THE DEVELOPMENT, IMPLEMENTATION AND EVALUATION OF A COUNSELLING MODEL FOR ADOLESCENTS AND YOUTH LIVING WITH HIV/AIDS IN LUSIKISIKI, EASTERN CAPE

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CHAPTER 1

BACKGROUND TO THE STUDY

1. 1 INTRODUCTION

According to the United Nations Programme on HIV/AIDS (UNAIDS) (2006a) at the end of 2006, an estimated 39.5 million people (adults and children) were living with HIV/AIDS globally. In the same year, an estimated 4.3 million people became infected with the disease, while approximately 2.9 million people lost their lives due to the disease (UNAIDS, 2006a). Globally, the majority of infected people (63% or an estimated 24.7 million) live in Sub-Saharan Africa (UNAIDS, 2006a). In 2006, Southern Africa was home to one-third of the global number of people living with HIV/AIDS and accounted for one-third of the total number of deaths due to AIDS globally (UNAIDS, 2006a).

Prevalence rates differ considerably across the African continent with some regions ranging from less than 1% while in others it is more than 30% (UNAIDS, 2006d). According to UNAIDS (2006d) most West African countries have a prevalence rate of between 1% and 5%, and no country has a prevalence rate of above 10%. By contrast, with the exception of Angola which has a prevalence rate of less than 5%, most countries in Southern Africa have shown exceptionally high levels of HIV (UNAIDS, 2006a). According to UNAIDS (2006d), Zimbabwe was the only country in which a recent decline in HIV prevalence has been noted, from 22.1% in 2003 to 20.1% in 2005. In Swaziland, an estimated 33.4% of adults were living with HIV/AIDS nationally in 2005 – the highest in the world (UNAIDS, 2006a). It was also found that “HIV prevalence among pregnant women attending antenatal clinics rose from 4% in 1992 to 43% in 2004” (UNAIDS, 2006b, p. 8). Exceptionally high levels of HIV prevalence were also reported in Botswana and Namibia, where national levels were estimated at 24.1% and 19.6% respectively (UNAIDS, 2006b).

Lesotho's epidemic is reportedly fairly stable but at very high levels, with the national adult HIV prevalence estimated at 23.2% (UNAIDS, 2006b).

According to UNAIDS (2006a), South Africa's epidemic is one of the worst in the world, with approximately 5.5 million people living with the virus at the end of 2005. It was estimated that more than 1400 new infections occur every day, and on average 950 South Africans die each day due to AIDS-related illnesses (Dorrington, Johnson, Bradshaw & Daniel, 2006).

In 2002, Shisana and Simbayi conducted a national household survey that randomly selected more than 10 197 households to be interviewed and tested for HIV upon their consent. Results from the study showed that an estimated 11.4% of South Africans (aged two years and older) were living with HIV/AIDS. Since then a second national-level household survey has been conducted (Shisana, Rehle, Simbayi, Parker, Zuma, Bhana, Connolly, Jooste & Pillay, 2005). Findings from the study indicated a national HIV prevalence of 10.8% (amongst persons aged two years and older) indicating a slight decline in the rate of prevalence between 2002 and 2005. In terms of the prevalence rates across the various provinces in South Africa, the results of the 2005 national household survey indicated that KwaZulu-Natal and Mpumalanga Provinces had the highest prevalence rates at 16.5% and 15.2% respectively (Shisana et al., 2005). Shisana et al. (2005) also reported the Eastern Cape Province as having a prevalence rate of 8.9%. Thus, despite the slight decline in prevalence rates that has been noted by the national survey (Shisana et al., 2005), the statistics indicate that high levels of HIV still exist across the various provinces in South Africa.

The youth are said to be the most affected by the disease, as approximately half of all new infections reportedly occur in people between the ages of 15 and 24 years (United Nations Population Fund - UNFPA, 2004). In the Eastern Cape Province alone, HIV prevalence among young people aged 15-24 years increased from 9.2% in 2002 (Shisana & Simbayi, 2002) to 11.7% in 2005 (Shisana et al., 2005). The Eastern Cape was also found to have the second highest prevalence of HIV in this age group (Shisana et al., 2005). This finding was found to be consistent with previous research on a national survey of HIV and sexual behaviour among young people between the ages of 15 and 24 conducted by Pettifor, Rees, Steffenson, Hlongwa-Madikizela, MacPhail, Vermaak, and Klienschmidt (2004). In terms of HIV incidence, Shisana et al. (2005) found that among the youth aged 15-24 years the annual incidence was 3.3%.

In a study conducted by Batohi (2004) on an assessment of the counselling needs of adolescents and youth living with HIV/AIDS in the Eastern Cape, it was found that the majority of young people interviewed (60% or n = 6) were the most concerned about issues relating to death. Community members were in agreement that this would be a major concern for adolescents and youth, although they were also of the opinion that family members would have their own personal concerns regarding infection and the possibility of their own resulting death. This highlights the possibility that many people in the family (including community members) can experience a great deal of stress as a result of the lack of understanding of the nature of the disease and its implications. This leads to people feeling the need to discriminate against and isolate people living with HIV/AIDS. Interestingly, Batohi (2004) also found that accepting the positive diagnosis of a young person is a difficult task for many families to perform, hence they find it easier to discriminate against the individual and to isolate him/her so as to remain detached from the situation. As a result, it can be seen that the experience of a positive diagnosis can be a traumatic event for both the infected adolescent and family members. Both require care and counselling to deal effectively with the condition.

1.2 RATIONALE FOR THE STUDY

The need for strategies and interventions aimed at young people is becoming increasingly critical as young people are said to be particularly vulnerable to HIV infection because of their risky sexual behaviour (Kelly, 2001; Van Dyk & Van Dyk, 2003). In addition, research findings have shown that most people who become infected with the disease acquire the disease during their adolescent years or during early adulthood (Department of Social Development, 2002; United Nations Population Fund, 2004). These years are said to be the most difficult and confusing in a growing person’s life as the young person has to search for his/her own personal and sexual identity and also as he/she finds a comfortable place in society (Erikson, 1968). This on its own is a tremendously trying period for the young individual, and having to cope with the added burden of being HIV-positive can have a devastating effect on the person's psychological development.

The task of counselling young people on the topic of well-being and HIV/AIDS is not an easy one. Counsellors need to understand the thinking and behaviour of young people in order to respond appropriately, which is sometimes difficult to do, as young people often vacillate between child-like and adult thinking and behaviour (Van Dyk, 2001).

Adolescents with HIV/AIDS are sometimes referred to as *resistant* patients (Bor, Miller & Goldman, 1992). This is often due to the extensive development that takes place during this phase and also to the many difficulties they need to overcome in their search for identity. They may demonstrate feelings of resistance, scepticism and distrust towards counselling, and counsellors are required to be understanding of this type of behaviour that is considered "normal" in people of this age group (Bor et al., 1992). In addition, there are many young people who, as a result of their own experiences, and also as a result of information they have received from others, hold unfavourable perceptions of health-care workers (Health & Social Services Consortium, 2002; Kelly, 2001; Olley, Seedat & Stein, 2004; Russell & Schneider, 2000). This is likely to increase the amount of resistance they demonstrate towards counsellors themselves and also towards the counselling process. In this situation, the counsellor is encouraged not to precipitate an argument by trying to agree with the young person regarding his/her scepticism about counselling. While maintaining this approach the counsellor also needs to try to maintain a balance with firmness, which conveys boundaries and limits (Bor et al., 1992).

According to Bor et al. (1992), one of the aims of counselling an adolescent infected with HIV virus is to help normalise the situation for him/her without denying reality. The counsellor's purpose is to help the young person grow and develop as a person and to have hopes and dreams for the future.

Research has found that counsellors are often said to be unaware of what young people need in terms of counselling. Batohi (2004) reported that issues that were of major concern to young people living with HIV/AIDS were not perceived by any of the service providers as possible concerns for young people. For example, the study found that while the entire sample of adolescents and youth interviewed made mention of the need for persons giving counselling to focus on what was referred to as "appropriate behaviour" for young people, service providers remained unsuccessful in recognising this as an area of importance and one which they should focus on during counselling. Furthermore, while both groups made mention of the need to focus on counselling issues such as condom usage and abstinence, adolescents still highlighted the need for counselling on "appropriate behaviour". It can be said, therefore, that adolescents and youth require more information over and above that which service providers are currently aware of, pointing to the need for service providers to become more creative and innovative in devising new ways to educate and counsel young people on issues of behaviour change. Thus, although counselling young people with HIV/AIDS is similar in many ways to that of counselling adults, in that much of the material to be covered in sessions is the same, counsellors need to pay special attention to the unique needs of young people living with HIV/AIDS in South Africa.

It has been found that there is a lack of published research on child and adolescent mental health in low- and middle-income countries (Patel & Sumathipala, 2001; Saxena et al., 2006). In fact, mental health research in these areas contributes to only 3% - 6% of all published material in the world on mental health (Patel & Sumathipala, 2001; Saxena et al., 2006). In South Africa specifically, there is currently a dearth of studies that have focused on the development of interventions for adolescents and youth living with HIV/AIDS. There are a number of interventions that have been developed in South Africa that have been aimed at prevention (such as Lovelife, etc.) which encompass a counselling component. These interventions, however, are centred on concepts and theories adopted from the West without being adequately adapted to suit the local context, thus making them relatively ineffective in the South African context. Although some evidence does exist to support these concepts and theories, they have been criticised for being somewhat inappropriate for application in the South African context. This is because they fail to take into sufficient consideration the social contexts that make actions and behaviours meaningful (Singer & Weeks, 1996 as cited in Freudenthal, 2001). In addition, the traditions, beliefs and practices that inform behaviour may be different in South Africa and in the African culture from those of the American and European cultures (where these theories were developed).

New alternatives need to be found that take into consideration the role of the social, political and economic contexts within which the virus is spreading (Shisana & Simbayi, 2002). It is also evident that health-care facilities and communities alone cannot bear the burden of HIV/AIDS. What is needed is a "framework that stresses a multi-sectoral approach and views HIV/AIDS not only as a health problem, but also as a general development issue" (Freudenthal, 2001, p. 1). Strategies need to be developed that cater for the needs of individuals, families and communities.

Working within the framework of the African tradition together with its beliefs, practices and customs, this study aims to develop a cognitive-behavioural counselling model for young people living with HIV/AIDS (particularly in rural areas) that will meet both their developmental and cultural needs in terms of managing the virus. In training both professional and non-professional service providers to apply the model, the study also aims to increase the awareness of both these groups of the special needs of these young people as well as issues of prevention, care and support, thus enabling them to make appropriate responses in dealing with the crisis.

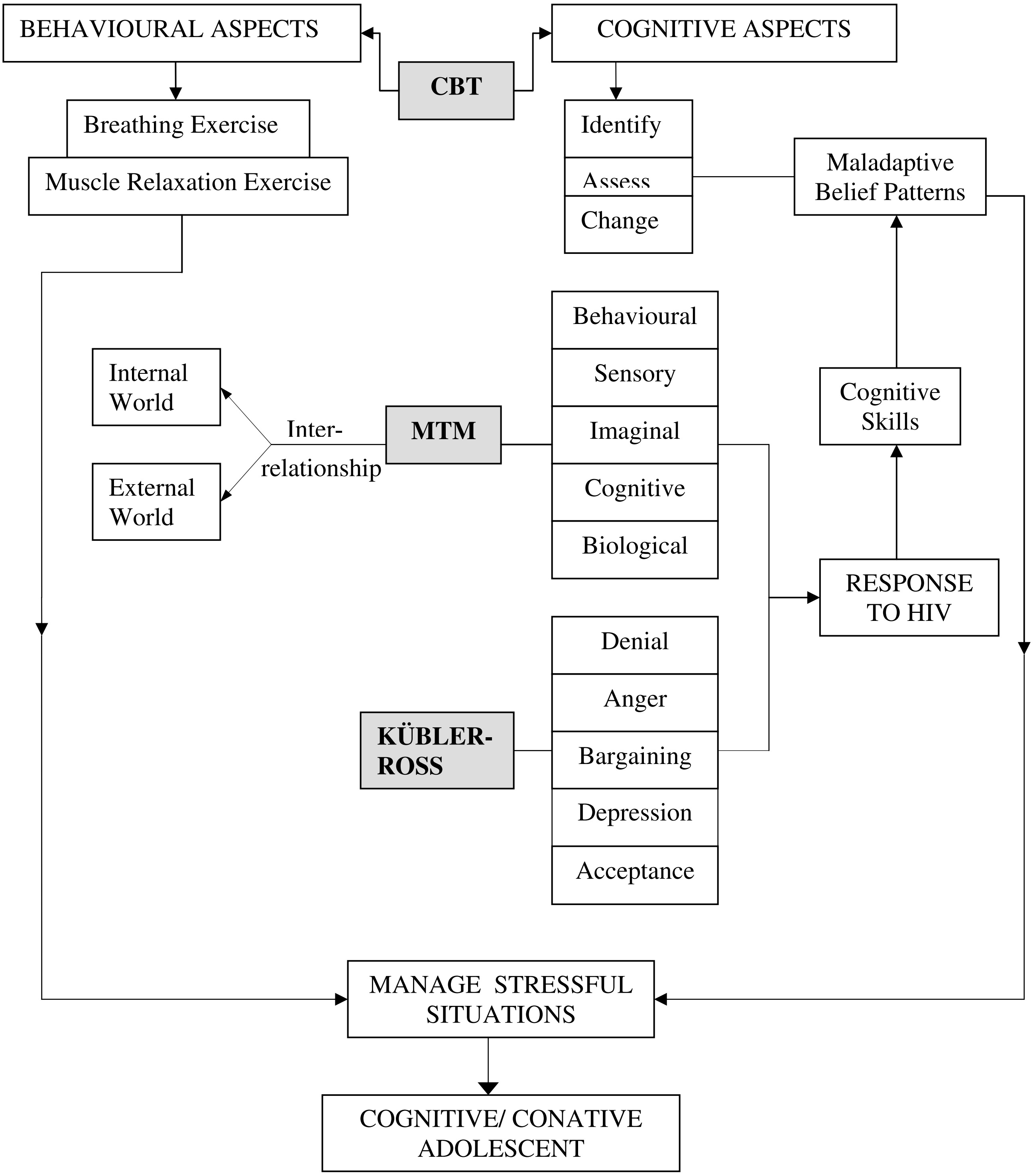
1.3 THE THEORETICAL MODEL FOR THE STUDY

Various theories and models have been used to inform the development of the counselling model (refer to Figure 1). Several researchers have reported the effectiveness of interventions based on Cognitive Behaviour Therapy (CBT) in the treatment of people living with HIV/AIDS (PLWHAs). Blanch, Rousand, Hautzinger et al. (2002) introduced a structured cognitive behavioural group psychotherapy programme to 39 HIV-positive patients who served as their own control group. Over a period of 16 weeks the study found that the group made significant decreases in depression and anxiety and that this improvement was maintained through the 3-

month follow-up period. Kelly, Murphy, Bahr et al. (1993) assessed the effectiveness of randomly assigning 68 depressed HIV-infected participants to an 8-week CBT programme, an 8-week social support group therapy programme, or a usual care programme. Both experimental groups were found to produce reductions in depression, hostility and somatisation. Similarly, Molassiotis et al. (2002), in a comparative study to test the effectiveness of a CBT intervention and a peer support/counselling (PSC) intervention to 46 patients living with HIV/AIDS showed that both experimental groups were effective in alleviating the psychological symptoms of PLWHAs as compared to the control group. Cognitive Behaviour Therapy was used in this current study to help participants to identify, assess and change any maladaptive belief patterns and to help participants to manage stressful situations. It was incorporated in the current model in the following manner: participants received counselling on cognitive restructuring, that is, help with identifying and challenging their negative thoughts (cognitive aspect); they were taught breathing and deep muscle relaxation techniques so as to respond to a given situation with a more clear and relaxed state of mind (behavioural aspect); and they were helped through the process of change through the use of homework exercises which helped to strengthen the skills learnt by clients and to practise their application between sessions.

The Multimodal Transactional Model (MTM) (Palmer &Dryden, 1995) is of relevance to HIV/AIDS counselling as it aims to provide a comprehensive assessment of all modalities of an individual, as opposed to looking at aspects in isolation (Palmer & Dryden, 1995). This is seen as essential to the attainment of an effective therapeutic outcome (Palmer &Dryden, 1995). In addition, depending on the nature of the assessment conducted, interventions that are relevant across the modalities are applied by MTM counsellors (Palmer &Dryden, 1995). In other words, MTM counsellors do not try to fit the client's needs to one particular type of therapy, but rather tailor the therapy intervention to suit the needs of the client, which contributes to the achievement of the goal of counselling. Similar to CBT, the MTM also focuses, for example, on the effects of negative thoughts and feelings on behaviour. However, the MTM also takes into account the interaction of different modalities which can produce an emotional/affective response. In this way, the MTM can be seen as a comprehensive approach to the treatment of stressful situations, such as dealing with an HIV-positive diagnosis. It can be argued that a comprehensive approach such as the MTM approach to therapy may be imperative to HIV/AIDS counselling in order meet the unique needs of all clients, especially those in the adolescent phases of development. Through the use of the MTM, the current model aims to highlight the importance of understanding the inter-relationship between the internal and external world. The Multimodal Transactional Model has been incorporated in the current counselling model by helping clients to emphasise their reactions to an event or situation in relation to the perceptions that they hold of that event or situation, as well as their perceived abilities, rather than the event or situation itself. They were encouraged to express their thoughts and feelings in relation to living with HIV. By drawing on both the Multimodal Transactional Model (Palmer & Dryden, 1995) and the Five Stage Model in the Psychological Process of Dying (Kübler-Ross, 1969), attention has been paid to participants' reactions to the disease in relation to the different modalities which can interact with each other. It is probable that both these theories may have important significance for the HIV/AIDS illness as they may help health-care professionals and family members to better understand the psychological processes involved in the different stages of the illness. In other words, these theories may serve an educational purpose to all those involved in the caring process, as they can learn more about the needs of those facing stressful situations such as HIV/AIDS and death. It may also serve to be especially beneficial in the counselling of adolescents and youth living with HIV/AIDS because health-care professionals, family members and others involved in the caring process may be less experienced in the area of caring for adolescents facing death, seeing that this is usually a time when adolescents are at their prime, which may point to a need for those involved in the caring process to be better educated on the topic.

With reference to Erikson's (1968) theory of psychosocial development, Elkind's theory (1978) of understanding the young adolescent and Havighurst's (1972) developmental tasks of adolescence, service providers have been informed about the counselling of adolescents in relation to their development. Understanding adolescent development was seen as crucial to the success of this study as it is important to understand how young people are changing physically, cognitively, socially, emotionally and behaviourally, in order to develop and implement an effective adolescent counselling intervention. In the counselling manual that has been developed in this study for service providers, they were reminded that counselling young people on HIV/AIDS is not an easy task because adolescence on its own is a tremendously trying period for young people; having to cope with the added burden of being HIV-positive can have a devastating impact on the young person, particularly in terms of his/her psychological development. For these reasons, the counsellors were urged to be sensitive to the unique needs of people in this age group so as to be of maximum assistance to them.



CBT: Cognitive Behaviour Therapy
MTM: Multimodal Transactional Model

Figure 1: Diagrammatic representation of the theoretical model chosen to guide the study.

Several international evidenced-based models (such as those listed in Table 1 below) that focus on youth living with HIV/AIDS from a care/treatment perspective, have been developed. Although, the models presented in Table 1 differ markedly from one another, five major elements have been identified from these models, which have been shown to be successful in the development and implementation of adolescent-focused HIV/AIDS service models (Huba & Melchior, 1998). These elements entail:

(1) including youth in the information development and dissemination phases so as to identify key areas that are of relevance to young people
(2) including youth on the advisory board to inform and assess progress, to ensure greater client satisfaction and quality of services
(3) engaging youth in outreach activities to identify, attract and link appropriate youth to services
(4) developing a continuum of medically and socially linked services that are related to the HIV/AIDS care for adolescents and youth
(5) including ongoing case management and advocacy to ensure that service providers are more aware of the needs of their adolescent clients (Huba & Melchior, 1998).

Although these models have been shown to be effective in meeting the needs of adolescents and youth, they were developed in the United States (US) for a different target population and not for South African adolescents and youth. From this review it became evident that it would be beneficial to develop a model that focused on HIV/AIDS counselling of adolescents and youth post-diagnosis in a South African context, in an attempt to meet both their developmental and cultural needs. The review of several international models and the account of many of the lessons learned have made it clear that the counselling model would need to encompass the following guiding principles for its development:

Table 1: Some of the models that are used in the care/treatment of adolescents and youth living with HIV and AIDS

Model Name	**Main Program Elements**	**Authors and Year**
Children's Hospital Los Angeles: *A Model of Integrated Care for HIV-Positive and Very High –Risk Youth*	Developed tightly linked medical and social networks for both youth living with HIV and those at risk for HIV infection	Schneir, Kipke, Melchior, et al. (1998)
Boston HAPPENS Program: *A Model of Health Care For HIV- Positive, Homeless and At-Risk Youth*	Developed tightly linked medical and social networks for both youth living with HIV and those at risk for HIV infection	Woods, Samples, Melchiono, et al. (1998)
Health Initiative for Youth: *A Model of Youth/Adult Partnership Approach for HIV/AIDS Services*	Improved the capacity of the local service network for youth living with HIV	Bourdon, Tierney, Huba, et al. (1998)
Bay Area Young Positives: *A Model of a Youth-Based Approach to HIV/AIDS Services*	Direct services program, youth-run and youth-based organization	Bettencourt, Hodgins, Huba, et al. (1998)
The University of Minnesota Youth and AIDS Projects' Adolescent Early Intervention Program: *A Model to Link HIV-Seropositive Youth with Care*	Worked with the Minnesota Department of Health to link HIV positive youths with health care services	Remafedi (1998)
Seattle YouthCare's Prevention, Intervention, and Education Program: *A Model of Care for HIV-Positive, Homeless, and At-Risk Youth*	Developed a continuum of services that are youth-specific and attractive to youth on the street	Tenner, Trevithick, Wagner, et al. (1998)
Indiana Youth Assess Project: *A model for Responding to the HIV Risk Behaviors of Gay, Lesbian, and Bisexual Youth in the Heartland*	Provided multiple services to gay, lesbian and bisexual youth	Wright, Gonzalez, Werner, et al. (1998)
The University of Alabama Teenage Access Project: *A Model for Prevention, Referrals, and Linkages to testing for High-risk Young Women*	Expanded access to health and supportive services for disadvantaged HIV-positive and at-risk adolescents and young women	Sturdevant, Kohler, Williams, et al. (1998)
The Walden House Young Adult HIV, Project: *Meeting the Needs of Multidiagnosed Youth*	Provided residential care to young people with multiple diagnoses including HIV/AIDS and substance abuse	Hymel & Greenberg (1998)

(1) The model would need to be reflective of the needs of the target population. It is arguable that the needs of adolescents and youth living in rural Lusikisiki in South Africa, which is a developing country with a limited or constrained health-care system, would be different from the needs of adolescents and youth living, for instance, in the US, which is considered a developed country with an extensive health-care infrastructure. It can be argued therefore that the unique counselling needs of adolescents and youth in South Africa may need to be deciphered by need assessment studies in order to show the uniqueness of the target group.

(2) The model would need to be reflective of the culture of the target group in order to meet their needs. It would seem imperative that the model take into consideration the African belief systems and worldviews in the development phase. American or European models, by contrast, which have not been specifically designed for an African target group, may not be appropriate for application in the South African context.

(3) To respond effectively to the needs of adolescents and youth in Lusikisiki, adolescents and youth themselves should be involved in the development of the model so as to take into account the knowledge people have about their own environment and about the problems that commonly exist in these environments. By taking into consideration this key informational element, the resultant model would be likely to heighten quality of service and greater client satisfaction, as it would have particular relevance to the target population.

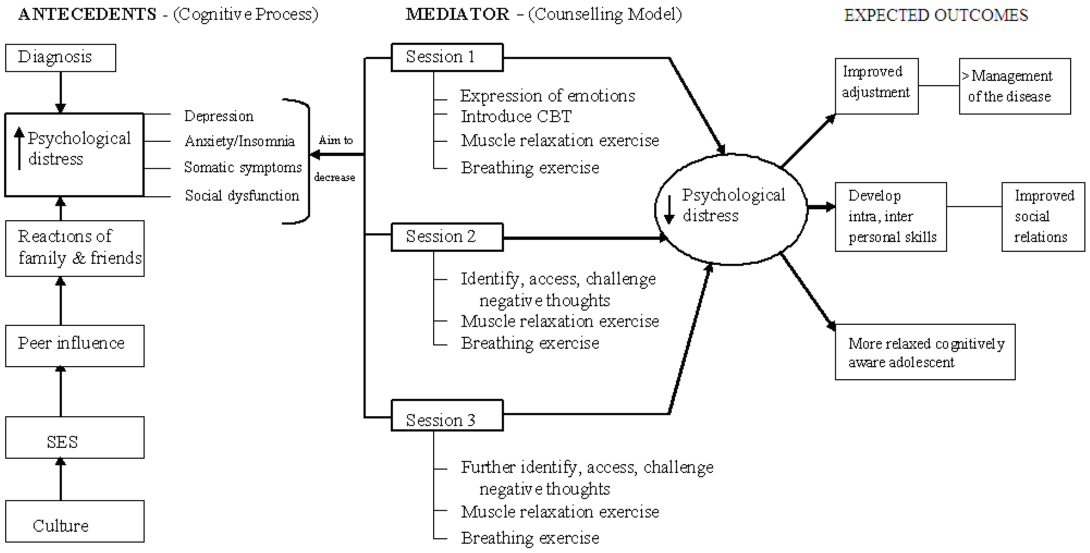


Figure 2: Cognitive – Behavioural based Counselling Model

Antecedents – cognitive process

Figure 2, shows the conceptual model that guided this study. This model provides a holistic perspective in which the culture of the target group is taken into consideration in the development of the counselling model. Broadly speaking, the culture of adolescents and youth of the current study sets cultural standards that need to be learned and followed. These cultural standards promote teaching systems that influence the reactions and behaviour of family, schools and media (Hovell et al., 1994) that is consistent with acceptable cultural norms. According to the conceptual model, the reactions of family, friends, health professionals, etc. to the diagnosis of the adolescent may be prompted by cultural standards. However, because of the stigma attached to the HIV/AIDS disease, the diagnosis of the young person may not be easily accepted by society and may, for example, elicit fears and anxieties for the young person concerning issues relating to disclosure, isolation, social rejection and even death thereby increasing his/her levels of psychological distress.

Socio-economic status (SES) is determined by education, income, religion, etc. (Hovell et al., 1994) and may vary extensively within subgroups of a specific culture. According to Hovell et al. (1994) SES may influence the quality of formal education, community services as well as the type of peer group that a young person will be involved with. In the U.S., for example, “the SES of a community in general has been associated with condom use among teenagers - the poorer and less educated the community, the less the condom use (Mosher & McNally, 1991 as cited in Hovell et al., 1994, p. 271). Similarly, research conducted in South Africa has also indicated that factors such as peer influence and socio-economic influences plays a large role in adolescent sexuality (Brook, Morojele, Zhang & Brook, 2006). The reactions of the peer group to the diagnosis of adolescent may therefore be crucial to his/her adjustment to the disease. However, if the reaction of the peer group is influenced by the stigma attached to the disease and by cultural standards this may interfere with the relationships of the young person and his/her social standing especially with regard to being part of the peer group which may subsequently increase their levels of social dysfunction.

Mediators (counselling model) and expected outcomes

Based on this model, the counselling model can directly mediate psychological symptoms including anxiety and insomnia, depression, social dysfunction and somatic symptoms. Session 1 aimed to deal with the exploration of the young person's presenting problems regarding their diagnosis so as to reduce their psychological distress by optimising the adjustment process to living with a chronic illness as well as contributing to the management of living with the stressors of the disease. Part of the session focused on introducing and explaining CBT as a problem-solving approach that would be used in the forth-coming sessions to deal effectively with the thoughts and feelings they may be having in relation to their diagnosis. Through the breathing and deep muscle relaxation exercises the session also aimed to introduce to the individual two techniques to meet the challenges and opportunities of life with a more clear and relaxed state of mind. Session 2 aimed to help the client to identify some of their negative thoughts and to guide them through the process of challenging these thoughts with a relaxed state of mind through the re-enforcement of exercises learnt in the previous session. In session 3 the aim was to help the client to further identify and challenge their negative thoughts for the purpose of beneficial change and to re-enforce the breathing and deep muscle relaxation exercises to promote a relaxed state of mind so that they can respond appropriately to a given situation.

1.4 RESEARCH QUESTION

The present study seeks to provide answers to the following question:

- Can the psychological needs of adolescents and youth (ages 18 to 24) living with HIV/AIDS be addressed using a counselling model?

1.5 HYPOTHESES

The main empirical hypothesis tested was that the counselling model would demonstrate significantly greater reductions in the mean level of psychological distress experienced by the experimental group relative to the control group.

Specifically, the study hypothesised that the counselling model would impact on the experimental group in the following manner:

- It would demonstrate significantly greater reductions in the mean level of somatic symptoms relative to the control group.
- It would demonstrate significantly greater reductions in the mean level of anxiety and insomnia relative to the control group.
- It would demonstrate significantly greater reductions in the mean level of social dysfunction relative to the control group.
- It would demonstrate significantly greater reductions in the mean level of severe depression relative to the control group.

1.6 THE AIMS OF THE STUDY

The main aim of the study is to develop a counselling model for adolescents and youth living with HIV/AIDS in Lusikisiki in the Eastern Cape.

Specifically the study aims to develop, implement and evaluate a counselling model that could be applied to adolescents and youth living with HIV/AIDS, and that could assist service providers and caregivers to deal more effectively with the needs of adolescents and youth.

1.7 LAYOUT OF THE REPORT OF THE PRESENT INVESTIGATION

In Chapter 2, some of the pertinent literature in this field of study is reviewed. Chapter 3 presents the theoretical foundation for the study. Chapter 4 discusses the methodology employed in the three phases of data collection, namely, the development of the counselling model, the implementation of the counselling model, and the evaluation of the counselling model. The analysis of data collected during the implementation and evaluation phases, as well as the ethical considerations of the study, is also detailed in this chapter. Chapter 5 deals with the results of the development, implementation and evaluation of the counselling model. In Chapter 6, the results obtained from the present study are discussed. Lastly, Chapter 7 presents a summary of the study, the conclusions, the limitations, the recommendations for the implementation of the counselling model, and the recommendations for future research.

CHAPTER 2

LITERATURE REVIEW

2. 1 INTRODUCTION

This chapter reviews some of the literature pertaining to the salient issues in the area of HIV/AIDS and counselling that affect adolescents and youth living with HIV/AIDS. These areas include: the psychosocial aspects associated with living with HIV/AIDS; issues that are considered of importance when counselling adolescents and youth; and the attitudes of and challenges faced by service providers in counselling young people. In addition, the chapter will discuss some aspects of inadequate attention having been given in interventions aimed at prevention.

2.2 ADOLESCENTS AND HIV/AIDS

2.2.1 Adolescent sexuality

The lack of sex education among adolescents has been implicated in the causation of major social problems, such as the increasing rate of teenage pregnancy, HIV/AIDS and sexual abuse among adolescents (Driskill & Dekampo, 1992). In a study conducted by Inazu and Fox (1980) on the influence of mothers on the sexual behaviour of adolescents in Kenya, it was found that when parents are the main informants of sex education for their children, sexual initiation takes place at a later stage and adolescents are more accepting of the use of contraceptives. Similar findings were reported by Kalmuss et al. (2003) in a study conducted on the prevention of risky sexual behaviour and pregnancy.

However, studies have shown that the lines of communication between parents and children with regard to sex education are not always open, with parents often showing limited involvement in the sex education of their children. Mayekiso and Twaise

(1993) in a study on the parental involvement in sex education to adolescents in the Eastern Cape, revealed that as little as 1% of the fathers and 32% of mothers were involved in imparting sexual knowledge to their adolescent children. In addition, as Gilbert and Bailis (1980) have found, parents sometimes fail to fully explain to their children the implications of sexual intercourse. Similar findings have been reported by Siboyana (2006) in a study conducted in Vosloorus Township, Boksburg, on the involvement of paternal figures in the sex education of their adolescent children from the perspective of adolescents themselves. The study found, for example, that sexual intercourse was not mentioned by paternal figures in relation to pregnancy. In addition, because the very nature of sexual activity among adolescents is often unplanned, irregular and infrequent, the consistent use of contraceptives may become difficult to maintain, which in turn may have serious health implications, especially for the young person, with regard to pregnancy, HIV/AIDS and other sexually transmitted infections (STIs) as these are all regarded as unintended consequences of unprotected sex. This is why it is said that "parents play an essential role in the forming of positive subjective norms regarding sexual behaviour and the prevention of teenage pregnancies" (Grobler, Botma, Jacobs & Nel, 2007, p. 36).

Pregnancy statistics, however, provide an indication that many young people in South Africa are having unprotected sex. Pettifor et al. (2004) report that of those who had had sex in the past 12 months (i.e. 56 % of a sample of 11 904 participants) only 33% reported using a condom "always" and that as many as 33% of adolescents interviewed between 15-19 years old reported being pregnant at some point. The number of young people who were pregnant between the ages of 20-24 years was almost double that found among the 15-19-year-olds (i.e. 59% and 33% respectively). The problem is further exacerbated by adolescents feeling embarrassed and fearful at being perceived as promiscuous by their partners were they to insist on the use of contraception, which is why the use of contraceptives often remains under-utilised (Lipovesek, Karim, Gutierrez, & del Carmen Castro, 2002, as cited in Mokwena, 2003). Service providers, such as clinic staff, also serve as a hindrance to adolescents acquiring condoms as they sometimes scold or mock the adolescents when they come to collect condoms at the clinic (MacPhail & Campbell, 2001). It has also been reported that service providers were embarrassed to provide young people with advice regarding condom usage and have also in some instances tried to persuade girls to use alternate methods of contraception that they viewed as more "reliable" without giving thought to prevention against HIV/AIDS (Abdool Karim, 1992b).

Adolescent sexuality is also related to other factors such as peer influence and socioeconomic influences (Brook, Morojele, Zhang & Brook, 2006). Research has shown that males, for example, are strongly influenced by peer disapproval of condom use to be more sexually active and to engage in unprotected sex (MacPhail & Campbell, 2001). This in turn results in increased levels of unsafe sexual activity. Risky sexual behaviour has also been shown to be associated with drugs and alcohol, which usually involve peers in social gatherings. Findings of a South African study conducted by Morojele, Brook and Kachieng'a (2006) reveals that when adolescents are under the influence of drugs and alcohol as a result of influence from their peers, they are more likely to engage in either voluntary or involuntary acts of unprotected sexual intercourse that may be unplanned or unintended.

Socioeconomic factors such as poverty also play a large role in understanding the sexuality of adolescents in many contexts in South Africa. This is because evidence has been found to suggest an association between poverty and adolescent risky sexual behaviour; poverty has been associated with a weak parent-child relationship (Brook et al., 2006). As a result of this weak parent-child relationship, adolescents are likely to develop what is referred to as *vulnerable personality and behavioural attributes* (Brook et al., 2006, p. 268) and they are likely to associate with deviant peers, thereby increasing their risk of unsafe sexual behaviour. More and more young people are becoming infected with HIV/AIDS, and according to the statistics, approximately half of all new infections are said to occur in people between the ages of 15 and 24 (UNFPA, 2004).

One group that is severely affected by the disease is that of young people, "with approximately 60% of all adults who acquire HIV becoming infected before they turn 25" (Department of Social Development, 2002, p. 11). In particular, studies indicate that the 20-24-year-old age group is at high risk for acquiring the disease as a result of their heightened levels of sexual experience by this age (Pettifor et al., 2004). For example, in a study conducted in a rural region in Uganda, HIV prevalence was reportedly highest among men and women between the ages of 20 and 24 (Warmer, 1989). Similarly, Pettifor et al. (2004) found that the 20-24 year old age group had the highest HIV prevalence as compared to other age groups investigated. Women, in particular, have been shown to have a higher HIV-prevalence rate than men. For example, in a study conducted by Cakata (2003) in an epidemiological study of STIs in the Eastern Cape, it was found that women between the ages of 15 and 39 were at highest risk of infection. Similarly, Pettifor et al. (2004) found that women in all age groups investigated had a higher HIV prevelance than men. The highest HIV prevalence for females was found among the 20-24-year-olds (24.5%).

Not long ago studies showed that sexual initiation began at very young ages for many children and adolescents. UNAIDS (2000 as cited in Van Dyk, 2001) reported that 10% of respondents in South Africa said that they started having sex at age 11 or younger. LoveLife (2001) found that out of a random sample of 2000 young people between the ages of 12 to 17, 18% of sexually active respondents said that their first sexual experience was at the age of 12 or younger. Results from a study conducted in Lusikisiki in the Eastern Cape, found that the average age of first sexual intercourse experience for the youth was 11.8 years among males and 15.6 years among females (Kelly, 2001).

More recent research, however, has found that there appears to be a delay in the age of sexual initiation (Pettifor et al., 2004). Pettifor et al. (2004) found that the average age of first sex experience was 16.7 years and the median (i.e. the point at which half of the respondents in a particular age category have had sex) was 17 years. In addition, the study found that only 8% of respondents report having sex at less than 15 years of age, which is the chosen cut-off indicator (by the World Health Organisation and as well as other organizations) of early age of first sexual experience. Similarly, Shisana et al. (2005) found that among the youth aged 15-24 years, the median age at first sex wais 17 years. In a study conducted by James et al. (2004) on awareness and behaviours related to HIV/AIDS/STIs among young people, it has been found that 47.8% of a sample of 1113 Grade 11 students in the Midlands district of KwaZulu-Natal were in agreement that the right age to start having sex is between the ages of

15-19 years. Interestingly, according to Bakilana (2005), the age of sexual debut in other African countries such as Tanzania and Zimbabwe, have been found to be younger than that reported in South Africa. However, as noted by Bakilana (2005), a large number of Tanzanian women are already married by that time, compared to Zimbabweans and more so for South Africans, where a long gap exists between the onset of sexual relations and that of first marriage. "Assuming that the rate of partner change is higher outside stable unions such as marriage, then the longer this gap the higher the risk of sexually transmitted infections (STIs) or HIV infection" (Bakilana, 2005, p. 4).

These statistics show that adolescents and youth of South Africa are living in a period of very rapid change. In the transition to adulthood, they are confronted with issues such as HIV/AIDS that were not part of the adolescence of the previous generation. This points to the need for parents, teachers, counsellors and the community at large, who are involved in the lives of these young people, to make a more concerted effort to understand the issues facing the youth of today, and to be dedicated to providing them with the love and support they need, as well as sufficient and accurate information to stop the spread of HIV/AIDS. To this end, there exists a dire need for sex and life-skills education to be introduced to children and adolescents at a younger age (Kelly, 2001; Van Dyk, 2001).

2.3 HIV/AIDS COUNSELLING

The term *counselling* has been defined in many ways, but for the purposes of this study the following definition by Sims and Moss (1995, p. 93) will be used: Counselling is "the facilitation of a personal understanding of, adjustment to, and acceptance of the disease and effect upon their lives, by the patients, the people important to them and those caring for them."

Counselling has two main functions:

(1) *Education* which aims to spread information about AIDS, alleviate the fear and ignorance around AIDS and its transmission, and prompt people to change their behaviour to prevent the spread of the disease (Van Dyk, 1993); and

(2) *Support* which involves assisting people with HIV/AIDS by offering them emotional and social support and by helping them remain functional as part of their family and community (Van Dyk, 1993).

Both these functions can be achieved by health-care providers if certain basic counselling guidelines are followed and proper pre- and post-test counselling (which is an example of HIV/AIDS counselling) is conducted. Pre-test counselling is of extreme importance because of the psychosocial implications that an HIV test is known to produce in clients. And because clients are often too relieved or shocked to absorb much information during the post-test, counsellors must be sure to make the most of pre-test counselling in terms of providing education and support to the client (Van Dyk, 2001).

2.3.1 Pre-test counselling

The main purpose of pre-test counselling is to provide the client with the necessary information and support he/she needs to make an informed decision (Van Dyk, 2005). According to the Southern African AIDS Training (SAT) Programme (2001) reasons why the client wants to take an HIV test needs to be explored. This is especially necessary when counselling young people, as it is possible that they may have been pressurised by others into having the test. Because it is important for consent to be obtained from the client prior to the test, the client needs to be informed of the implications of testing (Van Dyk, 2005). Accurate and up-to-date information about the transmission and prevention of the disease must be provided, and any misconceptions that the client may have need to be addressed (SAT Programme, 2001). However, it is also important for the counsellor to be responsive to the client's needs, allow the client time to express any fears and concerns, and deal with these before testing commences (Anderson, 1992). The client needs to be told that both counselling and testing will be treated with confidentiality. The counsellor should also try to prepare the client for both a positive and a negative result. A positive result should be prepared for by mentioning issues such as survival skills and living positively beyond the diagnosis (SAT Programme, 2001). In the case of preparing the client for a negative result, means of reducing personal risk of HIV infection should be discussed (SAT Programme, 2001). A follow-up interview needs to be scheduled, and it is necessary to explain to the client how the results will be given to him/her and by whom (if it is not a *Rapid HIV antibody test,* in which case the results are available within 10 to 30 minutes) (Van Dyk, 2001). However, it is preferable that the same person conduct the follow–up interview/s as a relationship has already been established between the counsellor and client, and this will allow the client to experience a feeling of continuity (Van Dyk, 2005).

2.3.2 Post-test counselling

Before revealing the results of the test the counsellor should inquire from the client if a pre-test counselling session was conducted and if so, the subject matter that was discussed (if conducted by a different person) (Van Dyk, 2005). If a pre-test was not conducted, the counsellor should try to cover the main points of the pre-test counselling to try to prepare the client for the test result. The content to be discussed during the post-test counselling session may vary depending on the results of the HIV test, that is, whether the person has tested negative or positive.

In the case of a negative result, the client should be educated about risk reduction and safer-sex practices (Van Dyk, 2005). This is extremely important for persons that are involved in high-risk behaviour in order to reduce their chances of contracting the disease in the future. It is also important for counsellors to mention to clients that there is a possibility that they could be in the *window period* and explain the likelihood of a *false negative* result (Van Dyk, 2005). If there is uncertainty about the result, the client should be advised to take a repeat test after 3 to 6 months (Van Dyk, 2005).

In the case of a positive result, the counsellor needs to approach the client with as much empathy, warmth and caring as possible. The counsellor should assist the client in dealing with his/her emotions as the client expresses them (SAT Programme, 2001). The discussion should be led by the client, and the counsellor should be able to determine the needs of the client and respond accordingly. Clients' needs may also vary depending on how thoroughly the client was educated and prepared for the result. Issues such as disclosure of HIV status, emotional support, fears and anxiety should be discussed. According to Van Dyk (2001), talking to clients about these and other issues depending on their specific needs is one of the most important therapeutic interventions that a counsellor can make. And finally, Macfie (1997 as cited in Van Dyk, 2001, p.11) says: "in responding to clients' needs, an attitude of non-judgemental empathetic attentiveness is more important than doing or saying specific things. Listening is more important than talking, *being with* more important than *doing to.*"

Although the importance of intensive short-term counselling has been indicated, psychological intervention and psychological support should continue until the death of the infected individual. At present in South Africa, there seems to be a focus on pre-test and post-test counselling with inadequate attention given to the provision of psychological intervention and psychological support to those infected and affected by HIV/AIDS. This was confirmed in a study conducted by Coetzee and Spangenberg (2003) on coping and quality of life for people living with HIV/AIDS (PLWHAs) as it was reported that participants felt that living with the knowledge of one’s positive HIV status without follow-up care and support could lead to depression, despair and death. Further, because the loss of health is a bereavement, which brings with it many emotional needs and responses, counselling should be made available throughout the stages of the illness. Thus, HIV/AIDS counselling is not limited to pre- and post-test counselling. The following sections highlight the issues that need to form part of the comprehensive HIV/AIDS counselling of adolescents and youth.

2.4 THE PSYCHOSOCIAL DISTRESS ASSOCIATED WITH LIVING WITH A CHRONIC LIFE-THREATENING ILLNESS

This section discusses some of the psychosocial distress that people living with HIV/AIDS are subjected to as a result of their illness, and in so doing highlights how these issues need to be made part of HIV/AIDS counselling.

2.4.1 Stigma

In South Africa, as a result of the stigma attached to HIV/AIDS, many people live in fear of the consequences of their status becoming known in the community. Some fear that they will not be accepted in the community (The Institute for Multi-Party Democracy, 2002) while others fear for the safety of their lives (Russell & Schneider, 2000). Results from a study conducted by Thomas et al. (2005) in South India revealed that individuals were highly fearful of being stigmatised. A significant negative relationship was found between internalised stigma and quality of life in the psychological domain. According to Thomas et al. (2005), internalised stigma robs the individual of financial and social support, which can negatively affect the individual's quality of life. This in turn denies people the care and support they require to live positively beyond their illness.

A study conducted by Pelzer (2003) on the knowledge, attitudes, beliefs and behaviours in relation to HIV/AIDS/STI among a rural South African adult population, revealed that while there were many participants who were willing to provide support and care to people living with HIV/AIDS, there were also some who were afraid of living next to someone infected with HIV in case they also became infected. An interview by Kambule-Makgati and Makgati (2005) with three persons infected with HIV/AIDS in an "AIDS-racked village" (p. 21) in the North-West province, revealed that PLWHAs are often treated like outcasts in their communities. The three participants reported that they were banned by their community members from making use of public toilets as community members were fearful of becoming infected if they shared the facility with them. Similar findings were reported by Greeff and Phetlhu (2007) in a study on the stigma associated with HIV/AIDS in the North West Province. Pelzer (2003) found that the stigma associated with the disease was so severe that one participant felt that it would be better to kill himself and his family if they were found to be HIV-positive. "If my wife and I get AIDS I will kill her, the children, and then myself. People will point fingers at us, and my wife and I will soon die. My children will also face the same discrimination, even after we have died. At that time they will suffer bitterly, as there will be no-one to take care of them. I won’t let that happen to them" (Pelzer, 2003, p. 26).

2.4.2 Loss

For many adolescents and youth, the experience of living with a life-threatening disease such as HIV/AIDS brings with it the experience of many losses among a vast array of domains, and the manner in which they cope with loss varies greatly depending on their developmental stage. This is why it is important for counsellors to monitor the reactions of young persons and allow them time to express their grief (Battles & Wiener, 2002). The multiple losses that an adolescent or youth may experience range from the loss of one's physical well-being, to relationships and hope for the future (Plattner & Meiring, 2006; Van Dyk, 2005). For the young person, dreams of establishing supportive networks with others and of developing intimate relationships and starting a family are often shattered by the devastating news of being diagnosed as HIV-positive. People are said to experience a similar sense of loss when their physical and mental health deteriorates (Crowley, 1995). They may fear the loss of their sexual relationships, and of life in general (Van Dyk, 2005). They may even begin to fear the loss of their confidentiality, anonymity and privacy (Crowley, 1995), and even the loss of their HIV-negative status in society (Van Walt & McKay, 1991). Their sense of loss of status may be intensified when the individual becomes more dependent on others for financial and other types of practical support. Adolescents and youth, for example, may be particularly fearful of becoming more dependent on their parents and of losing their sense of independence or of never being able to fully achieve a sense of independence. This in turn, may lead to the fear of a loss of identity or self-esteem (Van Walt & McKay, 1991). The loss of confidence and self-worth resulting from the rejection by friends and loved ones has also been reported as common to the experience of loss (Van Dyk, 2005). In addition, as Crowley (1995) explains, the situation is further complicated as "the stigma associated with the disease is [also] associated with a loss of self-esteem" (p. 39). This is why it is said that "the person with HIV's experience of loss is therefore realistic on a wide variety of levels" (D'Anzi, 1987 as cited in Crowley, 1995, p. 39).

2.4.3 Loneliness and self-consciousness

It is not uncommon for PLWHAs to fear or experience loneliness. These feelings of loneliness may develop because others do not understand what the infected individual is going through, and/or because people avoid them as a result of their illness. According to Crowley (1995), these feelings of loneliness are intensified when people who used to be part of a support network for the infected individual start to keep their distance from the person in preparation for their inevitable passing on. Even the routine procedure by health-care providers of wearing gloves to prevent infection can make the HIV-positive person feel isolated (D'Anzi, 1987 as cited in Crowley, 1995) and can lead to feelings of self-consciousness "because the comfort of human touch is lost" (D'Anzi, 1987 as cited in Crowley, 1995, p. 41).

The loneliness and self-consciousness associated with living with HIV is likely to affect adolescents more severely than other age groups as a result of the importance that adolescents place on their bodies. This may be especially evident when the adolescent begins to notice a change in his/her appearance and body image, which may make him/her particularly self-conscious. In a study conducted in Abidjan (Dago-Akribi & Adjoua, 2004), it was found that bodily development was of major importance to adolescents living with HIV/AIDS, with many often experiencing painful emotions as a result of the judgment and scrutiny their bodies were subjected to. Dago-Akribi and Adjoua (2004, p. 27) argue that for the adolescent patient, "the body becomes identified as the carrier of the virus and marks the person as negatively different from others". This points to the need for psychological intervention that allows the young persons the opportunity to express their distress.

2.4.4 Low self-esteem

Owing to the rejection that may be experienced from their friends and loved ones, adolescents living with HIV/AIDS may lose confidence in themselves and in their sense of social identity (Van Dyk, 2005). The adolescent may also be concerned about his/her physical attractiveness, especially when he/she becomes ill, and this may interfere with forming relationships. This may lead to feelings of a low self-esteem, embarrassment, withdrawal and acting-out behaviours. Their sense of self-esteem may also be compromised if they are rejected and ostracised from peer groups as a result of their HIV status or as a result of the disclosure of their sexual orientation (Van Dyl, 2005).

2.4.5 Guilt

Guilt is a tremendous burden that may be experienced for a number of different reasons. Research has found that it is not uncommon for infected individuals to feel guilty for infecting a loved one.

Soal (1997) reports that one may also experience guilt for not being able to fulfil one's household responsibilities and for leaving this responsibility for others to cope with. In addition, guilt can be felt over the anxiety caused to partners or family members because of the burden of care that is placed on them. However, while feelings of guilt together with fears of helplessness and dependence should not be underestimated given the fact that HIV/AIDS makes health deteriorate, it should also be mentioned that the intensity of such feelings may be culturally-specific (Aorki, 1989). For example, Oriental and African cultures place considerable value on belonging to a community and on the connectedness of a community as compared to western cultures which place emphasis on individualism and independence (Crowley, 1995).

According to Chippindale and French (2001), feelings of guilt may also be experienced if HIV is interpreted as a punishment, for instance for being gay or using drugs, and this is said to be associated with social isolation and denial of one’s status (Crowley, 1995). Individuals may also manifest feelings of guilt because of the behaviour or lifestyle that has caused them to become infected (Van Walt & McKay, 1991). Findings by Soal (1997) revealed that many respondents experienced spiritual distress, which centred on their fears of being punished by God for contracting the disease.

2.4.6 Anger and frustration

HIV-positive individuals often exhibit feelings of anger and frustration for different reasons. Adolescents may display angry behaviours as a result of the perceived restrictions the disease may impose on their lifestyles. For example, they may see their diagnosis as interfering with their relationships and with their social life. Being able to attract a girlfriend/boyfriend may be viewed as more difficult if one is sick and has to stay away from school, which may elicit angry responses in the adolescent. The young person may also worry about his/her social standing, especially with regard to peer groups, and may be fearful of rejection, which may lead to feelings of a low self-esteem and acting-out behaviours.

Research has found that nurses often bear the brunt of angry behaviours by their patients for different reasons (Kemppainen, Obrien & Corpuz, 1998). In a study on the behavioural responses of patients with AIDS towards their nurses, it was found that violent and angry behaviours were found to be the second largest behavioural response category (Kemppainen et al., 1998). One third of a sample of 118 men and women responded with anger that was directed toward their nurses, and many of them admitted that they experience difficulties in managing their anger and irritability, making their nurses an easy target for such expressions (Kemppainen et al., 1998). Reasons for these angry behaviours included that of increased irritability with disease progression, intense psychological responses toward an AIDS diagnosis, or reflecting a violent or angry style of relating to others.

Counsellors, too, have been found to be the transference objects of anger by persons living with HIV/AIDS (Crowley, 1995). Crowley (1995) found that some of the reasons for this include the fact that the counsellor does not have a cure for the infected individual and also because the counsellor him/herself may not be HIV-positive. Anger may also be self-directed such as in cases of suicide, or may be acted out on a social level, for example when the person makes a deliberate effort to infect other people.

Friends and family may also be exposed to anger outbursts though for different reasons. It was also found by Sliep, Poggenpoel and Gmeiner (2001) that patients get angry when their friends and family neglect them and are only around when the ill person has practical resources, such as food to offer them. Other reasons for anger outbursts included the detachment of friends and family, their distancing and their lack of responsiveness (Silven & Cardarola, 1989).

While the foregoing paragraphs demonstrate the expression of angry responses felt by people infected with HIV/AIDS, it must be noted that many respond with passivity and try to internalise their anger. Some women, for example, opt to internalise their feelings so as to live up to the feminine role expectations of society and to behave in a manner that is seen as socially acceptable. DeMarco, Miller, Patsdaughter and Chisholm (1998) in a study on the experiences of women living with HIV/AIDS in the U.S., found that some women, as a coping strategy, tried to internalise their feelings of anger. One woman was quoted by DeMarco et al. (1998) as follows: "Sometimes when I get upset with my mother, the only way I can handle it is to back off. No matter how angry I get, I just back off and get out of the way" (p. 547).

This section has highlighted the psychosocial distress of PLWHAs on account of their illness. The next section provides a discussion of how these issues and other issues can be addressed in counselling so as to reduce the psychological distress experienced by PLWHAs.

2.5 COUNSELLING ISSUES OF ADOLESCENTS AND YOUTH LIVING WITH HIV/AIDS

There are a number of issues that are considered to be of importance when counselling a young person who has been diagnosed as HIV-positive. However, different individuals providing counselling hold different perspectives on the issues that should be covered during counselling. The following subsections show how service providers, community members and adolescents and youth themselves, differ in the perceptions they hold regarding this issue.

2.5.1 Acceptance

From a survey of literature it has become evident that there are two important types of acceptance that need to be discussed when counselling an adolescent or youth who is living with HIV/AIDS (Kelly, 2001; Modiba, Gilson & Schneider, 2001).

The first type applies to the person living with the illness, as he/she needs to accept his/her own health status. This is because, as pointed out by Kübler-Ross (1997), through the process of gradual acceptance people are able to overcome their state of denial and move forward with their lives. Various studies have highlighted the importance of discussing the acceptance of one’s HIV status during counselling given its beneficial role for clients (Kelly, 2001; Modiba, Gilson & Schneider, 2001). In a study by Mabunda (2004) on the knowledge and practices of rural South Africans in relation to HIV and AIDS, it was found that the act of accepting one’s status helped participants to cope more effectively with their illness. Similar results were found by DeMarco et al. (1998). In addition, research conducted by Feitsma, Koen, Pienaar and Minnie (2007) on the needs and experiences of PLWHAs in a poverty-stricken area in the Potchefstroom District in South Africa, has found that the act of accepting one’s HIV status is very important to participants as it makes them feel stronger. Thus, Feitsma et al. (2007, p. 58) are of the viewpoint that the acceptance of one’s HIV status is associated with a "stronger ability to deal with HIV", which can contribute to one's quality of life.

Adolescents often find difficulty in accepting their HIV/AIDS status (Van Dyk, 2005). This is because the adolescent period on its own, involves intensive psychosexual development, during which adolescents are preoccupied with their appearance and bodily development. These preoccupations may be more pronounced for the HIV-positive adolescent. and as Dago-Akribi and Adjoua (2004, p.27) have found, adolescents living with HIV/AIDS experience many painful emotions as a result of the judgment and scrutiny their bodies are subjected to, "because the body becomes identified as the carrier of the virus and marks the person as negatively different from others." Consequently, Dago-Akribi and Adjoua (2004) contend that in order to facilitate an acceptance of the situation by the young person, it is important for counselling interventions to also address the emotional impacts of bodily development on the HIV-positive adolescent client. However, the support of parents and peers is also indicated as vital to the success of the intervention. According to Dago-Akribi and Adjoua (2004), this type of counselling intervention has the potential of "re-establishing an identity that acknowledges HIV and is able to replace the inability to adapt by verbalizing and understanding the problems" (Dago-Akribi & Adjoua, 2004, p. 27).

The second type of acceptance refers to other people accepting the status of the infected individual. Batohi (2004) found that 60% (n = 6) of the sample of service providers and 70% (n = 7) of the sample of community members identified acceptance as one of vital importance and one that they would initially discuss with an adolescent or youth. This is a significant finding because it shows that as service providers and community members become more aware of the importance of accepting one's status, the process of disclosure for these young people becomes easier because a supportive environment will be created, which encourages people to talk openly. This, in turn, will contribute to the promotion of disclosure. According to an evaluation study by The Department of Communication Science, University of Zululand (2002) of the Ethembeni Care Centre in Kwa-Zulu Natal, there is a need to educate PLWHAs about the importance of the communication process and how it is linked to disclosure. Health professionals also need to know how they can be of assistance to PLWHAs in communicating their status to others, so that they can receive the support that they need.

Kelly (2001), in an evaluation of the Bambisanani Project, which aims to serve the needs of communities surrounding the Bizana, Lusikisiki and Umzimkulu areas of the Eastern Cape Province, states that this initial counselling and handling of the diagnosis is vital to the way the person will adapt to living positively and also to whether or not he/she will make use of health services for support in the future. Thus, health professionals play a major role in creating a context of support and assistance in dealing with the illness, especially during its initial phase, which may help the individual to adapt to the illness by gradually accepting his/her positive HIV status.

2.5.2 Condom usage

Condoms are seen as an important measure to prevent HIV-negative individuals from becoming infected with HIV/AIDS and other sexually transmitted diseases (STIs) as well as to prevent HIV-positive individuals from further spreading the disease or being infected by a more virulent HIV strain. Thus, condom usage forms an essential part of the counselling process as it provides individuals with the information they need on the options available to them, so as to make informed and responsible decisions on how to react in a given situation.

Batohi (2004) has found that not only do service providers and community members mention the importance of condom usage as an area that needs to be covered during counselling, but also that adolescents and youth themselves highlight this issue. This shows that young people in Lusikisiki are becoming more aware of the importance of condom usage and are becoming more willing for others to learn of its importance during counselling. This supports the finding by Kelly (2001) which shows that the youth are becoming more familiar with condoms and that condoms are no longer seen by them as foreign concepts.

However, Kelly (2001) added that adults are more likely to use condoms than young people, and that young people are more dubious about the safety of condoms as a means to prevent infection. Research by Van Dyk and Van Dyk (2003a) on the service-related barriers associated with voluntary counselling and testing (VCT) in South Africa, support this finding that condoms are sometimes viewed by the youth as an ineffective way to guard against infection. Owing to the development that takes place during the adolescent years, it is also possible that personal fable (that is, the adolescent belief that they are unique/special and that their personal experiences differ from the personal experiences of others) (Elkind, 1978c) may play a role in the refusal of adolescents to use condoms. They may engage in risky sexual behaviour, thinking that others can get infected with the HIV virus, but not them. In addition, according to Hovell et al. (1994), the process of normal sexual development in adolescence involves much experimentation which very often takes place without the use of condoms placing adolescents at increased risk of HIV/AIDS. Other reasons for the resistance by young people to the use of condoms include: condoms are less reliable than hormonal contraceptives as a means of contraception; condoms prevent men from demonstrating their virility, that is, it "wastes sperm"; Using condoms is less pleasurable than "flesh-to-flesh" sex; "too many condoms are needed for many rounds of sex"; fear of condoms breaking or slipping and awkwardness in purchasing condoms (Eaton, Flisher & Aaro, 2003, p. 158). There is also the myth that condoms "may disappear into the women" which may cause injury or even death, which obviously serves as a major deterrent to the use of condoms (Reddy & Meyer-Weitz, 1997 as cited in Eaton et al., 2003). Low self-esteem is also considered to be associated with the resistance against the use of condoms, as people with a low self-esteem are more likely to perceive the use of condoms as being offensive to their partner. For the young person with a low self-esteem, condom negotiation may be feared, and may thus become a significant barrier to the protection against infection. Young people may be embarrassed about using a condom (Perkel, Strebel & Joubert, 1991). Condoms are also thought to be associated with promiscuity, that is, they may be seen as a sign of distrust towards a partner, and/or the person initiating the use of a condom may be interpreted as the carrier of an STD (Meyer-Weitz, Reddy, Weijtz, van den Borne & Kok, 1998). As a result of the power imbalance that exists in many relationships, young women may fear violence or rejection and may consequently not insist on using a condom (Meyer-Weitz et al., 1998). Some believe that having sex without a condom symbolises commitment to their partner and to the relationship and that using a condom indicates "casual sex" or non-commitment (MacPhail & Campbell, 2001).

Research has found that home remedies have also been used as a means of contraception. The following are examples of methods that are used before sexual intercourse: drinking plenty of water; tying a rope (usually obtained from a traditional healer) around the waist; and drinking ZCC (Zion Christian Church) *mkhukhu* tea which is also carried out after sexual intercourse (Onya, Madu & Modiba, 1999; Mokwena, 2003). It is interesting to note that, in a study conducted by Mokwena (2003) with teenage mothers at Ga-Mothiba, Polokwane, all teenage mothers who participated in the study were under the impression that all traditional methods of contraception, such as the home remedies mentioned above, work effectively.

Although this is not always the case, it must be mentioned that some traditional medicines, especially herbs, do work, and have been the subject of further scientific investigation.

For these reasons, it is thought that although adolescents and youth are becoming more aware of the importance of the inclusion of condom usage in the counselling process, service providers must be careful to provide these young people with simple and accurate information in order to prevent further uncertainty and misunderstandings (Medappa, 1999; Van Dyk & Van Dyk, 2003a).

2.5.3 Disclosure

Disclosure of one's HIV status is an important psychological issue that many individuals have difficulty with, for fear of being treated harshly by family and community members and also for fear of being isolated, discriminated against, and losing the people most important to them. Kelly (2001) found that HIV-infected persons prefer to keep their status a secret or to disclose their status in a community other than their own, as they feel more comfortable talking to people who belong to other communities. Similarly, Van Dyk & Van Dyk (2003b) on the ppsychological barriers associated with VCT Programmes in South Africa, found that 33% of a sample of 1422 people reported that they would attend clinics where their identity was unknown. Thus, community prejudice proved to be a hindrance to the process of disclosure. The problem is further exacerbated by the reality that some counsellors have not been tested themselves and refuse to display their status, in spite of the possible effect this could have on communities' acceptance of the disease (The Institute for Multi-Party Democracy, 2002). As a result, these PLWHAs do not seek the help of services offered, which in turn creates a situation where these intervention programmes are unable to deliver their services effectively (The Institute for Multi-Party Democracy, 2002).

In a study conducted by Olley et al. (2004) among a sample that had been recently (less than one year) diagnosed with HIV in South Africa, it was found that as many as 78% (of a sample of 69 patients) had failed to disclose their HIV status to their sexual partners. In addition, the study found that 46% did not know the HIV status of their sexual partner. Research by Batohi (2004) revealed that the counselling issue of disclosure was not seen by adolescents and youth as one of vital importance and one that should be included in the counselling process. It was, therefore, thought that perhaps young people would prefer to keep their status a secret and do not want this issue to be discussed during counselling. Findings by Van Dyk and Van Dyk (2003a) support this possibility as it was reported that younger people with lower academic qualifications and those who live in rural areas were more likely to want to keep their status a secret.

Previous research has also found that one of the problems relating to why young people are reluctant to disclose their status, was that they were sometimes unaware of the benefits of disclosure (Arthur et al., 2000 as cited in Van Dyk & Van Dyk, 2003b). These benefits include: having the care and support of their loved ones, friends and health care workers during their illness, not having to live in fear; joining support groups that create a safe environment for discussion of personal issues; and developing new relationships with people of similar status. In one study, it was found that social support received in response to the disclosure was associated with lower levels of depression and anxiety, contributing to an overall improved quality of life for the infected individual (Hays et al., 1993). Further, in a study conducted by Battles and Wiener (1994), it was established that the act of disclosing one's HIV status among children and adolescents was associated with increased social support, social self-competence and decreased problem behaviour. It has also been found that satisfaction with social support received can serve as a buffer against the effects of physical condition on depressive symptomatology (Hays et al., 1993). Thus, the act of disclosing one's status to significant others can have a positive effect on the life of individuals, including the fact that they will be in a better position to manage their illness.

However, research has also found that in cases where people are forced to disclose their status, they are unsure of the benefits of disclosure but feel that they have no other choice (Mansergh, Marks & Simoni, 1995). This places them in a position where they are unable to decide whom they should disclose their status to, and in turn increases their chances of being subject to stigma and discrimination, leading to increased levels of anxiety and depression (Hays et al., 1993).

Following Elkind's theory (1978a), it is possible that an adolescent living with HIV may experience severe psychological distress on account of the imaginary audience and thinking of the reaction of others if he/she is to disclose his/her HIV status. The young person may become severely anxious as a result of spending time thinking of the combined responses from others, which may have severe negative consequences for the psychological development of the young person.

According to an evaluation study by The Department of Communication Science, University of Zululand (2002) on the Ethembeni Care Centre in Kwa-Zulu Natal, "the first challenge facing agencies involved with the epidemic is to develop methods and systems that assist HIV/AIDS-positive patients in dealing with their status from a psychological point of view" (p. 31). The study shows that there is a need to educate PLWHAs about the importance of the communication process and how it is linked to disclosure. Battles and Wiener (1994) found that social support and open communication about the diagnosis of HIV is particularly important for adolescent development as this is a time in a young person's life where he/she is confronted with decisions concerning relationships, sexual activity, drug use, and plans for the future. Health-care professionals need to know how they can be of assistance to young PLWHAs in communicating their status to others so that they can receive the support that they need. They can take pro-active steps in the fight against HIV/AIDS (Kelly, 2001; The Institute for Multi-Party Democracy, 2002) by encouraging young PLWHAs to disclose their status in stages (Kelly, 2001). Partial disclosure may have negative effects for the young person as it may be emotionally draining to remember who was told and who was not. He/she also stands the chance of creating hostility from people who are informed later than others. This situation may be particularly stressful as the young person to may also be confronted with an array of other complex decisions to make. Despite the possibility of the negative effects of partial disclosure, in Kelly's study (2001) this gradual approach to disclosure proved to be very beneficial; however, PLWHAs had to make this discovery for themselves instead of a health professional guiding them through the process. This highlights the need for all counsellors and health workers alike to be made aware of their role in the process of disclosure.

2.5.4 Fear and anxiety

Unpredictable painful emotional responses such as fear and anxiety are common responses to being infected with HIV/AIDS. For adolescents, such emotional changes are common on account of the enormous development that they experience; because of their self-conscious tendencies they often focus on themselves, which may contribute to their feelings of anxiety. Thus, a positive diagnosis of HIV for the adolescent may elicit particularly painful negative emotional responses, including those of fear and anxiety, that need to be understood in the counselling realm.

The term *anxiety* has been defined as an altering signal that warns the person of impending danger and enables him/her to take the necessary steps to deal with a threat. *Fear* is seen as similar to anxiety but is a "response to a known, external, definite, or nonconflictual threat" whereas "anxiety is a response to a threat that is unknown, internal, vague, or conflictual" (Kaplan & Sadock, 1998, p. 581). According to Kaplan and Sadock (1998), "when considered simply as an altering signal, anxiety seems basically the same emotion as fear" (p. 582). Research has found that people living with HIV/AIDS hold different fears and anxieties pertaining to different issues (Sethosa & Peltzer, 2005; Sliep et al., 2001; Van Dyk & Van Dyk, 2003a, b). These fears and anxieties relate to (amongst others): the reaction of health professionals; the reaction of partners, friends and family; infecting others and being infected by them; discrimination and isolation; abandonment and social/sexual rejection; death and symptoms of posttraumatic stress disorder.

2.5.4.1 The lack of confidentiality from health professionals

In many African communities health professionals know their clients personally, and are often unable to draw distinctions between the various roles they play in the lives of these members of the community. Some counsellors who participated in the focus groups conducted by Van Dyk and Van Dyk (2003a), revealed that they often disclosed a client's HIV status to the client's partner or family members as they saw it as their moral duty to protect community members. Hence, many infected individuals hold fears and anxieties about the confidentiality of their HIV test results. While other health-care providers maintain the confidentiality of their clients, they struggle with facing the clients' family and not being able to reveal to them the status of the client. In a report by Mayers (2005) that studied the types of support that are needed by health-care providers, one nurse shared her concern in the statement: "I had to tell my neighbour's daughter, counselling [her] that she is HIV positive today; how can I face her mother? I have to keep this confidential, yet she knows that her daughter came to see me today" (p. 125). For young people, receiving the results of an HIV/AIDS diagnosis may be all the more frightening and anxiety-provoking as they may not be fully prepared to face their family and friends if they have already been informed without the consent of the youngster.

In a study conducted by Pool et al. (2001) on the attitudes of pregnant women to voluntary counselling and testing in rural south-west Uganda, it was found that women were concerned that once they disclosed their status to a health-care professional, it would become widespread community knowledge. One participant made the following comment: "I would be afraid to inform her [the nurse] because when she meets her friends she will tell them: 'You know, Mrs. So-and-so told me that she is HIV-positive, she has slim disease.' So because of that I fear telling anybody that I have AIDS…" (p. 610). In addition, as a result of the disclosure that some counsellors make without their client's permission, many clients have become fearful of the consequences that may follow if their partners, friends and/or family members were to hear of their status without their permission. For this reason, some insist on keeping their status a secret.

Infected persons have also reported anxieties around the issue of prejudice as well as a perceived lack of care and support from health professionals, should they disclose their HIV status (Sethosa & Peltzer, 2005; Van Dyk & Van Dyk, 2003a). This is reflected in the following statement made by one of the participants of Van Dyk and Van Dyk's study (2003a, p. 121): "The nurses always gossip and they will tell everybody that I have AIDS"; and "She will be nice now, and when I go back with my baby, she will refuse to treat me or my baby." Pool et al. (2001) found similar results regarding this issue, as participants strongly agreed that discrimination by maternity staff is not at all uncommon. One woman said the following: "Yes, some midwives will refuse to attend to you, afraid they will also become infected" (p. 611). Others were concerned, because of rumours, that if their HIV status were to be revealed, medical staff would intentionally kill them in an effort to curb the spread of the disease. The following quote highlights this concern: "It would be good to know my status in order to get that medicine you are talking about, but we hear that when you are tested and the nurses get to know that you have HIV, they will give you a drug that will kill you soon because they want to reduce the number of infected people" (p. 612).

2.5.4.2 The reaction of significant others

Research has found that many people living with HIV/AIDS live in fear of disclosing their status to anyone, including those that are closest to them (Poggenpoel & Gmeiner, 2001; Pool et al., 2001; Sethosa & Peltzer, 2005; Sliep, Van Dyk & Van Dyk, 2003a, b). Reasons for this non-disclosure pertain to their fears of violence – "My husband will kill me" (Van Dyk & Van Dyk, 2003a, p. 122) being blamed for bringing HIV into the household – "Can you tell him that you are infected? Once you tell him that, he will say: ‘It is you who caused the infection' " (Pool et al., 2001, p. 613) or a break-up of their marriage – "He will kick me out and take another woman" (Van Dyk & Van Dyk, 2003a, p. 122). Similar findings have been reported by Sethosa and Peltzer (2005) among a rural sample of HIV patients in South Africa. Of the 47 participants counselled during the follow-up sessions, as many as 30 people (68.3%) had not disclosed their HIV status for reasons including that they were fearful of the negative reactions of their partners, family and friends (that they would abandon them) (24%); and that they were afraid of violence (12%), amongst other reasons. The fear that families will neglect or disown them or even that they will be murdered has also been reported in some studies (Pool et al., 2001; Sethosa & Peltzer, 2005; Van Dyk & Van Dyk, 2003a). The following statement is a reflection of this: "If I tell my husband, he will definitely kill me…or walk out on me…" (Sethosa & Peltzer, 2005; p. 36).

For the adolescent, thinking about the reaction of significant others, especially their parents, to their diagnosis, may be anxiety laden. Research has shown that intergenerational communication about sex and sexuality is avoided in many African communities (Campbell et al., 2005; Ntsayagae et al., 2008) which is why breaking the news of their positive HIV diagnosis may be an emotionally difficult task for the young person, which causes much psychological distress. In the past, the lack of parent-child communication regarding sex education was not a problem as members of the extended family often guided them through this aspect of their development (Ntsayagae et al., 2008). However, on account of urbanisation, extended families no longer play such integral parts of the lives of young people, which leaves them in a situation where they lack the guidance of trusted adults regarding their sex education (Ntsayagae et al., 2008) and even on issues relating to the disclosure of their HIV status, which may make them particularly anxious about the reactions of their parents.

2.5.4.3 Infection

Different anxieties concerning the transmission of the disease are also apparent from persons infected with HIV/AIDS. In a study conducted by Sliep et al. (2001) of HIV reactive patients in rural Malawi (2001), it was found that people have strong concerns about infecting their partners. In South Africa, research by Sethosa and Peltzer (2005) revealed that while only 17% of their sample reported having sex with a condom in the past three weeks, one of the various reasons for this was that they wanted to protect their partners from becoming infected with the virus and also wanted to protect themselves from the possibility of becoming re-infected. One participant said the following: "I do not want to infect my partner every time I have sex, that is why we use condoms" (p. 36). Confused others worry deeply about how they got infected if they had only one partner; pointing to the knowledge they have of their spouse’s infidelity and their resultant sick children (Sliep et al., 2001).

2.5.4.4 Isolation

Isolation is often feared as a common consequence of living with the HIV/AIDS disease, making many individuals anxious about how they will be treated.

The discovery of one’s sexual orientation (i.e. heterosexual or homosexual) for the adolescent may be a difficult developmental task, as adolescents have to satisfy their own sexual needs and at the same time ensure that they do so in a socially acceptable way to avoid being isolated from friends and family (Van Dyk, 2005). If the adolescent is known to be homosexual for example, the community, or more importantly the peer group to which the young person may belong, may isolate the individual as part of holding him/her responsible for his/her actions.

Pollack et al. (1987, as cited in Kelly & St. Lawrence, 1988) reported that HIV-positive individuals were often socially isolated from the outside world and spending more time by themselves, and if in a relationship, were hesitant to disclose their status to their partners. Russell and Schneider (2000), on the basis of an assessment of some of the community-based HIV/AIDS care and support programmes in South Africa, reported people sitting in (or being "locked in") their shacks or homes for long periods of time, and only making contact when attending a weekly support group. Research by Foulis, Maimane and Sibiya (2005) on the social context in relation to the effectiveness of HIV-prevention programmes in South Africa, lends support to this finding as some family members reportedly hid the ill person away and in so doing also deprived him/her of access to health care and support. In other situations, people have reported being "kicked out" of the home once their family members heard of their infection (Russell & Schneider, 2000). Similar findings have been reported by Kelly (2001), Shisana and Simbayi (2002), and Shisana et al. (2005), when people indicated that if a member of their family became infected with HIV, they would want it to remain a secret. This finding was confirmed by Batohi (2004), who found that some families find it difficult to accept the diagnosis of the young person and hence find it easier to isolate them.

Research by Duffy (2005) found that individuals living with HIV/AIDS in Zimbabwe were very often ill-treated. One nurse said the following: "They are treated differently; they isolate them, they don’t take care of them or listen to their problems…" (p. 16). Such studies highlight the perceptions that people have of HIV-infected individuals, which contribute to their social isolation and resultant anxieties. Batohi (2004) attributed this type of behaviour on the part of family members to the possibility of their being fearful of contracting the virus themselves, and further made mention of the finding that three out of a sample of ten family members mentioned their fear of infection and death as one of their concerns. Findings by Russell and Schneider (2000) support this reason for why family members would want to isolate infected members.

2.5.4.5 Abandonment and social/sexual rejection

A number of studies have found that it is not uncommon for people to worry about becoming abandoned by their partners should they disclose their status. Sethosa and Peltzer (2005) quoted the following participant’s fear: "If I tell my partner he will think I have been sleeping with other men and he will walk out on me" (p. 35). Another participant said: "If I tell my husband, he will definitely kill me … or walk out on me and refuse to take care of our children; I cannot risk that" (p. 36). Others were also afraid that their children would abandon them or even throw them out of the house if they were to become aware of their HIV status.

In relation to fears of sexual rejection, contrary to other studies reviewed by Van Dyk and Van Dyk (2003b) (e.g. Campbell, Marum, Alwano-Edyegu, Dillon, Moore & Gumisiriza, 1997; Gaillard, Meilis, Mwanyumba, Claeys, Muigai, Mandaliya, Bwayo & Temmerman, 2000) which found that women preferred not to reveal their status to their partners, Van Dyk and Van Dyk (2003b) found that men too had the same inclination to keep their status a secret from their partners. The main reason for this was that men’s fears mostly related to the loss of their sexuality as well as their sex appeal to women.

Social rejection was also reported to be very common, as many people expressed their fears of being rejected by their loved ones and community members (Van Dyk &Van Dyk, 2003b). Mabunda (2004) found that social rejection after the disclosure of one’s status is not uncommon, making many people fearful of disclosing their status to their loved ones and community members should they lose these valued ties. One woman told of her experiences after her husband had died of AIDS, a diagnosis that was revealed to her only after his death by clinic staff, because of confidentiality laws. She explained how people refused to eat the food she cooked, and that her family and co-workers rejected her (Mabunda, 2004). A study conducted in rural Zimbabwe revealed similar findings that highlight the fears people infected with the virus have of others coming to know of the status (Duffy, 2005). Duffy (2005) reported that people in the community often make an association between HIV and promiscuity, and that these members of society are generally rejected. Hence, people infected with HIV/AIDS worry that if they disclose their status, they will be classified as prostitutes, and that people will start to dislike and disrespect them. Two participants reported the following, which highlights the extent to which social rejection is a reality in rural Zimbabwe:"Let's say you go over to the river to bathe, everybody would stop washing and bathing until you finish", and "You would be an outcast in the society. Nobody would love you" (Duffy, 2005, p. 16).

HIV/AIDS stigma can rob the adolescent of a normal social development as a result of his/her associated life experiences. This is because, as part of their development, adolescents need to feel part of a peer group which serves the purpose of building friendships and relationships, and also allows for opportunities to experiment with new forms of behaviour, including opportunities to gain independence (Van Dyk, 2005). However, peer groups may develop negative attitudes toward infected adolescents because of the stigma attached to the HIV/AIDS disease and because of the development that takes place during adolescence, which includes the influence of reinforcement, modelling and imitation of the behaviour and attitudes of others (Van Dyk, 2005). This in turn may result in the social rejection and ostracism of the young person from the group, which may negatively affect his/her self-esteem and identity formation. This is why it is important that parents, teachers, health professionals and community members alike should take care about the manner in which they express and communicate information to adolescents.

2.5.4.6 Death

Living with a life-threatening disease is likely to be a frightening experience for anyone, but more so for the young person who is supposed to be at the prime of his/her life. Findings by Batohi (2004) reveal that issues relating to death are a major concern for many adolescents and youth in Lusikisiki. Service providers and community members also highlight this, as one of the concerns they think young people with the disease will have.

However, in spite of the issue of death being a major concern for young people, many of them are still unable to express their concerns. In a study conducted by Soal (1997) on an evaluation of a home-care project for PLWHAs, it was shown that because of the lack of communication, denial, and prevailing social taboos that exist in many communities, many PLWHAs are unable to discuss issues of death and hence are unable to make adequate preparations for its arrival. Soal (1997) found that discussing the issue of death was viewed as "an acceptance of it, or a kind of 'giving-up', which was frowned upon" (p. 42). Unfortunately, this avoidance of issues relating to death also leads to feelings of anxiety and confusion for the infected person about his/her own death. One participant made the following comment: "What bothers me is that people say I have five years left … (but) nobody tells me; I don't know where they heard this" (Soal, 1997, p. 43). In addition, research has found that failure to engage in such discussions reduces the ill person's availability to support networks (Soal, 1997) that are often necessary in order to work through his/her feelings of anxiety.

Mabunda (2004) has indicated that many people living in rural areas are illiterate, unemployed, and of a low socioeconomic status, and do not have access to accurate and adequate knowledge about HIV/AIDS. This in turn, has led to numerous misconceptions surrounding HIV/AIDS, which has exacerbated people's fears about death and HIV. As expressed by one participant: "We knew that HIV and AIDS is the same thing, and that it kills, and that once you get it, you die. We did not know that it takes a long time. We thought that after two days you would die" (Mabunda, 2004, p. 302). According to Mabunda (2004), one possible explanation for this misconception is that many people in South Africa are often diagnosed with the disease when they are at the end stages and are closer to death, which is why people are inclined to associate a diagnosis of HIV with that of death. Having said the above, however, it must be mentioned that it is important not to overgeneralise the ignorance of people living in rural areas concerning HIV/AIDS. Although the levels of knowledge and accuracy are relatively poor, many studies conducted in the Southern Africa region actually show that most people are quite knowledgeable about the disease. This is also very evident from national surveys such as those by Pettifor et al. (2004), Shisana and Simbayi (2002), and Shisana et al. (2005).

The level of mortality due to AIDS in South Africa is on the increase, and without access to antiretroviral treatment (ART) the situation becomes worse. According to Dorrington et al. (2004), "there is uncertainty concerning the coverage of ART roll-out and the number of deaths in 2010 could be anything between 290 000 and 450 000" (p. *iii*). As a result, many become hopeless and begin to anticipate their death. This sentiment was echoed by one of the HIV-positive interviewees of Kambule-Makgati and Makgati (2005) who said: "I wish I was dead, I am always in pain. No tablet or medicine helps me any more. I might as well die" (p. 21**).** According to The Department of Health (2006a, b) there has been a significant increase in ART roll-out. "Antiretroviral treatment (ART) is now available at 273 hospitals and clinics spread across the country for patients with a CD4 count of 200 and below" (Department of Health, 2006b, p. 2). The number of people receiving ART by September 2006 rose to 213 828 PLWHAs including children who were receiving treatment from both the public and private health sectors in the country (DoH, 2006) out of an estimated 599 298 PLWHAs requiring ARV treatment in South Africa (Dorrington et al., 2006). In addition, approximately 11 000 new patients are joining the programme each month. However, these figures imply that there is still a large proportion of people in need of ARVs (UNAIDS, 2006c).

In relation to fears and anxieties about death, research has indicated that many HIV-positive men and women, while experiencing their own physical and psychological losses because of the disease, also struggle to cope with the loss of their loved ones to AIDS (Sikkema, Kochman, DiFranceisco, Kelly, & Hoffman, 2003). In a study conducted by Sikkema and Bissett (1997) it was reported that HIV-positive persons found that coping with AIDS-related bereavement was one of their most severe life stressors. This in turn, is said to create uncertainty concerning their future health, and may also lead to complications regarding their adjustment after the loss of their loved ones. Sikkema et al. (2003) conducted a study on AIDS-related grief and coping in

New York, and found that HIV-positive participants who had lost a loved one because of AIDS, demonstrated high levels of psychological distress, including depressive symptoms, anxiety and traumatic stress related to their losses.

Some people with HIV also have what has been termed *death anxiety*. This occurs in the individual who is generally more anxious than average about death. This individual may react to a diagnosis of a life-threatening illness, such as HIV, with more psychological symptoms than one without such anxieties about death. Safren, Gershuny and Hendriksen (2003) found in a sample of HIV-positive men and women in America, that symptoms of posttraumatic stress disorder (PTSD) (i.e. re-experiencing, avoidance and arousal) were positively associated with death anxiety, meaning that those with higher death anxiety were more likely to react to their illness symptoms in a catastrophic way.

The statistics show that many South Africans are dying from AIDS. Pettifor et al. (2004) reported that 67% of their sample of young people reported attending at least one funeral in the past 12 months, and that 29% of those funerals were believed to be related to HIV/AIDS. In 2004, deaths due to AIDS were estimated to be 310 000 out of an estimated total of 700 000 deaths for that year (Medical Research Council, 2005). "The recent Burden of Disease analysis (2003) has shown that HIV/AIDS is the cause of almost 40% of premature mortality, measured as years of life lost, in the year 2000 and with no intervention strategies, will account for 75% of premature mortality by 2010" (cited in Medical Research Council, 2005, p. 1). In addition, it is said that if the rate of infection of HIV continues to increase at the rate it was in the year 2000, more than half of the South African population under the age of 15 could die within the next 5 to 10 years (LoveLife, 2001). Average life expectancy has decreased to below 50 years in three provinces in South Africa, namely, the Eastern Cape, Free State and KwaZulu-Natal (UNAIDS, 2006a). Given that many young people may be aware of these statistics, many may become fearful of its incidence and therefore suffer much psychological distress.

Green and McCreaner (1996) are of the opinion that counsellors providing assistance to adolescents and youth living with HIV/AIDS must allow these young people to express their fears and concerns around the issue of death so that they get the support they need and do not have to feel alone in their situation.

2.5.4.7 Posttraumatic stress disorder

Being diagnosed with a life-threatening condition such as HIV/AIDS with no cure has been described as a traumatic event in a person's life. Living with HIV has been described as a chronic stressor or traumatic situation as the individual is faced with numerous stressors including that of a declining health status, physical discomfort, issues of disclosure and its resultant implications, possible unemployment, etc. (Safren et al., 2003). How a person reacts to these stressors will determine how he/she adjusts to his/her illness. According to Safren et al. (2003), these responses can range from benign anxiety to that of the more severe posttraumatic stress disorder (PTSD) type of response. Kelly, Murphy, Bahr, Koob, Morgan, Kalichman, Stevenson, Brasfield, Berstein and St. Lawrence (1993) found that among 61 HIV-positive homosexual/bisexual men there was a 30% rate of PTSD and that this was associated with their HIV-positive diagnosis. Interestingly, the study also found that 60.9% of those cases of PTSD occurred within the initial six months after diagnosis. Safren et al. (2003) found that in a sample of 75 HIV-positive participants, more than half ($\underline{n}$ = 48 or 64%) met the criteria for a diagnosis of PTSD. Research has found that the prevalence rate of PTSD in people living with HIV/AIDS in South Africa is significantly higher than that of the general population (Carey et al., 2003; Emsley et al., 2003). Among a sample of 149 patients who had been recently diagnosed with HIV/AIDS, it was found that 22 patients (14.8%) met the criteria for current PTSD (Olley et al., 2005) and in 8 patients (36%) it was found that the knowledge of their positive diagnosis was the major traumatic stressor/event.

2.5.5 Depression

The term *depression* has been used interchangeably between brief periods of negative mood, an interrelated set of symptoms and experiences, and what has been defined as clinical depression which causes disruption and impairment to functioning (Gotlib & Hammen, 1996). Kaplan and Sadock (1998) consider key symptoms of depression as being a depressed mood and loss of interest. According to Blore, Schulze and Lessing (2004), because of the nature of the developmental period of adolescence owing to physical and cognitive changes, depressed adolescents can have multiple symptoms of depression including antisocial behaviour, sadness, irritability, low self-esteem, hopelessness, pessimism, anxiety, loneliness, social withdrawal, unusual attention to death, and anger and aggression, amongst others. "The depressive symptoms influence and interact with sets of other symptoms in the domains of cognition, behaviour and bodily functioning" (Gotlib & Hammen, 1996, p. 3).

With regard to cognitions and patterns of psychological adjustment to the disease, Gillard et al. (2000 as cited in Van Dyk & Van Dyk, 2003b), found that 15% of the female participants in their study would have preferred not to know their HIV status because there is no cure for it. This knowledge made them feel depressed. Participants of Van Dyk & Van Dyk's study (2003b) also reported feelings of fatalism and depression as the participants believed that that there was nothing they could do about AIDS. The situation is further exacerbated by the fact that medication in South Africa is costly and difficult to access, which further leads to feelings of hopelessness, negativity and fatalism (Van Dyk & Van Dyk, 2003b). In a study conducted by Kelly et al. (1998) on suicide ideation and attempts among persons infected with HIV in Australia, it was found that higher levels of a fighting spirit and a specific pattern of adjustment to the disease were associated with lower levels of suicidal ideation, while a greater sense of hopelessness was linked to higher levels of suicide. These findings lend support to the role of psychological responses to illness and their supportive functions against psychological morbidity (Kelly et al., 1998).

Hopelessness, negativity and fatalism, amongst other responses, in the face of a life-threatening illness are said to cause people to continue to use health-risk behaviours. Van Dyk and Van Dyk (2003b) found that out of a total sample of 1422 participants, 13.4% revealed that they would not change their sexual behaviour if they were found to be positive. As reported by one participant: "There is no cure so why bother? I will keep having sex until I die" (p. 122). Research by Murphy et al. (2001) found some evidence for an association between levels of depression and certain health-risk behaviours among adolescents infected with HIV. In an observational study of 323 subjects, higher levels of depression were associated with both frequent alcohol use and unprotected sex (Murphy et al., 2001). In addition, depressed adolescents were found to be significantly more likely to have unprotected sex than non-depressed adolescents. These findings highlight not only the psychological distress faced by many adolescents, but also their lack of understanding concerning their emotional responses to the disease. Counsellors need to pay special attention to the psychological presentations of their adolescent clients, not only to help them to cope better with these reactions but also that they may understand the seriousness of the disease and its implications for others.

According Komiti et al. (2001 as cited in Cooperman & Simoni, 2005, p. 149), "HIV-risk behaviours and infection are linked to factors associated with suicidal ideation and attempts", placing PLWHAs at higher risk for suicide. In South Africa, it has been found that PLWHAs are 36 times more likely to commit suicide than the general population (Schlebusch, 2005). According to McKegney and O'Dowd (1992 as cited in Kelly et al., 1998), there are at least two high-risk periods for suicide. These are: "(1) the initial 6 months after the diagnosis of infection with HIV and (2) the onset of physical complications of AIDS. Reasons for this include that suicidal ideation and attempted suicide at the time of diagnosis may be triggered by factors such as the way in which testing was carried out; a lack of social support at the time, the individual's inability to cope, and inadequate emotional responses" (Sheer, 1995 as cited in Van Dyk, 2005, p. 227). "Suicide in the later phase of AIDS is usually associated with deterioration of health; physical illness associated with pain; disability or disfigurement; a decrease in the quality of life; and a feeling that one at least wants to control the way one dies" (Pugh, 1995 as cited in Van Dyk, 2005, p. 227). However, research has found evidence that supports the probability that it is within the first three months that HIV-infected persons are at greatest risk for suicide. Cooperman and Simoni (2005) in a study on suicide and HIV/AIDS in New York, found that of the 207 women interviewed, 78% reported suicidal thoughts since their diagnosis, and that 26% had attempted to commit suicide since their diagnosis. Among those who had made an attempt, it was reported that 42% did so within the first month after testing positive and that 27% did so within the first week. Further, 63% of those who made an attempt stated that their attempt was closely related to their diagnosis. Judd and Mijch (1996) studied the depressive symptoms of patients living with HIV in Australia and found that of a sample of 100 patients, as many as 40 had experienced suicidal ideation as measured by the Beck Depression Inventory (BDI). Among them, 24 (41%) were asymptomatic while 16 (39%) were symptomatic, demonstrating that a high rate of suicidal ideation existed in both groups, though more so for the asymptomatic group. As such, Cooperman and Simoni (2005) suggest that people who test HIV-positive "need to be carefully monitored and counseled immediately after and during the early months after learning about their HIV status" (p. 155).

A study conducted by Mizuno, Purcell, Dawson-Rose, Parsons, and The SUDIS Team (2003) on correlates of depressive symptoms among persons infected with HIV in the U.S., found an association between perceived social support and levels of depressive symptoms, where the greater the perceived social support, the fewer the depressive symptoms reported. The study also found that when a person had a regular health-care facility for HIV medical care he/she reported fewer depressive symptoms. Similar results were found by Komiti et al. (2003) in a study on the rate of depressive disorder in people living with HIV/AIDS. Komiti et al. (2003) reported that for those who were found to be non-depressed, being in an intimate relationship served as a protective function against depression. The inverse relationship (i.e. less perceived social support and higher levels of depression) was found by Kalichman, Heckman, Kochman, Sikkema and Bergholte (2000) in a study on depression and suicidal ideation among persons living with HIV/AIDS. It was found that those participants (27% of 113 participants) who reported having thoughts of suicide in the past week had significantly higher levels of depression than those who did not consider suicide. Interestingly, those participants who had thoughts of suicide were also "more likely to have disclosed their status to those closest to them, and yet they perceived receiving significantly less social support from friends and family" (p. 903). These findings are consistent with those reported by Mizuno et al. (2003) on the relationship between perceived social support and levels of depression.

Previous research has found an association between HIV and depression, and that individuals infected with HIV were more vulnerable or were at higher risk for developing depression (Rogers, 2005). For example, Shisana et al. (2005) found that

HIV-positive individuals were more likely than their HIV-negative counterparts to feel sad, empty or depressed (41.8% vs. 29.6%) and to have experienced anxiety-related problems (34.4% vs. 26.4%). Ciesla and Roberts (2001) in a study that investigated the relationship between HIV infection and risk of depressive disorders, found a significant relationship between HIV status and the presence of major depressive disorder. Among the sample of HIV-positive participants 9.4% (n = 160 of 1,700) met the criteria for major depressive disorder compared to only 5.2% (n = 47 of 896) of the HIV-negative comparison group. In a study conducted by Komiti et al. (2003) it was found that 22% of a sample of 322 HIV-positive persons met the criteria for a current major depressive episode. Judd et al. (2005) in a study on the nature of depression among patients with HIV/AIDS, found that approximately one-third (34.8%) of a total sample of 129 patients with HIV/AIDS scored above the cut-off indicator for depression on the Beck Depression Inventory. According to Ferrando and Wapenyi (2002), depression is the most common mental health condition among persons infected with HIV. For many people, depression is said to develop as a result of the fact that they are living with an illness that has no cure. Although it is known that through effective antiretroviral treatment people can live longer lives, the majority of people infected with the virus in South Africa do not have access to such treatment, leading to increased levels of depression. For these members of society, quality of life is deteriorating as they experience many physical and psychological disturbances.

Research by Soal (1997) found that as a result of the difficulties people face in their relationships, as well as a result of their lack of communication with their loved ones, many people living with HIV/AIDS reported feeling "depressed, lonely, bored and hopeless." Soal (1997) further reported that much of the distress felt by these persons was related to the limits imposed by their ill health, pointing to the link between depressive symptoms and bodily functioning. One participant said the following: "I am a very outgoing person, I always used to live a full life. But now you can see me, I can’t live. I am merely existing" (p. 42).

Findings by Penzak, Reddy and Grimsley (2000), in a study on depression in persons living with HIV, have shown that although the signs and symptoms of depression are similar in both infected and non-infected individuals, HIV-infected individuals may experience more sleep disturbances than their counterparts. This finding was supported by Shisana et al. (2005) who reported that HIV-positive individuals had more sleeping problems than those who were without HIV infection (32.9% vs. 25.8%). Research by Robbins et al. (2004) also found a correlation between depression and quality of sleep among a sample of HIV-infected participants. Similar results were found by Judd and Mijch (1996), who reported that of a total sample of 100 HIV patients, sleep disturbances were reported by 65% of the sample. In addition, it was reported that among those who were found to be depressed ($\underline{n}$ = 44), the majority of the sample (77%) stated that they had experienced sleep disturbances.

Other somatic symptoms of depression have also been found in people living with HIV/AIDS. Research has shown that individuals living with full-blown AIDS experience difficulties in their physical health, including their sexual relationships, because of psychological problems. For example, in a study conducted by Gil et al. (1998) on the psychological adjustment of persons infected with HIV, it was found that among those who had progressed to the stage of an AIDS diagnosis, sexual adjustment was affected by the presence of psychological symptoms. Findings by Judd and Mijch (1996) have indicated that people living with HIV also experience difficulties in this regard. For example, the study found that of those who were found to be depressed, 73% (or $\underline{n}$ = 44) reported that they had lost interest in sex.

All the foregoing studies on increased rates of depression among PLWHAs point to the important role that counselling plays not only at the time of the diagnosis, but also throughout the illness, as it may aid in the process of improving the quality of life for PLWHAs. Careful consideration needs to be paid to the issues to be covered during counselling with a young person who has been diagnosed as HIV-positive, as well as the manner in which counselling is conducted, while paying special attention to the unique needs of the young person particularly, with regard to his/her developmental and cultural needs.

2.6 MAIN CONCERNS OF FAMILY MEMBERS OF ADOLESCENTS AND YOUTH LIVING WITH HIV/AIDS

An HIV/AIDS diagnosis within the family can create much stress and a heavy burden for the entire family unit (Altman, 1994). Often family members do not know how to react to the situation and have to endure many fears for their loved one, the rest of the family members, and themselves. This section discusses some of the main concerns of family members of adolescents and youth living with HIV/AIDS.

2.6.1 Shame and disgrace to the family

Because of the stigma attached to HIV/AIDS disease, many families live in fear of the shame and disgrace that is unfortunately associated with this disease. There are many factors that are said to exacerbate the situation. These, include: the disease is thought to be contagious, one that promiscuous people contract (Duffy, 2005); it is seen as an individual's personal responsibility to ensure that they do not get infected (Duffy, 2005); and it is linked to a number of cultural taboos, making people in the community even more prejudiced against infected individuals and their families (Kelly, 2001). Batohi (2004) found that both service providers and community members thought that the shame and disgrace this disease would bring to the family would be one of their main concerns. Research by McCann and Wadsworth (1992 as cited in Durman, 1993), as well as Duffy (2005), support this finding. Duffy (2005) found that because of the shame and disgrace associated with being HIV-positive, many families rarely, if ever, mention the true diagnosis of the ill person. Similar results were found by Campbell et al. (2005) in a study conducted in the Ekuthuleni community located in the Kwa-Zulu Natal Province. As a result of the stigma that was so severe in the community, few informants for the study were personally aware of anyone infected with the disease in their community.

Evidence has been found that suggests that family members are also fearful of being ostracised by the community and as a result they try to isolate the infected member (Batohi, 2004; Duffy, 2005; Grinstead, Gregorich, Choi & Coates, 2001 as cited in Van Dyk &Van Dyk, 2003b). Findings by Meursing and Sibindi (1995) in a study on family planning and HIV in Zimbabwe, revealed that because women are often blamed for being responsible for the infection they "may be sent-away or ostracized by in-laws and family of origin, even though such women most likely contracted the infection from their husbands" (p. 16). According to Batohi (2004) and The Institute of Multi-Party Democracy (2002), there exists a dire need to reduce the prejudice that communities feel towards infected individuals and their families on account of the HIV/AIDS disease.

2.6.2 Lack of balanced diet

Research has shown that families are often concerned about their financial ability to provide for the sick individual. In this regard, Russell and Schneider (2000) found that many families were trying to survive under conditions of extreme desperation for basic essentials. Russell and Schneider (2000) quoted a nurse from their sample who said, "You know I really wonder whether some patients aren't dying of starvation and not AIDS" (p. 15). Another participant in the same study made the following statement: "If we could address malnutrition we'd reduce the risks of infection" (p. 29). Duffy (2005) found that it is the responsibility of the wife to care for her ill spouse, but following the death of her husband she is often left with very few resources to care for her own illness. Similar findings were reported by Batohi (2004) as many young people made constant reference to their need for financial assistance and as some identified this issue as one that would possibly be a major concern for family members.

2.6.3 Death of the loved one

Batohi (2004) and LoveLife (2001) found that service providers, community members and adolescents and youth were of the opinion that the death of a loved one would be one of the main concerns for family members. Research by Soal (1997) found that some people were reluctant to accept that their loved one was facing death. For example, one participant said that the reason that she failed to talk to her brother about the issue of dying was because: "I don't think of my brother as a dying person" (p.42). Another participant said: "We could still have liked two or three years together, you know. We could go out, go to the Waterfront, go to the movies, stuff like that. But he is lying there all the time" (p. 43). Sadly, it was reported by Soal (1997) that his partner died three weeks later.

2.7 THE CHALLENGES FACED BY SERVICE PROVIDERS AND COMMUNITY MEMBERS IN COUNSELLING YOUNG PEOPLE

Service providers and community members face a number of challenges in providing counselling and assistance to adolescents and youth living with HIV/AIDS. This section discusses some of these challenges as identified by these groups themselves.

2.7.1 Denial of HIV status

Many young people living with HIV/AIDS find it difficult to accept their HIV status and are therefore said to have what is termed a *denial syndrome* that can sometimes be linked to a state of "hopelessness" (The Department of Communication Science (2002). Findings by Mabunda (2004) show that many HIV-positive people who have not been educated about HIV/AIDS tend to be hopeless about life. They just "give up" on life (Mabunda, 2004). Similar findings were reported by Graham (2005), as one participant admitted his state of complete denial and resultant risky sexual behaviour which he said was due to the fact that he was not post-test counselled. "The problem was that I was not counseled or explained to about what actually happens to your body when you have HIV/AIDS, nor what needs to be done to keep healthy. So while in hospital I was counseled and I joined a support group" (p. 21).

According to Batohi (2004), this "state of hopelessness" felt by many, can possibly be attributed to the feeling that "nothing can be done for them, given the shortage of drugs and the limited [ability] of many of them to buy such drugs" (p. 96). For these reasons Batohi (2004) found that nearly all the service providers interviewed ($\underline{n}$ = 9) identified this area as a challenging one. Previous research by Kelly (2001); Modiba et al. (2001); and Russell and Schneider (2000), support this finding.

A study conducted in Zimbabwe (Duffy, 2005) found that people search desperately for other reasons why their loved ones have become ill, and look for supernatural causes. As stated by one participant: "…we start looking for the unknown but we don't want to deal with what is before us" (Duffy, 2005, p. 17). And when the ill person makes a partial recovery, they look upon the doctor as though he/she was being used by the devil because the person appears to be well again. Many also do not believe that AIDS is a real disease and are of the view that God wants them to die.

Mabunda (2004) found that traditional healers, nurses and other health-care providers are said to support the state of denial experienced. Traditional healers (or *N'angas*) explain the disease as caused by unhappy ancestors or bewitching. "The spirit mediums will say, 'Ah, it's not a virus, it's because the spirits are not happy' " (Mabunda, 2004, p. 17). Nurses, too, are said to fuel the level of denial experienced as they ask doctors not to write the cause of death on the death certificate or true diagnosis on the chart, for insurance reasons and possible family problems. Instead, what is used is the term *RVI* which stands for Retroviral Illness. One hospital counsellor said, "It is easy to talk about malaria or tuberculosis, but with AIDS, we feel we should not mention it …" (Mabunda, 2004, p. 18).

On a more positive note, however, recent research in South Africa, has found that people are becoming aware of the importance attached to accepting one's status. One reason for this is that people see it as a way for them to move on with their lives and a way for them to move beyond their diagnosis (Mabunda, 2004). One participant aptly put this sentiment into words: "Denying HIV testing is denying life" (Mabunda, 2004, p. 302).

2.7.2 Confidentiality

Confidentiality is an essential component of the counselling process. This is because without the assurance that confidentiality will be maintained, many people (including adolescents and youth) find it difficult to seek the help and assistance of counsellors (Russell & Schneider, 2000). Although some may opt to make use of these services, they may be reluctant to confide in service providers or to reveal sensitive information to them fearing that this information may become common knowledge in the community.

Batohi (2004) found that as a result of limited space and privacy, many service providers highlighted the issue of confidentiality as one that they felt was challenging. This shows that many service providers are aware of their ethical and legal responsibilities but owing to infrastructural problems they are unable to maintain them. Mayers (2005) has reported similar findings as service providers complained of overcrowded clinics with insufficient space to provide clients with adequate counselling. In such health care facilities, service providers are therefore unable to assure their clients of confidentiality and privacy.

Contrary findings, however, were reported by Kelly (2000) and Van Dyk and Van Dyk (2003a) as many of the counsellors in their studies were found to be unaware or simply did not pay adequate attention to the principle of confidentiality between their clients and themselves. In Kelly's study, it was reported that after a patient was tested a family member might return to the hospital for the result, and hospital staff often revealed the patient's status. This in turn led to the patient's status becoming common knowledge and to the patient's rights being violated. However, in spite of the positive findings by Batohi (2004) that service providers were aware of the need for confidentiality, the study also found that some young people showed distrust towards service providers which made it even more difficult to offer them counselling. This finding indicates that more needs to be done to build the relationship between counsellors and young people receiving counselling. This is supported by Duffy (2005), who says that it is in establishing open and trusting relationships, while maintaining confidentiality, that people will begin to talk about issues relating to HIV without the fear of being stigmatised.

2.7.3 Capacity problems

Many studies have found that owing to the lack of personnel in many hospitals and clinics around the country, long waiting periods for service delivery are common experiences for many clients (Makhubele & Pronky, 2000 as cited in Van Dyk & Van

Dyk, 2003a). Because many of these people do not have time to queue for long periods to receive HIV counselling and testing, and because their limited resources do not allow them to make repeated visits to the clinic, findings have revealed that they do not return for their test results. Masuku (2002 as cited in Van Dyk & Van Dyk, 2003a) reported that as many as 80% of clients who had gone for HIV counselling and testing in certain clinics around the country did not return for their test results.

Rohleder and Swartz (2005) on counselling as part of HIV testing in South Africa, have found that counsellors experience many difficulties in administering adequate counselling to their clients as a result of the high patient load in many clinics. A similar finding was reported by Fawcett (2001) in a rural hospital in the Eastern Cape where the average number of patients counselled per hour is six, which by calculation, implies that each patient is allowed only ten minutes with a counsellor. Unsurprisingly, such circumstances do not convert into proper HIV/AIDS counselling. Nursing managers, it was reported, exacerbate the problem by concentrating heavily on the numbers of people getting tested each day, while ignoring the emotional needs of the counsellor and the person being counselled (Rohleder & Swartz, 2005). This state of affairs is untenable, and calls for an accelerated intervention.

It can be seen from the literature surveyed that, while there are many service providers who are attempting to meet the needs of people infected with HIV/AIDS (including the youth) and their families, many have different focuses, and counselling appears to be of different standards. It can be argued, therefore, that if service providers and programmers worked together on one set of counselling guidelines and principles, they could, perhaps, produce an outstanding model for the care and support of these individuals. However, given the slim chance of this happening, the onus is on the government to meet this challenge of developing an appropriate care and support model. Studies show that there is an urgent need for such an intervention. For example, Russell and Schneider (2000) on community-based HIV/AIDS care and support programmes in South Africa, found that "due to a lack of guidelines and accepted standards, there was no uniformity across or within provinces on the types of services offered, the manner in which these are provided, and their quality" (p. 50). To this end, Russell and Schneider (2000) recommended that the government take a more active stance in these and other related issues.

Since then, however, the government has responded favourably to this challenge by developing the first National HIV/AIDS/STI Strategic Plan for 2000–2005, which includes the objective to "develop guidelines for the treatment and care of HIV/AIDS patients in health facilities and the community" (Department of Health, 2000, p.18). In addition, the HIV/AIDS division of the Eastern Cape Department of Health, together with the Department's health resources division, has recruited more than 500 nurses to work in the various provincial hospitals and clinics, and has stated that a third of the annual HIV/AIDS budget has gone towards employing additional staff (Anonymous, 2006). The government has implemented The Comprehensive HIV and AIDS Care, Management and Treatment Plan for South Africa, and has increased its annual HIV/AIDS budget from R264 million during 2001/02 to R1,5 billion in 2005/06 financial years (Department of Health, 2006). In addition, it is also working towards the implementation of the Revised National HIV/AIDS/STI Strategic Plan for 2007–2011.

2.8 THE ATTITUDES OF SERVICE PROVIDERS WHEN PROVIDING SERVICES TO PEOPLE INFECTED WITH HIV/AIDS

HIV/AIDS is described as a life-threatening illness, which places fear in the infected person, his/her family members, community members and all those who come to know of it. Health-care professionals are no different, as many are afraid of contracting the virus themselves through caring for infected patients. Doctors, nurses and other health personnel who are in contact with free-flowing blood are at risk of HIV infection. Although prescribed precautions to prevent infection are available, the risk of infection through needle-stick injury, for example, still exists and is a profound fear for many (McCarthy et al., 2002 as cited in Ncama & Uys, 2003). The situation is further complicated by the fact that service providers are said not only to be concerned about their own risk of infection, but also that of their families, should they get infected and transmit the disease to those closest to them (Ncama & Uys, 2003).

Thus, HIV/AIDS presents health-care professionals with a serious challenge as they endeavour to care for their patients with a non-discriminatory attitude.

It has been found that as a result of the fear that some nurses have of contracting the virus, their willingness to provide services to patients living with HIV has decreased (Lohramann, Valimaki, Suominen, Muinonnen, Dassen & Peate, 2001) and some would prefer to have a choice as to whether they have to care for patients with HIV or not (Sherman, 2002 as cited in Ncama & Uys, 2003). For many, this unwillingness to work with HIV-infected patients could be the result of their own unresolved feelings regarding their mortality (Crowley, 1995). Other nurses may feel that because of the nature of their jobs, they are forced to offer counselling to patients and may do so as an obligation rather than a real interest or dedication to the profession (Van Dyk & Van Dyk, 2003a). Consequently, the quality of care received by the clients/patients can be jeopardised.

Findings by Bachmann, Colvin, Nsibande, Connolly and Curtis (2004) on the quality of primary care received for STIs in Durban, South Africa, revealed that between 49% and 63% of patients were of the opinion that the nurses' attitudes were respectful, friendly and caring. In addition, the study found that between 51% and 89% of patients made note of other favourable attitudes of nurses, and that 89% felt that their nurses were non-judgmental. However, contrary findings were reported by Kelly (2001) as it was revealed that the counselling services offered to PLWHAs in the Eastern Cape were of a very poor standard. PLWHAs reported that counsellors were not very sensitive in their approach to the initial diagnosis, and mentioned occasions during which "a counsellor was reading off a pamphlet, and talking on the telephone during a session" (Kelly, 2001, p. 40). They reported that nurses and social workers demonstrated a lack of understanding (especially toward the youth) of what it must feel like to be diagnosed as HIV-positive, and did not realise the support that a person may need in the event of a positive diagnosis. They felt that it would have been more encouraging to have had the opportunity to be counselled by someone who had had similar experiences and challenges. Much the same was reported in a case-study on the Bushbuckridge Health and Social Services Consortium, in which service users "complained about the often unfriendly, even irritable, attitude of the nursing staff" (Health & Social Services Consortium, 2002).

Russell and Schneider (2000) also reported unsympathetic and ineffective helping attitudes of health and social workers. As one service user said - *"You go to the clinic with a headache, they say they can't help you. They send you to the hospital. You go to the hospital – they say: You know you have this disease, we can do nothing for you, go home. Sometimes the clinic people will say, "You know you are sick, you know this will happen. So why are you calling us?"* (p. 17).

Inadequate standards of counselling were also reported by Olley et al. (2004) as it was found that of a sample of 69 patients, only 44 (64%) had received HIV/AIDS counselling after they received their test result. This figure is low, considering that all persons going for an HIV test are supposed to receive counselling and information about safe sexual practices, regardless of the test result.

It is interesting that many researchers and health-care practitioners encourage PLWHAs and their families (in booklets, pamphlets and newspaper articles) to speak to counsellors about their status, their feelings, and the decisions they need to make in their lives. This is because they expect, and also tell persons going for counselling that they can expect from a counsellor the following: to be understanding and allow the client to express his/her feelings, to be obligated to treat whatever clients tell them with confidentiality, to provide a private space for clients to talk, not to judge them or their situation, to give advice on the options that are available to the client but not to make decisions for the client, and to give the him/her information to help make informed choices. However, in spite of these expectations that clients have of what their counsellors can offer them, studies show (for instance as given in the paragraphs above) that clients are often at the receiving end of what can be considered as inadequate services for meeting the counselling needs of PLWHAs and their families. This indicates that health-care professionals need to be made more aware of the psychological aspects of HIV/AIDS and also of the common reactions that accompany a positive diagnosis, so that they can address these needs with some sort of understanding. Nefale (2004) found that many skills are needed by counsellors to help equip them to deal with the challenges they face daily. She added that one way to curb the spread of HIV is through prevention, which, by implication, means training more lay counsellors in the area of HIV/AIDS.

2.9 INTERVENTIONS AIMED AT PREVENTION

Most interventions aimed at prevention have been designed with the intent to focus on and instil risk-reduction to HIV/AIDS and other STI infections. Specifically, the risk-reduction strategy of South Africa is represented by the ABC (Abstain, Be faithful, Condomise) Campaign. However, such campaigns and programmes have been known to reach urban areas more effectively than rural formal and informal settlements (Shisana et al., 2005). Another major challenge as identified by the Takalani HIV/AIDS Resource Centre (in the Aliwal North District located in the North of the Eastern Cape Province) is that more needs to be done in South Africa in the fight against HIV/AIDS than just creating awareness of the problem. "The problem in most HIV/AIDS campaigns, is that they are all aimed at creating awareness of the problem and yet people are still being infected everyday...There needs to be a shift from awareness to vigilance in the way people confront this problem…" (The Institute of Multi-Party Democracy, 2002, p. 87).

With regard to the effectiveness of the ABC (Abstain, Be faithful, Condomise) campaign, research has shown mixed findings in promoting the message of prevention against HIV/AIDS and other STIs. For example, Simbayi et al. (2004) in a paper based on the data collected as part of the Nelson Mandela/HSRC Study of HIV/AIDS (2002), found that among sexually active females aged 15-19, condom use had increased from 19.5% in 1998 to 48.9% in 2002, and among females aged 20-24 condom use had increased from 7.6% in 1998 to 47% in 2002. LoveLife (2001) reported that although the majority of their sample of South African youth indicated that they were aware of what the terms *unprotected sex* (74%) and *safe sex* (78%) meant, the study also found that 53% of sexually active youth used a condom *some of the time* or *never* in the past year, and that only 30% *always* used a condom in the past year. Similar results were found by Pettifor et al. (2004), who reported that of those who had had sex in the past 12 months (i.e. 56 % of a sample of 11 904 participants) only 33% reported using a condom *always.* Further, Eaton et al. (2003) in a review of

75 research reports and papers on youth sexual risk behaviour in South Africa (dated between 1990 and 2000), reported poor condom use amongst the sexually active youth (between 50% and 60% who reported never using condoms). Similarly James et al. (2004) reported that out of a sample of 1113 participants, 42.6% answered that they had been sexually active in the past 12 months. Interestingly, the study found that although participants had a good level of knowledge regarding the causes, spread, treatment and protection against STIs, an alarming 33.3% of sexually active participants reported not having used a condom at all. Thus, although some studies argue that South African youth are taking note of, and applying, prevention messages, others like Frizelle and King (2002) and James et al. (2004) argue that high levels of knowledge and awareness of HIV/AIDS do not imply its translation into the use of condoms and/or other preventative measures. According to these researchers, not enough is known about why such vital information is not heeded, and more needs to be done to fill the gap between awareness and practice.

The Health and Development Networks (HDNET) (1999) argue that one reason for this failure is that current interventions aimed at prevention are based on Western concepts and paradigms that are largely inappropriate for the African population, given that the African worldview is so different from Western perspectives.

From this viewpoint, interventions aimed at prevention fail to take into account African beliefs and practices. For example, it is not uncommon for HIV/AIDS to be believed to be caused by spirits, supernatural forces, ancestral retribution and/or witchcraft (*AIDS*-Weekly, 2001; HDNET, 1999). In a study conducted by Shisana and Simbayi (2002) it was reported that 4% of South Africans held the belief that AIDS is caused by witchcraft, followed by 14% who were unsure of this causal link. Kalichman and Simbayi (2004), in a street survey of men and women living in a Black township in Cape Town, found that 11% of respondents believed that AIDS is caused by spirits and supernatural forces, while 21% reported that they were unsure. Others deny the existence of the virus, holding on to the belief that the illness is due to bewitchment (Kambule-Makgati & Makgati, 2005). According to Van Dyk (2005), people believe in witchcraft because it helps them attribute meaning to the illness which science fails to provide. Answers to questions such as "why some people who are ‘at risk’ do not contract AIDS and why some die much more quickly" help them understand the personal or fundamental causes of the illness (Seeley et al., 1991 as cited in Van Dyk, 2005, p. 118).

Witchcraft beliefs may have serious implications for HIV/AIDS counselling. This is because people who hold these beliefs believe that everything that happens in their lives happens as a result of witchcraft and is caused by external forces. This is supported by the finding of Boahene (1996), who reported that many African people do not see themselves as responsible for their actions, and by implication cannot be held accountable. This, in turn, leads to a lack of interest in the use of HIV-preventative methods (Van Dyk, 2005). However, there have been some studies that have found successful ways of conducting HIV/AIDS counselling with people who hold the traditional African world-view. Zazayokwe (1989 as cited in Van Dyk, 2005, p. 118) for example, told "people that *they* may know where the HIV infection originated, but *she* knows what the disease does inside the body and how they can avoid contracting it."

Another contributing factor to the low levels of application of prevention messages is that although health and sex education do exist in many schools, many of these programmes fail to equip young people with the skills deemed necessary for negotiation and decision-making concerning prevention issues (HDNET, 1999). Parents from a traditional African background, as with many other South African parents from other backgrounds, are very often unable to provide their children with such information, because talking openly about issues relating to sex is regarded as taboo in many cultures. Campbell et al. (2005) have also found that some parents struggle to communicate with their children about sexual health issues because they lack the confidence to do so as a result of their own limited education on the issue. In a study that sought to determine the perceptions of South African youth from different cultural backgrounds on issues of information dissemination and its relation to behaviour change, it was found that among both Black and Indian youth, speaking to parents about sex is largely discouraged because of the cultural taboos that are attached to this issue (Frizelle & King, 2002). Campbell et al. (2005) found similar results in their study, and added that because of the stigma that is attached to the disease, many parents are unwilling to allow their children to attend HIV-prevention activities. It has also been reported that some parents have punished their children for attending these activities because they see their involvement as proof that they are sexually active (Campbell et al., 2005). Counsellors need to be made aware of these issues and not take for granted that all young people are being exposed to such needed information at schools or at home. They need to speak as openly and clearly as possible to adolescents and youth without making them feel uncomfortable.

Researchers argue that these facts cannot be ignored in the planning and development of interventions aimed at prevention in the African population, as mistaken attitudes fail to empower the African youth to protect themselves against infection (Eaton et al., 2003; Frizelle & King, 2002; HDNET, 1999). As Campbell puts it (as cited in Frizelle & King, 2002, p. 1), "health-related behaviours such as condom use are determined not only by conscious rational choice on the basis of factual knowledge, but also by the extent to which the broader contextual factors support the performance of such behaviours." The study conducted by Simbayi et al. (2004) supports this viewpoint as it was found that factors relating to culture, race, geography (urban or rural) and socio-economics determined to some degree the risk to HIV/AIDS felt by South African youth.

The other problem that current preventive interventions face lies in the areas of information dissemination, education and communication interventions in rural areas. It is argued that because of the high levels of illiteracy that exist in Africa (and in South Africa) many people will be excluded from communication initiatives that endorse pamphlets, billboards and print media to spread the message of HIV/AIDS (HDNET, 1999). Accordingly, many argue that what is needed is a two-way channel of communication that allows for open dialogue between educators and learners in a given community (HDNET, 1999). Such dialogue appears to be possible within the African context, as information is very often conveyed orally. Oral communication will be of benefit to community members not only because they are familiar with it, but also because it is seen as a productive means to generate critical thinking and hence make persons more aware of their vulnerabilities to the disease (HDNET, 1999). Crewe (2002 as cited in Frizelle & King) concurs with this view, saying that it is only when young people are encouraged to openly debate AIDS as a social and cultural issue without feeling ashamed about it, and only when they become aware that older people have found ways to talk about such issues amongst themselves and with young people too, will we as a people find a way around this problem. Findings by Frizelle and King (2002) also support this viewpoint, as adolescents in their study, regardless of their cultural background, found it most insightful for issues of HIV/AIDS to be shared in the form of a discussion that prompted interaction and debate around such issues.

Peer education and support groups can also serve as a viable means to promote oral communication amongst members of the community. Peer leaders are viewed as being able to bridge the gap of communication between different cultures and age groups. As young people see the peer leaders acting responsibly and demonstrating their understanding towards risky sexual behaviour, they too become inspired and start to make informed choices of their own about their sexual behaviour and are encouraged to develop positive attitudes towards those living with AIDS (Prodigy Business Services, 2002).

Many organizations have acknowledged the role that volunteers play in information, education and communication interventions. It is believed that volunteers can relieve some of the burden of care and support experienced by health professionals, as much of the literature reviewed indicates that health professionals alone cannot cope with the whole health-care package (Dreyer & Associates, 2002; Prodigy Business Services, 2002; The Institute of Multi-Party Democracy, 2002). As a result, many AIDS intervention programmes throughout the country have started to recognise the value of working together with volunteers to share the workload. This method of education and communication is proving to be successful, especially with regard to young people, as some studies have found that young people tend to be more receptive to messages when they are received from people of a similar age group and cultural background (Frizelle & King, 2002).

2.11 CONCLUSION

This chapter has reviewed the psychosocial factors associated with HIV/AIDS, the counselling issues of adolescents and youth, some of the attitudes and challenges of service providers in their pursuit to counsel young people with HIV/AIDS, and finally some of the weaknesses of interventions aimed at prevention. The next chapter focuses on the theoretical foundation of the study.

CHAPTER 3

THEORETICAL FOUNDATION OF THE STUDY

3.1 INTRODUCTION

This chapter focuses on the various theories and models such as Cognitive Behaviour Therapy and Erikson's theory of psychosocial development, which lend insight into the development of an adolescent, and which serve as the theoretical basis for the development of the counselling model that has been utilized in this study.

3.2 COGNITIVE BEHAVIOUR THERAPY

3.2.1 The history of Behavioural Therapy and Cognitive Therapy

In order to gain a full appreciation of the amalgamated CBT approach, it is first essential to briefly review the history of behavioural theory and cognitive theory.

3.2.1.1 A brief history of Behavioural Theory

The behaviour component of CBT began with the notion of Watson (1930) that behaviourism should be the focus of psychology and not that of consciousness, as was the case in psychoanalysis following the Freudian emphasis (Kalodner, 1995). Two important principles of animal learning shaped the thinking of behaviouralists. The first was *classical conditioning* based on the work of Pavlov, in which experiments were conducted with dogs, in which a bell (unconditioned stimulus) was rung and food (unconditioned stimulus) was given (Hawton, Salkovskis, Kirk & Clark, 1991). This pairing of the sound of the bell (which became a conditioned stimulus) followed by the food was repeated a number of times. This led to the discovery that the dogs began to salivate (conditioned response) as soon as the bell was rung before the food was given (Hawton et al., 1991). In other words, the dogs had learned or had been conditioned to respond to the sound of the bell (conditioned stimulus) that would be followed by food, hence they came to elicit salivation (conditioned response). In the same way, experiments were conducted with humans, such as the experiment in which Little Albert was trained by Watson "to fear a white rat, white cotton and even Watson's white hair" (Kalodner, 1995, p. 355) using the principles of classical conditioning. As a result, Watson demonstrated "that human emotions can be learned and modified" by means of *learning principles* (Kalodner, 1995, p. 355).

The second principle is known as *operant conditioning* and was founded on the work of Thorndike, Tolman, and Guthrie as they observed that "if a particular behaviour was consistently followed by a reward the behaviour was likely to occur again" (Hawton et al., 1991, p. 2). Skinner developed behaviourism further as he extended this principle and defined reinforcement as "the effect they have on an individual's behaviour" (Hawton et al., 1991, p. 2) and showed how different amounts of reinforcement can support behavioural changes. Two types of reinforcements were introduced by Skinner, namely *positive reinforcement,* which is defined as a behaviour that becomes more frequent (e.g. being on time) on account of positive consequences (e.g. praise), and *negative reinforcement,* which refers to a behaviour that increases as a result of the absence of an expected unpleasant event (e.g. anxiety (Hawton et al., 1991). Thus, in operant conditioning, reinforced behaviour is defined as a behaviour that follows a particular event that increases in frequency (Hawton et al., 1991). However, other methods were also used that brought about a decrease in the frequency of a behaviour. For example, by using *punishment* the frequency of a behaviour decreases as a result of an unpleasant event (e.g. electric shock) and by using *frustrative non-reward* the frequency of a behaviour decreases because it is not followed by an anticipated reward (e.g. not being praised) (Hawton et al., 1991). The collective use of these techniques became known as "applied behaviour analysis" which is used to demonstrate the role of behavioural techniques in everyday situations (Kalodner, 1995).

In 1976, behavioural approaches became popular in the counselling and psychotherapy domain. Krumboltz (1976) identified behaviour counselling and psychotherapy as "a process of helping people to learn how to solve interpersonal, emotional and decision problems" (p. 2). In this view, learning is seen as the main method of change and clients are encouraged to make changes in their behaviour as a result of counselling and psychotherapy. These behavioural changes were perceived as indications that the counselling or psychotherapeutic intervention was successful.

3.2.1.1 A brief history of Cognitive Theory

The rise of the cognitive movement founded by Ellis, Beck, Bandura and others took place as a result of recognising that the existing systems of psychotherapy at that time were inadequate. This recognition came about as Ellis (1962, p. 14 as cited in Kalodner, 1995, p. 356), for example, pointed out that "human beings… are not the same as Pavlovian dogs or other lower animals; and their emotional disturbances are quite different from the experimental neuroses and other emotional upsets we produce in the laboratory." Language aspects of neurosis were other issues that Ellis found to be neglected by systems of psychotherapy. Ellis believed that people are different from animals and that it is their ability to communicate with others and themselves that contributes to their psychological difficulties. Thus, Ellis (1955) developed a form of psychotherapy called "rational-emotive therapy" (RET) (which contributed to the emergence of the CBT approach) based on the principle that an individual’s psychological disturbance is formed by their faulty pattern of thinking (Kalodner, 1995). In RET, the therapist seeks to change the faulty pattern of the client’s thinking, and the premises, assumptions and attitudes that underlie these cognitions (Meichenbaum, 1985). It is a phenomenologically orientated approach as it attempts to enter into the client’s worldview (Meichenbaum, 1985).

Beck (1976) also developed a form of cognitive therapy that, in opposition to psychoanalysis and behaviour therapy, focuses on the client’s thought processes (Kalodner, 1995; Meichenbaum, 1985). According to Beck, from as early as childhood negative thinking originates in attitudes (assumptions) (Hawton et al., 1991). These assumptions can serve either a positive or negative function in an individual’s life (Hawton et al., 1991). For example, the assumption "I must always do well at whatever I am doing" can perform a positive function by serving to motivate the individual. On the other hand, it can also serve negatively, if, for example, the individual took an examination and failed, which could lead to the production of negative automatic thoughts such as "I am an idiot", or "I am worthless." Such thoughts have the potential of negatively affecting one's mood, which increases the likelihood of the production of additional negative thoughts, leading to a vicious cycle which has the potential to sustain the depression (Hawton et al., 1991). However, Beck (1976) claimed that "people can be aware of the factors that are responsible for emotional upsets and blurred thinking" (as cited in Kalodner, 1995, p. 357) and that these aspects are not unconsciousness to them. In addition, while working with depressed patients, Beck (1976) deduced that radical behavioural explanation of human emotional disturbance was too limited to sufficiently explain the complexity of these difficulties (Kalodner, 1995). From this viewpoint, Beck (1976) considered that psychological disturbances might be the result of "faulty learning, making incorrect inferences on the basis of inadequate or incorrect information, and not distinguishing adequately between imagination and reality" (p. 19-20, Kalodner, 1995, 357).

Bandura (1977) developed the social learning theory, which asserts that cognitive processes intercede the development and maintenance of behaviour (Kalodner, 1995; Meichenbaum, 1985). Some examples of cognitive process include the manner in which an individual appraises situations, sets expectations, selectively recalls events, and engages in problem-solving routines (Kalodner, 1995; Meichenbaum, 1985). It is interesting to note that Bandura's social learning theory includes principles of classical conditioning as well as reinforcement, although the main focus is on "the role of cognitive factors in determining the environmental influence on behavior" (Kalodner, 1995, p. 357). Kalodner (1995) aptly highlights the essence of Bandura's theory with the statement that "he (Bandura) maintained an emphasis on behavioural procedures to change behaviour but developed the use of cognitive processes to explain the process of change" (p. 357). Some of the features of social learning theory are the following:

- A large portion of human learning takes place through what Bandura termed *observational learning*, that is, learning by observing others by means of imitating or modelling them. It is a type of learning which occurs when an individual had been influenced by the observation of another's conditioning (Hawton et al., 1991);

- Both the environment and the individual influence one another, that is, they are reciprocal. Bandura advocates that not only does the environment determine behaviour but that the individual can shape the environment, in that the way an individual acts can alter the environment. This is referred to as *reciprocal determinism* (Kalodner, 1995);
- Personal factors such as an individual's perception of self-efficacy can determine behaviour. *Self-efficacy* refers to an individual's belief in his/her ability to perform the behaviour in question to bring about an expected outcome (Hawton et al., 1991).

3.2.2 The birth of Cognitive Behaviour Therapy

The union between behaviour therapy and cognitive therapy gradually took place as it became increasingly recognised that both approaches had much merit and usefulness to theory and practice. As more behaviourists started becoming interested in thought processes, together with the increasing curiosity of cognitive therapists towards behaviourism, the birth of cognitive behaviour therapy slowly began.

The first goal of CBT is to help the client become aware of the multiple factors that have contributed to the emergence of psychological disturbance. This is achieved through an exploration of the meanings attached to events and situations in an individual's life and then by conducting a re-evaluation of these meanings (Grazebrook, Garland & the Board of BABCP, 2005). The purpose is to assist the client to acquire and utilise skills to deal with the problems he/she faces, by using his/her own resources (Grazebrook et al., 2005). This process of change is strengthened between sessions, as clients are instructed to apply what has been learned into practice by completing the "homework exercises" (Grazebrook et al., 2005). The overall aim, therefore, is for the client to gain a sense of improvement in his/her problems according to his/her own efforts while working together with the therapist or counsellor (Grazebrook et al., 2005). Thus, it is evident that this is a learning process that involves the collaboration of the therapist and the client to help the client discover his/her thoughts, feelings, and behaviours that contribute to the problems presented by the client (Meichenbaum, 1985). The therapist then aims to help the client take responsibility for the situation and the problem, and to see that he/she is in charge of changing it. This is done in two ways: the first involves helping the client to shift his/her thinking patterns for the purpose of beneficial change (the cognitive aspect) and the second involves helping the client to meet the challenges and opportunities of life with a clearer and more relaxed state of mind so that he/she can respond appropriately in a given situation (the behavioural aspect) (Bush, 2003; Grazebrook et al., 2005). In so doing, the therapist helps the client to overcome feelings of helplessness and hopelessness. The role of the therapist is that of a coach in helping the client develop and apply intra- and inter-personal skills that will enable him/her to handle stressful situations (Meichenbaum, 1985). Thus, CBT aims to equip individuals with the skills deemed necessary to deal with future problems and failures.

3.2.3 The process of change

The process of change is important to understand as it highlights the way in which the theory explains the means for counselling or therapeutic change (Kalodner, 1995). However, it must be mentioned that providing CBT to PLWHAs can be particularly challenging as the process of change may not be as successful as with other clinical populations (Church, 1998). This is because the internal reality of many PLWHAs is often in line with the objective reality of their stressful daily lives, which stems from their social reality (Church, 1998). For this reason, it is said that many of their cognitions/behaviours may actually be a true reflection of their lives, hence the term *depressive realism* (Church, 1998).

3.2.4 Self-efficacy

Cognitive Behaviour Therapy draws on Bandura's self-efficacy theory (1977) as an explanation for how people change. The term *self-efficacy* can be defined as the degree to which an individual performs specific behaviours in relation to the amount of success which those behaviours are expected to produce (Kalodner, 1995). These expectations in turn influence the individual's future decisions to attempt new behaviours and also to maintain changes in behaviour (Kalodner, 1995). Thus, CBT is built on the principle that if the self-efficacy of an individual is increased, then the degree of effort a person applies to a situation will also increase, thereby creating the possibility of an increased chance of the therapeutic intervention being a success (Kalodner, 1995).

According to Bandura (1986 as cited in Kalodner, 1995, p. 363), there are "four mechanisms through which self-efficacy can be developed: *Enactive attainments,* refer to an individual's own experience with achieving a goal. V*icarious experiences*, refer to observing others as they succeed or fail. Through the process of observing, individuals are provided with a basis for making comparisons with their own competence to perform the task. With v*erbal persuasion,* an individual is told "you can do it"... The final source of self-efficacy, *psychological states*, refers to the emotional arousal or degree of apprehension one feels" Lastly, it is said that all four of these sources of self-efficacy are involved in CBT interventions and that each of them plays a major role in helping the individual to learn that cognitions contribute to behaviour and affective disturbances (Kalodner, 1995).

3.2.5 Does changing beliefs change behaviour?

Theorists hold varied viewpoints regarding whether or not changing a person's beliefs can help in changing his/her behaviour. Although the link between changes in cognitions and their causal effect on behaviour has not been constructively defined, findings have shown that "counselling interventions that are based at least in part on cognitive-behavioural skills-building approaches have been effective in smoking cessation (Bruvold, 1993) cardiovascular risk reduction and weight loss" (Mullen, Mains & Velez, 1992) (Belcher & Kalichman, 1998, p. 856-857). In addition, interventions based on cognitive behavioural approaches with as few as one or two sessions of counselling (Belcher & Kalichman, 1998; Fleming et al., 1997, respectively) have been reported to demonstrate positive outcomes in reducing health-related behaviours.

The effectiveness of CBT has also been demonstrated by showing that a change in thoughts does indeed contribute to a reduction in psychological distress (e.g. Molassiotis et al., 2002). For these reasons, the present study has been based in part on CBT and in so doing attempts to bring about a change in the thoughts of adolescents and youth living with HIV/AIDS that may lead to a reduction in the level psychological distress experienced.

3.3 THE MULTIMODAL TRANSACTIONAL MODEL

The multimodal transactional model is an approach that stresses the importance of understanding the inter-relationship between the internal and external world of the individual (Palmer & Dryden, 1995). Although this model has been used extensively in stress management, it is also considered to be applicable to people living with HIV/AIDS. The multimodal transactional model emphasises that a person's reaction to an event or situation is a function of the perceptions that he/she holds of that event or situation and his/her perceived abilities rather than the event or situation itself (Palmer & Dryden, 1995). In other words, the event can act as a *trigger* to elicit a stress response in the individual but not necessarily that it initiated it. Some individuals may remain disturbed even after the event has passed, as result of the action or of the interaction of the different modalities (Palmer & Dryden, 1995). People living with HIV/AIDS are no different, as they are often confronted with difficulties relating to many modalities. These include the behavioural response, the cognitive response, the imaginal response, the interpersonal response, the biological response, the sensory response and the affective response.

According to this model, the following responses could be expected from a person (including a person living with HIV/AIDS):

- **Behaviour** - This includes alcohol or drug abuse, avoidance or phobias, sleep disturbances or insomnia, increased nicotine or caffeine intake, restlessness, loss of appetite, aggression or irritability, accident proneness, low productivity, withdrawing from relationships, increased absenteeism, decreased or increased sexual activity, frequent crying, unkempt appearance, poor eye contact, etc.

- **Cognitive –** Includes feelings of hopelessness, worthlessness and feelings of a lack of a future.

- **Imaginal –** Includes images of isolation or being alone, losing control, accidents or injury, failure, humiliation or shame or embarrassment, hopelessness, self and/or others dying or committing suicide, physical or sexual abuse, nightmares or distressing recurring dreams, visual flashbacks, poor self-image, etc.

- **Interpersonal** – Includes passive/aggressiveness in relationships, timidity or unassertiveness, having no friends, putting others' needs before one's own, sycophantic behaviour, being withdrawn, suspiciousness or secretiveness, manipulative tendencies, gossiping, etc.

- **Biological** – Includes the use of drugs or stimulants or alcohol or tranquilizers or hallucinogens, diarrhoea or constipation, frequent urination, high blood pressure, chronic fatigue, flu or common colds, lowered immune system, poor nutrition, poor exercise, poor recreation, organic problems, etc.

- **Sensational** – Includes tension, headaches, palpitations, rapid heart beat, nausea, aches or pains, dizziness or feeling faint, indigestion, limited sensual and sexual awareness, dry mouth, clammy hands, abdominal cramps, sensory flashbacks, etc.

- **Affective** – Includes emotions such as anxiety, depression, anger, guilt, hurt, morbid jealousy, shame or embarrassment, suicidal thoughts, etc.

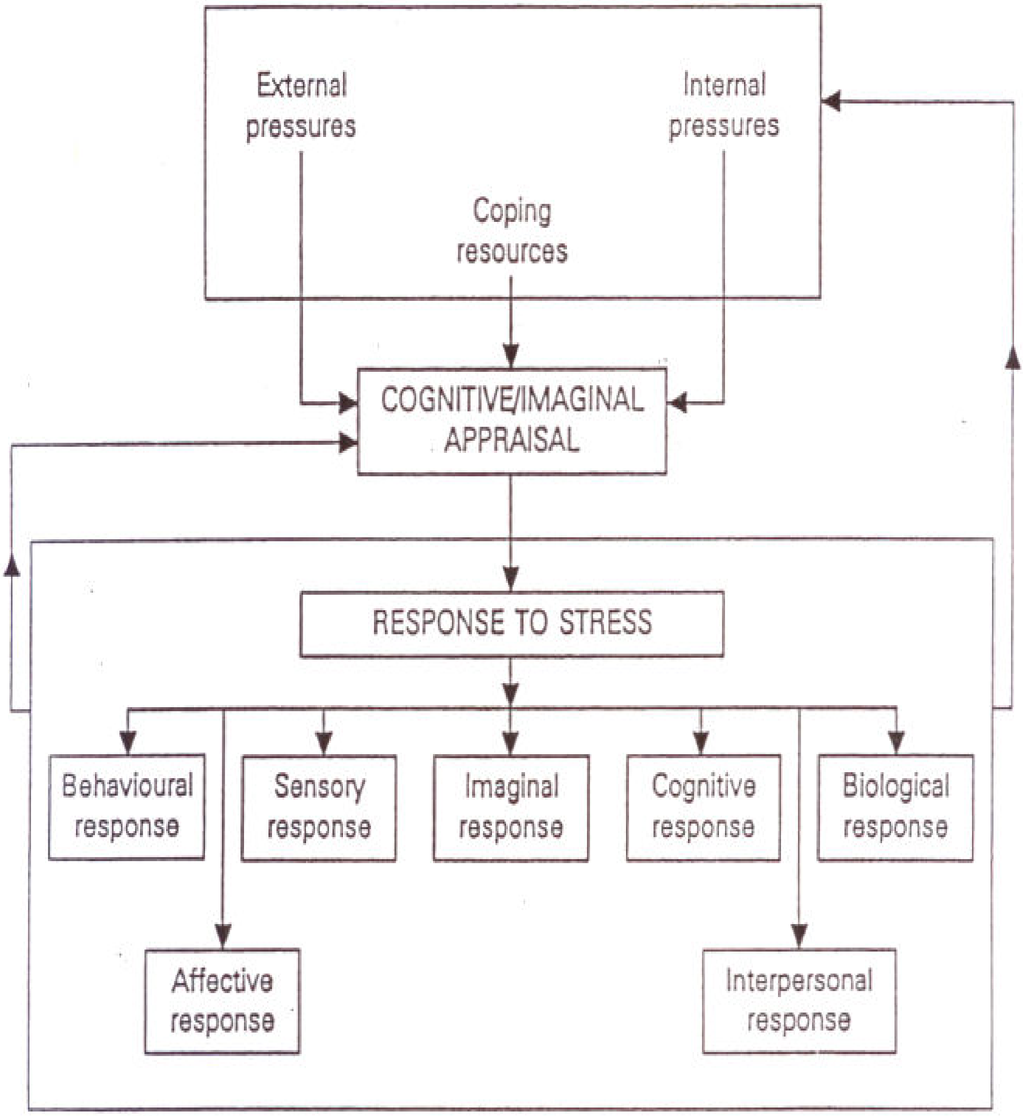


Figure 3: Multimodal Transactional Model of Stress (Palmer & Dryden, 1995)

What is important to note is that the multimodal transactional model emphasises that counsellors be aware of the various ways in which different modalities can interact with each other. Thus, counselling is not limited to one modality per session, but rather focuses on the whole person in relation to the possible array of difficulties. For example, an infected individual may become disturbed about a negative self-image, which may then lead to thoughts about it in the cognitive modality, and this in turn may elicit a response in the sensational modality. Thus, according to Palmer and

Dryden (1995), the modalities of an individual can be linked together to produce an emotional/affective response.

3.4 THE PEN-3 MODEL

The PEN-3 model was developed by Airhihenbuwa (1995) and allows programme developers of health-promotion programmes to address cultural sensitivity and cultural appropriateness in the development of a programme with a degree of flexibility. The PEN-3 model argues that health and cultural workers should try to address health issues at both the macro and micro level in the development of health interventions (Airhihenbuwa, 1995). Airhihenbuwa (1995, p. 29) further argues that "this method incorporates existing models/theories and frameworks in health education while drawing on theory and application in cultural studies", making it relevant for application in the current study.

According to Airhihenbuwa (1995), the PEN-3 model consists of three dimensions, each comprising three categories according to the model acronym (PEN) (refer to Figure 4).

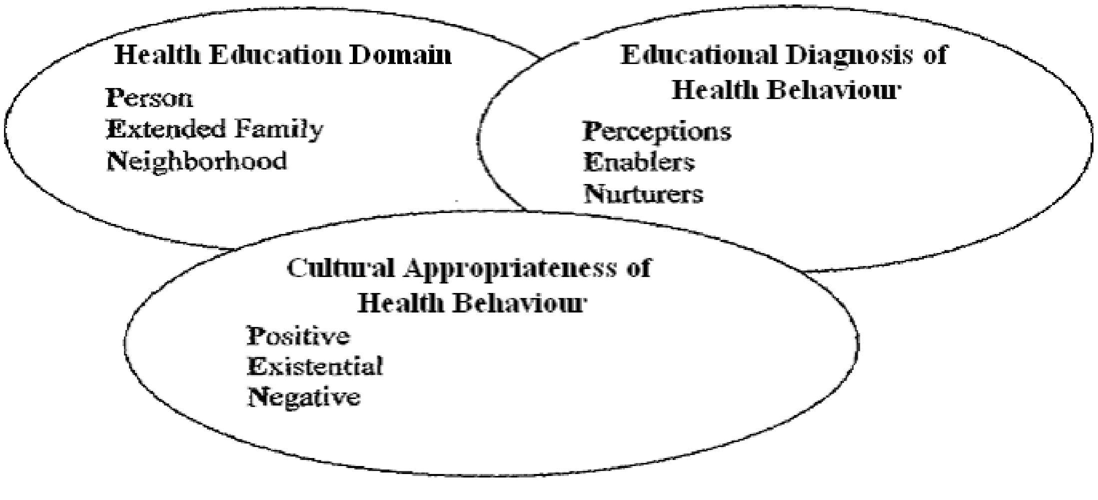


Figure 4: The PEN-3 Model (Airhihenbuwa, 1995, p. 34)

The first dimension is health education with three categories, namely the person, extended family and neighbourhood. A disease such as HIV/AIDS, for example, affects not only the infected person but also the family and neighbours (the significant others), and according to this model they too should be made part of health interventions.

The second dimension of the model is the educational diagnosis of health behaviour, which relates to the factors that influence individual, family, and/or community health actions (Airhihenbuwa, 1995). According to Airhihenbuwa (1995), this dimension evolved from the combination of three health-related models, namely, the Health Belief Model (Rosenstock, 1974), the Theory of Reasoned Action (Fishbein & Ajzen, 1975) and the PRECEDE framework (Mullen, Hersey & Iverson, 1987). However, it must be mentioned, that unlike the PEN-3 model, culture does not play a central role in the aforementioned theories. The role of culture therefore distinguishes the PEN-3 model from other models in the development of health-promotion programmes (Airhihenbuwa, 1995). The factors in this dimension are perceptions, enablers and nurturers (Airhihenbuwa, 1995). "Perceptions comprise the knowledge, attitudes, values and beliefs, within a cultural context, that may facilitate or hinder personal, family, and community motivation to change" (Airhihenbuwa, 1995, p. 31). For example, research has found that some South Africans believe that HIV/AIDS is caused by spirits, supernatural forces, ancestral retribution and/or witchcraft (*AIDS*-Weekly, 2001; HDNET, 1999). Shisana and Simbayi (2002) found that 4% of South Africans held the belief that AIDS is caused by witchcraft, followed by 14% who were unsure of this causal link. Such cultural beliefs, however, may have implications for HIV/AIDS counselling, as this in turn leads to a lack of interest in the use of HIV-preventative methods (Van Dyk, 2005). Enablers are defined by Airhihenbuwa (1995, p. 32) as "cultural, societal, systematic, or structural influences or forces that may enhance or be barriers to change, such as the availability of resources, accessibility, referrals, employers, government officials, skills and types of services (e.g. traditional medicine)". For example, the availability of resources is not the same in all communities in South Africa, especially in disadvantaged communities like Lusikisiki, which is an area that is severely under-resourced as compared to communities in the more developed parts of the country. *Nurturers* are another important factor; this term refers to "the degree to which health beliefs, attitudes and actions are influenced and mediated, or nurtured, by extended family, kin, friends, peers, and the community" (Airhihenbuwa, 1995, p. 32). In the case of an HIV/AIDS diagnosis, for example, the nurturance and support of the immediate and extended family are of extreme importance to the survival of the infected individual, and the manner in which these significant others react to the infected person during the various stages often determines his/her ability to manage and cope (Miller & Bor, 1988). However, research has found that because of the fear and prejudices associated with the disease, PLWHAs do not always receive the psychosocial support and nurturance they need from their significant others, and as a result find it difficult to care for the infected person (Batohi, 2004). Furthermore, Airhihenbuwa (1995) argues that the concept of nurturers highlights the importance of increasing the numbers of health professionals who have an understanding of and respect for traditional African beliefs and practices.

Cultural appropriateness of health behaviour is the third dimension of the PEN-3 model. According to Airhihenbuwa (1995), this dimension is crucial to the development of any programme that aims to be culturally sensitive. It "situates culture in dynamic and interacting forces that manifest themselves in individual, family, and community behaviour" and "consists of the categories of positive, existential, and negative behaviours" (Airhihenbuwa, 1995, p. 33). Positive behaviours are "behaviours that are based on health beliefs and actions that are known to be beneficial and must be encouraged" (Airhihenbuwa, 1995, p. 33). They are viewed by Airhihenbuwa (1995) as being vital to the success of the programme "because they are examples of these cultures' contributions to the global production of knowledge and meaning" (Airhihenbuwa, 1995, p. 33). "Existential behaviours comprise those cultural beliefs, practices, and/or behaviours that are indigenous to a group and have no harmful health consequences, and thus need not be targeted for change and should not be blamed for program failure simply because they are ill understood" (Airhihenbuwa, 1995, p. 34). For example, people should be allowed to make use of traditional practices in conjunction with Western practices for health purposes. This should not be viewed as detrimental to the success of the programme or as a possible reason for programme failure simply because it is misunderstood. What is needed is to match intervention/programme design to current health practices and perhaps to work in conjunction with both professional and non-professional health-care providers to bring about a meaningful intervention that shows understanding of existential beliefs and practices. Negative behaviours are defined by Airhihenbuwa (1995, p. 34) as "behaviours that are based on health beliefs and actions that are known to be harmful to health." In the case of adolescents, the tendency to deny the existence of a serious diagnosis such as HIV/AIDS and to continue to engage in unsafe sexual practices can be referred to as negative behaviour. According to Airhihenbuwa (1995), such beliefs need to be considered and recognised within their cultural contexts before attempting to change them. Airhihenbuwa (1995) points out that the process of understanding the beliefs, attitudes and practices of the target group from a cultural perspective does not assume that the target group is powerless and ignorant. He argues that the process accepts the diversity of people and the way in which they create their realities. Finally, it can be said that the PEN-3 model allows programme developers to approach the conceptualisation of HIV/AIDS models from a psychological point of view that is applicable to specific communities.

3.5 THE DEVELOPMENTAL TASKS DURING ADOLESCENCE

There are a number of developmental tasks that are involved in the transition from childhood to adulthood as individuals gain more freedom and responsibility in the various areas of life. The following paragraphs give a brief explanation of the developmental tasks (Havighurst, 1972) that are seen as important for an adolescent to complete.

3.5.1 Acceptance of a changed physical appearance

Puberty is said to be characteristic of extensive physical growth and sexual maturity commencing at the ages of 12 and 13 in boys and 10 and 11 in girls (Havighurst, 1972). Initiated by the secretion of male and female hormones (androgen and oestrogen) the sudden weight increase or the development of breasts for girls and the lowering of voices for boys, amongst other changes in both genders, is often a difficult task for many adolescents to accept (Louw, Van Ede & Louw, 1998). In addition, societal expectations of youth complicate this phase with the norms and pressures that exist in different cultures (Louw et al., 1998). The structure and content of adolescence vary from culture to culture, each reflecting its own social and institutional patterns. For example, young girls in Western cultures often try to adapt to the slenderness norm while some in the process develop health risks such as eating disorders (Havighurst, 1972; Louw et al., 1998; Schulenberg, Maggs & Hurrelmann, 1997). In the Zulu culture, on the other hand, young girls are encouraged to gain weight to "fit in" with their norm (Louw et al., 1998). However, the developmental task in both cultures is for adolescents to accept their changing bodies and to learn to use them effectively.

This phase is also marked by the discovery of one’s sexual orientation (i.e. heterosexual or homosexual). For many, this is a difficult developmental task as they have to satisfy their own sexual needs and at the same time ensure that they do so in a socially acceptable way (Van Dyk, 2005). Adolescents, although curious about sex, often fail to ask questions for fear of being embarrassed if they appear to be unaware (Davidson, 1988). This is why Van Dyk (2005) says that it is more beneficial to start sex education during early adolescence as young adolescents do not feel as embarrassed to talk about sex as older adolescents do.

3.5.2 Development of a masculine or feminine gender-role identity

The development of a masculine or feminine gender-role identity was in previous years associated with the sex-roles adopted by others in society (Manaster, 1977). In other words, adolescents were expected to develop their sex-roles in accordance with their gender and what was the norm (Havighurst, 1972). While there are a number of people who accept these sex-roles, research has shown that times have changed and many individuals do not follow these normative roles (Crockett, 1997; Manaster, 1977). People are now able to decide for themselves whether to adopt a conception of oneself as a man or a woman, which is sometimes a difficult choice for the growing adolescent to make. According to Manaster (1977), the decision one makes in this developmental task can also influence the nature of other tasks to come.

3.5.3 Development of cognitive skills and the acquisition of knowledge

Cognitive development is said to be less obvious than physical changes as it involves the ability to comprehend, to analyse, to reason logically and to think about abstract possibilities (Beyth-Moram & Fischhoff, 1997; Louw et al., 1998). Cognitive development, therefore, allows for the differentiation between fantasy and reality, and between theory and evidence. The development of abstract thinking gives adolescents the ability to think in abstract terms, to examine hypotheses, to think about the future and the possibilities it holds, and to plan ahead (hypothetical thinking) (Van Dyk, 2005). Utilising this information in the development of health messages may prove to be valuable, as it would make more sense to focus on the *immediate* risks or benefits of behaviour for younger adolescents (who are still developing in this regard) and to concentrate on *future* consequences or benefits of present behaviour choices for older adolescents. This in turn, helps adolescents further develop cognitively as they learn to make good decisions based on rational thought (Van Dyk, 2005). Gradually adolescents develop the skills of scientific thinking and they are able to draw distinctions between theory and evidence.

3.5.4 Development of an own identity

Identity formation is recognised as a key task during the development of adolescence (Havighurst, 1972). Development of one's identity takes place in the young person as a result of the other significant changes that are taking place, forcing him/her to question his/her world view, and to go through a period of exploring, examining and integrating his/her abilities, interests, and opportunities to form an achieved identity (Louw et al., 1998; Phinney & Kohatsu, 1997). Thus, the integration of these developments is acknowledged as important to the formation of an identity. Steinberg (1999 as cited in Van Dyk, 2005, p. 167) describes the development of identity during adolescence in the following manner: "Before adolescence the child's identity is like pieces of a puzzle scattered about the table. Both cognitive development and social situations encountered during adolescence push individuals to combine puzzle pieces – to reflect on their place in society, on the way others view them, and on their options for the future"

3.5.5 Development of independence from parents and other adults

The development of independence on the part of the adolescent is a difficult task for both the parents and the adolescent (Havighurst, 1972). This is because this task involves the assimilation of two polar opposites, that is, separation and connectedness. Separation is defined "in terms of behaviours that express a psychological sense of distinctiveness from parents" (Galambos & Ehrenberg, 1997, p. 143) and connectedness is identified as "behaviours that demonstrate sensitivity, responsiveness, and openness to the views of others" (Grotevant & Cooper, 1985 as cited in Galambos & Ehrenberg, 1997, p. 143). Separation is thought to allow the adolescent to grow into a unique person, to go out into the world and to make his/her own decisions, while connectedness helps the adolescent stay close to family members for support, guidance and encouragement. While both separation and connectedness have their benefits for the adolescent, too much of one or the other will create difficulties in the development of the young person (Havighurst, 1972). According to Manaster (1977), equilibrium needs to be found that allows for "give-and-take" between the parents and the adolescent, and for both parties to be satisfied.

3.5.6 Selection and preparation for a career

Planning and organising are two important goals that need to be achieved for the preparation of a career (Havighurst, 1972). Schooling offers adolescents the opportunity to fulfil these goals as they begin to learn what they are good at, and also what they want to do in the future (Havighurst, 1972). Adolescents need to feel that the choice they make is entirely their own decision based on what they are good at and what they think they can do best (Manaster, 1977). Part-time work during vacations and on weekends has also been shown to be of benefit to adolescents as they are introduced into the working world and as opportunities are created for growth and development, on which they can base their decisions for future career options (Havighurst, 1972; Finch & Mortimer, 1997).

3.5.7 Development of socially responsible behaviour

The development of socially responsible behaviour in adolescents is influenced largely by the society's influence on the adolescent, by the interaction of parents and adolescents, and by the way in which parents lay down the rules governing behaviour (Havighurst, 1972). According to Havighurst (1972), it is important for there to be both sacrifice and reward. Some sacrifice on the part of the adolescent will be warranted in order for him/her to develop a social ideology that is in accordance with the values of his/her society. At the same time, the adolescent must also be rewarded in terms of social approval and by being given the privileges of an adult. The concept of *monitoring* is also important during this process. It refers to "the parent's knowledge of what the adolescent is doing, where the adolescent is, and with whom he/she is doing it" (Galambos & Ehrenberg, 1997, p. 144). Through the appropriate level of monitoring, adolescents are given the opportunity to explore friendships and the environment, and gain personal autonomy (or separation) from parents (Galambos & Ehrenberg, 1997). Too little monitoring on the part of the parent can allow the adolescent too much freedom and hence increase his/her likelihood of making the wrong choices. On the other hand, too much monitoring can also be detrimental to the development of the adolescent as it is viewed by the adolescent as controlling and intrusive rather than guiding (Galambos & Ehrenberg, 1997).

3.5.8 Acceptance of and adjustment to certain groups

Peer groups are an important part of the development of adolescence as they provide a safe place for the young person to explore and to be him/herself. Peer groups also create a feeling of acceptance and of belonging that eases the transition from childhood to adulthood (Louw et al., 1998). They are said to contribute to the personal image and reputation of young people, and can contribute to health behaviours (Brown, Dolcini & Leventhal, 1997). However, it is also known that peer-group relationships can produce peer pressure in both young and older adolescents, but more so for younger adolescents as they are more concerned about being accepted as part of a group. They have also not yet fully developed their self-confidence and independence, and therefore seek the guidance of the group in making their choices.

While such conformity to the group can have some beneficial outcomes for the young adolescent, it can also impact negatively on his/her identity development. Research has shown that group norms can influence the extent to which the adolescent engages in health-promoting or health-compromising behaviours such as high-risk and/or early sexual behaviour, smoking, alcohol or drug abuse etc. (Brown et al., 1997; Van Dyk, 2005). However, according to Brown et al. (1997), these peer influences can be moderated by family, community and school norms.

3.5.9 Establishment of heterosexual relationships

The development of romantic relationships is seen as a healthy development and is encouraged and nurtured by parents through mixed-party dances, school sponsor dances and through the media of images of "teenagers in love" (Brown et al., 1997). The benefits of romantic relationships include the following: the development of independence and identity formation; opportunities for companionship; acquiring communication skills; acquiring interactional and social skills (Louw et al., 1998). However, research has also shown that some adolescents become preoccupied with romantic relationships, making them engage in health-compromising behaviours such as sexual intercourse at an early age, leading to unplanned pregnancies, early marriages, and the risk of acquiring HIV/AIDS (Brown et al., 1997).

3.5.10 Development of a strong emotional bond with another person

A strong emotional bond can develop with a friend, a romantic partner, or a parent or other family member. Any one of these or any combination of these could elicit a strong emotional bond. Such bonds serve the purpose of helping the adolescent develop his/her emotional attachments to other people and to not be restricted to him/herself (Louw et al., 1998).

3.5.11 Preparation for marriage and other family responsibilities

This developmental task is said to define the transition of late adolescence to young adulthood. It involves a commitment to new roles and responsibilities including that of new living arrangements and new friends and acquaintances, as well as situations that may elicit new behaviours and attitudes (Bachman et al., 1997). Beyth-Moram and Fischhoff (1997) add that as the young adult begins to identify more with these adult roles, he/she may also invest more in meeting the norms and expectations of society. It is also important to note that this task would become difficult if the developmental tasks of the achievement of satisfactory relations with persons of the opposite sex and that of emotional independence of parents had not been successfully achieved. The period of adolescence is thus said to be a period during which one prepares the foundations for marriage and other family relationships.

3.5.12 Achievement of financial independence

The movement towards financial independence begins during one's adolescent years as one begins to gradually learn how to manage one's money. For adolescents it also means learning the value attached to money and about the freedom it can bring. Parents, teachers and community members alike encourage young people to take on part-time employment over weekends and/or during the week after school, so as to begin working toward this goal (Havighurst, 1972). This is because it is from these experiences that an adolescent learns to manage his/her own finances and learn what it means to be financially independent.

3.4.13 Development of moral concepts and values that could serve as guidelines for behaviour

The development of moral concepts and values stems from the values of one's parents, peers and community, as well as the values of the ethical system of the religious organisation that one belongs to. However, conflict begins in other life situations areas when the adolescent chooses the values and moral concepts of his/her friends over those of his/her parents. This is because, as adolescents experiment with different ideologies, they confront conflicts between their behaviour and what is expected of them from others in terms of life tasks (Manaster, 1977). It is only once they are able to think in abstract terms and are able to differentiate between the perspectives and opinions of others and their own, that they will be able to develop more maturely on issues of moral standing (Van Dyk, 2005).

3.4.14 Development of a value system based on a realistic and scientific world-view and the development of a philosophy of life

In order for an adolescent to develop his/her own personal value system, he/she is required to evaluate his/her existing values to see if they are acceptable, and then decide on the values to incorporate into his/her personal value system.

In addition to the above brief explanation of the tasks that are involved in the development of an adolescent, it is important to mention that these developmental tasks may not be fully accomplished by an adolescent who has been diagnosed as HIV positive as he/she may now have the added responsibility of taking care of his/her health, together with the added dilemma of adjustment, and fears about the future that the diagnosis brings. The young person may not know how to cope with the knowledge of having a fatal disease and may, therefore, find it difficult to manage emotions such as anger, rejection, isolation, depression and so forth. Adolescents may also find it difficult to socialise with other young people of their own age.

Thus, it is important for these and other psychological issues to be focused on in counselling sessions to help the HIV-positive adolescent adjust to these feelings and other emotions.

3.6 KÜBLER-ROSS' FIVE STAGE MODEL OF THE PSYCHOLOGICAL PROCESS OF DYING

The five stage model of Kübler-Ross (1969) discusses the various emotions and psychological reactions that a person goes through when facing death and dying. These five interrelated stages can also be applied to a young person infected with HIV or AIDS as he/she goes through the stages of the illness. This section discusses the five stages of death and dying in relation to some of the specific counselling needs of HIV-infected individuals and their affected loved ones. These emotional responses are, according to Van Dyk (2001), an important component in counselling a person with HIV/AIDS. This is because a positive diagnosis of HIV can evoke severe emotional responses, not only for the infected individual but also for his/her significant others, throughout the stages of the illness. Counsellors, therefore, need to be aware of these responses to effectively help the individual manage his/her life and live "positively" beyond the diagnosis.

The five stages are those of: denial, anger, bargaining, depression, and acceptance, although they do not necessarily follow the same order of occurrence (Gormly, 1997). They may last for different periods of time, may be experienced more than once, replace each other, or exist together. According to Kübler-Ross (1997), the process of death and dying is no different for the individual infected with HIV/AIDS as compared to people with other illness, except that persons with AIDS have the added burden of having to deal with the social consequences of bearing this "dreaded disease."

- **Denial**

Numbness or shock is usually the typical reaction to a terminal illness, and marks the first stage of the dying process as seen by Kübler-Ross. The person may assert that the doctor and the diagnosis were wrong, and/or try to deny the existence of the situation (Gormly, 1997). Some deny their HIV status because they show no symptoms and seem perfectly healthy. For many who are given the life-shattering news at a relatively young age, it is very difficult to accept the fact they are living with a life-threatening illness that will lead to their eventual death (Van Dyk, 2005). Research has shown that adolescents, for example, have a tendency to deny the existence of a serious diagnosis such as HIV/AIDS and to continue engaging in unsafe sexual practices (Johnson et al., 2003) as a result of their denial.

Turner and Helms (1995) believe that denial is a healthy way of dealing with the pain caused by the situation for a temporary period of time. This is because it allows the patient time to mobilise other defences and re-collect their thoughts tp serve as a buffer against shocking unexpected news. Denial, therefore, according to Kelly and St. Lawrence (1988) has a self-protective function in the short term because it reduces the chances of emotional distress, although in the long term it may have the danger of preventing the person from reducing his/her risky behaviour to avoid further HIV transmission and/or of becoming infected by a more virulent HIV virus (Kelly & St. Lawrence, 1988). According to Van Dyk (2005, p.239), "in the case of HIV-positive people it is especially difficult to distinguish between a healthy sense of hope (e.g. that a cure of effective treatment for AIDS may be found) and a systematic denial or refusal to accept that they will eventually die." However, as the disease progresses, other reactions begin to take over, and denial becomes difficult to maintain.

- **Anger**

During the second phase denial may be replaced by anger, rage, resentment and envy. Infected adolescents may be angry for many reasons including the following: they may be fearful of the progression of the virus to the full-blown phase of AIDS and may not know what to expect or what will be expected of them; they may worry about the social consequences of becoming infected with a socially unaccepted disease and/or they worry that there is no cure for their disease (Kelly & St. Lawrence, 1988). All these concerns (and others) may contribute to people's self-directed anger as they start to regret and blame themselves for failing to make behaviour and life-style changes that would have prevented them from becoming infected (Kelly & St. Lawrence, 1988). The young person may turn to maladaptive coping habits such as excessive drinking and/or drug abuse as a means to escape from the psychological distress caused by the disease (Kelly & St. Lawrence, 1988). In addition, these maladaptive habits have further consequences for the individual as they begin to weaken the functioning of the immune system.

Adolescents may act out in anger as they are likely to see their diagnosis as interfering with their relationships and with their social life, especially with regard to their ability to attract a girlfriend/boyfriend. Being sick and having to stay away from school, for example, may elicit anger in the adolescent, as this time spent at home may be viewed as restricting or as a possible deterrent to his/her social standing, especially with regard to peer groups. The adolescent may also be concerned about physical attractiveness, especially when he/she becomes ill, and worry about how this may interfere with forming relationships. This may lead to feelings of a low self-esteem, embarrassment, withdrawal and acting-out behaviours. The need to gain independence from parents may also be compromised as a result of their deteriorating health, which may make them more dependent on their parents and may elicit feelings of anger and ambivalence.

It is also not uncommon for the person to direct his/her anger towards the environment, family members, medical staff and all those closest to him/her (Van Dyk, 2005). There are also people who find difficulty in venting their anger, and hence try to deny or suppress it (Van Dyk, 2005). For this reason, it is important during this stage for patients to be heard and felt for, and for the family and medical staff to understand how and why such anger originates and in so doing to empathise with the dying patient (Turner & Helms, 1995). In the case of the patient who has suppressed his/her anger it is the role of the counsellor to help the person identify the anger and to express it in counselling sessions.

- **Bargaining**

Bargaining is the third phase of the dying process and is evident in older children, adolescents, adults, family members and often health-care professionals. This stage involves the change in attitude of the infected individual as he/she now begin to hope that death can be postponed or delayed in some way (Diessner & Tiegs, 2001). It is often a difficult time for family members, especially when they have adolescents and youth with HIV/AIDS. For the adolescent, bargaining may include a wish for an extension of life or for a few days without pain. They may ask for one special day just to feel young and normal again, perhaps a day spent with peers, away from adults and doctors and hospitals, in an attempt to postpone death for a while. The bargaining may include a promise that the he/she will not ask for anything else if this one postponement is granted.

However, the bargaining stage is said not to last for too long and is gradually replaced by a mixture of anger, frustration, exhaustion and *depression* (Kübler-Ross, 1997).

- **Depression**

During the fourth stage, it becomes apparent to the patient that he/she cannot deny the existence of the illness any longer as more symptoms are developing. This leads to the experience of a great sense of loss for the patient. Symptoms of depression include: common obsessive thoughts regarding the contamination of the disease and the unfairness of the situation; guilt about past behaviour and life-style; sadness; hopelessness; withdrawal; isolation; lethargy; etc. Suicidal ideation is also said to be common among individuals living with HIV/AIDS (Cooperman & Simoni, 2005; Judd & Mijch, 1996). There may also be reactive and participatory depression. Reactive depression relates to past issues and can be dealt with by reassurance, hope and encouragement (Van Dyk, 2005). Participatory depression relates to future loss, and can be dealt with by expressing sorrow.

Because the experience of dying from HIV/AIDS is different from other more "acceptable" diseases, this stage is somewhat different for the HIV/AIDS-infected individual. This is because many people with HIV/AIDS find it difficult to talk to others about their illness and about their feelings because of the large degree of stigma attached to the disease. This may be especially difficult for the young person as he/she may have a limited number of contacts to discuss his/her feelings with, who are aware of the diagnosis. Because of this they have to grieve through this period by themselves, and often do not find much compassion and empathy from others, even though they desperately need to be welcomed and accepted. In cases such as these, it is important that counsellors should refer clients to support groups where they can share their pain with others who are likely to understand (Van Dyk, 2005). Personal hardships such as financial problems, loss of employment and physical problems are also ripe during this stage of the illness. For the adolescent, depression may set in as a result of the a loss of physical attractiveness or a change in body image which may result in a self-imposed restriction in socialising, or a loss of friends on account of their physical appearance. For this reason, Turner and Helms (1995) urge family members, friends and medical staff to allow the patient the opportunity to express his/her sorrow, and to offer nurturance and support.

- **Acceptance**

Acceptance is the final phase of the dying process. Most terminally ill patients at this stage have been given enough time to work through the previous stages, and have been given the opportunity to mourn their losses and reach the expectation of death. It is a time devoid of feelings, in which the patient is not resigned or hopeless, but is removing him/herself from the world. However, as mentioned earlier, the situation is different for AIDS patients as they find themselves in a position where they may not have not had enough time to work through the previous stages and mourn their losses. For many, this last stage still holds many painful emotions as they have not had the opportunity to successfully adjust to the illness. This may be the case for the young person living with HIV/AIDS who may feel robbed of time to live a full life and to enjoy his/her growing up years. Owing to the uncertainty about the future, he/she may choose to break off a relationship with a partner in an attempt to spare the loved one the pain associated with death. This may also serve in the acceptance of the final stage of the illness. According to Van Dyk (2005), for a person living with HIV/AIDS to successfully adjust to the disease, he/she needs to reassess his/her loss, such that one does not focus solely on the negative aspects of the loss but also on the possible positive aspects of the loss. For example, if the adolescent or youth got involved as a volunteer/peer counsellor at his/her local clinic and started to educate young other people about the disease and the preventative options available to them, he/she might make a difference in the lives of others. He/she might begin to live life positively and in so doing begin to enjoy his/her life. Following Bowlby (1977), for people with HIV/AIDS the completion of this task requires that they recognise that the circumstances of their lives have changed, and that it is necessary for them to re-evaluate their goals in life.

As a final point, Kübler-Ross (1997) has said that AIDS patients can experience this stage in the process of death and dying, as with any other terminally ill patient.

She said (1997, p.10): *"If they* (AIDS patients) *receive and give themselves enough permission to express their anguish and their tears, their sense of impotence against a vicious killer virus and against a society that discriminates, judges, blames, and viciously enjoys the 'fruit of these patients' unhealthy life-styles'; if they have enough* *of a support system with people who simply love and accept them and give them the natural nurturing that all human beings need, especially when they are sick , then, and then only, will they develop the stage of peace and serenity that makes the transition we call death a quiet slipping over into another form of existence."*

Kübler-Ross's theory has important significance for the HIV/AIDS illness as it helps health-care professionals and family members better understand the psychological processes involved in the different stages of the illness. This theory has much merit as it suggests ways in which all those involved in the caring process can be more alert to the needs of those facing death, and in so doing help maintain their quality of life.

3.7 ERIKSON'S THEORY OF PSYCHOSOCIAL DEVELOPMENT

According to Erikson, there are two developmental crises faced by an individual between the ages of 18 and 24 years; they are *identity versus role confusion* and *intimacy versus isolation.*

The words *identity* and *role confusion* are meant to be two opposing poles used to describe the situation an adolescent will encounter during this developmental phase and must solve. This developmental situation is thus termed a *crisis* and the solution of the crisis is termed a *synthesis* (a combination of the two opposite poles) (Erikson, 1968). During the process of identity development an adolescent goes through what is called a temporary period of confusion, during which he/she engages in extensive exploration and experimentation of his/her existing values, and also of other roles so as to form his/her own set of values and goals (Erikson, 1968). This in turn leads to the formation of his/her own philosophy of life. Other challenges the adolescent faces during the development of identity are the following: *ego- synthesis,* where the individual recognises that he/she is still the same person regardless of time or changes; *gender-role identity,* which requires the adolescent to accept his/her identity as male or female; and *career identity*, requiring the individual to take a realistic stance in making the decision to choose a career by being aware of his/her abilities and achievements in realistic terms (Erikson, 1968). The successful completion of these challenges allows the adolescent to establish self-confidence and also allows him/her the opportunity to know who he/she is and what he/she wants from life.

However, this process is not simple, and often results in adolescents being indecisive about themselves and their roles (role confusion). They lack self-confidence and are unable to make decisions regarding various roles and value systems, which in turn causes feelings of anxiety and also those of apathy or hostility toward roles or values (Erikson, 1968). Because of the difficulties experienced during this period, adolescents are said to be given a certain amount of freedom by society, which allows them to find their identity. This is sometimes commonly referred to as "tolerance" or, as Erikson (1968) calls it, *psychosocial moratorium.*

According to Erikson (1968), intimacy versus isolation is the first crisis of young adulthood and is seen as the next phase of development. *Intimacy* refers to "the ability to experience an open, supportive, tender relationship with another person, without fear of losing one's own identity in the process of growing close" (Newman & Newman, 1979, p. 371). Marriage is usually a good example within which the context of intimacy is formed, but the marital relationship does not always imply intimacy. According to Newman and Newman (1979), there are three factors that can potentially disrupt the formation of intimacy within a marriage. These are:

(1) the adjustment period of early marriage
(2) the arrival of the first-born
(3) the expectations of family members.

The marital bond is not the only relationship within which personal commitments of an enduring nature can be formed. Some people, for example, never formally commit by ceremony while others choose to remain committed to a celibate life (Gross, 1987). In other cases, long friendships lead to marriage which is why it is said that "mature friendship is built on the same foundation as marriage" (Gross, 1987, p. 50). Personal commitments such as marriage and friendship all lead to the formation of intimacy, which, according to Erikson (1987), is the opposite of isolation. However, it must be mentioned that isolation can also occur in a partnership, as isolation does not only refer to physical isolation but can also refer to keeping things from each other, in other words, not sharing one’s innermost thoughts. Thus, isolation can also serve to keep people at bay or from getting to know one another better.

Because of the difference in the patterns of socialisation, men and women may attribute different meanings to the development of intimacy and may consequently experience different problems relating to the formation of intimate relationships (Bernard, 1971 as cited in Newman & Newman, 1979). Boys, for example, are taught from a young age to suppress their emotions and to be less dependent. Hence, the establishment of intimacy during this stage may be difficult for men to meet because the tendency of young men "is to resist intimate interdependent relationships" (Newman & Newman, 1979, p. 373). If, however, the young man successfully completes this stage, the establishment of an interpersonal relationship may create a safe and protective environment in which he can freely express his emotions.

Women, on the other hand, are more emotionally equipped to establish an intimate relationship (Newman & Newman, 1979). This is because, from a young age, girls tend to be rewarded for expressing their emotions and for being nurturing and compassionate. However, according to Newman and Newman (1979), women may also have tendencies to be too dependent, and may rely too heavily on their husbands for reassurance; this points to the reason why Erikson made the statement that "women in our society frequently fuse the crisis of identity with that of intimacy" (as cited in Gross, 1987, p. 51).

For some, the concept of intimacy with another person threatens their self-identity; hence they do not allow many people to get close to them, in an effort to keep their sense of self intact. This fragile self-identity results from unresolved past crises. This is why it is said that "the stage of intimacy is sometimes merged with the stage before it or the one after" (Gross, 1987, p. 50). Erikson (1968) is of the opinion that both intimacy and isolation go hand-in-hand, as one cannot have intimacy without the risk of isolation. One has to take a chance to achieve intimacy.

Erikson’s theory of psychosocial development has contributed extensively towards understanding the identity development that takes place during the adolescent years, and lends much importance to this study. This is because having knowledge of the development of identity and the confusion that it brings with it, can help one better understand the complexity of such issues and thus can help one to better understand the behaviour of adolescents.

However, in spite of its usefulness, it must be noted that many critics have mentioned shortcomings of this theory. These include the fact that the terms used by Erikson have created some confusion regarding its meaning. For example, the term *crisis* or *identity crisis* is said to give the impression of an intense traumatic experience when this may not always be the case (Louw et al., 1998). The other problem with the term *crisis* is that it indicates that identity development takes place at a specific point in time during the adolescent’s life, as opposed to taking place throughout adolescence and also extending into adulthood. Hence, the preference given many researchers in recent times to the term *exploration* (Louw et al., 1998).

In addition, Erikson's view is that the identity developmental crisis occurs during early adolescence and terminates or is resolved around the age of 15 or 18 years of age. Yet research has shown that this is not the case, but that that this developmental crisis takes place for many adolescents during late adolescence, and that only 20% of adolescents are sure of their identity at the age of 18 (Meilman, 1979, as cited in Louw et al., 1998).

Other researchers suggest that identity formation does not to have to take place in all areas of the adolescent’s life at one time, but rather that it can take place at different times, with certain areas being stronger than others (Louw et al., 1998).
One critic of the intimacy verses isolation stage pertains to Erikson’s viewpoint that intimacy and sexual promiscuity are unrelated. Given the fact that many people around the world have had "intimacies without intimacy" (Gross, 1987, p. 53) and without the intention of commitment, which Erikson implies is paramount to this stage, it is argued that "lists of promiscuous 'intimacies', no matter how long, don’t add up to Intimacy; generally, they are classic examples of Isolation" (Gross, 1987, p. 53) which could in turn have serious consequences with regard to HIV and AIDS.

3.8 ELKIND’S THEORY: UNDERSTANDING THE YOUNG ADOLESCENT

Elkind and Weiner (1978a), based on the work of Piaget, wrote about the affective as well as the cognitive domain involved in understanding the young adolescent. These are important concepts because they help one to understand the motives behind behaviours that may otherwise be thought of as troublesome. The following is a discussion of the intellectual processes that bring about such behaviours.

- **Pseudostupidity**

The term *pseudostupidity* refers to the tendency of adolescents (at times) to interpret situations in a more complex manner than is required (Elkind, 1978c). This type of behaviour is said to derive from what Piaget calls *formal operations* in that the adolescent can envisage many ideas at one time including opposing ideas, and can also comprehend both similes and metaphors (Elkind, 1978c). Adolescents' ability to achieve this type of comprehension indicates that they are in fact not stupid, but rather that they are "too bright" in spite of their appearing to be less than bright or stupid (Elkind, 1978c).

- **Intellectual Egocentrism**

The term *intellectual egocentrism* refers to the adolescent’s inability to distinguish clearly between what he/she is thinking and what others are thinking (Elkind & Weiner, 1978a). Elkind (1978b) attributes this inability to the extensive physical and mental growth that has taken place in a short period of time in the adolescent’s life, and argues that as a result of this, adolescents become obsessed with their own bodies and minds. In addition, because they are unable as yet to differentiate between "the subjective content of their own thoughts and the objective content of others, they assume that others are as interested and observant of them as they are of themselves" (Elkind, 1978b, p. 122). An example given by Elkind (1978a, p. 551) is as follows: "In social situations, young adolescents feel as if they are on stage, and assume that everyone else is watching and evaluating their performance. Thus, the term *imaginary audience* for which the young adolescent is always performing."

- **The Imaginary Audience**

The imaginary audience enables the young person to think about what other people are thinking, but at the same time he/she is unable to distinguish between what is of interest to others and what is of interest to him/her. Thus, all the changes that occur within the adolescent are felt (by the adolescent) to be of concern and to be noticed by everyone else. For this reason, Elkind (1978c) says that adolescents have an imaginary audience that watches their every move in terms of behaviour and appearance, and that as a result of this they become very self-conscious. An example given by Elkind and Weiner (1978a) is that of the adolescent who spends long periods of time standing before a mirror. Elkind’s explanation for this is that the young people are "imagining how the audience will react to them" (1978a, p. 551). The development of self-consciousness is not the only consequence of the existence of the imaginary audience. It can be the ground for a range of other behaviours based on the reaction of the imagined audience (Elkind, 1978b). Some examples include working out at the gym, playing sports, or taking up music (Elkind, 1978b). The young person may also "have fantasies of performing before an audience as a concert pianist, a pop singer, or a star football player" (Elkind, 1978b, p. 123). Elkind (1978b) says that the reason the imaginary audience is so important at this age is that the young person needs approval from the outside world because he/she does not have as yet a wealth of past experience from which to draw upon self-approval and support.

- **The Personal Fable**

According to Elkind (1978c), the *personal fable* is that type of behaviour that often appears as destructive to the individual. For example, adolescent girls who get pregnant often think that others will get pregnant but not they themselves. This is an important concept as it lends insight into the reason adolescents may engage in risky sexual behaviour, for example, thinking that others can get infected with the HIV virus but not they. They believe that they are special and that no harm can come their way. However, it must be noted that the personal fable works together with other forces to bring about the resulting behaviour, and that the personal fable is not solely responsible for it (Elkind, 1978b).

According to Elkind (1978c), the personal fable is a feature of all people, manifests in childhood and also enters into adulthood although to a lesser degree. However, for the child and the adult, Elkind (1978c) says that the personal fable is in the background while for the adolescent it is at the forefront. Elkind (1978c) adds that in such circumstances as the young person believing that he/she is unique or special to others, or even the reverse, that his/her personal preoccupation is common to everyone. The only help that one can offer the young person is accept his/her reality for what it is and to encourage him/her to check this reality against that held by others. As a consequence of the personal fable, adolescents may feel lonely because of their feeling of being special and apart from others. The personal fable, according to Elkind & Weiner (1978a) is said to diminish with growth.

- **Apparent Hypocrisy**

According to Elkind (1978c) adolescents often acquire a hypocritical stance in that what they say is not always congruent with what they do. This is another area that can lend insight into the behaviour of the young person who, for example, is often knowledgeable about the use of contraception and may assert that he/she will use it but fails to do so when confronted with the opportunity. Elkind (1978c) says that adolescents are often unable to make the connection between principles of behaviour and examples that are linked to them. Thus, despite having been told to use contraceptives, the young person as a result of a lack of experience, fails to see its relevance to behaviour and the consequences thereof. The personal fable applies here too, as the young person holds the view that rules apply to others and not to him/herself. However, as pointed out by Elkind (1978c), one must remember that such behaviour is a result of the intellectual immaturity of the adolescent and not a result of defects in his/her moral character.

This theory has much importance for those who work closely with young people as it demonstrates that the behaviours many young people employ, which adults regard as "bad" or "destructive" are not in fact always a result of their negative attitude, but can be as a result of their intellectual immaturity. If one understands these developments that take place during adolescence, one will be in a better position to understand their subsequent behaviour.

However, given the relevance of this theory for understanding the behaviour of adolescents who engage in risky sexual behaviour, it must be noted that there is much debate by critics regarding the theoretical grounding of the constructs involved in Elkind's theory. For example, there are said to be at least three operational definitions of the imaginary audience and the personal fable, and that as a result of this, the actual existence of the imaginary audience and the personal fable has been questioned by some critics (Lerner, 1988). In addition, some have argued that empirical research does not support the theory. For example, while Elkind (1978) contends that the imaginary audience and personal fable will diminish with age, some research studies have found greater levels of these ideations among older adolescents (Adams & Jones, 1981; Peterson & Roscoe, 1991).

3.9 CONCLUSION

This chapter has explained the development of an adolescent from the perspective of various theorists and has highlighted the relevance of these theories and models that serve as the foundation of the counselling model that has been developed in this study. For example, by drawing on CBT as one of the fundamental tenets of the counselling model, this study has attempted to bring about a change in the thoughts of adolescents and youth living with HIV/AIDS that would lead to a reduction in the level of psychological distress experienced. Applying the Multimodal Transactional Model to the development of the counselling model has highlighted the different modalities and how they can interact with one another to produce an emotional/affective response. It has also highlighted the difficulties in completing the developmental tasks of adolescence while adjusting to the chronic illness of HIV/AIDS at such a young age. The next chapter focuses on the methodology employed in the collection and analysis of data.

CHAPTER 4

METHODOLOGY

4.1 INTRODUCTION

This chapter discusses the methodology used in the collection and analysis of data. Information pertaining to the setting, the design, the sample and sampling procedure, research instruments and the procedure, are outlined first. Thereafter, information is presented on the collection of data. Data collection was divided into three phases. Phase 1 involved the development of the counselling model, phase 2 involved the implementation of the counselling model, and phase 3 involved the evaluation of the counselling model. Following this, the analysis of data and the ethical considerations are discussed.

4.2 SETTING

The study aims to cover the area of Lusikisiki which is located in the O.R. Tambo District Municipal Area in the Eastern Cape. This area is made up of four local municipalities, each composed of a number of towns. Lusikisiki forms part of the local municipality of Mbizana. The sample was drawn from two sites in Lusikisiki, namely Goso Forest Primary Health Care Clinic and The Village Primary Health Care Clinic. These two sites were chosen because data for the needs assessment phase of the study was gathered from Goso Forest Primary Health Care Clinic as well as The Village Primary Health Care Clinic, Palmerton Primary Health Care Clinic and St. Elizabeth’s Hospital. Goso Forest Primary Health Care Clinic and The Village Primary Health Care Clinic were both chosen to be part of the present study because they were seen as more accessible areas to adolescents and youth living with HIV/AIDS and because they had a higher patient-load compared to the Palmerton Primary Health Care Clinic.

The reason that the Eastern Cape was chosen as the principal site for this study is that many areas (particularly rural areas) in the Eastern Cape have been referred to as areas of deepening poverty. It is within such contexts of poverty that the HIV/AIDS virus is said to flourish and to deprive families and communities of young people at their most productive years (Freudenthal, 2001). Lusikisiki is no different to other rural areas in the Eastern Cape in that many of its people live under conditions of extreme poverty. Unemployment levels are very high, forcing people to find jobs in other areas. Both migrant workers and poverty contribute to the spread of HIV in Lusikisiki. Prevalence rates in Lusikisiki are said to range from 25% to 83% among those who attend the different voluntary counselling and test sites in the area (Beresford, 2004).

The Eastern Cape, which has a population of 6 302 525 people (with 65% of its population living in rural areas) is said to be one of the poorest and least-resourced areas in the country (Sipuka, Mayekiso & Nyambali, 2002). While most areas in South Africa have access to piped water, only 62.4% of households in the Eastern Cape are said to have access to this necessity (Bradshaw & Nannan, 2004). Proper sanitation facilities are also limited in this area, with only 30% of its household population having access to sanitation (Bradshaw & Nannan, 2004). The lack of these basic necessities consequently makes rural areas in the Eastern Cape particularly vulnerable to infectious diseases such as HIV/AIDS. Education, which plays an important role in promoting healthy sexual behaviours, is also of major concern for the province. This is because 22.8% of people aged 20 years and over in the Eastern Cape have no formal education (Bradshaw & Nannan, 2004). In addition, because many of these areas are under-developed with limited access to transportation facilities, as well as limited access to adequate health-care facilities, residents have no other option but to travel long distances in order to seek assistance from what has been termed a "fragile healthcare infrastructure" (Medecins Sans Frontieres, 2003).

The other reason why the Eastern Cape has been chosen for this research, is that very few studies have been conducted in this area on the provision of adequate care and support services to address the health and social needs of people (including adolescence and youth) infected and affected by HIV/AIDS (Dickson-Tetteh &

Ladha, 2000). Among the limited research available, a study conducted by Mango (2004) found that, although there were various psychological services for PLWHAs and their communities in existence in Lusikisiki, no mention was made of any specific counselling services to address the needs of adolescents and youth living with HIV/AIDS. According to Dickson-Tetteh and Ladha (2000), this is an important area because in order to effectively help these members of society, the knowledge of what they need in terms of prevention, care and support, is of vital importance. Without such knowledge, very little can be done to avoid making these members of society feel abandoned by the health-care profession.

4.3 RESEARCH DESIGN

The chosen design of this study involves both qualitative and quantitative research approaches and makes use of the research technique of triangulation, which employs multiple data collection strategies in the study of the same phenomenon (Patton, 1987). The design forms part of the qualitative research domain as it aims to provide greater insight into the needs and concerns of adolescents and youth so as to develop a counselling model that meets these needs. The qualitative approach is appropriate and relevant to this research as "it is concerned with the meanings people attach to their experiences of the social world and how people make sense of that world" (Pope & Mays, 2000, p. 3). Qualitative research is also said to be particularly useful in the health-care setting as it offers health-care professionals and others working in this arena, the opportunity to understand the complexity of human interaction and how people interpret this interaction, before attempting to quantify such behaviours and events (Pope & Mays, 2000; MacPhail & Campbell, 1999; Wigersma, Singh, & Van den Boom, 1998). "In contrast, quantitative studies emphasize the measurement and analysis of causal relationships between variables, not processes. Inquiry is purported to be within a value-free framework" (Denzin & Lincoln, 1998, p.8). The quantitative research approach is advantageous to the study because it allows for the evaluation of the counselling model and enables the researcher to draw statistical conclusions from the results obtained.

The term *action research* (which forms part of the qualitative research approach) is said to involve two main criteria, that of action (change or improvement) and research (knowledge, understanding), both of which can be achieved simultaneously through a flexible spiral process. What makes action research appropriate for the present study is that action research aims to empower people to confront the dominant power-holding and control elements of society by constructing and using their own knowledge. In so doing, it aims to produce knowledge and action that can be used by those individuals.

In action research, the researcher is encouraged to actively participate in group processes and to learn from them. Thus, it is referred to as *learning by doing* (Huizer, 1989). According to Bhana (1999), action research is a method for developing understanding of a community's existing ways of understanding itself, and for developing new ways of understanding and new strategies of problem-solving based on this knowledge. Another reason that adds to the appropriateness of this design is that in action research participants play an extensive role throughout the research, making it a collaborative process between the researcher and participants. The application of action research has also been widely encouraged in rural areas as it takes into account the knowledge people have about their own environment and about the problems that commonly exist within these environments (Huizer, 1989).

In this design there is a continual recycling or spiral set of activities that are followed by action researchers. These are as follows (Susman, 1983 as cited in Naidoo, 1997, p. 142-143):

1. **Diagnosing** – involves identifying the problem. Working hypotheses are generated which guide the researcher towards which facts should be collected.
2. **Action Planning and Action Taking** – involves considering alternative courses of action for solving the problem at hand, selecting the course of action, and then implementing it.
3. **Evaluating and Specifying Learning** – involves studying the consequences of an action and thereafter identifying general findings.

The design of the study falls within quasi-experimental research design, and is termed specifically a *Pretest-Posttest Non Equivalent Untreated Comparison Group design*. Such a design involves the manipulation of independent variables, or treatments (in the case of the present study, a counselling model) by consideration of the effects of these independent variables on participants' performance on certain outcome measures (e.g. cognitive and behavioural outcomes) (Rosenthal & Rosnow, 1991). It employs a control or a comparison group in order for comparisons to be made between and/or within groups under investigation. However, comparison does not take place based on the performance of groups formed by random assignment. In other words, Pretest-Posttest Non Equivalent Untreated Comparison Group designs lack the feature of random assignment, as it is often unfeasible or unethical to randomly assign people to treatment groups (Rosenthal & Rosnow, 1991). It is also used in situations where the experimental treatment is administered to intact groups receiving treatment (e.g. people already receiving treatment from clinics they attend).

One of the strengths of quasi-experimental designs is that they are flexible and can be used in many applied settings. According to Kelinger (1973, 1986) quasi-experimental designs can be referred to as *compromise designs* because additional features can be added to the design to strengthen it and to help overcome its threats to internal validity. One such additional feature that the present study includes is the exploration of the effects of history as a possible deterrent to the internal validity of the study. This was conducted during the final post-test assessment whereby the effects of history (i.e. the possibility of the influence of some particular event or circumstance on the behaviour of subjects or their performance in the experimental or control group) were determined.

4.4 SAMPLE AND SAMPLING PROCEDURE

All participants were sampled using non-probability, purposive sampling techniques. *Non-probability sampling* refers to a sample that is composed of the first units that are available (Rosnow & Rosenthal, 1991) and *purposive sampling* refers to a sample that is formed based on the judgement of the researcher. In purposive sampling, individuals are sampled based on the notion that they are likely to possess useful information for the purposes of the study. One of the disadvantages of purposive sampling is that it does not allow for random sampling, therefore all persons in a given category are not given an equal chance of being sampled. Using this sampling procedure, participants were sampled for each of the three phases of the study.

4.4.1 The sample for phase 1

The sample for phase 1 comprised 16 service providers (from both Goso Forest Primary Health Care Clinic and the Village Primary health Care Clinic) who provide services to adolescents and youth living with HIV/AIDS, as well as one adolescent living with HIV/AIDS. The demographic features of the service providers are presented below.

The information presented in the table below describes the breakdown of the professions of the service providers from the two clinics.

Table 2: Distribution of the sample of service providers by profession/ designation (n = 16)

Profession	**Frequency**
Professional nurse	6
Trained counsellor	4
Nursing assistant	4
Lay counsellor	2
Total	**16**

From Table 2, it can be seen that a total of 10 service providers were professional service providers while 6 were non-professional service providers.

4.4.2 The sample for phase 2

The sample for phase 2 comprised 8 service providers (from Goso Forest Primary Health Care Clinic) who provided services to adolescents and youth living with HIV/AIDS; 40 adolescents and youth living with HIV/AIDS who were sampled from Goso Forest Primary Health Care Clinic to serve as the experimental group; and 38 adolescents and youth living with HIV/AIDS who were sampled from the Village Primary health Care Clinic to serve as the control group. Seventy-six participants remained throughout the study and completed all four assessments. An attrition rate of 3% of the total sample was found in this study as two subjects withdrew from the experimental group. The reasons for withdrawal were as follows: relocated to Durban (one subject) and the death of one subject after the first assessment. Ultimately, both samples comprised 38 participants each. The biographical details of the sample of service providers as well as the sample of adolescents and youth that comprised both the experimental and control groups are presented the subsections below.

4.4.2.1 Biographical information of service providers

The following table presents the biographical information of service providers from Goso Forest Primary Health Care Clinic.

Table 3: Biographical information of service providers (n =8) from Goso Forest Primary Health Care Clinic

Gender	**Frequency**
Male	4
Female	4
Total	**8**
Profession	**Frequency**
Professional nurse	1
Trained counsellor	2
Nursing assistant	1
Staff Nurse	1
Lay counsellor	**3**
Total	**8**
Experience in HIV management (years)	**Frequency**
Less than 1 year	3
1 – 3 years	5
Total	**8**

From Table 3, it can be seen that the sample was equally represented by both males (n = 4) and females (n = 4). Two of the service providers were trained counsellors while three were lay counsellors, and their experience in relation to HIV management ranged from less than one year to three years. The majority of the sample (n = 5) indicated that they had between one and three years of experience in HIV management.

4.4.2.2 Biographical information of adolescents and youth living with HIV who comprised the experimental and control groups

A biographical questionnaire was developed that included five questions pertaining to gender, age, education, occupation and living arrangements (refer to Appendix L).

The following table presents the age of the adolescents and youth who comprised the experimental and control groups.

Table 4: Age of adolescents and youth comprising the experimental (n = 38) and control groups (n = 38)

Group	Mean	Standard Deviation	Minimum	Maximum
Experimental	22.2	2.0	18	24
Control	22.3	2.1	18	24

According to Table 4, all adolescents and youth included in the present study were between the ages of 18 and 24 years. The experimental group had a mean of 22.2 and a standard deviation of 2.0 while the control group had a mean of 22.3 and a standard deviation of 2.1.

The results of the t-test conducted showed that there was no significant difference in the age of participants in the experimental and control groups ($\underline{t}$ = -0.05, $\underline{df}$ = 74, $\underline{p}$ = 0.957).

The next table presents the biographical information of the experimental and control groups with regard to gender, education, occupation, and living arrangements.

Table 5: Biographical information of adolescents and youth living with HIV who comprised the experimental (n = 38) and control (n = 38) groups

Gender	**Group** **Experimental** **(Frequency)**	 **Control** **(Frequency)**
Male	7	8
Female	31	30
Total	**38**	**38**
Education		
Grade 3 and below	2	15
Grade 4 – Grade 7	16	4
Grade 8– Grade 11	20	17
Grade 12	0	2
Total	**38**	**38**
Occupation		
Unemployed	31	37
Student	2	1
Labourer	2	0
Cook	1	0
Shelf-packer	1	0
Shepherd boy	1	0
Total	**38**	**38**
Living Arrangement		
Living with relatives	23	11
Living with relatives and children	31	37
Living alone	2	1
Living with children	2	0
Living with spouse and children	1	0
Living with spouse, children and relatives	1	0
Living with partner, children and relatives	1	0
Total	**38**	**38**

From Table 5, it can be seen that the majority of participants in both samples were female. Their levels of education ranged from Grade 3 and below, to Grade 12, with most participants of both the experimental and control groups having completed between a Grade 8 and Grade 11 level of education. The majority of both the samples were unemployed (i.e. n = 31 and n = 37 of the experimental and control groups, respectively). With regard to their living arrangements, the table shows that the majority of the experimental group lived with their relatives (n = 23) while the majority of the control group lived with their relatives and children (n = 21).

4.4.3 The sample for phase 3

The sample for phase 3 of the study consisted of the same 38 adolescents and youth living with HIV/AIDS from Goso Forest Primary Health Care Clinic who served as the experimental group, and the same 38 adolescents and youth living with HIV/AIDS from the Village Primary Health Care Clinic who served as the control group.

4.5 Research Instruments

The following research instruments were used to gather data to test the hypotheses.

4.5.1 The General Health Questionnaire-28

The General Health Questionnaire (GHQ) is a self-report screening instrument that was designed to detect "potential cases" of a psychiatric disorder in community or non-psychiatric clinical settings (Goldberg, 1972; Goldberg & Hillier, 1979). In other words, it was not designed to identify "actual cases" of psychiatric disorder, but rather to be used as a screening device that suggests the likely presence of a psychiatric disorder (Goldberg, 1972). Specifically, the GHQ assesses two main classes of phenomena: "inability to carry out one’s normal ‘healthy’ functions, and the appearance of new phenomena of a distressing nature" (Goldberg & Hillier, 1979, p. 139). It is, therefore, said to focus "on breaks in normal functioning rather than on lifelong traits" (Goldberg & Williams, 1991, p. 5).

There are four versions of the GHQ: a 60-item, a 30-item, a 28-item and a 12-item version. The 28-item version or "the scaled version of the GHQ" was the chosen version for the present study as it was "intended for studies in which an investigator requires more information than is provided by a single severity score" (Goldberg & Hillier, 1979, p. 143). The GHQ-28 provides an overall severity score of psychological health as well as four scores relative to its four 7-item subscales: Somatic Symptoms (Scale A) Anxiety and Insomnia (Scale B) Social Dysfunction (Scale C) and Severe Depression (Scale D). Each item enquires whether the person has recently experienced a particular symptom such as abnormal feelings and thoughts, and/or aspects of observable behaviour (Goldberg, 1972). Item emphasis is on the individual's changes in condition, that is, one's present state in comparison to one's usual state (Goldberg, 1972). An example of an item from the questionnaire is as follows:

Have you recently:

Been feeling perfectly well and in good health?	Better than usual	Same as usual	Worse than usual	Much worse than usual

The literature indicates that there are two scoring methods for the GHQ:

The *GHQ Method* uses a bimodal response scale and rates each problem as either present or absent, ignoring frequency. Responses are coded 0-0-1-1 and are totalled to arrive at a *GHQ score*. This method is usually used for case identification (i.e. above a predetermined cut-off score) where the GHQ-scores are then compared to other reference groups in order to distinguish between normal and case scores (Banks et al., 1980).

The *Likert Method* uses a four-point response scale where weights of 0-1-2-3 are assigned to each position (i.e. *better than usual, same as usual, worse than usual, much worse than usual,* respectively). The severity score is a sum of the four subscales.

According to Goldberg and Williams (1991), the GHQ method focuses only on the number of symptoms and is therefore referred to as an *area measure* while the Likert method considers both area and intensity and is referred to as a *composite measure.*

For this reason, if subscale scores are required, the Likert method is advised (Goldberg & Williams, 1991). In addition, in comparison to the GHQ method, the Likert method is said to produce a less skewed score distribution (Goldberg & Williams, 1991). For these reasons, in the present study, the Likert method was used.

4.5.1.1 Reliability and validity of the GHQ-28

The GHQ-28 was demonstrated to have good internal consistency; split-half coefficients ranged from 0.78 to 0.95 for all versions (Goldman et al., 2000). A test-retest reliability study of the GHQ-28 was undertaken by Robinson and Price (1982) in which the questionnaire was administered to patients who had had strokes eight months apart. The findings were a test-retest coefficient of $\underline{r} = 0.90$. Goldberg (1972) reported a reliability coefficient of $\underline{r} = 0.58$ for Likert scaling.

According to Goldberg and Williams (1991), the GHQ possesses adequate content validity, in that each test item has been shown to be highly discriminating between respondents who are psychologically distressed and those who are not.

The construct validity of the questionnaire is best supported by factor analytic studies (Goldberg & Hillier, 1979). Goldberg and Hillier (1979) studied the original factor structure of the 60-item GHQ and used this as the basis for the development of the scaled version of the GHQ. Through the subsequent factor analysis, four significant factors emerged which accounted for 59% of the variance. Since one general factor (severity of psychological illness) accounted for 35% of the variance, the authors pointed out that "the various scales will not be pure measures of the 4 factors" (p. 140) but that some overlap does in fact exist. Thus, the scales are not independent of each other; correlations range from 0.33 to 0.58.

Although the GHQ was not intended to possess predictive validity (as it is a measure of state rather than trait) some evidence has been found that suggests minimal predictive validity. In some studies (Ballinger, Smith & Hobbs, 1985; Goldmeier & Johnson, 1982; Hughes, 1982 as cited in Goldberg & Williams, 1991) GHQ scores were found to predict future medical problems and associated distress.

The GHQ-28 has demonstrated high levels of concurrent validity against established external validity criteria such as the Present State Examination (PSE) and the Clinical Interview Schedule (CIS). Goldberg and Hillier (1979) found that the total severity score from the GHQ-28 correlated well with the CIS ($r = 0.76$). In addition, a correlation coefficient of $r = 0.74$ was found between the GHQ Likert scores and PSE total scores (Banks, 1983). All versions of the GHQ were found to have acceptable sensitivity (proportion of correctly identified cases) and specificity (proportion of normal persons correctly identified) (Goldberg & Williams, 1991; Goldman et al., 2000).

The GHQ was originally designed for use in London and thus was intended to be culture-specific to Londoners. However, much to the surprise of the author (Goldberg), the GHQ was found to work "almost as well" with respondents from other cultures as it did with Londoners, in that the validity coefficients did not differ considerably. Some may argue that the high validity coefficients are a reflection of certain common characteristics of psychological illness that exist in many diverse settings. For example, Goldberg and Williams (1991) argue that "symptoms such as being unable to sleep because of worry, feeling under strain, being unable to concentrate and feeling unable to face-up to one's problems would appear to be common to the human condition, rather than specific to Londoners" (p. 5). However, it must be noted that Goldberg and Williams (1991) point out that attention should be paid to "culturally relevant ways of expressing distress" when screening for psychological illness (p.5). It is reported that the GHQ has been translated into at least 36 languages (Goldman et al., 2000) and that over 50 validity studies have been conducted (Goldberg & Williams, 1991).

The GHQ-28 has been used in previous studies conducted in South Africa, including research with people living with HIV/AIDS (Dageid & Duckert, 2007). However, information regarding its reliability and validity is not widely available. The GHQ-28 has been used in the current study to measure the levels of depression, anxiety, social dysfunction, and somatic symptoms experienced by adolescents and youth living with HIV/AIDS.

Cronbach alpha coefficients were calculated to assess the reliability (internal consistency) of GHQ-28 as used in this study. Table 6 presents the Cronbach Alpha Coefficients of each of the four subscales, namely, *somatic symptoms, anxiety and insomnia, social dysfunction* and *severe depression* at the four assessment trials, that is, T1 (pre-intervention) T2 (immediately post-intervention) T3 (1-month follow-up) and T4 (3-month follow-up).

Table 6: Cronbach alpha coefficients of each subscale of the GHQ-28 between T1 and T4 with the experimental (n = 38) and control (n = 38) groups

	Pre-intervention (T1)		**Immediately Post-intervention (T2)**		**1-month follow-up (T3)**		**3-month follow-up (T4)**	
	Experimental group	**Control group**	**Experimental group**	**Control group**	**Experimental group**	**Control group**	**Experimental group**	**Control group**
Sub-scales	**Standard-ised**	**Standard-ised**	**Standard-ised**	**Standard-ised**	**Standard-ised**	**Standard-ised**	**Standard-ised**	**Standard-ised**
Somatic symptoms	0.61	0.89	0.90	0.90	0.85	0.78	0.71	0.75
Anxiety and Insomnia	0.68	0.89	0.90	0.92	0.88	0.61	0.76	0.60
Social Dysfunction	0.69	0.92	0.93	0.90	0.92	0.85	0.77	0.80
Severe Depression	0.86	0.85	0.94	0.89	0.89	0.78	0.86	0.69

Note: All subscales have 7 items

From Table 6, it can be seen that majority of the Cronbach alpha coefficients for the various subscales were found to be acceptable across the four assessment trials. However, there were some instances in which the Cronbach alpha coefficients were found to be below the acceptable level of between 0.7 and 0.9. Among the experimental group these were found at T1 for the somatic symptoms, anxiety and insomnia and social dysfunction subscales, and among the control group these occurred at T3 and T4 for the anxiety and insomnia subscale. Hence some variation in alpha coefficients was indicated from trial to trial. However, it is important to note that the GHQ-28 is not an invariant measure and that it is inevitable for changes to occur over time.

4.5.2 The Revised BDI

The Beck Depression Inventory (BDI) is a self-report measure that is structured to include graded levels of intensity of each of the 21 symptoms it comprises (McDowell & Newell, 1996). The revised BDI (which is the version used in the present study) asks the respondent to rate him/herself for the *past week, including today,* whereas in the original version respondents were asked to assess themselves *right now*. As such, the revised version assesses *trait* depression as opposed to the original version which assesses *state* depression (Beck & Steer, 1993). The present study administered the BDI orally, following the instructions given in the manual for oral administration. An example following these instructions together with one of the items of the BDI is given below:

> This questionnaire consists of 21 groups of statements. After I read each group of statements, I want you to pick out the one statement in each group which *best* describes the way you have been feeling during the *past week, including today*.
>
> 1 (A) I do not feel sad.
> (B) I feel sad.
> (C) I am sad all the time and I can't snap out of it.
> (D) I am so sad or unhappy that I can't stand it.

Symptoms are rated on a 4-point scale ranging from 0-3 in terms of intensity. Total scores are arrived at by adding each individual score to give a total ranging from 0 to 63; higher scores represent more severe depression (Dozois & Dobson, 2002). According to the revised BDI manual (1993), scores of 0-9 indicate *Minimal* depression; scores between 10 and 16 are referred to as *Mild;* scores of 17-29 indicate *Moderate* depression; and scores of 30-63 are classified as *Severe* depression.

4.5.2.1 Reliability and validity of the Revised BDI

The revised BDI has been shown to possess high internal consistency in both clinical and non-clinical populations. For example, in six normative-outpatient samples, Cronbach's alpha coefficients ranged from 0.86 to 0.88 (Beck & Steer, 1993). These results have been shown to be consistent with the alpha coefficients reported in other studies. For example, in a meta-analysis with nine psychiatric samples, Beck, Steer and Garbin (1988) reported alpha coefficients ranging from 0.76 to 0.95 with a mean of 0.86, and in 15 non-psychiatric samples, alpha coefficients ranged from 0.73 to 0.92 with a mean of 0.81. Beck et al. (1988) reviewed 10 studies that administered the BDI at varying time intervals (pre-test and post-test administrations) in an effort to determine the reliability of the test. For psychiatric patients, Pearson correlations between administrations ranged from 0.48 to 0.86, and for the nine studies of non-psychiatric patients, Pearson correlations ranged from 0.60 and 0.90 (Beck et al., 1988).

In terms of content validity, the content of the revised BDI was compared against the criteria of the *Diagnostic and Statistical Manual on Mental Disorders, 3rd Edition* (DSM-III) affective disorder, and was found to cover six of the nine DSM-III criteria directly, two partially (appetite and sleep) and one (agitation) was found to be omitted (Moran & Lambert, 1983). For example, the test asks about decreases in appetite but fails to inquire about appetite increases that may be experienced by some depressed persons. With respect to sleep changes, the test asks the respondent about sleep disturbance but fails to enquire whether the respondent has been sleeping significantly more than usual. However, as the manual points out, these omissions were intentional, as previous research (upon which the test was developed) found that these symptoms were frequently found in normal persons and that inclusion of such symptoms was likely to produce a high rate of false positives (Beck & Steer, 1993). The manual (1993) also states that the symptom of agitation "was excluded because it was not considered appropriate for a self-report instrument" (p. 12).

Although the BDI was not designed with the intention of being able to discriminate "among patients with different psychiatric diagnoses" (Beck & Steer, 1993, p. 12), some evidence has been found that suggests that the BDI possesses discriminant validity. For example, it has been found that the BDI can differentiate between psychiatric and normal patients, and also that it is able to discriminate between groups that differ in levels of depression (Steer, Beck & Garrison, 1986 as cited in Beck & Steer, 1993).

There have been a number of concurrent validation studies that have been conducted between the revised BDI and other ratings of depression (Dozois & Dobson, 2002).

Beck et al. (1988) reported 14 studies that showed correlations between the revised BDI and clinical ratings of depression; coefficients ranged from 0.55 to 0.96 with a mean of 0.72 for psychiatric patients, and from 0.55 to 0.73 with a mean of 0.60 for non-psychiatric patients.

The factorial validity of the instrument was examined by Tanaka and Huba (1984) and Clark, Cavanaugh and Gibbons (1983 as cited in Beck & Steer, 1993), who found that the BDI contains one underlying factor which can be divided into three interrelated factors. The three factors represent *cognitive-affective, performance* and *somatic disturbance* (Beck & Steer, 1993).

Although there is limited information regarding the reliability and validity of the BDI for use in the South African context, one study with a sample of 104 South African adolescents has shown the BDI to have acceptable reliability and good internal consistency (Ward et al., 2003). All items reportedly had "fair" kappa scores with a Cronbach's alpha of 0.86. However, it must be mentioned that these results are not widely generalisable as the study was limited by its small sample size that was not specifically representative of the broader South African population (Ward et al., 2003).

The BDI was used in the current study to measure the levels of depression experienced by adolescents and youth living with HIV/AIDS.

Cronbach alpha coefficients were calculated to assess the reliability (internal consistency) of BDI as used in the current study. Table 6 presents the Cronbach alpha coefficients at each of the four assessment trials, that is, between T1 and T4.

Table 7: Cronbach alpha coefficients of the BDI between T1 and T4 with the experimental (n = 38) and control (n = 38) groups

Group	**Pre-intervention (T1)**	**Immediately Post-intervention (T2)**	**1-month follow-up (T3)**	**3-month follow-up (T4)**
Experimental	0.88	0.91	0.87	0.90
Control	0.94	0.92	0.89	0.86

According to Table 7, the BDI demonstrates an alpha of 0.88 with the experimental group at pre-intervention which increased to 0.90 at the 3-month follow-up. It is interesting to note that immediately post-intervention (T2) the alpha coefficient increased to 0.91 and declined at the next assessment interval to 0.87. In terms of the control group, the alpha coefficient of the BDI was highest at pre-intervention (0.94) and showed decreases across the subsequent assessment trials.

4.6 PROCEDURE

The researcher first sought the permission of the Head of Department of the Eastern Cape Department of Health to conduct the study. Thereafter, both clinics (Goso Forest Primary Health Care Clinic and The Village Primary Health Care Clinic) were contacted telephonically and verbal consent from the professional Nurses in Charge of the clinics was obtained.

The research procedure followed three phases. The first phase involved the development of the counselling model, which consisted of a number of steps. These were a needs assessment (Batohi, 2004), a literature review, and the incorporation of the chosen theoretical framework to guide the research. Once the counselling model was drafted, the next step involved the presentation of the model to the service providers (from both the primary health-care clinics) in the form of focus group discussions. The aims and procedure of the study were explained to the service providers, and caution was taken to ensure that all participants were made aware of their ethical rights. Subject information sheets were given to the service providers, and informed consent forms were signed and collected. Based on the qualitative information received during the focus group discussions, the counselling model was modified accordingly. Following this, a pilot study was conducted, in which one client received three counselling sessions based on the counselling model. The model was then further refined based on the results of the pilot study.

The second phase of the research procedure involved the implementation of the counselling model. This consisted of a training workshop during which service providers from Goso Forest Primary Health Care Clinic were trained in the use of the counselling model. In addition, four fieldworkers were trained in the research protocol and design, which included the research process of sampling and selection, in order to select participants to be included in the experimental and control groups. Ethical procedures were discussed and fieldworkers were trained on the informed consent procedure to be followed. Two fieldworkers were assigned to each clinic (i.e. Goso Forest Primary Health Care Clinic and The Village Primary Health Care Clinic). The two fieldworkers who were assigned to work at Goso Forest Primary Health Care Clinic were each instructed to select a sample 20 participants to be included in the experimental group (i.e. individuals to receive counselling based on the counselling model) based on selection criteria. Similarly, the two fieldworkers who were to work at The Village Primary Health Care Clinic were trained to each select a sample of 20 participants to serve as the control group. In other words, the experimental group was to be made up of a total of 40 adolescents and youth living with HIV/AIDS who met the selection criteria (i.e. they had been diagnosed within less than a month, and were between the ages of 18 and 24). The control group was also to be comprised of 40 adolescents and youth living with HIV/AIDS who had similar characteristics to the experimental group. Allowances were made for a 10% drop-out rate. Details of the actual attrition rate found in this study, as well as the final samples selected, are presented in section 4.4 (sample and sampling procedure).

Following the selection of participants to be included in the experimental and control groups, the pre-intervention assessment was conducted with all participants in order to gather the baseline data. Instruments used to gather data included the Beck Depression Inventory (BDI) and the General Health Questionnaire-28 (GHQ-28) that were administered during both the implementation and evaluation phases so as to gather data for the pre-intervention assessment and the post-intervention assessments respectively. The counselling model was implemented for a period of six months at Goso Forest Primary Health Care Clinic and was monitored throughout. The control group received routine counselling in the form of a weekly support group facilitated by MSF counsellors. This weekly support group consisted of approximately 30 people who had either been recently diagnosed or who had been diagnosed for a long period of time.

The third phase entailed the evaluation of the counselling model. This was achieved through a series of post-intervention assessments with all participants from the two groups. The first assessment was conducted after the end of the third session of counselling. Thereafter, 1-month and 3-month follow-up assessments were conducted.

4.7 DATA COLLECTION

Data was collected in three phases. These were: the development of the counselling model (Phase 1), the implementation of the counselling model (Phase 2), and the evaluation of the counselling model (Phase 3). Details of the data collected in each phase are presented below.

4.7.1 Phase 1 – The development of the counselling model

The development of the counselling model involved a number of steps. These were a needs assessment (Batohi, 2004), a review of relevant literature in the field, an incorporation of the theoretical framework chosen to guide the research, a focus group discussion with the service providers, modifications made to the model based on the qualitative information received during the focus groups, and lastly a pilot study.

4.7.1.1 The needs assessment

The needs assessment (Batohi, 2004) was conducted in Lusikisiki and involved 30 participants from St. Elizabeth's Hospital (which has an HIV/AIDS unit) Goso Forest Primary Health Care Clinic, The Village Primary Health Care Clinic, Palmerton Primary Health Care Clinic, The Treatment Action Campaign (TAC) Medecins Sans Frontierers (MSF) and The College of Education (Lusikisiki). These 30 participants comprised three groups, namely 10 service providers who provided services to adolescents and youth living with HIV/AIDS, 10 community members, and 10 adolescents and youth living with HIV/AIDS (between the ages of 18 to 24 years). The interview method was the main method of data collection for the needs assessment. The key findings were as follows: The three groups highlighted a number of counselling issues they thought should be included in the counselling process with adolescents and youth living with HIV/AIDS. There were some issues that were highlighted by all three groups (such as those relating to acceptance, disclosure, condom usage, treatment and diet) as well as those that were unique to specific groups. For example, the sample of adolescents and youth made mention of the following issues that were not mentioned by the other two samples. These related to counselling issues of depression and what was described as "appropriate behaviour". The term *appropriate behaviour* is an important issue as it refers to changes in one's behaviour that can possibly stop or reduce the spread of HIV and also help young people by preventing re-infection. These counselling issues were thought to be important and should be incorporated in the counselling model because they were not only perceived by adolescents and youth themselves as issues that young people living with HIV/AIDS would need to be counselled on, but also because these were issues that the service providers failed to recognise as issues that would be of concern to such young people. As such, following the concerns made by the sample of adolescents and youth, one of the broad aims in developing the counselling model was to challenge issues relating to depression and in so doing to reduce the level of depression experienced by adolescents and youth living with HIV/AIDS.

Data was also gathered on the perceptions of the three groups (service providers, community members, and adolescents and youth) regarding the main concerns of adolescents and youth living with HIV/AIDS. The results indicated that there are a number of issues that are of concern to such young people. Some of them were death, discrimination and isolation, and the future of their children. Many of these concerns relate to or stem from the various anxieties that young people have once they are diagnosed with HIV/AIDS. For this reason, the counselling model was developed to deal with issues relating to anxiety and in so doing to reduce the level of anxiety experienced by adolescents and youth living with HIV/AIDS.

In addition, the needs assessment revealed that the majority of the sample of service providers interviewed (70% or $\underline{n} = 7$) were of the professional opinion that adolescents and youth face many difficulties in the area of relationships in connection with their diagnosis and hence highlighted this area as one that they perceived to be of main concern to young people living with HIV. For this reason, the counselling model was developed with the aim of challenging issues that relate to social dysfunction by teaching people living with HIV/AIDS skills that would help them communicate better with others, as well as skills to help them to challenge their negative thoughts and in so doing to solve their problems or to get past their situations, thereby overcoming their fears and concerns and building self-confidence in their lives and relationships.

4.7.1.2 A review of relevant literature in the field

A survey of relevant literature in the field revealed that PLWHAs, as a result of their illness, are subjected to many psychosocial consequences that need to be made part of HIV/AIDS counselling. As a result, these studies lent support to the development of the counselling model.

There are many studies that have aided in informing and refining the counselling model with respect to its major areas of focus, namely somatic symptoms, anxiety and insomnia, social dysfunction and depression. As a detailed description has been given in Chapter 2, only a summary is given here. These studies include: *somatic symptoms* (Judd & Mijch, 1996; Kelly et al., 1993; Kelly et al., 1991; Kelly & St. Lawrence, 1988; Shisana et al., 2005; Soal, 1995; Robbins et al., 2004); *anxiety and insomnia* (Kelly, 2001; Mabunda, 2004; Molassiotis et al., 2002; Peltzer, 2005; Pool et al., 2001; Russell & Schneider, 2000; Sethosa & Peltzer, 2005; Sikkema et al., 2003; Sliep et al., 2001; Van Dyk & Van Dyk, 2003a, b); *social dysfunction* (Duffy, 2005; Mabunda, 2004; Sethosa & Peltzer 2005; Soal, 1995; Russell & Schneider, 2000; Van Dyk &Van Dyk, 2003b); *depression* (Ciesla & Roberts, 2001; Cooperman & Simoni, 2005; Judd & Mijch, 1996; Kalichman et al., 2000; Kelly et al., 1998; LaPerriere et al., 2005; Murphy et al., 2001; Schlebusch, 2005; Shisana et al., 2005; Van Dyk, 2005; Van Dyk & Van Dyk, 2003b).

In relation to the selection of relevant research instruments for the study, the GHQ-28 and BDI were considered most suitable as the GHQ-28 covers all four areas of focus, that is, somatic symptoms, anxiety and insomnia, social dysfunction and severe depression, while the BDI focuses mainly on depression.

4.7.1.3 An incorporation of the theoretical framework chosen to guide the research

Various theories and models have been used to inform the development of the counselling model. These include: Cognitive Behaviour Therapy, Multimodal Transactional Model (Palmer & Dryden, 1995) the Five Stage Model in the Psychological Process of Dying (Kübler-Ross, 1969), Erikson's (1968) theory of psychosocial development, Elkind's theory (1978) of understanding the young adolescent and Havighurst's (1972) developmental tasks of adolescence.

4.7.1.4 Focus group discussions with service providers

The next step in the development of the counselling model involved two focus group discussions with the service providers (one from each of the primary health-care clinics).

The aim of the focus group discussions was to present the counselling model to the service providers, for the model to be discussed as a group, and for the comments and suggestions made by the service providers to be noted, so that the model could be revised in accordance with the feedback received. Copies of the counselling model together with the manual were made available for the service providers so that they would find it easier to follow the discussion. The focus group interview schedule comprising one statement was as follows: "Based on a needs assessment study in this area I have developed a counselling model. I would like to share this model with you and get your input as to whether or not it covers the aspects that you consider necessary in providing counselling to adolescents and youth living with HIV/AIDS" (Appendix K).

The model was then introduced by explaining its aims and procedures. Each of the three sessions was discussed, and service providers were encouraged to make comments and suggestions throughout the discussion. These comments and suggestions were discussed as a group until some form of consensus was reached. The researcher noted all feedback as the discussion took place. In this way, two focus groups were conducted at the Village Primary Health Care Clinic.

A focus group was also held at the Goso Forest Primary Health Care Clinic, where the same procedure that was followed at The Village Primary Health Care Clinic was followed. The comments and suggestions that were made by the service providers were discussed within the group until a consensus was reached. The researcher noted all feedback as the discussion took place.

4.7.1.5 Modifications made to the counselling model based on the qualitative information received during the focus groups

The homework exercise, which involved the client keeping a written daily record (in the form of a table – refer to appendix D) of his/her thoughts and feelings in accordance with the situations he/she experienced and the consequences that followed, was modified in accordance with the concern that service providers had for clients who would be unable to fill in the table if they were illiterate. It was then suggested that the clients try to remember their negative thoughts, situations and consequences for the next session. Following this suggestion, the filling in of the table as part of the homework exercise was made optional. Clients had the choice of either filling in the table or trying to remember their thoughts and feelings in relation to the situations they experienced and the consequences that followed.

Among those that would be able to fill in the table it was suggested that they be allowed to fill it in in their vernacular. It was also suggested that the headings on the table be labelled in isiXhosa. As such, the table was modified accordingly (refer to appendix E) and in addition the counselling model itself (i.e. excluding the manual) was translated into isiXhosa (refer to appendix B) so that counsellors would find it easier to conduct the counselling session without having to translate the questions throughout the session.

Service providers felt that the task of explaining all the different types of negative thinking to the patient would be too time-consuming. This issue was discussed in the group and it was agreed that it was not necessary to go through all the different types of negative thinking with the patient, but just the ones that the patient was being challenged by, as evident in the homework exercise.

With regard to the muscle relaxation exercises, attention was drawn to the fact that clients must be told not to tense too much such that they felt pain during the deep muscle relaxation exercise. This point was therefore highlighted in the manual for counsellors as they follow the exercises.

Service providers were concerned that some clients would not be able to close their eyes for a long period of time. Thus, the model was modified such that clients are given the option of either closing their eyes or trying to focus their attention on one spot in the room.

4.7.1.6 The pilot study

Owing to the exploratory nature of the study, a pilot study was considered necessary to devise the final wording of the counselling model before implementation. The pilot study was conducted by the professional Nurse in Charge, during which one participant was given three counselling sessions based on the counselling model. The reason that only one participant was used for the pilot study was that it was thought that the information gathered from the focus group discussions with service providers would also add to the information from the pilot study. The feedback received from the professional Nurse in Charge was as follows:

In session 1, the client was concerned as to why so many questions were being asked of her. In session 2, it was found that the client did not fill in the homework exercise correctly because the counsellor was unable to explain it adequately to the client as he himself failed to understand it fully. Lastly, in session 3, no concerns were reported.

The conclusions of the pilot study and implications for the main study included that it would be necessary for service providers at the beginning of session 1 to remind the client that the counselling sessions he/she was attending was part of a research study (to which he/she had given consent), which was based on a counselling model that was being implemented at the clinic. It was also clear that during the training workshop with service providers (to be held at the beginning of the implementation phase of the model), the researcher would need to spend ample time explaining the homework exercise to be used in counselling sessions in order for service providers to understand the homework exercise and to be able to adequately explain it to the client.

4.7.1.7 Counselling sessions based on the counselling model

It was the intention of the researcher to conduct short-term counselling which usually lasts between two to six sessions (Turner & Hurley, 2003). However, because of the problems envisaged for participants to find transport to and from the clinic for the duration of counselling, it was decided to develop a model that consisted of three sessions so that participants could commit to attending all sessions without having to drop out at a later stage. The duration of each session was approximately 45 minutes. The sessions explained below are based on the counselling model (refer to appendix A - English, B – isiXhosa). The accompanying manual for each of the three sessions is presented in appendix C.

- **Session 1**

From the counselling perspective, it is important to first develop a therapeutic relationship with the client (Sikkema & Bissett, 1997). This is why the first session aimed to develop the relationship between the counsellor and client. It aimed to provide the client with the experience of expressing his/her feelings and emotions regarding his/her diagnosis in a safe environment so as to improve adjustment to the disease and to reduce psychological distress. It also aimed to inform the client about what he/she could expect from the other sessions. In so doing, it was seen as important that part of the session should focus on introducing and explaining CBT as a problem-solving approach that would be used in the forthcoming sessions, to deal effectively with the thoughts and feelings that might arise in relation to the diagnosis.

- **Session 2**

As the aim of CBT is to identify, to assess and to change any maladaptive beliefs the client might have (Molassiotis et al., 2002), this session aimed to help the client to modify cognition, by beginning to identify and challenge some of his/her negative thoughts and to help the client to shift his/her thinking patterns for the purpose of beneficial change (the cognitive aspect). By working through the breathing and deep muscle relaxation exercises, it also aimed to help the individual to meet the challenges and opportunities of life with a clearer and more relaxed state of mind, so that he/she could respond appropriately to a given situation (the behavioural aspect).

- **Session 3**

Session 3 aimed to help the client to further identify and challenge his/her negative thoughts with a relaxed state of mind through the re-enforcement of exercises learned in the previous sessions. In so doing, the counsellor would coach the client to overcome feelings of helplessness and hopelessness and to develop and apply intra- and inter-personal skills that would enable him/her to handle stressful situations even after counselling sessions had ended. Another way in which counselling aimed to equip the client for future stressful situations was by assigning homework exercises to be completed during the week, which would provide him/her with the opportunity to practise the skills and techniques learned during sessions and to integrate them into his/her everyday life.

4.7.2 Phase 2 - Implementation of the counselling model

The counselling model was implemented by service providers from Goso Forest Primary Health Care Clinic over a period of six months. For this reason, the implementation of the model first began with the training of the service providers on the use of the model. It also involved the training of the fieldworkers on the process of sample selection and on data-gathering techniques and procedures to be followed.

4.7.2.1 Training of service providers

A two-day training workshop was conducted at Goso Forest Primary Health Care Clinic during which service providers were trained by the researcher in the use of the counselling model. In order for service providers to use the same structure of counselling during sessions (i.e. to avoid counsellor drift) service providers were also trained to use the treatment manual. They were provided with copies of the modified counselling model and its accompanying manual so as to follow the discussion of the model, and on which to make additional notes. Each session of the counselling model was discussed in detail. By working in pairs, service providers were given the opportunity to role-play the exercises of each of the three counselling sessions. Modifications made on the model based on the feedback received from the previous focus group session were brought to their attention.

4.7.2.2 Training of fieldworkers

The use of fieldworkers during the data gathering phase is well documented (Pettifor et al., 2004; Shisana et al., 2005; Van Dyk & Van Dyk, 2003b). Four fieldworkers were trained by the researcher over two days on the research protocol and design. They were also given training on the research process of sampling and selection, and on the manner in which they should approach people. With the help of a community member who was fluent in both English and isiXhosa, each item on both the General Health Questionnaire-28 and the Beck Depression Inventory was discussed with the fieldworkers. Copies of all questionnaires were made available to each fieldworker to follow throughout the training process. Each item was translated in order to clarify the definition of each question, and each fieldworker was given an opportunity to participate in the role-playing of the questionnaires in isiXhosa. They were also encouraged to ask questions regarding the content of the questionnaires. Ethical procedures were discussed at length, and fieldworkers were trained on the informed-consent procedure to be followed. They were made aware of the importance of maintaining the confidentiality of participants, and that all information obtained in the collection of data should remain within the research team.

Thereafter, the implementation of counselling model proceeded as follows:

The pre-intervention assessment (at T1) was conducted with all participants from the experimental group and the control group to gather baseline data that was used during the evaluation phase to determine the impact of the intervention against the outcomes. The counselling model was implemented for a period of six months at Goso Forest Primary Health Care Clinic and was monitored throughout. Counselling with each adolescent or youth included three sessions (i.e. one session per week).

4.7.3 Phase 3 - Evaluation of the counselling model

The evaluation of the counselling model followed a systematic evaluation framework, namely, the CIPP model for evaluation proposed by Stufflebeam (1968, 1972). In systematic evaluation, programmes are viewed "as integrated systems that can be observed or measured" (Potter & Kruger, 2001, p. 194). However, Stufflebeam introduced the idea of evaluation being more than just an instrument of accountability. According to Madaus, Scriven and Stufflebeam (1983), evaluation is a tool for improving on programmes so as to serve the needs of the client and intended parties. It is intended to promote growth and aid leadership in decision-making by systematically obtaining and utilising feedback.

Stufflebeam's CIPP model (1968, 1972) involves four types of evaluation. The acronym CIPP consists of the first letters of the four kinds of evaluation (***C****ontext evaluation,* ***I****nput evaluation,* ***P****rocess evaluation* and ***P****roduct evaluation*). It is important to bear in mind that although these four types of educational designs serve unique functions, they are also synergistic, as evaluation is an activity that is linked to programme development. Thus, the following discussion of the four types of evaluation that were utilised in the current study is reflective of a number of different phases, including the development and implementation phases.

Context evaluation involves identifying the target population, assessing their needs and identifying the desired objectives to serve as sufficient responses to the assessed needs (Stufflebeam, 1983; Worthen & Sanders, 1973). In so doing, it can be used to serve many purposes such as deciding upon the setting to be served, as well as the objectives to be achieved (Worthen & Sanders, 1973). It also involves identifying the strengths and weaknesses of a programme in order to provide directions for improvement (Stufflebeam et al., 1971; Stufflebeam, 1983; Worthen & Sanders, 1973). The methods employed in a context evaluation can include individual interviews, surveys and/or document reviews (Madaus et al., 1983). In the context evaluation of the current study, a needs assessment of adolescents and youth living with HIV/AIDS in Lusikisiki (Batohi, 2004) was conducted.

The aim of *input evaluation* is to prescribe a programme aimed at bringing about improved change. It involves identifying and assessing programme capabilities, developing alternative programme strategies for improvement, and formulating procedural designs for implementing these strategies (Stufflebeam, 1983; Worthen & Sanders, 1973). The methods involved in an input evaluation generally include literature searches, analysis of available resources, pilot trials, and advocate teams (Madaus et al., 1983). Information generated for the input evaluation of the present study was as follows: a review of relevant literature in the field, an incorporation of the theoretical framework chosen to guide the research, a focus group discussion with the service providers, and lastly a pilot study. This information assisted in the development of a counselling model to be implemented with young people living with HIV/AIDS in Lusikisiki.

Process evaluation is directed at the process of programme implementation. It involves continual monitoring during the implementation of a programme to determine whether the programme is being implemented as intended. It aims to identify and predict defects in a programme and also to provide guidance on what should be done to improve the design (Madaus et al., 1983). This is achieved in interacting continuously with programme members and in keeping a record of all procedural activities as well as in remaining alert to unanticipated procedural barriers. Process evaluation also helps to keep accountability in assessing later outcomes. In the current study, process evaluation was carried out through the continuous interaction between the researcher and programme members (service providers and fieldworkers, etc.) In addition, one community member was employed to monitor the implementation of the counselling model in Lusikisiki and to provide regular feedback to the researcher on all observed activities and procedural barriers. A record of the implementation design was kept over the six-month period in order to detect defects in the design, so that appropriate decisions could be made to improve the design. Regular telephonic feedback meetings were arranged between the researcher and all involved in the project, which also helped in keeping them involved and aware of their responsibilities.

The main purpose of *product evaluation* is to compare or judge the outcomes, effect or impact of the programme against the objectives, and to ascertain the extent to which a programme has met the identified needs of the group which it was to serve (Stufflebeam, 1983; Worthen & Sanders, 1973). According to Worthen and Sanders (1973), product evaluation is used for deciding whether to continue, terminate, modify or re-focus a change activity. The methods used include assessing performance against objectives and/or identified needs, by means of selected norms, predetermined standards, and pre-test performance. It involves investigating indicators pertaining to programme efficiency, which is why it often includes quasi-experimental designs (Potter & Kruger, 2001). Product evaluation can involve both quantitative and qualitative analysis. The product evaluation of the current study involved a quasi-experimental design and was conducted as follows: service providers were instructed to conduct counselling sessions with adolescents and youth based on the counselling model for a period of six months. The pre-intervention assessment was conducted with the participants attending the two clinics, namely Goso Forest and The Village Clinic, which served as the experimental and control groups respectively. With the help of four fieldworkers, two questionnaires were administered to each participant of the experimental and control groups. Within less than a week from the end of the last session of counselling, that is, immediately post-intervention, each participant was re-assessed so as to determine the impact of the counselling model on cognitive and behavioural outcomes against the pre-intervention assessment. Previous studies such as Blanch et al. (2002); Kelly et al. (1993); and Molassiotis et al. (2002), have also conducted a repeated measure immediately post-intervention. Two more post-interventions were conducted after a period of one and threeemonths, to serve as follow-up assessments, as these time frames have been found to be reliable periods for re-assessment (Belcher & Kalichman, 1998; Blanch et al., 2002; Simbayi et al., 2004;

Taylor, 1995). During the 3-month follow-up interview, adolescents and youth from both the experimental and control groups were asked if there were any major life events that had taken place between the period of the pre-intervention and post-interventions. This was done in order to determine if there were any threats to the internal validity of the study. Fieldworkers conducted once-a-month follow-ups with each participant from both groups. Follow-ups took place at each participant's home, or in some cases fieldworkers arranged to meet with participants at the clinic if the participant was still attending the clinic. The impact of the counselling model was assessed by comparing participants' cognitive and behavioural outcomes against their pre-intervention performance, and also by comparing the effect of the counselling model on the experimental group relative to the control group receiving routine counselling. The routine counselling received by the control group was in the form of a weekly support group facilitated by MSF counsellors. This weekly support group consisted of approximately 30 people who had either been recently diagnosed or who had been diagnosed for a long period of time.

With reference to Stufflebeam's CIPP model (1968, 1972), it can be seen how all four types of evaluation were used in the current study to provide an integrated understanding of the development, implementation and evaluation of a counselling model for young people with HIV/AIDS in Lusikisiki.

4.8 Data analysis

During Phase 2, the baseline assessment data was gathered. All outcome variables were first inspected for distribution properties. Although the data was found to be normally distributed as revealed by the histogram plots, a Levene's test for equality of variances revealed that the variances of the two groups were unequal on each of the subscales of the GHQ-28, namely somatic symptoms ($\underline{F} = 3.18$, $\underline{p} < 0.000$), anxiety and insomnia ($\underline{F} = 4.38$, $\underline{p} < 0.000$), social dysfunction ($\underline{F} = 3.71$, $\underline{p} < 0.000$), and severe depression ($\underline{F} = 2.34$, $\underline{p} = 0.011$), as well as depression as measured by the BDI ($\underline{F} = 2.06$, $\underline{p} = 0.030$). As a result, a $\underline{t}$ test for unequal variances was used to assess if the experimental and control groups differed significantly from each other on each of the subscales of the GHQ-28 as well as on the BDI before the commencement of the study.

Phase 3 involved the evaluation of the counselling model. To test the main study hypotheses, a 2 (Group: Experimental vs. Comparison) X 4 (Trial: T1 vs. T2 vs. T3 vs. T4) repeated measures analysis of variance (ANOVA) using SAS PROC GLM was conducted for each subscale of the GHQ-28. However, because the assumption of homogeneity of variances as revealed by the Levene's test for homogeneity of variance was violated, the repeated measures ANOVA could not be conducted using the original data.

The data set was then transformed using the transformation formula for *arc cos* so as to meet the assumptions required to run the repeated measures ANOVA test with non-transformed observed values presented in the tables and figures. The resultant data set met all the general ANOVA assumptions as well as the assumption of sphericity for repeated measures ANOVA (SAS, 1997). The Levene's test revealed that the variances of the two groups were equal on each of the subscales of the GHQ-28, namely somatic symptoms ($\underline{F} = 0.66$, $\underline{p} = 0.574$), anxiety and insomnia ($\underline{F} = 1.05$, $\underline{p} = 0.37$), social dysfunction ($\underline{F} = 0.45$, $\underline{p} = 0.717$), and severe depression ($\underline{F} = 1.49$, $\underline{p} = 0.217$). The Mauchly's test of sphericity demonstrated that the chi-square approximation for the somatic symptoms subscale was 3.834 with 5 degrees of freedom and an associated probability of 0.573. Since this is greater than the alpha level of .05 it was concluded that the data met the sphericity assumption. Similarly, the study found that anxiety and insomnia (chi-square approximation = 0.693, df = 5, $\underline{p} = 0.983$) social dysfunction (chi-square approximation = 2.025, df = 5, $\underline{p} = 0.845$) and severe depression (chi-square approximation = 5.666, df = 5, $\underline{p} = 0.340$) subscales of the GHQ-28 all met the assumption of sphericity for repeated measures ANOVA.

Because there were more than two levels of the within-subjects factor PROC GLM printed both the multivariate and univariate approach of the within-subjects hypothesis tests (SAS, 1997). According to SAS (1997), the use of multivariate or univariate approach is dependent on whether or not the assumption of sphericity has been met. If this assumption is met, SAS (1997) advises that the univariate approach be used. As such, the within-subjects data presented in the chapter to follow are based on the univariate repeated measures ANOVA.

Thereafter, to test for the short-term, medium-term, and retention effects of the counselling model, separate matched-sample $\underline{t}$ tests or repeated measures were conducted for each subscale of the GHQ-28. The short-term effectiveness of the counselling model was determined by comparing the results of the first and second trial (**T1 vs. T2**), while a comparison of the first and last trial (**T1 vs. T4**) and second and last (**T2 vs. T4**) revealed the medium-term and retention effects, respectively.

A $\underline{t}$ test for unequal variances was used to determine if there was a difference in the mean level of depression (according to the BDI) between the experimental and control groups at trials T2 and T3 post-intervention. This was because a Levene's test revealed that the variances of the two groups were unequal at T2 ($\underline{F} = 10.78$, $\underline{p} < 0.001$) and T3 ($\underline{F} = 21.58$, $\underline{p} < 0.001$). The assumption of equality of variances was upheld at T4 (the final assessment trial) as the Levene's test found the variances of the two groups to be equal ($\underline{F} = 1.05$, $\underline{p} = 0.878$) hence a $\underline{t}$ test for equal variances was used. In addition, frequency tables indicating the breakdown in levels of severity of depression for the experimental and control groups at each trial were presented. All data was analysed using the Statistical Analytic System (SAS) at the .05 level of significance.

4.9 Ethical considerations

Permission to conduct the study was obtained from the Head of Department of the Eastern Cape Department of Health. Ethical clearance was sought from the Medical Research Ethics Committee at the University of the Witwatersrand. Thereafter, permission to conduct the study was sought from the Professional Nurse in Charge of the Goso Forest Primary Health Care Clinic as well as the Professional Nurse in Charge of The Village Primary Health Care Clinic.

Informed consent from all participants was obtained (refer to Appendix J) and participants were assured of their confidentiality and privacy, and that their participation was voluntary. They were made aware that they were free to withdraw from the study at any point if they wished to do so. In addition, they were informed that they were not obliged to answer any of the questions and that if they felt that some of the questions were too personal or if they were uncomfortable answering them, they had the right to refuse to answer them (refer to subject information sheets--Appendices H, I, J, K). All participants were provided with the contact details of available counselling services at the various clinics and at St. Elizabeth's Hospital in Lusikisiki in the event of distress. In addition, fieldworkers were advised to go for debriefing at the various clinics and at St. Elizabeth's Hospital in Lusikisiki, if necessary. Both fieldworkers and health-care professionals were urged throughout the course of data collection to maintain confidentiality and not to disclose information gathered to anyone other than the researcher and her supervisor.

Lastly, because the counselling model was found to be effective in meeting the needs of adolescents and youth living with HIV/AIDS and was found to be helpful to service providers assisting these young people, the counselling model will be implemented at The Village Primary Health Care Clinic as a delayed intervention.

4.10 CONCLUSION

This chapter has discussed the methodology employed in the collection and analysis of data. It has included a description of the setting, the design, the sample and sampling procedure, research instruments and the procedure. In addition, it has covered a detailed description of the three phases of data collection, the analysis of data and the ethical considerations. The next chapter focuses on the results of the study.

CHAPTER 5

RESULTS

5.1 INTRODUCTION

This chapter describes the results of the analyses that were conducted, in accordance with the research aims and hypotheses. The aims of the study were to develop, to implement and to evaluate a counselling model for adolescents and youth living with HIV/AIDS in the Eastern Cape. A detailed description of the development and implementation of the model has been presented in Chapter 4. This chapter presents a summary of the results obtained from the study.

The results will be presented as follows: a summary of the development of the counselling model; a summary of the implementation of the model; a comparison of the baseline data obtained from the experimental and control groups; the differences between the experimental and control groups over the four assessment time intervals; the short-term, medium-term and retention effects of the counselling model; the levels of depression of the experimental and control groups according to the BDI; the testing of the hypotheses; and lastly, the summary of findings.

5.2 SUMMARY OF THE DEVELOPMENT OF THE COUNSELLING MODEL

The counselling model was developed through a number of various steps. These were: a needs assessment (Batohi, 2004) which consisted of a sample of 30 participants, made up of 10 service providers, 10 community members and 10 adolescents and youth in the area of Lusikisiki; a literature review (refer to Chapter 2) and the incorporation of the chosen theoretical framework to guide the research (refer to Chapter 3). The next step in the development of the counselling model involved the presentation of the draft model to service providers (from both the primary health-care clinics) in the form of focus group discussions (refer to Chapter 4). The aims and procedure of the study were explained to the service providers, and detailed information was given to all participants about what was required from them should they decide to participate in the study. They were also made aware of their ethical rights. Subject information sheets were given to the service providers, and informed consent forms were signed and collected. Based on the qualitative information received during the focus group discussions, the counselling model was modified. Subsequently, a pilot study was conducted in which one client received three counselling sessions based on the counselling model. The model was then further refined, based on the results of the pilot study.

5.3 SUMMARY OF THE IMPLEMENTATION OF THE MODEL

The implementation of the counselling model consisted of two training workshops, one with service providers from Goso Forest Primary Health Care Clinic who were trained on the use of the counselling model, and the other with the fieldworkers who were trained on the research process of sampling and selection in order to select participants to be included in the experimental and control groups. Following the selection criteria of the study (i.e. participants had been diagnosed within less than a month, and were between the ages of 18 and 24) fieldworkers selected participants to serve as the experimental and control groups from Goso Forest Primary Health Care Clinic and the Village Primary Health Care Clinic, respectively. Both the experimental and control groups comprised 40 adolescents and youth living with HIV/AIDS. Allowances were made for a 10% drop-out rate. Details of the actual attrition rate found in this study, as well as the final samples selected, are presented in Chapter 4 (sampling procedure). Subsequently, the pre-intervention assessment was conducted with all participants in order to gather the baseline data. Instruments, namely, the GHQ-28 and the BDI, were administered to gather data for pre-intervention assessment. The counselling model was implemented for a period of six months at Goso Forest Primary Health Care Clinic and was monitored throughout. Fieldworkers conducted once-a-month follow-ups with each participant from both the experimental and control groups.

5.4 COMPARISON OF THE BASELINE DATA OBTAINED FROM THE EXPERIMENTAL AND CONTROL GROUPS

Baseline data was obtained from the experimental and control groups on the following: somatic symptoms, anxiety and insomnia, social dysfunction, and severe depression. This data was collected from participants to serve as a reference against which any subsequent changes post-intervention could be compared. A comparison between the experimental and control groups was conducted, based on the data obtained. Results are presented in the sections below.

5.4.1 Comparison of baseline data between the experimental and control groups as measured by the GHQ-28

The information presented in this section pertains to the differences in the baseline data between the experimental and control groups according to the subscales of the GHQ-28, that is, somatic symptoms, anxiety and insomnia, social dysfunction, and severe depression. Findings are presented in the following table.

Table 8: Differences in baseline data between the experimental (n = 38) and control (n = 38) groups according to the GHQ-28

		Group					
		Experimental		Control			
Subscale	**DF**	**M**	**SD**	**M**	**SD**	**t-value**	**p-value**
Somatic Symptoms	1,74	11.026	3.175	16.842	5.669	5.518	<0.001*
Anxiety and Insomnia	1 74	11.421	3.252	15.211	6.811	3.095	0.003*
Social Dysfunction	1,74	12.737	3.326	15.079	6.407	2.000	0.050
Severe Depression	1,74	13.605	4.143	12.658	6.343	-0.771	0.444

*$p < .05$

Table 8 shows that the experimental group differed from the control group on the somatic symptoms and anxiety and insomnia subscales at the .05 level of significance, the latter demonstrating higher levels of somatic symptoms as well as anxiety and insomnia. No significant differences were found between the experimental and control groups regarding the social dysfunction and severe depression subscales at the .05 level of significance.

5.4.2 Comparison of baseline data between the experimental and control groups as measured by the BDI

This section presents the information obtained on the levels of depression for the experimental and control groups at baseline according to the BDI, using frequency counts of occurrence of levels of severity of depression. The result of the t test that was conducted in order to test the differences in depression between the experimental and control groups as a whole (as opposed to in levels) is also presented.

Table 9: Levels of depression of the experimental (n = 38) and control (n = 38) groups at pre-intervention (T1) as measured by the BDI

Level of Depression	**Group**			
	Experimental		**Control**	
	Frequency	**Percent (%)**	**Frequency**	**Percent (%)**
Minimal Depression **(0-9)**	1	3	8	21
Mild Depression **(10-16)**	11	29	8	21
Moderate Depression **(17-29)**	15	39	7	18
Severe Depression **(30-63)**	11	29	15	40
Total	**38**	**100**	**38**	**100**

From this table, it can be seen that a higher percentage of the experimental group were presenting with moderate depression (39%) compared to the control group (18%), while a lower percentage of the experimental group were presenting with severe depression (29%) as compared to the control group (40%). Additionally, 29% of the experimental group were at the level of mild depression in comparison to 21% of the control group. Interestingly, the study found that only 3% of the experimental group were found to be minimally depressed at baseline, as compared to 21% of the control group.

The results of the t-test conducted revealed that at baseline there was no significant difference in the level of depression between the experimental and control groups as a whole at the .05 level of significance ($\underline{t} = -0.36$, $\underline{df} = 74$, $\underline{p} < 0.719$).

5.5 EVALUATION OF THE INTERVENTION EFFECTS

The information presented in the sub-sections below pertains to the means and standard deviations of the experimental and control groups on the subscales of the GHQ-28 at each assessment interval post-intervention, the effect of the counselling model on the somatic symptoms, anxiety and insomnia, social dysfunction and severe depression of participants over time, the effect of the counselling model on the experimental group based on the subscales of the GHQ-28 (within-subjects analysis), and the levels of depression for the experimental and control groups on the BDI.

5.5.1 Means and standard deviations of the experimental and control groups at each trial post-intervention on the subscales of the GHQ-28

This section presents the means and standard deviations of the experimental and control groups at each assessment post-intervention.

Table 10: Means and standard deviations of the experimental ($\underline{n}$ = 38) and control ($\underline{n}$ = 38) groups immediately post-intervention (T2) on the subscales of the GHQ-28

Subscale	**Group**			
	Experimental		**Control**	
	M	**SD**	**M**	**SD**
Somatic Symptoms	5.76	4.56	17.63	0.63
Anxiety and Insomnia	4.29	4.54	16.58	1.31
Social Dysfunction	8.63	4.68	20.45	0.83
Severe Depression	4.95	4.68	15.58	0.89

Table 10 shows that in the experimental group, participants scored highest on the social dysfunction subscale (8.63). Interestingly, the control group also scored highest on the social dysfunction subscale although the mean score of social dysfunction for the control group (20.45) was higher than that of the experimental group (8.63). Another interesting point was that in both the experimental and control groups, the next highest group mean was on the somatic symptoms subscale (5.76 and 17.63, respectively). The table shows that overall, at T2 the control group scored higher on all subscales of the GHQ-28 in comparison to the experimental group.

Table 11: Means and standard deviations of the experimental (n = 38) and control (n = 38) groups at 1-month follow-up (T3) on the subscales of the GHQ-28

Subscale	**Group**			
	Experimental		**Control**	
	M	**SD**	**M**	**SD**
Somatic Symptoms	7.26	4.42	17.32	2.24
Anxiety and Insomnia	6.05	4.69	17.13	2.16
Social Dysfunction	9.29	4.60	20.24	2.10
Severe Depression	5.97	4.71	15.61	1.88

According to Table 11, in the experimental group, adolescents and youth scored higher on social dysfunction (9.29) than on somatic symptoms, anxiety and insomnia or severe depression. Interestingly, the control group also scored highest in the area of social dysfunction (20.24) compared to the other subscales. However, when comparing the scores of the experimental and control groups, it can also be seen that the mean scores of the control group were higher than those of the experimental group on all four subscales. In terms of somatic symptoms, the experimental group had a mean of 7.26 whereas the control group had a mean of 17.32. Similarly, in terms of severe depression, the experimental group had a mean of 5.97 whereas the control group had a mean of 15.61.

Table 12: Means and standard deviations of the experimental (n = 38) and control (n = 38) groups at 3-month follow-up (T4) on the subscales of the GHQ-28

Subscale	Group			
	Experimental		Control	
	M	**SD**	**M**	**SD**
Somatic Symptoms	6.82	3.01	16.03	1.31
Anxiety and Insomnia	7.34	3.46	16.29	1.56
Social Dysfunction	7.45	3.44	15.63	0.97
Severe Depression	8.66	4.12	12.32	2.44

From Table 12, in terms of anxiety and insomnia, it can be seen that the control group had a mean of 16.29 while the experimental group had a mean of 7.34. It is interesting to note that participants in the control group scored lowest in the area of severe depression (12.32) while the experimental group scored highest on the severe depression subscale (8.66) relative to the other subscales.

5.5.2 The effect of the counselling model on the somatic symptoms, anxiety and insomnia, social dysfunction and severe depression of participants

The results presented in this section relate to the effects of the counselling model on somatic symptoms, anxiety and insomnia, social dysfunction and severe depression of the experimental group relative to the control group, over the four assessment intervals. The results of the repeated measures ANOVA that were conducted in order to test these effects are presented in the sub-sections below.

5.5.2.1 Definitions of statistical terms used

"A sample member is called a *subject.* When a dependent variable is measured repeatedly for all sample members across a set of conditions, this set of conditions is called a *within-subjects factor.* The set of conditions that constitute this factor are called *trials.* When a dependent variable is measured on independent groups of sample members, where each group is exposed to a different condition, the set of conditions is called a *between-subjects factor.* The conditions that constitute this factor type are called *groups"* (SAS Library, 1997, p. 1).

5.5.2.2 Somatic symptoms

This section presents the results of the repeated measures ANOVA for the somatic symptoms subscale.

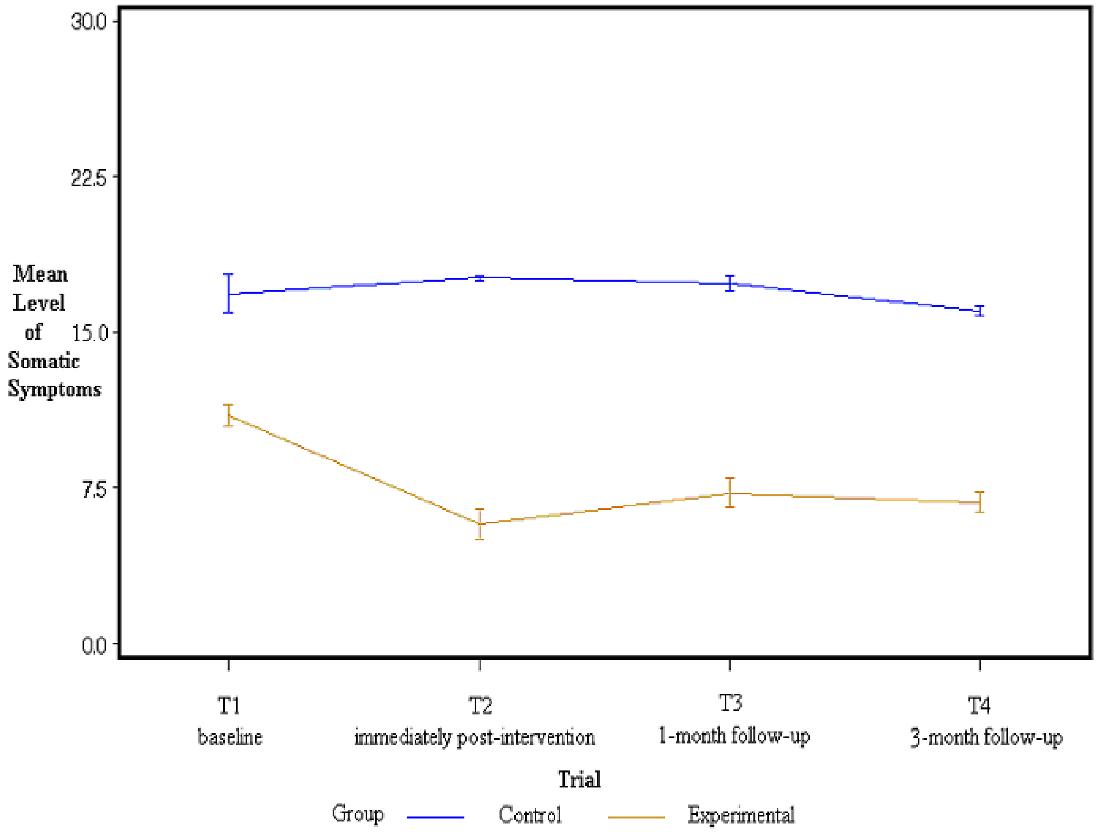
Table 13: Results of repeated measures ANOVA for somatic symptoms (n = 76)

Source	**DF**	**Sum of Squares**	**Mean Square**	**F Value**	**Pr > F**
Group	1,74	0.766	0.766	1.32	0.255
Trial	3,222	17.243	5.748	16.47	< 0.001*
Group*Trial	3,222	5.069	1.690	4.84	0.003*

*$p < .05$

According to this table, at the .05 level of significance there was a significant group-by-trial interaction. This means that the influence of group on the level of somatic symptoms was dependent on the trial. Because of a p value of < 0.001 at the .05 level of significance, it is evident that there was a significant change in the mean level of somatic symptoms in at least one instance in the experimental and control groups. It can also be seen that at the .05 level of significance, no group effect was found, indicating that whether participants belonged to the experimental or control group made no impact on their mean level of somatic symptoms. The following figure of the group means at each of the four assessment intervals illustrates these points.

Figure 5 : Means Plot of Mean Level of Somatic Symptoms by Trial



From this figure, it can be seen that the experimental group decreased more with regard to the level of somatic symptoms between the baseline and second assessment trial (T2) relative to the control group. The experimental group had a mean of 11.02 at baseline, which decreased to 5.76 at T2, whereas the control group had a mean of 16.84 at baseline, which increased to 17.63 at T2.

5.5.2.3 Anxiety and insomnia

This section presents the results of the repeated measures ANOVA for the anxiety and insomnia subscale.

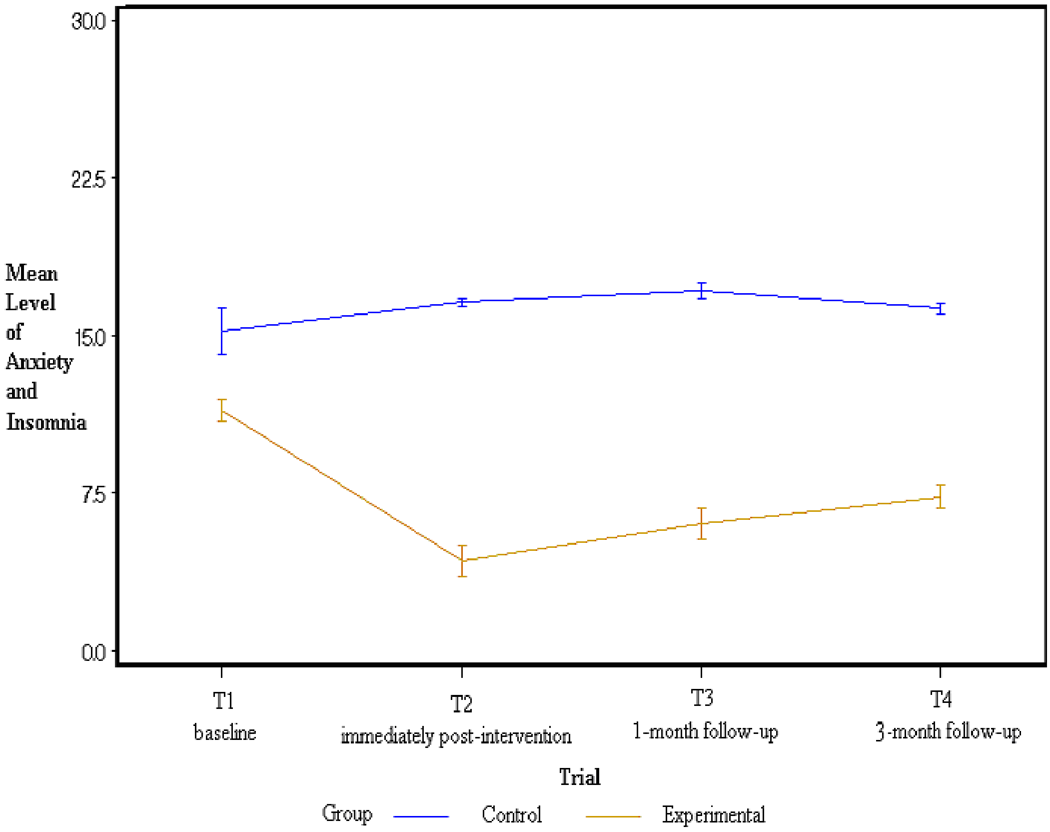
Table 14: Results of repeated measures ANOVA for anxiety and insomnia (n = 76)

Source	**DF**	**Sum of Squares**	**Mean Square**	**F Value**	**Pr > F**
Group	1,74	3.863	3.863	9.37	0.003*
Trial	3,222	7.966	2.655	6.82	<0.001*
Group*Trial	3,222	7.602	2.534	6.51	<0.001*

*p < .05

From the data presented in the table above, it can be seen that there was a significant group-by-trial interaction effect for this subscale at the .05 level of significance, suggesting that the type of group that participants belonged to interacted with the trial and influenced the mean level of anxiety and insomnia. There was also a significant trial effect at the .05 level of significance ($p < 0.001$), indicating that there was at least one significant change in the level of anxiety and insomnia experienced in the experimental and control groups. In addition, there was a significant main effect for group at the .05 level of significance, meaning that there was a statistically significant difference in the mean level of anxiety and insomnia between the experimental and control groups. This is illustrated by Figure 6 in a plot of the means.

Figure 6: Means Plot of Mean Level of Anxiety and Insomnia by Trial



In Figure 6, the main effect of group is reflected in the fact that the experimental group had a lower level of anxiety and insomnia than that of the control group. The figure shows that while the experimental group had made an improvement in the level of anxiety and insomnia between T1 and T2 (11.42 and 4.29 respectively,) the mean level of anxiety and insomnia of the control group had increased between these two assessment trials (15.21 and 16.58 respectively).

5.5.2.4 Social dysfunction

This section presents the results of the repeated measures ANOVA of the social dysfunction subscale.

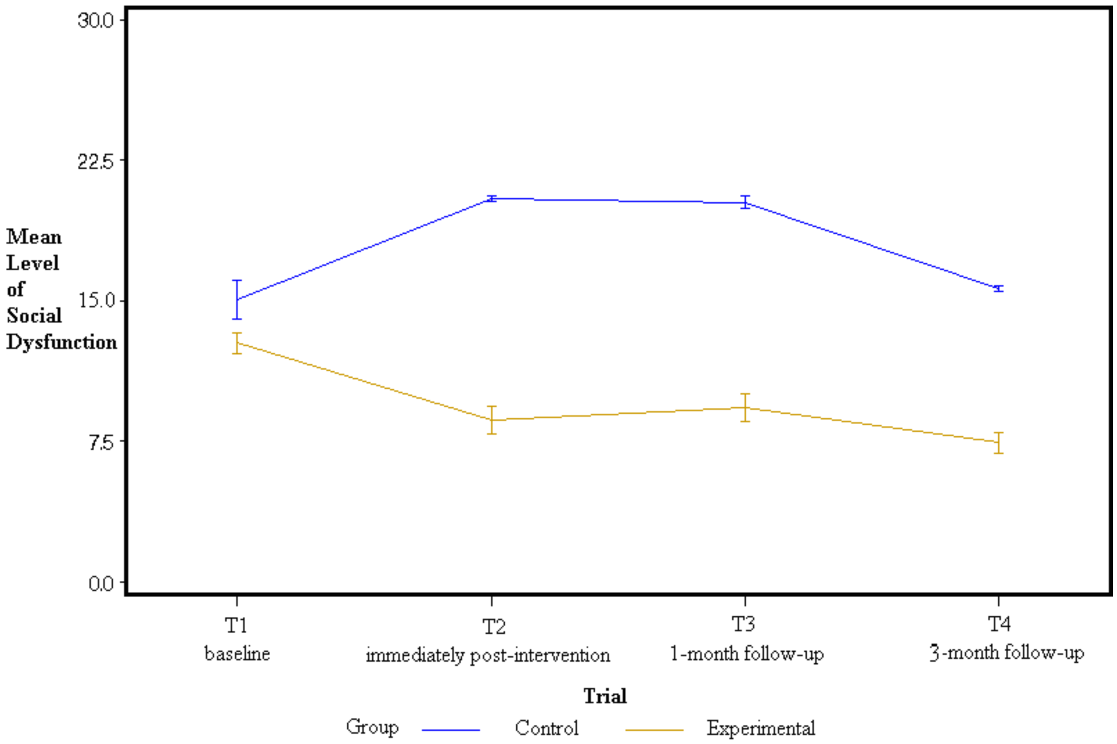
Table 15: Results of repeated measures ANOVA for social dysfunction (n = 76)

Source	**DF**	**Sum of Squares**	**Mean Square**	**F Value**	**Pr > F**
Group	1,74	14.677	14.677	30.19	<0.001*
Trial	3,222	7.238	2.413	7.22	<0.001*
Group*Trial	3,222	1.169	0.390	1.17	0.324

*$p < .05$

Table 15 shows that at the .05 level of significance, there was a significant main effect for trial, suggesting that there was a significant change in the mean level of social dysfunction in at least one instance in the experimental and control groups. The resultant p value of < 0.001 demonstrates that a significant group effect was found at the .05 level of significance. This suggests that the level of social dysfunction experienced was contingent on whether the participants belonged to the experimental or control group. No group-by-trial interaction effect was found at the .05 level of significance, indicating that there was no significant difference between the mean level of social dysfunction of the experimental and control groups across the trials. The following figure illustrates these effects.

Figure 7 : Means Plot of Mean Level of Social Dysfunction by Trial



From Figure 7, it can be seen that across that the four trials, the mean level of social dysfunction of the experimental group decreased more than that of the control group. While the level of social dysfunction of the experimental group decreased from 12.73 at T1 to 7.45 at T4, the level of social dysfunction of the control group had increased from 15.07 to 20.45 between T1 and T2, remained much the same at T3 (20.24), and only decreased at the final assessment trial (15.63).

5.5.2.5 Severe depression

This section presents the results of the repeated measures ANOVA of the severe depression subscale.

Table 16: Results of repeated measures ANOVA for severe depression (n = 76)

Source	DF	Sum of Squares	Mean Square	F Value	Pr > F
Group	1,74	18.671	18.671	57.60	<0.001*
Trial	3,222	12.149	4.050	11.09	<0.001*
Group*Trial	3,222	6.266	2.089	5.72	<0.001*

*$p < .05$

Table 16 demonstrates that there was a significant group-by-trial interaction effect for this subscale at the .05 level of significance. This suggests that the mean level of severe depression of the experimental group differed significantly from the mean level of severe depression of the control group across the trials. From the data presented in the table above, it can also be seen that the level of severe depression experienced by subjects was determined by the type of group they belonged to. Because of a p value of < 0.001 at the .05 level of significance, it is evident that there was at least one significant change in the mean level of severe depression experienced in the experimental and control groups (significant trial effect). The figure below illustrates these findings.

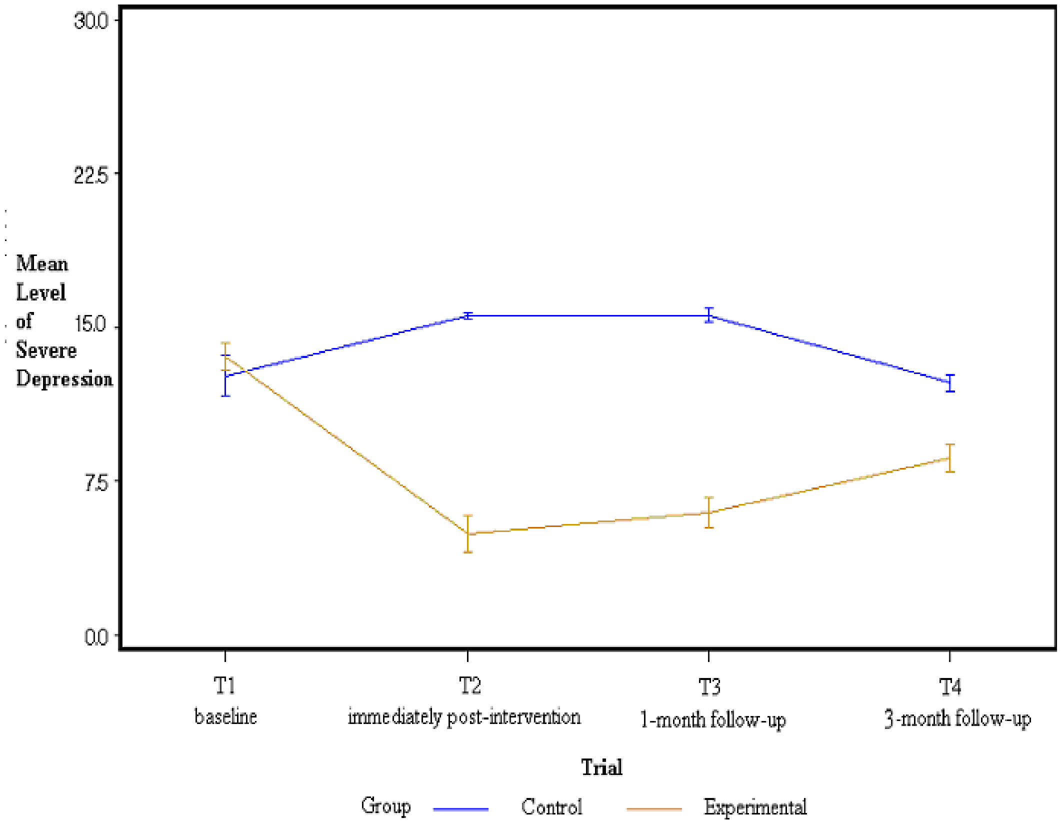


Figure 8 : Means Plot of Mean Level of Severe Depression by Trial

From Figure 8, it can be seen that the experimental group had a lower level of severe depression compared to the control group. The mean level of severe depression of the experimental group was 13.60 at T1, which decreased to 4.95 at T2, whereas the control group had a mean of 12.65 at T1, which increased to 15.58 at T2. It is interesting to note that at the 3-month follow-up (T4), the experimental group still scored lower on severe depression (8.66) than that of the control group (12.32).

5.5.3 Effects of the counselling model on the experimental group, based on the subscales of the GHQ-28 (within-subjects analysis)

The effects of the counselling model on the experimental group were assessed immediately post-intervention (T2) (short-term effect) and at the 3-month follow-up (T4) (full-term effect). In addition, the improvement retained between T2 and T4 was investigated (retention effect). Findings are presented below.

5.5.3.1 Short-term effect of the counselling model

For the purposes of the present study, the term *short-term effect* refers to the differences in the levels of somatic symptoms, anxiety and insomnia, social dysfunction and severe depression between the first and second assessment, that is, between the baseline assessment (T1) and the assessment immediately post-intervention (T2).

Table 17: **Short-term effect (between T1 and T2) of the counselling model on the experimental group (n = 38)**

Subscales	DF	Pre-intervention (T1)	Immediately Post-intervention (T2)	t-value	p-value
		M (SD)	M (SD)		
Somatic Symptoms	74	11.03 (3.18)	5.76 (4.56)	6.998	<0.001*
Anxiety and Insomnia	74	11.42 (3.25)	4.29 (4.54)	9.749	<0.001*
Social Dysfunction	74	12.74 (3.33)	8.63 (4.68)	4.879	<0.001*
Severe Depression	74	13.61 (4.14)	4.95 (4.68)	9.588	<0.001*

*$p < .05$

From the data presented in Table 17, it can be seen that the experimental group showed a significant difference on all subscales of the GHQ-28 between T1 and T2 at the .05 level of significance ($p < 0.001$). By examining the means between the T1 and T2, it can be seen that in terms of severe depression, the experimental group had a mean score of 13.61 at T1 which decreased significantly to 4.95 at T2. Similarly, the table shows that the mean level of anxiety and insomnia was substantially reduced from 11.42 (T1) to 4.29 (T2). In relation to social dysfunction and somatic symptoms, the study found that the experimental group showed significant improvement from 12.74 at baseline to 8.63 at T2 and 11.03 at baseline to 5.76 at T2, respectively.

5.5.3.2 Medium-term effect of the counselling model

The term *medium-term effect* refers to the differences in the levels of somatic symptoms, anxiety and insomnia, social dysfunction and severe depression between the first and last assessment, that is, between the baseline assessment (T1) and the 3-month follow-up assessment (T4).

Table 18: **Medium-term effect (between T1 and T4) of the counselling model on the experimental group (n = 38)**

Subscales	**DF**	**Pre-intervention (T1)**	**3-month Follow-up (T4)**	**t-value**	**p-value**
		M (SD)	**M (SD)**		
Somatic Symptoms	74	11.03 (3.18)	6.82 (3.01)	7.030	<0.001*
Anxiety and Insomnia	74	11.42 (3.25)	7.34 (3.46)	7.737	<0.001*
Social Dysfunction	74	12.74 (3.33)	7.45 (3.44)	9.229	<0.001*
Severe Depression	74	13.61 (4.14)	8.66 (4.12)	8.264	<0.001*

*$p < .05$

This table demonstrates that a significant difference in somatic symptoms, anxiety and insomnia, social dysfunction and severe depression was found between T1 and T4 at the .05 level of significance. With respect to the level of somatic symptoms, it can be seen that the experimental group had a mean of 11.03 at T1, which decreased significantly to 6.82 at T4, while in terms of social dysfunction, a mean of 12.74 was found at baseline, compared to 7.45 at T4. The mean level of anxiety and insomnia at T1 was reportedly 11.42, in contrast to 7.34 at T4. Similarly, in terms of severe depression, the experimental group had a mean score of 13.61 at baseline, which differed significantly from that noted at T4 (8.66).

5.5.3.3 Retention effect of the counselling model

For the purposes of the current study, the term *retention effects* refers to the differences in somatic symptoms, anxiety and insomnia, social dysfunction and severe depression between the second and last assessment, that is, between the assessments immediately post-intervention (T2) and the 3-month follow-up assessment (T4).

Table 19: **Retention effect (between T2 and T4) of the counselling model on the experimental group (n = 38)**

	DF	Immediately Post-intervention (T2)	3-month Follow-up (T4)	t-value	p-value
		M (SD)	M (SD)		
Somatic Symptoms	74	5.76 (4.56)	6.82 (3.01)	-1.841	0.0737
Anxiety and Insomnia	74	4.29 (4.54)	7.34 (3.46)	-4.945	<0.001*
Social Dysfunction	74	8.63 (4.68)	7.45 (3.44)	1.617	0.1143
Severe Depression	74	4.95 (4.68)	8.66 (4.12)	-4.242	<0.001*

*$p < .05$

From Table 19, it can be seen that a retention effect was found on both the somatic symptoms subscale and the social dysfunction subscale, as no significant differences were found for these two subscales at the .05 level of significance. This implies that there was no significant change in the levels of somatic symptoms and social dysfunction of participants between these two points in time, and that their improvement did not deteriorate over time reflecting a retention effect of the counselling model on the experimental group. No significant retention effects were observed for the anxiety and insomnia and severe depression subscales.

5.5.4 Levels of depression of the experimental and control groups as measured by the BDI.

The information presented in this section highlights the levels of severity of depression of the experimental and control groups at each trial post-intervention. Frequency tables indicating the breakdown in levels of severity of depression for experimental and control groups at each trial are presented. This section also presents the findings of the differences in the mean level of depression between the experimental and control groups as a whole.

5.5.4.1 Immediately post-intervention assessment (T2)

The following table shows the breakdown in the levels of severity of depression for the experimental and control groups immediately post-intervention.

Table 20: Levels of depression of the experimental (n = 38) and control (n = 38) groups immediately post-intervention (T2) as measured by the BDI

Level of Depression	**Group**			
	Experimental		**Control**	
	Frequency	**Percent (%)**	**Frequency**	**Percent (%)**
Minimal Depression **(0-9)**	30	79	0	0
Mild Depression **(10-16)**	3	8	0	0
Moderate Depression **(17-29)**	5	13	0	0
Severe Depression **(30-63)**	0	0	38	100
Total	**38**	**100**	**38**	**100**

From the data presented in this table, it can be seen that the majority of participants of the experimental group (79% or n = 30) were at the level of minimal depression at this assessment trial. The opposite effect was demonstrated by the control group, as the entire sample was found to be severely depressed.

According to the t-test conducted at the second assessment trial (T2), there was a significant difference in depression between the experimental and control groups as a whole ($t = -31.70$, $df = 74$, $p < 0.001$).

5.5.4.2 1-month post-intervention assessment (T3)

The table that follows shows the breakdown in the levels of severity of depression for the experimental and control groups at 1-month post-intervention.

Table 21: Levels of depression of the experimental (n = 38) and control (n = 38) groups at 1-month follow-up (T3) as measured by the BDI

Level of Depression	Group			
	Experimental		Control	
	Frequency	Percent (%)	Frequency	Percent (%)
Minimal Depression **(0-9)**	29	76	0	0
Mild Depression **(10-16)**	6	16	0	0
Moderate Depression **(17-29)**	3	8	0	0
Severe Depression **(30-63)**	0	0	38	100
Total	**38**	**100**	**38**	**100**

Table 21 shows that at the 1-month follow-up, the entire sample of the control group was found to be severely depressed, while the majority (n = 29 or 76%) of the experimental group were found to minimally depressed, followed by 16% (or n = 6) who were mildly depressed.

The results of the t-test conducted showed that at the third assessment interval (T3), there was a significant difference in the levels of depression between the experimental and control groups as a whole ($t = -39.47$, $df = 74$, $p < 0.001$).

5.5.4.3 3-month post-intervention assessment (T4)

The following table shows the breakdown in the levels of severity of depression for the experimental and control group at 3-months post-intervention.

Table 22: Levels of depression of the experimental (n = 38) and control (n = 38) groups at 3-month follow-up (T3) as measured by the BDI

Level of Depression	**Group**			
	Experimental		**Control**	
	Frequency	**Percent (%)**	**Frequency**	**Percent (%)**
Minimal Depression **(0-9)**	18	47	0	0
Mild Depression **(10-16)**	9	24	0	0
Moderate Depression **(17-29)**	11	29	14	37
Severe Depression **(30-63)**	0	0	24	63
Total	**38**	**100**	**38**	**100**

From this table, it can be seen that while the majority (63% or n = 24) of the control group were presenting with severe depression, none of the participants from the experimental group were found to be severely depressed, but instead 47% (or n = 18) of the experimental group were reportedly at the level of minimal depression. Interestingly, the study found that no-one from the control group was categorised as minimally or mildly depressed at the 3-month follow-up.

According to the t-test conducted at the final assessment interval (T4), there was a significant difference in the levels of depression between the experimental and control groups as a whole ($t = -12.69$, $df = 74$, $p < 0.001$).

5.5.5 Testing of the hypotheses

This section presents the results of the study in relation to the testing of the hypotheses. These are as follows:

1) ***The main empirical hypothesis tested was that the counselling model would demonstrate significantly greater reductions in the mean level of psychological distress experienced by the experimental group relative to the control group.***
   On the basis of a repeated measures ANOVA that were conducted, the study found that the counselling model demonstrated significantly greater reductions in

the mean level of psychological distress experienced by the experimental group relative to the control group. The above hypothesis is therefore accepted with regard to the level of anxiety and insomnia, social dysfunction and severe depression.

Specifically the study hypothesized that the counselling model would impact on the experimental group in the following manner:

2) It would demonstrate significantly greater reductions in the mean level of somatic symptoms relative to the control group.

The study found that there was no significant difference between experimental and control groups in terms of their mean level of somatic symptoms (p > .05). The above hypothesis is therefore rejected.

3) It would demonstrate significantly greater reductions in the mean level of anxiety and insomnia relative to the control group.

There was a significant difference between experimental and control groups in terms of their mean level of anxiety and insomnia (F [1,74] = 9.37, p = 0.003). The above hypothesis is therefore accepted.

4) It would demonstrate significantly greater reductions in the mean level of social dysfunction relative to the control group.

The study found that there was a significant difference between experimental and control groups in terms of their mean level of social dysfunction (F [1,74] = 30.19, p < 0.001). The hypothesis stated above is therefore accepted.

5) It would demonstrate significantly greater reductions in the mean level of severe depression relative to the control group.

There was a significant difference between experimental and control groups in terms of their mean level of severe depression (F [1,74] = 57.60, p < 0.001). The above hypothesis is therefore accepted.

5.5.6 Summary of findings

At baseline, the study found that the experimental group differed from the control group on the somatic symptoms and anxiety and insomnia subscales of the GHQ-28 ($p < .05$) with the control group reporting higher levels of somatic symptoms and anxiety and insomnia. No significant differences were found between the experimental and control groups in terms of depression on the BDI and on the social dysfunction and severe depression subscales of the GHQ-28 (all $p > .05$).

At both the second and third assessment intervals, in the experimental group, participants scored highest on the social dysfunction subscale (8.63; 9.29, respectively). Adolescents and youth in the control group also scored highest on the social dysfunction subscale at these two assessment intervals (20.45; 20.24 respectively) although it was evident that the mean score of social dysfunction of the control group was higher than that of the experimental group. In fact, the study found that at both the second and third assessment intervals, the mean scores of the control group were higher than that of the experimental group with respect to all four subscales of the GHQ-28. It is interesting to note that at the final assessment interval (i.e. at the 3-month follow-up), participants of the control group scored lowest in the area of severe depression (12.32) while the experimental group, on the other hand, scored highest on the severe depression subscale (8.66) relative to the other subscales.

In relation to information obtained from the BDI, the study found that at the second assessment trial (T2), there was a significant difference in depression between the experimental and control groups as a whole ($t = -31.70$, $df = 74$, $p < 0.001$). The breakdown in levels of severity of depression by frequency for experimental and control groups revealed that the majority of participants of the experimental group ($n = 30$ or 79%) were at the level of minimal depression, whereas the entire sample of the control group were reportedly severely depressed. At the third assessment interval (T3), it was demonstrated that in terms of depression, there was a significant difference between the experimental and control groups as a whole ($t = -39.47$, $df = 74$, $p < 0.001$). With regard to the levels of severity of depression, it was found that the entire sample of the control group were at the level of severe depression, while the majority (n = 29 or 76%) of the experimental group were at the level of minimal depression. At the 3-month follow-up, it was established that there was a significant difference between the experimental and control groups as a whole in relation to depression (t = -12.69, df = 74, p < 0.001), as the breakdown in levels of severity of depression by frequency for experimental and control groups demonstrated that the majority (63% or n = 24) of the control group were presenting with severe depression while the majority experimental group were presenting with minimal depression (47% or n = 18).

The repeated measures ANOVAs conducted demonstrated that there were significant group-by-trial interaction effects for somatic symptoms (F [3,222] = 4.84, p = 0.003) anxiety and insomnia (F [3,222] = 6.51, p < 0.001) and severe depression (F [3,222] = 5.72, p < 0.001). No group-by-trial effect was found for the social dysfunction subscale (p > .05). In addition, the repeated measures ANOVAs conducted revealed that at each trial the mean level of somatic symptoms (F [3,222] = 16.47, 4p = < 0.001) anxiety and insomnia (F [3,222] = 6.82, p < 0.001) social dysfunction (F [3,222] = 7.22, p < 0.001) and severe depression (F [3,222] = 11.09, p < 0.001) changed in the experimental and control groups. Furthermore, the study found that there were significant differences between the experimental and control groups between the four assessment intervals in relation to anxiety and insomnia (F [1,74] = 9.37, p = 0.003) social dysfunction (F [1,74] = 30.19, p < 0.001) and severe depression (F [1,74] = 57.60, p < 0.001). No significant group effect was found on the somatic symptoms (p > .05).

Within-subjects analysis showed that the experimental group made significant short-term improvements (i.e. between the first and second assessments) in somatic symptoms (t = 6.99, df = 74, p < 0.001) anxiety and insomnia (t = 9.74, df = 74, p < 0.001) social dysfunction (t = 4.87, df = 74, p < 0.001) and severe depression (t = 9.58, df = 74, p < 0.001). In addition, the study found that the experimental group showed improvement between the baseline and final assessment (i.e. in the full-term) in somatic symptoms (t = 7.03, df = 74, p < 0.001) anxiety and insomnia (t = 7.73, df = 74, p < 0.001) social dysfunction (t = 9.22, df = 74, p < 0.001) and severe depression (t = 8.26, df = 74, p < 0.001). Furthermore, a retention effect was found on both the somatic symptoms subscale and the social dysfunction subscale, as no significant differences were found for these two subscales between the second and final assessments (both $p > .05$). In other words, the level of somatic symptoms and social dysfunction experienced by the experimental group remained unchanged between these two points in time, and was reflective of a positive retention effect, as the improvement made at the second assessment interval did not deteriorate over time. No significant retention effects were observed for the anxiety and insomnia and severe depression subscales ($p < .05$).

5.6 CONCLUSION

This chapter has presented the results obtained from the study in terms of a summary of the development of the counselling model, a summary of the implementation of the model, a comparison of the baseline data obtained from the experimental and control groups, an evaluation of the counselling model, the testing of the hypotheses, and lastly, the summary of findings. The next chapter presents a discussion of the results presented in this chapter.

CHAPTER 6

DISCUSSION

6.1 INTRODUCTION

This chapter discusses the results obtained in the present study. Specific issues to be covered include: the development of the counselling model which incorporated the results of a needs assessment study previously conducted in Lusiksiki (Batohi, 2004); the implementation of the counselling model during which the service providers and fieldworkers were trained; a comparison of the baseline data obtained from the experimental and control groups; and the evaluation of the counselling model including a discussion of the intervention effects, that is, the overall, short-term, and medium-term effects of the counselling model; as well a discussion of the African culture in relation to mental health.

6.2 THE DEVELOPMENT OF THE COUNSELLING MODEL

The development of the current counselling model followed an action research design in which participants played an extensive role throughout the development of the model, that is, from the needs assessment stage that aided in the development of the model to the refinement of the counselling model. In this way, the design utilised in the development of the current counselling model was similar to that of other models developed previously in which a participatory or action research design was followed (Bettencourt et al., 1998; Schneir et al., 1998; Tenner et al., 1998).

A review of the relevant literature in the field revealed that it is often necessary to gain an understanding of the needs and concerns of the target group before commencing with the development of the model (Bettencourt et al., 1998; Schneir et al., 1998; Timmreck, 1995) so that the effect of the model can later be determined in relation to the identified needs of the group which it was to serve (Stufflebeam, 1983;

Worthen & Sanders, 1973). This finding had significant implications for the development of the current counselling model, as it was seen as crucial for youth and adolescent ideas and perspectives to be incorporated in the development of counselling model so as to develop a model that would adequately meet their needs and concerns. For this reason, data that was obtained as part of a previous research study (Batohi, 2004) which dealt with the needs of adolescents and youth, was used in the development of the current counselling model. This is consistent with other studies, such as Bettencourt et al. (1998); Bourdon et al. (1998); Rosenfeld et al. (2000) and Schneir et al. (1998), all of whom conducted a needs assessment with young people so as to develop intervention models that would ultimately serve the needs of the identified target group, that is, young people.

Another reason for assessing the needs and concerns of adolescents and youth from their own perspective was that it was thought that, as a result of their developmental needs, young people might have different reactions and experiences to living with HIV/AIDS, and consequently might present unique challenges as compared to people of other age groups.

According to Elkind (1978a), it is important to understand the intellectual process that sometimes motivates the behaviour of young people. The imaginary audience, for example, restricts the young adolescent from being able to distinguish between what is of interest to others and what is of interest to themselves, as they feel that all the changes that occur within themselves are noticed and are of concern to everyone else. For the young person living with HIV/AIDS, the imaginary audience can have severe negative consequences. Following Elkind’s theory (1978a), it is possible that the young person living with HIV may develop depression as a result of thinking of the reaction of the imagined audience if he/she were to disclose his/her HIV status. Elkind (1978b, p. 125) says that "when people are under the influence of strong emotion, the differentiation between subjective concerns and the concerns of others often breaks down." Consequently, the young person living with HIV/AIDS may develop intense fears and anxieties and may become preoccupied with the concerns of others. Suicide may be another possible negative consequence, as the young person may fantasise about the reaction of an audience. According to Elkind (1978b), it is common for suicidal persons to think of suicide as a means of punishing those who rejected them, and taking satisfaction in imagining the grief and remorse that will be felt by those left behind. Given the findings of many studies (Duffy, 2005; Mabunda, 2004; Sethosa & Peltzer, 2005) of the rejection faced by PLWHAs from friends, family and community members alike, it seems possible that suicidal thoughts may be fantasised of and even acted upon in light of the existence of the imaginary audience among young adolescents. By drawing on this theory, one is able to understand the developments that take place during adolescence, placing one in a better position to understand the subsequent behaviour and reactions of young people when faced with difficult situations such as the diagnosis of HIV. However, without insight into the concerns of young people themselves, the clarity needed on what they face in relation to their development will not be achieved. For this reason, the needs assessment study (Batohi, 2004) focused on the counselling and developmental needs identified by the sample of adolescents and youth themselves.

Previous studies (such as Bettencourt et al., 1998 and Schneir et al., 1998) have also pointed out the need to include the perspectives of health professionals who are familiar with working with adolescents and youth, and who can provide valuable information to the planning and development of the model. Consequently, the needs assessment study (Batohi, 2004) included a sample of service providers to determine their perceptions of the counselling needs of adolescents and youth living with HIV/AIDS, as well as to gain insight into the challenges they are faced with in providing counselling to young people. This information was also taken into consideration in the development of the current counselling model. The needs assessment study (Batohi, 2004) also went a step further to include a sample of community members, as it was thought that they, too, might provide valuable information on the main concerns of young PLWHAs as well as providing information on what they considered important in counselling young people. Similar findings were reported in a study conducted by Schneir et al. (1998). This information was also used in the development of the current counselling model. In this way, the current study incorporated information on the layman's perspective of counselling and provided a holistic perspective of HIV counselling in relation to adolescents and youth, which aided in the development of the current counselling model.

Various theories and models were used to inform the development of the counselling model, including Kübler-Ross's (1997) five stage model of the psychological process of dying, which discusses the various emotions and psychological reactions that a terminally ill person faces, as well as the multimodal transactional model (Palmer & Dryden, 1995) which discusses the different responses that people are often confronted with in stressful situations which relate to many modalities. Because of the importance of understanding these responses, the counselling model incorporated a section on emotional expression and at the same time pointed out to both service providers and adolescents and youth the different ways in which people react to situations, as well as the differences in how people deal with the process of adjustment to trauma.

According to Church (1998, p. 82), "If the cognitions associated with the emotional expression are in some way maladaptive, distorted or based on illogical thinking styles, referral for cognitive/psychological therapy would be appropriate". However, as pointed out in the literature (Church, 1998; Molassiotis et al., 2002) providing CBT to PLWHAs can be particularly challenging, as the process of change may not be as successful as that of other clinical populations. This is because the internal reality of many PLWHAs is often in line with the objective reality of their stressful daily lives which stems from their social reality (Church, 1998). For this reason, it is said that many of their cognitions/behaviours may actually be a true reflection of their lives, hence, the term "depressive realism" (Church, 1998). This finding posed a barrier to the development of the counselling model that was in part to be based on the principles of CBT and was aimed to bring about a positive realistic change in the lives of young PLWHAs. However, it was also found that although people in difficult situations (such as being diagnosed as HIV positive) tend to have negative cognitions that are often reality-based, they still tend to "associate surplus meanings to their condition/situation by neglecting the possible options open to them" (Beck, 1989 as cited in Church, 1998, p. 83). Consequently, this finding challenges the non-applicability notion of CBT to PLWHAs and argues that CBT can be used to change the distorted meanings that PLWHAs attach to their situation, by challenging their maladaptive thoughts. In other words, by examining the meanings people attach to their situations, their reactions can be reality-tested, using CBT. However, it must be mentioned that in all cases, service providers in the current study were urged to be sensitive to the ways in which the young person had chosen to deal with his/her illness. Thus, this study has examined the relevance of the application of CBT to PLWHAs in the development of the counselling model.

Based on the information gathered from the needs assessment, the literature review, and the incorporation of the chosen theoretical framework, a counselling model was developed for young people living with HIV/AIDS. As part of the action research design of the study that aimed to take into account the knowledge that people have about their own environment and about the problems that commonly exist within these environments, the counselling model was presented by the researcher to service providers who were familiar with providing counselling to young PLWHAs, making the development of the model a collaborative process between the researcher and those who would ultimately make use of the model. In so doing, the refinement of the model was achieved through the discussions of the model design between researcher and service providers. Through these discussions the following areas were identified as areas that needed modification: the applicability of the homework exercise to clients who might be illiterate; the language of instruction on the homework exercise (for those who were literate); the option of allowing the client to complete the homework exercise in their vernacular; the translation of the counselling model itself (i.e. excluding the manual) to isiXhosa; the refinement of the exercise on the different types of negative thinking; and the instructions that needed to be highlighted in the manual for counsellors to give their clients, with regard to the muscle relaxation exercise. This collaborative process between the researcher and service providers in the form of discussions of model design was found to be consistent with research conducted by Tenner et al. (1998) in the refinement of a model for HIV-positive youth, youth on the street, and youth that were at-risk.

Many lessons were learned in the development of the current counselling model. These include the following:

- A needs assessment study from the perspective of all stakeholders involved, to be conducted before the development of a model, is seen as vital to the applicability of the model to the identified target group which it is to serve;

- By taking into account the perspectives of the target group, one is able to take into consideration their traditions, beliefs and practices as well as the role of the social context that make actions and behaviours meaningful. In so doing, one is able to develop a model that applies to the target group and one that meets its needs

- Equally important is the need to draw on theories that relate to the target group and that may be of relevance to the development of an appropriate model. However, the applicability of these theories needs to be carefully examined before the development of the model.

6.3 THE IMPLEMENTATION OF THE COUNSELLING MODEL

The implementation of the counselling model involved the training of service providers on the use of the model as well as the training of fieldworkers on the research process of sampling and selection. In the training of the service providers, one of the aspects that was stressed was the role of the counsellor in providing services to such a difficult group. Previous research conducted by Lee et al. (1999) revealed that, on account of the many psychological problems that the HIV clients presented during counselling owing to their illness, many obstacles were created that might have hampered the progress of therapy to such an extent that therapy was described as "arduous and prolonged" (Lee et al., 1999, p. 951). In addition, these authors drew attention to the qualities of the therapist and how these can determine the effect of treatment. Some of the personal qualities mentioned by participants in their study were the need for the therapist to be: accepting, understanding, supportive, caring, gentle, non-confrontational and supportive (Lee et al., 1999). Further, the need for skilled counsellors has been raised in providing services to PLWHAs so as to "move forward such a difficult group" (Molassiotis et al., 2002, p. 94). For these reasons, the training workshop that was conducted with service providers of the present study emphasised the role of the counsellor in terms of their professional and personal qualities and their, association with treatment effects.

In addition to the above, service providers were requested to maintain professional conduct both within and outside of the health-care setting. The rationale for this is that previous research has shown that in many African communities health professionals are well-known to their clients in both a personal and professional sense making it difficult for them to draw boundaries between the roles they play in the community and the roles they play in the health-care setting. Van Dyk and Van Dyk (2003a) found that some counsellors will disclose a client's HIV status to the client's partner or family members, as they see it as their moral duty to protect community members. Similarly, Kelly (2000) found that many counsellors were unaware or simply did not pay adequate attention to the principle of confidentiality between their clients and themselves. Contrary to these findings, however, in the needs assessment study that was conducted by Batohi (2004) (which formed part of the current study), some service providers were aware of their ethical and legal responsibilities to their clients, but owing to structural problems (such as limited space) they would be unable to maintain confidentiality, making this a challenging area for them. Fortunately, since then, the Goso Forest Primary Health Clinic has been extended, which has meant that the service providers who were interviewed as part of the needs assessment study conducted by Batohi (2004) and who formed part of the implementation of the present counselling model, now had the opportunity to ensure that their clients' rights were not violated as a result of structural problems or as a result of the lack of professional conduct. As such, service providers were reminded of these issues during the training workshop.

Another aspect that was highlighted in the training of service providers was that of adolescent psychology and development in relation to HIV infection. This is because research has shown that there is a need for health professionals to understand the development of their adolescent clients so as to meet their special needs (Bettencourt et al., 1998; Schneir et al., 1998), and also so that they can be in tune with the thinking and behaviour of young people, thereby enabling them to respond appropriately (Van Dyk, 2001).

In the training of fieldworkers, attention was drawn to the importance of the recruitment of participants who met the selection criteria of the study. Studies have found that the selection criteria needs to be carefully considered and abided by, as they are vital to the success and outcomes of the study (Molassiotis et al., 2002; Kalichman, Sikkema & Somlai, 1996). Thus, the importance of the selection criteria in relation to the outcomes of the study was carefully explained to the fieldworkers. Similar to the training of service providers, fieldworkers were also reminded of the importance of maintaining the confidentiality of the participants so as to ensure these necessary procedures.

As part of the CIPP (Context, Input, Process and Product) evaluation design of the study, the implementation phase of the model was monitored throughout the six-month duration. This formed part of the *process* evaluation of the study (Madaus et al., 1983), during which the model was continually monitored to determine whether it was being implemented as intended. This was achieved through the continuous interaction of the researcher and all involved in the project via regular telephonic feedback meetings. In addition, one community member was employed to oversee the progress of the implementation phase in Lusikisiki and to provide the researcher with regular feedback on all activities and barriers. In a study conducted by Kelly et al., (1993), the lack of process evaluation was reported as one of the limitations of the study as the study focused solely on product evaluation. For this reason, these authors recommend that a process evaluation also be conducted in addition to product evaluation, as it may be helpful in the overall evaluation of the intervention. The importance of conducting a process evaluation was understood, which contributed to the selection of an appropriate evaluation design for the study which would take into account all aspects of the study as opposed to merely its outcomes.

6.4 COMPARISON OF THE BASELINE DATA OBTAINED FROM THE EXPERIMENTAL AND CONTROL GROUPS

At baseline, the results of the study revealed that the experimental group differed significantly from the control group at the .05 level of significance on two of the four subscales of the GHQ-28, that is, on the somatic symptoms and anxiety and insomnia subscales. One possibility for the differences between the experimental and control groups at baseline could be the differing patient loads at the Goso Forest and the Village Clinics (both of which offer VCT services) that comprised the experimental and control groups respectively. For example, health-care providers at the Goso Forest clinic treated approximately 90 patients in total per day as compared to health-care providers at the Village clinic who treated approximately 300 patients in total per day (Kganakga et al., 2003). By calculation this implies that the number of patients treated at the Village clinic per day is more than three times that at the Goso Forest clinic. Hence, it would seem that there are a larger proportion of people in need of VCT services at the Village Clinic than at the Goso Forest clinic.

As a result of the high patient load and expected intense time constraints at the Village clinic, it seems highly possible that patients attending the clinic for VCT services (including those that formed part of the control group) might not receive adequate pre- and post-test counselling, which might in turn have increased their levels of somatic symptoms and anxiety and insomnia. This possibility is supported by Fawcett (2001) who reported a high patient load for VCT in a rural hospital in the Eastern Cape, where the average number of patients counselled per hour was 6, implying that each patient was allowed only 10 minutes with a counsellor. Fawcett (2001) also commented that it was not surprising that such circumstances did not convert into proper HIV/AIDS counselling. Rohleder and Swartz (2005) reported similar findings, as well as the exacerbated problem of "nursing managers" concentrating heavily on the number of people getting tested each day while ignoring the emotional needs of the counsellor and the person being counselled.

The baseline results indicated that there was no significant difference in the level of depression experienced between the experimental and control groups (at the .05 level of significance) as measured by both the GHQ-28 and BDI. One explanation for this is that both the experimental and control groups lived under similar conditions of poverty which, in previous research, has been suggested to be implicated in the causation of mental disorder (including depression) (Saraceno & Barbui, 1997; Patel, 2001). Factors that are linked to the association between poverty and mental health include a lack of education, unemployment, and poor social welfare (National

Academies Press, 2001), all of which aptly apply to the two samples (that is, the experimental and control groups) that formed part of this study. In addition, research has found that on account of poverty and its associated stresses, there is a higher prevalence of mental disorders among low-income households than among the affluent (Patel, Araya, Lima, Ludermir & Todd, 1999). Hence, it is thought that in the context of poverty, both samples (the experimental and control groups) of the current study were subjected to similar economic stressors that led to the establishment of increased depression, which could serve to explain why there was no significant difference in the level of depression between the experimental and control groups at the baseline assessment.

The study also found that there was no significant difference in the level of social dysfunction experienced between the experimental and control groups (at the .05 level of significance) at the baseline assessment. Again, it is possible that because both samples lived under similar conditions of poverty, both the experimental and control groups might have experienced heightened levels of social dysfunction. Swartz et al. (2006) found that in a poverty-stricken area, people had to borrow from their neighbours, which added to the stress in the household and often created social tensions between neighbours and within families. This, in addition, was said to enhance the stigmas associated with mental disorders. For these reasons, it is possible that living in poverty along with its associated stressors may have contributed to the experimental and control groups' heightened levels of social dysfunction, which may explain why there was no significant difference between the experimental and control group at baseline.

6.5 EVALUATION OF THE INTERVENTION EFFECTS

6.5.1 Overall effects of the counselling model

The goal of this study was to determine the effect of a newly developed cognitive-behavioural based counselling model for adolescents and youth living with HIV/AIDS across the four assessment trials. It was hypothesised that the counselling model would demonstrate significantly greater reductions in the mean level of somatic symptoms, anxiety and insomnia, social dysfunction and severe depression of the experimental group, relative to the control group, at each trial. Post-intervention results of the study support the above hypothesis, as a significant difference was found in the mean level of somatic symptoms, anxiety and insomnia and severe depression between the experimental and control groups at each trial, with the experimental group presenting with a lower level of somatic symptoms, anxiety and insomnia, and severe depression, relative to the control group, at each trial. No group-by-trial effect was found for the social dysfunction subscale. However, the study revealed that there was a significant group effect as well as a significant trial effect in relation to social dysfunction. With regard to the results obtained from the BDI, the study indicated that there was a significant difference in depression between the experimental and control groups as a whole at each trial post-intervention, with the experimental group presenting with a lower level of depression compared to the control group.

Based on the above results, it can be said that the counselling model was shown to be effective in reducing the symptoms of psychological distress (somatic symptoms, anxiety and insomnia, social dysfunction and severe depression) among adolescents and youth living with HIV/AIDS. In so doing, the model may have optimised the adjustment process to living with a chronic illness as well as contributing to the management of living with the stressors of the disease. These findings are similar to the findings of Blanch et al. (2002); Kelly et al. (1993); LaPerriere et al. (2005); Lutgendorf et al. (1998); Molassiotis et al. (2002) and Taylor (1995), who also found a significant beneficial effect of a counselling intervention, specifically a CBT and/or a stress management intervention on psychological distress, when compared to a control group. Both CBT and stress management therapies have been shown to be effective in alleviating the psychological symptoms of PLWHAs (Antoni et al., 1991; Eller, 1995; Kelly et al., 1993; Lutgendorf et al., 1998; Mulder et al., 1994).

6.5.2 Short-term effects of the counselling model

The term *short-term effect* refers to the differences in the levels of somatic symptoms, anxiety and insomnia, social dysfunction and severe depression between the first and second assessment, that is, between the baseline assessment (T1) and the assessment immediately post-intervention (T2). The duration between the first and second assessments was three weeks.

The experimental group showed significant short-term changes in somatic symptoms, anxiety and insomnia, social dysfunction and severe depression at the .05 level of significance, as demonstrated by the change in GHQ and BDI scores, while the opposite effect was demonstrated by the control group. These findings support the findings of Kelly et al. (1993) in the assessment of a CBT intervention, and Molassiotis et al. (2002) in the evaluation of a CBT intervention and a peer support/counselling (PSC) intervention, as the experimental group showed significant reductions in terms of depression (Kelly et al., 1993; Molassiotis et al., 2002) somatisation (Kelly et al., 1993) and anxiety (Molassiotis et al., 2002) as compared to the control group. One possibility for the significant short-term changes of the current experimental group may be the cognitive development of the adolescent or youth which may have contributed to their improved capacity to process the information that was presented in the counselling sessions. Similar results were reported by Naidoo (1997) in a study on homeless youth infected with HIV.

Another possible explanation for the significant short-term changes in somatic symptoms, anxiety and insomnia, social dysfunction and severe depression is that participants may have perceived the techniques learned (such as the relaxation techniques, cognitive-behavioural skills training, etc.) as a useful means for coping with their diagnosis, and as a result this may have contributed to their decreased levels of somatic symptoms, anxiety and insomnia, social dysfunction and severe depression and greater sense of personal control or self-efficacy over their lives. This possibility is supported by Lutgendorf et al. (1998) who found a strong association between improvements in cognitive coping (in particular, acceptance of HIV status) and lower anxiety and total mood disturbance in both the intervention and control groups.

In contrast to the experimental group, the current study found that the control group made significant increases in level of social dysfunction and severe depression in the short term. This finding can be attributed to the possibility that they were in a state of denial at the time of diagnosis, and that it was only after their denial became difficult to maintain that other reactions began to encroach, forcing them to confront the realities of living with the virus, which may have contributed to their increased level of social dysfunction and severe depression immediately post-intervention. This possibility is supported by the finding that many young PLWHAs find it difficult to accept their HIV status and are said to have what is termed as a "denial syndrome" (The Department of Communication Science, 2002). However, according to Kübler-Ross (1997), after a while one's denial becomes difficult to maintain, and other reactions begin to replace it. At this point, the young person begins to be confronted with the reality of his/her stressful daily life, often stemming from his/her social reality. This is why, according to Molassiotis et al. (2002) without adequate therapeutic intervention, these persons (including those who comprised the control group in the current study) may need a significantly greater amount of time to work through these stressors in order to find a means of coping with them. In other words, they may have to make this discovery for themselves, instead of having a health professional guiding them through the process. Further, findings by Gore-Felton et al. (2006) suggest that if these individuals remain untreated, it is possible that their fragile emotional state will worsen over time.

6.5.3 Medium-term effects of the counselling model

The term *medium-term effect* refers to the differences in the levels of somatic symptoms, anxiety and insomnia, social dysfunction and severe depression between the first and last assessment, that is, between the baseline assessment (T1) and the 3-month follow-up (T4).

It was hypothesised that the counselling model would significantly reduce the levels of somatic symptoms, anxiety and insomnia, social dysfunction and severe depression experienced between the baseline and the 3-month follow-up assessment. The results generated by the study provide support in favour of this hypothesis, as it was found that at the .05 level of significance the counselling model produced significant reductions in all areas. This suggests that the counselling model made more than a

modest effect in the lives of the adolescents and youth, and in so doing has provided evidence of a lasting efficacy of the three-week counselling model.
The study found that at the .05 level of significance, the control group showed no significant difference on any of the subscales of the GHQ-28 between the baseline and 3-month follow-up, while the experimental group showed significant improvement on all four subscales. These findings are consistent with previous research conducted by Gore-Felton et al. (2006), who found that if psychological distress among PLWHAs in the initial stages of the disease was high it would persist if undetected and untreated.

At the 3-month follow-up, the current study found, as revealed by the BDI scores, that while the majority of the experimental group were reportedly minimally depressed, most participants of the control group, by contrast, continued to be at the level of severe depression. A significant difference in the mean level of depression between the experimental and control groups at the .05 level of significance was also found. Another possible explanation for the significant short-term changes in somatic symptoms, anxiety and insomnia, social dysfunction and severe depression is that participants may have perceived the techniques learned (such as the relaxation techniques and cognitive-behavioural skills training,) to be a useful means of coping with their diagnosis, and as a result this may have contributed to their decreased levels of somatic symptoms, anxiety and insomnia, social dysfunction and severe depression and greater sense of personal control or self-efficacy over their lives. This possibility is supported by Lutgendorf et al. (1998) who found a strong association between improvements in cognitive coping (in particular, acceptance of HIV status), lower anxiety and total mood disturbance in both the intervention and control groups.

It must be mentioned, however, that between the third (1-month post-intervention) and final assessment (3-months post-intervention) slight increases were noted for the experimental group with regard to the level of anxiety and insomnia and severe depression. This effect could be attributed to the knowledge gained by participants of the death of one participant in the experimental group, which may have contributed to their increased levels of distress. This possibility stems from the finding of the effects of history (that is, the possibility of the influence of some particular event or circumstance on the behaviour of subjects or their performance). By inquiring if there were any major life events that had taken place in the lives of participants between the assessment intervals, the effects of history were investigated. Findings revealed that many participants found the death of a patient as being particularly disturbing. A similar situation was reported in the study by Molassiotis et al. (2002), in which it was likely that the death of a group member might have contributed to an increase in mood disturbance (anger, depression, tension, fatigue, confusion and vigour). Similarly, research conducted by Lee et al. (1999) found that patients attending cognitive behavioural group therapy were very sensitive to the health status of other group members, such that if one member was to take ill, it often evoked hopelessness and fear in others. In addition, research by (Sikkema et al., 2003) found that HIV-positive participants who had lost a loved one from AIDS, demonstrated high levels of psychological distress including depressive symptoms, anxiety and traumatic stress related to their losses. Further, Sikkema et al. (1997) reported that coping with AIDS-related bereavement was one of the most severe life stressors for PLWHAs.

Given that previous research has found evidence suggesting that depressive symptoms are likely to increase in persons infected with HIV in the first three months of diagnosis (Cooperman & Simoni, 2005; Judd & Mijch, 1996) it must be said that the rate of depression found in the current study (even in the control group) is not surprising. This is why it has been suggested that people who test HIV-positive "need to be carefully monitored and counseled immediately after and during the early months after learning about their HIV status" (Cooperman & Simoni, 2005, p. 155). This, in turn, points to the need for psychosocial interventions that meet the needs of PLWHAs, and also for these interventions to be adequately evaluated both immediately post-intervention and at follow-up.

Although there have been some studies that have included follow-up measures, many of the other studies reviewed have provided very brief, if any, follow-up measures, and consequently fail to establish the effects of interventions after the short term (for instance Goodkin et al., 1999; Lutgendorf et al., 1998; Mulder et al., 1994; Targ et al., 1994.). According to Blanch et al. (2002), it is important for interventions not only to aim to bring about reductions in the area of distress and improvement in the area of adjustment, but also for them to aim to produce lasting effects. Kelly et al. (1993) add that as the number of infected people increases, many will be faced with the emotional consequences of the disease, which points to the relative importance of evaluating therapy interventions in an effort to meet the mental health needs of PLWHAs.

The finding of the present study that the counselling model had a lasting efficacy is an important one because as more people acquire access to antiretroviral treatment as well as other combinations of treatment, HIV/AIDS will become more a chronic than a terminal illness in this country, and will therefore need to be chronically managed (Blanch et al., 2002). According to Blanch et al. (2002), one way to make the best use of the public health system and to decrease patient load is to provide short but effective long-lasting interventions. Another benefit of developing such interventions is that they may also bear health benefits for the general public (Kelly et al., 1993). Research by Murphy et al. (2001) has provided evidence of the association between higher levels of depression, frequent alcohol use and unprotected sex that increase the risk of infection to others.

For these reasons, this study contends that programme developers need to be innovative in developing new ways to meet the mental health needs of adolescents and youth living with HIV/AIDS in the long term.

6.5.4 African culture and mental health

Although research has shown that CBT and stress management interventions can be effective in alleviating the psychological distress associated with living with HIV/AIDS, it is important to bear in mind the culture of the people for whom the current intervention was developed, in determining its effectiveness.

Different languages express emotion in various ways and have a different set of vocabulary for it. Thus, the emotional expression of distress is not universal but rather varies from culture to culture. In isiXhosa, for example, the word *ububele* has two meanings. It can mean either *emotion* or *kindness,* which in the English vocabulary, are two separate words (Swartz, 2002). Similarly, in a study conducted by Drennan, Levett and Swartz (1991) on the translation of an assessment tool, it was found that the word *sad* which was translated (by an isiXhosa speaking psychologist) as *khatazekile,* was back-translated to mean *worried* (by two senior students of African languages). According to Swartz (2002, p. 104), "sadness and worry have, from a psychiatric point of view, very different implications for diagnosis and treatment, as sadness may be a key symptom in depression, with worry a feature of an anxiety state." Fieldworkers in the current study also reported difficulties in the translation of assessment tools used, as there were some instances in which participants found it difficult to understand the nature of the questions being asked. Hence, it may be possible that in those instances, the meaning or some essence of the question was not expressed in its correct form to the participant owing to difficulties with the translation of emotional words. However, as pointed out by Swartz (2002, p. 41), what is needed under these circumstances is to take into account "the impossibility of finding a perfect translation" and the ability of researchers or in the case of the current study, fieldworkers, to make sense of the difficulties in relation to clinical purposes.

In general, apart from the language differences outlined above, rural Africans do not express emotion in the same way as do Western cultures. They are less inclined to openly communicate their emotional difficulties in terms of depression, anxiety and/or other psychological labels and are more inclined to express their problems in a physiological way, that is, to complain of somatic symptoms (Swift & Asuni, 1975). According to Swift and Ansuni (1975, p. 147), "practically every organ or system in the body can be used to express depressive symptoms", which is why some refer to it as the "language of the body" (Swartz, 2002).

Research has shown that Africans are also inclined to think of their illness as caused by spirits, supernatural forces, ancestral retribution and/or witchcraft (*AIDS*-Weekly, 2001; HDNET, 1999). In a study conducted by Rumble et al. (1996) on mental illness in a South African community, it was found that a number of depressed participants attributed their illness to witchcraft. According to Van Dyk (2005), people believe in witchcraft because it helps them attribute meaning to the illness which science fails to provide. This is because Western medicine does not understand the diversity of emotional experience and the cultural beliefs that go with it, hence they fail to recognise the significance of the somatic presentation of depression and anxiety in the treatment of the basic problem, which results in many people being misdiagnosed or in some cases denied treatment (Swartz, 20002; Swift & Ansuni, 1975). For these reasons, the current study took into consideration the possible likelihood of the presentation of somatic symptoms amongst adolescents and youth living with HIV/AIDS in Lusikisiki by using the GHQ-28 as a screening instrument to detect psychiatric morbidity.

Finally, it is evident that in providing mental health services to people of African culture, what is needed is the understanding that the categories and labels given to mental illness in Western culture are not universal, and that in order to be of assistance to people in other contexts, one needs to understand their symptoms in the context in which they live (Swartz, 2002).

6.6 CONCLUSION

This chapter has discussed the results obtained in the present study. In particular, it focused on the process that led to development of the counselling model, including the implications for the development of the model in relation to the findings of other studies, the implementation of the counselling model during which service providers were trained and made aware of important issues to consider (such as maintaining confidentiality) a comparison of the baseline data obtained from the experimental and control groups, and the evaluation of the counselling model which focused on the overall intervention effects as well as the short-term and medium-term effects of the counselling model. A discussion of the African culture in relation to mental health was also presented.

CHAPTER 7

SUMMARY, CONCLUSIONS, LIMITATIONS AND RECOMMENDATIONS

7.1 SUMMARY

The main aim of the study was to develop a counselling model for adolescents and youth living with HIV/AIDS in the Eastern Cape. Specifically, the study sought to develop, implement and evaluate a counselling model that could be applied to adolescents and youth living with HIV/AIDS and that could help assist service providers and caregivers to deal more effectively with the needs of adolescents and youth. The main hypothesis of the study was that the counselling model would demonstrate significantly greater reductions in the mean level of somatic symptoms, anxiety and insomnia, social dysfunction and severe depression of the experimental group relative to the control group at each trial.

Data was collected in three phases in accordance with the aims of each phase and was both qualitative and quantitative. Phase 1 detailed the development of the counselling model for adolescents and youth living with HIV/AIDS in Lusikiski. Extensive explanation of the procedures followed was given in the development of the counselling model that aimed to meet both the developmental and psychological needs of young people attending counselling. These procedures included: a needs assessment (Batohi, 2004); a review of relevant literature in the field; an incorporation of the theoretical framework chosen to guide the research; a focus group discussion with the service providers; modifications made to the model based on the qualitative information received during the focus groups; and lastly, a pilot study.

Phase 2 (the implementation of the counselling model) involved the training of service providers and fieldworkers on the use of the model and on the sample selection. A sample of 38 adolescents and youth living with HIV/AIDS was drawn from Goso Forest Primary Health Care Clinic, who served as the experimental group, as well as 38 adolescents and youth living with HIV/AIDS who were drawn from the

Village Primary health Care Clinic to serve as the control group. Phase 2 also involved conducting the pre-intervention assessment (T1) with all participants from the experimental and control groups. The model was implemented for a period of six months, during which every effort was taken to ensure that it was implemented as intended. In addition, through the process evaluation of the model, a record of the implementation design was kept throughout the six-month implementation period so that possible defects in the design could be detected, allowing the researcher to make appropriate decisions to improve on the design. In this way, the feedback obtained from programme members was systematically utilised to improve the design.

In phase 3 (the evaluation of the counselling model) the model was evaluated by conducting a series of post-interventions -- one immediately post-intervention (T2), one after a period of one month (T3), and another after three months (T4). In the product evaluation of the study, the effect of the counselling model was assessed by comparing participants' cognitive and behavioural outcomes against their pre-intervention performance (within-subjects analysis) and also by comparing the effect of the counselling model on the experimental group relative to the control group receiving routine counselling. The routine counselling received by the control group was in the form of a weekly support group facilitated by MSF counsellors. This weekly support group consisted of approximately 30 people who had either been recently diagnosed or who had been diagnosed for a long period of time.

With regard to the within-subjects analysis, the results of the study indicated that exposure to the counselling model was associated with a significant reduction in the level of somatic symptoms, anxiety and insomnia, social dysfunction and severe depression of the experimental group in both the short-term [that is, between the baseline assessment (T1) and the assessment immediately post-intervention (T2)] and the medium term [that is, between the baseline assessment (T1) and the 3-month follow-up assessment (T4)]. Thus, the counselling model appeared to have made a positive impact on the experimental group.

With regard to the effect of the counselling model on the experimental group relative to the control group receiving routine counselling (in the form of a weekly support group facilitated by MSF counsellors), the main findings of the study revealed that there was a significant difference in the mean level of somatic symptoms, anxiety and insomnia and severe depression between the experimental and control groups, in at least one trial (group-by-trial interaction effects) with the experimental group presenting with a lower level of somatic symptoms, anxiety and insomnia and severe depression relative to the control group at each trial. No group-by-trial effect was found for the social dysfunction subscale. In relation to information obtained from the BDI, the post-intervention results of the study indicated that there was a significant difference in depression between the experimental and control groups as a whole at T2 (i.e. immediately post-intervention), T3 (3-month follow-up), and T4 (3-month follow-up), with the experimental group presenting with a lower level of depression compared to the control group. Thus, the intervention can be regarded as being successful with respect to the effect of the counselling model on the experimental group relative to the control group receiving routine counselling.

Lastly, because of the positive findings of the study regarding the effectiveness of the counselling model in meeting the needs of adolescents and youth living with HIV/AIDS and in assisting service providers providing counselling to young people, the counselling model will be implemented at The Village Primary Health Care Clinic as a delayed intervention.

7.2 CONCLUSIONS

On the basis of the findings of the study, it is concluded that the psychological needs of adolescents and youth living with HIV/AIDS can be addressed using the current counselling model. The model is a brief-term model as it involves three counselling sessions and was developed based on the principles of CBT and stress management.

The model may be applied to adolescents and youth between the ages of 18 and 24 who have been recently diagnosed as HIV-positive. If applied during the early stages of diagnosis (within less than a month since diagnosis), the model can produce significant short-term changes in the level of somatic symptoms, anxiety and insomnia, social dysfunction and severe depression of adolescents and youth. The model is also able to provide a longer-lasting efficacy, as the current study reported significant positive changes in the level of somatic symptoms, anxiety and insomnia, social dysfunction and severe depression at the 3-month follow-up.

Based on the findings of the study, it is said that the exposure of the experimental group to the counselling model was associated with a lower level of somatic symptoms, anxiety and insomnia and severe depression relative to the control group in at least one trial. No group-by-trial effect was found with regard to social dysfunction. The counselling model was found to be particularly useful in reducing the levels of depression of PLWHAs. This was reflected in the fact that at each trial post-intervention significant differences were found between the experimental and control groups, where the experimental group was presenting with a significantly lower level of depression compared to the control group receiving routine counselling.

7.3 LIMITATIONS OF THE STUDY

Various methodological limitations must be taken into consideration when analysing this study. Firstly, the sample used was limited by the fact that participants were not randomly selected and assigned to groups, but were patients who volunteered to participate in the study, creating a selection bias. Volunteers often provide information that is socially desirable (Rosnow & Rosenthal, 1991) and may not always provide answers in accordance with their true experiences because they know that they are part of a study (the Hawthorne effect). It is also possible that they may have a particular motivation to participate in the study and may be more receptive of interventions than others (Blanch et al., 2002). It is, therefore, possible that the information presented by participants may be biased and not completely reflective of the groups concerned. As such, the results of the study should be interpreted with caution.

Another limitation of the study is that it is not possible to link with absolute certainty participants' pre-intervention depression levels to their HIV condition. It may be that depressed participants were in fact depressed before their HIV diagnosis, perhaps on account of the stressors faced in relation to their socioeconomic status. It is known that both the experimental and control groups lived under similar conditions of impoverishment, as Lusikisiki has been described as an area of deepening poverty. Evidently, it is within low-income households that a higher prevalence of mental disorders, including depression, has been shown to exist (Patel et al., 1999). However, because the current study did not seek to determine whether participants' depression was a result of their HIV status or a result of their socioeconomic status or some other factor, it is not possible to say for sure why they were depressed. Having said this, it must be noted, however, that this does not diminish the importance of psychosocial interventions, though it does point to the need for future studies to also investigate "the natural history of mental health processes in persons with HIV infection" (Kelly et al., 1993, p. 1685).

The majority of the sample of adolescents and youth were individuals who were not fluent in English. Communication, therefore, took place by means of an interpreter who explained the question in isiXhosa to the participants. Although fieldworkers were provided with training, feedback from them during the course of the implementation of the model indicated that there were some circumstances in which participants reported difficulty in understanding the questions being asked. Thus, it may be possible that owing to the difficulties in translation, the meaning of the question might not have been relayed correctly to the participant. Also, in some instances examples had to be used to prompt an answer from a participant if he/she did not understand the question. Thus, it is possible that some of the responses were not a true reflection of the participant’s experiences but that they were merely identified because the fieldworker had mentioned it. However, having said the above, it must be said that care was taken in most cases not to influence the participants' responses.

Despite these limitations, however, it must be added that this study yielded valuable data pertaining to challenges in meeting the needs and concerns of adolescents and youth living with HIV/AIDS in South Africa.

7.4 RECOMMENDATIONS

7.4.1 RECOMMENDATIONS FOR THE IMPLEMENTATION OF THE COUNSELLING MODEL

The study recommends that the counselling model be used as part of the holistic management of adolescents and youth living with HIV/AIDS. Following the Biopsychosocial paradigm, for example, "which accepts that disease has both biological, psychological and social aspects" (Schlebusch, 1990, p. 15), the counselling model may be implemented during the early stages of the illness, that is, soon after diagnosis in conjunction with other treatments. However, in order for the model to be of maximum benefit to adolescents and youth, there needs to be greater collaboration amongst all parties involved in the treatment and care of these young people, including policy makers, researchers, and both professional and non-professional service providers. Such collaborative efforts will need to take into account the social realities of living with the virus, and address the psychological trauma that may have been suffered on account of it. Within the Biopsychosocial paradigm, "each person is comprised of systems which in turn are part of bigger external systems" (Schlebusch, 1990, p. 15). For example, while individuals are made up of biological matter such as cells and organisms, they are also part of a family, community, culture and ultimately a larger society which forms part of the world. These systems are said to influence one another, which is why, within the Biopsychosocial paradigm, HIV/AIDS is viewed as a disease that affects the biology of an individual but also as a disease which is related to the lifestyle and behaviour of that individual from an etiological point of view. Thus, the Biopsychosocial paradigm provides one with a holistic understanding of the nature of the HIV/AIDS disease that filters through to almost every aspect of a person's life, as opposed to viewing it in isolation. This is why this study recommends that the counselling model be used as part of a comprehensive, integrated health-care approach that takes into consideration all the relevant needs of the client.

The counselling model may be implemented by a health-care professional who is familiar with providing counselling to adolescents and youth. Lay counsellors may also apply the model once brief training on the use of the model has been provided.

It is recommended that a modified version of the counselling model be applied to PLWHAs who have known of their diagnosis for a substantial period of time and who are in a more advanced stage of their illness, as it is possible that this group of individuals may also benefit from the counselling intervention (Mulder et al., 1994). The modified version should ensure that the discussion topics are made relevant to the advanced stage of the illness. For example, focusing on issues such as death and dying as opposed to the adjustment and management of the illness may be more relevant to persons in the advanced stages of the illness (Mulder et al., 1994). Additionally, the modified version of counselling may need to consider the possible physical impairments that persons may have in the advanced stage of the illness, and may need to ensure that the muscle relaxation exercises are appropriate.

7.4.2 RECOMMENDATIONS FOR FUTURE RESEARCH

Although the counselling model was developed specifically for a rural population of adolescents and youth, it is recommended that future studies make use of the model with urban populations to see if one can generalise the findings to other populations.

Based on the results of this study, it is recommended that a long-term study be conducted where the model is implemented for a period of between one and three years, to establish the long-term effect of the intervention. It is also recommended that long-term studies include a series of booster sessions on some of the content covered during the counselling sessions, as it is possible that this may sustain the knowledge gained by participants during the intervention, as well as sustain the improvement made in psychological functioning.

The study recommends that the model be implemented with other age groups in order to determine if it can be used as is, or requires modification.

Although service providers of the present study were trained in the use of the counselling model, this study recommends that future research provide service providers with sufficient training in the implementation phase of the model so that they can understand the process it involves and the necessary steps that are needed to be worked through in the counselling of young people.

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APPENDIX A

A COUNSELLING MODEL FOR ADOLESCENTS AND YOUTH LIVING WITH HIV/AIDS IN LUSIKISIKI IN THE EASTERN CAPE

SHLAINE L’ETANG

Intake Form - Session 1

1. General Information

Name of Client: ____ Reference No: ________

Date of Birth: ________________________Date of First Consultation: ____________

Address: _________________________ Name of Counsellor: ____________________

____

____

Contact Details:____

____

Marital status: ____

Date of Diagnosis:____

Referral Source: ____

Before the beginning of the first session, the counsellor should remember to make sure that the client is aware that he/she has given consent to participate in the implementation of the model. He/she needs to be reminded that the clinic is implementing a model that has been developed by a psychology student at the University of The Witwatersrand. The counsellor has to explain that the model consists of 3 weekly sessions, and encourage the client to attend.

2. Give an explanation of how HIV/AIDS can be managed.

3. Description of presenting problems

I'm aware that a positive diagnosis brings with it many thoughts, feelings and even changes in behaviour over this difficult period. I would like you to share with me some of the experiences you have had.

RESPONSE	**DESCRIPTION**
Behavioural	
Cognitive	
Imaginal	
Interpersonal	
Biological	
Sensational	
Affect (emotions)	

4. I would like to introduce you to a form of counselling called Cognitive Behaviour Counselling that I will be using over the next few sessions. Let me explain it you… (Explain the ABC model; refer to page 4 of the manual).

5. Over this week, as a homework exercise, I would like you to keep a daily record of the situations you come across, the thoughts you have on the situation, and the consequences that follow. You can either fill in the table or you can try to remember them. This will help us in our next session to identify any negative thoughts you may be having and the consequences of those thoughts.

6. I would like to teach you a breathing exercise that you can use whenever you are feeling tense, worried, angry or any unpleasant emotion/feeling. These feelings lead to tension building in your muscles although you do not always realise it. By doing this breathing exercise you will learn how to relax your muscles and how to regulate your breathing pattern which will help you to feel less tense, and more calm and relaxed.

   Check how the client is feeling afterwards.

7. Now I want to show you a deep muscle relaxation exercise, which like the breathing exercise, will help relieve your tension. You can use this exercise whenever you are feeling tense, worried, tired, angry or any unpleasant emotion/feeling.

   Check how the client is feeling afterwards.

8. Is there anything else you would like to talk about that we have not covered today?

Session 2

Name of Client: ____________________________________ Reference No: ________
Date of Consultation: ____
Name of Counsellor: ____

Greet the client. Check how the client is feeling today.

1. Is there anything you would like to share with me that has happened over the past week?

____
____
____
____
____
____
____
____
____
____

2. Last week as a homework exercise I asked you to keep a daily record of your thoughts by either filling in the table or by trying to remember them. Let's have a look at the table if you have filled it in, or what you can remember of the thoughts you have been having. Tell me about what you have written or what you have been thinking, starting with the first situation.

____
____
____
____
____

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____

____

3. Explain to the client the different types of negative thinking, and ask him/her to identify the ones they have difficulty with, by helping them refer to the homework exercise.

4. There are many skills that you can learn that will help you to challenge these negative thoughts. Let's look at some of them…

5. I have been doing a lot of talking today. Is there anything you would like to talk about?

____

____

____

____

____

____

____

6. Like we did in the last session, let's do the breathing exercise.

   Check how the client is feeling afterwards.

7. Now let's work through the various muscle groups in your body by doing the deep muscle relaxation exercise.

Check how the client is feeling afterwards.

8. Again, I would like to ask you to keep a daily record of the thoughts and situations you have, and their consequences. You can either fill in the table or you can try to remember them. This will help us in our next session to identify any negative thoughts you may be having and the consequences of those thoughts. It will also help us to start challenging these negative thoughts.

Session 3

Name of Client: ____________________ Reference No: ________
Date of First Consultation: ____________________
Name of Counsellor: ____________________

Greet the client. Check how the client is feeling today.

1. Is there anything you would like to share with me that has happened over the past week?

2. Let’s look at the homework exercise. In the last session, I was talking about the different types of negative thinking that people sometimes have. Let’s talk about some of the negative thoughts you have written in your homework exercise, or if you have not written it down, some of the negative thoughts you can remember having over the past week. What was the situation and what were the consequences of your thoughts?

3. You gave me some examples of the negative thoughts you have been having. What I would like you to do in a few minutes is to think about the ways of challenging those negative thoughts. For instance, when you experienced _ _ _ _ these are the thoughts you had _ _ _ _. How can you challenge these thoughts?

4. Like we did in the last session, let’s do the breathing exercise.

   Check how the client is feeling afterwards.

5. Now let’s work through the various muscle groups in your body by doing the deep muscle relaxation exercise.

   Check how the client is feeling afterwards.

6. As you know, this is the last of the 3 sessions of the model that I explained to you during our first session. I encourage you to continue to identify your negative thoughts and to try to challenge them by making use of all the skills you have learned. Practise your skills every day because the more you use them the better you will get at it. Please note that you are free to come back to the clinic whenever you feel the need to do so.

APPENDIX B

(COUNSELLING MODEL – isiXhosa)

UMFUZISELO WOKUCEBISA NGEXESHA LOBUNZIMA KUBANTWANA ABAFIKELELA EBUDALENI NAKULUTSHA OLUPHILA NOGAWULAYO NENTSHOLONGWANE YAKHE ELUSIKISIKI EMPUMA KOLONI

SHLAINE L'ETANG

IFomu yolwamkelo - iSeshini 1

1. Ulwazi Jikelele

Igama lomxhasi: ______________________________Inombolo yokuakhangela: ________

UMhla wokuZalwa: ____________UMhla woCebiswano lokuQala: ___________

Idilesi: ___________Igama loMcebisi ngexesha lobunzima: __________________

____

____

Iinombolo zoNxibelelwano:____

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Isimo somtshato:

____

UMhla weziphumo zoXilongo:

____

INtsusa yokuBhekisela:

____

Phambi kokuqaliswa kweseshini yokuqala, umcebisi kufuneka akhumbule ukuqinisekisa ukuba umxhasi uyazi ukuba unike isivumelwano sokuthatha inxaxheba ekuqhutyweni kwalo mfuziselo. Kufuneka akhunjuzwe ukuba iklinikhi iqhuba umfuziselo ovezwe ngumfundi wesayikholoji kwiYunivesithi yaseWitwatersrand. Umcebisi ngexesha lobunzima kufuneka acacise ukuba umfuziselo uneeseshini ezi-3 rhoqo ngeveki yaye akhuthaze umxhasi ukuba aye.

2. Nika inkcazelo yendlela ekungalawulwa ngayo ugawulayo nentsholongwane yakhe.

3. Inkcazelo yokwandlala iingxaki

Ndiyazi ukuba isiphumo soxilongo sokubanentsholongwane kagawulayo siza neengcinga ezininzi kwakunye neenguqulelo ekuziphatheni ngeli thuba lobunzima. Ndingathanda ukuba wena wabelane nam ngamanye wamava othe wanawo.

IMPENDULO	INKCAZELO
Eyokuziphatha	
Eyocamngco	
Eyengcinga	
Eyothungelwano	
Eyebhayoloji	
Eyoluvo	
Eyovakalelo (uchukumiseko)	

4. Ndingathanda ukukwazisa ngemo yokucebisa ebizwa ngokuba kukuCetyiswa kweMpatheko yaseNgqondweni endiza kuyisebenzisa kwezi seshini zimbalwa zilandelayo. Mandikuchazele yona…(Chaza umfuziselo weABC; khombisa kwiphepha 4 lencwadana).

5. Kule veki, njengomsebenzi wasekhaya, ndiyakuthanda ukuba ugcine okubhaliweyo imihla ngemihla kweemeko odibene nazo, iingcinga onazo ngemeko leyo yaye neziphumo ezilandelayo. Usenokugcwalisa mhlawumbi itheyibhile okanye ungazama ukuzikhumbula. Oku kuza kusinceda kwiseshini yethu elandelayo ukuba sichonge naziphi na iingcinga ezingalunganga onokuba unazo neziphumo zezo ngcinga.

6. Ndingathanda ukukufundisa umsebenzi wokuphefumla onokuwusebenzisa nanini na uziva usindeka, ukhathazekile, unomsindo okanye naluphi na uvakalelo olungamnandanga. Ezi mvakalelo zikhokelela kubunzima obakheka kwizihlunu zakho nangona ungasoloko ukuqaphela oko. Ngokwenza lo msebenzi wokuphefumla uza kufunda indlela yokuphumza izihlunu zakho nendlela yokulawula imo yokuphefumla eza kukunceda ukuba uzive unokusindeka okuphungulekileyo, nokuzinza kwanokuphumla..

   Jonga ukuba umxhasi uziva njani na emva koko.

7. Ngoku ndifuna ukukubonisa umsebenzi wophumzo lwezihlunu, onzulu, oza kuthi nawo njengomsebenzi wokuphefumla ukuncede ekuthobeni ukusindeka. Ungawusebenzisa lo msebenzi nanini na uzuva usindekile, ukhathazekile, udiniwe, unomsindo okanye naluphi na uvakalelo/uchukumiseko olungamnandanga.

   Jonga ukuba umxhasi uziva njani na emva koko.

8. Ingaba ikhona enye into ongathanda ukuthetha ngayo esingayifikelelanga namhlanje?

Iseshini 2

Igama lomXhasi: ______________________________iNo. yokuKhangela: _________
UMhla wokuCebisana: ____
Igama loMcebisi ngexesha lobunzima:
____

Bulisa umxhasi. Jonga ukuba umxhasi uziva njani na namhlanje.

1. Ingaba ikhona nantoni na ongathanda ukwabelana ngayo nam eyenzeke kwiveki ephelileyo?

2. Kwiveki ephelileyo njengomsebenzi wasekhaya ndikucele ukuba ugcine okubhaliweyo kwemihla ngemihla kweengcinga zakho ngokuba mhlawumbi ugcwalise kwitheyibhile okanye ngokuzama ukuzikhumbula. Masijonge itheyibhile ukuba uyigcwalisile okanye onokukukhumbula ngeengcinga obunazo. Ndixelele ngento oyibhalileyo okanye ngento obuyicinga ukuqala kwimeko yokuqala.

3. Chazela umxhasi iintlobo ezahlukeneyo zokucinga okungalunganga, yaye umcele ukuba achonge ezo anobunzima ngazo ngokuncedisa ekubhekiseleleni kumsebenzi wasekhaya.

4. Zininzi izakhono onokuzifunda ezinokukunceda ukukhawulelana nemiceli-mngeni ephathelele kwezi ngcinga zingalunganga. Masijonge kwezinye zazo…

5. Oko bendisoloko ndithetha namhlanje. Ingaba ikhona nantoni na ongathanda ukuthetha ngayo?

6. Njengoko besenzile kwiseshini yokugqibela masenze umsebenzi wokuphefumla.

Jonga ukuba umxhasi uziva njani na emva koko.

7. Ngoku masisebenze ngamaqela ezihlunu awohlukeneyo emzimbeni wakho ngokwenza umsebenzi wokuphumza izihlunu.

   Jonga ukuba umxhasi uziva njani na emva koko.

8. Kwakhona, ndiyakuthanda ukuba ugcine okubhaliweyo imihla ngemihla kweengcinga neemeko odibene nazo, iingcinga onazo ngemeko leyo yaye neziphumo ezilandelayo. Usenokugcwalisa mhlawumbi itheyibhile okanye ungazama ukuzikhumbula. Oku kuza kusinceda kwiseshini yethu elandelayo ukuba sichonge naziphi na iingcinga ezingalunganga onokuba unazo neziphumo zezo ngcinga. Kuza kusinceda kwanasekubeni siqalise ukukhawulelana nemiceli-mngeni yezo ngcinga zingalunganga.

Iseshini 3

Igama lomXhasi: ____________________________iNo. yokuKhangela: ________
UMhla wokuCebisana: ____
Igama loMcebisi ngexesha lobunzima:
____

Bulisa umxhasi. Jonga ukuba umxhasi uziva njani na namhlanje.

1. Ingaba ikhona nantoni na ongathanda ukwabelana ngayo nam eyenzeke kwiveki ephelileyo?

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2. Masijonge umsebenzi wasekhaya. Kwiseshini yokugqibela, bendicinga ngeentlobo ezahlukeneyo zokucinga okungalunganga abathi abantu babe nazo ngamanye amaxesha. Masithethe ngezinye zeengcinga ezingalunganga ozibhalileyo kumsebenzi wakho wasekhaya okanye ukuba awuzibhalanga phantsi, ezinye zeengcinga ezingalunganga onokukhumbula ukuba ube nazo kule veki idlulileyo. Yayisithini imeko yaye zazisithini iziphumo zeengcinga zakho?

____
____

3. Undinike imizekelo ethile yeengcinga ezingalunganga obunazo. Endingathanda ukuba ukwenze kwimizuzu embalwa kukucinga ngeendlela zokukhawulelana nezo ngcinga zingalunganga. Umzekelo, xa ufumana amava _ _ _ _ ezi ziingcinga obe nazo _ _ _ _. Ungakhawulelana njani nemiceli-mngeni yezi ngcinga?

4. Njengoko senze njalo kwiseshini yokugqibela masenze umsebenzi wokuphefumla.

Jonga ukuba uziva njani umxhasi emva koko.

5. Ngoku masisebenze ngamaqela ezihlunu awohlukeneyo emzimbeni wakho ngokwenza umsebenzi wokuphumza izihlunu.

   Jonga ukuba umxhasi uziva njani na emva koko.

6. Njengoko usazi, le yeyokugqibela kwiiseshini ezi-3 zomfuziselo endikuchazele wona kwiseshini yethu yokuqala. Ndiyakukhuthaza ukuba uqhubeleke nokuchonga iingcinga zakho ezingalunganga yaye uzame ukukhawulelana nemiceli-mngeni yazo ngokusebenzisa zonke izakhono ozifundileyo. Ziqhelanise nezakhono zakho yonke imihla kuba okuye uzisebenzisa kokukhona uza kuba ngcono ekufikeleleni kuzo. Nceda uqaphele ukuba ukhululekile ukuba ubuyele eklinikhi nanini na usiva imfuneko yokwenza njalo.

APPENDIX C

MANUAL FOR COUNSELLING ADOLESCENTS AND YOUTH LIVING WITH HIV/AIDS

SHLAINE L'ETANG

Introduction

This manual has been designed as a tool to assist counsellors during their counselling sessions with young people between the ages of 18 and 24. It should be used during each counselling session as a guide through the counselling process. Counsellors are also encouraged to make use of their own counselling skills and examples they may have that may be relevant to the session.

Counselling young people on HIV/AIDS is not an easy task. This is because adolescence on its own is a tremendously trying period for young people, and having to cope with the added burden of being HIV-positive can have a devastating impact on the young person, particularly in terms of their psychological development. For this reason, counsellors need to be sensitive to the unique needs of people in this age group so as to be of maximum assistance to them.

The model is based on an approach called Cognitive Behaviour Therapy (CBT) which focuses on an individual's cognitions (or thoughts and feelings) and behaviours in relation to the situation they are experiencing. The model also draws on The Multimodal Transactional Model as it tries to capture the different responses that a person living with HIV/AIDS may experience. Following these two approaches, this counselling model attempts to highlight to the individual that the reactions they have to an event or situation is a result of the perceptions that they have of that event or situation and of their abilities and not of the event or situation itself. It also attempts to equip the individual with the skills that are thought to be necessary to deal with these perceptions.

The model is divided into 3 sessions each lasting for about 45 minutes. Session 1 covers HIV/AIDS management. It deals with the exploration of the young person's presenting problems. Cognitive Behaviour Therapy is introduced and a homework exercise to capture thoughts and situations is given. In session 2, the different types of negative thinking are highlighted and with the help of the counsellor the young person is asked to identify the ones they have difficulty with, by referring to the homework exercise of the previous session. Ways to challenge their negative thoughts are demonstrated, and the same homework exercise as the previous one is given. In session 3, the young person is asked to identify some of their negative thoughts according to the written homework exercise, and is guided through the process of challenging these thoughts.

Session 1

Before you begin the counselling session you need to explain to the young person that these counselling sessions will be taking place over 3 sessions and that each time they come for counselling you will be counselling them.

Explain to them that you will be asking them a number of questions, which will help you to get a better idea of the problems they are dealing with.

Assure them of their privacy and that they are in a safe environment.
Let them know that you are aware that much of the information they will be giving you will be very personal and for this reason no outsider will be allowed to see their records without their permission.

2. An example of an explanation of how HIV/AIDS can be managed:

HIV/AIDS can be managed in many ways like eating the correct diet, exercising, taking medication, talking to other people, and so on. Counselling is also an important part of managing HIV because it gives you an opportunity to speak about your thoughts and feelings in a safe environment. Counselling also helps you to learn skills to better manage these thoughts and feelings. Over the next 3 sessions I will be asking you about some of your thoughts and feelings. I will also be teaching you some skills that you can use that will help you to manage HIV and to manage your life.

3. Description of presenting problems

Exploring thoughts, feelings and behaviours:

When trying to explore their thoughts, feelings and behaviours, it might be helpful to explain to the young person some of the feelings and behaviours that others have when they are told that they are HIV positive. This will help them to recognise that many of their unpredictable and painful emotional responses are normal. It will also help to reduce some of their fears and concerns, like feelings of anxiety, hopelessness, and so on. The young person will be more likely to express their feelings and emotions to you if they know that you will not be shocked to receive this information.

You may want to say something like… "An HIV/AIDS diagnosis can be experienced at times as frightening, overwhelming and distressing. Many young people do not know how to react when they hear the news that they are HIV-positive. Many are in shock and take a while before they come to terms with their status. They feel sad and feel like crying. They feel like no one understands what they are going through and they feel they are alone. They lose hope in their future. Others feel angry with themselves and the world, and start to regret and blame themselves..." Then try to ask them to share their experiences with you.

As they are talking, try to make a note of the different responses they may be having. Use the following headings as a guide:

RESPONSE TYPE	EXAMPLE
Behavioural	This includes alcohol/drug abuse, avoidance or phobias, sleep disturbances, increased use of cigarettes, restlessness, loss of appetite, aggression/irritability, low productivity, withdrawing from relationships, increased absenteeism, decreased or increased sexual activity, frequent crying, unkempt appearance, poor eye contact, etc.
Cognitive	Includes feelings and thoughts of hopelessness, worthlessness and the lack of a future.
Imaginal	This includes images of isolation or being alone, losing control, accidents or injury, failure, humiliation/shame/ embarrassment, hopelessness, self and/or others dying or committing suicide, physical or sexual abuse, nightmares/distressing recurring dreams, visual flashbacks, poor self-image, etc.
Interpersonal	Includes passive/aggressiveness in relationships, timidity/ unassertiveness, having no friends, putting others' needs before one's own, sycophantic behaviour, being withdrawn, suspiciousness/secretiveness, manipulative tendencies, gossiping, etc.
Biological	Use of drugs/stimulants/alcohol/tranquilisers/hallucinogens, diarrhoea/constipation, frequent urination, high blood pressure, chronic fatigue, flu/common colds, lowered immune system, poor nutrition, poor exercise, poor recreation, organic problems, etc.
Sensational	Includes tension, headaches, palpitations, rapid heart beat, nausea, aches/pains, dizziness/feeling faint, indigestion, limited sensual and sexual awareness, dry mouth, clammy hands, abdominal cramps, sensory flashbacks.
Affect (emotions)	This includes emotions such as anxiety, depression, anger, guilt, hurt, morbid jealousy, shame or embarrassment, suicidal thoughts, etc.

4. Explaining Cognitive Behaviour Counselling (The ABC Model):

Let's say for example we had A, B and C. Where A = the situation, B = your thoughts and C = the consequences.

A	B	C
Situation	Thoughts	Consequences

Let's say the situation (A) was that you discovered that you have HIV. You started to have many difficult thoughts (B) just like the ones you told me earlier (counsellor can name a few, e.g. you felt sad, depressed or hopeless). Now, as a result of these thoughts and feelings, you don’t feel like eating any more, you have difficulty relating to people, you have mood-swings and you can’t sleep any more. These are what we call the consequences (C) of the thoughts (B) and feelings you were having.

Let's say we had the same situation (A) where you discovered that you were HIV-positive but instead of feeling sad, depressed or hopeless, you said to yourself that as difficult as this is going to be, you are going to have learn to accept your status and move on with your life. So you started to think of how you could get help and how you could learn from others. Now, as a result of these thoughts, you got information about a support group in your area, joined a support group, and now have many friends you can talk to who understand what you are going through. This would be called the consequences (C) of your thoughts (B) and feelings.

Can you see how your thoughts and feelings can influence the consequences? Remember in the first example you were thinking and feeling sad, depressed or hopeless, while in the second example you decided that you were going to have learn to accept your status and move on with your life. These are examples of two different types of thoughts and feelings, which also had different types of consequences. In the first, the consequences were that you didn’t feel like eating any more, you were having difficulty relating to people, you had mood-swings and you couldn’t sleep any more, compared to the other example where you joined a support group, made many friends that you can talk to and who know what it is like be living with HIV.

This is why we say that your thoughts are very important, because not only do they influence how you feel, but they also have consequences.

5. Explain the homework exercise to the client.

6. Breathing exercise:

- Let’s begin. Try to get as comfortable as you can in your chair. Close your eyes, or if you don’t want to close your eyes try to focus your attention on one spot without moving your eyes around too much. Pay attention to your normal breathing as you take a few breaths in. Place one hand on your stomach and the other on your chest. As we start the breathing exercise notice how your hand on your stomach rises and your hand on your chest rises as your lungs become full of air when you breathe in.
- Now take a slow deep breath in through your nose. Once you have taken in as much air as you can, hold that breath … and now slowly breathe out through your nose. Notice how your lungs have become empty and your stomach has sunk. This is because you have used your stomach muscles to push all the air out. Good! Let’s try that one more time.
- This time, as you are breathing in, imagine that all your muscles are being filled with air and they are expanding.
- Let’s begin. Take another slow deep breath in through your nose. Once you have taken in as much air as you can, hold that breath … and now slowly breathe out through your nose. Imagine your muscles slowly relaxing, leaving you feeling relaxed and calm.
- Lie still and enjoy the relaxed feeling you are experiencing. When you are ready, you can open your eyes.

7. Deep Muscle Relaxation Exercise:

The deep muscle relaxation exercise will help you to know the difference between tension and relaxation of your muscles and it will teach you how to relax the tension away. We will work through various groups, first tensing some muscles while your other muscles will remain relaxed, and then relaxing the whole body when I say the word "relax". **Try not to tense your muscles too much so that it causes pain.**

- Sit comfortably in your chair and try to relax. Close your eyes and notice your breathing pattern.
- Now take a deep breath in and then slowly breathe out. Let yourself feel completely calm and peaceful.
- Slowly clench your fists making them tighter and tighter. Notice the tension in your fists, your hands and your forearms. Now relax your hands and let your fingers go loose. Notice the difference between the feeling of tension and relaxation. Let your whole body relax completely.
- Now bend both your elbows by lifting your fists towards your shoulders. Tense the muscles in your arms. Notice the feeling of tension in your arms. Hold it there. Now relax your arms and let them drop down to your sides. Notice the feeling of relaxation compared to the tension you just felt.
- Shift your attention now to your neck, your shoulders and your upper back. As you take a deep breath in, imagine all the tension from your neck, shoulders and upper back being released. Each time you take another breath, begin to feel more and more relaxed. Feel this relaxation move the other parts of your body.
- Now tighten the muscles in your buttocks and legs. Hold the tension. Now relax your muscles. Notice the difference between the feeling of tension and relaxation. Feel your entire lower body becoming more and more relaxed as you relax the tension away.
- Take a deep breath in and slowly breathe out. As you breathe, feel your whole body completely relaxing. Think the following thoughts: "I feel

relaxed. My whole body is calm. I am at peace." Remain in your relaxed position and when you feel ready, open your eyes.

Session 2

3. Explaining the different types of negative thinking:

I want to teach you about some of the different types of negative thinking. Many people don't know about the different types of negative thinking and because of this they continue to have difficulty in solving their problems or getting past their situations. These are some examples of them:

TYPE OF NEGATIVE THINKING	EXAMPLE
Concentrating on the negative aspects:	"Everything is going wrong in my life, nothing good will ever happen."
Ignoring the positive aspects:	"I only got my driver's licence because my instructor was in a good mood and he was feeling generous."
All-or-nothing, with no middle ground:	"If I can’t perform at my best in my job then I shouldn’t have one at all."
Labelling:	"I'm an idiot"; "I am worthless."
Fortune-telling:	"I know I’m not going to fit in with the others," or "Today is definitely going to be a bad day."
Should’s, must’s and have to’s:	"I should always do what others want me to"; "I must always do well at whatever I am doing"; "I have to be liked by everyone I know."
Magnification:	"If I lose my friends my whole life will fall apart."
Minimisation:	"It has to be my good luck because even my good shots were hopeless."
Emotional reasoning:	"I feel like an idiot, so I must be one" or "I always get myself into trouble, so I deserve what I’m getting."
Personalisation (blaming yourself for something that you are not totally responsible for):	"My boyfriend / girlfriend left me and it’s all my fault."
Generalisation:	"I don’t see why I should try again, I always fail."
Blame:	"It’s all my fault, I should have known better."
Mind-reading:	"I think she saw me on the street today but she pretended not to, so I guess we are not friends any more."

4. Explaining the skills that are necessary to challenge negative thoughts:

THINKING SKILLS	EXAMPLE
Befriend yourself:	When you feel that you are concentrating too much on the negative aspects, try to ask yourself what you would say to a friend of yours if they were in a similar situation. Would you be as critical or harsh to them as you are to yourself? Also try give some thought to your positive aspects.
De-labelling:	As soon as you give yourself a label such as "I am an idiot" try to think about how you got to thinking of yourself as "an idiot." Challenge this thought by asking yourself if one failure justifies such a harsh label? Then try to think of any other possible way you can think of yourself that may be less negative.
Think more coolly:	Thinking more coolly means placing less pressure on yourself. Instead of using words like "I must", "I should" or "I have to", try to use other words like "I will try to", "I prefer to", "If I can" and so on.
Broaden the picture	When you begin to think that you are totally to blame for a situation, try to think of all the other aspects involved and then try to decide whether you really are entirely to blame.
Look for evidence:	Rather than jumping to conclusions or making false assumptions, ask for clarity from others if you are unsure. Also try to ask for feedback from others from time to time. This will help you to get a more realistic point of view on the situation.
Relative thinking	Instead of looking at a situation in extreme terms like "terrible" versus "terrific", try to look for some middle ground. This will help to make it less complicated.
Writing down your negative thoughts	Try making a list of your negative thoughts. This can serve as a guide to help you avoid making them in the future.

5. Ask the client if there is anything he/she would like to talk about.

You may want to say something like… "I have been doing a lot of talking today. Is there anything you would like to talk about?" Make a record to his/her answer in the space provided on the counselling model.

6. Breathing exercise

- Let’s begin. Try to get as comfortable as you can in your chair. Close your eyes and pay attention to your normal breathing as you take a few breaths in. Place one hand on your stomach and the other on your chest. As we start the breathing exercise notice how your hand on your stomach rises and your hand on your chest rises as your lungs become full of air when you breathe in.
- Now take a slow deep breath in through your nose. Once you have taken in as much air as you can, hold that breath … and now slowly breathe out through your nose. Notice how your lungs have become empty and your stomach has sunk. This is because you have used your stomach muscles to push all the air out. Good! Let’s try that one more time.
- This time, as you are breathing in, imagine that all your muscles are being filled with air and they are expanding.
- Let’s begin. Take another slow deep breath in through your nose. Once you have taken in as much air as you can, hold that breath … and now slowly breathe out through your nose. Imagine your muscles slowly relaxing, leaving you feeling relaxed and calm.
- Lie still and enjoy the relaxed feeling you are experiencing. When you are ready, you can open your eyes.

7. Deep Muscle Relaxation Exercise:

The deep muscle relaxation exercise will help you to know the difference between tension and relaxation of your muscles, and it will teach you how to relax the tension away. We will work through various groups, first tensing some muscles while your other muscles will remain relaxed, and then relaxing the whole body when I say the word "relax". Try not to tense your muscles too much so that it causes pain.

- Sit comfortably in your chair and try to relax. Close your eyes and notice your breathing pattern.

- Now take a deep breath in and let yourself feel completely calm and peaceful.
- Slowly clench your fists, making them tighter and tighter. Notice the tension in your fists, your hands and your forearms. Now relax your hands and let your fingers go loose. Notice the difference between the feeling of tension and relaxation. Let your whole body relax completely.
- Now bend both your elbows and tense the large muscles on your upper arms. Notice the tension in your arms. Hold it there. Now relax your arms and let them drop down to your sides. Notice the feeling of relaxation compared to the tension you just felt.
- Shift your attention now to your neck, your shoulders and your upper back. As you take a deep breath in, imagine all the tension from your neck, shoulders and upper back being released. Each time you take another breath begin to feel more and more relaxed. Feel this relaxation move the other parts of your body.
- Now tighten the muscles in your buttocks and legs. Hold the tension. Now relax your muscles. Notice the difference between the feeling of tension and relaxation. Feel your entire lower body becoming more and more relaxed as you relax the tension away.
- Take a deep breath in and slowly breathe out. As you breathe, feel your whole body completely relaxing. Think the following thoughts: "I feel relaxed. My whole body is calm. I am at peace." Remain in your relaxed position and when you feel ready, open your eyes.

Session 3

4. Breathing exercise:

- Let’s begin. Try to get as comfortable as you can in your chair. Close your eyes and pay attention to your normal breathing as you take a few breaths in. Place one hand on your stomach and the other on your chest. As we start the breathing exercise notice how your hand on your stomach rises and your hand on your chest rises as your lungs become full of air when you breathe in.
- Now take a slow deep breath in through your nose. Once you have taken in as much air as you can, hold that breath … and now slowly breathe out through your nose. Notice how your lungs have become empty and your stomach has sunk. This is because you have used your stomach muscles to push all the air out. Good! Let’s try that one more time.
- This time, as you are breathing in, imagine that all your muscles are being filled with air and they are expanding.
- Let’s begin. Take another slow deep breath in through your nose. Once you have taken in as much air as you can, hold that breath … and now slowly breathe out through your nose. Imagine your muscles slowly relaxing, leaving you feeling relaxed and calm.
- Lie still and enjoy the relaxed feeling you are experiencing. When you are ready, you can open your eyes.

5. Deep Muscle Relaxation Exercise:

The deep muscle relaxation exercise will help you to know the difference between tension and relaxation of your muscles and it will teach you how to relax the tension away. We will work through various groups, first tensing some muscles while your other muscles will remain relaxed, and then relaxing the whole body when I say the word "relax". Try not to tense your muscles too much so that it causes pain.

- Sit comfortably in your chair and try to relax. Close your eyes and notice your breathing pattern.
- Now take a deep breath in and let yourself feel completely calm and peaceful.
- Slowly clench your fists, making them tighter and tighter. Notice the tension in your fists, your hands and your forearms. Now relax your hands and let your fingers go loose. Notice the difference between the feeling of tension and relaxation. Let your whole body relax completely.
- Now bend both your elbows and tense the large muscles on your upper arms. Notice the tension in your arms. Hold it there. Now relax your arms and let them drop down to your sides. Notice the feeling of relaxation compared to the tension you just felt.
- Shift your attention now to your neck, your shoulders and your upper back. As you take a deep breath in, imagine all the tension from your neck, shoulders and upper back being released. Each time you take another breath begin to feel more and more relaxed. Feel this relaxation move the other parts of your body.
- Now tighten the muscles in your buttocks and legs. Hold the tension. Now relax your muscles. Notice the difference between the feeling of tension and relaxation. Feel your entire lower body becoming more and more relaxed as you relax the tension away.
- Take a deep breath in and slowly breathe out. As you breathe, feel your whole body completely relaxing. Think the following thoughts: "I feel relaxed. My whole body is calm. I am at peace." Remain in your relaxed position and when you feel ready, open your eyes.

APPENDIX D

HOMEWORK EXERCISE (ENGLISH)

Date	Situation	Thoughts and Feelings	Consequences

APPENDIX E

HOMEWORK EXERCISE (ISIXHOSA)

UMSEBENZI WASEKHAZA

Umhla	Intlalo	Ingcinga kunye Nemizwa	Iziqhamo

APPENDIX F

SUBJECT INFORMATION SHEET FOR SERVICE PROVIDERS DURING THE DEVELOPMENT PHASE

Hello,
My name is Shlaine L'Etang. I am a Ph.D. student in Psychology at the University of the Witwatersrand. As part of my degree I am conducting a research study on counselling adolescents and youth living with HIV/AIDS.

The main aim of the study is to develop, implement and evaluate a counselling model that meets the needs of young people living with HIV/AIDS.

I wish to invite you to participate in my study. Please note that your participation is voluntary and that non-participation will have no negative consequences. Should you decide to participate in the study you will need to be part of a focus group interview to discuss a few issues that will help me in developing the counselling model. If you agree, a fieldworker will be present to assist me with translation.

Please note that you can withdraw from the study at any time, should you feel that you do not want to continue. If you feel that some of the questions are too personal or if you are uncomfortable answering them, you have the right to refuse to answer should you wish to do so. Although I cannot guarantee confidentiality, I advise all participants in the focus group interview to main confidentiality. Under no circumstances will any of your responses be shown to anyone other than my research supervisor and myself. No identifying information will be included in the final report.

In the event of stress occurring you will be provided with the details of available psychological services in the clinic.

By taking part in this study I hope to bring awareness of the needs of adolescents and youth living with HIV/AIDS and to equip service providers to make the appropriate responses in dealing with the crisis.

The results of the study will be sent to the clinic to be made available to you at your request.

Yours sincerely

Shlaine L'Etang	Professor T.V. Mayekiso
(Researcher)	(Research supervisor)
Telephone: 082 490 7282	Telephone: 011-717 4525

APPENDIX G

SUBJECT INFORMATION SHEET FOR SERVICE PROVIDERS DURING THE IMPLEMENTATION AND EVALUATION PHASES

Hello,
My name is Shlaine L'Etang. I am a Ph.D. student in Psychology at the University of the Witwatersrand. As part of my degree I am conducting a research study on counselling adolescents and youth living with HIV/AIDS.

The study has 3 main aims, that is, to develop, implement and evaluate a counselling model that meets the needs of young people living with HIV/AIDS. I have already completed the first phase of the study, which involved the development of a counselling model.

I now wish to invite you to participate in the implementation and evaluation phases of the study. Please note that your participation is voluntary and that non-participation will have no negative consequences. Should you decide to participate in the study you will need to counsel young people living with HIV/AIDS, following the guidelines of the counselling model, over a period of 6 months. After 6 months, I would like to ask you a few questions in the form of an interview about your experiences in counselling young people using this model.

Please note that you can withdraw from the study at any time, should you feel that you do not want to continue. If you feel that some of the questions are too personal or if you are uncomfortable answering them, you have the right to refuse to answer should you wish to do so. All information that I obtain in this study will be treated as private and confidential. Under no circumstances will any of your responses be shown to anyone other than my research supervisor and myself. No identifying information will be included in the final report.

By taking part in this study I hope to bring awareness of the needs of adolescents and youth living with HIV/AIDS and to equip service providers to make the appropriate responses in dealing with the crisis.

The results of the study will be sent to the clinic to be made available to you at your request.

Yours sincerely

Shlaine L'Etang	Professor T.V. Mayekiso
(Researcher)	(Research supervisor)
Telephone: 082 490 7282	Telephone: 011-717 4525

APPENDIX H

SUBJECT INFORMATION SHEET FOR ADOLESCENTS AND YOUTH (EXPERIMENTAL GROUP)

Hello,
My name is Shlaine L'Etang. I am a Ph.D. student in Psychology at the University of the Witwatersrand. As part of my degree I am conducting a research study on counselling adolescents and youth living with HIV/AIDS.

The study has 3 main aims, that is, to develop, implement and evaluate a counselling model that meets the needs of young people living with HIV/AIDS. I have already completed the first phase of the study, which involved the development of the counseling model.

I now wish to invite you to participate in the implementation and evaluation phases of the study. Please note that your participation is voluntary and that non-participation will have no negative consequences. Should you decide to participate in the study you will need to answer a questions in the form of an interview that will take about 60 minutes. Service providers will be offering you 3 sessions of counselling based on the counselling model that I have developed. At the end of the last session you will need to answer questions in the form of another interview. After about 6 months you will need to answer a few more questions in the form of an interview that will be used as part of the evaluation of the model. I will also ask you a few questions about any events that have been happening in your life during the period of the implementation of the model. After another 3 months, I will contact you to see how you are doing and to ask you some questions.

Please note that you can withdraw from the study at any time, should you feel that you do not want to continue. If you feel that some of the questions are too personal or if you are uncomfortable answering them, you have the right to refuse to answer should you wish to do so. All information that I obtain in this study will be treated as private and confidential. Under no circumstances will any of your responses be shown to anyone other than my research supervisor and myself. No identifying information will be included in the final report.

In the event of stress occurring you will be provided with the details of available psychological services in the clinic.

By taking part in this study I hope to bring awareness of the needs of adolescents and youth living with HIV/AIDS and to equip service providers to make the appropriate responses in dealing with the crisis.

The results of the study will be sent to the clinic to be made available to you at your request.

Yours sincerely

Shlaine L'Etang	Professor T.V. Mayekiso
(Researcher)	(Research supervisor)
Telephone: 082 490 7282	Telephone: 011-717 4525

APPENDIX I

SUBJECT INFORMATION SHEET FOR ADOLESCENTS AND YOUTH (CONTROL GROUP)

Hello,
My name is Shlaine L'Etang. I am a Ph.D. student in Psychology at the University of the Witwatersrand. As part of my degree I am conducting a research study on counselling adolescents and youth living with HIV/AIDS.

The study has 3 main aims, that is, to develop, implement and evaluate a counselling model that meets the needs of young people living with HIV/AIDS. I have already completed the first phase of the study, which involved the development of the counseling model.

I now wish to invite you to participate in the next phases of the study. Please note that your participation is voluntary and that non-participation will have no negative consequences. Should you decide to participate in the study you will need to answer a questions in the form of an interview that will take about 60 minutes. Service providers will be offering you counselling, although this counselling will not be based on the counselling model I have developed. At the end of your last session of counselling you will need to answer questions in the form of another interview. After about 6 months you will need to answer a few more questions in the form of an interview that will be used as part of the evaluation of the model. I will also ask you a few questions about any events that have been happening in your life during the period of the implementation of the model. After another 3 months, I will contact you to see how you are doing and to ask you some questions.

Please note that you can withdraw from the study at any time, should you feel that you do not want to continue. If you feel that some of the questions are too personal or if you are uncomfortable answering them, you have the right to refuse to answer should you wish to do so. All information that I obtain in this study will be treated as private and confidential. Under no circumstances will any of your responses be shown to anyone other than my research supervisor and myself. No identifying information will be included in the final report.

In the event of stress occurring you will be provided with the details of available psychological services in the clinic.

If the counselling model that I have developed is found to be effective with the other group of individuals, then 2 sessions of counselling based on the model also be offered to you after I have completed the study.

By taking part in this study I hope to bring awareness of the needs of adolescents and youth living with HIV/AIDS and to equip service providers to make the appropriate responses in dealing with the crisis.

The results of the study will be sent to the clinic to be made available to you at your request.

Yours sincerely

Shlaine L'Etang	Professor T.V. Mayekiso
(Researcher)	(Research supervisor)
Telephone: 082 490 7282	Telephone: 011-717 4525

APPENDIX J

INFORMED CONSENT FORM

Participant

I have read the information about the study listed in the information sheet. I understand that my participation is voluntary and that I can withdraw from the study at any time.

I agree to take part in the study, by participating in the interview.

Signature:__________________________________Date: _________________

Researcher

I have explained the aims and procedures of the study. I have assured the participant that participation is voluntary and I have explained the research to the best of my ability.

Name: Mrs Shlaine L'Etang

Signature: ________________________________ Date: __________________

Name: Professor T.V. Mayekesio

Signature: ________________________________ Date: __________________

APPENDIX K

FOCUS GROUP INTERVIEW SCHEDULE FOR SERVICE PROVIDERS

Based on a needs assessment study in this area I have developed a counselling model. I would to share this model with you and get your input as to whether or not it covers the aspects that you consider necessary in providing counselling to adolescents and youth living with HIV/AIDS.

APPENDIX L

BIOGRAPHICAL QUESTIONNAIRE FOR ADOLESCENTS AND YOUTH

1. Identification code:

2. Gender:

Male	Female

3. How old are you?

18 years	19 years	20 years	21 years	22 years	23 years	24 years

4. What was the last standard/grade you completed at school?

Standard 8	Standard 9	Standard 10	Not applicable

5. What is your occupation?

6. Who do you live with?

Relationship	Age

7. Have you disclosed your HIV status to them?

Yes	No