

**THE EXPERIENCES AND NEEDS OF HIV/AIDS COUNSELLORS
AT SETTLERS HOSPITAL, GRAHAMSTOWN:**

A MULTIPLE CASE STUDY

by

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Abstract

Cognisant of the fact that counselling has become an essential aspect of dealing with HIV/AIDS in South Africa, the researcher aimed to explore the stressors experienced by HIV/AIDS counsellors. It was envisioned that the results obtained would both help to improve the counselling services provided at Settlers Hospital, and assist other organisations to do so. The research focused on how the participants dealt with the dual roles of non-directive listening and the more prescriptive advice-giving, the stressors they experienced and the support structures they had, or needed, to assist them in being more effective HIV/AIDS counsellors. The sample consisted of four HIV/AIDS counsellors working at Settlers Hospital, Grahamstown. The co-ordinator of HIV/AIDS at the hospital was interviewed for collateral information. A qualitative, multiple case study was undertaken. In-depth, semi-structured interviews were used to collect the data which were recorded and transcribed and then constructed into coherently organised personal narratives of each participant's experiences. A composite description of all the results was arrived at through the use of a reading guide which reduced the data into a thematic content analysis. The analysed data served to present an understanding of the counsellors' experiences and to enable recommendations to be made which could assist them in pursuing their work more effectively. The findings of this study indicate that HIV/AIDS counselling is an emotionally stressful occupation. Contributory factors include the twofold role of promoting prevention and serving as empathic listeners. Other stressors derive from issues of confidentiality and stigma concerning HIV/AIDS, counsellors' identification with clients' experiences and the demographics of HIV/AIDS in South Africa. Situational stressors which arise from working as both nurses and counsellors in a public health institution were also identified. Recommendations are made to alleviate the counsellors' stress in the form of facilitated emotional support groups, professional supervision, managerial support to improve the working environment, and ongoing in-service training.

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Chapter One
A HISTORICAL AND CONTEXTUAL CONCEPTUALISATION OF HIV/AIDS
AT SETTLERS HOSPITAL

Counselling has become an essential aspect of dealing with the HIV/AIDS pandemic since epidemiological evidence established that the spread of the HIV virus is primarily affected by human behaviour (Balmer, 1992). What is more, HIV/AIDS confronts individuals with issues that are often emotionally avoided - sex and sexuality; disease, disfigurement and disability; death and dying – so that moral culpability is attached to people who become infected with the virus leading to stigmatisation of, and discrimination against, both the infected and affected. Society's reactions and fears concerning HIV/AIDS result in feelings of anger, guilt, blame and punishment which are internalised not only by clients, but also by their partners, families and carers. What is more, there is as yet no cure for AIDS, so that the fear of dying and concern for the future of survivors is an everyday reality for those infected by the virus. Hence the psychological demands placed on people affected by HIV/AIDS include a wide range of losses – loss of lifestyle, security, personal control and dignity, and eventually loss of life (Kiemle, 1994). Burnard (1992) states that HIV/AIDS counsellors have become an integral part of a patient's health care and serve as the most appropriate people to help with emotional life crises. These include not only matters of life and death but also emotionally charged issues such as sex and relationships (Grinstead & Van Der Straten, 2000). Accordingly, the role of HIV/AIDS counsellors is not only to educate and encourage people to change their behaviour (Delaney, 2000), but also to help clients and their families explore the psychological demands associated with this illness.

1.1 A brief historical overview of HIV/AIDS counselling

However, when and how did HIV/AIDS counselling come into being? According to Bond (1995), HIV/AIDS counselling is a recent development which occurred in two phases. The first phase, in the early 1980s, involved counselling people who had the symptoms of rare and life-threatening illnesses which were included in the classification of Acquired Immune Deficiency Syndrome (AIDS) as they were indicative of a damaged immune system. In the mid-1980s medical research discovered that the source of the damage was a slow-acting virus, now known as the Human Immunodeficiency Virus (HIV). This discovery resulted in the development of blood tests which could detect the presence of the virus in people well

before they displayed symptoms associated with AIDS, such as skin rashes, chronic diarrhoea, weight loss, fevers, swollen lymph glands and certain cancers (Kinghorn & Steinberg, 1998). These tests became part of an HIV prevention programme and led to the second phase in the development of HIV/AIDS counselling. A government directive in the United Kingdom in 1985 advised that anyone seeking the HIV antibody test should be counselled about the meanings and implications of the test (Bor & Miller, 1991). Such counselling is made up of at least two sessions, namely, a pre- and a post-test counselling session. The aim of the former is to ensure that the patient's decision to be tested is an informed one based on an understanding of the personal, medical and social implications of a positive result. Post-test counselling includes not only a discussion of the test result but also helping clients to come to terms with their status, whether 'positive' or 'negative, but at risk', and to plan for their futures accordingly (Seeley & Wagner, 1991).

Following on the initiative taken by the United Kingdom the World Health Organization's Global Programme on AIDS (WHO/GPA) produced a comprehensive definition of what constitutes HIV/AIDS counselling (Coyle & Soodin, 1992). It was described as an on-going dialogue and relationship between client and counsellor with the aims of preventing HIV transmission and providing psychosocial support for those affected by HIV/AIDS. The achievement of these aims involves the enhancement of self-determination, boosting self-confidence, and the improvement of family relationships, community interactions and general quality of life. Coyle & Soodin (1992) maintain that it would take a considerable amount of training and experience for an HIV/AIDS counsellor to meet these expectations.

1.2 HIV/AIDS Counselling in South Africa

In the early 1990s the National AIDS Co-ordinating Committee of South Africa (NACOSA) drew up a national HIV/AIDS counselling strategy as part of its plan to promote the prevention of HIV infection and to provide care and support to those infected or affected by HIV/AIDS (HIV/AIDS and STD Directorate, 1998). The WHO/GPA aims described above make up two of the three broad objectives contained in this national AIDS strategy, a fact which points to the "high expectations (which) are attached to counselling as a key element of AIDS strategies in South Africa" (Richter et al., 2001, p.153). The daunting task which is faced by HIV/AIDS counsellors is reflected in the five goals outlined by NACOSA's counselling strategy: to ensure that all people receive pre- and post-test counselling; to develop an extensive network of trained counsellors both within healthcare settings and in the

community; to ensure that all counselling is accessible and culturally sensitive; to develop and sustain an ethos of confidentiality and support; and to integrate counselling into other services (Richter et al., 2001).

To set these goals in motion, nineteen AIDS Training, Information and Counselling Centres (ATICCS) were opened to offer counselling services in relation to HIV testing. Then, in 1996, to increase capacity and push HIV counselling services out into the communities, the Lay Counsellor Project was set up throughout the country, with the aim of recruiting, training and employing lay counsellors in all the provinces. Common national standards were laid down to improve the quality of counselling services. These included adequate training based on minimum standards; ongoing in-service training programmes; and regular support, supervision and mentorship (HIV/AIDS and STD Directorate, 1998). Accordingly, the Department of Health (2001) published a manual for trainers which was formulated in line with the national minimum standards required for training HIV/AIDS counsellors. In addition to providing trainers with suitable material for training counsellors, this manual also includes a module which points out the aims and benefits of emotional support and professional supervision for counsellors as well as the value of in-service training to fill any gaps in the counsellors' knowledge and skills.

The counselling services offered at public health level focus mainly on pre- and post-test counselling because, unless people are tested, they do not realise that they are infected with HIV until they start to display one or more of the symptoms associated with AIDS (Van Dyk, 2001). As a result, people generally do not make use of HIV/AIDS counselling until they are already in the symptomatic phase of the illness. Moreover, although counselling services for HIV/AIDS are entrenched in the public health sector of South Africa, they are still a relatively new type of service. Hence there is a need to engage in vigorous promotional activities to create awareness about the benefits and proper use of counselling for the management of the trauma associated with HIV/AIDS, particularly amidst limited resources (HIV/AIDS and STD Directorate, 1998). This will ensure that people are counselled well before they become ill, or even infected. In addition, there is a growing demand for other types of counselling, such as ongoing counselling (HIV/AIDS and STD Directorate, 1998). According to Bond (1995), ongoing counselling is regarded as an essential part of providing health care as it helps to lower the symptoms of stress associated with HIV infection.

HIV/AIDS counselling relationships have increasingly becoming long term ones because counselling changes self-concept and improves self-esteem (Balmer, 1992).

A national evaluation of counselling services in South Africa was conducted in 1998. Amongst other things, the survey revealed that only 25% of the organisations offering counselling services have supervisory structures in place to support their counsellors and even fewer collect any data for evaluating these services. In addition, these services are rendered primarily in an educational rather than a client-centred model and are predominantly once-off pre-test encounters. The (mostly female) counsellors find it very difficult to counsel men, to deal with sexual components of preventive behaviours in an explicit way, and to apply the advice they give to their clients in their own lives, such as communication with partners about sexual risk and the use of condoms (Richter et al., 2001).

The evaluation also highlighted the fact that the majority of HIV/AIDS counsellors in South Africa are full-time paid nurses and part-time unpaid lay counsellors, most of whom have received training for the duration of at least one week (Richter et al., 2001). Accordingly, it is not only clinical issues concerning HIV/AIDS counselling in the public health sector which need to be addressed but also management and organisational ones, something which Bor, Miller & Perry found from the study which they conducted already in 1988. In 1992 Burnard stated that nurses would increasingly fulfil the role of HIV/AIDS counsellor since they are at the forefront of professional care giving to people affected with or by HIV/AIDS. However, as nurse-counsellors HIV/AIDS counselling is only one task among a full range of nursing services which they are expected to provide at their sites of practice (Gerber, 2002). According to Seidel (1996), nurse-counsellors carry an additional workload because of their counselling work, and often with unacknowledged burnout. Miller (2000) states that health workers doing HIV/AIDS counselling have not been given additional status, nor has their work as counsellors led to substantive posts or even job descriptions which include acknowledgement of the extra work – and stresses – involved. A study conducted by Grinstead & Van Der Straten (2000) revealed that public health counsellors experienced stress related to the structure of the job, including the hours, client flow, compensation and benefits, and relationships with co-workers.

1.3 The demographics of HIV/AIDS in South Africa

HIV/AIDS counsellors in South Africa are faced with difficulties which are specific to developing countries. One of these is the fact that the highest prevalence of HIV/AIDS in South Africa is amongst young women. Statistics for the Eastern Cape indicate that in 2001 the prevalence for HIV infection was 28,3% for women in the age group of 25-29 years and 24,6% for women aged 20-24 (Eastern Cape Department of Health, 2002). However, even women as young as 13 years of age are being found to be HIV positive, a finding which points to their subordinate position in society compared to men (Taylor, 1998). The experiences of some of these young women underline their vulnerability to HIV infection as well as the extent to which they are subjected to sexual violence, including rape (Taylor, 1998). This not only exposes counsellors to the dark side of society's sexual practices but, as they are mostly women, can mean that they lose belief in a safe world (Coppenhall, 1995).

Although young women are particularly vulnerable to HIV/AIDS, statistics show that the youth in general are a target population as 65% of South African teenagers have had their first sexual intercourse by the age of 13 (HIV/AIDS and STD Directorate, 1998). Accordingly, not only do counsellors have to help clients deal with the pain and suffering inherent in HIV/AIDS, but they are also faced with counselling people who have to face death in the prime of their lives and who, in some cases, have gone through the added trauma of being raped. These factors add to the stressors which are experienced by HIV/AIDS counsellors, who are mostly women with children of their own.

What is more, in South Africa "HIV/AIDS counsellors are acting as a de facto welfare response in the face of a complete absence of welfare provision and support for people affected by AIDS" (Richter et al., 2001, p.153). As such they find themselves dealing with issues stemming from the socio-economic problems caused by the poverty of most of their clients. Poor people usually have less access to information about HIV/AIDS and are often less able to protect themselves from infection as they may depend on unsafe sexual relationships for economic security, social acceptance or entertainment (Kinghorn & Steinberg, 1998). More specifically, high levels of unemployment cause rural men to migrate to the cities where they become involved in multiple-partner relationships which often results in their becoming infected with HIV and, on their periodic return visits home, they, in turn, infect their wives (Brummelhuis & Herdt, 1995; Van Dyk, 2001). Eventually, while still relatively young, these migrant workers return to their rural homes to die under the care of

those who once depended on them for support (Taylor, 1998). Women, on the other hand, are often forced to resort to prostitution in order to obtain money to survive and thereby run the risk of becoming infected with HIV (Baylies & Bujra, 2000; Van Dyk, 2001). In addition to poverty serving as a high risk factor for HIV infection, the poor are also more susceptible to the development of AIDS because they are more likely to suffer from malnutrition which depresses the immune system. The human body's inherent ability to defend itself against infection and disease is weakened by being infected with HIV and thus requires optimal nutrition and care to prevent it from acquiring one or more of the many opportunistic illnesses associated with HIV (Van Dyk, 2001). AIDS is a debilitating condition and takes its toll on family resources in a number of ways so that there is a mutually reinforcing relationship between poverty and HIV/AIDS. Moreover, institutions set up to provide support, counselling and other services are inadequately equipped and have limited resources to deal effectively with the range of problems faced by poor communities affected by the epidemic (Taylor, 1998).

1.4 The twofold role of HIV/AIDS counselling

The expectations and difficulties associated with HIV/AIDS counselling described above all serve to indicate the potential for stress among those offering HIV/AIDS counselling services. Another potential stressor concerns the conflict which can result from the twofold role which HIV/AIDS counsellors serve.

According to Lie & Biswalo (1994), counselling can be defined in two ways. It can either be seen as giving someone information and advice for solving or coping with a problem, or as facilitating a process whereby that person can make an informed decision concerning how to solve or cope with that problem. This is supported by research on the functions of HIV/AIDS counselling which is described as both the provision of HIV-related information and of support for HIV-infected persons in order to help them accept the diagnosis and 'live positively' (Balmer, 1992; Burnard, 1992; Grinstead & Van Der Straten, 2000; Delaney, 2000). This twofold role of counselling accords with the aims for HIV/AIDS counselling as described by the World Health Organisation's Global Programme on AIDS:

- (1) the prevention of HIV infection;
- (2) psychosocial support for people affected by the virus (Balmer, 1992).

However, as already stated, these two aims rest upon two different definitions of counselling: to guide, advise and inform; to provide a means of psychological support for people experiencing problems. When operationalised they reflect conflicting goals and correspond to the disease-centred and person-centred approaches respectively (Balmer, 1992). The former concentrates on directive counselling in the form of prescribing behaviour change through information, education and advice. In poorly resourced countries, including South Africa, which do not have adequate education and awareness campaigns, HIV/AIDS counselling carries an undue burden of responsibility for the education of the population about HIV/AIDS (Richter, Durrheim, Griesel & Solomon, 1999). The second aim is person-centred and involves non-directive counselling through encouraging clients to talk and discuss their problems and fears both before (pre-test counselling) and after (post-test counselling) agreeing to be tested for possible HIV-infection.

Different counselling models are called for to implement these two aims. It follows then that an important question is whether HIV/AIDS counsellors experience any conflict between non-directive counselling, which requires empathic listening and is generally insight-oriented and supportive, and directive counselling, which aims mainly at giving advice and promoting specific behavioural change. Most counsellors are trained in, and attempt to practice, a non-directive form of exploratory counselling in one-to-one formats (Delaney, 2000; Richter et al., 2001). Yet in practice this appears to clash with the behaviour change message which is seen as central to HIV/AIDS counselling (Balmer, 1992; Delaney, 2000).

There are varying research reports on the efficacy and appropriateness of either the more directive, counsellor-centred approach or the non-directive, client-centred approach. Some indicate that a balance is needed between the fact-giving and the person-centred approaches in that working with HIV-infected patients requires working with both their external and internal realities. Consequently, counsellors sometimes need to be actively directive in a session, as opposed to staying with the patients' anxiety and waiting for them to find a new way of bringing about change (Lie & Biswalo, 1994; Kiemle, 1994). According to Burnard (1992), this view of counselling describes it as being both 'authoritative' and 'facilitative'. However, although not dismissive of the more confronting and prescriptive approach, Burnard (1992) questions whether enough emphasis is placed on the emotional and personal aspects of a patient's experience of AIDS. Balmer (1992), on the other hand, argues that counselling is not going to prevent the spread of HIV, particularly in developing countries

where research has shown that various factors compound to confuse the true facts concerning the epidemiology of HIV/AIDS. He thus maintains that the directive approach serves no purpose as epidemiology is an unsatisfactory foundation upon which to base a counselling intervention. He favours the person-centred approach because counselling is inevitably concerned with individuals, not populations. Accordingly, he believes it is more efficacious in the promotion of preventative measures as it may facilitate the discovery of the motivational factors which compel people to persist in high risk behaviour.

1.5 Other stressors experienced by HIV/AIDS counsellors

The research literature reviewed in the previous section serves to highlight the fact that counsellors often find it difficult to reconcile the two ways of being with their clients, resulting in role confusion and role ambiguity, which has been reported to be a major source of stress and frustration for HIV/AIDS counsellors (Bond, 1995). However, to counsel effectively, counsellors need to be relatively free from stress themselves (Dryden, 1995). Accordingly, in addition to conducting research on the two ways of being which HIV/AIDS counsellors experience with their clients, this study explored the research on other stressors experienced by them, both in the course of their work as counsellors and as a result of their own personal life experiences.

1.5.1 Confidentiality and stigma surrounding HIV/AIDS

Research on counselling indicates that it is a stressful activity for those who offer this service (Dryden, 1995; Miller, 2000; Grinstead & Van Der Straten, 2000). However, this is especially so for those who are counselling people with HIV/AIDS as they are dealing with the realities of “probably the most dreaded and stigmatised medical diagnosis” (Bond, 1995, p.48). According to Uys (2000), this has led to staff, family and clients becoming “obsessed by secrecy” (p.160). so much so that they do not feel free to change their sexual practices, such as the use of condoms, for fear that it could be seen as a form of disclosure.

Health professionals regard this practice of maintaining confidentiality concerning HIV/AIDS at all costs as problematic (Uys, 2000). It is frustrating for them to know that many people are dying but, in spite of the public information campaign, their deaths are not acknowledged as caused by the primary diagnosis of AIDS but attributed to other symptomatic illnesses such as TB (tuberculosis) or pneumonia. A very serious outcome of such secrecy has led to a quest for finding other causes for the death of so many people, such

as bewitchment (Uys, 2000). Van Dyk (2001) states that most Africans recognise both an immediate cause as well as an ultimate cause for disease or misfortune, and that the latter is usually ascribed to some form of bewitchment. In some African cultures the physical wasting which is brought on by AIDS is attributed to the power of witches to eat the life souls of their victims (Pryor, Reeder & Landau, 1999). Accordingly, even if people with HIV/AIDS understand that the immediate cause of the illness is a virus, they may still wonder why they have been afflicted and not their neighbour and hence will consult not only Western health care professionals, but also traditional healers, who will tell them who bewitched them (Uys, 2000; Van Dyk, 2001). The resultant fear and suspicion can lead to family feuds and even violence which disturbs community life and interferes with their ability to cope with the disease.

The secrecy and stigma which surround HIV/AIDS is also a function of its association with sexual promiscuity. Pryor et al., (1999) state that in Africa people are more likely to think of HIV as a disease associated with migratory labourers or those who break sexual taboos. Some research extends this further by saying that lack of conjugal trust and a high incidence of casual sexual relationships seem to prevail in many African families giving rise to fears and insecurities about the potential 'at risk' activities of partners, particularly men (Seeley & Wagner, 1991; Williams, Gilgen, Campbell, Taljaard & MacPhail, 2000). Accordingly, it is particularly difficult for women to negotiate safer sex as this implies either that they themselves are infected or that they do not trust their partners (Williams et al., 2000). What is more, condoms are often regarded as a symbol of immorality or women's uncontrolled sexuality and as unnatural because they curb fertility and procreation (Bond & Dover, 1997).

The fears and taboos which exist concerning sexual matters make the counsellors' work more stressful (Van Dyk, 2001). This is even more the case if they have to speak to people older than themselves because old age is associated with wisdom and it is considered culturally inappropriate to give advice to one's seniors (Van Dyk, 2001). In addition, the stigma and secrecy surrounding HIV/AIDS have given rise to cultural myths, some of them horrifying and even dangerous (Van Dyk, 2001). Some people believe that they cannot get HIV/AIDS, or can even be cured, if they have sex with very fat women, virgins, girls younger than twelve, or very young boys (Brummelhuis & Herdt, 1996; Amuyunzu-Nyamongo, Tendo-Wambua, Babishangire, Nyagero, Yitbarek, Matasha & Omurwa, 1999; Van Dyk, 2001). Counsellors are very aware that these ideas not only have the opposite effect, namely, to

cause HIV infection to ‘spread like wildfire’, but can also be the cause of abhorrent criminal behaviour (Van Dyk, 2001).

The stigma and secrecy attached to HIV/AIDS also make it difficult for counsellors to convey the message that this is just another disease and not a shameful thing which needs to be hidden or for which someone has to be blamed, resulting in further silence and isolation (Grinstead and Van Der Straten, 2000). However, research by Stein, Steinberg, Allwood, Karstaedt & Brouard (1997), found that nurse-counsellors’ desire to impart the understanding that HIV/AIDS is no different from any other disease and is therefore illegitimately stigmatised, stems from the need to alleviate their clients’ guilt. Moreover, the counsellors would be implying that patients did not need to take any special measures regarding their HIV status. Stein et al. (1997) maintain that this is counter-productive because, in the interests of alleviating client distress, the nurse-counsellors were suppressing information regarding both the causes and the consequences of HIV infection. Such practices would merely place counsellors in the double bind situation of trying to normalise the illness while, at the same time, conveying the message that special measures are needed to deal with it.

Potential stresses to both client and counsellor arise in sharing the difficulties and risks inherent in deciding the level of disclosure which is appropriate. Most counsellors report that the day-to-day management of confidentiality is a constant background stress because they are aware of the consequences to the client of inappropriate disclosures (Bond, 1995). The fear and stigma surrounding this illness is such that, in many cases, isolation and rejection have become synonymous with disclosing one’s HIV status. Such disclosures could threaten the economic survival of those affected (Brummelhuis & Herdt, 1995), a fact which is especially relevant in a country like South Africa which has a very limited social security system, making patients heavily dependent on their families and communities for economic and emotional support and even physical care. Accordingly, health workers who encourage disclosure could be held responsible by patients who are left without someone to take care of them, particularly in the terminal stage of their illness (Uys, 2000). This serves to highlight the twofold role of counsellors discussed earlier in this literature review, namely, to promote prevention of HIV/AIDS through raising levels of awareness and knowledge while at the same time respecting the needs and wishes of their clients, who may insist on their diagnosis remaining confidential (Gerber, 2002). Seidel (1996) maintains that counsellors should in fact encourage clients to share the knowledge of their HIV status with others, when they feel

ready to do so, as this will serve to obtain, rather than destroy, support and will, in turn, help to reduce isolation, rejection and stigma, all of which lead to a premature 'social death'.

On the other hand, if a client postpones telling a partner indefinitely, or decides against disclosure, the counsellor may experience an ethical conflict (Bond, 1995; Grinstead & Van Der Straten, 2000). According to Uys (2000), "the position of total confidentiality neglects the respect that should be afforded the health worker and his or her need to live in truth within the community" (p.164). Uys (2000) maintains that this is particularly relevant in an African context where a person is seen as a person in a group, not as an individual, so that secrets are traditionally kept within families but not from families. Accordingly, the notion of 'shared confidentiality', that is, confining the sharing of sensitive information such as a patient's HIV/AIDS status to a small number of specified people within a given community, would seem to be more appropriate in an African context (Seidel, 1996). Uys (2000) argues that health care professionals who practise confidentiality according to the individualistic tradition and thereby disregard the needs of the community involved, are surely not giving culturally sensitive care. Uys (2000) even wonders whether a person or community can ever again trust a health care professional who has kept the lethal secret of HIV/AIDS from those intimately connected with it. It would thus be culturally correct to involve the client's family in the counselling process which would also serve to give the individual access to the traditional framework of care and support provided by the extended family (Seeley & Wagner, 1991). Seidel maintains that, in addition to obtaining support, by sharing the knowledge of their HIV status with others, patients would also be helping to reduce the isolation, rejection and stigma associated with HIV/AIDS.

Uys (2000) maintains that the strong focus on secrecy and confidentiality surrounding HIV/AIDS is part of a tradition imported without much thought into South Africa from the West. Counselling has traditionally been conceptualised in Western individualistic terms with the result that many of the values and characteristics seen in both the goals and processes of counselling, including professional secrecy, are not shared by Third World clients. (Lie & Biswalo, 1994; Seidel, 1996). Accordingly, since counselling is not culture-free, more research is needed on HIV/AIDS counselling in the African context. (Lie & Biswalo, 1994).

The stress of maintaining confidentiality can produce various responses in counsellors, including retreat into secrecy and helplessness or "entering into combat perhaps fuelled by

aggression”, neither of which is helpful (Bond, 1995, p.53). Unfortunately, the confidentiality requirement prevents them from utilising the coping mechanism of seeking emotional support from family and friends (Brady, Healy, Norcross, & Guy, 1995; Gerber, 2002). According to Bond (1995), the management of confidentiality requires the active fostering of mutual trust and respect between service providers in order to minimise the pressures towards inappropriate disclosures. Although it is not easy for counsellors to establish this climate of trust between colleagues, it has long-term benefits. In contrast, total secrecy often lowers stress in the short-term but the pressure of resisting all disclosures, both appropriate and inappropriate, is likely to accumulate (Bond, 1995).

1.5.2 Identification with clients’ experiences, particularly loss

HIV/AIDS counsellors belong to a profession which aims to help others but, in doing so, they become part of a process which involves progressive human suffering and impending death (Brady et al., 1995). For those counsellors who are full-time nurses there is the added stress of dealing with the death of patients from AIDS. Bond (1995) argues that this is perhaps the most stressful aspect of working with clients with HIV-related illnesses. Volatile emotions occur periodically for staff working in terminal care (Bennett, 1995). These arise firstly, during the process of coming to terms with managing the actual loss of their patients and secondly, as a result of the intensification of their awareness of death, including their own inevitable death, whether from HIV/AIDS or other causes (Bond, 1995). Understanding and dealing with guilt is another important stage for health care professionals in the process of successfully adapting to the loss of their patients, particularly as the death of a patient may result in a conscientious review of the standard of healthcare which they provided (Bennett, 1995). Bennett (1995) maintains that few can manage such a review without feeling some real or imagined failure to give the highest level of care, and that learning to deal with these feelings of guilt has a considerable effect on the quality of future care provided.

However, counselling people who have been diagnosed HIV positive is not only about helping them to die. It also entails helping them to deal with their fears of the unknown, of being a burden to their family and friends, of loneliness, of physical disfigurement and pain and the resultant potential for loss of self-control, of dying alone, and perhaps even the fear of what will happen to them after death (Department of Health, 2001). Bond (1995) maintains that coping with loss pervades counselling around HIV. Counsellors need to assist their clients with the process of the acceptance of their diagnosis, a process which involves the loss

of a previous concept of self and future health. Adjustments in relationships, sexual behaviour, employment possibilities, physical capabilities and general way of life may also involve loss. In fact “the burden of grief is the silent backdrop that looms behind the high profile AIDS and HIV epidemic” (Sher, 1995, p.ix). The many losses inherent in the progression of HIV infection not only create distress and pain for clients but may also produce intense feelings in counsellors and seem overwhelming for them, especially if they are empathic, resulting in psychic discomfort (Bond, 1995; Brady et al., 1995). Accordingly, counsellors have to recognise and empathise with their clients’ feelings yet, at the same time, have to avoid being caught up in those same feelings (Coppenhall, 1995). Bennett (1995) maintains that it is difficult for them to know how to remain empathic and caring while still protecting themselves from over-involvement as there is a fine line between involvement and over-involvement with patients.

Grinstead & Van Der Straten’s study (2000) confirms that counsellors tend to become emotionally involved in their work. Although they may be aware that this is inappropriate and sometimes even counterproductive, many struggle with their tendency to carry the weight of their clients’ problems. Bond (1995) states that the stresses of caring for people with HIV are shared by all the caring professions, but counsellors in particular are personally affected as they experience intense feelings which often parallel the feelings of their clients. This emotional intensity stems from the fact that, unlike other terminal illnesses, HIV/AIDS is a condition which provokes the most prejudice and the greatest likelihood of social rejection. As a result, some counsellors may want to ‘save’ the client from death, loneliness and isolation and even move into the role of friend, confidante or family caregiver (Bor & Sher, 1992). However, this difficulty in distancing themselves from the client’s emotional experiences may lead to a reduction in the counsellors’ ability to understand the client’s world and to communicate this understanding to the client (Coppenhall, 1995).

It is important that those counsellors who find it difficult to keep their own emotional boundaries distinct from those of their clients be made aware of this, as research has shown that higher levels of grief are associated with higher levels of identification with patients and their problems (Miller, 1995). Accordingly, Bennett (1995) maintains that those who identify closely with their patients may need to be taught methods to maintain a healthy emotional distance in their work. Moreover, the process of making personal adjustments to strong and overwhelming feelings is stressful and, over time, burnout can develop which may include

disillusionment, loss of motivation for creative involvement, withdrawal from emotional aspects of relationships with clients and co-workers, and may even jeopardise personal relationships (Bennett, 1995).

It is particularly difficult for counsellors to deal with those clients who, faced with the prospect of living with the stigma of HIV and the losses it entails, as well as the suffering caused by AIDS, consider that suicide may well be an option. According to Brady et al., (1995), suicidal statements are the most stressful of all client behaviours experienced by counsellors. When a client becomes desperate enough to consider “nothingness (as) a viable option” (p.2), the counsellor may feel responsible for not having been able to assist the client to accept the losses incurred by HIV/AIDS and may feel obliged to help the client work through the suicidal thoughts. This is both terrifying and stressful for counsellors and, as with the process of dealing with loss described above, contributes to burnout and is likely to cause substantial disruptions in their personal and professional lives (Bond, 1995).

1.6 Effect of personal life experiences

Brady et al. (1995) state that the most common precipitating events of counsellor distress are disruptions in their own lives as opposed to client problems. Personal life events can cause considerable distress in counsellors’ inner worlds and need to be taken into account as they often impact on their professional lives as well, thereby affecting the effectiveness of their counselling (Brady et al., 1995; Baggaley & Sulwe, 1996; Grinstead & Van Der Straten, 2000). This is more likely to be the case in Africa than in developed countries where the majority are not affected so directly by HIV/AIDS in their personal lives and where a supportive network is available to those counsellors who perceive themselves to be at risk (Baggaley & Sulwe, 1996). A study undertaken by Grinstead & Van Der Straten (2000) in Kenya and Tanzania found that external physical and economic conditions increased their level of strain and worry about travelling to work and supporting their families.

Another personal factor which affects counsellors concerns their own fears of HIV transmission (Buwalda & Kruijthoff, 1994; Bond, 1995; Grinstead & Van Der Straten, 2000). Seven out of nine of the subjects in the Buwalda & Kruijthoff (1994) study considered themselves at risk due to the behaviour of their male sexual partners. According to Bond (1995), these risks should be evaluated and the counsellors need to be helped to decide how to proceed. They may want to know their status or they may prefer to remain ignorant rather

than face the periods of anxiety and depression which usually follow a positive diagnosis. Alternately, they may already know their status. Whatever the case, it is important to help them acknowledge the reality of their situation and how they want to manage it (Bond, 1995).

1.7 Support structures for HIV/AIDS counsellors

It is clear from the literature reviewed that the tasks of HIV/AIDS counsellors are complex and challenging, thereby creating the potential for them to become overwhelmed by several different stressors operating simultaneously (Bor & Miller, 1991; Bond, 1995). According to Miller (1995), irrespective of the severity of the stresses that are experienced by health-care staff working with people affected by HIV/AIDS, they are perceived as real by those involved and, as such, need to be addressed if staff morale, sickness, absenteeism and turnover in vital areas of health care are not to become unmanageable. Jenkins (1997) maintains that counsellors need practical help with the difficulties and challenges of their everyday work to assist them in working effectively without burnout. However, studies conducted in the United Kingdom have shown that health workers have difficulty in admitting to occupational stress. In addition, they construed the expression of a need for emotional support as evidence of being unfit to work in their profession, a point which needs to be borne in mind by those organising and/or providing any type of support (Miller, 1995).

1.7.1 Description of support structures in developed countries

The relevant literature describes various support structures which firstly, serve to assist HIV/AIDS counsellors to cope with the stresses which they experience and secondly, enhance the counselling services which are so much a part of the strategy to counter the HIV/AIDS epidemic, as stated earlier in this study. One of these is the provision of mentoring in some parts of the United Kingdom, where groups of counsellors meet on a regular basis to share experiences and mutually support one another (Jenkins, 1997). Such discussion groups may diffuse intense emotions and assist with adaptation to stress (Bennett, 1995). They also have a mentor who can be available to them on an individual basis for support in coping with the various difficulties and challenges of everyday work (Bennett, 1995; Jenkins, 1997). The value of mentoring is underscored by studies which have shown that stress and the presumed potential for burnout are a function of health workers not having their own emotional needs met while meeting the needs of others by caring for them or listening to their pain (Miller, 1995). Moreover, understanding and alleviating the distress experienced by counsellors

enhances their personal functioning and clinical effectiveness so that they are more able to assist in alleviating the distress experienced by their clients (Brady et al., 1995).

Regular clinical supervision, which enables professional growth and development, is another support structure which is highlighted by research on HIV/AIDS counselling (Bor & Sher, 1992; Jenkins, 1997). It enables counsellors to consider counselling, and the therapeutic relationship, in a more flexible and adaptive way and, in so doing, allows its continued accessibility to HIV-positive clients who will change as their condition changes (Kiemle, 1994). At times counsellors can be 'knocked sideways' by the strength of expression of clients' hopelessness so that they respond with inappropriate self-doubt. Supervision enables them to understand what is happening and thus to reinforce their sense of purpose (Bond, 1995). The results of a study examining counsellors' experiences of supervision showed that they valued the supervisor's contribution in support, containment, feedback, working through 'stuckness', learning new skills and in helping them to maintain boundaries so as to stay appropriately focused and not go over time in their work (Burton & Henderson, 1997). Unfortunately, many service providers do not appreciate that good supervision has developed into a highly skilled role and settle for interdisciplinary staff support groups as an alternative (Bond, 1995). Coyle & Soodin (1992) maintain that inadequate supervision deprives counsellors of a valuable opportunity to reflect constructively on the problems they encounter, consider possible solutions, and consequently enhance their counselling skills and improve their confidence.

Bond (1995) states that both counselling supervision and staff support (mentoring) are necessary to lower the stress of HIV/AIDS counsellors in that the former focuses primarily on clients' interests (which counsellors have at heart) while the latter validates the importance of giving time to the personal needs of the counsellors. However, various other forms of support for HIV/AIDS counsellors are cited in the literature, including personal therapy. Most of the respondents in a research study on supervision thought that personal therapy was important for their effectiveness as primary care counsellors and two thirds of them said it was essential and should be required for all counsellors (Burton & Henderson, 1997). Kiemle (1994) believes that personal therapy is needed, in addition to supervision, as counsellors must work through their own personal feelings, including unresolved conflicts and any negative feelings which they may feel towards particular patients, in order to enable them to be more therapeutic to their clients. On a more practical level, recognition of the stressful nature of

HIV/AIDS counselling and the valuable service offered by the counsellors would also serve to make them feel more supported (Miller, 2000), as would the alleviation of administrative tasks such as typing letters and making telephone calls or appointments (Bor & Sher, 1992).

1.7.2 Support structures in developing countries like South Africa

Research conducted in Zambia found that HIV/AIDS counsellors need continuing confidential support to help them cope with their own worries as well as the anxieties created by the job itself (Baggaley & Sulwe, 1996). Counsellors interviewed in Kenya and Tanzania confirmed the value of group therapy for counsellors in the form of weekly meetings in which they could share the problems encountered in the previous week (Grinstead & Van Der Straten, 2000). The findings of a study conducted in the Eastern Cape emphasise the need for addressing HIV/AIDS counsellors' own emotions and reactions which are evoked as a result of their work with clients (Gerber, 2002). In addition to individual support from managers, the counsellors who participated in this study suggested that they meet regularly with other counsellors in support groups.

Already in 1997 funds were set aside by the Department of Health with the purpose of appointing a Mentor Co-ordinator in every province whose function was to provide guidance and support to HIV/AIDS counsellors by institutionalising mentorship and establishing a mentorship programme in their respective province (HIV/AIDS and STD Directorate, 1998). The guidance and emotional support provided by a mentor serves to “help the counsellor develop and mature in counselling skills” (Department of Health, 2001, p. 182). Unfortunately, although the mentorship programme has been put into effect in some of the provinces, this has not yet been actualised in the Eastern Cape (Botha, 2002). What is more, Gerber's research findings (2002), also from the Eastern Cape, indicate that managers of HIV/AIDS counselling do not seem to have an awareness of the emotional needs of the counsellors.

Buwalda & Kruijthoff (1994) recommend an institutionalised support mechanism whereby HIV/AIDS counsellors would have their own counsellor with whom to discuss problematic cases, in addition to personal emotional problems. This suggests that it would be preferable to use an outsider to fulfil this supervisory role, rather than the managers of HIV/AIDS counselling. Grinstead & Van Der Straten's study (2000) indicated that the provision of supportive supervision was a way of reducing counsellor stress and improving their

effectiveness. The participants in this research thought that supervision should give counsellors the opportunity to discuss difficult cases and the ways in which they felt they were not doing the best job. Through supervision counsellors are helped to explore alternative ways of intervening and to develop an understanding of what issues and options are available in the counselling situation (Department of Health, 2001). Grinstead & Van Der Straten (2000) suggest that such clinical supervision needs to be conducted by an external supervisor who is not directly responsible for evaluating the counsellors' job performance.

As mentioned in the previous section, other forms of support include the availability of personal therapy for those counsellors who need more than the support offered through supervision and emotional mentoring (Department of Health, 2001). The provision of ongoing education and training is yet another support structure which would ensure the growth and development of HIV/AIDS counsellors. Grinstead & Van Der Straten (2000) maintain that additional educational opportunities for those counsellors who request them should also be made available to them. Counsellors need to be afforded the time to attend seminars and conferences since a lot of research is still being done on HIV/AIDS (Department of Health, 2001). Grinstead & Van Der Straten (2000) add that any resources put to ongoing education and training, such as access to the latest available literature and in-service training, would be well spent as it not only supplies counsellors with new information which can be applied to their cases, but also gives them a break from service provision and helps them to feel that their professional development is a priority to the organisation. More specifically, the results of a survey conducted in the Grahamstown area revealed that 68,2% of the staff sampled, which included HIV/AIDS counsellors, expressed a need for training to help them cope with suicidal patients (Whiteley & Mdzeke, 2002).

In addition to structural or formalised procedures for reducing or coping with work stresses, the findings of Grinstead & Van Der Straten (2000) highlighted the value of informal means of reducing stress. These include sharing personal experiences or particular cases with other counsellors during the course of the day. Supervisors could also informally visit the counsellors to observe how they are coping, whether they have the necessary equipment to make their job easier, and to either praise or correct them on the performance of their work (Department of Health, 2001). This contradicts the findings of Grinstead & Van Der Straten (2000) mentioned above, namely, that supervision should be separate from any evaluation of job performance.

The above literature review on the various forms of support which can be made available to counsellors highlights the positive role which support plays in the provision of an HIV/AIDS counselling service. However, it is of interest to note that, contrary to these findings, a South African survey revealed that only a quarter of organisations offering HIV/AIDS counselling have a supervisory framework to support their counsellors (Richter et al., 2001).

1.7.3 Integrative models of support

Research on support for HIV/AIDS counsellors indicates that it is multifaceted. This suggests that the provision of support for counsellors is made up of various core components, particularly professional supervision, mentoring for emotional support and interventions for improved working conditions. These three components are all included in the four approaches which Miller (1995) outlined for the prevention and care of occupational morbidity in the context of HIV/AIDS. His first approach consists of professional supervision which involves monitoring and enhancing the clinical and professional activities of counsellors in order to maintain appropriate standards. The second approach corresponds with mentoring and is intended to assist counsellors in relieving stresses identified in their job. Miller (1995) maintains that this approach implies that their work does contain stresses which may need to be addressed, and that the expression of emotional vulnerability associated with work is seen as a legitimate issue rather than as a sign of weakness or unprofessionalism. Stress management makes up the third approach which could be coupled with either professional supervision or emotional support as it consists of the employment and/or the development of stress-reduction skills. The fourth approach reflects the third component of support for counsellors and is termed context management by Miller (1995). It consists of the improvement of working conditions, recognition of work stresses as well as achievements, provision of in-service training, and generally providing a pleasant working environment.

Following research into supervision as experienced by counsellors in primary health care, Jenkins (1997) proposed a model for supervision which also has four constituent parts like Miller's (1995) model. Three of these parts, mentoring, counselling supervision and managerial supervision, correspond with the three core components of counsellor support mentioned above. The fourth aspect of supervision for counsellors proposed by Jenkins (1997) is expert or joint consultation which capitalises on a multi-skill approach in that

professionals working in secondary services have made time available for counsellors who wish to consult them concerning difficult or new cases.

Hawkins & Shoet (1989) maintains that supervision has three different aspects, namely, educational, supportive and managerial. In addition to being very similar to the models drawn up by both Miller (1995) and Jenkins (1997), these three aspects also correspond with the core components of counsellor support described by the literature. The educational aspect provides supervisees with a regular space within which to reflect upon the content and process of their work and with feedback on such content and process (Hawkins & Shoet, 1989). The supportive aspect allows for the expression and processing of emotions which arise out of the pain and distress of their clients and thereby validates and supports the counsellors both personally and professionally (Hawkins & Shoet, 1989). The managerial aspect assists them with planning and utilising their personal and professional resources better so that they are “pro-active rather than re-active” (Hawkins & Shoet, 1989, p. 43).

1.8 HIV/AIDS Counselling at Settlers Hospital

Cognisant of the fact that counselling is regarded as an indispensable part of the services offered to those who are infected or affected by HIV/AIDS (Coyle & Soodin, 1991) and, after discussion with both the Matron and the Co-ordinator of HIV/AIDS at Settlers Hospital, it was felt that research was needed concerning the experiences and needs of the HIV/AIDS counsellors working at this hospital, which is situated in Grahamstown in the Eastern Cape. This province is presently one of three in South Africa which are critically underserved by counselling and testing services. (Richter, Van Rooyen, Solomon, Griesel & Durrheim, 2001).

As part of the plan to increase the counselling services offered in this province, nurses from Settlers Hospital were asked in 1999 to volunteer to be trained as HIV/AIDS counsellors. The response to this request was so good that selection was needed to limit the number of nurses who participated. At present there are 35 trained HIV/AIDS counsellors at the hospital, all of whom counsel in a part-time capacity, as they are also full-time nurses. They have all been trained by health care workers who are officially recognised as trainers in HIV/AIDS counselling by the Eastern Cape Department of Health. These trainers are all experienced HIV/AIDS counsellors in their own right and received their training, both in HIV/AIDS counselling skills and subsequently as trainers of other counsellors, from ATICC (AIDS

Training, Information and Counselling Centre), a body set up by the National Department of Health to promote awareness in HIV/AIDS through education and counselling. However, since their training, there has been no exploration of the experiences of the HIV/AIDS counsellors at Settlers hospital, nor have any formal support structures been set up to assist them in their work.

The counselling services which are provided by the counsellors at Settlers Hospital accord with the five goals laid down by the national HIV/AIDS counselling strategy in 1994 (cf. Section 1.2, p.2). However, as pointed out by the HIV/AIDS Co-ordinator of the hospital, these services also display some of the difficulties revealed by the outcome of the 1998 national evaluation of HIV/AIDS counselling, namely, a lack of any supervisory support structures to assist the counsellors in managing their stress and an absence of data collected to date with which to evaluate the existing counselling services.

Further difficulties were revealed by the results of a survey conducted three years ago to investigate the perceptions of staff, community and youth from the whole of the Grahamstown area concerning the introduction of Voluntary Counselling and Testing (VCT) services in this area. The majority of the HIV/AIDS counsellors, who are also nurses, reported that the introduction of VCT would make more demands on an already demanding work schedule (Whiteley & Mdzeke, 2002). VCT is a service which includes, in addition to pre- and post-test counselling, the administration of a blood test which can determine the presence of the HIV virus within half an hour so that it is not necessary for the client to return at a later stage to obtain the test results. The survey further revealed that 19.1% of the staff sampled did not feel supported in their work and requested some kind of mentorship (Whiteley & Mdzeke, 2002).

The above-mentioned factors, namely, the lack of supervisory support structures for the HIV/AIDS counsellors at Settlers Hospital, the absence of data with which to determine the effectiveness of the counselling programme, the need for an evaluation of the experiences of the counsellors, and the outcome of the VCT survey, attest to the relevance of this study. It was envisioned that the results of this study would not only assist staff, including management, to increase their understanding of what it means to work as an HIV/AIDS counsellor at Settlers Hospital, but could also be used to provide appropriate support for the counsellors and thereby improve the counselling services rendered at the hospital. What is

more, the data obtained from this research could also assist other institutions providing HIV/AIDS counselling as there have been only a few previous studies that describe counsellors' roles and experiences providing HIV-related counselling in developing countries (Grinstead & Van Der Straten, 2000).

Chapter Two

RESEARCH METHODOLOGY

As mentioned in the previous chapter, this research study was undertaken with a view to understanding the nature of the HIV/AIDS counselling which is offered at Settlers Hospital and making recommendations, where necessary, for the benefit of both the counsellors and the clients.

2.1 Research questions

To realise these aims, the study addressed the following questions:

- Identifying data of the participants
- Their motivation for becoming HIV/AIDS counsellors
- Training received by the HIV/AIDS counsellors
- How this training informed their work as counsellors
- Whether the participants experienced any conflict in the twofold role which they are expected to fulfil as HIV/AIDS counsellors
- Identification of stressors in their work, together with examples of counselling cases
- Description of personal life experiences
- Description of the management structure of the hospital
- Availability of support, if any, and suggestions for further support structures to assist the counsellors and increase effectiveness.

2.2 Research Design

This study is qualitative in nature as it seeks to understand phenomena in context-specific settings (Hoepfl, 1997). The multiple case study method is used in order to provide answers to the research questions which are based on a personal understanding of data obtained from 'the ground', i.e. in a natural setting and as close as humanly possible, within the constraints of researcher bias, to the lived experiences of HIV/AIDS counsellors in a hospital setting. According to Edwards (1998), case studies have better external validity because they examine people in or close to real situations and do not distort naturally occurring behaviour through experimental manipulation and the setting up of artificial conditions. Accordingly, by obtaining results in this manner this study aimed to achieve a realistic degree of generalisability so that its conclusions and recommendations could assist those health institutions which seek to find ways of improving the provision of HIV/AIDS counselling for

their clients. The strategies implemented to establish internal validity are discussed later in this chapter.

2.3 Participants

Purposeful sampling was used to recruit the main sample of participants. They were selected out of a pool of 35 trained HIV/AIDS counsellors working at Settlers Hospital and conform to the following criteria:

- at least one year's experience as an HIV/AIDS counsellor at Settlers Hospital,
- a willingness to participate in the research by being interviewed and to have the interviews audio-taped,
- ability to converse comfortably in English.

Four counsellors were interviewed as this number was considered adequate to provide a data base which was both sufficient in scope and manageable. In addition, the co-ordinator of HIV/AIDS counselling at Settlers Hospital, who is herself both a nurse and an HIV/AIDS counsellor, as well as a trainer of HIV/AIDS counsellors, was interviewed. The collateral obtained included the context of HIV/AIDS counselling at Settlers Hospital, the training received by the counsellors, and their experiences and needs.

Part of the procedure included the following ethical considerations:

- ***Information and consent forms:*** The aims and nature of the study were made clear to the participants, after which they were asked to sign a consent form which stated what the aims and nature of the study were, in addition to the voluntary and confidential nature of their participation.
- ***Confidentiality of data:*** They were also informed of the confidential nature of the data collected. The researcher made use of pseudonyms throughout the report to ensure the maintenance of such confidentiality. Permission was obtained for the co-ordinator of HIV/AIDS at Settlers Hospital to be referred to by name. Research participants were asked to sign a standard departmental permission form for all interviews to be taped. As indicated on this form all audiotapes were destroyed at the completion of the report.
- ***Feedback to participants:*** The participants were informed further that a summary of the main findings and recommendations of this study would be sent to the matron of Settlers Hospital who agreed to make it available to the research participants.

2.4 Data Collection

Semi-structured, in-depth, face-to-face interviews were used as the method of data collection for this study in order to understand the world in which the subjects live every day from their own perspectives (Kvale, 1996). An interview guide containing key questions was drawn up for each interview. These questions were such that they could be elaborated upon by the respondents. Following responses to the questions, the researcher often asked further questions to clarify a point or develop a theme (Burnard, 1992). According to Seidman (1991), “people’s behaviour becomes meaningful and understandable when placed in the context of their lives and the lives of those around them” (p.10). In order to achieve such a contextual exploration of their experiences, Seidman (1991) contends that a researcher has to do more than arrange a “one-shot meeting” (p.10) with the research participants and describes the three-interview method of acquiring meaningful data. Accordingly, each of the four counsellors was interviewed three times with each interview lasting between 60-90 minutes. An added advantage to employing the three-interview series for collecting data is that it allows for clarification and expansion of material obtained in a previous interview.

Before obtaining material from the HIV/AIDS counsellors at Settlers Hospital with which to conduct this research, background information was obtained from them in order to gain a better understanding of who they were and contextualise the answers to the research questions. This had the added advantage of serving to establish a relationship between the researcher and the research participants before working through the research questions with them. After this introduction to the data collection process, the first interview concentrated on the training which the counsellors received, followed by examples of a few cases they had encountered. The second interview focused on the personal history and life circumstances of the counsellors, both of which would situate, and offer an understanding of, critical events in the present (Edwards, 1998). The third interview looked at the stressful situations experienced by the HIV/AIDS counsellors and explored any support structures which either existed already, or needed to be set up, to assist the HIV/AIDS counsellors in coping with these stressors. Although some alterations were made to the three-interview structure outlined by Seidman (1991), particularly regarding the sequence of questions asked, the necessary logic to the interviews was not lost and participants were still able to reconstruct their experiences as HIV/AIDS counsellors within the context of their lives.

As mentioned earlier, the HIV/AIDS co-ordinator at Settlers Hospital was also interviewed since her input could serve as valuable collateral information, particularly as she herself has worked as both a nurse and an HIV/AIDS counsellor, and has trained three of the four counsellors interviewed. Only one single, semi-structured, in-depth, face-to-face interview was conducted with her, which lasted just under two hours, as this was considered to be sufficient for the purpose intended. After initially asking questions which placed the co-ordinator's experiences both in a personal and professional context, the researcher sought to obtain data which could be compared to that obtained by the counsellors, namely, the training received by the counsellors, the stressful situations which they encounter and the availability of, or need for, any support structures to assist them in their work.

In addition to collecting data from the counsellors through interviews, the BAI (Beck Anxiety Inventory, Beck & Steer, 1993) and BDI-II (Beck Depression Inventory – Second Edition, Beck, Steer & Brown, 1996) were administered to them. Like interviewing, these inventories are self-report methods so that the results obtained could serve to shed further light on the counsellors' experiences. To avoid the counsellors' responses being influenced in any way, the most appropriate time for administering these questionnaires was judged to be at the beginning of the second interview, before the counsellors were asked to describe either their personal or their work experiences, both of which were considered likely to highlight any possible presence of anxiety or depression.

2.5 Data Processing

The recorded material obtained from the interviews with the counsellors was transcribed, after which the transcriptions were reduced into separate case narratives for each counsellor, with pseudonyms being used to distinguish each one's story. This form of data reduction was used to summarise the participants' experiences, remove redundancies and coherently organise the research material (Edwards, 1998) into the following sections which corresponded broadly with the research questions:

- Setting the scene
- Conflict, if any, between two ways of being with clients
- Stressful aspects of the counsellors' work
- Personal life experiences
- Support structures available or needed.

The data obtained from the interview with the co-ordinator were also transcribed and similarly reduced into a brief thematic summary which outlined whether

- there is any conflict between the different counselling models
- the counsellors experience their work as stressful
- any support structures for the counsellors were available, or needed to be put in place.

An independent judge was asked to listen to a randomly selected ten-minute sample of the audiotaped interviews to ensure that they correctly reflected the data obtained from the research participants. In addition to confirming the accuracy of the transcription, the judge was asked to note whether any important information had been left out or whether anything extra had been inserted. With the case narratives the judge was asked to take a five-page sample and check that it did not distort the information received from the counsellors but gave a true reflection of their experiences.

Through the use of a reading guide based on the research questions the data contained in the counsellors' case narratives and the co-ordinator's thematic summary was then interpreted and further reduced into a thematic content analysis. Here, too, the independent judge was asked to ensure that a randomly selected theme was accurately interpreted and analysed by checking whether any material had been left out or incorrectly inserted. By examining and systematising the knowledge gained from all the case studies and synthesising it into a thematic content analysis, a basic theory could be arrived at which contained the essential concepts, distinctions and principles (Edwards, 1998) underlying the experiences and needs of HIV/AIDS counsellors at Settlers Hospital. Accordingly, the thematic analysis was used to firstly, produce an understanding of the HIV/AIDS counsellors' experiences, particularly the situations at work which they regard as stressful and how these interact with any stressors at home; and secondly, enable recommendations to be made concerning the extension or development of support structures which could assist the counsellors in pursuing their work more effectively.

2.6 Validity

The disadvantage of self-report research methods such as interviews is that there are a number of potential validity problems associated with them (Barker, Pistrang & Elliott, 1994). As mentioned earlier in the chapter, the case study method used for this research has

an advantage over controlled experiments with regard to external validity. On the other hand, to improve the internal validity of this study, a number of strategies were adopted. Firstly, to assist the researcher in avoiding leading questions, an interview guide was drawn up for each interview which contained a list of the important areas which needed to be addressed as well as any standard questions which were deemed necessary (Barker, Pistrang & Elliott, 1994). Secondly, audio-recordings were made of each interview with the informed consent of the interviewees, which, in addition to allowing the interviews to flow more freely and freeing the researcher to be more present to the participants during the interviews, prevented responses from being selectively recorded. Thirdly, English was used for all the interviews to avoid the possible bias resulting from translating them for analysis. However, this means that the participants were not interviewed in their first language, so that nuances of meaning may well have been lost or added during the interviews (Grinstead & Van Der Straten, 2000). And fourthly, provision was made for an independent judge to check the accuracy of the transcriptions, case narratives and thematic analysis.

Chapter Three

PUTTING TOGETHER THE PARTICIPANTS' STORIES

The chapter begins with an introduction to the four HIV/AIDS counsellors who participated in this research. This is then followed by a summary of the management structure at Settlers Hospital to give the reader an idea of the system to which the participants belong. The rest of the chapter is devoted to the presentation of the findings of this research which have been divided into sub-sections corresponding to the research questions.

In order to arrive at these findings, the information obtained from each participant was first organised into four case narratives, each of which provide the reader with a sense of the richness of the material which all four participants shared with the researcher. Together with the collateral information obtained from the HIV/AIDS co-ordinator at Settlers Hospital, these case narratives were then integrated into a thematic content analysis in order to arrive at a composite description and a comparative discussion of all the data obtained for this research study (Edwards, 1998). Unfortunately, due to the limited space available, the case narratives are not included in the main body of the thesis. However, copies of the individual case narratives have been added as an appendix for the benefit of anyone who would like to get a fuller and more detailed picture of each counsellor's personal experiences. For reasons of confidentiality pseudonyms have been used for the counsellors throughout the study.

3.1 Introducing the 'cast'

The four HIV/AIDS counsellors who participated in this research are Xhosa-speaking women ranging from 32 – 46 years of age. Dina is a widow and has two children, a son of 23 and a daughter who is ten years old. After the death of her husband she found another partner but was disappointed by his reaction after she was obliged to go and look after her parents when they became ill. She has been without a partner since the death of her parents about ten years ago. After their death she took her older sister, who is ill and unable to work, and her nephew, who is sixteen, into her home. Dina runs the household alone and feels the weight of her domestic responsibilities both emotionally and financially. She misses the support her parents gave her when they were still alive and gets very little support from her extended family. She believes that education is the key to improving her situation in life and she loves to study. It also provides her with the opportunity to go to the library and get away from her difficulties

at home. She enjoys being an active member of her church and finds comfort in her daily scripture readings and prayer.

Nosipho is a single parent and has two daughters, one 22 years old and the other eight. She does all her own housework but does find the time to relax at home. Like Dina, she is studying to improve her qualifications and this adds to her already full life. She has a partner who has three children but they live in separate homes. However, he is a source of support for her, as are the members of her extended family. Although she and her partner have a good relationship, she can never let go completely of the fear that she herself could become infected with HIV.

Nomawethu is a divorced mother of three children, two of whom, aged 19 and nine, live with her as well as one of her grandchildren (10), all of whom are at school. She describes herself as a very busy woman and a survivor. Apart from caring for her children she does all her own housework and is very active as a healer in her church. She has always struggled to make ends meet but, at the time of the interviews, was finding it especially difficult to manage financially as the back of her house had recently burned down. Nomawethu does not have a partner and prefers it that way as she does no longer wants to be dominated by a man. She cannot rely on her parents or sisters for help but feels supported by the members of her church. She finds strength through her faith in God and uses prayer to lift her spirits and get her through her difficulties.

Zanele has never been married and does not have any children. When on duty she stays in the nurses' home which she enjoys. She has a very good support structure at home where she lives with her mother and her older sister who has two sons, aged thirteen and seven. Her maternal aunt also lives with them, as well as her two adult daughters and the housekeeper. They all get on well together and there are no financial problems in the family but they have to share bedrooms as there are so many of them living together. She has a close relationship with her mother, as well as with her partner although she worries about the possibility of HIV infection.

Sr. Sue Whiteley heads up the Central Sterilising Department at Settlers Hospital which includes matters pertaining to HIV/AIDS. In 1999 she was also formally recognised as the HIV/AIDS co-ordinator at the hospital after being appointed as the HIV/AIDS co-ordinator

of the then Albany District, which is now made up of the Makana and Ndlambe sub-districts, in the Eastern Cape. Before then she had had many years of experience in nursing and had also worked as an HIV/AIDS counsellor. She started training HIV/AIDS counsellors in 1999 and gradually increased her qualifications and skills until in 2002 she was officially recognised as one of the Department of Health's trainers qualified to train HIV/AIDS counsellors according to the minimum standards laid down by the department. In the same year she also attended a VCT (Voluntary Counselling and Testing) trainers' course in accordance with the Department of Health's decision to implement VCT as a way of counteracting the spread of HIV/AIDS.

3.2 Management structure within Settlers Hospital

At the commencement of this research the hospital was headed by a Chief Executive Officer. However, during the course of this study this position became vacant and an Acting Medical Superintendent was appointed as executive head of the hospital. The Acting Medical Superintendent, together with the Matron of the hospital, the Head of Administration and the Head of Finance, make up the top management structure. Middle management consists of the Heads of each ward at the hospital and of the various departments, such as Theatre, Stores, Maintenance, Housekeeping and the Central Sterilising Department, of which HIV/AIDS is a part. Anyone working at the hospital can approach a member of the middle management to address specific issues on their behalf. The HIV/AIDS counsellors can particularly ask Sr. Sue Whiteley, who is a member of this group, to represent them and address matters on their behalf. At a lower level of management are the meetings held by representatives from each ward and department. These representatives are appointed on a rotational basis and are not necessarily the heads of their respective wards or departments. As members of staff, both counsellors and nurses can request that specific matters pertaining to them be brought to the attention of these meetings. Infection Control Meetings also occur at a lower level of management and, as the name implies, HIV/AIDS forms part of their agenda. All these groups meet on a monthly basis, and meeting dates are arranged in such a way that matters discussed at the lower level of management can be referred to middle management, if necessary. Similarly, middle management meetings occur before those of top management to allow for the latter to address any specific issues which have come up from the other levels of management.

3.3 Nature and implications of training received by the participants

The researcher felt that information concerning the training which the participants received in order to become HIV/AIDS counsellors and the impact which this training had on their work, would provide a better understanding of their role as counsellors.

3.3.1 Content of training received in HIV/AIDS counselling

All the counsellors interviewed were trained in 1999. Three of them attended a course in HIV/AIDS counselling at Settlers Hospital facilitated by Sr. Sue Whiteley and Buyiswa Yako, a health worker stationed at the District Office in Grahamstown. Initially this course ran for ten days as stipulated by the East London branch of ATTIC (AIDS Information, Training and Counselling Centre) but for practical reasons it was condensed into five days. Hence two of the counsellors had a ten-day training course while the third one formed part of the revised five-day training course. The fourth counsellor interviewed did not attend the same training course since her training was organised by the Port Elizabeth branch of ATTIC. However, it was also a five-day course and, according to Sue Whiteley, the material covered was the same, as it was facilitated by two health workers officially recognised as trainers by the Eastern Cape Health Department. The main difference was that the latter course required participants to write a test on the material covered whereas the former one asked them to evaluate their experiences of the course on a daily basis.

The training course was divided into two parts. The first part started off with participants sharing some of their personal experiences, both happy and sad, and exploring their own values and prejudices concerning sensitive issues, including HIV/AIDS. Emphasis was laid on not being biased or judgemental, no matter what they were told by their clients. This section also included factual information about the disease such as the nature and cause of the virus, how it is spread, how testing determines whether one is HIV positive or not, preventive measures, the difference between HIV and AIDS, the signs and symptoms of AIDS, and effective medications. It was emphasised that the ‘Who? When? and Where?’ of becoming infected was not the main aim of a counselling session, but rather the ‘Where to from here?’.

The second section of the course looked at general counselling skills such as how to approach the client and introduce oneself, minimising outside noise and interference, distinguishing between sympathy and empathy, facilitating disclosure and expression of feelings, providing containment, maintaining confidentiality and avoiding reassurance. It also included more

specific communication skills such as eye contact, awareness of one's own and the client's body language, active listening, and speaking in the client's home language wherever possible. Practical exercises and role-play were used to make the counselling training more experiential in nature. Furthermore, the course differentiated between pre-test counselling which occurs before taking a patient's blood sample for testing, and post-test counselling which is given about ten days later, once the results of the test have arrived from the laboratory.

3.3.2 How the training informed their work as HIV/AIDS counsellors

According to the HIV/AIDS Co-ordinator at Settlers Hospital, the counsellors have been able to assimilate their training through their experience in counselling work which has consequently "improved considerably". She said further that another positive outcome of their training has been that everyone who needs to be counselled in HIV/AIDS at the hospital is able to be attended to. The counsellors, too, felt that their training had been worthwhile and that it had given them the confidence to take on their new role as counsellors. As one of the counsellors put it, the training course was a "mind-opener" because it helped her develop a "way of talking" to clients which takes into account the importance of listening attentively.

The beginning of the course was especially beneficial for their own personal growth as it included what Nosipho described as "working on themselves". They appreciated the opportunity of getting to know themselves better because by doing this they could know and understand others better. One of the ways in which they did this was through sharing their feelings with a fellow trainee (particularly anger and stress) which, in turn, helped them to appreciate what their clients experience when they share their feelings with the counsellors. This part of the training assisted Dina in her subsequent experience in counselling when she realised that a counsellor can never "fully appreciate the client's personal experience". This section of the course also allowed them the opportunity to examine their attitudes about judging others and how being judgemental serves to increase feelings such as anxiety, anger, guilt and even hatred in their clients. Consequently, no matter what clients say in a counselling session, the counsellors try to be aware of not being biased or judgemental in their response. To minimise the clients' own prejudices the counsellors encourage them to concentrate on accepting the fact that they have the HIV virus rather than wanting to know how they obtained it or blaming and passing judgement on their partners. Accordingly, the counsellors prefer to focus on the present and the future in their sessions, rather than the past,

except to emphasise the value of learning from one's mistakes. Although Nosipho still experiences some prejudice towards certain clients, the self-awareness she obtained in the training has made her realise that this is because she has her own opinion, which is not necessarily the same as that of her clients, and that both need to be equally respected. Similarly, all clients are different from one another and have varying needs and issues which require the attention of an empathic listener.

The counsellors were taught the basics of what factual information needs to be communicated to the client. Thus they were placed in a better position to assist their clients in making informed decisions on matters such as breastfeeding, MTCT (mother-to-child transmission) and living positively. Dina said that she learned that living positively entails a balanced diet, regular exercise, safer sexual practices and a constructive mental outlook on life. The training also made her more aware of the increased risk of HIV infection in the presence of an STI (Sexually Transmitted Infection) and so she enquires about the possibility of such an infection and, if necessary, encourages clients to obtain treatment both for themselves and their partners. Other important HIV-related information acquired on the course concerned the window period stage of HIV infection. This is very important when counselling patients who initially test negative, as they need to be aware that they may still be infected and need to be retested in three months' time to make sure that they are indeed negative.

In addition to educating clients about issues related to HIV/AIDS, the counsellors realised, through their training, the importance of establishing a good interpersonal relationship with their clients to facilitate their opening up and talking freely in the counselling session. However, such a relationship has to be set up within a short space of time and thus requires effective communication skills. They became familiar with these skills in the training through role-play and other practical exercises. In addition to verbal skills and active listening, they became aware of their own body language and thereby learned to look out for the messages which clients relay through various non-verbal cues.

Through role-playing pre-and post-test counselling sessions it became clear to the trainees that post-test counselling was more difficult and stressful than pre-test counselling. In post-test counselling sessions counsellors need to make their clients feel comfortable before giving them their test results – all the more reason for ensuring that a positive therapeutic relationship is established between counsellor and client. Although it is difficult to do so, the

counsellors were told that test results have to be given face to face to ensure accuracy and confidentiality. Furthermore, giving clients their test results at the end of the week is not a good idea as that does not leave them time to arrange for some kind of follow-up before the weekend if necessary, such as going to the local clinic for support. After being informed of the outcome of their blood test, clients needed to be given space in which to take in the information and explore their feelings. In addition, with those clients who reacted adversely to the news of their test result it was best to recommend that they return for further counselling and make use of whatever support structures they have. Their experience as counsellors has confirmed the value of encouraging clients to engage the support of a close family member or friend, but only when they feel ready to do so. As explained in the training, people can only confide their HIV status in others once they have accepted it themselves.

Although it was easier to hold a post-test counselling session with someone whose result proved negative, it was nevertheless essential for the counsellors to treat it as if it were positive to make allowance for the window period, and thus to emphasise prevention and positive living and further testing in three months' time. Accordingly, in their role as HIV/AIDS counsellors, they are always stressing caution and responsible behaviour, something which none of them had in mind when they decided to undergo training in HIV/AIDS counselling. Fortunately, the training did help them to become more skilled in dealing with people's emotions, not only in the HIV/AIDS field but generally. Nosipho went further and said that the inherent personal quality which she believes forms part of the personality of all counsellors, was enhanced through their training thereby making them more skilled and confident in dealing with the emotional aspects of their counselling work.

Only two of the counsellors had the opportunity of meeting PWAs (People Living With AIDS) as part of their training course, an experience which gave both of them some idea of what was helpful or not when interacting with PWAs and their families. Both Nosipho and Zanele were made aware of the stigma which communities still attach to PWAs and their families and of the discrimination which they have to endure. This has helped them to understand their clients' feelings of anxiety, frustration and anger. They also realised how important it is for clients to know who the "culprit" was who brought this shame onto them and how long they have been afflicted with it. However, such knowledge only serves to increase their anger and/or self-blame and counsellors need to help their clients express such feelings in order to resolve their need to find a scapegoat. Another lesson which Zanele

learned from being able to interact with PWAs during her training is the value of arranging for a PWA to speak to a client whom she feels is not really responding to her counselling. She finds this is usually very effective for “getting through” to that client, just as she herself was moved from speaking to PWAs during her training.

According to the HIV/AIDS co-ordinator, the participants have all been trained in pre- and post-test counselling and, in their work as nurses, are able to draw blood samples which are sent to the laboratory for screening. They all work with patients who originally come to the hospital for treatment of ailments other than HIV/AIDS but are then referred to the HIV/AIDS counsellors by the doctors who see these patients. Hence the counsellors generally do not work with people who voluntarily wish to be tested for HIV. However, with VCT, any member of the public who would like to know their HIV status is both counselled and tested in one session. In addition to pre-and post-test counselling VCT practitioners are trained to apply the Rapid Test which allows clients to know their result within twenty minutes. This ensures that clients who would ordinarily not return for post-test counselling after being tested, receive the necessary information and support to help them deal with their HIV status, be it positive or negative. With HIV positive clients, the emphasis is on confidentiality, informing partners or family members, and positive living, i.e. living healthily and practising safer sex. With those who do not test HIV positive, the aim of post-test counselling is to ensure that their status remains negative. None of the participants works as a VCT practitioner but Sue Whiteley said that one of the other nursing sisters has been specially trained and appointed in this position at the hospital. Accordingly, any volunteers who come to the hospital to find out what their HIV status is can be referred to this person.

3.4 The extent to which the counsellors experience any conflict in their twofold role of empathic listening and advice-giving

From her own experience as a counsellor the Co-ordinator of HIV/AIDS at Settlers Hospital believes that counsellors need to both give their clients factual information and also listen actively to them in order to create a safe environment for them in which to “tell their story”. In her training course she emphasises that, unlike nurses, who tend to be prescriptive, counsellors need to be non-directive in their approach. However, she realises that talking about things such as prevention and positive living on the one hand, and listening attentively on the other, is like a “two-edged sword” and may not work well. Nevertheless she does not feel that the two kinds of counselling necessarily create conflict because, although the counsellor gives the client options, she does not tell them which one to choose. Sue maintains

that the conflict lies rather between being both a nurse and a counsellor. As nurses the counsellors are used to telling people what to do so that, if clients who are being counselled are unsure about what to do, the counsellors sometimes make the decision for them.

The counsellors did not think there was any conflict between being a prescriptive “expert” on the one hand and a non-directive listener on the other and, as Zanele explained, they tended to “interchange” between the two ways of being with a client. Nevertheless they all maintain that it is easier to be directive because, as Dina put it, there are fewer emotions involved and they know exactly what needs to be said. They feel more in control when dealing with factual information as opposed to listening to the clients and letting them dictate the pace and direction of the session. However, Zanele believes that, if counsellors have most of the control in a session, it encourages the clients to be deceitful in order to save face. In addition, when they are in the listening or non-directive mode, they are “never sure what to expect nor what to say in response” (Dina). It is also uncomfortable to interrupt clients while they are speaking although it is necessary to do so when needing to present a possible solution or correct an erroneous idea.

In spite of the difficulty of doing so, the counsellors all agree that the most important part of the counselling session is allowing the clients to do most of the talking in order to be able to let out their feelings, such as fear and anger, while the counsellors listen attentively and actively. Nosipho believes that the clients want someone to talk to and that it is essential that they be given the opportunity to do this. Accordingly, she feels satisfied that she is being a better counsellor when she has given them “the listening ear” and prefers to sit with the discomfort of not knowing where the clients will lead her rather than taking over control of the session. Nomawethu believes that, although it is difficult, allowing the clients to express their painful feelings enables her to win their trust. This initiates the development of a relationship between them and the clients are then able to transform their pain through this relationship. All four counsellors reported that, by listening to their clients, they are not only able to empathise with them but also pick up problem areas and discern what needs to be said. It is the clients who have to face their problems and the counsellor merely acts as a facilitator to enable them to decide for themselves what to do about them.

Notwithstanding the above, it is not possible for the counsellors to avoid being prescriptive as they have to help the clients to help themselves (Dina) by educating them on matters

concerning HIV/AIDS, such as preventive measures and a healthy lifestyle, and dispelling the “myths” surrounding AIDS. In doing so Zanele avoids talking too much as this could give her clients the impression that she knows everything and thus intimidate them. It is also necessary for counsellors to stress the importance of informing someone close to them of their health status. This they try to do as tactfully and confidently as possible in order to gain the co-operation of their clients. In addition, the counsellors are very aware that they may not see their clients again and thus have to ensure that they receive all the basic information which they need. Many clients also discuss their plans with their counsellor and want advice on whether they are on the right track. But whatever information they give their clients, the important thing is to enable them to make an informed decision which makes them more likely to take responsibility for their actions and less likely to find excuses for not being able to change their lifestyle.

According to Nosipho, the degree to which a counsellor is prescriptive depends on the client. Some clients are very talkative which results in her doing most of the listening while others say very little so that she finds herself doing most of the talking. It is less disconcerting to be with a client who is open and talks easily as this enables her to determine what they are feeling and whether they are gaining anything from the session. Yet with very talkative clients the counsellors sometimes experience conflict between allowing them to express whatever is on their minds or in their hearts and interrupting them in order to relay some relevant information. In such situations the counsellors feel pressured to stop the client and take them back to a particular point. There is also the danger that, if they allow the client to continue talking uninterrupted, they will forget to mention certain things which they believe are important for the client to be aware of. Making notes is not a solution as clients then want to know what has been written down and this takes them away from their feelings and where they are in the session. But the positive side of working with such clients is that they let the counsellor know whether they have enjoyed the session and gained anything from it.

The most difficult clients to work with are those who are very closed as it not easy to “read” their mind or know what they are feeling. With such clients Nosipho finds that she constantly has to check whether they have any questions to ask or comments to make. Because these clients offer very little information and give very little feedback, it is difficult to know whether one is getting through to them and whether the session is helping them in any way. Consequently the counsellor has to be very directive rather than try to achieve a balance

between being prescriptive on the one hand and non-directive on the other. In such cases the counsellor is left at the end of the session with the disconcerting feeling that she may not have succeeded in getting through to the client or that the client may be disappointed with the outcome and thus be even less likely to open up to anyone after this experience.

When it comes to counselling the elderly it is more difficult to be directive because the African culture requires that people should be respectful towards those who are their elders. Dina gave the example of an older woman who refused to be tested because the idea repulsed her and she was adamant that she had not had any sexual contact for many years. Dina felt obliged to just let her talk and did not insist on obtaining a blood sample for testing. Parents, on the other hand, appreciate the advice they receive after getting the opportunity to express their feelings about their children, particularly their behaviour. Accordingly, after listening to the parents, Dina becomes more directive in order to “normalise” the children’s behaviour which reassures both the parents and the children. This, in turn, encourages the children to open up so that she once again becomes an active listener as they talk about their experiences and, in so doing, disclose information which was previously unknown to their parents. After such disclosure Dina once again adopts a more prescriptive way of being with the clients by educating them about the dangers of substance abuse and unsafe sex.

The example given above is a good illustration of how the information-centred approach is used interchangeably with the person-centred approach. It also suggests that the counsellors make use of family sessions at times, particularly when dealing with young children and adolescents. Couple counselling is also practised by the counsellors, as in the case of a young couple whom Nomawethu dealt with. They had been referred for post-test counselling although they had known of their positive HIV status for quite a long time already. Nomawethu had given them an opportunity to express their grief concerning their illness and their feelings about the husband being the one who had infected his wife. They had explained that this had been the first time they had been able to talk about their emotions since discovering that they were both infected with HIV. They had cried a lot which Nomawethu described as “painful, painful”. She had then changed to the fact-giving approach by helping them to look at the implications of their situation and deciding what they were going to do about it. This serves as another illustration of dealing with practical issues as a way of containing clients after they have worked through intense emotions.

3.5 Stressors identified by the participants

The participants identified a number of stressors in response to the question concerning the stressful aspects of their work as HIV/AIDS counsellors.

3.5.1 Working as an HIV/AIDS counsellor in South Africa

Working in a public health institution in a developing country like South Africa means that the participants come across many problems which are related to the limited resources and resultant difficult circumstances experienced by their clients. In addition, they experience difficulties in their counselling which are related to the socio-cultural customs of their clients.

The counsellors are painfully aware of the poverty of most of their clients and that this is usually the reason why their HIV status advances to full-blown AIDS. For example, in spite of being educated by the counsellors about living healthily, poor people who are HIV positive cannot acquire antiretrovirals or even, in some cases, obtain nutritious food. It is sad for Dina to know that “poverty does not allow” most of her patients to have these things so that their chances of living healthily for a reasonable time are poor. What is even more saddening for her is that the younger females in a household sometimes have no alternative but to be sexually intimate with the brother, stepbrother, uncle, or some family member who is the sole breadwinner in order to avoid being told to leave home. In this way “everyone in the family” eventually becomes infected. A disturbing phenomenon which Nosipho came across last year is that, in some cases, people prefer their test results to turn out positive as it could give them access to the monthly disability grant which the state makes available to those who are ill because of AIDS. Nosipho recalled how, on one occasion, she was so pleased at being able to tell someone that her test result had shown her to be HIV negative, only to discover that the patient was disappointed with this result and insisted that she had to be positive as she was so thin. Other patients explain to Nosipho that everyone dies eventually so why can she not “let them have the grant in the meantime”. For Nosipho it is saddening and “very difficult to believe” that poverty is such a big factor that some people prefer to have AIDS in order to access the grant.

Two of the counsellors specifically mentioned rape cases as being stressful ones to handle, particularly as they may not be treated with antiretrovirals if the test results prove that they were HIV positive before being raped. Another problem is that antiretroviral treatment is only effective if it is administered immediately after exposure to any risk of HIV infection. This

means that someone who has been raped needs to receive medical treatment as soon as possible after the trauma has occurred. Nosipho recalled a pre-test counselling session in which she had discovered that her client had been raped three years previously while still a virgin but she had not reported the incident to the police or gone to her local clinic. At the time of being counselled this young girl had still been recovering from her traumatic experience and hence had not been in any relationship since then. Accordingly, after testing as HIV positive, Nosipho realised that her client had become infected as a result of being raped. This experience was doubly stressful for Nosipho because, not only was her client's HIV positive status due to the horror of rape, but it was then too late for her to receive such treatment as the rape had occurred such a long time ago.

Another very saddening factor for the counsellors concerns the age of their clients, most of whom are under 30 years of age. According to Nomawethu, it is even more disturbing when the clients are so young that they are still seen as children. She was particularly "shocked" one day to have to counsel a fourteen year-old "child", the youngest HIV positive person she had ever met (except for infants infected through their mothers). She seemed so "naïve and honest" and did not "know anything about sex". The young girl reported that she had "never had a man" and the mother was not aware of any abuse although she had been living with relatives "in the location" while attending school. Nomawethu described this experience as "terrible, terrible" because she felt that her client was telling her the truth. Zanele, on the other hand, has found that many young people become infected during their first relationship and her task is to alleviate the guilt they usually feel for having become sexually involved. In addition, she realises that these young people have dreams of marriage, a home and children but that they might never materialise. She cited the example of a client who was going to be married soon. Zanele identified quite closely with this client because, like herself, she was of an age at which thoughts of marriage and setting up home were important. After Zanele told her that she was HIV positive her reaction was not to cry, as expected, but to become very angry and determined not to tell her partner as she was not prepared to give up her marriage plans. Zanele was worried about her client but felt she could not shatter her dreams for the future and so concentrated on emphasising the importance of getting her partner tested so that they could openly practise safer sex. According to Sue Whiteley, another difficulty concerning the young age of the clients is that it reminds the counsellors of the possibility that their own children might become infected and die young.

Nosipho does not know what else can be done to make people more aware of the implications of HIV and AIDS. She maintains that “there are pamphlets everywhere, over the radio and on TV” as well as “living examples” of people dying from AIDS. She believes that people are guilty of “negligence” for not showing more insight in the face of all the measures taken to educate them. She used the present rate of teenage pregnancies to illustrate this as it means that people are not taking heed of the message of safer sexual practices and she wonders “where it is all going to end”. Sue believes that a restricting factor in the education of the young concerning sexual practices stems from the reticence which black parents experience about talking to their children concerning sexual matters. This applies to the counsellors too, who “just hope and pray that nothing will ever happen” to their children.

However, it is not only the young who need to be counselled but, increasingly, even the elderly are having to be counselled. This has been a “shocking and painful” discovery for Dina, who recently experienced the case of a 67 year-old woman who tested HIV positive. Two of the counsellors believe this is usually the result of indiscriminate sexual activity on the part of older men who then infect their partners. For Nosipho it is saddening that, in addition to having to care for children who have AIDS, the elderly are sometimes infected from not taking precautionary measures while nursing these children. As a result, when their son or daughter dies, they themselves are already infected and yet have to look after their grandchild(ren), who are often also HIV positive – “it’s pathetic” says Nosipho.

All the counsellors experience frustration and become despondent about the fact that “our people are not faithful”. Nosipho says this is because it is more acceptable for black men to have more than one partner than in the western cultures. Accordingly, although the counsellors always promote safer sex they maintain that women have no control over the actions of their men and are always at risk of being infected as their men can never be completely trusted to remain totally faithful to them. Moreover, the counsellors appreciate how difficult it is for women to insist on safer sex as it implies that they suspect infidelity on the men’s part. Zanele’s mother, who is the matron of a hospital in Port Elizabeth, aptly represented their concerns when she told her daughter that most black people who are sexually active will become infected sooner or later. These fears of an ever-increasing rate of infection arouse feelings of anger, helplessness and despair in the counsellors which affect both their own personal lives and their work with their clients.

The fact that many of the clients are either very young or quite a bit older than the counsellors renders it more difficult for the counsellors to talk about sexual matters, although it is part and parcel of HIV/AIDS counselling. Two of the counsellors mentioned the difficulty of speaking about sexuality to young people who are not yet sexually active and so do not really comprehend what is being said to them. The elderly, on the other hand, sometimes feel offended when a counsellor speaks to them about such intimate matters and Nosipho says they often question what the counsellors tell them. For example, they may believe they are too old to become infected or declare that it is impossible for them to have contracted the disease as they have been widowed for so many years. When this occurs it becomes a real challenge for the counsellors to convince them to agree to being tested for HIV.

What is more, according to African culture, it is a sign of disrespect to counsel older people because of their seniority. This makes it even more difficult for the counsellors to speak to them about sexual matters and to question their lifestyle. Dina feels that she has to be particularly tactful when working with older people. For Nosipho it is stressful enough to correct people's "erroneous ideas" but when they are her seniors it is doubly taxing because of her awareness that it is not culturally sanctioned to question one's elders. Nevertheless, she braces herself and "sheepishly" does so as she feels she would be "doing them an injustice" were she to leave important things unsaid.

3.5.2 Confidentiality and stigma surrounding HIV/AIDS

Although the terms HIV and AIDS are probably known to almost everyone in South Africa today, the fact that HIV is a sexually transmitted disease and that there are various myths surrounding HIV and AIDS has resulted in varying societal and cultural biases towards this syndrome. Consequently, in addition to maintaining confidentiality because it is an intrinsic part of counselling, it is also essential for the counsellors to maintain confidentiality in order to protect their clients from being stigmatised. However, this makes it all the more difficult for the counsellors to convince their clients of the importance of informing their partners, or a family member, of their HIV status. Nomawethu explained how a client of hers who was quite ill was too afraid of telling her husband that she had AIDS. While she had been in hospital she had used Nomawethu as a confidante but, having been discharged, Nomawethu was concerned that she would have no way of sharing her pain. It is also upsetting for her that people are hiding such information instead of being honest with each other. What is more,

after learning of their HIV status, some of them leave their partners and find someone else, thereby infecting yet another person.

Dina has found that one of the reasons why some patients “spend years without telling anybody” concerns “myths about witchcraft” which are attached to HIV/AIDS. She maintains that people need to blame someone for bewitching them as an explanation for their HIV positive status or for the death of their child. Conversely, people who are infected are afraid to solicit the help of family and neighbours in case they are accused of being bewitched. Consequently, some of them visit traditional healers to find a way to end the bewitchment but Dina maintains that the herbal potions which they are given may make them feel worse and even result in complications such as damage to the kidneys. In addition, she believes that, by going to a traditional healer, clients are in fact increasing the likelihood that others will suspect them of some kind of witchcraft. As a result, people will be less inclined to provide support when necessary and may even regard them as “enemies” because of their illness. Accordingly, through education Dina tries not to encourage this “perception of witchcraft” as she realises how important it is for those infected and affected by HIV/AIDS to feel supported by others.

It is clear that the counsellors try their utmost to ensure that their clients do not keep their status a secret. However, if their clients are unable or unwilling to disclose their status to a family member, they feel it is their painful responsibility to do so provided that their clients have consented to this. One of Dina’s clients had been brought by his family to the hospital for medical assistance as he had full-blown AIDS although they were unaware of this. Because he was too ill to talk Dina had obtained his consent to inform his family, a difficult and sad thing to do, especially as he was dying.

However, there are occasions when telling family members has a negative outcome for the patient. According to Dina, a client’s reticence in opening up to a family member can stem from the fear of “family disintegration” after receiving such news. She finds that in such cases the sessions are usually very long and both physically and mentally exhausting. Thus it can be also stressful for a counsellor to decide whether, in fact, it would be in the client’s best interest to disclose their status or not.

This is borne out by Zanele who feels it is heartbreaking to discover that some family members are not really interested in, or concerned about, the health of some of her clients. On the other hand, it is also distressing for her to witness how painful it is for some family members to learn of a loved one's illness. She related the example of an HIV mother who had a close relationship with her seventeen year-old daughter but had not yet told her she had AIDS. This daughter had already lost her father to TB, which Zanele suspected had been AIDS-related, and was faithfully caring for her ailing mother. She managed to convince the mother that it was in her daughter's best interests to be informed so that she could take the necessary precautions in the course of looking after her mother. Having done so, it was "depressing" for Zanele to witness "the way the daughter was crying", so much so that Zanele cried too. On days like these when there has been "a lot of crying", she feels so emotionally exhausted that she is unable to do any further counselling that day and asks another counsellor to help out if necessary.

Maintaining confidentiality and protecting clients from being stigmatised often places Nosipho in an awkward situation when she comes into contact with them outside the hospital. Some of them do not greet her but look blankly at her, particularly if she is wearing her nursing uniform. She empathises with their need to keep their HIV status private but this also poses an ethical dilemma for her. What if she were to see one of her male HIV-positive clients accompanying her daughter? Would she have to keep quiet and not tell her daughter that he was positive, thereby risking her health? Could she even suggest that they use condoms without creating suspicion? Nosipho further illustrated her conflict surrounding the maintenance of confidentiality by giving an actual example of how torn she felt at her inability to speak out. She related how, on more than one occasion, she had seen HIV-positive daughters being regularly visited by their parents who brought them gifts and wanted to do everything possible to help them recover. In spite of her attempts to persuade these young women to disclose their illness to their parents, they refused to do so and there was nothing which Nosipho could do except stand helplessly by and think that if she were the mother she would want to be informed. In such cases she experiences conflict between maintaining confidentiality on the one hand and, on the other, making the family member(s) aware of the situation and of the risks involved.

When faced with these kinds of situations Nosipho wonders what would be more unprofessional, to break the seal of confidentiality or to say nothing and in this way put

someone at risk of obtaining a terminal illness? Nosipho was placed in just such an uncompromising situation in the case of a female patient whose results had proved positive but her husband had tested negative. Nosipho was not in a position to inform the husband of his wife's status and she unsuccessfully tried to convince the wife to persuade her husband to practise safer sex as the wife was afraid he would suspect her reason for doing so. Since then, whenever Nosipho sees that man she feels guilty and finds herself thinking it would have been easier if they had both proved positive. "That's where the stress comes in" for her and she asks herself how long she has to "carry that lie" with her? Yet, were she to break the seal of confidentiality to protect someone's health, she would not only experience conflict at having disclosed information given in confidence, but would experience further conflict at having to speak confidentially to someone about very personal matters without being asked to do so. Such considerations make her feel torn as to what course of action to take, but, ultimately, she realises she is bound to the oath of confidentiality and has to live with the inevitable conflict and stress.

For Nomawethu, although she appreciates the importance of maintaining confidentiality, doing so also means that she is unable to "share her stress" with someone without feeling that she has been "gossiping". Not having an appropriate outlet results in her sometimes going to bed at night feeling "frustrated and not (her)self". Zanele used a similar expression and said she felt "depressed and not (her)self" when not able to share her feelings with a colleague, particularly with rape cases, which are the ones that most distress her and make her want to speak to someone in order to release some of her stress. However, she worries about the possibility that she may talk too much and give away a client's identity, or that she may be misunderstood or misquoted by her colleagues.

All four counsellors said that HIV/AIDS counselling for friends, colleagues or even "somebody who lives in the same street" is not easy for them. The fear of stigmatisation is so great that the counsellors are afraid they would be unjustly accused of disseminating confidential information if it were to 'leak out' that they had counselled such close acquaintances. They also find it far more emotionally stressful to deal with the knowledge that someone well-known to them is HIV positive as well as far more difficult to keep such information confidential. Dina reported that, in such cases, she asks another counsellor to take the session unless the person concerned has specifically asked her to do it. She prefers to avoid the possibility that such a person might feel she "knows everything about him".

3.5.3 Identification with clients' emotional experiences, particularly concerning death and dying

Another stressor which is intrinsic to HIV/AIDS counselling is having to inform so many clients that they are HIV positive, an illness which evokes intense emotional responses and is often compared to a death sentence. Consequently, thoughts of death are always uppermost in their minds, especially if they are very ill. The counsellors not only have to deal with their clients' fear of dying but also have to speak to them about making preparations for their death as well as arrangements for the care of those who will be left behind after their death. Zanele feels it is very stressful for her to deal with issues concerning death and dying with clients when they are not ready to do so as most of them are still in the prime of their lives. She mentioned the example of a man in his early twenties whom she had met through counselling him. After being admitted to hospital he had asked Zanele for treatment which would prevent him from dying and had also requested that she visit him in the ward every day. She had agreed to visit him but had been unable to tell him that he was dying as she had felt she had to help him feel the hope he was trying to give himself. Nomawethu, on the other hand, more readily speaks to her clients about their death as she is aware that they need to face this reality, but she tries to reassure them by telling them that everyone will die one day. However, in doing so, she finds that she too, carries their pain, "maybe even for a whole day". In Nosipho's experience it often happens that HIV positive clients are so aware of dying that it results in a "block" between herself and such clients, which makes it very hard for her to get through to them so that, no matter what she says to them, she is not "actually talking to (them)".

The reaction of clients on hearing that they are HIV positive is usually one of such distress that three of the counsellors mentioned their fear of a suicidal reaction from some clients after a difficult and tense post-counselling session. Dina gave the example of what she described as one of her most difficult cases which involved a young lady who was planning to get married. She had not been feeling well and had willingly agreed to an HIV test after proving HIV negative three months previously. But when her results came back as positive she had cried desperately at the thought of still being so young and on the verge of marriage. Dina had not seen her since then but she still wonders whether the young lady had contemplated suicide. She added that, whenever she has to spend time with someone who appears to be suicidal, she gives the client the opportunity to work through her pain but finds this a difficult thing to do. In addition, she finds it necessary "to go over the same things quite a few times"

in order to “take the idea away” and this is both taxing and draining for her. Nomawethu experiences “a strange feeling and a pain” after giving them “the bad news” as they initially want “to give up hope”, a pain which she has to keep to herself as she feels she cannot disclose it to the clients. Nosipho said that, after becoming aware of being HIV positive, some clients react as if they have “closed the curtain already” so that she knows she is “in trouble as the patient is not going to cope with the disease emotionally”. From her experience these are the clients who come back to the hospital “after trying to kill themselves”.

It is particularly with post-test counselling that the counsellors identify with their clients’ feelings. Nomawethu said that, after a post-test counselling session, she sometimes feels like being “alone in a dark room” without seeing anyone. During the session itself, she so empathises with the clients while they speak about their pain that she often experiences conflict between, on the one hand, not taking their problems on as her own, and, on the other, just letting them talk about their feelings and how they intend to cope with the fact that they are HIV positive. Accordingly, before they leave the session she gives them some factual advice and tries to instil hope in them, both of which make her feel she is doing something for them. Zanele also finds her work emotionally stressful as she is aware that HIV/AIDS affects “people’s families and lives”. Like Nomawethu, she sometimes wishes she could do something for them in order to “make things better” for them and “stop the crying”. When a client appears very upset she sometimes worries that she may not have been able to “deliver the message properly” and thus not fully assist the client. At other times she would like to be angry with the client for being neglectful of herself or her child but she has to remind herself that she cannot control what the client does and has to “let things be”. She so readily empathises with her clients that she easily agrees to speak to them, even if they do not have an appointment, although it may mean that she has to give up her lunch hour to do so.

For Nosipho it is also difficult at times to separate her emotions from what the client is feeling during a post-test counselling session. In fact, she finds herself “in the patient’s shoes most of the time” so that she experiences difficulty in distancing herself from her clients, so much so that she cannot even forget about them when she goes home. For example, after watching the news on the television she may realise that she did not take anything in as her mind “was still on the patient”. She even dreams about them on occasions, something which can “affect her mood” because she feels powerless to do anything about their plight. All these things prevent her from having “a good night’s rest” which might otherwise help to diffuse a

lot of the emotional stress which accumulates from her work as a counsellor. In short, the stress of conducting a post-test counselling session is sometimes so great that the counsellors refuse to do any further counselling that day as they are “human beings and have feelings”, like their clients, and do not “take an injection which will make (them) tough” (Zanele).

3.5.4 Working at Settlers Hospital

The research participants are nurses first and then HIV/AIDS counsellors as they all counsel only in a part-time capacity and have to give priority to their nursing duties. In her position as co-ordinator of HIV/AIDS at Settlers Hospital, Sue maintains that nursing and counselling are both stressful. However, the extra demands made on the hospital by the increasing numbers of AIDS patients being admitted raises their stress levels even further. Sue said that the hospital’s statistics show that the number of AIDS patients being cared for translates into more than 300 patient days a month at times, and this does not include those patients who are being nursed for acute and other chronic diseases. According to Dina, not only is it in the nature of nursing to have to work very hard, but they have to play many roles in addition to nursing, such as carer, social worker and general counsellor. This results in their sessions being interrupted at times as they are needed elsewhere, thereby undermining their effectiveness as counsellors and creating conflict for them. It is upsetting for Dina when she is obliged to speed up a session in order to attend to some urgent nursing duty. Not only does it restrict the time she is able to spend with a client but it also interferes with the quality of her counselling which threatens to become a “slapdash thing”. She does not feel comfortable putting up a “Do Not Disturb” sign on her door as people would then “be aware of a special room for HIV counselling” which would compromise confidentiality. She believes that the solution to minimising the number of interruptions is to place the counselling room in a more secluded area of the hospital.

Nomawethu explained that the demands made on her as a nurse require her to go back to her work on the ward after a counselling session which means that she cannot sit down and process the feelings which arose during the course of the session. She recalled an occasion when, in the middle of an emotionally taxing session, she was interrupted by a telephonic message asking her to go to another ward. She had not responded to that request as she had needed time to process the painful feelings expressed by her client during the session. On being asked why she had not followed up on the request she had found it very stressful to explain the reason to her supervisor. All this accumulated stress had made her “feel like

taking (her) bag and going home”. She had felt she “ was not a person, just a thing” and had not even come to work the next day as she had not wanted to see anyone. On that same day the supervisor had asked the counsellors whether they were experiencing any stress in their counselling work. They had replied in the affirmative and had added that Nomawethu had not come in to work that day because of her experience the previous day, whereupon the supervisor had asked one of them to speak to Nomawethu.

Sue believes that the conflict which arises from fulfilling the twofold role of nurse and counsellor is a fundamental one. She maintains that it is never easy to have to tell people that they are HIV positive, but it becomes especially difficult for the counsellors at the hospital because, as nurses, they “are supposed to make people better”. But instead of healing people, their task is often one of helping them to die as comfortably as possible. Nosipho maintains that nursing someone who is not “going to get well” is particularly stressful, unlike other diseases which afford “some measure of control”. This is exacerbated by the fact that more and more patients at the hospital are dying of AIDS-related causes. As Sue explained, ten years ago it was not an everyday occurrence for someone to die in the hospital whereas this year, in January alone, there were 22 deaths from AIDS at Settlers hospital. This, in turn, has resulted in the counsellors having to do more and more bereavement work both with the dying patients and with their families. Dealing with dying patients and grieving family members is never easy, but is rendered even more difficult by the anxiety which people experience at not having the resources to afford an appropriate burial. In addition, many of the family are unaware that the patient is dying of AIDS and, as nurses, they are not allowed to divulge the nature of their illness without obtaining permission from a doctor. Consequently, they often have to carry the strain of keeping this information a secret until it is out.

Although nursing adds to their stress load, the counsellors all felt that counselling someone is far more stressful than nursing. In the words of Nosipho, counselling is “very, very strenuous” as it is not easy to remain objective while counselling. Were she to have to choose between being a counsellor or a nurse, she would choose the latter as counselling entails more emotional stress, which is more difficult to bear than the physical stress involved in nursing. As a nurse she is able to recover after a good night’s rest, but as a counsellor, she feels she is still carrying the stress the next day. This stress is made up of feelings such as helplessness, frustration, and even anger, which result from having to work with clients who react in

various ways to the news that they are infected with a disease which has no cure and which is still mostly spoken about in whispers and behind closed doors.

The shortage of staff at the hospital creates further stress for the HIV/AIDS counsellors in various ways. Firstly, the extra demands made on them as nurses results in their not always being able to meet the needs of their patients. The patients tend to react by holding the nurses responsible which leads to strained interpersonal relations and further stress for the nurses. In addition, there are sometimes long queues of clients waiting to be counselled so that they have to wait quite a few hours before being seen. They often ascribe their long waiting to an uncaring attitude on the part of the counsellors, so that, in the words of Nomawethu, they are “nice and cross” when they start the session while the counsellors, too, are not at their best as they are feeling tired from the additional demands made on them. The conflict which the counsellors experience between their nursing duties and counselling work is particularly felt by them on those days when they have five or six counselling sessions in one day, as opposed to their usual two or three. On those occasions when Nomawethu finds herself alone with a long queue of patients waiting for attention, she focuses on getting her work done to the satisfaction of both the patients and the doctors, even if it means delaying her tea break in order to do so. However, this tires her and Nomawethu believes that counsellors should not be expected to counsel someone when they are feeling tired as the clients could sense that the counsellors are not at their best and it could even prejudice the outcome of the session.

Secondly, the pressure which the counsellors feel due to their extra workload as nurses can result in their not being able to be with a client long enough so that their needs are not always met. When this happens, Zanele is left with a “disturbing” feeling that she has not given of her best. To illustrate this she gave the example of how she had only noticed on a client’s return visit to the hospital, two days after she had post-test counselled her, that this same client had oral thrush, something she had missed during the actual session. Even as a nurse she is not always able to spend enough time with her patients because of the extra demands made on her. As a result she sometimes merely dispenses medication or refers the patients to a doctor without examining them thoroughly before hand. On one occasion Zanele noticed that a baby she had treated previously had come back for further treatment and she experienced much anxiety wondering whether she had treated him sufficiently on his previous visit. At such times she does not sleep well at night due to the worrying thought that the patient might have died because she had not been thorough enough in her work.

Thirdly, the shortage of staff extends to the doctors too, who thus have to rely on the nurses to carry out most of the preliminary examination of patients as they are only able to come in at the end and make a diagnosis. What is more, those nurses who are also HIV/AIDS counsellors are usually requested by the other nurses to take all the blood samples, not only those for HIV testing, to save the patients from having to have their blood taken twice. Dina resents the extra work she does for both doctors and nurses as it not only tires her but she is not paid for it and there are no added incentives for having to do so.

A fourth source of frustration arising from the staff shortage is that the counsellors are not always able to offer their clients both a pre-and a post-test counselling session. This means that they sometimes have to take a post-test counselling session without having seen the client for their pre-test counselling session. Such a situation not only disturbs the process of continuity but also interferes with the relationship of trust which developed between client and counsellor in the first counselling session. Insufficient resources also make it difficult to provide for ongoing counselling at the hospital, so that the counsellors cannot offer additional sessions for clients other than for exceptional cases. For Zanele it is “saddening” that she cannot follow up on her clients, especially if they are so “sad or ill” that she would like to see them again. Nosipho says the lack of follow-up makes it virtually impossible to determine the effectiveness of the counsellors’ sessions.

Certain aspects of present practice at the hospital serve as yet another stressful factor for the HIV/AIDS counsellors. The counsellors find it difficult to follow up on those clients who do not keep their scheduled appointments due to restrictions on the use of telephones at the hospital. In addition, Dina says there is no longer a system in place for reaching clients through the mail without going through a lengthy authorisation procedure. However, the difficulties encountered with contacting people are also due to the clients’ own problems related to lack of finance, transport problems and inability to get sufficient time off work.

Two of the counsellors are unhappy with the fact that they themselves may not conduct HIV testing on anyone unless they have been referred by a doctor. They have been told that HIV testing is an expensive procedure and hence people who come voluntarily for testing but do not need to see a doctor have to go either to their local clinic or a private doctor as the hospital only deals with the “real cases”. However, Nosipho maintains that, in their capacity as nurses, the counsellors may indeed refer people for pre-counselling and testing. She also

believes that it is a pity that so few people come voluntarily for testing as they then lose out on the opportunity of experiencing the benefits of counselling. The HIV/AIDS co-ordinator could not understand why the counsellors did not seem to be aware of the VCT (Voluntary Counselling and Testing) which is available at the hospital, especially as VCT training sessions have been made available to them, and at least one of them had attended one of these sessions. She wondered whether this was due to a lack of communication or a result of the initial delay in implementing VCT due to financial concerns on the part of top management.

Some dissatisfaction was also expressed by the participants concerning the management at the hospital. It appears that those in the upper echelons of the management structure are not always aware of, or interested in, what happens in the various wards or clinics. It was also felt that lack of communication occurs at various levels in the hierarchy so that messages which the counsellors send are not always received by those in charge of a section or a ward. In addition, although the counsellors work very hard, sometimes even delaying their tea break or seeing people during their lunch hour, they feel that their efforts are not acknowledged nor recognised. Some of the participants mentioned financial incentives, promotional opportunities, and/or official affirmation of their diligence and worth.

3.6 Effect of personal life experiences

Zanele and Nosipho both have strong and reliable support structures at home in their family members and partners and feel that they can speak to them whenever they need to. Zanele comes from a high-functioning family with no financial difficulties and with whom she gets on very well. She does not experience any stresses at home except that she has to share her mother's home with so many other family members that there is a lack of privacy at home. However, she has been able to circumvent this problem by making special arrangements, without offending her aunt, when she wants to speak confidentially to her mother, with whom she has a close relationship. When distressed, she finds some relief by talking to her mother who has taught her that "life is too short to harbour hurtful feelings". She enjoys going home to Port Elizabeth to be with her family when she is not on duty and, while working, she willingly stays at the nurses' home where she has some good friends. Furthermore, she is able to see her partner quite regularly and enjoys going out with him. Her only personal problem is her consistent fear of becoming infected with HIV by her partner. However, it is the stress of being an HIV/AIDS counsellor which often makes Zanele feel sad and tearful, even at home, but fortunately she is able to speak to her mother when this happens.

Nosipho also feels she has a good family support system but, unlike Zanele, she is a single parent and runs her own home. She has a good relationship with her parents and her sisters and gets on particularly well with her cousin, whom she sees regularly. She also feels supported by her partner with whom she has many things in common. Her hobbies include watching television, reading and crochet and she also likes to study which, like her hobbies, distracts her from her problems. She relaxes for two hours every day after work by sitting down in front of the TV with a cup of coffee. She would like to do so for longer but has to see to her daily household duties, such as doing the washing, preparing the dinner, and assisting her younger daughter with homework and getting ready for bed. She also has to get up early in the morning to see to the many domestic tasks which require her attention so that, on arriving at work in the morning, she already feels she has worked very hard. She resents having to do housekeeping every day and labelled that as the chief source of her stress at home. She would like to hire a housekeeper but feels that she has other priorities which need to be paid for, such as the education of her two daughters, one of whom lives at home with her and is in primary school while the other is in residence at a Technikon in Pretoria. Her financial responsibilities worry her to some extent, but she ascribes this anxiety partly to her desire to have “nice things” at home and partly to her need to always feel in control which is not the case when she has any outstanding accounts. As with Zanele, Nosipho is afraid of becoming infected with HIV by her partner and also fears that her older daughter may contract HIV, although she has tried to educate her about this risk. She also tends to take her clients’ problems home with her, like Zanele. However, she does not feel completely free to talk to people at home about them because, apart from having to keep “professional secrecy”, they are not really interested in what happens to her at work or tell her that she should not be carrying her clients’ problems on her shoulders.

Nomawethu and Dina, on the other hand, do not feel they have any support systems at home but rather that they themselves have to serve as sources of support for all their family members. They are both single parents and experience financial difficulties and cannot rely on any assistance from their extended family. Each has three dependants living with them, including their own children. Neither of them has a partner and, although it means they are alone, they prefer it that way as it allows them to be independent rather than feel dominated by someone else which would create further stress for them. Not having a partner also frees them from the worry of possible HIV infection. They are both active members of their church and find joy in belonging to an accepting congregation and in the work which they do for the

church, which takes their mind away from their work. They both find their solace in prayer and trust that their faith in a loving God will see them through their problems.

In addition, Nomawethu describes herself as a “busy woman” as she does all her own housework and has three children to look after. She feels she does not get any support from her family and what is more, she often has to provide meals and accommodation for her parents and sisters, particularly her mother, who often stays with her for quite some time before returning to her own home. Nomawethu appreciates that they are her family but is resentful of the fact that they do not contribute anything towards their stay in her home as it puts a strain on her finances. She was finding it particularly difficult to cope financially at the time of this study because of the extra expenses incurred by the damages from the fire which burned parts of her house. In addition to having to bear the cost and inconvenience of repairing parts of her home, she was having to cope without electricity which made life more difficult, such as using a primus stove and candles and doing without a refrigerator. Hence she was unable to buy food in bulk and even had to do without lunch sometimes. However, she describes herself as a survivor who tries to cope as best as possible on her own. She tends not to ask for assistance from others but still manages to give her children a “warm home”.

Over and above her responsibilities and chores at home Nomawethu participates actively in the healing ministry of her church and often talks to people and prays with them when they come and visit her in their distress. In fact, she feels totally committed to counselling people both privately and professionally as she believes she has a special gift for helping people with their problems, something which she discovered in the course of her working for the church. In her personal life Nomawethu thus acts as a tower of strength for many and does not herself have anyone to lean on. Nevertheless she generally copes with her stresses at home and experiences them as less taxing than those at work. She says she enjoys being at home where she relaxes by singing as she works or watching the television. She is content to be alone at home because it gives her “the chance to hear from God”. If she feels down, anxious or stressed, particularly after a hard day at work, she finds the time to pray at home as she believes that, through divine providence, she will be made to feel better.

A big sadness for Nomawethu is that the little outside shed in which she used to be able to pray privately and even loudly, if she wished, was also burned down in the fire so that she has to pray in her own room now, which is more limiting. Another disappointment for

Nomawethu is her lack of professional qualifications. She believes this contributes quite a bit to her stress at work as she would gain both financially and in rank if she were a sister, like the other counsellors interviewed. Accordingly, she realises how important it is that she should study further, even if it will take her quite a few years to do so and will add to her already busy life.

Unlike Nomawethu, Dina experiences her stresses at home as more taxing than those at work. In fact, of all the counsellors interviewed, Dina was the only one who said that she was happier at work than at home. She said that life has been very difficult for her since her parents' illness in the early nineties when she had to leave Johannesburg where she was living with her partner and return to Grahamstown to look after them. After their death in the mid-nineties she not only lost the support of her parents but had to take her older sister, who is mentally ill and cannot work, as well as her teenage son, into her home and look after them as they had been staying with her parents. Although she wants the best for her nephew, she finds him very difficult to manage, especially after she obtained custody of him in 2000 as her sister proved unable to care for him. Moreover, she has a poor relationship with her sister and there is often friction between them for financial reasons. Although she receives a Foster Grant for her nephew, and her sister gets a Disability Grant, these are insufficient for their needs and thus they are a source of additional financial responsibility for her. Her financial concerns are exacerbated by the fact that she is extending her home in order to properly accommodate all then members of her household. The alterations involved have also meant living in cramped and uncomfortable conditions.

Dina cannot lean on anyone in her family for support, except her younger sister, whom she does not see often as she lives far away. Consequently, she generally feels "down" at home because there is no one with whom to share her problems whereas at work "there are people to talk to and laugh with". She feels she has to "be a support" for everyone at home but cannot, in turn, rely on them for support. She does have a good relationship with her ten year-old daughter who often serves as a source of comfort and joy. However, she is too young to act as a source of support and her 23 year-old son, of whom she is proud, lives in Johannesburg and is thus too far away. Dina believes that her experience of widowhood 21 years ago, which strengthened her and taught her to be independent, has helped her to deal with all the personal adversity she has faced since then.

Dina does not have any hobbies and she seldom goes out due to her domestic responsibilities. Her only form of relaxation is studying which she finds energising as it serves as an escape from all her domestic pressures. She likes to go to the library which helps to “fill up her time at night” and serves as a place where she can “rather be alone than morose at home”. She believes that, through education, she can “make positive” that which is negative. Another source of support for Dina is her daily prayer in the form of a Bible reading and meditation every evening. She is also an active member of her church and participates in the Sunday service in addition to attending a Mother’s Union meeting once a week as she is a member of the Women’s League.

3.7 Assessment of participants’ levels of anxiety and depression

In addition to asking the participants about their stressful experiences, the researcher administered both the BAI (Beck Anxiety Inventory) and BDI-II (Beck Depression Inventory - Second Edition) scales to measure their levels of anxiety and depression. As shown in the above-mentioned sections of this chapter, the counsellors all reported experiencing stress in their work. Nevertheless, the scores which they obtained on these self-report measures do not reflect any signs of clinical anxiety or depression. More specifically, the results indicate the presence of moderate anxiety in one of the participants, mild to moderate in another, and only mild levels of anxiety in the other two. All four of them display only minimal levels of depression, although one of these borders on moderate depression.

<u>Actual scores obtained on BAI</u>	<u>Range</u>
Zanele: 18	0 - 7: minimal
Nosipho: 15	8 - 15: mild
Nomawethu: 12	16 - 25: moderate
Dina: 8	26 - 63: severe

<u>Actual scores obtained on BDI-II</u>	<u>Range</u>
Dina: 13	0 - 13: minimal
Zanele: 9	14 - 19: mild
Nomawethu: 6	20 - 28: moderate
Nosipho: 5	29 - 63: severe

3.8 Support structures which the counsellors have, or need, at work to assist them in coping with their stress

The hospital makes provision for monthly meetings and some in-service training seminars which gives all the counsellors an opportunity to get together and share experiences, ask questions and generally support one another. It also enables them to acquire new information and remain updated on matters related to HIV/AIDS. Unfortunately, these seem to have fallen away because, according to Nosipho, they are difficult to arrange since the counsellors are so busy and not all on duty at the same time. Sue maintains that they were voluntary and became “just another meeting which had to be attended”. Zanele stressed the importance of these meetings so that all the counsellors could be kept up to date on matters related to their work. She also felt that the plenary nature of these meetings would ensure that all the counsellors relayed the same information to their clients. However, she too appreciated the difficulty of getting everyone to attend.

Sue mentioned that last year she had arranged for Hospice to give three workshops on how to handle people who are dying from AIDS, dealing with one’s own emotions after they have died and assisting family members with their bereavement process. Following these workshops, which were attended by any interested staff member and not only HIV/AIDS counsellors, smaller support groups were set up with the aim of meeting regularly. However, these also seem to have fallen away and it does not appear that any of the counsellors participated in this arrangement.

Accordingly, at present there is no regular avenue which provides some stress relief for the counsellors. The only other support structure available to the counsellors is an informal one, namely, discussing their problems, both professional and personal, with colleagues at work. Dina said that if she has a problem at work she “finds someone to talk to and share (her) problem and that helps”. Nomawethu maintains that talking to someone “gives me something in my life”, even if they can’t help her in any way, as her “problem has been divided”. Accordingly, by talking to trusted colleagues at work she is able to “offload” some of the stress she accumulates at work which helps her not to feel emotionally overwhelmed. If necessary, she goes to the bathroom for some privacy where she can lift her spirits by crying and praying to God to help her find a solution to her problems.

Nosipho and Sue, who both form part of the management structure at the hospital, would like the in-service training to be revived so that the counsellors remain up to date with the latest information concerning HIV/AIDS issues. Sue referred specifically to the Nevirapine debate for the prevention of MTCT (mother-to-child transmission) and exclusive breastfeeding. Contrary to previous thinking, the latter promotes breastfeeding by HIV positive mothers provided that it is done exclusively for three months only and that their CD4 count is not too low. Other areas on which some of the other counsellors felt they needed input included the sensitivity of counselling people older than themselves, dealing with sexual matters in the black culture and managing one's feelings when counselling friends or colleagues.

All the counsellors expressed the need for something to be put in place which would afford them the opportunity of alleviating some of the emotional stress inherent in their work as counsellors and learning new coping skills. They liked the idea of meeting in small groups of about six people which would make it easier for them to open up and share confidential matters and also for them to support one another. They all thought that a suitably qualified person, such as a psychologist, should facilitate these groups and two of them would prefer an outsider, as this would encourage more openness. They confirmed this by referring to how they had benefited from their interviews with the researcher in that they had felt energised after talking about their experiences. As Zanele put it, she was able to be herself and open up without feeling she was "gossiping". Nosipho, on the other hand, believed that, for ethical considerations, such as the maintenance of confidentiality, and ease of organising these groups, the facilitator needed to be an insider. Zanele added that it would be important for all the counsellors to be part of such small groups and that they should be required to attend them regularly. Furthermore, the facilitator, without jeopardising confidentiality, should summarise what seemed to be the main problems and any suggestions that came out of these meetings and then discuss them at plenary meetings attended by all the counsellors so that everyone was kept in the know. Nosipho maintained that, to derive full benefit from these groups and try and relieve some of the stress, it would be essential to explore the factors underlying the stress experienced by the counsellors, e.g. lack of finance or staff shortage.

Sue said that one-to-one mentoring or supervision would be the ideal and mentioned that one of the HIV/AIDS counsellors at the hospital had found her work so stressful last year that it had been arranged for her to go to Hospice for individual support. She also said that the national HIV/AIDS Directorate were aware of this need and have made mention of this in the

minimum standards training manual which is used by the Department of Health's trainers of HIV/AIDS counsellors. Both Nosipho and Nomawethu felt that such a service should be made available to anyone who wanted it and that it should take place off the hospital premises to avoid being stigmatised.

Apart from wanting some kind of personal support, the counsellors also suggested that some changes in present hospital practices would lighten their load somewhat. They feel they work very hard and, as mentioned earlier, some of the counsellors think that there should be more recognition for this, such as financial incentives, more promotion opportunities, or some formal means of acknowledging the value of their efforts. The counsellors would also like a system to be put in place which would prevent the occurrence of interruptions during counselling sessions. In addition, they believe there should be more ongoing counselling at the hospital and easier accessibility to telephonic and postal communication with clients.

Chapter Four

INTERPRETING THE PARTICIPANTS' EXPERIENCES

In light of the findings presented in the previous chapter, this chapter discusses the experiences and needs of HIV/AIDS counsellors at Settlers Hospital in terms of the specific areas of research undertaken by this study. Furthermore, the discussion serves to make recommendations for improving the support provided to the counsellors at the hospital.

4.1 How the counsellors' experience their twofold role of empathic listening and advice-giving

The findings of this research indicate that the counsellors do experience some conflict between being a non-directive listener on the one hand and a prescriptive 'expert' on the other. Listening attentively to feelings on the one hand, and talking about things such as prevention and positive living on the other, is like a "two-edged sword" (Sue Whiteley) and results in inevitable conflict (Delaney, 2000). The participants all find it easier to be directive with their clients as they feel more in control when dealing with facts rather than emotions and can determine the pace of the session. One of the counsellors expressed this by saying that the non-directive way of being with a client meant that she had to sit with the discomfort of not knowing where the client would take her. This accords with Burnard's view (1992) that client-centred counselling puts personal responsibility and freedom of choice in the hands of the client, not the counsellor.

Not only do the counsellors experience the client-centred approach as more demanding than the fact-giving one, but it also conflicts with their role as nurses. Sue Whiteley maintains that this role is prescriptive in nature as nurses are used to telling people what to do about their health. Accordingly, when working as counsellors, they are inclined to make decisions for those clients who are not sure what direction to take after being told of their HIV status. This is confirmed by Balmer (1992), who states that HIV/AIDS counselling developed out of the medical profession's need to address the pandemic and the approach used concentrated on prevention through attempting to change people's behaviour. This preventative role of HIV/AIDS counselling means that it involves a strong element of information giving, particularly in biomedical settings (Delaney, 2000). The counsellors value their fact-giving role as they believe they have to educate their clients on matters relating to HIV/AIDS in order to help them to help themselves. They appreciate the importance of stressing preventive

measures and a healthy lifestyle, of dispelling the myths surrounding HIV/AIDS, and of encouraging their clients to inform someone close to them of their positive status.

Nevertheless, the counsellors are aware of the importance of allowing the clients to express their feelings while they listen attentively and actively. This accords with the view of Kiemle (1994) who states that counsellors need to understand the emotional material which clients bring them. Consequently, the counsellors aim to balance the experience and routine of being directive and giving informative advice, which they already have as health workers in the hospital setting, with a more exploring and person-centred attitude (Lie & Biswalo, 1992). As one of them put it, giving clients “the listening ear” makes her a better counsellor. Another participant believes that allowing her clients to express their painful feelings enables her to win their trust. This, in turn, initiates the development of a relationship between them through which they are then able to transform their pain.

In the end they are aware that their function as counsellors is to enable their clients to make an informed decision, something they can only do after having both been given the necessary information and allowed open expression of their feelings. This reflects the message which was emphasised in their training, namely, the value of the person-centred approach in addition to providing information and advice. Hence they try to achieve a balance between the fact-giving and person-centred approaches and interchange them accordingly. This suggests that they are able to manage the tension between directing the session on the one hand, and allowing the clients to do so on the other. However, the counsellors believe that the degree to which they succeed in obtaining this balance is a function of the disposition of their clients. With those clients who discuss their plans and request appropriate advice or with those who say very little the counsellors tend to be more prescriptive. On the other hand, with very talkative clients the counsellors have to decide how long to allow them to express whatever is on their minds before interrupting them to relay important and relevant information, something which they find difficult to do. With the elderly they find it particularly difficult to be directive for fear of coming across as intrusive and showing disrespect. In trying to meet the varying needs of their clients they change their counselling mode accordingly so that it is the clients who direct the way the session is conducted. Hence the counsellors feel that they are not fully in control and sometimes they are left wondering whether they were able to facilitate enough expression of feelings in their clients, or to inform them as well as they would have liked to. This reflects the confusion and ambiguity which

Balmer (1992) maintains results from trying to accommodate both the disease-centred and the person-centred approaches.

In addition to reflecting the conflict which arises through interchanging the fact-giving and person-centred approaches, this study also highlights the interdependence of these approaches. The literature confirms the complementarity of these two approaches, and recommends a continuing dialogue between them (Edwards, 1990). The participants maintain that, through listening attentively and actively to their clients, they not only empathise with them but also pick up problem areas and this, in turn, informs the advice and education they give their clients. This is illustrated by the example given by one of the participants of how she succeeds in counselling parents and children together in one session. After giving the parents the opportunity to voice their feelings concerning their children and thus be heard, they are more ready to accept the counsellor's suggestions for dealing with their children in a more understanding way. The children, in turn, feel that the counsellor has normalised their behaviour to their parents and consequently are prepared to open up more about their experiences and feelings. This then gives the counsellor the space in which to educate both parties about the dangers of substance abuse and unsafe sex.

Hence the findings of this research confirm that the counsellors are aware of the importance of both the prescriptive and empathic counselling approaches, which they use interchangeably throughout the counselling process. However, contrary to their belief that this does not create any conflict for them, this study has shown that alternating between these two roles in order to both emphasise prevention and provide psychosocial support, does indeed create conflict and tension, which can lead to the build up of stress (Bond, 1995).

4.2 Stressful aspects of the HIV/AIDS counsellors' work

The stressful experiences described by the participants stem in part from some of the stressors inherent to HIV/AIDS counselling, such as dealing with the stigma surrounding HIV/AIDS and the resultant stress on confidentiality, as well as identification with the emotional experiences of those infected and affected by the disease. However, some of the stressors they identified are more specifically concerned with their working as counsellors in South Africa. In addition, their stressful experiences are also related to the fact that they are full-time nurses working as part-time counsellors at Settlers Hospital.

4.2.1 The stresses of working as HIV/AIDS counsellors in South Africa

A very saddening factor for the counsellors concerns the age of their clients, most of whom are under 30 years of age, an observation which is confirmed by the results obtained by the Antenatal HIV Survey for 2001 conducted by the Eastern Cape Department of Health (2002). They are aware that many of their clients will die while still in the prime of their lives. According to the antenatal survey, “around half of all people who acquire HIV become infected before they turn 25 and typically die of the life-threatening illness called ‘AIDS’ before their 35th birthday” (p.7). One of the participants was particularly “shocked” one day when she had to counsel a 14 year-old girl. Working with the youth also serves to remind the counsellors, three of whom have children of their own, of the real possibility that members of their own families could become infected too.

Sometimes the clients are so young that it is difficult for the counsellors to speak to them about intimate sexual matters. Not only is it uncomfortable to deal with these matters but, as another participant reported, it is frustrating for them to see the ever-increasing rate of teenage pregnancies which proves that the youth are not taking heed of the message of safer sexual practices. Statistics reflect this concern in that there has been an increase in HIV prevalence from 20,6% in 2000 to 22,3% in 2001 for women who become pregnant for the first time (Eastern Cape Health Department, 2002). It is even more stressful for the counsellors when they have to deal with young clients who have been traumatised by the experience of being raped, particularly if it is not clinically possible to administer antiretroviral treatment to them.

A finding of this study which is not reflected in the literature refers to the fact that it is not only the young, but increasingly the elderly, too, who need to be counselled concerning HIV/AIDS. Statistics confirm an increase from 7% in 2000 to 12,5% in 2001 in the rate of HIV among people older than 40 (Eastern Cape Health Department, 2002). The participants find it difficult to counsel people older than themselves as it is not culturally sanctioned to speak to one’s elders about intimate matters, or to question their lifestyle and correct “erroneous ideas”. Moreover, they believe that it is due to the indiscriminate sexual activity of older men that they are needing to counsel increasing numbers of older people, particularly women.

Another stressor for the participants is the contribution which poverty makes to the distress of most of their clients, a factor over which the counsellors have no control. They know very well that, in spite of their efforts to educate their clients about living healthily, the majority of them are too poor to obtain retroviral medication, let alone nutritious food. Van Dyk (2001) maintains that one of the causes of stress among health care professionals comes from giving people the message about living positively and eating well, a message that seems cruel when they are struggling to bring any food at all into the home. A further distressing factor related to poverty is that the younger females in a household sometimes have no alternative but to be sexually intimate with the older males who are the breadwinners, thereby re-infecting themselves as well as spreading the infection (Kinghorn & Steinberg, 1998). A shocking discovery for one of the participants is that poverty makes some people reason that, as they are going to die anyway, they prefer to be tested HIV positive so that they can access the disability grant which is made available to AIDS patients. Research shows that the notion of death as uncontrollable by humans complicates behaviour change in that it leads some people to believe that HIV infection and death from AIDS is preordained by their God (Amuyunzu-Nyamongo et al., 1999). Accordingly, the participants are expected to respond to the lack of welfare provision and support for people affected by HIV/AIDS, as stated by Richter et al., (2001). Being expected to act as caregivers who can meet all the needs of their clients places an additional burden on HIV/AIDS counsellors (Van Dyk, 2001).

4.2.2 Confidentiality and stigma surrounding HIV/AIDS

A substantial amount of the stress experienced by the participants results from their having to maintain confidentiality, not only because it is intrinsic to their work as counsellors, but also because they have to protect their clients from the stigma associated with HIV/AIDS, which makes the public afraid of people with HIV/AIDS (Bond, 1995). Pryor et al. (1999) maintain that people react negatively towards HIV-infected persons due to instrumental (fear of contamination) and symbolic (connection of the disease to negatively evaluated causes) considerations. The former represents a real concern for the participants. As one of them said, “our people are not faithful”, something which all of them attribute to the ever-increasing rate of HIV infection generally. They maintain that the frequency of multiple-partner sex is far more rife in the black communities, where it is more acceptable than in western cultures (cf. Section 1.5.1, p.9, Seeley & Wagner, 1991; Williams et al., 2000). Their fears concerning the spread of HIV/AIDS due to sexual promiscuity also extends into their own personal lives. Not only do they live with the fear that their own children could become infected, as

mentioned earlier, but those who have partners carry the additional stress of their own vulnerability to HIV infection (Buwalda & Kruijthoff, 1994).

One of the participants referred to the stigma which arises from the association of HIV/AIDS with “myths about witchcraft”, which are not easy to dispel and require a lot of cultural sensitivity and tact on the part of the counsellors. The negative symbolic connotation of this illness with being bewitched, or with the danger of bewitching others, prevents clients from speaking out and seeking support. Alternately, some of them seek the help of traditional healers, whose treatments often fail to improve the symptoms of their clients, and sometimes even cause complications. According to this participant, it is thus crucial that HIV/AIDS counsellors should discourage these “perceptions of witchcraft”. Her concerns not only attest to the fear and suspicion which result from these attributions of witchcraft (Uys, 2000), but to the fact that they are still present in some communities. What is more, to ensure a more mutually beneficial relationship between traditional healing and counselling, these concerns are worthy of further consideration. Doing so would also serve to diminish the secrecy and stigma which is attached to HIV/AIDS because of its association with witchcraft, which is regarded as a negatively evaluated cause of the illness (Pryor et al., 1999).

Rather than live with the label of sexual promiscuity or bewitchment many HIV-infected people prefer to suffer secretly. This makes it very difficult for the counsellors to convince their clients to tell their partners or family members about their positive HIV status as the clients are often afraid of how those close to them will react to such information. One of the participants said that some clients fear that their families will disintegrate upon hearing the news and dealing with these fears usually requires long sessions which she finds physically and mentally exhausting. The counsellors realise that, should their clients decide not to inform anyone of their illness, their only source of comfort and support is the one or two counselling sessions which the participants are able to provide. Other than that their clients have no way of sharing their pain or feeling supported but instead, live in a long and lonely silence. Hence the counsellors sometimes take on the responsibility of informing the partner or family themselves, after obtaining the client’s consent, but it is never an easy thing to do. However, even when clients do decide to disclose their status, it can be “heartbreaking” and distressing to witness either that some family members are not really concerned about the health of the infected person or, alternately, how painful it is for some family members to learn of their loved one’s illness. It is clear that it can be very stressful for counsellors to

decide whether it is in their client's best interest to disclose their status. In doing so they have to weigh up whether their clients would obtain more support and care from family members by disclosing their status or by keeping it concealed (Uys, 2000).

The participants are presented with an ethical dilemma when they see their HIV positive clients in the company of a loved one but are unable to inform them of the clients' health status. This difficulty is also highlighted in the literature which suggests that practising confidentiality according to the individualistic tradition does not allow due regard for the culturally sensitive care of the needs of the community (cf. Section 1.5.1, p.11, Uys, 2000). Accordingly, as aptly expressed by one of the participants, they have to "carry that lie" and thereby put someone else at risk of becoming infected. This can lead to feelings of guilt which are exacerbated whenever the counsellors come upon an unsuspecting partner. In addition, the counsellors have to learn to live with the inevitable conflict which arises from their professional responsibility to maintain confidentiality concerning their clients' health status. Research reflects this conflict by highlighting the contradictory messages which are delivered by promoting public information campaigns on the one hand, and yet maintaining the enforcement of strict confidentiality on the other, creating a double-bind situation for HIV/AIDS counsellors (Uys, 2000; Gerber, 2002).

The privacy of the client is rigorously protected by the present policy for health workers with regard to confidentiality (Uys, 2000). However, as explained above, the counsellors feel restricted by their obligation to maintain confidentiality. They would experience less tension and feel more effective as counsellors if they could inform not only those **infected**, but also those **affected**, by the disease. What is more, in their position as counsellors they have first-hand knowledge of the destructive effects of the stigma which is associated with HIV/AIDS, but they are unable to do anything constructive about it. Yet research has shown that personally knowing someone who has AIDS seems to relate to less stigmatisation of PWAs (Pryor et al., 1999). This is due to the fact that people's initial affective reaction to an event is followed by a more cognitive consideration of its causes (Pryor et al., 1999) Accordingly, even if people were to be initially horrified at the news that someone in their family was HIV positive, after some thoughtful consideration of the circumstances involved, they would eventually be able to set aside their prejudices and accept the situation. These findings indicate that HIV/AIDS counsellors too, need to set aside their concerns about the initial negative reactions of their clients' families after hearing of the clients' positive HIV status. In

addition, these findings serve to support the participants' belief that the disclosure of their clients' HIV status to their families would ensure the provision of support for their clients. What is more, counsellors could play a very important role in reducing the spread of HIV/AIDS if they were in a position to inform families of their clients' HIV status as it would both increase awareness of HIV/AIDS and decrease the stigma attached to them. This is substantiated by Uys (2000) who states that lack of disclosure allows for the continued denial of the spread of the disease in South African communities.

Ironically, the counsellors' need to maintain confidentiality and protect people from being stigmatised not only serves to increase their stress, but also limits them from finding some relief from this stress. In sharing their feelings with others, the participants fear they may say too much and give away confidences or, as described by one of the participants, be "gossiping". They confuse confidentiality with secrecy (Uys, 2000) in that they believe that any kind of sharing could be regarded as gossiping. This conflict is confirmed by Brady et al., (1995), who state that, while many professionals seek emotional support from family and friends, the confidentiality requirement may stand in the way of utilising this coping mechanism. Hence it is essential that the counsellors be encouraged to share their difficulties with their colleagues in order to reduce the stress which results from being unable to vent their frustrations or share their therapeutic successes with their peers (Brady et al., 1995). However, to facilitate such emotional expression, it is also essential that they be trained and encouraged to respect the confidences they share with one another (Bond, 1995). In addition, the provision of professional supervision is another avenue which enables health professionals to make disclosures without such action being labelled as 'gossiping' or a breach of confidentiality.

The participants are particularly concerned about counselling close acquaintances because, in addition to dealing with the pain that someone well known to them is HIV positive, they are especially anxious about keeping such information confidential. They are often asked for their opinion or advice, even if only informally, from people they know since, in their capacity as nurses, they are regarded as people who have the knowledge to be able to assist others with many problems, including HIV/AIDS. The literature does not make mention of the stress which accompanies the provision of HIV/AIDS counselling to close acquaintances. Yet the participants all said that, maintaining confidentiality and protecting people from being stigmatised, makes it far more emotionally stressful for them to counsel family

members, friends and colleagues. Not only is the experience of such counselling distressing, but it is even more so if they have to deal with the knowledge that someone well known to them is HIV positive. What is more, should the news of the positive HIV status of a close acquaintance 'leak out', they feel they are more vulnerable to being labelled as responsible for this breach of confidence. This fear is further reflected by an observation made by one of the participants, namely, that it is more difficult to keep information confidential which concerns someone well known to them. Accordingly, the counsellors try and avoid counselling close acquaintances if possible, but they are sometimes torn by the sense of responsibility they feel in having to do so, especially if they have been specifically asked to provide assistance.

4.2.3 Identification with client's experiences, particularly concerning death and dying

Discussion with the participants revealed that helping clients to deal with an illness which is so dreaded and stigmatised evokes strong emotional responses in both the clients and the counsellors. What is more, the counsellors experience additional stress if they over-identify with clients and their families.

The participants' described their reactions as ranging from wanting to be "alone in a dark room" to a desire to "stop the crying" and "make things better" and even to having difficulty getting a "good night's rest". One of them sometimes even takes her clients' problems home with her where she spends time thinking or even dreaming about them. Another participant was so overcome by "the way the daughter was crying" after hearing that her mother's illness was AIDS-related, that she cried with her. This participant also said that, whenever there has been "a lot of crying", she feels emotionally exhausted and is unable to do any further counselling that day. What is more, the stress of conducting a post-test counselling session in which a positive test result is relayed to the client is sometimes so intense that the counsellors refuse to do any further counselling that day because, in the words of one of the participants, they are "human beings and have feelings", like their clients, and do not "take an injection which will make (them) tough".

These emotional stresses indicate that the counsellors' own unresolved feelings are often activated by their clients' pain. Hence they are caught in the dilemma of trying to empathise with the clients' feelings while, at the same time, trying to avoid being adversely affected by them (Brady et al., 1995). Such a process can create distress for counsellors in that they are

either lost in overwhelming emotions or need to excessively disengage from them (Bond, 1995). Whatever their reactions, counsellors need emotional support in order to feel free to express their underlying feelings. In addition, they require professional supervision which will assist them in distinguishing between their clients' difficulties and their own unresolved issues.

Another way in which the counsellors show that they are emotionally involved in the welfare of their clients is evident in their eagerness to ensure that they have done enough for their clients. Research has shown that many HIV/AIDS counsellors struggle with this tendency to carry the weight of their clients' problems (cf. Section 1.5.2, p.13, Grinstead & Van Der Straten, 2000). Van Dyk (2001) states that caregivers often experience stress when they are unable to meet their clients' needs because of the feelings of inadequacy and guilt which result when they can do no more for them. Accordingly, they sometimes take too much responsibility for their clients' lives in that they make appointments informally with the result that they attend to clients in between their other duties or even out of hours. Two of the participants mentioned working with clients during their tea or lunch breaks. Although this reveals the counsellors' appropriate concern for more follow-up sessions for their clients, it could also be a reflection of the clients not receiving enough counselling, and hence of the need for the provision of ongoing counselling at the hospital.

Because HIV/AIDS is a terminal illness, informing clients that they are HIV positive could be compared to giving them the death sentence. Consequently, an important part of the counsellors' work is to help their clients work through their fears of dying and then make appropriate arrangements. Research conducted by Bennett (1995) found that death and issues surrounding the deaths of patients were the greatest cause of concern for all health workers. One of the participants said that it is "really, really a painful time" for her when she is dealing with a dying person and that she tends to carry that pain, "maybe even for a day". Relief from this pain is obtained by reassuring the client, and perhaps herself, with the knowledge that everyone will die one day. Alternately, she feels "bad" about the death of her clients and deals with this by "not attaching the disease to the death" and instead, tells the client that it is not HIV/AIDS which causes death, but one's attributions concerning this disease. She believes that patients will feel "more sick" if their attributions are negative ones as they are more likely to give up and say, "Okay, I better die because I've got this diagnosis". Two of the participants make use of some form of denial to deal with their distress concerning the

terminal nature of HIV/AIDS. One of them gave the example of agreeing to pay daily visits to a client after he was admitted to hospital but being unable to tell him that he was dying as it was too painful for her to manage his fear of dying. The other said that she only refers to the terminal nature of HIV/AIDS in the pre-counselling session as she does not want people to think about dying when she counsels them, but rather about living. It is clear that it is stressful for the participants to manage their clients' feelings concerning death and dying and hence they would benefit from regular training in skills concerning this essential aspect of HIV/AIDS counselling.

Another stressful factor for HIV/AIDS counsellors is the fact that they sometimes have to deal with clients who, faced with the stigma and suffering which is associated with HIV/AIDS, consider suicide as a possible solution. This study confirms research findings which describe the high levels of stress which counsellors experience following suicidal statements from their clients. Firstly, clinicians may feel terrified at the knowledge that someone is so desperate as to consider nothingness as a viable option (Brady et al., 1995). One of the participants expressed this fear by saying that she knows she is "in trouble" when clients react as if they have "closed the curtain already". Secondly, Brady et al. (1995) maintain that clinicians can experience immense responsibility to help a suicidal patient and realise that any mistake may prove to be lethal. This was reflected by a second participant who feels that she cannot disclose the "strange feeling and pain" which she experiences to those clients who seem to want to "give up hope". Thirdly, the entire therapeutic process is altered once a patient is assessed as suicidal (Brady et al., 1995). This, too, was expressed by one of the participants who said that, with a suicidal patient, she has to "go over the same things quite a few times" in order to try and "take the idea away", something which she experiences as taxing and draining.

This section has illustrated that the emotional distress which is inherent in the process of HIV/AIDS counselling makes it difficult for the counsellors to remain objective while counselling. In the words of one of the participants, they are "in the patient's shoes most of the time" and cannot always distance themselves from their clients' world. Bennett (1995) maintains that the intensity of grief and burnout experienced by HIV/AIDS health workers is related to their level of identification with clients. Brady et al. (1995) state that over-identification and over-involvement with patients may result in the practitioner losing her ability to communicate her understanding to them and thereby diminish therapeutic

effectiveness. Hence it is thus clear that the counsellors need the emotional support with which to process their own feelings as well as professional supervision to avoid their clients' issues becoming their own.

4.2.4 Working as nurse-counsellors at Settlers Hospital

Some of the stresses identified by the participants relate to their place of employment, i.e. Settlers Hospital (cf, Section 3.5.4, p.49). This confirms that the potential for occupational stress may be an institutional experience, in addition to an individual one (Miller, 2000). What is more, it highlights how essential it is that those responsible for the day-to-day running of the HIV/AIDS counselling programme at the hospital should attend to the problems which give rise to these stressors. Literature supports the fact that any constraints and challenges to counselling implementation need to be addressed by developing services that appear attractive, relevant and accessible, and overcoming staff fears, exhaustion and burnout (Miller, 2000). The alternative, he maintains, results in very serious consequences for those most directly involved, i.e. those trained to counsel and charged with implementing what they know.

As already mentioned in the previous chapter, the participants are nurses first and then HIV/AIDS counsellors in that they all counsel in a part-time capacity only and have to give priority to their nursing duties. This means that their counselling sessions are sometimes interrupted with a request to attend to urgent nursing duties, or need to be speeded up in order to do so. In addition, having to attend to their nursing duties after a counselling session means that there is usually no time in which to process the feelings which arose during that session. Consequently, the demands made on them as nurses not only undermine their effectiveness as counsellors but also create conflict for the participants, both of which lead to an accumulation of stress. Perhaps this reflects a failure on the part of those in authority to grasp that HIV/AIDS counselling is an emotionally demanding task and does not merely involve the giving of information and the dispensing of advice (Coyle & Soodin, 1992).

There is also a more fundamental conflict which arises from fulfilling the twofold role of nurse and counsellor in that, as nurses the participants have been trained to "make people better", but as HIV/AIDS counsellors their task is to assist people to come to terms with the implications of an incurable disease. Hence, although both roles are experienced as demanding by the participants, they feel more in control as nurses than as counsellors. Since

research indicates that some perception of control mitigates job stress (Van Der Straten, 2000), it follows that counselling is experienced as more stressful than nursing. In fact, three of the counsellors said that they find it easier to be nurses than counsellors, which further highlights the need for those in management to be both be cognisant of, and address, the stressful nature of counselling work.

The participants all feel that the shortage of nursing staff at the hospital serves to increase their level of stress. Insufficient staff sometimes translates into long queues of patients requiring nursing or counselling. This results in insufficient attention being given to the patients and, in turn, strained interpersonal relations between nurses and patients, or counsellors and clients. Not only does this situation demand extra energy of the nurse-counsellors but it can mean that they are not at their best. Both of these serve to prejudice the quality of nursing and/or counselling care rendered and is something which the participants reported to be disconcerting. Research confirms that nurse-counsellors in health institutions have a demanding workload so that counselling can become an additional burden (cf. Section 1.2, p.4, Seidel, 1996; Gerber, 2002). Reduced staffing at the hospital also restricts the counsellors to offering only pre- and post-test counselling, rather than ongoing counselling, which is regarded as an essential part of providing health care to those infected with HIV (cf. Section 1.2, p.3, Bond, 1995).

In addition to the staff shortage and interruptions during counselling sessions, there are a few other practices at Settlers Hospital which add to the counsellors' stress load. They sometimes have to take a post-test counselling session, which is always emotionally demanding, without having previously built a therapeutic relationship with the client concerned. The counsellors feel this makes the session even more taxing for them. Furthermore, the restricted use of telephones not only makes it difficult for them to contact clients who do not keep their scheduled appointments, or whose appointment bookings need to be changed, but also increases their frustration levels. One of the participants added that it is also no longer possible to contact clients through the mail without going through a lengthy authorisation procedure.

Dissatisfaction was also expressed at the fact that the counsellors may not conduct HIV testing on anyone without a referral from a doctor and that volunteers have to be referred elsewhere. This contradicts the view of the HIV/AIDS co-ordinator as well as one of the

participants, both of whom referred to the availability of VCT (Voluntary Counselling and Testing) at the hospital, thereby suggesting some lack of communication between management and the counsellors. This lack of communication also extends to the fact that, in spite of their hard work and the difficulties which they encounter in the course of their work, the counsellors feel that their efforts are not acknowledged by management, either financially or through other incentives.

The findings of this study thus indicate that some of the frustration and stress experienced by the participants is the function of difficulties experienced at an organisational level and, as such, need to be resolved at an organisation level, to prevent overworked counsellors from becoming less effective in their work (Bor & Sher, 1992). The Department of Health (2001) maintains that lack of consultation, an absence of performance appraisals, poor promotional prospects and “demotivating” salaries are contributory factors of work-related stress. In addition, the literature cites context management as a way of preventing occupational morbidity (cf. Section 1.7.3, p.19, Miller, 1995). This makes provision for management to set up initiatives which serve to improve the counsellors’ work experience, including tangible recognition of diligence and positive outcomes.

4.3 Effect of personal life experiences

Upon examining their personal life situations this study found that the two participants who have good family support and partners experience fewer difficulties at home than those who do not. They are also able to speak to people at home if they are feeling stressed. The literature confirms that family members are generally viewed as the most appropriate group for providing extensive long-term help, advice and comfort (Taylor & Chatters, 1986). It is interesting to note that these two participants are the ones who find more time to relax and take part in leisure activities. However, the two participants who do not have partners and feel they do not have a support network available at home, have learned to turn to their colleagues at work when they need to share their problems. In addition, they rely on daily prayer and faith in a loving God for support and socialise through participation in church activities. This concurs with research conducted by Taylor & Chatters (1986) in America, that black churches are an important component of both formal and informal support to their members. Following on these observations, it is hypothesised that the counsellors who do not have a support network available at home turn to institutions, such as their place of work and the church, for support.

Although the two participants with partners appreciate the support they receive from their partners, they also consistently have to deal with their fear of the possibility of HIV infection. Research by Grinstead & Van Der Straten (2000) found that counselling made married female counsellors reflect on their own vulnerability to HIV, mostly as a result of their husbands' behaviour. Moreover, one of these participants also expressed concern about her daughter's risk of becoming infected. On the other hand, the participants who do not have partners find it a relief not to have to worry about the personal risk of becoming infected with HIV. However, it was their previous unpleasant experiences with partners which resulted in their choosing not to be in a relationship. These findings accord with Bond's view (1995), that it would be an exceptional counsellor who is not periodically stressed by the possibility of HIV infection of themselves or of significant others. This once again highlights the participants' unanimous view that, in their experience, men cannot be trusted to be faithful to one woman (cf. Section 3.5.1, p.42). Consequently, although the findings of this research indicate that a partner can act as a source of support for the counsellors, the converse is also true, since having a partner can create additional emotional stress.

Another noteworthy finding with regard to the personal experiences of the participants concerns the resilience which they display in the face of the difficult circumstances which they live through. One of the participants lives with the daily tension of stressful living arrangements caused both by the friction of sharing accommodation with her sister and nephew and also the discomfort of living in a home while it is being renovated and extended. Another participant has lived without electricity for at least six months, which not only makes life far more primitive and uncomfortable, but has also increased her already tight budget. In spite of these very difficult living conditions, they have come to work every day and still have the energy and compassion to care for others. This is remarkable when one considers that personal life events may significantly interfere with counsellors' attempts to remain consistent and caring in their therapeutic relationships (Brady et al., 1995).

4.4 Discussion of results obtained on BAI and BDI-II

In determining the stressful experiences encountered by the participants this study assessed whether the demands made on the HIV/AIDS counsellors resulted in any form of clinical anxiety or depression. However, although the participants' responses indicate that they experience many stressors in their work, and that their personal lives are not untouched by stress, the results obtained on the BAI and BDI-II self-report scales (cf. Section 3.7, p.57) do

not point to any clinical diagnosis. Instead, they indicate that the participants' level of anxiety and/or depression are situational in nature. It is interesting to note that the participant who identifies the most closely with her clients' emotional experiences scored the highest number of anxiety symptoms on the BAI while the one who felt that her home situation caused her more distress than her work obtained the highest score on the BDI-II.

4.5 Support structures available to, or needed by, the counsellors

Although some attempts were made to set up some form of support for the HIV/AIDS counsellors, these are no longer operational so that, at present, there are no formal structures in place which serve to meet their needs for support (cf. Section 3.8, p.58). Hence the only way in which the participants are able to get some relief from their stress is informally, which they do by discussing their problems with their colleagues. However, the findings of this research indicate the need for formal structures to be put in place which would afford the counsellors the opportunity of alleviating some of the stress inherent in their work and of acquiring new coping skills to prevent the unnecessary build-up of stress.

All of the participants liked the idea of meeting in small groups of about six people which would not only encourage them to open up and share confidential matters but also enable them to support one another. Bennett (1995) maintains that support groups are necessary for offering counsellors empathy and acceptance of their true feelings, particularly because, although they are good at giving support, they are notoriously bad at receiving it. These groups should be facilitated by a suitably qualified person, who should also be an outsider as this would make it easier for them to open up (Grinstead & Van Der Straten, 2000). However, as substantiated by one of the participants, it is not enough to merely provide support for the counsellors as it is essential to also explore the factors underlying the stress experienced by them. These concerns are reflected by research which found that only a quarter of organisations offering counselling in South Africa have a supervisory framework to support counsellors, but even fewer than that collect any data which can be used for evaluation purposes (Richter et al., 2001).

Some of those involved in HIV/AIDS counselling at managerial level believe that one-to-one mentoring and/or supervision would be the ideal form of support for the counsellors (Botha, 2002; Sue Whitley, 2003). Research confirms the need for such support in order to enable counsellors to work through the powerful feelings and anxieties which they experience in

their work and thereby avoid being overwhelmed by them (Kiemle, 1994). Furthermore, this form of support is recognised by the Department of Health's National HIV/AIDS programme (Department of Health, 2001), although it has not yet been implemented in the Eastern Cape (cf. Section 1.7.2, p.17, Botha, 2002). As the counsellors work in public surroundings it would be necessary to ensure the privacy of the venue for such a service (Department of Health, 2001). Two of the participants were concerned about anonymity and even suggested that mentoring/supervision take place off the premises.

Discussion with both the participants and the HIV/AIDS co-ordinator revealed that they all recognise the need for in-service training. Topics suggested include input on the sensitivity of counselling people older than themselves, dealing with sexual matters in the black culture and managing one's feelings when counselling close acquaintances. The co-ordinator felt that the counsellors needed to be updated on the latest information concerning HIV/AIDS, such as the Nevirapine debate for MTCT (mother-to-child-transmission) and exclusive breastfeeding. Ongoing training is mentioned as a requirement for maintaining common national standards among HIV/AIDS counsellors (HIV/AIDS and STD Directorate, 1998). What is more, HIV/AIDS counsellors need to be constantly updated since the HIV/AIDS epidemic is "not yet quite understood" (Department of Health, 2001, p.184).

The discussion presented in this chapter concludes that the HIV/AIDS counsellors at Settlers Hospital face various challenges in their work, which concurs with the findings of other studies conducted in developing countries (Buwalda & Kruijthoff, 1992; Grinstead & Van Der Straten, 2000). One of these stems from their having to alternate from being prescriptive advice-givers to non-directive and empathic listeners in order to encourage prevention and a healthy lifestyle on the one hand, and provide psycho-social support for all those affected by HIV/AIDS on the other. Working as HIV/AIDS counsellors in a developing country provides a further challenge due to socio-economic factors, particularly the young age and the poverty of most of their clients. Another significant stressor stems from dealing with the stigma and resultant secrecy which surrounds HIV/AIDS, as well as its association with a death sentence, all of which make it difficult for the counsellors not to become emotionally involved with their clients' experiences. The limitations and demands placed on them in their dual role of nurse and counsellor at a public health institution serve as yet another factor which contributes to the stresses and challenges they face as HIV/AIDS counsellors, particularly in light of the constraints which they experience at their place of work, namely Settlers Hospital.

This chapter concludes further that the results obtained on the BAI and BDI-II would seem to indicate that the counsellors are presently able to contain and manage the stresses which they experience in their work. The above discussion also indicates that the counsellors' personal lives do not appear to adversely affect their stress levels at work but rather, that some of them show signs of resilience in being able to continue working in the face of difficult personal circumstances. However, the counsellors all expressed the need for various forms of support to assist in alleviating their stress. Consequently, the final chapter of this study includes a number of recommendations which would serve to lighten the load of the counsellors and thereby improve the quality of service provided to their clients (Bond, 1995).

Chapter Five

THE WAY FORWARD

This study concludes with recommendations which have been informed by the research findings. These recommendations serve firstly, to ease some of the stresses which the HIV/AIDS counsellors at Settlers Hospital experience and secondly, to highlight further research needed concerning HIV/AIDS counselling in South Africa.

5.1 Recommendations for alleviating counsellor stress

The results obtained in this research have shown that the HIV/AIDS counsellors at Settlers Hospital encounter many stressful experiences in the course of their work. Accordingly, it is recommended that management, in consultation with the HIV/AIDS counsellors, set up various structures at the hospital which will ensure that counsellors have access to frequent and consistent support.

5.1.1 Provision of emotional support

As shown by this study, the counsellors experience many emotions in the course of their work. Such emotions include those which arise in the course of their empathising with clients, whether this be because of the latter's pain, grief, anger or fears concerning their illness or their difficult socio-economic conditions. Intense feelings also result from having to be both nurse and counsellor, advice-giver and empathic listener, as well as someone who has to protect the rights and interests of both the **infected** and the **affected**. In addition, the counsellors have to deal with the emotions which pertain to their own personal life experiences.

However, according to the results obtained from this study, the counsellors only rely on informal measures as a way of receiving emotional support and mitigating their stress since there are no formal structures in place through which to do so. It is thus essential that formal support structures be set up at the hospital to afford the counsellors a regular avenue for expressing their emotions and addressing their underlying concerns. Counsellors cannot 'be there' for their clients if someone, in turn, is not 'there' for them (Kiemle, 1994). Accordingly, a suitably qualified person, who is not a member of the hospital staff, needs to be employed to facilitate peer support meetings for the counsellors. Details such as the size of these support groups (the participants in this research recommend about six people) and the

frequency of meetings could be determined in consultation with the counsellors, but such meetings need to be held regularly in order for the counsellors to feel emotionally supported and hence benefit from their existence (Jenkins, 1997).

5.1.2 Provision of professional supervision

In addition to receiving emotional support, the counsellors need to improve their clinical skills in order to address some of the difficulties they encounter. These include managing the two ways of being with clients, encouraging disclosure, over-identification with clients, dealing with sensitive issues such as sexual practices and inaccurate beliefs surrounding HIV/AIDS, and overcoming practical constraints. Hence the support groups mentioned above, which would serve to fulfil the counsellors' need for emotional support, are not to be confused with the provision of professional supervision. The former validates the importance of giving time to the counsellor's personal needs while the latter focuses on understanding the client's experience and improving clinical skills. Supervision thus helps the counsellor to separate her responses from those of the client and hence work more effectively (Kiemle, 1994; Bond, 1995). According to Bor & Sher (1992), supervision enables counsellors, *inter alia*, to recognise the constraints of the therapeutic context and how their personal styles facilitate or hinder the achievement of their therapeutic goals.

In order to be effective, professional supervision needs to be offered by an experienced counsellor (Department of Health, 2001), preferably a psychologist, who not only has the necessary skills but is used specifically for the purpose of supervising the counsellors. Gerber (2001) states that it is a common complaint among counsellors that they do not receive good supervision as it is usually managers who are expected to perform this role and they have neither the time nor the ability to do so. Professional supervision does not include the planning and utilisation of the counsellors' resources but rather the provision of a regular space in which they can reflect constructively upon the content and process of their work and thereby find possible solutions to the problems they encounter (Hawkins & Shohet, 1989). By promoting their professional growth and development in this way the counsellors would not only enhance their counselling skills but would also improve their confidence, both of which would serve to diminish their job-related stress (Bor & Sher, 1992; Department of Health, 2001).

5.1.3 Provision of ongoing in-service training

This study has shown that the counsellors do not receive regular in-service training and, what is more, they feel they would benefit from such a service. What is more, it is stressful for counsellors to perform effectively in such a responsible position without the skills needed to do so. The participants maintain that they need to feel confident about their ability to handle certain issues with ease in order to be more effective as HIV/AIDS counsellors. These include how to counsel people older than the counsellors themselves without transgressing cultural customs, and how to deal with sexual matters, especially in the African culture where it is generally considered a taboo topic. The co-ordinator of HIV/AIDS at Settlers Hospital specified the Nevirapine debate for MTCT (mother-to-child-transmission) and exclusive breastfeeding as areas in which the counsellors need to be updated.

In addition, the results of this research have revealed further ways in which the counsellors would benefit from in-service training. It is clear that they do not only engage in individual counselling, but are often required to practise couple and family counselling. As they did not acquire these counselling skills in their training as HIV/AIDS counsellors, it is important that they acquire them through in-service training. This will not only make them more effective couple and family counsellors, but will also help to relieve them of the stress involved in implementing a form of counselling without the necessary skills. Addressing clients' fears and concerns around dying, death and bereavement is yet another stressful experience for the counsellors which needs to be addressed on an ongoing basis through regular input from an in-service training programme.

The literature cites the provision of ongoing in-service training as yet another form of professional support for HIV/AIDS counsellors (cf. Section 1.7.2, p.18). Furthermore, Miller (1995) lists lack of training as a significant stressor in HIV/AIDS work. Hence it is recommended that the present sporadic provision of in-service training be replaced with a system which will ensure that counsellors are regularly equipped with additional skills and knowledge, particularly in areas which are crucial to HIV/AIDS counselling or which have been requested by the counsellors.

5.1.4 Provision of managerial support

Managerial support is yet another form of support which this study recommends should be made available to the counsellors. This entails the provision of a forum which will address

the counsellors' concerns with regard to matters pertaining to counselling practice, the working environment, and administrative or practical restraints. Not only will such support result in better communication between the counsellors and those responsible for the provision of HIV/AIDS counselling at Settlers Hospital, but it will also ensure that the counsellors have a say in reshaping the counselling services which they have been entrusted to deliver (Miller, 1995).

However, the findings of this research indicate that there are already a number of present practices which need to be addressed by management, in consultation with the counsellors:

- *Interruptions during counselling sessions*

It is essential that administrative procedures at the hospital take into account that interruptions during counselling sessions undermine the effectiveness of these sessions. Participant data highlight how stressful it is for the counsellors to have to deal with interruptions, whether personal or telephonic. Accordingly, hospital staff need to be informed of the sensitive and confidential nature of counselling sessions and of the need to respect the privacy of both the client and the counsellor while a session is in progress. As mentioned by one of the participants, allocating a designated room for counselling in a more secluded area of the hospital would help to minimise interruptions. It should also be accepted practice for counsellors to unplug their phones during sessions, as well as ten minutes before and after sessions. This would not only prevent people from disturbing the therapeutic relationship, but would also afford the counsellors some space in which to prepare for the sessions beforehand as well as contain and reflect on their feelings at the end.

- *Counselling close acquaintances*

This study shows that counsellors find it difficult to counsel close acquaintances, including staff members, as they are particularly concerned about the maintenance of confidentiality. In addition, such situations create a blurring of professional and personal boundaries which further serves to limit the effectiveness of such therapeutic encounters. Accordingly, it should become part of the HIV/AIDS counselling policy that counsellors do not work with anyone whom they know well. Should it be a staff member who requires or requests counselling, it would be in their best interest for this to be provided, wherever possible, away from work and by someone who is not a fellow member of staff.

- *Need for ongoing counselling*

The minimum standards training manual for trainers of HIV/AIDS counsellors includes a module on ongoing counselling for clients to ensure that they are supported throughout the various stages of their illness as they become progressively more debilitated by the symptoms of AIDS (Department of Health, 2001). However, this research indicates that it is not common practice for the participants to provide further counselling after the pre- and post-test counselling sessions. In spite of the limited resources available and the practical difficulties associated with clients being able to get to the hospital, every effort must be made to ensure that clients have access to ongoing counselling as HIV/AIDS presents clients with a progressively poor prognosis and thus requires a continuation of emotional support. This would have the added benefit of doing away with some of the counsellors' present practice of meeting with clients at odd times in between their other duties or even in their tea or lunch breaks.

- *Affirmation of counsellors' work*

It is necessary for management to recognise the stressful nature of HIV/AIDS counselling and the valuable service which it provides in order to help the counsellors feel appreciated and affirmed for this emotionally demanding work. Such acknowledgement could take various forms, but is only effective if combined with the ongoing evaluation and improvement of present practices and the provision of emotional, professional and managerial support, as indicated above.

- *Keeping up to date with developments in professional practice*

Last, but not least, it must be borne in mind that any new knowledge obtained, whether it be from the findings of this study or from the benefits of in-service training, will result in the creation of new ideas and possibilities. Accordingly, it is important that management remain open to change and update their programmes accordingly.

In considering these recommendations it must be borne in mind that they are the product of the findings of this research which was conducted with a view to firstly, understanding the experiences of those providing HIV/AIDS counselling at Settlers Hospital and then secondly, using these experiences to bring about whatever changes were needed to meet their professional needs and thereby improve the delivery of this valuable service. In this way the HIV/AIDS counselling programme at the hospital can work towards becoming one which is

able to make an even greater contribution to reducing the debilitating effects of HIV/AIDS in South Africa.

However, on a broader level, it is hoped that other institutions which offer HIV/AIDS counselling will also be able to use these findings to assist them in understanding the nature of some of the stressors underlying the experiences of their counsellors. It is further hoped that, where applicable, they will implement the above recommendations in order to provide more appropriate support structures for their counsellors and thereby improve the effectiveness of their services.

5.2 Recommendations for further research

The findings of this study have opened up other research areas relevant to the provision of HIV/AIDS counselling, particularly in a developing country like South Africa. One of these concerns the value of ongoing in-service training for HIV/AIDS counsellors, which could be explored at Settlers Hospital once it has been underway for some time or alternately, at an institution where such a service has already been in place for a number of years. In similar vein, it would be worth exploring the effectiveness of the provision of both emotional support and professional supervision to the HIV/AIDS counsellors at Settlers Hospital once these have been in operation for some time, or in any other healthcare setting where these support structures are in place.

Two other areas which require further research were suggested by the HIV/AIDS coordinator at Settlers Hospital. One of these reflects her concern with the dropout rate of volunteer counsellors. She would like to see an investigation into the number of HIV/AIDS counsellors who are still providing counselling after having been trained, or who have stopped doing so, together with the reasons for the statistics obtained. The findings of such a study would be valuable for assisting with the adoption of measures for the retention of counsellors and thereby ensure that more are made available for the ever-increasing need for their services. The other area involves an evaluation of the counselling offered to clients. This would include questions concerning the effectiveness of pre- and post-test counselling sessions and whether the counsellors are able to put into practise the skills which they acquired in their training.

In terms of the findings of this study such an evaluation should be extended to include an investigation of the need for further counselling after pre- and post-test counselling. This would entail a comparison of the benefits to clients of receiving pre-and post-test counselling only, as opposed to receiving ongoing counselling in addition to these two important sessions. An indication of the need, if any, for ongoing counselling, is particularly relevant in the face of VCT, which reduces, rather than increases, the counselling available to clients. A further aspect related to this concerns an investigation into which particular clients would benefit most from either short-term or long-term HIV/AIDS counselling.

Yet another aspect of research in the HIV/AIDS field which arises from this study concerns the role which witchcraft still plays in HIV/AIDS. Although only one participant referred specifically to the dangers of cultural myths and risky healing practices, they merit investigation in light of the fact that some traditional methods of healing can be beneficial to those infected with HIV/AIDS. What is more, traditional healers are becoming increasingly integrated into the health care system in South Africa.

5.3 Concluding thoughts

The findings of this study agree with current research which describes HIV/AIDS counselling as a stressful occupation in that it increasingly deals with the psychosocial context of the disease rather than merely educating clients about its prevention. What is more, in developing countries like South Africa, where HIV/AIDS is still on the increase (Eastern Cape Department of Health, 2002), the occupational stress which counsellors experience can be expected to increase and consequently needs to be addressed. However, the results of this research indicate that, in practice, health managers do not seem to be aware of the psychological aspects involved in the provision of an HIV/AIDS counselling service. Hence there is a need for more psychological research to ensure that this dimension is accorded its rightful place in the planning and practice of HIV/AIDS counselling services provided by health organisations.

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APPENDIX: Case Narratives

Dina

Setting the scene

Dina is a 43 year-old, Xhosa-speaking woman from Grahamstown. She has a three-year diploma in General Nursing and one-year diplomas in Midwifery, Psychology and Community Nursing. She is currently registered for a B.Care degree in Administration and Education through Potchefstroom University as she would like to be a nursing tutor.

At present Dina is working in the Specialist Clinic which attends to patients who have been referred by local clinics, OPD (Out-Patients Department), or private GPs. She also helps out at OPD whenever she can as they are often busy. Dina counsels as the need arises and, on average, sees about three clients a day, in addition to her nursing duties.

Motivation for becoming an HIV/AIDS counsellor

Dina became an HIV/AIDS counsellor because she likes helping people. Furthermore, she has realised that it is important to educate people about HIV, such as the value of good nutrition and the “myths” which exist concerning this illness. Dina also realises the importance of making people aware of HIV as many people are “so blind” about it and think “it will never happen to them”. But she believes that everyone is involved as they all have a relative or a friend who is HIV positive, even if they themselves are not.

Training received

In 2000 Dina attended a two-week course given by Sr. Sue Whiteley from Settlers Hospital and Buyiswa Yako, a Health Worker at the District Office in Grahamstown who is also an HIV/AIDS trainer. The course attended by Dina did not include input from a PWA (Person Living With AIDS) and there was no evaluation of the material covered except for being asked what the participants felt about the course. At the end of the course Dina was awarded a certificate which states that she completed a course in HIV/AIDS counselling and the Syndromic Approach of STIs (Sexually Transmitted Infections).

The first section of the course looked at personal experiences and values. Emphasis was laid on not being biased or judgemental, no matter what the clients tell the counsellor, as there is always a reason for people’s actions. The course thus stressed that it was not as important to know how the virus was obtained as it was for the person to accept that they had the virus and not to blame or pass judgement on their partner.

The second part of the course covered the virus itself, including the CD4 count and the window period. Although the Results of the Rapid Test are available within a couple of days, patients are asked to return for their results ten days after taking the test as this gives the counsellor/nurse the opportunity to do the Eliza Test as well which serves to give a confirmatory result of the Rapid Test. The results have to be given face to face to ensure accuracy and confidentiality. If the result is negative a further test is taken after three months to allow for the window period. But with any test, if the result is positive the person is definitely infected. Positive living, such as proper diet, exercise and mental health, was also included in this part of the course as was the use of precautionary measures, namely, abstinence, being faithful to one partner, and/or the use of condoms, and how to handle people’s body fluids without becoming infected.

Communication formed a large part of this second section of the course and aimed at giving health workers pre- and post-test counselling skills. She learned that the venue should be a quiet room and free from disturbances. Also how to approach the client, introduce yourself, use of eye contact and a language that is understandable to the client. In addition, make her comfortable, avoid distracting mannerisms such as playing with your pen, and then give the patient the space to talk about anything they want to, including how they became infected, while adopting good listening skills. The trainees were taught to encourage people to take the blood test, as well as their partners. Informing the client about the window period, positive living and taking precautions was essential even if they tested negative, as they could be in the window period and thus actually be positive. Enquiring about the possibility of any STIs was encouraged and, if necessary, advising the clients to obtain treatment both for themselves and their partners as this is a good preventive measure. In addition, those clients who require further counselling should be encouraged to return for another appointment. Although it was important to encourage clients to involve their partners or parents, clients are advised not to tell anyone until they are ready to do so as they have to accept the news first before they can tell others. If requested to do so, the counsellor can do the disclosing to others, after having obtained written consent from the patient, and usually in the presence of the patient.

Dina described her training as a “mind opener” because it helped her develop a “way of talking” to clients which takes into account the importance of listening. Being trained as a counsellor also gave her the confidence to address her church congregation on matters related to HIV/AIDS.

Conflict, if any, between two ways of being with clients

Dina thinks the most important part of counselling is to listen to the client because it helps her to empathise with the client. Many clients trust the counsellor enough to talk about personal issues which are far removed from HIV-related issues. But it is the client who is faced with the problem(s) and it's up to her to find a solution. By listening to the client and pointing out possible ways of solving her problem(s) the counsellor acts as a facilitator so that the client can decide for herself what she wants to do. Dina does not feel there is a conflict between being the expert on the one hand and the silent listener on the other. However, she finds it less taxing to be directive and give facts because there are fewer emotions involved and one knows exactly what needs to be said, such as how to eat well. In addition, providing information is a way of helping the client to help herself because she cannot always be there for her client. But in the listening or non-directive mode one is never sure what to expect nor what one is going to say in response. It is also uncomfortable to interrupt the client while she is speaking but Dina feels she has to in order to present a possible solution to her, a solution which may be a biased one as she cannot fully appreciate the client's personal experience. For example, she may tell the client about nutritional eating habits, only to find that poverty prevents the client from eating balanced meals. Dina finds that it is more difficult to be directive with elderly people. She gave the example of a lady who refused to be tested, saying that she was old and had not had sexual contact for many years. The idea of being tested was repulsive to her so Dina let her do most of the talking and did not insist on recommending an HIV test. But parents appreciate the opportunity to have someone who will listen to them as they relate the difficulties they experience with their children's behaviour, particularly substance abuse and sexual activities. However, they often do it to embarrass their children in front of the counsellor in the hope that they will change their behaviour. Accordingly, after listening to them, Dina becomes more directive in order to normalise the children's behaviour which reassures both the parents and the children. This encourages the children to become more open so that Dina once again becomes the listener as

they talk about their experiences and thereby disclose information previously unknown to their mother/parents. After such disclosure Dina again adopts a more prescriptive way of being with the clients by educating them about the dangers of substance abuse and unsafe sex.

Stressful aspects of the work

Although Dina believes that her work as a counsellor is essential for keeping people informed about HIV/AIDS, she nevertheless finds that it is often stressful. On average she counsels three patients a day, but sometimes she has to see up to six/seven clients a day and this makes her very tired. At times clients insist on seeing her and no one else so she feels obliged to do so but often has to cut the session short because of other duties which are pressing. This creates further stress as Dina feels she has not spent sufficient time with them and so asks them to return for another session, although she may not be available to see them if they do return. If she were only a counsellor and not also a nurse she feels she would be able to spend more time with her clients and would also be able to follow up on them if necessary.

However, as a nurse, Dina realises that it is in the nature of nursing to have to work very hard and to play different roles in addition to nursing, such as counsellor, carer and social worker. The shortage of nurses experienced at the hospital exacerbates the demands made on the nurses, who strive to meet the needs of their patients, for example, with applications for disability grants. If these needs are not met then the patients tend to hold the nurses responsible which leads to strained interpersonal relations and further stress for the nurses. In addition to a nursing shortage there is also a shortage of doctors, who thus have to rely on the nurses to do most of the examination of patients and then they only come in at the end to make a diagnosis. Another problem experienced by Dina is that, if a doctor has ordered blood samples for tests other than the HIV Rapid Test, for example, ESR (Estimated Sedimentation Rate of the blood) or FBC (Full Blood Count), those nurses who are not counsellors do not want this person to have their blood taken twice. As a result, the HIV/AIDS counsellor, after doing the pre-counselling, has to take all the tubes of blood, which adds to the workload. But it is important to take an FBC because the doctor may be very interested to diagnose PTB (Pulmonary Tuberculosis), or an ESR which tests the possibility of inflammation which, if high, points to definite TB (Tuberculosis) in which case the doctor would be interested in a Rapid Test. Dina resents having to do all this extra work as it not only tires her but she is not paid for it nor are there any incentives for doing it.

These demands made on her as a nurse also affect her effectiveness as a counsellor, particularly with intense and difficult sessions. Dina cited the example of a case involving a lady and her partner who were both negative. They were contemplating marriage but when the lady tested positive she became very frightened and did not know how she was going to explain this to her boyfriend. This session took at least an hour and Dina found it to be exhausting. She often has to deal with cases where one of the partners tests positive for HIV but is afraid to tell his/her partner. Then she as the counsellor finds it difficult to have to persuade that partner to disclose because it could result in “family disintegration”.

An added source of stress to these already taxing sessions is the fact that Dina is often interrupted during a session either by a counsellor who needs to get results from the cabinet or even by someone in the hospital asking her to go and do something else. As her nursing duties take priority she sometimes has to speed up the session in order that she can attend to what came up while she was counselling. This not only restricts the time she is able to spend with clients but also interferes with the quality of the counselling session, which threatens to

become a “slapdash thing”. She does not believe it is possible to put up a ‘Do Not Disturb’ sign to try and curb the interruptions as this could lead people to suspect that people in the room are HIV patients which would compromise confidentiality. She would prefer it if the counselling room were in a more secluded place where the sessions could continue uninterrupted for about an hour instead of having to cut them short sometimes. Besides the interruptions it is not always possible to be with patients for as long as they require, especially if Dina is the only counsellor available and there are other clients waiting to be counselled, in addition to patients requiring medical attention.

A very stressful aspect of Dina’s work concerns the poverty of many of her clients. As a counsellor Dina is aware that poverty is usually the reason for people who are HIV positive developing AIDS. Poor people who are HIV positive cannot obtain nutritious food even if they have been educated by Dina about the value of healthy eating. In addition, because of poverty the younger females in a household sometimes have no alternative but to be sexually intimate with the brother, stepbrother, uncle, or some family member who is the sole breadwinner. If they did not comply he could chase them away and they would have nowhere else to go. In this way everyone in the family becomes infected.

Dina finds it sad that some patients “spend years without telling anybody” about their HIV status, i.e. live in a long and lonely silence. She gave the example of a man in his fifties who had recently come to the hospital with full-blown AIDS. His family were unaware of the nature of his illness and had brought him to the hospital to get help for him and perhaps have him referred to the hospice. But Dina realised he was dying and had him admitted to a ward. The social worker had also come along to ask how the family could be told about his illness. Because he was too ill to talk Dina had asked the patient if she could tell his family and he had agreed. Sadly, he died two days later.

One of the reasons why the counsellors encourage their clients to tell their families is to prevent the unnecessary use of traditional medicines “which don’t help much”. Dina herself has had experience of seeing patients who have become more ill after taking traditional herbs. Nevertheless, she does not blame families for taking them to traditional healers because they want to try everything that may help but the counsellors discourage it because the herbal potions can not only make the patients feel worse but can sometimes result in complications such as damage to the kidneys. However, it is difficult for the counsellors to be too prescriptive as some people have strong beliefs concerning traditional customs. Dina counsels them to discontinue such treatment as they would merely be wasting their money. She also tells them that by going to a traditional healer the neighbours may think they are ill because of being bewitched which would make them less likely to provide support when necessary and may even make enemies out of them.

Dina says that “it’s always difficult to counsel your friends, or somebody who lives in the same street, because once it is known she will think it was you who disseminated the information”. Consequently, if someone comes for counselling who is a neighbour or a friend she calls another counsellor to take that case unless the patient has specifically chosen to be counselled by her. She gave the example of someone who lives in the same street as she does and came to the hospital to be tested for TB. He had x-rays taken but forgot to have his sputum tested so Dina took the bottles home and then called him to come back to the hospital when the sputum result turned out to be positive for PTB (Pulmonary Tuberculosis). He is a teacher and comes from a well-to-do and enlightened family and his mother was so concerned that she asked for an HIV test to be done. Dina felt it was enough that she had

diagnosed him for PTB and didn't want him to think that she knew everything about him so she sent him to someone else for counselling.

Dina is also afraid of counselling a colleague because it would mean she would know something very personal about her. She has not yet had this experience but other counsellors who have opened up to their colleagues have shared with her that they are not sure if they did the right thing as the colleagues may be afraid of a breach in confidentiality. However, in her capacity as a member of the Committee for Infection Control at the hospital, she has pre-test counselled some of her colleagues if they have suffered a needle stick injury. It is Dina's responsibility to arrange for both the source patient and the nurse to be tested for the possible presence of HIV. Dina not only pre-test counsels all the nurses in these cases but sometimes also post-test counsels them, although they can choose whom to use as their counsellor in this case. Dina reports that this kind of counselling is very sensitive but fortunately most of the results prove to be negative.

Most of the patients seen by Dina are young people, which leaves her feeling sad. However, it has also been shocking and painful for Dina to discover that even people over fifty are being infected with HIV, and recently experienced a case where a 67 year-old man tested positive. She believes this is because the older men like to become sexually involved with younger women, who are usually infected already, and then in addition to becoming infected themselves, spread the virus to their partners at home. It is difficult for her to accept that some men indiscriminately have sex with women, particularly due to the effects of alcohol. Even the young become more reckless when under the influence of alcohol, and do not bother to take time to use a condom, saying they are "desperate to make love".

As an HIV/AIDS counsellor Dina has to speak to patients about death and dying but, fortunately, she does not find it difficult to do so due to her own experience of losing her husband in her twenties. However, she only talks about the various stages of the illness, including death, in the pre-test counselling session in order to prepare them in some way for what is to come should they prove to be HIV positive. In the post-test counselling sessions she would rather that her client think about living than dying, in order to give them hope. However, she does find it stressful to deal with the death of patients who died while being resuscitated as it leaves her wondering whether she did enough for the patient, which gives rise to some self-blame.

Bereavement work is also difficult and, as a nurse, she often has to make the family feel more at ease about the death of a patient. They are not only distraught at the loss of a loved one, but often have to worry about how they will be able to afford the burial costs. Most of the deaths which occur in the hospital are AIDS-related although the family are not aware of this in many cases. This creates the conflict of whether to tell them or not as the patient may not be able or willing to do so personally. It is up to the doctor to decide whether the family should be told or not but the nurses carry the strain of keeping the secret until it is out.

A big fear for Dina is that one of her patients might commit suicide and it is particularly stressful to counsel such a patient. She realised this in the course of dealing with one of her most difficult cases which involved a couple who were thinking of getting married. The lady had come to see the doctor because she had not been feeling well and the doctor had referred her for an HIV test which she had agreed to as she had tested negative three months previously. After being told that she was positive she had cried so much, saying that she was still young and had been looking forward to her marriage. Dina did not see her again but she

had been afraid that this client might have contemplated suicide. She finds it difficult to spend time with someone who appears suicidal but knows she has to give the client the opportunity to work through her pain. During such a session she finds that it is necessary to go over the same things quite a few times “to take the idea away”. She tries to reassure them that “it’s not the end of the world because there are people who are living with HIV, either with retrovirals (sic) or with a good diet” but knows that, for most of her patients, “poverty does not allow them” to get these things and their chances of living healthily for a reasonable time are poor.

Some of the difficulties experienced by Dina stem from present practices employed at the hospital. The counsellors may not test patients unless they have been referred by a doctor as testing is expensive and has to be reserved for patients at the hospital who are ill. Hence people who approach the counsellors voluntarily for testing have to be turned away and referred to their local clinics unless they are symptomatic (weight loss/stomach complaints/TB/etc.) and can be referred to a doctor. This means that a counsellor at the hospital is not free to pre- and post- test counsel anyone who is willing to be tested.

Another difficulty for Dina is that she is unable to follow up on her clients if they do not return for their post-test counselling session. Often clients have difficulty with transport costs or getting more time off work or alternatively, they do not fully appreciate the import of returning for their results and a further counselling session. Dina would like to contact them because she is afraid the patient may be endangering her health by continuing with her present lifestyle. However, trying to locate patients is time consuming and due to financial constraints there are also restrictions at the hospital pertaining to phoning. In addition, there is no longer a system in place for sending letters by post without going through a lengthy authorisation procedure which is stressful so that one gives up in the end. Instead Dina has to wait for patients to come back to her when they are ready and at times they do not even return to find out the results of their test as they are too afraid of the possibility of being told they are HIV positive. Dina believes it would be easier if she were a full-time counsellor with her own consulting room and was responsible for all the counselling cases. Then she would be able to follow up as soon as results came in. Not being able to contact clients also poses a problem for her as a nurse in that she is unable to inform them about a change in their appointment date with a doctor. On arriving at the hospital and discovering that the doctor is unavailable they become angry at the waste of time and money which they have been subjected to and take their anger out on her.

Personal life experiences

Dina says that her life has been very difficult since her parents’ illnesses and death (mother in 1993 and father in 1995). She returned to Grahamstown from Johannesburg to care for them before they died and, after their death, she had to take her older sister, who has schizophrenia, and her son, who is now 16 years old, into her home as they need someone to watch over them. Dina eventually obtained custody of her nephew in 2000 as her sister proved unable to care for him properly. She receives a R460 pm. foster grant for taking care of him but this causes friction between her and her sister, although she gets a monthly disability grant of her own. Dina has to attend meetings with her sister’s social worker every few months in order to settle complaints and disputes brought by her sister. What causes Dina the most stress concerning the fostering of her nephew is that she finds him difficult to manage as he does not always abide by the house rules. She reports that she has to reprimand him every day as he does not want to listen and is not prepared to take any responsibility for his life. For example, he has to be woken up every morning to go to school and this tires her. She

sometimes despairs of ever being able to teach him to be a respectful and responsible person although she is determined to bring him up well so that he does not one day blame her for not caring for him as much as for her own children. Consequently she tries to be strict with him but her sister often spoils him and undermines her efforts to bring him up well.

Dina has two of her own children, a son (23) who is a fashion designer in Johannesburg and a ten year-old daughter who lives with her. Dina was widowed in 1982 after two years of marriage. She eventually met another partner in Johannesburg with whom she had her daughter. However, since coming back to Grahamstown he has not made any attempts to contact her. Dina has not had a partner since then and although it means that she is alone, she does not have to worry about the risk of becoming infected with HIV. She did on one occasion arrange to meet him for her daughter's sake but he did not show up at the pre-arranged place. She does not get any moral or financial support from him and no longer has a contact address for him. However, as her daughter is keen to meet her father, Dina will ensure that she puts aside money to enable her to take her daughter to visit her paternal grandparents one day so that she can get to know her father. Dina has a very close relationship with her daughter, who often gives her comfort and is Dina's purpose in life. However, there is rivalry between her daughter and her nephew as her daughter takes over from her mother when Dina is away and tells her cousin how to behave. The friction between her and her nephew is such that she has said she would like to go overseas once her nephew turns 18 in order to get away from this situation.

Financial concerns create further stress for Dina. Since September she has been in the process of renovating and enlarging her house and this has placed extra demands on her budget, in addition to the stress of living in more cramped conditions since she is presently sharing a room with her daughter. She is also looking at ways of assisting her son with a R6 000 loan to help him start his own business and is behind with the payment of her daughter's school fees. In spite of the R460 Foster Grant which she receives every month to care for her nephew, she finds that this is not enough to cover the cost of taking care of him. Moreover, this grant expires when he turns 18 and Dina will then have to fully support him financially until he is able to do so himself. All these financial considerations prevent Dina from going out much, which she used to do while living in Johannesburg, making it more difficult for her to find a source of relaxation.

Dina feels that her domestic problems create more stress for her than her difficulties at work. She feels "down" at home because there is no one with whom to share her problems whereas at work "there are people to talk to and laugh with". She also attributes some of this stress to her wanting everything to be done "properly". Her only form of relaxation is studying which she enjoys as it energises her to get away from home and find some retreat in the company of her books in the library. She believes that, through education, she can "make positive" that which is negative. She also maintains that her experience of widowhood 21 years ago strengthened her and taught her to be independent, both of which helped her to deal with all the adversity she has faced since then.

Support structures available or needed

Although Dina feels that the many roles she has to play in her work contribute to a "burnout syndrome", she does not take her work stresses home but rather finds someone at work with whom to share her problems. It is her problems at home which get to her more and make her feel she does not want to go to work so that she sometimes phones in to say she will be late as she needs to attend to those problems immediately.

Dina's youngest sister is her only source of emotional support in the family but she lives far away and at home her older sister is not in a fit state to help her in any way. She gets on well with her daughter but she is still rather young. Hence it is mainly people who are not related to her who give her strength at times. She feels she alone carries the responsibility of solving all the problems that arise. In fact, she has to be a support for everyone at home and cannot rely on them for support. She is much happier at work where she can open up to a few people than at home where she has no one to turn to for support. Prayer serves as a source of daily support for Dina through her daily Bible reading and meditation. She also prays when she feels stressed as she believes God has a purpose in giving her problems and will help her deal with them. She is an active member of her church and participates in the Sunday service in addition to attending a Mother's Union meeting once a week as she is a member of the Women's League. Dina enjoys studying as it fills up her time at night and going to the library acts as a retreat from the pressures at home as she would "rather be alone than morose at home". Studying also makes her feel she is doing something constructive as she realises that, with a good education, she will not be a failure but will be able to get what she wants in life.

Dina reported that Sr. Whiteley had said last year that support groups were to have been set up for the counsellors by someone from outside the hospital. However, nothing has come of this yet and Dina relies on talking to a few colleagues for some relief. She believes it is important to verbalise one's emotional experiences and would like to be in a support group of about eight counsellors which would meet at least once a quarter with an outside facilitator. In this way the counsellors could not only express their feelings but learn additional coping skills.

Dina would also like to see more promotion opportunities at the hospital or some kind of recognition, not only financial, for one's experience and qualifications. She believes things have not changed much since the apartheid days as people in the upper echelons are still afraid of being replaced by new people.

Nosipho

Setting the scene

Nosipho is a 41 year-old, Xhosa-speaking woman from Grahamstown. She has a four-year diploma in General Nursing and Midwifery and one-year diplomas in Nursing Dynamics and Nursing Education. In 2001 she obtained a Certificate in Management Practice and is currently registered for a Masters in Public Health and Welfare Management.

She is presently working on the Medical Ward and no longer rotates on other wards as she is now the overall supervisor and also does a lot of administrative work to assist the Matron although she would prefer to be working with the patients more as she feels she is becoming removed from them. She enjoys it when, after a ward round, she finds herself wearing her gloves and working with the nurses because they are so short-staffed and busy. Compared to other wards, there are many dying patients on her ward as they are suffering from illnesses such as diabetes, hypertension, epilepsy, and HIV/AIDS. Because of her administrative workload she is only able to counsel, on average, two patients a week.

Motivation for becoming an HIV/AIDS counsellor

Nosipho wanted to find out all she could about HIV/AIDS as she realised that most people did not know much about this disease and she had been frightened when told that it was incurable. She felt something had to be done for those living with the disease and also for all the other people affected by it. She needed to become a counsellor as this disease was “everywhere”. In addition, nurses in the community are regarded as “a light”; people think that nurses know everything as far as health is concerned. They were already approaching her for help when she decided to become a counsellor and she knew she needed the necessary skills to deal with the situation.

Training received

Nosipho attended the same course which Dina attended, but a year earlier, in 1999. It was also held at Settlers Hospital and given by Sr. Sue Whiteley, who is the HIV/AIDS Co-ordinator at the hospital, and Buyiswa Yako, a health worker from the District Office who is also a trainer. In Nosipho’s course two PWAs (People Living with AIDS) were invited to give input on their experiences. They were both “plump”, according to Nosipho, so she found it difficult to believe they had HIV and she could not take them seriously although she “knows differently” now. Evaluation was ongoing, in the sense that participants had to do exercises, role-plays, and questionnaires with tests during the course, but there was no formal examination. At the end of the course each participant received a certificate of competence in HIV/AIDS counselling.

Upon starting the course Nosipho felt that it was not what she had expected. She had thought that the first thing they should learn is what to say to clients but instead they started off with working on themselves. They were asked to recall previous experiences, both good and bad, as well as emotional grudges which they held against others. This part of the course informed Nosipho’s attitude concerning judging others as she realised that people have different ways of interpreting the same situation. Moreover, being in any way judgemental does not help the clients as it makes them feel they did something wrong which, in turn, serves to increase feelings such as stress, anger, guilt, and hatred. Consequently Nosipho focuses on the present and the future, rather than on the past, except to emphasise the value of learning from one’s mistakes. Notwithstanding her striving to be non-judgemental, Nosipho still, at times,

experiences some prejudice towards the client, believing that the client has invited the situation in which she finds herself.

The trainees were asked to keep everything confidential so that people would feel more free to open up about their experiences. Nosipho appreciated the opportunity to air her anger because she believes people tend to push things to the back of their minds and leave them there, as if by pretending they do not exist they will not haunt them anymore. But during the course it became clear that this was not the case as the participants were already crying about their difficult emotional experiences while merely writing about them, let alone talking about them. Nosipho maintains that being able to get in touch with one's anger, stress, and other emotions was valuable because one needs to know oneself first before one can know and understand the next person. She also learned that people are all different so that client A would have different issues from client B. This was particularly important in the context of dealing with HIV/AIDS patients who not only have to each be treated as separate individuals but also have so many needs and other things to get off their chest that they require an empathic listener in order to do so.

After sharing some of their own personal experiences the counsellors were taught the basics of what needs to be communicated to the client concerning the disease itself – the causes, how it is spread, how testing determines whether one is positive or not, medication which can be used, and preventative measures to control it. The difference between HIV and AIDS was emphasised as people usually think they are one and the same thing. It was stressed that the 'who, when and where' of becoming infected was not the main aim of a counselling session, but rather the 'where to from here'. Yet in practice Nosipho has found that clients want to know when they became infected and who the "culprit" was.

Counselling skills were covered in the second half of the course and included an understanding of non-verbal cues, how to sit when talking to clients, being aware of the messages one is imparting as one sits with them, the difference between sympathy and empathy, and taking care not to make false promises. In addition to becoming aware of her own body language, Nosipho became aware of looking out for the messages which the clients give her through their body language. In addition Nosipho learnt that it was necessary to establish a good interpersonal relationship with a client before they can open up and talk freely in the counselling session. However, this has to be done in a short space of time because the counsellor will not be able to see that person for three days, or even a week – in many cases there is not even a second session, but only the here and now.

Nosipho feels that the course was worthwhile as she gained a lot of information which made her a better health worker in the sense that she became more skilled in dealing with people's emotions, not only in the HIV/AIDS field, but generally. But she believes that the training is only one part of what makes for a good counsellor. The other is the nature and personality of the counsellor herself. Some people naturally invite others to open up to them and training serves to enhance this inherent quality by providing additional skills, such as listening.

Conflict, if any, between two ways of being with clients

Nosipho reports that it is easier for her to give information to clients, where she is in control, than to listen to them so that they control the direction of the session. Nevertheless, she believes they are the ones who should be doing the talking in order to get their feelings, such as fear and anger, out. Accordingly, Nosipho prefers to just be there for the client as they talk about their experiences, particularly if they know about the disease such as how it is spread

and its various stages. She feels satisfied when she feels she has given her clients a “listening ear” as she believes that what they want is someone to talk to and it is thus extremely important that they feel heard. For Nosipho being heard is part and parcel of the therapy and if clients are not able to open up and express their feelings she feels something essential is missing. Thus, in spite of the fact that she feels more in control when she is giving clients important facts, she believes she is being a better counsellor when she allows the session to be controlled by them. She prefers to sit with the discomfort of not knowing where the clients will lead her, although it is more difficult to do so.

However, preferences aside, Nosipho has noticed that it depends on the client whether she is more or less prescriptive in her approach and, as such, does not experience a conflict between being directive or non-directive. She has found that some clients are very talkative so that she mostly sits and listens whereas others say very little while she does most of the talking, such as telling them what is important and what needs to be done. Nosipho finds it more comfortable to be with a client who is open and talks easily as it is easier to determine what they are feeling and thinking and whether they have gained anything from the session. However, with very talkative clients there is the conflict between tactfully interrupting in order to relay important information or correct an erroneous idea on the one hand, and not disturbing the client while she relates her experiences and feelings on the other. In these situations Nosipho feels “pushed” to try and stop the client and take her back to the point. In addition, Nosipho is afraid that if the client continues uninterruptedly she will forget to mention important points which need to be mentioned. She has found that making notes is not a good idea as clients want to know what has been written which takes them away from where they are in the session and from their feelings.

The opposite happens with clients who are closed as it is so difficult for her to “read” their mind and to know what they are feeling and thinking, so much so that she does not really know whether she is getting through to them and whether she has counselled effectively. With these clients she does most of the talking in the session and continuously asks them if they have any questions or comments. She finds this stressful as she is not really sure what they are feeling at the end of a session and does not know how much such clients get out of the counselling session, unlike the more open clients, who let Nosipho know that they gained from the session and feel better for it. With the more withdrawn clients Nosipho even wonders whether at the end of the session they themselves feel that they didn’t get through to the counsellor as much as they would have liked to. Nosipho believes that the more open clients are at an advantage because, not only are they more easily able to talk about their problems and thus assimilate them, but they can also more readily be referred to others for assistance or more easily ask for help from their family or friends. However, with the more closed clients Nosipho feels that if they are not able to open up to the counsellor then they are even less likely to open up to others who are less aware of the HIV/AIDS situation and this is a source of worry for Nosipho.

Stressful aspects of the work

For Nosipho the most important part of the counselling process is enabling the patient to accept the disease. Accordingly, she finds it difficult to try and speak to someone when she senses that they have “closed the curtain already”. Nosipho maintains that she can feel when there is a block between herself and the client, so that, although they have come for post-test counselling, they are only aware of the fact that, because they are HIV positive, they are going to die. Nosipho tries very hard to get through to such patients but because they have closed up she feels that, although she is talking to them, they are not actually taking it in.

When she finds herself in that situation she knows she is “in trouble as the patient is not going to cope with the disease emotionally”. And the frightening thing for Nosipho is that these are usually the people who come back after trying to kill themselves with a drug overdose, or the ingestion of paraffin/Rattex/Jik/etc., or a combination of both.

Nosipho forms part of the management structure and, as such, does not work full-time on a ward. This limits her as a counsellor in that she can only see about two patients a week. However, Nosipho finds that when she is counselling she is able to give her client her full attention without being torn by the demands of her other duties. Yet she can never be sure whether she was able to really get through to the clients and whether the session was a constructive one for them. She is sometimes left wondering how much of the information which she gave them was taken in and whether they will be able to utilise that information constructively. A further source of frustration for Nosipho arises from the fact that she is often unable to give them a post-test counselling session. This means that another counsellor has to take the post-test counselling session without having seen the client for the pre-test counselling session, which not only interferes with the process of continuity but also with the relationship of trust which exists between client and counsellor.

Acquiring a full-time counsellor would serve to alleviate this difficulty but there is insufficient staff to allow for this. Besides, such a position would be extremely stressful because counselling is “very, very strenuous” as it is difficult to remain objective while counselling. In fact, Nosipho says “you find yourself in the patient’s shoes most of the time” so that she experiences difficulty in distancing herself from her clients. On those days when Nosipho has had to counsel two patients per day, especially with post-test counselling, “then you feel you are done and you just want to go to bed and sleep”. And what is more, unlike working in a factory where “you finish work at 5:00pm, take off your overall, brush your hair and leave” with counselling, “even if you are going home, you still carry all the load on your shoulders”. For example, although Nosipho may have watched the news on the TV at home, when someone refers to something that was reported she realises that she had not taken it in because her mind was still on the patient. In addition this emotional stress causes her to dream about her patients on occasions and can even affect her mood at times because she feels helpless to do anything about her patient’s plight.

Were she to have to choose between being a nurse or a counsellor, she would choose the former as counselling entails more emotional stress, which is more difficult to bear than physical stress. As a nurse she feels recovered after a good night’s rest but, as a counsellor, she feels she is still carrying the stress the next day. However, as a nurse she is aware of the possibility of becoming infected through a needle stick injury although she can do nothing about this except observe the correct protocol when handling a patient.

Overload is another stressful factor in Nosipho’s work. Due to the staff shortage the queues of patients are longer and more demands are made on nurses. Having waited for long hours the patients tend to take out their stress on the nurses who are seen as not caring about the discomfort of the patients. In addition the shortage of nurses means that it is sometimes difficult to get one’s day off when it is due which contributes to both physical and emotional fatigue. Accordingly, it sometimes happens that Nosipho has to work eight to ten days in a row when she happens to be on weekend duty, which comes up every six weeks. For nurses working with AIDS patients there is the added stress of nursing someone who is not going to get well, unlike other diseases which afford some measure of control thanks to the availability of more effective treatment. What is more, these patients often do not realise they

are dying, in spite of being seriously ill, so that it becomes more difficult for nurses to know what to say to them. When such a patient is a member of staff the emotional stress becomes very hard to bear. Once they have died, it is easier to deal with emotionally as Nosipho is able to console herself by remembering that everyone has to die in the end.

Dealing with clients who have been raped is particularly difficult for Nosipho. During a pre-test counselling session Nosipho learned that the girl she was counselling had been raped three years previously while still a virgin. Although she had been to crisis counselling at the time she was still recovering from the incident and had thus not had any intimate relationship since her traumatic experience. After testing as HIV positive Nosipho realised that her client had become infected as a result of her being raped. An additional stress factor for Nosipho was that it was too late to give the client anti-retroviral treatment as such treatment is only effective if a person tests negative.

Another stressful case for Nosipho did not involve HIV/AIDS counselling but concerned a patient who had come in for TOP (Termination of Pregnancy) counselling. In addition to realising that this patient was too far advanced (8 months) for a TOP, Nosipho discovered that the pregnancy was the result of her having been raped. Although the patient had gone to the police station in Alexandria to lay a charge her case had never been managed properly. Consequently, she had never been to a clinic to get help and had later found herself pregnant, after which she still took a long time before coming for help at Settlers. Nosipho discussed with her that her only alternative was adoption. The patient had left without making a decision and there was no follow-up session. However, she had presented as depressed and Nosipho would have liked to know what happened to her in the end as she had been afraid that the patient might have ended up going for a back-street abortion.

The question of confidentiality often places Nosipho in an awkward situation when she comes into contact with patients outside the hospital. She realises how sensitive an issue this is as she herself would not like her status to be made public and believes this could be the reason why some clients do not greet her but look blankly at her when they meet her in the street. They are even more likely to avoid her if she is wearing her nurses' uniform which can more easily be associated with HIV/AIDS. In addition, having access to confidential information about a patient's HIV status sometimes poses an ethical dilemma for Nosipho. She gave the hypothetical example of having post-test counselled someone and then seeing this person going out with her daughter. Should she keep quiet and not tell her daughter that he is positive and thereby risk her daughter's health? Could she even suggest that they use condoms without her daughter wondering what lay behind this suggestion?

Nosipho further illustrated her conflict surrounding the maintenance of confidentiality by giving an actual example of how torn she felt at her inability to speak out. She related how, on more than one occasion, she had seen HIV positive daughters being regularly visited by their parents who brought them gifts and wanted to do everything possible to help them recover. In spite of her attempts to persuade these young women to disclose their illness to their parents, they refused to do so and there was nothing which Nosipho could do except stand helplessly by and think that if she were the mother she would want to be informed. In such cases she experiences conflict between maintaining confidentiality on the one hand and, on the other, making the family member(s) aware of the situation and of the risks involved.

When faced with these kinds of situations Nosipho wonders what would be more unprofessional, to break the seal of confidentiality or to say nothing and in this way put

someone at risk of obtaining a terminal illness? Nosipho was placed in just such an uncompromising situation in the case of a female patient whose results had proved positive but her husband had tested negative. Nosipho informed them separately as their results were not the same after which the wife refused to break the news to her husband, who believed they were both negative as he had been found to be negative. Nosipho then tried to tell the wife to persuade her husband to use a condom but the wife felt she could not all of a sudden tell him to do that as they had never used one before and so he would realize she was positive. Since then, whenever Nosipho sees that man she feels guilty and finds herself thinking it would have been easier if they had both proved positive. “That’s where the stress comes in” for her and she asks herself how long she has to “carry that lie” with her? Yet, were she to break the seal of confidentiality to protect someone’s health, she would not only experience conflict at having disclosed information given in confidence, but she would experience further conflict at having to speak to someone whom she does not know about intimate concerns without being asked to do so. Such considerations make her feel torn as to what course of action to take, but, ultimately, she realises she is bound to the oath of confidentiality and has to live with the inevitable conflict and stress.

Another stressful factor for Nosipho is the fact that, where AIDS used to be a disease affecting mainly the young, i.e. those between 18 and 40 years of age, there appears to be no age limit now as anyone from 0-80 can be affected. Infants are born infected from the womb and young children are often infected through sexual abuse. From the age of about 14 they expose themselves to the risk of infection by becoming sexually active and with those who are infected over the age of about 45 the partner is usually dishonest. Nosipho believes that elderly men “like to go for younger women, whether married or single” but have wives at home who become infected. As a result even pensioners over the age of 65 are being infected with HIV and are dying from AIDS. In addition, the elderly are nursing their family members who have AIDS and, because they do not know about the disease, are not taking precautionary measures to protect themselves from being infected. Consequently it often happens that, by the time their daughter or son dies, they themselves are already infected and do not realise that their grandchild, whom they are looking after, is also suffering from HIV/AIDS – “it’s pathetic”.

At the end of last year Nosipho discovered a disturbing phenomenon, namely, that in some cases people would like to be tested positive as it could give them access to the disability grant (R600pm) which the government makes available to those who are ill because of AIDS. She experienced this personally with a patient whom she had pre-test counselled and whose result was negative. Nosipho was so pleased to be able to break the good news to her but the patient was so disappointed at testing negative and insisted that she could not be negative as she was so thin. Although this grant has helped to remove some of the stigma because it encourages people to disclose their status, Nosipho feels that people are “looking for the disease in order to get the grant and so do not want to accept that they are negative”. They explain to Nosipho that everyone dies eventually so why can she not “let them have the grant in the meantime”. It is saddening for Nosipho to realise that poverty is such a big factor that some people prefer to have AIDS in order to access the grant, something she finds “very difficult to believe”. She personally feels that, instead of giving AIDS sufferers a grant, the government should give hospitals and clinics the anti-retrovirals which are needed to help people feel well so that they can find work and lead more independent lives and then eventually some of them will be able to buy their own treatment.

Nosipho does not know what else can be done to make people aware of the implications of HIV/AIDS. She maintains that there are pamphlets everywhere, over the radio and on TV, and there are living examples of people dying from AIDS. She feels helpless about the situation and wonders what more can be done to make people more aware of the “disease process”. She believes that people are guilty of negligence for not having insight in the face of all the measures taken to educate them. She feels very frustrated when she considers the rate of teenage pregnancies today as it means that people are not using condoms and wonders where it is all going to end.

It is difficult for Nosipho to talk about sexual matters, especially with the elderly as in her culture it is not customary to talk about such things to people as old as one’s parents or even older. What is more, they often don’t know much about the disease process and question what the counsellor tells them. For example, they may believe they are too old to become infected or declare that it is impossible for them to have contracted the disease as they have been widowed for 15 years. When this happens Nosipho feels obliged to correct their erroneous ideas which is also not culturally sanctioned and therefore doubly stressful. It becomes even more difficult if Nosipho has to tell them that they are HIV positive, an action which could be seen to show lack of respect for someone older than herself. However, she braces herself and sheepishly tells them all the same as she feels she would be doing them an injustice were she not to do so. Besides the elderly, Nosipho stated that it is not easy for her to talk about sexual matters to young people who are not yet sexually active. In one case she had to tell a girl who had been raped but who had never had a boyfriend that she had tested HIV positive as a result of the rape. She said there are quite a few such cases and they are very painful for a counsellor to deal with.

Nosipho says that it is a pity that so few people come voluntarily for counselling as they cannot appreciate the benefits of counselling without experiencing it. Unlike Dina, Nosipho maintains that patients may be pre-test counselled without being referred by a doctor. Nurses can also refer someone for counselling and, what is more, in their capacity as nurses, they are able to recognise the symptoms (such as wasted appearance, shortness of breath, respiratory infections, skin conditions, anaemia, TB – “HIV/AIDS and TB are twins actually and like to go together”) which indicate that patients should be pre-test counselled. It is also disappointing when a patient has agreed to being pre-test counselled but then refuses to sign the consent form for being tested. Often it is only in the presence of some strong motivating factor, such as the death of a partner from AIDS, that they readily sign the consent form.

However, even with those clients who do attend both the pre- and post-test counselling sessions, it is virtually impossible to follow up on the effectiveness of these sessions due to the lack of ongoing counselling available at the hospital. People need to be regularly empowered and encouraged to deal with their illness but this is not possible without regular follow-up. In special cases a counsellor does ask a client to come back for a third counselling session, but the hospital does not have the resources to provide even a third session for all their clients. Another limiting factor is that, even if clients are asked to return for further counselling, they usually do not do so due to financial or employment difficulties. In some cases they can be referred to the nearest clinic where they can be counselled if necessary and join the local support group.

Personal life experiences

Nosipho is a single parent and lives with her eight year-old daughter. She has an older daughter (22) who is studying at the Pretoria Technikon and lives in residence. Nosipho gets up at 5:00 am every morning, wakes up her young daughter, washes her and gets her ready for school. She also prepares their lunch, makes the beds and does some hand washing if needed. By the time she gets to work at 7:00 am she feels she has already worked very hard. When she gets home at 5:00 pm in the afternoon she relaxes and watches TV with a cup of coffee for about two hours, after which she does more hand washing and then cooks the evening meal. After supper she helps her daughter with her homework as well as having a bath. She has to assist her daughter with bathing and washes all her clothes by hand as she suffers from various allergies. Having put her daughter to bed she still has to wash the dishes, polish the shoes and do the ironing for the next day, before going to bed at 10 o'clock. Nosipho wishes she could afford a housekeeper as she often cannot keep up with her household chores and hates returning home to dishes piled up in the sink or washing which has not been hung out to dry. What is more, if someone were in the house during the day the windows could be left open and she would not have to come home to a stuffy and stale-smelling house. She would also not have to do any housework over the weekend, such as the bulk of the washing and cleaning the house. Nosipho resents having to do housekeeping duties every day and cites them as the chief source of stress at home, far more than her financial responsibilities.

Nosipho only sees her older daughter when she comes home during her vacations. They have a close relationship but Nosipho feels her daughter does not study as hard as she would like her to. She herself studies while working and keeping house while her daughter has no other responsibilities other than to study so she expects her daughter to get at least 70%. However, Nosipho consoles herself by the fact that she does pass every year so that the financial sacrifice she is making for her daughter is not in vain. But a concern which does create stress for Nosipho is the fear that her daughter may contract HIV one day. In spite of educating her about this risk, she is aware that her daughter may not be able to be completely open with her. This fear is exacerbated by the fact that she has seen so many young people become infected and die from an AIDS-related disease, without their parents ever knowing their HIV status and thus being unable to support their children in their distress.

Nosipho feels very supported by her partner. Although he is unable to assist her financially he drives her to work in the morning and fetches her too, so that she does not have to worry about transport arrangements. Unlike her, he has been married before but is also a single parent at present and has three children, the youngest of whom is fourteen years old. When it comes to their personal lives they thus both speak the same language. However, Nosipho is not sure if she would like to get married: on the one hand she would like to have someone with whom to share her daily responsibilities but on the other, as she cannot be sure what her partner would be like if they were married, she feels she should perhaps accept her life the way it is. Being married would certainly help her to feel less afraid at times, especially after a burglar broke into her home one night while her daughters were sleeping. Fortunately her daughters were not hurt but she is still in the process of replacing some of the items which were stolen, which has increased her financial burden although Nosipho maintains that she has expensive taste and this increases her financial liabilities. Not only does she like to have "nice things" but she likes to be in control and when in debt, she feels she is not in control and it is this which stresses her about her financial situation. But in the end she would rather have what makes her happy than buy things which do not give her any sense of satisfaction.

Another source of stress is the possibility that she may become infected with HIV by her partner, a fear which is always there, at the back of her mind. Although she generally trusts her partner she feels she cannot trust him 100%. This means that she vacillates between using condoms for a few months when she feels unsure and then relaxing once she feels more at ease again. However, she is able to talk to her partner about her fears and this helps to allay them. What is more, she has recently started using the condom as a form of contraceptive too which further serves to allay her fears.

Nosipho's parents are divorced but she gets on well with both of them, particularly her mother. She sees her mother and her two sisters quite regularly and her father once or twice a year. They are all financially self-sufficient but help each other with the odd R200 every now and then. She has a particularly good relationship with her cousin whom she sees even if she has no major problems. She also belongs to a savings club which consists of a group of women who have meals together and share their accumulated savings at the end of the year. In short, Nosipho feels she has strong and reliable support structures at home.

In order to relax Nosipho likes to sit and watch the television, read a book or crochet. She watches the television every day for about two hours when she gets home from work in order to unwind. She reads mainly over the weekend and crochets whenever she has an opportunity as it is her most pleasurable hobby, so much so that she feels she is addicted to it and finds that, once she starts crocheting, she does not want to stop so that she sometimes goes to sleep at night later than she should. Nosipho does a lot of part-time studying, whenever time and money permit it, and finds that, like crocheting, it distracts her from her problems. She also enjoys going out with her partner which they do about once or twice a month over the weekend.

Support structures

Although Nosipho feels she has a good support system at home, she feels that "professional secrecy" obliges her to tell people at home that she is fine if they comment that she is not feeling herself. She has also found that if she does say something about the cause of her dampened spirits, albeit vaguely, people at home are not really interested in what happens at her work or tell her that she should not be carrying her client's problems.

As far as the provision of support at work is concerned, Nosipho would like to see various people coming in to the hospital, one at a time, to offer their expertise and give some monthly input to the counsellors on issues related to HIV/AIDS in the workplace. At present the hospital provides monthly meetings, or in-service training seminars, where the counsellors are able to share experiences, ask questions and support one another. Although these get-togethers do provide some form of emotional support for counsellors they are difficult to arrange because the counsellors are so busy, or not all on duty at the same time, so that there is at present no regular avenue which provides some stress relief for the counsellors. Accordingly, in addition to monthly input meetings, Nosipho feels that smaller groups would be more effective in giving the counsellors an opportunity to talk about the problems they are encountering as well as being easier to arrange. Nosipho maintains that such a group should be facilitated by someone from within the hospital staff firstly, due to the ethical issues involved concerning exceeding the parameters of hospital-related information and secondly, because of the difficulty of finding a time when all the members of a group would be available.

However, providing some form of support for the counsellors would serve no purpose without a simultaneous exploration of some of the factors contributing to their stress, such as lack of finance and staff at the hospital. This would go a long way in relieving some of the stressful situations faced by counsellors although it would also be important to regularly have a support structure which can help alleviate the emotional stress inherent in counselling. Should any of the counsellors require one-to-one counselling, this would need to be offered off the hospital premises to avoid any stigma being attached to such a counsellor.

Nomawethu

Setting the scene

Nomawethu is a 46 year-old, Xhosa-speaking woman from Grahamstown. She completed her two years' training as a nursing assistant at Settlers Hospital and since 1983 has been registered as a nursing assistant at the hospital. In 2000 she attended a one-week course in Excellent Customer Care, a course which covered how to deal with patients.

Nomawethu works in the Specialist Clinic. Because of her many years' experience in this clinic she is able to cope with anything that comes up, even in the Sister's absence, and to show any new staff what to do. The patients who attend this clinic have all been referred to specialists by doctors for medical attention for things such as skin problems, broken bones, rheumatoid arthritis, lumps/tumours/cancer, tubal legations, appointments with an eye specialist.

Nomawethu usually does her clinic work in the mornings, after which she is available for HIV/AIDS counselling. However, there is not much demand for such counselling on the Specialist Clinic so she finds she is sometimes called to help with counselling on the Medical (M1) or Surgical (F1) wards, or in Casualty and OPD. She sees an average of five patients a week, with each counselling session taking from ½ hour to an hour, depending on how difficult the case is. Nomawethu finds that sometimes she talks for half an hour in a pre-test counselling session, only to be told by the patient that she will not sign a consent form for testing. In such cases she then has to change her strategy to try and get her to sign. But she feels that the longest sessions are the post-counselling ones, especially if the patient has not attended a pre-test counselling session. In such cases she finds that she has to establish a relationship with the patient first before the patient is able to open up about her problem and only then can she "break the news", after which the patient still needs time to express how she feels.

Motivation for becoming an HIV/AIDS counsellor

Nomawethu has always enjoyed talking to patients as she feels she has a particular gift to discern when someone needs help with a problem. She first became aware of this gift in the course of her work in the church where she ministers to people through water and the Holy Spirit. Sometimes, while sitting with someone and being with them as they speak, she feels herself become "quiet because (she) feels something". This enables her to connect with people at a deep emotional level and feel their pain. Because of this she believes she is able to explain to people that their illness is not merely a medical one, and that they need to open up and share with someone if they want to feel better.

However, Nomawethu realised she did not know enough about the "killer disease" HIV/AIDS to really be of help to people who were affected by this disease and so decided to be trained as an HIV/AIDS counsellor. Another motive for Nomawethu's desire to be trained as an HIV/AIDS counsellor stems from her conviction that people can still have life and reach their goals even if they are diagnosed with HIV. In her work she thus strives to help people understand that they are not doomed to die just because they are HIV positive.

Training received

In 1999 Nomawethu, like Dina and Nosipho, attended a course in HIV/AIDS counselling which was run at Settlers Hospital and was given by Sr. Sue Whiteley who is the HIV/AIDS Co-ordinator at the hospital, and Buyiswa Yako, a health worker from the District Office who

is also a trainer. Like Dina, Nomawethu did not receive any input from a PWA (Person Living With AIDS) as part of the course. In addition to the practical exercises which the participants did during the course, they were asked to role play a counselling scenario at the end and to evaluate the course by stating what they had gained from it. At the end of the course each participant received a certificate of competence in HIV/AIDS counselling.

The course did not only arm Nomawethu with the factual information necessary for being an HIV/AIDS counsellor, but also taught her how important it was to help clients get in touch with their feelings and express them. Nomawethu had always been ready to talk to people about their problems but after the course she learned how to do so more effectively, which increased her self-confidence. The course material ranged from the more physical/medical side of HIV/AIDS, such as information about the virus itself, the difference between HIV and AIDS, treatment, prevention measures and positive living, to the emotional aspects such as listening, allowing clients to get in touch with their feelings and express them, and providing containment.

Nomawethu feels that she benefited greatly from the course on a personal level too as it started off with exercises, both written and oral, on getting to know oneself and expression of feelings, as well as the motivation for doing the course. This part of the course not only led to self-growth for Nomawethu but also gave her an idea of what her clients would experience when they opened up about their feelings. In general the course was significant for Nomawethu spiritually and emotionally as it put her in touch with her own pain and made her realise that so many people suffer pain, even without having HIV/AIDS. But she also learned that being open about one's feelings brings about healing. She was given the opportunity to share some of her personal difficulties with a fellow participant who only knows her professionally. By being empowered to expose her vulnerabilities and find some healing the course gave her the strength and skills to be able to cope with the recent loss of part of her home due to a fire. She realised she needed to talk to someone about her feelings and by doing this was able to overcome the shock and grief inherent in such a traumatic experience without losing control.

Conflict, if any, between two ways of being with clients

Nomawethu does not experience a conflict between being a listener and giving information to clients and believes the two go hand in hand. By listening to the clients she is able to discern what she needs to say to them. Some people cannot understand why they are suffering from HIV while others talk about what they think was the source of their illness. But whatever they say, Nomawethu maintains that it is necessary to let them know what her opinion concerning HIV/AIDS is, to inform them about the disease, including preventive measures and a healthy lifestyle, and to stress the importance of informing their families of their status. Giving her clients such factual information is easier than listening to their painful experiences but Nomawethu feels that clients need to be able to express their feelings and discuss their plans. Yet for some clients it is difficult to be open about their feelings and they merely say they have not yet decided what to do whereas others ask if they can come back once they are ready to speak freely about their emotions and to discuss what to do about telling their families.

However, HIV/AIDS counselling is stressful as it is not easy for Nomawethu to “give someone the bad news about being positive” and she also finds it difficult to listen to them expressing their emotional reaction to receiving the news. She experiences “a strange feeling and a pain” after giving them the news because initially they want to give up hope. She has to keep this pain to herself as she realises she cannot disclose this to the clients. But by allowing

the clients to talk about their pain she is able to win their trust which initiates the development of a relationship between them and herself and they are then able to transform their pain through this relationship with the realisation that they have someone to turn to if things beco

me too difficult. Once such a relationship has developed between them Nomawethu finds the session less stressful with the result that she more easily remembers what she has to say to them. Moreover, having developed such a relationship, she is able to “go deeper” with them and even talk about the preparations for the terminal stage. They, in turn, are more ready to accept her advice, health wise, and to come back to her for further help and even bring along a parent or partner and open up to them in front of her. Where she does experience some conflict is not to take on their problems as her own but just to allow them to express their feelings and talk about how they intend to cope with the fact that they are HIV positive. Accordingly, before they leave the session she gives them some factual advice and tries to instil hope in them, both of which make her feel she is doing something for them.

In giving her clients factual advice Nomawethu is careful not to come across as prescriptive but to allow them to make an informed decision after telling them about the advantages of things such as safer sex and healthy eating habits. By doing this she has found that people are more able to take responsibility for their lives and less likely to find excuses for not being able to change their lifestyle. For example, if they are told what the benefits of using a condom are, they are more likely to consider doing so than if they are told they should do so. Alternatively, having been told how to buy vegetables economically they will be more inclined to eat healthily.

Stressful aspects of the work

A particular difficulty is that, after a post-test counselling session, Nomawethu sometimes feels like being “alone in a dark room” without seeing anyone. However, even after an emotionally taxing counselling session, she usually has to get back to her work on the ward which means that she cannot sit down and process the feelings which arose during the course of the session. On one occasion, after having been interrupted by a telephonic message in the middle of a counselling session, Nomawethu did not respond to the request to go to another ward at the end of her session as she had needed time to process the pain expressed by her client in that session. Upon being asked for the reason for not going to the ward, Nomawethu had explained why she had been unable to go but had found it very stressful to explain herself to the supervisor. All this accumulated stress had made her “feel like taking (her) bag and going home”. She had felt she “was not a person, just a thing” and had not even come to work the next day as she had not felt like seeing anyone in the hospital. It so happened that the supervisor had called the counsellors and asked them if the counsellors were experiencing any stress in their counselling work. They had told her they were and added that Nomawethu had not come in to work that day because of her experience the previous day, whereupon the supervisor had asked one of them to go and speak to Nomawethu.

Nomawethu always finds it more stressful to counsel people who have not had a pre-test counselling session with her but need a post-test counselling session. This was the case in the example just mentioned where she was post-test counselling a couple who had come from Johannesburg, having never seen them before. They explained to Nomawethu that they had been pre-test counselled and their test results had proved positive but they had never been post-test counselled. The husband, a 33 year-old man, realised he had been the one who had infected his 27 year-old wife but they had never thought about the implications. They cried a lot in the session as they had never had an opportunity to express their pain and grieve after

discovering that they were HIV positive. The husband explained to Nomawethu that no one had ever spoken to them in the way she was doing. While in the middle of this emotional session Nomawethu was called to go and counsel on another ward. She felt that that would be too much for her at the time and it was then that she had found herself wanting to “just take (her) bag, go straight home and not talk to anyone”.

Another aspect of her work which is difficult for Nomawethu is that often, after she has post-test counselled someone, they do not want to inform their partner of their HIV positive status. She described a case she was dealing with at the time of the interview in which the lady had become quite ill but was still afraid of telling her husband, even after being discharged from a stay in the hospital. However, while she was in hospital she had come to look for Nomawethu as she needed to talk to her. Nomawethu feels that this lady’s only way of sharing her pain was through talking to her as she could not overcome her fear of sharing her situation with her husband. But at least she had someone with whom to share her feelings and this was making her feel stronger.

Even in cases where both partners are aware of each other’s positive status, it is difficult for them to discuss their feelings together. Nomawethu gave the example of a young man who had come in to apply for a disability grant. He had already been tested positive in 2000 but he and his girlfriend were no longer together as “they had stopped loving each other”. Nomawethu suspected that he thought he had been infected by her and so the relationship had ended. She explained to him that they were the only ones who knew and understood each other’s situation and so could take precautions and live a shared and mutually satisfying life together. Instead he would soon find someone else but not tell her that he was positive until she became positive too. It is upsetting for Nomawethu that people are hiding such information instead of being honest with each other and remaining faithful to each other. “But unfortunately our people are not faithful” and, as a result, expose themselves to more and more germs thereby overloading an already weakened immune system.

A source of stress for Nomawethu arises from the conflict she sometimes experiences between her nursing duties and her counselling work. At times clients have to wait a long time to be counselled because she is tied up with her nursing duties so that, by the time she eventually sees them, they are “nice and cross” from all the waiting and she, too, is not at her best as she feels tired from her nursing duties. Nomawethu maintains that a counsellor should not be expected to offer counselling if she is feeling tired as the client could sense that the counsellor is not at her best and it could prejudice the outcome of the session. She also finds it tiring when she has five or six sessions scheduled for a particular day, although she does her best to give the clients her full attention. Nomawethu feels that being an HIV/AIDS counsellor is definitely not an easy thing to do.

Most of Nomawethu’s clients are young people, less than 30 years of age. She was particularly shocked one day when she had to post-test counsel a child of 14 years. She was the youngest HIV positive person she had met, except for very young children who were infected by their mothers. This made it doubly painful for Nomawethu when she had to relay a positive result, especially as the young girl seemed to be so naïve and honest. Even her mother, who had to be present as the girl was still a minor, came across as a simple woman. As with all post-test counselling sessions Nomawethu had to talk about sexual matters but the girl did not “know anything about sex” and said she had “never had a man”. The mother was not aware of any possible rape or abuse and had not been told of anything by the relatives “in the location” with whom her daughter had been staying while attending school. Nomawethu

described this experience as “terrible, terrible” because she felt that the young girl was telling her the truth. Nomawethu tried other avenues to find out the source of the young girl’s infection, even asking one of the sisters to contact the organisation for survivors of rape, but to no avail. But, on a more positive note, she has seen the young girl on a few occasions since then and they have become friends, so that, when the girl sees Nomawethu in town, she smiles at her.

It is very painful for Nomawethu to deal with a dying person but she no longer has to do this in the course of her nursing duties. However, with HIV clients thoughts of death are always uppermost in their minds, especially for those who are ill. Accordingly, Nomawethu talks to them about dying, funeral arrangements and what will happen after their death. She tries to reassure them that everyone will die in the end but, particularly with women who often have many dependants, they need to face the reality of their death and make preparations for those who will remain behind while they are still well enough to do so. However, in speaking to them about their death, Nomawethu finds that she, too, carries their pain, sometimes even for a whole day.

It is upsetting for Nomawethu when people do not return for a post-test counselling session as they are the ones who need it most because they are usually the ones who are quite ill yet they have not been prepared “for the end”. Sometimes it is not easy for Nomawethu to tell them about the terminal stage in the first session as she does not want them to think they are already dying. However, it is difficult to follow up on clients who do not come back for a session as the counsellors cannot go to their homes to locate them because of their other duties. Phoning them is not easy either unless you have a pin number allocated to you for phoning. But generally she does not follow up on HIV patients as she does not know them well enough, particularly if she has only done either a pre- or post-test counselling session with them, which is often the case. This is because clients often do not return for their session on the pre-arranged date due to transport or financial difficulties, work-related problems or fear of facing the truth. If or when they do eventually arrive for a post-test counselling session Nomawethu is often unavailable, either because she has a clinic session or is off duty.

Nomawethu maintains that she works very hard, even delaying her tea break if there are still patients waiting to be seen. Although she is not a qualified sister, on a practical level she is able to perform the work that a sister does and at times she has to manage on her own as there is no one else available due to the staff shortage at the hospital. She sometimes experiences difficulties with management due to lack of communication or even favouritism. However, Nomawethu tends to keep quiet as she is aware of her junior status as a nursing assistant. She only speaks if people approach her directly and believes management is not really involved in what happens in the specialist clinic where she works and so she does not get any recognition for all the hard work that she does. At times she even has to clean the two rooms which make up this clinic as there are problems with getting the cleaning staff to do so. She would really like to get her matric and then go on to get her nursing qualifications and eventually be registered as a sister so that she would be responsible for certain things and have the authority to ensure that they happen.

Personal life experiences

Nomawethu is a single parent of three children. Her eldest daughter lives in Cape Town and has two children, one of whom (10) lives with Nomawethu. She lives with her other two children, 19 and 9, in a house in Grahamstown. Nomawethu describes herself as a “busy woman” in that she works full-time and does all her own housework as she cannot afford a

house-keeper. She is a regular churchgoer and actively involved in the healing ministry of her church. Her parents come and visit her often and her mother usually stays with her for quite some time before going back to her own home. Her sisters also stay at her home at times but none of her family members offer to contribute financially to assist with expenses, even after her house was partly burnt down. Repairing the damage caused by the fire has exacerbated her financial problems. In addition, being without electricity for a while meant she had to use a primus stove and paraffin for cooking and do without a fridge and shopping in bulk, which not only increased her financial strain but also her stress levels. There were days when Nomawethu had to go without lunch as she had run out of food or wanted to keep whatever food she had for her children but she managed to get through this added stress with the help of prayer. Unfortunately, the little outside shed in which she used to be able to pray aloud was also burned down so that she has to pray in her room now. But her faith in God is very strong and she believes He will provide for her in the end.

Nomawethu has been divorced for 16 years and does not have a partner at present although she did have a few partners after her divorce. However, she decided last year not to have any more partners as she did not enjoy being told what she had to do as it only served to create further stress for her. She is also very afraid of being infected with HIV through a partner as she believes one cannot trust men to be faithful and it is difficult for older women to insist on safer sex. Furthermore, she is unable to go out with anyone as she has her children to look after and she wants to concentrate more of her energies on prayer and ministering to those people from her church who come to her house for help. Fortunately, being without a partner does not make her feel lonely but rather, gives her the opportunity to “hear from God”. In fact, Nomawethu regards herself as a happy person and enjoys going to her church and singing in her home. She usually goes to sleep at about nine o'clock at night and gets up at five in order to get to work at 7:30 am. Sometimes she wakes up in the early hours of the morning but, after praying for about fifteen minutes she is able to go back to sleep. She enjoys watching the television and missed it while she had no electricity. Generally she copes with her stress at home and experiences the stress at work as more taxing.

Support structures

Although there are always difficulties in her life Nomawethu regards herself as a survivor who tries to cope as best as possible. She feels she does not get any support from her family but instead is usually the one who has to support them. She has learnt not to ask for help from others at home to avoid being disappointed but rather tries to make do on her own and still give her children a warm home. However, she does “offload” at work when she feels stressed as it helps to make her feel better because, the more she can talk about her problems, the easier it becomes for her to deal with them. Speaking to people at work whom she can trust also acts as a source of support for her even if they can only listen and not really do anything to change her situation, whether at work or at home. Accordingly, whenever Nomawethu needs to process the painful feelings expressed in a session, she goes to a colleague and tells them what she is feeling. After that she goes to the toilet for some quiet time and a cry, if necessary, which helps to lift her stress. She also finds strength and support in prayer and ministering to people from her church. Once she gets home she finds time to pray if she is still feeling down, anxious or stressed in any way as she believes that, through divine providence, she will be made to feel better. Unfortunately, she no longer has a private space in which to pray but she is thinking of creating another one by building a garage once she has the necessary finances.

Nomawethu would like some assistance in learning how to deal with her stress when counselling older people, something she finds difficult to do. She referred to a suggestion made by Sr. Sue Whiteley that the counsellors needed individual supervision to help them deal with their stress but, as yet, she has not had any. She would like to have a supervision session in order to know whether it is something she could benefit from, although she already knows that opening up to someone about her difficulties helps her to dilute them and thus feel more at ease. Nomawethu gave the example of how she had enjoyed the interviews with the researcher as it gave her an opportunity to share her thoughts and feelings. Before one of the interviews she had told her friend that she was feeling emotional but did not know what the source of her emotional discomfort was. However, by the end of the interview that feeling had disappeared and she ascribed that to having been able to talk to the researcher in such a way that her problems were “divided”, i.e. minimised. Accordingly, she would like the hospital to organise some supervision and would prefer the facilitator to be someone from outside the hospital so that she would feel freer to say what she needed to.

Zanele

Setting the scene

Zanele is a 32 year-old, Xhosa-speaking woman from Port Elizabeth. She has a three-year diploma in General Nursing and, while nursing in Port Elizabeth, attended many courses offered by the in-service training programme of the Department of Health. These included a six-week course in Primary Health Care, a three-week Family Planning course, a six-week course in Mother and Child Health, and a six-week course in TB. In 2000 she completed a one-year Diploma in Midwifery.

Just before starting night duty on Casualty Ward at the end of January Zanele had been working on F1 Ward, a surgical ward which cares for patients needing surgery for things such as septic sores, ulcers, burns, MVAs (motor vehicle accidents) and TOPs (termination of pregnancies). This ward also includes private medical patients with illnesses such as diabetes/hypertension or cardiac/blood pressure/gynaecological problems. Some of these patients developed signs and symptoms of being HIV-positive, e.g. ulcers/skin problems not healing, and so were referred for HIV/AIDS counselling and testing.

Zanele works part-time as an HIV/AIDS counsellor and only counselled 5/6 patients during her two-month stay on F1 Ward. But she was called out to other wards whenever they were too busy to do pre- or post-test counselling or if no counsellor was available that day. Such callouts were usually to the Outpatients, Casualty or M1 wards as they have the greatest demand for HIV/AIDS counselling and testing. Now that she was going onto night duty on the Casualty Ward she would counsel at night if not too busy. Otherwise, the day staff would do the counselling needed.

Motivation for becoming an HIV/AIDS counsellor

Zanele became an HIV/AIDS counsellor as a matter of course as all the employees of the Day Hospital in Port Elizabeth, where she was working in 1998-9, were required to attend an HIV/AIDS course - the matron, nurses, general assistants, clerks and workers.

Training received

Zanele was not trained as an HIV/AIDS counsellor by Sue Whiteley and Buyiswa Yako, as with the other subjects of this research as she had already been trained when she started working at Settlers Hospital. Instead she attended a five-day HIV/AIDS course which was given by two other health workers from the Eastern Cape Health Department. Zanele enjoyed the course as it was experiential in nature and made use of videos, practical exercises and role-plays. Participants were given notes during the course to help them prepare for both a written test and a pre- or post-test counselling practical which were administered on completion of the course.

Zanele believes that the training she received was beneficial in that the facilitators had dealt with people who were very involved with HIV/AIDS-related issues, such as sex workers and their clients and had shared their experiences with the course participants. Her training course also afforded her the opportunity of coming face-to-face with people who were themselves positive and who openly shared their experiences with the trainee counsellors, thereby giving them an idea of what was helpful and what was not. Similarly, if Zanele feels that she is not getting through to a patient, she looks for a patient in the hospital who is HIV positive and, with their consent, gets them to talk to her client which is usually very effective.

The first three days of the course covered general information for all participants, including nurses, domestic workers, clerks and factory workers. It included the virus itself, the signs and symptoms of the disease, prevention measures and positive living for those infected. The last two days of the course were specifically geared towards health workers as it dealt with pre- and post-test counselling. Zanele learned that pre-test counselling needs to take place before taking a patient's blood sample after which an appointment must be made for a post-test counselling session about ten days later. When a patient proves to be HIV-positive the counsellor needs to give the client an opportunity to take in the result and then explore their feelings. But even a negative result should be dealt with in a way which implies a positive result to make allowance for the window period, in other words, emphasis needs to be placed on prevention and positive living. If the results are negative clients should always be asked to return for another test.

Conflict, if any, between two ways of being with clients

Zanele prefers to listen to her clients most of the time to prevent her from having the most control in the session, which she believes encourages them to be deceitful. Consequently she listens carefully, nodding where appropriate, and intervening where necessary so as not to omit important facts which have to be relayed to them. Zanele has also found that she is able to pick up problem areas more by listening than by talking. When she does speak she does so tactfully in order not to be too prescriptive, which she feels is dangerous as the clients would think she was being interfering or domineering. She concentrates on education and positive living rather than negative aspects in order not to increase their pain. Informing patients in this way helps Zanele to feel that she is serving a good cause by being an HIV/AIDS counsellor. For example, by teaching clients about the advantages of using condoms, she may be curbing further infections or even preventing the birth of HIV positive babies. Nevertheless Zanele avoids talking too much as that would give the clients the impression that she knows everything and this could intimidate them. But when she does play the directive role she does so confidently in order to gain their trust and because she realises she is doing her duty. She is also aware that she may not see them again and thus has to ensure that she has given all the basic information they need. However, generally speaking, Zanele does not experience conflict as such between the two ways of being with a client as she uses both forms. She does not consciously choose either way but finds that she interchanges between them during the session.

Stressful aspects of the work

Zanele experiences her work as an HIV/AIDS counsellor as stressful, particularly with post-test counselling where the clients become very distressed, so much so that at times she is worried about the possibility of attempted suicide. She suggested that the researcher should visit the counsellors unexpectedly one day so that she could get a sense of the stress they are exposed to. In this way the researcher would also understand why, on some days, the counsellors refuse to do any further counselling as they are "human beings and have feelings", like their clients, and do not "take an injection which will make us tough".

Zanele says that she takes her work seriously because she is "dealing with people's families and lives" and so work is her main source of stress. Working as an HIV/AIDS counsellor often makes Zanele feel sad and tearful, even at home. She often feels uncomfortable, even shaky, when she has to talk to someone in a post-test counselling session. Whenever the patient cries a lot she wishes she could stop the crying and make things better for the client. At times she cries with the client and then feels she may not have been able to "deliver the message properly", i.e. not been an effective counsellor. At other times she would like to be

angry with the client for being neglectful of herself or her baby but has to remind herself that she cannot control what the client does and has to “let things be”.

Although Zanele has found that talking to someone about her stress helps to relieve it, in doing so she worries about the possibility that she may talk too much and give away a client’s identity. She is especially anxious about this possibility with rape cases, which are the ones that most distress her and make her want to speak to someone in order to release some of her stress. Zanele finds it particularly painful to counsel people who have been raped. What is more, if they prove to have been HIV positive before being raped, the experience is doubly traumatic as antiretroviral treatment may only be administered to a rape victim if their positive status can be ascribed to the rape. With rape cases Zanele usually feels particularly “depressed and not (her)self” but is unable to offload on anyone because of confidentiality.

The shortage of staff at the hospital creates further stress for Zanele in that she is not always able to spend enough time with her patients but finds herself merely dispensing medication or referring patients to a doctor without examining them thoroughly beforehand. On one occasion Zanele noticed that a baby she had seen previously had returned to the hospital for further treatment and she had experienced great anxiety wondering whether she had treated him sufficiently on his previous visit. At such times Zanele does not sleep well at night due to her anxiety at the thought that the baby could have died due to her not having done her work well enough. Similarly, she sometimes realises that because of pressure of work she did not take enough time to be with a client during a counselling session and is left with the feeling of something “disturbing” her. An example of this occurred when a patient came back two days after Zanele had post-test counselled her and Zanele found that she had not even noticed that the patient had oral thrush.

At the moment Zanele is on night duty in the casualty section which is always very busy and pressured but now even more so because there are so few nurses on duty. Night duty is also more trying as she finds it difficult to stay awake at night and yet she needs to remain alert for any emergencies which inevitably arise. As a nurse Zanele also worries that she may become infected with HIV due to a needle stick injury, particularly if she is working under pressure. She also does not wear gloves when putting up a drip as she finds them too large for such a procedure. However, she wears gloves in all other cases except dire emergencies. Zanele finds some solace in the fact that she is particularly fortunate to belong to a medical aid through the hospital and would be able to go on treatment if it became necessary.

Although it is stressful to do so, Zanele encourages HIV positive patients to inform a trusted family member or friend of their HIV status in order to not only ensure that they have someone to turn to when they need emotional or physical support but also to protect that family member or friend from the risk of becoming infected too. For example, a mother may be the one who does the cleaning up when a patient has diarrhoea and Zanele believes she should be aware of taking whatever precautions are necessary. In doing so it is heartbreaking for Zanele to discover that some family members are not really interested in, or concerned about, the patients.

However, it is also painful for Zanele to see how difficult it is for close family members to learn of their loved one’s illness. She related the example of an HIV positive mother who had a close relationship with her 17/18 year-old daughter but had not yet told her of her illness. At the time of seeing Zanele she was already very ill and weak and her faithful daughter had accompanied her all the way from Alicedale, where they had had to wait days for an

ambulance in order to get to the hospital. Zanele realised the importance of informing the daughter who was looking after her mother and needed to take the necessary precautions. She tactfully explained this to her client who then agreed that it should be done. It was “depressing” for Zanele to witness “the way the daughter was crying”, so much so that Zanele cried too. She had already lost her father four years ago from TB although Zanele suspected he had probably also had AIDS. She thus only had her mother left and was afraid of losing her too. On those days when Zanele has had two such post-counselling sessions, in which there has been a lot of crying, she feels so emotionally exhausted that she does no further counselling for that day and asks another counsellor to help out if necessary.

Sometimes it is not possible for the patient to inform a family member of their status and this difficult task becomes the painful responsibility of the counsellor. Zanele recalled how difficult it was for her to do this in the case of a husband who was no longer in a fit mental state to inform his wife of his illness. He had been hospitalised and everyone on the ward knew that someone would have to break the news to her so that she could be tested. Zanele obtained permission from the doctor to inform the wife but delayed doing so for a few days in the hope that the husband would regain consciousness. A week later she found this lady waiting to be tested, having been told by another nurse that her husband was positive. Although Zanele did not pre-test counsel her, she could see that this lady was “depressed, worried, confused, frustrated” and perhaps even afraid that, if she proved to be positive, “she would die tomorrow”.

Another stressful factor for Zanele concerns the number of young people who are HIV positive, especially as she often finds that they become infected during a first relationship. In such cases she tries to alleviate the guilt which they usually feel for having become sexually involved with their boyfriend in the first place. However, as with herself, Zanele realises that the youth all have dreams of marriage, a home and children and sometimes enter into an intimate relationship with someone, even if they know that they are positive. She once post-test counselled a patient who was about her age and was going to get married soon. She was “enlightened” about HIV/AIDS and thus well aware of the implications of a positive result, making it even more “painful” for Zanele to tell her that she was HIV positive. Contrary to Zanele’s expectations, the patient’s reaction to this news was not to be very distressed and cry a lot, but to become angry and determined not to tell her boyfriend. She was not prepared to give up the idea of getting married as everything had been arranged already, even the ‘lobola’ had been paid. But she did wonder whether her partner had asked her to marry him because he knew he was positive. Zanele could see that her patient was very confused and she was worried about her. Her boyfriend might even have been negative as her patient had recently become involved with him and had had a previous relationship. However, Zanele felt she could not shatter her dreams and encourage her not to get married but she did emphasise the importance of asking him to be tested too so that they could practise safer sex and she could openly take precautions to ensure the safety of her children.

Another source of stress for Zanele is having to live with the knowledge that more and more people, especially young ones, are dying from AIDS. It is difficult for her to accept that most of them will die without having been able to fully enjoy their lives or fulfil their dreams. Informing the family of this impending death is also painful, as well as dealing with the patient’s fear of dying. She mentioned the example of a man in his late twenties who was already very thin and struggled to walk unaided. After being given a positive result, he asked for treatment which would prevent him from dying. He asked Zanele to visit him in the ward everyday and would tell her that he was not feeling well. Zanele was unable to tell him that

he was dying as she felt she had to help him feel the hope he was trying to give himself. On another occasion a mother was so afraid of leaving her children behind that she also asked for something to stop her from dying. Zanele finds that people often react to the knowledge that they have HIV by thinking they will die almost immediately. Although she explains to them that this is not the case, it is very stressful for her to deal with people's fear of dying before they feel ready to do so. Hence, were she to have to choose between being a nurse or a counsellor, she would choose the former because as a nurse she was taught to save lives but as a counsellor she often has to deal with people who believe they are dying.

Zanele is unhappy with the fact that it is only those patients who are ill, or their partners, who are referred by doctors for pre-test counselling and she herself may not authorise any testing without a referral from a doctor. She was told on her arrival at the hospital that testing is very expensive hence people who voluntarily want to be tested have to go to a private doctor as the hospital only deals with "the real cases". Fortunately, VCT is now available to people who are interested to know their HIV status so anyone can be tested at no charge. She also does not like it that she is generally not able to follow up on clients after a post-test counselling session, partly due to hospital policy and partly due to the difficult personal circumstances of the clients, such as getting time off from their work or requesting an explanatory letter from the hospital in order to do so. It is only when clients have been particularly distressed during a post-test counselling session that Zanele makes an appointment for a third session. After their post-test counselling session they are usually referred to the nearest clinic for their monthly supply of Vitamin B Complex and Bactrim as it is a more convenient and economical option for both the hospital and the clients. Thus, generally speaking, Zanele does not know what happens to most of her clients after she has counselled them and this is saddening for her. At times she sees some of them and "they look so sad or ill that you wish you could talk to them again". Those who return to the hospital due to other serious ailments, such as heart disease, often come and look for Zanele to chat to her. If she is too busy to see them then she makes herself available to see them in her lunch hour, which she does not resent although it does shorten her time for getting some relief from her responsibilities.

Personal life experiences

Zanele describes herself as being relaxed about most things except her work, which she takes seriously as it deals with people's "lives and families". She is basically a happy person who enjoys life and does not believe in 'keeping things in'. Accordingly, she tries to keep her anxiety and stress levels down by talking to people about her problems. When working Zanele lives in the Nurses' Home where she has good friends who are a source of support to her in the absence of her mother. When she is not on duty she goes home to her mother's house in Port Elizabeth. She does not mind living between two homes but at times really misses her mother, with whom she has a very good relationship. Her parents were divorced in 1986 and her father has remarried but she gets on well with his new wife. Her older sister and her two sons, 13 and 7, also live at her mother's home, as well as her maternal aunt (70), and the housekeeper. There are no financial concerns in her family and everyone gets on well but there is lack of privacy due to having to share bedrooms. Zanele finds this frustrating at times as she is unable to talk privately with her mother without feeling that her aunt might think that she and her mother are gossiping about her. So when she needs to talk confidentially to her mother she has to be content with waiting until her mother has some free time at work to phone her, or she meets her mother at work so that they can talk in the car on the way home. If she is at the Nurses' Home and has had a disturbing day she still turns to her mother by telephoning her firstly, because she shares most things with her and can trust her mother to be

honest with her and secondly, because it avoids the danger of being misunderstood and/or misquoted by her colleagues. In fact, she is able to confide in her mother about everything, even if she were to become HIV positive one day. Her sister is another person whom she can rely on for support and honest feedback.

Zanele also has a good relationship with her partner who, like her mother, serves as a source of support for her. One aspect of the relationship which she finds very stressful is the fear of becoming infected with HIV. She lives with this fear every day as Zanele cannot fully trust that male partners are sincere and faithful, something which has been reinforced by her mother's belief that most people who are sexually active will become infected sooner or later.

Support structures

Whenever Zanele becomes upset or stressed because of something which a colleague at work has done, she also finds relief through talking to someone. However, she has learned to wait until she has calmed down before approaching the person concerned. If she is unable to sort out the problem, Zanele has found that she becomes negative towards that person. Fortunately she has grown enough to realise that, when this happens, she can call on a close friend of hers, who is a fellow counsellor, to act as arbitrator and thus resolve the tension through a third party. As her mother has told her, "life is too short to harbour hurtful feelings".

According to Zanele the counsellors are called together whenever a change or correction is necessary but there are no regular meetings for the counsellors to meet and discuss their problems. Zanele would like to see a regular meeting facilitated by someone like Sr. Whiteley or Sr. Toni but realises it would be difficult to get everyone to attend because some would be on night duty and others on leave or off duty. She believes all 35 counsellors need to meet together about matters related to updating or correcting information so that all of them receive the same information which would ensure uniformity in their counselling. In addition, she would like the opportunity of meeting in a small group with an external facilitator where she and the other group members could talk confidentially about whatever was on their mind, including personal difficulties, without fear of any reprisals. These smaller groups would ideally consist of about five or six people and would be made up of all three categories of nurses, namely, sisters, nurses and assistant nurses. Such group interaction would serve to diffuse some of the stress experienced by the counsellors, provided that the small group meetings were taken seriously and attended regularly. The main problems presented to the facilitator at these meetings would be summarised, without jeopardising confidentiality in any way, and addressed at the plenary meetings.

Zanele based her suggestion of meeting in small groups on the enjoyment she had experienced at being interviewed by the researcher as it had refreshed her so that, if she had been asked to counsel someone that day she would have felt eager to do so. She had found that the opportunity to talk to the researcher had made her feel at ease and had allowed her to be herself so that she could share her stress without feeling that she had been "gossiping". Because she is "not supposed to discuss" her clients with other counsellors she finds she sometimes goes to bed at night feeling "frustrated and not (her)self". She is afraid to say anything even to a fellow counsellor who is a close friend of hers, as she cannot "trust (her) mouth" that she will not let something slip out which will enable her friend to identify the client she is referring to. So neither of them discuss their clients with each other, even anonymously. She would thus appreciate having someone to speak to who, as in the case of the researcher, was not likely to know the hospital set-up and would maintain confidentiality.