# The experiences and needs of HIV/AIDS counsellors at a South African hospital

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To increase the availability of HIV/AIDS counselling in South Africa, nurses have been trained to serve as counsellors within hospital services. The aim of the study was to document the experiences and needs of nurse HIV/AIDS counsellors at a small South African hospital (with 279 beds and 10 medical doctors on the staff). The design was a qualitative, multiple-case study. The sample consisted of four nurse counsellors and the co-ordinator of HIV/AIDS services at the hospital. Three semi-structured interviews with the counsellors were used as the basis for case narratives of their experiences. These narratives were in turn subjected to content analysis to determine the range and nature of the concerns identified by the counsellors. The counsellors found their HIV/AIDS counselling work to be emotionally demanding and identified several significant problems. These were related to confidentiality, stigmatisation, emotional responses to informing clients of their HIV-positive status, cultural and contextual factors and situational stressors related to the organisation of the work environment. They did not feel sufficiently supported by their work infrastructure. It is recommended that in setting up counselling services of this sort, managers need to be aware of the need for ongoing support in the form of facilitated groups, professional supervision, managerial attention to problems in the working environment, and regular in-service training.

Keywords: counselling, training, workplace stressors, management

#### Introduction

Informing a client that he or she is infected with the AIDS virus is a demanding task because it typically evokes overwhelming and disturbing emotions as well as attempts at denial of the implications of being infected (Cartwright and Cassidy 2001). HIV/AIDS counsellors have the task not only to educate and encourage behaviour change, but also to help clients and their families explore the psychological demands associated with this illness (Delaney 2000). HIV/AIDS confronts individuals with emotionally-charged issues such as sex and sexuality, disease, disfigurement and disability, and death and dying. Moral culpability is often attached to becoming infected with the virus, leading to stigmatisation and discrimination. Anger, guilt and blame are internalised by both the infected and affected. Fear of dying and concern for the future of survivors is an everyday reality. Those affected by HIV/AIDS face a wide range of losses: of lifestyle, security, personal control and dignity, and eventually of life itself (Kiemle 1994). When incorporated as an integral part of a patient's health care HIV/AIDS counsellors are the most appropriate people to help with such emotional crises (Burnard 1992, Grinstead and Van der Straten 2000).

**HIV/AIDS counselling services at South African hospitals** A national HIV/AIDS counselling strategy was developed in the early 1990s by the National AIDS Co-ordinating Committee of South Africa (NACOSA) to promote the prevention of HIV infection and support those infected or affected by HIV/AIDS. It is directed towards five goals: 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, Van Rooyen, Solomon, Griesel and Durrheim 2001). In 1996, the Lay Counsellor Project was set up to train lay counsellors in all the provinces. Common national standards were laid down that included minimum standards for training, ongoing in-service training programmes, and regular support, supervision and mentorship. The manual for training HIV/AIDS counsellors, based on these standards, refers to the importance of in-service training, emotional support and professional supervision for counsellors (Department of Health 2001). This manual is, however, mainly seen by a small number of certified trainers.

Most people remain unaware that they are infected and fail to make use of HIV/AIDS counselling until they are already symptomatic. Consequently, counselling services in the public sector focus mainly on pre- and post-test counselling (Van Dyk 2001). There is a need to promote awareness of the benefits of testing before symptoms appear and of the benefits of counselling for managing the trauma associated with infection. There is also a growing demand for ongoing counselling that can lower the symptoms of stress associated with HIV infection (Bond 1995). HIV/AIDS counselling relationships have increasingly become long-term ones because counselling changes self-concept and improves self-esteem (Balmer 1992). However, in South Africa, such services are predominantly once-off pre-test encounters with an educational rather than a client-centred focus. Counsellors, who are generally female, are reported to find it difficult to counsel men or deal explicitly with sexual aspects of preventive behaviours, or even to apply the recommendations about communication about sexual risk and safe sex practices with partners in their own lives. Only 25% of counselling services provided any infrastructure for supervisory or personal support for counsellors (Richter et al. 2001). In South Africa, most HIV/AIDS counsellors are full-time nurses and unpaid lay counsellors (Richter et al. 2001). They are trained to provide education in the form of HIV-related information and prescribed behaviour change. This is especially important because of the limited impact of public awareness campaigns (Richter, Durrheim, Griesel and Solomon 1999). They must also provide support by inviting clients to express their difficulties and fears and motivating them to accept the diagnosis and live positively. Counsellors often find it difficult to integrate the different demands of the counsellor role (Balmer 1992, Burnard 1992, Bond 1995, Delaney 2000). For nurses, with an already demanding workload, the additional stressors from counselling, in the absence of compensation in the form of additional status or promotion, can result in unacknowledged burn-out (Seidel 1996, Grinstead and Van der Straten 2000, Miller 2000, Gerber 2002).

#### Goals of the present study

The aim of the present study was to conduct an analysis of the needs and experiences of nurses serving as HIV/AIDS counsellors in a state hospital in the Eastern Cape, South Africa. Nurses have been acting in this capacity since 1999, but a recent survey revealed that 19.1% of these counsellors did not feel supported in their work and requested some kind of mentorship (Whiteley and Mdzeke 2002). A specific focus of the study was on stressors impacting on the counsellors at work and at home, and the extent to which they felt personally and professionally supported. A final aim was to make recommendations as to how any problems that were identified might be addressed.

#### Method

The research design was a qualitative multiple case study. Case studies can use a range of data collection methods that provide data with immediate relevance to the setting, and furnish an understanding of the psychological dimensions of the behaviour and experience of the individual within that setting (Bromley 1986, Hoepfl 1997, Edwards 1998).

## Setting and participants

At the time of this study the hospital had 279 beds, 10 medical doctors on the staff, and was providing in-patient and out-patient medical services. Thirty-five nurse-HIV/AIDS counsellors were offering counselling in accordance with the five NACOSA goals referred to above. The English-speaking HIV/AIDS co-ordinator at the hospital (Sue), who is an HIV/AIDS counselling trainer and also both a nurse and counsellor, provided general background information. The main participants were four female Xhosa-speaking HIV/AIDS counsellors who were recruited through purposeful sampling. Inclusion criteria were: at least one year's experience, ability to converse in English, willingness to be interviewed, and to have the interviews audio-taped.

Dina, a widow with a son and a daughter, has been without a partner since the death of her parents about 10 years ago and lives with her older sister, who is ill and unable to work, and her nephew. She runs the household alone and feels the weight of her domestic responsibilities both emotionally and financially. She is an active church member and finds comfort in daily scripture readings and prayer.

Nosipho, a single parent with two daughters, does all her own housework but still finds time to relax and to study to improve her qualifications. Her partner has three children but the couple live separately. Although she and her partner have a good relationship, she is never free of the fear that she herself could become infected with HIV.

Nomawethu, a divorced mother who lives with two of her three children and a grandchild, describes herself as a busy woman and a survivor. She does her own housework and is very active as a healer in her church. She was finding it especially difficult to manage financially, as part of her house had recently burnt down. Nomawethu does not have a partner and says she no longer wants to be dominated by a man. She finds strength through her faith in God and uses prayer to lift her spirits.

Zanele has never been married and has no children. She lives with her mother, her older sister who has two sons, an aunt and her two adult daughters, and a housekeeper. They have to share bedrooms but they get on well together. She has a close relationship with her mother, and also her partner, but worries about the possibility of HIV infection.

Participants were informed of the aims and nature of the study and signed a consent form stating the voluntary and confidential nature of their participation. They were informed that pseudonyms would be used in all reports and publications and that audio tapes would be destroyed on completion of the report. However, the co-ordinator, Sue, did not want a pseudonym to be used in her own case.

#### Interviews

Data was collected by means of semi-structured interviews based on interview guides following principles summarised by Kvale (1996) and Smith and Osborn (2003). All interviews were tape-recorded. There was a single interview with the co-ordinator, Sue, which focussed on the training process, the organisation of the counselling service and her perspective on what the current problems and concerns were. A series of three 60 to 90-minute interviews were used with each of the counsellors. This was in line with Seidman (1991), who has emphasised the importance of a series of interviews for building trust and gaining a comprehensive understanding. The interview guide for the first interview focussed firstly on their experience of training (they were asked about the length and content of their training as well as about their personal responses to the training process), and secondly focussed on examples of the kinds of cases they saw in their counselling work (they were particularly asked to describe cases they had found challenging or upsetting to deal with). The interview guide for the second

interview focussed on the counsellors' personal history and life circumstances. As such, it was similar to a clinical interview. One aim was to identify stressful aspects of their life experiences and they were questioned about family circumstances while growing up and asked about significant losses or traumatic events. A second aim was to understand their present life circumstances, whether they were living alone or with a partner, whether there was marital support or discord, what responsibilities they carried for looking after children and domestic work at home, and their sources of recreation and support at home. The Beck Anxiety Inventory or BAI (Beck and Steer 1993) and the Beck Depression Inventory, second edition/BDI-II (Beck, Steer and Brown 1996), were also administered. The focus of the third interview was on those aspects of their work that participants found stressful both in relation to their HIV/AIDS counselling work and to their other hospital duties. They were also asked about the kinds of support they received formally and informally within the hospital setting. In all interviews, following responses to the questions, the researcher often asked further questions to clarify a point or develop a theme (Burnard 1992). The interviews were carried out over a period of six weeks in early 2003. Interviews were transcribed as they were completed, so that points which required clarification or expansion could be raised at the interviews which followed.

# Data processing

The main points from the interview with the co-ordinator were summarised thematically. For each counsellor separately, the interview material was reduced into a case narrative (Edwards 1998) by organising the material under the following themes: the counsellor in her context; experiences of prescriptive and client-centred modes of counselling; stressful aspects; personal life experiences; support structures. Sub-themes that emerged from the material of the interviews were identified and used to organise the material on stressful aspects (see Smith and Osborn 2003). In a second data reduction step (Miles and Huberman 1994) the case narratives were organised into a thematic content analysis using the same headings, in which the experiences of all four counsellors were integrated. These procedures are relatively straightforward; however, some critics have pointed out that researchers may introduce bias in the way they transcribe tape recordings or by being selective in their choice of material in content or thematic analysis (Barker, Pistrang and Elliot 1994). As a quality assurance check, another master's level researcher acted as an independent judge and randomly selected and checked a 10-minute sample of audiotape against the transcription, to ensure that nothing had been omitted or inserted. The judge reported that there was no bias in the transcribed version. The judge also conducted a check on the reduction into case narratives by selecting at random one theme (of five pages) from one of the narratives and reviewing the transcribed interviews to check that no bias had been introduced into the reduction.

## Results

The case narratives document the experiences of individual counsellors and provide a window into their idiosyncratic experiential worlds. They portray in human terms the strengths and struggles of individuals coping with the challenges of particular life and work contexts (Taylor and Bogdan 1998). Because of space limitations, only the thematic content analysis is presented here. This focusses on aspects relevant to the planning of HIV/AIDS counselling services. It is organised under the following headings: training; prescriptive and client-centred counselling modes; cultural and social sources of stress; confidentiality and stigma as sources of stress; feelings about disclosing HIV-positive status to clients; role conflict and role overload; institutional stressors; support structures.

#### Training

In the first part of the course participants explored their own values and prejudices, particularly concerning HIV/AIDS. They learned that being judgemental served to increase dysfunctional emotions in their clients, such as anxiety, anger, guilt and even hatred. They also received information about the nature of the virus, preventive measures and HIV testing, the difference between HIV and AIDS, and effective medications. The second section of the course concentrated on counselling skills including approaching the client, distinguishing between sympathy and empathy, facilitating disclosure and expression of feelings, maintaining confidentiality and avoiding reassurance. They were sensitised to the fact that, after hearing their results, clients need space in which to absorb the information and explore their feelings, and that counsellors should encourage clients to engage the support of a close relative or friend. All counsellors reported that the course provided a good basis for their work; through sharing their own feelings they got to know themselves better and so understand others. They also developed practical skills that increased their confidence in their ability to respond appropriately to a wide range of different emotional reactions in their clients.

## Prescriptive and client-centred counselling modes

All participants were aware that counselling involved both prescriptive/educational and empathic/client-centred modes of relating to clients. However, none reported significant difficulty moving between these two modes. Nevertheless, they did report feeling more in control when dealing with factual information whereas, by contrast, in non-directive mode, they were 'never sure what to expect nor what to say in response' (Dina). They concurred that it was essential to allow the clients to do most of the talking so that they could express their feelings, such as fear and anger. Nosipho felt she was a better counsellor when she gave 'the listening ear' and preferred to sit with the discomfort of not knowing where clients might lead her rather than attempting to control the session. For Nomawethu, allowing clients to express their painful feelings enabled them to establish a meaningful relationship with her through which they were able to transform their pain. One couple had told her that their session with her had been the first time they had been able to talk about their emotions since discovering their status. After they had cried a lot, which she described as 'painful, painful', she had moved to an information-giving approach which served to provide clients with a practical focus on how to cope with the challenges of the future.

All the counsellors reported that listening to their clients helped them identify particular problems that needed attention, such as how to inform someone close to them of their status. Zanele said she avoids talking too much so as not to intimidate clients by giving the impression that she knows everything. This approach needs to be balanced by the need to ensure that clients receive all the basic information, since clients mostly do not receive any further counselling sessions. According to Nosipho, the degree to which a counsellor is prescriptive depends on how 'talkative' the client is. It is less disconcerting to be with clients who talk openly, as this enables her to determine what they are feeling. With very talkative clients the counsellors must sometimes juggle between allowing them to speak freely and interrupting them in order to furnish relevant information. On the positive side, such clients let the counsellor know whether they have enjoyed the session and gained anything from it.

#### Cultural and social sources of stress

When counselling the elderly it is more difficult to be directive and to insist that they be tested, because African culture emphasises respect for elders, who may feel offended when counsellors address intimate sexual matters or question their lifestyle. Some even believe they are too old to become infected or that it is impossible for them to have contracted the disease as they have been widowed for so long. One older woman refused to be tested and was adamant that she had not had any sexual contact for many years. Dina just let her talk and did not insist on obtaining a blood sample for testing. For Nosipho, it is stressful enough to correct people's 'erroneous ideas' but when they are her seniors it is doubly taxing because of the cultural norms of respect for elders. Nevertheless, she braces herself and 'sheepishly' does so because she would be 'doing them an injustice' if she left important things unsaid.

Counsellors are painfully aware of the material poverty in which most of their clients live, and the contribution that this makes to the development of full-blown AIDS. Dina observed that 'poverty does not allow' most patients to afford anti-retrovirals or, in some cases, obtain nutritious food, hence their chances of living healthily are 'poor'. Sadly, sometimes a whole family becomes infected because younger females are forced to be sexually intimate with the sole breadwinner to avoid being thrown out. Nosipho was surprised that some people actually wanted to receive an HIV-positive result, as this could give them access to a disability grant. 'Everyone dies eventually', they would say, so why could she not 'let them have the grant in the meantime'. Two counsellors specifically mentioned rape cases as being stressful, particularly as the victims may not receive anti-retroviral treatment if test results prove that they were HIV-positive before being raped. Nosipho recalled her sadness for a client who had been raped three years previously while still a virgin but had been seen too late to prevent infection with HIV. Counsellors expressed dismay at the young age of many clients. Working with children or teenagers reminded them of the possibility of their own children becoming infected and dying young. They found it difficult to speak about sexual matters to people who were not yet sexually active and could not always comprehend what was being said to them. Nomawethu described as 'terrible, terrible' the plight of a 14-year-old 'child' who seemed so 'naïve and honest' and did not 'know anything about sex'. She had 'never had a man' and her mother was not aware of any abuse. Zanele said many young people become infected during their first relationship and she would work to alleviate the guilt they felt and help them deal with the loss of so many dreams. Zanele found herself identifying with a client who was angry on hearing that she was HIV-positive, and who decided not to tell her partner as she was not prepared to give up her marriage plans.

Nosipho expressed frustration at people's 'negligence' concerning sexual behaviour and wondered 'where it is all going to end'. Sue attributed the negligence in part to the reticence of black parents to talk to their children about sex. Even the counsellors 'just hope and pray that nothing will ever happen' to their own children. The elderly are also affected by this negligence. Dina found it 'shocking and painful' that a 67-year-old woman had tested HIV-positive. Nosipho felt sad that elderly people often nursed their dying sons and daughters and, after burying them, still had to care for the grandchildren, who were often HIV-positive too. In addition, they themselves could become infected from not taking sufficient precautions while nursing their relatives.

Nosipho believed that black people regarded it as more acceptable to have more than one sexual partner than did those from Western cultures. However, participants expressed anger, helplessness and despair because 'our people are not faithful' and they foresaw an ever-increasing rate of infection because, as they saw it, men could never be completely trusted to remain sexually faithful, and this put women at risk for infection. Despite this, women hesitated to insist on safe sex practices since this would imply that they suspected their partner of infidelity.

Counsellors reported that many people would attribute misfortune such as the death of a child or HIV infection to witchcraft and seek help from traditional healers. According to Dina, the herbal remedies they are given may make them feel worse and even result in complications such as damage to the kidneys. Consulting a traditional healer can actually increase the likelihood of being suspected of witchcraft, resulting in less support from family and neighbours and even in being regarded as 'enemies'. These 'myths about witchcraft' result in some patients 'spending years without telling anybody', so Dina tries to change people's 'perception of witchcraft'.

#### Confidentiality and stigma as sources of stress

While confidentiality is an intrinsic part of counselling, it carried the drawback of allowing clients to keep their HIVpositive status secret from close family members and lovers despite the fact that it might directly affect them too. The counsellors tried their utmost to ensure that clients did not keep their illness a secret but found this a demanding process that could require long sessions, which Dina found mentally exhausting. She believed that a client's reticence to disclose may stem from the fear of 'family disintegration'. Nomawethu referred to one woman whom, she feared, would be too reticent to share her pain with her husband. Some of those infected went on to find new sexual partners, who were likely to become infected. Zanele used the term 'heartbreaking' for this lack of concern about the health of family members and lovers. When the infected individual did disclose, this brought with it another kind of pain, that of the family member learning of a loved one's illness. Zanele convinced a mother that it was in the best interests of her 17year-old daughter to be informed of her mother's HIVpositive status, but was in turn so deeply affected by 'the way the daughter was crying' in response to the disclosure that she had cried too.

Maintaining confidentiality often posed ethical dilemmas. Nosipho wondered what would be more unprofessional: to break the seal of confidentiality, or to say nothing and put someone at risk of being infected with a terminal illness. She had experienced this conflict when she was unable to inform a husband, who had tested negative, of his wife's HIVpositive status. The wife had even refused to practise safer sex for fear he would suspect her motive for doing so. When Nosipho saw the husband she felt guilty and believed it would have been easier had husband and wife both tested positive. How long would she have to 'carry that lie,' Nosipho asked. She felt that 'that's where the stress comes in'. Yet, were she to tell the husband the truth she would feel guilty as a counsellor about disclosing confidential information without the wife's consent. She also wondered what she would do if she were to see one of her male HIV-positive clients accompanying her own daughter? Would she have to refrain from disclosing his status to her own daughter? Could she even suggest the use of condoms without creating suspicion? She also told of cases where parents visited daughters with AIDS, bringing gifts and doing everything possible to help them recover, but remained ignorant of the true cause of their illness. These young women had refused to disclose their status to their parents, leaving Nosipho standing helplessly by. If she were in this situation, she hoped that her daughter would inform her.

Counsellors found it particularly stressful if they had to counsel someone well-known to them who was HIV-positive. They found it more difficult to keep such information confidential and feared unjust accusations if it were to 'leak out' that they had counselled such close acquaintances. Dina observed that her relationship with the person would be affected, since he or she might feel that Dina 'knows everything about him [or her]'. In such cases she would, if possible, ask another counsellor to conduct the session.

Counsellors also reported that the principle of confidentiality made it difficult for them to find support in dealing with their own feelings. Nomawethu was unable to 'share her stress' without feeling that she had been 'gossiping' and, as a result, would feel 'frustrated and not myself'. Zanele worried that she might say too much and give away a client's identity, or be misunderstood or misquoted by her colleagues yet, when unable to share her feelings, would become 'depressed and not myself', particularly with rape cases.

## Feelings on disclosing HIV-positive status to clients

Disclosing HIV-positive status to someone was like giving them a death sentence. Counsellors not only had to address clients' fear of dying but also had to speak to them about making preparations for their death and for the care of those who would be left behind. Most clients are not ready for this, as they are still in the prime of their lives, observed Zanele. Even with patients in the ward who were dying of AIDS, it was difficult to acknowledge to them that they were dying. Despite visiting him daily, Zanele found herself unable to tell a young man he was dying, as she had wanted to give him the hope he was trying to give himself. Nomawethu was aware that clients need to face the reality of death. She would tell someone that everyone would die one day but found herself feeling pain about it herself 'maybe even for a whole day'. With some, she felt a 'block' between them and herself which made it very hard to get through to them and she would feel as if she was not 'actually talking to [them]'.

Three counsellors mentioned their fear that clients might become suicidal on learning that they were HIV-positive. A young bride-to-be wept desperately when Dina told her of her HIV-positive status. Dina had not seen her again and still wondered what became of her. With suicidal clients she would work to 'take the idea away' but often found this taxing and draining as she had to 'go over the same things quite a few times'. After Nomawethu had given a client 'the bad news', she experienced 'a strange feeling and a pain' when they would initially want 'to give up hope'. Some reacted as if they had 'closed the curtain already', observed Nosipho. In such cases she would know she was 'in trouble as the patient is not going to cope with the disease emotionally'. Such clients would be likely to return to hospital later 'after trying to kill themselves'.

After disclosing to a client that they were HIV-positive, Nomawethu sometimes felt she wanted to be 'alone in a dark room'. She often found it difficult not to take their problems on as her own. However, by being prescriptive and trying to instill hope, she would feel she was doing something for them. Similarly, Nosipho found herself 'in the patient's shoes most of the time' and often could not forget about them when she went home. After watching the news on television she would sometimes realise she had not taken anything in as her mind 'was still on the patient'. This interfered with having 'a good night's rest'. Sometimes, she even dreamed about clients, and experienced a feeling of being powerless to help them. Zanele, too, was painfully aware that HIV/AIDS affected 'people's families and lives' and wished she could do something to 'make things better' and 'stop the crying'. When clients were very upset she sometimes worried that she had failed in 'delivering the message properly'. At other times she felt angry with the client for being neglectful and she had to remind herself that she could not control the client's actions and must 'let things be'. She would feel so concerned that she would often agree to see to them without an appointment, although it might mean giving up her lunch break. At times when there had been 'a lot of crying', Zanele felt so emotionally exhausted that she would be unable to do further counselling and would ask another counsellor to help out. We are 'human beings [and cannot] take an injection which will make us tough', she commented.

#### Role overload and role conflict

Nosipho experiences a conflict between being a nurse who is trained to help people get better and attending to AIDS patients who are 'not going to get well', thereby denying her 'some measure of control'. Sue explained that 10 years ago death was not an everyday occurrence in hospitals but that that year, in January alone, there had been 22 deaths from AIDS. At times there was severe work overload and the counsellors found five or six counselling sessions in one day to be very taxing. Nomawethu sometimes delayed her tea break to accommodate a long queue of patients waiting for attention, and was aware that she would become tired and that clients could sense that the counsellors were not at their best. Clients who waited several hours might ascribe the delay to the counsellors' lack of concern and were 'nice and cross', as Nomawethu put it, when they started the session. Counsellors expressed concern that they were not spending enough time with clients to ensure that their needs were met. This left Zanele with a 'disturbing' feeling that she had not given of her best. Once, she had only noticed that a client had oral thrush two days after she had done the posttest counselling. Staff shortages could also mean that clients received pre- and post-test counselling from different counsellors. This interfered with the process of continuity and with the initial relationship of trust between client and counsellor. Furthermore, no provision was made for additional sessions even though they were obviously needed. This was demoralising for the counsellors and, as Nosipho observed, the lack of follow-up made it impossible to determine the effectiveness of sessions.

The counsellors also experienced role conflict between their nursing duties and counselling work. As Dina put it, they have to be nurses, caregivers, social workers and general counsellors. They all experienced counselling as far more stressful than nursing. Nosipho called it 'very, very strenuous', as it was not easy to remain objective while counselling. Given the choice, she would prefer to be just a nurse, as the emotional stress of counselling was more difficult to bear than the physical stress involved in nursing. After a good night's rest, Nisipho felt she had recovered from the demands of her work as a nurse, but the helplessness, frustration and anger experienced in the counselling process stayed with her. Even nursing duties were often performed under time pressure. Zanele sometimes felt forced to merely dispense medication or refer patients to a doctor without examining them thoroughly beforehand. When she noticed that a baby she had treated had returned she became anxious about the quality of her treatment. She sometimes worried that a patient could die through her lack of thoroughness, and this would disturb her sleep. Because of a shortage of doctors, nurses carried out most of the preliminary examinations of patients. Dina resented the fact that nurses who were also HIV/AIDS counsellors were usually requested to take all the blood samples, not only those for HIV testing, so as to save other staff from taking a person's blood on another occassion.

#### Institutional stressors

Counsellors did not feel that their efforts were acknowledged verbally, or rewarded through financial incentives or promotional opportunities. They perceived hospital management as not interested in the practical problems experienced in the wards or clinics. Lack of communication at various levels in the hierarchy prevented messages from the counsellors reaching those in charge. Aspects of hospital practice that contributed to their lack of job satisfaction included restrictions on the use of telephones and a lengthy authorisation procedure for mailing information. These made it difficult to follow up on clients, a problem exacerbated by clients' own lack of finance, transport difficulties and difficulty in getting time off work. Two counsellors were unhappy because they could not conduct HIV testing without a doctor's referral. This meant that those who come voluntarily for testing but who did not need to see a doctor had to go either to their local clinic or a private doctor because hospital doctors only dealt with the 'real cases'.

There were practical factors that interfered with the counselling process itself. The counselling room was very prominent and this made it easy for counsellors to be interrupted by staff bringing telephone messages or calling them for duties elsewhere. Dina said that such interruptions put pressure on them to shorten the sessions so that counselling became 'a slapdash thing'. She had thought of putting up a 'do not disturb' sign, but was concerned that this would tell all passersby that this was the counselling room and this would compromise the confidentiality of the clients who visited it. Once Nomawethu was so upset by one of these interruptions that she had wanted to 'take [her] bag and go home'. She had taken time to process what had happened during the session, but had found it difficult to explain this to her supervisor. She had felt that she 'was not a person, just a thing' and had been absent from work the next day as she had not wanted to see anyone. On this occasion one of the supervisors had noted that there was significant emotional strain involved in counselling work, and had asked another counsellor to talk to Nomawethu.

#### Current levels of anxiety and depression

The counsellors' scores on the BDI-II ranged from 13 (Dina) to five (Nosipho) — all within the 'minimal' range. Thus, while Dina exhibited some depressive symptomatology, none of the counsellors seemed to be experiencing disabling symptoms of depression. There was more evidence of anxiety symptoms: the BAI scores of Dina (8), Nomawethu (12) and Nosipho (15) were all in the 'mild' range, while Zanele (18) scored in the 'moderate' range. Zanele's anxiety may be related to her tendency to worry about the quality of her work and the fate of her clients, as described above.

## Personal life stressors

Zanele and Nosipho both had strong and reliable support structures at home. Zanele was from a high-functioning family with no financial difficulties, and experienced no stressors at home except some lack of privacy. She saw her partner quite regularly and enjoyed going out with him but was consistently afraid of becoming infected with HIV. The most stressful aspect of her life was her work as an HIV/AIDS counsellor, which evoked feelings of sadness. However, she found some relief through confiding in her mother. Like Zanele, Nosipho tended to take her clients' problems home with her. However, although she was a single parent, she felt she had a good family support system. She would relax every day after work in front of the television with a cup of coffee but resented housework, which she experienced as her chief source of stress. She wanted to hire a housekeeper but had other financial priorities, such as the education of her two daughters. Her financial responsibilities worried her to some extent, but she recognised that her anxiety was partly due to her desire to have nice things at home and partly to her need to always feel in control. Although she felt supported by her partner, Nosipho was also afraid of becoming infected with HIV. She further feared that her older daughter might become infected, although she had tried to educate her about this risk.

By contrast, Nomawethu and Dina did not feel they had support systems at home. Instead, they saw themselves as serving as sources of support for their family members. They were both single parents each with three dependants living with them. Neither of them could rely on assistance from their extended families. Neither of them had a partner and both stated that they preferred this as it allowed them to be independent and free from worry about HIV infection. They both enjoyed involvement with a church and found solace in prayer and trusting in a loving God who would see them through their problems.

Nomawethu saw herself as a survivor who tended not to ask for assistance from others but still managed to give her children a warm home. She did all her own housework and often had to provide meals and accommodation for her parents and sisters, particularly her mother. A recent fire that had damaged parts of her house had resulted in extra expenses, which were causing her financial strain. She had no electricity and had to use a primus stove and candles, and cope without a refrigerator. Hence, she was unable to buy food in bulk and even had to do without lunch sometimes. She was active in the healing ministry of her church and church members would often visit her and she would often counsel them and pray with them. She believed she had a special gift for helping people with their problems, and would act as a tower of strength for others, while not having anvone to lean on herself.

Nevertheless, Nomawethu experienced stressors at home as less taxing than those at work. If she felt down or stressed after a hard day at work, she would make time to pray at home and believed that, through divine providence, she would be made to feel better. She used to pray in a little shed outside, but this burnt down in the fire; she then, sadly, had to pray in her own room, which was more limiting. Nomawethu was also concerned about her lack of professional qualifications, since she would gain both financially and in rank if she were a sister, like the other counsellors interviewed.

Unlike Nomawethu, Dina experienced stressors at home as more taxing than those at work. With the death of her parents, she had not only lost their support but also had to take in her older sister and teenage son. Her sister was mentally ill and could not work, and she found her nephew difficult to manage. This gave rise to regular conflict. She was extending her home to accommodate all the members of her household, but this placed her under financial strain and also meant living in cramped and uncomfortable conditions for many months. Unlike the work context, where there were people to talk to and laugh with, at home there was no-one with whom to share her problems and she found herself providing support for everyone else without being able to rely on them for support in return. However, her 10-year-old daughter served as a source of comfort and joy and she believed that her experience of widowhood 21 years previously had strengthened her and helped her to deal with subsequent adversity. Her only form of relaxation at home was studying. This provided an escape from domestic pressures, and she believed that education was a means to turn the negative into the positive. She also found support in her daily prayer and church activities.

#### Support structures

Currently, the hospital makes little provision for support of counsellors. Monthly meetings and some in-service training had been arranged, but had lapsed because they were difficult to schedule since the counsellors are very busy and not all on duty at the same time. Sue even guestioned their value, as 'they just became another meeting to attend', but Zanele stressed their importance for keeping up to date. The previous year. Sue had arranged for Hospice to give three workshops on caring for those dying from AIDS, including dealing with one's own emotions and assisting family members with the bereavement process. Following these, support groups were set up but none of the counsellors participated in them, and they also fell away. The only support available to the counsellors was informal sharing with work colleagues. Dina and Nomawethu both commented on the value of this, and Nomawethu also mentioned that, when feeling overwhelmed, she would go to the bathroom where she could cry and pray to God to help her find a solution, and this lifted her spirits.

All the counsellors expressed the need to find means of alleviating the stress inherent in their work and of gaining new coping skills, and made several suggestions for addressing the many concerns expressed in the interviews. They wanted attention given to the problems identified in the section above entitled 'Institutional stressors'. They also liked the idea of meeting in small groups of about six people where they could share confidential matters and support one another. They remarked that they had felt energised by talking to the researcher about their experiences. Zanele felt she was able to be herself and open up without feeling that she was gossiping. She felt that all the counsellors should be required to attend such groups regularly. It was also suggested that a mechanism should be found for ensuring that points of concern identified in these groups were identified as problems to be addressed by management, where appropriate.

Nosipho and Sue, who were both part of the hospital management structure, wanted to revive the in-service training so that the counsellors remain up to date with the latest HIV/AIDS information and can gain the skills to enable them to handle the kinds of problems identified in the present study. In addition, Sue recommended the provision of one-to-one mentoring or supervision. She noted that one counsellor had benefitted from individual counselling received at Hospice.

## **Discussion and recommendations**

The findings of this study showed that the counsellors at the hospital experienced many of the kinds of problems

described more widely in the literature reviewed in the introduction, and that little was being done to address them, despite the fact that standards are set out by the Department of Health (2001). While the authors recognise the problems posed by shortages of resources in the public sector, this research points to a range of measures that need to be taken to provide consistent support for counsellors.

First, it is recommended that a suitably qualified person, independent of the hospital staff, be employed to facilitate regular support meetings (Jenkins 1997). All counsellors experienced difficult emotional states and painful conflicts evoked by aspects of their work. Two experienced no support at home, and those that did still showed evidence of needing support within their professional setting. It is widely recognised that counsellors cannot 'be there' for their clients if someone, in turn, is not 'there' for them (Kiemle 1994), and facilitated support groups would afford counsellors a regular avenue for expressing emotions and addressing underlying concerns.

Second, counsellors need regular supervision with an experienced counsellor, preferably a psychologist who can provide a regular space in which they can reflect constructively upon the content and process of their work. Supervision can enable them to recognise the constraints of the therapeutic context, see how personal styles facilitate or hinder the achievement of therapeutic goals, deal with their own emotional responses and separate them out from those of the client (Bor and Sher 1992, Kiemle 1994, Bond 1995). It can also assist in managing the balance between prescriptive and client-centred modes, and address sensitive issues such as sexual practices and inaccurate beliefs surrounding HIV/AIDS. This would enhance counselling skills, improve confidence, and diminish job-related stress (Hawkins and Shohet 2000, Bor and Sher 1992, Department of Health 2001). Managers are not qualified to provide this kind of supervision (Gerber 2000).

Third, counsellors need ongoing in-service training that will ensure that they are regularly equipped with additional skills and knowledge (Miller 1995). The following areas, identified in this study, should be included: (1) counselling older people without transgressing cultural customs; (2) dealing explicitly with sexual matters; (3) interfacing with traditional beliefs with respect to bewitchment and dealing with the ensuing mistrust and suspicion which these beliefs may engender (see Eagle 2004); (4) training in couple and family counselling; (5) addressing clients' fears and concerns around dying, death and bereavement; (6) keeping updated with ongoing developments concerning the medical management of HIV/AIDS.

Fourth, management needs to be aware of the need to address practical problems, in consultation with the counsellors (Bor, Miller and Perry 1988, Gerber 2000). A forum is needed whereby counsellors' concerns can be aired on an ongoing basis to ensure that they have a say in shaping the services they have been entrusted to deliver (Miller 1995). Concerns identified in this study include: (1) interruptions during sessions, which undermine counsellors' effectiveness and are stressful. Hospital staff need to be informed of the importance of respecting the privacy of client and counsellor while sessions are in progress. Allocating a designated room in a more secluded area of the hospital would help to minimise interruptions. Counsellors should be allowed to unplug their telephones 10 minutes before and for 10 minutes after each session, so as to minimise interruptions and afford space in which to prepare for sessions and reflect on them afterwards; (2) counsellors should not be expected to work with anyone they know well. Such situations limit the effectiveness of the therapeutic encounter and compromise confidentiality. Where staff members require counselling, this should be provided away from work and by someone who is not a colleague; (3) the service needs to be expanded to provide clients with access to ongoing counselling after the pre- and post-test counselling sessions. The training manual includes a module on ongoing counselling for clients to ensure that they are supported throughout the progressively debilitating stages of AIDS (Department of Health 2001). This would reduce the stress caused by counsellors feeling obliged to provide this informally by meeting clients in between their other duties or even in their tea or lunch breaks; (4) the task of following up clients' needs to be simplified by addressing restrictions on the use of telephones and the lengthy authorisation procedure for the use of mailing facilities; (5) formal recognition needs to be given of the valuable service provided by HIV/AIDS counsellors and the additional demands made on them. Even if this cannot take the form of financial incentives at this stage, acknowledgement in the form of enhanced status or other tokens of recognition could improve morale.

## Strengths and weaknesses of the study and suggestions for future research

A strength of this study is that by interviewing a small number of participants in depth, a comprehensive account of the factors that concern them could be obtained. The casebased approach also served to provide insight into aspects of the lived experience of individual nurses, something that may easily be lost using other qualitative methods. A consequent limitation is that the findings are based on a small sample of four counsellors at a single hospital. Nonetheless, the present findings are likely to be of more general relevance because they reflect and confirm the seriousness of many of the problems identified in the existing literature and in the previous study conducted at the hospital by Whiteley and Mdzeke (2002). The findings of the present study are also consistent with the field experience of the first author (Maria Nulty) in other settings and localities. For instance, working at a semi-rural hospital in Mpumalanga during 2003, Nulty also found that HIV/AIDS counsellors needed emotional support to deal with personal issues which impacted on their counselling, such as their own HIV-positive status, relationship difficulties and financial problems. The counsellors also complained of lack of recognition of their work by management, expressed the need for supervision to help them deal with the demands of counselling situations and asked for ongoing training to enhance their competence and increase self-esteem, and in particular to provide skills for working with couples and families. Home-based carers working with the terminally ill in a nearby township reported feeling affirmed, appreciated and supported by weekly group meetings run by the first author. Mutual support increased as they became more aware of one another's circumstances. They valued having a space in which they could work with feelings evoked in the face of the helplessness, poverty and death which they encountered among the people they cared for. Some followed up the experience by arranging to have individual therapy.

Nulty is currently managing HIV/AIDS counsellors working in a Cape Town township. These counsellors also complained of lack of recognition, wanted ongoing training and were frustrated by management demands that they see large numbers of clients for only one or two sessions. They appreciated one-to-one meetings where they felt heard and valued, and needed support in dealing with their own personal problems such as substance abuse, absenteeism due to family problems and difficulties related to their poor economic circumstances. They have also wanted to learn more about balancing educational and prescriptive aspects with addressing clients' personal issues. It seems probable, therefore, that other institutions could use these findings to assist them in understanding the nature of stressors encountered by their HIV/AIDS counsellors.

In developing countries like South Africa, where HIV/AIDS is still on the increase (Eastern Cape Department of Health 2002), counsellors' occupational stress can be expected to increase as they increasingly deal with the psychosocial context of the disease rather than merely educating clients about its prevention. Future research should be directed at three areas. First, Sue expressed concern that after training many counsellors do not continue to offer a counselling service. This means that resources devoted to training programmes are wasted. However, there is no hard data on this, and research on this would provide valuable information. Second, the implementation of the above recommendations would provide a setting for ongoing research on the impact of the different interventions on the effectiveness and morale of counsellors. Third, research needs to address the evaluation of the counselling offered to clients (Richter et al. 2001). This could include studies of clients' evaluations of the counselling they received as well as investigation into the need for follow-up counselling. Analysis of recordings of counselling sessions could be used to evaluate the extent to which counsellors adhere to the counselling models they are taught, and provide a basis for improving initial and follow-up training.

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## References

Barker, C., Pistrang, N. and Elliot, R. (1994). *Research methods in clinical and counselling psychology*. Chichester. John Wiley

- Balmer, D.H. (1992). The aims of HIV/AIDS counselling revisited. *Counseling Psychology Quarterly, 5(2),* 204–214.
- Beck, A.T. and Steer, R.A. (1993). BAI: Beck Anxiety Inventory

(manual). San Antonio, TX, USA: The Psychological Corporation Beck, A.T., Steer, R.A. and Brown, G.K. (1996). *BDI-II: Beck* 

- Depression Inventory Second Edition (manual). San Antonio, TX, USA: The Psychological Corporation
- Bond, T. (1995). The stresses of working with clients with HIV/AIDS. In W. Dryden (Ed.), *The stresses of counselling in action* (pp. 44–57). Thousand Oaks, CA: Sage
- Bor, R. and Sher, I. (1992). Supervising professionals involved in the psychological care of people infected with HIV/AIDS. *Counseling Psychology Quarterly*, 5(1), 95–109
- Bor, R., Miller, R. and Perry, L. (1988). Systemic counselling for patients with HIV/AIDS infections. *Family Systems Medicine*, 6(1), 21–39
- Bromley, D.B. (1986). *The case study method in psychology and related disciplines*. Wiley, Chichester
- Burnard, P. (1992). *Perceptions of AIDS counselling.* Aldershot: Avebury, UK
- Cartwright, D. and Cassidy, M. (2001). Helping HIV/AIDS sufferers: a psychodynamic approach. *New Therapist, 14,* 18–23
- Delaney, E. (2000). Issues around the preventative role of HIV counselling. Available at www.procaare.org/procaare-hma2/procaare.200011/msg000 [February 2003]
- Department of Health (2001). HIV/AIDS counsellor training course: facilitator's manual. Pretoria: Department of Health, South Africa
- Eagle, G.T. (2004). Therapy at the cultural interface: implications of African cosmology for traumatic stress intervention. *Psychology in Society, 30,* 1–22
- Eastern Cape Department of Health (2002). HIV infection in the Eastern Cape. Provincial Update 2001. *Eastern Cape Epidemiological Notes, Year 5 (No. 16)*
- Edwards, D.J.A. (1998). Types of case study work: a conceptual framework for case-based research. *Journal of Humanistic Psychology*, *38*, 36–70
- Gerber, B. (2002). The challenges of managing HIV/AIDS counsellors in a rural district in the Eastern Cape, South Africa. Master's thesis in Counselling Psychology, Rhodes University, Grahamstown, South Africa
- Grinstead, O.A. and Van der Straten, A. (2000). Counsellors' perspectives on the experience of providing HIV counselling in Kenya and Tanzania: the voluntary HIV-1 counselling and testing efficacy study. *Aids Care, 12(5),* 625–642
- Hawkings, P. and Shohet, R. (2000). Supervision in the helping professions (2nd edition). Buckingham, UK.: Open University Press
- Hoepfl, M.C. (1997). Choosing qualitative research: a primer for technology education researchers. *Journal of Technology Education*, 9(1), [page numbers used?]. Available at <u>http://borg.lib.vt.edu/ejour-</u> nals/JTE/jte-v9n1/hoepfl. html [February 2003]
- Jenkins, G.C. (1997). Setting the scene: supervision of counsellors in general practice — a four-fold model. In G.C. Jenkins and P. Henderson (Eds.), *Counselling in Primary Care Trust, supplement no. 3: supervision of counsellors in primary health care.* Available at www.cpct.co.uk/cpct/supplems/supp3/s3sts.htm [February 2003]
- Kiemle, G. (1994). 'What's so special about HIV and AIDS?': stresses and strains for clients and counsellors. *British Journal of Guidance and Counselling, 22(3),* 343–351
- Kvale, S. (1996). InterViews: an introduction to qualitative research interviewing. Thousand Oaks, CA: Sage
- Miles, M.B. and Huberman, A.M. (1994). Qualitative data analysis: an expanded sourcebook (2<sup>nd</sup> edn). Thousand Oaks, CA, US: Sage
- Miller, D. (1995). Stress and burn-out among health-care staff working with people affected by HIV. *British Journal of Guidance and Counselling*, 23(1), 19–31
- Miller, D. (2000). *Dying to care? Work, stress and burnout in HIV/AIDS*. London: Routledge
- Richter, L., Durrheim, K., Griesel, D. and Solomon, V. (1999).

*Evaluation of HIV/AIDS counselling in South Africa.* Contract report submitted to Department of Health, School of Psychology, University of Natal, Pietermaritzburg

- Richter, L., Van Rooyen, H., Solomon, V., Griesel, D. and Durrheim,
  K. (2001). Putting HIV/AIDS counselling in South Africa in its place. Society in Transition, 32(1), 148–154
- Seidel, G. (1996). Confidentiality and HIV status in KwaZulu-Natal, South Africa: implications, resistances and challenges. <u>Health</u> Policy and Planning, 11(4), 418–427
- Seidman, I.E. (1991). Interviewing as qualitative research: a guide for researchers in education and the social sciences. New York, US. Teachers College Press
- Smith, J.A. and Osborn, M. (2003). Interpretive phenomenological analysis. In J.A. Smith (Ed.), *Qualitative psychology: a practical guide* to research methods (pp. 51–79). Thousand Oaks, CA, US: Sage
- Taylor, S.J., and Bogdan, R. (1998). Introduction to qualitative research methods: a guidebook and resource. Chichester, UK: Wiley
- Van Dyk, A. (2001). HIV/AIDS care and counselling: a multidisciplinary approach. Cape Town: Pearson Education, South Africa
- Whiteley, S. and Mdzeke, N. (2002). A study into the perceptions of groups of people on voluntary counselling and testing (VCT) services in Grahamstown, Albany District. Limited circulation report, Settlers Hospital, Grahamstown, South Africa