
HIV TESTING FOR INSURANCE PURPOSES:

A MULTI-FACETED EXPLORATION OF THE

CLIENTS' EXPERIENCE

AND ASPECTS OF CURRENT PRACTICE

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Thesis presented for the Degree of Master of Arts (Clinical Psychology)

University of Natal, Pietermaritzburg

July 2001

ACKNOWLEDGEMENTS:

I would like to thank the people who encouraged and believed in this research, as well as the people who made the effort personally meaningful.

I would like to thank my supervisors Professor. L. Richter and Professor. R. Griesel.

I would like to thank Dr. J. Van Wyk, of the pathology company, Dietrich Street and Partners, for his continued encouragement, and Dr. Penman for his agreement to participate. Similarly, I would like to thank the members of the Life Officers Association, for being receptive to research of this nature. I would also like to thank Desire Daniels of Old Mutual, for her insightful contributions and support.

On a more personal note, I would like to thank my sons Joshua and Gideon Shapiro, for their encouragement and for putting up with me whilst in the throes of research fever, and during the periods of research apathy. I would also like to thank Leonard Schneider for unfailing belief in me, and Eric Joffe for his invaluable practical computer assistance.

Finally, I would like to thank the staff of the Cape Town based pathology depots who took the time to distribute the questionnaires, and the nursing sisters and insurance brokers who expressed their opinions regarding insurance HIV testing protocol. I would also like to thank all the insurance clients who were willing to complete the questionnaires, knowing that the benefit would hopefully accrue to others in time to come.

ABSTRACT

HIV testing is required for life assurance applications. A written information document distributed at blood collection (venisection) serves as pre-test preparation. This study reviewed the adequacy of the document and explored possible alternative arrangements, by means of three research phases conducted at the point of venisection. Phase 1 used a specifically designed questionnaire which included a demographic section and questions assessing the applicant's appraisal of being adequately prepared, and their understanding and experience of testing. Constructed measures established their state of anxiety at testing and their range of information about HIV/AIDS. Phase 2 consisted of a counselling intervention, followed by the questionnaire used in Phase 1. Phase 3 consisted of semi-structured interviews with nursing personnel and insurance brokers. The phase 1 results indicated that the majority of applicants knew they were having an HIV test, did not feel coerced, had a moderate level of information about HIV and were not overly anxious at testing. The level of information about HIV/AIDS showed a significant correlation with their level of education, and the information document emerged as inadequate preparation. Answers given in Phase 2 differed qualitatively from those in Phase 1. Greater consideration of the impact of a positive result was shown, with increased concern about the implications for other people and anticipated acceptance of a positive result emerged in Phase 2. The personnel interviewed for Phase 3 indicated that they felt ill equipped to offer pre-test preparation.

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CHAPTER 1

CONTEXT OF THE STUDY

1. INTRODUCTION

Insurance cover is an essential component of modern finance, serving both as collateral and as a promise of security against life's misfortunes or crisis. Underwriting is the exercise of risk assessment and classification of potential clients. It is a cornerstone of insurance practice, argued to preserve the continued financial survival of the company. Based on an underwriting assessment, an applicant who represents potentially excessive risk for the insurer would be refused cover, or have a premium loading. Underwriting has been practised since the inception of insurance, but with the advent of HIV / AIDS these traditional underwriting practices have been questioned for their current relevance and possible impact on human rights.

Human-immunodeficiency virus (HIV) testing is a requirement for life assurance application. This practise, although challenged by AIDS activists and other groups, is now an established component of insurance underwriting procedure. As there is little possibility of altering these entrenched underwriting principles, a pragmatic focus for improving the protocol would therefore lie in ensuring proper and ethical management of client preparation for the HIV test and notification of the results. This pragmatism is the guiding principle underpinning this research. The primary intention of the study was to ascertain the adequacy and effectiveness of current client preparation procedures, and to explore areas of possible improvement. This was achieved by examining three related dimensions of insurance HIV testing at the point of venisection (blood sample collection):

1. The client's subjective preparedness for HIV testing for insurance purposes. This was achieved through the distribution of a questionnaire, which was completed by the insurance applicant at the venue, immediately following venisection.
2. The practicality and feasibility of offering in-situ pre-HIV test counselling was explored by means of individual, semi-structured interviews conducted with fourteen nursing sisters and ten insurance brokers.

3. A pilot intervention was conducted by the researcher and evaluated. The intervention consisted of pre-test counselling given to a sample of 35 insurance applicants, as an integral component of the venisection procedure.

A literature review was undertaken to assist with the design and construction of the questionnaire. The current state of the pandemic, relevant psychosocial issues, as well as life assurance and ethical principles were considered. As there is such a paucity of specifically South African research on the subject, these are noted when they appear in the text.

Sub-Saharan Africa has become the global epicentre of infection. Recent estimations indicated that between 72-90% of people living with HIV or AIDS, are living in developing countries (Doyle & Esterhuysen, 1994; Lachman, 1999; SAFAID News, 1997; Stenicki, 1999; UNAIDS, 2000; Webb, 1994). Predictably, 80% of all AIDS-related deaths between 1998 and 2000 occurred in these areas (Stenicki, 1999; UNAIDS, 2000). In the early 1990's South Africa was 'trailing behind' on these statistics. In the later part of the decade the rates began to increase rapidly, and currently 1 in 7 new infections occurring in Africa, are occurring in South Africa (ibid.).

South African reviews confirm the spread of infection has remained largely unchecked in this country (Lachman, 1995, 1999; SAFAID News, 1999; Slawski, 1996; Stenicki, 1999; Swanevelder, 1996; Swiss Re Life & Health, 1998a, b). The reviews are conducted primarily through antenatal epidemiological surveys, which reveal a prevalence rate of 15-25%, with women in their twenties most frequently infected (Carpenter, Kamali, Ruberantqari, Malamba & Whitworth 1999; Stenicki, 1999; Swiss Re Life & Health, 1998a, b).

This scenario makes it clear that many of the catastrophic predictions of the impact of HIV and AIDS on the survival of the life assurance industry, whilst justifiably challenged in some countries, are relevant in Southern and Sub-Saharan Africa (Booth, 1993; Theys, 1994). This high prevalence rate not only justifies ongoing risk assessment for HIV/AIDS as an essential component of life assurance application, but also the need for optimum responsibility in applicant preparation for the HIV test.

1.1.HUMAN IMMUNE-DEFICIENCY VIRUS (HIV) AND ACQUIRED-IMMUNE DEFICIENCY SYNDROME (AIDS)

Sexually transmitted diseases (STDs), including HIV and AIDS, have been identified as one of the most important public health problems in Sub-Saharan Africa, including South Africa (Abdool-Karim, 1996; AIDS Scan, 1997; Alexander, 1996; Entmacher, 1988; Stenicki, 1999; Vancouver Report, 1996; World Health Organisation [WHO], 1996a, b). The South African context mirrors the worldwide pattern of the spread and management of HIV and AIDS in many important respects, whilst also representing a unique scenario, with distinctive difficulties, limitations and potential solutions. Much of the literature distinguishes between different aspects of the HIV and AIDS pandemic. The pandemic has been described as occurring at two or more inter-related tiers. The first tier relates to distinctive geographical or regional population group patterns of new infection. Sexual orientation and socio-economic circumstances are central defining features for these patterns. The second tier pertains to characteristic stages of the progression of the epidemic itself. Three stages identified describe the rate of new infection, the impact of the illness and death, and the social response to those infected. Both tiers are discussed below.

1.1.1. Regional Patterns

The rate of infection is spreading at an alarming rate amongst some regions and is declining in others, leading to a bi-phase characteristic epidemiological pattern of HIV infection occurring in different regions of the world (Aggleton, 1989; Frankenberg, 1989; Lachman, 1995, 1999; Smallman-Raynor, Cliff & Haggett, 1992). The first regional pattern was identified in the United States of America, Europe, Australia and Latin America in the 1980s, where the population groups known as the four 'H's'¹ were most susceptible to infection. These groups bore the full brunt of the first negative social response to the epidemic (Frankenberg, 1989). White middle class homosexual men, however, represented a wealthy and well-organised group, who mobilised themselves to respond to both the rate of infection and the social repercussions of the epidemic (Frankenberg, 1989; Panos Dossier, 1990, 1992). Currently, due to effective preventative education, and the screening of all blood products, the infection rate within these regions has begun to plateau or decline, but they are still faced with people who are sick and dying of AIDS. In the 1990s, a second regional pattern was identified in East, Central and Southern Africa, and the Caribbean, where a heterosexual spread of infection predominated (ibid). During this period,

1 Homosexual men, Haitians, habitual intravenous drug users and haemophiliacs

the pattern in the U.S.A. also shifted to affect under-privileged members of black and Latino communities, who were simultaneously exposed to infection through the use of shared needles and heterosexual sex. The rate of infection in these regions is unchecked and still rising steadily, with a prevalence estimation in Sub-Saharan and South African studies ranging from between 25-80% of the 20-40-year-old population, depending on the specific geographic area (Lachman, 1999; SAFAID News, 1997; Slawski, 1996; Stenicki, 1999; Swanevelder, 1996). Women constitute a significant proportion of these rates, with up to 20-25 % of pregnant women being diagnosed sero-positive (Carpenter, et. al., 1999; Lindegger, 1996; Moodie & Alexander, 1996; Strebel, 1994; Swanevelder, 1996; Swiss Re Life and Health, 1998a, b).

1.1.2. The Third Epidemic

The simultaneous occurrence of three separate, although closely interconnected 'epidemics' has been suggested (Aggleton, 1989; Frankenberg, 1989; Mann & Bagnoud, 1993; Namir, Alumbaugh, Fawzy & Wolcott, 1989; Panos Dossier, 1990). The first of these epidemics relates to the continuing spread of HIV infection. This is a silent and insidious process, with people infecting and becoming infected with little awareness, mainly due to the protracted period between infection and symptoms. The first epidemic is being addressed, predominantly through preventive education, with variable effectiveness. The second epidemic involves the increasing numbers of people who are sick and dying from AIDS (Aggleton, 1989; Aggleton, Homans, Mojsa, Watson, & Watney, 1989; Frankenberg, 1989; Mann & Bagnoud, 1993; Namir et al., 1989; Panos Dossier, 1990; Van Dyk, 1999; WHO, 1996a, b). There are enormous financial and social repercussions of this phase.

The third epidemic is the social, cultural and political reactions to HIV and AIDS. This phase is charged with emotion and opinions evoking denial, blame, stigmatisation, prejudice and discrimination in both the individual and the collective, undermining efforts at prevention and intervention (Gilmore & Somerville, 1994; Joffe, 1992, 1994; Kubler-Ross, 1987; Panos Dossier, 1990, 1992; Schulman, 1988b; Slawski, 1996; Sontag, 1988; Watney, 1988). The prolonged time from infection until the occurrence of symptoms, ranging from 4 – 10 or more years, represents a major difference between HIV and AIDS and other epidemics experienced in the past (Panos Dossier, 1990; Smallman-Raynor et al., 1992). This extended period has accentuated and intensified the impact of the third epidemic (Panos Dossier, 1990). Norms and social practices

have been challenged and compelled to change to accommodate people's co-existence with the threat of the virus. The social response to the AIDS pandemic has proved to be the most difficult area to manage, as AIDS is not merely an illness but has been ascribed meaning and judgement (Babcock, 1978; Gilman, 1988a, b; Helman, 1984, 1991; Kubler-Ross, 1975, 1987; Sontag, 1979, 1988).

This third pandemic is interwoven with the others, as social stigma has influenced the management of all aspects of the pandemic. Life assurance testing occurs within this social milieu, escaping none of the stigma or social repercussions associated with an HIV positive result. The relevance of this third epidemic is therefore an unquestionable aspect of insurance-related HIV testing.

1. 2. PSYCHO-SOCIAL ISSUES ASSOCIATED WITH HIV / AIDS

Numerous psycho-social, medico-legal and ethical issues have either a general or specific relevance to HIV and AIDS (Aggleton & Homans, 1988). The general issues relate to the emotional response and need for social support, which would be precipitated by any major life event or crisis (Hedge, 1990; Namir et. al., 1989; Sinah & Verma, 1994). More specific issues, such as social sanctions and myths associated with HIV / AIDS, or the debate regarding the primacy of individual versus community rights in managing the pandemic, have evolved in direct response to the current pandemic. The issues are mutually influential and play a significant role in the subjective experience and concerns inherent in testing for HIV, and as such will be discussed below.

1.2.1. Social Support

The availability of real or perceived social support is important in the management of every aspect of the epidemic (Hedge, 1990; Namir et al, 1989; Sinah & Verma, 1994). As the syndrome is known to be contagious and devastating in character, combined with the stigmatising qualities, accentuates the need for social support. These features, however, tend to reduce the psychosocial support available. Lack of support has been widely associated with poor physical and mental health, especially in the event of a major negative life event (ibid). Concern about the availability of social support could be regarded as a major consideration and concern for almost any person undergoing an HIV test, and justifies serious consideration of pre-test counselling.

1.2.2. Social Sanctions

The stigma associated with AIDS and HIV infection appears to be universal, deep and pervasive (Abramson, 1992; Panos Dossier, 1990; 1992), and has influenced the public response both to the epidemic and to individuals who are sero-positive or at high risk of infection. An illness, which is sexually transmitted, is automatically vulnerable to social judgement and sanctions (Gilmore & Somerville, 1994; Goldin, 1994; Panos Dossier, 1990). When the sexuality referred to is of a 'deviant' or alternative form (Hernandez, 1993; Watney, 1987, 1988), or relates to an impoverished (Theys, 1994) or marginalized population group (Marcham, 1990; Strebel, 1994), the negative social attributions are multiplied.

1.2.3. Myths About HIV / AIDS

There are still numerous myths and beliefs about HIV and AIDS. Most of these involve misconceptions about means of transmission, fears about casual contagion, and preventative actions taken by the authorities (Whiteside, 1991, 1994). People still believe that HIV and AIDS can be spread through a handshake, by using public swimming pools or toilets (Gray, 1988) or by working with a person with HIV or AIDS (International Consultation on AIDS and Human Rights, 1989). These myths and beliefs persist independently of educational levels. Some of these myths reflect a degree of mis-information, while others express underlying social prejudices (Clift & Stears, 1989), taboos and sanctions (Panos Dossier, 1990). The continued breach of human rights is one effect of these persistent myths (Mann & Bagnoud, 1993; Whiteside, 1990, 1991).

1.2.4. Media

The media has had a significant impact on public awareness and perception of HIV and AIDS. A great deal of valuable information has been disseminated in the media, but there have also been distortions and sensationalist reports, many of which have left lasting misconceptions (Grover, 1989; Herdt, 1992; Barcena cited in Panos Dossier, 1990; Pippert, 1989; Shilts, 1987; Silverman, 1989; Swenson, 1989; Watney, 1987, 1988). The negative effects of this kind of reporting have been to create excessive anxiety about HIV (Editorial, Aids Analysis, 1991; Mhitsi, 1996; Van Niftrik, 1995; Van Niftrik & Whiteside, 1991; Whiteside, 1990, 1991, 1994, 1996a). This is counter-productive to social and behavioural change (Campbell, 1967; Fishbein & Ajzen, 1975; Fishbein, Middlestadt & Hitchcock, 1994), as people tend to ignore or deny that which makes them too anxious. Sadly, after all the media attention, knowledge about HIV and AIDS in South Africa remains superficial (Armstrong, 1994; Cameron, 1993; Mhitsi, 1996; Van Niftrik, 1995; Van Niftrik & Whiteside, 1991).

1.2.5. HIV / AIDS Highlighting Disempowerment and Bio-Psycho-Social Injustice

Theys (1994) eloquently states that 'AIDS is an equal opportunity disease which does not distinguish between male or female, rich or poor, black or white, nor does it stop to enquire about a victim's sexual orientation before it infects him or her' (p54). Although this statement is essentially true, the last decade has demonstrated that certain persons are more vulnerable to infection than others, due largely to a lack of personal autonomy, diminished social status and disempowerment, often, but not exclusively, associated with poverty (Aggleton & Homans, 1988; Marcham, 1990; Strebel, 1994; Swenson, 1989). Such persons also frequently experience greater stigmatisation when they become HIV positive. As the 'gay' community is increasingly seen as hermetically sealed (Patton, 1989), the ongoing transmission of HIV is frequently attributed to women (Aggleton & Homans, 1988; Maduna-Butshe, 1997; Van Niftrik, 1994), who are held largely responsible for the practise of safer sex (Strebel, 1994). The political role of women in society, combined with their widespread financial vulnerability and dependence on a male partner translates into an inability to insist on either abstinence from sexual activity or the practise of safer sex, and renders women an easy scapegoat (Maduna-Butshe, 1997; Schoepf, 1992; Sobo, 1995). Women are also anatomically more likely to become infected than their male counterparts (Carpenter et. al., 1999; Salus, 1991). Women therefore experience a 'quadruple jeopardy' in relation to the virus: being vulnerable as individual sufferers, as mothers who can transmit the virus vertically to their infants, as caregivers who will be responsible for the care of the sick (Marcham, 1990) and as the recipients of stigma and violence when infected. Of a reported 2.7 million new infections, over 50% are among women (Sobo, 1995). In South Africa, black women, in particular, are experiencing a rapidly increasing rate of infection (Wilkinson & Habgood, 1997), along with the teenage population (Solomon, 1996). HIV testing threatens the woman's 'dream of monogamy', and many prefer not to be tested or, if they are tested, prefer to think of the test as merely a routine procedure (Sobo, 1995), thereby minimising the significance of the precautionary education and the result.

1.2.6. Age as a Variable for Consideration

The prevalence estimation of between 25-80% of the 20-40-year-old population highlights the need to address this group in particular (Lachman, 1999; SAFAID News, 1997; Slawski, 1996; Stenicki, 1999; Swanevelder, 1996). Balmer, Seeley & Bachengana (1996) found that the group making the greatest use of the counseling service were in the 25-34-year-age range,

probably due to extensive pre-marital testing, and a high rate of sexual activity. This result indicates that this age group are aware of the need to be tested, and are willing to present themselves for voluntary counseling and testing when this service is made more accessible. This is also an age group likely to apply for life assurance, due to the frequency of marriage in this age range. The insurance industry could therefore be argued to be in an ideal position to offer testing, and counseling where possible, to a group clearly needing and wanting such an intervention. ~

1.2.7. A Cross-Cultural Psychological Perspective

In the South African context, an important consideration lies with cultural diversity and variable needs. A primary error within traditional western psychology has been the assumption of the 'psychic unity' of all persons, assuming that psychological processes are universal and in accordance with established western norms (Berry, 1994; Draguns, 1989; Jahoda, 1989; Mkhize, 1994).

Triandis (1989, 1994) identifies the socio-cultural dimension of individualism and collectivism as a primary focus within the field of cross-cultural psychology. This paradigm underpins numerous aspects of social life, including economic development, social organisation, religious and moral views, and the conceptualisation and management of illness and death (Van Dyk, 1992).

The attributes which constitute 'individualism' or 'collectivism' are well established. Individualism pertains to societies in which the 'I' consciousness is emphasised, and where autonomy, emotional independence, individual initiative, the right to privacy, pleasure seeking, financial security, the need for specific friendships and universalism are valued (Kagitcibasi, 1994; Kim, Triandis, Kagitcibasi, Choi & Yoon, 1994; Triandis, 1989, 1994). An ethic of idiocentrism prevails, where individual rights form a central moral and ethical basis upon which institutions and institutionalised ethics are erected.

In collectivist societies people are integrated from birth onwards into a strong, cohesive in-group which continues to protect them in exchange for loyalty. The emphasis is upon a 'we' consciousness and a collective identity, with the views, needs and goals of the 'in-group' prioritised (Triandis, 1989, p 52). Social norms and duties are defined by this group, and

emotional interdependence, group solidarity and sharing duties and obligations are prioritized (Bond, 1994; Kagitcibasi, 1994; Kim, 1994; Kim et al., 1994; Triandis, 1989, 1994). The South African context contains variations of both orientations among the population, requiring conceptual coexistence for psychological understanding (Sinha & Tripathi, 1994).

The distinction between these cultural dimensions is important in regard to preparation for HIV testing, as the prevalent western or individualistic assumptions and practices are not always relevant or ethical when viewed against a collectivist backdrop (Van Dyk, 1992; Wassenaar, 1992). The level of difficulty or ease in interpersonal communication is found to vary significantly cross-culturally (Tan, 1980; Triandis, 1989). An extension of this ability to communicate, relates to the real or perceived availability of social support as an important social facet, particularly at times of major life stress. Generally, the individual in an allocentric culture receives more social support than the individual living in an idiocentric environment (Triandis, 1989, 1994). The reverse situation may, however, occur should the individual within the allocentric culture represent a threat to the safety of the group, which is always regarded as paramount. Extreme ostracism and social isolation is then more likely to occur (*ibid*). The social implications of a positive result is therefore likely to vary, depending on the prevailing cultural orientation. Similarly, people from different cultures experience a professional counselling intervention or the request for informed consent quite differently. An individual not accustomed to holding or voicing individualistic opinions or wishes may submit to a test without being aware of their right to challenge the practice if they wanted to.

In noting cultural differences in emotional or psychological manifestations, some researchers argue a dramatic variation (Benedict 1934, cited in Draguns, 1989: p237), while others claim a virtual universality of expression (Draguns, 1989). Odejide (1979 cited in Draguns, 1989; p. 240) proposes that the impact of negative life events would seem to depend on expectations, where an event which is anticipated has a less devastating impact and is easier to tolerate (Kim et al 1996; Triandis, 1989). This concept could have a direct bearing on preparation for HIV testing.

Manifestations of major psychological distress or illness also vary cross-culturally. In excluding major mental illness, these variations relate in particular to the areas of anxiety, depression and guilt, which are all emotions frequently evoked in the process of HIV testing. A difference has been noted in non-western manifestation or expression of depression (Krapelin, 1904 cited in Draguns, 1989 p 238; Tan, 1980) with a less frequent expression of feelings of guilt in collectivist

cultures (Draguns, 1989). Murphy (1978 cited in Draguns, 1989 p 246) proposes that the experience of 'guilt' is inextricably linked to the advent of individualism, due to the individuation from the group. This leads to an autonomous sense of selfhood and of personal responsibility for the course of one's life.

The influence of cultural variability in the context of HIV and AIDS is clearly profound. As the social consequences of the syndrome are pronounced, so must be the influence of culture, stressing the importance of a consideration of cross-cultural psychology in the planning and implementation of testing protocol (Dana, 1996).

1.2.8. Individual versus Community Rights

A longstanding tenuous balance exists in public health between community rights and needs, and those of the individual (Bayer, 1991; Childress, 1991). This balance is continuously re-assessed in regard to the AIDS pandemic (Melton & Gray, 1988; Panos Dossier, 1990). The rights of the individual however could be argued to be paramount, not only in protection of basic human rights, but also as an essential instrument of prevention and control. Respectful management of the person who is HIV positive would facilitate cooperation in their self-care and of those who are not infected. (International Consultation on AIDS and Human Rights Report, 1989; Panos Dossier, 1990; Reamer, 1991). The life assurance industry has not escaped being challenged by this dilemma, partly due to exclusionary underwriting practise and mandatory testing. The exclusionary policy tends to tip the scale towards a greater protection of the rights of the insurance community or 'pool'.

1.2.9. HIV and AIDS in South Africa

As noted, HIV, AIDS and sexually transmitted diseases (STDS) have been identified as a major public health problem in South Africa (SAFAID News, 1997; Swiss Re Life and Health, 1998 b; WHO, 1996a, b). While many South Africans live in a first world context, in modern cities with access to advanced technologies and commercial frameworks, a large proportions of the population still live in dire poverty within underdeveloped third world conditions (Theys, 1994). This presents a serious risk situation, particularly as the link between link between AIDS and poverty is now well established (Evian, 1995b; Theys, 1994).

Social systems in South Africa underwent major disruptions with the establishment of migrant labour practices entrenched in the apartheid system. Overcrowded single-sex hostels proliferated

to accommodate the labourers, particularly on the mines, away from their homes. This created conditions that encouraged multiple sexual partners (Theys, 1994; Williams & Campbell, 1996), with inevitable high rates of STDs. The presence of STD's established a ready wildfire environment for the subsequent spread of HIV / AIDS. As a carry over, the current South African pattern of transmission is mainly through heterosexual contacts (Evian, 1991; Lachman, 1999; Mann & Bagnoud, 1993; Webb, 1994), driven by both the high incidence of sexually transmitted disease, and cultural values which do not endorse monogamy, or the practice of safer sex and the use of condoms (Kelly , Murphy, Sikkema & Kalichman, 1993).

In conclusion, it is clear that all these socio-cultural variables have either a direct or indirect association with HIV / AIDS and are therefore an implicit component of insurance HIV testing. Fears associated with possible stigmatisation, knowledge of personal risk and anxiety about survival if infected, all have a direct impact on the individual experience of the testing process and, as such, they need to be considered and addressed by the governing protocol and practice.

1.3. LIFE ASSURANCE IN THE ERA OF HIV AND AIDS

1.3.1. Life Assurance

Life assurance is a modern institution, which aims to provide financial security for old age for policyholders, and a degree of security for the dependants of policyholders in the event of death. Insurance confers 'peace of mind' (Visser, 1993 cited in Theys, 1994, p11), through protecting oneself and one's family financially from an uncertain future (Giddens, 1990; Theys, 1994). Insurance is also required as collateral in many financial transactions, such as a bond application, without which the transactions do not take place. The acquisition of life assurance has, therefore, become common financial practice, being a non-luxury, essential and 'indispensable instrument of finance' (Visser, 1993 cited in Theys 1994, p14).

The practice of underwriting is the fundamental cornerstone of the insurance industry (Booth, 1993; Greene, 1971). This is the process by which 'an insurer determines whether or not and on what basis it will accept an application for insurance' by the prediction of future mortality and morbidity costs (Clifford & Iuculano, 1987 cited in Theys, 1994 p12; Booth, 1993). Life assurance is structured upon the principle of shared risk, by the establishment of a common risk

‘pool’, which is administered and managed by the insurance company (Pinington, 1995; Slawski, 1996). It is argued that it would be unjust to the majority of the participants of the pool to accept an applicant who presents a predictably high financial risk or a burden to the pool (Hoffman & Kincaid, 1989 cited in Theys, 1994, p13; Pinington, 1995; Swanson, 1993).

A process of risk classification is therefore undertaken to assess the extent of predictable financial risk an applicant presents to the pool, in order to organise and categorise applicants as insurable and at what cost (Booth, 1993; Slawski, 1996; Visser, 1993). An individual, who presents a risk that is calculated to be too high for the pool to bear, would be deemed uninsurable and be declined cover (Booth, 1993; Hartwig, 1995; Kinney & Steinmetz, 1994; Theys, 1994). Many characteristics are taken into account in establishing this classification including: age, gender, occupation, health status, family or possible inherited propensity to illness, lifestyle, and habits such as alcohol or tobacco use. The higher the risk the individual presents to the pool, the higher the premiums need to be to compensate for this increased risk. Thus, based on risk classification, persons with a medical disorder such as severe or uncontrolled diabetes, or a history of serious or chronic cardiac problems, would be deemed uninsurable due to the inequitable risk they represent to the rest of the pool (Greene, 1971; Kinney & Steinmetz, 1994). The insurance industry have argued that HIV / AIDS fall within the same category of uninsurable medical disorders, in accordance with established criteria.

1.3.2. Modernization

South Africa is striving to incorporate two co-existing ‘worlds’, representing an affluent ‘first world’ society with a modern, global economy; and an underdeveloped, usually impoverished, ‘third world’ society, with a survival economy. Whilst the modern industrialised world presents people with greater opportunities to enjoy a secure and rewarding existence, it has also not escaped the same threats of nuclear annihilation, the seemingly insoluble problem of interpersonal violence and crime, and the advent of HIV/AIDS, experienced by developing countries. These threats have altered the post-modern person’s sense of a certain future, reintroducing the need for contingency security (Giddens, 1990; Gordon, 1978; Kubler-Ross, 1987; Sontag, 1988).

In pre-modern times, the kinship system operated and served the function of ensuring that people felt secure. Kin people could be relied upon to meet a range of obligations in the face of contingency. Similarly, the small local community was able to offer a degree of security. In the

modern context, this function has been replaced by institutionalised, expert systems of security (Giddens, 1990). Banks, universities, medical or other specialists, and the insurance industry, are all part of such an expert system. Increasing affluence, population growth and diversification seem to lead inevitably to a 'modern', individualistic social organisation (Kagitcibasi, 1994; Kim et al., 1994; Triandis, 1989). These systems are then relied upon to act as the resource and financial buffer in the face of adversity.

1.3.3. Life Assurance and HIV/AIDS

During the last two decades life assurance has become inexorably linked with HIV/AIDS. While mortality statistics improved steadily over the latter part of the last century due to medical advances and a rise in living conditions in general, the AIDS epidemic has significantly altered predicted statistics, throwing claims projections and established underwriting practise into confusion (Cape Argus, 1997; Keir, 1990a, b, 1994). This precipitated the establishment of exclusionary policies in the early 1990s (DiBlase, 1987a, b; Geisel, 1989). There has recently been some debate regarding the constitutionality of mandatory HIV testing for insurance purposes (Cameron, 1993; Hermann, 1991; Rosier, 1993; Theys, 1994; Van Niftrik, 1995), although the threat to the viability of the industry in the absence of such testing remains the counter argument (Alpaugh, 1991; DiBlase, 1987 a, b; Keir, 1994; SAFAID News, 1995; Whiteside, 1996a, b).

Several methods of managing HIV/AIDS were conceptualised and employed by the insurance industry in various parts of the world. The primary concern initially was to minimise and contain the predicted financial burden to the industry (Anonymous, 1992; Booth, 1993; Hartwig, 1995; Slawski, 1995; Swanson, 1993; Visser, 1993), but in time, the concern expanded to include the need to reduce discrimination against the insurance applicant as-well (Theys, 1994). The methods attempted in America at various periods, included one or more of the following:

- By the middle of the 1980s applicants were assessed for risk by means of historical and lifestyle questionnaires in an attempt to identify and exclude high-risk individuals and groups (Booth, 1993; Visser, 1993). This led to increased homophobia and the entrenchment of stereotyping, necessitating that the method be abandoned (Cameron, 1993; Swanson, 1993);
- A refusal of insurance to a person who was known to be infected with HIV and exclusion of AIDS as a covered condition;
- The practice of capping the insurable sum, where the applicant was not required to undergo an HIV test for insurance below a specified figure (Swanson, 1993);

- The current general practice of selective underwriting, where applicants are required to have an HIV test as a condition of coverage was adopted (Theys, 1994; Swanson, 1993);
- The most recent addition includes the requirement of repeat testing for HIV at predetermined periods (such as 5 yearly) to ensure continued comprehensive cover.

Comparative methods have been attempted and employed worldwide with similar results. Despite attempts at establishing alternative policy, capping of claims or submission for an HIV antibody test as a condition of acceptance for life assurance cover has proved the most acceptable and workable. This is the strategy adopted in South Africa (Keir, 1990 a, b; Theys, 1994).

Although many overseas companies are now reconsidering their initial catastrophic predictions of the impact of HIV and AIDS on the survival of the industry (Booth, 1993; Theys, 1994), there is still cause for concern in South Africa where the spread of infection has remained largely unchecked (Moultrie, 1995; SAFAID News, 1997; Slawski, 1996; Swanevelder, 1996). According to the Doyle Model (cited in Lachman, 1995, p 82), it was predicted that 27% of the South African population would be infected by the year 2010, a figure of 3,7 million to 4,1 million HIV positive persons, which would require the use of a substantial portion of the national health budget. Recent estimations also suggest that between 90-94% of people living with HIV or AIDS, are living in developing countries (Doyle & Esterhuyse, 1994; Lachman, 1999; SAFAID News, 1997), with South Africa qualifying for this designation. While modelling of the epidemic in South Africa confirms that there is no longer a yearly doubling of new infections, there is still a continuing rise in the rate of infection, with a saturation point still to be reached in many areas. The impact of the second epidemic, with increasing AIDS related deaths, has also not been fully experienced as yet (ibid).

This analysis would suggest that the industry has a realistic financial concern regarding the impact of HIV / AIDS on their financial survival (Moultrie, 1995; SAFAID News, 1995; Whiteside, 1996a, b). This concern should not however be allowed to overrule all other considerations. The humane perspective should not be forgotten, particularly in the light of the statistically high probability of a person receiving a positive result. Based on the information available, all evidence points to the need for an ethically sound, culturally appropriate, sensitive and responsible protocol for the management of HIV testing, which need not conflict with the preservation of the viability of the insurance company.

1.4. CONCLUSION

The pandemic in the South African context falls within the second identified regional pattern, where the spread of infection is still rising. An estimate of incidence ranges from between 25-50% of the 20-40 year old population by the year 2005 (Lachman, 1999; UNAIDS report, 2000). Whilst not affecting any single group, the mode of transmission is predominantly heterosexual, more commonly occurring in marginalized, impoverished people, with women generally having an increased susceptibility due to their social and physiological vulnerability. These circumstances tend to accentuate the impact of the third epidemic, with social sanctions proliferating, including stigmatisation, scape-goating, and victim blaming. Such sanctions destroy the availability of social support so desperately needed by the person living with HIV or AIDS.

The psychosocial influences implicitly at play at the time of insurance testing will influence the individual's response to a positive result. It is therefore important to remain mindful of the influence of cross-cultural dimensions, such as individualism and collectivism, which would influence both the availability of social support, and the extent to which the person is seen as jeopardising the social group, possibly precipitating ostracism. Culture would also influence the persons' coping style as well as their manifestation of emotional distress, pertaining most notably to anxiety and depression.

The modern institution of life assurance, replacing the pre-modern kinship system, provides for security against adversity, and is an essential requirement for many financial transactions. Assurance rests upon the practice of underwriting, which constitutes a risk assessment of the individual applicant. In the last two decades, HIV and life assurance became closely linked, precipitating the establishment of various exclusionary policies and practices by the assurance industry. Over time, most of the methods attempted were abandoned in favour of the current practice of HIV testing at the time of policy application. This practice is now well established and unlikely to change in the foreseeable future, confirming that the area for improvement in the current protocol lies within the parameters of the management of the testing situation. The direction for improvement should optimally be guided by well researched and established empirical and bio-ethical principles, which are discussed in Chapter Two.

CHAPTER TWO

AN ETHICAL INQUIRY

2.1. THE RELEVANCE OF ETHICS

Ethics may be 'recognised as a philosophical discipline primarily concerned with the evaluation and justification of norms and standards of personal and interpersonal behaviour' (Homan, 1991, p1). These principles are particularly relevant in connection with emotive and conflicting interests, such as debates around the primacy of the rights of the general public or the individual. Debates of this nature commonly occur in relation to HIV / AIDS as an aspect of the life assurance industry exclusionary underwriting practice (Melton & Gray, 1988; Warwick, & Pettigrew, 1983). Sound, ethical decision making is therefore imperative to avoid transgression of basic human rights.

The primary and fundamental principles of a liberal society are the protection of individual civil rights. Here the principles of beneficence, non-maleficence, justice, respect for persons and their autonomy are universally accepted as the basis of ethical professional practice (American Psychological Association, 1981, 1990, 1992; Canadian Psychological Association Guidelines, 1991, 1992; Childress, 1991; Francis, 1999; Miller & Bor, 1993; Melton, 1988; Manuel, 1999; Reamer, 1991; Warwick & Pettigrew, 1983; Wassenaar, 1992). Within this paradigm, strong justification is needed to allow for any breach of these fundamental human rights (Childress, 1991). Childress (1991) states that should a breach be unavoidable, the principle of 'least infringement' of human rights should be applied, and accompanied by explicit justification. This would include an assessment of a 'harm-to-benefits' ratio (Manuel, 1999). When translating this principle to HIV testing, it would indicate that the rights of the individual should not be transgressed. Should testing be unavoidable, the protocol must adhere to the principle of 'least infringement', with any potential harm minimized by ensuring proper management of the client, for example, by offering suitable pre-and post- test counselling.

A common conflict regarding public health relates to the rights of the individual versus the protection of the majority. Fundamental ethical principles underlie each perspective. Deontological reasoning, with a focus on the inherent 'rightness' of an action, would emphasise the primacy of individual rights over those of the group, whereas the practically motivated emphasis on the 'good

of the group', is based on 'rule' or 'act' utilitarian principles (Francis, 1999; Reamer, 1991; Slack, 1997). In practice, a 'weak' or 'working' version of ethics is employed, wherein the theory and concepts are used to 'illuminate policy issues and their moral features' (Reamer, 1991, p14). These 'weak' ethics are important for resolving conflicting theories and issues, and to help clarify and inform practical policy issues and their underlying moral features and in the creation of new guiding principles when necessary (ibid).

2.1.1. Principles and Practices in Relation to HIV / AIDS

There is currently an 'unstable balance between public health safeguards and civil liberties' (Bayer, 1991, p 27). This can be seen in society's need to establish equity in care and service delivery, offset against organisational priorities, such as the safeguarding of economic profitability. The AIDS epidemic emerged at a time of growing crisis in health care, and precipitated a strong protective response by the assurance industry (Oppenheimer & Padgug, 1991). The costs have, however, proved lower than predicted, justifying a reappraisal of crisis management (ibid).

There has been acceptance in the field of public health that individual rights are not absolute, and can be overruled in a crisis or emergency situation (Reamer, 1991). With this understanding, a common method of containing past epidemics, resulted in the curtailment of individual human rights (Childress, 1991). Popular slogans such as 'AIDS has no civil rights' denote that the crisis has cancelled out other moral imperatives and are commonly quoted as justification for mandatory screening and other ethically contentious practices (Childress, 1991; p53). A distinction should, however, be made between a true crisis, and a fear-based reaction, a dilemma that has occurred in relation to the AIDS pandemic (Francis, 1999; Klouda, 1994; Schulman, 1988b). The issues are not always clear-cut, often resulting in contradictory perspectives. When this controversial nature is combined with the potential threat to human rights, responsible management should fall back upon established ethical principles (Francis, 1999; Reamer, 1991). A consideration of ethical principles therefore remains central to the ongoing debate around the medico-legal management of HIV, which would include all aspects of testing.

2.2. ETHICS of HIV TEST PREPARATION

2.2.1. Principles of HIV Antibody Testing

There are fundamental principles relating to general HIV testing, which are directly applicable to insurance motivated testing (Melton, 1988). The most basic principles relate to confidentiality of testing and results, informed consent (including knowledge regarding the purpose, implications and scope of the test) and pre-and post-HIV test counselling (Miller & Bor, 1991, 1993; Reamer, 1991). This includes recognition that client attributes, such as educational standing, socio-economic circumstances, marital status and cultural heritage, form an integral part of the testing experience (Van Dyk, 1992, 1999). Finally, there are issues concerning the voluntarily nature of the testing. Testing for insurance purposes has often been criticised as coercive (Sorell & Drayer, 1999).

The dissemination of information about HIV testing is intrinsic to both 'informed consent' and 'pre-test counselling', making them closely interwoven (Balmer, Seely & Bachengana, 1996; Van Dyk, 1992). The attribute that most clearly distinguishes pre-test counselling from informed consent is the intensive exploration of emotional responses and practical options, inherent in the former (Ubel, & Loewenstein, 1997). Informed consent and pre-test counselling are discussed in more detail below.

2.2.2. Informed Consent

Informed consent, now regarded as routine medical practice, is a major aspect of bio-ethics (Volskenk, 1989), and is cited as possibly the single most important medico-legal principle (Childress, 1991; Knobel, 1992; Melton, 1988; Shore, 1996; Strauss, 1990). The principles underlying informed consent relate to the individual right to autonomy, confidentiality and personal decision making (Knobel, 1992; Lo, Steinbrook, Cooke, Coates, Walters & Hulley, 1989; McClean & Jenkins, 1994; Ubel, & Loewenstein, 1997). 'Valid consent' denotes voluntary, informed agreement, which would require full disclosure and giving explicit consent (Francis, 1999; Lo et al., 1989; Van Dyk, 1992, 1999; Wassenaar, 1992). Full disclosure would encompass an awareness of the available options, the possible consequences of the test (including both advantages and disadvantages), as well as the right to refuse testing (Ubel, & Loewenstein, 1997; Wassenaar, 1992).

Although HIV testing has become a common medical practice (Manuel, 1999; Strauss, 1990), it cannot yet be regarded as a routine medical procedure in South Africa. This has led to the specific requirement of informed consent prior to testing advocated by the Health Professions Council guidelines (Knobel, 1992; Shore, 1996; South African Medical and Dental Council Draft, 1992).

2.2.2.1. Consent or Acquiescence

Lord (1995) questions whether the consent given by the people in medical settings is properly informed, or whether it constitutes mere acquiescence on the part of a trusting public. This distinction is important in relation to insurance HIV testing, which represents a voluntary, non-life saving medical action, not performed for the client's direct benefit, but one which could have severe, negative, psycho-social or even medical implications for the uninformed or unprepared applicant (Fountain & Masieta, 1996a, b). This is not 'just another test' (Lo et al., 1989), nor is it 'an ordinary disease' (Knobel, 1992, p189). It is therefore important to establish if the person signing consent for venisection is in a position to make a competent decision. Knobel (1992) states that, for consent to be valid, the person giving the consent must be competent to do so, must clearly understand the implications of the consent, and, with adequate information, must make such informed decision without coercion (Venesy, 1994). Language barriers or educational limitations are examples where a legally competent person may not be in a position to understand the implications of the consent given, rendering it essentially invalid.

2.2.2.2. Consent for Insurance HIV Testing

Consent can be given orally or in writing. It is still, however, common bio-ethical practice to accept agreement to treatment as tacit consent (Childress 1982a cited in Childress, 1991). Knobel (1992) states that consent for an HIV test should always be in the form of written documentation, deeming oral or implicit consent morally and legally unacceptable. He argues further that even with the correct documentation, this consent cannot be regarded as 'informed consent' in the absence of necessary knowledge about the scope and nature of the test.

Knobel (1992) and Miller (1987) both posit that fully informed consent for HIV testing must include pre-test counselling. In practice, however, interactive pre-test counselling seldom occurs and there are logistic and practical constraints associated with ensuring informed consent. An ideal

protocol would therefore include a means to evaluate whether the client has understood the nature of the test prior to signing consent. This would include an awareness of the distinction between HIV and AIDS, knowledge about the 'window period', and knowledge about the approximate time span from infection to the appearance of symptoms. It would also be important to clarify common misunderstandings about the meaning of a 'positive' or a 'negative' result (Sobo, 1995), and the repercussions for life assurance application. This ideal could possibly be approximated with innovative changes to current protocol, such as the inclusion of an easily scored 'information grid' in the application form.

2.2.2.3. Levels of Counselling and Information

Venesy (1994) proposes three different levels of pre-consenting information, depending on the nature of the intervention. The first and least restrictive level required is for routine, non-invasive treatment. The second or intermediate level applies to non-routine decisions that may include invasive techniques and less certain treatments or risks. The final and most restrictive level is applied prior to making a decision about an intervention which has the potential to result in irreversible harm or death. This last level calls for the most comprehensive amount of information. Undertaking an HIV test would require at least an intermediate standard of preparation to ensure adequate informed consent. It could also be argued that HIV testing justifies the most comprehensive level of information since, despite the lack of risk inherent in venisection, the consequences of a positive result are irreversible and portend an untimely death (Strauss, 1990).

2.2.2.4. Special Status of HIV Testing

HIV testing, which calls for explicit, written, informed consent, has acquired an apparent 'special status'. Those who challenge this 'special status', are opposed to the need for informed consent on the basis that HIV testing would be best managed without this designation (Dysell, 1995; Fennel, 1994; Knobel, 1992). It is argued further, that patients will be emotionally burdened by the information, at a time when they (the in-patient in particular), may not be able to integrate the information or the experience (Fennel, 1994; Fountain & Masieta, 1996a, b; McCoy, 1995). McCoy (1995) found that, in situations of limited financial and personnel resources, the most effective approach was to only offer post-test counselling, once an HIV positive result was received. This counselling would include the equivalent of 'pre-test' preparation for a positive result, performed retrospectively (Fountain & Masieta, 1996a). In her South African based work,

Tallis (1994), however, argued that the life assurance industry is better equipped financially to offer comprehensive preparation, and should therefore do so.

2.2.3. Pre-Test Counselling

Counselling plays a vital role in the way people receive and integrate news about an HIV sero-positive result, as well as how they cope with life thereafter (Miller, 1987; Miller & Bor, 1991, 1993; Winiarski, 1991). Ideally, a degree of counselling would be beneficial for anyone undergoing medical evaluation, assessment or intervention, but this is seldom done. In the case of HIV and AIDS, where the social consequences are so severe, this need for counselling is accentuated, and the test therefore ought not to be carried out without pre- and post test counselling (Bor, Perry, Miller & Salt, 1989; Gaines, 1988; Miller & Bor, 1991; Perry & Markowitz, 1988; Van Dyk, 1992, 1999).

There are two basic aspects to counselling. The first addresses a requirement for information and the second a need for emotional support (Miller & Bor, 1991; Van Dyk, 1992, 1999). Wood (1994), Miller & Bor (1991), Sahlu, Kassa, Agonafer, Tsegaye, Rinke De wit, Gebremariani, Doorly, Spikerman, Yenench, Coutinho & Fontanel, 1999) and Van Dyk (1992, 1999 p. 109) all define pre-test counselling similarly as 'helping to identify options, discussing possible implications, and helping to achieve some direction in planning for future decision and actions'. Counselling allows the person to prepare themselves for the possible consequences of a positive result and to be cautioned against a false negative or positive result. Psychologically, the person has an opportunity to consider the impact of the result, either positive or negative, and can explore 'where and how' to obtain personal, emotional, social or financial support. In post-test counselling preventive measures would be discussed, psychological support adjusted to the situation, and referrals made as needed (Sahlu et. al., 1999).

2.2.3.1. Emotional Support Associated with Counselling

The emotional state of the person at the time of testing is relevant. There are a great many myths and fears associated with the test (Helman, 1984; Kubler-Ross, 1987; Sontag, 1988), making it common for the life assurance applicant undergoing testing to experience a range of distressing thoughts and emotions. The opportunity of pre-test counselling should be used to alleviate some of the potential distress associated with the testing process (Bor, Perry, Miller & Salt, 1989; Gaines, 1988; Miller & Bor, 1991; Perry & Markowitz, 1988; Schulman, 1988 a; Van Dyk, 1992, 1999).

In a classic study Janis (1958) conducted with surgical patients, he found that if people were adequately prepared for surgery, they co-operated better with their own treatment, prior to and following the procedure. Adequate preparation implies being neither over- nor under-prepared. Over preparation occurs when the patient's anticipated level of discomfort exceeds the level of discomfort actually experienced. The reverse occurs with under preparation. The findings of this study relate directly to HIV testing. The person who is adequately and realistically prepared for the test, which includes an exploration of a possible sero-positive result and the associated social, health and economic consequences of it, would be more cooperative and would adjust better to both the testing situation and the result (Childress, 1991).

2.2.3.2. Anxiety and Knowledge: Psychological Attributes Associated with HIV Testing

Anxiety is probably the most common emotion associated with HIV testing (Bor, Perry, Miller & Salt, 1989; Miller & Bor, 1991, 1993; Ubel, & Loewenstein, 1997). The type and degree of anxiety experienced by the client in general, and in combination with exaggerating or mediating factors, is of central interest to this study. Spielberger (1966, 1972 a, b) states that fear and anxiety are primary and fundamental human emotions which, although distressing at times, also serve an adaptive human function (Izard & Tomkins, 1966; Spielberger, 1972 a). Freud (1924 cited in Spielberger, 1972a) defined anxiety as 'something felt' as an unpleasant, universally experienced, albeit transitory, emotional state (p9). Anxiety, along with love, hate and depression is a complex, multi-dimensional emotion. Izard (1972) explains that anxiety invariably contains elements of two or more fundamental emotions, such as fear and shame or guilt, which may exist and interact at varying levels of intensity. Analyses of these combinations reveal that fear can be associated with danger of punishment and failure, and shame and guilt with self-derogation and feelings of inadequacy (Saranson, 1967 in Izard, 1972, p75). Anxiety is therefore a generic term that includes fear, shame and guilt (Janis, 1969 in Izard, 1972, p75). These are emotions commonly identified in association with an HIV positive result, highlighting the importance of addressing the experience of anxiety prior to the test.

Anxiety is also based on the appraisal of threat, which entails symbolic, anticipatory and other uncertain elements (Beck, 1995; Beck, Emery & Greenberg, 1985; Fischer, 1970; Lazarus & Averill, 1972; Spielberger, 1972). Spielberger (1972) found that although a stressful situation may initially produce distress and arousal, it is the sense of 'helplessness', should the person find that

there is no action or behaviour available to him that will relieve his distress, that would maintain the anxiety. This suggests that the opportunity to discuss fears or anxiety at the time of venisection would contribute to the reduction of a sense of powerlessness, reducing excessive or distressing anxiety (Cattel, 1972; Izard, 1972; Izard & Tomkins, 1966).

The importance of anxiety as a component in HIV testing is illustrated by Janis (1958) with his proposal of two basic reasons for offering a person adequate preparation prior to any stressful life event. The first relates to education and information giving, and the second reason is associated with the reduction of excessive anxiety, which could also optimise an appropriate level of arousal to facilitate education. Since public education is an implicit component of HIV testing, it would be advantageous to reach an optimum state to facilitate the learning process. Such learning would also ensure that the person has a realistic expectation of the event and the consequences of the event, resulting in better immediate and long-term adaptation (Beck, 1995; Beck et al., 1985; Janis, 1958). Cognitive factors have also been identified as an important mediator in the phenomena of anxiety. These factors act as justification for pre-test counselling (ibid.), which allows for both an emotional and cognitive resolution of anxiety.

2.2.2.3. Counsellor Competence

The insurance industry claim to have insufficient trained counsellors for them to offer comprehensive pre-test counselling. They also argue that it would be an unjustified and excessive cost to employ additional trained personnel for this purpose. This view is challenged on the grounds that an acceptable minimum standard in the range of personnel training required for pre-test counselling can vary. Wood (1994), who is experienced in counsellor training, identified differing levels of training available to trainee lay counsellors, resulting in different competence levels and scope of administration of pre-test counselling. On this basis, it could be argued that pre-test counselling need not be an 'all-or-nothing' scenario as, quite obviously, different people may require a different depth of counselling. There are the certain basic and fundamental requirements for effective counselling, with a gradient towards more in-depth counselling as required. From an established infrastructure of basic counselling, more in-depth counselling could be developed. The need for in-depth counselling can be recognised during basic counselling at the disclosure of high-risk behaviour, or if the person expresses anxiety about the test.

In the life assurance context, a need for comprehensive counselling could be determined at any of three easily identified stages of the testing procedure:

- On learning that they will be required to have an HIV test;
- On presentation for venisection;
- At any time while awaiting the result.

2.2.4. The Role of Testing in the Control of the Spread of HIV / AIDS

The primary means identified for the prevention of the continued spread of HIV infection lies with a change in risk behaviour, influenced by belief and attitude (Kelly et al., 1993). Over time, some of the methods of control have proven effective (Boruch, Coyle & Turner, 1991; Bowser & Sieber, 1993; Kelly et al., 1993; Miller & Bor, 1991, 1993), and others have been found inadequate (Bell, 1991; Fishbein, Middlestadt & Hitchcock 1994; Lachenicht, 1993). Research has shown that an increase in accurate information alone is not effective in reducing high-risk behaviour (Fishbein, 1967; Fishbein, & Ajzen, 1975; Fishbein, et al., 1994; Fishbein & Raven, 1967; Lachenicht, 1993). In contrast, the identification of such personal factors as self-efficacy, an accurate assessment of personal risk, and a recognition of social norms controlling behaviour, has emerged as critical in effecting desired change (Balmer, 1991; Cleland, 1995; Ickovics, Morrill, Beren, & Walsh, 1994; Morrill & Ickovics, 1996; Sweat, Gregorich, Sangiwa, Furlonge, Balmer, Kamenga, Grinstead, & Coates, 2000; Temmerman, Moses & Kiragu, 1990).

Some studies, therefore, have shown counselling to be an important intervention in HIV/AIDS prevention and control (Sahlu et. al., 1999; Padian, O'Brien & Chang, 1993; Wenger, Linn & Epstein, 1991), where other studies are inconclusive, showing counselling to have limited or variable success (Cleland, 1995; Temmerman et. al., 1990; Weinhardt, Carey, Johnson & Bickham, 1999). Interactive counselling, although not found to be conclusively effective, is, however, still the best medium for prevention and control.

An initiative of the Centre for Disease Control (CDC) promoted widespread screening through a program of voluntary counselling and HIV testing. By 1992, the program had allowed for a third of adult population to be tested. An HIV voluntary counselling and testing system (HIV-VCT), has now become 'the largest' (albeit most costly), 'preventative program in the United States', with a similar program strongly advocated for developing countries, despite the initial high cost (Weinhardt, et al., 1999; UNAIDS Policy Statement, 1997).

Two predominant HIV-VCT methods of control have emerged:

- HIV testing as a deterrent. It is a means to ascertain and inform people of their HIV status, and if infected, to obtain referral to prompt medical and psychosocial care
- Education and counselling to effect behaviour change in order to prevent primary (self) infection and transmission to others (secondary infection). This is achieved through client centred approach, which allows for a personalised risk assessment, leading to the development of a risk reduction plan (Bell, 1991; Reamer, 1991; Weinhardt et. al., 1999).

An evaluate the effectiveness of this system was undertaken by means of a comprehensive outcome study (Carpenter et. al., 1999; Sweat et. al., 2000; Weinhardt, et. al., 1999). Success was evaluated as:

- a. Increased condom use, implying a reduction in unprotected intercourse, and
- b. A reduction in number of sexual partners

The study proved inconclusive due to methodological problems. The results indicated that VCT was not effective in primary prevention, but was effective as a means of secondary prevention, with a lowering of risk behaviour evident between sero-discordant couples (ibid.).

The effect of counselling has therefore not proved consistently useful. An explanation for the limited efficacy could rest with the brevity of counselling offered. Short or single sessions may not always allow adequate time for a full understanding of the issues, both emotional and informative. This led to the suggestion of a need for expanded or enhanced counselling, occurring over several, rather than a single session (Balmer, 1991; Balmer, Gikundi, Nasio, Kihuho & Plummer 2000; Ickovics et al., 1994; Morrill & Ickovics, 1996; Temmerman et al., 1990). Bell (1991) and Fishbein (et al., 1994) also suggest that a critical variable in altering behaviour may be the dissemination of the information, as a component of pre-test counselling, at a critical or receptive point, such as when the person is undergoing the HIV test, but with the necessity for both pre- and post test counselling stressed (Sahlu et al., 1999). The common factor in all the above extensions would, however, appear to be the motivation of the individual to change, based on their perceived urgency for this change either for themselves or others (Balmer, et. al., 2000; Fishbein & Reven, 1967; Fischer & Fischer, 1992; Ickovics et al., 1994; Sweat, et al., 2000).

Wood (1994) cautions that with the limited, scarce and diverse counselling provision in South Africa, the danger exists that persons being tested could experience secondary risk, through increased distress or a misunderstanding of the nature and content of the test and counselling. Once again, the option of several sessions may be required to ensure understanding and motivation, especially in the African context, where limited educational and multiple language use limits the scope of pre-test counselling (Ickovics et al., 1994; Morrill, & Ickovics, 1996; Temmerman et al., 1990; Wood, 1994).

2.3. LIFE ASSURANCE HIV-ANTIBODY TESTING PROTOCOL

Life assurance does not operate in a vacuum, and HIV / AIDS holds significant business and social implications for the industry as an institution operating within the broader social spectrum (Daniels, 1995). There has been considerable South African deliberation about HIV testing and the drawing up of life assurance policies and 'testing protocol' in a socially responsible manner (Daniels, 1995; Sorell & Drayer, 1999; Van Der Merwe, 1994).

For the applicant seeking life assurance, the most basic expectation is that the assurance industry will honour its financial obligations. Equally important is the expectation that assurance companies will not discriminate unnecessarily. The process of HIV testing should be conducted in a manner that is not injurious to the client (Manuel, 1999). This has led to debate regarding the constitutionality and socio-economic necessity for insurance-related HIV testing. Briefly, arguments for and against testing are:

Arguments in favour of insurance HIV testing:

- That HIV testing is wholly in line with underwriting practice
- Testing is an incentive to reduce high risk behaviour
- The role of widespread HIV screening, allows for prompt referral and treatment following diagnosis, protection of sexual partner(s), and the opportunity to make plans.

Arguments against HIV testing:

- The inability of the test to predict with certainty those HIV positive persons who will definitely develop full-blown AIDS
- The fallibility of the test, particularly in the window period

- The sentiment that the insurance industry should make an exception of HIV and not test applicants. This argument is based on the prolonged prodromal period prior to the emergence of symptoms, suggesting that the applicant would contribute equitably to the insurance pool before ever making a claim
- The HIV test may burden the applicant with information, which they did not request or want
- HIV testing has raised ethical issues around confidentiality and privacy.

While the assurance industry applies the same exclusionary principles applied to other non-insurable diseases, to HIV/ AIDS, these principles are not, however, ethically acceptable in terms of the HIV testing procedure, due to the social repercussions of the diagnosis (Knobel, 1992; Lo et al., 1989).

2.3.1. Life Assurance Protocol Associated with Informed Consent and Pre-test Counselling

The life assurance industry has recognised the importance of informed consent (Van Der Merwe, 1994). The motivation for this emphasis, however, appears to be legalistic and indemnity driven rather than a concern about the client being fully prepared for the test. The current protocol in relation to informed consent has been established and practised worldwide. The protocol dictates that clients are given, and asked to read, the pre-test counselling document or information brochure. At present, there is no research available which would indicate any objections to this practise.

The information in the document addresses the most relevant issues associated with testing, and promotes an understanding of informed consent (ibid). This document has been assumed to be adequate, based on the premise that most insurance applicants would not want to expend the additional time and effort required for pre-test counselling, again on the assumption that insurance applicants are of a higher socio-economic position and are therefore deemed a low risk population (ibid). This presumption, however, appears contestable in the South African context, as evidenced by the epidemiological statistics. Applicants for life assurance are derived from the population, and must be deemed to have some risk (Keir, 1994). Based on these factors, criticism remains that insufficient importance is attached to the need for pre-test counselling (Van Der Linde, 1994).

It would appear that clients do not object, in principle, to life assurance testing, as this has been accepted as an integral part of the application process. Despite this acceptance of testing, there is a continued assumption that the client may resent additional time required for counselling. This objection is based on the layperson's misconceptions about the scope, purpose and value of pre-test counselling, combined with a self-defensive tendency. A universally applied policy of comprehensive test preparation is therefore justified. Tallis (1994) proposes that if people really wanted insurance, and they found that counselling and testing were a non-negotiable aspect, they would comply with the process. Tallis (1994) adds weight to this argument by stating that the insurance companies are in a position to create the necessary infrastructure to ensure adequate pre-test counselling.

The Life Officers Association (L.O.A.)² protocol was reviewed in 1995, and in 1996/7 an expanded pre-test information document was compiled. A further comprehensive document has been available at the pathology depots since 1998 (*see appendix 8*). There is still concern, however, that this document is too difficult for a large proportion of clients to understand, owing to complex terminology and concepts. This difficulty is increased for persons not having English or Afrikaans as a home language, and for those who are not fully literate. Although it might seem that an information document is adequate preparation for some, it is not sufficient for all. The benefit of person-to-person counselling cannot be over-emphasized (Miller, 1987; Miller & Bor, 1993; Tallis, 1994).

The desirability of pre-test counselling is indisputable, but the best agent to provide it is still uncertain at present. An awareness of cultural differences between the counsellor and the person receiving counselling remains fundamental in both the South African and AIDS context (Dana, 1996; Van Dyk, 1992; Wassenaar, 1992). Wassenaar (1992) states that ethical principles dictate that ideally a counsellor should be competent to work within specific cultural contexts. Conversely, limited knowledge on the part of the counsellor should not be justification to withhold counselling when this is indicated, particularly if a more informed counsellor is not available (*ibid*). The counsellor's continued awareness of the person's cultural background and language comprehension could ensure the availability of sensitive and ethical practice (Van Dyk,

2 A voluntary association of Life Assurance companies conducting and regulating business in South Africa

1992). Various persons involved in the process, such as the nursing sister or the life assurance representative, may be capable of rendering the service where others are not, but they may also lack both the time and expertise. The need to ensure that the person providing the pre-test counselling is competent to do so should be a primary guiding principle in the choice of protocol to be adopted (Knobel, 1992; Van Dyk, 1992).

2.4. CONCLUSION

A review of ethical management of HIV testing is justified by the importance of ethics in guiding policy actions around emotive issues and conflicting interests. HIV testing clearly falls within this arena as the diagnosis has more than just medical consequences. This magnifies the need to preserve the fundamental bio-ethical rights of the individual involved. A perennial debate associated with HIV pertains to the primacy of the right of the individual or the general public. The life assurance practice of underwriting falls within the range of prioritising the rights of the public, or in this context, the insurance pool, over those of the applicant, making this a relevant area for ethical inquiry regarding the preservation of individual rights as-well.

Fundamental ethical principle of HIV testing delineate the requirement for adequate pre-test preparation, which incorporates pre-test counselling and the signing of informed consent for the procedure. The life assurance industry, recognising the importance of informed consent, has established criteria regarding what constitutes adequate preparation. The comprehensive written document presented to the applicant at the point of venisection serves the function of preparation, resulting in the signing of consent. There is still concern that where this protocol, although inadequate, has been accepted world wide, it is particularly lacking in the South African context. The definitive features of counselling as opposed to giving of information were also noted. Finally, the mutual dependence of both information and emotional support were recognised as inherent in both counselling and consent. The experience of anxiety was also reviewed as a component of testing.

It was argued that differing degrees or levels of preparation are applicable to different medical procedures, depending on the amount of trauma or risk involved. Despite the lack of trauma involved in venisection, an HIV test was seen to fall within the range of requiring comprehensive preparation due to the potential psycho-social devastation associated with a positive result.

There has, however, also been some argument that HIV testing and prevention would be more easily managed if it was divested of its special status.

The important role of testing in the prevention of the spread was noted. There was some debate regarding the effectiveness of pre-test counselling as a preventative strategy, but it was also still seen to be potentially the most effective medium available.

A consideration of how the pre-test preparation protocol was understood and experienced by the applicants was of interest in this study. A review was therefore made of the range of pre-test preparation. The basic principles of education and emotional support inherent in counselling were explored, and the efficacy of the pre-test intervention on future adjustment and as a method of controlling the spread of HIV infection was considered.

CHAPTER 3

METHODOLOGY

3. 1. RATIONALE FOR THE STUDY

In the last decade HIV and life assurance have become inexorably linked, with HIV impinging on all aspects of the industries' principles and practices. This link has resulted in the industry being criticised by various sectors, such as AIDS activist organisations, for not providing adequate and appropriate pre-and post counselling for the mandatory insurance motivated HIV test (Daniels, 1995; McCoy, 1995; Miller & Bor, 1993; Perry & Markowitz, 1988; Shore, 1996; South African Medical and Dental Council, 1992; Tallis, 1994; Van Der Linde, 1994; Van Der Merwe, 1994; Van Niftrik, 1995; Visser, 1993; Wymack, 1991). In order to address this criticism, the Life Offices Association (L.O.A.) drew up a protocol to which all in the field must adhere. The L.O.A. protocol specifies a limited amount of pre-test counselling, which is given in a written format providing information about HIV and AIDS¹. The very nature of this document is however uncertain, serving the function of counselling and as the basis for informed consent. It is also uncertain whether this document fulfils any of these designated functions. Based on numerous unanswered questions pertaining to the current testing practice, research into the effect of the protocol is indicated, and constitutes the rationale for the study.

3.2. AIMS AND OBJECTIVES OF THE STUDY

The current trend has been for the life industry to offer increasingly comprehensive pre-test information and preparation. Many companies are proposing to assist in the management of the pandemic, in part by facilitating widespread screening and the dissemination of information. Based on these objectives, and the uncertainty of the scope and effectiveness of the counselling document noted above, the objectives for the study were:

- To undertake a qualitative and quantitative assessment to ascertain whether clients want or need counselling, and to evaluate the effectiveness of the counselling / information document itself
- To establish whether it is feasible to add pre-test counselling at an established point within the existing framework of current practice. The nursing staff involved in the venisection and the life assurance brokers were identified as possible resources to offer the counselling.

- To establish whether pre-test counselling offered at the depot could be logistically feasible or effective in informing the client about the HIV test and in reducing their level of anxiety.

3.3. METHOD

3.3.1. Research Questions

Two central research questions were posed in the study. These were:

- a) ‘To what extent are insurance applicants suitably prepared for an HIV test by the current protocol?’;
- b) ‘Which aspects of the current protocol could feasibly be altered to ensure that insurance applicants are suitably prepared’?

These questions were measured against the ethical and practical counselling criteria of informed consent and pre-test counselling. Sufficient knowledge and information about HIV and the implications of the test are the basis for consent to be ‘informed’, and a reduction in anxiety, resulting in an improvement in psychosocial coping, are the primary goals of pre-test counselling. Knowledge about HIV/AIDS and the level of anxiety in relation to all relevant aspects of the testing situation, were, therefore, central to answering the questions a and b above.

3.3.2. Research Design

The research was a cross-sectional, descriptive and exploratory study of life assurance applications across the Cape Peninsula. A multiple methods, or triangulation approach, was used in recognition of the complexity of the situation (Anastasi, 1982; Bouma & Atkinson, 1995; Brewer & Hunter, 1989; Miles & Huberman, 1994; Mouton & Marais, 1990). This included the use of multiple sources of information in combination with quantitative and qualitative data collection and analysis. The study was undertaken in the form of three separate phases.

¹ The written format is printed on the flip side of the pathology or application form

3.3.2.1. Phase 1: This was a questionnaire survey presented to clients having venisection for HIV testing. The questionnaire served to gather a range of information about the client experience of the procedure.

3.3.2.2. Phase 2:

This was a pilot study, conducted to explore the possible effect of adding time limited, in-situ interactive counseling prior to venisection. A sample of insurance clients were therefore offered interactive counseling by the attending nursing sister at the pathology depot. They were then asked to complete the same questionnaire used in phase one. The responses in phase 2 were used as a comparison to those in phase 1, indicating any possible effects of the counseling.

3.3.2.3. Phase 3:

The third phase consisted of semi-structured interviews with nursing staff conducting the venisection, and with life assurance brokers who had accompanied their clients for venisection.

3.3.3. Procedure

In order to clarify the experience of the sample population, the current venisection practice is outlined as follows. Upon application for life assurance, the client is informed that they need to undergo an HIV antibody blood test. They are instructed by the insurance broker or representative that:

- As applicants, they are requested to present themselves to a pathology laboratories collection room for blood to be drawn for the HIV anti-body test
- They are required to bring an identification document with them to facilitate photo identification
- They are asked, by the attendant nursing sister, to read the information / counselling document attached to the application form (*see appendix 8*)
- They are then requested to sign consent for the test to be done. This signature is taken as 'informed consent', as they are assumed to have read and understood the information / counselling document
- Clients are also asked to nominate a medical doctor or institution where a positive

result can be forwarded if necessary. The client is informed of the purpose of this nomination

- The client then has the blood sample drawn for testing, by the registered nursing sister. The venisection procedure is now complete for the client, and they leave the depot.

For this study, the client was given the questionnaire by the attending nursing staff, for completion at the depot, at the end of the venisection procedure. This format was duplicated for both phases 1 & 2. The researcher was present as a nursing sister at some of the depots, the remaining nursing staff had been personally instructed to request that all applicants be approached to complete the questionnaire. Participation was voluntary, but from personal observation and direct feedback from other nursing sisters, it was evident that some self-selection of participants occurred.

3.3.4. Population and Sampling

The sample for phases 1 & 2 was derived from life assurance applicants across the Cape Peninsula presenting themselves at pathology depots for venisection for HIV testing, during the period of June, July and August 1997. One thousand questionnaires (and envelopes), consisting of English, Afrikaans and Xhosa translations (*see appendix 7*) were distributed to the various depots for phase 1. The completed questionnaires in sealed envelopes were returned to a central point for collection by the researcher. The researcher subsequently screened responses, and incomplete questionnaires were removed from the study. Phase 1 yielded 450 returned questionnaires of 1000 distributed. Of these 429 were completed in full, with the remaining 22 considered unusable for the study. This presented a response rate of 43% (429/1000).

The pre-test counselling intervention for phase 2 was consistently brief, and lasted for approximately 10-15 minutes for each person. The intervention was conducted at three separate depots, on different occasions, by the researcher. Two criteria guided the depot selection. The first was to select a depot with a high client turnover in order to maximise the researchers' time spent at the venue. The second was to select depots offering service to a lower socio-economic population. It is known that lower socio-economic population groups are more vulnerable to infection (Aggleton & Homans,

1988; Marcham, 1990; Strebel, 1994; Swenson, 1989; Theys, 1994; Van Dyk, 1992), and could possibly also be assumed to have a lower level of education and information about HIV. Information gathered from this population group was therefore deemed valuable. It must, however, be noted that this selection process creates a negative bias against showing effects of the counselling intervention, based on the lower base-line of education.

The three depots selected were those associated with the Mitchells Plain Medi-Clinic, Jan S. Marais Hospital in Parow and Gatesville Medi-Clinic. Once venisection was completed, the applicant was asked to complete the questionnaire. This phase used 35 of 36 questionnaires completed, with 1 incomplete questionnaire discarded from the sample.

The sample size for the semi-structured interviews conducted with the nursing sisters and brokers was 14 and 10 respectively. The interviews were conducted whilst the researcher was at the depots collecting questionnaires for study two. Consistent with the principles of qualitative data collection, the interviews were conducted until a saturation point of new information was reached and themes began emerging repetitively (Miles & Huberman, 1994; Mouton & Marias, 1990).

3.3.5. Instruments

A) A questionnaire was designed (*see appendix 7*) consisting of a demographic and a test specific section. The questionnaire was constructed in English and translated into Afrikaans and Xhosa by professional translators. The Xhosa translation was reviewed by a Xhosa speaking non-governmental organisation employee to ensure ease of comprehension and message accuracy. The questionnaire was anonymous, with confidentiality assured. An introductory front page described the nature of the research and the researcher's university affiliation and interest. The questionnaire included:

- A demographic section which covered questions pertaining to: age, gender, home language (as opposed to race²), income, education, occupation, marital status,

² After discussion and deliberation with staff of a large life assurance company, it was decided that a question relating to racial category would not be included, with a focus rather upon home language.

children, number of sexual partners in preceding 5 years, and an assessment of availability and source of social support

- Categorical questions relating directly to the test reviewed: understanding the nature of the test, acknowledging signing consent, reason for testing, receipt of information from various sources, or nervousness and subjective preparation relating to several aspects of the test
- Three specially designed variable measures:
 - a). An information grid, was included to ascertain general knowledge about HIV and AIDS (*see section 3.3.5.2. below, for construction of grid*);
 - b). A 'state' or test-related anxiety measure and;
 - c). A 'trait' or characteristic anxiety measure (*see section 3.3.5.1. below, for construction of the anxiety scales*)
- Seven open-ended, qualitative questions asking: whether the respondent had thought about the possible result and the consequences of the test, either if positive or negative: the person they had chosen to give them the result and why: any suggestions regarding improvement of the testing experience: and comments or any other relevant information.

The questionnaire was administered in both phases 1 and 2, but served a different purpose in each instance. The information was largely descriptive and exploratory in phase 1, but was utilized as a measure of effect for the intervention applied in phase 2.

B) Semi-structured interviews, conducted with nursing staff and brokers, were employed in phase 3. The interviewer was guided by an opening question: 'What are your thoughts about insurance HIV testing?'. The interview was then allowed to develop in accordance with the respondents answer to the initial question. The implicit goal was nonetheless to probe for feasibility and anticipated reception of an extended informed consent and pre-test counselling procedure.

3.3.5.1. Construction of the Anxiety Measures

An anxiety scale was constructed and included in the questionnaire (see appendix 7, question 12). Anxiety is an emotion commonly experienced in association with medical procedures in general (Cattel, 1972; Izard & Tomkins, 1966; Spielberger, 1972), and especially so in association with an HIV test (Bor, Perry, Miller & Salt,

1989; Miller & Bor, 1991, 1993; Ubel & Loewenstein, 1997; Van Dyk, 1992, 1999). The scale was a self-report, adjective selection check-list, based on the 'inventory premise' which assumes that people are willing and able to correctly describe their own feelings and behaviour (Cattell, 1972; Spielberger, 1972b; Tyrer, 1976). These reports become a verbal surrogate for behaviour. This is a commonly employed format for measuring anxiety (ibid.). Three broad categories of adjectives pertaining to anxiety states are identified in the literature (Eriksen, 1966; Spielberger, 1972; Tyrer, 1976). The first of these refers to general factors relating to neuro-physiological functioning, which includes the psychological states of attention, vigilance, wakefulness and efficiency (ibid.). The second factor relates to a subjective sense of contentment, and the third to feelings of calm. There is an emphasis on the importance of a subjective interpretation of 'bodily feelings', especially in the absence of objective measuring instruments (ibid.). This interpretation appears to be reliable, although bodily or somatic symptoms are seldom considered separately from mood states. Somatic or peripheral measures of anxiety include: a) Sweating, with palmar sweating in particular; b) tremor, such as shivering with fear, which can also be a subjective sense such as experiencing 'butterflies'; and c) tachycardia and palpitations with an increased rate of respiration and feeling slightly distant from their own body or the current experience (Tyrer, 1976). Questions eliciting the presence of all three somatic measures were included in the questionnaire, as discussed below.

3.3.5.1.1.Trait Anxiety

It was also deemed helpful to differentiate between anxiety precipitated by life events, and a general proneness to anxiety. Lader (1980) states that it is normal for all people to experience a degree of anxiety at times (Epstein, 1972). There are, however, certain individuals who are more prone to anxiety than others. These people are classed as experiencing characteristic anxiety, which appears to be quantitatively different to 'normal' situationally precipitated anxiety (Bakal, Hesson, & Demjon, 1995; Epstein, 1972; Spielberger, 1972a). It was found that in a non-prone individual, anxiety can be induced, even with great intensity, but it will subside fairly quickly. In contrast, the emotional arousal tends to be persistent over time for a person exhibiting characteristic anxiety (ibid.). The former is described as 'state' anxiety and the latter as 'trait' or characteristic anxiety, where a trait is defined as a relatively enduring propensity to perceive the world in a certain way (ibid.). The rationale for establishing respondent's score of trait anxiety was to exclude the possibility that a person

presenting with great anxiety at the time of testing, was characteristically anxious, and so would have been anxious regardless of preparation.

Based predominantly on the work of Spielberger (1972) and empirical research supporting the use of ‘anxiety words’, an adaptation of his adjective check-list targeting enduring and character based anxiety was constructed and included in the questionnaire (*see appendix 7, question 8: demographic section*) (Spielberger, 1972a; Tyrer, 1976). Care was taken to limit the length and complexity of the questionnaire, in order to encourage it’s completion by the rushed insurance applicant. The condensed, less intrusive checklist adaptation of the measure was therefore chosen in preference to a more elaborate gold standard Spielberger ‘Trait anxiety’ measure. Seven possible options to tick were included, and were elicited by asking ‘Would you describe yourself as’:

- | | |
|--|---|
| <input type="checkbox"/> A worrier | <input type="checkbox"/> Concerned with what other people thin of you |
| <input type="checkbox"/> Usually a calm person | <input type="checkbox"/> Bothered by headaches |
| <input type="checkbox"/> Seeing ‘the funny side of things’ easily | <input type="checkbox"/> Feel afraid often |
| <input type="checkbox"/> Sometimes having tingling or numbness in parts of your body | |

There was an intentional bias toward eliciting explicit anxiety responses, with only 2 of the 7 questions gauging non-anxiety (‘usually a calm person’ and ‘seeing the funny side of things easily’). This approach was adopted due to the ease with which the absence of anxiety could be established in contrast with the varied and often subtle measures required to establish a definite presence of anxiety. Each anxiety response was allocated a score of 1, with a blank or non- anxiety response receiving a score of zero. A score of 1 was also allocated, by reverse scoring, to a response indicating an absence of calm, assumed to implicitly suggest the presence a anxiety. The scores were summed for each respondent, to give a possible maximum total of 7 and a minimum of zero.

3.3.5.1.2. State Anxiety

The self-report measure for state anxiety consisted of 18 adjectives in all, with 8 measuring the absence of anxiety and 10 measuring the presence of anxiety. As with the trait anxiety measure above, a slight bias towards eliciting the presence rather than

the absence of anxiety was favoured. The absence of anxiety was noted by descriptions of:

- | | |
|---|---|
| <input type="checkbox"/> Calm | <input type="checkbox"/> Feeling relaxed |
| <input type="checkbox"/> Happy and unconcerned | <input type="checkbox"/> Feeling contented |
| <input type="checkbox"/> A sense of well-being | <input type="checkbox"/> Feeling no different |
| <input type="checkbox"/> Interest or curiosity about the test | <input type="checkbox"/> Not thinking about the test much |

The presence of anxiety was noted by descriptions of:

- | | |
|---|--|
| <input type="checkbox"/> Sweating palms | <input type="checkbox"/> Feeling tense or 'wound up' |
| <input type="checkbox"/> Butterflies in your stomach | <input type="checkbox"/> Thinking about past actions a lot |
| <input type="checkbox"/> An uneasy feeling | <input type="checkbox"/> Restlessness |
| <input type="checkbox"/> Feeling light-headed or dizzy | <input type="checkbox"/> More headaches than usual |
| <input type="checkbox"/> Thinking about the test frequently | <input type="checkbox"/> Anxiety about the test |

The measure was scored by allocating the presence of anxiety with a score of 1 and the absence with a score of 0. This scale was also scored with a bias towards eliciting anxiety. Reverse scoring was used, and a non-response to a question indicating an absence of anxiety was therefore also given a score of 1. The highest possible score, indicating extreme anxiety, was 18 with 0 as the lowest possible score, indicating absolutely no anxiety. Both the trait and state anxiety measures utilised were found to be reliable in both phases 1 and 2, as indicated by the Cronbach Co-efficient of Reliability (*see table 1 below*) (Bouma & Atkinson, 1995; De Vellis, 1991; Howell, 1989).

Table 1:

Attribute	Phases 1 or 2	Cronbach Alpha	Standardized Alpha
Trait Anxiety	1	0.587	0.73
State anxiety	1	0.707	0.83
Trait Anxiety	2	0.720	0.76
State anxiety	2	0.670	0.69

3.3.5.2. Establishment of the Information Grid

An information grid was constructed and included as part of the questionnaire (*see appendix 7*). The purpose of this grid was to ascertain the general level of knowledge regarding HIV / AIDS of the applicants. Inclusion of this grid enabled an assessment of the effectiveness of the information / counselling document, included in the

insurance application forms, in imparting information. The grid was based on the format used by a South African AIDS awareness and counsellor training organisation called ‘ATICC’ (Training and Information Counselling Centre).

The questionnaire grid included a selection of 12 items and was scored by allocating each correct answer a score of ‘1’ and each incorrect answer a score of ‘0’, creating an ordinal scale. The maximum score possible was therefore 12, with zero the minimum. It was hypothesized that the level of knowledge regarding HIV and AIDS would have a negative correlation with the level of anxiety experienced by the applicant. The level of anxiety and information were therefore measured as a matter of central interest in the study. The reliability of the scale was established by means of the Cronbach Co-efficient of Reliability (Bouma & Atkinson, 1995; De Vellis, 1991; Howell, 1989) (*see table 2 below*).

Table 2:

Attribute	Phase (1 & 2)	Cronbach Alpha	Standardized Alpha
Information	1	0.705	0.77
Information	2	0.474*	0.53

(* = A low score, suggesting a poor reliability of this particular scale)

The poor reliability of the scale for Phase 2 could be attributed to the selection bias in the direction of a generally lower education and socio-economic status of this sample.

3.4. DATA COLLECTION

This study focused on the client experience of HIV testing at the time of blood being drawn. The questionnaires were distributed with the assistance of nursing staff at varied depots around the Western Cape. For practical and ethical reasons, the research proposal was presented to the LOA and 2 Pathology Laboratories in the Cape, in order to gain their permission to conduct the research. Permission was granted, based on their interest in an assessment of the effectiveness of their counselling document. It was expressly understood that the research would however be conducted independently.

3.4.1. Phase 1

The questionnaires were distributed, in an unsystematic fashion, across the Western Cape, by the nursing sisters employed at the pathology sites, to all persons presenting themselves for an HIV test. The majority of the questionnaires were completed by insurance applicants, due to the predominance of HIV testing undertaken for this purpose. Some self-selection, however, did occur, as noted and reported by the various nursing sisters distributing the questionnaire. Some of the people approached to answer the questionnaire refused, due at times to time constraints, but also due to mistrust and anxiety. The Xhosa-speaking applicants were notably reticent to participate, as observed by the sisters in Eerste Rivier, Worcester and Jan S. Marais Hospital. The sample is therefore not as representative of the target population as desired.

3.4.2. Phase 2

Phase 2 was a smaller study with 35 questionnaire respondents. This phase mirrored phase 1 in all respects of administration, but with the addition of basic interactive pre-test counselling by the nursing sister drawing the blood sample, added as an integral part of the testing process. Clients were not given the choice to have counselling, nor were they aware of the protocol being different to that experienced by any other life assurance applicant. The scope of the counselling however was within the range of information and expertise of any informed nursing sister conducting venisection.

Only two counselling questions were consistently addressed. The first was to establish that the applicant understood the nature of the test ('this is an HIV test'), with the distinction between having an 'HIV' test and being diagnosed with AIDS clarified. Secondly, they were also all given the opportunity to express anxiety or fear relating to the test, with clarification made regarding anxiety about the needle or the result. The remainder of the interaction then assumed a predominantly open-ended questioning format, and the client was asked if they had any questions they wanted answered or concerns they wanted addressed. This elicited varied responses, with the counsellor then addressing the particular concern presented. The sessions lasted between 10-15 minutes. The length was determined by the client's interest in continuing discussions. None showed any particular interest for longer than 15 minutes. If the client showed little initial engagement they were encouraged to ask questions, which they invariably did, but again, for this short period only.

3.4.3. Phase 3

The third phase consisted of semi-structured interviews with 14 nursing sisters and 10 insurance brokers at various depots across the Cape Peninsula (*see appendix 6 for interview transcripts*). The interviews emerged as an unplanned addition to the data. The researcher spent time at the depots, and found it a natural progression to talk to the nursing staff present and then later to request an interview with some of the brokers who had accompanied their clients for the test. The only question asked was: 'what the professional felt or thought about insurance HIV testing,' allowing the interview to then develop naturally, based upon the person's expressed opinions.

3.5. METHOD OF ANALYSIS

- a. The socio-demographic characteristics of the sample population, and the test specific questionnaire responses in phases 1 and 2 were analyzed using descriptive statistics, employing frequency tables and figures.
- b. Statistical analyses were conducted using the STATISTICA program. The data was not normally distributed and was discrete, being largely ordinal in nature. This necessitated the adoption of non-parametric analysis. The Kruskal-Wallis ANOVA (comparable to the parametric ANOVA), the Mann-Whitney U test, Spearman Rank Order Correlations and Correspondence Analysis, were used to determine the statistical significance of associations between variables of interest (Howell, 1989).
- c. The open-ended questions incorporated in the questionnaire and the semi-structured interviews were analyzed using qualitative, thematic content analysis methods (Anastasi, 1982; Miles & Huberman, 1994). The data was coded according to themes, with the frequency of the themes also being noted. A 'composite' narrative of the expressed opinions was then compiled, so that the emerging Narrative Therapy 'story' could be told (White & Epston, 1990).

CHAPTER 4

RESULTS AND DISCUSSION

PHASE 1

4.1. DEMOGRAPHIC INFORMATION

4.1.1. Sex

Out of the total 429 respondents, 55% were male and 45% female.

4.1.2. Language

Afrikaans was spoken as a first language by 52% of respondents, English by 41% and Xhosa by 4%. In the Western Cape home language cannot be conflated with race. For instance, it was noted that several black applicants marked English as their home language.

4.1.3. Age Groups

There was a slightly higher percentage of insurance applicants falling within the 25-35-year-old age group. The remainder of the applicants were evenly distributed across the age span. The age distribution of the sample is outlined in table 3 (*below*).

Table 3: Distribution of Age:

Age Categories	Percentage	:	Age Categories	Percentage
15-25	18%	:	35-40	15%
25-30	24%	:	40-45	12%
30-35	21%	:	>45	15%

4.1.4. Socio-economic Status

As life assurance represents an ongoing expense for the applicant, the tendency is for the more economically viable rather than for impoverished persons to apply for cover. The respondent population indicated a 90% employment rate. The remaining 10 included students, housewives and retired persons as well as the currently unemployed.

In terms of income, 38% of the respondents earned R4000 or more per month, 35% earned between R2-4000 per month, and the remaining 28% earned less than R2000 per month.

4.1.5. Education

Forty three percent of respondents had a diploma or a degree, 37% had completed 11 or 12 years of schooling, and 20% had lesser schooling.

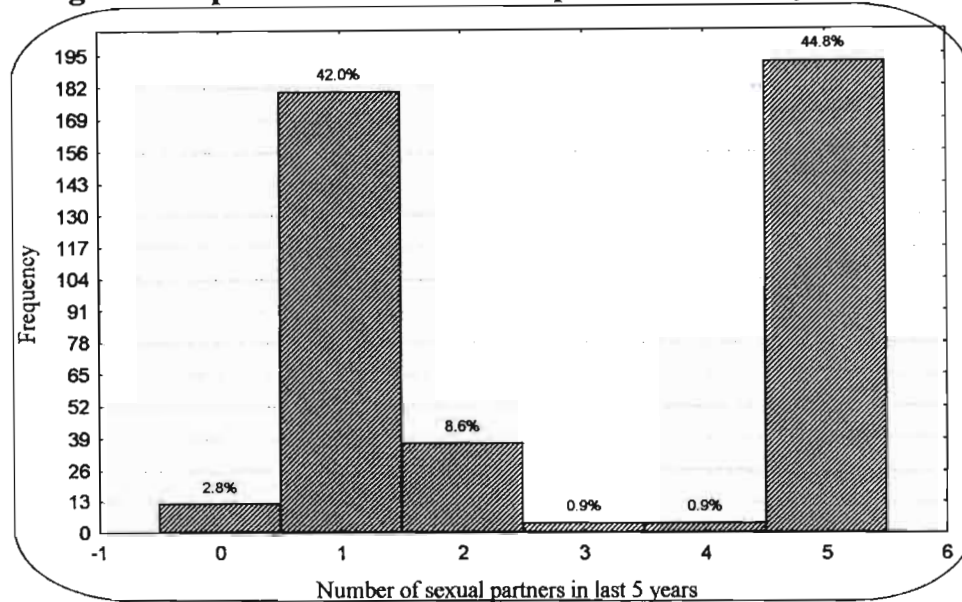
4.1.6. Relationships

It was found that 60% of respondents were married, 15% were in a relationship and 25% were not in a relationship.

In assessing the duration of the marriages, it was found that 10% had a duration of 2 years, 19% 5 or less years, 9% 6-10 years and 11% 10-20 years.

The number of sexual partners is reported in Figure 1 (*below*). This question generated a generally low response rate, hence the necessity of a category 'not answered' (*noted as category '5' in Figure 1*).

Figure 1: Reported number of sexual partners in last 5 years:



4.1.7. Assessment of the Availability of Practical and Emotional Support from Family, Partner and Friends:

There was a poor response rate to this question, suggesting either a reluctance to answer or the absence of such support. Respondents indicated that they received most support, both practical and emotional, from family (37% and 32% respectively), with diminishing support from partners (22% and 27% respectively) and the least from

friends (16% and 18% respectively). The quality of support received from the different sources is listed in table 4 (*below*).

Table 4: The Self-assessed quality of support received:

Practical support from:	Good	Fair	Poor
Family	62 %	11 %	3 %
Partner	49 %	9 %	0.7 %
Friends	30 %	19 %	2 %
Emotional support from:	Good	Fair	Poor
Family	60 %	10 %	3 %
Partner	54 %	7 %	0.7 %
Friends	33 %	17 %	3 %

4.2. RESULTS OF THE TEST SPECIFIC QUESTIONS

This section assessed the respondent's specified emotional and cognitive state immediately following the venisection for HIV testing.

4.2.1.Understanding the Nature of the Test

Ninety-nine percent of respondents stated that they were aware of the nature of the test they were undertaking. The finer distinction between an HIV or AIDS test was not ascertained at this point, but was later explored in section 6 of the questionnaire. These results indicated that 60% of respondents believed they were having an 'AIDS' test, with 35 % aware that it was in-fact an HIV test.

4.2.2.Previous Testing Experience

Forty percent of the respondents reported that they were having the HIV test done for the first time, and 28% were presenting for a second time within a year. The remaining 30 % had been tested more than a year previously.

4.2.3.Reasons for Testing

The reasons for presenting for testing, showed a predictably high percentage of the respondents, 84%, were being tested for insurance purposes; 12 % for a bond application; 0.46% for work reasons; 1.6% for personal reasons (which were not elicited) and 1.4 % for 'other' reasons, predominantly for antenatal screening and travel.

4.2.4.Consent

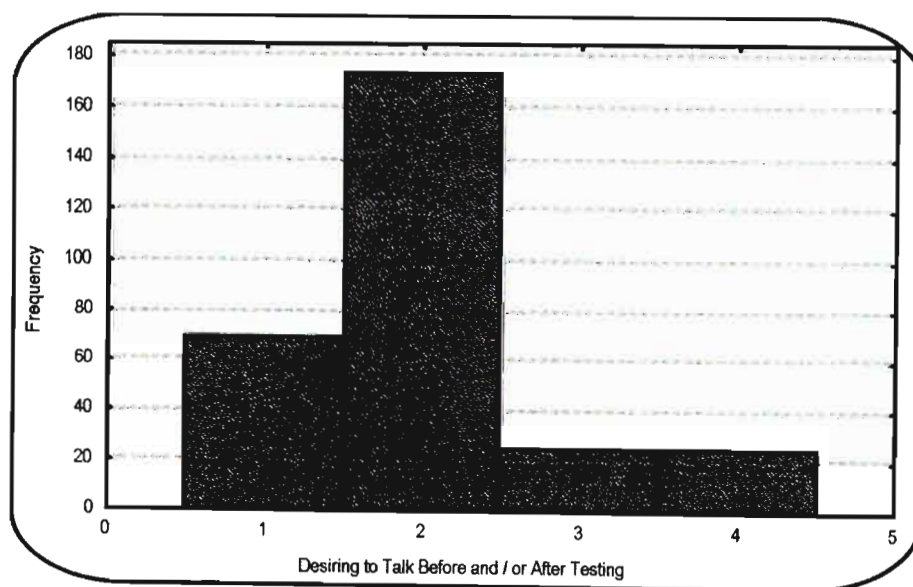
It was found that 94% of respondents indicated that they had given signed consent for testing. There were 19 persons not responding to the question and 9 persons who indicated that they had not signed consent. On closer analysis, 4 of the 9 had the test for other reasons, which would indicate that they had not been required to give written consent. Written consent for HIV testing for reasons other than insurance purposes is not at present obligatory. The remaining 5 had, however, presented for insurance purposes. Since the life assurance testing protocol is very stringent, with all persons being asked to sign consent prior to testing, this can only mean that these 5 people had signed, but were not aware of the significance of their signature.

4.2.5.Subjective Assessment of Being Adequately Informed about Testing

Sixty two percent of the respondents indicated that they felt adequately informed about HIV / AIDS, and a third (33%) indicated that they did not feel adequately informed, and 5% did not answer the question.

The respondent's subjective desire to have verbal input regarding the test, assessed as 'wanting the opportunity to talk about the test' at varied stages, is reported in Figure 2 (*below*).

Figure 2: 'Wanting to talk about the test':



- 1 = Yes: wanting to talk before and after testing (16%)
- 2 = No: not wanting to talk either before or after testing (40%)
- 3 = Yes: wanting to talk before but not after testing (6%)
- 4 = Yes: wanting to talk after testing but not before (6%)

4.2.6. Test Choice

Sixty-five percent of respondents stated that they would have chosen to have an HIV test, and 30 % indicated that they would not have chosen to do this test, if it had not been requested for insurance purposes, 5% did not answer the question.

Despite choosing or not choosing the test, 93% of respondents felt that it was a 'good thing' to have done, 4% answered that it was not a good thing to have done, and 3% did not answer the question.

4.2.7. Nervousness Relating to Testing

The majority of respondents, 74%, said they were not nervous about the test, with 23% admitting nervousness. In response to the specific aspect of the 'needle-prick', 35% indicated that they were nervous of the needle, with 63% indicating no distress about the procedure. Only 22% of the respondents indicated that they were concerned about the possible result, and 75% stated that they were not concerned or nervous.

4.2.8. Effect of the Information Received from Varied Sources on Nervousness

A third (34%) of respondents answered that the information they received had reduced their nervousness, 14% did not answer the question and 51% indicated that the information had not altered their nervousness. This last response is ambiguous, as it could indicate that these people were nervous and the information had not alleviated this distress, or that they were not nervous, and therefore the information had not altered this state.

4.2.9. Having Taken the Time to Think about the Test Result

More than half of the respondents (59%), had thought about the implications of the result, with 37% indicating that they had not.

4.2.10. Having taken the time to think about the possible consequences of the result:

These results differed from 4.2.9. above, where 75% of respondents indicated that they had thought about the implications, 20% indicated that they had not, and 6% did

not answer the question. This could indicate that the greater concern and thought relates to consequences, rather than thinking about a result as an abstract concept.

4.2.11. Assessment of the Sufficiency and Helpfulness of the Pre-Test Information Received from Varied Sources

This section had a poor response rate, with non-response per category varying from 59-90%. The most complete response was in assessing the sufficiency of the information received from the health professional, followed by the question assessing the sufficiency of the information received from the life assurance advisor. There was a non-response rate of 58% in assessing the sufficiency of the counseling document, and an 82% non-response to the helpfulness of the document. The rating of the varied sources of information where the respondent indicated sufficiency and helpfulness are listed below with the percentage for sufficiency noted first, and helpfulness noted second:

- 35% / 15% from the Health Professional
- 30% / 13% from the life assurance advisor
- 29% / 11% from the counselling document
- 16% / 11% from friends and family.

The percentage rating from the various sources are listed similarly below with the category of not sufficient first, and not helpful second:

- 7,4% / 5.3% from the Life Assurance Advisor
- 6% / 3% from a health professional
- 5% / 4% from family and friends.
- 4,4% / 2.3% from the counseling document

The rating of information received from bond advisor, employers and other sources has been omitted, as they had a very poor response rate ³.

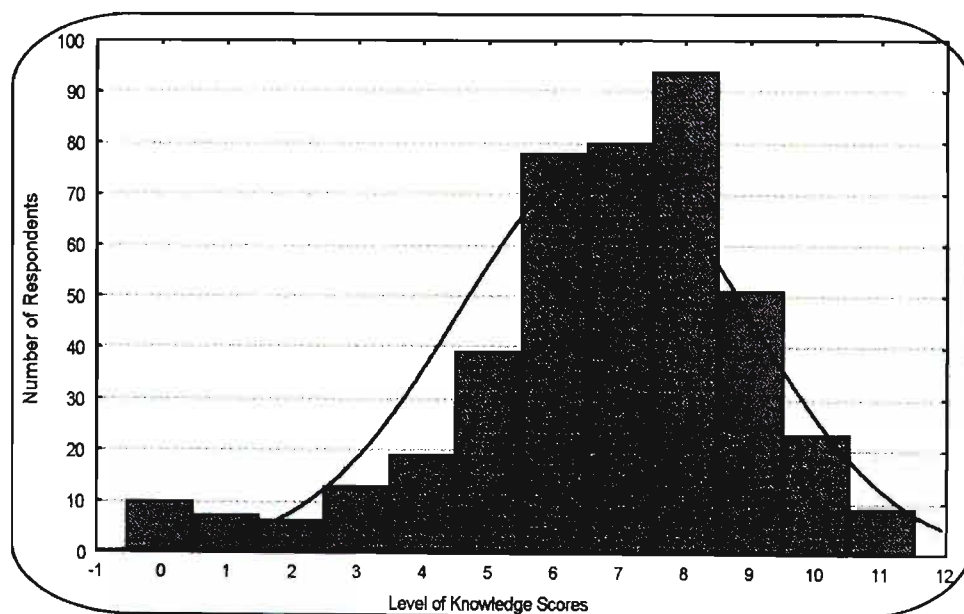
³ A full table of responses is included as Appendix 1

4.3. GENERAL KNOWLEDGE ABOUT HIV AND AIDS

The results of sections 4.3. and 4.4. are based on the sample of 429 respondents, which included people having the HIV test for differing reasons⁴. The results are illustrated in Figure 3 (*below*). The insurance applicants represented 84% of this sample, but to ensure that the results of this subgroup were comparative, a second figure which included only the insurance applicants was constructed and included in the appendix. As anticipated, the configuration of both graphs were virtually identical (*see Appendix 3, Figure 1*).

The results of this section indicated a moderate level of general knowledge about HIV / AIDS, with a small percent of the respondents exhibiting either very poor (including zero) or comprehensive knowledge.

Figure 3: Measured level of Knowledge about HIV / AIDS:



Level of Knowledge about HIV / AIDS rating of the total sample population:

0 = no information (2%)

4-8 = fair knowledge (73%)

1-3 = poor knowledge (7%)

9-11 = good level of knowledge (18%)⁵

⁴ such as ante-natal screening, travel, bond application and personal reasons in addition to the assurance applicants

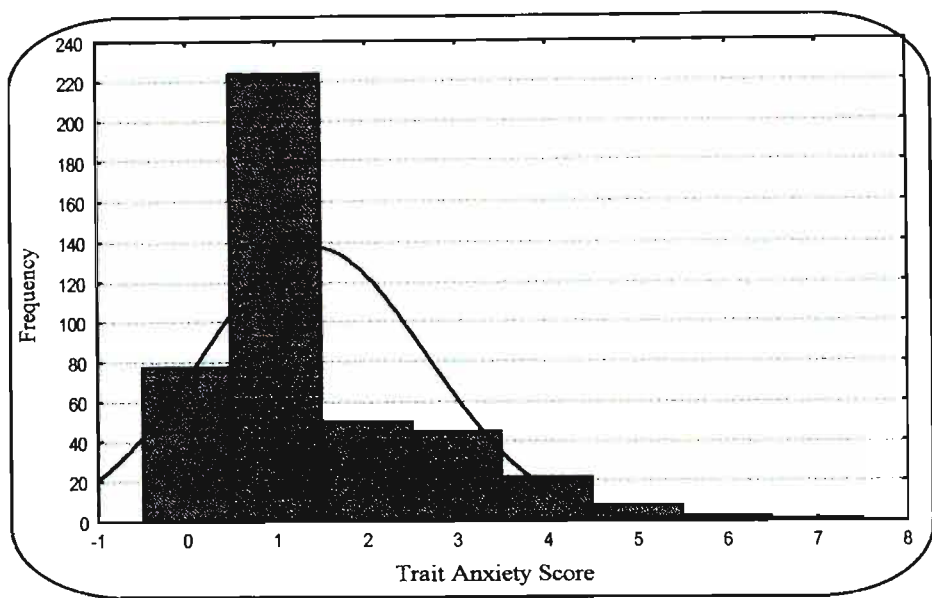
⁵ The scores range from zero accurate information (0) to a score of 10 or 11. The question regarding infection through contact with saliva became an issue under debate at the time the questionnaire was distributed, and therefore either a true or false answer could be deemed accurate

4.4. ANXIETY MEASURES

4.4.1.Trait Anxiety Measure Scores

Figure 4 (*below*) indicates that the majority of respondents (64%) scored on the measure as having low characteristic anxiety; that is they would not describe themselves as overly anxious people. A small percentage, 3%, scored with high characteristic anxiety. This would have significance in the assessment of the state of anxiety they experienced at the time of testing.

Figure 4: Measured Trait Anxiety Scores:



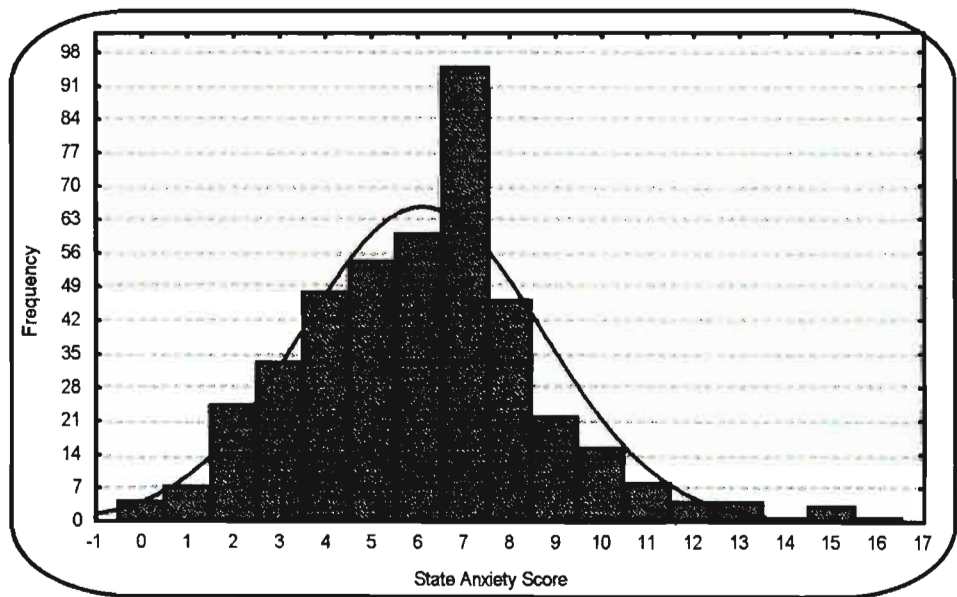
- 0 = no anxiety (N: 77 = 18%)
- 1-2 = low anxiety (N: 274 = 64%)
- 3-4 =moderate anxiety (N: 66 = 15%)
- 5-7 = high anxiety (N: 12 = 3 %)

4.4.2. State Anxiety Measure Scores:

The results of the state anxiety measure scores are illustrated in Figure 5 (*below*). Forty-five percent of the respondents scored at a moderate level of anxiety at the time of testing, 8% scored zero or minimal anxiety, and 2% scored high anxiety. The extreme scores are important. The zero or minimal anxiety scores could possibly denote the respondent’s certainty about a negative result, due to their minimal exposure to risk, but they could equally indicate a strong denial of the significance of

the test. This could represent a person who is not even considering the possibility of a positive result, and who would therefore be devastated by the unexpected. A state anxiety figure was constructed for the insurance applicants only, to ensure that this group had a similar level of anxiety to the sample population (*see Appendix 3, Figure 2*). The results were comparative.

Figure 5: Level of State Anxiety:



0	= no anxiety (1%)	6-9	= moderate anxiety (52%)
1-2	= minimal anxiety (8%)	10-12	= anxious (7%)
3-5	= mild anxiety (32%)	13-17	= very anxious (2 %)

4. 5. SUMMARY AND DISCUSSION OF TEST SPECIFIC RESPONSES:

In conclusion of this section it was found that:

- The majority of the respondents, (99%) were aware that they were having the HIV test, although 65% were not aware of the finer distinction between HIV and AIDS;
- There was a majority assessment, (93%), that having an HIV test was personally valuable, even though they may not have voluntarily chosen to do so without the insurance motivation;
- The respondents indicated that they were generally aware, to varying degrees, of the significance and consequences of the HIV test;
- In assessing the client preparation prior to testing, as measured by the variable of anxiety, it was found that people were nervous about the test, again to

varying degrees and for various reasons, but that for most people, the level of anxiety was not excessive or distressing to themselves;

- The respondents did not judge the input they had received, from the various sources, as either helpful or reducing their anxiety, but that the greater proportion of the limited help they received was from the health professional, and then to a lesser extent from the broker and the counselling / information document. This result signifies that the current pre-test preparation the client is receiving is not assessed as effective;
- In measuring the applicant's level of information / knowledge about HIV / AIDS as a component of pre-test preparation, a normal distribution of knowledge was found, with the majority having some information, and a small proportion of people knowing very little or a great deal. This cannot however be taken as a measure of the effect of the information / counselling document, but may merely be a reflection of people's general level of knowledge.

The results indicate that the current protocol is generally, at face value, satisfactory for most people. The applicants do not object in principle to having the test, nor are they traumatised by the procedure. The situation is not, however, as satisfactory when viewed through the prism of informed consent. From this perspective, it emerges that people are not being prepared at an emotional or information level, by either the health professional, the broker or the counselling / information document. Common errors in understanding and attitude are not addressed or corrected. This lack of preparation would challenge the prevalent assumption that the insurance client is signing informed consent prior to testing. Subtle changes found with the counselling intervention component are discussed below (*see phase 2 below*), but the results between the two studies were generally comparable. This would suggest that alternative interventions still need to be explored.

PHASE 2

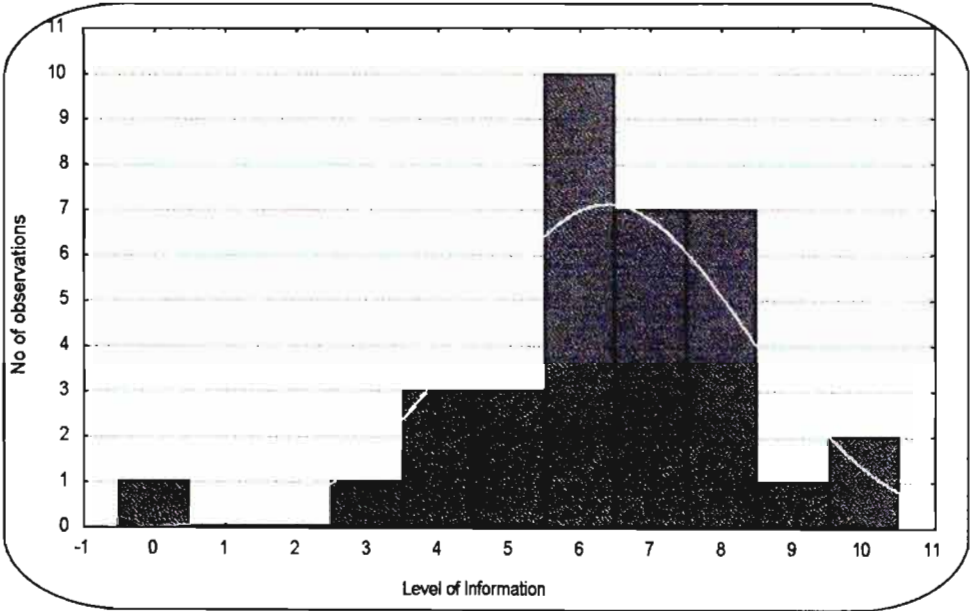
Phase 2 consisted of HIV testing following the interactive counselling intervention. The selection bias anticipated due to the choice of depots serving a lower socio-economic population, was confirmed for the variables of education and income. The sample for Phase 2 had a lower income range with 45% earning less than R2000 per month (compared with 28% in Phase 1), and only 17% earning R4000 or more per

month (compared with 38% in Phase 1). The middle income range was comparative between the two phases. Similarly, the level of education ranged from 34% having between 8-10 years of schooling (compared with 20% in Phase 1), and 29% having a degree (compared with 34% in Phase 1). The relevant results of the pilot study are given below.

4.6. GENERAL KNOWLEDGE ABOUT HIV AND AIDS:

The level of information about HIV / AIDS are illustrated in Figure 6 (*below*):

Figure 6: Measured level of information about HIV/AIDS (phase 2):



Level of Information about HIV / AIDS rating (N: 35):

- 0 = no information/ knowledge (3%)
- 1-3 = poor knowledge (3%)
- 4-7 = moderate or fair level of knowledge (65%)
- 8-11= good level of knowledge (29 %)

The results show a slight qualitative shift to the right, in the pattern of responses. Nearly 50% of the respondents answered the question pertaining to the difference between an HIV test and AIDS accurately, in contrast with 35% in Phase 1 (*see Appendix 2*). These are positive differences, particularly in light of the selection bias of this sample.

4.7. ANXIETY MEASURES:

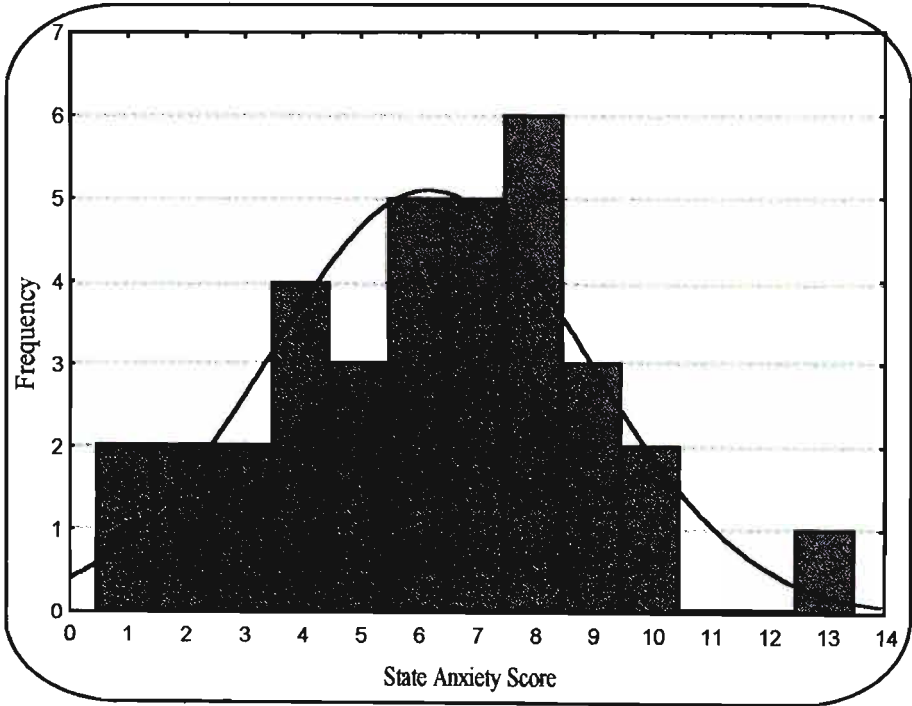
4.7.1. Trait Anxiety:

The Phase 2 results emulate those found in Phase 1, with the majority of the respondents (90%), characterising themselves as not overly anxious people.

4.7.2. State Anxiety Measurement:

None of the respondents in Phase 2 indicated having experienced either zero or extreme anxiety. This difference could be hypothesised to be due to the small sample size, or could optimistically indicate that even minimal counselling produces a more moderate and appropriate anxiety state in response to the experience of testing. This led to a slight qualitative difference in the histogram pattern emerging in phases 1 and 2, as illustrated in figure 7 (*below*).

Figure 7: State anxiety score (phase 2):



Level of State Anxiety (N: 35):

0 = no anxiety (0)

1-2 = minimal anxiety (13%)

3-5 = mild anxiety (28%)

6-9 = moderate anxiety (46%)

10-14 = very anxious (11%)

4.8. RELEVANT RESULTS OF THE TEST SPECIFIC QUESTIONS:

In response to the questions: ‘having had a chance to think what the result might be?’ and ‘having thought what this result might mean for them?’, 66% of respondents answered that they had had a chance to think about what the result might be and 34%

answered that they had not. Seventy-seven percent answered that they had thought about what this result would mean for them, 20% answered that they had not considered the meaning or implications of the result, and 3% (1 person) did not answer the question.

4.9. CONCLUSION / SUMMARY OF PHASE TWO:

It would appear that the process of in-situ, time limited counseling at the depot, did not seem effective in reducing anxiety, increasing level of knowledge about HIV / AIDS, or in improving the person's subjective sense of being adequately informed or prepared for the test.

The qualitative differences which emerged are, however, notable. The shift, towards greater consideration of relationships with others, and a greater emphasis on future preventative actions, in consideration of the consequences of the result, are in the desired direction of change associated with pre-test counselling. This result suggests that that even minimal counselling, in a highly unsuitable environment, begins to produce a desired effect, and would therefore bear further validation. The effectiveness of comprehensive intervention also cannot be discounted on the basis of these dependent variable results, with a need for further research indicated.

4.10. STATISTICAL ANALYSIS

Statistical analysis focused on:

- The client's level of information about HIV and AIDS
- The client's measured state of anxiety at the time of testing
- A consideration of the client's characteristic (trait) anxiety as a confounding factor to the state anxiety at the time of testing

The analyses of these variables was based on the scores obtained by the constructed scales. The data was discrete and ordinal, requiring the use of non-parametric analyses. Spearman Rank Order correlation analyses were conducted initially. When significant, further confirmatory and comprehensively explanatory analyses were required. The tests used were the Kruskal-Wallis ANOVA, the Mann-Whitney U test and where indicated, correspondence analyses. The level of information and the level of anxiety were correlated with each of the other variables. The significant results,

ordered by the three primary variables, information and anxiety, are listed in table 5 (below).

4.10.1. Phase 1 - Analysis associated with the measured information about HIV / AIDS:

Table 5:

<i>Test</i>	<i>Variable Compared</i>	<i>Result</i>	<i>Significance</i> ⁶	
Spearman Rank Correlation		SR	t (n-2)	P
	Language	-0.165	- 3.44	0.0006
	Education	0. 308	6.645	0.0000
	Income	0.116	2.318	0.0200
	Number of partners	-0.104	- 2.16	0.0312
	Children	0.110	2.27	0.0233
	Why test done	-0.110	-2.27	0.0233
	Desire to talk before	0.16	3.12	0.0010
	Desire to talk after	1.33	2.39	0.0174
	Would have chosen test	0.137	2.79	0.0054
	Nervous of result	-0.15	-3.164	0.0013

The significant results were analysed further with the Kruskal-Wallis Anova (Anova) and the Mann-Whitney U test (U test). The Anova gave a non-specific indication of the presence of a significant difference in the information score (*see table 6 below*). The subsequent U-test performed on the significant results identified where the significant differences lay. This translates as occurring in (a) below indicating a significant difference in the range of information between people with a degree and people with a Std. 9-10 level of education. The results for both tests are listed below.

Table 6:

<i>Test</i>	<i>Variable Compared</i>	<i>Result</i>	<i>Significance</i> ⁷	
Kruskal-Wallis Anova		Chi-Square	df	P
	Educational Standing ⁸	23.5	4	0.0001
	Language	15.030	3	0.0018
	Nervous of the result	7.41	1	0.0060

⁶ Statistically significant results noted in bold print

⁷ Significant scores noted in bold type

⁸ Inclusive of number of years at school and a Degree or 'other' post matric qualification

<i>Test</i>	<i>Variable Compared</i>	<i>Result</i>	<i>Significance</i>
Mann Whitney U test		U	P
a. Educational Standing			
	Degree & Std. 9 –10 ⁹	1128	0.0004
	Degree & Std. 6-8	2991	0.0000
	Degree & Std. 3-5	356	0.0030
	Std. 9-10 & Std. 6-8	3573	0.0018
	Degree & 'other'	7760	0.4000
	Std. 6-8 & Std. 3-5	231	0.4060
b. Language			
	English / Afrikaans	14900	0.00001
	English / Xhosa	1377	0.5820
	Afrikaans / Xhosa	1285	0.0224
c. Nervousness Regarding the Test Result			
	Yes / No (to nervousness)	12067	0.0017

Discussion of results:

- Based on the results in analyses 'a' above, a person's level of education is a significant factor in the HIV / AIDS information score. The analysis suggests that a person with a degree is likely to have the most information, with the level of information declining with a reducing number of years of schooling. It could, therefore, be argued that only the applicants with a degree were signing truly informed consent for the HIV test. Persons with a Std. 9-10 education show a moderate level of information, and could probably benefit from some interactive informative counseling, but it is less critical for this group, than for the groups which follow. A person with a Std. 8 or a lower level of education seems to require more comprehensive counseling failing which, it is argued, the consent given cannot be regarded as informed. This finding motivates the suggestion that, in the presence of limited resources, level of education be regarded as a central determinant of who should receive counseling as opposed to allowing for individual preference. This pattern is illustrated in the configuration of the variables in a correspondence analysis (*see Appendix 3, Figure 3*).

⁹ Std. 10 is equivalent to 12 years education; Std. 9 = 11 years; Std 8 = 10 years; Std 7 = 9 years;

- In the second analyses, 'b', language also emerges as a significant variable in the level of information regarding HIV / AIDS. There was a significant difference between English and Afrikaans, and Afrikaans and Xhosa, but not between English and Xhosa speaking respondents. The category of 'other' was not analyzed due to the heterogeneity of this group. A box-plot graph (*see Appendix 3, Figure 4*) illustrates that the Xhosa speaking respondents had the highest level of information, followed by the English speakers. The Afrikaans speaking respondents demonstrated the lowest level of information about HIV / AIDS
- The small sample size of the Xhosa speaking respondent (N = 17, representing 4% of the total sample) is a suggested explanation for this result. Additional analyses comparing the educational level between the language groups (*see Appendix 3, Figure 5*) revealed that Xhosa speaking respondents had a generally higher education level than the Afrikaans-speaking respondents. A wider standard deviation in the latter group also suggests a greater educational range and variability amongst the Afrikaans-speaking respondents. The results indicate that level of education is an important attribute influencing level of information about HIV / AIDS
- The third analyses, 'c', indicates a significant difference in level of information between respondents answering either 'yes' or 'no' to nervousness relating to the potential test result. A box plot graph (*see Appendix 3, Figure 6*) shows a greater level of information about HIV / AIDS amongst the group answering that they were nervous of the result. It could be suggested that it is appropriate to be nervous about such a result. The lower information score corresponding with the negative (no) response could suggest that person's who answered that they were not nervous about the result, were responding with little real understanding of the nature of the test. The 'no' answer to this question possibly indicates an ill-informed and glib response.

4.10.2. Phase 1 -Analysis associated with the Level of State Anxiety:

Table 7:

Test	Variable Compared	Result	Significance	
Spearman Rank				
Order Correlation (S.R.)	S.R.	t(N-2)	P	
	Trait	0.119	2.49	0.0120
	Age	- 0.179	- 3.607	0.0003
	Test	0.10	2.062	0.0390
	Education	- 0.105	- 2.180	0.0200
	Income	- 0.157	- 3.153	0.0017
	Children	0.151	3.152	0.0010
	Test	- 0.09	- 2.05	0.0400
	Nervous	- 0.419	- 9.43	0.0000
	Needle	- 0.230	- 4.83	0.0000
	Result	- 0.32	- 6.97	0.0000
	Talk before	- 0.113	- 2.19	0.0280

The Kruskal-Wallis Anova was used with the significant variables (*see Table 8a below*). The significant Kruskal-Wallis Anova results were then subjected to group-by-group analyses with the Mann-Whitney U test (*see Table 8b below*), which allowed the specifics of the differences to be identified. Only the significant results are listed, with interpretations based on these final analyses.

Table 8:

<i>Test</i>	<i>Variable Compared</i>	<i>Result</i>	<i>Significance</i> ¹⁰	
a. Kruskal-Wallis Anova		Chi-Square	df	P
	Trait Anxiety	17.214	9	0.0460
	Having Children	6.691	1	0.0097
	Nervous about test	43.96	1	0.0000
	Nervous about needle	10.577	1	0.0010
	Nervous about result	22.708	1	0.0000
	Wanting to Talk before testing	5.301	1	0.0213
Assessment of having enough information:		4.557	1	0.0328

¹⁰ Non-significant results listed in appendix 4

b. Mann-Whitney U test	U	P
Trait Anxiety comparing a low score (2)		
and a high score (11)	17.500	0.0048
Trait Anxiety comparing a higher score (8)		
and a high score (11)	0.00	0.0482
Having Children	16933	0.0018
Nervous about test	6949	0.0000
Nervous about needle	14636	0.0000
Nervous about result	8511	0.0000
Wanting to Talk before testing	14143	0.0290

Discussion of results:

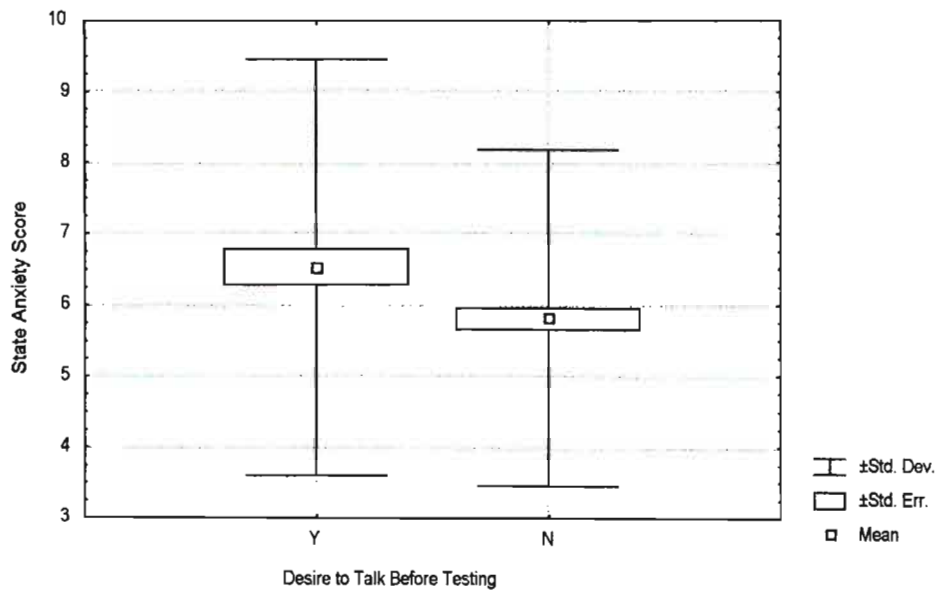
- The Kruskal-Wallis analyses produced a significant result between trait and state anxiety, confirming that each scale is measuring a qualitatively distinctive anxiety. The Mann-Whitney U test, however, identified that the significant difference in the degree of state anxiety experienced by the applicants occurred only in association with a high trait anxiety score (11 or 13). A non-significant difference was found for all the lower ranges (scoring 2-9)¹¹ of trait anxiety. The result would, therefore, suggest that only the characteristically very anxious person was experiencing this qualitative differentiation
- There was a significant difference in the degree of anxiety experienced by persons with and those without children. A box-plot graph (*see Appendix 3, Figure 7*) indicated that the group experiencing the higher degree of state anxiety, were persons who did not have children. This was contrary to an expectation for persons with children to be more nervous. A hypothetical explanation for this tendency could be fear or anxiety that a positive result would mean an end to the prospect of having children, or that they perceived themselves to be at greater risk
- The criteria of being nervous about the test, the needle and the result, all demonstrated a significant difference in the degree of anxiety experienced by those who reported being nervous (about the test, the needle or the result respectively), and those who reported not being nervous. The tendency of anxiety moved in the expected direction, with a report of being nervous associated with a higher state anxiety score. This could be operationalised in the testing situation by an expectation that the insurance applicant's admission, at the point of venisection, that they felt nervous about the test,

¹¹ None of the respondents had a score of 10 or 12. These scores are therefore excluded from interpretation.

would be a reliable indicator of situational anxiety relating to the test. Such a person would qualify as needing additional support

- A significant difference was also found in the degree of anxiety experienced by the applicant that wanted the opportunity to talk before the test, and those who did not. Anxiety moved in the expected direction, with persons wanting the opportunity to talk exhibiting higher anxiety (*see Figure 8 below*). This confirms the desirability for emotional support prior to testing, offered by means of counseling, for persons who are feeling anxious about the test. Analyses of anxiety in relation to the desire to talk after testing was not-significant

Figure 8: Association between anxiety score and a desire for pre-test communication:



- A subjective assessment of having enough information about HIV / AIDS was not significant ($p = 0.056$). A box-plot graph (*see Appendix 3, Figure 10*), however, illustrates that an appraisal of not having enough information was linked to a higher anxiety score
- Level of education and language were analyzed despite having a non-significant Kruskal-Wallis score, based on the prominence of these variables in relation to level of information about HIV / AIDS. The results confirmed a non-significant difference between the language groups, level of information or education and the degree of anxiety experienced at the time of testing. These are therefore not the factors influencing the degree of anxiety

experienced at the time of testing. Only the comparison of a degree with a standard 6-8 education suggested any proximity to a significant difference ($p = 0.054$), and there was a tendency towards a higher anxiety score with lower levels of education

- As the research is focused on the experience of testing for insurance purposes, a box-plot graph (*see Appendix 3, Figure 8*) was constructed to ascertain any particular pattern of anxiety associated with the different reasons for having the test. The results indicate a low level of anxiety experienced in association with insurance HIV testing, and a high level associated with testing for work purposes. Contrary to what might be expected, testing for personal reasons was not associated with a high degree of anxiety. The small numbers for these category, however, make interpretation of the results speculative
- A correspondence analysis was done between the degrees of anxiety experienced relating to the time period since the last test. It was hypothesized that a more recent test would correspond with a lower level of anxiety, and no previous test, or a longer interim period would correspond with a higher level of anxiety. A correspondence graph (*see Appendix 3, Figure 9*) did not however show any particular pattern configuration associated with the time lapse since previous testing.

4.10.3. Phase 1 - Analysis associated with measured trait anxiety:

The trait anxiety score was correlated with all the variables, and the significant results are noted in Table 9 (*below*).

Table 9:

<i>Test</i>	<i>Variable Compared</i>	<i>Result</i>	<i>Significance¹²</i>	
Spearman R Correlations		SR	t(n-2)	P
	Language	- 0.16	-3.33	0.0009
	Nervous about the test	- 0.137	-2.83	0.0040
	Nervous about the result	- 0.109	- 2.23	0.0250
Kruskal-Wallis Anova		Chi-Square	df	P
	Language	21.343	3	0.0001
	Nervous about the test	10.88	1	0.0010
	Nervous about the result	7.79	1	0.0050

Mann-Whitney U Test		U	P
Language:	English / Afrikaans	16420	0.0010
	English / Xhosa	1170	0.1220
	Xhosa / Afrikaans	1832	0.7400
	Nervousness about Test	13178	0.0040
	Nervousness about the result	13131	0.0250

Discussion of results:

- The ANOVA associated with trait anxiety and language indicated a significant score. The Mann-Whitney U test identified that the primary area of difference lay between the characteristic anxiety of English and Afrikaans speakers, with the English speakers showing a higher trait anxiety score
- Nervousness relating to the test in general, and specifically to the result showed a significant difference in the characteristic anxiety experienced by persons indicating that they are anxious, and those stating that they were not anxious.

4.10.4. Comparison of the central variables of interest between phases 1 & 2:

Analyses were also conducted between the central variables, namely information about HIV and the anxiety scores, of the main study (Phase 1) and the intervention study (Phase 2). The interest lay in establishing any significant differences possibly associated with the counseling intervention in phase 2.

Table 10:

<i>Test</i>	<i>Variable Compared</i>	<i>Result</i>	<i>Significance</i>	
Spearman R		SR	t(n-2)	P
Between studies:	Information	0.1877	1.098	0.28
	Anxiety	0.027	0.157	0.875
Phase 2: Information and Anxiety		-0.011	-0.066	0.947

Discussion of results:

- None of the results were significant. As a means of gathering additional insights, a box-plot graph (*Appendix 3:Figure 11*) was constructed, which offered no additional information. The sample bias towards a lower socio-economic

¹² Significant results indicated in bold print

and educational group could be postulated to have had an unmeasured effect on the results in phase 2. The strong association between the level of information and education in Phase 1 further supports this proposal.

4.10.5. Analyses associated with information and anxiety for phase 2:

The dependent variables in phase 2 were also subjected to statistical analyses, following the same format as above.

4.10.5.1. Analysis associated with Information About HIV / AIDS:

Table 11:

<i>Test</i>	<i>Variable Compared</i>	<i>Result</i>	<i>Significance</i>	
Spearman R		SR	t(n-2)	P
	Education	.494	3.265	0.0020
	Nervous for Result	.361	2.156	0.0380
	Information received from the health professional	-.54	-.310	0.7570
Mann-Whitney U Test		U	P	
Nervous for Result (Yes / No)		64.000	0.0400	

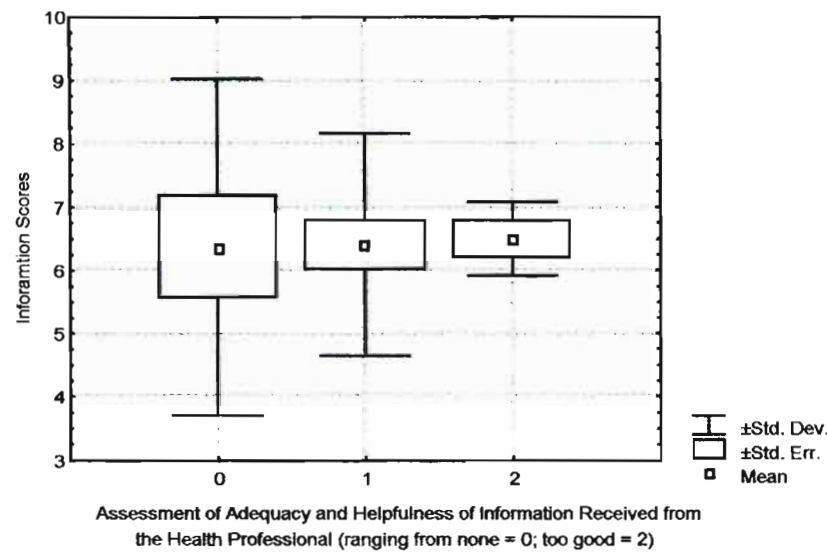
Discussion of results:

- A box-plot (*see Appendix 3: Figure 12*) of the significant difference found between education and level of information about HIV / AIDS confirms the direction: a higher education associated with a higher level of information. This concurs with the finding in Phase 1, and requires no further explanation
- The Mann-Whitney U test indicated a significant difference in the experience of being nervous about the result, in relation to the information score obtained. A box-plot graph (*see Appendix 3, Figure 13*) showed a higher information score to be associated with an absence of nervousness about the result, which represents a desired association. This result differs from those found in phase 1 (where a lower information score was associated with reporting less nervousness). A suggested explanation would be that the applicant now had an increased ability to ascertain accurately what is known or not known about the HIV test. The information imparted in the counseling intervention would have acted as confirmation to the applicant that they had accurate and adequate information, in part by clarifying queries they may have had. This

confirmation is hypothesized to have reduced the more informed person's level of anxiety. Conversely, the intervention would have confirmed the lack of accurate information for the applicants who demonstrated a lower level of information about HIV/AIDS. The greater anxiety in this instance would also be reflecting a more realistic self-evaluation of not being sufficiently prepared for this test.

- Despite a non-significant result with the correlation analyses, the association between level of measured information and input from the health professional was subjected to additional qualitative interpretation. The interpretation was based on a box-plot representation (*see Figure 9 below*). Inspection of Figure 9 shows a wide standard deviation from the mean, or range of information, with regards to the information score, where the respondents indicated no input from the health professional. The respondents information score was lower, as was the standard deviation, associated with an assessment of more information imparted by the health professional. An explanatory hypothesis would suggest a reduction in confusion about HIV / AIDS possibly as a result of the intervention, and an increased awareness of what is not known. Although this is not a desired effect of counseling, the result is not entirely unexpected as the content of the intervention, based on the client directive, was on the route of notification and the implication of the result for the life assurance application as opposed to comprehensive clarification of information pertaining to HIV / AIDS.

Figure 9: Phase 2: Level of measured information in association with input from the health professional:



4.10.5.2. Analysis associated with the measured state anxiety at venisection (phase 2):

Table 12:

<i>Test</i>	<i>Variable Compared</i>	<i>Result</i>	<i>Significance¹³</i>	
Spearman R		SR	t(n-2)	P
	Education	-.425	-2.69	0.0100
	Previous testing	0.572	4.013	0.0003
Information received from the health professional				
	Sufficiency	-.512	-3.43	0.0016
	Helpfulness	0.009	-0.05	0.9500
	Overall assessment	-0.48	-3.21	0.0030
Information from the broker				
	Sufficiency	-.017	-.102	0.9190
	Helpfulness	-.354	-2.17	0.0400
	Overall assessment	-.348	-2.13	0.0400

<i>Test</i>	<i>Variable Compared</i>	<i>Result</i>	<i>Significance¹⁴</i>	
Spearman R		SR	t(n-2)	P
	Test that they would have chosen to do	0.379	2.32	0.0270
	Feeling Nervous about the test	-.52	-3.53	0.0010
	Feeling nervous about the result	-.334	-1.978	0.0560

¹³ significant results noted in bold type

¹⁴ significant results noted in bold type

Kruskal-Wallis Anova	Chi-Square	df	P
Education	9.729	3	0.0210
Previous testing	8.29	1	0.0040
Information received from:			
The Health professional	9.23	2	0.0090
The Broker	3.546	2	0.1690
Test that they would have chosen to do	3.848	1	0.0490
Desire to talk before testing	1076923	1	0.7420
Feeling Nervous about the test	6.443	1	0.0110

Mann-Whitney U Test	U	P
Education : Degree/ Std. 9-10	33.5	0.0490
Information received from the health professional		
None (0)/ moderate information (1)	53.5	0.0180
None (0)/ good (2)	3.000	0.0120
Moderate (1) / good (2)	29.00	0.3900
Information received from the broker		
None (0)/ moderate (1)	70.5	0.0400

Discussion of results:

- The Anova showed a big difference between the level of education and state anxiety. The Mann-Whitney U test identified that the primary area of difference lay between the anxiety score obtained by persons with a degree and Std. 9-10 (and subsequent diminishing levels of education), where people with a degree exhibited a lower level of anxiety. This result is different to that found in Phase 1, where education was not associated with level of anxiety. This result is a possible reflection of an effect of the intervention on the anxiety experienced by the respondents in study two, but this suggestion would require additional confirmation.
- ANOVA associated with previous testing gave a significant result, with a box-plot graph (*see Appendix 3, Figure 14*) showing a lower anxiety score with previous testing.
- A significant difference was also found in the degree of anxiety experienced by the respondents who assessed having received none or a moderate amount of information from the health professional (*see Appendix 3, Figure 15*). This was the range at which the most notable change occurred. Predictably, a significant difference was also found between receiving none or a good amount of information from this source. A non-significant difference was found in the

anxiety experienced between the levels of receiving moderate to good information. The shift was also towards lower anxiety associated with the receipt of information.

- Although the Anova examining the influence of information from the broker on anxiety, was not significant, finer analysis with the Mann-Whitney test, and associated box-plot graph (*see Appendix 3, Figure 16*), indicated a significant difference in the anxiety experienced when the respondent had received moderate, as opposed to no information from the broker. The result obtained when the respondent assessed having received a greater amount of information revealed a non-significant difference, which was explained by a wide range of standard deviation in this category. Although the response numbers were very small, a hypothetical explanation would suggest that confusion or an increase in anxiety was experienced if the broker attempted to give more than a moderate amount of information
- A non-significant difference was found in the degree of anxiety experienced between the respondents who reported wanting to talk and those reporting not wanting to talk prior to testing. The standard deviation in the 'no' group was however much larger, suggesting a wider range of anxiety experienced by this group (*see Appendix 3, Figure 17*). A suggested explanation could be that reasons for not wanting to talk varied widely amongst this group, ranging from not feeling nervous and therefore not requiring the input, to experiencing considerable anxiety, which is prompting the person's fear to talk. It could then be proposed that the latter group require intervention for the very reason they fear the communication.

This represents an appropriate assessment of the range and content of the brief counseling offered. Clearly some of the respondents absorbed little or no information or comfort from the interaction, where others were reassured. Thus, in some cases, even minimal input from the health professional could be judged to have had an effect.

4.11. QUALITATIVE ANALYSIS:

A dual qualitative component was included in the research. The first was incorporated in the client's questionnaire in Phases 1 and 2, by the addition of several open-ended questions, with analysis appearing in section 4.11.1. (*see below*). The second was incorporated as Phase 3, and emerged with semi-structured interviews with nursing staff and brokers present at the depots at opportune times. Analyses of these latter results appear in section 4.12. (*see below*).

4.11.1. Qualitative Analysis of Questionnaire Responses:

The open-ended questions included elicited responses and encouraged client's suggestions on how the protocol could or should be altered. The questions included for the clients were:

9. Any other information, which you think, relates to how you experienced this test?

(The final question at the end of the questionnaire, found in the demographic section)

13. c. How do you imagine this result could affect your life if it was negative (no virus present)?

13. d. How do you imagine this could affect your life if the result was positive (the virus was present)?

14. Who have you chosen to give you this result and why?

15. What, if anything, could have made this testing experience easier for you?

Few people answered the 'why component of question 14, so an analysis was not undertaken. Questions 13.c. and d. were both worded 'imagined' to elicit and encourage a less rational, defensive and more emotive response (Achterberg, 1984; Ahsen, 1988; Alessandro, Giorgetti, Resinelli, & Scafidi, 1995). The nature of the responses reflect that emotive responses were tendered in many instances.

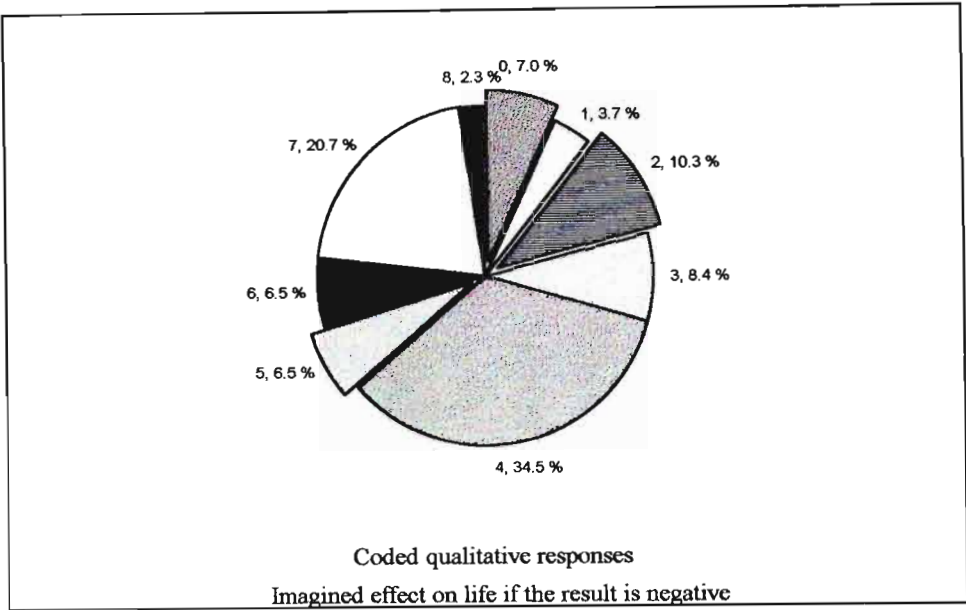
4.11.1.1. Question 13. C:

'Imagined effect on life if the result is negative'

The response to this question, in Phase 1 (*see figure 10 below*), indicated that the greatest proportion of people (35%) did not anticipate any life changes in the event of a negative result or that the whole issue was not relevant to themselves (21%). In some regards this is a perfectly appropriate response to a negative result, but it also indicates that there has been little thought about the consequences of HIV and AIDS on all their lives. A cumulative total of 21% of respondents indicated that the applicant would be pleased or relieved to have confirmation of a negative HIV status.

Of this group, only 7% indicated that having the HIV test would influence their future planned actions.

Figure 10: Phase 1: Imagined effect on life if the result is negative:



Code number relevant to response:	Number of Respondents:
0 = Blank (no answer):	30 (7%)
1 = Would feel relief:	16 (4%)
2 = Would feel happy/ pleasure / reassured:	44 (10%)
3 = Life would just continue as before:	36 (8%)
4 = Would feel no different:	148 (35%)
5 = No surprise / the expected result:	28 (7%)
6 = Would feel good, and would take more care in future:	28 (7%)
7 = Indications that question not applicable to themselves (N/A or -):	89 (21%)
8 = Unsure how they would feel; or an answer indicating confusion regarding the question	10 (2%)

There was a different response rate to this question in phase 2 (see Table 13 below), where the majority of respondents (a cumulative 48%) indicated that they would be happy and would feel reassured to receive a negative test result. A further 14% (in contrast to 7%) indicated that they would take better care in the future to ensure retaining a negative status. Only 23% (as opposed to 35% in phase 1) indicated that they would not be feeling different upon receipt of the result. These results indicate a subtle but notable shift in attitude between persons receiving some counselling (phase 2) and those who did not (phase 1). This difference could be attributed to chance alone, but the impact of even simple counselling can also not be discounted without further validation.

Table 13: Phase 2:

Frequency table for responses to ‘anticipated effect on life if the result was negative’:

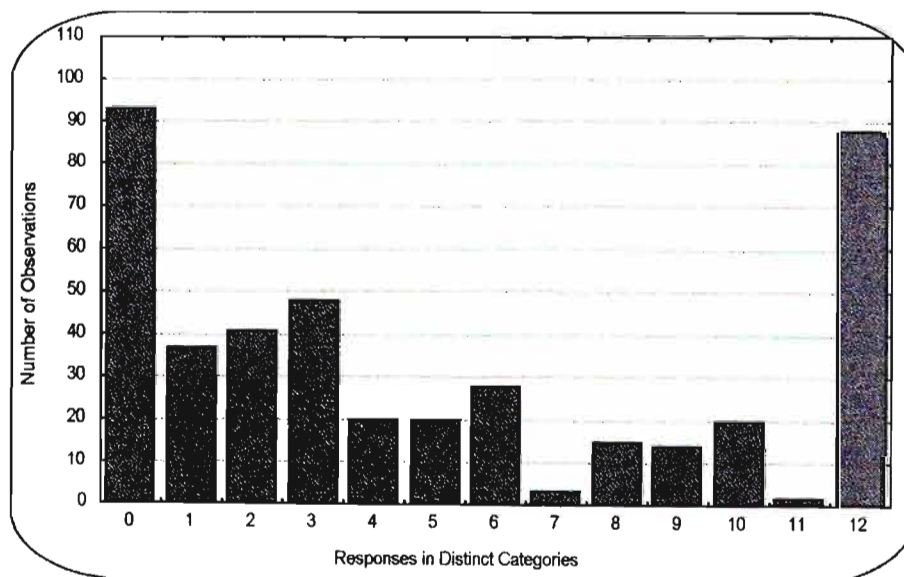
<i>Code number relevant to response:</i>	<i>Number of Respondents:</i>
0 = Blank (no answer):	0
1 = Would feel relief:	5 (14%)
2 = Would feel happy/ pleasure / reassured:	12 (34%)
3 = Life would just continue as before no indication of relief or similar response):	1 (3%)
4 = Would feel ‘no different’:	7 (20 %)
5 = No surprise / the expected result:	1 (3%)
6 = Would feel good, and would take more care in future:	5 (14%)
7 = Indications that question not applicable to themselves (N/A or -):	2 (6%)
8 = Unsure how they would feel; or an answer indicating confusion regarding the question	2 (6%)

4.11.1.2. Question 13. d.

‘Imagined effect on Life if the Result was Positive’:

This was the more evocative question, yet approximately 56% of the applicants, in Phase 1, indicated that the question was not relevant to themselves, or that they were unable or unwilling to answer the question (see Figure11 below).

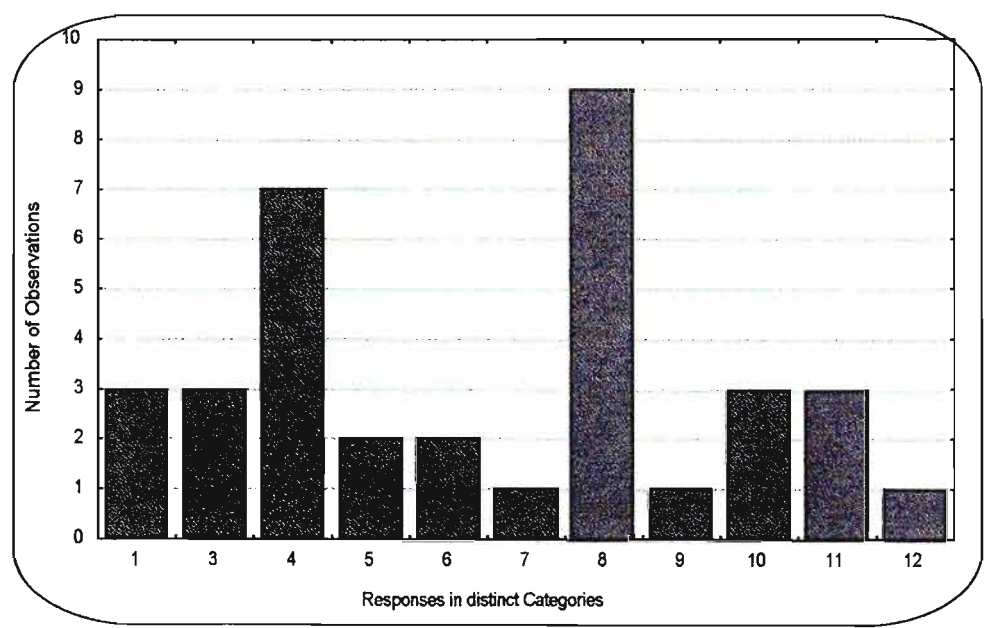
Figure 11: Phase 1: Imagined effect on life if the result is positive:



<i>Code number relevant to response:</i>	<i>Number of Respondents and Percentages:</i>
0 = Blank (no answer):	93 (22%)
1 =Negative effect (not specified further):	37 (9%)
2 = Big changes would occur (not specified):	41 (10%)
3 = Catastrophic (indications that they would be devastated / ‘life over’):	48 (11%)
4 = Resigned acceptance; turning to prayer):	20 (5 %)
5 = No change / unconcern (due to certainty that result will be negative):	20 (5%)
6 = They don’t know or have not thought about it:	28 (7%)
7 = They don’t want to think about it):	3 (0.7%)
8 = Indications that there would be an effect on relationships (loss off or stress too others):	15 (4%)
9 = Shock or anger	14 (3 %)
10= Active problems solving or help seeking intentions	20 (5 %)
11= Sense that this is self inflicted (eg. would be angry with themselves)	2 (0.5 %)
12=Indications that the question is not applicable to themselves (N/A or /)	88 (21 %)

This is a high proportion of people who suggested that they could not be, nor would even consider, being HIV positive. In contrast, 11% indicated that the result would have a catastrophic impact on their lives. The remainder of the applicants fell between these two extremes.

Figure 12: Phase 2: Imagined effect on life if the result is positive:



Code number relevant to response:	Number of Respondents and Percentages:
0 = Blank (no answer):	0
1 =Negative effect (not specified further):	3(9%)
2 = Big changes would occur (not specified):	0
3 = Catastrophic (indications that they would be devastated / 'life over'):	3 (9%)
4 = Resigned acceptance; turning to prayer):	7(20 %)
5 = No change / unconcern (due to certainty that result will be negative):	2 (6%)
6 = They don't know or have not thought about it:	2 (6%)
7 = They don't want to think about it):	1 (3%)
8 = Indications that there would be an effect on relationships (loss off or stress too others):	9 (26%)
9 = Shock or anger	1 (3 %)
10= Active problems solving or help seeking intentions	3 (9 %)
11= Sense that this is self inflicted (eg. would be angry with themselves)	3(9 %)
12=Indications that the question is not applicable to themselves (N/A or /)	1(3 %)

The sample size of phase 2 makes a definitive comparison between the responses of the two phases difficult. There does however appear to be a definite qualitative difference in the focus of the answers given (see Figure 12 above). Where the largest response category in Phase 1 indicated either a refusal to answer the question (a blank space, category 0) or the indication that the question was not applicable to themselves (category 12), the largest response rate for Phase 2 indicated a consideration of relationships and other people (category 8), and a resigning of oneself to the result

and the life consequences (category 4)¹⁵. This shift in emphasis may well be due to chance alone, but the possibility of an effect having occurred as a result of an opportunity to talk about their particular concerns and the minimal counselling, can also not be discounted. The latter consideration is supported by the contrasting low response rate in Phase 2, and to the largest categories in Phase 1 (categories 0 & 12), suggesting that the respondents were less able to dismiss the consequences as not applicable to themselves. There was also a pattern shift in the response rate between categories 7 and 9. Where category 7 was very low (0.7%) and category 9 was relatively low (3%) in Phase 1, they were more even in Phase 2, both having a 3% representation. A possible, albeit far stretching argument or explanation for this pattern shift, could state that there would not be a proportionate increase in anticipated emotions of shock or anger with recognition that one is fearful of thinking about the results. This is a most subtle shift, and may serve to illustrate the direction of change in focus, associated with counselling. Where there has been little support for brief, in-situ counselling by the Professional Nurse, demonstrated in the remainder of the research, this qualitative illustration should not be minimised in significance. The qualitative shifts are also all in accord with experiential and literature supported predictions of the influence of pre-test counselling both in reducing shock at a positive result, and in increasing socially responsible behaviour (Bor, 1991; Gaines, 1988; Miller, 1987; Miller & Bor, 1993; Tallis, 1994).

4.11.1.3. Question 14:

‘Who have you chosen to give you the result?’:

Giving the test result is a difficult process, particularly if ‘positive’. Part of the insurance protocol is the requirement for a written designation, at the time of venisection, of the name of a medical person or clinic that would be responsible for giving the applicant the result. There is commonly some confusion regarding this system, as clients frequently want to receive a result, regardless of whether it is positive or negative. Clients are however only informed of a positive result, via the designated person, and are never informed of a negative result, apart from being issued the policy they applied for. This question was added to ascertain the

¹⁵ The issue of relationships was not dealt with directly as part of the counselling session, and appears to be secondary to internal processing occurring following a more direct confrontation with the anticipated reality of a positive result

understanding that the clients have of the protocol, and preference of informer if they were given the choice (*see Table 14 below*).

Table 14:

Person selected by the applicants to give them the result in phases 1 and 2:

Phase 1:

Designated Person /Organisation (code in bracket)	Number of Respondents	%
Own Medical Doctor (1) ¹⁶	32	8 %
The Pathologist (2)	4	1%
Nursing Sister (3)	2	0.5%
The Broker (4)	3	0.7 %
An incongruent answer (indicating not understood) (5)	3	0.7%
Other / anyone / no-one / N/A (6)	3	0.7%
Question not answered (8)	381	89 %

Phase 2:

Designated person /organisation (code in bracket)	Number of Respondents	%
Own Medical Doctor (1)	25	72%
The Pathologist (2)	1	3%
The Broker (4)	2	6%
Anyone (7)	2	6%
Question not answered (8)	5	14%

These results suggest firstly, that people did not understand the question, or, due to the low response rate, that they were indifferent to the selection. The majority of respondents in Phase 2, however indicated choosing their own medical doctor. Few people answered the ‘why’ component of question 14, precluding any interpretation, beyond past experience that indicates people often chose their doctor for reasons of professional confidentiality, and the easy access to practical care and advice if this is needed.

4.11.1.4. Question 9: ‘Any Other Information Which You Think Relates to How You Experienced this Test?’:

This question was included to invite client comments, which would help to contextualise an understanding of the results. The response rate in both phases was very poor, which made interpretation impossible. The responses are listed below for interest (*see Table 15 below*).

¹⁶ Qualitative thematic categories or codes included
(code 1): Known by Dr., confidentiality; advise and care could be given; (code 4): Insurance test

Table 15: Comments Relevant to the Testing Experience:**Phase 1:**

Comments Relevant to the Testing Experience (code)	Number of Respondents - %	
No/ nothing (1)	89	21%
Certainty that they did not have AIDS (2) ¹⁷	8	2%
Annoyed at the requirement (3)	1	0.23%
Anxiety experienced (4)	7	2%
Other comments (5)	7	2%
Indications of 'not applicable' (6)	317	74%

Phase 2:

Comments Relevant to the Testing Experience (code)	Number of Respondents - %	
No/ nothing (1)	9	26%
Certainty that they did not have AIDS (2)	1	3%
Anxiety experienced (4)	1	3%
Other comments (5)	2	6%
Indications of 'not applicable' (6)	22	63%

**4.11.1.5. Question 15: 'What, if Anything, Could Have Made
This Testing Experience Easier?':**

This question was included in order to invite client suggestions on how to improve the current practice. Half the applicants in phase 1, and 23% of applicants in phase 2 did not answer this question. Forty percent of applicants in Phase 1 indicated that the procedure was either acceptable as it was, or that no improvements could be made, with 59% responding similarly in phase 2. Additional suggestions appear in the Table 16 (*below*).

¹⁷ Phase 1: (code 2): recent result; single partner; safer sex practice; (code 4): fear of needle 2:7; fear of test 5:7
phase 2: (code 4): they knew that their partner had been unfaithful

Table 16: Suggestions Made:**Phase 1:**

Suggestions Made (code in bracket) %	Number	of	Respondents
No / nothing ¹⁸	142		33%
Fine as was	30		7%
Relating to convenience and comfort	9		2%
Relating directly to the testing process	33		8%
Question not answered / indications of 'N/A'	210		49%
Reduced Anxiety for Personal Reasons	5		1%

Phase 2:

Suggestions Made (code in bracket)	Number of Respondents	%
No / Nothing	17	49%
Fine as Was	3	9%
Relating to Convenience and Comfort	3	9%
Relating directly to the Testing Process	4	12%
Question Not Answered / Indications of 'N/A'	8	23%

4.12. PHASE THREE:**THEMATIC CONTENT ANALYSIS OF PERSONNEL INTERVIEWS:**

A further dimension of this study was concerned with exploring the practicality and feasibility of offering pre-HIV test counselling. This aspect was examined by means of semi-structured interviews with 14 nursing sisters responsible for drawing the blood samples at various depots around the Cape Peninsula, and with 10 Insurance Representatives who had accompanied their clients to the pathology rooms. These two groups were selected as both have direct contact with the client and could feasibly provide pre-test counselling. An initial question, '*what are your thoughts and feelings about insurance HIV testing?*' was posed to members of both groups. The earliest interviews were largely undirected, but respondents were encouraged to elaborate on the opinions they were expressing. With continued interviews, clear common themes began to emerge, which then informed slightly more directed questions, asked after the initial question. Thoughts and views were then elicited from later respondents regarding the feasibility of pre-test counselling (such as whom they thought could be suitable counsellors), and on the establishment of an 'Insurance telephonic HOT line'.

¹⁸ (code 1)Included: No elaboration made or that it was a difficult experience and nothing could have made it easier

(Code 3): Tea/coffee/ biscuits (x2); venisectionist to travel to client, venisectionist's skill; no needle; no questionnaire (x1); less paper work

(Code 4): Wanting more information, either verbal or pamphlet; reassurance from venisectionist; opportunity to talk; speedy result; direct result route

(Code 6): Knowledge of having practiced safer sex, single partner, recent result

Some of the respondents expressed few opinions, being either rushed or unwilling to talk, where others became very thoughtful about the matter and expressed a wide range of their frequently inclusive and even contradictory opinions. The two categories of personnel were analyzed separately due to the clear difference in basic perspective (*see Appendix 6 for the interview transcripts*).

The interviews were subjected to a thematic content analysis (Anastasi, 1982; Miles & Huberman, 1994). All emerging themes were extracted and number coded, none were discarded. The nursing staff expressed 34 (xxxiv) different themes, and the brokers expressed 19 (xix) differing themes (*see Appendix 5*). Themes were then listed in order of the frequency of occurrence. These were checked and refined by combining those with subtle similarities. The identified, ordered themes were then combined to create a composite first person narratives, one for each group, wherein the opinions expressed are presented as the group 'story' which emerged (White & Epston, 1990). The more frequent themes were therefore expressed early in the narrative, combined with the less frequent but associated opinions. More diverse and less frequently expressed opinions occur later in the narrative.

4.12.1. Composite Narrative of the Interviews with the Nursing Staff:¹⁹

We, the interviewed nursing staff at the various depots around the Cape Peninsula are directly involved with venisection for HIV testing generally and specifically for insurance purposes. As nursing staff, our role has traditionally been largely supportive and unquestioning of the medical profession, whilst simultaneously being genuinely concerned and interested in the well being of our clients. Although we seldom give voice to our thoughts, we all, knowingly or unknowingly, have opinions regarding the current protocol. Once we were given the opportunity to consider and verbalise these, many of us were surprised to discover the extent of our own thoughts and feelings around this issue. We know that this is a difficult, sensitive issue, with multiple aspects, so that at times we ourselves are not absolutely clear about how we perceive this practice. Some of us had clear opinions, where others found that during the course of the interview (which allowed a serious consideration of the problem), we

¹⁹ Appendix 5 themes are noted in the text by number eg. '(Theme: 3)' for theme number 3
Direct quotes from Appendix 6 (the interview transcripts) are noted as 'Nurse' for Nursing staff or 'Broker' for broker interviews and the line number eg. Nurse: 24 or Broker: 305.

experienced and expressed contradictory or even conflicting opinions, as we recognised the complexity of the practice (theme 7).

With regards to the practice of testing, half of us expressed the belief that widespread screening for HIV is generally a good thing to do (theme 2). Some of us recognise that screening is important for the survival of the insurance industry (theme 18). As a group we have mixed opinions regarding the significance and sensitivity associated with this test (theme 7). A few feel that there has been 'too much hype' around the sensitivity associated with testing (theme 27), with some of us considering HIV testing now a routine procedure (theme 9), which includes testing for insurance purposes (theme 25). One participant expressed this sentiment as follows:

'people are not so worried about it (the test) when it's for insurance, then it's just routine... and the sisters also then just treat it as routine' (Nurse: 43).

In contrast, others feel that 'HIV' itself is a problem (theme 14), and that the HIV test does require special and careful management (theme 15). This was expressed by the same participant as:

'but sometimes even for insurance, they are nervous and worried for the result. I phoned someone once to come back to us because we didn't have the ID number, ... he was really worried then' (Nurse: 48-49),

and reiterated by another participant as:

'It's not just a routine test,.... It's something VERY personal' (Nurse: 197), adding 'the clients are not informed or counselled enough,... they're just dummies coming for the test' (Nurse: 199).

Upon consideration, half of us stated that proper client preparation, which would include counselling prior to testing, is important (theme 3). This was expressed by one person as:

'the client needs to know exactly why it (the test) has to be done.... then they would not be so anxious when they come in here, besides being petrified of the needle' (Nurse: 482).

Most of us have considered the contentious issue of pre-test preparation (themes 5 & 7), which is definitely relevant to our work. Many of us feel that the insurance brokers should be preparing the client, as the test is an insurance requirement, and the broker is earning his commission based on the outcome (theme 1); with some of us specifying that the ultimate responsibility lies with the insurance company (theme 17).

In observing the clients, some of us feel that, despite the broker's preparation of the client, people are still not properly prepared with regards to even the practical component, such as the identification document or deciding on the person who will be designated to give them the result, when they arrive for the test (theme 28). We have noted that the brokers, escorting their clients to the depot, behave as if the test is 'nothing' (theme 23), which is not an accurate reflection of the significance of the test, and that at times the brokers only accompany their clients in order to speed up the policy administration, being concerned about the commission and not the client's well-being (theme 32).

Because we are often short staffed at work combined with the fact that we do so many insurance tests (theme 4), we have made it routine for our clients and ourselves. We do not feel really equipped to offer more comprehensive pre-test counselling as we have neither the time nor the experience (theme 6), and because this is such a sensitive issue, we would not wish to embark on counselling without proper training. If we received this training, then we think we would like to be more involved with counselling (theme 5), as it would make our own work more interesting, and we would feel that we are caring for our clients. We would then need more time with clients, and privacy. This sentiment was expressed as:

'If I knew a bit more, I would feel more comfortable doing it, and it would enrich my experience... I do feel that we have the time, at times, to counsel if need be.... I actually enjoy doing counselling,... if we were more informed' (Nurse: 246).

Even with these changes, this remains a bit awkward, as pre-test counselling is such a personal issue, and people actually are quite nervous. More specifically, half of us do not feel competent or trained to do this counselling at present, and partly based on this fear of doing more harm, and some of us feel that some other professional person or agency (such as the insurance company, the general practitioner or a trained

professional) but not the nursing sister or broker, should be responsible for the counselling (theme 8).

A third of us have observed that the clients do not actually read the counselling / information document at all (theme 11), so some of us make a special effort to ensure that they read and understand the counselling document (theme 21). A result-oriented comment (including concern about a positive result for the client) was expressed by a third of us (theme 13), with a similar percentage expressing concern regarding the consequences of a false negative result, which could occur with testing within the 'window period' (theme 16). This concern was extended to include being anxious about the level of preparation and understanding of the 'black' population in particular. This concern is based on language issues hindering their understanding of the pre-test information document, and noting a high prevalence of fear amongst these applicants (theme 20). A concerned participant remarked that:

'A lot of people don't really understand what is happening, like the black patients,... if they don't get the policy, then they just think, ... well I'm HIV positive!' (Nurse: 330).

In commenting on our own personal observations, a third of us judged that the client is often frightened of the test result (theme 10), with some assessing that this is really a fear of the needle prick (theme 24). One of us felt that clients, at times, appear defensive about their reaction to the test (theme 29), where others of us do not think that the client experiences any nervousness about the insurance HIV test (theme 22).

Upon consideration of the current protocol, some of us feel that the confidentiality of the results is managed satisfactorily (theme 19), with one of us noting that there has been an improvement in the management of testing over the last few years (theme 31), and another indicating that we thought it would be helpful and valuable for the clients to receive a take home booklet (theme 30). A third of us have however become aware over time that clients definitely want to receive their results – be they positive or negative (theme 12), and that presently, we recognise that the reality for the client is that the refusal of the policy is tantamount to knowing the result is positive (theme 26). One of us anticipated that clients could in time become litigious (theme 34).

Only one participant was directly asked, whether she thought an insurance motivated information 'Hot Line' would be used effectively, and she answered positively. At the end of the interview, one person felt the need to say 'thank-you', 'that someone is listening' (theme 33).

4.12.2. The Insurance Representative:

When approached to comment on insurance testing, most of us expressed the belief that clients need information-based preparation before having the HIV test done (theme 1). Some of us think that it would be valuable to have a 'take home information booklet' that we can distribute to clients, to cover this information (theme 17). Upon consideration, most of us think that counselling may also be a good idea for clients, but we do not feel that we are trained or equipped to do this (theme 2). Nearly half of us think that it is the health care professionals, such as nursing staff, trained counsellors in the field or the pathologists, who should be responsible for that aspect of preparation (theme 6). At least a third also feel that full, comprehensive preparation is time consuming for us, and for our clients, who would not want to devote the additional time or effort to more preparation (theme 10).

Actually, the HIV test for insurance is now routine, and is not regarded as a big issue, by our clients or us (theme 3). If clients are scared, we think that this is just due to needle fears (theme 11), and there is not a big emotional component associated with the test (theme 19). Half of us believe that clients now know that if they want a policy, then they must have the HIV test done (theme 4). You can get insurance cover without the test, but the coverage would be low, so some of us feel it is our responsibility to advise the client that they should have the test done to ensure better cover (theme 9).

We think that screening for HIV is generally 'a good thing', as people should know their status (theme 8). We think that HIV and AIDS is a major problem, but not just in terms of life assurance (theme 16), although when we think about someone getting a positive result, due to insurance testing, we recognise that it could be very distressing (theme 7). This was described by one of the participants as:

'most people are scared of it (the HIV test),... they think that they are going to lose their job or their friends won't accept them (Broker: 997).... and if they have fear, I wouldn't know how to cope with it (Broker: 1000)'

and by another participant as:

‘people are scared of the needle and the test’... ‘especially when they are married, they are even more scared of the test.... they don’t say so , but you pick it up..... Everything is fine until the point when you talk about the test and then they back out of it (Broker: 741)..... it is tricky and concerns more than just what it seems to be (Broker: 749)’

Only some of us anticipate that the industry would not survive if we did not conduct these tests (theme 18).

As brokers, half of us choose to accompany our clients to the depot for testing, partly to make sure that the clients get the test done so that the policy can be issued promptly (theme 14), and we can get our commission (theme 13). Some of us also feel that it is part of the service to accompany the client to the depot, as a means of offering them some support (theme 15).

Over time, we have become accustomed to being criticised for the insurance HIV testing practice, but when you (the researcher) acknowledged from our responses that it seemed that we do care about our clients, half of us felt validated and were then able to relax and express that we are concerned for the client’s well being (theme 5). This was expressed by one of the brokers who stated:

‘YES... I do care.... And it does matter that they (the client) are prepared and not anxious. If I had known about this questionnaire, I would have allocated more time for it....(Broker: 704).... can I take a form and check that my other clients are properly prepared when they come again? (Broker: 707)’

When you asked four of us whether we thought a ‘Hot Line’ would be useful, 3:4 responded affirmatively, with one negative, dismissive answer (theme 12).

4.12.3. Summary:

The insurance brokers and nursing sisters generally felt that pre-test preparation was important, although there was uncertainty regarding the extent of the need and the scope of intervention. Both groups were unsure about their own ability or skills to perform this function, with a lack of available time given as an additional reason for not doing it.

The brokers had the attitude that if the persons wants the policy, they just must have the HIV test. They felt that their responsibility lay with giving clients the advice that

they would get better insurance coverage with the HIV test. The brokers interviewed chose to accompany their clients to the depot for support, which represents a selection bias towards a more aware and concerned group. Even with this group, however, a change in the broker's attitude was observed when their concern for the client was acknowledged by the interviewer. They visibly relaxed, and were more willing to express that they had some concerns about the whole issue of HIV testing for insurance.

The nursing sisters were not 'commission oriented', and were generally more concerned with the client's well-being. A marked change in attitude was therefore not as apparent in this group. Their central consideration was for preparation of the client, which included the practicalities associated with testing, alongside the counselling considerations.

The interviews were generally enjoyed by the participants, and they warmed to the process in the course of talking. Thoughtful and creative alternatives were suggested at times, indicating that both professional groups have the potential to be mobilised as a problem solving resource.

CHAPTER 5

CONCLUSION

The conclusion follows the same format used in the body of the thesis. The demographic conclusions pertaining to the insurance applicants are therefore noted first, followed by the conclusions relating to the answers given about the HIV test. The qualitative and quantitative evidence is incorporated where relevant, followed by the statistical analysis.

5.1. DEMOGRAPHIC PROFILE:

The insurance applicants were a fair representation of the general population in terms of age, gender, marital status and socio-economic status. The sample in Phase 1, in particular, showed a bias towards a higher educational status and earning capacity. As the association between education and the level of information about HIV/AIDS was a significant finding in the study, this bias has relevance in relation to the general management of the testing protocol, and in particular to pre-test counselling and informed consent for the lower socio-economic and less educated applicants.

Almost half the age range (25-35years) of the sample in Phase 1 fell within the range outlined in the literature as being most likely to make use of the counselling services researched in their studies (Slawski, 1996; Stenicki, 1999; Swanevelder, 1996). The insurance population are therefore an important age grouping to target for pre-test preparation, as they represent a traditionally sexually active sector that have shown a willingness to avail themselves of pre-test counselling (ibid.). As a group they are not, however, easily accessible to most prevention programs. Scholars and students at universities and technical colleges are exposed to education programs on campus, but the insurance age range tend to be in the working sector which have not as yet mobilised similar programs. The insurance application with the required HIV test therefore represents an ideal opportunity for an educative and preventive intervention.

5.2. THE TEST PREPARATION PROTOCOL:

The value and effect of the information document used in the pre-test preparation protocol proved inadequate in two ways. Firstly, the document serves to inform the client about the test, thereby

satisfying the legal requirement of informed consent. Informed consent, however, also inherently includes a component of emotional preparation based on the knowledge of the right to refuse the test and a comprehensive understanding of the possible consequences of the test (Francis, 1999; Lo et al., 1989; Ubel, & Loewenstein, 1997; Wassenaar, 1992). As no additional preparation other than the document is offered, the vital component of emotional preparation is missing. Secondly, the personnel observation that the document was not actually read by clients, suggests that the information function is not being fulfilled either. The adequacy of the pre-test preparation protocol is, therefore, highly questionable, in terms of emotional and information input and the extent to which the consent is sufficiently informed.

5.3. THE PROTOCOL OF TESTING:

Contrary to the concerns of Sorell & Drayer (1999) that insurance clients are unprepared and coerced to have the HIV test, the results of Phase 1 showed a general acceptance of the requirement that an HIV test be taken, and satisfaction with the protocol governing the practice. The majority indicated that they felt it was good to be tested regardless of whether it had been their choice originally or not. Most of the applicants indicated that they were not overly nervous about the test, and there were very few recommendations made for change in the protocol.

Similarly, the attitude that testing was now simply a normal part of insurance application was expressed by several of the brokers. This easy acceptance could, therefore, be extended to support the Tallis' (1994) proposal, that if people wanting insurance found that pre-test counselling was an established part of the procedure, they would simply comply with that process.

5.3.1. The Value of Pre-Test Counselling:

Despite the initial high cost and variable, inconclusive results (Cleland, 1995; Temmerman et. al., 1990; Weinhardt et. al., 1999), a 'voluntary counselling and testing' program has been strongly advocated as necessary for developing countries (UNAIDS Policy Statement, 1997).

5.3.1.1. Limiting Factors

Weinhardt (et. al., 1999) found that counselling was most effective as a means of secondary prevention, when addressed to the HIV positive individual, or sero-discordant couples. Pre-test

counselling as a primary intervention in HIV/AIDS prevention and control was, however, found to be variable or limited in effectiveness. This was largely attributed to the brevity of counselling offered, as short or single sessions do not always allow adequate time for a full understanding of the issues, both emotional and informative. Similar constraints were identified in the counselling applied in Phase 2 of this study, suggesting that the lack of time was influential in the limited effects found.

The intervention in Phase 2 was undertaken with several additional constraints beyond a lack of available time. The venues lacked real privacy and the clients had not been primed to expect counselling. These limitations, however, make the positive changes noted significant.

5.3.1.2. Effects of counselling

In their studies, Bell (1991), Reamer (1991) and Weinhardt (et. al., 1999) found qualitative changes in the responses given following the intervention. As part of pre-test counselling, the responses given in anticipation of an HIV positive result showed a greater concern for the safety and well being of the person's sexual partner(s) and significant persons. They also expressed the intention to take more care to protect themselves from possible infection in the future. These are desirable changes, and illustrate the means by which counselling acts as a deterrent to the ongoing spread of infection. The qualitative differences found between the responses given in Phases 1 and 2 of this study showed similar shifts, which was a major finding of the study.

It does, therefore, appear likely that these qualitative changes can be attributed to the intervention, as every other aspect of the procedure was identical to Phase 1. A possible conclusion to be drawn is that counselling allows a person the opportunity to consider the implications and effects of the result more fully, as widely indicated in the literature. As there are methodological shortcomings in the study these conclusions cannot, however, be stated categorically.

5.3.1.3. Maximising the Effect of the Intervention:

A perceived urgency for change has been identified as important in enhancing the positive response to counselling (Bell, 1991; Balmer, et. al., 2000; Fishbein et. al., 1994; Sweat et. al., 2000). This sense of urgency was most likely to occur when the information was received at a

critical period, when interest was at a peak, such as at the point of venisection. As there were numerous constraints on the intervention applied in Phase 2, the beneficial qualitative changes noted would, therefore, seem to be at least partially due to the enhanced receptivity of the person at the time of testing.

5.3.2. Counsellor Selection:

There remains some difficulty in selecting the most suitable persons or group to administer the counselling. Wood (1994) cautioned that persons being tested could experience secondary risk, through increased distress or a misunderstanding of the nature and content of the test and counselling, linked in part to counsellor competence. A similar concern emerged in Phase 3 of the study where the potential for the insurance brokers or nursing staff to provide this service was explored. Both groups felt that pre-test preparation was important, but they were unsure about their own ability or skills to perform this function. The reasons given for their reticence were the lack of time available and more importantly a lack of training and their own perception of their limited skill. The brokers did not believe that counselling was within their scope of expertise, but some of the nursing staff indicated that they would be interested were they to have had sufficient training.

The need for a sensitive and experienced counsellor is endorsed by the increase in the anxiety scores found in Phase 2. Several reasons for this increase are proposed. The anxiety could simply represent an appropriate shift towards taking the test more seriously or it could indicate that the brief counselling undermined the possibility of reaching emotional resolution. Other factors potentially at play were not identified in this study.

5.4. QUANTITATIVE RESULTS:

The results from the statistical analysis showed a significant correlation between the state anxiety score and reports of being nervous about the test, the possible result and the needle. This confirms that an applicant reporting feeling nervous about any of these aspects, at the time of testing, is also experiencing a degree of state anxiety. A lower information score was associated with the response of 'not being nervous about the potential result' in Phase 1. This indicates that the absence of nervousness was due to a lack of awareness of the implications of the test or result. In

Phase 2, a higher level of information was associated with a 'not nervous' response. This probably represents the client's more realistic evaluation of their lack of information, precipitating greater nervousness about the test. The shift in Phase 2 also confirms the hypothesis that the responses given in Phase 1 had not been given much thought.

There was also a significant association between the level of education and the scores obtained for information about HIV / AIDS. A higher level of education (having a degree) was associated with greater knowledge about HIV / AIDS, with a reducing general knowledge in association with a reducing level of education. Respondents with 11-12 years (Std. 9-10) of education had a moderate information score, but those below this range indicating a tendency towards an inadequate information score. This would suggest that consent given by the applicants with a Std. 6-8 or lower education (8-10 years of schooling), can not truly be regarded as 'informed'. This trend was confirmed in Phase 2. This represents the second major finding of this study. The results lead to very definite suggestions regarding which applicants should receive comprehensive pre-test counselling as a priority. These are elaborated upon further in the recommendations, which follow.

5. 5. LIMITATIONS OF THE STUDY:

5.5.1. Phase 1:

Phase 1 was limited in three important areas:

- a. Potential racial differences in the level of information about HIV / AIDS and anxiety at venisection (according to race) was not elicited.
- b. A question pertaining to the practice of 'safer sex' was not included. This limited establishing any association this may have had to information about HIV/AIDS or anxiety about the test. The question was excluded as it was considered overly personal for the questionnaire context. The poor response rate to the question on number of sexual partners confirmed this.
- c. A larger sample size would have offered greater statistical power.

5.5.2. Phase 2:

Phase 2 was limited in several important areas:

- a. The small sample size of phase 2 was a limitation. This was however a pilot study and it is hoped that it will motivate further research.
- b. Limited control of or measurement of the effect of several variables potentially at play in the counselling, which included:
 - The effects of the sample selection bias on the receptiveness to counselling and the subsequent study results
 - A lack of standardisation of the counselling intervention and goals. There was variation in the content and form of the counselling. The format was completely open with the first few clients, but as a pattern emerged in the responses and needs expressed, these were applied more formally to the subsequent clients
 - Variation in the time spent with each client, moderated by the respondent's interest and engagement in the intervention
 - The impact of the clients not anticipating counselling as part of the venisection procedure
 - The impact of the lack of privacy of the venues used
 - The effect of language constraints, as the counselling was conducted in English.

5.5.3. Phase 3:

Phase 3 was limited in two areas:

- a. The small number of interviews conducted with both categories of personnel, limited the extent to which the results could be generalized to all personnel.
- b. The brokers who were interviewed may be a group with distinctive characteristics. The fact that they accompanied their clients to the interview could be indicative of a particular concern that they might have had for their clients. This group was not compared with a group of brokers who had not accompanied their clients to the depot.

RECOMMENDATIONS

The small sample size, particularly in Phase 2, and the methodological limitations of the study indicate the need for additional research. The measurements used to ascertain the level of anxiety and information about HIV/AIDS could be refined. The qualitative changes noted in Phase 2 also indicate the need for more rigorous and extensive research.

The insurance industry should be given feedback on the findings of the study, highlighting in particular the two criteria which emerged as important in identifying which insurance applicants needed comprehensive preparation most urgently.

Based on the results the following protocol suggestions could be made:

- A further revision of the pre-test counselling / information document is needed. The feedback that the document was not being read suggests that the direction of revision should be towards simplifying it to make it more comprehensible and less intimidating in size
- In order to ensure that consent was informed, an easily scored information grid could be included in the counselling document. Once scored, this would allow for misunderstood concepts to be corrected
- Similarly, a 'take home booklet' could be constructed, and distributed by either the broker, prior to testing or the nursing sister at the depot. It is preferable for the broker to distribute the booklet, as this would afford the client more time to read and absorb the information. An information grid could also be included in this booklet, with a completed grid needing to be presented at venisection along with the insurance form, and a form of photo-identification. The nursing sister could mark the grid, and quickly correct any minor misconceptions. Clients demonstrating a serious deficit in information could then be referred for more comprehensive pre-test counselling
- The most common query emerging from Phase 2 was regarding the process of notification of the results, and the granting of the policy. This expressed need should be addressed more formally, making it a part of the pre-test information
- A central L.O.A. 'hot line' could be established. Applicants would then be able to have questions and concerns, pertaining to HIV /AIDS or life assurance protocol, answered easily, without additional travel or inconvenience. They would also be assured of confidentiality and anonymity of the interaction.
- Perhaps the most important addition would still be the option of offering interactive pre-test counselling, at least upon request for counselling, where the client expressed feeling anxious about the test, or when the person's level of education was Std. 8 or below.
- Further research could be undertaken to establish the effect of more comprehensive counselling on the two primary variables identified and measured in this study.
- Some of the applicants commented that they had enjoyed the information grid and the mental stimulation of the questions. This would suggest limited resistance to the addition of a grid of this nature in the document

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APPENDICES:

APPENDIX 1.

Assessment of sufficiency (enough) and helpfulness of pre-test information received from varied sources:

a) Health professional (nursing sister or medical doctor):

<i>Enough information</i>	Number of respondents	%
No response	252	58.74
Enough	150	34.97
Not enough	27	6.29
Total	429	100.00
<i>Helpfulness of information</i>	Number of respondents	%
No response	354	82.52
Helpful	62	14.45
Not helpful	13	3.03
Total	429	100.00

b) Counselling document:

<i>Sufficient information</i>	Number of respondents	%
No response	285	66.43
Enough	125	29.14
Not enough	19	4.43
Total	429	100.00
<i>Helpfulness of information</i>	Number of respondents	%
No response	368	85.78
Helpful	51	11.89
Not helpful	10	2.33
Total	429	100.00

c) Information from life assurance advisor (broker)

<i>Enough information</i>	Number of respondents	%
No response	268	62.47
Enough	127	30.07
Not enough	32	7.46
Total	429	100.00
<i>Helpfulness of information</i>	Number of respondents	%
No response	348	81.12
Helpful	58	13.52
Not helpful	23	5.36
Total	429	100.00

d) Information from bank advisor:

<i>Sufficient information</i>	Number of respondents	%
No response	355	82.75
Enough	47	10.96
Not enough	27	6.29
Total	429	100.00
<i>Helpfulness of the information</i>	Number of respondents	%
No response	392	91.38
Helpful	14	3.26
Not helpful	23	5.36
Total	429	100.00

e) Information from an employer:

<i>Enough information</i>	Number of respondents	%
No response	352	82.05
Enough	57	13.29
Not enough	20	4.66
Total	429	100.00
<i>Helpfulness of information</i>	Number of respondents	%
No response	389	90.68
Helpful	15	3.50
Not helpful	25	5.83
Total	429	100.00

f) Information from family and friends:

<i>Enough information</i>	Number of respondents	%
No response	339	79.02
Enough	69	16.08
Not enough	21	4.90
Total	429	100.00
<i>Helpfulness of information</i>	Number of respondents	%
No response	366	85.31
Helpful	48	11.19
Not helpful	15	3.50
Total	429	100.00

g) No information received *

<i>Enough information:</i>	Number of respondents	%
No response	390	90.91
Enough	25	5.83
Not enough	14	3.26
Total	429	100.00
<i>Helpfulness of information:</i>	Number of respondents	%
No response	412	96.04
Helpful	7	1.63
Not helpful	10	2.33
Total	429	100.00

*This response could be interpreted as sufficiency of information the person had without pre-test input from any source

h) Information from other sources:

<i>Enough information</i>	Number of respondents	%
No response	380	88.58
Enough	39	9.09
Not enough	10	2.33
Total	429	100.00
<i>Helpfulness of information</i>	Number of respondents	%
No response	408	95.10
Helpful	18	4.20
Not helpful	3	.70
Total	429	100.00

Source of 'other' information:

	Percent		%
Not specified	6.29	T.V. & magazines	.23
T V	1.86	School	.23
Media	1.63	A talk	.23
ATICC*	.23	T V and news	.47
T V and media	.23	ATICC & T/P**	.23
T V and radio	.70	an H/P***	1.86
Work and T V	.23	Not answered	85.55

* AIDS Training, Information and Counselling Centre

** ATICC and Triangle Project

*** The respondent is a Health Professional

[Television would appear to be a major source of information, based on the response of a small sample of the respondents.]

APPENDIX 2:
GENERAL KNOWLEDGE ABOUT HIV AND AIDS:

Phase 1:

*(Critical questions noted as ** in the table title)*

*(The correct answer noted as * within the table)*

'HIV infection is another name for AIDS' **:

Answer:	Count	Percent
True	259	60.37
False *	148	34.50
No response	22	5.13
Total	429	100.00

'The 'window period' last from the time of infection with HIV until signs and symptoms appear ' **:

Answer	Count	Percent
True	286	66.67
False *	75	17.48
No response	68	15.85
Total	429	100.00

'A negative result means the person is immune to HIV infection':

Answer	Count	Percent
True	72	16.78
False *	332	77.39
No response	25	5.83
Total	429	100.00

'A person can be infected with HIV and still feel completely well' **:

Answer	Count	Percent
True *	366	85.31
False	46	10.72
No response	17	3.96
Total	429	100.00

'If an adult has antibodies to HIV he/she must be assumed to be infected':

Answer	Count	Percent
True *	176	41.03
False	190	44.29
No response	63	14.69
Total	429	100.00

'People who have HIV do not usually develop symptoms for 3-7 years':

Answer	Count	Percent
True *	258	60.14
False	135	31.47
No response	36	8.39
Total	429	100.00

'If a person has an HIV test whilst they are in the window period, their result may be inaccurate' **::

Answer	Count	Percent
True *	217	50.58
False	131	30.54
Missing	81	18.88
Total	429	100.00

'Is it possible to contract HIV from hugging a person with HIV'.

Answer	Count	Percent
True	23	5.36
False *	365	85.08
Missing	41	9.56
Total	429	100.00

'Is it possible to contract HIV from using public toilets'

Answer	Count	Percent
True	32	7.46
False *	361	84.15
Missing	36	8.39
Total	429	100.00

'Is it possible to contract HIV from sharing eating utensils'

Answer	Count	Percent
True	33	7.69
False *	361	84.15
Missing	35	8.16
Total	429	100.00

'Is it possible to contract HIV from contact with saliva or sweat from a person with HIV'

Answer	Count	Percent
True	161	37.53
False *	238	55.48
No response	30	6.99
Total	429	100.00

(A media case reported in June 1997, of a women allegedly contracted the virus from kissing her infected husband. This case would appear to have altered the truth or falseness of this answer. People may or may not be aware that she had open sores in her mouth, which allowed the infection to occur).

Phase 2:

Only two aspects were covered comprehensively and consistently with the brief pre-test counselling undertaken. These are noted as '@' within the table.

'HIV is another name for AIDS':**

@	Count	Percent
True	17	48.57
False *	17	48.57
Not answered	1	2.86

'The 'window period' lasts from the time of infection with HIV until signs and symptoms appear':**

	Count	Percent
True	23	68.71
False *	5	14.29
Not answered	7	20.00

'A negative result means the person is immune to HIV infection':

	Count	Percent
True	9	25.71
False *	22	62.86
Not answered	4	11.43

'A person can be infected with HIV and still feel completely well':**

@	Count	Percent
True *	31	88.57
False	2	5.71
Not answered	2	5.71

'If an adult has antibodies to HIV he/she must be assumed to be infected':

	Count	Percent
True *	14	40.00
False	14	40.00
Not answered	7	20.00

'People who have HIV do not usually develop symptoms for 3-7 years':

	Count	Percent
True *	22	62.86
False	8	22.86
Not answered	5	14.29

'If a person has an HIV test whilst they are in the window period, their result may be inaccurate': **

	Count	Percent
True *	8	22.86
False	15	42.86
Not answered	12	34.29

'Is it possible to contract HIV from hugging a person with HIV':

	Count	Percent
True	2	5.71
False *	30	85.71
Not answered	3	8.57

'Is it possible to contract HIV from using public toilets':

	Count	Percent
True	1	2.86
False *	29	82.86
Not answered	5	14.29

'Is it possible to contract HIV from sharing eating utensils':

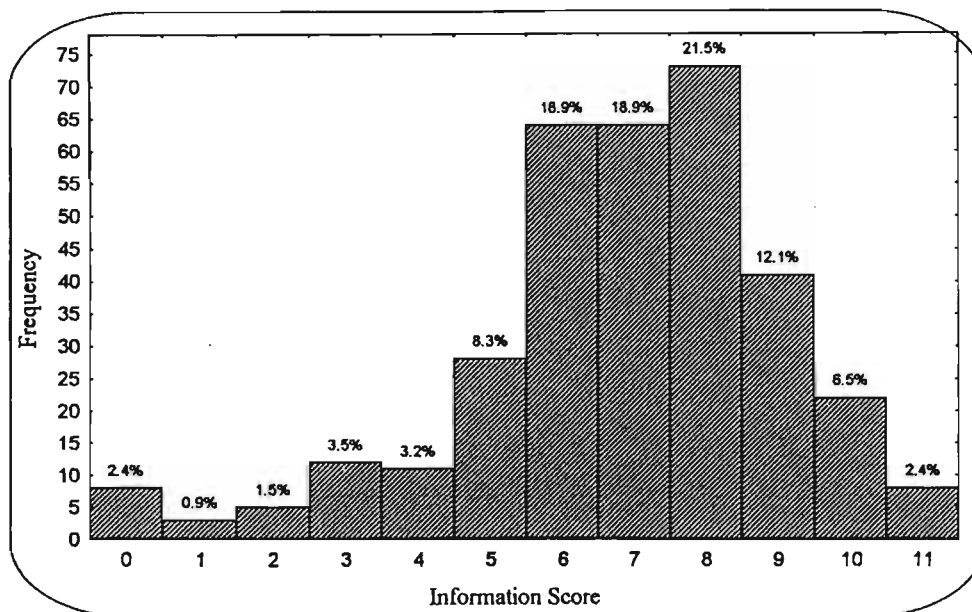
	Count	Percent
True	3	8.57
False *	28	80.00
Not answered	4	11.43

'Is it possible to contract HIV from contact with saliva or sweat from a person with HIV':

	Count	Percent
True	12	34.29
False *	17	48.57
Not answered	6	17.14

APPENDIX 3:
STATISTICAL ANALYSIS FIGURES:

Figure 1: Histogram of Level of information about HIV / AIDS of the insurance applicant population:



Score Rating:

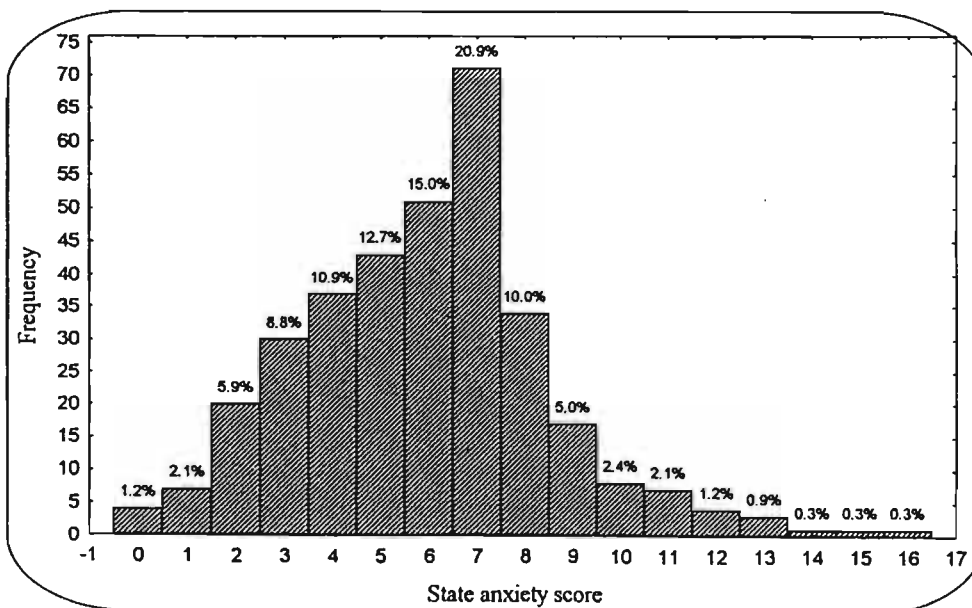
0 = no information (2%)

1-3 = poor knowledge (7%)

4-8 = fair knowledge (71%)

9-11 = good level of knowledge (21%)

Figure 2: Histogram of state anxiety score for the insurance applicant population only:



0 = no anxiety (1%)

1-2 = minimal anxiety (8%)

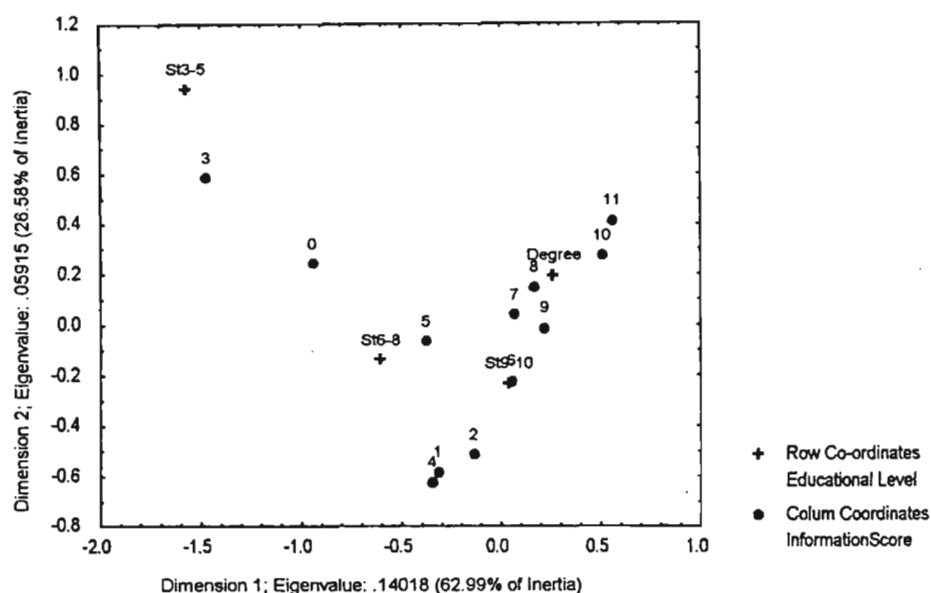
3-5 = mild anxiety (32%)

6-9 = moderate anxiety (51%)

10-12 = anxious (6%)

13-17 = very anxious (2 %)

Figure 3: Correspondence co-ordinates between level of information about HIV / AIDS and level of education



The association configuration indicates a link between a low score of 3 and a std. 3-5 education, with the majority of the higher information scores (7,8,9,10 & 11) clustering around a degree. A score of 6, representing a moderate level of information was associated with a std. 9-10 education, and 5 around a std. 6-8 level of education.

Figure 4: Box-plot graph by groups for information and language:

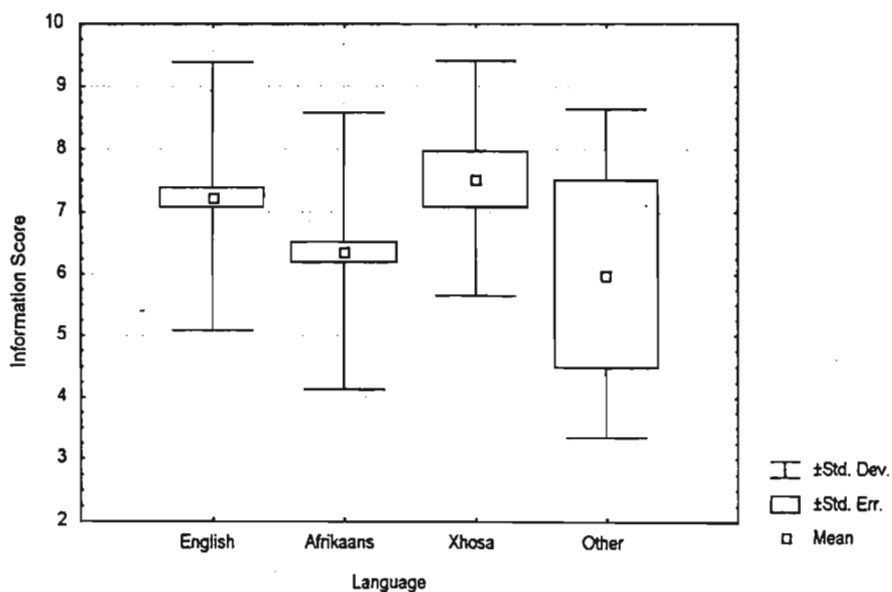


Figure 5: Language breakdown for Xhosa and Afrikaans in relation to education:

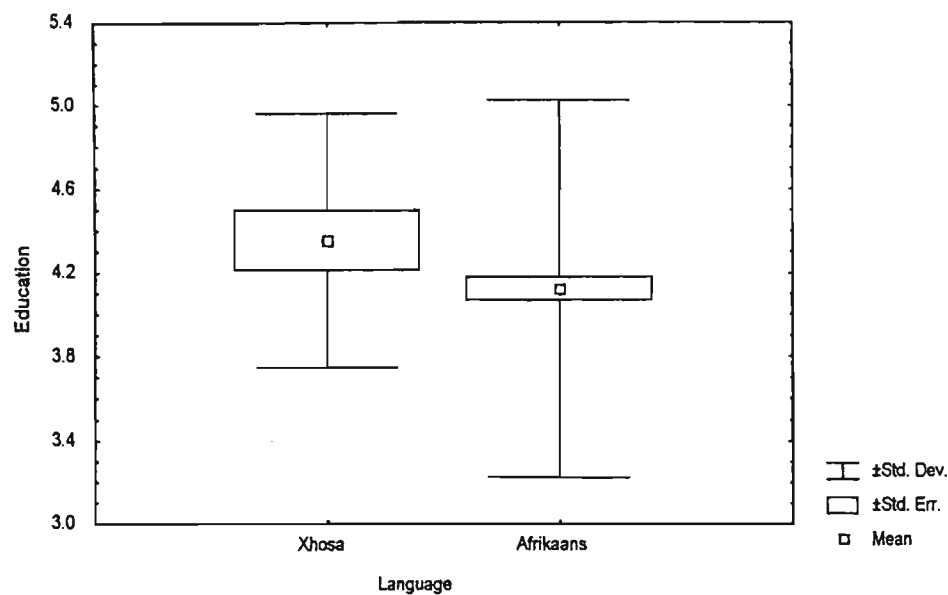


Figure 6: box-plot graph by groups for information and nervousness relating to the test result

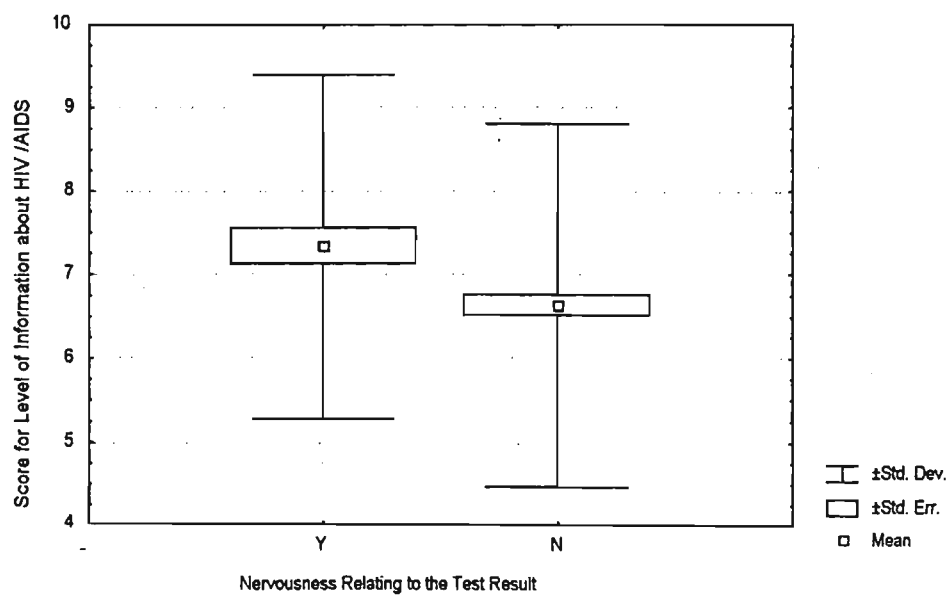


Figure 7: Phase 1: Level of state anxiety in association with having children

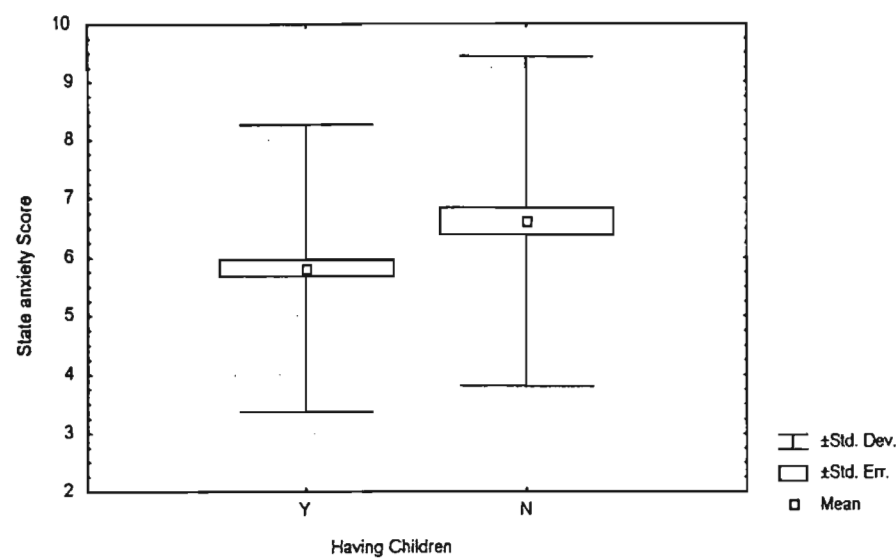


Figure 8: Degree of anxiety experienced in association with reason for testing

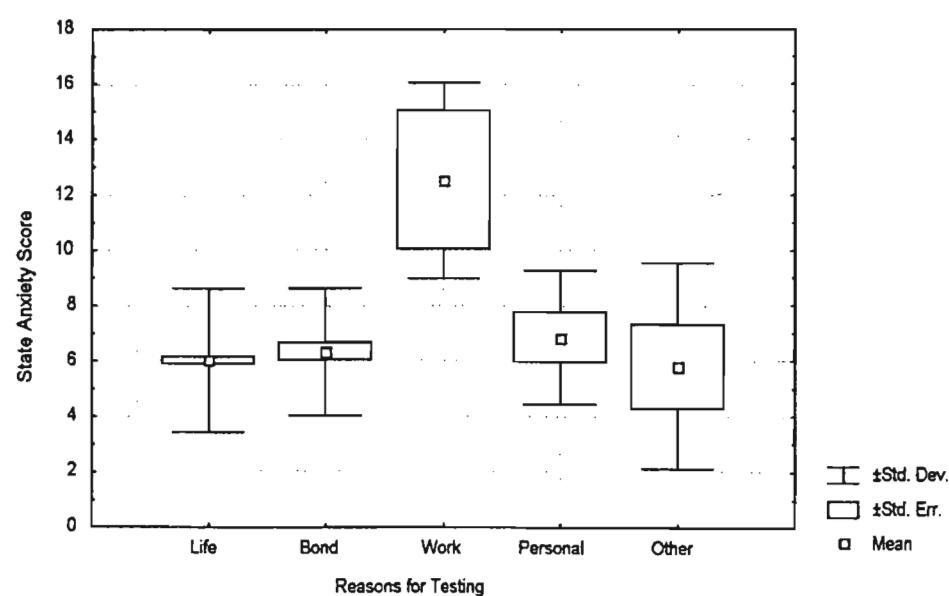


Figure 9: Time lapse since previous testing in correspondence with anxiety score

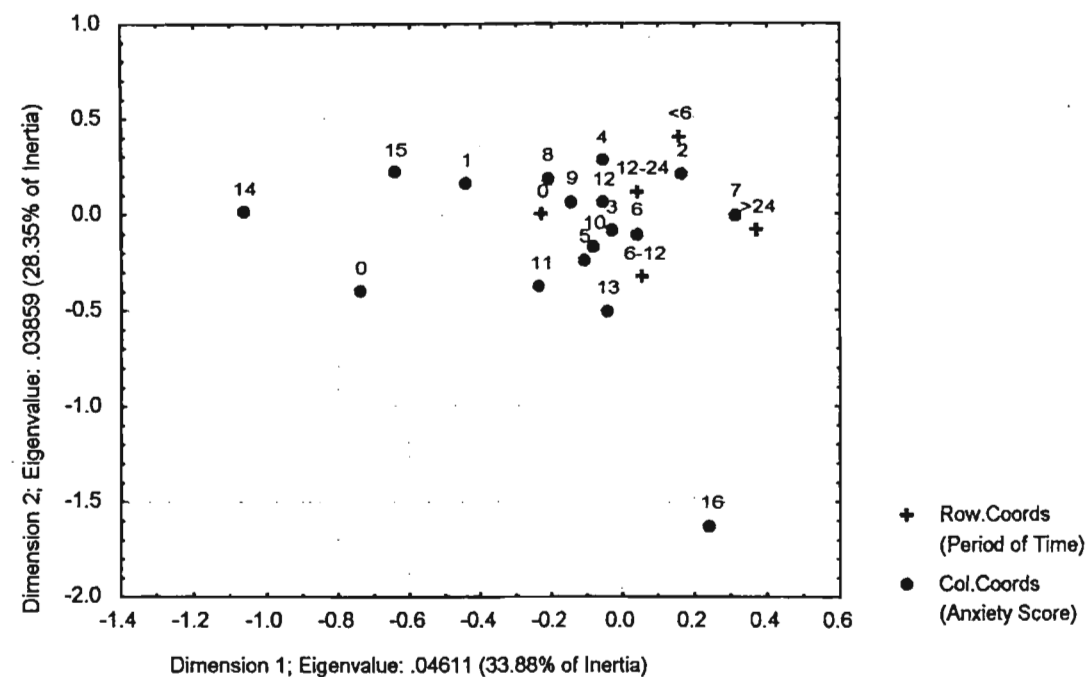


Figure 10: Phase 1: Assessment of sufficient (Y) or not sufficient (N) information associated with state anxiety

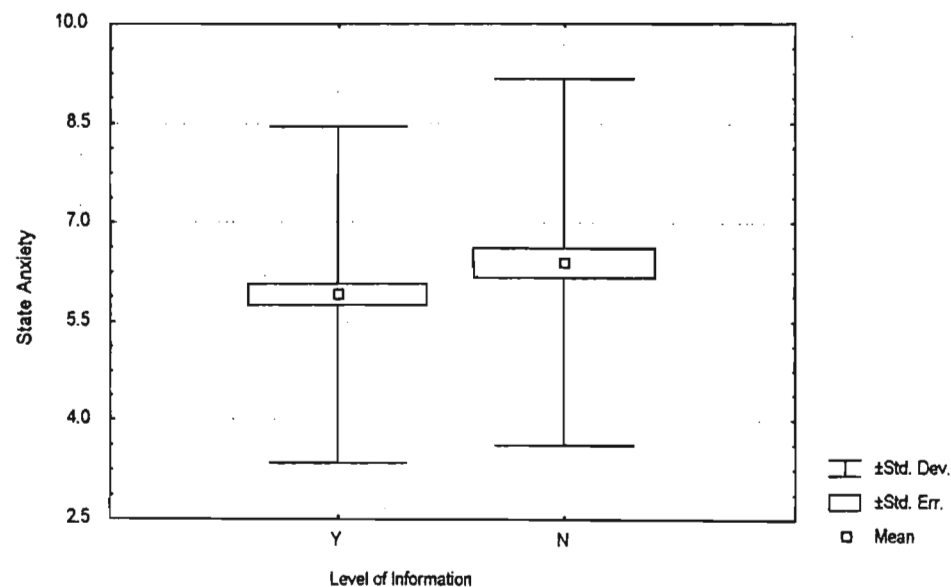


Figure 11: Information scores between phases 1 & 2:

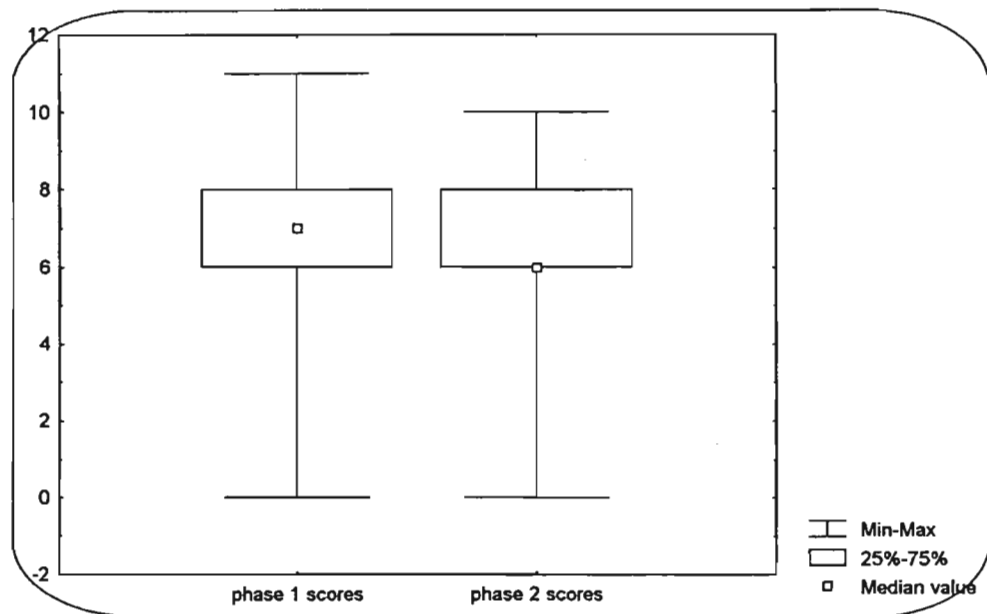


Figure 12: Phase 2: Information about HIV/ AIDS and level of education

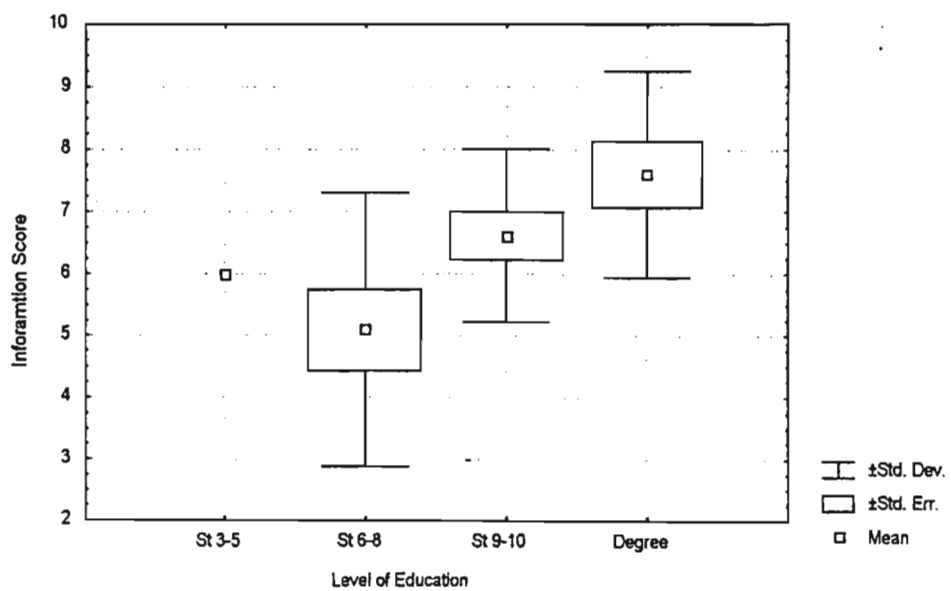


Figure 13: Phase 2: Level of information in association with nervousness for result:

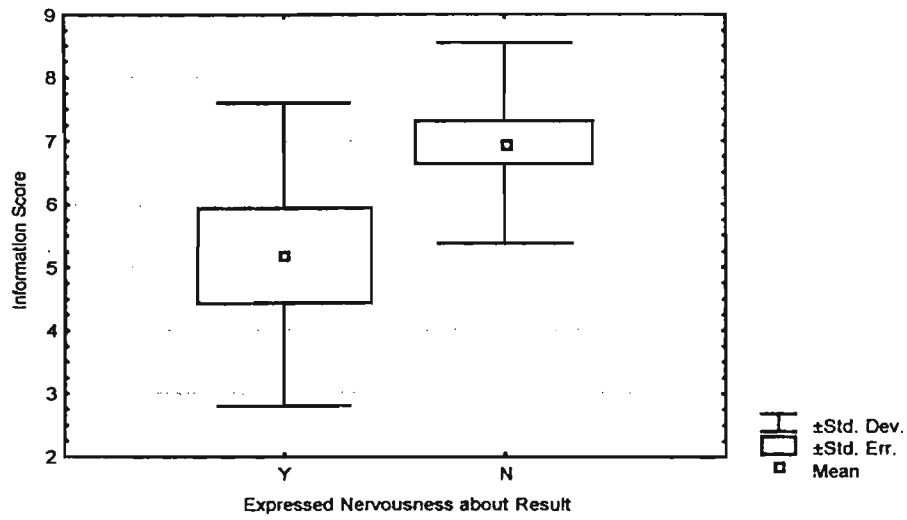


Figure 14: Phase 2: Variation of anxiety experienced associated with previous testing

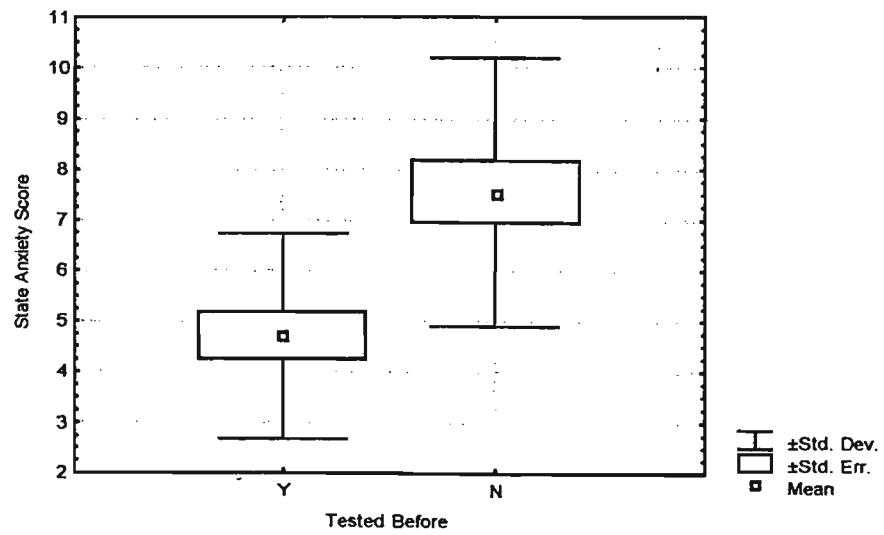
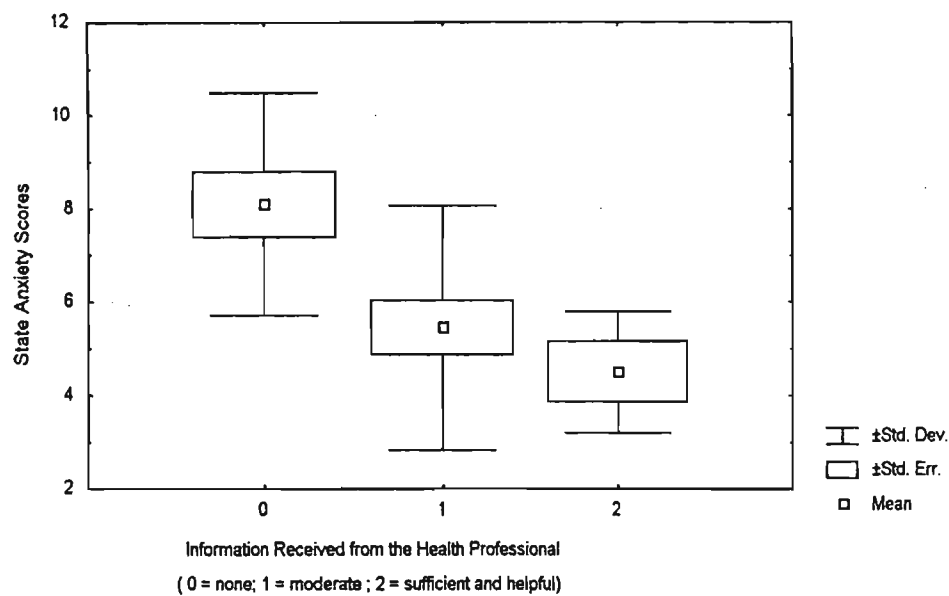


Figure 15: Phase 2: Variation in level of state anxiety in association with assessed quality of information received from the health professional :



(11 respondents answered 0; 20-answered 1 and 4 answered 2 = N: 35)

Figure 16: Phase 2: Association between information from the insurance broker and the state anxiety score:

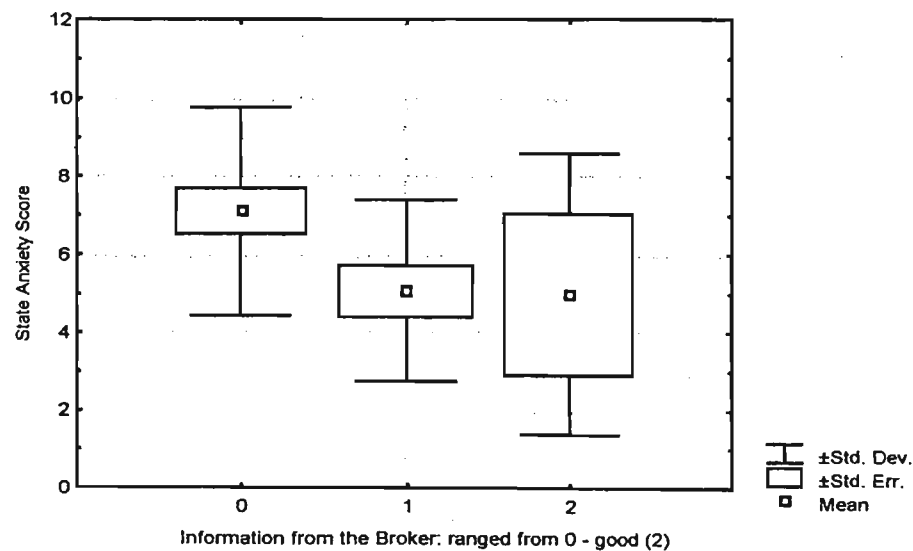
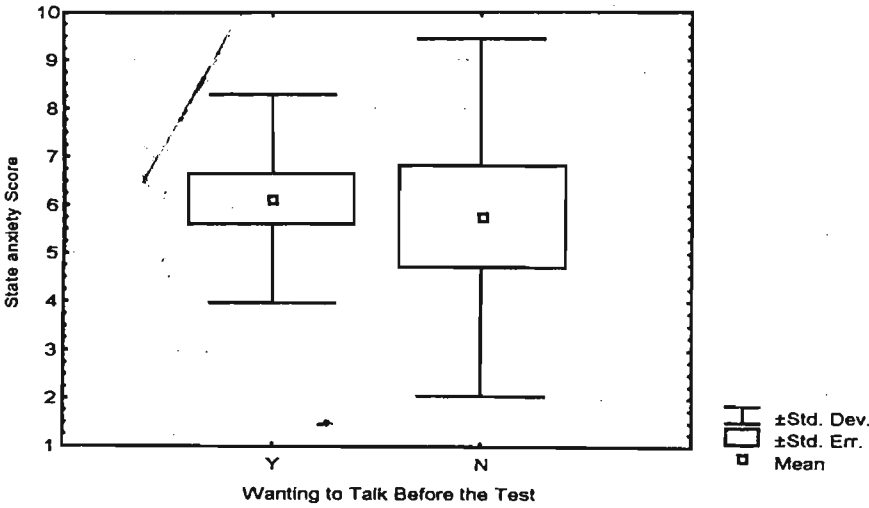


Figure 17: Phase2: State anxiety experienced at testing in association with a desire for pre-test communication



APPENDIX 4:

NON-SIGNIFICANT RESULTS OF ANALYSIS ASSOCIATED WITH THE LEVEL OF STATE ANXIETY EXPERIENCED:

<i>Test</i>	<i>Variable Compared</i>	<i>Result</i>		<i>Significance</i>
Kruskal-Wallis Anova		Chi-Square	df	P
	Age	10,68	9	0,298
	Level of Education	5,815	3	0,121
	Income	6,007	5	0,3055
	Understanding nature of test	1,728	1	0,1886
	Language	0,545	3	0,908
	Number of sexual partners	8,767	5	0,1186
	Having had this test before	0,097	1	0,7553
	Period of time since last test 1	2,533	3	0,469
	Reason for test 2	7,2846	4	0,1216
	Having received information from:			
	Health Professional	7,06	6	0,3146
	Reading the written document	2,673	6	0,8486
	Insurance Broker	5,57	6	0,47
	Family or friends	7,817	6	0,251
Mann-Whitney U test		U	P	
Assessment of having enough information		17123	0,057	
	Language			
	English / Afrikaans	19360	0,7000	
	English / Xhosa	1437	0,788	
	Xhosa / Afrikaans	1886	0,9233	

1 ranging from < 6 months to > 24 months

2 for insurance, ante-natal, travel or personal reasons

APPENDIX 5:

THEMES FROM THE INTERVIEWS WITH THE NURSING STAFF:

- i. (8:14): The insurance brokers should be preparing the client (as the test is an insurance requirement, and the broker is earning his commission based on the outcome)
- ii. (7:14): Screening for HIV is generally a good thing to do
- iii. (7:14): Preparation prior to testing is important ³
- iv. (7:14): The time required to do Pre-test counseling is not available at the depot
- v. (7:14): The P/N ⁴ would be interested in counseling if they received proper training
- vi. (6:14): The P/N does not feel competent or trained to do counseling
- vii. (6:14): The person expressed contradictory / conflicting opinions (which emerged during the course of the interview, and were based on their serious consideration of the problem as part of the interview process)
- viii. (5:14): Deferring the responsibility of counseling to someone else, besides the broker (such as the G.P.; the insurance company or a trained professional)
- ix. (5:14): The HIV test is routine, and 'not a big deal'
- x. (5:14): Personal assessment that the client is frightened of the test result
- xi. (5:14): The observation that the clients are not reading the counseling document
- xii. (5:14): Awareness that clients want to receive their results (positive or negative)
- xiii. (4:14): A result oriented comment (concern about a positive result for the client)
- xiv. (4:14): HIV itself is a problem, and is a 'big deal'
- xv. (4:14): The HIV test is a 'big deal'
- xvi. (4:14): A concern expressed regarding testing during the 'window period'
- xvii. (4:14): The insurance company should be responsible for client preparation as the test is their requirement
- xviii. (3:14): Screening is important for the survival of the insurance industry
- xix. (3:14): Satisfaction regarding the confidentiality of the results
- xx. (3:14): The expression of concern regarding the understanding and preparation of the 'black' population in particular (based on language issues hindering understanding the pre-test information document, and personnel noting a high prevalence of fear)
- xxi. (3:14): The P/N checking that the clients read / understand the counseling document
- xxii. (2:14): The assessment that clients are not nervous about the insurance HIV test
- xxiii. (2:14): Perception that the brokers behave as if the test is 'nothing', which is not deemed to be an accurate reflection of the significance of the test

³ Nature of preparation not specified ie. information / educative or counseling

⁴ P/N = Professional Nurse

- xxiv. (2:14): The assessment that clients are frightened of the needle
- xxv. (2:14): HIV testing for insurance purposes is routine ('not a big deal')
- xxvi. (2:14): Not receiving the policy is tantamount to knowing the result is positive
- xxvii. (2:14): Denial of any sensitivity around the issue
- xxviii. (2:14): Despite the brokers input, people are still not properly prepared when they arrive
- xxix. (1: 14): Noting that clients appear defensive at times
- xxx. (1: 14): Endorsing the value of a take-home booklet
- xxxi. (1: 14): There has been an improvement of the management of testing over the last few years
- xxxii. (1:14): Brokers accompany their clients in order to speed up the policy administration
- xxxiii. (1:14): The interviewee thanked the interviewer for doing the research, 'that someone is listening'
- xxxiv. (1:14): Clients could become litigious

INTERVIEW THEMES WITH THE INSURANCE REPRESENTATIVES:

- i. (7:10): An acknowledgement of the need for some form of preparation prior to testing. This preparation however related more to information regarding the policy itself than to information about HIV and AIDS or a need for emotional preparation (counseling).
- ii. (7:10): The sense that although preparation and / or counseling may be important, the brokers did not feel trained or equipped to administer this themselves
- iii. (6:10): The sense that the HIV test is routine, and is not 'a big deal'
- iv. (5:10): The sentiment that clients know that they simply must have the test done in order to receive their policy (ie. a policy application = having the test)
- v. (5:10): A validation of the broker's genuine concern for the client resulted in a change of attitude on the part of the broker, from a defensive minimizing of the impact of the test to a relieved and open attitude. Many of these brokers thanked the interviewer at the end of the interview, for the input and for having undertaking the research
- vi. (4:10): Deferring the responsibility of the counseling to someone else (either to the nursing sister, trained professionals in the field, or to the pathologist)
- vi. (3:10): Some concern or thought regarding the result of the test
- vii. (3:10): The sentiment that screening for HIV was generally important
- viii. (3:10): The broker prefers to advise their client to have the test, thereby gaining better, more comprehensive cover

5 This number is not an accurate representation, as there was no consistency in the interviewer's validation of the broker's concern. The numbers responding in this manner, would in all likelihood have been **higher**, with earlier and more consistent validation. This appears to be an important response, possibly indicating that the broker, who is willing to accompany their client for the venisection, would be willing to show greater concern for the clients well being if they knew how to do this

- ix. (3:10): The time required for preparation is troublesome (not wanting to invest the additional time needed)
- xi. (3:10): Assessment that the client is fearful of the needle
- x. (4:10): With the last interviews, the broker was asked directly whether they thought a telephonic 'Hot Line' would be a useful addition to the service. 3 (:10) responded affirmatively, and 1 was negative about the concept
- xiii. (2:10): The broker was purely commission oriented (by their own admission)
- xiv. (2:10): Valued escorting the client to the depot to ensure that they have the test done, facilitating the policy issue without delay
- xv. (2:10): Valued escorting the client to the depot, as part of the service, to offer support
- xvi. (2:10): The issue of HIV and AIDS is generally very problematic, and not just in the insurance context
- xvii. (2:10): The expressed need for a take home booklet for the client
- xviii. (2:10): Screening for HIV is important for the survival of the insurance industry
- xix. (2:10): Denial of any emotional component to testing

APPENDIX 6:
INTERVIEW TRANSCRIPTS

531 A: If you give them the papers here,... you can see they are just going to throw it away....(turning to the other
532 sister)..would you read it?
533 (Second sister)I would,... but I'm educated.... I think it's the uneducated people who don't read it.... but most
534 people have at least heard about HIV or rather AIDS,... they may not know how you get it, but at least they
535 know.
536 Q: Do you think that the clients are prepared for this test?
537 A: I don't think the agents do prepare the clients... they just say go for a test,... but they don't give them much
538 information.....
539 ... often they come,... and they don't even know why... or they get the booklet in a sealed envelope addressed to
540 the pathologist,... so they never read it....
541 Q: Would you say that is a problem?
542 A: I wouldn't say so.... no,... because if they wanted to know about HIV they would ask... but most people don't
543 ask.
544I think the broker should tell their clients about it ... it's his duty..... we don't have the time ... we are too
545 busy....but that's why it's not a problem....if I went somewhere and I wanted to know I would ask....so if they
546 don't ask...that's their business..... but they don'tsometimes they just say 'it's for
547 insurance'.....mm...sometimes they do ask 'if it's positive, who would know?';... so then I explain that it is
548 confidential and the broker will let them know..... I stress the confidentiality.
549 Q: Should the information be given by the broker.... or the sister?
550 A: Maybe both.... the broker and us.... if we had the time..... but often we don't.... but it is the broker's duty to
551 tell them about HIV.
552 Q: What should they be telling the client about HIV?
553 A: Well.... how you get the disease... I thin that is the most important thing..... because sometimes they don't
554 know that.... and they must tell them,...it is positive,...what is going to happen....
555 Q: To the blood and result or to them?
556 A: No... to them....
557 Q: About the policy or their lives?
558 A: The policy and their lives.... because they're not going to get the policy....
559 Q: Do you think pre-test counselling is necessary,... or do you think the current procedure is reasonable?
560 A: I think it's reasonable... what we do is reasonable... we try our best and couldn't do more.... or the broker
561 can do it or... a separate person....another sister or....we are definitely not trained enough to do it.
562
563
564 13. Jan S Marais - 10/9/97
565 Q: What are your thoughts and feelings about insurance HIV testing?
566 A: I wouldn't want to know my status,... then I would have a moral obligation to tell others,... I mean look at the
567 youngsters of today.
568 I heard someone say that everyone should be tested routinely,... whether they like it or not.... I had some one
569 say 'if I had HIV I wouldn't stop sleeping around... if I have to die then others must die with me'.
570 Q: What do you think the clients should be told?
571 A: You don't have to tell them much... it's printed on the form.... one could just go through the form with the
572 client.
573 Q: Would it be just information?
574 A: :Yes.... which includes that the virus is sexually transmitted etc.
575 Q: Do you think it's reasonable to have some counselling, or is it not necessary?
576 A: Well,... if they are +ve, the will need to be counselled.... especially if they have the attitude that they want to
577 spread it...
578 ...Many people just don't realise.....
579 Q: And do you think the pre-counselling is necessary?
580 A: Well,... in a way it might be necessary,... but it would never happen.... the agents just push to get their
581 commission.... that's the feeling I get....
582 Q: And the sisters,... is it our job?
583 A: If it had to be our job then we would need more manpower....we couldn't manage like this.... especially
584 here... people really don't even know what is a 'sexually transmitted disease' or they ask 'is the needle clean'....
585 the HIV tests here are like a production line,... there are so many and we go so fast.....
586 the insurance company could have some one who is trained.... like by ATICC,... who is available to answer
587 the questions for an area.... because it's difficult.....someone could come with the questions that we couldn't
588 answer... it's not a simple thing and we need to give answer....it's not a simple thing and we need to give

589 answers we can trust... keeping up with information is an ongoing learning experience.... I'm not sure that
590 anyone really knows the answers....
591 Q: Are we qualified to do it?
592 A: If we were given enough training or information....
593 Q: Would you want that training?
594 A: I would like it... but we still wouldn't have the time to spend with each client...
595 if they wanted the counselling....then you could have one person for each area.... that would make things
596 easier for us... if they were counselled and had everything filled in and ready when they come here and it would
597 all go smoothly....
598 Q: Do you think they would go elsewhere first and then come here?
599 A: You're right... I don't think so....
600 Q: What about a HOT line that people could phone?
601 A: Yes I think that would work....they must be able to answer everything... even from where the blood is drawn. I
602 had a person who come and when they were asked to sign the consent,... they said, 'oh,... an AIDS test....no I'm
603 not having that' and he left.

604
605
606 14. Jan S Marais - 9/9/97

607 Q: What are your thoughts and feelings about insurance HIV testing?
608 A: I would like people to have read the document before they come.... because they do have one,... and they get
609 here....just because they know they have to have the test done for the policy.... but they don't really read why the
610 company wants them to do it.... that the insurance industry don't want to insure a dead person.... but I don't
611 really think that they learn anything from it....

612
613
614
615
616 **INTERVIEWS WITH INSURANCE BROKERS:**

617 1. 6/8/1997 - Atlantis

618 Q: What are your thoughts about insurance HIV testing?
619 A: I think it's important to prepare the client properly,... otherwise the client is upset when they get to the
620 depot. For the last two months ** (name of the company) has been distributing a booklet to the client with
621 information,... which they take home with them.... I then check that they understand it....

622
623 2. 6/8/1997 Atlantis (Metropol)

624 Q: What are your thoughts and feelings about insurance HIV testing?
625 A: Mmmm.... you know we have a new booklet out, which explains everything really well, and the client gets this
626 to take home. No client of mine has ever refused the test,... they don't see it as a problem.... they want the policy
627 and therefore they have the test as a condition of the policy...
628I've only ever had one client who had a problem and they were a generally nervous person, and I think
629 they were scared of the needle....

630This new L.O.A. thing (the pamphlet) prepares them.. well ...

631 Q: Does that feel good for you?

632 A: Yes, it does feel good... you know if they are positive,we never get to see the client again.... and the client
633 never really asks about it.... it's perfunctionary..... if the person is properly prepared....

634It's not an issue in my mind.... never has been....but I do like the new L.O.A. protocol..... it removes
635 some of the responsibility from me.... although I never really check whether they know or understand
636 or not.... I think the onus is on them.
637Some people say that they are happy to know (on receiving a negative result) that they are safe.....
638 don't really think about the other possibility.....
639
640 3. 18/8/1997 - Mitchells Plain - independent broker:
641 Q: What are your thoughts and feeling about insurance HIV testing?
642 A: HIV is a major problem....
643 Q: For insurance?
644 A: For the country.... it's not a problem with underwriting, the clients don't mind having the test. I
645 sometimes struggle to get the clients to go for the test, because they are so busy, and they don't have
646 the time....
647 Q: Do you prepare your clients in anyway for this test?
648 A: I do... briefly.... I say that the test is for HIV.... the clients get the form before hand, so they have the
649 time to read it if they want to,.... but I don't check on that....
650 I think that it is important to deal with it,.... but that people are aware of the issue..... that's what
651 I've found with the people that I deal with.... mmm.... it should be in the form that it has been checked
652 that the broker has made an effort to inform the client....
653 Q: Whose responsibility do you think it is,.... to inform the client?
654 A: The brokers check that the clients know, if they have the virus now, or if they get it in the future,....
655 what the implications would be for their policy..... but not the actual counselling.... the pathology
656 company should be responsible for the counselling....
657 but HIV is not different.... it's just another disease.... and it's not the broker's responsibility...
658 Q: Why not?
659 A: His job (the broker),... is just to check that the client knows what would happen if it were positive....
660 that their only responsibility towards HIV is a personal one.... you know in a personal capacity.... I
661 would go into detail if the client asked for it.... or if they came in and said they were nervous,.... or
662 positive....
663 Q: Has that ever happened?
664 A: No,.... that's never happened....., but with counselling it's becoming to personal,.... and many people
665 don't want to talk about it.... it's too personal....
666 Q: Do you feel equipped to deal with it,.... if clients ask?
667 A: Yes.....mmmm... no,.... I would be ill equipped to deal with counselling.... we are not properly
668 trained for it....
669we went to a conference in North Africa, and what is happening in Africa is really frightening....
670 Q: I've found that each group I've spoken to feels that it is someone else's responsibility to inform the
671 client....
672 A: (He just smiled at me and nodded).... It is an issue, but it's uncomfortable for everyone....
673 (I had shown him the questionnaire with the information grid) Maybe if there was an information
674 check done at the depot.... which they bring with them filled in, and then any queries could be answered
675 or corrected..... also if the broker and the form state the avenues where the person could go if they
676 wanted counselling....
677 4. Gatesville - 4/9/97:
678 Q: Thoughts about HIV testing?
679 A: I don't really have too much time.... but I don't have a problem with it....
680 Q: What aspect do you not have a problem with?
681 A: My clients are comfortable to come for this test. I talk to them about it and they are happy to
682 come.....
683 Q: If you are talking to your clients, it would seem that your are concerned about it and so you prepare
684 your clients?
685 A: Yes..... I do prepare them..... I ask them to read the counselling form before they come and I prepare
686 all their forms for them....
687 Q: Do you insist that they read the form?
688 A:.... Well I ask them to ... before they come... I do think it is important that they know what they are
689 coming for.....
690 Q: It seems to matter to you that they are not anxious when they come?
691 A: Yes.... I want them to be comfortable and relaxed when they come.... and I usually come with them. I
692 also talk to them about their life style and risk.....
693 Q: Do you discuss this with them?

694 A: Yes.... a bit.... you know about future life style changes and risk.... you know we're not
695 professionals.... so we.... can't.....
696 Q: Go into too much detail?
697 A: Yes.... but I do talk about future changes. You know I have been a rep for 30 years,... and I have a
698 very large client base,.... and I know them all.... they are all friends or past clients or referred by past
699 clients....
700 Q: So you feel you can talk to them about lifestyle?
701 A: Yes.
702 Q: In a sense, the fact that your clients are referring other clients to you means that they are happy
703 with the way you have been with them.... that you do care...?
704 A: YES!.... I do care.... and it does matter that they are prepared and not anxious. If I had known about
705 this questionnaire, I would have allocated more time for it. Are you going to be here for a while?
706 Q: For the next few days.....
707 A: Can I take a form and check that my other clients are properly prepared when they come again?
708 Q: Yes. Thank you for your time.
709
710 5. 9/9/1997 - Sanlam -Jan S Marais
711 Q: Any thoughts or feelings you have about insurance HIV testing.... is it a problem for you?
712 A: It's not a problem because I have never had a positive patient... up to now.... which I would know
713 about because the policy would not be issued....
714 Q: Is that something you fear?
715 A: Yes,... because if clients are positive it will cost me the commission.... mm... some of the clients do
716 fear that they have HIV or not....
717 Q: What do you think that is about?... is that they do not have enough information or that they fear past
718 actions?
719 A: Yes,... it could be that they do not have enough information or that they fear past actions.....
720 Q: Do you fear for the person?
721 A: To be honest,....no..... I have pity for him,.... but I'm mostly concerned about my own commission... if
722 he has not been careful,... that's his own responsibility....
723 Q: Has no one ever come back to you angry about the testing?
724 A: Actually,... I had two clients who said 'no HIV test',.... but because they feared the needle more than
725 anything else....
726 Q: Do you think people are being properly prepared for this test?
727 A: No..... I'll tell you why..... because....I'm just writing the policy number..... well,....not everyone must
728 have this test,.... and if it is decided that they must, then they let the broker know whether the client
729 must go for the test,... and then we must notify the client,.... and I say, 'sorry buddy but you must also
730 go for the HIV test',....
731 ...but I don't want to talk too much to my clients about HIV and medicals and also....I'm.... I just want
732 to settle the business side.....
733 Q: Why not?
734 Q: Because I'm scared he'll then say I'm not going to take off from work and that.... so that's why I take
735 them (to the depot to have the blood drawn).... otherwise they just never go.... in the past,.... when I let
736 them go by themselves, then they just wouldn't go and then I would hear that the policy hasn't been
737 issued because they didn't go for the test....
738 Q: Why do you think they don't go.... do you think they are scared?
739 A: Yes,... definitely....
740 Q: Of the needle or the result?
741 A: Of both.... you especially when they are married.... they are even more scared of the test.... they
742 don't say so but you pick it up. Everything is fine until the point when you talk about the test and then
743 they back out of it....
744 Q: So people are scared?
745 A: Yes, definitely.....
746 Q: If more information was to be given,... who do you think should do it?
747 A: Must be qualified people.... not me or the man on the street....
748 Q: It's a tricky subject?
749 A: It is tricky and it needs to be handled properly.... it concerns more than just what it seems to be....
750 Q: Mm.... it seems to me that you are clearly more concerned for the clients than you admit,... but that
751 you are saying it needs to be done properly?
752 A: YES! Absolutely.
753 Q: Any thing else you would like to add?

754 A: No...

755 Q: Thank you for your time and your honesty.

756 A: (Smiles as me) Thank you too.

757

758 6. Jan S Marais - 10/9/1997:

759 Q: Thoughts and feelings about HIV testing ?

760 A: Biggest problem is trying to get black people to do it... a lot of people would prefer not to know

761 whether they are HIV positive or negative....but it's not a problem in terms of insurance....people

762 understand the need for insurance and they do understand why the HIV test needs to be done. If they

763 don't, this should be explained to them by the consultant.

764 Q: Do you explain to you clients?

765 A: Yes.... they need to know they are coming for this test and why.... this protects the company,...

766 indirectly.... and the client....

767It's important that the rep. does not know the outcome... There is also a problem related to the G.P.

768 or hospital when they are involved.... they sometimes don't take the time to approach the client if they

769 are positive...either the doctor does not contact the person or the insurance company does not notify

770 the doctor....mm... whose responsibility is it really?...I suppose you can just say 'we can't cover you'

771 and that's all,...but the person would want to know why... but I also think it's in the interest of society

772 that the person know and so the company needs to take that responsibility.....it's a service to society..

773 ..not necessarily to that individual, but for society even more that for that person...

774 ...We would also know about the problem if these tests are being done...it's a way of screening and it's

775 good to do that....

776 Q: What do you think is important to inform your client about?

777 A: We do not inform them of the result.....

778 Q: And at the pre-test stage....

779 A: They need to know that it is the HIV test that is being done.... to protect the company in terms of

780 policy holders, not because they are particularly at risk....

781 Q: Do you find that people understand that?

782 A: They do understand that investments are growth linked... the consultant needs to be informed about

783 this themselves.....

784 Q: And the matter of pre-test counselling.....?

785 A: It cannot be totally expected of the companies and brokers in terms of the knowledge..... we are

786 business people and we are also time constrained....some information is necessary,...we maybe need to

787 be informed by the pathologist etc as to what information needs to be given to the client.... the medical

788 profession needs to notify us about that.... (indicating that he is ready to end the talk)

789 Q: Anything you would like to add?

790 A: Again about the HIV test.... my great concern is that a lot of people have HIV and can't get

791 insurance, and so it creates poverty and I'm not sure how one could get around that.....it's a great

792 concern...

793 Q: You seem concerned about your clients?

794 A: Well,... I'm also a priest...

795 Q: Oh... that's an unusual combination of interests (we both laugh).

796

797 7. Gatesville - 11/9/1997 -older broker

798 Q: Do you have any particular thoughts or feelings about insurance HIV testing?

799 A: I feel it's something that is necessary,but it is very time consuming to do with each and every

800 client. Some brokers just send the client themselves, but I prefer,... over the years... To attend to client

801 as part of the service.

802 Q: So you feel it's necessary to do?

803 A: It's necessary,... when they have to do the test.... then.. if they are positive,.... this would be the only

804 time that they would find out.

805 Q: So it is important for them?

806 A: Yeah....it works both way,... for the client and for the company...

807 Q: For the client to find out and for the company to be protected financially?

808 A: Yes.

809 Q: Are all your clients just accepting of the need to have the test?

810 A: Some brokers do the exclusionary clause,... but I thin that would be a disservice to the client. You

811 take the insurance because you want to be protected,.... if it (the policy) excludes AIDS ,... that would

812 be a disservice,... as they would want to be protected from all eventualities....

813 Q: Mm.... how do you prepare your clients for the test?

814 A: Sometimes....it also depends on the client.... if they ask questions then I can answer them.... if they
815 ask more, then I can inform more....
816 Q: Do you like it when they ask you questions?
817 A: Yes, definitely....
818 Q: What would you say is critical for them to know before coming for the test?
819 A: Why they're doing it.... and technicalities of the policy,... if they are negative now and then got it
820 later, that they are fully covered... but before they can be accepted for that policy they must do the
821 test....
822 ... Also it's important what questions the clients ask.... like,... 'if I were positive, would you let me
823 know?' and then I say that's why we ask for the doctor's name....so that if they were positive the
824 company would notify the doctor and he will counsel you.
825 Q: Do they ask that?
826 A: Sometimes.... some are inquisitive,... some are scared to ask... they don't want to seem stupid..
827 Q: Some people say that it is important for the client to get some pre-testing counselling,... have you
828 ever thought that to be important?
829 A: I always make the read the information at the back of the form....
830 Q: And you feel that is enough?
831 A: Ja,... I would say,...ja....I'm not qualified to for into in-depth discussion with them..
832 Q: DO you think it is necessary?
833 A: No,...not really....
834 Q: Who do you think should be informing the client the most?
835 A: Well some-one that is properly trained.... anyone with necessary skills and training....mmm... if it
836 had to be done,...then we are probably the best people....
837 Q: Tell me about that?
838 A: Because we are there... at the right place and at the right time.... otherwise they would have to go
839 elsewhere.... and today's time,...people are very busy,... they've got things to do.
840 Q: Would it be realistic for the brokers to do it?
841 A: I would say, 'ja',... it could be on the application forms whether the client received counselling and
842 was it adequate or not....
843 Q: Do you think a Hot Line, where people could phone in to get any information would work?
844 A: Yes,... I think that would work.
845 Q: Thank you.. Anything else you would like to add?
846 A: No.
847
848 8. J. S. Marais - 12/09/1997 - young broker:
849 Q: What are your thoughts and feelings about insurance HIV testing? (Silence) Like,...do you think it's
850 a good thing or a bad thing?
851 A: I have a facility where I work,... it's a bakery supplies store,...and it's a big company,... and there is
852 a sister that works there,... who fills in the forms for me,... and then takes and sends the blood away for
853 me. It goes to the lab. And then the results from there go to M. But there have been problems in not
854 receiving the bloods... so now I'm back to these depots. It was taking time waiting for the policy to be
855 issued....it was wasting time,... and sometimes they never issued the policy because they never got the
856 results.
857 Q: So now you are bringing your own clients again?
858 A: It's money and time saving....
859 Q: Is it a nuisance to have to bring them?
860 A: No... after two days it (the policy) is issued.... so this is much better,... rather to spend the money on
861 petrol and get the policy issued.
862 Q: How do you go about preparing your clients for the test?
863 A: I tell them that under 30 000,... they don't need the test,... but if it is higher than that then they must
864 go. If it's a male,... then I tell them that they need maximum life cover.... but if it's a woman, it's usually
865 a second policy so it's not so important for them.
866 Q: So you advise them on what the options are, and they can chose?
867 A: Yes... say a young guy is not married.... then he can take a lower policy... my concern is that a lot of
868 people write low life policies just to avoid the medical and HIV test....
869 Q: That it's better to inform and advise the client properly?
870 A: Yes....I do that with all my clients....
871 Q: I have the impression that you take pride in doing the job properly.... and that you care about the
872 client?

873 A: (Looking shy) Yes,...I do. I advise them properly.... if something happens to him,... then at least the
874 policy was looked after.
875 Q: It's a difficult test to have,...what do you think is most important for them to know?
876 A: The result.... If the policy is accepted it means that the test is negative,... and if it's positive,...well
877 'M' will contact them... that's not in my hands.... I'm only the rep., doing my job,... giving him the
878 policy he wants...
879 Q: So for you the most important thing to tell them is how they will hear the result?
880 A: In my opinion,... he will then know if he has AIDS or not without having to pay for it....
881 Q: Some people say that counselling is important before this test, do you agree?
882 A: This is just a simple test.... either you do have it or you don't. And it's the most threatening disease,
883 so you should find out.....
884 Q: It would be a shock to get a positive result,... do you think that proper counselling could make that
885 less?
886 A: Ja....that comes from head office,... they will tell the client,... it's out of my hands....
887 Q: If it was agreed that people needed pre-test counselling,... who do you think should do it?
888 A: Professional.... the people that normally work with HIV testing,... and know the consequences of
889 it.....We are all professionals in our own field,... but I couldn't prepare people on HIV...
890 Q: Do you think an information hot line that the clients can phone before or even after the test, if they
891 had any questions or worries,... could work?
892 A: I honestly don't know....they can read or talk...
893 Q: To whom?
894 A: To friend....
895 Q: Mmm... anything else?
896 A: No,...I must go...I'm late.
897 Q: Thank you.
898 9.Mitchells Plain - 13/09/1997 - young male broker:
899 Q: I would like to ask you about what you think or feel about insurance HIV testing?
900 A: Most people, they don't actually make the client read the information.... but I found that you did and
901 in T., they also made them read the forms.... but they are not there anymore....
902 Q: Are you referring to the sisters asking the client to read the form?
903 A: Yes.
904 Q: Is that a problem?
905 A: Look,... if it is information they must have, then they must have it.... The more information they have
906 the better.... we just take it from granted
907 Q: Can you explain that?
908 A: Well,... I explain to my people why they are taking the test.... and also what happens with the blood,
909 and if something is wrong.... A lot of people are scared of the AIDS test,...and they just don't want to
910 come.... they would rather pay loaded rates,...but the extra, even if it is just an extra R3,00 a
911 month,...accumulates over time..... so if he comes for that test,.. he makes that saving....
912 Q: So you advise it?
913 A: I always advise it... but at the end of the day,... the option is theirs'. What a lot of the guys (brokers),
914 you know it is inconvenient to bring the client in,... just....don't suggest the HIV test,... but they are
915 robbing the client in the long run. You know there is now a 24 hour medical and test service
916 available?
917 Q: No....
918 A: Ja,... you just have to make an appointment.... to go in....
919 Q: So your company offers a policy where there is no requirement to have the HIV test? [He nods]
920 ...That's important for personal choice..... You also seem to be providing your clients with a good
921 service...?
922 A: My dad is in the business for 30 years....and it is a company policy to always bring our clients
923 personally..... You know some of the brokers just wait and see if they have to bring the client in,
924 because it's too much effort to bring them in for HIV... but I always advise my client,... you know I had
925 a situation where a guy married a 16 year old girl, but she didn't have an I.D. so she couldn't come for
926 the test, or get the good cover.....
927 Q: So it is not essential to have the HIV test?
928 A: It's not.... what could happen is... the application form goes to the medical selectors,... and they
929 have the final say about that.... you know if a guy has 4 children out of wedlock or something, and they
930 think he could be a high risk....you know,... if they are really concerned....
931 Q: Do you think the clients get enough information when they do come for the test?

932 A: As long as they read the information form.... even if the broker tells them nothing at all.... it's very
 933 important for the sisters to make them read the form....
 934 Q: What do you think the brokers should be doing?
 935 A: They should tell the client that the test is optional.... and they should know the 'pros and cons' of
 936 coming or not coming.
 937 Q: anything else?
 938 A: That's it.... our policy is to bring them personally... for most people it's a phobia to come for the
 939 HIV test....
 940 Q: Is that for a blood test or the HIV test?
 941 A: A combination.... the needle and a fear of this test.... so we bring them ourselves. Some brokers
 942 don't take their people.... they just send them with the I.D., tell them where to go.... and that's all....
 943 Q: Some people say that it's important to have counselling before this test, what do you think?
 944 A: A tough question....any information they get is good.... but is it practical in terms of insurance....
 945 time again... it would be an hour or so time out of the person's life.... so... 'yes' but if it could be
 946 made very practical then it would be O.K.
 947 Q: Do you have any ideas on that?
 948 A: No,... I don't....[smiles]
 949 Q: How do you think a company Hot Line would work, so that people phone that number if they have
 950 any questions or worries, and they don't have to go anywhere?
 951 A: Yes,... I think that would work.
 952 You know, some of the guys are even happy when the client say they don't want the test, then they
 953 don't hassle,... but when you are struggling to come out with a good premium, an extra R3,00 doesn't
 954 seem so much,... but over the years you are robbing the client....
 955 ... My father and I were just taking about it the other day,... if a client is positive,... how do you deal
 956 with that....it just makes you think,... and I'm sure the ratio is going to increase.... I just wouldn't know
 957 how to handle it....
 958
 959 10. Mitchells Plain 13/09/1997 - young male broker:
 960 Q: What are your thoughts or feelings about insurance HIV testing... a good thing or...
 961 A: I don't have any problems with the way it's done now.... the service is speedy,... we just walk in and
 962 out....although sometimes we have a problem with the computer.... I don't think they can do anything
 963 to dramatic to improve the service at the moment,... except they close too early.....most people are only
 964 available after 6 'ish'.
 965 Q: Do you always bring your clients?
 966 A: Always,... that way I know it's done.... At our company we have a doctor on the premises and
 967 sometimes we take him with us and do the blood on the premises...
 968 Q: Do your client s object to coming for the test?
 969 A: Not really,... I just make an appointment with them, and I pick them up and bring them....
 970 Q: Are they scared of the test?
 971 A: Some,... yes... but not so much the test,... but the needle. I had one last year who was very scared,...
 972 so I just asked the sister to keep talking to her...
 973 Q: Scared of the test or the needle?
 974 A: Of the needle...
 975 Q: And the test itself?
 976 A: I don't think so,... no.
 977 Q: How do you prepare your clients for this test?
 978 A: Insurance is not like it used to be,... people want information... and they just know that to have a
 979 policy,...they must have the blood test..... some are staunch that they don't want a medical or the bloods
 980 drawn... so we try to accommodate them.....so that they can still have cover..... you don't say HIV
 981 test,... that sounds crude,... so I say 'blood test'.
 982 Q: When you say a blood test,...do you think they know what test it's for?
 983 A: No... they just think it's blood.... we don't talk about cholesterol or anything otherwise they think
 984 something is wrong with them.... we just have the blood extracted and sort of do it under cover....
 985 Q: With HIV, the result can change the person's life,...so it is different...?
 986 A: We don't get the results.... we just get the doctor to contact the client and help the client....
 987 Q: So if there is a problem, someone else deals with it?
 988 A: We will be there to comfort the client....but we need professional help.... In my personal experience I
 989 have two clients who are HIV positive and two with cancer, and one died last year....
 990 Q: I can understand why it would be easier not to mention the word HIV, and have all that emotional
 991 reaction....

992 A: It puts panic into them....they can't cope with the reality....
993 Q: But do you not also think that the client is entitled to know what test they are having?
994 A: They know,... we just say 'blood test' it's easier.... if they ask me is it for HIV,... then I say yes,...
995 obviously I would not lie....but I prefer saying 'blood test'....
996 Q: I wonder what about saying 'HIV' scares you? You are clearly uncomfortable with it....
997 A: I'm not scared...I've often had the HIV test for policies, but most people are scared of it,... they
998 think that they are going to lose their job or their friends won't accept them.....
999 Q: The clients have fear? And if you talk about it....
1000 A: Yes.... if they have the fear then I won't know how to cope with it.... you know it's a fine line thing....
1001 we are numbers oriented....not emotionally oriented.... the professionals must deal with that...
1002 Q: And if there was a company AIDS Hot Line that the clients could phone, do you think you would use
1003 it?
1004 A: Yes,... I would use it.
1005 Q: Anything else you would like to add?
1006 A: No...
1007 Q: Thank you...
1008 A: No,... thank you...it was my pleasure....

APPENDIX 6:

INTERVIEW TRANSCRIPTS:

THE NURSING SISTERS:

1. (July 1997) Kingsbury

Q: What are your thoughts or feelings about insurance HIV testing at the depots?

A: Initially I was quite upset that people weren't properly prepared,... that was about 3-4 years ago.... clients came on their own without a broker,... without ID books etc..... they didn't even know what the tests were..... now people are coming with their broker..... but they still come without a policy number,.... and they are still not properly informed.....

....Some of the brokers are good and supportive,... but others are not.....

....They have not had pre-test counselling....mm... 'S' and 'O' have a nice comprehensive form,.... but people are not reading it.....and they have not been pre-counselled.... you know like,... 'do you know what test', and 'do you know what are the consequences... relationship issues and treatment etc '..... at Red Cross they counsel better....

.... And it is a problem because this is an HIV test.... for other tests I don't mind so much,.... like for cholesterol,.... but even that,... there is no real information or direction on where to go,... such as to their doctor,... or what the normal base results are,...etc....

...People are also wanting the results,.... but we tell them that the insurance paid for the test and so the result belongs to them....

...But the ones (the brokers) who send the clients in with no information are not good... it is better that the broker accompanies the client....

....Actually,... I think that the brokers should be preparing the client,.... they are getting the commission for this....

...Mmm ... they should have a medical division which deals with this..... if the clients want to know what would happen with the policy if they are positive later....

...In a way it's senseless to test for HIV.... do they (the client) have a full medical check up?... I'm not really sure of the insurance protocol... you must look at the whole history.... and the HIV test should be treated the same as the others (tests).

.... People objected in the beginning,... but now they just say,... 'well O.K'.... 'I know I'll be negative anyway'...most clients are not really worried about it... a few say that they are worrying about the results....if you know you are a risk case.... if you've been promiscuous,... then.... and the policy has gone through,... then you know you are negative.... BUT there is the issue of the window period which has not been addressed.... no one is advising them to go for another test in 3 months because they might be in the window period... or also not getting advise on how to change their life style.....

.... (indicating the counselling form)... It says that we must do the counselling,... but we are not trained to do this,.... and it's not the sister's responsibility.... I know that one sister went for training at ATICC... in 1991.... but she is no longer with the company.... but I think it was a good thing...

... Maybe there could be a sister at each depot who could go for the ATICC training.....maybe the sister in charge of the depot..... because she could then train all the others....we would then know what we were doing....and we would be more comfortable.....

Q: Why do you not talk more to your clients?

A: We do,...when there is the time.... but even the brokers are not properly informed,... where they could send their clients for convenience....

.... People are not so worried about it (the test) when it's for insurance.... then it's just routine....and the sisters also then just treat it as routine....

.... Lots of couples come in,... then they are not so anxious,.... when they come alone,.... they are more anxious....

.... I would want to be prepared to deal with the client who comes in worried.... but I'm not so concerned when it's for insurance.... because then the insurance company will deal with it (the result).

....But sometimes even for insurance,... they are nervous and worried for the result..... I phoned someone once to come back to us,... because we didn't have the ID number,... and he was really worried then.....

...Mmm... people are nervous,... but they are just not showing it... so they feel 'protected' that they haven't come for themselves.... people are putting up a bit of a show for the sisters..... some are really not worried,.... but many are.....so people are more worried that they are showing it.....

Q: How do you handle them then?

A: I am just sensitive to each patient.... and I listen to what they are saying.... but we do need more information..... they want to know what happens with the policy.... I think the broker should give more information

..Mm... possibly the broker could give the information about the policy and the later consequences about the policy etc..... and the sister could give the information about the consequences of the test,... or they could get counselling from a health care worker... but not from the sisters,... I don't feel trained for it....

60 ... Mm.... it's a bit senseless,... because a negative result could change later and no-one is counselling them to
61 avoid this.....so it's senseless unless there is also a lifestyle change.... or people must know to go for a further
62 test if their life style is risky....

63I'm actually worried about the long term handling of this problem,... beyond just the insurance test....

64 ... The client is not really getting a fair deal.... it makes a difference if the client is more fully informed,... about
65 the policy and the cost etc.... not just the HIV..... (looks at me to indicate she is finished)....

66 Q: Would you like to add anything else?

67 A: (Shakes her head and smiles at me).

68

69 2. (August 1997) Kingsbury

70 Q: What are your thoughts and feelings about HIV insurance testing?

71 A: I would like to know what the LOA protocol is.... why are they doing this....they are so strict,... there must be
72 a reason that they are so confidential etc....but the brokers are sending people in as if it was nothing.... but
73 people are scared

74There is not enough information about the window period and then if they develop it later they are
75 devastated....

76 ... The brokers come and some of them are rude....mm... but many are polite.... but the brokers get away with
77 everything....

78 ... I had a young man who just came to get information(about HIV and AIDS),... and I wasn't equipped to give
79 him this information... but we should be because we are nursing sisters,... and so we should know....just
80 generally,... so the role of the nurse is important.... but that case was different to the insurance testing..... he
81 really wanted the information... but I don't feel that I handled it adequately.... I would like the sisters to be more
82 informed.... I would be scared to counsel.... which is not the same with the insurance tests... they are NOT
83 nervous,... because they were just asked to come by someone else.... it's the young people who come in really
84 worried that are the issue.... there is a stigma to it....

85mm... the implications.....social, financial and emotional could be devastating.... and they could take the
86 insurance company to court.... so people must also be educated at the same time....

87 I think that the brokers should take care of the client.... they should inform and prepare them,... and they (the
88 client) should be here at the right time with the right stuff (referring to the necessary documentation)

89 ...The insurance test is a negative thing.... they have to come..... they are not sent by their doctor for their own
90 needs.... but it does seem less serious when someone comes for the insurance HIV test, and not because they just
91 want the test done.... there is less resistance... less fear....

92HIV is a problem....and we mustn't make a stigma about it.... but it is a serious thing and it is tricky....

93 Q: How do you feel about drawing the blood?

94 A: We're just skilled to take the blood....it's not the sister's responsibility to inform the client.... we don't have
95 enough information.....but it upsets us that we could help the client....(implying wanting to but being unable)...

96 It is a routine thing as a part of the job....and we follow the LOA protocol....which protects us.... so it is the
97 insurance companies responsibility to deal with it (the result)....

98 I think the way we do it,... the procedure is fine as it is.... it's enough....and I'm not uncomfortable with it....
99 we do it so often that it just is not an issue....but outside the insurance testing realm,... then I'm nervous (such as
100 the person who wants testing for personal reasons)....

101But I don't think that the broker's take on enough on themselves....

102 Q: Anything else you would like to add?

103 A: No....I talk too much.... (and laughs)....

104

105 3. 6/8/1997 (Atlantis)

106 Q: What do you think or feel about these Insurance HIV tests?:

107 A: I feel it's a good thing.... as a way of screening people. I am happy about the confidentiality of the results
108 (results cannot be accessed in the normal result access fashion).

109 (She was unable to add anything more to the interview as she went home at this point)

110

111 4. Atlantis -6/8/97:

112 A: What gets me..... is that I feel it's good to have the insurance, and good to have the test as a way of screening
113 people, but that the client identification at the depots is a problem. Clients are not properly prepared for what
114 they need to bring, for the blood test. The brokers used to be good about this, but they are not so good
115 anymore....

116 I think that DSP (the pathology company) gives a good service, to the broker and the client...

117 ...I always ask if the client has read the information document and I always ask the brokers if they have given
118 the client the information....

119 ...I feel that clients should be informed that they may need a medical (in the course of applying for insurance).....
 120I think that it is for the broker to explain (to the client),as it is his job,....so that the client would be more at
 121 ease. It is the sister's job to just finalise the forms, that we should end off finally.
 122Our job is also to reassure (the client) about what test has been requested.....
 123The sister must check what test was requested, and what protocol needs to be used.....
 124 I have worked a lot with the brokers, and I have found that they are well informed about HIV..... the sisters
 125 are also informed..... as a nurse, the sisters should also be informed and give the final touch up (to the client
 126 information).....
 127 I am worried about the paper work involved and the protocol, to follow what the insurance companies
 128 want..... But I don't feel that it is the sister's role to prepare the client (for the test).
 129 I found that the clients don't really know what the test (they have to have) is for.....when this happens, then I
 130 just phone the broker and jack him up that he hasn't done his job properly.... although this is not happening
 131 much anymore.
 132 There were lot's of problems with the brokers in the beginning (about three years ago)..... but that clients
 133 are now coming for the test, knowing what they are being tested for.....
 134I feel that the broker is doing a better job now,..... but I still always asks the client if they know that the test is
 135 for HIV.....
 136I think that the situation is much better now.... the brokers are doing a better job of telling their clients what
 137 to bring and what they are to be tested for....
 138I know all the brokers well, and ...I just jack them up.....
 139 Q: Who do you think should be responsible for informing and preparing the client?
 140 A: The broker and the sister should be responsible for the informed consent.... but it is not the sisters job only....
 141In preparing the client, when you use the word 'HIV', people don't know what you're talking about,... but
 142 they know what AIDS is.... and then they agree to the test...
 143 ...I've noticed that the clients are scared of the needle.... lots of the clients are nervous, and when you ask them
 144 what this is about,..... they say they're scared of the needle.... but some of them say they are scared of the test as
 145 well.... you can see exactly when that is,.... because they start asking questions, and then they admit it is not the
 146 needle,... but the test.....when that happens, then I talk to them and calm them down...
 147When the client has been to the depot before, and they know the sister,... then they are more relaxed.... both
 148 the client and the broker. When the sister is known, she is trusted more.....
 149 Q: Is the test for HIV different form other tests?
 150 A: I feel that HIV is different to other tests,.... others are easier to explain.... but they (the clients) know the
 151 word 'HIV', and they want more information.... many clients come back to the depot for the result..... and then I
 152 refer them back to the laboratory (in town) or to the insurance company....
 153It is different.... clients are more worried.... they are scared to die.....mmmm ...maybe they are not more
 154 worried for this test than other teststhey are all nervous about having the blood drawn..... maybe a bit of
 155 both...
 156 ...You know,.... you get used to doing this test and you don't really think about the consequences much
 157 anymore... in the different areas... one knows the patients and the people in that area.... in the beginning I was
 158 frightened to take the blood,.... but the public is now more aware..... the young men are less promiscuous....
 159If the insurance policy is rejected,.... then they come back to the depot and want more information, and then I
 160 refer them back to the laboratory or the insurance industry..... but in my mind,.... then I'm scared that they are
 161 positive..... I also send them to their doctor. I feel sad for them.... they are very agitated when they come,.... and
 162 they say, 'you did my blood'.... but it doesn't happen very often. When it does happen, I always remember that
 163 client..... I feel more worried when I take blood from gay men....
 164I think they should be prepared (all clients)..... even just a simple explanation..... so that they are prepared
 165 for the consent (which all clients must sign)..... and the identification (which all clients must bring with them),
 166 and they must know what the test is for and information about whom they could contact if there is a
 167 problem....
 168 ...People do hear and take notice of what the sister is saying.....
 169 ... This test is very important for the client.... especially the women....they are happy to have the test, and then
 170 know that they are free (of the virus).....
 171 If the depot is quiet,.... then I can talk more but the depots are often too busy.... I wish I could talk to them
 172 more....
 173I always put clients at ease when I'm drawing blood...
 174 People are very ignorant.... to read... maybe they do need to talk... that would be very good... maybe
 175 better.... so that they know what is HIV,... what the protocol is.... they must know about consent and the I.D..
 176 ...but the most important information for them is to know who will give them the result..... who will tell them....
 177 Maybe it's fine as it is.....

178 Well, maybe more pictures and information on HIV put on the walls, so that while people are waiting for
 179 the sister they can see it.... maybe pamphlets and things in the waiting room....
 180 The government should be spreading more information....
 181 Well.... the information on the application form is good enough.... but they don't read it....
 182 Mmm... education and prevention should be part of the testing,.... and they should take a pamphlet
 183 home....these could be distributed at the depots.....then people would know why they are coming for the test.....
 184 and we could also keep statistics....
 185 People were talking about AIDS a lot in the beginning,.... but not so much anymore..... they're less scared
 186 and anxious of it....
 187 Mmmm.... proper preparation would make no difference... in the country,... we treat the clients and the
 188 brokers like friends....

189
 190 5. Gatesville - 13/8/1997

191 Q: Thoughts and feelings about HIV insurance testing?
 192 A: I think that it is very biased we could be testing during the window period and the policy would go
 193 through,.... whereas if the person is HIV positive, they would get no policy,... so it's just a matter of luck....
 194 ... It's also for the benefit of the insurance industry,.... just a money making thing... but there are 'pros and cons'
 195 to it.... it is good that the insurance do it..... looking at it from the insurance point of view,... its good.. but what
 196 about the people who are infected,... they cannot be covered...
 197 ...It's not just a routine test,... it is something VERY personal....
 198It's also a way of getting stats,... which is a good thing....
 199 ...The clients are not informed or counselled enough.... they're just dummies coming for the test.... when you tell
 200 the black communities,... then they don't want to come,.... but if you counselled more,... then they would
 201 come....as it is a free test.... there's a lot of ignorance still..... especially amongst the black populations....and a
 202 little knowledge is frightening.... more knowledge would be helpful...
 203 ...So the pro is that there is some kind of control coming in (testing and knowledge of status and stats)... but
 204 not the way we do it,... the sisters don't give counselling.... but realistically it's impossible to give counselling,
 205 we are too busy most of the time....
 206 ... The ideal would be to take the patient confidentially into a room and tell them about it.... some people are
 207 very frightened to come for an HIV test.... to alleviate the fear..... (silence)...
 208 Q: Whose job do you think it would be to give this counselling?
 209 A: The brokers...or the referring doctor.....should be taught how to do it..... it's their job..... because they are
 210 sending the client. The sisters job is to confirm the knowledge....
 211 Q: Do you have any discomfort doing the HIV tests?
 212 A: It's not comfortable.... it is a good thing.... but you can't feel insecure or scared taking blood.... but I do feel
 213 uncomfortable with people coming in not properly prepared.... you know,... that can't be given enough time.....to
 214 prepare them properly....
 215A person was declined the policy at Mitchells Plain, and they were very angry with the sister.... saying he had
 216 not given her permission to do it.... he blamed the sister for doing it....
 217 ... Mmmm...it could be out job to prepare,.... but we don't always have the time to do it.... ideally it should be out
 218 job.... but also the brokers' job....
 219 ... Some of the sisters feel that we should counsel each and every patient,.... mostly from the community or
 220 hospitals,... who are locuming (doing sessional work) with D....(the pathology company)....
 221Ideally,.... I would love to tell each patient,... if I knew more.....the sisters don't feel they know enough or how
 222 to do it.....mmm
 223 Q: Would you like to add anything else?
 224 A: No....
 225

226 6. Gatesville - 16/8/97

227 Q: What are your thoughts or feelings about insurance HIV testing...?
 228 A: Well,... the clients should know all the requirements for HIV,.... all the details.... I would want to see the
 229 insurance protocol..... where it relates to our aspect of the work..... you know,... when the client comes in and
 230 asks for an HIV test..... to have proper verification... identification..... the legal aspect,.... what are our legal
 231 obligations..... it would be nice to have a list of all the acceptable forms of I.D..... but.... you know like from the
 232 home affairs office issuing temporary I.D....
 233They should also have general information about HIV itself.... A lot of people have different views.... what it
 234 entails.... and information..... people need clarification....
 235 ...Some people ask what symptoms people could have... and I'm not sure how much information we should
 236 give.....

237 Q: How do you think that information could happen?

238 A: ... The brokers..... or they could contact someone who know more,... such as their family doctor.... but people

239 don't want to make that effort for themselves.... but they would want it to be handed to them.... like,... all the

240 information given by the sister.....

241It feels,...not right for the sister to do it....it is personal and confidential.... maybe it should be done by the

242 doctor or the broker

243 I don't think that it is possible for the sister to do it... I don't feel we are adequately equipped to deal with

244 it.... we could say the wrong thing,... which could jeopardise the client....

245 Q: If you were more informed, would you happier to do it?

246 A: If I knew a bit more.... I would feel more comfortable doing it.... it would enrich my experience.... I do feel

247 that we have the time,... at times,... to counsel if need be....we use to have police officers asking us, before they

248 were recruited..... I would actually enjoy doing counselling,.... if we were more informed....

249 Q: Do you think that it is important for the client to come informed?

250 A:.....It is preferable.... it minimises the trauma,.... and then we would deal with a more relaxed, informed

251 client.... I have noticed a difference..... if they are not informed,.... you can sense a barrier with the client and it

252 produces a barrier with the sister..... they don't know what they are looking at.... what they fear....

253 Q: Are you saying that the clients are sometimes fearful?

254 A: Yes.... sometimes...

255 Q: Have you notice who is more fearful?

256 A: Not being prejudiced,... but the so called African groupings.... seem to react more and be more

257 sensitive.... we were also testing for TPH, and we found a lot of confusion.... that the client didn't know what

258 they were coming for....

259 Q: How did you feel working with them?

260 A:..... It is more difficult to deal with someone that has reservations....

261 Certain insurance companies, such as (**),... well their form is not clear, and so the client lacks

262 information....

263 Q: Do you find a difference between brokers?

264 A: Some (clients) will come with everything ready, and their clients are quite happy and it's plain sailing.... with

265 other's it's not so....

266 Q: Are you saying that you think it is important that clients come prepared?

267 A: (Nods).

268 Q: (Pause)....Who do you think should do this preparation?

269 A:Either the doctor sending the client, if they are coming for personal reasons, or the broker..... they should

270 be the first level of dealing with this,... is with the broker.... so that the broker also knows what to expect and

271 what kind of follow up is needed.... they are also the one selling the policy and so there should be that kind of

272 agreement between them....

273 ... The client should feel that the broker is there for them and can answer questions for them.....

274

275 7. Mitchells Plain 18/8/1997

276 Q: What are your thought and feelings about Insurance HIV testing?

277 A: (Silence, uncertain about the question)

278 Q: Do you think that this is like any other test?

279 A: ...To be honest,... it is.... when the problem comes,....when you hear the clients part of the story..... their

280 fear..... because sometimes they do ask you....

281 Q: What do they ask you?

282 A:..... 'What if it is positive?'.....= Why must I do this test,.... cos 'I know that I'm not positive'.....

283 then the sister gets more involved.... when the client comes scared....

284 Q: Does that happen often.... or seldom?

285 A: It happens often....

286 Q: How do you recognise if a client is nervous?

287 A: ... You can see the expression of the client,... the way they sit or the way they hold out their arm (for the blood

288 to be drawn)..... or that they are not so talkative,.... or others talk a lot and say, 'I'm scared sister'....

289 Q: What do you do when you have a client that is scared?

290 A: I try to calm them down.... I say, 'it's human nature to be scared',... and I say, 'it's normal,.... you don't have

291 to be scared'.... and that he will get the results and know what is going to happen.... that if something is wrong,

292 they (the insurance company) will inform him,.... that 'no news is good news'....

293 Q: Does that reassure them?

294 A: Sometimes....

295 Q: If you could do it differently, what would you change?

296 A: I would not change anything....
 297 Q: Do you think that the patients are coming prepared.... or not?
 298 A: ... Sometimes they are.....but most of the time they are not prepared. They come without I.D. even.... and most
 299 of the time they don't know what is going to happen with them..... afterwards they are surprised that it's such a
 300 small thing.... they were expecting it to be such a big thing....
 301 Q: How would you assess that a client is prepared?
 302 A:.... Well, when they know exactly..... that blood is going to drawn, and that it's for HIV.....
 303 Q: Is this the same as any other test?
 304 A:It is different..... because the patients, for any other test, are more relaxed, they know what is going
 305 on. Some say that they don't like needles, but that it's for a good cause, that their doctor will get the result and
 306 they will be treated,.... but with HIV it's different..... they actually need more reassurance,..... they are more
 307 nervous. Their whole lifestyle can change with the result....
 308 Q: Who do you think should be preparing the patient for this test?
 309 A:The nursing staff.... or the patient's doctor.... Maybe the best would be for the G.P.,..... because they know
 310 them (the patient)..... so when they are applying for insurance, they should be referred to their own G.P.,.....
 311 where they would be informed and then they could have the test..... they could be sent to the depot for the
 312 bloods..... because he (the G.P.) is the one who is going to inform that same client if it is positive.... but it should
 313 be the client's choice..... but they would probably not go.... only some would go.
 314 Q: Do you think there should be greater sensitivity about this test?
 315 A: Yes, because it would change their lives.....
 316 Q: Should the broker be responsible for this?
 317 A: No,.... because they don't do it right.... Sometimes the broker doesn't know what it's all about.... they just
 318 work for the commission. As a sister we are more aware, but we can't really do anything about it,....and so we
 319 just do the work.
 320
 321 8. 20/8/1997 - Claremont
 322 Q: As a sister what are your thoughts and feelings working with insurance HIV tests?
 323 A: I think it is a good idea,.... informing people about HIV.... so they know,.... where they may not have
 324 known..... People are more concerned about not being informed about their results.... especially if they have no
 325 referring doctor.... they have been told basically that if there is no policy issued, then they should follow it up.
 326 Lots of people don't think that's fair....,but we just say that the insurance company is paying for the test, and
 327 that is what we do.... but what if their own doctor hasn't seen them for say, 5 years,.... no doctor is going to give
 328 a result to someone that they have not even counselled....
 329 Q: Are you more concerned about the few clients who's results will come back positive?
 330 A:.... Mmmm.... a lot of patients don't really understand,.... what is happening,..... like the black patients,.... if
 331 they don't get the policy, then they just think, 'well I'm HIV positive!'.
 332 (Silence)
 333 Q: Anything else that comes to mind?
 334 A:.... Not really,.... that's just mainly a concern of mine..... that just keeps coming up.... that the clients want to
 335 get the results themselves..... especially if they don't have a doctor..... then they are not going to get a definite
 336 answer. (Addressing me).... Have you spoke to any of the nominated G.P.'s?..... You know when the person is
 337 HIV positive and the doctor has to give them the result..... even if he hasn't seen the patient for 5 years..... Have
 338 you followed any of that up?
 339 (I shake my head)..... because some of the sister's are very insistent about nominating a doctor,.... but to me, it's
 340 a choice..... it's optional.... I ask 'would you like your G.P. informed?'..... but we are not forcing them.... I
 341 would just like to know how those doctors feel. It's fine if the doctor has taken the blood and has counselled
 342 them..
 343 you know they have the 'splab' at the back of the form.... but they never read it.... they just sign it....
 344 ...They (the client) also often ask what the positive rate is.... and they want to know about the window period....
 345 what it is..... and I need to find out about that..... you know your read
 346 '6 months', but you also hear about a person who was raped and 6 months or a year later getting it....
 347 When I had a scare,.... when I pricked myself,.... I was told that a couple of months is fine..... so,.... I just tell
 348 them what I know..... I've also been told that the rate is 10%... but that was years ago....
 349 Q: Are you saying that you don't feel adequately informed?
 350 A: Ja,.... definitely.... what I know is what I've read or found out myself....
 351 Q: Do you think this test is different....?
 352 A: Ja,....no.... definitely. I mean if you've got a positive result.... you're going to die.....
 353 Q: Do you think that it should be handled differently?

354 A: I don't know if it's the sister or the doctor requesting the test..... the doctors should inform their
355 patients...mmm... for insurance,.... you are offering them consent and information at the back of the form,.... but
356 they aren't reading it. You are giving them the choice,.... but they are always in such a hurry.... maybe 1% read
357 it..... but you also just kind of expect people to know more.... from my point of view..... I'm giving them the
358 option and informing them of the counselling at the back (of the form) there often isn't time to do more..... the
359 ball is in their court.

360 Q: Whose responsibility do you think it is to inform the client?

361 A: Mmm.... well it's not O.K. as it is..... people do misunderstand.... and the black patient,.... it's not even in
362 their own language..... and that's all were offering them.... but in the busy depots,.... there isn't time for proper
363 counselling.

364 Q: Do you think that the broker should do it?

365 A: I don't think they will do it.... they also have on their form, the written counselling.....

366 You know, even the gynaecologists don't prepare for this or any other test.... I had a lady burst into tears about
367 a Down's screen (a test done during pregnancy to identify if the baby will have Down's syndrome)..... and I
368 knew a patient who saw her HIV result on her doctor's desk, without her having had knowledge of him taking
369 the test, and she asked him what he would have done if the result had come back positive.

370

371

372 9. 20/8/1997 - Gatesville

373 Q: What are your thought and feelings, as a sister about this insurance HIV test?

374 A: Personally,.... I feel that it's something very good.... a lot of people are becoming exposed to pathology, and
375 looking after their health, in a way they didn't before....

376 Q: As a result of coming for this test?

377 A: Yes. But for me the downside is that there is not sufficient follow up on the part of the insurance companies....
378 for the patient that is positive.... if the policy is rejected.... then there is the general feeling that the person is
379 positive.... What was explained to us, is that we take down the doctors name.... but the industry are not
380 informing those doctors.... so people are just not being notified....

381 Q: How are you aware of this?

382 A: Well I'm involved with a broker as a friend.....but also clients come back to us,.... and ask... 'has the test
383 reached the laboratory, because they have heard nothing'....or not received the policy. That is the down
384 side.....mm ... and I feel really upset about that.... why go through the whole thing here, of asking for the doctor
385 and all that, ... if the doctor is not notified,.... and you feel like a liar,.... and you don't know at the end of the day
386 where to send them.....

387 and if it's a youngster, and they have other partners,.... then other people are also being infected.....and
388 that's the scary part.....

389 Q: If you could get more information, would you want it?

390 A: Yes!

391 Q: What kind?

392 A: If we as sisters could have some form of training to counsel these patients..... that we take the responsibility
393 on ourselves to counsel these patients....as you'd want to counsel them when you know..... we are kind of the
394 first to know.....and then we could guide them where to go and what to do.... because the pre-counselling is on
395 these forms,.... if they take the time to read it..... the form is adequate,.... if they read them.....

396 Q: Do they take the time to read the form?

397 A: I make them read it... and I question them on it.... so I make sure that they have read it..... Often they ask you
398 what is this for and then get scared when you tell them.... if they read the form,.... then they would be
399 prepared....

400 The broker is not always telling the patient what the test is for..... just that they must go for a test.....

401it's important that we, the sister's..... know.... well maybe 1 person who is told 'these are the patients that are
402 positive for this month, please contact and notify them' There are always those patients that sit around biting
403 their nails as they wait for the test result....

404I just feel that maybe the company (of pathologists) should get organised with this one person to go and
405 inform the client,.... and give them counselling.

406 Q: Do you think that proper preparation makes a difference?

407 A: Preparation,.... proper pre-counselling does make a difference to the result..... you have some one who is
408 educated and then others who are not so sure and then bite their nails the whole time they are waiting..... I hope
409 that they would be less nervous....but it's also important the kind of lifestyle you've had.... if you feel at risk,....
410 it doesn't matter what anyone says,.... you are going to panic....

411It was nice that somebody listened, who could maybe make a difference.....(in response to the interview).

412

413 10. Mitchells Plain - 4/9/97

414 Q: I would like you to comment about your thoughts and feelings about insurance HIV testing...

415 A: ... I don't know why all of a sudden they are doing the HIV test....since it became a problem in the last few
416 years they have been asking people to have this test.... I think that the insurance industry don't want to pay... it's
417 not for the client.... and even if you are positive,there are policies, but then there are benefits that you don't
418 get. They are not concerned about the client.... but only about their own profits..... I understand that if you are a
419 diabetic.... they also don't take you.... before HIV you could just buy a policy without any testing....

420 Q: (A comment) There has always been loading if a person is considered a high risk.... people have always
421 been tested and excluded if they are a high risk,... such as being diabetic or a history of cardiac problems....

422 A: Oh....

423 Q: Do you think of HIV as the same as these tests...?

424 A: Yes,same.

425 Q:Do you think it's fair... or unfair..?

426 A: It's unfair,... because they (the insurance companies) just don't want to lose the profit. Even if she is
427 diabetic,... she could live for 18 years, in which time she pays for the policy..... . If a person becomes HIV
428 positive later, they forfeit the profit..... and that also seems unfair....

429 Q: Are the clients coming for HIV testing different from the other clients...?

430 A: They are just like any other.... I don't feel any different about them..... some of them are worried,... and then
431 I console them,... but it's just my job to take blood and so I do it.

432 Q: Do you think we should be preparing these clients in a different way,... or do you think this way is O.K.?

433 A: What we're doing now is O.K. I don't think there is any difference if you prepare them or not.... when the
434 result comes,... they still feel uncomfortable... the shock would be just the same. It just depends on that
435 individual how they are going to handle it....

436 Q: What could change how they handle it?

437 A: It depends on your personality how you handle it.... you could get drunk, frustrated, aggressive and 'don't
438 care' and take it out on others, or you could think, 'well it's fine,... I'll handle it'....

439 Q: Do you think support would make a difference....?

440 A: Even if there is support, it still depends on the personality.

441 Q: Are you saying that preparation would make no difference, and that it is only the personality that will effect
442 how they cope?

443 A: Yes.

444 Q: Any other thoughts or comments?

445 A: No.

446

447 11. Gatesville - 4/9/97

448 Q: Thoughts and feelings about HIV testing...

449 A: Most of the patients coming for HIV.... if they had a choice, they would not come... Some of them are
450 perturbed about the result.... others are not too perturbed about the result,... but they're worried about the
451 needle....

452 Q: How have you drawn this conclusion?

453 A: They say.... they want to know how soon they will get the result,... they are anxious for it...., they have not
454 gone to their G.P. for it (an HIV test),.... but now they sort of have to be realistic about it.... it's like they have
455 been forced to have it done....

456 Q: So you gauge whether they chose to have this test from what they say?

457 A: ...They say,...=if they had not been forced, they would not have had it done.... that they would not have had
458 the guts to go to their G.P.,.... that they wouldn't want to know the results....

459 Q: Are you saying you think this testing is a good thing or a bad thing?

460 A: Good,... they,... definitely.... even though HIV must have been around since..... even if there was no name for
461 it,... people must have died of AIDS before they even knew what it was....

462 Some patients actually admit that it's quite scary,... especially the older ones.... there wasn't such a thing as
463 AIDS to them,..... and with this long incubation period...

464 Q: That it has been a worry at the back of their minds? (She nods)..... you say it's good to have this testing,....
465 why is that?

466 A: Well, they know their own life styles, but they don't have the guts to go to their G.P....now they are forced
467 to,... and they then will know the result.... People don't know enough about it. One woman came in for a test.
468 anxious because her boyfriend had a sore in his mouth, and she had used his tooth brush,... and now she is
469 worried...

470 Q: Do you think that the way the testing is being done is O.K.?

471 A: Yes.... the confidentiality is good,... the broker never even knows....

472 Q: And the preparation of the patient.....?

473 A: Most are not prepared.... they are just told they have to come. They are not told why,... and what the reason

474 is in the policy....

475 Q: Are you saying it's O.K.?

476 A: It's not O.K. the client needs to know exactly why it has to be done...

477 Q: Who do you think should do that?

478 A: The broker,... I think,... or... some-one..... before the client comes to the depot....

479 Q: But you're not sure who?

480 A: No..... I suppose some-one from the insurance company.....

481 Q: Do you think that would make a difference?

482 A: Yes,... they would not be as anxious when they come in here,... besides being petrified of the needle....

483 Q: How do you feel when you are dealing with an anxious patient?

484 A: It depends on what they are anxious about... if it's about the result.... then I can do nothing... but I can put

485 them at ease about the procedure.... because we don't ask about life style,... or why they're anxious..... because

486 what we tell them won't affect the result anyway....

487 Q:... That it's not your responsibility to prepare or counsel the client?

488 A: We don't always have the time but I do feel that I could do it,.. if we had the time..... if we put the

489 emphasis on HIV..... but what we would counsel the patient about would be very superficial.... if they came via

490 their G.P. they would have a good reason,... but if it's for insurance, they might not have a good reason,... so

491 what ever we tell the client might not be enough.....

492 Q: That you could prepare the client up to a point and no more?

493 A: Yes.... the more information we have the better.... then we could put the client at ease....

494 Q: Is it something that needs to be looked at,... or is it O.K. as is?

495 A: No.... it needs to be looked at because we get quite a few anxious patients... who are not sure what they are

496 signing. I thin the insurance companies should look at it... because it's their requirement that the client have the

497 test.

498 Q: In an ideal situation,... how would you do it?

499 A: I would prefer that the client comes here absolutely prepared, knowing why the test was being done,... with

500 the information given by the insurance company sending them,... because they are requiring it.... we don't even

501 know what that policy entails,... when they come from the doctor,... we know why (they have come) and they are

502 also fully prepared by the doctor....

503 Q: Like the ante-natal women?

504 A: They are not prepared really.... they also often don't know that they are having this test....

505 Q: How could the insurance company let people know?

506 A: The brokers..... they could have some training.... or even if they just briefly tell the client... . We don't know if

507 it's positive,... what will happen with them,... how they are told or if the policy is loaded or what.... . We just

508 know that the G.P. gets involved.

509 Q: Would you like to see some change?

510 A: That would be a good idea... because some of them think they are going to get the result,... they don't know

511 the procedure even....

512 Q: Anything else you would like to add? (She shakes her head).

513

514 12. Jan S Marais -10/9/97

515 Q: What are your thoughts and feelings about insurance HIV testing?

516 A: I think it's goodit's one way to find out if you are HIV +ve. I don't think that someone would just walk in

517 and ask to be tested.... so in a way they are forced by this....

518 I don't think I would have the guts to say 'test me'.... so it's a good way to find out,... through insurance.....

519 I thin if you do have more than one partner you should go.... but I believe you should just stick to one...

520 Q: And that if you did have more than one, you should go for a test?

521 A: I think some people worry and some don't but I think if you have more than one partner it's because

522 you're not worried ... otherwise you would stick to one.

523 Q: Do you think our process of doing the testing is O.K.?

524 A: Yes...it's fine.... I don't have a problem with it....it's confidential... as long as it stay that way..... it's

525 important to know who should know the result and who should not....

526 Q: And the preparation of the client?

527 A: 'S' I think have a booklet which they are supposed to get,... but they don't get it....

528 Q: Is that a problem?

529 A: I won't say a problem....

530 Q: Mm... why not?

APPENDIX 7:

The questionnaire (in English, Afrikaans and Xhosa):

Please note:

The research was commenced during a period of registration at the University of Cape Town in 1997, and in 1998, was transferred to and later completed at the University of Natal, Pietermaritzburg.

03 / 6 / 1997.

Dear Sister;

I am a Psychology Masters student at U.C.T. and I am conducting independent research into Life Assurance HIV testing. I have obtained permission to proceed with this research from the Life Officers Association (L.O.A.), the controlling body for the Insurance Industry and from your own Pathology company.

You have been sent 15-20 questionnaires with envelopes marked confidential. You have also received 10 covering letters to give to the broker if they have accompanied their client for this test. I am requesting that you please give each person having an Insurance HIV test one of the questionnaires to complete, immediately after they have had blood drawn. They are to please complete the questionnaire at your rooms, and then leave the completed questionnaire with you in the sealed, confidential envelope provided. The questionnaire does not take long to complete, taking between 5 and 15 minutes.

The covering letter to the broker is to request that they allow their client to fill in the form. A pilot study conducted showed that the Sisters felt awkward asking the client to complete the form in front of the broker, so I trust that the letter will make this easier for you to do.

The research will proceed over a one month period only, with the final overall result and recommendations being offered to the L.O.A. Most of the rooms have between 5-10 insurance tests per week, and I have therefore estimated that completing the 15-20 questionnaires should not be too much of an intrusion on your often very busy schedule.

Once the questionnaires are all completed, please place them in the large brown envelope provided and forward this to your head office in town, where I will retrieve them.

Please do not alter the way you interact with your client / patient in any other respect. This is not an analysis of your client management. If you have any questions, I will be glad to respond (Tel: 448-7946).

As a locum pathology Sister, I would really appreciate your co-operation, and thank you for taking the time to assist in this necessary research.

Yours,

Michelle Shapiro

(Research Psychology Masters Student - U.C.T)



Department of Psychology

University of Cape Town · Rondebosch 7700 · South Africa

Telephone: (021) 650-9111

Fax No (021) 689-7572

15/06/1997

Dear Intermediary;

I am a Psychology Masters student at U.C.T. and I am conducting independent research into Life Assurance HIV testing. I have obtained consent to proceed with this research from the Life Officers Association (L.O.A.) and from the Pathology companies concerned.

Your client will be asked to fill in a questionnaire directly after they have had blood drawn for the mandatory life assurance HIV testing. The questionnaire is comprehensive yet fairly quick to complete, and should take your client between 5 and 15 minutes. The information is personal and private, and will be treated confidentially.

The research will proceed over a one month period only, with the final overall result and recommendations being offered to the L.O.A. Your co-operation in this matter would therefore be desired and appreciated. A pilot study conducted revealed that nursing staff felt awkward to dispense the questionnaire in the presence of the broker, and that clients felt rushed and unable to complete the questionnaire for the same reason. Your assurance to your client that they may have the time and the privacy to fill in the form would greatly assist the research, the ultimate aim of which is to improve the service to your client.

Please do not alter the way you interact with your client in any other respect. This is not an analysis of your client management. If you have any questions, I will be glad to respond.

Thank-you for taking this time to allow your client to participate,

Yours,

Michelle Shapiro

(Research Psychology Masters Student - U.C.T)

Tel: 448-7946



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HUMAN IMMUNE-DEFICIENCY VIRUS (HIV) TESTING QUESTIONNAIRE

HIV and AIDS is a very real and increasing problem in South Africa. It is something which affects us all, either directly or indirectly.

This questionnaire is an independent study aimed at finding out your thoughts and feelings about having an HIV test. All responses are anonymous and therefore also strictly confidential. Permission has been granted by all professional groups involved, and the overall results will be presented to these interested and concerned groups. The aim of the research is to ensure ongoing improvement of the service around this sensitive issue. Your honest contribution would therefore greatly assist in achieving this goal.

Thank-you for taking this time to participate,

Yours,

Michelle Shapiro

(Research Psychology Masters Student - U.C.T)

HIV TESTING QUESTIONNAIRE:*(Please tick all appropriate boxes)*

1. Do you understand what test was done?: ☐ Yes ☐ No
2. Have you had this test before: ☐ Yes ☐ No
- If yes: ☐ Less than 6 months ago; ☐ 6 - 12 months ago;
☐ 12 - 24 months ago; ☐ more than 2 years ago.
3. What is your main reason for having the test now?:
- ☐ Life assurance ☐ Bond application
- ☐ Employment related ☐ Personal reasons
- ☐ Other reasons (please indicate) _____
4. Did you sign consent for the test? ☐ Yes ☐ No
5. Prior to testing you may have received information about HIV and testing from one or more of the below:

INFORMATION FROM (tick to indicate 'yes' and show if you think the information you received was enough and was helpful to you):	N/A	enough	not enough	helpful	not helpful
Health Professionals (such as the Nursing Sister or your Doctor)					
The counselling form about HIV you may have been asked to read *					
* Was this form: <input type="checkbox"/> a single page <input type="checkbox"/> many pages					
Your Life Assurance Advisor					
Your Bank (Bond) Advisor					
Your Employer					
Family or friends					
No information received					
Other source (please specify)					

6.

GENERAL KNOWLEDGE ABOUT HIV (indicate the answer as true or false)	True	False
HIV infection is another name for AIDS...		
The 'window period' lasts from the time of infection with HIV until the signs and symptoms appear....		
A negative HIV result means the person is immune to HIV infection....		
A person can be infected with HIV, yet still feel completely well....		
If an adult has antibodies to HIV he/she must be assumed to be infected.....		
People who have HIV do not usually develop symptoms for 3 - 7 years after infection.....		
If a person has an HIV test whilst they are in the window period, their test result may be inaccurate.....		
It is possible to contract HIV from : hugging a person with HIV or AIDS		
: using public toilets		
: sharing eating utensils		
: contact with saliva or sweat from a person with HIV or AIDS		

7. Do you feel adequately informed about HIV and AIDS? ☐ Yes ☐ No
8. Would you have liked the opportunity to talk more to some one about the test:
 a) *Before* it was done? ☐ Yes ☐ No b) *After* it was done ? ☐ Yes ☐ No
9. Would you have chosen to have this test done ? : ☐ Yes ☐ No:
10. Whether or not you would have chosen to have this test done, do you think that having the test done was a good thing for you to do? ☐ Yes ☐ No
11. Were you nervous when having the test done ? : ☐ Yes ☐ No
 a) Were you nervous about 'the needle prick' ? ☐ Yes ☐ No
 b) Were you nervous about the possible result ? ☐ Yes ☐ No
 c) Did the information you received make you less nervous? ☐ Yes ☐ No
12. Did you experience one or more of the following before or at the time of testing (please tick boxes):

I did not feel any different	<input type="checkbox"/>	thinking about the test frequently	<input type="checkbox"/>	calmness	<input type="checkbox"/>
not thinking about the test much	<input type="checkbox"/>	feeling relaxed	<input type="checkbox"/>	thinking about past actions a lot	<input type="checkbox"/>
sweating palms	<input type="checkbox"/>	interested or curious about the test	<input type="checkbox"/>	restlessness	<input type="checkbox"/>
'butterflies' in your stomach	<input type="checkbox"/>	anxiety about the test	<input type="checkbox"/>	more headaches than usual	<input type="checkbox"/>
an uneasy feeling	<input type="checkbox"/>	feeling tense or 'wound up'	<input type="checkbox"/>	happy and unconcerned	<input type="checkbox"/>
feeling lightheaded or dizzy	<input type="checkbox"/>	feeling contented	<input type="checkbox"/>	sense of well being	<input type="checkbox"/>

13. a. Have you had a chance to think about what the result might be? ☐ Yes ☐ No
 b. Have you thought about what this might mean for you? ☐ Yes ☐ No
 c. How do you imagine this result could affect your life if it was negative (no virus)? _____

d. How do you imagine this could affect your life if the result was positive (the virus was present)? _____

14. Who have you chosen to give you this result and why ? _____

15. What, if anything, could have made this testing experience easier for you? _____

P.T.O.

CONFIDENTIAL and ANONYMOUS PERSONAL DETAILS:

1. Sex : ☐ Male ☐ Female Age: _____ Date of blood test: ____/____/1997
Home language: ☐ English ☐ Afrikaans ☐ Xhosa ☐ Other: _____
Religion: _____ Area in which you live: _____

2. What is your educational qualification?:

☐ Std. 2 or less ☐ Std. 3 - 5 ☐ Std. 6 - 8 ☐ Std. 9 - 10 ☐ Diploma / Degree
☐ Other (please specify): _____

3. Are you currently employed?: ☐ yes ☐ no

What is your occupation? _____

Is your monthly income: ☐ Less than R500 ☐ R500 - R1000 ☐ R1000-R2000
☐ R2000-R3000 ☐ R3000- R4000 ☐ More than R4000

4. Are you: ☐ Single ☐ In a relationship ☐ Living with a partner ☐ Married
☐ Divorced ☐ Widowed ☐ Other: _____

If you are in a relationship, how long have you been together? : _____ months _____ years.

If you have had more than one sexual partner in the last 5 years, approximately how many? _____

5. Do you have children: ☐ yes ☐ no

If 'yes', how many? _____ What are their ages?: _____

6. From whom do you generally receive practical / material support?:

☐ Family: Is it: ☐ good ☐ fair ☐ poor;
☐ Partner: Is it: ☐ good ☐ fair ☐ poor;
☐ Friends: Is it: ☐ good ☐ fair ☐ poor;
☐ Any other source (please specify): _____

7. From whom do you generally receive emotional support?:

☐ Family: Is it: ☐ good ☐ fair ☐ poor;
☐ Partner: Is it: ☐ good ☐ fair ☐ poor;
☐ Friends: Is it: ☐ good ☐ fair ☐ poor;
☐ Any other source (please specify): _____

8. Would you describe yourself as: ☐ a 'worrier' ☐ usually a calm person ☐ bothered by headaches
☐ seeing 'the funny side of things' easily ☐ concerned about what other people think of you
☐ sometimes having tingling or numbness in parts of your body ☐ feel afraid often

9. Any other information which you think relates to how you experienced this test? _____

Thank you for participating in this research. As indicated above, the final results will be made available to the groups that have expressed interest and concern. The intention of the research is to improve the service around this sensitive issue. As mentioned before, all responses are confidential and anonymous.



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MENSLIKE IMMUNGEBREK VIRUS (MIV of HIV) TOETSING VRAELYS

MIV (of HIV) en VIGS is 'n egte en toenemende probleem in Suid-Afrika. Dit het 'n direkte of indirekte invloed op ons almal.

Hierdie vraelys is 'n onafhanklike studie gemik daarop om u gevoelens en gedagtes rondom die toets wat u ondergaan te bestudeer. Alle vraelyste is anoniem en is dus streng konfidensieel. Toestemming vir hierdie navorsing is van alle proffesionele groepe ontvang, en die resultate sal aan die toepaslike groepe voorgele word. Die doel van die navorsing is om die diens rondom hierdie sensitiewe saak te verbeter. U eerlike deelname sal grootliks van hulp wees om hierdie doel te bereik.

Baie dankie vir u tyd,

Michelle Shapiro

(Navorsings-Meestergraad Student)

HIV TOETS NAVORSING:

(Merk asseblief die nodige spasies)

1. Verstaan u watter toets gedoen is?: ☐ Ja ☐ Nee
2. Het u al vantevore so n toets ondergaan? : ☐ Ja ☐ Nee
- Indien 'ja': ☐ Minder as 6 maande gelede ☐ 6 - 12 maande gelede
☐ 12 - 24 maande gelede ☐ meer as 2 jaar gelede
3. Hoekom laat u nou die toets doen?:
☐ Lewensversekering ☐ Verbandaanzoek ☐ Werksindiensneming
☐ Persoonlike redes ☐ Ander redes (verskaf asseblief) _____
4. Het u toestemming geteken vir die toets? ☐ Ja ☐ Nee
5. Voor die toets afgele is, het u miskien inligting oor HIV en die toets self van een van die volgende ontvang:

INLIGTING VERKRY VAN (merk of u dink die inligting voldoende en van hulp was):	voldoende	nie-vol-doende	hulpsaam	nie-hulp-saam
Gesondheidspersoneel (soos verpleegkundiges of u dokter)				
Die inligtingsvorm oor HIV wat u indien gevra was om te lees *				
* Het die vorm bestaan uit: <input type="checkbox"/> een bladsy <input type="checkbox"/> meer as een bladsy				
U Lewensversekerings makelaar				
U Bank (bond)-adviseur				
U werkgever				
Familie of vriende				
U het geen inligting ontvang nie				
Ander bronne (verskaf asseblief)				

6.

ALGEMENE KENNIS OOR HIV (merk antwoord as waar of onwaar)	Waar	Onwaar
HIV infeksie is n ander naam vir VIGS....		
Die 'vensterperiode' begin by infeksie met HIV en deur tot die tekens en simptome begin		
n Negatiewe HIV resultaat beteken dat die persoon immun is teen HIV infeksie....		
n HIV-positiewe persoon kan nog heeltemaal gesond voel....		
As n volwassene teenliggame teen HIV ontwikkel, kon jy aanneem dat die persoon die infeksie het....		
Mense met HIV ontwikkel gewoonlik eers simptome na 3 - 7 jaar na die infeksie....		
As n persoon n HIV toets laat deel in die vensterperiode, kan die resultaat onakkuraat wees....		
Dit is moontlik om HIV te kry van : n persoon met VIGS of wie HIV-positief is, te omhels		
: publieke toilette te gebruik		
: eetgerei met iemand te deel		
: kontak te he met sweet of speeksel van n persoon met HIV of VIGS		

7. Voel u voldoende ingelig oor HIV of VIGS ☐ ja ☐ nee

8. Sou u graag 'n geleentheid wou he om met iemand te kan gesels oor die toets?:

a) *Voordat* die toets gedoen word? ☐ ja ☐ nee b) *Nadat* die toets gedoen is? ☐ ja ☐ nee

9. Sou u gekies het om die toets te laat doen?: ☐ ja ☐ nee:

10. Al het u wel of nie hierdie toets gekies nie, dink u dat dit 'n goeie ding is dat u wel die toets ondergaan het?

☐ ja ☐ nee

11. Was u senuweeagtig oor die toets?: ☐ ja ☐ nee

a) Was u senuweeagtig oor 'die naaldprik'? ☐ ja ☐ nee

b) Was u senuweeagtig oor die moontlike resultaat? ☐ ja ☐ nee

c) Het die inligting wat u ontvang het, u minder senuweeagtig gemaak? ☐ ja ☐ nee

12. Het u enige van die onderstaande 'n paar dae voor of tydens die toets ervaar (merk asb. die spasies):

ek het nie anders gevoel nie	gereeld oor die toets gedink	kalm
vergeet van die komende toets	ontspanne	gereeld oor u verlede gedink
sweterige hande	ongeïnteresseerd en nuuskierig	rusteloos
kriewelrige gevoel in die maag	angstig oor die toets	meer hooftpyne as gewoonlik
'n ongemaklike gevoel	gespanne	gelukkig en onbetref
duiseligheid of lighoofdigheid	tevrede	welstand

13 a. Het u al kans gehad om te dink wat die resultaat kan wees? ☐ ja ☐ nee

b. Besef u wat dit vir u sal beteken? ☐ ja ☐ nee

c. Hoe verbeel u sal dit u lewe beïnvloed as die resultaat negatief is (geen virus)? _____

d. Hoe verbeel u sal dit u lewe beïnvloed as die resultaat positief is (die virus is teenwoordig)? _____

14. Wie sou u verkies, as u kon, om u resultaat aan u te verskaf, en hoekom?

15. Het u enige voorstelle hoe ons hierdie toetsverriging vir u makliker kon maak? _____

P.T.O.

Konfidensiele en Anonieme Persoonlike Inligting:

1. Geslag : ☐ Manlik ☐ Vroulik Ouderdom: _____ Datum van bloettoets: ____/____/1997

Huistaal: ☐ Engels ☐ Afrikaans ☐ Xhosa ☐ Ander: _____

Geloof: _____ Area in waarin u woon: _____

2. Wat is u skoolopleiding ?:

☐ St. 2 of minder ☐ St. 3 - 5 ☐ St. 6 - 8 ☐ St. 9 - 10 ☐ Diploma / Graad

☐ Ander (spesifiseer asseblief): _____

3. Werk u op die oomblik?: ☐ ja ☐ nee

Wat is u beroep? _____

Wat is u maandelikse inkomste: ☐ Minder as R500 ☐ R500 - R1000 ☐ R1000-R2000
☐ R2000-R3000 ☐ R3000- R4000 ☐ Meer as R4000

4. Is u: ☐ Ongetroud ☐ In a verhouding ☐ In n saamwoon-verhouding ☐ Getroud
☐ Geskei ☐ Wewenaar / weduwee ☐ Ander: _____

Indien u tans n verhouding het, hoe lank is u al saam? : _____maande _____jare.

Indien meer as een, hoeveel seksuele maats het u die afgelope 5 jaar gehad? _____

5. Het u kinders: ☐ ja ☐ nee

Indien 'ja', hoeveel? _____ Hoe oud is hulle?: _____

6. Van wie kry u gewoonlik praktiese / materiele ondersteuning?:

☐ Familie: Is dit: ☐ goed ☐ gemiddeld ☐ swak;

☐ Maat: Is dit: ☐ goed ☐ gemiddeld ☐ swak;

☐ Vriende: Is dit: ☐ goed ☐ gemiddeld ☐ swak;

☐ Enige ander bron (spesifiseer asseblief): _____

7. Van wie kry u gewoonlik emosionele ondersteuning?:

☐ Familie: Is dit: ☐ goed ☐ gemiddeld ☐ swak;

☐ Maat: Is dit: ☐ goed ☐ gemiddeld ☐ swak;

☐ Vriende: Is dit: ☐ goed ☐ gemiddeld ☐ swak;

☐ Enige ander bron (spesifiseer asseblief): _____

8. Sal u uself beskryf as: ☐ altyd bekommerd ☐ gewoonlik n rustige persoon ☐ voel gereeld bang

☐ n opgeruimde, optimistiese persoon ☐ bekommerd oor wat ander mense van u dink

☐ het soms lamheid of n prikkelende gevoel in dele van u liggaam ☐ kry gereeld baie hoofpyne

9. Is daar enige ander inligting wat verband hou met hoe u die toets ervaar het? _____

Dankie vir u deelname in hierdie navorsing. Soos genoem, sal die finale resultate beskikbaar gestel word vir belangstellende en geïnteresseerde groepe. Die doel van hierdie navorsing is om die diens rondom hierdie sensitiewe saak te verbeter. Soos reeds genoem, is alle inligting privaat en konfidensieel.



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IMIBUZO NOVAVANYO NGENTSHOLONGWANE U GAWULAYO (i HIV)

I-Human Immune-deficiency (HIV) ne AIDS zikhona, kwaye yingxaki eyandayo apha e Mzantsi Afrika. Iyasichaphazela xa sisonke.

Zonke iimpendulo ziyakugcinwa ngokufihlakeleyo. Sifuna ukuva iingcinga neembono zakho ngovavanyo lwe HIV. Iimvume zonke zifumanekile kumahlelo ngamahlelo ezifundiswa ezichaphazelekayo. Iziphumo zento yonke ziyakunikwa abanomdla. Injongo yoluphando kukuqinisekisa inkqubela kulomsebenzi.

Igalelo lakho liyakusanceda ekuphuhliseni ezinjongo.

Enkosi ngokuthatha inxaxheba,

Oweni ozithobileyo

Michelle Shapiro

(umfundi owenza iMasters kuphando ngezengqondo -U.C.T.)

IMIBUZO-VAVANYO NGENTSHOLONGWANE -HIV : (Nceda korekisha ibhokisi efanelekileyo)

1. Uyaluqonda ngokupheleleyo uvavanyo olusanda kwenziwa ngoku? ☐ ewe ☐ hayi
2. Wakhe walwenziwa ngaphambili: ☐ ewe ☐ hayi
ewe: ☐ Less than 6 months ago; ☐ 6 - 12 months ago;
☐ 12 - 24 months ago; ☐ more than 2 years ago.
3. Yintoni oyena nobangela wokuba ube uyalwenza ngoku?:
☐ Life assurance ☐ Bond application
☐ Employment related ☐ Personal reasons
☐ Kwenye indawo (chaza) _____
4. Uye wavuma ukulenziwa olu vavanyo ngokuthi utyikitye isivumelwano? ☐ ewe ☐ hayi

5. Phambi kokuba lwenziwe uvavanyo usenokuba ubufumene ingcaciso malunga ne-HIV kwenye yezi ndawo zilandelayo:

UYIFUMENE PHI INGCACISO (korekisha apho wayifumana khona ingcaciso uze ubonise ukuba yayanele na kwaye iluncedo na kuwe):	ingcaciso enganelaga	eyaneleyo	eluncedo	engoluncedo
kubasebenzi bezempilo (nje ngonesi okanye ugqirha)				
kwifomu ocelwe ukuba uyifunde enengcaciso malunga ne HIV				
ingaba le fomu ibiliphepha: elinye <input type="checkbox"/> okanye amaninzi <input type="checkbox"/>				
kumcebisi wakho we-inshorensi				
kumcebisi wakho webhanki				
kumqeshi wakho				
kwifemeli okanye kubahlobo				
akukhange ufumane ingcaciso				
kwenye indawo engakhankanywanga apha (chaza)				

6.

ULWAZI NGOKUBANZI MALUNGA NE-HIV (indicate the answer as true or false)	yinyaniso	asiyonyaniso
I-HIV lelinye igama le-AIDS...		
Ithuba lokufukama (window period) liqhuba ukususela kumhla wosuleleka yiHIV ukuya kuma ngethuba kuvela iimpawu		
Xa kusithiwa umntu u 'HIV negative' kuthethwa ukuba lo mntu akanakusulelewa yiHIV		
Umntu usenokusulelwa yiHIV kodwa azive ephile qete		
Ukuba umntu omdala unezilwa-buhlungu (antibodies) zeHIV kufuneka athathwe ukuba wosulelwe yiHIV		
Abantu abaneHIV badla ngokungabonisi zimpawu de kube yiminyaka emi-3 ukuya kwesi-7 besulelekile		
Ukuba umntu wenziwe uvavanyo iwe-HIV ngethuba lokufukama, iziphumo zakhe zisenokungachaneki		
Unako ukosulelwa yiHIV ngezi ndlela zilandelayo : ngokuwola umntu		
: Ngokusebenzisa ithoyilethi kawonke-wonke		
: Ngokusebenzisa izinto zokutyela ezinye		
: Ngokudibana namathe okanye umbilo womntu oneHIV okanye oneAIDS		

7. Ingaba ufumanisa ngathi ubufumene ingcaciso eyaneleyo ? ☐ ewe ☐ hayi
8. Ungathanda ukufumana ithuba lokuthetha ngokungaphezulu nomnye umntu malunga novavanyo
a) *Phambi* kokuba lwenziwe? ☐ ewe ☐ hayi b) *Emva* kokuba lwenziwe? ☐ ewe ☐ hayi
9. Ubunokukhetha ukuba lwenziwe?: ☐ ewe ☐ hayi
10. Nokuba ukhethe ukuba lwenziwe uvavanyo okanye hayi, ucinga ukuba ibiyinto elungileyo ukuba wenziwe uvavanyo? ☐ ewe ☐ hayi
11. Ubuxhalabile ngoku ubusenziwa uvavanyo?: ☐ ewe ☐ hayi
a) Ingaba ubunexhala lenaliti ? ☐ ewe ☐ hayi
b) Ingaba ubunexhala leziphumo ? ☐ ewe ☐ hayi
c) Ingaba inkcazelo obuyifumene iye yalithoba ixhala lakho? ☐ ewe ☐ hayi
12. Ingaba ukhe wafumana enye yezi zinto zilandelayo malunga neentsuku ezimbalwa phambi kokuba uvavanywe okanye ngethuba lovavanyo (korekisha kwiibhokisi ezifanelekileyo):

ukuxuxuzela kwesisu	ukucinga ngovavanyo ngalo lonke ixesha	ukuzola
ukulibala malunga novavanyo oluzayo	waziva uzolile	ukusoloko ucinga ngezinto ozenzileyo kwixesha elidlulileyo
ukubila izandla	ukungaqiniseki ngesiqu sakho	ukungonwabi
ukuva intliziyo yakho ibetha	ixhala malunga novavanyo	ukusoloko unentloko ebuhlungu
ukungonwabi	ukuziva uxhalabile	ukungcangcazela
ukuziva unesiyezi	ukuxola	ukungevezela amadolo

- 13 a. Ukhe wafumana ithuba lokucinga ukuba ziza kuthini iziphumo? ☐ ewe ☐ hayi
b. Ukhe wacinga oko kuza kuthetha ntoni kuwe? ☐ ewe ☐ hayi
c. Ucinga ukuba zibuye zisithi akosulelekanga oko kuza kubuchaphazela njani ubomi bakho? _____

d. Ucinga ukuba zibuye zisithi unayo le ntsholongwane oko kuza buchaphazela njani ubomi bakho ? _____

14. Ubunokhetha bani ukuba bakunike ezi ziphumo, kutheni ukhetha bona ? _____

15. Yintoni ocinga ukuba ibinokuyenza lula inkqubo yovavanyo? _____

INKCAZO EYIMFIHLO MALUNGA NOMNTU ONGAZUKWAZISWA:

- Isini : ☐ Indoda ☐ Umfazi Umhla wokutsalwa kwegazi: ____ / ____ / 1997
 Ulwimi Iwasekhaya: ☐ IsiNgesi ☐ IsiBhulu ☐ isiXhosa ☐
 Olunye: _____
 Inkolo ngokwenkonzo: _____ Indawo ohlala kuyo: _____
- Uyeke kweliphi ibanga kwezemfundo?:
☐ Std. 2 nangaphantsi ☐ Std. 3 - 5 ☐ Std. 6 - 8 ☐ Std. 9 - 10 ☐ Diploma /
 Isidanga ☐ Enye (chaza): _____
- Ingaba uqeshiwe ngoku? : ☐ ewe ☐ hayi
 Yintoni umsebenzi wakho? _____
- Imali oyamkela ngenyanga: ☐ Ingaphantsi kwe R500 ☐ R500 - R1000 ☐ R1000-R2000
☐ R2000-R3000 ☐ R3000- R4000 ☐ ngaphezu kwe R4000
- Malunga nomtshato: ☐ akutshatanga ☐ Uyahambisana ☐ uhlala nesithandwa sakho
☐ utshatile ☐ waqhawuka umtshato ☐ ungumhlolo/kazi ☐ enya
 (chaza): _____
 Ukuba uyahambisana, lixesha elingakanani nikunye? : _____ iinyanga _____ iminyaka
 Ukuba ubunczithandwa ezininzi kuleminyaka mihlanu idlulileyo, inokuba bezingaphi? _____
- Ingaba unabo abantwana?: ☐ ewe ☐ hayi
 Ukuba ngu-ewe, bangaphi? _____ Ithini iminyaka yabo? _____
- Ngubani okunika inkxaso?:
☐ kwifemeli: ingaba ☐ ifanelekile ☐ ingcono ☐ incinane;
☐ Kwisithandwa sakho: ingaba ☐ ifanelekile ☐ ingcono ☐ incinane;
☐ Kubahlobo: ingaba ☐ ifanelekile ☐ ingcono ☐ incinane;
☐ kwenye indawo (chaza): _____
- Uyifumana kubani inkxaso ngokwasemphefumleni?:
☐ kwifemeli: ingaba ☐ ifanelekile ☐ ingcono ☐ incinane;
☐ Kwisithandwa sakho: ingaba ☐ ifanelekile ☐ ingcono ☐ incinane;
☐ Kubahlobo: ingaba ☐ ifanelekile ☐ ingcono ☐ incinane;
☐ Kwenye indawo (chaza): _____
- Ungazichaza: ☐ njengomntu okhathazekileyo ngalo lonke ixesha ☐ osoloko ezolile
☐ osoloko ebona okungalunganga kwizinto ☐ okhathalayo ukuba abanye abantu bacinga ntoni ngawe
☐ ngamanye amaxesha uzive ingasebenzi imithambo kwindawo ezithile zomzimba
☐ osoloko enentloko ebuhlungu ☐ osoloko esoyika
- Ingaba ikhona enye ingcaciso/inkcazelo ofuna ukuyinika malunga nolu vavanyo? _____

APPENDIX 8:

The counselling document in use at the time of the research:

A. APPLICANT (Life to be assured)

Surname : _____ Date of birth : YY _____ MM _____ DD _____
First Names : _____ Sex : _____
Address : _____ Tel : (W) _____ (H) : _____

INSURANCE COMPANY DATA

Name of Company : _____ Broker : _____
* Policy No(s) / Pre-employment Ref(s) : _____ Broker's Code : _____
Branch : _____ Tel No : _____

IDENTIFICATION OF CLIENT FOR HIV &/OR OTHER PATHOLOGICAL TESTS (MUST ALWAYS BE FILLED IN)

* IDENTITY NUMBER :
* PASSPORT NUMBER : _____ Country : _____
OTHER FORMS OF ID ACCEPTED BY INSURANCE COMPANY : _____
CONFIRMED WITH : _____ DATE : _____

B. IDENTIFICATION OF PERSON TAKING SAMPLE (HIV &/OR OTHER) (MUST ALWAYS BE FILLED IN)

Name of person collecting blood or urine sample : _____ Practice No. : _____
Address : _____ Sister's Code : _____

DECLARATION BY PERSON TAKING SAMPLE (MUST ALWAYS BE FILLED IN)

VINCENT PALOTTI
6680

ONLY APPLICABLE IF AN HIV ANTIBODY TEST IS REQUIRED

I have satisfied myself that the person being tested has received the Informed Consent Document, and I have verified the identity of the applicant and that he/she has freely consented to have the sample drawn and tested for HIV antibodies. In compliance with the provisions of the LOA HIV Testing Protocol, I have inspected the following document to verify the identity of the applicant. ☐ Identity document ☐ Passport

ALWAYS APPLICABLE

I DECLARE THAT I HAVE VERIFIED THE IDENTITY OF THE PERSON FROM WHOM I HAVE TAKEN A BLOOD AND/OR URINE SAMPLE BY CHECKING THE ABOVE-MENTIONED DOCUMENT.

* Signature of person taking the sample : _____ Date : _____ Time : _____

C. LABORATORY EXAMINATIONS REQUIRED (Tick appropriate block)

G 345	HIV (Complete Consent)	M 006	Glucose (Fasting)	H 210	Full Blood Count
G 444	COTININE (Serum)	M 008	Glucose (Random)	H 209	ESR
2.G 319	HIV & COTININE (Serum)	G 062	ALT	H 404	MCV
P 182	Lipogram (✓) Fasting <input type="checkbox"/> Random <input type="checkbox"/>	G 063	AST	G 322	TPHA
P 011	Total Cholesterol (✓) Fasting <input type="checkbox"/> Random <input type="checkbox"/>	G 065	γ-GT	401	Micro Albuminuria
P 012	HDL Cholesterol (✓) Fasting <input type="checkbox"/> Random <input type="checkbox"/>	G 061	Alkaline Phosphatase		(Screen) (Urine)
P 013	Triglycerides (✓) Fasting <input type="checkbox"/> Random <input type="checkbox"/>	G 899	(T) Bilirubin only	400	M&C Urine
004+056	2 Hrs Mod, GTT, (+3 Urine spec)	G 036	Serum Urea	Other	
H 005	HbA1c	G 037	Serum Creatinine		

D. INFORMED CONSENT TO HIV &/OR OTHER PATHOLOGICAL TESTS

- I understand the information contained in this Consent Document.
- I freely consent to the withdrawal of blood from me.
- I freely consent to the testing of that blood.
- I understand that the results of my test will be kept confidential, except for the disclosure of any reactive result to the doctor whom I have named below.
- I have read the information on this form about what a test result means.
- I understand that I should contact my nominated doctor for further information and counselling if required.
- I understand that the insurance Company will pay for one session of post-test counselling with a doctor of my choice, if I desire it, and if the test result is positive.
- I understand that I have the right to request and receive a copy of this form.
- I understand that details of a positive test result will be held confidentially by the LOA on its register.

VINCENT PALOTTI
6680

*Name of nominated doctor : _____ Date : _____
Address : _____ Telephone : _____

* Signature of person to be tested : _____

INFORMED CONSENT AND IDENTIFICATION TO HIV ANTIBODY TESTING. (MUST BE FILLED IN ONLY IF APPLICANT IS UNDERAGE)

IDENTITY NUMBER : (PARENT/ GUARDIAN'S ID ON BEHALF OF MINOR)

CONSENT : _____ (PARENT/ GUARDIAN ON BEHALF OF MINOR)

I DECLARE THAT I HAVE READ AND UNDERSTOOD BOTH PAGES OF THIS FORM AND CONSENT TO HIV TESTING.

THE LIFE OFFICES ASSOCIATION OF SOUTH AFRICA (LOA) INFORMED CONSENT DOCUMENT

**YOU MUST READ THIS BEFORE THE TEST IS DONE .IF YOU HAVE ANY PROBLEMS UNDERSTANDING
THIS ASK THE NURSE OR LABORATORY ASSISTANT OR YOUR DOCTOR TO EXPLAIN IT TO YOU.**

NOTE TO THE PERSON PERFORMING THE TEST

Some applicants may not be able to read the document below, as a result of blindness, illiteracy or any other reason. There is an obligation on you to ensure that under these circumstances, the applicant has received the document, and consents to the test.

INTRODUCTION

This document contains the information that you have a right to be given before agreeing to be tested for HIV antibodies. The HIV antibody test (sometimes called an "AIDS test") is a test that will tell you whether or not you have been infected with HIV, "the AIDS virus". Below we set out your rights with respect to this test, information about HIV and AIDS and the AIDS test, and why the insurance company wants to test you for HIV antibodies before it decides whether or not to give you a life insurance policy.

WHAT ARE MY RIGHTS ?

Your rights are:

1. **Not to be tested** for the AIDS virus without your free and informed consent.
2. **To be given all material information on the harms, risks and benefits of taking, or not taking, the AIDS test.**
3. **To refuse to take the test.** If you do this, your application for insurance will be denied.
4. **To receive pre-test counselling** upon request which is private and confidential, and which will inform you more about the test and its implications before you consent to the test. Should you in any way be unfamiliar with the issues involved, you are strongly advised to seek pre-test counselling. This pre-test counselling will not be at the expense of the Life Office concerned.
5. **To have your test results treated confidentially.** The result will be made available to your doctor only with your prior consent. A test result will also be stored by the Life Offices' Association on their Registry. You have the right to access this information to check that it is correct.
6. **To one session of post-test counselling, if the test is positive,** at the expense of the Life Office concerned. Counselling for any negative test result will not be at the expense of the Life Office concerned.

WHAT IS HIV ?

HIV is the virus that causes AIDS and is sometimes called "the AIDS virus". While infected with HIV, and before a person develops AIDS, he or she will feel well and healthy. During this time, the person will be able to infect other people with the virus.

WHAT IS AIDS ?

AIDS is the name for a number of illnesses that develop as a result of being infected with HIV. The AIDS virus attacks the immune system and leaves it unable to fight various illnesses.

More than half of people infected with the AIDS virus will get AIDS within ten years of infection. When you are sick with AIDS, you can usually no longer work. AIDS is a serious disease that eventually leads to death.

WHAT IS THE HIV TEST ?

The HIV test checks your blood for antibodies to the AIDS virus. This test cannot tell you the date when you were infected, or by whom you were infected. A sample of blood will be drawn from you. It will be sent to a pathologist's laboratory, where it will be tested.

HOW DO I BECOME INFECTED WITH THE VIRUS THAT CAUSES AIDS ?

Almost all cases of infection result from sexual intercourse. The AIDS virus is transmitted in this way from one person to another through semen and vaginal fluids. The AIDS virus can also be passed on to babies through the mother's blood or through breast feeding. Although rare, the AIDS virus can be transmitted by contact with infected blood for example, through blood transfusions and through sharing needles during drug use. Most cases of infection are transmitted either from men to women, or from women to men. Men and women of all ages, races and religious beliefs can be infected with the AIDS virus. Homosexual transmission also occurs.

IS THERE A CURE FOR HIV AND AIDS?

There is no known cure for HIV or AIDS. Modern medical science, as well as traditional healers, have searched for cures for the AIDS virus. So far these efforts have been unsuccessful. However, should you be HIV positive, by adopting a healthy lifestyle and having your HIV managed properly by health care workers, you can greatly enhance your quality of life before AIDS sets in. It is therefore of utmost importance that you keep yourself both mentally and physically healthy in spite of being HIV positive. It is also possible that a cure might be found over this time.

WHY DO LIFE INSURANCE COMPANIES TEST FOR THE AIDS VIRUS?

Underwriting is the cornerstone of individual life assurance, and this ensures that each applicant pays a premium appropriate to the risk. This ensures equity amongst policyholders. An applicant's decision to apply for a life insurance contract between a company and an applicant is voluntary. Equally, a life insurance company is not under any obligation to accept an application put forward to it. To ensure that the terms of the contract are fair and equitable, the insurance company requires information from applicants to

help it assess the risk of issuing a contract. This information also helps to ensure that the appropriate premiums are charged. Insurance companies screen applicants for serious diseases or habits that may affect their life expectancy. This is done through questionnaires (for example, about smoking), medical examinations, urine, blood and other tests. In particular, life insurance companies are now also screening applicants for life insurance policies for the AIDS virus. The insurance company will make a decision, based on the information supplied on the application form, together with any test results on the acceptability or otherwise of the application, and if acceptable, the terms and conditions under which it will be accepted.

IS THE TEST ALWAYS CORRECT? CAN THERE BE MISTAKES?

The tests used are very accurate and are performed by registered pathology laboratories. If your test result shows that you are infected with the AIDS virus, you can have this confirmed by having further tests done at your own expense, or by going to your nearest ATICC, clinic or public hospital for a free AIDS test.

WHAT DOES IT MEAN IF THE TEST IS NEGATIVE?

If your test result is negative, this does not mean that you may not become infected in the future. If you engage in unprotected sex, you may be infected at some time in the future. You should think very seriously about the ways in which you can ensure that you are not infected in the future, in particular, you should consider using safer sexual practices, for example, a condom. There is a time of approximately six weeks after infection when an HIV test will not detect the AIDS virus. This happens because the test for antibodies cannot detect them for a short while after infection. This time is called the "window period". If you are in the "window period" your test results will be negative, although you are actually infected with the AIDS virus. The chance of being in the "window period" is very small. If you suspect that you may have become infected recently and are in the "window period", you can arrange to be tested again in three or more months time at your own expense, or go to your nearest ATICC, clinic or public hospital for a free test and counselling.

WHAT DOES IT MEAN IF THE TEST IS POSITIVE?

If your test result is positive, this means that you have been infected with the AIDS virus. A positive test result will result in this application for insurance being declined. Existing insurance policies will remain valid unless you require periodic retesting for the AIDS virus. An existing policy may also have an AIDS exclusion or repudiation clause. This means that if you die of an AIDS related cause your claim will not be paid. Other existing policies which do not have an exclusion or repudiation clause will not be invalidated as a result of this test result being positive. The implications of a positive test result should be discussed with your doctor. The Life Office concerned will pay for one session for you to discuss these implications with your doctor.

WHAT ARE THE HARMS AND RISKS OF THE AIDS TEST?

Many people do not understand the facts about infection with the AIDS virus. This has led to people infected with the AIDS virus being stigmatised and isolated by their families and communities. A positive test can lead to difficulties in seeking housing bonds, employment, as well as medical and dental treatment. Psychological difficulties might also arise. For these reasons, the life insurance company concerned, as well as the Life Offices Association, will keep your test results confidential.

WHAT ARE THE BENEFITS OF THE AIDS TEST?

If the test is negative, this can reassure you and help you to make sure you do not become infected with the AIDS virus. A positive test result can offer an opportunity to get early treatment, to change your life plans and to prevent infection of your sexual partners.

WHAT OTHER FINANCIAL OPTIONS ARE AVAILABLE IF THE APPLICATION IS REFUSED?

Alternative financial products are available to people who are infected with HIV. Some limited forms of insurance, as well as saving products (such as unit trusts) are available. If you test positive for HIV, you are advised to seek financial advice from a suitably qualified advisor.

NOTIFICATION OF TEST RESULTS

If your test result is negative:

Your insurance policy will be issued if all other requirements have been met.

If your test result is positive:

Because a trained person should deliver that information so that you can understand clearly what the test result means you are asked at the end of this form to name a doctor or clinic.

Consequently it is of utmost importance that you think carefully about the person who should receive the results. Should you not know who to name please ask someone for assistance or suggestions.

You will be advised to contact this doctor or clinic so that he/she can discuss the meaning of the test result with you. Please note that if you receive a letter to contact the nominated doctor, it does not automatically mean that the AIDS test results are positive, as many other medical impairments may lead to the refusal of the insurance application. The doctor will be fully informed and inform you accordingly.