (Meyerowitz, 1980), haemodialysis (Diamond, 1979), strokes (Evans and Northwood, 1983) rheumatoid arthritis (Shearn and Fireman, 1985) and cutaneous disease (Papadopoulos et al., 1999), HIV is a medical condition which has psychosocial implications. The early recognition of the psychosocial implications of HIV is evident through many publications (Deucher, 1984; Donlou et al., 1985; Martin & Vance, 1984; Miller & Green, 1985; Miller & Bor, 1988). In response there were some unique HIV counselling service developments in the mid-eighties, such as the one at the Royal Free Hospital, London (Bor et al., 1987 and 1990). The Department of Health and Social Security HIV/AIDS guidelines also brought early recognition of the psychosocial impact of HIV, and states that counselling should be offered to all those who seek the HIV antibody test.

The combination of social, moral, legal, sexual and political issues associated with HIV/AIDS impacts uniquely on each individual. In order to accommodate this, HIV counsellors, psychologists and mental health workers need a special knowledge, experience and understanding of HIV issues in addition to their professional skills.

In response to the recognition of the psychosocial needs of people with HIV infection, and a notable increase in the number of HIV referrals to Guy's Hospital, London adult Psychology Department in the late 1980's, the department needed to investigate how best to re-arrange services. In order to both accommodate the increase in numbers of HIV referrals the author was asked to investigate the feasibility of a dedicated HIV psychology service in July 1990. As with most service developments, different aspects of this service were developed over a period of many years. The developments are not necessarily discussed chronologically, but indications of the time of developments are given in each section. For example, the service started off as a psychology service and as the need for other mental health professionals arose, it became an integrated mental health service. This did not happen in a seamless way.

This case study describes the development of an HIV psychology and mental health service from its inception in 1990 through to April 1999. As with services of this kind, it continues to develop and adapt to accommodate the needs of service users. The service is known in South London as *CASCAID* and is commissioned by the Lambeth, Southwark and Lewisham Health Authority (LSLHA).The service will be referred to as *CASCAID* throughout this discussion.

Despite the existence of established Lambeth, Southwark and Lewisham (LSL) HIV medical services in the 1980's, none had mental health components. Only a few dedicated HIV counselling services existed in London at the time. Most of these focused on the psychological preparation of an individual for an HIV antibody test and the impact that testing positive for HIV had on individuals. This was termed "pre- and post-test counselling". When this service investigation started in 1990, a proportion of HIV infected people had been tested HIV positive for 5 years and longer. The psychosocial impact of living with HIV had became more apparent and had been investigated and documented (Forstein, 1984; Stulberg and Smith, 1988; Tross and Hirsh, 1988, to name a few). Developments on the medical front in the UK gave people hope that their life span might be considerably longer than they envisaged during the middle of the 1980's. In the early 1990's there were suggestions that some people who were infected with the HIV virus would not go on to develop AIDS. However confusing these messages may have been, it gave hope to some. Continuing developments and media announcements about new medical treatments, sometimes contradictory, made it stressful for people with HIV. Good access to well-disseminated HIV information made the contradiction of various medical opinion and research even more apparent. Most HIV infected people had to emotionally adjust to frequently changing medical situations and the resulting consequences, which seemed to make the development of a dedicated psychology service for people affected by HIV very timely.

9.2 Defining an HIV Psychology Service: Identifying the Context

It seemed appropriate for the purposes of the development of this service to have a working definition, which would be flexible and reflect the ever-changing "HIV world". Throughout the development of the HIV Psychology Service, it was clear that relatively rapid changes in the various arenas of HIV were likely to continue. Therefore, any definition of a dedicated HIV psychology service should be a working definition, one that recognises the needs of HIV infected individuals at a particular time and context and one which would be re-visited from time to time. This presupposes flexibility in service provision and an ongoing need for service evaluation and audit. Before suggesting a definition the background to the formulation of the definition is discussed.

The start and development of *CASCAID* took place within several contexts. "It is the context that fixes the meaning" (Bateson, 1979). The first context of the *CASCAID* development was that of the Mental Health Trust which was already providing a generic psychology service that took HIV referrals. Furthermore, there were existing non-mental health HIV services operating at the time. These consisted of the HIV medical services that operated from two different Genito-Urinary Medicine (GUM) clinics, community HIV specialist nursing services, health advisors who provided pre- and post-HIV-test counselling and local non-statutory agencies which provided a basic but unplanned counselling service. None provided a psychology service, psychological assessment, neuropsychological assessments for HIV associated dementia or a wider mental health service.

From early on in the investigation it became clear that the experience and perception of a wide range of people involved in HIV, including those that provide care and services were varied depending on the context. This was particularly true of the psychological and social experience of people affected by HIV. Family, friends, social system, work, society, school, the media and many agencies (such as non-statutory HIV organisations) played a part in the formation of how a particular individual experienced their own involvement with HIV and AIDS. A psychology or mental health service needed to be responsive to the individual presentation as well as the larger context (system) of each presenting individual in which it became involved. Psychologists can make a significant contribution by understanding the systems and positioning themselves to understand the experiences of patients, families and medical staff. This presupposed accessibility to medical staff and at the same time being accessible to medical staff.

An HIV mental health service could not address the needs of its service users if the development or maintenance of the service exclusively addressed needs in terms of lineal sequences of cause and effect. An HIV mental health service should be culture specific: no assumptions should be made about the impact of AIDS/HIV on people, nor about what is the best way of managing it (Bor & Miller, 1990).

Another context was demography. The part of inner London, for which the HIV psychology service was intended, covered LSL. It has a varied population which includes: (a) a large Sub-Saharan population of immigrants and refugees, (b) a large number of haemophiliacs who attend the haemophilia centre at St Thomas Hospital, (c) a large gay population and (d) the largest number of families in the country with more than one HIV infected person. A sizeable number of infected children continue to be treated in the LSL Paediatric Services. For example, 58 of HIV infected people treated in LSL during the year ending 31 March 1999, were under the age of 15, an increase of 49% on the number treated in 1993 (CDSC HIV Information Exchange, 1993; Survey of Prevalent Diagnosed HIV Infections [SOPHID98]). More comprehensive epidemiological figures are discussed under section 9.3: *Establishing the Need for an HIV Psychology Service.*

The groups of people mostly affected by HIV include a substantial number of individuals and families unlikely to access mental health services were it not for their exposure (physically or emotionally) to HIV. The knowledge of one's own or a loved one's HIV infection impacts in various ways. Some people are likely to seek counselling and other mental health interventions at some stage of the HIV life cycle. The establishment of a dedicated HIV service had to take into account both the different contexts that HIV presented in but also consider a change in the context of mental health service provision. Such a service might have to challenge the *status quo* to provide appropriate mental health care to a population with a different reality to those of a generic adult mental health service. A dedicated HIV psychology service, as opposed to a generic service, had to a) allow patients to talk about their health freely, b) know the patient's health difficulties, c) have good general and medical knowledge of issues in HIV, d) work closely with inpatient staff and see patients on wards, e) be prepared to do more home visits, to name a few.

A proposed definition for an HIV psychology service is:

> An HIV psychology service is one that provides psychological assessment and treatment to those who are directly or indirectly emotionally affected by HIV/AIDS. In addition it has a liaison and consultation function and

collaborates with relevant HIV and generic services and organisations. A dedicated HIV psychology service will perform these tasks within the changing context of the affected individual and the systems in which they organise their personal and work life and medical treatment.

9.3 Establishing a Need for an HIV Psychology Service

Establishing the need for a dedicated service is a difficult task. Looking at the generic psychology service statistics is not useful in itself because an unknown number of HIV positive individuals may use dedicated HIV services in adjacent geographical areas. The following were considered in establishing a need for: a) the existing demands on services in units of the catchment area, b) the current epidemiological figures of the region, c) the projected epidemiological trends and d) local problems such as a high haemophilia or intravenous drug user population (Bor et al., 1987). Lago (1981) suggested that service needs become clear by asking questions such as “what is happening here?”, “where could these people be referred?” and “how come there is no organisation to respond to such important needs?”. These questions were also considered. Some service developments are motivated by a juxtaposition of two elements: a) a hunch/hypothesis that a need exists and b) the enthusiasm, commitment and readiness of the original founders to create such a service. Lago and Kitchen (1998) described an equation for the establishment of a new service as follows: perceived need of a client group + the human therapeutic capacity to respond = foundation stones of a counselling service.

9.3.1 Epidemiology

Epidemiological data for LSL demonstrates the need for an HIV psychology and mental health service in the area. A description of the population in this part of inner London is relevant to the development and planning of this service. Prevalent Diagnosed HIV Infections (SOPHID) was not available at the time the service development started. Some data of the total number of people who were infected by the HIV virus and data for HIV related deaths up to March 1991, gives a crude picture of the epidemiology up to that time. Examination of data between 1993 and 1994 (HIV Information Exchange) and 1995 to 1998 (SOPHID95-98) demonstrates an increase in the HIV population in the years following. If these epidemiological figures are used to extrapolate to the few years before data was officially collected, some indication of the HIV population in the early 1990's emerges. The available epidemiological data is therefore reported in this section.

The epidemiological data also provides a picture of the diversity of the HIV infected population in LSL. The diversity is evident in the range of ethnic origin, age range, gender ratios and wide range of lifestyles as is demonstrated by the number of immigrant families, gay men and intravenous drug users who are treated for a range of HIV related problems in LSL. In this section epidemiological data will be reported to illustrate the diversity of the population that *CASCAID* served. Epidemiological data further suggests the probable psychological and mental difficulties that may be encountered by people from mainly minority and often stigmatised groups, reinforcing the concept of a need for dedicated HIV services as provided by the *CASCAID* service.

The total number of cases of AIDS reported as occurring amongst residents of LSL since reporting began and up to the end of March 1991 was 287, of whom 178 were known to have died. At the end of March 1991, 109 residents were living with AIDS, which is a prevalence of 15.7 per 100 000 (Population denominator taken from the Office of Population Censuses and Surveys, 1991 Census). Since 1991, this figure has increased notably. By the end of March 1998, 1533 cases of AIDS had been reported amongst the residents of LSL, of whom 1060 were known to have died. Therefore 473 residents were living with AIDS, a prevalence of 64 per 100 000 (Population denominator taken from the Office for National Statistics 1997 Mid Year Estimate of Resident Population). The increase in HIV infection is also reflected in the increase in the activity figures of the *CASCAID* service (Table 9.1).

Table 9.1: Number of *CASCAID* Treatments by Year

Age in years	1996/7	1997/8	1998/9
0-14	45	253	241
15-24	39	64	70
25-39	543	770	1036
40-54	359	380	521
55+	53	73	89
TOTAL	1039	1540	1957

Taken from the CASCAID data base

Table 9.2 reports on ethnic data for HIV sero-positive people resident in LSL. A large proportion of HIV sero-positive people in LSL was white male (53% for 1998). A significant proportion of people was from various black ethnic groups (674 or 31% in total for 1998) with a wide range of cultural backgrounds and beliefs.

Table 9.2: Number of HIV Sero-positive People Treated in LSL by Year

Ethnic Group	**1993**	**1994**	**1995**	**1996**	**1997**	**1998**
White Male	-	599	751	823	1031	1134
White Female	-	40	57	57	69	82
Black-Caribbean Male	-	25	40	50	56	69
Black-Caribbean Female	-	12	12	26	24	28
Black-African Male	-	49	96	94	141	210
Black-African Female	-	71	125	145	229	305
Black Other Male	-	18	31	49	50	51
Black Other Female	-	10	15	#	10	11
Indian/Pakistani/Bangladeshi	-	#	46*	#	62*	11
Other/Mixed	-	#	46*	51	62*	132
Not Known	-	528	429	232	189	106
TOTAL	1046	1359	1604	1539	1863	2140

HIV Information Exchange, CDSC (1993/94) (data on Ethnicity was not collected for 1993)

Survey of prevalent diagnosed HIV infections 1995-1998 (SOPHID)

#In order to preserve the confidentiality of HIV infected individuals, numbers less than ten will not be reported, in line with LSL Health Authority recommendations.

*For 1995 and 1997, Indian/Pakistani/Bangladeshi and Other/Mixed figures were combined to preserve confidentiality.

A large part of the HIV infected population in LSL were recent immigrants, struggling with the adjustment to both a new country and culture, as well as being HIV infected. Some were refugees who left their country for their own safety and who may in addition have had multiple recent traumas to adjust to. The additional trauma of illness, stigma and the knowledge of being HIV infected, or knowing that family members are HIV infected, left this part of the population particularly vulnerable. Traditionally, a proportion of people from Africa would avoid using a Western-style psychology or mental health service as they are either unfamiliar with it or do not believe in its value. Traditional treatments are not readily available in London. These factors necessitated cultural responsiveness that required flexible service delivery for *CASCAID*.

In response to the predominantly adult epidemiological picture that was available at the time, the initial *CASCAID* development was mainly adult focussed. However, the changing proportions and increasing numbers of infants reported to be HIV infected during the nineties made it clear that one of the neglected areas was a service for children and families. The number of mother to infant infections suggests both an increase in the number of infants infected and an increase in families where more than one person is HIV infected (Table 9.3). *CASCAID* responded by the introduction of an HIV psychology service for children and families affected by HIV in October 1996. *CASCAID* data indicates that a total of 91 affected children were referred to the service between October 1996 and March 1999. Of these 21 were HIV infected. During the same period the *CASCAID* child service provided a total of 539 clinical sessions for children.

Table 9.3: Number of HIV Infected People by Risk Group in LSL by Year

Risk Group	**1993**	**1994**	**1995**	**1996**	**1997**	**1998**
Homosexual/Bisexual (all male)	848	784	1034	926	1165	1257
Injecting drug use	61	71	97	37	44	73
Heterosexual Male	51	59	117	142	156	234
Heterosexual Female	82	96	192	208	240	346
Blood/blood products	13	19	15	12	14	19
Mother to infant	*	17	33	35	50	59
Not known	113	313	116	179	194	151
TOTAL	1173	1359	1604	1539	1863	2140

HIV Information Exchange, CDSC (1993 and 1994)

Survey of prevalent diagnosed HIV infections 1995-1998 (SOPHID98)

The route of HIV infection for a large proportion of HIV positive LSL residents is through same-sex male partners (Table 9.3). Many gay men move to London from other parts of England where an open gay lifestyle may be generally more acceptable than in rural communities. In London LSL attracts gay men due to its proximity to

West End gay bars and clubs.

Similarly, LSL has a large number of injecting drug users with several dedicated addictions services. *CASCAID* has close links with the Addictions Services in LSL and works collaboratively with these services when a dual diagnosis of HIV and drug addiction is made.

The available data on the number of residents with HIV infection for LSL is not altogether reliable. The laboratory reporting system provides information on the number of cases of HIV infection locally, but hospital HIV outpatient centres have an open access policy and therefore not all cases reported can be ascribed to local residents. However, laboratory reports remain a good proxy of local incidence and it is important to point out that CASCAID provides a service to all HIV infected people attending the local HIV medical centres irrespective of their area of residence. Between 1 April 1990 and 31 March 1991, a total of 177 new laboratory reports of HIV infection had been received from testing centres within LSL. This rose to 255 for the same period in 1997/98 and the latest data from these centres indicate 359 new reports of HIV infection for the same period in 1998/99.

9.3.2 Service Provider and User needs

Initial investigations about the feasibility of an HIV Psychology Service led to discussions with other HIV service providers in LSL and an investigation of established counselling services in other demographic areas. These investigations yielded valuable information of what should be considered for the new service. The importance of issues such as a) accessibility for minority populations such as ethnic, black, drug using communities as well as families, children, carers, partners, friends and the gay community; b) response times to referrals; c) flexibility regarding home visits, inpatient interventions and a presence at community HIV clinics; d) accessibility of *CASCAID* staff for consultation by staff from other HIV services, needed to be incorporated in the planning of the *CASCAID.* The generic adult psychology services followed a traditional model of referral whereby a formal written referral was required before any discussion of a patient would take place. This was contrary to the perceived needs of HIV professionals in the LSL HIV services who wanted a flexible HIV psychology service that focused on consultation and liaison. In response to this need potential referrers were encouraged to discuss HIV patients with members of the *CASCAID* team before making a referral.

A model of collaboration contributed to the quality of the overall service to patients. Where appropriate, HIV workers who approached CASCAID for help with a particular person, were encouraged to deal with the problem themselves after discussion and sometimes supervision from a team member, especially where they had an existing relationship with the patient. The exploratory discussions with the exiting HIV services revealed that some of these services were using a consultative model without necessarily labelling it as such. This provided an opportunity to build on by the new CASCAID service.

As a new service *CASCAID* could be either competing or supporting to existing HIV services. The needs identified suggested that the service had to aim to strengthen consultation and collaboration by encouraging and reinforcing other professionals' skills. This early stage of the service development provided opportunities for communication and information exchange about what the service might provide. In retrospect this was a valuable engagement process as other HIV teams felt part of the HIV mental health service development from the start.

An overview of the HIV sero-positive people seen by the generic adult psychology service pointed to a wide range of psychological problems. Unfortunately the generic psychology service did not keep identifiable data about HIV infected people referred. As a consequence information was gained by going through patient files. An overview of this process indicated that the most common problems among HIV infected patients referred to the generic psychology department were a) adjustment problems to a recent HIV diagnosis or recent changes in medical status; b) anxiety, c) depression d) relationship problems with partners, work colleagues, family members and friends.

From the different service need investigations that were done it became clear that *CASCAID* would rarely be involved with any patient without multiple professional or agency involvement. A combination of a wide range of possible psychological and mental health needs made each individual presentation fairly unique. This required CASCAID to become part of a larger HIV treatment system to effectively respond to relevant individuals, teams and organisations.

9.4 Objectives of the Service

The overall objective of the service was to provide an accessible, patient-focused, flexible and individually tailored service that worked collaboratively with other HIV and generic services with seamless referral procedures and good communications with other services and organisations as well as service users. Another emphasis was to monitor and promote mental health.

Other service objectives include formal and informal training for other staff as well as continuing professional development of *CASCAID* staff. *CASCAID* acquired a supervision contract in 1994 to provide regular supervision to Health Advisors and HIV counsellors from 2 other NHS Trusts and were committed to provide high quality supervision.

Specific Service Objectives were:

1. An uncomplicated open referral system.
2. Rapid respond to referrals: 1 day for quick response referrals and less than 14 days for non-urgent referrals.
3. Collaborative work with other generic and specialist statutory and independent organisations e.g. GUM Services, Social Services, Landmark, Positive Place, etc.
4. Appropriate communications with GP's and other referrers.
5. To provide formal and informal training to other specialist and generic staff.
6. To provide and receive high quality professional supervision.

7. To implement and support appropriate monitoring and evaluation systems.
8. To keep up to date with HIV research and issues.
9. To develop the service in line with new information, research findings and own evaluations.
10. To undertake and publish research projects that will improve services locally and nationally.
11. To ensure fair and equitable access to the service, particularly by vulnerable or disadvantaged groups within the catchment population, e.g. women, black and ethnic minorities.
12. To continually improve the support/services to service users, their partners, family, children and carers.
13. To ensure staff and continuing professional development to promote a high quality service.

As with other aspects of the development, the objectives of the service needed to be reviewed from time to time in order to be responsive to changing needs.

9.5 Management and Service Models

Although *CASCAID* brought together the expertise and experience of a range of mental health disciplines with different levels of experience and seniority, the team operated a flat hierarchical management structure. Different skills, abilities and specialisations were recognised in the team but on the whole seniority did not play a role. This applied to administrative staff who played an integral role in both internal and external communication and collaboration. However, exceptions were made, for example, when medico-legal requirements obliged the consultant psychiatrist to take decisions in cases where an individual needed to be detained under sections of the law. The manager made most organisational decisions after discussion with the team. Clinical decisions were made collaboratively at weekly team meetings.

CASCAID developed an organisational model by exploring other models of service provision and developing a *CASCAID* model that was responsive to local needs and circumstances. These models and the resultant *CASCAID* model are presented in this section.

9.5.1 Models of Service Provision

All of the HIV mental health staff had prior experience of working in multidisciplinary settings and some had formal and informal training and experience in working systemically. No one in the team started with experience in HIV work. There was some commitment to work together (collaboratively) in developing a model of work that would be responsive to the needs of the HIV service users.

The ecological systems approach model (Auerswald, 1968) illustrates some of the aspects of the *CASCAID* team's organisational development. This model allows multiple perspectives from various disciplines to be used to create new approaches, in comparison to an interdisciplinary approach where each discipline maintains its own point of view. This is particularly appropriate in HIV mental health care because the complex combination of medical, social and emotional presentations require a unique formulation for each individual affected by HIV. This formulation is best achieved by a collaboration of all disciplines and ideally, all professionals and carers involved.

Aspects of the biopsychosocial model also illustrate collaboration. This model acknowledges the interdependent relationships of biological, psychological, individual, family and community systems and is a reminder to health care professionals that they affect multiple levels of systems simultaneously (McDaniel et al., 1992). The *CASCAID* team endeavoured to incorporate relevant aspects of these models and to some extent succeeded in doing this within the team. However, it proved more difficult to maintain the collaborative approach when *CASCAID* team members temporarily became part of multidisciplinary discussions in other services, however much it was encouraged. Although medical staff has accepted the psychosocial role of illness presentation, few have incorporated a biopsychosocial model and medical teams were more transient as a result of the 6-month rotation system used for medical registrars.

9.5.2 *CASCAID* Experience

Professionals in the team had to adapt their experience and practice in order to appropriately respond to a wide range of needs and issues related to HIV patients. Issues connected with medical ethics, counselling, relationships, sexuality and the dynamics of interdisciplinary health-care teams had to be re-examined (Bor et al., 1988). Staff joining the team was encouraged to visit various HIV teams and organisations and to do HIV familiarisation courses as part of their early induction. However, most of the learning came through working together as a team and learning continuously as part of the development process.

Each member of the *CASCAID* team also joined one or more other HIV teams as part of their duties. These teams included HIV medical teams (in- and outpatient), paediatric teams, community-nursing teams, social services teams and teams based in HIV voluntary sector organisations. Geographically staff would regularly work in and travel to 5 hospitals, 3 HIV community centres and patients' homes. This required good co-ordination, communication and a secure base. The weekly *CASCAID* team meeting was essential to the team functioning.

The weekly *CASCAID* team meetings also formed part of the learning process. It was during these meetings that the team increasingly realised the value of the alternative point of view. In addition to exchanging specialist knowledge and experience it helped to identify biases. Each patient would be allocated for assessment according to the information available. When appropriate, joint, multidisciplinary assessments were made. Once an assessment was completed the patient would again be discussed at the *CASCAID* meeting and formulations and treatments would be decided on collaboratively. Not everyone in the team accepted the collaborative model from the outset. The difficulty in building collaborative relationships relates to differences in training, language, theoretical models and culture. The recognition of these differences is crucial to building collaborative relationships (McDaniel et al., 1992). Tension and misunderstandings can arise from differences in theoretical backgrounds and working styles of different disciplines and different individuals. Over a period of time, good, regular communication and respect for each other's skills grew and encouraged collaboration amongst *CASCAID* team members as they realised the advantages of this method of working.

Collaboration also facilitates staff support. There is an implicit danger that people working in the HIV field could emotional 'burn out'. Collaboration shares the burden of care and identifies when a fellow colleague may become over-involved and exceeds the professional boundaries. Discussion and checking with fellow staff may prevent this.

As an extension of the informal support to staff outside the mental health team, *CASCAID* staff provided formal supervision and support to health advisors and HIV counsellors from 2 other NHS Trusts. This in turn provided funding for CASCAID staff to have expert supervision outside the team and further training.

The therapeutic models utilised in the team were mainly cognitive behavioural and systemic. Whereas the cognitive behavioural model lender itself well to brief and focused therapeutic work, the systemic approach provided a wider context within which all therapeutic and consultation work was carried out.

9.6 Starting up

Starting the CASCAID service off required some initial planning. Although most of the associated HIV services knew of the CASCAID service development, basic information such as the actual launch date, service criteria and referral procedures needed to be disseminated to potential referrers. For the team members certain basic protocols had to be in place. Facilities such as appropriate a reception room, telephones, consulting rooms and administrative support had to be in place. Some of these are discussed in this section.

9.6.1 Marketing and Information Distribution

In addition to the practical and logistical aspects of the service, publishing and marketing the service and establishing working procedures were fundamental to service delivery. This consisted of communicating with potential referrers and providing clear information on procedures. A *CASCAID* service information pack included an information booklet for referrers (Appendix 1), a standardised referral form (Appendix 2) and an information booklet for service users (Appendix 3).

For the patient the therapeutic process starts at the moment they first consider psychological treatment. Since *CASCAID* service had a relatively fixed referrer base, it was possible to focus on specific referrers. In discussion with referrers the *CASCAID* service collaborative model were discussed as well as ways in which referrers could make a positive contribution to the patients' experience of therapy. Team members did brief presentations and discussed referral procedures and models used in *CASCAID* to referring staff at their established meetings. This became an integral part of the consultation function of the team.

Information about the service was important for several reasons:

1. It provided information to referrers that would assist in assessing a patient for referral to the CASCAID service.
2. It assisted the referrer in supplying information to the patient about CASCAID.
3. It assisted the referrer in providing the appropriate information required by the CASCAID team about the patient. A standardised referral form was designed with this in mind.
4. It provided information that helped the patient to:

a. Decide whether to attend the service and to prepare for the first consultation.

b. Decide whether to continue with the specific services offered after assessment and formulation.

c. Ensure expectations are within the remit of what the team can provide.

d. Assist in practical matters such as how/when to cancel an appointment and how to find a clinic.

e. Ensure that the patient feels that they still have some control in the process of consulting a psychologist/mental health worker.

Information regarding the team was regularly supplied to referrers and service users. Disadvantaged and vulnerable people such as woman, families, children and black and ethnic minorities were particularly at risk of not having fair and equitable access in the early days of the service. Information was therefore targeted on organisations such as BHAN (Black HIV/AIDS Network), “Positively Woman, Positive Youth” and the Naz Project for the South Asian, Turkish, Irani and Arab communities.

9.6.2 Building the Building, Building the Team

The facilities such as offices, consulting rooms and administrative support were quite basic when CASCAID was launched. The increase in the number of *CASCAID* staff over the first 3 years created a need for additional accommodation and provided a good example of how a health service team can function in a similar way to a family system: Different members have different ages (how long they have been in the service), perform different functions (responsibilities in the team: primary role) and have different roles (how they perceive their own place in the team and how others perceive their place on the team: secondary role). As with families, discrepancies in the self-perception as opposed to the team's perception of a particular team member can cause tension in the team if left unchecked.

One of the difficulties of establishing the extent of need for an HIV mental health/psychology service was that such a service is likely to grow over a period of years. It makes planning more complicated. Community psychiatric nurses and psychiatrists were not included in the initial service proposal due to the limited funding available. One had to bear in mind that the need for a more multidisciplinary team may emerge from the ongoing service assessments. The use of generic community psychiatric nurses and generic psychiatrist in the early years of the CASCAID service did not proof satisfactory. Additional staff costs were covered by the renewal of service contracts with health commissioners, but good evidence of the increase in growth or change of service need is essential to provide.

It is equally complex to assess the level of non-pay costs. For example, accommodation and administrative cost does not readily appear simply because the money had been made available. Four years into the establishment of the service it was stretched for appropriate therapy rooms and offices following the additional funding for a psychiatrist, a community psychiatric nurse, an additional psychologist and a child psychologist. Accommodation can take time to organise and in the interim, team members had to be very creative in their use of the available space and facilities. As with any other system, times of “hardship” can be used productively as morale building exercises. Being split between several sites did not help and team members had to make great effort to communicate, support and liase with each other. Team building should be an ongoing process and this was certainly a time for team building. Team members responded well by working out clinic times and schedules and through the use of “borrowed” space. The team experienced first hand that through being creative the capacity to make the most of minimal resources is possible (Lago, 1998).

During the period of minimal accommodation the health authority was approached for capital development money. A proposal to the health authority elaborated on the need for safe, confidential and accessible space team. The development was agreed and an appropriate building was identified. As a system the team grew through involvement of all the team members in the discussions regarding office design and resettlement planning. As a consequence the move and settling into the new accommodation were relatively smooth and adjustments were made quickly. The now larger CASCAID team was accommodated together for the first time. Involving the whole team (system) in the different stages of the development of new accommodation was certainly a positive step for the team cohesion.

It became apparent through team discussions that clear information and a clear understanding of the operating and staffing structure assisted team members in their adjustment to the inevitable changes that occurred as part of the development of a service. It is important as Lago (1998) suggests that some modification and 'tweaking' of operational structure is required from time to time. This has become apparent in the CASCAID team when relationship difficulties arose between team members and when staff changes occurred. On a few occasions when staff changes occurred, each individual in the team had to make an adjustment to their own position and role in the team to accommodate the skills and personality of the new staff member. This was more difficult for some team members who required increased support in times of change. Overall, the team tried to make the induction of new staff an activity that involved all members of the team and an activity that facilitated new staff member's adjustment in the team.

From time to time, team building required the team to take time away from the usual activities of the team. On several occasions, approximately once a year, a day was set aside for the team to evaluate the non-clinical functioning of the team. On these occasions the team met in venues that were clearly unrelated to work and some pleasurable activities was included to facilitate familiarisation.

9.7 Operational Policy

As the service developed concepts such as the philosophy and ethics of practice, confidentiality and paths of consultation and liaison were often discussed. Although the team was often in agreement regarding these and other operational matters, the development of a formalised operational policy for the team was desirable. A clear operational policy facilitates a competent, professional and safe service provision. As with other aspects of the ongoing changes and developments in the service, it was decided that this would be a working document, allowing the team to review operations from time to time, and make the necessary modifications.

The operational policy contained the following:

a) *CASCAID* Mission Statement

CASCAID developed a team mission statement complimentary to the NHS Trust mission statement, ensuring that there were no contradictions.

b) Description of the Team.

A description of the team was included as background to the operational issues that were specific to professions.

c) Referral, Allocation, Assessment and Named Worker Arrangements.

A description of the client population and procedures for various referrals were given. Allocation procedures and main worker allocation was set out as well as the procedures for urgent referrals.

d) Specific Service Objectives.

Specific objectives were identified. As previously discussed, these were reviewed from time to time and were particularly dependent on changes in HIV developments and client needs.

e) Potential Client Groups

Potential client groups were defined and identified. Local census information and Health commission information specific to HIV were used as an initial description. When the operational policy was subsequently reviewed information gained from quality assurance projects (see section 8) and the *CASCAID* database (see section 9) were used.

f) Planned Interventions

This section covered different treatment modalities offered by the team. The treatment modalities included psychological therapy (frequency and duration) and psychiatric interventions (frequency and duration) as well as discharge procedures and procedures about non-active clients.

g) Prevention

Prevention was part of the early objectives of the team and this was discussed in this document in terms of the educational aspects, research and information.

h) Confidentiality

A specific definition for the HIV mental health service is discussed as well as issues of confidentiality in team communication and communication with other agencies, particularly during consultation and liaison. Some exceptions to the confidentiality rule are included.

The operational policy served CASCAID well as a guide to clinical practice, especially at times when aspects of the service provision seemed unclear. As with other services, the team had a considerable workload and it was easy at times to forget what our real objectives were. The operational policy helped the team to address this.

9.8. Quality Standards

“The open system is open to its environment, without which it cannot survive and on which it depends for those aspects of its time-dependent development which are not controlled by the internal rules and constraints related to self-differentiation” (Wilden, 1972)

Since the start of the *CASCAID* service there was an emphasis on service evaluation. During the early years of the CASDCAID development, the Health Authority became increasingly focussed on the quality of services (as opposed to audit and statistics alone) which was reflected in most of their service specifications. It seemed prudent to set up good quality assurance projects before the Health Authority imposed them on the service. In addition, quality assurance projects provided ongoing service information on which continuous service developments were based. It is unlikely that any health service development would be agreed in the absence of evidence supporting the need for such a development. The systematic gathering and evaluation of data makes it easier to motivate for funding. (Du Plessis & Bor, 1999) The early *CASCAID* quality assessments were unfortunately crude and not formalised with the health authority, but valuable lessons were learned. The biggest mistake was not to re-evaluate the recommendations that were implemented as a result of the earlier projects. Table 9.4 gives a selection of these projects.

Table 9.4: Selection of *CASCAID* Quality Assurance Projects

PROJECT	DESCRIPTION	MEASURE	OUTCOME
Service user satisfaction (1995)	Establish patient satisfaction with: where seen, information received, referrers, appointments, therapeutic process and overall impression.	Anonymous questionnaire.	1. Overall satisfaction 2. Unsatisfactory aspects i.e. number of sessions were incorporated in 1996 proposal
Service to Carers (1995)	1. Establish carers use of *CASCAID* services. 2. Monitor service user knowledge of carer component of service.	1 month client and staff survey	1. *CASCAID* adopts standardised questions regarding carers 2. Information entered into database
Development of communication: 1. General Practitioners. 2. Antenatel Services. (1996)	1. Ensure GP's awareness of contact and referral procedures. 2. Establish the level of communication with GP's and antenatel staff.	1. Log of all GPs sent information. 2. Monitor number of reports sent. 3. Monitor referrals.	Development of protocols for: 1. Routine service information distribution. 2. Communication with GPs specifically 3. Communication with referrers in general 4. Development of Information pack
Investigate alcohol and drug issues amongst service users. (1997)	Establish: 1. Types, mode and frequency of drug use 2. Assess knowledge of impact on physical/mental health 3. Assess *CASCAID* staff knowledge on drug interventions	1. A questionnaire survey of service users 2. A questionnaire survey of staff members.	1. Inclusion of standardised assessment of drug use in assessments 2. Development of a policy to assist drug users in the service. 3. Information about drug made available to service users
Responsiveness of *CASCAID* service. (1998)	Audit to contain: 1. Waiting times for first assessments 2. Waiting time for formal intervention offered 3. Audit non-attendance rate (DNA)	Generating required information from *CASCAID* database (3 quarters)	72% had 1st assessment within 20 days 76% had formal intervention within 20 days A DNA rate of 17% Development of policy to improve response time

9.9 Data Collection and Reporting

One of the service aims was to develop an appropriate database which would truly express the activity of the service, would be easy to use as part of daily activities and easy to access statistics, audit information, quality control measures and research information.

9.9.1 Aims of Data Collection

Monitoring and evaluation of a service is considered a dynamic issue, which needs constant review and requires flexibility and comprehensive monitoring. A good database system is essential in monitoring services and can contribute to assessments of quality, equity, accessibility, appropriateness and responsiveness of the service. The CASCAID database had a further application: it produced regular quarterly and annual reports which were important in preparing health service commissioners for the possibility of asking for increased funding based on actual increases in service demand and changing patterns of need. This was particularly useful for *CASCAID* as patient needs change rapidly in an HIV service.

The *CASCAID* service agreed to produce meaningful data by the third or fourth quarter of the second year after its launch. This required investment in time, person, software and additional computer equipment and had to be incorporated in the operating costs of the HIV mental health service.

The information that *CASCAID* agreed to provide quarterly to the health authority consisted mainly of activity figures such as number of new referrals, number of open cases and the number of patient sessions offered. In addition information on age, gender, ethnicity, district of residence and presenting problems were provided to the Health Authority quarterly.

9.9.2 The Database

A database was developed with the skills and expertise of the Trust Information Technology Department in conjunction with an outside consultant who had experience in developing a database for another HIV project. In developing the database we had to ensure that it would fulfil the needs of all the stakeholders i.e. the Health Authority, the Trust Headquarters and the CASCAID service. The CASCAID team's requirements related to audit, quality assurance and research.

An outside information technology consultant originally supplied a database system for a number of Substance Misuse services in the Trust. We therefore had an example of a system that worked but which needed modification for the CASCAID service. The data base system decided on was TOPP Client (TC), which is a relational U.S. PC-based database system.

The advantage of TC is that it was a database system designed for use by clinical teams without the need for data analysis. The reports produced by TC are comprehensive enough and easy to use so that staff at Team level can produce reports themselves on a regular basis. The ability to generate Main Worker reports are important in the day to day use of a team-focused database (McGilvray, 1994). Without the means to assist in keeping records up to date a database system is likely to fall into misuse as team members will not use it if they feel there is no recognisable benefit from it. This benefit has to be for individual team members as well as for management (reporting) and commissioning of services.

Management of any database is of course the key issue in producing sensible data. The *CASCAID* team administrator regularly checks client records to see if they are being kept up to date and encourage staff to use the database system as agreed.

The way in which support for the database is delivered is also very important. All system require continuous development and 'tweaking' so as to ensure that it continues to meet the requirements as they evolve. An ongoing agreement that minor amendments to the database and system would be made encouraged CASCAID team members to provide ideas for changes and ensures that the system continues to meet the user needs.

An example of a report generated by this system is provided in Appendix 5.

9.10 Discussion

The continuing development of the CASCAID service illustrated several issues associated with new service developments. The people involved in the development were certainly enthusiastic, continually asking how to do things right and how to continue to positively develop the service. In retrospect some aspects of the development could clearly be improved on. The most obvious examples are:

a. An individual as opposed to systemic focus right at the beginning of the service may have excluded some family members, partners, carers and others affected by the HIV epidemic. This was redressed by a growing awareness of the needs of our patients and feedback from referrers. The influence of the clinical child psychologist encouraged the team to look at things more systemically on several levels i.e. clinically, operationally, in our consultations and in our relationships with each other.

b. Initially team members provided clinics at treatment centres without integrating fully into those teams. The *CASCAID* staff member was therefore seen as a visiting consultant rather than a member of the team. This was addressed through the attendance of local team meetings and establishing working relationships with other staff. *CASCAID* team members became more integrated with other HIV teams. This has been achieved with the teams that *CASCAID* team members regularly visited, but further work need to be done on developing appropriate relationships with the relevant voluntary organisations and teams.

c. The service was too psychologically focused at first. It soon became clear that a multidisciplinary mental health team would better serve the needs of our patients. The addition to the team of staff psychiatry who had an interest and commitment to HIV greatly enhanced the quality of the service for our patients and fellow colleagues from other teams.

CASCAID is committed to maintain and improve the quality of the present service developments. New developments and areas of focus have been identified. *CASCAID* has made good progress in being accessible to patients who clearly have HIV associated psychological, relationship and mental health problems. However, this results in people accessing the service only when they have already developed an obvious problem. Identifying those who are emotionally vulnerable through early assessment and treatment can enhance the quality of care. *CASCAID* therefore plans to extend its preventative role through early intervention. The intention is to make referrers increasingly aware of the early signs of emotional vulnerability through information and shared assessments. Information encouraging people who feel vulnerable to have an informal discussion will be distributed to HIV treatment centres and voluntary organisations.

Internal to the team there are plans to increase experience by observing each other's clinical work, either through joint sessions when appropriate or by using the observation facility at the *CASCAID* team base. A clinical team peer supervision group was recently started which lends further insight into team members' clinical work. CASCAID is committed to continue to make a contribution to two main areas of concern in HIV: Adherence to combination treatments and assisting those who want to return to work. As with so many issues in HIV, *CASCAID* team members find that they continually learn from colleagues and patients. The CASCAID team is committed to encourage the discussion regarding these and other HIV issues with both our patients and colleagues.

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SECTION D

LITERATURE REVIEW

THE IMPACT OF HIV/AIDS ON FAMILIES: AN OVERVIEW OF RESEARCH

Chapter 10: The Impact of HIV/AIDS Illness on Families: an Overview of Research

Nearly 20 years have elapsed since AIDS was first reported. On 5 June 1981, the US Centers for Disease Control reported five cases of a rare pneumonia among young homosexual men living in Los Angeles (Centers for Disease Control, 1981). By 27 November 1998, 1,987,217 cumulative cases of AIDS had been reported to the World Health Organisation (WHO, 1998), an increase of more than 35% over the number of cases reported by the end of 1995. It is estimated that there are 7 million cases of AIDS worldwide. Reporting delays, incomplete reporting, underdiagnosis and lack of access to healthcare accounts for the discrepancy between the number of reported and estimated cases. HIV is not distributed uniformly throughout the world: more than 90% of all adults living with HIV/AIDS live in developing countries.

In spite of evidence for the continued spread of HIV, the WHO (1998) reports some hopeful trends. HIV prevalence is decreasing or stabilising in some industrialised countries, part of sub-Saharan Africa, and in some populations in Thailand. In the USA, there has been a decrease in the number of new cases per year from 100,000 a few years ago to 40,000. Further evidence of decline comes from pregnant Ugandan women attending antenatal clinics, military recruits in Thailand and from Australia, New Zealand and northern European countries. These changes appear to be linked to behavioural changes such as increased condom use, reduction in the number of sex partners, and later initiation of sexual activity.

From the start of the epidemic, there has been a concerted effort to understand more about the psychosocial consequences of HIV disease and to translate that understanding into support for those affected. This review focuses on the impact of HIV on the family - and the family's impact on illness. It would be unwise to claim that any review in this field is both comprehensive and without omission. New research and clinical issues emerge almost every day. Orphaned children, the impact of long-term survival, clinical issues regarding families and AIDS, and the interactions between the family and healthcare system are not covered in this review. Instead, the review focuses on a) the definition of family, because HIV/AIDS disproportionately affects non-traditional families; b) individual presentation as it sets the context for the family response; c) adaptation to illness and changes in roles within families, since this provides insights into family dynamics when a person has a chronic and life-threatening illness; d) social support, because many people with HIV/AIDS rely on non-biological family members and friends for support; e) bereavement, because survivors may themselves be infected with HIV or may continue to have to endure social stigma even after someone has died; and f) general methodological issues, because researchers and clinicians will want to evaluate current knowledge in the light of the methods used in published research. Disclosure is recognised as important because it is a marker of social stigma, but it is only discussed in brief as it is the focus of the main part of this dissertation.

We know that people diagnosed with HIV may experience a wide range of psychological problems ranging from depression to psychosis, when compared with matched healthy controls. HIV is not solely a medical or psychological issue but also has profound implications for social and family relationships (Landau-Stanton &

Clements, 1993; Walker, 1991). Traditionally, when a person is ill, the family will provide emotional, practical and social support. Experience has shown that HIV disrupts this pattern of support. While HIV disease, like any other serious illness, affects family members from day to day and in the long term, it is misleading to suggest that all families coping with illness are affected in the same way. Although there are some similarities, the issues of transmission, social stigma, the age range of those most affected, and meanings associated with how the illness was contracted each set HIV apart from other potentially fatal conditions (Bor & Elford, 1994).

It is striking that the topic of HIV and the family has only recently become a focus for HIV research. This may stem from an erroneous belief that "family" is unimportant for gay men or from a popular myth that families reject members with HIV (Bor et al., 1993). It is clear from the literature, however, that there is neither consensus as to what constitutes the family nor a universal concept of a "traditional" family. The fact that HIV affects social networks beyond the nuclear family (comprising two parents and children living in the same household) has meant that researchers have had to re-examine definitions of the family. The social networks of African families and gay men are of particular relevance in this instance because the devastating impact of HIV disease on these two groups has been the subject of considerable research.

HIV challenges the conventional view that the family is determined solely by blood relationships. Carol Levine (1990) suggests that the family is a social system comprising individuals "who by birth, adoption, marriage or declared commitment share deep, personal connections are and mutually entitled to receive ... and provide support...especially in times of need." Thus, the family, both of origin and affiliation, may embrace a matrix of relationships including same-sex couples and networks of close friends as well as parents, siblings, children, and other relatives. Research demonstrates that gay men define “family” as both their family of origin (biological family) as well as family of choice (social family) (Leask et al., 1997). This includes parents, siblings, and grandparents as well as lovers, partners, and friends. Family can be characterised not only by blood relationships but also by whether people provide support or can be relied upon to do so.

Family is important, not only for the provision of support but also because HIV patients identify family relationships as stressful and among the top five most stressful areas of life (McShane et al., 1994). Family members themselves may experience stress and problems as carers, especially if a child comes home to convalesce or die. Researchers have found that caregivers had to develop a range of interacting and complimentary psychosocial and instrumental skills to provide support, live with the responsibility of caregiving and stigma when the person with HIV ultimately dies. Although at times faced with uncertainty and distress, the caregivers also experienced a sense of coherence and personal growth in these difficult times (Reynolds, Alonzo, 1998). Little is known about the psychological health of family and caregivers or whether they seek professional health for coping with illness in the family.

The response of family members relates in some degree to the way that the HIV infected individual responds individually to these family members. A brief look at the literature covering the psychological impact of an HIV diagnosis on the HIV infected individual sets this context.

10.1 Impact of HIV on the Individual

HIV infection has a profound affect on the lives of most HIV infected individuals. Often a search for meaning and explanations about how one became infected helps to restore a sense of the world. Self explanations of the HIV infection affects coping style and the nature of the psychological response to HIV infection. In most cases HIV infected patients were found to take personal responsibility and blame for their infection. Those who blame themselves are prone to an avoidant coping style, depressive mood and life dissatisfaction (Clement & Schönnesson, 1998).

HIV infection affects the body image of HIV infected individuals. They may experience significant feelings of contamination, brought about through internalisation of stigma, in addition to physical decline, as the illness progresses (Chapman, 1998). Physical, psychological and social influences are identified as the main spheres that influence body image. Physically, the HIV infected individual has to adapt to a changing body as the illness symptoms change, often unexpectedly. The anti-contagion measures they may adopt in everyday life are a continuous reminder of the HIV diagnosis. Sometimes people decide not to have children because of their HIV status, which is particularly damaging for the body image, self-concept and general identity of woman. Certain body areas like the face, hands and genitals showing visible signs of HIV infection cause considerable distress for the infected person and disruptions in their body image (Firn and Norman, 1995). In addition to the uncertainty and experience of physical symptoms, depression, anxiety and stigma all have an influence on the way an infected individual views his or her body.

There appears to be a high prevalence of psychiatric illness diagnosed in HIV infected individuals such as adjustment problems, anxiety disorders, depression, mania, paranoia and dementia (Katz et al., 1996; Meadows et al., 1998; Spiegel & Mayers, 1991). Depression could have a profound impact on the quality of life. Diagnosing depression in HIV infected people is complex as the somatic symptoms associated with HIV infection such as fatigue, low libido, low appetite and weight loss could be due to either depression, medication or HIV-related illness or a combination of these. Particularly in the early stages of HIV infection, patients often present with complaints indicative of depression such as exaggerated fears about their health and about dying. Symptoms include insomnia, low appetite, increased anxiety, vague pain, anhedonia and hopelessness (Fishman et al., 1996).

Research findings are not consistent as to the prevalence of depression in HIV infected populations. This may be as a result of different methodologies used. Some studies show that the prevalence of depression in HIV infected individuals is higher than that in the normal population, but similar to rates found in inpatients suffering from other chronic medical illnesses (Rabkin, 1996; Fishman et al., 1996). The lifetime prevalence of major depression among HIV positive groups were dramatically higher, ranging from 30% to 35% compared to the total population lifetime rate of major depression which is 3%.

There is also inconsistent research results as to whether the severity of HIV symptoms predict depressive symptomatology. Some findings suggest that patients with AIDS are no more depressed than those who are HIV positive but asymptomatic (Rabkin, 1996) and that Axis I DSM disorders do not increase as HIV illness progresses.

(Rabkin et al., 1997) However, Lyketsos et al. (1996) found that depressive symptoms started to rise before a diagnosis of AIDS and continued beyond the diagnosis. Their findings provide strong evidence that depression increases toward the later stages of HIV infection, especially if depression was a factor earlier in the course of HIV infection. A high prevalence of depression (37.1%) is associated with HIV-related symptoms, drug use, low social support and unemployment (Johnson et al., 1999; Katz, et al., 1996). The incidence of depression and dysthymia rises amongst those intravenous drug users who had previous episodes of major depression (Fishman et al., 1996; Johnson et al., 1999).

HIV status did not predict bipolar disorders or anxiety disorders (Rabkin, 1996). Patients who did report with mania either had a pre-existing bipolar disorder or had secondary mania as a result of HIV brain involvement (Fishman et al., 1996). Symptoms characteristic of mania in HIV positive patients include irritability and the delusional belief of having discovered a cure for HIV, or having been cured.

Different age groups have different needs, which must be taken into account when treating HIV infected people. In a study that compared older adults with younger HIV infected individuals, it was found that mood disorders were commonly found in both groups (Meadows et al., 1998). In older adults, brain disorders were more prevalent and issues such as social isolation, poverty and physical frailty were of most concern. The younger population had a higher prevalence of panic disorders and experienced more problems with employment. In children with HIV infection, it is common to see apathy, social withdrawal, and anorexia (Spiegel & Mayers, 1991). Children with HIV infection often have developmental difficulties such as attachment issues, separation anxiety, individuation difficulties and problems with developing a sense of competence and self esteem (Spiegel & Mayers, 1991).

HIV infection leads to an increased risk of the development of delirium as a result of HIV disease, side effects of medication and comorbid use of alcohol and drugs. Risk factors that could lead to an onset of delirium are prior cognitive impairment, vision and hearing impairment, malnourishment and chronic physical illness (Judd, 1996). There appears to be a prevalence of dementia, characterised by a decline in memory functions and intellectual abilities in HIV infected individuals: as many as 15% of HIV infected individuals develop dementia prior to their death (Catalan & Burgess, 1996). Although asymptomatic individuals showed no sign of cognitive impairment, it was found that HIV symptomatic individuals without an AIDS diagnosis suffer from EEG abnormalities, poorer memory and attention, slower information processing and difficulty in abstract thinking (Catalan & Burgess, 1996).

The nature of the HIV positive individual's experience predictably affects the larger family in a wide variety of ways.

10.2 Impact of HIV on Families

In an attempt to describe the extent of the impact of HIV on the family, McShane and colleagues (1994) estimated that one million families in the USA are affected. The average family size of 3.3 in the USA was multiplied by the number of AIDS cases in 1993 (250,000). However, this estimation is limited for a number of reasons: a) HIV-infected people are not included (a number potentially ten times larger); b) the impact on the extended family is not addressed; and c) indirect effects, such as bereaved survivors who are not included owing to the death of the index case, cannot be accessed and studied.

Because the majority of HIV infections worldwide occur in the 15-44 year age group, it is reasonable to assume that at least three generations are likely to be affected. To suggest that the main impact will fall on the nuclear family significantly underestimates the true extent of the problem. Further research is urgently needed in different communities to map a series of scenarios that depict the impact of HIV on families and from which we can extrapolate more realistic predictions of the scope of the problem. This should include the emotional, social, and economic impact in each relationship constellation. The psychological impact on family members also needs to be understood within the cultural context of the family, necessitating a truly multi-disciplinary research approach. Not only are there culture-specific definitions of "family," but also culturally mediated meanings about illness, how it is contracted, and expectations about who will care for whom in the family. There is paucity of empirical research into how culture influences and mediates the impact of HIV on the family.

The effect of HIV reverberates through the whole family system. Caregiving often implies a bi-directional relationship because the person with HIV has an effect on other family members, as much as they do on him or her. Each person influences and moderates how others cope. In most cases, there are issues of secrecy, confusion and blame if children are unaware of the presence of HIV in their family. This can lead to the whole family being affected (White et al., 1997). For example, a 10-year-old child may develop symptoms of anxiety and distress, such as bed-wetting, at the time a parent is diagnosed as HIV positive. So as not to add to the child's problems, the parents may choose to keep this secret from the child and other family members. The parents, in turn, are forced to cope without the support of others and may not be able to address directly the cause of their child's distress. When parents and children are infected, there is the potential for material and emotional deprivation within the family if the children become orphans.

The presence of HIV in the family can expose children to serious conflict between parents and uncertainty about their future. Childhood needs are often ignored and parenting can become erratic because of fatigue, sickness or hospitalisation (White et al., 1997). Furthermore, non-infected siblings may act out or seek attention if the health needs of their brother or sister eclipse their own need to belong within the family. Research has shown that the developmental stage of children also plays a role in parents' decision to disclose their diagnosis of HIV. Parents are more likely to disclose to adolescents than to younger children. This could be because parents feel that adolescents may cope better with the information than their younger siblings. However, some research suggests that adolescents who were informed of their parents HIV infection tended to engage in more frequent risky sexual acts, increased their use of nicotine and other substances and showed great emotional distress (Rotheram-Borus et al., 1997).

The experience of families affected by HIV is broadly similar. They fear disclosure, ostracism, stigma, transmission, inability to cope, and the impact on their emotional and material resources (Miller et al., 1994). Parents of children with HIV experience clinically significant levels of depression and anxiety when compared to general medical patients (Wiener et al., 1994). The impact of HIV on the family is determined by:

a) prevalence of HIV in the community
b) meanings attached to HIV and how it is acquired
c) expectations regarding support and involvement
d) availability of support and involvement
e) quality of family relationships and attachments
f) the role of the person with HIV in the family
g) the stage of illness
h) the individuals and family's stage of development
i) the extent to which the family will be relied upon to provide support
j) views about where people should cared for
k) the extent of secrecy or openness about the diagnosis
l) the family's ability to cope with change and adjust to loss.

10.3 Disclosure of HIV Status

Patterns of disclosure of HIV status are the channel to understanding how HIV infected individuals define their close family, as well as the strength of relationships and social support. There is an assumption that when a person decides to disclose his or her HIV status to other family members, everyone in the family is informed.

Research suggests otherwise, and disclosure is often in stages and selective (Foley, Skurnick, Kennedy, et al., 1994; Holt, Court, Vedhara, Nott, Holmes & Snow, 1998; Leask et al., 1997). Individual family members may draw a boundary between the wider family and others outside this system by not disclosing the diagnosis to more distant relatives, friends, and close colleagues (Bettoli-Vaughan, Brown, Brown, & Baldwin, 1998). Parents who are HIV infected face the dilemma of whether to inform their children or not.

The importance of disclosure of HIV status is considered of major relevance to studying HIV and its impact on the family. The main part of the research therefore focus on disclosure and contains a comprehensive literature review.

10.4 Social Support and the Family

It is well accepted that social support can act as a buffer against severe stress associated with coping with illness and even against disease progression (Berkman & Syme, 1979; Verbrugge, 1979). The responsibility for care and support usually falls on the family, and particularly on women (Bulmer, 1987; Hill & Zimmerman, 1995). If support is unavailable, withheld, or not asked for, this can adversely affect how people cope. However, these patterns may not be generalised for people with HIV. Most research to date has mainly focused on gay men (Green, 1993); nonetheless, some important insights have been made.

Social support may promote psychological adjustment to illness. Gay men with HIV who report available social support demonstrate higher measures on quality-of-life scales (Blainey et al., 1991; Ostrow et al., 1989; Zich & Temoshock, 1987), satisfaction with levels of support (Namir et al., 1987), and experience fewer psychological problems. While the relationship between the number of HIV-related symptoms and CD4 lymphocyte counts, and levels of social support is currently being studied, an association has been found between survival time and levels of social support (Soloman et al., 1987), and negative attributions related to health beliefs about oneself and immune system functioning (Segerstrom et al., 1996).

The usual pattern when someone is unwell is that there is a single ill person in the family, and the well persons affected by the illness will be carers. However, with HIV, some carers may not be physically present because of the effects of stigma or nondisclosure of the illness on them. In addition, some carers may themselves be infected with HIV and be unwell. Social stigma can lead to social distance, which mitigates against support. Stigma can result in total absence of care and support, or it may dilute levels of care and lead to reduced contact time or maintaining contact at a distance (by telephone or letter). There are, in addition, more subtle expressions of social distance, including increased advice giving, denying others access, denying problems, "inflicting cheeriness" on people (Wortman & Lehman, 1985), defusing tension, usurping the sick role by asserting one's own needs, and judging others.

Gay men may develop their own support networks, comprising friends and lovers, outside their biological family (Britton, Zarski & Hobsfoll, 1993). The question arises as to why the family of origin is not their principal source of social support. It is suggested that the family is absent as a support network because of the family's lack of acceptance of homosexuality and the relationship with a male partner, the stigma associated with AIDS, the inability of members to talk openly about homosexuality and AIDS, the incompetence of family members when dealing with issues related to AIDS, and the overprotective behaviour of parents (Kadushin, 1996). In the United States, a study among gay men with asymptomatic HIV infection found that satisfaction with one's social support was related to healthy coping strategies. Interestingly, the same study found that black gay men were less likely to seek social support than their white counterparts (Lesserman, Perkins & Evans, 1992).

In the UK, a study revealed the extent to which gay men provide support to other gay men with AIDS; a quarter of men interviewed said they had provided practical help and support to at least one other person with AIDS. The caring relationship may work both ways, with today's carers themselves requiring support in the future. It was encouraging that, in this study, 90% of the subjects interviewed reported having access to people they could turn to at times of illness, mostly friends or partners. This finding challenges the assumption that gay men do not have easy access to social support (Hart et al., 1990).

According to research conducted in London, the informal carers of gay men with HIV infection at an inner city hospital were predominantly their male partners or friends. While carers provided both physical and emotional support to their friends with HIV, they themselves felt inadequately supported both practically and emotionally. Carers have to deal with multiple and complex stressors. As the illness progresses, they have to assume more and more responsibility. The shifting of responsibility is often a sign of deteriorating health and can cause a lot of conflict in the carer's life. They are not always comfortable with assuming so much control over someone else's life and doubt their own competency in the tasks they have to carry out. HIV illness may also result in caregivers feeling helpless which in turn could lead to feelings of anger and frustration. Partners often have to cope with conflicting roles: on the one hand they may have to take care of their partner, but on the other hand they may have to work outside the home, spending less time at work to take care of their partner. This may result in increased levels of psychological stress, reduced financial resources and even unemployment (Folkman et al., 1994). Among heterosexual couples, uninfected partners have felt that support systems are not available to them whereas they are to their infected partner (Van der Straten et al., 1998). Indeed, some of the carers have expressed a desire for help from their biological family in supporting the person with HIV. These studies highlight the crucial supporting role of one’s family of affiliation at times of illness. The biological family may be limited in the extent to which it alone can provide support for a relation with HIV. Seeley, Kajura, Bachengana, and their colleagues (1993) found that the impact of HIV disease in certain communities in Uganda was so great that traditional extended family networks were unable to cope with the increased demands put on them.

Carers may be at increased risk of psychological problems because of their having to negotiate the complex relationship patterns emanating from secrets, stigma, and absence of wider support (Irving, Bor & Catalan, 1995; Reynolds & Alonzo, 1998). Furthermore, to lose a partner at a young age is especially grievous for the survivor (Foley et al., 1994) and could even be accompanied by a preoccupation with suicide (Rosengard & Folkman, 1997). Partners face many of the difficulties experienced by those with HIV: uncertainty, helplessness, stigma, isolation, lack of support, and practical concerns (Van der Straten et al., 1998).

Research has found that among gay men, more positive family relationships emerged when people chose to disclose their HIV status (Fisher et al., 1993). Even though some people may disclose their diagnosis to potential carers, the extent of support may be rudimentary. There is an assumption that the positive relationship between social support and psychological well being is valid for all ethnic populations. Gant and Ostrow (1995) found that for African American men with HIV there is a negative relationship between mental health measures and social support, and that they may have different access to support and use support differently.

There are different kinds of support available and needed, including emotional, informational, practical (instrumental), or financial (Schaefer, Coyne, & Lazarus, 1981). The type of support needed or wanted may vary between carers, although it may also overlap. Instrumental support can also convey emotional support. Emotional support can include help with financial matters. This can lead to conflictual or problematic relationships (for example, between partners of gay men and the biological family). Support that is naturally expected may also be absent because of deprivation, impoverishment, and illness among carers.

While support may be available, there are individual factors that account for a) whether it is taken up or used and b) perceptions of support. This may result from the person's position or role within the family, the person's self-concept in relation to others; the ability of people to provide or receive support, the psychological impact of illness (which may physically prevent people from taking up support), and stage of illness (Tuner, Hays, & Coates, 1993). In the West, heterosexuals with HIV are often still in a minority and may choose not to disclose their HIV status to others because they perceive people as likely to be unsupportive (Pergami et al., 1994). It is also important to recognise that, over time, the nature of support as well as the quality of so-called supportive relationships may be transient.

Patterns of care among children born to HIV-infected parents in the USA are beginning to emerge. The primary caretakers of children born to HIV-infected mothers are single mothers (Schable et al., 1995). Not only do these mothers have to address the needs of their child, but also their own social and health needs. In a study comparing the extent of the stress that HIV positive and HIV negative caregivers of HIV positive children experience, it was found that although both groups experienced clinically significant stress, the HIV positive group perceived themselves as physically and emotional less healthy (Amodei et al., 1997). These caregivers experienced multiple stressors in dealing with their own and their child's illness and solving problems related to meeting their own and their child's basic needs (Hansell et al., 1998). The amount of stress that HIV positive caregivers experience could result in the perception of less than adequate social support (Amodei et al., 1997; Hansell et al., 1998). Interestingly enough, HIV positive parents felt less pessimistic about the future of their child and family (Amodei et al., 1997). Among a cohort of orphans in Zimbabwe, the extended family plays an important role; 45% of caregivers were grandparents (Foster et al., 1996). We know little about patterns of social support in communities outside of developed Western countries. There is also a need to understand how and when patterns of support change and the barriers to obtaining support. Research suggest that rural parents of HIV-seropositive children have less places or people in their communities to turn to because of the stigma associated with their child's illness (McGinn, 1996). Furthermore, support is usually characterised in terms of social interaction, but we know little about individual factors that influence patterns of support and the impact of support giving on family relationships.

10.5 Family Responses to Illness

All families are affected by illness; some will be drawn together; others will be split apart. Major themes for parents of HIV infected children are: 1) isolation, 2) secrecy and disclosure of HIV diagnosis, 3) accepting the family infection, 4) planning the family's future and 5) couple tension and sexual relationships (Goldie et al., 1997). Adverse conditions within the family may be transitory and, with adequate coping mechanisms, some families adjust well to changes resulting from illness and the death of a family member. However, high levels of psychological stress have been reported in carers of people with HIV, which can continue for years after the person has died (Irving et al., 1995). Changes within the family can be characterised by shifting patterns of attachment that may not be synchronised with the needs of the person with HIV. Some carers may, for example, be anxious and try to get close at a time when the person needs some emotional separateness from others. Life-threatening illness can also disturb secure attachments. This can lead to altered, predictable, stereotypic, disordered, or overly flexible patterns of relating, communicating, problem-solving, or intimacy. To this end it is reasonable to hypothesise that the crisis of illness puts family members at risk of psychological problems.

Some family members may become immobilised by not being able to identify the challenges and problems facing them or to assign priority in dealing with them. Stress of this kind can become may be contagious and others may also start to doubt their ability to cope and manage their stress (Murphy & Perry, 1988). HIV-positive mothers who experienced problems in adjusting to their illness affected their children's level of adjustment. Their children experienced more internalising symptoms of depression and anxiety (Bettoli-Vaughan et al., 1998). No significant relationship was found between marital adjustment and internalising problems in children (Steele et al., 1997). From the above it seems as if a cycle of symptomatic behaviour may follow in which depression in one family member either triggers the same or its complement in another (Bor et al., 1990). This in turn may be exacerbated by secrets about how family members appear to be coping. Some family members function by “putting on a brave face” and concealing their hurt, anger, disappointment, or anxiety. Others may display the same psychological symptoms as the infected person, ranging from fear, anger, agitation, and withdrawal, to anxiety and depression (Beckett & Rutan, 1990).

Obstacles to adjustment, acceptance and reconciliation between family members may arise at different stages in the course of illness as issues about lifestyle and blame re-emerge. The stress that emanates from these conflicting forces can lead to suicidal thoughts, paranoid beliefs, and even psychosis (Lovejoy, 1989). Arguments, threats, accusations, alcohol and drug abuse, and treatment non-compliance may be symptoms of psychological problems in families, arising from ambivalent feelings between members.

Behaviour in the family may become dysfunctional when reality is denied (for example, in a family where both parents are infected with HIV yet make no provision for the future care of their children), or when illness becomes the only reality that they attend to (for example, day-to-day activities are neglected). Children's psychosocial adjustment seems to be related to the impact the illness has on the family rather than the severity of the illness (Kotchick et al., 1997). However, this does not mean that the severity of the illness has no effect on the family system. Illness severity does cause more disruptions in the family process and increased depression in the parents, which could have an effect on the psychosocial adjustment of the child (Steele et al., 1997). As with all families that experience or are threatened by rapid and profound change, there is an increased risk of psychological problems. Parents of HIV infected children face numerous problems of isolation, shame, anger, stigmatisation, ostracism, disclosure, uncertainty, terminal illness and preparation for the child's death. The emotional burden that these parents have to deal with includes dealing with their feelings of guilt, grief, emotional pain and exhaustion. A multitude of stressors could lead to clinical depression and anxiety (Hansell et al., 1998; Lewis, Wesley & Haiken, 1996). The risk of psychological problems is probably greater when external support networks, such as the extended family and friends do not know about the HIV diagnosis and are therefore excluded from providing a supportive and normalising experience within the family. Extra-familial and parental support is shown to have a beneficial effect on internalising problems in children (Kotchick et al., 1997). Studies that compare stress and coping in HIV-affected families that have engaged external support systems versus those that have not, will throw light on this important issue. Social support interventions have been beneficial for seronegative caregivers in assisting them in dealing with their problems. Although their stress levels and coping was not affected, these caregivers did find the social support helpful with other problems. This finding was not applicable to the seropositive group, who rated their social support as unhelpful. A possible explanation for this could be that they experience more stress when they also have to contend with their own illness and imminent death (Hansell et al., 1998).

The typology of illness (Rolland, 1994) is important in relation to how the family is affected. The slow, progressive, and usually unpredictable course of illness associated with HIV is an additional source of stress. The family needs a level of stability and predictability in order to recoup after episodes of illness, but sometimes pressures and stresses are unremitting. This interferes with attachments especially if carers become overprotective, overreact to situations, or withdraw their support. Carers of HIV infected children also face the challenge of caring for a well and developing child on the one hand and dealing with episodes of recurrent acute illnesses on the other hand. The family must continue with its “normal” activities and meet the demands of every day life. They cannot be constantly deflected by illness while in pursuit of providing care.

At the stage of terminal illness, rivalry may surface between family members as they struggle to redefine their relationship with the dying person (O’Donnell & Berrier, 1990). Parents, siblings, and when appropriate, the patient’s partner, may become the most important source of emotional support (Catania et al., 1992). There may be arguments about approaches to care and decisions about advanced life-support directives such as resuscitation. Friends and more distant relatives may seek to create some distance between themselves and the family by decreasing their contact and visits through fear or a difficulty in dealing with the anticipation of separation, loss, and dying.

Each episode of illness introduces new stress into relationships as family members adjust to anticipatory and actual loss. Research is being conducted into how and when patterns of attachment change in these families. It will also address whether highly threatened families with insecure attachments are at greater risk of psychological problems.

10.6 Changes in the Family Structure

In addition to the profound psychological changes that a family may undergo when confronted with illness relating to HIV disease, important changes in the structure of families can also be observed. Illness almost always places a financial burden on families. This results from the direct costs of care and treatment and the disruption caused by loss of productivity. When ill health interferes with the family breadwinner's mobility and employment, income may need to be replaced by other family members who may also be unwell (Manopaiboon et al., 1998) This scenario is now all too common in parts of Sub-Saharan Africa and Thailand (Ankrah, 1993; Manopaiboon et al., 1998). In families where the wife/mother is infected, the uninfected husband/father experiences a change in role from breadwinner to primary carer for their children. They also have to care for their partner, which could lead to unemployment (White et al., 1997). If both parents are infected, it is most often the case that the woman will have to take care of her partner and children. Many have to return to work because of the death of their partner and economic hardships. It can also happen that the death of both parents shifts the responsibility of childcare to the grandparents. It is clear from the above that HIV infection has a huge impact not only on the HIV infected individual's life but also on the family's dynamics (Manopaiboon et al., 1998).

Normal developmental patterns are reversed in HIV disease. Children may die before their parents, leaving grandparents to look after themselves at a time when they might have looked forward to increased support from their own children. This is particularly relevant in those third world countries where poor medical and no welfare systems exist. Grandparents may have to take on the responsibilities of a parent once again and care for grandchildren orphaned by the loss of their parents. In other cases, young adults come back to their parents' home to die at a stage when children would normally be establishing themselves away from home. Poverty and lack of access to adequate healthcare facilities may prompt some families to migrate. Refugees with HIV may become dislocated from a familiar and supportive environment, which may exacerbate problems associated with coping and adjustment.

Changes in structure of the family may become evident at the different stages of illness or points of crisis. If both parents are infected, there is an increased likelihood that their children will be orphaned. As the number of "AIDS orphans" increased world-wide and the extended family becomes overburdened with orphans, an increasing number will have to be cared for in institutions rather than within the extended family (Prebble, 1990). The erosion of traditional views and attitudes toward sex, marriage, and emotional bonds between spouses may result in sexual risk-taking in spite of health education messages. Termination of the mother's childbearing has profound implications not only for her nurturing role, but also for the family's relationship with the extended family and the community, and for future economic security (Ankrah, 1993). Even if targeted counselling is offered to couples when one or both partners are infected with HIV, there may be an overriding desire to have a child (Goldman et al., 1992). This is often an attempt on the woman's part to maintain and sustain the relationship between her and her partner (White et al., 1997). There may also be periods of relapse into unsafe sexual practices as a means of revitalising or redressing the balance in a sexual relationship in which one partner is infected.

10.7 Impact of Loss on Families

Social stigma, secrecy, and the possibility that other family members may also be infected with HIV complicate the psychological impact of loss on the family. The scale of the epidemic is such that in some communities there is the potential for multiple losses whereby whole families are infected (Mallinson, 1999). Uninfected children of mothers who die from AIDS face issues of loss adjustment (Siegal & Gorey, 1994). In the USA, many of these are single-parent families, and the absence of the father shifts the burden of care of the mother and her family. Fear of stigma in the adoptive family may prevent the child from openly talking about the circumstances of the loss of the parent. Many children grow up denying the illness of the parent as a way of coping (Halperon, 1993). Not only is there the actual loss at the time and following death, but throughout the parent's illness there is also anticipatory loss (Brown & Powell-Cope, 1993), which affects attachments and lifestyle.

Recent studies have sought to investigate whether bereavement has an adverse effect on the function of the immune system: whether survivors infected with HIV progress to AIDS more quickly than others who have not experienced a bereavement; and whether social support buffers people infected with HIV from stress and the deleterious effects of adverse life events. Results of one study (Chesney et al., 1992) suggest that the survivor's immune system is not adversely affected by an AIDS-related bereavement. The effects of the death of a partner on depressive symptoms, anxiety, and morale both in HIV-infected and non-infected gay, care giving men was also investigated. Results of this prospective study revealed that, prior to the death of the partner, HIV infected caregivers were less distressed than those who were not infected. The profile was reversed after the death of the partner: HIV-infected partners displayed greater distress than non-infected men did. The latter may have experience relief after the death of their partner, while HIV-infected men were left on their own to confront their disease. Partners who had felt burdened by care-giving, perceived social support as ineffective and coped by avoiding or escaping from their problems showed more suicidal ideation after the death of their partner (Rosengard & Folkman, 1997). As most psychoneuroimmunological research pertaining to HIV/AIDS has been carried out on the infected individual, it is not yet possible to compare these findings with cohorts of other bereaved relatives.

In parts of Africa that have been heavily affected by deaths resulting from AIDS, rituals associated with funeral arrangements and mourning have had to be abandoned.

Financial and other demands on kinsfolk and neighbours have become a significant burden as a result of multiple deaths (Ankrah, 1993). The survival of some clans in Africa could be threatened by a lack of available marriage partners for both young adults reaching maturity and those who have widowed. A trend toward marrying very young women who are seemingly free from infection has also been noted. Little is known about the long-tern impact of loss on the family and especially the impact of loss on non-gay families. Some preliminary findings suggest that when a loved one with HIV infection dies, family and friends feels ostracised by society. The value of the deceased life is undermined in a way by the stigma involved with HIV/AIDS and could lead family and friends to question their own value in society. The overload of deaths that some communities experience causes bereavement overload with limited opportunities to process their grief feelings. This in turn could lead to unresolved grief, accompanied by anxiety, depression, physical exhaustion and spiritual demoralisation. Many of these individuals have feelings of anger and anxiety about their own death as well as perceptions of discontinuity and upheaval Their greatest wish in times like this is to protect themselves from future losses which could cause more isolation from other people. In addition to loss through death, HIV positive people also experience loss of their community, their connection to others, their sense of self and personal losses such as loss of privacy and intimate relationships.

10.8 Methodological Research Issues

It is only in the last 5 years that research has started to focus on how HIV affects the family. Consequently, there are large gaps in our understanding of how HIV impacts on family relationships. Furthermore, although HIV disease is a global problem, we already have evidence that the impact of illness in families is neither uniform nor necessarily predictable across different communities. Many questions remain unanswered and research is currently underway in a number of settings designed to improve over understanding in this area. It seems prudent, nonetheless, to briefly highlight some of the methodological and conceptual constraints that have so far challenged researchers in this area. The following is a partial list of these, which has been derived from experience and review of recent research:

a) There is no consensus as to what constitutes the 'family.'
b) Applying epidemiological constructs to family functioning is problematic and caseness (specifying what constitutes an adverse impact on the family) is sometimes vague and difficult to define.
c) Of the few standardised measures of the impact of illness on families that are available, some are either inappropriate for use with people with HIV or are specifically orientated to Western, intact, nuclear, heterosexual families.
d) Because HIV can be transmitted within the family, it is sometimes difficult to delineate who is a carer.
e) As the natural history of HIV unfolds, and illness progresses in the individual, the impact changes the family; cross-sectional studies are therefore of limited value. A more rigorous examination is needed of families at several points in time in order to capture underlying trends. Results from cross-sectional studies may reflect transient relationships or temporary changes within these relationships.

f) Social stigma may make it difficult to gain access to families affected by HIV; research may be thwarted by the fact that some family members are never informed about the diagnosis.

g) Little research has been conducted in developing countries; it is difficult to make comparisons or reflect on patterns of coping across families.

h) Samples have tended to be small.

i) Many studies have looked at psychological distress rather than prevalence rates for psychiatric disorders.

j) Many studies rely on self-rating questions rather than assessments made by trained interviewers using standardised interviews.

k) Most published research focuses on gay men and their families in the USA and is the dominant topic in the field of HIV and family research; there is little research on the impact on children and adolescents.

l) There have been surprisingly few studies in the literature that have addressed the important issues of the economic impact of HIV on the family, sexuality, gender, and power issues.

m) Most research reflects the views of the HIV-infected persons and their perceptions of relationships. Little have been reported on the perceptions of adult family members of the infected person, or a child's perception of its parents.

n) All articles conclude with the need for further studies of the impact of HIV on the family.

Table 10.1 lists selected publications on the impact of HIV on families, delineating research questions, sample sizes, measures used, study design and country of study.

Table 10.1: Selected Publications on the Impact of HIV

Research Topic	*N*	Measures	Study design	Location	Reference
Psychological adaptation of parents with HIV infected children	101	Health Status Questionnaire, Spielberger State-Trait Anxiety Inventory, Beck Depression Inventory, Parental Coping Scale, Anticipatory Grief Scale, Demographic Questionnaire	Descriptive Pilot Study	USA	Wiener et al., 1994
Psychosocial concerns of HIV and AIDS	1		Case Study	USA	Lewis, Wesley & Haiken, 1996
HIV infection and challenges for heterosexual couples	82		Prospective qualitative design	USA	VanDeventer et al., 1999
Stress, coping and social support in caregivers of children with HIV/AIDS	70	Derogatis Stress Profile, Family Crisis Oriented Personal Evaluation Scale, Tilden Interpersonal Relationship Inventory	Experimental Design, stratified randomised sample	USA	Hansell et al., 1998
Stress and coping in partners of men with AIDS	314	Clinical assessment of depression and physical health, Neuropsychological Impairment, paper-and-pencil assessments of mood, stress, coping, social support, personality, semi-structured interviews	Longitudinal study	USA	Folkman et al., 1994
Impact of HIV on families	342	Standardised scales to assess levels of psychosocial functioning	Prospective Study	Thailand	Manopaiboon et al., 1998 Amodei et al., 1998

Stress in families living with HIV/AIDS	22	Questionnaire on Resources and Stress	Pilot Study	USA	
Maternal HIV infection and influence on parenting	234	Data on maternal physical health, parenting behaviours, psychosocial adjustment of child	Descriptive Study	USA	Kotchick et al., 1997
Psychological functioning of HIV infected individuals	57	Questionnaires measuring HIV attribution theories, Freiburg Coping List, Life Satisfaction Questionnaire	Cross-sectional, correlational analysis	Germany, Sweden	Clement et al., 1998
Age differences in mental health problems for HIV infected individuals	103	Information regarding demographics, reason for referral, principle diagnosis, previous psychiatric history, and problems reported obtained from computer data base	Correlational Analysis, case studies	UK	Meadows et al., 1998
Body image changes during progression of HIV infection	13	Repertory Grids (Kelly, 1955), Semi-structured interviews, HIV Symptom checklist	Longitudinal Study	UK	Chapman, 1998
Depression amongst HIV infected patients	475	Interviews obtaining information regarding socio-demographic characteristics, medical insurance, HIV-related symptoms, drug use, depression measured by CES-D, Social support measured by 14 item scale	Cross-sectional study	USA	Katz et al., 1996

10.9 Conclusion

Research into the psychological effects of HIV disease in the first decade focused primarily on its impact on the infected individual Recently, there has been interest in how the family is affected, who is defined as the family, and the family's impact on the course of illness. As is the case with other potentially life-threatening illnesses, HIV disease affects the entire family system and has the potential to disrupt relationships severely. The evidence from research suggests that it is unusual for there to be a complete breakdown of family relationships when news of an HIV diagnosis is shared with other family members. However, it is not yet possible to determine the long-term impact of HIV on the family. Although research in this field is still in its infancy, more studies are urgently needed to determine the impact of HIV on a) male same-sex relationships; b) gay men and their family of origin; c) women, both those who are infected and those what are affected; d) children and adolescents, and e) the family of origin and family of affiliation of those diagnosed with HIV, among others.

There is also a need to set up long-term studies in different settings so that comparisons can be drawn between how families cope and adjust in different communities. A range of methodologies need to be applied in research in this field in order to address the complex and challenging issues posed by the psychological consequences of illness in general, and HIV disease in particular. Lastly, although there are some unique and specific feature that HIV/AIDS different from other medical conditions, there are also major similarities. Research that compares psychological adjustment to HIV/AIDS with other chronic illnesses may help to present a more balanced approach to care. It may also counter a sense that HIV/AIDS is so different and special, which leads some professional and non-professional carers to feel deskilled and to inadvertently withdraw their support.

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APPENDICES

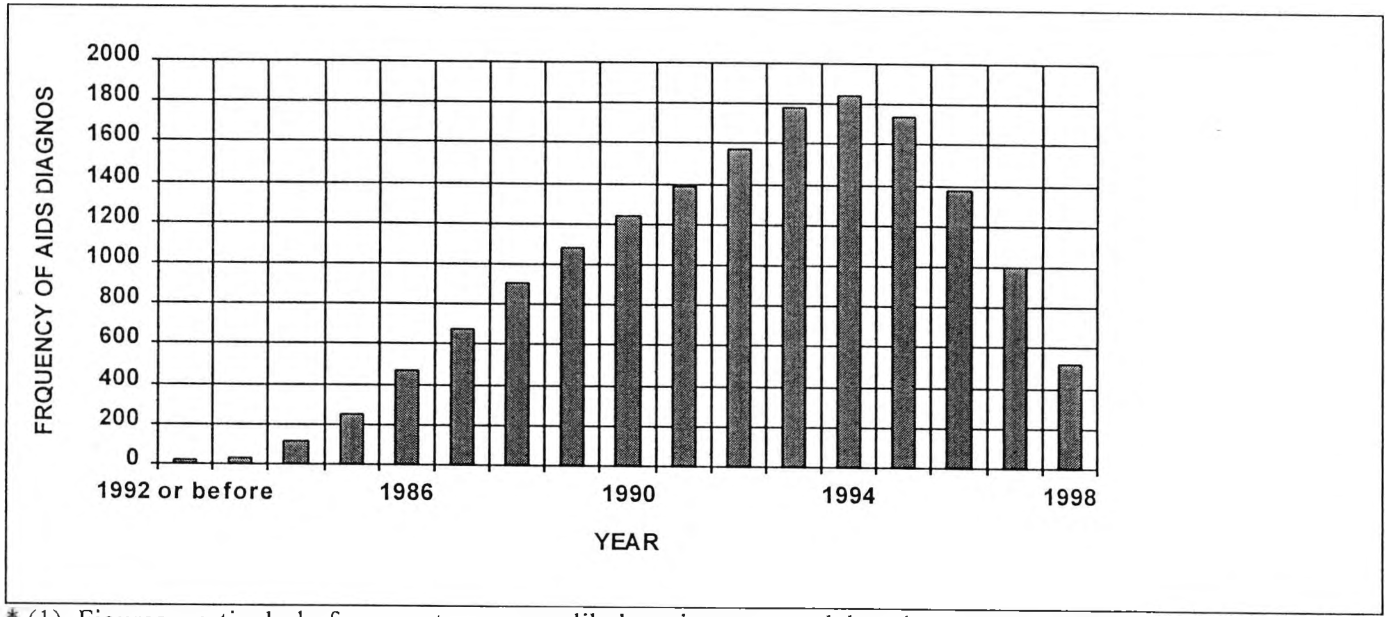
Appendix 1: HIV UK Data, December 1998

Year	AIDS Diagnoses	Known Deaths*	AIDS Reports	Known Deaths*	Deaths without AIDS#	Total Deaths by year
1982	18	18	3	3	2	10
1983	33	32	26	25	5	20
1984	110	109	77	77	12	58
1985	245	238	158	156	27	148
1986	472	466	297	296	50	320
1987	679	650	638	629	59	411
1988	904	860	754	733	63	476
1989	1081	1031	842	812	84	749
1990	1242	1102	1264	1173	112	898
1991	1388	1206	1350	1196	122	1117
1992	1570	1324	1471	1277	153	1245
1993	1780	1433	1598	1317	188	1542
1994	1839	1269	1775	1308	152	1682
1995	1740	905	1573	905	157	1669
1996	1379	433	1857	851	148	1371
1997	1003	216	1381	404	119	631
1998	524	81	964	228	85	364
Unknown	21	17	0	0	74	291
Total	16028	11390	16028	11390	1612	13002

Figures, particularly for recent years, are likely to increase as delayed reports are received.
*Of the cases diagnosed or reported in each year, these are the numbers of deaths reported by the end of December 1998.
#Deaths in HIV infected people where no record of AIDS was received by CDSC. Includes pre-AIDS deaths as well as unreported AIDS cases, year of death.

Source: Public Health Laboratory Service AIDS Centre - Communicable Disease Surveillance Centre, and Scottish Centre for Infection & Environmental Health. Unpublished AIDS/HIV Quarterly Surveillance Tables - UK data to end December 1998, No. 42, 98/4 Table B.

Appendix 2: AIDS Cases by Year of Diagnosis: UK December 1998



* (1). Figures, particularly for recent years, are likely to increase as delayed reports are received.

Source: Public Health Laboratory Service AIDS Centre - Communicable Disease Surveillance Centre, and Scottish Centre for Infection & Environmental Health. Unpublished AIDS/HIV Quarterly Surveillance Tables - UK data to end December 1998, No. 42, 98/4 Table B.

Appendix 3: Year of HIV Diagnosis by Country of First Report: UK, March 1999.

	YEAR																**Total #**
Country	**<85**	**1985**	**1986**	**1987**	**1988**	**1989**	**1990**	**1991**	**1992**	**1993**	**1994**	**1995**	**1996**	**1997**	**1998**	**1999**	
England	1206	2911	2417	2229	1741	1967	2348	2461	2511	2360	2313	2401	2408	2374	2405	267	34319
Wales	39	31	32	31	36	32	35	35	49	40	43	46	36	41	29	3	558
Northern Ireland	11	13	12	9	10	9	12	19	12	12	14	11	16	8	10	4	182
Scotland	349	260	297	228	132	111	118	169	130	166	144	139	157	164	142	25	2731
UK Total	1605	3215	2758	2497	1919	2119	2513	2684	2702	2578	2514	2597	2617	2587	2586	299	37790

Numbers, particularly for recent years, are likely to increase as delayed reports are received.
*Includes reports of laboratory diagnoses, reports of AIDS and reports of deaths in HIV infected individuals without reported AIDS.
#Excludes 20 reports with regions not known.

Source: Public Health Laboratory Service AIDS Centre - Communicable Disease Surveillance Centre, and Scottish Centre for Infection & Environmental Health. Communicable Disease Report. Vol. 9, No. 18, p. 164.

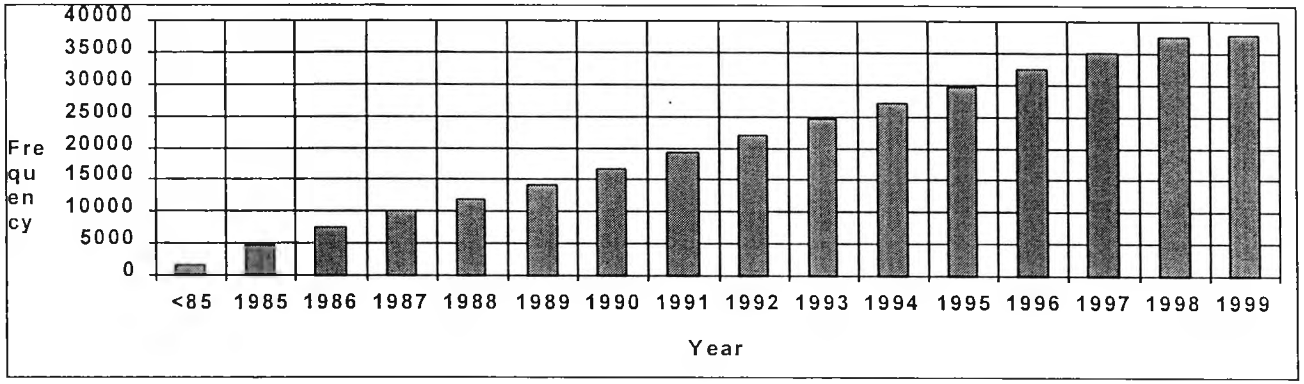
Appendix 4: Cumulative Frequency of HIV Diagnosis by Country of First Report: UK, March 1999

	YEAR																Total #
Country	<85	**1985**	**1986**	**1987**	**1988**	**1989**	**1990**	**1991**	**1992**	**1993**	**1994**	**1995**	**1996**	**1997**	**1998**	**1999**	
England	1206	4117	6534	8763	10504	12471	14819	17280	19791	22151	24464	26865	29273	31647	34052	34319	34319
Wales	39	70	102	133	169	201	236	271	320	360	403	449	485	526	555	558	558
Northern Ireland	11	24	36	45	55	64	76	95	107	119	133	144	160	168	178	182	182
Scotland	349	609	906	1134	1266	1377	1495	1664	1794	1960	2104	2243	2400	2564	2706	2731	2731
UK Total	1605	4820	7578	10075	11994	14113	16626	19310	22012	24590	27104	29701	32318	34905	37491	37790	37790

Numbers, particularly for recent years, are likely to increase as delayed reports are received.
* Includes reports of laboratory diagnoses, reports of AIDS and reports of deaths in HIV infected individuals without reported AIDS.
# Excludes 20 reports with regions not known.

Source: Public Health Laboratory Service AIDS Centre - Communicable Disease Surveillance Centre, and Scottish Centre for Infection & Environmental Health. Communicable Disease Report, Vol. 9, No. 18, p. 164.

Appendix 5: Cumulative Frequency of HIV Diagnosis: UK Total, March 1999



Numbers, particularly for recent years, are likely to increase as delayed reports are received.
* Includes reports of laboratory diagnoses, reports of AIDS and reports of deaths in HIV infected individuals without reported AIDS.
#Excludes 20 reports with regions not known.

Source: Public Health Laboratory Service AIDS Centre - Communicable Disease Surveillance Centre, and Scottish Centre for Infection & Environmental Health. <u>Communicable Disease Report</u>, Vol. 9, No. 18, p. 164.

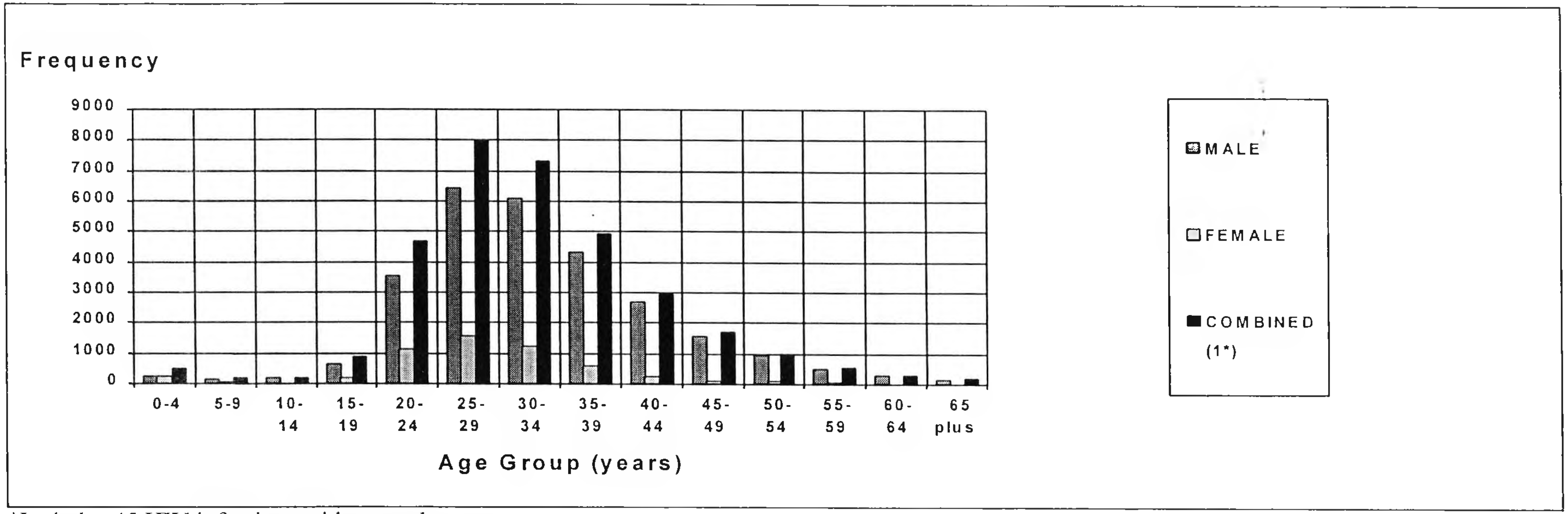
Appendix 6: HIV Infections by Age and Gender: UK December 1998

		Age Group (years)															
		0-4	**5-9**	**10-14**	**15-19**	**20-24**	**25-29**	**30-34**	**35-39**	**40-44**	**45-49**	**50-54**	**55-59**	**60-64**	**65+**	**Total 100%**	**Unknown**
Male	No.	260	135	178	655	3534	6421	6096	4336	2689	1587	928	506	283	166	27774	335
	%	1	0	1	3	13	23	22	15	10	6	3	2	1	1	100	
Female	No.	232	50	11	208	1120	1598	1216	579	247	120	77	50	24	19	5551	59
	%	4	1	0	4	20	28	22	10	4	2	1	1	0	0	100	
Combined *	No.	495	188	190	866	4659	8022	7313	4915	2938	1707	1005	556	307	186	33347	417
	%	1	1	1	3	14	24	22	15	9	5	3	2	1	1	100	

*Includes 45 HIV infections with sex unknown.

Source: Public Health Laboratory Service AIDS Centre - Communicable Disease Surveillance Centre, and Scottish Centre for Infection & Environmental Health.

Appendix 7: HIV Infections by Age and Gender: UK December 1998



*Includes 45 HIV infections with sex unknown.

Source: Public Health Laboratory Service AIDS Centre - Communicable Disease Surveillance Centre, and Scottish Centre for Infection & Environmental Health. Unpublished AIDS/HIV Quarterly Surveillance Tables - UK data to end December 1998, No. 42, 98/4 Table

Appendix 8: Number of HIV Infected People Treated in LSL by Year

Ethnic Group	**1993**	**1994**	**1995**	**1996**	**1997**	**1998**
White Male	-	599	751	823	1031	1134
White Female	-	40	57	57	69	82
Black-Caribbean Male	-	25	40	50	56	69
Black-Caribbean Female	-	12	12	26	24	28
Black-African Male	-	49	96	94	141	210
Black-African Female	-	71	125	145	229	305
Black Other Male	-	18	31	49	50	51
Black Other Female	-	10	15	#	10	11
Indian/Pakistani/Bangladeshi	-	#	46*	#	62*	11
Other/Mixed	-	#	46*	51	62*	132
Not Known	-	528	429	232	189	106
TOTAL	1046	1359	1604	1539	1863	2140

HIV Information Exchange, CDSC (1993/94) (data on Ethnicity was not collected for 1993)

Survey of prevalent diagnosed HIV infections 1995-1998 (SOPHID)

#In order to preserve the confidentiality of HIV infected individuals, numbers less than ten will not be reported, in line with LSL Health Authority recommendations.

*For 1995 and 1997, Indian/Pakistani/Bangladeshi and Other/Mixed figures were combined to preserve confidentiality.

Appendix 9: Number of HIV Infected People by Risk Group in LSL

Risk Group	1993	1994	1995	1996	1997	1998
Homosexual/Bisexual (all male)	848	784	1034	926	1165	1257
Injecting drug use	61	71	97	37	44	73
Heterosexual Male	51	59	117	142	156	234
Heterosexual Female	82	96	192	208	240	346
Blood/blood products	13	19	15	12	14	19
Mother to infant	*	17	33	35	50	59
Not known	113	313	116	179	194	151
TOTAL	1173	1359	1604	1539	1863	2140

HIV Information Exchange, CDSC (1993 and 1994)

Survey of prevalent diagnosed HIV infections 1995-1998 (SOPHID98)

Invitation: To attendees at Harrison Wing

We are investigating social support in HIV through a survey of people who attend the Harrison Wing in order to find out more about your social support.

Please feel free to contact me directly to arrange a meeting when I am at Harrison Wing. My research collegue, Rob, or I will be in the Harrison Wing for the next 4 to 6 weeks and one of us are likely to be available when you are visiting the Harrison Wing for other appointments.

The interview will last about 20 minutes, and if you discuss something that you feel you need to explore further, you can be referred to a psychologist on the *CASCAID* team. The interview and all material will be confidential and anonymous. Members of *CASCAID* attend at the Harrison Wing several times a week.

Thank you for your participation.

Peter du Plessis

Telephone: 0171 955 4405

Appendix 11: Questionnaire: Research, Part 1

Serial Number ☐
Today's Date ☐

CD4 ☐
Date of CD4 ☐

1. Age (years) ☐
2. Sex Female ☐ Male ☐

3. Country of Birth ☐

4. Ethnic Origin *please tick*

White UK ☐
White Other ☐
Indian ☐
Pakistani ☐
E African Asian ☐
Bangladeshi ☐
Chinese *(Hong Kong)* ☐
Chinese other ☐
Vietnamese ☐
African (excl. West Indies) ☐
Caribbean (inc. West Indies) ☐
Other *(please specify)* ☐

5. Are you Employed? ☐ Unemployed? ☐

5a. If unemployed, is this as a result of your HIV infection?

Yes ☐ No ☐

5b. If unemployed, was it because of:

Discrimination? ☐ Sickness? ☐

6. Occupation (current or last job) ☐

7. Employment Position *(please tick)*

Self employed ☐
Manager/Supervisor ☐
Employee ☐
Apprentice ☐

7a. Are you a Student ☐

7b. Are you a Housecarer ☐

8. Concerning your living arrangements, do you: *(please tick)*

Rent from landlord ☐
Rent from Housing Association ☐
Own your own home ☐
Squat ☐
Live with parents ☐
Stay in bed and breakfast ☐
Have no fixed living arrangements ☐
Other, please specify: ☐

9. Do you remember the date when you were first diagnosed with HIV?

Yes ☐ No ☐

If Yes: When? ☐

10. How do you think you contracted HIV?
(Please tick more than one if necessary)

Sex with same sex partner ☐
Sex with opposite sex partner ☐
Sex with both men and women ☐
Through injecting drugs ☐
Through blood transfusion ☐
Other ☐

11. How would you describe your health?

HIV+ symptom free ____________
HIV+ with symptoms (past) ____________
HIV+ with symptoms present ____________
AIDS or very ill ____________

12. Looking back, what has been the most stressful for you in becoming HIV +?

Relationships	Sex
Uncertainty	Disclosure
Secrets	Unmanageable feelings
Health problems	Other

13. What has been most supportive to you since your HIV+ diagnosis?

14a. The following questions concern the people you would consider being close and they may include:

- your parents, grandparents, brother, sister, children
- your wider (extended) family: uncles, aunts, cousins, brother-in-law, sister-in-law
- your partner(s), husband, wife, boyfriend, girlfriend
- close friends

We shall refer to those whom you consider emotionally close as your “family”

	Person 1	Person 2	Person 3
Who do you regard as your close family?			
Relationship to you			
Sex			
Age			
Do you live with this person (Y/N)			
Which of these people knows your HIV status			
For those who know, whom did you tell yourself			
Who told the others?			
Why did you tell/not tell them?			
Has there been any major changes in these relationships since your diagnosis (N/Y)			
Do you regard any of these as your next of kin?			

14b. I would now like to ask you the same questions about the following people: *(They include members of the biological family or partner, only if they have been omitted in the first section).*

	Person 1	Person 2	Person 3	Person 4	Person 5	Person 6
Relationship to you (rank)	Mother	Father	Partner	Brother	Sister	Child
Sex						
Age						
Do you live with ….. (Y/N)						
Does ….. know your HIV status? (Y/N) **If no, skip next 2 Q's**						
Did you tell your ….. yourself?						
If you did not tell, how does … know?						
Is there any special reason for …… knowing/not knowing						
Has there been any major changes in these relationships since your diagnosis (N/Y)						
Do you regard ….. as your next of kin?						

15.

The following questions concern the extent of support you are able to get from these people.

INSTRUCTIONS

The following section concerns the people you have described as being close to you. For each person please circle a number from 1 to 7 to show how well he or she provides the type of help that is listed. The second part of each question asks you to rate how you would like things to be if they were exactly what you hoped for. As before, please put a circle around one number between 1 and 7 to show what your rating is.

Person 1

Relationship to you ______________________________

		Never			Sometimes			Always
1a.	Can you trust, talk frankly and share your feelings with this person?	1	2	3	4	5	6	7
1b.	What rating would your ideal be?	1	2	3	4	5	6	7
2a.	Can you lean on and turn to this person in times of difficulty?	1	2	3	4	5	6	7
2b.	What rating would your ideal be?	1	2	3	4	5	6	7
3a.	Does this person give you practical help?	1	2	3	4	5	6	7
3b.	What rating would your ideal be?	1	2	3	4	5	6	7
4a.	Can you spend time with this person?	1	2	3	4	5	6	7
4b.	What rating would your ideal be?	1	2	3	4	5	6	7

Person 2
Relationship to you____

Never Sometimes Always

1a.	Can you trust, talk frankly and share your feelings with this person?	1	2	3	4	5	6	7
1b.	What rating would your ideal be?	1	2	3	4	5	6	7
2a.	Can you lean on and turn to this person in times of difficulty?	1	2	3	4	5	6	7
2b.	What rating would your ideal be?	1	2	3	4	5	6	7
3a.	Does this person give you practical help?	1	2	3	4	5	6	7
3b.	What rating would your ideal be?	1	2	3	4	5	6	7
4a.	Can you spend time with this person?	1	2	3	4	5	6	7
4b.	What rating would your ideal be?	1	2	3	4	5	6	7

Person 3
Relationship to you____

Never Sometimes Always

1a.	Can you trust, talk frankly and share your feelings with this person?	1	2	3	4	5	6	7
1b.	What rating would your ideal be?	1	2	3	4	5	6	7
2a.	Can you lean on and turn to this person in times of difficulty?	1	2	3	4	5	6	7
2b.	What rating would your ideal be?	1	2	3	4	5	6	7
3a.	Does this person give you practical help?	1	2	3	4	5	6	7
3b.	What rating would your ideal be?	1	2	3	4	5	6	7
4a.	Can you spend time with this person?	1	2	3	4	5	6	7
4b.	What rating would your ideal be?	1	2	3	4	5	6	7

How do my family, friends and partner cope?

An invitation

Dear Clinic Attendee,

Partners, friends and family are important when it comes to emotional support, especially when we are going through a difficult time and when we are ill. We would like to explore how the supportive people in your life that know about your HIV status cope and adjust to that knowledge. We would like to talk to you, and if you agree, also to 1 or more of those people who support you. The aim is to identify how they feel about things like knowing your status, how they see the relationship with you and where they may be getting their support from. If your relative agree, their interview will be audio-taped for data collection purposes, and destroyed after the study is completed.

We hope that this will help us to identify more closely when and how we can support those who support you emotionally. It will also help us to help others affected by HIV.

The results of the study will be used to influence the psychological service we offer you and your loved ones directly. If you would like information or if you are interested in taking part in this study, please approach the receptionist or one of the doctors or nurses and tell them you want to make an appointment to see one of us.

Even if you are sure you do not want anyone to talk to a loved one, we would still like your views. At no point will we contact anyone without your written permission. Please do not hesitate to call me if you have any questions.

Thank you for your consideration.

Peter du Plessis
CASCAID

Appendix 13: Family Consent Form

Lambeth, Southwark & Lewisham Health Commission
Guy's & St Thomas' Hospital Trust, St Thomas' Hospital

CONSENT FORM FOR PARTICIPATION IN RESEARCH PROJECTS & CLINICAL TRIALS

Title of Project: Family Perceptions and Experience of Disclosure of HIV Positive Status

Principal Investigator: Peter du Plessis
Other Investigator/s:
enrolling patients:

Ethics Committee No: EC98/369

Outline explanation:

The purpose of this study is to investigate how we may be able to emotionally support relatives, partners and close friends of someone who is unwell. The result of the study should help us to provide optimum care for people who use our service and their loved ones. Your involvement would consist of a 30 minute interview between yourself and one of us, arranged at a mutually convenient time and place. Your participation is entirely voluntary and if you wish not to participate it would in no way affect the care your relative/friend receives.

Please read and sign if appropriate:

If I agree to the interview being audio-taped, the researchers assure confidentiality and security of the tapes and that the tapes will be destroyed when they are no longer required for research. If I so wish, a transcript of the tape will be supplied to me.
I consent/do not consent to the interview being audio-taped (Please delete as appropriate)

Signed: ____________________

I (name) ____

of (address) ____

____

hereby consent to take part in the above investigation, the nature and purpose of which have been explained to me. Any questions I wished to ask have been answered to my satisfaction. I understand that I may withdraw from the investigation at any stage without necessarily giving a reason for doing so and that this will in no way affect the care my relative/friend receives.

SIGNED (Volunteer) ____________________________ **Date:** ____________

(Doctor) ______________________________ **Date** ________________

(Witness, where appropriate) ________________________ **Date** __________

3 copies required:- one for researcher, one for patient/volunteer, one for patient's notes

Appendix 14: Family Information and Return Slip

LEWISHAM
& GUY'S
MENTAL HEALTH NHS TRUST

Telephone: 0171 407 2000
Extension 222

Date: ____________

Name ______________________

Dear,

Thank you for your consideration to participate in a study we are carrying out. The purpose of this study is to investigate how we may be able to emotionally support relatives, partners and friends of someone who is unwell. The results of the study should help us to provide good care for people who use our service and their loved ones. Your participation will be very valuable and appreciated. Please note that your participation is entirely voluntary and if you decide you do not wish to take part, this will not affect the care your relative/friend receives in any way.

The interview will be confidential and last approximately 30 minutes. During the interview you will be asked about aspects of your relatives/friends health, how you found out about their health status and about your own experiences since then. We accept that you may decide not to answer certain questions during the interview.

If you allow us, we would like to audio-tape the interview. We assure you of the confidentiality and security of the tapes and that the tapes will be destroyed when they are no longer required for research. If you so wish, a transcript of the tape will be send to you. The interview will be arranged at a mutually convenient time, either at the clinic or at your home. If you decide to participate could you please contact me by returning the slip below in the stamped addressed envelope provided, or if you wish, telephone me on the above number. If you need more information about the project please do not hesitate to telephone me on the above number.

Peter du Plessis
Consultant Clinical Psychologist

✂---

I am interested in taking part in this study: Yes ☐ No ☐ (Please ✓)
Your name: ______________________________ Serial number: __________
Address: ____
____________________________________ Postal Code: ____________
Telephone numbers: Day time: ________________
Evening: ________________

Permission to leave message: Yes ☐ No ☐ (Please ✓)
Please return to: 307 Borough High Street, LONDON, SE1 1JJ (Stamped envelope supplied)

Appendix 15: Questionnaire for Patients who Agreed to a Family Interview

Serial Number	☐	CD4	☐
Today's Date	☐	Date of CD4	

1. Age (years) ☐☐

2. Sex: Female ☐ 1 Male ☐ 2

3. Country of Birth: ☐

4. Ethnic Origin *please tick*

White	☐	1	Chinese other	☐	8
White Other	☐	2	Vietnamese	☐	9
Indian	☐	3	African (excl West Indies)	☐	10
Pakistani	☐	4	Caribbean (inc West Indies)	☐	11
E African Asian	☐	5	Other *(please specify)*	☐	12
Bangladeshi	☐	6	________________		
Chinese *(Hong Kong)*	☐	7	________________		

5. Are you Employed ☐ 1 Unemployed ☐ 2

5a. If unemployed, is this a result of your HIV infection?

Yes ☐ 1 No ☐ 2

5b. If unemployed, was it because of:

Discrimination ☐ 1 Sickness ☐ 2

6. Occupation (current or last job) ☐

7. Employment Position *(please tick)*

Self employed	☐	1
Manager/Supervisor	☐	2
Employee	☐	3
Apprentice	☐	4
Student	☐	5

8. Concerning your living arrangements, do you: *(please tick)*

Rent from landlord	☐	1
Rent from Housing Association	☐	2
Own your own home	☐	3
Squat	☐	4
Live with parents	☐	5
Stay in bed and breakfast	☐	6
Have no fixed living arrangements	☐	7
Other	☐	8

9. Do you remember the date when you were first diagnosed with HIV?

Yes ☐ 1 No ☐ 2

If Yes: When? ☐

10. How do you think you contracted HIV?
(Please tick more than one if necessary)

Sex with same sex partner		1
Sex with opposite sex partner		2
Sex with both men and women		3
Through injecting drugs		4
Through blood transfusion		5
Do not know		6
Other		7

11. If you are receiving any treatment for HIV, can you please list them?

1		5	
2		6	
3		7	
4		8	

12. What is the relationship you have with the person/s that I am going to interview?

Male partner		1
Female partner		2
Mother		3
Father		4
Sister		5
Brother		6
Close friend		7

13. Do you have any concerns about the effect an interview would have on:

a. this person	Yes	1	No	2
b. your relationship with this person	Yes	1	No	2

14. If YES, what are these concerns? ______________________________

15. Do you think the relationship has changed since you told this person about your HIV+ status?

Yes	1	No	2

How? ______________________________

16. Has the way this person behaves towards you changed over the time since they have known about your HIV+ status?

Yes	1	No	2

if YES, how? ______________________________

17. Did this person find out other things about you at the time you told them about your HIV+ status?

Yes	1	No	2

What? ______________________________

____

Any additional information: ______________________________

Appendix 16: Questionnaire for those who said NO to a Family Interview

Serial Number		CD4	
Today's Date		Date of CD4	

1. Age (years) ☐☐

2. Sex Female ☐ 1 Male ☐ 2

3. Country of Birth ________________

4. Ethnic Origin *please tick*

White		1	Chinese other		8
White Other		2	Vietnamese		9
Indian		3	African (excl West Indies)		10
Pakistani		4	Caribbean (inc West Indies)		11
E African Asian		5	Other *(please specify)*		12
Bangladeshi		6	________________		
Chinese *(Hong Kong)*		7	________________		

5. Are you Employed ☐ 1 Unemployed ☐ 2

5a. If unemployed, is this a result of your HIV infection?
Yes ☐ 1 No ☐ 2

5b. If unemployed, was it because of:
Discrimination ☐ 1 Sickness ☐ 2

6. Occupation (current or last job) ________________

7. Employment Position *(please tick)*

Self employed		1
Manager/Supervisor		2
Employee		3
Apprentice		4
Student		5

8. Concerning your living arrangements, do you: *(please tick)*

Rent from landlord		1
Rent from Housing Association		2
Own your own home		3
Squat		4
Live with parents		5
Stay in bed and breakfast		6
Have no fixed living arrangements		7
Other		8

9. Do you remember the date when you were first diagnosed with HIV?

Yes		1	No		2

If Yes: When? ☐

10. How do you think you contracted HIV?
(Please tick more than one if necessary)

Sex with same sex partner		1
Sex with opposite sex partner		2
Sex with both men and women		3
Through injecting drugs		4
Through blood transfusion		5
Do not know		6
Other		7

11. If you are receiving any treatment for HIV, can you please list them?

1		*5*	
2		*6*	
3		*7*	
4		*8*	

12. What are your concerns about someone close to you being interviewed?

____

13. Do you think your relationship has changed with people you told about your HIV status?

Yes	1	No	2

If YES, How? ____

15. Has some people who you told about your HIV diagnosis changed in their behaviour towards you?

Yes	1	No	2

If YES, how?

____

Any additional information:

____

____

____

____

____

Appendix 17: Self-defined Family Questionnaire

Patient Serial Number Today's Date

Family member:

1. Age:

	✓	
15-20		1
21-25		2
26-30		3
31-35		4
36-40		5
41-50		6
51-60		7
61-70		8
70+		9

2. Relationship to HIV+ patient:

	✓	
Male partner		1
Female partner		2
Mother		3
Father		4
Sister		5
Brother		6
Other		7

3. Country of Birth

England		1	Europe		7
Scotland		2	Africa		8
Wales		3	Asia		9
Ireland		4	Australia		10
North America		5	Caribbean		11
South America		6	Other		12

4. Ethnic Origin

	✓			✓	
White		1	Chinese other		8
White Other		2	Vietnamese		9
Indian		3	African (excl West Indies)		10
Pakistani		4	Caribbean (inc West Indies)		11
E African Asian		5	Other *(please specify)*		12
Bangladeshi		6			
Chinese *(Hong Kong)*		7			

5. Employment Position

	✓	
Self employed		1
Manager/Supervisor		2
Employee		3

Apprentice		4
Retired		5

6. Have you ever had an HIV test?

	✓		✓
Yes		No	

7. Own HIV status

	✓		✓		✓
Positive		Negative		Do not know	

8. Do you remember when ...... told you about his HIV status?

Yes		No	

If YES, what do you remember about that situation? ______________________________

____

9. What do you think prompted .... to tell you that he is HIV+? ____________________

____

10. Do you think he planned to tell you at that time?

YES		NO	

11. What was your first reaction when you found out about ..... being HIV+?

	✓	
Shock		1
Sadness		2
Anger		3
Surprise		4
Not surprised		5
Other		6

Other: ______________________________

12. Did you ever suspect that your .... may be HIV+?

	✓		✓
YES		NO	

13. How are things now, ...months/years later? ______________________________

14. Do you feel your feelings about it has changed over time?

	✓		✓
YES		NO	

How? ____

15. Could you explain what made your feelings change? ______________________________

16. What has helped you to cope? ______________________________________

17. What makes it difficult to cope? ______________________________________

18. Would you say the relationship with .... has changed since you found out about his HIV+ status?

	✓		✓
YES		NO	

19. If Yes:

a. Could you tell me how it has changed? ______________________________

b. What do you think has changed it? ______________________________

c. Did you the way you found out make a difference in how you reacted and feel today?

	✓		✓
YES		NO	

How? ____

20. If No

a. Why would you say it has not changed? ______________________

21. a. Does anyone close to you know that .... is HIV+

	✓		✓
YES		NO	

Who?

	✓	
Male partner		1
Female partner		2
Mother		3
Father		4
Sister		5
Brother		6
Friend		7
Other		8

Other: ______________________

b. How did they find out? ______________________

c. Do you talk about ... being HIV+?

	✓		✓
YES		NO	

How? ______________________

d. Does talking help?

	✓		✓
YES		NO	

How? ______________________

22. Where or who do you get your support from?

	✓	
Male partner		1
Female partner		2
Mother		3
Father		4
Sister		5
Brother		6
Friend		7
Other		8

Other: ______________________

23. Were there other things that you did not know of that you found out at the time?

	✓		✓
YES		NO	

If Yes, what? ______________________

How did that make you feel? (What was your reaction to that?) ______________________

Ask person if they have anything to add relating to:

1. Their relationship with the person who is HIV? ______________________
2. Their own coping mechanisms? ______________________
3. Anything else relating to their knowledge of the person's HIV+ status? ______________________

Appendix 18: Thematic Framework: Qualitative Analysis

1 **HIV status affecting relationships**
1.1 Disclosure: planned or unplanned (method)
1.2 Direct or indirect disclosure
1.3 Reasons for disclosure
1.4 Reaction to disclosure
1.5 Change in relationship due to disclosure?
1.6 Differences in reaction to disclosure by different relationship
1.7 Other relatives / friends involvement

2. **Knowledge of HIV**
2.1 Degree of knowledge before or at disclosure
2.2 Where/how obtained knowledge
2.3 Knowledge at time of interview

3. **Adjustment**
3.1 Change in relationship over time?
3.2 Level of knowledge affecting adjustment
3.3 Other factors affecting adjustment

4. **Support mechanisms**
4.1 Who gives support?
4.2 Degree of support
4.3 How support obtained
4.3.1 Through talking
4.3.2 By being informed
4.3.3 Own coping mechanisms
4.4 Level of support at disclosure
4.5 Recognising the need for support
4.6 Reasons for not getting support
4.6.1 Suppression of feelings
4.6.2 People only supportive to PP
4.7 Other problems in getting support

5. **Coping mechanisms**
5.1 Factors influencing coping
5.1.1 Coping of PP
5.1.2 Personality of FP
5.1.3 Meaning of death + future implications
5.1.4 Level of involvement
5.1.5 Support network
5.1.5.1 Talking
5.1.5.2 Ignorance
5.1.6 Information/Knowledge
5.1.7 Characteristics of HIV

CASCAID is part of the Substance Misuse and HIV Directorate of Lewisham & Guy's Mental Health NHS Trust. The other services provided by the Directorate include:

Signpost

Castlewood Centre, 25 Shooters Hill,
London SE18 4LG

Telephone **0181 319 8632**

DUAL Team Catford

Unit 7, Eros House, Brownhill Road,
London SE6 2EG

Telephone **0181 695 1090**

DUAL Team Blackfriars

151 Blackfriars Road,
London SE1 8EL

Telephone **0171 620 1888**

The Beresford Project

36-42 Hare Street,
Woolwich SE18 6LZ

Telephone **0181 854 9518**

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307 Borough High Street, London SE1 1JJ
Telephone 0171 407 2000

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HIV/AIDS Mental Health services

0171 407 2000

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LEWISHAM
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Who we are and what we do
Who we help
How the service works
Confidentiality

Psychological therapies
Neuropsychological assessments
Psychiatric service
Working with families and children
Working with other health services
Advice and information for professionals

What to tell your client
What to do in a crisis or emergency
The team's base
Comments, suggestions or complaints
Useful names and addresses

Introducing CASCAID

CASCAID forms part of the Substance Misuse and HIV Directorate of Lewisham & Guy's Mental Health NHS Trust. The Directorate is managed and staffed by a team of professionals who are highly experienced in the field of problem drug and alcohol use and HIV.

CASCAID provides a specialist psychological, psychiatric and counselling service to people who are infected and/or affected by HIV/AIDS.

With its up-to-date knowledge of relevant research on HIV/AIDS issues, the team keeps pace with changing needs, introducing new services as appropriate, whilst monitoring and improving upon those that are already in place.

Who we are and what we do

The CASCAID team was formed in 1991 to provide a specialist mental health service to local people affected by HIV/AIDS.

The team includes psychologists, psychiatrists, a community psychiatric nurse (CPN) and administrative support. The team works closely with support staff to create a multidisciplinary team providing specialist support, treatment and information on mental health. The team has been very successful in forming collaborative links with other generic and specialist services.

Who we help

The people who use our services include:

- those who have recently been diagnosed and require support with psychological adjustment to their status
- those infected by the HIV virus who develop formal mental health problems which may or may not be related
- those with known mental health problems prior to a HIV/AIDS diagnosis

- people infected by the HIV virus who have organic brain problems related to HIV/AIDS
- those who need ongoing support to manage and live with their HIV/AIDS status
- partners, families, carers and significant others of people who have been diagnosed HIV positive
- children and parents infected or affected by the virus
- those who are at significant risk, or who feel they are at risk.

How the service works

We are keen to ensure that the referral of clients is made as simple as possible, so that the service is easily accessible to those who need it. We have an open referral system which means that clients can be referred by a variety of professionals, or by self-referral.

We have provided advice on making referrals on page 8.

Clients referring themselves or being referred will be given an appointment for a full assessment. This is a critical stage in the care and support of clients and it is important to ensure that the assessment is as comprehensive as possible. We explore and determine the needs of the client, with the client, and consider the whole picture - the more obvious problems the client is experiencing as well as other relevant factors, such as the needs of family, child care, partners and carers.

An appropriate care plan is then agreed with the client. CASCAID provides a wide range of services and, if appropriate, we can also refer the client on to other agencies, for example if they should need assistance with housing, or if they have specific behavioural problems.

Confidentiality

We understand the importance of confidentiality and we have drawn up a policy, clearly setting out the guidelines we work to, a copy of which is available on request.

The services we provide

Psychological therapies

CASCAID provides a wide range of therapies which include cognitive behavioural therapy and systemic therapy, all of which can be used in different ways when counselling individuals, couples, families, children and groups.

Neuropsychological assessment

When appropriate we carry out psychometric or neuropsychological assessments which can provide information about organic brain functioning, which may include the identification of early dementia.

Psychiatric service

If the initial assessment of a client indicates that psychiatric assessment is necessary we will arrange for the client to meet the appropriate members of the team who will devise a treatment plan, as necessary.

Working with families and children

When someone is diagnosed as having HIV/AIDS there are many issues to consider which can affect the whole family. A person may decide that non-disclosure or total secrecy is the best option for them, or they may want to be completely open about their situation. Any of these scenarios can affect the psychological functioning of the rest of the family.

If an individual affected by HIV/AIDS develops psychological problems this may relate to their family. For example, they may be concerned about how to help their family deal with their illness. We aim to provide the appropriate support in these situations, which may involve working with the family.

HIV-positive children have difficulties of their own, ie secrecy at school and with friends, sadness, difficulties in dealing with their parents. A specialist clinical child psychologist in the team attends to the needs of these young clients.

By offering a family service CASCAID can provide support and advice, with counselling for family members by team members who are very experienced with the particular problems created by HIV/AIDS.

Working with other health services

We believe that a close working relationship with other agencies is vital when trying to provide a seamless service to clients. We have several formal relationships with other specialist teams, but also strive to work constructively with GPs, social workers, district nurses and other professionals. We believe this method of working improves the services to clients and leads to mutual support, understanding and learning.

Inpatient services

CASCAID provides a therapeutic service to inpatients at Guy's, St Thomas' and Lewisham hospitals. In addition, we offer support and advice to staff who are caring for patients diagnosed as being infected by HIV, and guidance on the management of depression, adjustment problems, psychiatric disorders and dementia.

Specialist services

Members of the CASCAID team provide clinics at three genito-urinary medicine (GUM) clinics: the Lloyd Clinic at Guy's Hospital, Harrison Wing at St Thomas' and the Alexis Clinic at Lewisham Hospital, as well as a psychology clinic at Guy's Hospital and at the Blackfriars Road Resource Centre.

CASCAID provides a psychology clinic at Landmark, a community-based, non-statutory organisation which provides support to people with HIV/AIDS. Landmark is a community centre in Tulse Hill where people go to socialise, for meals, or for complementary therapies, such as massage.

We take referrals directly from these services or introduce clients to them if they are referred from elsewhere.

General

It is important for us to develop close links with other professionals who are or may become involved with the care of a client, for example district nurses. Effective two-way communication with anyone else who may be providing support to the client, including general practitioners or social workers, will be of benefit both to the client and to the professionals.

Any collaboration is always undertaken within the framework of our confidentiality policy.

We are keen to develop similar links with other agencies, thereby continually enhancing the services available to our clients.

Advice and information for professionals

We actively encourage people to call on us for advice and information and we are seeking to develop training programmes for others who would like to set up similar services or improve their existing services for people infected with the HIV virus.

The referral process

What to tell your client

If you wish to refer a client, please discuss the referral with them fully. Explain to them about CASCAID, how we include them in their treatment plan, and how you think they might benefit. Tell them that it would be helpful if they could provide the following information in order for us to provide maximum support and treatment, and please emphasise that the team has a policy of confidentiality:

- **name**
- **date of birth**
- **contact address**
- **a *brief* summary of present problems**
- **a *brief* recent history**
- **details of any prescribed or illicit drugs**
- **details of other agencies involved.**

If clients are resistant or reluctant to divulge information we will still accept the referral, and the client may be reassured by speaking to one of our team directly over the telephone. This can be arranged if required.

If you have any other questions about our service do call us, we are always happy to help.

What to do in a crisis or emergency

The CASCAID team is not a crisis service, but will always try to provide as much support as possible to people in need. In some circumstances, however, the use of emergency services is appropriate. All accident and emergency departments have on-call psychiatrists who will be able to assess clients if it is felt to be an emergency.

The team's base

The team is located at 307 Borough High Street, London SE1. The centre accommodates the staff and provides private counselling, interview space and training facilities. We plan to run training events and we would be happy to talk to other interested groups/individuals about using the premises for self-help groups, mutual support groups, etc.

We expect to occupy the building in late 1996.

Comments, suggestions or complaints

The team welcomes comments, suggestions, and complaints. We use any feedback as an opportunity to review our services, using constructive comment to improve the quality of our services to clients and other stakeholders.

For more information on how to comment or complain please contact the team manager.

Useful names and addresses

The Terrence Higgins Trust Helpline

Telephone 0171 242 1010 (3 pm to 10 pm)

BHAN (Black HIV/AIDS Network)

Telephone 0171 485 6756

Positively Women

Telephone 0171 490 5501

The Landmark

Telephone 0181 678 6686

Positive Youth

Telephone 0171 244 7495 or
0171 835 1045

National AIDS Helpline

Telephone 0800 567 123 (24 hours)

The Naz Project (London) for the South Asian, Turkish, Irani and Arab communities

Telephone 0181 741 1879

Appendix 20: CASCAID Referral Form

CONFIDENTIAL REFERRAL FORM - *CASCAID*

Patient Details

Is this person aware of the referral and why it is being made? Please ✓ Yes ☐ No ☐

Name: ______________________________ Date of birth: ____/______/________

Address:

____

______________________________________Postal Code: ________________

Telephone numbers: Day: ____________________ Evening: ________________

Please ✓ if the person has given permission to leave messages: ☐

Referral Details

Name: __________________ Telephone no: ____________

Address: ____

____Postal Code ____________

Reason for referral and brief summary of presenting problems:

Signed by referrer: ________________

General Practitioner

Name: ____________________________ Address (GP):____________________

____ Postal Code: ________________

Please ✓ if permission given for *CASCAID* to contact GP: ☐

Other agencies and people involved in patient care:

1.

2.

SEND TO:

CASCAID
307 Borough High Street
LONDON SE1 1JJ
Tel: 0171 407 2000 Fax: 0171 403 1328

***CASCAID* is part of the Specialist Directorate of the South London and Maudsley NHS Trust**

CASCAID is part of the Substance Misuse and HIV Directorate of Lewisham & Guy's Mental Health NHS Trust. The other services provided by the Directorate include:

Signpost

Castlewood Centre, 25 Shooters Hill,
London SE18 4LG

Telephone **0181 319 8632**

DUAL Team Blackfriars

151 Blackfriars Road,
London SE1 8EL

Telephone **0171 620 1888**

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For help, advice, or information about any problem related to HIV/AIDS

0171 407 2000

Provided by Lewisham & Guy's Mental Health NHS Trust for local people

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LEWISHAM
& GUY'S
MENTAL HEALTH NHS TRUST

CASCAID provides advice and support to people in the Lewisham and North Southwark area of London who have psychological problems relating to being infected or affected by HIV/AIDS.

For example, the people who use our services include:

- people who have recently been told they are infected with HIV/AIDS and need help with emotional adjustment
- people who are infected with HIV/AIDS and have mental health problems
- people who need psychological support to manage and live with their HIV/AIDS status
- partners, families and carers of people who have been diagnosed HIV-positive or who have AIDS
- people who are at significant risk of being infected, or who see themselves as being at risk.

When you visit us for the first time we will ask you for some details about your situation. The more we know about any problems you may be experiencing the more we will be able to help you. A contact address would also be useful.

Whatever you decide to tell us is treated in confidence, and if we have to talk to anyone else about your care - like your GP - we will tell you first.

All the services that CASCAID offers will be explained and then a course of action will be agreed.

Your treatment plan could involve any of the services that we offer.

These include:

- psychological assessment
- psychiatric assessment
- psychological therapies
- couple and family therapy
- psychological treatment for children
- neuropsychological assessments.

The CASCAID team also provides advice and support to other health services so that they, in turn, can help their patients who are infected with HIV/AIDS.

We also hold a clinic at Landmark, a community centre in Tulse Hill, where people can go to socialise, for meals, or for complementary therapies, such as massage.

The CASCAID team understands many of the problems associated with being infected with HIV/AIDS - problems that affect you, as well as those around you.

Appendix 22: Operational Policy

CASCAID OPERATIONAL POLICY

A. *CASCAID* is the specialist HIV Mental Health Team within the Specialist Directory of the South London and Maudsley NHS Trust (SLAM). SLAM is the main statutory providers of mental health care for the residents of Lambeth, Southwark and Lewisham.

Mission Statement

CASCAID provide a specialist psychological, psychiatric and counselling service to people infected and/or affected with HIV with a view to monitor and promote mental health through a client focused, flexible and individually tailored service and effective liaison with other generic and specialist services.

B. Description of the Team

The team is comprised of a group of multi-disciplinary mental health professionals who have all undertaken specialist training to ensure appropriate and effective responses to individuals, partners, families, carers and other professionals.

The team members include:

Consultant Clinical Psychologist (Manager) (1 WTE.)

Clinical Psychologists (2.2 WTE.)

Psychiatrist (0.4 WTE.)

Liaison CPN (1.0 WTE.)

Clinical Assistant in Psychiatry (0.6 WTE.)

Management and Secretarial staff (1.3 WTE.)

The team is based at 307 Borough High Street, London SE1, but operates clinics from various medical and community settings.

C. Referral, Allocation, Assessment and Named Worker Arrangements

The HIV Mental Health Team has been successful in developing professional working relationships with other HIV service providers.

i. Referral System

Referrers should be encouraged to use and fully complete the *CASCAID* standardised referral form. The administrative staff will process routine referrals as soon as it is received. When a referrer requests a quick response, administrative staff will inform one of the clinical staff and that team member will further investigate the request and make a decision about the management of the referral. In self-referral cases and referrals by telephone, a *CASCAID* team member will take the details and complete the referral form as comprehensively as possible. Routine referrals will be discussed at the weekly *CASCAID* team meeting.

ii. Quick response needs

When a quick response is requested and a "fast-track" response is required, the following apply:

1. If the patient for whom a quick response is requested lives in Lewisham or North Southwark.
2. If the "quick response" referral is made for someone outside the *CASCAID* catchment area, the following applies:

a) If the patient is attending one of the designated clinics and a member of the *CASCAID* team is available at the clinic at the time of the referral, that team member should assess the patient. If the intervention required does not fall within the remit of *CASCAID*, the patient's local HIV service or local emergency service should be advised of the necessary required action. This will usually apply to patients who need inpatient psychiatric treatment.

b) If the referred service user is not at a clinic or none of the *CASCAID* team members are available, the referrer should be asked to contact the patient's local specialist HIV or emergency services.

Out of district home visits should not be offered or undertaken. In the event of a quick response referral, the CASCAID team member dealing with the referral should discuss the basis of the quick response referral with the referrer. Administrative staff will not accept quick response referrals.

iii. Allocation

Allocations will be done as part of a weekly team meeting. The purpose of the meeting is the allocation of all new referrals to the team, feedback from new assessments and relevant update information on existing service users. In allocating new referrals the following will be considered:

a) The clinic/ venue which is most likely to be convenient to the service user.

b) The most suitable worker: Psychologist, CPN or Psychiatrist.

c) Whether a multi-professional assessment would be beneficial.

The service user will be informed of their appointment on the day of the allocation

D. Specific Service Objectives

The CASCAID team will work towards achieving the following objectives:

- An uncomplicated open referral system.
- To rapidly respond to referrals: 1 day for quick response referrals.
  Up to 14 days for non-urgent.
- Work collaboratively with other generic and specialist statutory and independent organisations e.g. GUM Services, Social Services, Landmark, Positive Place, etc.
- Appropriate communications with GP's and other referrers.
- Provide formal and informal training to other specialist and generic staff.
- Provide and receive high quality professional supervision.
- Implement and support appropriate monitoring and evaluation systems.
- Keep up to date with HIV research and issues.
- Develop the service in line with new information, research findings and own evaluations.
- Seek to undertake and publish research projects that will improve services locally and nationally.
- Seek to ensure fair and equitable access to the service, particularly by vulnerable or disadvantaged groups within the catchment population, e.g. women, black and ethnic minorities.
- Continually improve the support/services to service users, their partners, family, children and carers.
- Ensure staff and continuing professional development to promote a high quality service.

E. Client Groups

i. Service User Population

The team mainly provides services to the residents of Lewisham and North Southwark who are HIV infected and/or psychologically and mentally affected by HIV. There are some exceptions where the service are extended to residents outside the catchment area, but only where special arrangements are in place with particular teams or projects. These include:

Harrison Wing, St Thomas' Hospital
Lloyds Clinic, Guy's Hospital
Haemophilia Clinic, St Thomas's Hospital
Alexis Clinic, Lewisham Hospital
Haemophilia Clinic, Lewisham Hospital
King's Hospital Paediatric Clinics
New Cross Hospital Paediatric Clinic
Positive Place
Positive Parents, Positive Children
Landmark

The *CASCAID* Team offers services to residents of L&NS and to attendees of the above projects according to agreed protocols. Services will only be provided to attendees who attend the projects for **ongoing** treatment or care. Where an initial assessment by the *CASCAID* team indicate a need for community psychiatric support or where inpatient psychiatric care is likely to occur, the service user will be referred to a local service. In these cases clear information should be given to the patient about the decision to refer and support should be given to them until the local service responds.

Unless special circumstances apply the referral will be made according to the guidelines in this policy. The team manager has to be consulted in these circumstances and his/her decision will be final.

The service user group consists of all people infected or psychologically affected by HIV, residing in L&NS or attending a *CASCAID* associated project.

Within this definition certain groups take priority:

- Those with HIV related organic syndromes.
- Those with HIV who develop formal mental health problems subsequent to their HIV positive diagnosis.

- Those with known mental health problems prior to their HIV positive diagnosis.
- Those that benefit from ongoing support in managing and living with the knowledge of being HIV positive.
- Partners, family, children and significant others affected by the knowledge, illness or death of someone with an HIV positive diagnosis.
- People who repeatedly expose themselves to the risk of being infected with the HIV virus and who would like to change that behaviour.
- Those with an irrational fear of being infected with the HIV virus.

F. Interventions and Treatment

The interventions provided are based on individual need. The team seeks to promote optimal physical, psychological and social well being. This aim is best met in collaboration with other services. The *CASCAID* service considers mental health assessments as a key element to the planning of comprehensive interventions. Identifying individual need may be achieved in an initial meeting with a service user, or over multiple sessions.

In an attempt to optimise continuity of care, collaboration with community services should form a part of planned intervention throughout the treatment episode and in some cases beyond discharge as appropriate. All service users will be encouraged to register with a GP. The GP may act as an co-ordinator of different services for a particular service user.

i. Episode of Treatment

In an HIV mental health service, service users often return for treatment several times over a period of time. A definition of “treatment periods” is essential to conform to reporting requirements and to aid administration. An episode of treatment in the *CASCAID* service is defined by ongoing treatment with breaks in treatment of less than 3 months. A new episode of treatment starts after a period of 3 months has elapsed since discharge from the *CASCAID* service. Different criteria apply to different treatment modalities:

ii. Therapeutic interventions

Frequency:

People are seen on average every second week but this may vary according to the mental health assessment and the ongoing assessment of the team members involved.

Duration:

Duration of treatment is expressed in the number of therapeutic sessions. A session lasts between 50 and 60 minutes.

Short Term: 2 to 6 sessions per episode
Medium Term: 7 to 16 sessions per episode
Long Term: 17 sessions or more per episode

iii. Psychiatric Interventions

Frequency

People are seen on average every second week but this may increase depending on the presenting condition.

Short Term: Up to 2 months per episode
Medium Term: 3 to 8 months per episode
Long Term: Longer than 8 months;
(usually in the context of major psychiatric illness)

Patient management may include organising and attending case conferences of people with complex presentations. It may also include occasional community and home visits.

The initial response is to offer assessment, followed by the identification and planning of appropriate interventions. *CASCAID* aims to contribute to a co-ordinated response needs, taking a lead role in respect of the assessment of psychiatric and psychological needs and providing support and treatment with regard to service users' mental health needs.

The following terms would be used to describe the status with the service:

Active:

These service users are seen on a regular basis. They are considered formal service users and the length of contact is dependent on the service users needs.

Non-Active:

The team may or may not have had formal contact with the service user but they are aware of the service users potential or actual need from other workers, e.g. a service user who develops dementia and may not be wholly co-operative. On occasions unsolicited contact may be appropriate. In these circumstances the consent of the most immediate "relative should be acquired.

Discharged:

- When a service user has had formal contact with the service and the negotiated intervention is completed, or repeated offers for a mental health assessment has been decline. Other conditions for discharge are when a service user has moved to another district or the service user has died.

G. Prevention

In the context of this policy prevention is divided into two headings.

- Reducing the spread of HIV infection.
- Monitoring and promoting mental health of those affected by HIV.

i. Reducing the spread of HIV

The majority of service users seen by the team are HIV positive. Therefore it is of extreme importance that the service user understands the transmission routes of the virus so they may make informed decisions in regard to risk reductions in relation to; sexual partners, unborn children, other Intravenous Drug Users etc.

This will be achieved through:

- Information and explanation, when appropriate.
- Developing negotiating skills relating to sexual activity.
- Referral to other specialist workers e.g. Specialist drug teams.

H. Confidentiality

Confidentiality is a sensitive issue and must be considered in terms of offering the service user the optimum level of confidentiality whilst not interfering in appropriate collaboration and discussion and allow team members to work in a safe and acceptable professional framework.

Sharing information would be advocated when it is deemed to be in the service users' "best interests", usually with the service users' informed written consent (exceptions will be discussed).

CASCAID will share information in confidence where appropriate. Confidentiality is not about "keeping secrets" but about maintaining the trust, confidence and privacy of the service user. It cannot be assumed that other services would respond appropriately to confidentiality issues and it is deemed necessary to discuss confidentiality arrangements with other services as part of establishing a collaborative working relationship.

i. Staff Discussions

All discussions regarding service users should be carried out within:-

- Clinical meetings.

- Supervision/Support sessions.
- Private areas.

Staff must take responsibility for ensuring that information regarding individuals is not inappropriately or inadvertently disclosed.

ii. Other Agencies/Services

No information, verbal or written, is available to other agencies unless the permission of the service user is given. Permission for disclosure must be in writing. Disclosure forms must be completed, dated and signed by the service user. If necessary it should indicate the nature of the information disclosed and to whom.

iii. Exceptions to disclosure of information

- When there is a risk to a child of disclosure or abuse the welfare of the child is paramount. In cases where the *CASCAID* team member identifies a need to breach confidentiality, such a decision should be taken following in consultation with an appropriate member of the *CASCAID* team.
- In cases of actual and or threat of violence it may be necessary to inform other staff, other service users or the police. Where possible consultation with other team members should take place prior to disclosure.
- In cases of service users requiring urgent medical attention where emergency services need to be summoned, relevant information may need to be disclosed.
- Supervision register.
- If a member of staff is under subpoena they are legally bound to attend a court of law. Full support, including legal consultation will be provided to staff in this eventuality.

This operational policy aims to give the service:

- Boundaries.

- Structure.
- Direction.

The Mission Statement will be used to ensure the maintenance of overall service objectives and to evaluate the specific aims regarding the effectiveness of services and interventions. Service evaluations and annual quality assurance projects will be line with the operational objectives. The Operational Policy is a working document and will be reviewed from time to time to take into account development in the field of HIV.

The policy should be in line with national and local policy.

OpPolicy/Sept.99

Cascaid Service Statistics

Appendix 23

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Search Criteria for this Report: 1. Referral Dates: 01/01/99 To 31/12/99
2. Events/Bookings = Between 01/01/99 And 31/12/99

1. Services - Totals During Period	Total	Percentage
C/Agency	27	3.78%
C/Client	91	12.75%
Missed	111	15.55%
OK	485	67.93%

2. Services - By Type	Total	Percentage	Hours
Couple	2	0.28%	2.00
Family	26	3.64%	26.00
Group	0	0.00%	
Individual	691	96.78%	660.00
Teresa Mullaney	0	0.00%	

3. Services - Location	Total	Percentage
307 Borough High Street	383	53.64%
Alexis Clinic	13	1.82%
Beresford Project	32	4.48%
Blackfriars Road	0	0.00%
Bloomfield/Newcomen	0	0.00%
GP Surgery	0	0.00%
Harrison Wing	159	22.27%
Health Centre	0	0.00%
Home	31	4.34%
Hospital - In patient Guy's	6	0.84%
Hospital - In patient Lewisham	6	0.84%
Hospital - In patient Mildmay	9	1.26%
Hospital - In patient St Thomas	15	2.10%
King's College -Outpatient	0	0.00%
Landmark	5	0.70%
Lewisham Area Clinic	1	0.14%
Lewisham Outpatients	1	0.14%
New Cross Clinic	0	0.00%
Other	5	0.70%
Positive Place	0	0.00%
Signpost Clinic	51	7.14%
St Thomas' - Outpatients	2	0.28%

4. Services - Client Clinics	Total	Percentage
307 Borough High Street	48	6.72%
Beresford Project	29	4.06%
Blackfriars	9	1.26%
Harrison Wing	20	2.80%
Landmark	0	0.00%
Lewisham Hospital	20	2.80%

Positive Place	0	0.00%
Signpost	40	5.60%
York Clinic	8	1.12%

4. Patients Charter (Clients On-Time)	Total	Percentage
Clients Seen Within 30 Minutes	422	100.00%
Clients Notes Available	422	100.00%